

# **How the State of Minnesota can most effectively assist older adults with selecting and purchasing housing with services, assisted living, and in-home services**

*Literature Review*

**J U N E 2 0 0 8**

# Literature Review

*A study for the Minnesota Department of Human Services of housing with services, assisted living, and in-home services*

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# Background

In January 2008, the Minnesota Department of Human Services' Continuing Care Administration (DHS) contracted with Wilder Research to conduct a study and report on housing with services, assisted living, and in-home provider services. This study was commissioned by the 2007 Minnesota Legislature (see Appendix).

The purpose of this report and the overall study is to increase understanding of how the State of Minnesota can most effectively assist persons age 65 and older in selecting long-term care services that meet their needs, reflect their preferences, and enable them to maintain financial self-sufficiency as long as possible. As described in the research plan, there are six phases included in this study:

- 1) A detailed research plan
- 2) A literature review
- 3) Provider and Long-term Care Consultant (LTCC) web-based surveys and key informant interviews
- 4) Secondary data analysis
- 5) Consumer and friend/relative survey
- 6) Final report

This report provides the findings from the literature review (phase 2). The following general research questions were developed by the study team and were used as a guide to the literature review as well as the other components of this study:

- 1) What factors influence the Long-Term Care (LTC) choices and decision-making process of consumers and those who make decisions on their behalf? Which of these factors can the State influence to effectively assist persons age 65 and older in Minnesota in selecting services that meet their needs and reflect their preferences?
- 2) What factors enable LTC consumers in Minnesota to maintain financial self-sufficiency as long as possible? What factors contribute to increasing or decreasing the cost-efficiency of State-paid LTC services? What service substitution options would prolong financial self-sufficiency? Which of these factors can the State influence to effectively assist persons age 65 and older in Minnesota to maintain financial self-sufficiency as long as possible and to ensure the State is using its limited resources in the most cost-efficient manner possible?

# Methods

Wilder Research utilized web-based search indices, including those available through the University of Minnesota's library system, to identify articles relevant to this study. Only articles that address one of the research questions listed above were included. Most of the items included in this literature review are published in peer-reviewed journals, although unpublished papers, presentations, and other items that are relevant but were not necessarily screened by the peer-review process were also included. This literature review is national in scope. Many items that have information specific to Minnesota were incorporated.

Keywords used in searching the online EBSCO and Academic Search Premier databases include: long-term care, Minnesota, the depletion of personal financial resources and assets, Medicaid, long-term care decision-making, long-term care planning, home and community based care, and long-term care policy.

Each article was read by one or more Wilder Research staff, and was summarized and recorded using RefWorks, a web-based citation manager. The articles were grouped by topic area and used to prepare topical memos summarizing the findings within each sub-question in the research plan. Finally, these memos were synthesized and examined for any possible ideas for how to improve this study's methodology. The following section of this report describes the results of this process. All articles found relevant to the above research questions are cited.

# Findings

Research indicates that older adults strongly prefer home and community based services to institutional care, and believe the care they may receive through these services is superior to what they would get with institutional care (Wiener et al. 2004; Koloski and Montgomery 1995; Woolf et al. 2005; Nakashima et al. 2004; Donnelly and Taylor 2006). “Given a choice between nursing home care and no formal services, many older people will choose no formal services. But when the choice is expanded to include home care, many people will choose home care” (Wiener et al. 2004, p. 13). Steven Slon, editor of *AARP The Magazine*, asserts that “[m]ore and more people are choosing to age in place or live closer to the community they have always been in,” a fact which is changing some of the dynamics of long-term care decision-making (Kokman 2008, p. 10). Alternatives to institutional care for older adults are increasingly being emphasized by the federal government and many states as a more cost-effective way to provide long-term care services to older adults (Wiener et al. 2004). The process older adults use to select long-term care services and the mechanisms they use to pay for these services has been documented with qualitative and quantitative studies. The following sections of this report provide a summary of this research.

## *Factors affecting long-term care decision-making*

**Long-term care decision-making is a complex and often highly emotional and individualized process.** Each consumer and his or her network of informal caregivers approach the decision-making process somewhat differently, and a combination of factors interact to determine an appropriate arrangement for a particular individual. Jerald Winakur (2005, p. 1065), a long-term care specialist, illustrates the difficulty of making generalizations: “I do not have a pat solution for my father or yours – neither as a son, a man past middle age with grown children of his own; nor as a doctor, a specialist in geriatrics, and a credentialed long-term care medical director.”

