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The Value of Independence in Old Age

Paula C. Carder
Portland State University

THE VALUE OF INDEPENDENCE IN OLD AGE

by

PAULA CHRISTINA CARDER

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COMMITTEE APPROVALS:

[redacted]
David L. Morgan, Chair

[redacted]
Nancy J. Chapman

[redacted]
Michael R. DeShane

[redacted]
Elizabeth A. Kutza

[redacted]
Patricia A. Schechter

[redacted]
Michael J. Flower
Representative of the Office of Graduate Studies

DOCTORAL PROGRAM APPROVALS:

[redacted]
Henry D. Kass, Program Coordinator
Ph.D. Program in Public Administration and Policy

[redacted]
Nohad A. Toulan, Dean
College of Urban and Public Affairs

ABSTRACT

An abstract of the dissertation of Paula Christina Carder for the Doctor of Philosophy in Public Administration and Policy presented May 7, 1999.

Title: The Value of Independence in Old Age

Why is independence a central theme for proponents of assisted living facilities? How do assisted living providers respond to this theme? These questions are pursued in an ethnographic study centered on Oregon's assisted living program. Assisted living facilities (ALF), defined and monitored by Oregon's Senior and Disabled Services Division (SDSD), are a type of housing for disabled, primarily elderly, persons. Oregon Administrative Rules (OAR-411-56) define independence, requiring ALF providers to support resident independence.

Using social worlds theory as a sensitizing concept, assisted living is treated as a distinct social world. The activities of key groups, including SDSD staff, an ALF professional group, and assisted living managers, are described. These members commit to a "social model" approach to long-term care for which independence is the unifying construct. This approach offers a value-practice "package" that explains how to implement the value of independence (Fujimura, 1997). Three arenas where this package is apparent are described: marketing, manager training, and daily operations.

Content analysis of marketing brochures from 63 assisted living facilities shows that independence is a dominant theme, promoted like any other product. These

materials indicate that assisted living operators promote resident independence by providing a barrier-free environment, helping residents with daily tasks, and allowing residents control over their decisions.

Manager training programs are another arena where the policy value of independence is evident. Here, new managers learn "who we are" and "what we do" in this social world. They learn a new vocabulary and are introduced to tools for daily practice. They learn the boundaries of this social world, and above all, how to behave differently from nursing facilities that they associate with the "medical model."

In daily practice, managers use institutional conventions, including the "negotiated service agreement" and "managed risk agreement." These tools are designed to respond to the tension between supporting independence and providing care to chronically ill, disabled individuals.

Observations of marketing, management training, and resident assessments indicate that the social world of assisted living is in a formative stage, as members attempt to define and legitimate who they are and what they do.

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Chapter 1

Introduction and Background

This research explores the intersection of the recent marketing boom in assisted living facilities, the American cultural concept of independence, and the human phenomenon of aging. Assisted living facilities, as implemented in Oregon since 1989, represent a philosophical departure from existing types of senior housing and services, especially nursing homes. Wilson (1991) and Regnier, Hamilton, and Yatabe (1991) stated that assisted living facilities (ALF) conform to a "social model" approach as opposed to a "medical model" approach to the health, social and personal care services that many aged individuals require on a daily basis. Assisted living proponents argue that the medical model treats individuals only in terms of medical diagnosis while the social model considers the individual holistically, as a multi-dimensional being with psycho-social needs in addition to biological needs.

Oregon's Administrative Rules (OAR 411-56) for assisted living facilities, adopted in 1989, list six human values as defining features for the development and enactment of assisted living: independence, individuality, privacy, choice, dignity, and a home-like environment. The value of independence, as viewed from a variety of contemporary perspectives, is the focus of this study. This value, and the social model ideology as presented by Oregon's assisted living proponents, may explain the national interest and growth in numbers of assisted living facilities since 1990. In Oregon alone, the number of facilities grew from three in 1989 to 74 in 1996 when

this research began, and to over 100 in 1998. This thesis seeks to explain why.

At first glance, the goal of supporting the independence of chronically ill and disabled elderly persons (generally aged 80 and older) seemed paradoxical to me. When I initially told a committee member of this interest in how assisted living facilities promote independence, she said, "That's just the marketing." Is it? Why is independence a new and central concern in long-term care? How do assisted living facilities, on a daily basis, keep the promise of promoting independence for frail individuals who are at a "liminal" (Turner, 1967, cited in Shield, 1988) stage in their life cycle? Assisted living facilities (ALFs) certainly promote an image of independent living in a "home-like" setting for seniors. The target population, people in their seventh, eighth and ninth decade of life, are in transition between living at home, representing ultimate independence for frail older persons, and moving to a nursing home, representing ultimate dependence and loss of freedom, privacy and dignity.

This study asks a set of cultural and policy questions. Why is independence a central theme for Oregon's assisted living facility program that was designed for frail older persons? How do ALF providers attempt to support independence on a daily basis?

In order to study these concepts, it became necessary to place a boundary around the area of research. The existing scholarship on which I rely considers the development of assisted living facilities as a distinct "social world." My thesis is that

independence serves as a unifying construct in the creation of this social world, and that the independence understood at the institutional level requires webs of interdependence among key groups. These groups include Senior and Disabled Services Division (SDSD) staff, Oregon Assisted Living Facilities Association (OALFA) representatives, and ALF managers and staff. By especially focusing on the work that assisted living proponents do, I explain how various actors with varying stakes in the enterprise attempt to define and enact the public policy defined value of independence.

This introductory chapter presents the organizing framework, defines the key terms, summarizes the research methods, and outlines the findings of my research.

Social Worlds Theory

The organizing framework for this study considers assisted living as a "social world" (Becker, 1982; Clarke 4,1997; Fujimura, 1997; Strauss, 1982). A social world refers to "a set of common or joint activities or concerns, bound together by a network of communication" (Strauss, 1982: 172). In the language of this theory, assisted living is the result of "collective action" among key groups who have a "legitimate" and "shared commitment" to work that will achieve certain goals. This is not to suggest that all members of the assisted living world, including private developers, policy makers, providers and clients, share the same motive. For some, the motive might be profit, for others, a less costly alternative to institutional care, and for others, a safe

place to live. However, the groups described here do have an interest in seeing assisted living succeed, regardless of personal motives, and the very nature of the work requires interdependent relationships, commitment, and cooperation at many levels. The social worlds framework is used here not as a theory to be tested but rather as a sensitizing concept that provides, in Clarke's words, "suggestive ideas about what might be potentially fruitful to examine and consider, an emergent meaningful vocabulary that alerts the researcher to promising avenues of investigation" (Clarke, 1997, p. 65). The terms and conceptualizations of this framework allow one to consider the language and actions of groups as well as individuals. Social worlds theory[1] considers work a central research focus. What work is necessary, by what actors, to create and sustain a social world? These individuals, or groups, compare themselves to other people or groups, in order to define and legitimize their own behaviors to ascertain that their actions are appropriate. In the present case, I will show how assisted living proponents look to nursing facility operators to decide what not to do in defining and legitimizing their actions. The members of the social world share a "commitment" to a central idea or agenda as the basis for their actions. In this case, the notion of a "social model of care" is the source of commitment the identified groups have to assisted living. Finally, the social worlds perspective is founded on the

[1] To provide a brief example before continuing with what may be familiar terms used in unfamiliar ways, the concept of the "scientific community" is offered as an example. This social world is constructed by scientists, government, the media, and various advocates. These reference groups have a shared commitment to, for example, scientific freedom, basic research, and external funding that will lead to improvements in human life, environmental protection, or industrial efficiency. The arts (Becker 1982),

sociology of legitimation. What makes this world legitimate? How believable are the claims made by various individuals and groups? What distinguishes this world from similar social worlds? The fact that assisted living in Oregon has an established boundary, as defined by state rules, helps organize this research. More detail on the social worlds framework is provided in Chapter Two.

Key Terms

In Oregon, assisted living facilities are an apartment-style housing alternative to intermediate-care nursing facilities and are state-licensed and monitored. The purpose of this housing model, according to SDSD, is to provide long-term care services in a non-institutional living environment to elderly people in need of daily support services. Thus, assisted living facilities attempt to respond both to needs (help with bathing, cooking, medications, and transportation) and wants (apartment-style living with privacy, choice, and independence) of clients.

Oregon Administrative Rules define assisted living.

> Assisted living means a program approach, within a physical structure, which provides or coordinates a range of services, available on a 24 hour basis, for support of resident independence in a residential setting. Assisted living promotes resident self-direction and participation in decisions that emphasize choice, dignity, privacy, individuality, independence and home-like surroundings. (OAR 411-56-005-#6)

A typical assisted living facility includes private, unfurnished apartments (from fewer

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social movements (Lofland 1996), and science (Clark 1997; Fujimura 1997) have all been studied as social worlds.

than ten to over one hundred) and a variety of shared spaces, including one or more dining rooms where meals are served three times daily, social activity rooms, and laundry facilities. Residents may choose to share an apartment with another person, but regulations prevent forced sharing. All apartments must be handicapped-accessible and include a kitchenette, private bathroom, locking doors, individual temperature controls, telephone hook-up, and an emergency call system. Many facilities permit pets. Most Oregon facilities, including all three facilities observed for this study, accept Medicaid clients. Monthly fees are based on apartment size and the number of services required or desired by the individual, but the price ranges from fifteen hundred to well over three thousand dollars per month.

Another key term of importance for this introduction is "independence" which means, according to the State guidelines,

> supporting resident capabilities and facilitating use of those abilities. Independence is supported by creating barrier free structures and careful design of assistive devices. (OAR 411-560-010-#13)

As mentioned, independence is a central concept in the social model. Of the six defined values, independence is most closely linked to existing gerontological research and practice. One important example of this link is the experimental psychological research conducted in U.S. nursing homes in the early 1970s (Langer & Rodin, 1976; 1977). Nursing home residents in the experimental group received a plant to care for and what the authors called a "responsibility scenario" in which residents were given control over a set of specific decisions made within the facility. This group fared better

than the control group who receive neither a plant nor choice about facility decisions. Langer and Rodin's work, based on the "locus of control" psychological theory, inspired other experimental research validating the importance to institutionalized persons of control and independence in their daily lives (e.g., Baltes & Zerbe, 1976; Baltes, Neumann, & Zank,1994; Schulz, 1976). Environmental psychologists (Howell, 1980; Lawton, 1980; Moos & Lemke, 1985) added the relationship between physical environment and independence to this research. This work was then built on by architects who developed designs to support the independence of frail and disabled elders (Regnier & Pynoos, 1987; Regnier, Hamilton, & Yatabe, 1991). Thus, as the most empirically grounded of the six values, independence serves as a legitimate and scientifically sound "unifying construct" (Fox, 1989) for the social world of assisted living.

Finally, the social model construct is important to this research because it is described here as the basis of the commitment shared by key groups in this social world of assisted living. In 1989, SDSD staff produced a white paper, entitled "Assisted Living: A social model approach to services," that defined the social model as:

> beginning with a premise of looking for [the individual's] capabilities and strengths in day to day activities. In this social model there is an assumption that all individuals should have a right to live independently with respect for their privacy and dignity, free from restraints... The resident, family members, and other significant people sit down together to assess what is needed to support the resident in their greatest capacity for living independently. (Senior and Disabled Services Division 1989)

The policy paper emphasized the importance of supporting resident independence in enacting the model.

The "social model" became a subject of gerontological discussions in the late 1970s with the development of community-based care options for frail elders, especially adult day care centers for individuals with physical disabilities and cognitive impairments. In particular, the On Lok Senior Health Services Center in San Francisco set the standard for the social model approach. There, program goals included avoiding institutionalization of the primarily Chinese clientele, integration with existing community services, multi-disciplinary staff, and social activities (Ansak, 1983). Client independence, privacy, and control were other components of this approach. The social model literature typically presents the concept in relation to the prior "medical model" approach to long-term care. For example, the medical model views the individual as "someone with a medical dysfunction requiring treatment" while the social model considers medical diagnosis as only one of several needs, including psychosocial, housing, transportation, and financial needs (Smith & Eggleston, 1991, p. 34). The medical model is associated with hospitals and nursing homes and with medical responses to acute rather than chronic health conditions common to people over age 65. The way in which assisted living proponents define their actions in contrast to nursing homes is informed by the existing discussion of social and medical model comparisons.

The focus of this study is on the value of independence. As mentioned, Oregon's

administrative rules for assisted living facilities define a set of six core values. These six values are interconnected in varying ways. The nature of private apartments both requires and allows for a certain level of independence. It suggests that the individual does not require constant surveillance by staff members. The ability to make choices is also clearly linked to independence, especially as available choices diminish (Rubinstein, Kilbride, & Nagy, 1992). Individuality, the right to behave and be treated as a distinct person, is interconnected to the above values as well as to a larger societal understanding of what it means to be an American. Individualism and autonomy are two cornerstones of U.S. governance. As a country, we are independent of foreign rule. As individuals we are free to choose where and how we live, what we say and believe, and to make poor or foolish choices so long as by our own actions we do not impinge on the rights of others or, in certain cases, do not put ourselves at undue risk for death or serious injury. Dignity is also connected to the above in terms of the respect afforded the individual to make choices, to be free, and to have privacy. The final value, "home-like," evokes emotional images of home and the related concept of property rights, another foundation of American governance. We are free to behave as we choose in our own homes. In Oregon's assisted living facilities, residents rent rather than own their apartment units, but the concept of property rights, added to the psychosocial attachment individuals have to personal items (Rubinstein, 1987), results in practices by which staff members consider each individual's apartment as their home (i.e., knocking before entering). That independence is the primary focus of this

study is partly a matter of research design practicalities—it set a clear focus for field observations and interviews. I do not mean to suggest that independence is the most important value although I will present evidence that independence serves as an organizing principle for assisted living proponents.

Although the Oregon Administrative Rules and SDSD definitions are important to this study, the primary goal is to examine how the social world of assisted living is constructed by multiple actors in three defined situations: marketing, manager training, and the resident assessment process. Rather than beginning with *a priori* definitions, emphasis is on multiple constructed realities in the context of work activities performed by the key groups inhabiting this social world.

Research Methods

The methodology includes content analysis of printed marketing materials, an ethnographic study of three assisted living facilities, analysis of the state policy that defines and monitors assisted living, and participation in several SDSD-OALFA sponsored assisted living manager training programs. Although the Oregon Administrative Rules are of interest, this is not a traditional policy analysis given that the goal is not to measure specific outcomes or implementation strategies. Instead, the goal is to examine assisted living proponents' claim that assisted living facilities promote resident independence.

The data were collected using traditional ethnographic methods, including

participant observation, in-depth and informal interviews, and analysis of text-based institutional documents produced by assisted living owner/operators and SDSD. The unit of analysis for conceptualizing a social world may be either individuals in relation to their social world, or the social world as the unit of analysis, as in the study of collective action. The primary focus in this analysis is the latter, including the activities of assisted living operators, staff, residents, and families, and educators affiliated with SDSD and the OALFA. The research plan is detailed in Chapter Three.

Relevance

By explaining why and how assisted living proponents commit to the social model approach and the construct of independence, I hope to inform the on-going policy discussion related to quality care outcomes in assisted living (AARP, 1996; Wilson, 1996). In these debates, a major concern revolves around how to implement values like independence and how to measure success. My contention is that a better understanding of the role of independence as a policy directive for assisted living operators is vital to such debates. The present work represents a window into the underlying assumptions of assisted living advocates of the late 1990s. As such, it serves as a valuable historical marker for future long-term care changes; as new alternatives are offered and the current model expands and shifts, future policy makers, developers and other senior advocates may ask why and how things are the way they are. This document will provide part of the answer. By making problematic the commitment that assisted living proponents have to independence and a social model

of care, I do not mean to suggest that these goals are wrong or misdirected. Rather, I begin from where assisted living proponents say they are in an effort to explicate how and why this is so or not. My hope is that assisted living proponents will find both explanations for their current assumptions and directions for their future behavior in these pages.

Document Overview

Chapter Two highlights relevant literature, including gerontology, long-term care policy, and ethnographic research. Chapter Three details the research strategies employed. Chapters Four, Five and Six include the findings, beginning with the most "outsideness" and moving to the most "insideness" (Marshall & Rossman, 1995) of this social world. Specifically, Chapter Four is based on content analysis of marketing materials produced by 63 assisted living facilities in Oregon. Chapter Five, based largely on participant observation in assisted living manager education courses, details how managers, staff, residents and families are socialized to the assisted living values, focusing on independence. Chapter Six describes the institutional event when each resident's independence is formally defined, the resident assessment process. This is the event that brings together the key groups, although they have different perspectives about the central concern of independence. Chapter Seven summarizes the thesis, explaining the reasons that independence is considered a value in old age by assisted living proponents and that the social world of assisted living facilities is still a work in

progress. In addition, policy and practice implications are presented, including the importance of providing a policy "package." I critique the contemporary assessment process, the problem of using independence as an outcome variable in evaluating success in assisted living facilities, the limitations of the "least restrictive alternative" argument, and the role of interdependence in enacting the social model. Finally, I offer suggestions for training direct care staff and for future research on assisted living.

Chapter 2

Literature Review

Independence is an American[2] cultural value idealized by people of many ages. It is also a major subject area in gerontology. The relevant literature for this research derives from three primary sources: gerontology, senior housing, and ethnography, especially in nursing facilities. This chapter is organized around these multi-disciplinary arenas.

Gerontology

In gerontology, several theoretical approaches and practice concepts share a central, organizing theme of independence. Early theories included a basic, if implicit, reference to independence. For example, in "disengagement theory" (Cumming & Henry, 1961), older persons became more separate from, or independent of, the larger society. In "activity theory" (Maddox, 1970), older persons increased their well-being if they maintain an active, independent lifestyle. Even though each theory has been criticized by gerontologists (Estes, 1979; Hendricks & Hendricks, 1986), it is noteworthy that independence was an underlying theme of these two early gerontological theories. Many practice concepts are based on the idea that independence is the opposite of dependence, with dependence referring to physical disability, limited economic resources, or need for assistance with daily living needs.

[2] It must be noted that this value is not common to all races or ethnic groups (Clark 1969; Jitapunke,

In practice, many programs and policies attempt to avoid dependence by supporting independent living, whether through housing and transportation services (Golant, 1992) or home-delivered and community-based services (Kane & Kane, 1987).

Among the various theories and practice concepts are overlapping disciplinary threads: independence as a right, based on the concept of autonomy, and independence as an ability, defined as mental or physical function. Hofland's (1988) typology of gerontological research on autonomy included three disciplinary perspectives: law (freedom and rights), medical ethics (informed consent and self-determination), and psycho-social (control and independence). Basic concepts from these disciplinary headings, presented here in parentheses, are central to the theories and practices of assisted living proponents. In particular, two conventions adopted by assisted living practitioners, the "negotiated service agreement" and the "managed risk agreement" are based on the above concepts. How and why this is so will be detailed in Chapter Six.

Public policy is another disciplinary influence on gerontology. How should government respond to the needs of frail, often poor, seniors? From an economic perspective, there is value in promoting independence because of the (perceived) high cost of dependence to long-term care programs (Rivlin & Weiner, 1988). Dependencies in terms of physical ability, economic and/or social status, and how to transform dependence into independence, are primary topics of concern in policies

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Kamolratanakul, and Ebrahim 1994).

designed for older persons, especially given the economic costs of long-term care (Kane & Kane, 1987; Rivlin & Weiner, 1988). The sources of these costs derive from personal care providers, transportation, homemaker, lost wages for family caregivers, and health care among others.

In 1988, a supplemental issue of The Gerontologist was devoted to autonomy and long-term care. Discussions ranged from alarm over the high costs of dependence (i.e., immobility, economic resources and medical assistance) to interest in community-based and social models of long-term care in which the individual is viewed as a consumer deserving of choice and control over his or her individual circumstances.

Case managers and policy makers for the elderly often cite the goal of avoiding institutionalization by providing the "least restrictive environment." However, Cohen (1988) argues that this attitude does not promote independence, and that instead program goals should include a commitment to the "right to flourish," defined by the individual. This concept is explored in the Sixth and Seventh chapters. The principles of assisted living facilities appear on the surface to support this notion of thriving rather than merely surviving. Explaining what this looks like in practice is one goal of the present study.

Senior Housing Worlds and Assisted Living

Assisted living facilities, although considered as a unique social world here, exist within a larger world of senior housing and societal attitudes about age-segregated

housing. Although nursing homes and retirement homes might make up the total popular understanding of senior housing, a wide range of categories exist. Assisted living is not a new idea given that life-care communities, continuing care retirement communities, and retirement housing have been available for several decades, offering at least some base level of assistance. Nationally, assisted living facilities are typically seen as existing somewhere "between independent living and nursing care" (Golant, 1992, p. 249). In Oregon, one goal was to offer an alternative to the intermediate level of nursing facilities (Kane & Wilson, 1993). In theory, Oregon's assisted living residents should be comparable, in terms of functional ability, to intermediate nursing care residents.

People move into assisted living facilities because they have needs, not because they are looking for leisure amenities common to retirement housing (i.e., golf, tennis, or swimming). They "are no longer able to live alone and unsupervised in their conventional dwelling" (Golant, 1992, p. 249). Assisted living facility residents are said to include two types. The first group include those who have relatively few physical impairments but have mild confusion, memory loss, or judgement problems, and the second group include those with one or more chronic health conditions requiring physical assistance with daily activities, but not on-going skilled nursing care (Regnier et al., 1991). A 1996 national survey conducted by the Assisted Living Federation of America indicates that the typical resident is "an 84-year old female who needs assistance with three activities of daily living" (AARP, 1998a, p. 1). In addition,

48% of assisted living residents reportedly have cognitive impairments and 38% use a wheelchair.

