

Glossary of Acronyms and Terms

Acronyms

AAA	— <i>area</i> agency on aging
AAHA	—American Association of Homes for the Aging
AARP	—American Association of Retired Persons
ADEAR	—Alzheimer's Disease Education and Referral (Center)
ADLs	—activities of daily living
ADRCs	—Alzheimer's Disease Research Centers
ADRDA	—Alzheimer's Disease and Related Disorders Association
AIDs	—acquired immunodeficiency syndrome
CASA	—Community Alternative Systems Agency program (New York State)
CCCI	—Connecticut Community Care, Inc.
CCP	—Community Care Program (Illinois)
CDs	—Consumer-Directed Services Initiative
CHC	—community health center
CMHC	—community mental health center
CSE	—Community Services for the Elderly (New York State)
ECA	—Epidemiologic Catchment Area (Survey)
EISEP	—Expanded h-Home Services for the Elderly (New York State)
FHHC	—Foundation for Hospice and Home Care
FSP	—Family Survival Project (California)
GEU	—Geriatric Evaluation Unit
GRECC	—Geriatric Research, Education, and Clinical Center
HMO	—health maintenance organization
HRSA	—Health Resources and Services Administration
IADL	—instrumental activities of daily living
IHSS	—In-Home Supportive Services (program) (California)
JCAHO	—Joint Commission on the Accreditation of Healthcare Organizations
LAMP	—Long-Term Care Assessment and Management Program (Pennsylvania)
MSSP	—Multipurpose Senior Services Program (California)
NLN	—National League for Nursing
OTA	—Office of Technology Assessment, U.S. Congress
PASSSPORT	—1% Admission Screening System Providing Options and Resources Today (Ohio)
PRO	—peer review organization
SCAN	—Senior Care Action Network (California)
SEED	—Service Enriched Communities for the Elderly and Disabled (program) (California)
S/HMO	—social health maintenance organization
SSI	—Supplemental Security Income

TEFRA	—Tax Equity and Fiscal Responsibility Act of 1982
VA	—Veterans Administration
VHS&RA	—Veterans Health Services and Research Administration
VNA	—Visiting Nurse Association

Terms

- Activities of daily living (ADLs): Activities related to personal care including bathing, dressing, getting in and out of bed or a chair, dressing, using the toilet, and eating. Compare *instrumental activities of daily living*.
- Acute illness: An illness characterized by a single episode of fairly short duration, usually less than 30 days, and from which the patient can be expected to his or her normal or previous state of activity. Examples include infections such as pneumonia and influenza. Compare *chronic illness*.
- Administration on Aging: The Federal agency within the U.S. Department of Health and Human Services that was established under the Older Americans Act of 1965 to administer the provisions of the act at the Federal level.
- Adult day care centers: See *adult day centers*.
- Adult day centers: Community-based entities that provide health care, social, and other services for small groups of functionally impaired adults in group setting during specified hours of the week. Some adult day centers are freestanding, and others are situated in hospitals, nursing homes, senior centers, or other agencies.
- Aging network agencies: Agencies that are part of a loosely related network of agencies that have developed to serve elderly people since the enactment of the Older Americans Act in 1965. These agencies include the 57 State units on aging, the 670 area agencies on aging (AAAs), and thousands of other agencies that provide services for elderly people through contracts or other agreements with AAAs.
- AIDS (acquired immunodeficiency syndrome): A disease caused by the retrovirus HTLV-III (human T-cell lymphotropic virus, type III) and characterized by a deficiency of the immune system.
- AIDS dementia: A form of dementia that is due to brain infection by the virus that causes AIDS. The majority of people who have AIDS develop dementia. The special problems people with AIDS dementia confront in locating and arranging services are an important topic that is beyond the scope of this OTA report.
- Alzheimer's Association: A national, privately funded, voluntary association, founded in 1980, to: 1) support research on Alzheimer's disease and related disorders; 2) stimulate awareness of Alzheimer's disease among the public and professionals; 3) encourage the forma-

