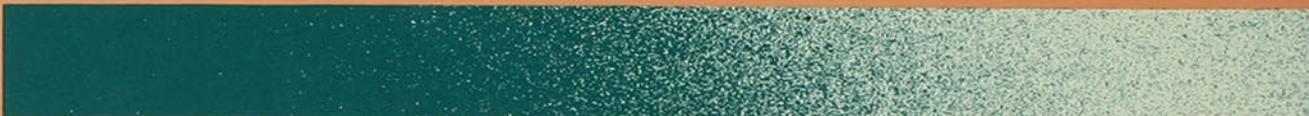


Alzheimer's Day Care



A
BASIC
GUIDE



David A. Lindeman
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ALZHEIMER'S DAY CARE

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A Basic Guide

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PREFACE

The purpose of this book is to provide direction to individuals, organizations, and agencies that are considering developing a day care program for patients with Alzheimer's disease (AD) or a related dementia or are at present operating an adult day care program they wish to modify, in one fashion or another, to include persons with dementia. This book was originally developed for the California Department of Aging to assist groups seeking to set up Alzheimer's Day Care Resource Centers (ADCRCs), which are the dementia day care centers supported by state general funds in California. However, it quickly became apparent to us that a reference book of larger scope would be useful to groups planning to provide dementia day care, regardless of the model or setting.

Alzheimer's day care, or dementia day care, is expanding rapidly across the United States. Our goal here is to help readers avoid having to reinvent the wheel by providing them with a foundation of experience and knowledge that others have brought to the field. The experience of directors, staffs, board of directors, family caregivers, and clients of a large number of Alzheimer's day care centers has been combined here to help the widest possible audience. We have focused on the specific knowledge and skills needed to develop or conduct a day care program for persons with dementia, regardless of whether that dementia is the result of Alzheimer's disease, multi-infarct dementia, Parkinson's disease, or any number of other causes.

The book covers the many aspects of developing day care for clients with dementia, including administration, financing, fund raising, public relations, client issues, program activities, program evaluation, supplemental resources, and problems facing participants' families. While some of the material consists of background information that is needed to begin

any adult day care program, the emphasis of this book is on material that is required specifically to develop adult day care programs for persons with Alzheimer's disease or a related dementia.

In this book, we assume that readers have general knowledge and skills in a number of important areas not specific to dementia. While we do not expect readers to be experts in all these areas, we emphasize that for an Alzheimer's day care program to be successful, its operators must know or have access to the following information:

- program development
- program administration
- diagnosis, care, maintenance, and prognosis of individuals with Alzheimer's disease or related dementias
- client assessment and care planning
- recruitment, selection, training, and supervision of staff
- record keeping
- budgeting and fiscal management
- grant writing
- working with the elderly and their families
- organizations and resources in gerontology and geriatrics

While this book is not intended as a source for this general type of knowledge, individuals or groups can develop the requisite background and related skills by taking university courses, obtaining professional assistance and consultation, reading books, and networking. In particular, they can turn to specific state programs, such as the California Department of Aging Alzheimer's Day Care Resource Center Program, for further information and guidance. Other resources include State Units on Aging, National Institute on Adult Day Care, state day care associations, the Robert Wood Johnson Foundation Dementia Care and Respite Services Program, and other organizations mentioned in the text.

The organization of the chapters reflects the approximate order in which readers will face the issues involved in setting up an Alzheimer's day care program. Chapters 1 and 2 discuss factors to consider in the decision to begin a day care program for participants with Alzheimer's, and provide a brief history of Alzheimer's day care in the United States. The desire to develop an Alzheimer's day care program needs to be matched with a realistic understanding of the complexity and difficulty of setting up such a program. Furthermore, background on the development of Alzheimer's and adult day care programs nationally, and discussion of the types of models and the variety of programs that have been developed over the last decade, provide a context in which to consider the issues involved in setting up an Alzheimer's day care program.

Chapters 3–7 address administrative and management issues in setting up and running an Alzheimer's day care program. These issues include

developing a governing and administrative structure; obtaining, building, or modifying a facility; staffing a program; addressing fiscal issues, such as budgets, fees, and fund raising; and promoting and marketing the program. Chapter 8 addresses the *client pathway*—the steps in the participant's involvement in the program, including definition of the target population, the referral process, client assessment, development of case plans, follow-up, and discharge. Record keeping and documentation for these specific tasks are also discussed.