“The health care system as a whole faces its own difficulties in implementing informed decision-making because it is not well designed for this task... The system is not equipped to inform patients in a manner that is timely, easily understood, and jargon-free, nor does it encourage people to consider consequences, to ask questions, to clarify values, and to express preferences” (Woolf et al. 2005, p. 295).

**There are many factors that impact the decision making process.** “Making decisions in the search for the best possible care is often a complex and emotionally difficult experience because there are many factors affecting the decision process” (Nakashima et al. 2004, p. 80). These factors include individual values; access to formal care and

adequacy of provider skills; availability and willingness of informal care providers; individual financial resources; age; physical decline, especially limitations in Activities of Daily Living (ADLs) and falls/fractures; cognitive decline, especially dementia and inability to manage medications; the consumers' confidence in their ability to care for themselves and their fear of returning to their own home (alone); incontinence; health-related needs; sleep problems; and nutrition (Alkema et al. 2006; Nakashima et al. 2004; Donnelly and Taylor 2006; Wiener et al. 2004).

Overall, the long-term care decision-making process is based on a belief system that is influenced by everything from societal pressures to personal finances. "Older adults frequently based their decisions on a convergence of beliefs – the prognosis, health status, previous experiences (either personal or those of people they knew), and perceived outcomes" (Roberto et al. 2001, p. 86).

**Availability of services impacts choices available to seniors.** The long-term care industry has several broad problems related to the availability and quality of needed services, which can impact the range of decisions available to consumers. Front-line long-term care workers are difficult to recruit and retain due to the low pay of many of these jobs. Turnover among these professions is very high, and the low status of these types of jobs can result in low worker morale (Wiener et al. 2004). In addition, developing standards for and measuring the quality of home and community based services is difficult given the wide variety of specific services that fall under this umbrella (Wiener et al. 2004). Quality assurance for home and community based long-term care services is also increasingly important on a policy level, due to the growing consumer demand for these services as well as increased public expenditures. However, at this point, most states rely mainly on informal mechanisms to ensure quality in home and community based services (Wiener et al. 2004).

**Family provision of informal supports is a key factor.** Besides the older individuals' circumstances and preferences, "[f]amilies were a critical factor in keeping older relatives out of institutional care" (Donnelly and Taylor 2006, p. 817), primarily based on their ability (or inability) to informally provide the needed care. According to Kosloski and Montgomery, "Informal care giving among family members is the primary instrument of long-term care in America... Approximately 80 percent of disabled elders reside in the community" (1995, p. 67). "Substituting informal care with paid long-term care would almost triple long-term care expenditures" (Wiener et al. 2004, p. 23), so maintaining the option of informal care is important to the cost-saving goals of states. Families also influence long-term care decisions more directly by making the decision for the older adult or by negotiating the long-term care arrangements with their loved one and/or professionals (Nakashima et al. 2004).

**Other factors also influence choice of institutional vs. community care.** Forbes and Hoffart (1998) illustrated a model of decision-making that consumers use to select home and community based services or institutional care. These researchers interviewed 27 older adults who had recently made a decision to opt for one of these two types of services in response to increasing care needs. The first factor that impacted the choice was whether or not the consumer required 24-hour supervision, which was often associated with their degree of cognitive impairment. Second, consumers had to assess the level of formal and informal support available to them to help them stay in the community. Third, consumers had to determine if these services were affordable to them. Only in the cases when 24-hour supervision was necessary, when formal and informal support in the community was lacking, and/or when these supports were not affordable was institutional care selected over community based care.

**The implications of income and assets on long-term care decisions are unclear.**

Existing research finds mixed effects of income on utilization of home and community based long-term care services. Higher income people are more likely to be able to afford these services, but on the other hand, Medicaid and other public programs for low-income older adults may increase their access to these services. In their review of the home and community based services literature, Wiener et al. (2004) found that one-third of home and community based service users were in the lowest income quartile whereas only 14 percent of users were in the top income quartile.

