

**CONSUMER PERSPECTIVES ON PRIVATE VERSUS SHARED
ACCOMMODATIONS IN ASSISTED LIVING SETTINGS**

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The Public Policy Institute, formed in 1985, is part of the Research Division of the American Association of Retired Persons. One of the missions of the Institute is to foster research and analysis on public policy issues of interest to older Americans. This paper represents part of that effort.

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FOREWORD

The philosophy of independence, dignity, and privacy has been a distinctive characteristic of assisted living, enshrined in discussions by industry and consumer groups alike. Private apartments, as the embodiment of the commitment to privacy, have become a defining feature of assisted living settings in most areas. According to a survey done in 1996 for the Assisted Living Federation of America (ALFA), only 14 percent of the nearly 15,000 units in 268 assisted living settings surveyed involved shared living units. Despite the prevalence of private apartments, policy discussions of whether to require private rooms for licensure as assisted living have generated substantial debate. Solid research on consumer preferences regarding private or shared accommodations has been absent from this debate. To begin to address the issue, the American Association of Retired Persons (AARP), in 1996, surveyed persons aged 50 and over about their preferences. The survey found that older people preferred private to shared rooms by a margin of more than 20 to 1 (82 percent to 4 percent), a preference that cut across all gender, geographic, and income groups.

To deepen our understanding of consumer preferences with more experience-based data, we turned to the researchers at the National Long Term Care Resource Center at the University of Minnesota to conduct the research for the report that follows. Their research included three distinct components, each of which is presented in a separate part of this report:

1. a review of disparate literature to glean insights on the meanings of privacy and sharing rooms within various care settings;
2. original analyses of quantitative data that give insight into the relative importance of physical privacy compared to other attributes of the care settings; and
3. original focus group research to tap the perspectives of residents and potential residents of assisted living settings (including those in private accommodations and those in shared accommodations), family members of current and potential residents with cognitive impairments, and staff of assisted living settings.

The data in this report strongly reaffirm the preference of consumers and their families for private apartments in assisted living. If there was a surprising finding, it was the strength of the preference for private bathrooms as well as bedrooms. The findings from this research should help inform the debates currently being conducted in state legislatures and regulatory agencies.

Given the nearly universal commitment to the principle of privacy and the strong consumer preference for privacy, future research should concentrate on how to achieve an acceptable level of privacy for all assisted living residents. The following areas of research would be especially helpful to policy decision-makers as they design and implement policies to protect privacy:

- Whether or not an acceptable level of privacy can be achieved in shared accommodations, a question that would require exploring the following dimensions:

Ø Design issues for shared accommodations: What amount and configuration of space would be required to securely accommodate a resident's personal furnishings and possessions? What

visual and auditory barriers would be needed to accommodate individual activities (e.g., reading, watching television, and listening to radio), supportive service delivery, and personal visits and conversations at various times of the day and night without disturbing a roommate? What bathroom configurations would be necessary to assure easy access and cleanliness for each resident whenever she needs it? What other design features would be necessary to allow access to windows, food storage and preparation facilities, and other features that create a homelike environment?

Ø Operating issues for shared accommodations: What amount of staffing and training would be necessary to handle conflicts that arise in shared accommodations? What procedures would maximize resident choice of a roommate? What procedures are necessary to give residents options when roommates are incompatible? What distinctive rights and procedures are needed for both cognitively impaired and cognitively intact residents?

Ø Regulatory issues for shared accommodations: Are state regulatory agencies willing and able to enforce design and operating standards necessary for an acceptable level of privacy in shared accommodations? What additional staffing and training would be necessary to monitor and enforce such standards?

- The actual relative costs associated with shared versus private accommodations, including:

Ø Construction costs: What would be the actual relative costs associated with building or retrofitting to provide the design features necessary for an acceptable level of privacy in shared accommodations versus the costs associated with building private units and bathrooms?

Ø Operating costs: What would be the actual relative costs of operating settings with shared versus private accommodations, including: staffing, management, maintenance, resident turnover, unit vacancies, and marketing?

Ø Regulatory costs: What would be the actual relative costs associated with monitoring and enforcing privacy standards in shared versus private accommodations? How might states pass on those costs to providers?

- The potential problems and benefits experienced by persons with dementia and other cognitive disabilities in shared versus private accommodations, a topic on which strong contentions have been made but on which little data exist.

AARP appreciates the important work done by the University of Minnesota researchers in advancing our understanding of the privacy issue. We look forward to working with states and other interested parties to gain further information on this topic of vital concern to older consumers of long-term care services.

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EXECUTIVE SUMMARY

Purpose

The overall purpose of this paper is to describe the consumer perspective on the absolute and relative importance of privacy in assisted living facilities (ALFs) and to derive general insights into how current and prospective residents view privacy.

Assisted living has introduced innovative housing and services options for older people who can no longer live independently in their communities. An ALF offers a homelike atmosphere that emphasizes autonomy and choice, while providing services to ensure that residents are physically safe. A significant aspect of a homelike atmosphere is individual physical privacy. Considerable inter-state and intra-state variation exists in whether ALFs have private accommodations.

How to provide adequate privacy is an issue still evolving in the long-term care arena. Many state officials, consumer advocates, and providers are currently considering whether privacy should be required in ALFs, either by state licensure or reimbursement policy. Before such a policy is undertaken, policy decision-makers should understand both the wishes and needs of residents.

Methods

This report presents the findings of a three-part study that examined the issue of private accommodations in assisted living facilities (ALFs) from a consumer perspective. Part I describes results of the literature review; Part II presents an original analysis of two existing data sets that describe the relative importance consumers place on private accommodations; and Part III presents the results of a focus group study conducted by the report authors.

Findings

Part I: Literature Review

The authors undertook a comprehensive review of theoretical and empirical literature related to privacy in residential accommodations for older people. Only a few empirical studies directly on point were identified. The main findings included:

- ∅ Theoretical work on physical privacy from philosophy, law, political science, sociology, architecture, and communication theory all suggest that humans require physical privacy.
- ∅ Scholars discussing privacy typically note that it is an experience with many dimensions, including physical privacy, informational privacy, and decision-making privacy.

Little empirical work directly indicates how older consumers view private accommodations in long-term care settings. We found no studies of the actual effects of private versus shared rooms on resident outcomes. The relationships between private space and meaningful socialization are poorly understood. Some researchers and observers argue that private space enhances socialization and that people often feel isolated in shared living spaces (Kaakinen 1992, Friedan 1993). Examples of empirical research include:

- ∅ A qualitative study of nursing homes linked privacy to dignity (Abt Associates 1996).
- ∅ A 28-year old study (Lawton & Bader 1970) of preferences for private rooms in nursing homes that polled nursing home residents, family members, staff, and community-dwelling older persons, identified a strong preference of all subgroups for private rooms.
- ∅ A survey of 694 community-dwelling people over age 50 (Jenkins 1997) showed overwhelming preference for private accommodations in assisted living.

The literature on private accommodations for people with cognitive impairment is sparse, largely not empirical, and inconclusive (Hawes et al. 1997).

- ∅ Those who believe that sharing a room has a positive value or does not matter are likely to argue that the costs of private rooms might better be spent on additional staff. Some have argued further that people with dementia tend to become anxious or suspicious if alone and, therefore, benefit from a roommate.
- ∅ At the other end of the spectrum are those who argue that many people with dementia tend to be territorial or suspicious and, therefore, do better in private rooms.
- ∅ In a focus-group study with family members of ALF residents with dementia (Greene et al. 1997), some participants linked “homelike” and the ability to bring possessions and furniture to privacy, but privacy itself was not emphasized.
- ∅ Empirical evidence indicates a strong preference of cognitively intact older people not to share rooms in long-term care residential settings with people with dementia (Kane et al. 1997; Abt Associates 1996; Teresi, Holmes, & Monaco 1993).

Part II: Quantitative Study

The authors conducted original analyses of two existing data sets from Oregon that offered some perspective on the relative importance of private accommodations to assisted living consumers. In the first, the authors analyzed a 1989 data set with 402 adult foster care residents and 420 nursing home residents in which respondents were given a list of features and asked which were important to them in looking for a place to live and receive care. This study found that:

- ∅ 79 percent of foster care residents and 66 percent of family members of residents with dementia indicated that “privacy” was an important consideration in moving to the foster home.
- ∅ 51 percent of nursing home residents and 45 percent of family proxies responding for nursing home residents with dementia indicated that privacy was an important consideration.

The authors also analyzed a 1995 data set of 605 assisted living residents in 38 facilities and 610 nursing home residents in 32 facilities. In this study, residents were asked to rate the importance of a list of 11 features including “a private room and bath” from “1” to “5”. “1” connoted the greatest importance and “5” the least importance with the following results:

- ∅ ALF residents rated the importance of a “private room and bath” highest; 94 percent rated “private room and bath” as “1” or “2,” a higher score than any of the other 11 features rated – including “a safe place to live,” access to medical care,” and “good food.”
- ∅ Cognitively intact nursing facility residents rated “private room and bath” less highly, though 59 percent rated it “1” or “2.”
- ∅ Family members of ALF residents with dementia tended to think a “private room and bath” was very important for their relatives (96 percent giving it either a “1” or a “2”).
- ∅ Being female and having fewer ADL impairments was associated with a higher preference for a private room and bath among assisted living residents. Private pay status was associated with the preference for private room and bath among family members of assisted living residents with dementia. No other factor, including length of stay, was significantly correlated with the preference for a private room and bath, in part because such a preference was very important to nearly all respondents.

Part III: Focus Group Study

The authors conducted 13 focus groups in Florida and Minnesota. The 62 participants included: current ALF residents; older persons with disabilities in the community; family caregivers of persons with dementia in ALFs and in the community; and ALF staff. We also included groups of older persons with low-income and African Americans. Both ALF residents and community-dwelling older persons cited numerous advantages to private rooms and apartments, including:

- ∅ keeping one’s possessions how and where one wants;
- ∅ controlling what happens in one’s space;
- ∅ getting away from groups;
- ∅ using own phone and entertaining visitors in private; and
- ∅ keeping one’s own personal timetable without disturbing or being disturbed by a roommate.

Family and staff cited the same advantages to private accommodations as did residents, staff adding that fewer conflicts arise in private rooms. Some family members indicated that a private room was very important during earlier stages of dementia. In later stages, privacy became less important, but room changes were a problem. Two advantages of roommates were mentioned (more often by family members and staff members), though each was a contingent advantage:

- ∅ Companionship advantages were described as dependent on compatibility.
- ∅ Potential assistance in an emergency depended on the capabilities of the roommate.

Participants said they would be uncomfortable in a wide range of activities or situations in the presence of a roommate. They would also be uncomfortable if roommates performed those activities or were in these situations with them present. These activities or situations ranged from being sick, talking on the phone, having a business conversation, staying up late, and praying. Every participant felt uncomfortable with at least some of these activities and situations.

Many residents commented that they would trade off extra space, amenities, and activities to have private accommodations. A private smaller room was more valued than a larger shared room. Good quality services and responsive care, however, were non-negotiable for most participants; they already often experienced what they considered as insufficient help and would not trade off even less help for private room accommodations. Participants were divided in their preferences for various floor-plans:

- ∅ Among apartments, most opted for a small studio apartment with a full bathroom and kitchenette.
- ∅ Some found the idea of a private bedroom within an apartment that had shared living space and kitchenette to be an odd arrangement. Others thought the sociability of sharing part of an apartment might be good as long as they had their own rooms and bathrooms.
- ∅ A private bathroom was seen as equally important as a private room. Reasons for this preference included: being able to have access to the bathroom whenever necessary to maintain continence; a desire to leave possessions safely in the bathroom; concerns about cleanliness and hazards (e.g., wet floors) in shared baths; and (among relatives of residents) a desire not to clean up messes from other residents.

If they were to have roommates, older participants wanted them to be similar to themselves on a wide range of dimensions. Roommates who were confused, deaf, very ill, or restless, noisy, or combative were deemed poor roommates. Discussions about former roommates highlighted the extent to which older persons had adapted and tolerated. ALF residents tended not to complain but tried to be understanding, even when they themselves were suffering. Not wanting to hurt roommates' feelings, ALF residents often silently suffered or referred to oblique problems instead of directly complaining against roommates. ALF residents and older persons in the community clearly saw socializing as distinct from having a roommate. Given a choice, they preferred to socialize from the distance created by having private accommodations.

Conclusions

The three parts of this study all supported the preference for private accommodations.

- ∅ The literature review and focus groups suggested reasons why that preference might also lead to better psychological, social, and even physical outcomes.
- ∅ Persons with low-incomes and African Americans had more similarities than differences in their views compared to the rest of the focus group participants.

- ∅ The quantitative study and the focus-group study suggested that length of stay and experience with roommates did not mitigate the preference for private accommodations. The focus groups showed that people tolerated what they thought they could not change, but did not get used to it.
- ∅ Family members of persons with dementia and ALF staff saw more advantages of shared space than did older participants. However, the literature review and focus groups indicate that cognitively intact people do not want to room with people with dementia.
- ∅ Although price was not a consideration for the focus group exercise, price is a real-life consideration for the participants.

The authors suggest three areas of further research:

- ∅ Studies examining the true development and operating costs of facilities offering private versus shared space to help inform reimbursement policy.
- ∅ Studies exploring what is needed to successfully sustain people with dementia and other cognitive impairments in private space, including: staffing levels, training, and environmental support.
- ∅ Studies of the outcomes of shared versus private accommodations for cognitively impaired individuals, and other subgroups of the population. These studies should be extended to nursing home populations and settings, including Alzheimer's Special Care Units.

CONSUMER PERSPECTIVES ON PRIVATE VERSUS SHARED ACCOMMODATIONS IN ASSISTED LIVING SETTINGS

INTRODUCTION

The overall purpose of the project was to gain a consumer perspective on the absolute and relative importance of privacy in assisted living facilities (ALFs) and to derive general insights into how privacy is viewed by actual or prospective consumers. For our purpose, an assisted living facility was defined as a residential program (not licensed as a nursing home) that offers personal care and routine nursing services to adults over age 65 with disabilities. ALFs are expected to combine some of the homelike qualities and opportunities to exercise autonomy associated with a private home or apartment in the community with some of the care, service capacity, and protection associated with a nursing home (Kane and Wilson 1993). States use a variety of terms for licensing facilities that meet this definition, and some states use the term “assisted living” *without* meeting our definition.

We undertook three distinct tasks: 1) review of the theoretical and empirical literature related to privacy in residential settings; 2) new analyses of two existing quantitative data sets from Oregon that illuminate consumer preferences for physical privacy relative to preferences for other features; and 3) a focus group study to explore the views of assisted living residents, potential assisted living residents, family members of residents and potential residents with cognitive impairment, and staff of assisted living programs. None of the three parts of the study investigated the financial implications of private accommodations versus shared rooms.