- tion of local chapters to create a nationwide family support network 4) advocate legislation at the Federal, State, and local levels; and 5) provide services for patients and their caregivers. The Alzheimer's Association is also known as the Alzheimer's Disease and Related Disorders Association (ADRDA).
- Alzheimer's Association chapters: Local chapters of the Alzheimer's Association. As of May 1990, there were 210 Alzheimer's Association chapters in 49 States (every State except Alaska).
- Alzheimer's diagnostic and assessment centers: See *States' regional Alzheimer's diagnostic and assessment centers*.
- Alzheimer's disease: A chronic, progressive disease of unknown cause that attacks brain cells or tissues and was first described by 1906 by German neurologist Alois Alzheimer. Alzheimer's disease is the most common cause of dementia in older people, accounting for 60 to 80 percent or more of all cases. A diagnosis of *definite* Alzheimer's disease requires histopathologic confirmation after the patient's death. A diagnosis of *probable* Alzheimer's disease can be made with confidence if there is a typical insidious onset of dementia with progression and if there are no other systemic or brain diseases-e. g., Parkinson's disease, multi-infarct dementia, drug intoxication, brain disease and other chronic infections of the nervous system, subdural hematoma, Huntington's disease, Creutzfeldt-Jacob disease, or brain tumor-that could account for the progressive memory and other cognitive deficits.
- Alzheimer's Disease and Related Disorders Association (ADRDA): See *Alzheimer's Association*.
- Alzheimer's Disease Research Centers (ADRCs): Fifteen centers, funded by the National Institute on Aging, that conduct biomedical and clinical research on Alzheimer's disease and provide educational programs for the public and information and referrals for people who are involved in their clinical research programs.
- Appropriateness of a service: In the context of this report, those aspects of the service that make it consistent with the needs of a person with dementia.
- Area agencies on aging (AAAs): Local public or private nonprofit agencies designated by States to implement certain provisions of the Older Americans Act. As of 1989, there were 670 AAAs. In general, AAAs are mandated to plan for and ensure the availability of services for elderly people rather than to provide the services directly. Some AAAs provide public education, information and referral, outreach, and case management for elderly people, including some people with dementia.
- Assessment: An evaluation of an individual that usually includes the individual's physical, mental, emotional, financial, and social status. One objective of an assessment is to identify the kinds of services the individual needs.
- Assessment instrument: A test or scale used to measure and evaluate an individual's status in various domains (e.g., physical, mental, emotional, financial, and social).
- Autonomy: The quality or state of being self-governing or directing.
- Behavioral problems: Behaviors of some individuals with dementia that are troublesome to the individual's family, other informal caregivers, and/or paid service providers (e.g., wandering, agitation, withdrawal, severe emotional outbursts, and disruptiveness at night).
- Benefits counseling:** Informing clients about sources of services and funding for services and how and where to apply for them.
- Board and care facilities: Residential care facilities that provide room and board and variable amounts of protective supervision, personal care, and other services but not nursing care. Board and care facilities include adult foster care homes that provide care for one or two individuals as well as group homes, homes for the aged, and large domiciliary care facilities that may house several hundred people.
- Cavitation (or per capita) payment: A method of payment for services in which a service provider (e.g., a physician, hospital, or other agency or individual) is paid a fixed amount for each person served regardless of the actual cost of services provided for the person.
- Care coordination: A term used by some people to refer generally to the functions OTA includes in its definition of case management.
- Care management: A term used by some people to refer generally to the functions OTA includes in its definition of case management.
- Caregiver: As used in this report, a relative, friend neighbor, or other individual who provides care for a physically or mentally impaired person *on an unpaid basis*. A *primary caregiver* is the individual who provides most of the person's care; a secondary *caregiver is an* individual who helps out occasionally. The caregivers of people with dementia are usually their adult children and spouses, most of whom are women.
- Caregiver support group: A group of people-including family members, friends, and others-who meet on a regular basis to share information, exchange coping strategies, and give and receive mutual support in caring for another person. Many support groups for caregivers of people with dementia are sponsored by Alzheimer's Association chapters. Other support groups for caregivers of people with dementia are sponsored by hospitals, other public and private agencies, and individual health care and social service professionals and service providers.
- Case management: 1) A term used in a wide range of

contexts in which its general meaning is the arrangement and coordination of services provided for an individual. The precise meaning of the term is often unclear. 2) As defined in this report, case management is a process that includes the following five functions:

- . assessing a client's needs,
- developing a plan of care for the client,
- arranging and coordinating services for the client,
- . monitoring and evaluating the services the client receives, and
- . reassessing the client's situation as the need arises.

Case management—along with public education, information and referral, and outreach—is identified in this OTA report as one of the components of an effective system to link people with dementia to services.

Case manager: An individual who performs the five functions just listed. Nurses, social workers, and individuals with a college, but not a professional degree in a human service field frequently act as case managers for people with dementia, but individuals with other backgrounds and training also perform case management functions for some people with dementia.

Chore services: Services such as heavy house cleaning, minor household repairs, and yard work.

Chronic illness: An illness that lasts over an extended period of time and from which a person is not expected to recover. Examples are Alzheimer's disease, osteoarthritis, and diabetes. Compare *acute illness*.

Coexisting medical conditions: As used in this report, medical illnesses and conditions in a person with dementia that are unrelated or only peripherally related to the person's dementing disease.