Chapters 9 and 10 consider the elements of program content and participant issues, particularly in regard to participant and staff activities and scheduling. This discussion includes examples of group activities and individual activities, daily schedules for participants, and daily coordination by the staff. In addition, major problem areas, such as incontinence, wandering, inappropriate behaviors, medical needs, and transportation, are also discussed.

A discussion of staff and volunteer training has been included in chapter 11 to emphasize the importance of special training in finding and retaining staff, and in providing the highest quality services. Volunteers are a critical part of many Alzheimer's day care programs, and strategies for recruiting, training, and retaining these valuable individuals are discussed. This material is followed by chapter 12 on working with the family, which covers the ways in which Alzheimer's care staff can provide assistance to families whose relatives are in day care programs, and the relationships between staff and family caregivers. A basic tenet of this book—and of Alzheimer's day care and adult day care centers in general—is that caregivers are just as much clients as are participants. The provision of respite to caregivers, which allows them a break from constant caregiving, is as much a part of dealing with Alzheimer's as is providing care directly to Alzheimer's patients.

The last two chapters of the text, chapters 13 and 14, have a broader scope. Chapter 13 considers the relationship of Alzheimer's day care centers to the community, and the use of community resources in setting up centers and providing care. It provides information about organizations serving the needs of demented people and their family caregivers, identifies resources for use by day care staff, and considers the importance of relationships with the community. Chapter 14 focuses on program evaluation and research, describing basic strategies for evaluating a program to improve services to participants and their families, and discussing how research can be useful to program staff and policy makers.

The appendix provides four basic types of resources for those interested in setting up an Alzheimer's day care center. The first set of resources is a list of organizations that can provide guidance and expertise in this area, including state agencies responsible for Alzheimer's day care/respite care, national organizations involved in Alzheimer's care, and Alzheimer's disease and memory disorder diagnostic centers. The second re-

source is a compilation of specific forms and documents currently being used in a number of Alzheimer's day care centers. These forms can be used as is or modified to meet the needs of any organization or center. The third and fourth resource items are examples of model job descriptions and sample tables of contents for program policies and procedures manuals, respectively.

Throughout this book, we have attempted to present information on day care from various points of view to help readers set up their own programs. Given that a number of successful models of Alzheimer's day care have evolved, we have tried to avoid promoting one particular model over another. There are many exciting examples of medical and social models, integrated and specialized models, private and public models. Regardless of the model employed in developing or improving Alzheimer's day care programs, each center will end up with its own program based on the abilities and interests of its staff, the needs of its clientele and their families, the limitations or advantages of its facility, budget parameters, the number of participants, and program philosophy.

We encourage readers to be creative within the constraints of funding, licensing, regulations, staffing limits, and good participant care, and to develop the best and most imaginative program possible. In the final analysis, all Alzheimer's day care programs reflect the experiences and orientation of their proponents and management. By applying the highest values and using creative strategies to implement a program philosophy, the director, board, and staff of an Alzheimer's day care program can deliver the highest quality and most effective services to demented participants and their families.

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The authors are indebted to the California Department of Aging for permission to use *Alzheimer's Day-Care Resource Center Guide* as the basis for this book. The *Guide* was developed by the authors under a contract with the Department of Aging to provide assistance to current and future directors of California Alzheimers' Day Care Resource Centers. Department of Aging staff contributed significant time and support to assist our completion of the project. We especially wish to thank Ellie Huffman and Marita McElvain for their assistance and contributions. Material extracted from the *Guide* for this publication may not be representative of the Department's views nor may any of the recommendations be considered those agreed to by the Department.

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1

ALZHEIMER'S DAY CARE: AN OVERVIEW

Recent decades have brought a significant increase both in the number of persons with Alzheimer's disease and related dementias, and in requests for help from families who are desperately in need of services to assist them in caring for their family member. As a result, there has been tremendous growth in the number of adult day care programs around the United States that now serve or wish to serve dementia patients. With the rapid spread of programs and the desire on the part of both professionals and communities to start new programs has come the realization that numerous issues and problems are unique to serving this population, particularly within adult day care settings. Before individuals, agencies, and communities begin the long and difficult process of setting up a dementia day care program or modifying an existing adult day care program, they must carefully review all the issues and challenges that need to be faced. This chapter provides an overview of the rationale for day care programs for individuals with Alzheimer's disease or related dementias, a history of the development of Alzheimer's and dementia day care centers in the United States, and a discussion of several of the key philosophical issues concerning dementia day care.