Oregon is a good place to study this housing model because the rules have been in effect longer than any other state. In fact, the American Association of Retired Persons reports that Oregon "pioneered the development of assisted living as an alternative to nursing home care" (AARP, 1998a, p. 3). Oregon's first licensed assisted living project, for private-pay clients only, was built in 1982 (Wilson, 1990). Senior and Disabled Services Division supported a Medicaid-demonstration project in 1987 and, in 1988, received a 1915(d) Home and Community-Based Waiver from the Department of Health and Human Services in order to waive some Medicaid requirements. This allowed many Medicaid-eligible clients to choose from an array of home and community-based services, including assisted living. Since then, SDSD has actively promoted assisted living and other community-based alternatives (e.g., adult foster care, homemaker, home health, congregate meals, residential care facilities).

Efforts to provide a range of services are, in part, a response to consumer demands. Aging advocates in Oregon pressured SDSD to support alternatives to institutionalization, ones that would support human values such as dignity, independence, and privacy (Hudson, 1991). Beginning in the late 1970s, a series of meetings between advocates and policy-makers led to the development and expansion of Oregon's successful adult foster care program (Kane, Kane, Illston, Nyman, & Finch, 1991) and to changes in the structure of the state's human services program

(Justice, Etheredge, Luehrs, & Burwell, 1988).

Currently, more than thirty states have or are developing regulations for assisted living facilities (Mollica, Wilson, Ryther, & Lamarche, 1995) and there are efforts to create national regulations and a common definition of this housing type (Wilson, 1996). The proposed national definition, but not all state definitions, include definition of and commitment to independence and the other Oregon values. The goal of promoting independence is based on an assumption that encouraging independence is a means of maintaining and promoting health and wellness. Independence is considered a quality of care issue in assisted living (Wilson, 1996) the way that lack of restraints or few patients with decubitus ulcers are quality care indicators in nursing homes. A recent AARP "Fact Sheet" (1998a) indicated the influence that Oregon's administrative rules have had on the overall understanding of assisted living in the United States:

> The philosophy of assisted living emphasizes personal dignity, autonomy, independence, and privacy. The objective of assisted living is to maintain or enhance the capabilities of frail older persons and persons with disabilities so that they can remain as independent as possible in a home-like environment. Assisted living also enhances a resident's ability to "age in place" by providing services that intensify or diminish, as resident's needs change. (AARP, 1998a, p. 1)

Existing Studies of Assisted Living

To policy planners, advocates, and researchers, "assisted living" is a "program" of care, a philosophy, and the newest phenomenon among long-term care options for frail

elders. Many people are curious about this housing model: Is it less expensive? Are resident outcomes better or worse than those in other settings? Will it replace nursing homes? Are residents satisfied? Recently, a few investigators have begun systematically addressing these questions. For example, Kane, Huck, and Frytak (1996) compared assisted living and nursing facilities in Oregon, Hawes (1996) examined assisted living policies, services, and residents at the national level, and Rose, Pruchno, and Burant (1996) compared mortality and morbidity in assisted living and nursing facilities. Defining assisted living, in terms of resident characteristics, services offered, and physical environment, is a major concern of these existing research efforts, all of which use large and/or national samples and survey-based methods. The research project described here differs by focusing on a small number of settings, three, and exploring in detail how the basic, but largely unexamined, concept of independence is understood and implemented.

Social worlds framework

A Focus on Activities

Social worlds theory considers work a central research focus. What work is necessary, by what actors, to create and sustain a social world? Thus, the existence of a social world provides the "meanings, commitments, and perspective in knowledge-making both to practices and to the people practicing them" (Fujimura, 1996, p. 12). In the present case, the work activities defined as most important to the social world of

assisted living include marketing, assessment, and assistance. The first three categories are the responsibility of assisted living owners, operators, and staff, with oversight from SDSD and representation from OALFA. Notably missing from this scenario are the assisted living residents and their family members. Although residents and families may be considered the target of the work that the key groups do, they are not necessarily knowing actors in the creation and maintenance of this social world. At one level, assisted living residents and their families must "buy" the notion of, or commit to, this world in order for it to succeed. Residents who do not buy in, either because they are too sick or disabled, or because they choose not to, threaten the stability of the social world of assisted living by challenging the parameters of the social model. In the present analysis, residents and families are described in the context of the work that assisted living providers do, especially assessment and assistance. However, the perspectives of these individuals toward independence, the social model, or assisted living in general is not provided in this analysis and this may be considered a limitation of this study.

Reference Groups

"Reference groups" are "organizers of social life that generate perspectives which form the basis for collective action organized through the construction of social worlds" (Clarke, 1997, p. 68). Individuals, or groups, compare themselves to other people, or groups, whose "attitudes, beliefs, or actions are taken as appropriate

measures" (Abercrombie, Hill, & Turner, 1988) by which to base their own actions. It is how people, or groups, identify themselves as part of a larger whole. In this case, local reference groups include SDSD, the state agency responsible for approving (legitimizing) and monitoring assisted living; OALFA, the professional organization representing Oregon's assisted living facilities; and assisted living facility operators, staff, residents and their families. External reference groups, which may also be considered as social worlds of their own, include gerontologists who conduct research forming the basis of scientific claims, long-term care policy experts, other long-term care settings like nursing and retirement communities, and related disciplines like medicine and law. In this document, I also use the terms "key groups" and "proponents" to describe these groups.

Commitment

Reference groups share a "commitment" to a central idea or agenda as the basis for social action. In this case, the notion of a "social model of care" is the source of commitment the identified groups have to assisted living. As mentioned, independence is the "unifying construct" (Fox, 1988) of this social model. The concept of independence, although a somewhat vague normative value, is supported in gerontological research and practice through several disciplinary lenses including psychology, medicine, medical ethics, social work, and law. These provide strong evidence for not only the importance of independence, but also, at least theoretically, how to support it. However, competing discourses are set up by these disciplinary categories which cause tension between supporting independence on one hand and managing risk on the other. Thus it is not unusual to read an assisted living resident file indicating that for the individual to remain independent, she must be willing to accept assistance with medications and showers. This tension will be examined further in Chapters Two and Seven.

Legitimacy

Finally, the social worlds perspective is founded on the sociology of legitimation. What makes an idea, an organization, or a social movement, legitimate? How believable are the claims made by reference groups? By what power, or authority, are they entitled to do what they do? What does it take for an adult child to believe that his

or her disabled parent will be safe and independent in "Happy Acres" before moving Mom or Dad in? What makes "Happy Acres" a worthwhile place to work despite low wages? Social worlds, especially new ones, require legitimacy to succeed. Strauss (1982) identifies several legitimacy processes, summarized in Table 1 below.

Table 1

Legitimacy Strategies of Social Worlds

Claiming worth	"a collective definition that certain activities are worth doing, and "we" are doing them"
Distancing	a new social world may form out of an existing world and "gain distance merely by distinctions being readily made between both what they do and what others so, and how differently they now talk and even think";
Theorizing and conceptualizing	"building an ideological base for defense and attack" and "legitimating conceptualizations"
Standard setting	"questions of authenticity" and "guides for properly performing, collecting, selling, appreciating, making products, improving technology"
Boundary setting	"what lies definitely within, what without, and what placements are ambiguous? How is all this to be determined, or ratified, and by whom?" (Strauss, 1982, pp. 174-185).

In varying degrees, each of the legitimacy processes identified by Strauss (1982) are evident in the social world of assisted living. In the following, the key terms are italicized for emphasis. First, social worlds participants must believe that their actions are *worthy* and that something of value will result. For example, assisted living proponents believe that their social model approach is what seniors demand, as adult consumers, and that it will improve the quality of frail elders' lives.

Second, social worlds must be *distinguished* from other similar worlds. A very clear example made by assisted living proponents is just how different their world is from the world of nursing facilities which they describe as operating under an older and outdated "medical model." Assisted living marketing professionals, managers, OALFA and SDSD representatives all make comparisons to nursing facilities in explaining what assisted living is. For example, nursing homes are said to be institutional, hospital-like settings which do not respect the "patients'" need for independence, dignity and choice. In contrast, assisted living facilities provide home-like environments where respect for "residents'" independence, dignity, and choice are the driving concerns. Chapter Five introduces the assisted living vocabulary that advocates adopt in order to distinguish themselves from nursing homes.

Third, legitimacy requires having a *theoretical* or *conceptual* basis for action and for defense against external criticism. Social worlds members must be able to convincingly argue their cause to outsiders as well as to prospective members. The "social model of care" serves as the conceptual model that drives and lends credibility

to members' actions. Managers can use this model to explain to a staff person why it is inappropriate to loudly ask a resident seated among friends in the dining room if she still has diarrhea: Because such behavior is not in keeping with the social model which emphasizes dignity and independence.

A fourth process for achieving legitimacy is *setting standards* for action. What is the best way to carry out the core activities involved in this social world? Various reference groups have authority in this arena. Senior and Disabled Services Division members act as consultants to assisted living facility managers, monitor facilities for compliance with the rules, and sponsor educational forums. The Oregon Assisted Living Facilities Association also sponsors educational events for managers, nurses and direct care staff in addition to political activities like lobbying the state legislature. Setting standards has to do with questions of authenticity rather than boundary questions of who belongs in this world and who does not, discussed below. For example, continuing education programs for assisted living facility managers often include awards for individuals and facilities that best exemplify the values of this social world. At one such event, a manager received a gift for developing the best mnemonic strategy for remembering the six core values of assisted living (presented in Chapter Five).

Finally, social worlds require some type of *boundary*, either formal or informal. In art worlds (Becker, 1982), where boundary lines are less clear, questions about who really counts as an artist, for example, are more complex. Because assisted living

facilities are licensed by SDSD, who is in and who is not is more clear. However, the administrative rules leave room for interpretation, and this has lead to complaints among some providers that certain facilities provide only "assisted living lite" rather than the more intensive care services originally intended.

In the present analysis, I consider efforts by the key groups to define and redefine situations at the local scene of assisted living. The situations that I identified as integral to the efforts that key groups make to achieve the social model mandate include marketing, manager training, and resident assessment and assistance. I consider these work activities as collective action necessary to produce the idea of independence in assisted living. The elements involved in assisted living activity situation include actors who do the work of assisted living (managers, staff, registered nurses), the actual organization of the work (documentation, forms, contracts), representational tools (marketing materials, conceptual framework), regulatory agencies (SDSD and others), professional organizations, clients, and the actual sites of assisted living.

Clark (1997) and Fujimura (1996; 1997) describe how social worlds participants rely on a "package" of concepts and techniques to define who they are and what they do. For example, Fujimura describes the "package of theory and methods" that was necessary to shift the U.S. cancer research focus from the cellular to the molecular level. This included new theories about the role of heredity in cancer formation and new molecular biological technologies developed in the 1970s. Oncogenes, or cancer

genes, are now the primary focus of cancer research, and this focus has resulted in a large scale commitment to what Fujimura calls the "oncogene bandwagon" (Fujimura, 1996, p. 2). I borrow these notions to describe the "social model bandwagon" which offers a "value-practice package," including the public policy defined value of independence and practice concepts like the "negotiated service plan" and "managed risk agreement."

Ethnography

This project follows an ethnographic tradition that examines the place in which aging occurs and the relationship between person and environment, broadly defined. There are several precursors for this study and the following citations provided instruction both substantively and methodologically. There are several nursing home ethnographies, of which Gubrium's (1975) Living and Dying at Murray Manor was the first. He used a social worlds approach, describing three worlds that existed within Murray Manor, including administration, staff, and residents.

> Each world provides its participants a way of looking at and understanding social life at the Manor. And each has its own logic: its own ideals, sense of justice and fair treatment, method of expedience, prescribed duties, rhetorical style, and proper mode of making decisions. (Gubrium, 1975, p. 37)

Gubrium noted the importance of place in understanding social worlds of the nursing home, although he confined himself to places within the walls of the facility. In the present analysis, assisted living facilities are broadly considered as a social

world, with external policy makers an important reference group.

Diamond (1992) also explored the nursing home, but from the perspective of a trained certified nursing assistant and participant-observer. He combined institutional ethnography with a political economy of aging perspective in order to argue for reforms such as unionization of nurse's aides. Finally, Shield's (1988) ethnography of a Jewish nursing home provides lessons about independence that rang true for the present study. For example, she observed a care conference in which staff discussed whether a resident should be encouraged to brush her own hair, as an act of independence, or if staff should do it for her, as an act of closeness. She explained the tension between care provision and independence.

> This incident raises a difficult and persistent quandary in the nursing home: How to provide aid and support in a humane way without promoting dependency. Indulging the resident too much is one extreme; expecting no dependency is the other. (Shield, 1988, p. 176)

A similar tension exists in assisted living facilities. Proponents emphasize independence but are wary of offering too much care and of balancing risks, sometimes fatal, faced by disabled older persons. This point will be taken up in Chapters Six and Seven.

Retirement Communities Ethnographies

Ross (1977) explored how old age could be the basis for community in a French retirement village. Morgan (1977) examined community life in a Mid-West home for

the aged. His study used the concept of "career" to show how elderly residents sought to avoid moving along a career of increasing institutional dependency in a facility that included three residential levels: independent apartment living, intermediate care, and the off-campus nursing facility. Increasing care needs, or dependency, were viewed by residents as an undesirable career trajectory. Notably, Morgan (1977) found that staff play an integral role in this process. However, while he observed that each move, including the initial one into the independent living apartments, represented a loss of independence, assisted living proponents claim that a move into assisted living is an opportunity for increased independence.

Community Ethnographies

Rowles' (1978) ethnographic study of the geography of aging in an Appalachian community explored the "geographical experience," of five elderly individuals. In context, geographical experience means the "involvement within the spaces and places of their lives," and refers to how the character of a place, or the dimensions of space, are "integral components of the experience" (Rowles, 1978, p. xviii). Rubinstein et al., (1992) described independence and frailty among 52 urban community elders and the resources employed to allow for independent living against all odds. They observed that

> the notion of independence is not an absolute, but significantly that it can be tactically and situationally redefined by the person and that even though each person's view of independence may be defined with respect to the widely shared cultural concept of independence, each view is also defined with

> practical reference to the living situations each encounters. (Rubinstein et al., 1992, p. 5)

Further, they observed that making choices is what operationalizes independence for frail or disabled elders.

Each of the above ethnographies provided sensitizing concepts and theoretical insights relevant to this research. These issues, some supported and others that differ from those observed in assisted living facilities, will be presented in the following chapters.

Chapter 3

Research Design

Assisted living proponents claim to follow a social model of care and to value resident independence. This study was designed to examine this claim. I ask why and how this claim is made and enacted. Because assisted living is a relatively new program in Oregon and little empirical research existed when I began, I considered this research to be exploratory. The research method that allowed the flexibility to begin with such broad questions and to consider individuals, organizations, and state policy requirements as potential sources of data was ethnography, a type of qualitative research. Qualitative research "can refer to research about persons' lives, stories, behavior, but also about organizational functioning, social movements, or interactional relationships" (Strauss & Corbin, 1990, p. 17). This approach was appropriate given the focus on a common concept that has multiple meanings and is difficult to quantify.

Ethnography is defined as "the direct observation of the activity of the members of a particular social group, and the description and evaluation of such activity" (LeCompte & Goetz, 1982, p. 32). One goal is to "untangle" what members of a group say they do from what their behaviors indicate they actually do (Shield, 1988, p.11). Another goal is to "make the familiar strange" and "the strange familiar" (Atkinson, 1992, p. 12). That is, I hope to provide tools that allow an audience familiar with assisted living new ways of seeing this world. For an audience new to assisted living, I

hope to describe this world in a way that explains why its members do the things they do.

The role of theory is not as central in ethnography as it is in other research methods. For example, ethnographers rarely set out to test an existing theory. LeCompte and Goetz explain it this way:

> In a sense, experimental researchers hope to find data to match a theory; ethnographers hope to find a theory that explains their data." (p.35)

Grounded theory methods, described below, provided the technical instructions for how to achieve this.

Research Theory

In addition to the social worlds framework introduced earlier, this project is influenced by a social constructionist perspective (Estes, 1979; Guba & Lincoln, 1994; Gubrium, 1993; Lyman, 1993; Sarbin & Kituse, 1994) and by Dorothy Smith's (1987) definition of "institutional ethnography", but the technical data collection and analysis rely on grounded theory methods (Lyman, 1993; Strauss & Corbin, 1990). The theories behind these three methodologies, and the application to this study, are defined below.

The social constructionist perspective is based on the idea that understandings--of facts, relations, of the way things work--are shaped by societal and cultural beliefs. In this line of thinking, knowledge about behavior and objects is "constructed,

negotiated, reformed, fashioned, and organized by human beings in their efforts to make sense of happenings in the world" (Sarbin & Kituse, 1994, p. 3). The reason for illuminating socially constructed realities is to better understand collective actions and belief systems (or claims) and to modify those actions or actions if warranted. Thus, my goal is not to determine if commitment to the value of independence is good or bad, or if assisted living facilities do or do not support independence, but rather to understand how this value was adopted and to make visible the daily manifestation of this social constructed reality.

Institutional ethnography is an approach designed to make visible institutional actions within the context of societal attitudes. Smith (1987) relies on Marxist sociology theory to identify how institutional relations support existing "power relations" in U.S. society. The lesson for the present analysis is the way in which Smith examines how institutional structures and ideologies (such as exist in public schools) organize the everyday world of participants. The organization's ideology (or values) categorizes individuals so as to match expected outcomes and organizational needs. The organization remains accountable to societal expectations and monitoring agencies. In this case, seniors are considered by assisted living proponents as a distinct group who are frail and in need of assistance and protection, but who are also active adult consumers.

Grounded theory methods (Strauss & Corbin, 1990) provide the technical framework for the above theoretical components. Although the primary goal of

grounded theory is to develop theory, a second reason for using grounded theory is that it is accessible to beginning researchers. Strauss and Corbin detail coding strategies for transforming volumes of textual data into a legible representation of the phenomena of interest. Their discussion of the use of literature was especially informative for this project. Existing literature may be used to sensitize one to important concepts and even as a form of data during analysis. In my case, I located two studies that used grounded theory methods, and these provided the social worlds framework that helped organize my on-going analysis. This also explains why Fujimura's study of cancer research (1996; 1997) is important to this study of assisted living in Oregon.

Data Sources and Sample Recruitment

The data for this study derive from participation in assisted living manager training, the marketing brochures from 63 facilities, interviews and observation of daily life in three facilities, and the state administrative rules. The specific details are described below and in the following chapters. Table 2 on page 36 outlines this information.

Table 2

Data Sources

Reference group	Focus	Data source
Policy makers: SDSD & OALFA	Definition of independence, implementation strategies	Administrative rules and manager training
Assisted living manager and staff	Marketing to new clients, assessing and assisting residents	Marketing materials, staff training, resident assessments and assistance

In addition to these formal data sources, my prior experience includes work as a research interviewer in assisted living facilities, nursing homes, and adult care homes.

Manager Training

At the time of data collection, SDSD contracted with four institutions to provide manager training. Assisted living managers must complete this initial 40-hour training session and annually thereafter, 20 hours of continuing education credit units. Fieldwork for this paper included attendance at three of these courses, two administered by proprietary assisted living developers and the third by a not-for-profit agency. In all three cases, the $500 fee was waived because of my student status. In addition, I attended three eight-hour continuing education courses. Permission to tape record was not granted by any of the instructors, so data include notes taken during the sessions and hundreds of pages of training materials provided by the course instructors. In each case, the other attendees were informed that I was a student doing

a paper on assisted living.

Marketing Materials

Promotional brochures were requested in writing from 66 facilities licensed as of August 1996 of which 63 responded. The analysis is described in Chapter Four.

Assisted Living Facilities

Three assisted living facilities are included in this study, and for the purposes of this study, they are called Timber Heights, Spring Hollow, and Valley View. The three are licensed for assisted living in Oregon, are in the same metropolitan county, and are owned by different companies. At the time of data collection, Timber Heights and Valley View were newly opened facilities and Spring Hollow had been operating for five years. Beginning at a new facility allowed for observation of how the various participants (staff, residents, family members) experience the facility for the first time and how it is marketed by the operator/owner. Spring Hollow, the older facility, was included for comparison in order to observe a facility with established policies and procedures.

Sampling Frame

The grounded theory method uses a specific sampling procedure referred to as "theoretical sampling" (Strauss & Corbin, 1990, p. 176). Specifically, the aim is to continue adding to the sample while testing the emerging theory. This is a conceptual

procedure designed for qualitative data collection and analysis; rather than sampling cases, or individuals, as is common in quantitative methods, grounded theory involves sampling events, incidents, and other examples of the phenomenon of interest. That Timber Heights was the first facility observed was one of timing -- it was scheduled to open around the time that data collection began. Valley View, another new facility, was added nearly eighteen months later in order to gain more information about the initial assessment stage. New facilities offered a good research setting because they afforded the opportunity to observe how assisted living staff define the new resident's "need" for assisted living. Need is the driving force behind most health service use (Aday, Begley, Lairson, & Slater, 1993) and the relationship between identification of needs and independence emerged as a central concern in this study.