**Decision-making approaches varied in terms of the consumer's role, degree of control, and satisfaction.** Despite high levels of individuation, researchers have been able to distinguish some patterns in how older adults approach the long-term care decision-making process and who is involved in that process. In their study of transition to nursing facilities using qualitative interviews (N=52) with consumers and proxies, Nakashima et al. (2004) identified three major approaches to long-term care decision-making. First, just under one-fifth (19%) of their sample of consumers used the "autonomous" approach whereby they relied on relatives and professionals for information and emotional support, but ultimately made the care decision independently. Another one-fifth (17%) of their study participants used the "collaborative" approach, whereby they often discussed all of the care options with professionals and/or family members in order to jointly come to the final decision. Finally, a majority (64%) of the consumers in this study used the "delegated" approach to long-term care decision-making. About half of the respondents who fit this type of decision-making approach experienced complete delegation of their decision to an adult child or other party due to their own health crisis or cognitive impairment that rendered them incapable of making any meaningful contribution to the decision. In these instances, those who made decisions on the consumers' behalf typically relied on their direct or indirect knowledge of the consumers' (pre-impairment or pre-crisis) wishes when making care arrangements.

The other half of consumers who fit the “delegated” decision-making approach in Nakashima et al.’s (2004) study were passive in the decision, meaning that they felt their needs and preferences were disregarded by their relatives and/or their doctors and other professionals in the ultimate selection of services.

Nakashima et al. (2004) also identified several factors that were critical in their respondents’ satisfaction with the decision-making process, including: whether they were given a chance to exercise their preferences, what information was available to aid in the decision, their ability to communicate and negotiate with professionals regarding their situation and needs, and the opportunities for clear and straightforward communication between their informal caregivers and professionals.

**Long-term care consumers can improve their ability to manage their own care.** One study found improved relationships with caregivers, improved self-care strategies, higher measures of quality of life, and improved self-performance among elders who participated in interventions designed to increase their ability to manage their own care. Improvements were shown to persist for at least 12 months following the interventions (Cox et al. 2007).

A national study found that one-third of assisted living residents had cognitive impairment, which creates problems in gathering information on the decision-making processes used by these consumers. These challenges are related to factors such as poorly developed satisfaction measures and lack of best practices information regarding collecting this type of information from seniors with cognitive impairments (Wiener et al. 2004).

The following sections of this report address some of the factors affecting long-term care decision-making process that are critical to understanding how to help older adults and those who make decisions on their behalf to select the long-term care services that best meet their needs and preferences and help them to maintain financial self-sufficiency as long as possible.

### **Who makes long-term care decisions?**

“There are a number of individuals involved in the process of health care decision-making including the older adults, family members, and health care professionals. However, these players are not necessarily always in agreement” (Nakashima et al. 2004, p. 82). It is often a difference in basic values that causes individuals involved in the long-term care decision-making process to disagree on the level and type of services needed. Specifically, professionals and relatives tend to value the safety of the consumer above all else, and also are concerned about the quality of care the person receives. On the other hand, the consumer often places more value on being in a familiar environment, maintaining their privacy and dignity, holding on to their self-identity, and their

autonomy (Nakashima et al. 2004). Similarly, research has found that many older adults would refuse life-saving invasive care like tube feeding, CPR, and kidney dialysis, whereas their family members would be more likely to opt for this type of treatment to prolong their loved one's life (Forbes and Hoffart 1998; Roberto et al. 2001; Woolf et al. 2005). "Elders had higher priorities than that of health; instead they focused on their living environment, self-identity, and relationships" (Forbes and Hoffart 1998). These differences in priorities can confuse the various perspectives and make it difficult for stakeholders in the decision-making process to fully understand each other and negotiate to reach the best option for the older adult consumer.

**Who an individual involves in his or her long-term care decisions depends greatly on his or her personal health and general wellness** according to Nakashima et al. (2004). If a person is relatively healthy and independent, he or she may make the decisions alone or by simply consulting their closest family members or respected professionals. If an older adult is neither healthy nor independent, there is a higher chance that professionals and others will be more involved in the decision-making process.