Policy Issues

Few issues facing the assisted living industry are as controversial as establishing a public policy regarding privacy in individual living units. Decisions concerning this issue affect potential construction costs and revenue returns of providers, the ability of some providers to receive reimbursements, and the likely financial liability of public payment programs. Purpose-built ALFs, which evolved as a result of the market-driven preferences of privately paying customers, often offer apartments (ranging from studios to two or more bedrooms) with full bathrooms inside the unit. Many also offer kitchenettes in the living unit. Still, the term “assisted living” is often used to encompass residential settings with shared as well as private accommodations. The Assisted Living Federation of America, a trade association, is made up of members with a wide range of service capacities and physical accommodations, ranging from those with variations on the private apartment model to those largely with shared accommodations.

Assisted living is a relatively new term for a type of housing and services that has evolved from residential care settings, sometimes known as board and care homes. Board and care homes that serve older people and people with disabilities who are unable or prefer not to live independently have historically offered little more than room and board and light housekeeping. A few larger facilities may have an activities program or, depending on size and target population, on-site health and wellness clinics. In the last decade, many such residential care settings have begun to offer a

wider range of personal care and health-related services to people with disabilities comparable to nursing home residents. Residential facilities with a substantial service capacity are often called “assisted living.”

In contrast to the apartments typically available in assisted living, nursing homes were originally modeled after hospitals and, therefore, typically have most of their stock in double-occupancy rooms. Some anecdotal reports suggest that some nursing homes have recently increased their proportion of private rooms for the minority of residents who are private pay. An influential study of nursing home quality conducted in 1983-1985 by a committee assembled by the Institute of Medicine (1986) issued recommendations for far-reaching nursing home reform. These reforms were largely incorporated into the 1987 Omnibus Budget Reconciliation Act, often referred to as “OBRA” in long-term care discussions. A largely ignored recommendation of the Institute of Medicine (IOM) report stated that “HCFA should commission a study of the costs and benefits of single-occupancy rooms compared to multiple-occupancy rooms in nursing homes” (Institute of Medicine 1986, p. 27). The report further specified that the study should examine the costs and benefits of private rooms for different subgroups in nursing homes. The IOM Committee suggested that the results be used to generate recommendations for the desired ratio of single rooms to multiple-occupancy rooms in new construction and major renovation of existing construction. The IOM Committee recommended the study because it sensed that routine double-occupancy was often undesirable, even in nursing homes, but was uncertain about how sweeping the recommendations for regulatory change should be.¹

As state Medicaid programs and other third-party payers begin to cover long-term care (LTC) services in group residential settings other than nursing homes, policy decision-makers must decide whether to require single-occupancy (except when residents prefer to share) and how to reimburse the services provided to individuals in single-occupancy units. In the nursing home context, Medicaid pays a single per diem rate for room and board and services that ordinarily covers only a shared-occupancy room. Currently, federal rules prohibit Medicaid programs from paying for room and board costs in any other residential care settings. In theory, therefore, states providing Medicaid reimbursements to assisted living or other residential care settings may pay only for services; the resident must pay for room and board out of income (sometimes augmented by state SSI supplements).

In practice, however, the allocation of costs between room and board and services is somewhat arbitrary. The Medicaid program must determine whether or not it will pay enough to make single-occupancy feasible. In some states, providers assert that the combined funds from all sources (resident income, SSI supplements where applicable, and Medicaid service payments) are insufficient to fund unshared accommodations. From the provider’s perspective, receiving service payments for two persons in a space rather than one is the way to offset the disadvantage of lower-than-market Medicaid rates.

Because of the higher cost, a state licensure policy requiring private units in assisted living settings

¹ In December 1997, HCFA issued a task order for research proposals from its master contractors in long-term care. Included in a larger study of how physical environment affects quality of life was a call for an examination of the costs and benefits of single rooms in nursing homes.

would not be sufficient to guarantee private accommodations to older persons with modest means. Just as important, state Medicaid programs will need to make decisions about requiring private accommodations (except for residents who prefer to share) and reimbursing services at a level sufficient to induce settings to provide private accommodations to persons with modest means. The actual additional funding required to provide private accommodations – including all construction and operating costs – is the subject of an unresolved debate. Such cost information will be critical to public policy decision-makers if private accommodations are to be made available to older persons with modest means.

Differences intensify among policy decision-makers, providers, and consumer advocates with reference to the appropriateness of assisted living settings for subgroups of residents such as those with Alzheimer's disease and those who are bed-bound or very ill. The various actors interested in assisted living also disagree about the extent to which private accommodations affect building and operating costs. Generally, ALF providers tend to justify the configuration they already have in place, be they private or shared accommodations. What is missing is a consumer perspective about whether accommodations should be private, a question that Regnier (1996) flags as one of the critical unresolved issues in assisted living.

Current State Practices

The Oregon Example

Oregon is a bellwether state for assisted living, having made an early and strong commitment to privacy in all facilities licensed as ALFs. The state also requires apartment-style accommodations with full bathrooms, roll-in showers, and kitchenettes. Because the state has regulated assisted living to require private accommodations unless by personal choice, its price is structured with the intent that units ordinarily will be singly occupied whether the payer is Medicaid or the residents themselves. For residents receiving Medicaid (about 30 percent of all residents), the lodging itself is paid for by the resident's income, sometimes supplemented by state Supplemental Security Income (SSI) payments. (Except for nursing homes, which are construed as health care facilities not housing, Medicaid presently prohibits coverage of room-and-board charges.) ALFs typically set a charge for the second occupant of the apartment to cover the cost of meals and extra linen and housekeeping costs, somewhat analogous to the small differential price hotels charge when the same room is occupied by two guests versus one guest. In Oregon, the vast majority of ALF units are single-occupied, and virtually all those that are double-occupied house people related to each other. Couples typically elect to pay the additional housing costs for a one-bedroom or larger unit, but some couples choose to live in studio apartments.

Assisted living is not the only recognized residential care program in Oregon that receives Medicaid payment for services. The state licenses and provides Medicaid reimbursement for Residential Care Facilities (RCFs), which are not constrained to meet the environmental features of single-occupancy or to meet other requirements of ALFs such as locking doors, full baths with roll-in showers, and refrigeration and cooking capacity. Oregon also has a large supply of registered adult foster homes, defined in regulation as private homes in residentially zoned areas that house up to five residents and have a live-in care provider. Adult foster homes vary as to whether rooms are private or shared.

Oregon's Medicaid program reimburses for personal care and related services for RCF and adult foster care residents who are nursing-home-certifiable; the program poses no requirements for single-occupancy in either setting.

At present, the Medicaid reimbursement rates in Oregon are higher for ALFs than for RCFs and adult foster homes. The state originally intended to give an incentive for providers to build ALFs, with their additional autonomy-enhancing features (including privacy) and their environmental capacity for service levels that allow most residents to age in place. However, RCF and foster care providers view this differential reimbursement favoring ALFs as inequitable, arguing that facilities providing identical services should be paid identically.

National Patterns

In a recent update of their state-by-state review of regulations related to licensing and financing assisted living, Mollica and Snow (whose original report was issued in 1996), report that, as of March 1998, 21 states had developed rules specific to entities called assisted living (see [Table 1](#)). Of these 21 states, 13 have some kind of requirement for privately occupied apartments with full baths (except for clear choice to share an apartment), either through their licensure requirements or through their Medicaid reimbursement policies. Five other states among the 21 license various levels of assisted living, one of which requires private rooms or apartments. Several states use the term "assisted living" more generically for any residential setting providing personal care, often recognizing a variety of licensed entities with different privacy requirements as eligible for public payments. Shared rooms, toilets, and baths are the norm in regulations for board and care homes (sometimes called residential care homes, rest homes, or other names). Generally, these regulations permit two to four people to share a bedroom and up to six to ten people to share a bathroom. As indicated, some state Medicaid programs cover payments for care in RCFs as well as in apartment-style assisted living (e.g., Oregon, Minnesota, Wisconsin, and Colorado).

Table 1 illustrates the wide range of policies currently in effect. In general, the trend is toward privacy—both in those states that specifically define assisted living as requiring single-occupancy and, to a lesser extent, in states that have developed a licensed single-occupancy apartment-style as one type of assisted living, while also recognizing and licensing other forms.

Summary

State policy decision-makers, third-party payers, and developers face decisions about the extent to which ALFs should be required to offer residents the option of single-occupancy rooms or apartments. Some states mandate privacy through licensure of the settings, Medicaid reimbursement policies for care in ALFs, or both. The debates about the issues often mingle economic arguments about the costs of requiring private accommodations with arguments about what private or shared accommodations mean for the well-being of the consumers. The rest of this document presents information developed to help clarify the views of consumers and their preferences for privacy or shared space.

Table 1: Privacy Requirements for Assisted Living and Residential Care in Selected States

Rules for entities called Assisted Living

Single-occupancy apartments with full baths required. (Illinois and Louisiana have authorized demonstration programs requiring private apartments. Vermont had draft regulations requiring private apartments.)	AZ, CT, HI, IL, LA, OR, VT, WI
Shared accommodations permissible, but Medicaid reimburses only for single-occupancy.	MN, ND, WA
Apartments required but two people previously unknown to each other may share them. (In addition, Iowa has regulations for private apartments if they are offered, but does not require that they be offered.)	KS, NJ
Licensed ALFs may have four people sharing apartments or rooms, but those qualifying for Medicaid reimbursement, must provide private rooms/ apartment/semi-private (if chosen) and no more than four can share a bath.	FL
Two people may share room in licensed ALF. (KY specifies Up apartments or “home style units” with at least semi-private baths and use of kitchens.)	MA, KY, TN
Four people may share room.	VA, OH

Intra-state variation in ALF privacy rules

Room-sharing allowed for board and care homes under Medicaid; private apartments required for “enriched housing” (purpose-built or congregate).	NY
Reimburses ALFs through Medicaid in three settings: assisted living apartments (single-occupancy required); residential care apartments and non-apartments (double-occupancy allowed in last two).	TX
Two forms of assisted living: residential care facilities (typically in shared rooms) and congregate housing projects (typically apartments).	ME
Up to four residents may share a room in adult care residences (also called rest homes); multi-unit assisted housing category requires apartments.	NC
Medicaid waiver covers care in two types of facilities: apartments with living and kitchen space and bathroom; single or semi-private rooms in adult residential care facilities, where rooms may be shared only by choice.	NM

Board and care privacy requirements

Limit of 2 to a room and requires lavatory in room.	SD
Limit of 2 to room; lavatory in room not required.	AL, AR, CA, CO, DE, ID, MD, NV, NH, NM, NY, OR, RI, UT, WV, WY
Four people may share room.	GE, IA, IN, MI, MS, MT, MO, NE, OK, PA, SC, VA

Adapted from Mollica and Snow (1996) and updated through personal communication with Robert Mollica, Portland, ME on March 13, 1998.

PART I: LITERATURE REVIEW

A wide range of sources potentially relate to the topics of privacy and sharing rooms in ALFs. These sources include:

- ⊗ philosophical, historical, and legal treatments of the idea of privacy (Schoeman 1984, Allen 1995, Hixon 1987, Mayer 1972, and O'Brien 1979);
- ⊗ architecture literature on use of physical space;
- ⊗ psychological and other social science studies about the value of privacy—how people define it, act on it, and weight its importance relative to other values — including territorial traits in humans (Altman 1970, Hall 1966, Newman 1972 and Sommer 1969, 1970); and
- ⊗ communication studies of the impact of privacy on communication (Burgoon 1982).

Unfortunately, little theoretical or empirical literature directly examines age-specific needs or interests related to privacy in living accommodations in LTC facilities. Relevant material is sparse, difficult to assemble, and often tangential to the specific interests of older people with physical or cognitive impairments living in residential care settings.

Definitions of Privacy

Definitions of privacy differ widely within disciplines as well as across them. Often, the definitions are a collection of descriptive attributes — of privacy itself, the purposes of privacy, or the ways that privacy is violated or enhanced. Formulations about privacy are sometimes linked to autonomy because privacy is seen as either an element of autonomy or as a prerequisite for it. Consider these definitions:

Privacy is a special kind of independence, which can be understood as an attempt to secure autonomy in at least a few personal and spiritual concerns...it seeks to erect an unbreachable wall of dignity and reserve against the entire world. (C. Rossiter *The free man in the free society*, The Essentials of Freedom, quoted by O'Brien 1979).

Privacy is not simply an absence of information about us in the minds of others; rather it is the control we have over information about ourselves...The person who enjoys privacy is able to grant or deny access to others (Fried 1970).

Viewed in relation of the individual to social participation, privacy is the voluntary and temporary withdrawal of a person from the general society through physical or psychological means, either in a state of solitude or small-group intimacy, or, when among larger groups, in a condition of anonymity or reserve (Westin 1967).

Such definitions take a broad view of privacy and its purposes. At issue in this report is the extent to which private physical space in assisted living accommodations is a prerequisite to achieving the “wall of dignity,” “the control of information about oneself,” or the “temporary withdrawal from general society” indicated in the cited definitions of privacy.

While scholars differ somewhat in their definitions, most emphasize that privacy is a multi-dimensional construct construed differently by older people under various circumstances. In his analysis of privacy among older people, Pastalan (1970) adopted the Westin (1967) formulation that posited four types of privacy: solitude, intimacy, anonymity, and reserve. To Westin, the reasons why privacy of one or another type is needed are four-fold: 1) to exercise autonomy and maintain individuality and consciousness of individual choice; 2) to achieve emotional release (particularly important at times of loss, shock, or sorrow); 3) to conduct self-evaluation, which requires private information-processing and reflection; and 4) to achieve limited and protected communication. Pastalan argues that these concepts are relevant to older people and that their care environments should permit the full range of privacy.

Degenholtz, Kane, and Kivnick (1997) developed a values assessment protocol that case managers administered to more than 800 older clients in an effort to determine systematically how important various values were to clients and how these values were defined. The undefined value “privacy” was rated as very important (as opposed to “somewhat important” and “not so important”) by 66 percent of the responding clients. Respondents went on to describe privacy in at least three ways: privacy with reference to their body and person; privacy with reference to their business and financial affairs; and various aspects of social privacy (e.g., the desire to be alone sometimes or the desire to socialize with selected people in private). Some clients emphasized multiple aspects of privacy; people who had been ill for some time and dependent on intimate help were less likely to stress bodily privacy.

The relationship between privacy and socialization is an important dimension to explore because one argument against private rooms maintains that residents without roommates tend to be isolated. Only a simplistic view equates isolation with being alone and socialization as being with other residents. The scant work on the topic emphasizes that a lack of privacy may, in fact, interfere with socialization and a meaningful sense of self. Kaakinen (1992) showed that nursing home residents tend to maintain silence and to interact rarely in public spaces as a coping mechanism. Betty Friedan (1993) asserts that institutional life is a recipe for, rather than an antidote to, loneliness. She suggests that older people have a particular need to create and control their own surroundings as a defense of a weakened sense of selfhood. In her view, such control of one’s home is a precondition for meaningful socialization:

Perhaps in our later years, when we are no longer so completely defined by those roles of family and professional career that structured our youth, home – the place from which we come and go, the place with which we are intimately familiar, whose very furnishings express the roots and order of our being – is more important to our essential sense of selfhood and well-being than any gerontological “care” (Friedan 1993, p. 350).

Empirical Studies of Aging and Residential Care Settings

Qualitative Studies

Despite anecdotal reports from providers describing the positive relationships that can develop between roommates previously unknown to each other, little qualitative research has examined the potential benefits of sharing rooms. One exception is Kidder's (1993) non-fiction account of a friendship between two older male roommates in a nursing home.