Access to Timber Heights was gained in exchange for volunteer activities such as assisting the manager with resident assessments and other daily tasks. Over ten months, I assisted with administrative duties like payroll and weekly reports to the owner, took prospective residents and their families on marketing "tours" of the building, cooked, served meals, cleaned resident apartments, did laundry, coordinated the admission of Medicaid clients, transported residents to doctor's appointments, and went grocery shopping. I averaged two eight-hour days a week for six months and one day a week for an additional four months.

Timber Heights is a one-story building with 30 apartments surrounding an interior courtyard. When I began, the building was still under construction and about ten

people had applied to move in. Ten months later there were 21 residents. Timber Height's decor is simple Americana, with prints and furniture that might be purchased at JC Penney or Sears stores. The building is located on a dead end road across from a gas station and two blocks from a convenience mart.

Access to Spring Hollow was gained in exchange for a minimum of 40 hours of volunteer time. The owner did not allow me to directly assist with personal care but stated that I could "shadow" the caregivers. In addition, I served meals, cleared dining room tables, and assisted with activities, primarily BINGO. I spent two full shifts per week for three months.

Spring Hollow is a two-story building with resident apartments on the first floor and administration on the second. It has 40 units, including studio and one-bedroom apartments. It is in the same county and of comparable size to Timber Heights. Compared to Timber Heights, the hallways are longer and darker, although the furniture is similar. Both facilities have a fireplace in the main living room and a central dining room with plenty of natural light. Spring Hollow is located on a dead end road near a park and community center.

Valley View had been open for about one month when I contacted the director. She gladly invited me to assist her with resident assessments because she was falling behind on this task. Valley View has 90 apartments and is a three story building in a new planned residential community. Although a smaller building might have been more comparable to the first two, it was more important to on-going data analysis to

locate a new facility that was actively marketing, conducting resident assessments, and that accepted Medicaid clients.

The only activity pursued at Valley View was resident assessments, both new and on-going, over a period of six months. Valley View has a more "upscale" feel to it. The furniture here is more modern and has the look of Pottery Barn rather than JC Penney. The building has three stories accessible via one elevator or four sets of steps. There are resident apartments, either one-bedroom or studio, on each floor. The building is the only one of the three not located on a public bus line, and this served as a barrier to hiring care staff who earn modest wages.

All three buildings are carpeted throughout, have one central dining room, an activity room, a resident laundry room, resident mailboxes, a bathtub, public restrooms, and a common living room. These spaces are required by state rules although decoration is up to the owner or manager. In addition, each facility has several small seating alcoves. Valley View has a separate room used as a chapel and an exercise room. Both Valley View and Spring Hollow have a van for transporting residents. Timber Hill is the only one with a locked front entry so that residents with cognitive impairments may not leave unattended, and both Spring Hollow and Valley View have multiple entry/exit ways that are not secured.

Data Collection

Data were gathered through participant observation, informal and formal

interviews, and collection of formal printed materials. As noted above, I took an active role, assisting the managers with tasks including resident assessments, marketing, cleaning, administrative duties, and limited personal care.

Initially, observations were fairly general, but a systematic plan of observing a few specific events and settings was soon adopted. Theoretically, this approach was informed by the notion of "defined situations" from social psychology (Thomas & Thomas [1928] 1970). Behaviors are influenced "partly by institutions, taken as situation, and partly by behavior of others, taken as situation" (Thomas & Thomas, 1970, p. 154). This perspective examines human behavior in specific situations and recognizes that multiple influences pattern human lives. The lesson for this research was to systematically examine opportunities for independent actions in one or more defined situations, and two quickly emerged as an important events to observe and analyze. The first situation, described in Chapter Six, is the formal training required of assisted living managers. If prospective managers do not believe that the social model is a legitimate idea by the end of these forty hours, they are not likely to succeed. The second event is the resident assessment. This defined situation is when the institutional knowledge of a prospective resident's independence is obtained through a formal process taught in manager training and defined in administrative rules. Chapter Six is based on this analysis.

Interviews were audio-taped, but much data are in the form of field notes, both written and tape recorded. I transcribed the audio-tapes and used The Ethnograph

computer software program for coding and organizing qualitative data (Seidel, Friese, & Leonard, 1995). Formal print materials include Oregon's administrative rules, manager training documents, promotional materials, and related facility documents.

This research followed the National Institutes of Health goals of research with "human subjects" by respecting the rights to privacy and confidentiality of participants. Those who agreed to formal interviews signed a consent form. While it is true that I observed people who did not officially agree to be interviewed, no names or other identifying characteristics of individual tenants, staff, or facilities are included in the final analysis. Instead, pseudonyms were created and any unique events that might identify an individual were modified.

One way to gather information about assisted living facilities is to look at marketing materials. This represents the outsider's view and might be the first impression for prospective assisted living residents and their families. In the next chapter, findings based on content analysis of such materials clearly indicate that the assisted living operators promote the concept of independence.

Chapter 4

Promoting Independence: An Analysis of Assisted Living Facility Marketing Brochures

"*Our licensed assisted living wing is for people who value their independence yet find that living alone without a little help is no longer practical*" (Community A[3]). Thus begins an assisted living facility promotional brochure, one that neatly characterizes the balance between respecting independence while recognizing that needing "a little help" may be a fact of old age. This chapter is based on analysis of marketing brochures from 63 of Oregon's 66 assisted living facilities licensed as of August 1996. Marketing materials reflect what the owners, or their marketing experts, believe is important for others to know. This is one way in which the legitimacy claims of assisted living proponents begin to appear valid and the distinction between nursing facilities and assisted living becomes clear. For example, print materials may offer details about how assisted living facilities differ from nursing homes, provide language that describes who they are and what they do, and list affiliations with reputable (sounding) institutions such as SDSD, OALFA, and public laws like the Fair Housing Act. If an individual were to look at more than one brochure, they would find enough similarities to realize that assisted living facilities are a specific and unique type of senior housing.

Analysis is based on formal content analysis of the marketing brochures. The

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3 The facility names have been modified to preserve confidentiality. Rather than inventing new names,

language is compared to Oregon's administrative rules that define assisted living because these rules represent official standards for the world of assisted living. How the requirements are re-packaged for sale is up to each assisted living owner, but it would not serve owners to make false claims that would mislead potential clients. Even though these marketing materials reflect the goals of only one of the reference groups operating within this social world, most of the legitimacy processes described in Chapter Two are evident, including claiming worth, distancing, and conceptualizing.

Method

Assisted living marketing brochures are a visible and accessible artifact offering insights into the state of the art in long-term care for frail elderly people in the 1990s. Many facilities create a special location in their front lobby, often on a narrow oak or cherry wood table (which also holds a guest book and a silk flower arrangement), where brochures are prominently displayed for visitors. Although brochures are only one marketing tool that facilities use, they offer, in a concise way, what the facility owner believes to be the primary concerns of assisted living consumers, either prospective residents or their families. For the present analysis, the brochures are considered an artifact of material culture, one that is produced for a specific purpose and under specific conditions. The strength of this approach is the recognition that

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I labeled the 14 brochures quoted from here from Community A to Community N.

elements of material culture are not passive but "are produced so as to transform, materially, socially, and ideologically" (Hodder, 1994, p. 395). Thus, the brochures are seen to both represent and construct what is normal and correct for frail older people to value and choose through their consumer behavior.

Sample

Marketing materials were requested, by letter, from all 66 facilities licensed in Oregon as of August 1996. A postage-paid envelope was included with the request. All but fifteen facilities responded, and brochures from these were requested by telephone, resulting in a response from all but three facilities for a total of 63 brochures.

Data Analysis

Both content analysis and thematic analysis were used to examine the text of the brochures, the former to identify relative importance of specific concepts, and the latter to the in which these concepts were presented. In addition, photographs were categorized by content. The formal content analysis identifies which of the six assisted living values (independence, privacy, dignity, choice, individuality, and home-like) was mentioned most frequently. Derivations of the words were included in the count; for example, when counting mentions of the word "privacy," the word "private" was also counted. However, the term "individual" was only used as a proxy for

"individuality" when it referred to a human rather than an inanimate object. For example, the term "individual temperature control" was used often, probably because the rules state that "each unit shall have individual heat controls." This particular usage does not capture the spirit in which the term "individuality" is used in the rules that define it as "variability in residents' needs and preferences."

The content analysis served as the primary means for establishing, in an empirical way (Morgan, 1993), the importance of independence. The next level of analysis included a thematic reading of the ways in which independence is promoted, both as a marketing concept and as a service strategy for supporting frail individuals.

Physical Description of the Brochures

The majority of the brochures have a professional quality, with glossy paper, multiple colors, and photographs. They range from folders filled with information and images, to tri-folds, to standard-size sheets of paper. The predominant trend is a folder-style packet, some large enough to hold standard paper, with a variety of inserts describing the programs, services, and building configuration. Many companies include a brief biography detailing their history and commitment to quality senior housing. Architectural floor plans are included in the majority of brochures, with the intent of indicating that the units are self-contained apartments with private bathroom and kitchen. Only a few of these floor plans include dimensions or window locations. Some of the brochures include an invitation for a free lunch and a few include the

monthly menu, activity schedule, or resident newsletter. One contained a letter written by two sisters to friends following their move to the facility; the top of the letter read, "*This is not an advertisement*!" Most of the brochures include an area map, and the text often exudes the benefits of the particular location, for example, "*the charm of suburban living with all the amenities of a Northwest town*" (Community B) or "*We're not located on a busy downtown intersection next to traffic and siren noises. Our Campus is built on acres of beautifully manicured lawns and gardens*" (Community C). Brochures for ALFs in small communities often remark on the benefit of not having to move: "... *now you can live in lovely surroundings while receiving the extra help you might need to keep your independence without leaving the area*" (Community C).

Results

Who Are the Consumers?

Women comprise the majority of assisted living residents. The photographic representations of residents printed in 15 brochures depicted more women than men, although a higher number of men were pictured than is statistically warranted. Based on a survey of 610 Oregon assisted living residents in 38 assisted living facilities, 84% of ALF residents are women, not surprising given that the median age is 85 years (Kane et al., 1996). The photographic images included a total of 89 elderly people: 61 (68.5%) women and 28 men (31.5%). Thirty-six images included a male-female

couple, suggesting that 40% of assisted living consumers are married, compared to 11% of married residents in Oregon's assisted living facilities reported by Kane et al. 1996. They reported that 66% of assisted living residents used at least one mobility device, but among the 89 human images in the brochures, only seven (8%) were shown with a mobility device such as a cane, walker, or wheelchair. Missing from the images are people of color, although this is not surprising given that fewer than 2% of a random sample of 610 assisted living residents identified themselves as a race or ethnicity other than White/Caucasian (Kane et al., 1996).

The Dominant Assisted Living Value

Given that the core of the State's administrative rules is based on the six principles of assisted living, the content analysis focused on these terms. The majority of brochures refer to the six values, although the most prominent value was independence, as indicated in Table 3 on page 49. Based on a total count of all mentions of the six terms (n=570), independence was used most often, followed by privacy, home, individuality, choice, and dignity. Only three of 63 brochures did not use the term "independence" at all, and one brochure incorporated the term 13 times.

Table 3

Content Analysis of Assisted Living Values Printed in Marketing Brochure

Term	Total number of mentions	Percent of total
Independence	164	28.8%
Privacy	130	22.8
Home	86	15.1
Individuality	78	13.7
Choice	77	13.5
Dignity	35	6.1
Total	570	100.0

The ways in which independence was described were often grounded in terms of the setting and services, but also through the language of consumers, such as "custom-designed" and "tailored" services, that supports independence. The specific ways in which assisted living facilities promote independence are described below.

Promoting Independence

Assisted living facilities have various methods for repackaging the required principles, services, and facility standards, including the concept of independence. The marketing materials indicate that independence is promoted in three ways: first, through individualized assistance with "personal care services," second, through the

physical environment, and finally, through control over which personal services to receive help with, how, and where.

Table 4 on page 51 contrasts the state's definition of independence to descriptions offered by assisted living facilities. The former emphasizes the importance of the physical environment and does not specifically refer to service provision as the brochures do. However, the term "independence" is integral to State definitions of assessment and activities of daily living, discussed in Chapter Six. Finally, many brochures mention the control that residents have in determining what services they will receive, when, and how. Again, this is not part of the specific definition of independence, but the rules do require that individuals who are capable should be actively involved in making such decisions.

Table 4

Comparison of Oregon Administrative Rules to Marketing Brochures

OAR 411-56 Definitions and requirements	From selected brochures Independence means...
"Independence" means supporting resident capabilities and facilitating use of those abilities. Independence is supported by creating barrier free structures and careful design of assistive devices.	**Barrier-free settings** "*The well-engineered apartments encourage your independence.*" (Community D)
The definition of "activities of daily living" includes: "Independent means the resident can perform the ADL without help; Assistance means the resident can perform some part of an activity, but cannot do it entirely alone; Dependent means the resident cannot perform any part of an activity; it must be done entirely by someone else."	**Help from others** "*Individuals can live independently in their own apartments, knowing that 24-hour staffing is available when needed.*" (Community E) "*Our number one goal is to promote independence. Personalized assistance with activities such as bathing, dressing, grooming, and walking are provided by a fully trained and supervised staff who will assure that prescribed medicines are taken in the proper amounts at the correct time.*" (Community F)
"Each resident shall actively participate in the development of the service plan to the extent of his/her ability to do so."	**Control** "Community G *allows you to be the center of the decision-making process so that you can enjoy life independent of an institution.*"

Rubinstein et al. (1992) noted that the ability to choose and make decisions is the

foundation of independence. Consumers have control and make choices, and assisted living residents are considered consumers.

Distinguishing Assisted Living From Nursing Homes

> Community G *allows you to be the center of the decision-making process so that you can enjoy life independent of an institution.*

The above reference to institutional care is an especially evocative image because most older people "know" that living in an institution does not allow for independence. Nursing facilities do not have "consumers," they have "patients" who are confined to beds or wheelchairs. Although only five brochures use the term "institution," all of them make it clear that they are not institutions by using terms like residence, apartment, senior living, retirement living, and home. A "home-like setting" is one of the state-mandated values, and "home" was the third most often mentioned of the six values. Only eleven of the 63 brochures did not use this term at all, but the images and vocabulary leave little doubt that the assisted living environment is not institutional. Most marketing brochures address the physical environment, from the "gracious" dining rooms to the "deluxe" studio or one-bedroom apartments. Of the 21 brochures that included graphic images, five included only images of the building, with both interior and exterior photographs. The majority of facilities advertise that the apartments are private, with individual temperature controls, private bathroom, (all required) and plenty of space for furniture and "*all your own treasures and familiar*

furnishings" (Community H). The required 15 square feet per resident of "common areas for social-recreational use" (per Oregon Administrative Rules) becomes the "*Trail Blazer TV Lounge*" or "*ice cream parlor*" (Community H), billiard room, library and fireplace rooms, garden room, and TV room. The role of the physical environment in promoting independence is a marketing feature:

> Community E *creates an environment where individuals can live independently in their own apartments, knowing that 24-hour staffing is available when needed.*

At Community I,

> *Apartments are spacious and provide accessible bathrooms, two-way emergency call systems, and superior barrier-free construction.*

With these terms and images, assisted living owners attempt to distance themselves from their poor cousins, the nursing facilities.

Levels of Independence

Interspersed throughout the language of personal care services are references to a "level of care." This stems from the State's definition of service levels in which each individual is assessed on a scale from independent (does not require staff assistance) to dependent (requires staff support). [This topic is discussed in detail in Chapter Six.] This language lends a "rhetoric of legitimacy" (Ball, 1970) to assisted living by indicating that there are standard operating procedures in place. At Community J, "Personal Support Services" are "available on four levels."

> *When you choose personal support services, you, along with our professional*

staff, will complete a personal assessment determining the services and level of personal support that best meets your needs.

Most assisted living facilities base monthly rates on the "level of care" needed by the resident. This stems, in part, from SDSD's reimbursement system which defines five levels of monthly service payment for SDSD clients. Based on a medical and psycho-social assessment, "Level 1" refers to persons who require little assistance and "Level 5" describes persons who require a great deal of physical assistance or protective oversight. In general, Level 5 people may be thought of as more dependent on others for their daily care needs than Level 1 people. Of the 63 ALF brochures reviewed, 29 referred to "levels," but only 17 defined the scope of services included under a particular level. Some facilities create new phrases that define their service levels while others simply use Level 1, Level 2, and so on. For example, at Community K, residents may choose from the "*Assisted Living Opportunity*," the "*Enhanced Service Opportunity*," or the "*Comprehensive Service Opportunity*." The printed rates indicate that the "*Comprehensive Service Opportunity*" is the most expensive, but exactly what this opportunity is, is not defined. At Community H, "personal care services" are offered at three levels: "*Level 1: Cheerful reminders designed for the independent and self-sufficient.*" This level includes "*cheerful reminders*" for various daily activities, from meals to medications; "*Level 2: Independence with Support*" which includes Level 1 services along with bathing assistance, and "*occasional assistance with dressing, ambulating, and incontinence*;"

"*Level 3: Independence with Full Support*" which offers "*more daily hands-on service*" related to typical activities of daily living in addition to the "*incontinence programs designed to help you avoid discomfort and embarrassment.*" Always, the emphasis on independence despite the need for daily "hands-on" assistance for everything from bathing, to medications, to dealing with incontinence. Clearly, Level 1 is preferable to Level 3, in part because it is less expensive. Despite the emphasis placed on consumer control in determining the need for assistance, this reading of the brochures suggests that there may be an underlying tension between what an individual feels is "enough" and what the facility determines is the appropriate level of care required. Whether and how this tension exists is addressed in the next two chapters.

Personalized Assistance

Direct care staff are an integral component of assisted living, and they are often referred to in the text. Community N owners assert that "*Personal support services, provided by our caring staff, will help you live as independently as possible for as long as possible*" and at Community L,

> *Dedicated professionals constitute the Assisted Living Team. Each of them truly enjoys working with older adults and doing anything to assist them in maintaining their independence.*

Despite the frequent mentions of support staff throughout the brochures, these people are noticeably absent from the photographic images. Only eleven images of potential

caregivers could be identified, perhaps because they are waiting in the background, not hovering, but available to help should the resident request it. The people at Community M say it best: "*Assistance is available (if and when you need it).*"

Discussion

Independence is a central theme in the marketing arena of the assisted living social world. Noticeably lacking from the language is the phrase "social model." Although the ethnographic component of this study shows how important this concept is within the social world of assisted living, it is not one that "sells" easily, nor is it specifically addressed in the State rules. In contrast, the other assisted living principles are commonly held values to which consumers may respond.

Independence is an American cultural value with different meanings for people of different ages and abilities. For many able-bodied people, requiring assistance from another person for basic daily tasks like taking a shower may seem like the ultimate loss of independence. Yet assisted living brochures freely use the term "independence" when describing daily assistance with incontinence, dressing, and bathing. This tension, between independence on one hand, and the inability to manage daily activities without assistance from another person, appears to be a contradiction. This reading of the brochures indicates societal attitudes about daily living activities such as using the toilet or taking a bath and about health needs that require medical attention: These personal matters should be "discreetly" handled, so as not to embarrass the

receiver or offend the observer, and they should be done as self-reliantly as possible.

At Community L,

> *When residents need assistance with such daily living activities as dressing, bathing, personal hygiene including incontinence care management, medication or general mobility, their needs are met right here at* Community L *where they are already home and independent. Assisted living, on one hand, is independent living, The resident has his or her individual apartment with long-cherished furnishings. Set within a retirement community, Assisted Living offers the independence of choice, as the resident may decide which activities to participate in and when to enjoy some quiet time with friends. But Assisted Living becomes an enhanced independence.* Community L's *philosophy is based on the fact that older adults' needs increase as they age. We provide expanded services in the resident's own apartment as increased care becomes necessary*. (Emphasis on "enhanced" in original.)

However, the messages from the brochures indicate that, at least in theory, independence can be respected by affording the individual a role in decisions about how much assistance he or she receives and by providing it in a private living area. The role that public policy plays in this story is important, because it suggests that public-value-based policies will be adopted by private industry. It suggests that there is a shared commitment and spirit of cooperation between these groups. What is not clear from this analysis is what assisted living residents are independent of. Instead, the value of independence is uncritically accepted. Independence implies not being dependent, or beholden, to someone or something, perhaps family, perhaps neighbors, or perhaps strangers.

As artifacts of material culture, these brochures clearly play a role in promoting the importance of independence as a value in old age. If this value is important to older

persons, the materials suggest that just needing help from another person does not mean that one cannot consider him or herself independent. Instead, it is the way in which help is provided that promotes independence.

A final question this analysis cannot answer is whether the promotion of independence extends beyond the marketing brochures. This chapter provided an overview of independence in assisted living based on marketing materials available to anyone who requests them. It suggests that the people behind assisted living promote independence. But how do these individuals come to adopt this value? The next chapter explores this question in detail by discussing the assisted living manager training program.