**Autonomy is supported through the "judicial approach," consumer direction, and informed decision-making.** Roberto et al. (2001) describe the "judicial approach" to decision-making, which they assert is the most commonly accepted model for health care decision-making. The judicial approach places primary emphasis on the autonomy of the individual, even if they are incompetent to make decisions. In this model, the process used to select services/treatment/care should be based first on the individual's expressed or inferred preferences (or prior choices, in the case of incompetent individuals), and second on their autonomy to control the future through advance directives (even if they are deemed incompetent). Similarly, Wiener et al. (2004) found in their review of the literature that "[a] significant minority of older people are interested in consumer-directed care" (p. 20), which is another option to preserve the autonomy of the consumer by allowing them to hire, train, supervise, and fire their service providers. In their discussion of more general health care decision-making models, Woolf et al. (2005) delineate several components of informed consumer decision-making, including consumer understanding of the risks associated with their health conditions, consumer understanding of the service/treatment options available to them, weighing of personal values, and their preferred level of participation in the decision.

**There are substitute decision-making models that are alternatives to and often in conflict with the values and processes of the judicial approach and consumer-directed care models,** including one model that emphasizes the current welfare of the individual, regardless of their past (real or hypothetical) health care decisions or preferences (Roberto et al. 2001).

In many cases, consumers neglect to specifically discuss their long-term care preferences with family, so when they become incapacitated and a long-term care decision is needed, family members must rely on their *implicit* understanding of their loved one's wishes (as described above in Nakashima et al.'s "delegated-complete" decision-making pattern). However, research has shown that proxy decision makers often make different choices than what the consumer would have made in the same situation (Roberto et al. 2001). Further, in their qualitative study of doctors, social workers, and other professionals in Northern Ireland who help consumers and their families to make long-term care decisions, Donnelly and Taylor (2006) found that these *decisions are very frequently made in a crisis situation, which significantly limits the ability of family members to be meaningfully involved in the selection of services.*

**Family members play various roles in the decision-making process.** They are often the ones who consult professionals to obtain information about care needs, available options, and other considerations (Nakashima et al. 2004). And, family members of older adults who are too ill to participate in any kind of discussion or decision-making process are often guided through the process by the physician or other professional, who makes recommendations about the appropriate level and type of care (Nakashima et al. 2004). Finally, consumers also take into consideration the quality of their relationships with relatives, and the pressures that informal care might place on these relationships, in determining who should be involved in the decisions and in ultimately selecting services (Nakashima et al. 2004).

### **Types and sources of information used in decision-making**

"Among the great ironies of the modern health care system is how poorly it delivers knowledge at a time when society enjoys unprecedented access to information" (Woolf et al. 2005, p. 293). In contrast to previous generations where health care consumers were expected to follow their physician's advice without asking questions, today's health care system operates differently, requiring consumers to be aware of the options available to them and the financial and health implications of those service options. This *increased importance of informed consumer decision-making* stems from several factors including *broader access to information, expanding service options, rising costs, increased prevalence of chronic illness, and greater accommodation of personal values* (Woolf et al. 2005).

Due to the complex nature of the long-term care decision-making process, the *information provided* to older adults, family members, health care and social service professionals, and long-term care consultants *is crucial to making effective and appropriate long-term care decisions* (Nakashima et al. 2004; Woolf et al. 2005). Consumers and those who make decisions on their behalf face not only an emotionally

and financially daunting list of options to choose from, but also an *unclear system of information retrieval* (Donnelly and Taylor 2006). There is currently information available on various websites, through local public and private health and human services offices, institutional outreach, and through public outreach and service announcements by nonprofit and advocacy organizations such as AARP. Yet, “[b]ecause of the enormous variability that exists among residential care providers, the public, including Medicaid beneficiaries, have little useful guidance in deciding whether this type of care can meet their needs” (Weiner et al. 2004, p. 19-20). In many cases, it is the *sheer volume of information, the lack of standardization of the information, and the inability of consumers to distinguish high-quality information from lower quality information or biased marketing materials that causes problems* (Woolf et al. 2005).

In general, information should be presented clearly and in a manner that older adults can understand. “The multidisciplinary health care team faces the challenge of improving interdisciplinary communication systems so they can provide crucial information to consumers and establish a more desirable care setting for older adults...The information should be presented in a way that is consumer-friendly” (Nakashima et al. 2004, p. 97-98). In their study of health care decision-making, Woolf et al. (2005) describe “decision aids” which are tools (available in various formats) used by health care consumers to *obtain information about their condition and various service/treatment options, exercises to clarify values, and coaching through the steps of the decision-making process.*

Access to information that guides decision-making is crucial to professionals who participate in the decision-making process with consumers and families (Donnelly and Taylor 2006). The professionals who participated in this study felt that their professional advice and expertise was welcomed by consumers and families, as it helped them to make more informed and appropriate decisions.