Most qualitative research has noted the negative impact of sharing rooms. For example, in their ethnographic study on nursing home life, Lidz, Fischer, and Arnold (1992) note a pervasive lack of physical privacy. They view this lack of privacy as interfering with personal autonomy in two senses: autonomy as free action and effective deliberation and autonomy as consistency and authenticity. To achieve the latter sense of personal autonomy, they argue, especially requires an environment structured to allow individuals to pursue their own interests and goals.

As part of an evaluation of the nursing home survey process, Abt Associates (1996) conducted a large anthropological study to examine how nursing home residents viewed quality of life. In qualitative interviews with cognitively intact residents, the residents identified four general themes: dignity, self-esteem, interpersonal relationships, and meaningful activity. Bodily privacy, and closing and locking doors of bedrooms and bathrooms were an important part of the residents' formulation of the dignity theme.

A smaller study by Baugh (1996) reports on the attitudes about shared housing among five focus groups of middle-aged and older women. The most pertinent groups were two focus groups of women over 65 living alone in houses or apartments. Participants in these groups perceived that sharing their space with another woman would be a threat to independence. They felt apprehensive about taking in a housemate or moving in with someone, even if their health or finances dictated this course of action. A specific question about assisted living revealed that participants lacked information regarding assisted living and how it differs from nursing homes. When given an explanation, they were positive about the concept and preferred living alone in an assisted living apartment of their own to sharing conventional housing with others.

A study of ethical issues identified by nursing home social workers found that disputes among roommates in nursing homes and requests for changes in roommates were their most common problems and most difficult to resolve fairly (Kane and Caplan 1990). Some qualitative studies in mental health settings also confirm the value of privacy (Davidson, et al. 1995, Nelson, et al. 1995). One qualitative study showed that chronically mentally ill people in single-room occupancy hotels value the opportunity to have social interaction with others while maintaining privacy in their single rooms (Linhorst, et al. 1991).

Quantitative Studies

As with qualitative studies, relatively little quantitative research specifically addresses the potential benefits and problems associated with sharing a room or having privacy. The few direct surveys about residential care settings involve varied samples: older people (including nursing home residents), family members, and staff who were surveyed about nursing home privacy (Lawton and Bader 1970); community-dwelling people over age 50 who were surveyed about assisted living

(Jenkins 1997); prospective users of retirement housing (Parr and Green 1990); upper- and middle-income people likely to enter life care communities (Parr, Green, and Behncke 1989); and mid-life and older women who were queried about shared housing (Baugh 1996). All these studies lend support to consumer preferences for privacy.

More than three decades ago, Lawton and Bader (1970) studied the preferences for private or shared space in nursing homes. They administered a simple questionnaire asking what kinds of rooms respondents preferred and what kinds of rooms they would endorse for others. Their sample of about 800 people included: residents in private and shared rooms in nursing homes, varying the affiliation of the homes and the income levels of the residents; community-dwelling lay people of varying ages, health status, and religion; and human services professionals. Across the sample, private rooms were the overwhelming preference. For example, 92 percent of respondents over age 80 in the community who saw themselves as well and 80 percent of those who saw themselves as sick preferred private rooms. Among nursing home residents, current rooming arrangement was a strong predictor of room preferences. Among those without roommates, 95 percent of the Protestant and 85 percent of the Jewish nursing home residents preferred private rooms. On the other hand, slightly less than half of those who had already shared rooms said they preferred private rooms. Respondents were more willing to endorse double rooms for others than for themselves. The researchers raised the possibility that older people may care about physical privacy more than younger people because they have less ability to move out of their environments.

Researchers have differed on the relationship between the degree of illness and the desirability of a roommate. Lawton and Bader (1970) conducted follow-up personal interviews with a sample of nursing home residents in double rooms who had indicated a preference for this arrangement. They concluded that some very ill residents liked the companionship and security of a roommate. On the other hand, Brill (1989) has suggested that sick people and people who are otherwise vulnerable need privacy most yet are most likely to be deprived of its possibility.

Jenkins (1997) put five questions about privacy in assisted living to a probability sample of 694 community-dwelling people over 50 who participated in a telephone survey on a number of other topics. Eighty-two percent preferred a private room, and only 4 percent preferred a shared room with someone previously unknown to them; the remainder did not know, did not answer, or said they did not care. Furthermore, 87 percent preferred a smaller private room to a larger shared room. These findings held across income, gender, and geographic groups. Only 13 percent agreed strongly or somewhat agreed with the statement that having a shared room would encourage family visits, whereas 82 percent disagreed somewhat or strongly. Seventy-one percent of the respondents were very concerned or somewhat concerned about having to share a bedroom with someone they did not know. This finding compares to 80 percent who were very or somewhat concerned that they would receive low-quality care. Finally, when respondents were asked their first reaction to the statement “think about spending two years living in a room that you share with a roommate that you did not know previously,” 78 percent of the sample gave unambiguously negative replies; 14 percent said that their opinions would depend on who the roommate was (e.g., someone compatible, someone with a shared background); and only 6% said shared space would be “okay” or gave a clearly positive response.

In a different context, a Florida-based firm conducted national studies on preferences for housing that would guide developers of senior retirement housing projects (Parr and Green 1990; Parr, Green, and Behncke 1989). The firm developed preference data from a national sample of about 1300 people, stratified by income and region and by whether they lived in a retirement region of the country. The percentage of prospective movers who would be willing to share a two-bedroom apartment with another resident was 8 percent in the group with incomes of \$15,000 to \$24,999, and 7 percent in the groups with incomes at \$25,000 to \$49,999. Unexpectedly, somewhat more people with incomes over \$50,000 (14 percent) would consider sharing a two-bedroom apartment. The same authors conducted a study of Florida residents likely to move to a life-care community with services on account of health needs. They found that 58 percent wanted a 2-bedroom, 2-bathroom apartment and that only 7 percent would consider even a studio apartment.

No experimental or quasi-experimental study could be found on the effects of private or shared rooms on resident outcomes. Indeed, such a study would be difficult to design. One longitudinal study in a newly opened assisted living program with mostly shared accommodations (Morrison, et al. 1997) evaluated 36 assisted living residents over a period of six months. The fact that residents' affective and physical functioning improved from baseline to follow-up has been widely mentioned as indicating the benefits of shared accommodations. Such an interpretation is not warranted because the study did not address the comparative benefits of private versus shared rooms. Most respondents occupied double rooms, and no comparable group of residents in private rooms was studied over a comparable time period. Without such a base of comparison, it is impossible to know whether the psychological improvement observed was because of or in spite of the sharing of rooms. Unfortunately, the study's goal did not include a comparison of shared and private rooms, although its findings have been misinterpreted as showing consumer support for double-occupancy.²

Cognitive Impairments

At least 50 percent of the nursing home population experiences some degree of cognitive disorientation and memory loss. One would expect high rates of cognitive disability in assisted living settings as well, although no prevalence data are available. The privacy issue has two facets with reference to dementia: 1) the effects of private versus shared space on the person with dementia and 2) the effects of private versus shared space on persons without dementia if the shared living unit houses people with dementia. Neither topic has been well studied.

The advantages and disadvantages of privacy, on the one hand, and roommates, on the other, for people with dementia are filtered through the observations of staff or of family members. Anecdotal comments from staff regarding the effects on privacy for the person with dementia are contradictory.

²When we began this project, we met several assisted living providers who referred us to the study done at a Birmingham Guest Homes facility as refutation of the idea that consumers prefer private-occupancy to shared space with strangers. We thank Norman L. Keltner, Ed.D., RN, Associate Professor, University of Alabama School of Nursing, University of Alabama at Birmingham, who generously shared his unpublished data with us. In our view, one cannot use the results of this study either in favor of or against shared or single rooms because it simply does not address the topic.

Some authorities suggest that people with dementia become fearful and anxious when left alone. Others point to a territoriality that sometimes exists for people with dementia, citing conflicts among residents with dementia regarding retaining their own space.³

Hawes and her colleagues (1998) conducted focus groups with family members of assisted living residents with Alzheimer's disease, focusing on how these family members perceived quality. The most important attributes regarding personal space for family members were cleanliness (without an unpleasant smell) and ability to take their own furniture to the rooms or apartments. The participants emphasized the quality of being "homelike," characterized by structures that look like houses and the ability to have one's personal possessions around. Some of the specific comments linked private space to the ability to achieve the homelike quality, but privacy itself was not emphasized by these participants.

Less ambiguity surrounds the issue of how cognitively intact residents react to intimate proximity with cognitively impaired residents. Though some providers cite positive relationships that develop between cognitively impaired and cognitively intact residents, the empirical research has found strongly negative results from such sharing for cognitively intact residents. In a qualitative study of choice and control for residents in nursing homes (Kane, et al. 1997), researchers found that cognitively intact residents were sympathetic towards residents with dementia but preferred not to be at close quarters with them. In a quantitative study, Teresi, Holmes, and Monaco (1993) found that cognitively intact nursing home residents had better outcomes when not mingled with cognitively impaired residents in the same units. Kane, Jordan and Grant (1997) tested the possibility that the presence of a Special Care Unit for dementia might be associated with better outcomes for people without dementia in the nursing home. The dementia care units made no difference but having a roommate with dementia was significantly related to poorer well-being for the cognitively intact sample.

Summary

For the most part, the sparse theoretical and empirical literature tends to affirm the importance of private rooms for most residents in long-term care settings. With some possible exceptions for the very sick and some persons with cognitive impairments, samples drawn from both the general public and residents of long-term care settings demonstrate strong support for private rooms. Though the theoretical literature has suggested important social and psychological benefits from private rooms, only a few qualitative studies have looked at the outcomes that result from private or shared rooms. No experimental or quasi-experimental research could be found linking private or shared rooms to any demonstrable outcomes. Finally, the literature on how people with dementia fare in private or shared rooms is sparse and mixed, with some speculation that people with dementia are frightened when alone and other speculation that people with dementia are territorial and need their own space. None of these ideas has been empirically tested. What is unequivocal, however, is that people who are cognitively intact are negative about rooming with people with dementia.

³ Geriatrician Bruce Robinson, MD described his experience with men with dementia in a Veterans Administration Nursing Care Home Unit in Tampa, FL; his observations were that older men with cognitive impairments often become aggressive unless they have a space of their own. Personal communication, January 1997. Duane Miner, Director of the Regency Park Assisted Living, Portland, OR, made the remark about anxiety when left alone. Personal communication, October 1997.

PART II. QUANTITATIVE ANALYSES

One way of examining how people feel about a particular preference is to compare the strength to other preferences. This strategy is particularly useful with residential care for older people since different types of physical settings, services, and staff patterns have implications for public and private expenditures.

This section includes data on the relative importance of privacy based on original analyses of data sets from two studies conducted in Oregon: a 1989 study of 402 adult foster care residents and 420 nursing home residents (Kane, et al. 1991) and a study in progress of 600 assisted living residents and 600 nursing home residents.⁴ One advantage of these data sets is that they include large samples of people actually receiving LTC services in group settings. Because family members replied to questions when residents could not respond, the data sets also provide insights into how family members view privacy relative to other attributes of a care setting.

Oregon Foster Care Study

In 1989, the University of Minnesota conducted a cross-sectional study of a representative sample of adult foster care residents and nursing home residents in four Oregon counties. Described elsewhere (Kane, et al. 1991; Kane, et al. 1989), the purpose of the study was to describe the characteristics of privately paying and Medicaid-supported residents of adult foster homes compared to residents of nursing homes. An adult foster home was defined as a private home in a residentially zoned area that housed and cared for up to five people with disabilities. In the final sample, 260 older adult foster care residents and 199 nursing home residents responded to the in-person questionnaires. For the 142 foster care residents and 221 nursing home residents who could not respond because of cognitive impairment, family members were asked the questions that referred to choice of and satisfaction with the setting.

Because we thought that residents of adult foster care might seek different attributes of a setting than residents of nursing homes, we asked a series of questions about the search process and choice of the current setting. As part of this battery, respondents were asked whether any of a list of 10 items were important to them as they chose their care setting. As [Table 2](#) shows, privacy, albeit undefined, was highly endorsed by foster care residents (79 percent) and proxy respondents for cognitively impaired residents (66 percent). In the nursing home, 51 percent of residents and 45 percent of proxies said privacy was important.

⁴ Rosalie Kane and colleagues at the University of Minnesota are conducting this study with funding from the Robert Wood Johnson Foundation. No papers had been published at the time this report was prepared because the main questions require three waves of data collection. For this report we analyzed the baseline data.

	AFC Residents (N=260) ^a	AFC Proxies (N=142) ^b	NH Residents (N=199) ^c	NH Proxies (N=221) ^d
Important in making move:				
Safe, supervised setting	87%	88%	78%	89%
Homelike atmosphere	86%	87%	53%	59%
Privacy	79%	66%	51%	45%
Personal assistance/care	74%	85%	73%	83%
Flexible routines	70%	70%	38%	51%
Access to medical care	65%	60%	71%	76%
Location neighborhood	61%	59%	56%	67%
Organized activities	31%	18%	39%	36%
Rehabilitation programs	26%	13%	36%	36%

Source: Kane, et al., 1989

% saying "yes". Does not include missing data.

^a 4-9% missing data. Does not include missing data.

^b 12% to 14% missing data. Does not include missing data.

^c 9% to 17% saying "yes". Does not include missing data.

^d 9% to 12% saying "yes". Does not include missing data.

Oregon Assisted Living Study

Between July 1995 and April 1996, researchers at the University of Minnesota interviewed a total of 1,215 of residents in 38 ALFs and in 32 nursing homes in Oregon. The purpose was to compare outcomes over time for residents of assisted living and nursing homes. One sub-question concerned the factors that consumers perceived as important in a care setting. In contrast to the foster care study just described, this study asked respondents to rate the importance of a variety of attributes of the setting on a “1” to “5” scale, with “1” being the most important and “5” being the least important. By permitting a gradation of responses, this strategy avoided the problem of the earlier study where respondents were forced into a “yes” or “no” answer. Also, in contrast to the foster care study, a specific item was “private room and bath,” removing some ambiguity about the definition of privacy in the foster care study.

In administering this battery of questions, we asked residents to think of what was important to them, regardless of what their facilities offered or how their facilities performed. As with the foster care study, family proxies were asked to reply about what was important in a care setting when the resident was too cognitively impaired to be interviewed. The responses of family proxies for cognitively impaired residents were separated from those of the residents. The final sample included 605 assisted living residents in 38 facilities (divided between 478 who were interviewed and 127 interviewed by proxy) and 610 nursing home residents (171 who were interviewed and 439 interviewed by proxy). Tables 3 and 4 present the findings for the residents and the proxies respectively.