Chapter 5

Socialization to the Value of Independence

> "I went through assisted living manager training, and at the end, the company director came in and gave this great speech and said, 'we're on a mission and journey together' and that 'our Tenants will die under your care.' I came from the hospitality industry where I was just worrying about wine and whether someone found a hair in their salad. Now I'm hoping that somebody I care for is going to die in my care. That five minutes was the most important of the whole week. If I hear a new manager say they have a hard time marketing assisted living, I say, 'go sit in the lobby of a nursing home for one and a half hours, it's a living Hell, and that's the alternative. In the brand new buildings, we have to educate, there's a lot of education involved. People don't know what assisted living is. That's marketing education, it's on-going, that's the difference between us and them, that education is forever after a building opens." (Assisted living marketing expert speaking to a management training group)

The above speech, delivered by the marketing director of an assisted living company to a course for new managers, sets the tone for how key groups in the social world of assisted living are socialized to the concepts and traditions. Although the administrative rules are vital to the legitimacy claims of assisted living, in terms of setting standards, providing an ideological base, and establishing boundaries, a reading of the brief rules does not tell one how to implement the values. Instead, the person who will manage the facility is required to complete a certified training program on this subject. This training provides substance, explaining what we do and why, how we differ from others, and setting practice standards and group expectations.

This chapter is based on participant observation in three 40-hour management training programs, each operated by a different organization, observation of three continuing education courses for managers, and time spent in three assisted living

facilities. As in Chapter Four, the administrative rules provide the point of departure. However, the assisted living manager is the central focus because it is this individual who sets the overall climate. At each of the observed sites, the manager hired all staff, marketed the product to potential clients, and provided personal care to residents when staff did not show up for work.

Assisted living managers learn that for the assisted living model to succeed, residents, their families, and associated community members such as health care and social service providers, in addition to facility staff, must be socialized to the assisted living values. Thus, a culture of assisted living must be established. Through their words and actions, managers and staff teach residents, families, and others what is expected of them. This culture is reinforced through manager training, adoption of a common vocabulary, and marketing.

Manager Training

Regulatory Background

Assisted living managers must complete a 40-hour training session and annually thereafter, 20 hours of continuing education credit units. Three of the four state-approved training courses are classroom-based and the fourth is an internship approach. The training is meant to inform managers about the basic values and how to incorporate them into daily operations. Managers are not licensed, but they must successfully complete the training session, which includes an examination. To qualify

as a manager, the individual must have a high school diploma and a clear criminal records check. The administrative rules do not require certification for direct care staff[4], but these employees must pass a criminal records check and be competent to perform basic health and personal care tasks ranging from insulin injections to removing soiled undergarments. The manager is responsible for educating direct care staff about the basic values. In addition, each assisted living facility must contract with a registered nurse, and this person teaches the basic nursing tasks and "bed and body work" (Gubrium, 1975), such as how to help an individual to transfer from wheelchair to commode.

Observation of Manager Training

Fieldwork for this paper included attendance at all three of the classroom-based courses and three one-day continuing education programs. Two of the full-week (40-hour) courses were run by proprietary assisted living developers and the third by a not-for profit agency, but all three operate under SDSD oversight. All three continuing education seminars were co-sponsored by SDSD and two of these were co-organized by the Oregon Assisted Living Facilities Association. For the purposes of this paper, the individuals who ran the courses are referred to as instructors. The full-week courses each had one primary instructor, but each also included a session taught by a registered nurse and a licensed pharmacist. The two proprietary courses also included a guest speaker who specialized in marketing assisted living and an SDSD

[4] As of Spring 1999, the rules are being revised to include additional educational requirements for both

representative spoke to the not-for profit course.

Each full-week class is 40 hours in length over five consecutive days. The first two courses were held in the meeting rooms of assisted living facilities and the third at a small conference center. Class sizes ranged from seven to 19 and included individuals, primarily women, ranging in age from about 28 to 55. The students listed a variety of work and education backgrounds, including retail, marketing, insurance, motherhood, hotel management, retirement housing, and nursing. These individuals traveled from various Oregon communities as well as from Washington and Idaho.

Although there were modest stylistic differences in teaching styles, each class followed a similar format. Each student receives a three-ring binder containing hundreds of pages of written materials, including the state rules, suggested resident bill of rights, sample menus and activity events, assessment strategies, and various interpretations on the rules. The instructors used overhead transparencies to emphasize key points. The students participated in "role playing" exercises designed to teach assessment skills. One half day was devoted to on-site observation in an assisted living facility and informal interviews or assessments with agreeable residents.

The one-day continuing education courses are designed for assisted living managers but are attended by residential care providers and some nursing facility staff. Typical attendance included around 100 individuals, mostly middle-aged women. The three courses I attended were high-energy events focusing on education and "creative"

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managers and direct care staff.

response to challenges. Education is an important feature of this social world, both in Oregon and nationally. This is one way that claims are presented, theories defined, standards set, and boundaries established in an on-going effort by proponents to legitimize assisted living.

At the national level, the quarterly publication of the Assisted Living Federation of America, Assisted living today, includes a regular "education forum." In fact, one of the stated goals of this professional organization is to educate providers by offering educational books and videotapes, annual meetings, and the Assisted Living Institute.

What We Do and Why We Do It

The process of legitimization includes several steps, one of which is "claiming worth." New managers are setting out in a new career in assisted living, otherwise they would not need to take this 40-hour training program. What makes this job worth doing? Strauss notes that something that is "worth doing" "gets translated into deserves doing, and for some issues, should be done, must be done. This is a claim to *worthiness*" (Strauss, 1982, p. 175, emphasis in original). Each instructor emphasized why assisted living is important and worth doing: consumers demand something different and the assisted living values provide it.

Consumer Demand

> What we're selling here is a lifestyle. Not just care. This is their home. We want them to look at the common spaces as an extension of their room. We like them to put their own objects in commons areas if they want to. Interior designers don't like it, but it's their home. One trademark of our projects is the large front desk. It looks more like a Marriott hotel than an institution. It looks like mahogany wood. We tried that and it doesn't work, I'll tell you, wheelchairs and mahogany don't mix. (Assisted living marketing expert)

One instructor noted that in assisted living, "the customer is the resident, we're consumer oriented and market driven" in comparison to nursing homes where "their customer is the government and patients become the product." By this, he reinforced the regulatory difference between assisted living and nursing facilities. The former have relatively little regulatory oversight and primarily exist in a private market, while nursing facilities are highly regulated institutions that developed, in part, from

Medicaid and Medicare financing mechanisms (Starr, 1982).

An understanding of the market is integral to assisted living, and, like any market, this includes consumers, competitors, and costs. As the first quote in this subsection indicates, not just care, but also image and lifestyle, is for sale. This individual described the importance of focus group interviews with assisted living residents:

> One lady told me, when it comes to the unit, don't skimp, put a refrigerator big enough to hold two gallons of ice cream. It comes back to what's important to the consumer.

All three instructors recognized the importance of market studies in order to identify the need for assisted living, emphasizing that this housing type is "consumer driven" and primarily private pay.

During the 1980s, SDSD began implementing home and community-based services as an alternative to institutional care. Surveys of client preferences since that time reveal the changing consumer perspective. Table 5 on page 67 lists results from these surveys as presented by one of the course instructors. (Note, the items are not listed in order of importance.) This instructor went on to explain that by the mid-1980s, "consumers" became more "astute and knowledgeable about long-term care services" and that this led to "changes in consumer preferences" such that by the early 1990s, "consumer preferences start to dictate services" rather than the other way around as in the health care industry where "health care workers tell you what it's all about." He summarized the difference in consumer demands over time this way: "Same question, different consumer. We've done a good job educating people on

what's expected. We've raised the bar. It's not just 'Is Mom dry?' but all of the above too" (referring to Table 5, page 67). The significance of this quote is the explicit recognition that the assisted living industry, as well as SDSD, has "educated" consumers about what they should expect and demand. In addition, he recognizes the importance of the family as an integral component of the "consumer."

Table 5

Oregon Consumer Preferences for Long-Term Care Services Over Time

1982	1988	1993
• Good physical & emotional care • Facility appearance • Near family • Bed availability • Cost	• Appearance of facility & staff • Financial considerations • Cleanliness/safety • Ability to maintain lifestyle • Personal identity & freedom • Wellbeing & lifestyle • Near family & hospital • Facility skill level	• Library services • Wall-to-wall carpeting • Recreational services • Newspaper delivery • Banking services • Beauty shop • Rehab services • Menu selection • One monthly fee • Transportation service • Post office service • Home-like • Private rooms • Security system

The two proprietary instructors mentioned competition many times over the week. One said, "We do mystery shopping, not to dig up dirt on others, to find what works. I'll steal from anybody, I make no bones about it. But that's what it's all about, service excellence." Recognizing the growth of assisted living facilities since 1989, one said, "It used to be, when you opened the doors, people would flood in, and now it takes longer, you have to do marketing, know the community." Not only is there competition with other assisted living facilities, but with other types of senior housing:

> We're not in competition with nursing homes, we're in competition with senior housing and other housing. We should cooperate with nursing homes, we benefit them and they benefit us.

By conceptualizing assisted living as a "consumer driven" response, assisted living proponents establish the "worthiness" of this world. The constant comparison to nursing facilities further serves to substantiate such claims, because most people "know" that elderly persons do not want to be institutionalized in nursing homes.

Assisted Living Values

The second reason that assisted living is important and worth doing is the focus on basic human values, reconceptualized as assisted living values. One instructor announced a competition for best mnemonic using the first letters of the six values, and at the end of the week, the winner, who came up with *"HIPDIC"* (home-like, independence, privacy, dignity, individuality, and choice), won a decorative wreath to place on the door of the facility she was to manage. Another said, "Our goal, I sound

like a broken record, is to promote independence. In the medical model, they create dependencies."

Each of the three instructors provided the OAR definition of independence as well as their own interpretations. Case studies were presented in which students had to decide how to respond to a resident's desire for independence and the associated potential for risk. Examples of how to meet resident's desires for independence were defined and discussed. The key concepts behind independence were defined as:

> Class 1: Recognizing, supporting, and building on the unique capabilities of each tenant; facilitating independence through the use of assistive devices and barrier-free design; and providing tenants with opportunities to express preferences and take responsibilities for decisions made.
>
> Class 2: Shared responsibility; managed risk; bounded choice; needs assessment; case history; negotiated service plan development; resident, staff and family/friends.
>
> Class 3: Lack of independence is equated with dependence upon the will and whim of others, it is an important element of self esteem; independence involves the free exercise of rights and the capacity to accept responsibility; independence is closely linked with the autonomy which may be instrumental (choices/activities carried out by the resident) or decisional (choices/activities implemented at the resident's direction); traditional care settings remove control and foster learned helplessness; the level of independence desired is also a matter of personal choice.

Each of these definitions refers to the role of personal responsibility. The second class specifically mentions "managed risk" and "negotiated service plan," two institutionalized efforts to balance risks with independence. Briefly, a managed risk agreement is a process by which a resident who is engaging in risky practices, as identified by the staff, signs an agreement whereby he or she indicates understanding of risks and

agrees to accept responsibility for negative results. The negotiated service plan is a process for designating which services the resident wants assistance with and who is responsible for assisting that person, whether staff, family, or outside health providers. Each of these concepts will be discussed in more detail in Chapter Seven. Here they are treated as concepts, as in the manager training when these terms were first presented to the class by the instructors. With these concepts, instructors are able to respond to student questions about how to respond to resident independence but also protect the resident from injury and the facility from liability.

How We're Different

An on-going legitimacy effort used by assisted living proponents like the instructors includes, as mentioned, distancing themselves from other types of long-term care, especially nursing facilities. How we're different also explains that our ways may be "even more legitimate than those of another, earlier, established, or more powerful" social world (Strauss, 1982, p.175). The instructors emphasized that assisted living represents a revolution in long-term care. And revolutions require new terms.

Revolution

> There's a corporate cultural shift that must be made in order to make it in this business coming from the long-term care model. (Assisted living instructor)

Each course instructor emphasized that the students were about to engage in something completely different, a revolution in long-term care. The concepts of the "social model of care" (Wilson, 1990; 1991; 1996), representing a "paradigm shift" in aging services, were emphasized. This shift evolved in direct response to nursing homes that are assumed to operate under a "medical model." The assisted living industry strives to be something completely different. One instructor explained that the social model came about for two primary reasons: "money matters and quality of life matters." Assisted living, it was explained, is a response to consumer demands for less expensive long-term care (compared to nursing facilities) that meets quality of life standards like a normal living environment and respect for privacy, independence, individuality, and choice. Another instructor said that comparing nursing homes and assisted living facilities is "comparing apples and oranges." He described the development of assisted living as an effort to provide an option for people who are "in-between -- not totally independent but not bed-bound."

Oregon is often described as the front-runner of a national revolution. One instructor explained, "In Oregon, we're not in bad shape because we have a philosophical approach, the six principles. Other states have adapted their nursing home rules and it's not the same." The same theme was evident at continuing education courses as well. An SDSD employee, described the state's contract nurse program (CRN) this way:

> Oregon is the first state to develop standards for the contract registered nurse, we're real proud of them, these are the standard for now and CRNs need to read every

word. They're real good, people all over the country are requesting them.

She went on to describe the evolution of the current array of community-based services in Oregon:

> Foster homes started just for Medicaid, then seniors demanded it and the rules were written in 1981. SDSD likes to stay out front in this country, people got tired of things, wanted something with few rules, and assisted living facilities came along in 1989.

The written materials for the contract registered nurse course emphasized by this speaker included the following information about SDSD, entitled "Senior and Disabled Services Division Values" ("hearts" in original).

Table 6

Senior and Disabled Services Division Values

GUIDING OPERATIONAL PRINCIPLES
♥ To provide choice
♥ To preserve dignity
♥ To enhance independence
♥ To create a home-like environment
♥ To maintain privacy
♥ To promote individuality
♥ To respect decision making

In summary, assisted living is presented as a revolution in long-term care with Oregon, lead by SDSD, as a front-runner in the nation. Each of the social model values may be considered equally important here.

Revolutionary Terms: The Assisted Living Vocabulary

Ball (1970) uses the phrase "rhetoric of legitimization" to describe the use of new vocabularies by specific groups. That is, the terms have a specific goal of organizing a particular image or impression: In this case, the social model of long-term care. The assisted living vocabulary is a direct reaction to nursing homes, although language is also drawn from real estate terminology. Because assisted living proponents seek to distance themselves from nursing homes, it is easy to take the traditional terms from nursing homes and convert them into appropriate assisted living terms. In addition, real estate lingo provides a non-institutional community-based housing framework for defining the assisted living culture. The adoption of the new language begins, for managers, with the formal training, but ultimately everyone, from residents to physicians, is expected to use the appropriate terms, listed in Table 7 on page 74.

Table 7

Vocabulary of Assisted Living Terms

Terms to avoid based on "medical model"	Assisted living terms to adopt based on "social model"
Aide	Resident care assistant, caregiver, personal service assistant
Administrator	Director or manager
Charge nurse or floor nurse	Health care coordinator or nurse consultant
Patient	Resident or tenant
Care plan	Service plan
Patient chart	Resident record
Chart	Document
Admission	Move-in
Discharge	Move-out
Bed or room	Apartment or unit
Facility or institution	Residence, community or setting
Physical therapy room	Exercise studio
Diaper	Incontinence product or undergarment

Nursing facility staff may well take issue with this presentation of terms; however, this information is presented to new managers who are expected to adopt it. From a "defined situations" perspective, if managers believe that this characterization of nursing facilities, compared to assisted living facilities, is accurate, it will influence

their behavior. This vocabulary is passed on to staff, residents, families, and others. For example, within the first few minutes of a resident care staff training at a newly opened facility, the manager offered this information after two people mentioned their nursing home work experience:

> Assisted living and nursing facilities are different things. We're more home-like, less institutional, and we emphasize respect, independence, individuality, and choice. We do not have patients, we have residents or tenants. Think of this as an apartment building. It's a new philosophy that we need to start ingraining.

The manager then emphasized that the training was going to cover "walking the talk no matter what." With these comments, she not only informed the new employees of the "new philosophy" but also suggested that "we" all needed to adopt and "ingrain" it in others. The latter point was emphasized in the discussion of assisted living values when she specifically addressed informing residents about the vocabulary for this social world:

> This generation of adults is not familiar with assisted living, they know nursing homes, and it's our responsibility to help them transition, walk this path, and stay here until they die.

The manager informed the new employees that they needed to memorize the six values of assisted living, and she provided a mnemonic to help them: HIPDIC. This is the same one developed by a student of the manager training class described earlier. She said to the new employees: "Remember, every morning, chant HIPDIC." Sometimes managers are unable to avoid medical model terms. For example, the manager at Valley View explained that she was "stuck with physician's orders," the report that

physician services generate to identify each resident's medical diagnosis, history, and prescription medications.

Although the staff was observed to adopt the assisted living vocabulary, there were occasional complaints and jokes about management's insistence on particular terms. For example, during a coffee break, two staff members discussed their take on the need to use specific words. Lucy, a nurse with hospital and home health experience, stated that she was "programmed" to use the word "patient" and that she was always catching herself before saying "tenant," the preferred term at this facility. She said,

> "Tenant" implies a different kind of relationship, a tenant-landlord relationship, and this is how they get away with having only one person on at night, because in a normal apartment building you don't have people on at night.

She went on to joke about how it is "criminal" to use the word "patient" in assisted living and complained that she had been admonished by the manager several times for her infractions.

The social model terms are not only spoken and used in written communications but also used for labeling physical spaces. Although managers strive to adopt the appropriate language, the rules of other governing agencies, which may have a view of aged individuals as vulnerable and in need of protection, sometimes interfere. The manager of Valley View described the labeling of rooms as "confusing" because SDSD wanted it one way, but the local fire marshal and health board demanded another. All of the rooms at Valley View are labeled, including some terms that definitely do not meet the parameters of the "social model." These include signs that

read "SOILED LINEN" to identify the room where staff wash laundry that might be soiled with urine or feces, "HOUSEKEEPING" and "TRASH" to mark the spaces where chemicals and refuse are kept, and "MECHANICAL" to note building operation centers (i.e., electrical, natural gas, heating and ventilating). Valley View's manager stated that she would rather not label every single room, but that the fire marshall had insisted. Thus, when walking the halls, one views small brown plastic signs with terms like, "STAFF LOUNGE," "FAMILY DINING ROOM," "CHAPEL," "ARTS AND CRAFTS," and "STAIRS." Timber Heights, the smallest of the three facilities with 30 apartments, was able to avoid labeling of rooms other than resident apartments that include room number and the resident's name. At Spring Hollow, a plaque that reads "WELLNESS CENTER" is affixed to the wall adjacent to the room that the staff and manager refer to as the "med-room." The "ASSISTED BATHING" room, unfortunately located behind the Marriott-style main entry counter, marks the space where residents may take a supervised Jacuzzi-style bath.

Setting Standards

All groups, including social worlds, require standards for action and ways of evaluating whether members have met these standards. Questions of authenticity may be raised. Is this member performing by the rules? Do they embody the commitment we all share to the social model of care? If so, they may be used as an example for others to emulate. If not, how do their actions threaten the stability of the entire group?

As mentioned, the administrative rules set standards, but these minimum standards leave room for interpretation. The management instructors must define the principles that future managers follow. They do this by offering examples, both what to do and what not to do, and by describing SDSD's expectations, particularly what concerns the evaluation team.

Using Examples

> Seminar Contest! (Educational, of course.) Please submit a brief description of your most difficult resident or family issue with your paid registration. Prizes will be awarded to those submitting entries used as case studies during the seminar. Enter early! Your challenge could be the educational highlight of the day. (January 29, 1998 OALFA flyer for a continuing education course.)

Case studies are the featured instructional tool in both the core training and the continuing education seminars. Students read sample cases, offer solutions, and the instructor evaluates these responses, offering suggestions for improvement.

Instructors focus on the values and how best to implement them in these case studies. The challenge of balancing risk and independence is a major concern. For example, should a staff person watch each resident to verify that medications are taken? Should staff check on individuals who do not attend a meal? How do you encourage a person who does not want to take a shower to do so anyway? What are the responsibilities to families who assume that Mother is safe and not lying on her apartment floor for six hours before being discovered? One instructor noted that assisted living is not a "safety deposit box" and that "we can't monitor people all the

time." We have to balance "concern versus monitoring." The manager trainees responded to case examples like: "What would you do if a resident ate in such a way as to gross other residents out so badly that they wanted to leave?" This example portrays the delicate balance between responding to one resident's needs without offending, and losing, other paying clients. Similar examples include questions about residents with "problem incontinence," cognitive and behavioral problems, and severe physical impairments. Managers in training theorize how they would respond to such situations using their newly adopted social model concepts and terms.

Another important standard integral to the social model of case is the notion of "shared responsibility." One instructor explained that shared responsibility "is based on shared expectations between regulators, consumers, and providers." Case study examples tended to include the concerns of all three groups. What if a resident becomes incontinent? Senior and Disabled Services Division expects that facility staff will offer assistance if the resident needs it, whether ordering incontinence products or physically helping the individual into and out of garments. What if the resident is cognitively impaired and cannot understand the need to use such products? The staff must continue trying, using "creative" approaches, possibly encouraging this individual to use the toilet every two hours or buying garments that do not look like diapers. In addition, the staff must document these efforts because SDSD staff monitor reasons that residents leave assisted living facilities. The two preferred reasons for leaving are resident choice and resident death. Some residents must leave because of

medical needs, and SDSD staff accepts this, but residents should not be asked to leave for unwarranted reasons. If an individual is asked to leave because of problem incontinence, SDSD evaluators will examine the resident's file to assess whether discharge was justifiable, and documentation should support justifiable claims.