### **Additional information and formats that would be helpful to consumers**

**Long-term care planning and decision-making includes a variety of topics.** For example, information on non-entitlement services that are offered by the state or other public programs should be disseminated. A study of long-term care commissioned by the Oregon Department of Human Services (2006) found that these non-entitlement services such as *planning, consulting, or information gathering, are valuable to the consumer and often lead to informed choices* which can save both the state and consumers money in the long-run.

Another example of a topic on which more information would be useful is **assistive technology** (i.e., devices such as walkers, wheelchairs, shower and toilet rails, specialized canes, etc.). “More than 75 percent of older adults with disabilities use some kind of

assistive device, usually to help with mobility” (Weiner et al. 2004, p. 22). In their extensive review of the literature on the topic of home and community based services, Weiner et al. (2004, p. 22) found that information about various assistive technologies would encourage increased use of such technologies, “...enabling many older persons to supplement and to some degree replace human assistance, through retaining mobility and avoiding injury from falls.” These researchers found that, in 2000, \$2.7 billion in medical costs could have been saved if assistive technologies would have been implemented with the 2.4 million older adults in the U.S. who have mobility limitations, via the 250,000 falls that would have been prevented through the use of these devices.

**Accessibility and ease of use of on-line and printed resources.** “Like many resources, information regarding long-term care services and supports is more readily available via the Internet” (Oregon 2006, p. 22). This is problematic because many older adults are not comfortable accessing information online. In addition, online information is currently more difficult for those of lower socioeconomic or education status to access (Woolf et al. 2005). However, this may not be as much of a problem with the baby boom generation and other future generations, due to the higher familiarity of these cohorts with the Internet and the increasing accessibility of the Internet, regardless of socioeconomic status (through free wireless services in some communities and computer access at public libraries, etc.).

“Brochures and pamphlets that provide this [long-term care] information should be widely disseminated. Not only at traditional spots where elders gather but also in places where ‘boomers’ find themselves today, such as work places and athletic clubs and at times when they are helping an elderly family member deal with age-related needs, including doctors’ offices, hospital waiting rooms and the like. Given boomers’ familiarity with the Internet, the same sorts of information should also be made available in interactive formats on the web” (Oregon 2006, p. 19). Information regarding other important areas in older adults’ lives such as how best to save (e.g., with a 401k or other financial plans) and how to effectively shop for long-term care insurance should also be disseminated (Oregon 2006, p. 19).

However, electronic and print materials are not a panacea. “*No electronic platform is likely to replace the human being’s capacity for guidance*” (Woolf et al. 2005, p. 295). Decision-making aids or other materials or resources are most effective when they are integrated into the consumer’s medical care, at least in the case of general health care decision-making (Woolf et al. 2005). Overall, some authors assert that the *ultimate solution to the problem of inadequate information for consumers to make informed decisions requires a complete overhaul of the health care system* (Woolf et al. 2005).

## **The role of providers and professionals in long-term care planning**

Long-term care providers and other professionals such as doctors, social workers, and case managers play important roles in informing consumers' decisions. In many instances, doctors and social workers are on the front lines of long-term care decision-making and possess individualized knowledge of the consumer; therefore, consumers and their networks of caregivers often consult these professionals at some point in the process of selecting long-term care services (Nakashima et al. 2004). *Informed consumer decision-making* "involves a level of counseling [from professionals] that goes beyond the offhand advice that clinicians conventionally offer in busy practice" (Woolf et al. 2005, p. 294).