As Table 3 shows, “a private room and bath” were extremely important to assisted living residents. Eighty-seven percent gave it the highest rating of “1,” surpassing the ratings for the next

most highly rated item, “a safe place to live,” by 12 percent. When the “1” and “2” scores are combined, a private room and bath garnered 94 percent. The next most highly rated items for “1” and “2” combined were “a safe place to live” (90 percent), “access to medical care” (87 percent), and “good food” (82 percent). In contrast, organized activities was rated either “1” or “2” by only 37 percent. Many nursing home residents also gave the highest possible rating to “a private room and bath” (59 percent rating as “1” or “2”) though a “safe place to live,” “good food,” and “access to medical care” were much more highly endorsed. It is notable that these residents resided for the most part in shared rooms at the time of the interviews.

Table 3: Relative Importance of Selected Features to ALF & NH Residents in Oregon, 1995-1996*

Feature	Importance Ratings (in percent)									
	ALF Residents (N=478)					NH Residents (N=171)				
	Highest		Lowest			Highest		Lowest		
	1	2	3	4	5	1	2	3	4	5
Private room & bath	87	7	3	-	2	41	18	11	12	19
Safe place to live	75	15	5	3	3	75	11	8	2	4
Access to medical care	65	22	5	4	5	62	22	6	2	8
Good food	59	23	12	4	4	57	25	9	2	7
Personal care staff	50	24	12	5	9	56	23	11	3	9
Own refrigerator/stove	48	21	12	7	12	18	9	9	9	54
Location/neighborhood	45	21	14	6	13	50	14	12	5	19
Homelike atmosphere	42	27	16	7	7	39	21	20	6	13
Price	38	21	19	6	16	38	19	14	3	27
Continuity of staff	26	26	23	6	19	28	32	20	7	14
Organized activities	20	17	23	16	23	28	19	13	13	27
Rehab program	18	15	10	15	41	36	15	7	7	34

* Dash represents less than 1 percent. Rows may not exactly total 100% because of rounding errors.

Table 4 (overleaf) shows the results when relatives were asked about what was important for a resident with cognitive impairment. For those whose relatives were in assisted living, 86 percent rated “a private room and bath” as “1” in importance, and the combined “1” and “2” ratings were 97 percent, an even a greater endorsement than that given by the assisted living residents themselves. Family members for nursing home residents who were cognitively impaired were much less likely to perceive a private room and bath as important.

Since private rooms and baths were overwhelmingly favored by the resident respondents, the sample preferring roommates was too small for a multivariate analysis of the factors associated with the preference. We conducted some bivariate analyses to see whether any resident features were significantly associated with a preference for a private room and bath. We examined relationships between the preference for a private room and bath and activities of daily living (ADL) impairment, perceived

Table 4: Relative Importance of Selected Features to Family Members of Cognitively Impaired ALF and NH Residents in Oregon, 1995-1996*

Feature	Importance Ratings (in percent)									
	ALF Residents Proxy (N=127)					NH Residents Proxy (N=439)				
	Highest		Lowest			Highest		Lowest		
	1	2	3	4	5	1	2	3	4	5
A safe place to live	89	6	4	1	-	92	7	-	-	-
Private room & bath	86	11	3	-	-	17	15	25	15	28
Personal care staff	80	14	2	2	2	83	13	3	-	1
Good food	67	24	7	1	2	49	28	13	4	6
Access to medical care	58	24	7	7	4	72	19	4	2	3
Homelike atmosphere	55	29	13	2	1	42	27	19	5	7
Location/Neighborhood	47	24	18	3	7	51	18	19	6	7
Continuity of staff	35	32	20	9	5	39	29	18	5	9
Own refrigerator/stove	28	14	21	11	25	1	1	1	6	90
Organized activities	25	29	19	13	13	24	18	25	11	22
Price	24	24	37	8	6	24	18	26	7	24
Rehab programs	18	17	24	18	23	32	20	19	10	20

* Dash represents less than 1 percent. Rows may not exactly total 100% because of rounding errors.

health, gender, length of stay, and Medicaid status. Among ALF residents, only gender and ADL status were significantly related. Being female was associated with the preference for a private room and bath (89 percent of women versus 76 percent of men gave private room and bath a “1” rating) and those with four or five ADL impairments rated a private room somewhat less highly (though the differences were in whether it was rated as a “1” versus a “2”). In nursing homes, where the strength of residents’ preferences for a private room and bath were more varied, none of our potential predictors made any statistically significant differences. Indeed, we found a non-significant tendency for those nursing home residents with the highest ADL impairments to rate the importance of a private room and bath as a “1.” Length of stay made no difference.

We found no significant associations with the family members’ views about whether they valued private rooms and baths highly for their cognitively impaired residents. Among the larger group of family members of cognitively impaired nursing home residents, we found that families were more likely to value the private room highly if they were on private-pay status.

Summary

In a 1989 study, Oregon residents of adult foster homes and their proxy respondents (N=402) tended to endorse “privacy” as an important feature in choosing their care setting (79 percent and 66 percent respectively). Nursing home residents and their proxies (N=420) were less likely to endorse privacy (51 percent and 45 percent, respectively). In a 1995 study of 605 assisted living residents and 610 nursing facility residents, private rooms and baths were overwhelmingly considered important by assisted living residents and relatives of assisted living residents with cognitive impairments. For the assisted living residents, a private room and bath was the most important feature of a list that in-

cluded a safe place to live, a homelike atmosphere, good food, and good personal care staff. Being female and having fewer ADL impairments was associated with the importance of a private room among assisted living residents, and being on private-pay status was associated with the importance of a private room for family members of cognitively impaired nursing home residents. Length of stay was not associated with the privacy preference in any subgroup. The ratings, however, reveal none of the reasoning that might explain the preferences for private rooms. For that, we turn to the focus group study.

PART III. FOCUS GROUP STUDY

Methods

According to Krueger (1994), a focus group is “a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment.” Participants in a focus group are chosen because of one or more shared characteristics related to the topic. Specifically, we used a focus group approach to elicit in some depth the experiences and attitudes about private rooms in assisted living from those who would be influenced by public policies in this arena. We sought input from people already in assisted living settings, people who might be prospective customers for assisted living, family members of cognitively impaired older people who were in assisted living, family members of cognitively impaired prospective customers of assisted living, and staff of assisted living. The latter were in a position to comment from the perspective of the attitudes they saw among assisted living residents.

Group Selection

Altogether 62 people participated in 13 focus groups. The groups represented older ALF residents in unshared rooms or apartments (three groups), older ALF residents in shared rooms or apartments (one group), older community-dwelling people with disabilities who might be candidates for ALFs (three groups), relatives of older ALF residents with dementia (two groups), relatives of older community-dwelling people with dementia who might be candidates for ALFs (two groups), and staff members of ALFs (two groups). Seven groups took place in Florida and six in Minnesota. One Florida group of community-dwelling participants consisted only of African American women. We made special efforts to include participants below the poverty line. ALF residents were not from the same ALF but were transported to central locations for the meetings.

The average age was 79 years among the 17 participating ALF residents and 77 years among the 16 participating community-dwelling older persons. All told, 24 women and 9 men participated with ages ranging up to 93 years. The 19 family caregivers of persons with dementia who participated included spouses and adult children. The 10 participating staff members had a range of job titles, including program directors, lead aide, activities director, and marketing director. In all focus groups, respondents were asked to assume that private accommodations would be the same price as shared accommodations of the same size and amenities to separate views about privacy from concerns about affordability.

Focus Group Methods

Focus groups were conducted in a method designed to elicit discussion. Facilitators followed a discussion guide and used additional visual aides and handouts to generate discussion. After an introductory section, our discussion guide was organized into five substantive topics: 1) a warm-up discussion about preferred activities to do in one’s room or apartment; 2) advantages and disadvantages of private rooms, on the one hand, and of having an assigned roommate, on the other; 3) activities or circumstances that might be uncomfortable with a roommate present; 4) trade-offs participants might make in other attributes of the settings to have private rooms; and 5) relative preferences for different floor plans of rooms and bathrooms. Questions and probes were slightly modified to relate to various subgroups in the study.

[Appendix A](#) describes the method and the participants in greater detail. [Appendix B](#) contains the actual focus group guide. [Appendix C](#) contains the floor plans of rooms and apartments used to facilitate the discussion, and [Appendix D](#) contains a checklist also used to facilitate discussion.

Findings

Findings are organized by the five substantive topics in the focus group guide. The findings conclude with a summary of two additional themes that emerged during the focus groups - the importance of private bathrooms and of privacy for socializing.

1) Activities to Do in One's Room

The first warm-up question asked participants what they would want to do in their own room. Family members were asked to answer in terms of their relative; and staff members, in terms of their observations of residents. This component was treated as a brainstorming session, and all ideas were written down. Some of these items were mentioned many times. The following four categories of responses were identified:

- room arrangement (e.g., decorate; have familiar furniture; keep space neat and clean; feel that oneself and one's possessions are secure from outside elements; put flowers around; go through my things);
- social interaction (e.g., use the telephone; talk to friends; have visitors; write letters);
- personal actions (e.g., perform routines; sleep; make plans (for what to do, where to go, what to wear); shower and bathe; be quiet; be noisy; be alone; have meals and snacks; pray; play with dog); and
- interests and activities (e.g., watch television; listen to radio or music; read, including late at night; play games; exercise; do cross-word puzzles; pursue hobbies).

2) Advantages and Disadvantages of Private Rooms and of Roommates

We asked the focus groups to discuss the pros and cons of shared and private rooms. In general, the overwhelming consensus was for a private room. One person said that comparing private versus shared space is "like comparing chocolate to sand." [Table 5](#) provides a composite list of the items mentioned by respondents.

Table 5: Positive and Negative Views on Private and Shared Rooms	
Private rooms/apartments	Roommates
<p><i>Positive Views</i></p> <ul style="list-style-type: none"> Do as you please Independence Enjoy being alone More homelike, can furnish Can choose amount of participation Choose whom to associate with Decide how to use space Control radio and TV Read late without disturbing More space for the wheelchair Can be a night person Temperature control Control of lights & bedtime Light sleeper Lack of aggravation from roommate's bad behavior Can do what I want w/o bothering anyone 	<p><i>Positive Views</i></p> <ul style="list-style-type: none"> Company good, if cognitively intact Company, if compatible Can help each other Relieve boredom Relieve loneliness Useful if you need help, if you fall <p><i>Negative Views</i></p> <ul style="list-style-type: none"> Stress, if not well matched Conflicts, personality conflicts Problem if roommate is confused Too much of a transition from home Feels like a hospital or nursing home Less quiet time and space Thefts Sharing a bathroom means waiting Not enough privacy with commode (privacy curtain not enough) Sleep disturbed Conversation with visitors disturbed Forced to talk and do things in front of other people Roommate's pets a problem Roommate's visitors a problem (including boyfriend late at night) Nobody should have to room with my husband My relative is possessive about own space Roommate might drink Roommate might snore Not nice to dress in front of strangers
<p><i>Negative Views</i></p> <ul style="list-style-type: none"> (Staff) Isolating for those with memory loss 	

Most older participants saw more disadvantages than advantages in having a roommate. To support their views, they emphasized the independence, choice, and normal aspects of private space. They described themselves as set in their ways, liking to do things the way they want. In many focus groups, participants agreed with each other about this desire to set things up the way they want them. For example:

Resident 1 (male): “I put a cup here, this is where I have to find it.”

Community Participant (female): “I don’t want anyone touching what I put down.”

Community Participant: “If it’s a mess, it’s my mess.”

Community Participant: “I have a plate here—false teeth on the bottom. And they come out at night in the bed. And I couldn’t find the damn things.”

Community Participant: “One of the things I wrote down (referring to notepad used by participants to jot down thoughts) was places for personal items such as pictures and favorite possessions. Also on this pad I had any prosthesis, teeth, or glasses that will not be moved. If I can’t reach for my glasses, forget it. It is very important to know where your possessions are at all times.”

Many ALF residents in single rooms or apartments had previously shared a room and did not like doing so. Some had experienced multiple roommates. Few of the community-dwelling older participants could envision moving to a shared room willingly. The participants who were currently in shared rooms often alluded to the cost of private rooms, and several mentioned they had previously had a room alone and preferred it.

The advantages cited for roommates were the potential for companionship and the availability of roommates to help in an emergency. The former was contingent on having a compatible roommate. The African American group discussed the compatibility issue in some detail. As one respondent put it:

“But for my part, I would like someone in the room with me. I would not like to be in a room by myself. If I had arthritis, I’d like somebody to be in the room with arthritis and not a heart patient or some other thing.”

Another woman in her group concurred:

“If I had a roommate in a home some place, I’d like to have one where we both had the same problem.” Another added, “If I had a roommate, we’d study the Bible together and then pray together.”

The group went on to clarify that the roommate should not be too much younger or older than themselves and should not smoke or drink. In general, across all groups, roommates were also not considered good companions if they were deaf, cognitively impaired, or very sick

Whether a roommate could be helpful was also contingent on the physical and mental capabilities of that roommate. The roommate would need to be able to perceive an emergency, for example, and call for help, as this dialogue indicates:

Resident 1: “The only reason I don’t like to be alone is in case I fell. If I fell, the roommate would be able to help.”

Resident 2: “Mine wouldn’t, because she’s fallen twice. I rang the bell to help her. I don’t want her to lay there, that would be selfish, so I just ring the bell.”

Similarly, some family members did not believe residents should be responsible for helping each other and doubted that roommates would do it well. One said:

“Some do not know where the pull strings are for emergency help or how to use them. You don’t have pull strings in your own home.”

Another in the same group added: “It’s not really their responsibility to be a watch dog either.”

One family member said:

"Let me tell you the condition of these people; they don’t necessarily know what the other person is having. They could be having a seizure and they don’t know it. Maybe if you saw blood. But you know if they fell down, he (my husband) would know it, but it’s not the roommate’s responsibility."

Some family members also thought their relative would be courteous, repress feelings, and yet be uncomfortable with roommates. An older participant living in the community expressed a similar concern with the idea of sharing:

“I would try and take care of her, then I would take a back seat.”

Others thought no roommate should have to bear living with their particular relatives.

Staff, particularly in Florida, noted both advantages and disadvantages to shared rooms. Many believed their work was easier in shared spaces. The staff saw several advantages to well-matched roommates, particularly for residents with memory loss – less isolation; relief from boredom; security for falls; and a “buddy system” (e.g., remind each other to take medications, go to dinner, go to bed). However, staff also noted that they spend a great deal of time problem-solving between roommates. One staff member explained:

“Seniors have difficulty problem-solving; they don’t want to hurt someone’s feelings, but they are angry...it comes out sideways [like suspicion of theft].”

Some participants illustrated disadvantages of roommates by describing problems with their past or present roommates. Their experiences revealed the extensive accommodations many had made. A long list of examples follows:

Female resident, in single space: “A roommate is nice sometimes but she (former room mate) had cats and you couldn’t really close the door because the cat wanted in and out. I like kittens but I don’t like cats...Now I have a very small room but it is all mine. I never knew what it was like to have a roommate, and I had one there and I don’t want one. She used to invite her boyfriend in. This is a lady, 69, and her boyfriend was 53 and he was epileptic. He was a boy in a man’s body. He was a very nice guy, and he loved everyone in the place, and he liked to talk. He was learning to talk again...A lot of times I wanted to go to bed at 10:00 or 11:00 and I couldn’t. I could have said, ‘Please leave,’ but I didn’t want to hurt anyone’s feelings.”