Within the discussion of how to incorporate the values are examples of what not to do. One instructor referred to the "recent proliferation of 'assisted living lite'" which she described as facilities that merely want to "provide a little help with bathing." This approach does not meet the standards set by the rules or SDSD's expectations. Other examples of what not to do include, "don't knock and walk" into a resident's apartment, do not close the dining room between meals because that is an important part of each individual's home, don't require residents to come to the medications storage area for their medications, and don't use a public address system to announce resident needs.

So far, the socialization of new managers to the assisted living world has been emphasized. The next section addresses the other key groups who must adopt the terms, standards, and expectations integral to assisted living.

Who Must Be Socialized

> We all know what a nursing home is, right? People don't know what assisted living is, they learn about it from the marketing that sometimes is ahead of itself. We need to educate a broad range of people, doctors, lawyers, judges, families, anyone in your community, what you are and how you're different from a nursing home. (Assisted living instructor)

As mentioned earlier, in order for the values to be implemented, not only facility staff, but also residents, families, health professionals, and community members must be socialized to the values of assisted living. This is true not only in Oregon, but at the national level as well. A goal of the Assisted Living Facilities of America is to "help educate legislators, regulators, health care professionals, the media and the general public."

I observed two basic methods of socializing key groups to assisted living: training and marketing. Manager training has already been presented and although there is no institutionalized training approach for direct care staff, the rules indicate that care providers must understand and implement the values. Marketing strategies are the way that all other groups are socialized, or educated, about the social model of assisted living. The way in which management training instructors describe marketing suggests that they think of it in the traditional way, as selling and buying products, but primarily as a form of education. Consumers, and others, must learn about the "product" in order to buy it, or buy into it. These marketing efforts must reach potential residents and their families as well as health care providers, especially physicians, and the general community. The assisted living managers I observed were expected to market their building on an on-going basis, even if all the units were filled. Some facilities hire marketing staff, though none of the three facilities observed hired individuals specifically for this purpose. Thus, marketing may be considered an important means of socializing individuals to the values of assisted living.

Staff Socialization

The staff of the three facilities observed included resident care assistants, nurses, receptionists, cooks, maintenance workers and housekeepers. All were expected to know something about the values although not all did. Formal training is not required for resident care assistants, the employees who have the most frequent contact with residents. Staff learns by "shadowing" an experienced assistant although those who will dispense medications or specified nursing tasks must receive documented training from the on-site registered nurse. These employees do receive printed materials that define the social model and assisted living values that they must sign to indicate that they have been oriented. However, most of the training on the values occurs via error -- care staff make mistakes and are corrected by the manager as to the expected behavior.

The Timber Heights nurse placed a post-it note on each resident's apartment door that read "Please open door slowly." This was an instruction to the care staff after the nurse herself nearly knocked over a resident when she opened the door to his room too quickly after knocking. She thought the best way to avoid accidents was to make sure that each staff person was reminded every time she went to open a door to do it carefully. She was informed by the manager that her action went against the values, that you wouldn't put notes like that in your own home, and that she shouldn't assume that just because residents were elderly they were going to fall.

One of the Timber Heights resident service assistants approached several residents

seated in the main living room and loudly asked each by name if he or she still had diarrhea. The manager overheard her and quickly called her to his office where he reprimanded her, asking how she would feel if someone did that to her in public. Similarly, when a different resident care assistant brought the weight scales into the main living room to weigh one of the residents, the manager told her that she should not do such things in public, that it was an invasion of privacy and dignity. She explained that she didn't want to make the resident come to her because of his arthritic knees and was instructed that she could have waited until the resident was in his apartment.

Even the advertisement for a new registered nurse was an opportunity for one manager to make a point about assisted living values. She was writing a newspaper ad to hire a replacement nurse and asked me what I thought of the way she had written it. She began with: "Come join our team with providing Quality Care in our Assisted living facility" but then crossed out the term "facility" and tried "environment" instead. Ultimately she ended up with: "RN wanted to join our team with providing quality care in our assisted living homelike environment." She explained to me that this description should be good since the terms came straight from the rules.

Resident and Family Socialization

Residents, and their families, primarily children, but also including grandchildren, nieces and nephews, and siblings, must adopt the assisted living values and terms.

Families often play an integral role in an assisted living resident's life. These individuals may initiate the move, sometimes on the advice of a family physician, and will locate a facility, taking tours of various places that may become their relative's new home. The assisted living manager training courses all mentioned the importance of marketing and responding to families. As one instructor repeatedly asked, "Would you want your mother to live in your facility?"

Residents begin learning about the differences between assisted living and the more familiar nursing home from their initial visit. When a prospective resident asked the Timber Heights manager, "How many patients do you have here?" she was told, "We don't have patients here, we have residents." At Valley View, a woman who had decided to move in the following week was shown around by the receptionist, who began by telling her, "We have a social model here, it's not a medical model" to which the woman nodded blankly. In addition to these verbal reminders, residents receive a "Tenant Handbook" (required by the rules) that describes what assisted living is and what services are available. For example, at Timber Heights, the first page of this document includes:

> Our caring and qualified staff provide an option for those individuals who need special services but who still want to be as self-sufficient as possible" and "We encourage all tenants to be as independent as possible, to maintain community contacts, and to continue the pursuit of lifelong skills and interests.

In addition, OAR requires each facility to develop a Resident Bill of Rights that addresses the six basic values, including independence. Residents must sign a release

that they have received these documents, and if this individual is not capable of reading or comprehending the forms, a family member may sign on his or her behalf. In addition, all new and prospective residents receive one or more promotional brochures, described in Chapter 4, and the language in these further emphasizes the values and assisted living expectations.

Families are socialized to the assisted living culture in several ways. First, they must understand that their relative, the assisted living resident, is the client, regardless of who is paying the rent. Second, they must learn that this is not a medical care facility, but a residence that provides personal care services. Third, by assisting their relative, the monthly rent may be reduced. These efforts are described in more detail below.

Although all three assisted living facilities considered families a valuable resource, a certain amount of tension exists in this relationship. The assisted living manager training instructed new managers to consider the resident as the client and families as secondary. Family members who make demands that do not respect the resident's preferences threaten the social model. For example, if a son wants his mother to follow a strict diabetic diet, but she wants cake for desert, it is the mother's wishes that are respected, so long as she is competent to understand the potential risks of her decision. A staff directive at Spring Hollow shows the tension that sometimes exists:

> [Apartment] #39 - In AM lay out a comb or brush, toothbrush and watch and make sure she brushes and combs her hair, if resident doesn't come down for meals-GO GET HER AND ESCORT HER!!!

This issue was also the topic of a staff meeting. The assistant manager at Spring Hollow informed care staff that this resident's son complained that his mother does not do "a good job herself" when brushing her hair and teeth. One of the staff stated that the resident preferred to do these things herself, to which the manager responded that the son was being charged for this service so it had to be done by staff. In addition, this son wanted his mother to eat her meals in the dining room, rather than her apartment, for the "socialization."

In addition to locating the facility and moving furniture and other personal belongings, families are encouraged to attend resident assessments and even to assist with their parent's care. Timber Heights and Spring Hollow, in particular, expected families to assist with transportation, personal laundry, shopping, and financial matters. Because residents are charged based on the number of services received, monthly rents can be reduced by hundreds of dollars in this manner.

Health Professionals Socialization

Educating associated health care providers, such as physicians, home health nurses, and case managers, is considered another way of enforcing the values while pursuing potential customers. Physicians are invited to open houses and potluck dinners, and managers visit physician offices. The manager of Timber Heights invited twenty local physicians, many with clients who lived at the facility, for breakfast. The invitation read, "Please join us for breakfast, a tour, and a brief discussion of available services."

However, not a single physician attended.

Home health nurses must learn that, while they may view the client as a "patient," the assisted living facility does not. Assisted living facilities do not contract directly with home health providers, residents do, and although the staff will coordinate resident care plans and medications with home health nurses, they will not follow orders from a home health nurse that do not match the values. For example, a home health nurse arrived to assist a Valley View resident with her oxygen equipment only to find that the resident was having lunch. The nurse was incredulous, telling me that she had rescheduled with the woman after arriving the previous day at 12:30 and learning that 12:30 was lunch time. It was now twenty minutes before two p.m., what was this woman doing having lunch? I explained that residents were given a range in which to have lunch, between 12:30 and 2:00, and that today the resident must have decided on a later lunch. The home health nurse informed me that if the resident was not in her apartment in the next ten minutes, that she was leaving. A care assistant told the home health nurse that the matter was between the nurse and the resident, that the facility had nothing to do with it and would not force the resident to leave her meal. The nurse ultimately left without seeing her client and a different home health nurse arrived the following day.

General Community Socialization

Educating the public is another way of marketing as well as reinforcing the values.

For example, assisted living managers host potlucks, open houses, garden tea parties, and various holiday events in which the local community is invited. Following are the comments from a presentation the Timber Heights manager gave to the local business association group:

> We're different from a nursing home and retirement center. Tenants, that's what we call them, have apartments, either studio or one bedroom, with kitchenette, bathroom, and living area. We provide services, meals, meds -- and that's both routine and injections, whatever the doctor prescribes. We have a nurse on staff, not full time but part time, but she's on call 24 hours and we have round the clock 24 hour care. Care is based on a thorough assessment; we may bring in home care or hospice. We have an "aging in place" philosophy, we like the tenants to think of our place as their home and like people to stay. We allow pets... we encourage that they bring their pet or anything that is important to them.

Valley View hosted a community party one month after opening its doors. The invitation read, "In celebration of our Grand Opening, you are cordially invited to an English style "Garden Party." Please join us for hors d' oeuvres, desserts, classical music and a personal tour of our elegant facility."

Barriers to Socializing a Community

Although assisted living managers go to great lengths to socialize facility staff, residents, their families, health care professionals and the local community to the assisted living culture, significant barriers exist. These include cognitively impaired residents, family demands, and staff turnover.

Some assisted living facilities get around the issue of whether to accept or retain

residents with significant cognitive impairment by not installing secured exterior doors that might prevent wandering behavior. Of the three facilities observed, only Timber Heights had secured doors that required an access code that some individuals were unable to remember. All three managers indicated that they would accept residents with cognitive impairments, but only Timber Heights would accept people who might "wander" away. As the Valley View marketing specialist said, "As long as they don't walk, we can take them." Other reasons that cognitively impaired persons threaten this social world are that they may not understand the cultural expectations, especially the concepts behind the negotiated service plans or managed risk agreement. Other residents and their families are often intolerant of people they perceive as crazy or inappropriate. Manager education courses attempt to respond to these issues. One example is a continuing education course sponsored by the OALFA and approved by SDSD. The course, entitled "Managing issues of the difficult resident/family" included the following sessions:

- Overview of difficult people and difficult behaviors
- Inappropriate sexual behavior, and
- If you can't be with the one you love - love the one you're with... Survival resources for managing difficult residents.

The language in the seminar advertisement indicates the tension and frustration that assisted living managers face:

- Your wonderful new resident has transformed into your worst nightmare
- Your staff is ready to quit because of a resident's sexual remarks and

groping while attempting any personal care, and

- How should you handle the resident that masturbates in your lobby?

However, it is clear that not only accepting, but retaining residents with "difficult behaviors" is a goal:

> We **will** admit residents to our facilities with emotional or behavioral problems that continue to challenge us. Learn how to identify available resources and tools to assist residents and staff when problem behaviors develop or persist. (OALFA advertisement, emphasis in original)

By noting that problems associated with cognitively impairments are at odds with the assisted living values, I do not mean to suggest that individuals with such disorders are not appropriate for assisted living. The issues are complex and reflect personal as well as societal attitudes about mental illness, successful aging and "appropriate" behavior in old age. A discussion of segregation versus integration of cognitively impaired persons is beyond the scope of this study.

Family Demands

Assisted living managers learn that the resident is considered the client regardless of who is paying the rent, whether family, guardian, or Medicaid. However, families and others often make demands based on what they believe is best for their relative. In particular, families often want their relative to "socialize" with the other residents rather than sitting in their apartment watching television or sleeping. Another point of contention is the amount of "care" provided. The assisted living values translated

means that staff will not force an individual to wash his or her hair, take a shower, or change into clean clothes, at least for a few days, if that person does not want to. The managers are taught to come up with "creative" efforts to "encourage" residents to shower, or whatever the care concern is, but they also respect the individual's choice to skip a shower, refuse to take a pill, skip a meal, or refuse invitations to participate in social activities.

Staffing

Finally, staffing issues sometimes serve as barriers to the socialization efforts of managers or owners. Specific issues include staff turnover, changes in management, difficulty recruiting staff, increasing care needs of residents, and insufficient staff training. Staff turnover, although not tracked in any systematic way by myself or by SDSD, is an on-going concern to many key groups in this social world. Observation at the three facilities, in combination with manager training materials, indicates that staff turnover is a barrier to the assisted living values. Spring Hollow had just experienced an almost complete change in staffing when my observations began. The assistant manager stated that there had been "one hundred percent turnover in caregivers in three months," including the kitchen staff, activities director, nurse, assistant manager, maintenance, housekeeping, and nearly all the care staff. Her resident newsletter for that month read:

> Throughout the past couple months, you have seen quite a change in our staffing. We have many new faces and some great workers.

The new staff members, listed by name and position, numbered fourteen in a facility with thirty-six residents. The January 1999 issue of the OALFA newsletter indicates that this is not an isolated concern. It includes an article recognizing the importance of staff and the issue of staff turnover with tips on saying "thank-you" and other ways of "retaining quality staff."

Recruiting staff may be hampered by features other than low pay. Valley View is not located on a bus line, and this served as a barrier to recruiting care staff. Timber Heights is located in a small town (population 2052) and although this was great for the seniors in the area who did not want to leave their community, locating individuals willing to work for low wages in combination with rumors about management problems was on on-going concern.

As the care needs of residents who "age in place" increase, staff may be unwilling to take on the associated heavier care responsibilities. In particular, the one staff member who remained at Timber Heights after one year indicated that the increased number of incontinent residents was a barrier to hiring and keeping staff.

Finally, insufficient staff training is a barrier to socialization. The 1989 rules do not require formal training for direct care staff, except that they are to learn basic nursing tasks from a registered nurse and understand the values of assisted living. Revisions to the 1989 rules, due to be adopted in 1999, include a staff training program.

Changes in staff are not limited to direct care staff. During the course of ten

months at Timber Heights, three different managers came and left, one of which did not even have time to attend manager training. The fourth was still there one year later, but only one of the original care staff remained.

Discussion

This chapter highlights how the assisted living values are imparted. In particular, the social world of assisted living is supported through manager training, adoption of a common vocabulary, and socialization of key groups. The management training program teaches managers both why and how to do what is expected within the paradigm of a social model. Assisted living is legitimated through several processes, although at this point it is still a fairly conceptual idea. The next chapter builds on this idea but focuses on the work that managers do: assessing resident independence based on the activities of daily living. The assessment represents an intersection point for several key groups and is the institutional effort to define each resident's level of independence.

Chapter 6

Negotiating Independence in Assisted Living Facilities

A 76-year old neighbor agreed to visit two assisted living facilities with me. We agreed that I would pretend to be her niece and her my aunt. In the senior housing industry, this is called "shopping the competition" and it is used to assess one's rivals in the marketplace. Char and I were being shown through a new facility by Linda, the "marketing and activities director." First we viewed the dining room and living room on the main floor, and then we went downstairs to see the beauty shop, activity area, and an apartment. As we stood in the elevator, Linda looked at Char and said, "so what's your problem?" Char looked blankly at Linda, unsure of the meaning of this question. Fortunately, because we had rehearsed discussing her actual health problems before arriving, she recovered and explained to Linda that she had macular degeneration. Linda made a quick note on her clipboard -- "mac. deg." -- and then asked whether we were interested in seeing a studio or one bedroom apartment.

What's your problem? This question, it would seem, is at the root of the traditional geriatric assessment. Although this vignette may seem extreme, it is not a one of a kind event in assisted living facilities where marketing personnel play a key role and may be the initial contact person for prospective residents. This chapter explores the resident assessment process, treating this institutional action as a defined situation. The social worlds framework considers work a central concern and the activities of reference groups as the basis of each social world's structure. The focus of this chapter is on work activities that have not yet been described in gerontological literature. Therefore, the goal of this chapter is to describe the actual work practices that thus far I have presented in conceptual terms. The policy and practice implications of these observations are presented in the final chapter.

The resident assessment is a major work activity for managers and it creates work for direct care staff, families, and other health care professionals by defining the resident's "problem" and how to address that problem. The questions asked and answered in the resident assessment variously define independence as an organizational goal, a way of being, a way of helping, an indicator of the need for more care, and as a relational concept linking residents, staff, managers, SDSD, and OALFA among others.

The assessment serves as an intersection point for several key groups: Each has an interest in the central variable of independence, but they construct it in different ways. Because SDSD's goal for resident assessments includes planning the type of assistance that each resident receives, I provide case studies to illustrate how these assessments are enacted. The resident assessment is the first organizational process for new residents; it is followed by two other components of the social model's value-practice package: The negotiated service agreement and the managed risk agreement. I present how the varied constructions of independence within these methods require a network of interdependence between the key groups and their activities. That is, independence enacted at the organizational level requires interdependence among key groups.

Analysis for this chapter is based on participant observation of resident assessments and service planning, the organizational efforts to make real for each resident the ideal construct of independence. At both Timber Heights and Valley View, I actively participated in resident assessments. I agreed to assist the Timber

Heights manager with initial assessments before the new building was open for occupancy, but when she quit, I became responsible for assessments. When a new manager was hired a few weeks later, I assisted him with new resident assessments, service planning, and related work. At Valley View, also a new facility, the manager gladly accepted my offer to assist because she was worried about being fined by SDSD because she was behind schedule on her forms. She assigned me the task of transforming her assessment forms into "service plans," explaining the purpose of this process as recognizing the "individuality" of each resident, deciding who is responsible to assist, and "the independence bit."

Negotiating Independence

The goal of promoting independence is informed by competing paradigms. As mentioned, the gerontological discussion about independence is informed by the disciplines of law (civil rights), medical ethics (informed consent), psychology (locus of control), social work (client focused), medicine (cure and rehabilitation) and Western individualism. Kaufman (1994) suggests that two competing paradigms operating within the American health care system directly affect older persons. The "autonomy paradigm," which includes medical ethics, law, psychological theories, and individualism, leads to the organizational commitment to client autonomy and independence. The competing framework is based on the "medicalization of aging paradigm" which derives from a critique that the medical goal of treating "problems"

has inappropriately attributed social, behavioral, political and moral issues to individuals rather than to society. She argues that these two paradigms, while possessing some positive features, produce tension between independence and autonomy on one hand, and risk management on the other. Kaufman's critique is based on her ethnography of a community-based geriatric assessment team composed of a physician, nurse, social worker, psychologist, and podiatrist. She described how elderly community residing seniors were "transformed" by the assessment process into "patients." During that process, the discourse of the autonomy paradigm was typically subsumed by the medicalization paradigm. That is, the geriatric assessment team used the language of risk reduction and oversight (medicalization paradigm) as

> *the key* to maintaining personal autonomy and independence...Thus, Mrs. A. will have to reduce the number of pets she cares for, receive a meal service, attend an adult day health center, and have her body and environment cleaned by a housekeeper / personal assistant *so that* she can remain 'independent' in her own home. Mrs. B. needs to be watched eight hours a day *in order* to reside in her apartment alone. (Kaufman, 1994, p. 55, emphasis in original)

The assessment team can legitimately define their activities as having successfully supported the independence of both Mrs. A. and Mrs. B. because these actions kept these women in the community and out of a nursing home. Whether either Mrs. A. or Mrs. B. believes that she is independent is not clear.

Kaufman's critique of competing paradigms resonates with the present study, although the "medicalization" paradigm is less evident in the social world of assisted living. Instead, a similar tension exists between the "autonomy paradigm" and what I

call the "care coefficient." The term "care" is problematic for assisted living proponents because of its association with the medical model, yet providing care is clearly a large component of what assisted living operators do. I doubt that any assisted living provider would want to be accused of *not* caring for their residents. Instead, assisted living operators use the term "service," or even "product," to define what they offer their residents. Nursing homes and other long-term care settings use the phrases "care conference" and "care plan" to describe the assessment process and subsequent instructions to staff and other health providers. However, assisted living facilities use "tenant service plan," "resident information file," "resident records" or similar rhetorical strategies to avoid any semblance of a medicalized approach. Even the color of three- ring binders became an issue at Timber Heights: When the nurse purchased light blue binders, the manager insisted that she return them for black ones because the powdery blue color conveyed a medical image as opposed to corporate black. Assisted living operational conventions, as presented in manager training, include the resident assessment, negotiated service plan, and the managed risk agreement. These strategies are the standard practice concepts in the value-practice package. The resident assessment is designed to identify the individual's functional abilities. The negotiated service agreement was created in recognition that what the individual wants or needs and what the facility can or will provide in the way of services, may be at odds. Therefore, the parties engage in a process of negotiation. For example, if an individual needs to use oxygen equipment, but the management is

unwilling to accept responsibility, an agreement might be negotiated whereby the resident contracts with an independent home health provider. All services are considered negotiated regardless of how intensive or mundane the task. The typical form includes 23 services (detailed below) and the manager records whether or not the resident wants or needs that service and who is responsible for that service, whether resident, family, or staff. A "managed risk agreement" may be used if the resident engages in behavior that the facility staff believe to be unsafe such as walking without aid of a walker, especially if advised to do so by a physician. The three operational elements of the value-practice package are described below.