Cognitive deficit/impairment: The loss of or a disturbance in one or more cognitive abilities, such as memory, intelligence, learning ability, problem-solving, judgment, comprehension, attention, and orientation to time and place and to oneself. Impairment of these abilities is a central feature of dementia.

Community health centers (CHCs): Organizations that provide primary health care and other health-related services to individuals in a local community. As of 1989, there were about 1,200 CHCs providing services at more than 2,000 sites throughout the country. Roughly half of these CHCs were receiving Federal grants under Section 330 of the Public Health Service Act, which authorizes grants to public and private nonprofit organizations that provide primary health care to populations or areas that are "medically underserved."

Community mental health centers (CMHCs): Local organizations that provide mental health services for people of all ages who have mental and emotional problems. There is no generally accepted figure for the number of CMHCs in the United States, in part

because of lack of agreement about which agencies should be counted as CMHCs, but available data indicate that there are probably at least 2,300 CMHCs nationwide. Some CMHCs receive funding through the Federal Alcohol, Drug Abuse, and Mental Health Services Block Grant.

Companion services: Supervision, socialization, and other services such as reading, letter writing, and light errands, provided by an individual who comes to the home, often in the absence of the primary caregiver.

Competent/competency: As used in this report, terms that refer to the legal status of an adult who has not been declared incompetent by a court. Under U.S. common law, competent individuals have the right to control their property, manage their personal affairs, and give or withhold consent for medical treatment.

Congregate meals: Meals provided to a group of older adults in a community setting, such as a senior center or school.

Consolidated service system: See *service system*.

Counseling: Assistance and guidance provided by social workers, psychologists, nurses, and others to help define and resolve problems of various kinds, including, in the context of this OTA report, emotional and relationship problems related to the care of a person with dementia.

Decisionally capable/incapable: As used in this report, terms that refer to a person's ability/lack of ability to make decisions in a general sense rather than a legal one. If a person with dementia is decisionally incapable, decisions about services must be made for him or her. Compare *competent* and *incompetent*.

Decisionmaking capacity: As used in this report, a term that refers to the ability of a person to make decisions for himself or herself. Three types of criteria are generally used to judge an individual's decisionmaking capacity: *status criteria* (e.g., consciousness or age), *outcome criteria* (e.g., a judgment about the "reasonableness" of a person's decision), and *functional criteria* (e.g., evidencing an understanding of relevant information and issues).

Decision-specific decisionmaking capacity: An individual's capacity to make a specific decision. A concept that has emerged in the legal and ethical debate about determining individuals' decisionmaking capacity is that an individual's capacity to make a decision may differ for each decision, depending on the characteristics of the decision and the circumstances in which it must be made.

Dementia: A clinical syndrome characterized by a decline in mental function of long duration (months to years) in an alert individual. Symptoms of dementia include memory loss and the loss or diminution of other cognitive abilities, such as learning ability, judgment, comprehension, attention, and orientation to time and place and to oneself. Self-care and

language abilities are usually also affected. Dementia can be caused by over 70 diseases and conditions, but the leading cause in older people is Alzheimer's disease.

Dementia-capable: As used in this report to characterize a system for linking people with dementia to services, a term that means being 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 a community.

Dementia-friendly: As used in this report to characterize a system for linking people with dementia to services, a term that means being responsive to people with dementia and their caregivers.

Dementia-specific: As used in this report to characterize a system for linking people with dementia to services, a term that means serving people with dementia exclusively.

Dementing illness, disease, or condition: One of the more than 70 illnesses, diseases, and conditions that can cause dementia. Dementing illnesses, diseases, and conditions are divisible into two groups: those in which the illness, disease, or condition inevitably produces dementia if it progresses through its full course, such as Alzheimer's disease, and those that may or may not produce dementia, such as certain infectious, metabolic, and nutritional disorders.

Domiciliary care facility: A nonmedical residential care facility that provides room and board and variable amounts of protective supervision, personal care, and other services. The term is used for the 29 large residential care facilities currently operated by the VA.

Durable power of attorney: A modification of the standard power of attorney that permits an individual (the principal) to transfer specified powers to another person. The power may be broad in scope or limited. The fundamental difference between standard and durable power of attorney is that the former loses its validity when the principal becomes incompetent and is therefore not useful for people with a dementing illness. A durable power of attorney provides a means of designating a surrogate decisionmaker that survives the incompetence of the principal.

Elderly: Generally referring to individuals over age 65.

Escort service: A service in which someone accompanies an individual to a medical appointment, another appointment, or an errand to provide assistance and supervision.