Before proceeding with a discussion of the background of day care programs for victims of Alzheimer's disease, we would first like to define some terms to ensure that readers understand their use throughout the book. The first set of terms involves the interrelationship between Alzheimer's disease and dementia. *Dementia* is a medical syndrome characterized by loss of memory and intellectual functioning. There are different causes of dementia, including *Alzheimer's disease*, multiple small strokes, Parkinson's disease (if the person has an impairment in thinking), and other disorders. Second, it is important to clarify the distinction among *adult day care*, *dementia day care*, and *Alzheimer's day care*. *Adult day*

care is a generic term that includes all types of day care programs for adults, whether these programs are called health, medical, or social models. *Dementia day care* and *Alzheimer's day care* are community-based, congregate programs with the primary goal of providing healthy and protective day care for people with Alzheimer's disease or other forms of dementia. These programs also furnish assistance to family caregivers and the general community. They frequently provide both health and social services in an adult day care setting for patients with dementia, provide respite and support for caregivers, and offer training opportunities for professionals and caregivers. As will be discussed, any or all adult day care programs, regardless of their focus or services, can serve patients with dementia or Alzheimer's disease. Since day care programs generally serve a range of dementia patients, the term *dementia day care* is used periodically throughout the book, for the sake of consistency as well as to emphasize the broad participant population of these programs. However, *Alzheimer's day care* will be the primary term used to describe programs that serve patients with Alzheimer's disease and other dementias and their families and caregivers. Nearly all of what we say in this book about Alzheimer's day care can be applied to dementia day care in general.

BACKGROUND

Within the last few years federal and state governments have acknowledged the significance of Alzheimer's disease and its physical, psychological, and economic impact on individuals, families, and the general public. In addition, Alzheimer's disease is receiving increased attention from the health and social service community, as well as from the general public, because it is a disease that can have overwhelming social and emotional impact, especially on the patient's family. It is a chronic, progressive, deteriorating neurological disease that afflicts its victims with major declines in cognition, memory, speech, and individual ability for self-care.

It has been estimated that Alzheimer's disease afflicts more than 4 million persons nationally, but recent studies suggest that the number of persons affected by the disease is far higher, particularly in the population over 85 years of age, where the prevalence of Alzheimer's disease may approach 47% (Evans et al., 1989). Alzheimer's victims suffer insidious and unrelenting brain failure, progressing from simple forgetfulness to the need for total care in carrying out the simplest routine activities of daily living. The need for total care may span several years and may eventually result in institutionalization. The monetary cost of caring for chronically demented persons is estimated to be as high as \$80 billion annually in the United States alone.

There is a critical shortage in the availability of services to Alzheimer's patients, as well as a lack of appropriate services. Patients with Alzheimer's disease or other dementias are now most often cared for by

their families at home or, in the later stages of the disease, in nursing homes. Most Alzheimer's patients, including those who are in the moderate to severe stages of the disease, can remain in a home or community-based setting if families and caregivers are provided with appropriate supportive services. Put another way, given adequate supportive services, most families and caregivers could maintain a demented person in a noninstitutionalized setting for a significant period of time. Evidence suggests that this service arrangement is generally preferable for families because of its greater level of satisfaction and lower financial costs. Evidence also suggests that this service modality is beneficial to society as a whole because it can result in reduced health and social service expenditures as a result of lower utilization of institutional services.

Unfortunately, many moderate to severely impaired dementia patients cannot be adequately served by the existing community-based service system. First, there is a dearth of appropriate, accessible, cost-effective alternative services. Second, the existing home and community-based service system frequently cannot address the special needs of many of these individuals, due to their cognitive, functional, or behavioral characteristics. All too often, families and caregivers of moderate to severely impaired dementia patients are forced to institutionalize their family members for lack of other alternatives.

Over the last decade, many health and social service providers have turned to day care as an appropriate, cost-effective option. Day care or other forms of respite care are important alternatives to having family caregivers exhaust themselves by providing 24-hour-a-day care to family members with dementia, or to the inappropriate institutionalization of dementia patients who could still function at home with the proper supervision and support, as long as the primary caregiver has some relief in providing care. Alzheimer's day care is a community-based, long-term care program, the goals of which are (1) to provide a structured, secure environment in a congregate setting for persons with Alzheimer's disease, and (2) to provide respite from extended caregiving for family caregivers. Alzheimer's day care programs serve patients with various forms of dementia, their families, and their caregivers, regardless of the cause of dementia.