Resident Assessment

The assisted living rules state that the goal of the resident assessment is to determine what each individual needs or prefers in order to best help that person be as independent as possible given physical or mental impairment. Not surprisingly, for managers the primary goal of the resident assessment becomes meeting organizational demands: First, identify which activities of daily living the resident requires staff assistance with and second, use terminology that satisfies the managing agency, SDSD. The managers I observed did believe that by following the assessment model learned in training, they could support each resident's need for independence regardless of that person's physical or cognitive capacity. However, the daily realities of work, including marketing, hiring and managing staff, ordering supplies, and filing

reports to SDSD and supervisors, meant that the primary goal became keeping up with the paperwork involved in the assessment process.

The state rules require that facilities assess each resident's needs before he or she moves in and quarterly thereafter. The reasons for this include: Determining whether the individual is capable of being an assisted living resident; that is, the individual must be medically stable and the facility staff must be able to respond to this person's needs. Individuals with insulin-dependent diabetes are regularly admitted, but those identified as "brittle" diabetics may not be admitted. Second, the assessment information is used to plan each individual's daily services which may be provided by direct care providers, family members, and/or other health professionals. Third, the assessment sets the monthly fee, with those requiring fewer services paying fewer dollars. The "activities of daily living" (described below) is the foundation of resident assessment procedures. Assisted living facilities have appropriated this measurement construct into a marketable product. The marketing brochures refer to "*daily activities*," "*daily living needs*," "*personal care services*," and "*a little help*" to describe what assisted living facilities do. However, just retooling terminology from the medicalized notion of "activities of daily living" begs the question of how appropriate this construct is as the basis of resident assessment in the "social model." The final reason SDSD requires assessment is for staff scheduling. The rules do not require minimum staff to resident ratios, instead requiring that staffing levels be determined by the service levels of the residents. Thus, a facility with a large number

of residents with high service levels would require more staff than a facility with more low service level residents. The assessment process is based on the "activities of daily living."

The "Activities of Daily Living"

"The Activities of Daily Living" is an icon of gerontological policy and practice. This construct is almost universally accepted as the measure of functional ability among elderly persons. This construct lends scientific legitimacy to an otherwise highly subjective and value-laden process (Kane 1990). Developed in 1959 by a group of physicians, this measure, fully entitled "The index of independence in Activities of Daily Living," was designed to objectively assess and predict the functional progress of elderly hip fracture patients (Katz, Ford, Moskowitz, Jackson, & Jaffe ,1963). Six activities of daily living were identified: toileting, feeding, dressing, grooming, physical ambulation/mobility, and bathing. The assessment goal is to determine whether or not the individual is capable of managing these activities with or without human assistance.

A few years later, Lawton and Brody (1969) added to this construct seven tasks relevant to "a minimally adequate social life" (Lawton, 1971, p. 470) and these, entitled the "Instrumental Activities of Daily Living" (or IADLs), include basic home-centered tasks such as using the telephone, shopping, food preparation, housekeeping, laundry, transportation, responsibility for personal medication, and ability to handle

finances. Again, a primary concern is whether the individual is capable of managing these daily tasks with or without human assistance.

Since the development of the ADL-IADL scales, at least 50 adaptations have been created, including generic and disease-based approaches (for a review, see Kane, 1990 or Spector, 1996). However, the focus of most assessment measures remains on the functional ability of the individual being assessed and whether others are needed to assist that person in the set of predefined activities. Recently, researchers interested in the validity of the ADL construct in non-industrial countries have critiqued this assessment approach. Subedi and Kunkel (1997) found that the important activities of daily living for a group of Asian Indian elders included playing music at community events, sweeping their dirt floor homes, and preparing food for relatives. Jitapunkul et al. (1994) developed a new index of ADLs based on activities important to Thai elders. These innovative efforts offer important lessons about finding out how individuals define "the" activities of daily living important to them. Using "The Activities of Daily Living" as a lens structures certain activities as the organizational product and ignores other activities that individuals might define as important.

Oregon's Use of the ADL Construct.

Senior and Disabled Services Division uses the ADL scale as the foundation of client assessment and service planning for all home and community-based services, including assisted living. Their Client Assessment/Planning Subsytem is a structured

questionnaire designed to quantify each client's characteristics, health conditions, functional impairments, and living situation into an "algorithm" used to plan services. Although this process is used with Medicaid clients only, it guided development of the assisted living assessment standards. The assessment process is described as,

> a *social model* for service delivery with a goal of promoting and maintaining an individual's *independence*. We want to support and enhance the client's ability to provide self-care, direct their own care, and actively include them in planning for care to be provided by others. (Front page of the SDSD form SDS 360, revised 7-96; emphasis added)

For each item in the protocol, clients are assessed on a continuum from independent (does not need assistance from another person) to totally dependent. For example, "toileting" is assessed from:

> 1: Can toilet self without physical assistance or supervision. May need grab bars/raised toilet seat or can manage own closed drainage system if has a catheter or sheath or uses protective aids

to

> 5: Physically unable to be toileted. Requires continual observation and total cleansing. May require protective garments or padding or linen changes. May or may not be aware of need.

Each individual is assigned a "service level" from one to five, with one representing the most independent person and five the least independent. The State reimburses facilities more for individuals assessed at level five than level one on the assumption that more staff time is required to care for a person at level five.

Oregon's administrative rules governing assisted living facilities provide this definition of the activities of daily living:

> ...those personal functional activities required by an individual for continued well-being including eating/nutrition, dressing, personal hygiene, mobility, toileting and

behavior management.

'Independent' means that the resident can perform the ADL without help;
'Assistance' means the resident can perform some part of an activity, but cannot do it entirely alone;
'Dependent' means the resident cannot perform any part of an activity; it must be done entirely by someone else.

The above definitions indicate that independence is a relational concept based on the individuals need for human assistance to accomplish a defined set of activities. Someone, whether staff, family, or other health professional, must agree to assist the individual with the identified activities. As defined by rule, a process of negotiation takes place in order to determine which of these individuals is responsible for each activity so that the resident's independence is best supported.

Assisted living facilities use the ADL scale but add several additional categories, listed in Table 8 on page 105.

Table 8

Typical Assisted Living Assessment Items

• Health monitoring	• Medication assistance	• Health care arrangements	• Ambulation
• Bowel incontinence	• Urine incontinence	• Food preparation	• Eating assistance
• Dressing	• Personal hygiene	• Bathing	• Night-time Assistance
• Laundry	• Housekeeping	• Orientation	• Safety
• Communication	• Counseling	• Behavioral issues	• Social activities
• Transportation	• Personal business or finances	• Anything else	

From Construct to Product

As discussed earlier, assisted living facilities have tapped into the societal value of independence by advertising, through brochures and newspaper ads, that independence is valued and supported. The content analysis of assisted living facility brochures described in Chapter Four revealed that of the six basic values, the most prominent theme was "independence." This example suggests how a construct from clinical geriatrics, combined with societal norms about aging and independence, is repackaged as a consumable item. Assisted living service plans are designed to be "negotiated." This concept reinforces the overall client-driven, market orientation of assisted living

facilities with the "activities of daily living" serving as the reason for this business. Yet, what are consumers really buying?

Case 1: Mrs. Morone's Assessment

> Mrs. Morone's family was moving her furniture into her apartment at Valley View as we sat down for her assessment. The manager had done a long distance assessment by telephone since Mrs. Morone lived in California prior to moving closer to her daughter. Louise, the registered nurse at Valley View, did the assessment, explaining that we needed to find out what kinds of services Mrs. Morone needed and immediately beginning with: "Monitoring health care, some residents need to have their blood pressure checked or need insulin or oxygen, do you need anything like that?" Mrs. Morone said there was no need. Louise continued with the items on her list and Mrs. Morone answered and occasionally asked her own questions. The clinic that would be treating her rheumatoid arthritis was beyond the transportation zone covered by the facility van so Mrs. Morone said that either her daughter would take her or she would take a cab. Her plan was to begin driving as soon as she learned her way around. Her daughter, who stopped between trips to her mother's new apartment, agreed. After Louise asked if Mrs. Morone needed help with "bowel or bladder management," her daughter stated that the trash would need to be emptied daily since her mother used pads for urine leakage at night. "Any need for help to go to the bathroom, get a drink, adjust mini blinds during the night?" Louise asked. "I can do that. I usually have to go to the bathroom but I do it myself. The only reason I'm here is to get three meals a day. It's an expensive way to do it." "Do you need assistance with bathing?" "No, but I am worried about the floor getting wet with that shower." Mrs. Morone's daughter asked Louise if they had "raised toilet seats" to which Louise responded: "No we're a social model not a medical model and so we don't provide things like that because not everyone needs it. Do you need assistance with dressing or undressing?"

Louise's reference to the social model went without comment from either Mrs. Morone or her daughter. However, her identification of the raised toilet seat as an object belonging to the medical model is an example of how assisted living staff are trained to legitimize some things as social while treating other similar objects as

medical. For example, all apartments include at least two emergency pull cords and all bathrooms have handicapped accessible sinks, showers, and bars adjacent to the toilet, per Oregon rules. Yet Louise had been trained to consider these items as elements of the social model that support resident independence. A raised toilet seat somehow crossed an invisible line into the medical model. The assessment continued with Louise asking Mrs. Morone about her ability to walk.

> Louise, "Do you use the wheelchair mostly or walk some?" Mrs. Morone, "I mostly use a walker or a cane but I can't walk long distances and I need to get help to get to the car in a wheelchair." She also explained that she would need someone to push her to and from the dining room in her wheelchair because she cannot propel it that distance herself because of rheumatoid arthritis in her hands. Mrs. Morone expressed disappointment that her apartment was so far from the dining room because if it had been closer she could walk using her walker. Her daughter mentioned that they were looking at motorized carts and Louise responded by explaining that Mrs. Morone's service plan could be changed at any time and to let her know if she no longer needed assistance getting to the dining room.

All of the items for which Mrs. Morone did not require Valley View staff assistance with were marked as "independent." Thus, an outside reviewer would see that the facility was completing its mission of supporting the resident's independence.

Mrs. Morone later told me that she did not know if she would stay at Valley View because it was too expensive for what she was getting. In her opinion, the only service that she required was help to and from the dining room and only because her apartment was too far away and her knees are "very bad" due to rheumatoid arthritis. She explained that she might have remained in California because "I like my independence," but that her daughter encouraged her to move. In addition, Mrs.

Morone hoped that her new doctor would perform the knee surgery that her previous doctor had refused.

The nurse concluded the assessment by asking if Mrs. Morone needed "anything extra?" to which she stated, "I'm not sure what you have in mind." This "anything extra" generally translates into additional services that residents might identify as important to them. Examples that assessors usually offer include letter writing or pet care. However, in the more than fifty assessments I observed, not a single resident added anything to the list of assessment items. Is this because these individuals only care about the twenty-three activities of daily living identified by assisted living assessors? Given that these individuals are new to assisted living at the time of assessment, it could be that they do not yet know what to expect. Or perhaps the "anything extra" is provided by friends and family. This dangling question, the only truly open-ended question included on the assessment measure, is highly suspect as a means of asking for information. If the goal of this question was to learn what activities the individual defined as important to his or her daily living, a better strategy would be to ask that person a series of questions about his or her goals and values, about what provides meaning, and about how that person lives life. However, given that SDSD only requires facilities to assess individuals with the index of activities of daily living, such qualitative questions have little organizational merit.

The Negotiated Service Plan

The negotiated service plan is an institutional response to the inherent tension between respecting independence and controlling risks associated with old age and disability. It serves as another means of legitimizing the social world of assisted living by offering a standardized approach with specific terms and methods. This convention is taught in the educational programs and monitored by SDSD staff. It also distinguishes what assisted living operators do from what other long-term care providers do. For example, although adult care homes, nursing facilities, and residential care facilities use the ADL categories, they are not required to specify resident preferences in the way that assisted living providers are.

The language used in these forms follows conventions set in the SDSD manager training programs, further serving operators' needs to define and legitimate their practices. All three of the facilities observed used a similar language based on managers' understandings of SDSD expectations. Table 9 on page 111 offers an example of typical services. The use of the resident's name is meant to convey to SDSD monitoring staff the degree of participation the individual has in this process. As part of the assisted living quality monitoring system, SDSD evaluation staff periodically reviews individual resident files to determine whether that person had a voice in the assessment procedure. These SDSD "client care monitors" review facility files to check that each resident, or a family member, signed the negotiated service agreement. In addition, the individual is expected to describe how specific services

should be delivered. For example, one resident's file might indicate that she chooses to be woken each day at seven a.m. and assisted to the toilet. Another resident's file might indicate that she prefers to sleep in and should not be disturbed in the morning.

One of the manager training instructors described a new process that some facilities are using. Instead of using the resident's name, as in "Bob prefers assistance to take a shower," they use first-person narrative scenarios: "I like to take a shower each morning around eight and I need someone to wash my back and feet." In this way, they attempt to prove that the resident has control over the assessment and service planning situation.

Table 9

Sample Tenant Service Plan

Service	Reason for service	Resident preference	How to provide service	When to provide	Responsible party
Bathing	Betty had a stroke and has left side paralysis	Betty prefers that staff assist her with showers	Betty likes to have a Jacuzzi bath once a week and shower with standby assist twice a week. She needs help to adjust water and wash her back & feet	Bath on Saturday evenings and shower Tuesday and Thursday mornings	Betty will refuse shower assistance from male staff
Laundry	Betty asks that we wash her personal clothing	Betty prefers that staff wash her personal clothing	Betty will sort her clothing for staff and leave it in her bathroom closet	Every Wednesday morning	Staff
Transportation	Betty is unable to drive	Betty likes to go for drives.	Betty's son or a friend will take her to doctor's appt. and for social visits	As needed. If Betty's family is not available, staff to arrange cab	Betty, her son or friends, or staff
Eating	Betty does not request assistance	To maintain her independence			Betty

The social model resident assessment requires interdependent relationships among several key groups. As a 1989 SDSD white paper stated, "The resident, family members, and other significant people sit down together to assess what is needed to support the resident in their greatest capacity for living independently." The "other significant people" may include case managers for Medicaid clients, guardians, home health nurses, hospice staff, and psychiatric personnel. Any combination of these individuals may be required to negotiate for the resident's independence. For example, one resident at Valley View was at risk of being relocated because she was refusing showers, to change her Depends (adult diapers), to go to bed at night, and was entering other resident's apartments. A note in her file read,

> Regarding whether Mrs. Lincoln can stay, involvement of the SW, RN, MD assessment [*sic*]. If they are unable to help us keep Mrs. Lincoln here, we will have to find alternative accommodation for her.

In some cases, the collaboration of such individuals will result in success, defined, as in this example, as keeping the resident at the assisted living facility and therefore, independent. Of course there are also examples where regardless of family or other health care professional negotiations, residents are relocated to other settings, including nursing homes.

The Managed Risk Agreement

The negotiated service plan should account for all services and activities in the assisted living facility. However, if a resident's approach to his or her activities of

daily living is considered unsafe, the manager may propose a "managed risk agreement." One of the managers training programs provided this definition:

> The medical model holds out physical wellbeing as its primary goal. The social model of long term care seeks to normalize an individual's environment and routine. Risk is a normal part of life and, with responsible caution, should be restored as an acceptable element in the lives of frail elders, to be managed with regard for *their* wishes. (ALA "Fundamental ground rules, p.9, emphasis in original)

This process is designed to alert all parties to risks identified by staff, document how the staff have attempted to mitigate the risks (i.e., reduce institutional liability), and still honor the individual's free will and independence to continue the practice with full understanding of associated risks. The conceptual basis derives from the medical ethics convention of informed consent and from legal case precedent regarding the right, as an adult, to make poor choices. For example, in re Bryden's Estate (211 PA 683, 61A250, 1905) stated that "[a] man may do what he pleases with his personal estate during his life, he may even beggar himself and his family if he chooses to commit such an act of folly." This case, and similar ones regarding the rights of individuals with physical and mental disabilities (Cohen, 1986) inform the concept of a managed risk agreement. This focus on rights shades the discussion of independence to include the related concept of autonomy. The former is generally discussed in terms of functional ability while the latter relates to legal rights and responsibilities. However, because the ADL construct so strongly directs the organizational focus of assisted living providers, managed risk agreements are generally discussed in terms of

ADLs.

A specific example, what I call "the case of the diabetic who ate cake," was used at each training session I attended. The scenario includes, for example, Mrs. Wilson, an 86-year old resident with insulin-dependent diabetes and a physician recommended diabetic diet. Yet Mrs. Wilson insists on eating cake, cookies, pie, or other sugary deserts. What should the staff do? The social model prescribes respect for the individual's independence and choice. Yet, the facility has some responsibility for Mrs. Wilson's health and well-being. Assisted living providers must balance respect for the individual's autonomy and right as an adult to make choices, even foolish ones, with institutional responsibility as a care provider to see that this individual does not harm herself. Should the staff prohibit her from eating cake? How can staff control what food items she has in her apartment or while on social outings? What if she has dementia? Participants in the manager training sessions consider such dilemmas in preparation for work as an assisted living manager. Responses include targeting family members and other health care professionals to support Mrs. Weaver's independence but also preserve her health. This then is another example of the interdependence required to support independence as defined by key group members.

Choice and responsibility are central concepts in the managed risk agreement. However, the choices are "bounded" and the responsibilities are "shared." As each of the manager training instructors explained, all adults have boundaries around the choices they may make, whether personal, financial, or legal. Similarly,

responsibilities typically have a relational quality, whether to family, coworker, or community. As one instructor explained, "These are key aspects of what you're going to be educating your residents on." He went on to explain to the class:

> Risk defines who you are. Why would you think you can define a risk for someone in your community? That's defining that person and we have no right to define these people. In the medical model, doctor's orders define the person. Things have changed.

Each instructor also explained that the managed risk agreement should only be used as a last resort. This document has a quasi-legal status and the process has the potential of setting up an adversarial relationship between staff and the resident and his or her family. One instructor noted that "it is not to be used in a punitive way or to avoid liability. The purpose is to empower." Assisted living residents are expected to recognize their own responsibilities, as adults, to themselves and the community in which they now live. The assisted living "bill of rights" is another institutional means of enforcing this idea. Oregon administrative rules require that each facility develop a resident bill of rights and responsibilities. This differs from the process used in nursing homes in which only resident rights are discussed. A sample assisted living resident rights document, provided by one of the instructors, included 14 "rights" and 22 "responsibilities" divided into categories including "responsibilities to yourself," "responsibilities to other residents," and "responsibilities to the staff and the facility."

Case 2: Mrs. Billing's Risky Behavior

> Mrs. Billings moved to Timber Heights with her husband. She was physically very active but had severe memory and judgement problems. Mr. Billings was very ill: He had diabetes, osteoporosis, bowel and bladder incontinence, cancer, and he was legally blind. Mrs. Billings enjoyed cleaning their one-bedroom apartment and doing the laundry. Her son said, "Mom wants to do the laundry everyday, as soon as she has one thing to wash. And now that she found where they keep the laundry soap in there, she wants to do it all the time." The problem that lead to a managed risk agreement was that Mrs. Billings sometimes could not recall how to use the washer and dryer. She would put soap in the dryer or forget to put soap in the washer. However, the more serious problem occurred when she attempted to wash her husband's clothing following his bowel or bladder accidents. Mrs. Billings would place soiled items directly into the dryer or onto the sorting tables, putting herself and others at risk of contamination. The manager and staff did not want to take away Mrs. Billings only meaningful activity. They placed step-by-step directions on the washer and dryer but Mrs. Billings did not read or understand these. They attempted intercepting Mrs. Billings each time they saw her going to the laundry room with her laundry cart, but this was not always possible. Mrs. Billings' son and daughter-in-law were called in, but they could not come up with a solution. Her son said, "Well I'd rather she did it, it gives her something to do. But I don't mind if they take it away from her if necessary."

The events in this case continued for about four months when Mr. Billings died. After that, the problem of clothing soiled with urine and feces ended, but Mrs. Billings continued to have difficulty understanding the proper sequence for washing her own clothes. The solution came from other residents who volunteered to assist Mrs. Billings in the laundry room. In this case, the individuals expected to "share" in the s-hared responsibility component of a managed risk agreement included Mrs. Billings, her son and daughter-in-law, and the direct care staff. Ultimately other residents volunteered to help Mrs. Billings, although this was an informal agreement that was not addressed in the formal managed risk agreement. Staff defined Mrs. Billing's

independence, and therefore quality of life, in terms of an ADL item--doing laundry. Doing laundry was certainly important to Mrs. Billings, but other ways of keeping this physically active, if confused, woman satisfied, were never discussed. Her family took her to church and out for dinner two to three times a month, but while at Timber Heights, Mrs. Billings meaningful activities were limited to washing clothes.

Assistance: How ADLs are Implemented by Staff

The residents' activities of daily living are translated into the daily tasks that must be accomplished by an individual staff member during the course of her eight-hour shift. Thus, for the direct care provider, ADLs become tasks, chores, and daily assignments that must be "documented" in order to "prove" that the service was provided. Some residents are very clear about their needs and expectations, others very unclear or confused, and others express hesitance about "bothering the girls" because they are "so busy." Still others, like Mrs. Reese below, have very limited options about their daily activities and the level of independence permitted.