Ethics committee: A multidisciplinary group established in a hospital or nursing home to address ethical dilemmas that arise within the facility and advise the staff, patients (or residents), and their caregivers about difficult treatment decisions.

Ethnic minority group: A subgroup of the population that is characterized by a common language, culture,

and historical background. According to this definition, everyone belongs to an ethnic minority group. In general, this report uses the term to refer to subgroups of four large minority groups (i.e., blacks, Hispanics, Asian Americans, and Native Americans).

Family caregiver: See *caregiver*.

Family consent laws: State statutes that authorize family members to make specified types of decisions (e.g., about life-sustaining medical treatments) for relatives who are decisionally incapable. Such statutes exist in only a few States.

Family support group: See *caregiver support group*.

Family Survival Project (FSP): An organization in San Francisco that provides public education, information and referral, care coordination, and a variety of other services for brain-impaired adults and their caregivers. Under contract with the State of California. FSP serves as: 1) as the Bay Area Regional Resource Center for a six-county area; and 2) as California's Statewide Resource Consultant, which helps coordinate California's network of 11 regional resource centers for the caregivers of brain-impaired adults. The majority of FSP's clients have dementia.

Fee-for-service payment: A method of paying for services in which each service performed by an individual provider bears a related charge. This charge is paid by the individual patient receiving the service or by an insurer on behalf of the patient.

Financial/benefits counseling: See *benefits counseling*.

Functional impairment: A deficit in an individual's ability to function independently. Functional impairments in elderly people are often described in terms of deficits in *activities of daily living (ADLs)* and *instrumental activities of daily living (IADLs)*.

Gatekeeper: As used in this report, a term that refers to an individual, such as a mail carrier or utility meter reader, who interacts with many people in the course of his or her regular activities and has been specially trained to identify isolated elderly people who maybe in need of assistance. (Note: To avoid confusion, this report does not use the term gatekeeper in another sense in which it is often used—namely to refer to an individual who allocates and controls the use of resources for an agency that provides health care, long-term care, social, or other services.)

Gatekeeper program: A type of outreach program used to identify isolated elderly people who maybe in need of assistance. A gatekeeper program recruits and trains individuals who interact with many people in the course of their regular activities—e.g., mail carriers, utility meter readers—to identify isolated elderly people who may be in need of assistance and notify a central agency. The central agency then contacts the people, evaluates their needs, and refers them to services. Gatekeeper programs frequently identify isolated people with dementia who need assistance but

- would not contact a health care, long-term care, or social service agency for themselves.
- Geriatric Research, Education, and Clinical Centers (GRECCs):** Centers established at VA medical centers to provide basic and clinical research and education and training for clinicians and researchers in the field of geriatrics. As of 1990, there were 12 GRECCs, at least 4 of which were caring for some veterans with dementia.
- Guardian:** A person lawfully invested with the power and charged with the duty of protecting and taking care of the property and/or person of an individual who has been judged legally incompetent. In some States, the term used instead of, or in addition to, guardian is conservator.
- Guardianship:** A legal mechanism that involves the appointment by a court of an individual or institution (the guardian) to protect and take care of the person and/or property of a person who is found incapable of managing his or her own affairs (the ward). In some States, the term used instead of, or in addition to, guardianship is conservatorship.
- Health care and social service professionals:** Physicians, nurses, social workers, psychologists, physical therapists, speech therapists, occupational therapists, and other professionals who provide health care, health-related, and social services.
- Health maintenance organization (HMO):** An organization that provides directly or arranges for the provision of specified health care services to a voluntarily enrolled population for a fixed per capita payment rather than a fee for each services. Typically, a physician, a nurse, or another individual is in charge of each enrollee's care and is responsible for authorizing and arranging any special services for the person.
- Home care agency:** See *home health agency*. Both terms are used synonymously in this report.
- Home care services:** Health care, long-term care, social, and other services provided in the home by a home health agency or other organization or individual. Home care services range from nonmedical services (e.g., paid companion and housekeeping services) to health care and health-related services (e.g., skilled nursing and physical therapy).
- Home-delivered meals:** Meals prepared at a central location and delivered to homebound people on a daily or less frequent basis.
- Home health agency:** A local organization that provides in-home services. As used in this report, the term includes agencies that provide skilled nursing care, physical therapy, and other health care and health-related services, as well as homemaker and other agencies that provide social and other nonmedical in-home services. In 1989, there were about 12,800 home health agencies in the United States, including about 5,700 agencies that were certified to provide Medicare-covered home health care and about 7,100 other agencies that provided in-home services but were not Medicare-certified. To be certified by Medicare, a home health agency must provide skilled nursing care and meet certain other requirements.
- Home health aide:** A person who is paid to provide health-related services in the home. The services provided by a home health aide may include assistance with medications and exercise, assistance with personal care (e.g., bathing, dressing, and feeding), and light household tasks. The term is sometimes used synonymously with the term homemaker, but some agencies and others make a distinction between the two terms.
- Home health care agency:** See *home health agency*.
- Homemaker:** A person who is paid to provide in-home services, such as assistance with personal care (e.g., bathing, dressing, and feeding), household tasks, meal preparation, and shopping. The term is sometimes used synonymously with the term home health aide, but some agencies and others make a distinction between the two terms.
- Hospice services:** Medical, nursing, counseling, and other supportive services rendered to terminally ill people and their families. Hospice care is intended to be palliative and to improve quality of life rather than to cure disease or extend life.
- Hospital-based geriatric assessment programs:** Special hospital inpatient or outpatient programs that use a multidisciplinary team to evaluate elderly patients with complicated medical or psychiatric problems and to develop a coordinated plan of care. Some hospital-based geriatric assessment programs also offer other services such as medical and psychiatric treatment, and rehabilitative services. Hospital-based geriatric assessment programs include inpatient geriatric specialty units, inpatient geriatric consultation services, outpatient geriatric services, and inpatient and outpatient geropsychiatry services. As of 1987, about 1,400 hospitals nationwide had a geriatric assessment program.
- Hospital discharge planner:** A person who arranges post-discharge care for hospitalized patients.
- Huntington's disease:** A genetic disease characterized by chronic progressive disorders of movement and mental deterioration culminating in dementia. Symptoms do not usually appear until late middle age, and death usually results within 15 years.
- Incompetent:** As used in this report, a term that refers to the legal status of a person who, on the basis of evidence presented to a court, has been declared incapable of managing his or her affairs. Compare *decisionally capable/incapable*.
- Informal caregivers:** See *caregivers*.
- Informal services:** As used in this report, unpaid services provided for an impaired person by his or her relatives,