HISTORY OF ALZHEIMER'S DAY CARE

One way to gain a perspective on Alzheimer's day care is to examine the roots from which it has sprung. Alzheimer's day care programs are a natural evolution from the adult day care movement in the United States. Persons with dementia have always been served by adult day care programs and continue to be served by them today. Specialized programs for this population, however, are for the most part a relatively recent development.

Adult day care is a service that began to be provided in the United

States in the early 1970s, when it emerged as part of the movement to shift people out of state hospitals for the mentally ill and to prevent inappropriate nursing home placement. Stimulated by legislative hearings about nursing home care and the enormous growth in nursing home utilization with the advent of Medicaid and Medicare in 1965, consumers and advocates were determined to find alternatives to unnecessary or premature institutionalization. In addition to the growing concern about the quality of nursing home care, various studies found that many persons in nursing homes did not need the level of care provided there, but were there because no other alternatives were available for protective, supervised care. In response to that need, adult day care developed as a grassroots movement throughout the United States. Influenced by the British day hospital program, adult day care programs were started around the United States in the early 1970s by concerned people seeking to find a way to keep functionally impaired persons in the community.

The goals of adult day care programs generally include the provision of health and/or social services in one setting, an attempt to maintain individuals in the community rather than in institutions, and a philosophy that values treating the whole person with emphasis on a therapeutic milieu. The essential elements of adult day care programs are a structured day program in a safe environment where functionally impaired adults can receive the social and health services needed to restore or maintain optimal functioning. Hallmarks of these programs are an individualized, comprehensive assessment and a plan of care, usually involving multidisciplinary staff. Attendance is planned and regular. Although the primary target population is the impaired adult, day programs also serve caregivers. Respite for caregivers is provided while the participants attend day programs, and other direct assistance is provided through support groups, education, training, referrals, and counseling.

While researchers and policy makers have attempted to identify a number of different models for adult day care, over time it has become apparent that there are no clear-cut categories. In fact, what has been developed is a broad spectrum of programs providing a range of social and health services. While some programs emphasize a social orientation, others concentrate on health services. Therapies are directed primarily at maintenance of functional abilities. Distinctions blur between programs that emphasize social day care services and those that emphasize health day care, as programs strive to meet the range of needs of their participants. Categories or models of day care are often developed as a response to licensing and reimbursement requirements. Although some programs receive funds from the Older Americans Act and/or Medicaid, federal and state funding sources that specifically provide for adult day care are uneven, and they are generally inadequate to fund programs at their full operational level. Still, adult day care continues to grow despite the lack of a stable funding base. Attempts have been made in recent years to seek

funding support for adult day care programs at the federal level and to expand the level of support from state and local governments.

Although demented clients have always been served by adult day care programs, regardless of whether the programs emphasized social or health services, it was not until the 1980s that specialized programs for dementia day care generally came into being. Persons with minimal cognitive impairments often fit right into day care settings without much adjustment on the part of staff or other participants. And in many cases, adult day care programs can serve a limited number of more cognitively impaired individuals. But as a response to the increasing number of individuals with severe cognitive impairments, who often could not be served in generic day care centers, or who could benefit from more specialized services, a number of programs were established that had a particular expertise in serving demented individuals. Some of the earliest examples of adult day programs specializing in treating persons with dementia were the Harbor Area Adult Day Care Center in Costa Mesa, California, which was established in 1980, and the Alzheimer's Family Center, Inc., in San Diego, which was established in 1982. Other specialized programs started independently throughout the country in the early 1980s.

Specialized dementia day care programs started proliferating in the mid-1980s as a number of states provided funds specifically for Alzheimer's disease services, particularly in the area of day care. One example was the creation of the Alzheimer's Day Care Resource Center (ADCRC) Program in 1984 within the California Department of Aging. Starting with a budget of \$300,000 and 8 centers in fiscal year 1984-85, the program has expanded to 36 centers and \$2,160,000 for fiscal year 1989-90. These centers may either serve cognitively impaired and noncognitively impaired individuals together or serve demented individuals only. They operate under a variety of licenses, including both social adult day care and adult day health care licenses, and they vary dramatically in size and budgets. California's ADCRCs are day care/respite centers as well as resource centers for families of persons with brain impairments. The most frequently used services in California's ADCRC programs are day care, individual and group family counseling, individual and group patient counseling, and case management.