Male resident with roommates: “I would like privacy, yes. I dislike the situation I am in now. I dislike it very much. I am sharing a room with two other people. It is two rooms actually, the front of a remodeled house...I have a medical situation that is very difficult for me to handle and I must have privacy. I have difficulty with my bladder. Going to the bathroom is a very difficult situation for me...I have to change these briefs at least three times a day, if not four and five. I am up four and five times at night like that and it’s disturbing in a room. How are you going to walk through a room like that and not disturb your roommates?”

Community participant with husband in ALF: “He did (have a roommate) part of the time and we got him a private room. He enjoyed talking to the roommate back and forth but as he deteriorated it was harder to manage. Our family would go in and we ended up helping both...my daughter’s idea was that (with a private room) we could groom him and care for him and visit with him and have the grand children in—seven of our grand children live close and they want to visit their grandfather.

Male resident, with roommate: Yeah, well, he (roommate) gave me a hard time this morning. I don’t think he means to do it so I said, ‘I’m going to get even with that boy.’ He is 10 years older than I am. This morning I think he went to extremes. I was asleep for about an hour before this. Bam, bam. Gets down to his dresser drawers, pulls it out, rakes through it...One night not long after he got here, he got up at about a quarter to twelve. I keep a clock where I can see it. He went over there to one drawer. Every time he moves something it would make a noise. He got up 11 times in less than 30 minutes and did the same thing. Who could help but hear him?”

Male resident, with roommate: “Before this one, yeah. Three of them. One of them they put in a nursing home. He was not able to take care of himself. The first one I had died. This last one they finally put in a nursing home, I don’t know, I’m assuming he died. He got thrown out for fighting. Another one should never have been put in there. He was what I call absolutely crazy. He wanted to fight. One night he came at me and he had both shoes, and was going to beat me with his shoes.”

Female resident, age 93, with roommate: “My roommate, I have now, we don’t speak. She tries to run everything, tells me what to do and what not to do, and I don’t go for that. The supervisor asked me if I wanted a different room and I said I hated to do that because people would think it was me who couldn’t get along with anybody. I just stay in my room and read and write and do whatever I want to do...I had a private room before it got too expensive. I liked that better.”

Female resident, presently in single room: “I’ll tell you one thing at (former program) nearly everyone has a roommate but they don’t screen them very well. For instance, they put someone in the room with me, someone who isn’t even in this world and doesn’t know up from down. I think they should screen a little better. I thought a retirement home was a place where elderly people go. It isn’t. It’s like an asylum.”

3) Activities that Might Be Uncomfortable with a Roommate Present

One goal of the study was to explore qualitatively the way having a roommate previously unknown to them might affect the daily lives of the participants. We used a checklist for participants to examine and consider (see [Appendix D](#)). The two teams handled the checklist somewhat differently. In Minnesota, the facilitator went down the list and briefly discussed each item, getting a show of hands for those who would have discomfort with the activity or circumstance if they did it or their roommate did it. In Florida, the facilitator went around the room asking participants to mention something that struck them in particular until the list was exhausted, in each case generating discussion from the entire group. At both sites, participants were encouraged to suggest other items. Family members responded in terms of their own relative; and staff, in terms of their observations of all residents.

[Table 6](#) presents the results of this exercise. All items endorsed show up on the table, but the counts may underestimate those who held particular opinions because of the method used in Florida. The items at the bottom of the list were generated by the groups. For example, five family members thought their relative would be uncomfortable if their roommate died in their presence, one family member mentioned discomfort with children or pets visiting in the presence of a roommate, and one family member mentioned discomfort with the roommate's pets or children visiting in their relative's presence.

Table 6: Specific Situations Causing Participants to be Uncomfortable.

Task/Situations	Uncomfortable doing in roommate's presence				Uncomfortable having roommate do in my presence			
	Res.	Com.	Fam.	Staff	Res.	Com.	Fam.	Staff
	N=17	N=16	N=19	N=10	17	N=16	N=19	N=9
Entertain	9	4	5	5	6	2	8	4
Music/TV	8	3	5	4	7	3	4	1
Reading	8	4	0	0	3	2	1	1
Discuss health	8	4	10	5	6	2	4	4
Discuss money	8	4	11	8	6	2	9	3
Talk with visitors	8	3	6	3	6	2	8	2
Overnight guests	7	6	9	6	7	5	12	5
Phone	7	3	5	3	5	1	4	1
Nap	7	4	3	2	3	2	2	1
Staying up late	6	5	5	5	3	5	9	2
Up at night	6	4	7	1	4	2	10	3
Dress/undress	6	6	9	5	4	5	8	0
Pray	6	2	3	4	3	1	0	1
Show emotion	5	5	9	8	3	3	9	4
Decorate	5	3	1	1	5	4	3	2
Have a bed bath	4	5	10	8	4	3	7	3
Use a bed pan	4	6	12	7	5	4	10	3
Have a short illness	3	3	5	2	3	2	7	3
Smoking	1	3	4	3	6	4	11	5
Drink	1	6	5	2	4	4	7	1
Complain	1	-	-	-	1	-	-	-
Die	-	-	-	-	-	-	5	-
Pets or kids visit	-	-	1	-	-	-	2	-
Adjust window shade	-	-	-	-	-	-	2	-
Rearrange furniture	-	-	-	-	-	-	1	-

Discussions became notably animated around the issues of care and social activities uncomfortable to conduct in front of roommates. Residents and older participants in the community who might consider moving to an ALF cited numerous examples of such activities, even activities as solitary as reading and using the phone. Some participants were adamant that they would not be able to tolerate a roommate who smoked. One community-dwelling participant went into detail about how her large, noisy family would probably disturb a roommate, especially since they would all visit at once. One family member felt her husband would be reluctant to talk on the phone in front of others and would not want a roommate to have visitors: “He’s all right on one-on-one, but if there’s more, he cannot handle it.” One staff member indicated that she had checked “pray” because she was aware of situations where one resident wanted to pray frequently and a roommate found it disturbing.

4) Trade-offs Participants Might Make for Private Rooms

In the next section of the focus group, we discussed the relative importance of a private room compared to other setting features. Facilitators suggested possible trade-offs such as smaller bedrooms, less public space, fewer trips outside the setting, and less frequent attention from staff. Some

participants made comments that privacy came first—they wouldn't trade it for anything. "If there's a trade-off, privacy comes first." Several said they would give up anything rather than privacy, one indicating that she could always arrange trips and social activities herself. Residents, older participants in the community, and families had difficulty assuming price neutrality. Some community-dwelling participants assumed they would have to share a room. The African American focus group members were emphatic that they would just want to stay home until the last moment. While family members felt privacy was important, they were less likely than older participants to make any trade-off in quality of care. Indeed, most participants felt that a good standard of care was essential and non-negotiable.

Some family members considered privacy as very important in the beginning to help their cognitively impaired parent or spouse make the transition to assisted living and said they would trade off "just about anything" for their relative to have a private room. As time goes on and their relative's dementia progresses, however, family members expected to trade privacy for other services, both because of limited resources and because they believe their relative's awareness of privacy will be lost.

Family member: "As time goes on, privacy becomes less important, especially with respect to resources, financing, and needs."

Family member: "When my mother's ready for the nursing home, privacy will not be as important...she won't know."

Family member: "Is privacy the thing that is so important for your parent, or is it the thing that's so important for the family...because they believe it's what they need?"

On the other hand, the Minnesota group emphasized that the hassle and disruption entailed in moving would be a problem for their relatives.

Several members described how their parents were already less modest about changing in front of others and about bathroom privacy because of their dementia. Other family members believed their parents were less modest because they have been "institutionalized" and are forced to do things in front of others. One daughter said that, because of her mother's shared situation in a nursing home (following a stroke), she felt powerless to be private about bodily functions and just got used to it.

Unlike the family groups, older participants, both residents and community-dwelling, found it difficult to imagine a time when they would willingly forgo privacy. As one older participant emphatically stated, "If my mind is with me, and I am the person I am, I will never give up my privacy." These groups granted that the ability to pay was a key factor in determining how much privacy they expected.

5) Preferences for Different Floor Plans

We did not take votes on alternative floor plans (pictured in [Appendix C](#)), but almost all participants preferred the studio apartment with the private bath, sitting area, and kitchenette. If they had to have a room rather than an apartment, they preferred the private room. Members of the African American focus group differed: the consensus was for the private room rather than the apartment. Some said that if you could be in an apartment you might as well be at home.

Opinions were divided about the best place for a bathroom when shared between the occupants of two rooms. Some liked the adjoining bathroom between two rooms because they envisaged quicker access and they would not need to get dressed to go to it. “If it’s in the hall, you don’t always have time to grab a robe. You need to keep your modesty.” Some expressed concerns, however, that the adjoining bathroom would be in use when they needed it or inadvertently locked. “It is a problem if the door is locked and they are in the bathroom. I’d rather have it in the hall so there’d be more choices.” One mobility-impaired woman who lived with the arrangement of a bathroom between the two rooms said that her roommate had accidents on the floor and made the bathroom hazardous for her as well as unpleasant. Some liked the concept of a private room and bath within a shared apartment where previously unknown people also had rooms and baths; others thought that was unnatural.

Residents, older community participants, and family caregivers all found the shared bedroom and bath within an apartment too crowded. The theoretical advantages of extra space in an apartment were not compelling to our participants as compensation for the shared bedroom and bath. However, some staff felt the arrangement could work well for cognitively impaired residents: one apartment-size unit would be less to memorize, and the defined boundaries would be beneficial (although they may have difficulty remembering which bed is theirs).

General Theme: Bathroom

Though not a specific topic, the significance of private bathrooms emerged as important, often early in the focus group. Some participants asserted that a private bath was equally as important as a private room. Participants indicated that they wanted to be able to use the bathroom when they needed and as long as they needed, pointing out that this is often an urgent situation. Another reason for preferring a private bathroom was being able to leave possessions in the bathroom and arrange them as they pleased. A family member – in this case, a spouse – said that nobody should have to share a bathroom with her husband because of his unpleasant habits. On the other hand, she was prepared to clean her husband’s bathroom when she visits but would resent cleaning up anyone else’s mess.

General Theme: Socializing from a private vantage point

Many comments referred to a desire to be in contact with other people but also a desire to have a place for retreat and solitude. One gentleman in private accommodations who was blind needed to rely on a neighbor to do certain functions but preferred that arrangement to having a roommate on hand to do the functions. Some of the comments:

I'd like to be alone—but free to interact with people. At my option.

We get set in our ways...We prefer to be single, by ourselves. Nearly everyone wants human companionship—more than social activities.

Well, I live alone and I would want to live there as long as I could be by myself. I'm used to living alone.

I will fight fiercely for my independence.

I just like to be by myself. There would be a problem with who I would have, whether I would get along. I am a very private person.

Some participants commented that talking on the phone is a private matter and best not to do in front of others. One family member mentioned that an aide usually takes the roommate away when she visits her relative, which our participants appreciated. One older community participant believed she would want to have romantic visitors in her room. Another mentioned that her family is large and tends to be noisy and would be unable to socialize freely if they had to consider a roommate. In general, it seemed that these participants favored social interaction and company but wanted to do so in the context of a private room. They also thought a private room would further their ability to socialize as well as to escape.

Exit Questions

On exit, each participant was asked two Likert-style questions (that is, questions whose responses ranged from very positive to very negative) regarding attitudes toward private rooms and sharing a bedroom. However, ambiguous wording may have thwarted our intention that participants take assisted living as their reference point. Some participants might have been answering more generally, especially since these questions were preceded by factual questions about marital status and previous experience sharing rooms across the life span. Despite this limitation, the predominant views were positive toward single rooms and negative toward sharing (see [Table 7](#) overleaf).

Summary

In summary, the focus group study indicated a strong preference for private rooms and apartments, and many negative examples were described for sharing, which one participant said “is a whole new way of life.” The strength of the sentiments is shown in the quotations themselves, only a selection of which are shown here.

Table 7: Attitudes Toward Private and Shared Rooms Among Focus Group Participants From Exit Surveys.

	Resident or Prospective Resident (N=31)	Family of Cognitively Impaired Residents or Prospective Residents (N=19)	Staff N=10
<i>1. Attitudes toward having a private room</i>			
Very positive	18	12	7 ^a
Somewhat positive	5	3	2
Didn't care	2	4	1
Somewhat negative	4	0	0
Very negative	1	0	0
No response	1	0	0
<i>2. Attitudes toward sharing a bedroom</i>			
Very positive	4	3	0
Somewhat positive	2	6	2
Didn't care	7	2	3
Somewhat negative	6	5	4
Very negative	10	3	0

^a One participant stated the answer was dependent on the situation.

CONCLUSIONS

The conclusions from the three very different strategies employed here – a literature review, an analysis of quantitative data that illuminates the relative strength of consumer preferences, and a focus group study that probes in-depth preferences related for privacy versus roommates–converge in their findings. The literature review presented in Part I suggests reasons why private space in assisted living meets deep-seated human needs. It may not be too strong to suggest that for some consumers, their very sense of self is involved. Analyses from Oregon presented in Part II show that privacy is perceived as extremely important relative to other values, even rehabilitation, activity programs, and “a safe place to live.” The focus group study presentation in Part III further supports the preference for private rooms and also gives insight into the depth of many consumers’ feelings on this issue and their reasoning behind their preferences.

Most of our focus group participants thought that a wide range of everyday life activities, as well as a number of less frequently arising circumstances, would be compromised by sharing a room or apartment with someone previously unknown to them. Participants perceived these disadvantages both from their own perspectives and the perspectives of their roommates. The participants valued friendship and companionship and contacts with others but viewed these features as a separate issue from their enthusiasm for privacy.

Although price was held constant for the purpose of the focus groups, our participants were keenly aware of price differentials. Those with low incomes knew they could not afford private accommodations. At least in Florida, those dependent on public subsidies knew they would need to share a room unless public policy changed so that private rooms were reimbursed.

Major conclusions include:

- The three separate parts of this study all supported the preference for private accommodations.
- The literature review and focus groups suggested reasons why that preference might also lead to better psychological, social, and even physical outcomes.
- Participants with low incomes and African Americans were similar to other focus groups participants in their desire for privacy.
- The quantitative study and the focus group study suggested that length of stay and experience with roommates did not mitigate the preference for private accommodations. The focus groups showed that people were tolerant of what they thought they could not change but did not get used to it or adapt.
- Family members of persons with dementia and ALF staff members saw more advantages to shared space than did older participants. However, results of the literature review and focus groups converged to suggest that people who are cognitively intact do not want to room with people with dementia.
- Although price was not supposed to be a consideration for the focus group exercise, price is a real-life consideration for the participants.

Since the preference for private rooms is strong, the bulk of future research should examine the logistics and costs of changed policies rather than the intrinsic worth of private accommodations. Such research should be directed toward examining the true development and operating costs of private versus shared space to help inform licensing and reimbursement policies. Many older persons, especially those with modest incomes or who depend on public subsidies, will not be able to realize their desire (and perhaps their need) for private rooms unless public policies are changed.