Case 3: Mrs. Reese's ADLs

> Mrs. Reese had lived at Spring Hollow for about five years. During this time, she had a stroke and her Parkinson's disease continued to progress to the point that walking became very difficult. Mrs. Reese did walk, slowly, and sometimes she fell down. The staff was instructed to walk with Mrs. Reese at all times and they told her to call for assistance if she needed to walk. Most days, the staff person assigned to Mrs. Reese would help her get dressed, walk her to the living room, and seat her on the couch where she could be observed. Mrs. Reese was not happy with this arrangement. Her service plan included

> two hour "bowel and bladder checks," but Mrs. Reese often got up unescorted and went to her apartment. One evening she repeatedly asked for assistance to go to the toilet, but the woman on shift told her she would have to wait, it wasn't time yet. Staff admonished Mrs. Reese, saying, "You don't want to fall do you?" or "I heard you fell last night, what were you thinking?" I asked a staff member if Mrs. Reese wouldn't fall even if someone was beside her and she said, "She's less likely to fall if someone is with her, but she's gonna fall and go to a nursing home and not be able to come back. She's not being bad, it's just her mental state, she forgets because of her condition. It's the same with Alzheimer's disease, Parkinson's, stroke. They forget." In fact, Mrs. Reese did end up in a nursing home but due to a massive stroke rather than a fall.

Mrs. Reese's independence was defined, by staff, in terms of keeping her out of an institution. The constraints they placed on her were justified in the name of safety and prevention, in keeping with the managed risk philosophy. Using the appropriate terminology, Mrs. Reese's choices were "bounded" in part due to her disability, in part because staff wanted to protect her from a fall that might lead to a nursing home placement. The manager expected Mrs. Reese to "share" in this responsibility to prevent such a move by agreeing not to walk unescorted.

Directions to Staff

Despite very detailed service plans that extend five to six pages in length, the daily directions to staff may be minimal. For example, at Spring Hollow the direct care providers receive "assignment sheets" that describe their daily care duties, organized by the building floor plan: Rhonda works wing 1 and 2 while Marie works wing 3. A few examples from this list include:

> #2 - assist with LE (lower extremity) dressing / put on hand and foot splint / empty commode / make bed / 2 hour checks - wears depends 24 hours. Have

resident walk to the dining room from the couch and to the bathroom from the couch.
#3 - 8:30 am: fix cereal in apt (make sure she is sitting at kitchen table!)/ Assist with dressing and hygiene (brushing teeth) / turn on lights, open drapes, turn on TV / walk resident to mailbox and back at 10:00 am/empty trash/make bed (BEFORE 10AM)/2hr incont. Check/give res. a glass of juice wears attends 24 hours.
#5 - **Wake at 7:00**--make sure that she is getting up--at 10:30 have resident walk or ride the bike for exercise--**so do not let her refuse**, she is going to do this twice weekly.
#8 - Wake at six am standby assist with transfers out of bed, standby assist with dressing.
#13 - Wake at 7am.
#15 - **Do not disturb in the morning, may or may not come down for breakfast.**
#28 - walk dog as needed when res is unable.
#39 - In AM lay out a comb or brush, toothbrush and watch and make sure she brushes and combs her hair, if resident doesn't come down for meals-GO GET HER AND ESCORT HER!!!

Another example includes the following note from the manager to direct care staff regarding two new residents. She has summarized the assessment information to provide only what she believes is relevant about each new resident:

> There are 2 new people moving in this weekend. Please make them feel welcome AND write in communication log when they arrive. #27 - Edith. Self-med, bath assist M-W-F, cue for meals, dresses self, grooms self, cont. --> kind of bull headed but nice lady. #33 - Regina - FULL care. meds, B&B every 2 hrs, dress, undress, 1 person transfer to & from w/c, wheel to meals, grooming, everything. Staff is responsible for everything. She's a stroke with L side paralysis & wears a brace on wrist, attends & drools a lot but is very shy and quiet.

In the above examples, the manager's directions to staff focus on only the immediate ADL problem of each resident. According to the image of the medical model presented in manager training, even the above goes beyond how nursing home

residents are uniformly treated. However, the efforts to incorporate independence as represented in the service plan are lost by the time staff directives are written. The service plan for #3 above might detail exactly how to assist this individual with dressing and hygiene so as best to support her independence. Perhaps she chooses her clothes and is able to put on upper body items. However, organizational realities like staff turnover and managers with too many other daily tasks results in abbreviated instructions like these.

In many ways, this is not so different from Gubrium's (1975) description of work practices in the nursing home. There, nurse's aides are expected to "chart" the care they provide and the daily behavior of their "patients." Despite administrative goals to treat the patients as whole beings, charting efforts describe these individuals only as bodies who have a "good appetite, good BM, or slept through the night" (Gubrium, 1975, p. 59). Thus, the focus is on ADL care given and received. This, Gubrium explains, is because the nurse's aides know that their work activities are being monitored and that the administrator expects to see that ADL assistance is charted since this is what their regulatory agency requires. Providing care is what nursing homes do. Assisted living operators face a similar circumstance--SDSD's client care monitoring staff examine resident records and do not systematically observe actual staff practices. Thus a great deal of management effort is expended on the assessment and service planning documents and less detail goes into staff directions.

Discussion

The way in which assisted living managers think about and ask questions about independence frames the definition of the situation. Thus, independence may be considered as a product marketed to potential consumers, as a state of being that can be measured through a structured assessment process (Kaufman, 1994), as instructions for helping someone, as an indication regarding risk for institutionalization (Kaufman, 1994), as an organizational goal, as the basis of a quasi-legal contractual agreement, and as a relational concept that links both individuals and groups. Above all, independence must be negotiated among the resident, her family, staff, management, and other health professionals, in this interdependent world of assisted living.

The examples of resident assessment, service planning and staff directions, and managed risk agreements indicate that managers attempt to respond to SDSD directions regarding resident control over the type and timing of services with which they receive assistance. However, this directive is redirected by managers' needs to meet organizational goals like avoiding regulatory penalties, managing staff, and other daily work activities. The institutionalized focus on ADLs narrows the conception of independence to merely managing residents' problems in terms of functional ability. Residents who either do not require assistance, or who receive family help rather than staff assistance, are defined as "independent," and because independence is an organizational goal, this outcome is measured as a success, both by management and SDSD client care monitors. However, even this poses a problem in terms of proving

that the facility staff is responsible for the resident's independence. As one manager said, "Some of the residents are so independent, they really don't need any documentation." In such cases, managers are instructed to record that the resident is "independent" as noted in the example in Table 9, page 111.

The activities of daily living are undoubtedly the ones that most healthy people would least prefer assistance with. However, most residents who were the focus of the many assessments I observed expressed a matter-of-fact attitude about this new fact of their lives. Beyond the assessment forum I heard from many residents a prevailing sentiment of boredom with daily life. Certainly some individuals expressed a desire to self-manage the assisted living facility-defined ADLs as a way of keeping busy. Doing laundry and light housekeeping were two tasks that people mentioned as basic strategies for keeping busy. Assisted living facilities proponents talk about "educating consumers" about what to expect from assisted living. Should they be educating these people to expect more than a predefined set of activities of daily living about which to be independent? Are residents interested in more than managing this predefined set of activities that make up a person's day? This question has not been asked of assisted living consumers. However, lessons may be drawn from cross-cultural studies of elders' self-identified meaningful daily activities (Jitapunkul et al., 1994; Subedi & Kunkel, 1997).

A final theme that the assessment process raises is interdependence. It is clear that assisted living facilities depend on families, other residents, and a wide range of other

health care providers to support the social model goals. As Sharon Kaufman notes, the ways in which very old persons and their families respond to frailty, or loss of independence, must force us "to think about interdependence in ways that do not yet exist in the wider culture" (Kaufman, 1994, p. 49). In the social world of assisted living, independence serves as a valuable unifying construct, one that at least some key groups strive to achieve, however they define it. Yet, it must be recognized by assisted living providers and other proponents that interdependence may be at least as important a value given the emphasis on negotiation, a process that requires group cooperation.

Chapter 7

The Value of Independence in Old Age

I began this study by focusing on assisted living facilities and independence. Data analysis from three primary sources indicates the importance of independence to assisted living proponents. It also provides details about significant changes taking place in Oregon's long-term care arena. Although residential housing for poor and disabled seniors is not a new concept in this decade or even this century, the value-practice package offered by assisted living proponents is new. The efforts of key groups within the social world of assisted living to adopt and implement a "social model" of care was an important finding in this study because it organizes the work practices of SDSD, OALFA, and ALF staff. In this final chapter, I summarize new knowledge about assisted living and independence, highlight the process and implications of the shift that assisted living proponents are making to the social model approach, discuss policy and practice implications, and ask questions that might guide future research.

Assisted Living Facilities and Independence

One goal of ethnographic research is to "untangle" what people say they do from what their behaviors suggest they do in practice. Assisted living proponents claim to promote resident independence. Is this claim more than a marketing slogan? While independence is certainly one marketing concept used by assisted living providers, this

study describes several other ways in which key members of this social world construct the value of independence for people who assist older persons. Independence may be considered an organizational goal, a state of being that can be assessed, the basis for helping someone, an indication of need for institutional care, the basis of contractual agreements, and a relational concept that links various groups in addition to a product that is marketed to consumers. Even though key members may have different definitions of the situation, they attempt to negotiate independence in ways that they believe will best meet the common goal of avoiding institutionalization. In practice, this very commitment to the idea of independence requires interdependent relationships between SDSD, operators, marketing professionals, OALFA representatives, and associated health care providers. These groups agree, in implicit and explicit ways, to negotiate, manage, and construct the independence of very frail individuals. Members of this social world effectively use independence as the unifying construct of their social model approach to long-term care.

The social model ideology provides a value-practice package that offers an alternative to what many assisted living proponents describe as the "medical model" of nursing facilities. Instead of fostering dependency, as nursing facilities do, assisted living facilities claim to promote independence. Marketing brochures advertise how independence is supported through "*well engineered apartments*," "*a little help*," and "*allowing*" residents to be at "*the center of the decision-making process so that you can enjoy life independent of an institution*." Assisted living facilities' marketing

materials lend a rhetoric of legitimacy to the enterprise by introducing 'who we are' and 'what we do' for those new to this world. A reading of these materials suggests the possibility of a tension between promoting independence and providing care. Thus, we see statements like the following:

> *Our number one goal is to promote independence. Personalized assistance with activities such as bathing, dressing, grooming, and walking are provided by a fully trained and supervised staff who will assure that prescribed medicines are taken in the proper amounts at the correct time.* (Community F)

Such a statement may lead one to wonder how independent a person is who requires a staff person to assure medication compliance. How different is this from the stereotypical image of a nursing facility? This is not to suggest that residents do not want to take their medications as prescribed, although some might choose not to sometimes, but that the image evoked by this marketing effort is at least as much about medical care as about social assistance.

Manager training programs represent another arena in which the value of independence was emphasized. Here, organizational strategies for balancing the tension between independence and care management were presented. Manager trainees were socialized to the value component of the value-practice package. In particular, the rationale for providing a revolutionary approach to long-term care services, along with appropriate terminology, was presented and enforced. Managers learned that success of the social model required residents, their families, and associated health and community members to be socialized, or "educated," to the value of independence.

The resident assessment, negotiated service agreement and managed risk agreement are important practice concepts in the value-practice package, ones that managers are expected to employ in their mission to promote resident independence.

How do managers implement what they learn in manager training? Based on the three facilities I observed, managers attempt to enact the State policy goal of supporting resident independence. They conduct detailed assessments and write detailed service plans. However, because the focus of assessment and service planning is so narrowly defined by the "activities of daily living" construct, and because these managers are primarily concerned with meeting SDSD expectations, managers limit their efforts to these tasks. Of the 23 service items, only one ("social activities") implies something other than those most basic elements of human existence like bathing, dressing, and laundry. Given that the social model ideology includes treating the individual in a holistic manner, these services appear to fall short of the goal.

This ethnographic study reveals that assisted living proponents value the idea of independence in old age. They are committed to this value and employ a variety of legitimacy and rhetorical strategies for enacting it. There are, of course, successes and failures in these efforts and documenting these would require another volume. However, two brief examples will provide a context for considering the value of independence as an organizational goal for assisted living providers. The first example involves Mrs. Weaver, who was 81 when she moved to Timber Heights from her daughter's home. Mrs. Weaver was plagued by significant short-term memory loss but

had no physical health problems. The medical record provided by her physician indicated non-specific "dementia" diagnosis. Mrs. Weaver was capable of managing her daily bodily functions but she needed to be reminded by staff about meal times and any social activities. She had trouble sleeping and sometimes awoke confused in the predawn hours. Mrs. Weaver made friends quickly and liked to walk to a nearby convenience store to purchase soft drinks, candy, or beer with the spending money provided by her daughter who described her mother's current living situation as "a blessing." Timber Heights provided a relatively more independent living situation despite the fact that Mrs. Weaver had been living in her daughter's home in the community. Mrs. Weaver maintained control over her daily routines, but this control occurred within a "very structured" environment according to her daughter. All three assisted living sites that I observed provided a relatively independent home for residents fitting this "diagnosis" of mild cognitive impairment and short-term memory loss. However, a less successful example is provided by the case of Mr. Adler.

Mr. Adler's five daughters were excited about their father moving to Timber Heights following a mild stroke. Although he had completed rehabilitation, he was quite weak and preferred using a wheelchair. His daughters wanted him to walk with support of a walker in order to further strengthen his muscles. On the evening of his second day at the facility, one of his daughters was beside him as he walked to the dining room. Mr. Adler stopped, his legs visibly shaking, and his daughter said, "Buck up Dad!" and lightly tapped him on his shoulder. He fell to the floor, was transported

to the hospital and diagnosed with a broken hip. The following day he suffered a massive stroke during surgery and died.

This tragic event occurred, in part, because of unrealistic family expectations but also because the manager was not willing to jeopardize the relationship with Mrs. Adler's daughters by reinforcing Mr. Adler's stated preference of using a wheelchair. It represents a failure based on efforts to achieve a societal or organizational definition of independence rather than Mr. Adler's definition.

These cases are not meant as generalizations of all assisted living resident experiences but rather as examples of how staff, residents, and families respond to the ideal of independence in assisted living. Mr. Adler's case, obviously the more extreme and tragic of the two, is representative of negative attitudes I observed among several staff, residents, and families, about using a wheelchair. The logic appears to be that if the wheelchair is the ultimate sign of dependence, disability, and the medical model, then not using a wheelchair represents independence, wellness, and the social model. However, in Mr. Adler's case, using a wheelchair might have expanded his personal boundaries, increased his choices, and even lengthened his life span. Smithers noted a similar pattern in staff and resident attitudes about wheelchair use in a nursing home (1992).

Assisted living represents a shift in thinking about how to approach long-term care. It is a world in transition, and its members are actively engaged in sorting out dilemmas like the one presented by Mr. Adler and repeating successes like Mrs.

Weaver's case as they attempt to enact the goal of independence. In the next section, I discuss the implications of making such a paradigm shift in long-term care.

Paradigm Shift

In 1993, the American Association of Retired Persons supported a national study of assisted living facilities (Kane & Wilson, 1993). The title of this report included a question: Assisted living in the United States: A new paradigm for residential care for frail older persons? The authors, possibly intending this as a rhetorical question, do not specifically answer it. When Kuhn (1970) introduced the concept of paradigm shifts, he highlighted major changes in the ways that physical scientists think and practice. Although it has not been my goal to address whether the "medical model" represents the normal science of long-term care for the 20th century and if the "social model" will replace it during the 21st century, Kuhn's (1970) discussion helps explain why assisted living proponents behave in the ways described in this manuscript. Specifically, in times of crisis and change, group members share "symbolic generalizations," commitments, values, and exemplary behaviors that guide behavior. Fujimura (1996; 1997) used the term "bandwagon" to describe commitments that various groups make to approach a given problem in one specific way. In her terms, increasing numbers of scientists joined the "oncogene bandwagon" approach to researching cancer. A new set of scientific theories and methods provided the basis of scientists' commitment to this new paradigm in cancer research. Similarly, I argue that assisted living proponents in

Oregon have joined the social model bandwagon, committing to this ideology and its value-practice package.

Using the social worlds theory as a sensitizing concept was a useful analytic tool. It provided a language, a theory of legitimation, and a means of organizing several data sets that included individual- and institutional-level patterns and behaviors. However, while it was useful to consider assisted living as an established social world in Oregon, it is better to consider assisted living as a world in the making, especially at the national level. Assisted living proponents are still seeking legitimacy, perfecting methods, and marketing their concepts. The social worlds perspective tells us that as more assisted living facilities are developed and as other states establish rules and guidelines, that legitimacy claims will be called into question, that boundaries may not remain stable and that the allegiances of key groups may waiver. Assisted living facilities in the next century may include "lite" versions as well as extended care models that meet the needs of all but the most medically unstable individuals.

Challenges to a stable social world boundary come from both within and outside. Chapter Five identified barriers to socialization that cause instability within the social world of assisted living. External pressure may come from a variety of sources, including government representatives like local fire marshals and the Occupational and Safety Health Administration, and from lobbying efforts by other health care providers like nursing facilities. Kane and Wilson (1993) found that many public officials cannot accept the idea that disabled older persons will be at risk in facilities

supported, in part, by public monies. The tendency is to err on the side of caution and eliminate as many risks as possible, even at the expense of resident independence and autonomy. Based on my research, these issues remain central to the people doing the work of assisted living. At this point, individuals who represent key groups internal and external to each assisted living facility are still actively interpreting and constructing this social world.

This study of Oregon's assisted living program offers lessons for other states considering adopting assisted living rules, the social model ideology, or similar institutional change. The analysis shows that change requires effort at both the local (facility) and non-local levels (government agency, professional organizations). Assisted living facility managers and staff must adopt the language, methods, and values of the social model in their daily practices. These local efforts require on-going work on the part of SDSD staff and OALFA representatives who not only provide support and education to local practitioners, but who have the resources and legitimacy to educate the broader community, other government agencies, and health care providers. In essence, SDSD and OALFA market the social model value-practice package to a broad audience while assisted living managers market the package to potential clients. Through these various processes, reference group members attempt to create a stable definition of the situation.

Policy and Practice Implications

This section presents several implications for assisted living policy development and practice concepts. The first includes providing a policy package, in this case one that neatly offered a set of values and practices that both private developers and consumers responded to. A second recommendation involves expanding the current ADL-structured assessment process to include qualitative components. The third presents an argument for not adapting independence as an outcome variable for evaluating success in assisted living facilities, as suggested by an AARP (1998b) report with backing by several national senior advocacy groups. Fourth, assisted living proponents need to reevaluate their commitment to several current policy goals, including the "least restrictive alternative" policy goal. Fifth, while independence has been a valuable construct in the creation of this social world, an explicit recognition of interdependent relationships may help proponents maintain the boundaries. Finally, I offer suggestions for training direct care staff, the individuals with the most daily contact with assisted living residents.

Provide a Policy Package

A public policy that offers a standard package of clear concepts and conventions will secure the commitment of, and even create important reference groups. In the present case, Oregon's public policy for assisted living facilities is based on a social model of care that emphasizes the independence of frail seniors. The policy provides a

clear package of conceptualizations about this social model and strategies for how to implement it, including the negotiated service agreement and managed risk agreement. Not only have existing groups committed to this value-practice package, new groups have been created, including consumers, a professional organization that lobbies on the behalf of this new industry, and private assisted living development companies.

That private assisted living development companies have formed in response to this public policy is significant. Private industry members have joined the bandwagon, committing to and adopting a public policy that makes sense to its members. Private developers have effectively co-opted the public policy language, using it in promotional materials, sometimes with very little revision to the actual terms and phrases. These terms are transferred to and adopted by assisted living facility staff via management training programs. Thus, Oregon's administrative rules defined both the marketplace and the practice concepts of assisted living facilities. This success indicates that SDSD and others involved in writing OAR 411-56 understood the motivations of both "buyers and sellers," or residents and ALF providers, in this social world (Brockett, Golden. & Aird, 1990).

Comparing ALFs to Oregon's residential care facilities offers another example of how significant the growth in numbers of assisted living facilities in Oregon has been. Although residential care facilities (RCF) were available several years before the assisted living rules were adopted, their growth in numbers has not been as dramatic. Oregon's residential care facilities are more diverse in size and scope of services

compared to ALFs. For example, RCFs may have either shared rooms or private apartments, shared or private bathrooms, and apartments with kitchens are rare. Although RCFs were designed as an alternative to nursing facilities, the rules may have been too broad. The public policy for this housing option did not provide a package of either values or practices, simply permission to be different from nursing homes. Since the development of assisted living rules, which built on the existing RCF rules, RCFs have come to adopt the ALF model and many are remodeling their physical structures to meet ALF standards.

In an historical analysis of long-term care regulatory oversight, Baggett and Adler (1990) suggested that the RCF goals of "freedom and protection" combined with regulatory agency efforts to use nursing home conventions for assessing quality care were "ingredients for confusion" (Baggett & Adler, 1990, p.19). They warned that public concern about inadequate care combined with issues of caring for very frail population might conspire to "overregulate" this housing alternative. Assisted living facilities faced a similar threat but approached it in a head-on fashion by offering the social model and a strong package of values and practice conventions. By offering clear arguments for not using nursing home practices and with commitment from several reference groups, assisted living facilities and their proponents remain independent from regulatory oversight. Currently, assisted living facilities are not regulated so much as they are monitored by SDSD. This distinction is important because it allows for flexibility and supports the social model conventions, including

the managed risk agreement. Senior and Disabled Services Division staff members describe themselves as "consultants" to the assisted living managers and they expect managers to discuss concerns and seek solutions before problems arise. Thus, by providing a strong value-practice package, ALFs were more widely accepted than RCFs and thus far appear to have avoided the "ingredients for confusion" discussed by Baggett and Adler (1990).