Many other states have encouraged or funded Alzheimer's or dementia day care programs (see appendix). Furthermore, there are numerous Alzheimer's/dementia day care programs around the country that do not receive any state support. Most of these programs are private, not-for-profit programs. Yet there are an increasing number of public and private for-profit Alzheimer's/dementia day care programs now in existence. Mace and Rabins (1984) conducted a survey to determine the number of day care centers serving dementia patients; they found nearly 450 that served this population, more than 80 of which indicated that 50% or more of their client population was demented. Since that survey was conducted, there

have been several initiatives, including those by the Alzheimer's Association, the Robert Wood Johnson Foundation, and the Brookdale Foundation, to expand the number of centers serving dementia patients and their families, and to explore the most appropriate and effective organizational, environmental, staffing, and care systems for service delivery to this population.

The rapid manner in which dementia day care programs have proliferated over the last few years is most clearly shown by the results of the 1990 National Adult Day Care Census Project survey of adult day care programs which was conducted by Zawadski and Von Behren (1990). Funding for the survey was from the American Association of Retired Persons and the Health Care Financing Administration in conjunction with the National Institute on Adult Daycare/National Council on the Aging. This survey of 1118 adult day care centers indicated that the number of adult day care centers in the U.S. serving dementia patients had grown dramatically, with 145 (13%) centers reporting they were established specifically to serve individuals with Alzheimer's disease, 524 (47%) reporting they have special programs for Alzheimer's patients within their center, and another 397 (36%) reporting they serve Alzheimer's disease patients within their adult day care program. Only 52 adult day care centers (5%) indicated they do not serve any Alzheimer's disease patients. This survey also found the median percentage of Alzheimer's disease participants served by all 1118 adult day care centers is 33%, and the percentage of center participants with cognitive impairments is 51% (not mutually exclusive). A particularly compelling point is that 21% of centers, or approximately 235 centers, have at least 50% or more Alzheimer's disease participants, nearly a three-fold increase since the 1984 survey by Mace and Robins. These current figures actually could under-represent the number and percentage of programs serving dementia patients, or exclusively serving dementia patients, given the difficulty in obtaining accurate diagnoses. However, the results of the survey clearly indicate that the number of programs serving this population is certainly very large, and is growing very rapidly.

PHILOSOPHY OF ALZHEIMER'S DAY CARE

Before addressing the planning goals and issues in starting a day care center for patients with Alzheimer's disease, there are several important philosophical constructs that should be understood. These include (1) who the day care client is; (2) day care's role as an alternative to institutionalization; (3) day care's role in the continuum of long-term care; (4) distinctions between integrated and specialized day care; (5) distinctions between health and social models of day care; and (6) day care centers' provision of a range of resources through multifaceted programs. We will address each of these in turn.

Client Dyads: Participant and Caregiver

As in all adult day care programs, programs that serve patients with Alzheimer's disease are providing important services to both family caregivers and patients. The fact that respite for caregivers is often just as important as, and in some cases more important than, the day care services provided for participants is the basis for considering the client of dementia day care programs as *both* the patient and the caregiver. Considering the patient and caregiver as a *client dyad* is a philosophy that is applied throughout this book. It is fundamental to most professionals' approach to serving patients with Alzheimer's disease and related dementias.

Alternative to Institutionalization

As part of benefiting both patient and caregiver, Alzheimer's day care often contributes to preventing premature or inappropriate institutionalization of the patient in a nursing home. Where avoiding institutionalization is possible, and where it is to the benefit of both patient and caregiver, we encourage it. However, we must caution that in the case of Alzheimer's disease and related dementias, there often comes a point where institutionalization is the preferable service alternative for both patient and caregiver. This happens when day care and other home- and community-based services can no longer meet the needs of the patient and/or caregiver. Furthermore, the danger in delaying institutionalization is that the level of care and management of behavioral problems required by persons with advanced dementia may make finding a suitable nursing home much more difficult.

Long-Term Care Continuum

Alzheimer's day care must be considered as part of a continuum of services for patients and caregivers. Alzheimer's disease and related dementias affect individuals differently; symptoms, rates of progression, and impact differ from person to person. Similarly, the impact of the disease on caregivers' ability to manage under the physical, emotional, and financial stress it brings differs dramatically. There are a wide range of services that are appropriate at different times in the course of the disease, to help either the patient or the caregiver. These services include home, community-based, and institutional services. It is becoming more and more apparent that Alzheimer's day care, and other services for dementia patients and their caregivers, has become a significant component of this continuum of care.