Research might also be directed at clarifying the staff and environmental support needed to sustain people with dementia in private space. Other studies could examine the outcomes of shared or private rooms for various subgroups of people, particularly those with dementia. Such studies are hard to design, especially since randomization would be ruled out for ethical and practical reasons. Studies of the effects of privacy should be extended to nursing home and other residential settings where double rooms are more taken-for-granted.

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Appendix A:

FOCUS GROUP METHODS AND PARTICIPANTS

The final study entailed 13 focus groups that ranged in size from four to seven participants. As recommended in the literature, with one exception, focus groups were composed so that participants were not previously acquainted (Krueger 1994, Morgan 1993). Therefore, no two ALF residents or staff members participating in a group lived or worked in the same ALF. Meetings were held in a neutral spot away from the ALFs. Six meetings were held on the University of Minnesota campus in Minneapolis; six were held on the University of South Florida, Tampa campus; and one was held in Dade City, Florida (a community in Pasco County, close to Tampa). Altogether 62 people participated in 13 focus groups.

In focus group studies, some characteristics are held constant within a given focus group, whereas others are purposely varied (Morgan 1993). The homogeneous characteristics are selected to achieve some commonality and comfort level for dialogue within a group. The varying characteristics are selected to represent a range of experience within a subgroup. In this study, focus groups were meant to be homogenous on the following criteria:

- older assisted living residents currently in single rooms or apartments (three groups);
- older assisted living residents currently in shared rooms or apartments (one group);
- older persons (“prospective customers”) with disabilities in the community (three groups);
- relatives of older assisted living residents with cognitive impairment (two groups);
- relatives of older persons with cognitive impairment in the community (two groups); and
- staff members in assisted living settings (two groups).

In each of the three groups where residents currently had single rooms, one or more participants had experienced a shared room in an ALF or a nursing home.

Within the homogenous groups, we sought variation in gender (for all but the staff groups, which we expected to be disproportionately female). Because of an interest in tapping the sentiment of older persons with low incomes, we attempted to ensure that at least half the community-dwelling older persons and assisted living residents were below the poverty level. In the family groups, we selected participants to reflect different relationships to the person needing care (spouse or adult child).

As a general rule, we conducted one group of each type in the Tampa area and one in the Minneapolis/St. Paul area. We also conducted one extra group of prospective assisted living residents in Florida. This last group had two additional features: all participants were African American and all came from a rather rural county composed of several small towns and unincorporated areas in Pasco County, Florida. These participants were all older people receiving in-home services or services from a nutrition site, and unlike our usual practice, the seven participants of this group were not complete strangers to each other. Given the size of the community, most African Americans in the area had some awareness of each other or historical connections.⁵

⁵ We also attempted unsuccessfully to recruit a group of African American assisted living residents. Even though the supply of ALFs is high in the Tampa area and some are minority-owned, we found that African American assisted living residents were, on the whole, too cognitively impaired to participate. The interpretation given to us by providers was that African Americans are extremely reluctant to enter any care outside their own homes and typically do not do so unless cognitively impaired.

Focus Group Guide

We developed a general focus group guide, with some variations in questions and probes for the various subgroups in the study. Focus groups took approximately two hours and were organized into an introduction and five topical areas for discussion: 1) a warm-up discussion about preferred ways to spend time in one's room or apartment; 2) advantages and disadvantages of private rooms, on the one hand, and of having an assigned roommate, on the other; 3) activities or circumstances that might be uncomfortable with a roommate present; 4) the relative importance of private rooms compared to other attributes of the setting; and 5) relative preferences for different floor plans with rooms and bathrooms. Diagrams of the proposed floor plans were distributed. (See [Appendix B](#) for copies of the focus group guides.)

To help further the discussion, we often paused for participants to gather their thoughts or jot down comments that occurred to them. We also used flip charts extensively to record any thoughts from participants. To advance the topic of the advantages and disadvantages of private and of shared accommodations, we distributed a worksheet with a list of activities or circumstances and asked participants to consider whether they would be uncomfortable doing the activity in front of a roommate or having the roommate do it in front of them. (See [Appendix D](#) for the discomfort checklist.) The worksheets were not collected or tabulated.

Recruitment

A two-stage recruitment process was used. To recruit residents and staff, we first contacted assisted living facilities to publicize the study and then did telephone screening of interested potential participants. Community participants were identified through advertisements in newspapers and on community bulletin boards; social agencies; and in the case of identifying family members of persons with dementia, local Alzheimer's Associations and mental health programs. Again we did telephone screening. Telephone screening interviews were used to describe the study and elicit informed consent (which was repeated in more depth at the focus groups), ensure that subjects met the criteria of age, ensure sufficient low-income participants, ensure that the assisted living resident group would include people in single and shared accommodations, and assign participants to groups. Slightly different recruitment procedures were used in Tampa and in Minneapolis/St. Paul, reflecting the different service and referral structures.

Logistics

All groups were held in either Tampa or Minneapolis in the Spring of 1997. Each was led by a team of two facilitators, one conducting the group and the other taking notes. The four authors personally served in that capacity, with one team conducting all focus groups in Florida and the other team conducting all focus groups in Minnesota. With signed permission of participants, all sessions were tape-recorded. We arranged for free transportation for all groups of older participants; provided lunch or a substantial snack, depending on the time of day; and paid each participant a stipend of \$20. At the end of each focus group, we asked each participant to complete a simple questionnaire about their marital status, their previous experience with shared rooms, and a rating of their attitudes towards private rooms and shared rooms in assisted living.

Participants

Table A-1 shows selected characteristics of the seniors who participated in the focus groups. ALF residents ranged in age from 65 to 93. Twenty participants had incomes below the poverty level of \$1,400 a month, including all those currently in shared accommodations in ALFs and all in the African American group. One was currently married, and only two were never married. Disabilities varied – many used wheelchairs, several were blind or had hearing problems – and participants had a wide range of chronic diseases affecting mobility and endurance. Ten of the 19 older persons with cognitive impairments (whose caregivers represented them) had incomes below the level of \$1,400 a month. The average age of the people with cognitive impairments was 80 in Minnesota and 82 in Florida, and the average age of the family caregivers was 43 in Minnesota and 61 in Florida. Across all groups, 16 of the persons receiving care had suspected Alzheimer’s disease, and three had suffered strokes with related dementia. The 10 staff who participated included program directors and lead caregivers (one of whom was a registered nurse), one activities director, and one marketing director.

	ALF residents (N=17)	Older participants in the community (N=16)
Florida	9	12
Minnesota	8	4
Female	11	13
Male	6	3
Average age	79	77
Below poverty level	7	13
White	15	9
African American	1	7
Hispanic	1	-

The participants in the groups often had multiple experiences relevant to the topic. For example, some residents in single accommodations had previously had roommates in either assisted living or a nursing home. Many older community-dwelling participants who were in the focus groups as prospective customers of assisted living had experience with other relatives such as parents or spouses in LTC facilities, an experience shared by almost all the prospective consumers in the African American group.

In Florida, family members with cognitively impaired relatives often had experienced more than one ALF setting for their relative. Some, particularly spouses, were in very close contact with that relative. All had observed situations affecting other people. Family members with cognitively impaired relatives in the community were often giving substantial care; in particular, one daughter, age 43, had uprooted herself, quit a job she loved, and moved into the small apartment of her mother who had had a stroke. (This caregiver was highly reluctant to move her relative into assisted living.) Staff members had sometimes worked in several different kinds of facilities. We tended to learn about these multiple experiences during the introductions, and facilitators encouraged participants to draw on all their experiences in responding to the issues.

Appendix B:

FOCUS GROUP GUIDE

FOCUS GROUP GUIDE

PREAMBLE (about 5 minutes)

Welcome. I am _____ and I will be the moderator for our discussion group today. I also want to introduce _____, our co-leader. She will be taking lots of notes while we talk.

First, I want to thank you all for being part of this discussion group and contributing your important perspective on assisted living and ACLFs for older people.

Let me tell you a little bit about the study. We are doing this study for the American Association of Retired Persons. The University of Minnesota's National Long-Term Care Resource Center is conducting the study with the help of the University of South Florida in Tampa.

As you probably know, many older people are reluctant to move into nursing homes even when they need the care that a nursing home provides. A new form of residential care is emerging around the country, sometimes called assisted living. Assisted living programs are meant to be more homelike than institutions so that people can live there and get care but also live more normally and independently. Lately government policy-makers and health care personnel have become interested in knowing what is important to residents about their rooms or, as is often the case, their apartments in assisted living settings like these. Therefore, we are holding discussion groups with older people who now live in assisted living, older people who might someday consider moving to assisted living, family members of older people who are not capable of discussing their preferences, and staff members of assisted living settings. Every participant in one of our focus groups can bring a consumer perspective to thoughts about the ideal room or apartment to meet the needs and preferences of older people with disabilities or that you would yourself prefer. Assuming that the older person is NOT moving in with a spouse or family member, we have a particular interest in the extent to which people would prefer private space or having a roommate, and why.

I'd like to give you some ground rules. The discussion group will take about 2 hours. If nobody objects, we will use first names to refer to each other—everyone has a large-print name card in front of them to help us remember. In this discussion group, there are no right or wrong answers, and we would like to hear from everybody. We are interested in everyone's opinions and their reasons for their opinions. We are NOT trying to get a majority opinion, take votes, or establish consensus. We want to get everybody's opinion.

To stay in our time-table, I may sometimes move the group ahead to a slightly different focus, but if you have other things you wanted to say, please jot them down and we will go back to general comments at the end—together if there's time, if not separately before you leave.

Do you have any general questions about the study?

INTRODUCTIONS (About 10 minutes)

Let's introduce ourselves. All of you here presently [INSERT ONE]:

- Ⓢ live in an ALF/ACLF in a private room or apartment;
- Ⓢ live in an ALF/ACLF with a roommate;
- Ⓢ have a family member with memory problems in an ALF/ACLF
- Ⓢ work in an ALF/ACLF;
- Ⓢ are receiving long-term care help in the community;
- Ⓢ are African American, live in a rural county, and are receiving long-term care help in the community;
- Ⓢ have a family member with memory problems receiving long-term care help in the community.

Please tell us your name and mention [INSERT ONE]:

- Ⓢ something about the ALF you (your relative) live(s) in and why you moved to it;
- Ⓢ something about the care you (your relative) receive(s) in the community;
- Ⓢ something briefly about your work.

2. WARM UP: WHAT WE DO IN OUR OWN SPACE (about 15 minutes)

Any group residential care setting, including nursing homes, assisted living, even an apartment building in the community, has private and public space. In assisted living, for example, the public space that all residents can use usually includes the dining room, TV rooms and living rooms, mail, hall, and lobby areas, and maybe outside space or laundry space. Sometimes bathrooms and kitchens are available as public space. There is usually some private space as well—at least a sleeping room or portion of a room, sometimes a bathroom and other living space.

Please think now about the space that would be your own in a residential setting, which would at least include the bedroom. What would you want to do in that space. How would you want to spend your time there. [GENERATE A LIST ON THE FLIP CHART.]

3. PROS AND CONS OF PRIVATE ROOMS AND ROOMMATES (about 30 minutes)

Now we would like to look at the pros and cons, or good points and weak points, of having a private room that is not shared with anyone.

Let's assume that price is not a factor and that you can afford to have a private room or Medicaid and SSI will cover the cost of a private room for you, if that is your choice.

Just think of what is good and bad about having a private room, and good and bad about having a roommate?

IN DISCUSSION, GENERATE A FLIP CHART LIST. USE TWO COLUMNS “PRIVATE ROOM” AND “ROOMMATE” AND PUT A PLUS OR MINUS SIGN BESIDE ITEMS DEPENDING ON WHETHER THEY ARE ADVANTAGES OR DISADVANTAGES.

Probes (if needed):

- Ⓢ what are the benefits of being alone?
- Ⓢ when would it be bad for you to be alone?
- Ⓢ what if you were very disabled and couldn't leave your bed?
- Ⓢ what if you were having some memory problems?
- Ⓢ in the activities you told us about before (what you do in your room), how would a private room or a roommate help or interfere?
- Ⓢ (for family members) how does (would) a private room or a roommate work for your relative with memory problems?
- Ⓢ (for family members) how does a private room or a roommate affect family visits
- Ⓢ (for staff) what have you noticed about how residents feel about private rooms or roommates
- Ⓢ (for staff) how do private rooms or roommates affect you doing your job

4. COMFORTS/DISCOMFORTS (about 15 minutes)

There are some things that you may be uncomfortable doing or having happen with a roommate present. There are also some things you might be uncomfortable having a roommate do with you present. We've made a list of such items. Please look it over and mark any of the boxes where you would be uncomfortable (for staff: think residents would be uncomfortable; for family: think your relative would be uncomfortable). This is not to hand in—just to help you think about it. You can add anything else that you think of that would be uncomfortable.

DISTRIBUTE DISCOMFORT LIST. IN DISCUSSION, GO AROUND THE TABLE AND ASK EACH PERSON TO CONTRIBUTE AN ITEM THAT STRUCK THEM IN PARTICULAR AND GENERATE DISCUSSION UNTIL ALL DISCUSSION IS EXHAUSTED.

5. TRADE OFF's (about 15 minutes)

Now let's think about how important a private room is compared to other things you might like to have.

..let's say that you could have a private room, but it would be a lot smaller than one you shared with a roommate. How do you feel about this choice? Would you rather share a room?

..let's say that you could have a private room, but the facility would have fewer staff so they couldn't help you as quickly. How do you feel about this choice? Would you rather share a room?

..let's say that you could have a private room, but the facility would not be able to provide free transportation to doctor's appointments, shopping, and the hairdresser/barber. How do you feel about this choice? Would you rather share a room?

..let's say that you could have a private room, but there wouldn't be a large common area like a living room or a recreation area. How do you feel about this choice? Would you rather share a room?

..overall, how important is a private room to you when you compare it to other things that are important to you-like having a telephone?

6. ROOM/SUITE/APARTMENT ARRANGEMENTS (About 15 minutes)

The last thing we want to do is get your opinions about different kinds of spaces, again thinking of what would be good or not so good about each. Let's take it for granted now that you would have a private room to sleep in. We want you to think of different kinds of spaces and we will take a minute to think about pros and cons of each:

Some are rooms and some are apartments. We have pictures for you to look at, labeled A-E, so you can imagine better what each might look like:

- a) a private sleeping room with a full private bath for you,
- b) a sleeping room with an adjoining full bathroom that is shared by you and the room on the other side
- c) a sleeping room with bathrooms in the hall, enough for one bathroom to every 2 rooms
- d) a room and full adjoining bath, both shared with one roommate.
- e) a studio apartment for yourself with an area for sleeping, a sitting area and kitchenette and a bathroom.
- f) an apartment that has two or three private bedrooms and private adjoining baths, one for you, and a sitting area, kitchenette, and bathroom shared by others in the apartment.
- g) an apartment that has 2 or 3 private bedrooms—one for you, and a living room, kitchenette, and bathroom shared by the others in your apartment.
- h) an apartment that has 2 or 3 bedrooms, one of which you share with someone, and a living room, sitting area, kitchenette and bathroom shared with others in the apartment.

