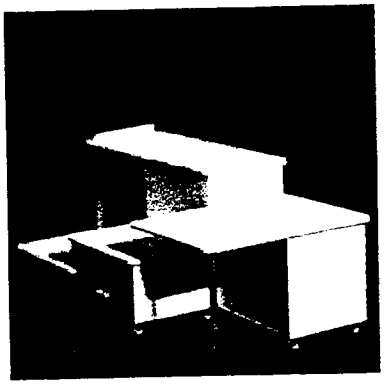
Chapter 2
The Evolving Context of Dementia Day Care



A Brief History of Long-term Care in the United States

In 1776, when the United States asserted its independence, the average life expectancy was 35. Advanced aging was of little concern. During the course of the twentieth century, however, biomedical advances facilitated a much larger number of individuals to survive to ages where issues of chronic illness and frailty become more likely. From a medical perspective, aging has historically been associated with longevity and maintaining physical health.

The twentieth century also brought with it dramatic shifts in demographic and social trends, thereby decreasing the likelihood families could provide daily care (e.g. Treas, 1977). These shifts, related to industrialization and urbanization, resulted in a changing social structure; one where the role of the older person was and remains ill-defined and often stigmatized (Atchley, 1988). These issues have only been exacerbated with time, to the point where many of the needs of our aging population go drastically unmet. Throughout history, how we as a society have addressed the aging has fundamentally been impacted by how we have conceptualized the issues. Historically, issues of aging have been seen to have two aspects: one biological or medical; and the other psychosocial.

The Medicalization of Aging: A Stress on Care Provision

Without question, the most influential perspective on shaping the care of the elderly to date in this country has been that focused on health care provision. This perspective -- what many controversially refer to as "the medical model" (e.g. Johnson & Grant, 1985; Weissert, 1990) -- holds the underlying premise that "the presenting problem is a disease condition that needs treatment, the subject is a patient with presenting symptoms, and the relevant background factors area health history and the etiology of the disease" (Johnson & Grant, 1985: 140). This position results in the care of the elderly being viewed in terms of treatments provided by care professionals to address a specified problematic condition. More specifically, problems are defined pathologically and interventions are conceptualized as isolated and singular events. Because of this, such a perspective has been called reductionist; eliminating or "controlling" the impact of all aspects of experience external to the "cause and effect" inter-action. This perspective is thus interested in identifying and defining the elements of both pathology and treatment and

attempting to develop universal laws that govern such interactions.

This perspective is more at ease when specific services are rendered to achieve specific outcomes and are done within a controlled setting. Institutions for the elderly have thus emulated the hospital as its place-type exemplar. This was reified by the U.S. Government in 1954 when the Hill-Burton Act was expanded, resulting in nursing home regulation being heavily influenced by hospital regulation (Vladeck, 1980). This is why many nursing homes share common characteristics with healthcare settings such as shiny floors, double-loaded corridors, cinder block construction and so forth. In the spirit of control, the 1960's saw a movement toward establishing a continuum of care, one in which specific needs are served within different facility types.

Aging as a societal issue has only emerged within the last century, and because of historical circumstance, has been in many ways "medicalized."

Additional alternatives to SNFs and ICFs emerged in the 1970s, driven by the spirit of developing a care continuum. These alternatives included residential care facilities (sometimes referred to as "board and care"), congregate housing, retirement communities and senior centers, each responding to specific community-based needs. These alternatives were also conceptualized as filling out the continuum of options. The continuum of care conceptualization often results in a "boxcar" approach to long-term care where older persons move progressively from home in increments up to skilled nursing care. The level of service provided was invariably coupled, through regulation, with a given environment type, reflective of the remaining cultural baggage of institutionalizing care for the elderly.

While this makes logical sense from the point of view of service provision, there are very few elderly persons that experience this progression. Most, quite simply, do everything in their power to remain in their homes as long as possible.

An Alternative Approach: The Socialization of Aging

During the 1960s, many gerontological researchers began to find that nursing homes, based upon on acute care model, were simply inappropriate for serving people with chronic conditions. In many cases, such environments in fact exacerbated the difficulties associated with life with a chronic condition (e.g. Goffman, 1961; Lawton & Simon, 1968). These researchers illuminated the significant shortcomings associated with the reductionist medical perspective. There was more at work in the life of the elderly than simply pathology and planned treatment; there is a complex dynamic

at work in environments for older persons.