During the decision-making process, "[f]amily members and health care professionals both play a major part and exert substantial influence" (Nakashima et al. 2004, p. 83). Many older individuals find the help they need in their children, spouses, or other family members or informal caregivers. These family members and other caregivers do not always have complete and accurate information about the options available to them, so they often consult professionals (Nakashima et al. 2004). Family members look to professionals to provide the expertise with which they can make responsible decisions and make the long-term care choice that is most appropriate for their loved one. Woolf et al. (2005) argue for *formal "informed choice training" for clinicians and other health care workers* involved in consumer decision-making processes. In their review of the literature of health care decision-making, these authors reported on one study that found *significant increases in the patient-centeredness of interactions among professionals who participated in this type of training.*

In addition to health care professionals, social workers, and case managers, *a new group of professionals, decision counselors and long-term care consultants* has grown to meet the increasing consumer demand for more information. This method of providing information to consumers is beneficial because dedicated decision counselors can *spend the time* that clinicians cannot, and because these professionals can *ensure increased consistency, quality, and efficiency in the types of information provided* to consumers. On the other hand, decision counselors can also contribute to undermined trust of the physician and other professionals who are directly involved in the consumer's care (Woolf et al. 2005).

Even though most long-term care decisions are made rather quickly and in response to a health crisis, to make the most out of the older adult-provider/professional relationship, *it is necessary that time be spent together.* Donnelly and Taylor (2006) assert that time must be set aside for professionals to get involved, because effective professional consultation requires a relationship that goes beyond the minimum requirements.

*“Professionals should make an assessment of the older adult’s wants and needs...and who can and should be involved in the decision-making process – family, others, etc. – and sometimes support of other caregivers is necessary to facilitate the decision-making process”* (Nakashima et al. 2004, p. 92). Again, in cases when the older individual is too sick to participate in the decision-making process, their relatives are often guided through the process by the person’s physician (Nakashima et al. 2004).

“Professionals can and should make recommendations based on their expertise, but be prepared to facilitate discussions with clear explanations when their recommendations are met with resistance by older adults” (Nakashima et al. 2004, p. 98). In addition to allowing extra time, as part of the relationship that is required for a provider or a professional to effectively aid in the long-term care decision-making process, it is necessary that they spend time communicating about needs, wants, expectations, and healthcare maintenance. During these conversations, negotiations between families, professionals, and older adults often occur, and through these negotiations a decision is made (Nakashima et al. 2004).

Professionals and providers are bound by the ethical codes of their respective professions. When working with clients, many social workers and medical providers must abide by a principle of client self-determination, thus requiring them to support older adults’ initial control regarding how they want to work and communicate with others involved in the long-term care decision-making process (Nakashima et al. 2004). *Since professionals and providers must respect the older adult’s choices regarding long-term care options, he or she is thrust into a role as a facilitator and consultant rather than an expert or technocrat who unilaterally makes decisions.*

This ethical principle of client self-determination is especially important in long-term care planning due to the value system that Forbes and Hoffart (1998) described in their qualitative study about the beliefs and attitudes regarding long-term care decision-making of older individuals. The seven values are: independence, sense of self, security, work ethic, privacy, quality of life, and trust. All of these values have an influence in determining which care options are appropriate for an individual. These authors assert that home and community based services may be more appropriate than institutional care in many cases because it is easier to align home and community based care with the values of independence, sense of self, and quality of life. “Case managers and primary care providers need to be educated about and sensitive to individual values and community service options” (Forbes and Hoffart 1998, p. 748). The success of new initiatives and the credibility of professionals and providers depends on their ability to align their values with those of the client.

## **Advance vs. crisis long-term care planning**

“Over 40 percent of Americans mistakenly believe that long-term care is an entitlement that all Americans are eligible for at retirement” (Oregon 2006, p. 18). This indicates a high degree of reliance of many individuals on public services and a societal lack of importance placed on advance planning for eventual long-term care needs. This in turn points to a need to inform the public about long-term care and individual options for appropriate planning. The literature reviewed here indicates that many older adults in the U.S. do not begin planning for their long-term care needs until it is absolutely necessary (Oregon 2006; Forbes and Hoffart 1998; Donnelly and Taylor 2006). *This delay in long-term care planning*, however, should not necessarily be interpreted as indicative of an unwillingness to plan for long-term care needs; rather, it *should be interpreted as a lack of education on how to effectively plan for long-term care needs* (Oregon 2006; Forbes and Hoffart 1998).

Older individuals are frequently forced into long-time care as a response to some sort of crisis such as illness or a fall that puts them in the hospital. After being discharged from the hospital, these individuals may require extra care and increased levels of assistance with various activities of daily living and other daily needs. In their research with professionals, Donnelly and Taylor (2006, p. 807) found that long-term care “[d]ecisions were often prompted by a crisis, hindering professionals seeking to make a measured assessment.”