IN DISCUSSION, ASK WHICH OF THE ROOM MODELS THEY LIKE BEST, AND WHY? ASK WHICH OF THE APARTMENT MODELS, THEY LIKE BEST, AND WHY? IF THEY LIKE ONE OF THE APARTMENT MODELS WITH PRIVATE BEDROOMS BEST, ASK IF THEY WOULD RATHER HAVE THE APARTMENT WITH A SHARED BEDROOM AND BATH, OR JUST A SHARED BEDROOM COMPARED TO THE PRIVATE ROOM AND BATH.

WRAP-UP (5 minutes)

Thanks to participants. Concluding comments, additional thoughts as time permits. Complete exit questionnaires.

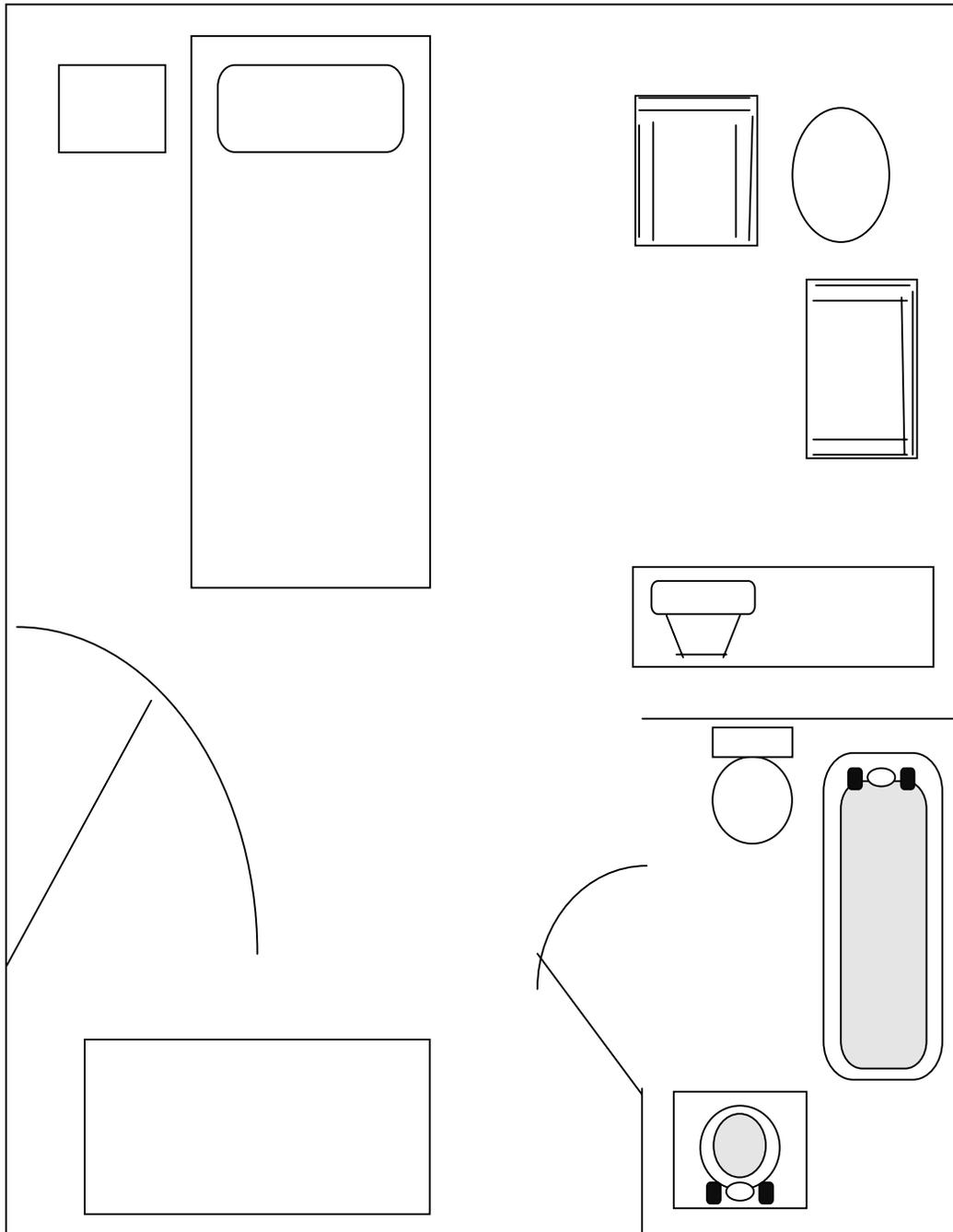
Note: This guide had some small differences as administered by the Minnesota and the Florida teams. We are showing a composite here. It was also intended to be followed generally rather than slavishly.

Appendix C:

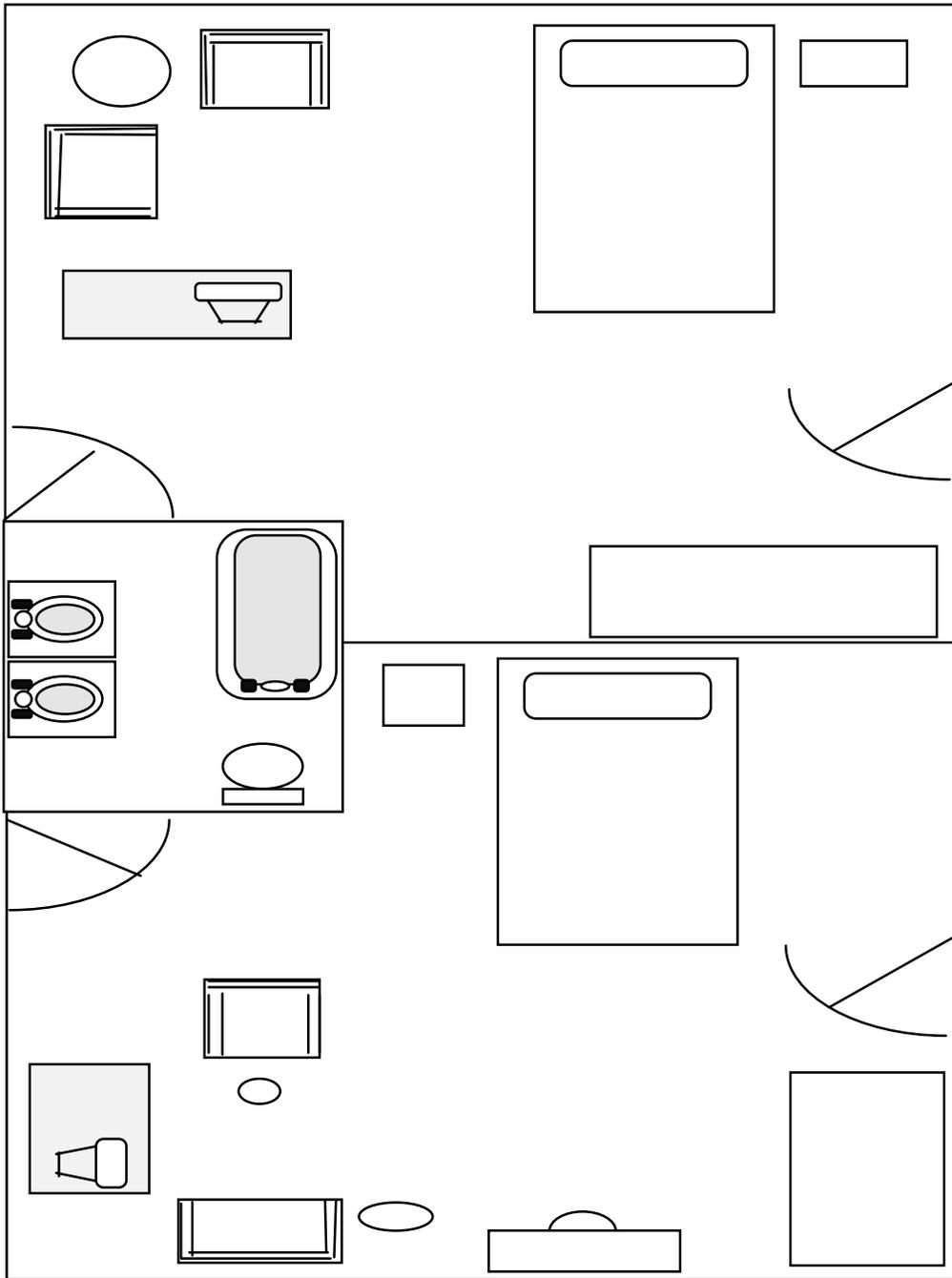
SAMPLE FLOOR PLANS FOR FOCUS GROUPS

Sample Room Floor Plans

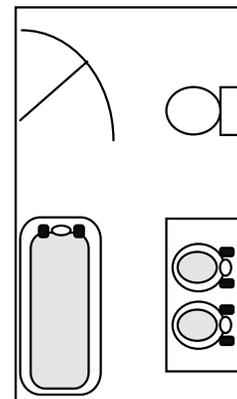
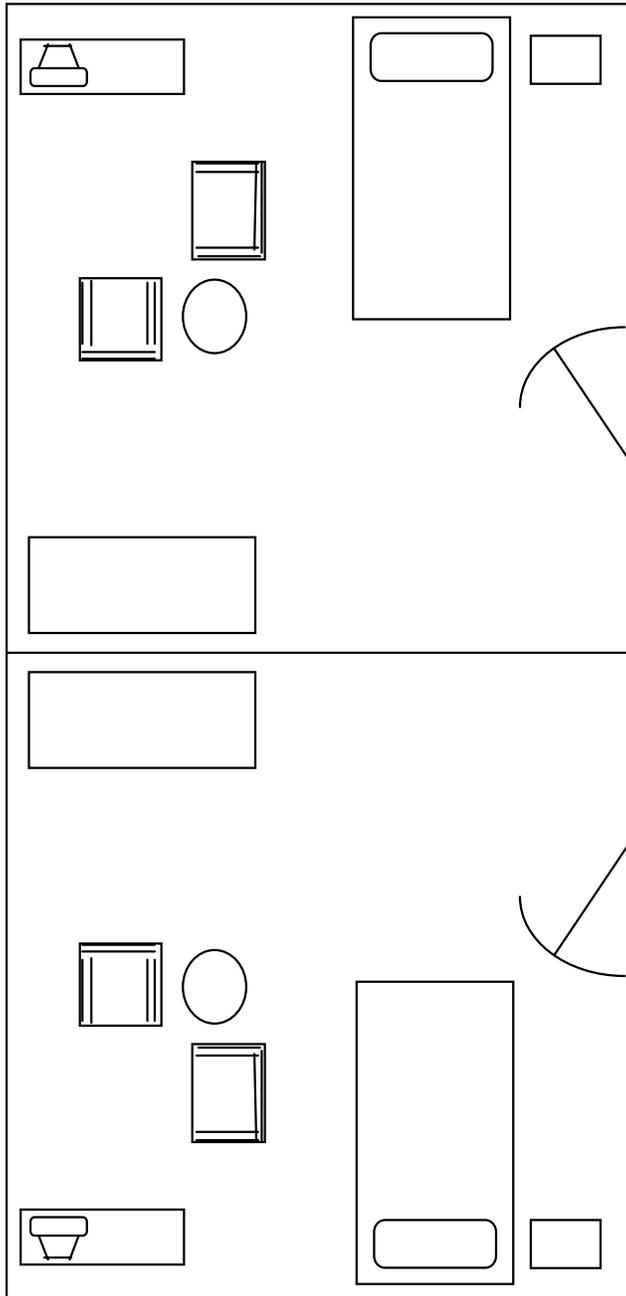
A: Private Room/Private Bath