friends, neighbors, or others.

Information and referral: As defined in this report, information and referral means providing information about and referrals to specific services and sources of funding for services in a community. Information and referral—along with public education, outreach, and case management—is identified in this OTA report as one of the essential components of an effective system to link people with dementia to services.

In-home services: Health care, long-term care, social, and other services provided in the home by a home health agency or other organization or individual. In this report, the term is used synonymously with the term *home care services*.

Instrumental activities of daily living (IADLs): Activities related to independent living, such as preparing meals, doing laundry, managing money, shopping for groceries, cleaning the house, cooking, using a telephone, and taking medications. Compare *activities of daily living*.

LAMP (Long-Term Care Assessment and Management Program): A program in Pennsylvania that contracts with local agencies (usually area agencies on aging) to provide case management for elderly people who are eligible for Medicaid-funded nursing home care but choose to remain at home. It is similar to Ohio's PASSPORT program but is paid for solely with State funds.

Legal services: Assistance with legal matters, such as property disposition, transfer of assets, wills, living wills, powers of attorney, and guardianship.

Life-sustaining medical treatments: Drugs, medical devices, or procedures that can keep a person alive who would otherwise die within a foreseeable, though usually uncertain, time. Examples include cardiopulmonary resuscitation, mechanical ventilation, renal dialysis, and nutritional support (i.e., tube or intravenous feeding).

Linking program: As used in this report, a program that provides one or more of the functions identified by OTA as essential components of an effective system to link people with dementia to services (i.e., public education, information and referral, outreach, and case management).

Living will: A legal mechanism, recognized in some States, that permits a competent individual to declare his or her wishes, especially the intent to refuse life-sustaining procedures once he or she is incompetent and death is imminent. Along with durable powers of attorney, living wills are legal mechanisms that give individuals the ability to direct treatment decisions after incompetence.

Long-distance caregiver: An adult child or other relative or friend of an impaired person who lives in a different locality or area of the country but still tries to function as a caregiver for the person—often by trying to locate,

arrange, and monitor services for the person. The difficulties long-distance caregivers face in locating and arranging appropriate services for a relative or friend with dementia are one of the primary reasons that a system to link people with dementia to services must be uniform in some way nationally.

Long-term care services: A variety of services that may be provided in a person's home, the community, or a residential or institutional setting, with the objective of maintaining and supporting a chronically ill or severely disabled individual. The services generally are needed for a prolonged period, even if intermittently.