Resident Assessment

The assisted living assessment, as observed in three facilities and six management training programs, is based on the "activities of daily living" construct. While this construct is certainly useful, it limits the organizational commitment to independence to only those 23 activities included on the scale. Considering that the social model ideology includes responding to the whole individual rather than the individual's illness or disability, it seems that an assessment grounded in a social model would seek to know more about the person. Although the resident's preferences are included in the assessment and the negotiated service agreement, those preferences are limited to the items on this preexisting list of items, including bathing, dressing, taking medications, and transportation needs.

Assisted living proponents have taken care to create an assessment process that appears to fit the social model ideology. That is, the resident attends the assessment meeting and is given choice about timing, location, and delivery of the care services

detailed in Chapter Six. However, it is not the assessment process, but rather the assessment construct and the very notion of "assessment" that constrains efforts made by managers and SDSD staff to meet the social model ideal.

Assisted living proponents need to move beyond the present assessment approach that attempts to quantify the individual's functional ability. Humans are more than the sum total of their functional abilities. I argue that a qualitative component should complement existing organizational efforts. A qualitative "assessment" would begin with the resident's self-defined values, goals, and needs. Using the language of qualitative researchers, this is an *emic* approach, beginning with the words of the individual rather than the *etic* approach that uses predetermined categories common to quantitative research strategies.

Efforts to develop a qualitative complement to the existing quantitative assessment should begin with a systematic qualitative study of assisted living resident values and preferences. Local lore has it that SDSD placed a great deal of time into standardizing and refining its "SDS 360 Client Assessment/Planning Subsystem." The "360" is said to be symbolic of SDSD staff having come full circle by perfecting this structured questionnaire and the resulting "algorithm" that is used to plan services for Medicaid clients. Although this specific form is not used by assisted living facilities, it is representative of the commitment that SDSD has to quantifiable assessment procedures, and this institutional commitment has been transferred to ALF proponents. A similar effort must be given to theorizing and perfecting a qualitative component.

Although it is beyond the current scope to design such an assessment, I offer the following guidelines.

The goal of most assisted living assessments is not to predict the individuals' capacity for rehabilitation but to identify the type of assistance that an individual requires on a regular basis. Although the purpose is not to conduct social science research, lessons may be drawn from qualitative research design strategies. A reevaluation of current ALF assessment processes should begin with two goals. First, we need to determine whether the current ADL-IADL list is accurate. Are the 23 items listed in Table 8 on page 105 the ones that residents would identify for themselves and are staff capable of delivering these services? For example, are staff members qualified to provide counseling to residents or their families? What do staff members provide on a regular basis to assist residents with communication? Is talking loudly to a hard of hearing resident a "service"? The goal of this first stage is to consider how residents would identify their "activities of daily living." What items other than the most basic requirements of daily life, like showering and taking medications, would residents identify as being important to a normal life? Newly identified items would be used for making revisions to the current list of ADL-IADLs. Such a qualitative approach is often used to guide quantitative research, especially to avoid Type III errors – solving the wrong problem (Miller & Crabtree, 1994).

The second goal is to develop a qualitative component to the assessment process. This goal is in keeping with the argument that the assessment is not about prediction

but rather planning. The social model strives to look at the individual in a holistic way and qualitative research strategies are uniquely qualified for this task. Adding a qualitative section to the assessment process meets the goal of "complementarity" of research methods (Morgan, 1998). That is, the strengths of each method are capitalized. In order to design the questions, I recommend a series of focus group interviews with members of key groups. First, assisted living managers should be asked to take a reflective look at their practice with a goal of challenging assumptions and focusing on the assessment process rather than identification of resident "needs." Second, SDSD staff members should be interviewed using a similar format. Third, assisted living residents and family members should be interviewed, in both focus group and individual interview formats. Questions about daily life, goals, and expectations should organize these interviews.

The above suggestions are designed to improve the current assessment process used by assisted living managers and SDSD staff. The goals include questioning existing assumptions about organizational practices and resident needs and developing practices that are in keeping with the social model imperative.

Independence as a Construct

Although independence makes for a strong unifying construct in the social world of assisted living, it remains as an ideal construct. If pressure to externally regulate assisted living facilities does increase, it is likely that surveyors will be asked to

measure this construct as either an outcome variable or as a predictor of quality of life. In fact, a recent AARP report with backing from the Alzheimer's Association, American Association of Homes and Services for the Aging, American Health Care Association/National Center for Assisted Living, American Seniors Housing Association, and the Assisted Living Federation of America advocated developing a measure to assess "quality of life outcomes, including autonomy, independence, and dignity" (AARP, 1998b, p. 19). This is problematic given the ways in which independence is situationally defined by key groups in this social world. How would monitors measure this construct? Currently, Oregon's SDSD monitors are satisfied to examine the language used on negotiated service agreements, look for resident signatures, and ask residents if they have complaints. The current evaluation process assesses the organizational commitment to independence rather than any resident-centered understanding of this ideal.

This argument is tied to the above critique of the assessment process. Because practitioners define resident independence in terms of ADL-IADL assistance provided by staff, this construct is highly suspect as a valid indicator of quality of life. However, if the above suggestions are enacted and a better understanding of any connection between quality of life and independence can be elicited from residents, such an evaluation may be designed.

"Least Restrictive Alternative" as a Policy Goal

Case managers and policy makers for the elderly often cite the goal of avoiding institutionalization by providing the "least restrictive environment. Thus SDSD staff members seek to place their clients in community-based housing like assisted living facilities and they encourage ALF staff to allow residents to remain even as physical and cognitive abilities decline. This policy goal is designed to promote independence by keeping the individual out of the nursing facility, representing dependence and failure. However, the goal is constrained by this constant comparison to nursing facilities as the end of the road. It restrains the policy conversation to what to avoid rather than what to seek.

Cohen (1988) argues that the "least restrictive alternative" argument does not promote independence, and that instead program goals should include a commitment to the "right to flourish" as defined by the individual. The organizational commitment to preventing institutionalization results in "low goal formulation and underestimated potentials for self-realization and full participation" in a larger community (Cohen, 1988, p. 24). This occurs in part because both care providers and disabled seniors have bought into the "elderly mystique which holds that the potentials for growth, development, and continuing engagement virtually disappear when disabled" (Cohen, 1988, p. 24). That is, just being different from a nursing home, in language and design, and forestalling institutionalization for as long as possible, does not support independence in daily living. It places the overall policy conversation in a negative

rather than a positive framework.

At the organizational level, this problem is a result of an uncomfortable boundary with nursing facilities. Although assisted living proponents like to use nursing homes as an example of what not to do, they do not have many positive models for what to do. Some providers attempt to emulate hotel management styles, though it is not clear what this imagery offers given that most assisted living residents have never lived in a hotel, and the hotel management strategies ALF providers adopt often do not go beyond interior decorating tips, menu planning, and a commitment to "service." Members of this social world of assisted living are right to use legitimacy strategies like boundary setting and distancing themselves from similar others in establishing who they are and what they do. However, their gaze seems to be extended in two extreme directions—toward nursing facilities in one direction and hotels in the other. More realistic settings for such comparative efforts include existing congregate living options like retirement housing, adult care homes, and life care communities. In addition, Cohen (1988) argues that important lessons may be drawn from the disability rights and independent living movements of the 1960s. Assisted living proponents would do well to examine how these long-term care alternatives set goals and boundaries both internally and externally.

At the local level of the individual assisted living facility, least restrictive alternative translates into policies about respecting residents' rights to make choices about daily activities. For example, residents are free to come and go as they choose.

However, most have limited means of getting to where they may choose. Although some facilities provide rides to medical appointments and shopping centers once or twice weekly, the majority of residents depend on family members in order to leave the facility.

At Timber Heights, Mrs. Paul, a new resident, aged 99, asked a staff member, "What do they want us to do now?" after she finished dinner. The staff member said, "You can do whatever you'd like!" Mrs. Paul looked around, then returned to her apartment. What is there to do in this unrestricted environment? Not much. Mrs. Paul tried to keep herself active with small tasks like mending socks and doing the laundry.

Can we strive for more than simply not being "institutional"? Just removing literal and figurative barriers do not lend much toward the SDSD goal of enhancing well being, however defined. Today's assisted living residents may be considered as living in a "liminal" stage (Turner, 1967, cited in Shield, 1988). Liminality implies the individual is neither here, nor there, caught in some kind of middle ground. It is more accurate to say that assisted living residents are neither there nor there, that is, neither home nor nursing home. Assisted living facilities promote an image of independent living in a "home-like" setting for seniors who are in transition between living in their own home, representing ultimate independence, and either death or moving to a nursing home, representing ultimate dependence and loss of freedom, privacy and dignity.

In an ethnographic study of a Jewish nursing home operating in the late 1970s,

Shield (1988) found similar conflicting ideologies among nursing home staff members who had the twin goals of supporting independence and protecting patients. She argued that "there is no cultural consensus about what nursing home residence means" (Shield, 1988, p.216). Similarly, because assisted living facilities offer new ideas about how disabled older persons can and should live, cultural attitudes about the role of assisted living in U.S. society are still being formed. Assisted living proponents are actively engaged in establishing the legitimacy of this social world, and distancing strategies like the "least restrictive alternative" policy are still being shaped. Although this policy was integral to early conceptualizations about what assisted living is not, it is time to focus more directly on what assisted living is. In this way, the liminal status may be replaced by a stable community of assisted living for disabled seniors. Rather than the low goal of the least restrictive alternative, a "best possible alternative" may be promoted.

Interdependence as a Policy Goal

As presented in Chapter 6, independence requires negotiation among several interdependent key groups. One public policy strategy would be to make interdependence explicit in the way that the value of independence is made explicit. A recent literature review of AgeLine, a database of gerontological publications, indicates that interdependence is, if not a "hot" topic, one that is receiving attention (120 articles since 1971). In particular, several authors specifically discuss the

interdependence of various organizations involved in providing long-term care services. The value-practice package offered by assisted living policy makers is one such strategy as discussed earlier in this chapter. The present relationship between SDSD and ALF providers is another example. That is, SDSD staff members are described as "consultants" rather than evaluators or surveyors, and as such, they attempt to strategize with ALF managers in order to solve problems rather than assess penalties.

At the local level of the individual assisted living facility, I observed interdependent relationships between pharmacies, hospice providers, home health nurses, physicians, and senior center staff. For example, pharmacists affiliated with the ALF's contract pharmacy reviewed resident files and worked with the ALF nurse and direct care staff to make certain that prescription instructions were understood and followed. Hospice providers in particular were considered valued allies. The relationship between ALF staff and both home health nurses and physicians was less stable. As mentioned in Chapter Five, the values of assisted living providers and home health nurses sometimes clashed, and this may derive from the boundaries that ALF proponents place between themselves and those they affiliate with the medical model. Physicians were described by ALF managers as a source of potential clients and thus were viewed from a marketing standpoint rather than as an equal partner in meeting the health care needs of residents. Currently, ALF proponents appear to be in the uncomfortable position of needing the services of physicians but also wanting to

educate physicians about what assisted living is or is not. Oddly, the most formalized relationships occur with medical care providers rather than with social and community-based agencies. The ALFs that I observed had varying degrees of formal relationships with community-based agencies like senior centers, libraries, senior transportation agencies, and various voluntary groups that provide anything from musical entertainment to friendly visitors to shopping assistance. However, most managers viewed these organizations as potential sources of clients rather than as community partners in enacting a social model of care.

At Timber Heights, relationships with several such organizations were broached and maintained by the outside agency or a resident or family member with no contribution by the staff or management. For example, a music group affiliated with a local retirement home volunteered to play music once a month, a local church set up a bible study group, and one resident explained the community senior transportation system to several new residents. Yet the manager was unwilling to coordinate a monthly payment plan on behalf of four mildly cognitively impaired residents who wanted to attend lunch at the local senior center but were unable to manage their money well enough to pay the three dollar fee. Thus, while community-based relationships can and do occur, assisted living providers need to redefine these as formal interdependent relationships rather than as a one-way source of new clientele.

Other arguments of the role of interdependence in long-term care have evolved from critiques of the dependence-independence dichotomy. Instead, interdependence is

offered as a more realistic model of how adults function in their families and in society (see for example, Holstein, 1995; Kaufman, 1994; Minkler & Estes, 1998; Robertson, 1997). A number of cross-cultural studies indicate the importance of interdependence to a wide range of cultures, including Chinese (Shaw, Patterson, Semple, Grant, Yu, Zhang, He, & Wu, 1997), Hawaiian (Braun, Mokuau, & Tsark, 1997), Japanese (Itai & McCrae, 1994), Native American (Carson, 1995), and several developing nations (Kaiser & Chawla, 1994). Although independence is an important cultural value to many Americans, there is room to add features from the value of interdependence when planning services and negotiating independence for frail older persons. This should occur at both the organizational and local levels.

Staff Training

Direct care staff have the most contact with assisted living residents. In essence, it is their hands-on assistance that is supposed to support resident independence. The 1989 State rules do not require specific training for resident assistants other than to "demonstrate competency in provision of services and principles of assisted living" (OAR 411-56-030 (e)). In addition, resident care staff must receive training by a registered nurse in order to perform nursing tasks like injections and certain types of wound care. However, the training is very modest, and when combined with high staffing turnover rates, it is not uncommon to meet staff members who have never heard of the assisted living values or do not know how to assist with transfers, bathing,

or use of incontinence products. Based on the observations I made during a total of eighteen months in three ALFs, the following staff training suggestions are offered.

The first step relates to hiring and retention efforts. I observed staff hiring practices at Timber Heights where new staff members were told that the work would be light and that the work was not at all like a nursing home. Such individuals were chagrined to learn that they were required to assist residents with either urine or bowel incontinence and promptly quit. Potential staff should be informed up front about the range of chores expected. Those who cannot or will not commit to the possibility of cleaning a resident who has had a bowel accident need not be hired. This, of course, applies to the entire range of service activities expected by the management.

Second, staff should receive frequent, but brief explanations about the social model ideology and the value-practice package. At Timber Heights, a homemade videotape produced by the company owner detailing the history of assisted living made a big impression on the staff who saw it. In addition, occasional half-page length descriptions of the social model values were distributed to staff members who were expected to read and sign it. The assisted living vocabulary terms were adopted by many staff members and this appeared to cause people to reflect on the implications of these terms to their work.

Third, assisted living direct care staff members require some education regarding normal aging and disability in late life. Currently there is no such effort and staff members come to assisted living facilities with preconceived stereotypes about older

persons and the aging process.

Fourth, assisted living managers should offer "in-service" training on social activities. Currently, in-service training efforts include medically necessary skills like cardiopulmonary resuscitation, dispensing medications, taking pulse and blood pressure readings, and similar tasks. Equally important are activities that might foster the social model, like reminiscence groups, discussion groups, educational forums, and other activities that residents might define as important to daily living.

Final Thoughts

Future research should be designed to examine changes in this social world as they occur. What will these shifts look like? Will more than one assisted living model be presented? Will the Oregon model set the standard for other states? Will new ALF models define themselves in relation to either the social or medical model or as something entirely different? Will the focus on independence remain important, or will a more communitarian model be of interest to aging baby boomers? Will an assisted living "lite" model and an "aging in place" model be offered? Is assisted living an appropriate response to individuals with severe cognitive impairments? Although the examples cited here work well for people with mild to moderate impairment, individuals with severe confusion and behavioral disorders are neither accepted nor retained. A social worlds framework will be useful in answering such questions.

Still missing from this greater understanding of assisted living is the resident

perspective. What is daily life like in the social model? How do residents define independence and how or is this construct relevant to their lives?

The assessment process currently used by assisted living providers raises questions that could guide future research. Although the suggestions made earlier in this chapter were designed to guide practice, these questions might also guide participatory action research, health services research, or basic research efforts.

Finally, assisted living facilities, as promoted by advocates, clearly represent a better choice for disabled elders than nursing facilities. However, the social world of assisted living is still in transition. Both SDSD staff members and AARP (1998a) hold forth Oregon as the pioneer in developing assisted living and the social model ideal. It is clear that Oregon ALFs are still in a developmental stage, setting standards and establishing boundaries in an attempt to define for themselves and others who they are and what they do. It is my hope that the "pioneers" in this social world find in this document new answers and directions to guide their on-going efforts to create a better way to live for disabled persons.

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IMAGE EVALUATION
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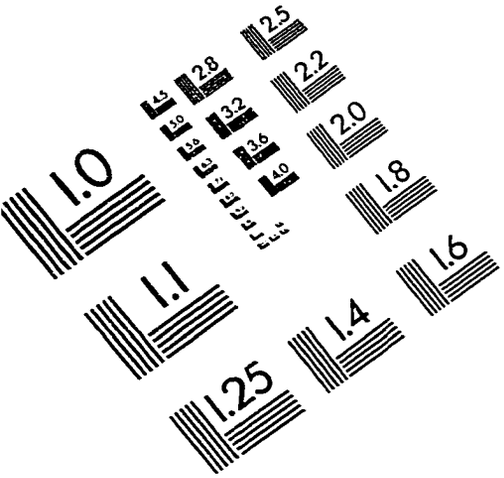

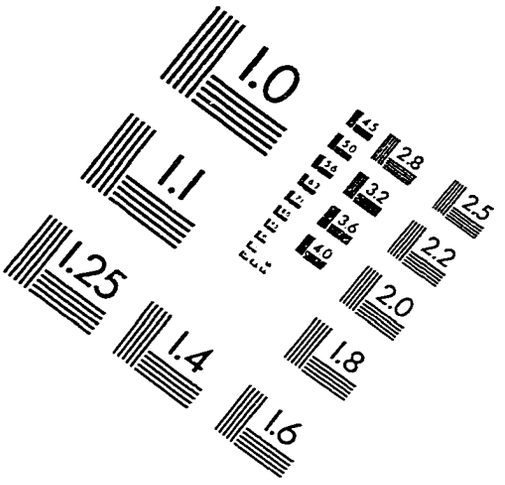

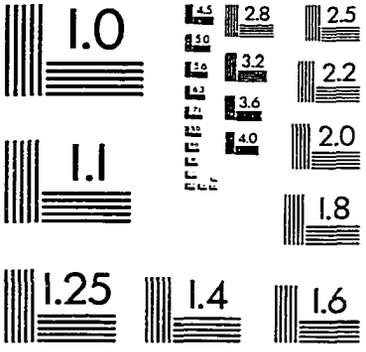

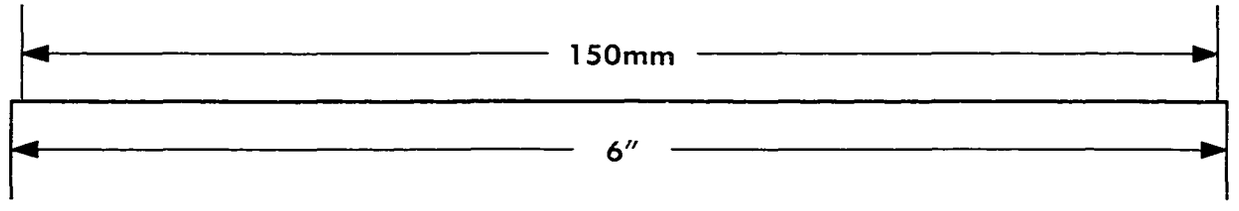

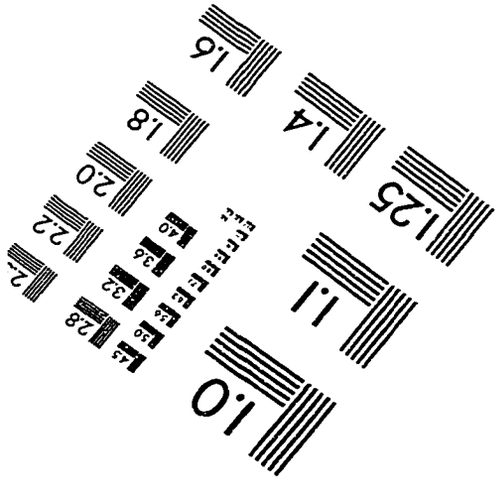

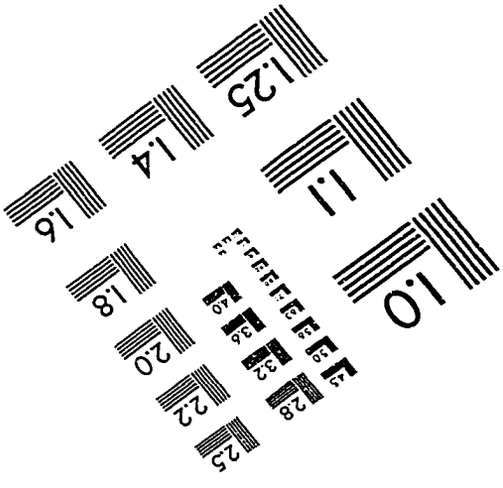

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