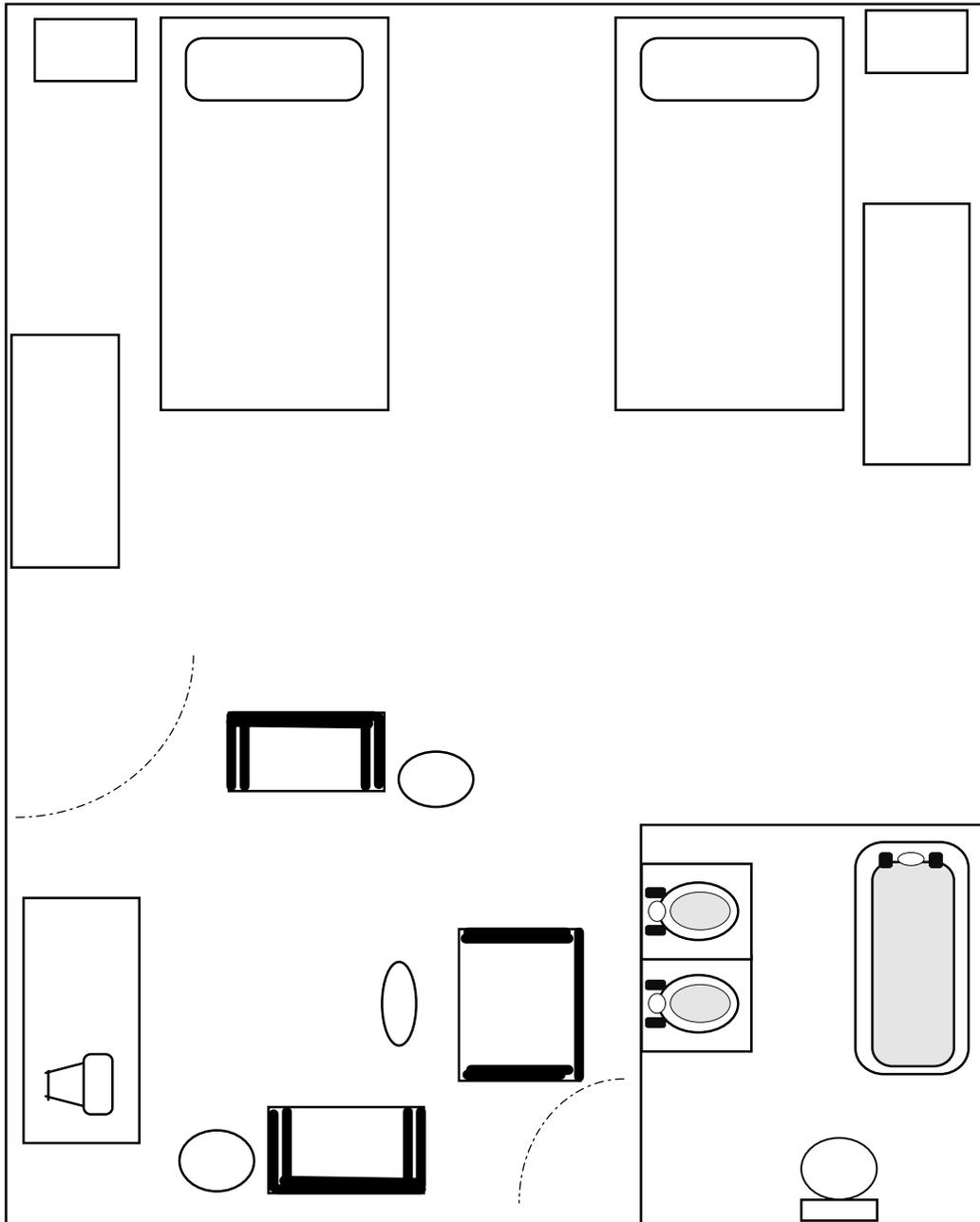
B: Private Room/Shared Bath



C: Private Room/Shared Bath Across Hall

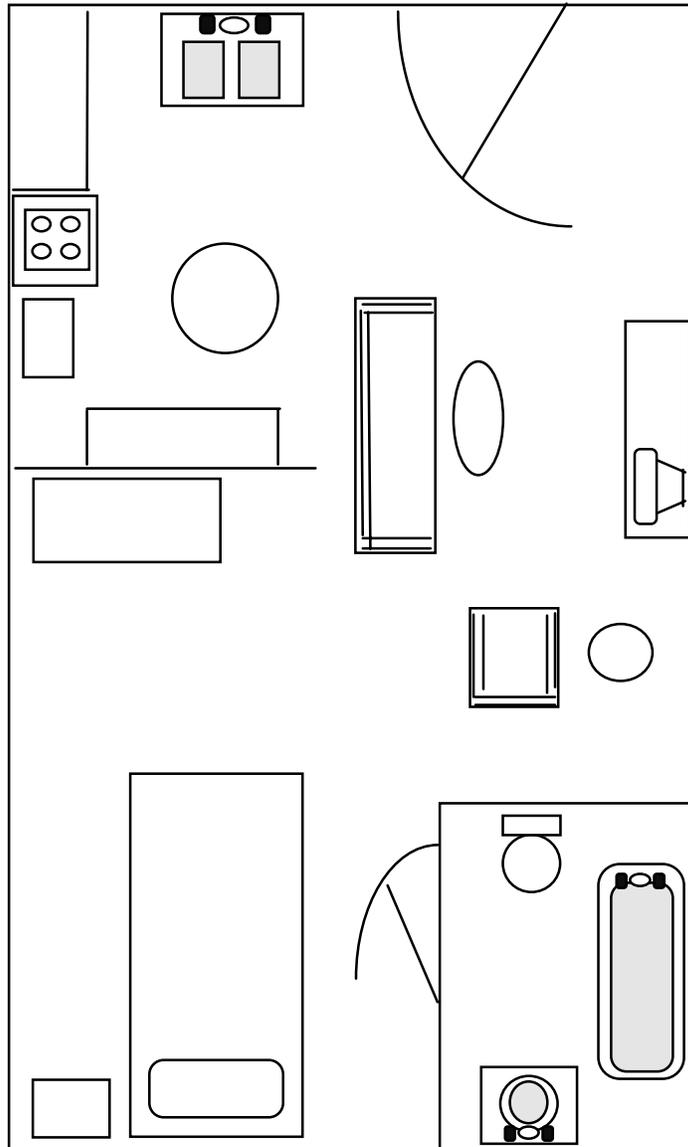


D: Shared Room/Shared Bath

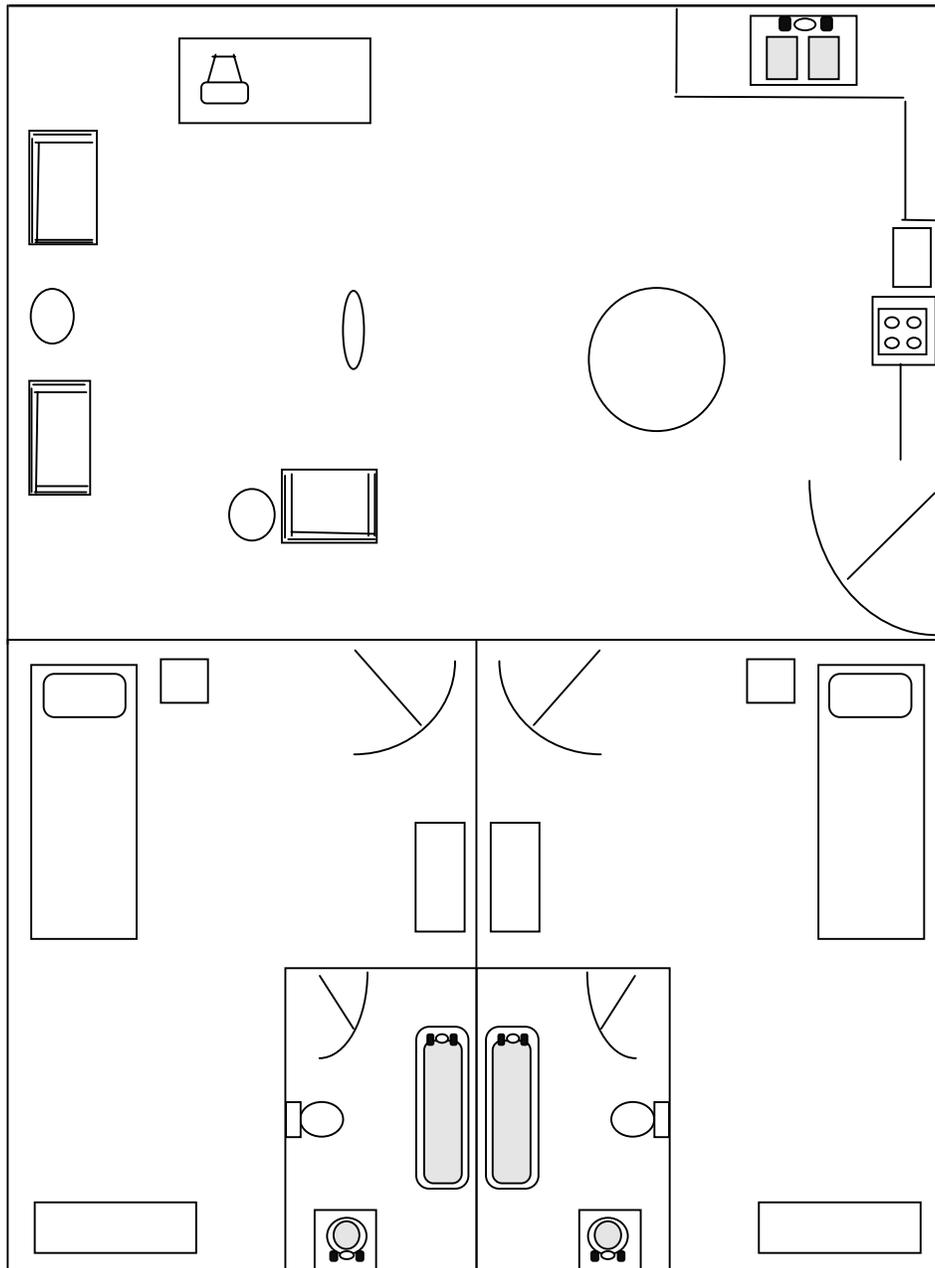


Sample Apartment Floor Plans

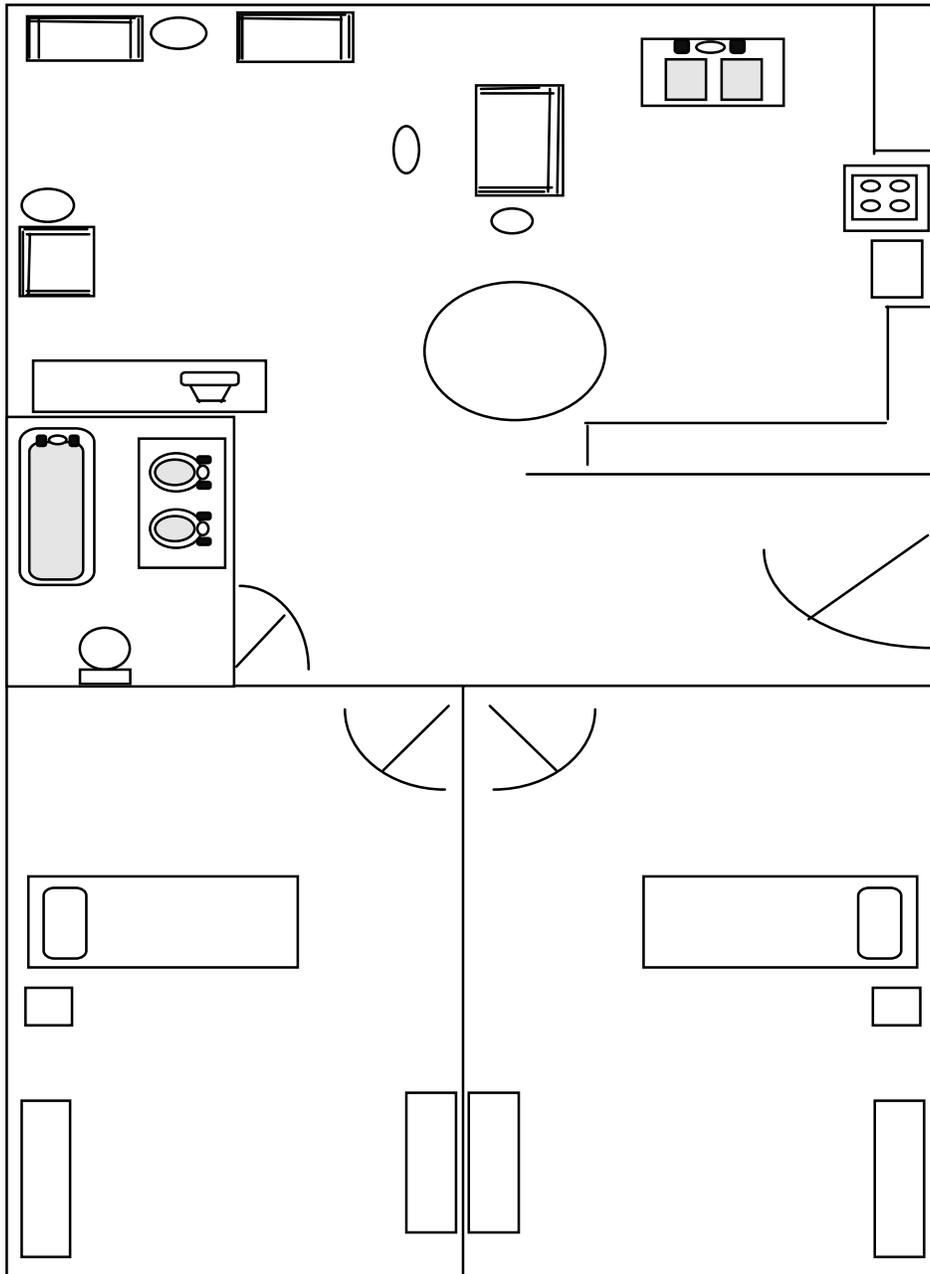
E: Private Apartment/Private Bath



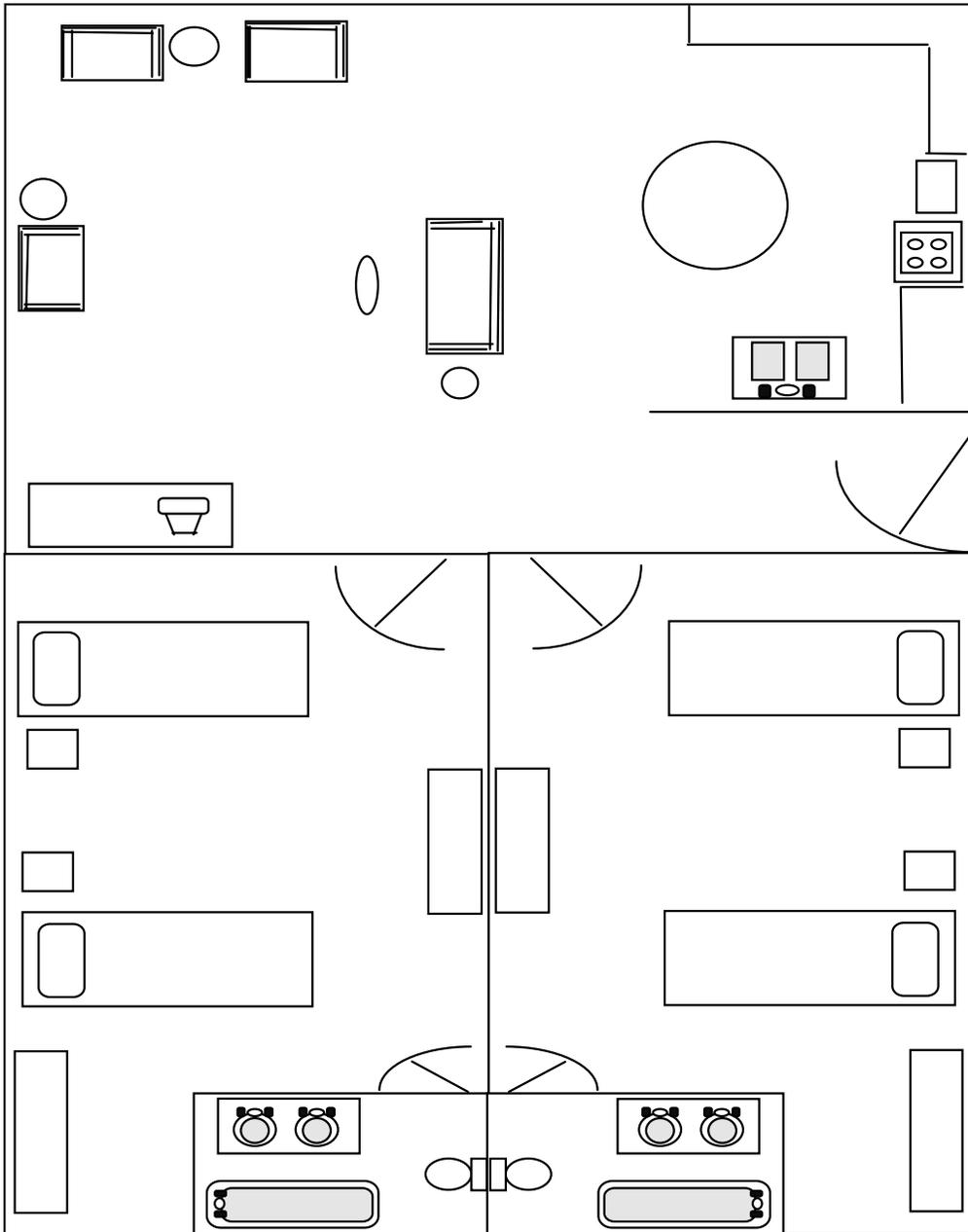
F: Private Room/Private Bath/Shared Apartment



G: Private Room/Shared Bath/Shared Apartment



H: Shared Apartment/Shared Room/Shared Bath



Appendix D:

DISCOMFORT CHECKLIST

Discomfort Checklist

Activities	I would be uncomfortable _____ in the presence of a roommate.	I would be uncomfortable if a roommate were _____ in my presence.
Reading		
Listening to music or watching television		
Having an alcoholic drink		
Getting up in the night		
Smoking		
Staying up late		
Decorating the room with personal items		
Talking on the telephone		
Entertaining other residents		
Talking with visitors		
Having overnight guests		
Getting dressed or undressed		
Having a nap in the day		
Showing emotion (cry, get angry)		
Discussing health concerns with a doctor		
Discussing business or money matters		
Praying		
Having a short illness		
Using a bed pan		
Having a bed bath		
Other (fill in)		
Other (fill in)		
Other (fill in)		