Medicaid: A joint Federal/State program intended to provide health care and health-related services for low-income individuals. Medicaid regulations are established by each State within Federal guidelines, and the eligibility requirements and services covered vary significantly among the States. In general, Medicaid pays for medical, nursing home, and home health care for individuals who meet the eligibility requirements for those services. In some States, Medicaid also pays for adult day care and in-home services such as personal care and homemaker services. Financial eligibility for Medicaid is determined by a means test, in which a ceiling is placed on the maximum income and assets an individual may have in order to qualify for assistance. The income and assets levels are low in all States and very low in some States.

Medicaid 2176 Home and Community-Based waiver:

A waiver obtained under the Medicaid 2176 Home and Community-Based Waiver program which allows States to 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. A State with a Medicaid 2176 waiver may use Medicaid funds to pay for services that are not ordinarily covered by Medicaid; may 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 eligibility for the waiver program than the standard used for other Medicaid services. Although States' Medicaid 2176 waiver programs are a valuable resource in linking some people with dementia to services, many people with dementia are not eligible for the programs because they do not have medical conditions, functional impairments, or financial resources that meet the eligibility requirements for Medicaid-funded nursing home care.

“Medically needy” people: Under Medicaid, people whose incomes are above the ceiling established by a State for Medicaid eligibility but who qualify for Medicaid, nevertheless, because their medical expenses reduce their incomes below the Medicaid eligibility level. Not all States allow Medicaid eligibility for “medically needy” people.

Medicare: A nationwide health insurance program authorized in 1965 to pay for hospitalization: medical care, and some related services for people over age 65, people who have received Social Security disability insurance payments for 2 years or longer, and people with end-stage renal disease. Medicare consists of two programs: hospital insurance (part A) and supplementary medical insurance (Part B).

Medicare Alzheimer's Disease Demonstration: A demonstration program, mandated by Congress in 1986, to determine the effectiveness, cost, and impact of providing comprehensive services for Medicare enrollees who have Alzheimer's disease or a related disorder. As of 1990, the demonstration is being implemented at eight sites nationally.

Minority group: See *ethnic minority group*.

Multidimensional assessment: A client evaluation that focuses on many different aspects of the client's status, e.g., physical, mental, emotional, functional, financial, and social.

Multidisciplinary assessment: A client evaluation conducted by individuals from various disciplines, usually including a physician, a nurse, and a social worker and, depending on the care setting, a physical therapist, a speech therapist, an occupational therapist, a psychologist, and various physician specialists.

Multidisciplinary team: A team composed of individuals from various disciplines that provides comprehensive client assessments, care planning, and/or treatment. Multidisciplinary teams usually include a physician, a nurse, and a social worker and, depending on the care setting, may also include a physical therapist, a speech therapist, an occupational therapist, a psychologist, and various physician specialists.

Multi-infarct dementia: An irreversible form of dementia resulting from many small strokes. This is the second most common cause of dementia in the elderly.

Nursing homes: Residential care facilities that provide 24-hour supervision, nursing care, personal care, and other services. An estimated 40 to 70 percent of nursing home residents have dementia and many people with dementia spend some time in a nursing home in the course of their illness. Medicaid pays for a significant proportion of nursing home care, but nationally half the cost of nursing home care is borne by residents and their families.

Nursing home preadmission screening programs: Programs to evaluate nursing home applicants and divert those who can be cared for at home. As of 1986, 29 States and the District of Columbia has nursing home preadmission screening programs. In 1987, a Federal law as enacted that requires States to establish a nursing home preadmission screening program to identify mentally ill and mentally retarded people for whom nursing home placement is inappropriate.

Occupational therapy: Therapy provided to people who

are physically or mentally impaired that is intended to improve functional abilities; provided by an occupational therapist.

Older Americans Act: A law enacted in 1965 that established the Federal Administration on Aging and a program of Federal grants to States for the development of a coordinated system of services for elderly people in their homes and communities. The act also required States to designate a single State agency—commonly referred to as a State unit on aging—to formulate a plan for developing the system of services envisioned in the act. The 1973 amendments to the act required each State to divide its jurisdiction into planning and service areas and to designate an area agency on aging to plan, coordinate, and arrange services for elderly people in each area.

On Lok Senior Health Services: An organization that plans, coordinates, and provides comprehensive health care, long-term care, social, and other services for about 300 very frail and severely impaired older adults in the Chinatown-North Beach area of San Francisco. On Lok's comprehensive, consolidated service program exemplifies a model of service delivery that eliminates for its clients the problems in locating and arranging services that are, the focus of this OTA report.

Outcome criteria to measure quality of care: Criteria for measuring quality that focus on the outcome of care (e.g., the patient's health and functional abilities and patient and family satisfaction). The use of outcome criteria to measure quality assumes a direct link between the process of care and the outcomes of care. In the case of people with dementia, however, that link is seldom straightforward or clear since many factors other than quality of care influence patient outcomes. Compare *process criteria* and *structural criteria to measure quality of care*.