An emerging perspective over the past 25 years emphasizes the social aspects of aging.

Lyman (1989: 604) argued that underlying this new perspective was the recognition "that all human experience involves intentional social action and interaction, in socially structured environments, in the context of taken-for-granted socially constructed knowledge about aging, development and disease." Immediately, Lyman's take is starkly different than that of the medical perspective in that here, people are viewed as purposive and thoughtful as opposed to simply responding to external stimuli. Within this perspective, issues of meaning and intention come to the fore. Critical discussion surrounding such issues as self-identity and the meaning of home ensued and the importance of continuity emerged as essential to the elderly's quality of life.

Adult Day Care and the Social Perspective

In reaction to the "over-institutionalization" of the elderly and also in response to the desire for the elderly to stay in their home communities, adult day care emerged as a chronic care alternative in the 1970s. While some long-term care organizations have envisioned adult day care as an entry point, or first "boxcar" of their continua, as early as 1982, Clark conceptualized adult day care as offering a broad array of services spanning the entire continuum of care. Rather than being thought of as one of the boxcars in the continuum of institutions, adult day care came to be modeled as a complimentary alternative, paralleling the continuum of care.

As a community-based alternative to the long term care continuum, adult day care stresses responsiveness to the needs of its constituents, and this fluidity is partially responsible for the ill-defined nature of adult day care as it currently exists.

Adult day care has traditionally been truly community-based, responding to the needs of the community and specifically the needs of participants. Thus many adult day cares have found their service provision to be fluid; changing and adapting to the needs of constituents. This has resulted in a tremendous diversity in the adult day care industry. While this diversity reflects adult day cares' attempt to respond and adapt to the needs of participants more than any other aspect of the continuum of care, it has had the less desirable result of causing confusion among regulatory and funding bodies as well as among the public at large. It has also placed adult day care in a competitive climate with a variety of the institutionalized approaches to elder care. For instance, many adult day cares provide services to clients with needs even beyond that found in most assisted living settings. While an important part of the long-term care equation, the confusion about what adult day care is among the public; the competitive situation with more established and well-known forms of long-term care; and the precarious regulatory and financial

situation all have made adult day care a difficult proposition.

Adult Day Care As An Alternative To Institutionalization

Adult day care continues to explode, doubling in number roughly every ten years.

Yet, adult day care continues to grow exponentially, from over 1200 adult day cares in 1986 (OnLok Senior Health Services, 1987), to 4000 by 1997 (National Institute on Aging, 1997) and an expected need for 10,000 adult day care programs by the year 2000. This growth in such an alternative to traditional long-term care reflects adult day care's ability and desire to respond more quickly and appropriately to the needs of the communities they serve. Such growth has thought to be stunted by society's general unawareness of this alternative, and the uncertainty and complexity of funding streams faced by adult day cares. The first point has served as the rationale for the marketing focus found in the Robert Wood Johnson Foundation's Partners-in-Caregiving project (c.f. Cox, Reifler & Yates, 1998). The second point has led to most adult day care operators, out of necessity, taking a "lasagna approach" to funding; layering a variety of public sources together with philanthropic sources and client out-of-pocket payments.

Bradsher and colleagues (1995: 20) state that, "this places ADCs in a position of economic uncertainty, focused on survival and maintaining the flow of funding, and on maintaining organizational viability (Scott, 1987)," and that because of this precarious situation, "ADCs are in a constant state of adaptation in regard to their funding and regulatory environment. In turn, the environment shapes the delivery of ADC services." The environment to which Bradsher and colleagues refer is the context of adult day care, which has regulatory, financial, competitive and historical dimensions. From this discussion, it is evident that adult day care plays at the precarious edge between the driving momentum of community need and the inertia of institutionalizing the aged.

Adult day care is difficult to define as it is a service program and place-type still to be defined by society. Defining adult day care has and remains a source of debate within the adult day care community to the point that Webb (1989: 15) warned, "if we redefined its definition, we would diminish its potential!" In many ways adult day care organizations have come to accept operating in an uncertain world. However, aware of the need for some agreed to definition, the National Adult Day Services Association (1997: 1) wrote that,

"Adult day services are community-based group programs designed to meet the needs of adults with impairments through individual plans of care. These structured, comprehensive, nonresidential programs provide a variety of health, social,

and related support services in a protective setting. By supporting families and other caregivers, adult day services enable participants to live in the community."