Individuals are not necessarily unwilling to consider different long-term care options, but research has shown that most older adults do prefer no services first, then community based services, and only select institutional care as a last resort (Wiener et al. 2004). This indicates that, when educated about the possibilities of alternative long-term care options to traditional nursing home care, many people are much more receptive to thinking about long-term care. The growth of home and community based care options has ameliorated the stigma many older individuals associate with traditional nursing facilities. For many older adults, nursing homes represent the ultimate loss of control and “[t]heir beliefs surrounding nursing homes and maintaining their independence were a strong impetus to remain in the community” (Forbes and Hoffart 1998, p. 741).

Education and information are key to advance planning. “Developing a long-term care advance plan like the completion of advance directives requires education that prepares the older adults and their caregivers to communicate their preferences in the event of a health care crisis” (Nakashumi et al. 2004). This educational element appears to be a place where many states fall short of achieving meaningful advance long-term care planning initiatives (Weiner et al. 2004).

Experts agree that increased planning is beneficial for responsible long-term care planning. To fully take advantage of other resources such as financial planners, doctors, social workers, geriatricians, etc., time is essential. However, enlisting the services of long-term care professionals and others whose input would be valuable is potentially complicated because effective planning requires relationship building (Donnelly and Taylor 2006).

Pande et al. (2007) assert that “[l]ong-term care will increasingly shift from institutions to home and community based services.” Using statewide data from a Medicaid home care waiver program in South Carolina, researchers compared 1995 data (N=3,748) to 2005 data (N=9,157) and found that despite increases in frailty measures, a higher proportion of individuals chose to age in place. The authors assert that this decrease in institutionalization is due to state policies intended to decrease Medicaid long-term care costs through home care programs (Pande et al. 2007).

In a reanalysis of data gathered in a Seattle respite study, researchers from the Universities of Kansas and Nebraska examined survey results from “541 dyads of an elder who had at least two limitations in Activities of Daily Living (ADLs) and a family member serving as a caregiver” (Kosloski and Montgomery 1995, p. 69) and found that the “use of respite services can delay nursing home placement among seniors” (p. 73). They also found that “[e]ach \$100 increase in respite care use delays nursing home placement by one week” (p.72). These researchers also determined variables associated with high levels of respite care use and found that the variables most highly associated with nursing facility use include the elder’s level of independence, caregiver’s health, the quality of the relationship of the caregiver, and the caregiver’s expressed level of affection for the elder.

### **Demographic differences in long-term care use**

As with many life situations, long-term care decision-making is a highly personal and at times emotional process that differs by demographic characteristics including location, race/ethnicity, gender, family situation, and type of services needed. Seniors are frequently choosing to remain living in the communities in which they have spent their lives (Kokmen 2008), which means an *increasing need for rural access to long-term care services*. Older adults living in rural settings do not necessarily face personal issues that are different than their urban peers, but face more obstacles accessing long-term care services or facilities (Oregon 2006, p. 22). The State of Oregon recently performed an internal focus group study to determine how its Department of Human Services should respond to their state’s future long-term care challenges. One of the primary recommendations that came out of this study is to increase long-term care services access in rural communities to address the increasing desire to age in place (Oregon 2006, p. 22).

In a 2006 article, Li used “[d]ata from the 1999 National Long Term Care Survey [to examine] the prevalence of access barriers to seven commonly used HCBS [home and community based services], in rural communities and identified the risk factors that were related to these access barriers” (Li 2006, p. 109). This study’s sample (N=283) was made up of seniors residing in areas outside of Metropolitan Statistical Areas, (i.e., areas with fewer than 50,000 people). They found that “[c]ompared with their urban counterparts, rural older adults are less educated, have fewer financial resources, and experience more health problems” (p. 109). In looking at specific types of home and community based services, this study found that *13 percent of caregivers reported barriers to the use of assistive devices, 84 percent reported barriers to the use of respite care, 75 percent to the use of transportation services, and 58 percent to the use of homemaker services*. Li asserts that these barriers are due to a combination of individual and structural problems such as individual education level and service availability in rural areas, which apparently can be eased with the technical assistance of Medicaid (2006, p. 116). This study concludes that *those who are enrolled in Medicaid or other social assistance programs face fewer barriers to various in-home and community based services. Therefore, “[o]utreach programs, including educational information about entitlement programs and locally available services, can be used improve clients’ awareness of HCBS [home and community based services]”* (p. 117).