Outreach: As defined in this report, outreach means using an active method to identify individuals 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. Outreach is likely to be needed for isolated people with dementia who live alone and have no relative or friend to help them and for people with dementia whose caregiver is isolated and overburdened. Outreach—along with public education, information and referral, and case management—is identified in this OTA report as one of the essential components of an effective system to link people with dementia to services.

Parkinson's disease: A disease affecting movement and leading to dementia in approximately one-third of those affected. The disease is associated with destruction of cells in the brain-stem. The symptoms of Parkinson's disease include tremors, rigidity, extreme

slowness of movement, and a mask-like facial expression.

PASSPORT (Pre-Admission Screening System Providing Options and Resources Today): A Medicaid 2176 waiver program in Ohio that provides case management and a range of in-home and community services for people who are eligible for Medicaid-covered nursing home care but choose to remain at home, including some people with dementia.

People with dementia: As used in this report, the term refers to people with Alzheimer's disease, and other dementing diseases that primarily affect elderly people.

Personal care services: Assistance with self-care activities, including eating, dressing, bathing, getting in and out of bed, and using the toilet.

Personal emergency response system: A telephone-based system to alert others that an individual who is alone is experiencing an emergency and needs assistance.

Physical therapy: Rehabilitative therapy provided by a physical therapist. The therapy may include a variety of methods, such as heat, hydrotherapy, massage, exercise, and the use of mechanical devices.

Preadmission screening: See *nursing home preadmission screening programs*.

Prevalence: The total number of individuals in a given population who have a specific disorder at one period in time.

Primary caregiver: See *caregiver*.

Private geriatric case manager: Individual professionals (usually social workers or nurses) and others who provide client assessment, care planning, service arrangement and coordination, monitoring, and a variety of services for elderly people on a fee-for-service basis. Although no data are available, anecdotal evidence suggests that many clients of private geriatric case managers have dementia.

Process criteria to measure quality of care: Criteria for measuring quality that focus on the activities involved in providing care (e.g., care planning and medication procedures and procedures for handling difficult patient behaviors). The use of process criteria to measure quality is valid only if the processes have been linked to desired or undesired outcomes of care. Compare *outcome criteria* and *structural criteria to measure quality*.

Prospective payment: Payment for medical care on the basis of rates set in advance of the time period in which they apply. Medicare's DRG payment system for inpatient hospital services is a particular form of prospective payment.

Protective services: Social and law enforcement services to prevent, eliminate, or remedy the effects of physical and emotional abuse or neglect.

Public education: As defined in this report, public

education means providing programs and materials to help people understand dementia and the kinds of services that may be helpful for individuals with dementia. Public education—along with information and referral, outreach, and case management—is identified in this OTA report as one of the essential components of an effective system to link people with dementia to services.

Quality assessment: The measurement and evaluation of quality of care.

Quality assurance: Procedures and activities to safeguard or improve quality by assessing quality and taking action to correct any problems found.

Quality of care: The extent to which the service increases the probability of desired outcomes and reduces the probability of undesired outcomes, given the constraints of existing knowledge.

Regional Alzheimer's diagnostic and assessment centers: See *States' regional Alzheimer's diagnostic and assessment centers*.

Regional resource centers: California's 11 regional centers that provide public education, information and referral, and care coordination, and a variety of other services for brain-impaired adults and their caregivers. The majority of the clients of California's regional resource centers are caregivers of people with dementia. One of the centers is the *Family Survival Project*, which is the model for the other 10 centers.

Residential care facility: A care setting in which the patient or client resides, such as a nursing home, board and care facility, or State mental hospitals.

Respite care services: Any short-term services that are intended to provide temporary relief for the primary caregiver of an impaired person. Such services may include in-home companion/sitter services, in-home personal care, adult day care, or short-term (e.g., overnight) stays in a nursing home.

Senior center: A community facility for elderly people. Senior centers provide various activities for elderly people, recreational, educational, cultural, or social events. Some centers provide adult day care, congregate meals, health screening, and limited health care services.

Service consciousness: As used in this report, a general awareness that services exist. Service consciousness is one of two components of patients' and caregivers' knowledge about services. Compare *service knowledge*.

Service knowledge: Knowledge about a specific service, including who provides it in a community. Service knowledge is one of two components of patients' and caregivers' knowledge about services. Compare *service consciousness*.