This last sentence is the raison d'etre for adult day care, which immediately thrusts its efforts in sharp contrast to traditional long-term care. The other two sentences attempt to describe adult day services in a fashion that implicitly juxtaposes it with the commonly held understanding of institutional living. The first sentence stresses that adult day services are community-based as opposed to institutional, thereby maintaining the person from the community. The same sentence also stresses that people receiving adult day services are receiving individualized care, however, the nature of that care is not expressed until expounded upon in sentence two. The second sentence emphasizes the multidimensional and holistic approach to care found in adult day care. The uncertainty, the concern for the unique over the general, and the multidimensional approach reveal that adult day care conceptually operates within the social perspective toward aging. So here is a place-type fundamentally acting according to a social perspective but operating within constraints imposed by a contradictory paradigm – that of the medical perspective.

Alzheimer's Disease and the Social Perspective

While still the reigning paradigm, the medical perspective has been found to be grossly incongruent with the psychological and sociological needs of most elderly (e.g. Johnson & Grant, 1985; Kane & Kane, 1978). Important in the recognition of the inadequacies of the medical perspective was its incessant failing to address effectively the needs of the elderly with cognitive impairment. Many expert researchers in dementia care began to point out that behavioral symptoms in persons with cognitive impairments were being exacerbated by common aspects of nursing home life, such as noise, glare, lack of exercise, and use of restraints (e.g. Hall & Buckwalter, 1987; Reifler & Larson, 1989).

In the 1980s, there was also growing social awareness of Alzheimer's Disease, its devastating impact on the socio-behavioral abilities of individuals and its impact on their families (socially, emotionally and financially), which found currency in political debate. Not only was society aging, but also with people living longer and chances of cognitive impairment growing as age increases, there was concern for the "coming epidemic of dementia" (Jorm, 1987: 10).

Such conclusions raised increasing criticism toward nursing homes as places for the care of those with dementia. Those elderly experiencing dementia revealed the "chinks in the armor" of the institutionalized long-term care system which assumes, and often imposes, order and regularity. The manifestations of dementia and how the syndrome progresses have a wide variance. Also, researchers began illuminating that the behavioral manifestations associated with dementia of the Alzheimer's type was not solely the effect of pathology, but rather had psychological, social and environmental aspects to them. This is problematic as once labeled as "demented," behaviors of individuals are often interpreted within that frame of reference. There is a social stigma attached to Alzheimer's; one that has significant impact on care. Gubrium (1978: 28) succinctly identifies the core issue regarding dementia care when he observes, "I have found that who or what behavior is spoken of or recorded as senile depends on place....By place, I mean geographic locations...that are taken for granted to have certain meanings on particular occasions when specific people are gathered there."

Adult day care is currently being heavily advocated for use by the Alzheimer's Association which sees ADC as a significant vehicle to meeting the needs of those with dementia in a manner that allows those individuals to remain in the community.

The Context of Dementia Day Care

In this brief overview, it becomes clear that adult day care exists in a muddled context; one in which the medical orientation of funding streams and of regulation are in stark conflict with the aspirations of adult day care. Such conflict has precluded efforts to define what adult day care is, leaving society at-large uncertain about the services and potentials associated with this place/service type. Unfortunately, adult day care providers have embraced this lack of definition, believing it creates opportunities for innovation. However, this is in response to prescriptive regulation that often stems from societal definition – this is why nursing homes look like hospitals. However, another manner in which a place could be defined is in terms of performance characteristics. What qualities does this sort of place engender?

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In a comparative case study of three adult day cares serving the cognitively-impaired, Diaz Moore (2000) found that in regard to five salient therapeutic goals established in the dementia care literature (c.f. Cohen & Weisman, 1991), these adult day cares were only slightly positive in terms of adaptability, and negative in terms of control, sociality, orientation and stimulation. Considering how critical place is for those with dementia, for whom "a small improvement in environmental quality could make all the difference in the world (Lawton, 1986: 14)," this quality assessment suggests that as currently embodied, adult day care as a place type is

Due to its ill-defined nature, adult day cares are generally not as therapeutically beneficial for people with cognitive impairment as they should strive to be.

woefully lacking in facilitating the therapeutic benefits sought for those with dementia. Diaz Moore concludes by suggesting that adult day care could be so much more than it is in its current languishing state and asks, "what kind of place do we want it to be?"