Integrated and Specialized Care

Adult day care programs have always served some patients with Alzheimer's disease or related dementias. Adult day care programs are often categorized by whether they have a health or social emphasis. *Adult day*

health care refers to an organized day program of therapeutic social and health services that serves elderly persons or other adults with physical or cognitive impairment, for the purpose of restoring or maintaining optimal capacity for self-care. These programs provide primarily maintenance services. *Social adult day care* provides nonmedical care and supervision to adults in need of personal services, protection, assistance, guidance, or training essential for sustaining the activities of daily living or for the protection of the individual. Like adult day health care, these programs provide social and related support services in a protective setting less than 24 hours per day, but they differ from adult day health care in that they do not have the same requirements for nursing and rehabilitative services. Regardless of the distinction, the vast majority of adult day care programs can and do serve some dementia patients. Generally, persons in the earlier stages of Alzheimer's disease can be easily integrated into any adult day care program. Difficulties often arise, however, when individuals with more severe cognitive problems or functional limitations try to participate in an adult day care program.

Since many adult day care centers are limited in their ability to serve individuals with moderate or severe cognitive impairments, many programs have been established solely to serve dementia patients, including Alzheimer's patients. Thus, a dementia day care program may be a stand-alone program that exclusively serves persons with Alzheimer's and other dementias, or it may be operated within a broader adult day care setting that serves noncognitively impaired individuals as well. While there are proponents of both forms of dementia day care, there is no evidence to date that specialization or nonspecialization of a center's participant population is any more or less successful. Establishing a dementia-specific versus a non-dementia-specific model is more a function of an agency's history or philosophy, or the range of cognitive and functional impairments of the participants to be served.

Health vs. Social Models

Alzheimer's day care programs operate in both health and social models. There are proponents of the policy that all dementia day care programs should have a nurse or other health professional as director or member of the staff. In contrast, many individuals feel that health care professionals are not necessary as permanent members of a program's staff but should be available on an as-needed basis. While there are pros and cons to each approach (which will be discussed in the text), ultimately it is important to note that both health and social models of dementia day care have been successfully and effectively implemented for patients with Alzheimer's disease.

Multifaceted Programs

Alzheimer's day care programs are often multidimensional, providing not only day care to participants and respite to caregivers, but also information and referral, family assistance, support groups, counseling, financial and legal consultations, and other types of direct services. Most programs are actively involved in training health and social service professionals as well as family caregivers. Many programs also participate actively in health and social service research.

CONCLUSION

The 1980s saw a rapid development in adult day care programs serving Alzheimer's patients and their families in the United States. From a handful of programs to hundreds of programs, Alzheimer's/dementia day care centers have proliferated to meet the demands of the burgeoning population of patients and their caregivers who are in desperate need of respite. Over the last decade a number of major events and initiatives have assisted the development of additional day care programs; these include the availability of public funds, state and foundation initiatives, and a groundswell of community efforts.

As in the case of adult day care in general, growth in Alzheimer's day care programs has occurred despite limited funding and lack of reliable sources of funding. Current and future initiatives may cause traditional funding sources, such as private health insurance, to begin covering Alzheimer's/dementia day care. Successful demonstration projects and proposed legislation may culminate in the inclusion of Alzheimer's/dementia day care as a Medicare benefit. Regardless of the outcome of these initiatives, Alzheimer's day care will continue to grow. Day care is a cost-effective service for both patients and families. Although there are no reliable government figures regarding the number of clients served, costs, or number of specialized programs, as the U.S. population ages and the number of persons with dementia increases, the demand for specialized day programs will inevitably continue to grow.

The development of day programs for specialized populations, such as persons with Alzheimer's disease and related dementias, should continue to be a major theme of health and social services for the elderly for the next several years. Regardless of whether Alzheimer's day care programs are specialized, have a health or social focus, or have any other distinctive features, they will continue to be established, and individuals, agencies, and communities need to understand the issues and challenges to be faced in setting up these programs. For the balance of this book, we will address the fundamental issues involved in planning, implementing, and managing an Alzheimer's day care program. Again, we emphasize that what we say applies to day care for dementia patients in general.