Services for people with dementia: In the context of this report, services for people with dementia means all health care, long-term care, social, and other services

- that may be needed by a person with dementia. Such services include diagnosis, acute medical care, adult day care, chore services, escort service, financial/benefits counseling, home-delivered meals, hospice, legal services, mental health services, multidimensional assessment; occupational therapy; personal care, homemaker services, physical therapy, recreation/exercise, respite care, skilled nursing, speech therapy, vision care, and other services. In this report, the term ‘services’ is not used for the four linking functions—public education, information and referral, outreach, and case management.
- Service system:** As used in this report, an organizational entity that pools funds from several sources and integrates 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.
- Service-connected disabilities:** With respect to the eligibility criteria for VA services, disabilities that were incurred or aggravated during military service. Veterans with a service-connected disability have priority for VA services.
- Severely mentally ill:** A term that usually refers to adults with a diagnosis of schizophrenia, a major affective disorder, psychosis, or a personality disorder and a recent history of psychiatric care that required more than voluntary outpatient treatment. The term is not usually used to refer to people with Alzheimer’s disease or other diseases that cause dementia.
- Social health maintenance organization (S/HMO):** An innovative organizational entity that offers voluntarily enrolled elderly Medicare beneficiaries a package of acute and long-term care services and operates on a capitated, prospectively fixed budget. As of 1990, there were four S/HMOs in this country, all of which were part of a congressionally mandated demonstration project—the National S/HMO Demonstration.
- Social Services Block Grant:** A Federal block grant to States for social services for elderly and disabled people and others. There are no Federal requirements for specific services that must be provided, but many States use a portion of their Social Services Block Grant funds for board and care, adult day care, home health aide, homemaker, and chore services. States determine the eligibility requirements for these services and may use a means test.
- Special care units:** Units in nursing homes and board and care facilities that provide “special care” for people with dementia.
- Speech therapy:** Treatment to improve or restore speech; provided by a speech therapist.
- State unit on aging:** A State agency designated under the provisions of the Older Americans Act to formulate a plan for developing the system of community services envisioned by the act and to oversee the use of Older Americans Act funds in the State. Currently, there is a State unit on aging in each of the 50 States, the District of Columbia, and 7 territories.
- States’ regional Alzheimer’s diagnostic and assessment centers:** A general name used in this report to refer to regional centers established by States to provide diagnosis, a comprehensive assessment, and a plan of care for people suspected of having Alzheimer’s disease or a related disorder. Some States’ regional Alzheimer’s diagnostic and assessment centers also provide services, such as medical treatment, psychiatric treatment, adult day care, caregiver education and training, and caregiver support groups, and most centers assist in locating and arranging services for their clients. Many of the centers also conduct biomedical and clinical research. States with such centers include California Connecticut, Florida, Illinois, Kentucky, Maryland, New Jersey, New York Ohio, and Pennsylvania.
- Structural criteria to measure quality:** Criteria for measuring quality that focus on the resources available for care (e.g., the number and qualifications of staff, and an agency’s physical plant, and financial resources). The use of structural criteria to measure quality is valid only if the specific structural characteristics measured are associated with better processes or outcomes of care. Compare *outcome criteria* and *process criteria to measure quality*.
- Supervision: Monitoring of an individual’s status and activities to ensure his or her safety.**
- Supplemental Security Income (SSI):** A Federal income support program that provides a monthly payment for disabled, aged, and blind people with incomes below a specified level.
- Support group:** See *caregiver support group*.
- Surrogate decision:** A decision made on behalf of another person, in particular a person who is decisionally incapable. Court rulings and legal analysis of decisions about the use of life-sustaining technologies have identified two standards to guide surrogate decisionmaking: 1) the “best interest standard” (which requires the surrogate to make decisions from the perspective of hypothetical reasonable person, using objective, societally shared criteria); and 2) the ‘substituted judgment standard’ (which requires the surrogate to make decisions from the perspective of the patient, using the patient’s personal values and preferences).
- Surrogate decisionmaker:** A person who makes decisions about the health care, lifestyle, and estate of another individual who is incapable of making the decisions for himself or herself. A surrogate decisionmaker can be a court-appointed conservator or guardian, or a family member who makes decisions for an impaired relative without being formally or legally charged to do so.

Temporary treatment guardian: Volunteers used at the University of New Mexico's Institute of Public Law to ascertain the wishes and preferences of hospitalized elderly people who were too cognitively impaired to make decisions about their own care and had no relative or friend to make decisions for them.

Third-party payment: Payment by a private insurer or government program to a service provider for care given to a patient.

Validity: As used in this report, the extent to which the

criteria used to measure the quality of services actually measure quality

Values history document: A document that expresses a person's wishes, values, and preferences with respect to his or her care. Such documents have been developed and tested at the University of New Mexico's Institute of Public Law.

Visiting nurse: A registered nurse who provides nursing care for an individual at home.