Another important factor in long-term care decision-making is one’s economic status. “[S]tudies have been mixed on the impact of income on increasing home care usage” (Weiner et al. 2004, p. 8). Therefore, social and economic demographics combined are important indicators of long-term care needs and propensity for use. This might indicate that those living in impoverished areas (i.e., rural areas or inner cities) approach long-term care decision-making in similar ways, not due to the place or location, but to the fact that they face similar economic constraints on their decisions. Those with less than a high school education also use long-term care services at a greater frequency than those who have attained higher levels of education (Alecxih 2001).

Race and ethnicity also play roles in long-term care decision-making. African Americans are more likely than whites to use long-term care (Alecxih 2001). Yet, minorities are more likely to receive care from friends and family and are less likely to use nursing-facility care (Alecxih 2001). On the other hand, “[w]hites are more likely to be in assisted living than home and community based care” (Alecxih, 2001, p. 8).

Gender is also another factor in long-term care decision-making. Females are more likely to use long-term care (Alecxih 2001), but within that statistic, “[w]omen with chronic diseases are more likely than men to be in nursing care than assisted living, and as likely to be in nursing care or assist living as in home and community based care” (Weiner et al. 2004, p. 8). Men are more likely to receive care from family and friends only and are

less likely to use nursing facility care, although this could be due to the fact that, on average, women live longer than men and therefore are more often left widowed without a spouse to serve as an informal caregiver (Alexih 2001).

Family situations also tend to influence decision-making processes. Widowed seniors or individuals who have never married have a greater probability of using long-term care services while married individuals are less likely to use any services (Alexih 2001). “Much of the responsibility for married older people with disabilities falls on spouses, who are generally old themselves and perhaps coping with their own health issues. Adult children, usually daughters, often help their frail parents” (Oregon 2006, p. 4), which means that older adults with children are more likely to rely on an informal system of care rather than depending on formal long-term care. Due to changing demographics, formal long-term care could be in higher demand in the near future. Families have provided 91 percent of care needed by older adults in the past, yet one-third of baby boomers will not have children and, therefore, will not have a traditional informal care network available to them (Rehkamp and Rice 2006).

When examining resources related to the use of assistive technologies for seniors and others with dementia and other cognitive disabilities, there is much agreement that the use of both “high-tech” aids such as picture phones, object locators, specialized clocks, and gas monitors for stoves, as well as mobility devices such as shower rails, specialized canes and walkers, and bed rails can give a senior with a cognitive impairment an increased sense of independence (Cahill et al. 2007; Molin et al. 2007; Agree and Freedman 2003; Duff and Dolphin 2007). The literature also makes it apparent that “[c]ognitive assistive technologies that can help both the individual and his or her caregiver will no doubt play a key role in future dementia care” (Cahill et al. 2007, p. 133).

In a study conducted in Ireland in the early part of this decade, researchers examined a sample (N=20) of seniors with dementia (Cahill et al. 2007; Duff and Dolphin 2007). Participants in this study were provided several different assistive devices and asked to test their usefulness and report their benefits. This experiment led the researchers to the conclusion that *assistive technology can help seniors with dementia achieve higher levels of independence. “Two outcomes were common across all devices, i.e., the outcome to support independence and the outcome to reduce general emotional burden from worry for the family”* (Duff and Dolphin 2007, p. 88).

Caregivers reported positive benefits from using these devices at a personal and family level, in essence making it easier for the family or other informal caregivers to provide in-home care (Duff and Dolphin 2007, p. 87). As noted by Molin et al. (2007) *one shortcoming in the field of assistive technologies is the information gap between those involved in the different areas of assistive technology, i.e., the caring professions,*

*housing operation and maintenance, and information technology. This gap in information and shared knowledge is important because it again illustrates a larger lack of effective societal communication around issues of long-term care and caretaking strategies. More information on using assistive technology to increase ADL ability is available (Agree and Freedman 2003; Molin et al. 2007; Duff and Dolphin 2007; Cahill et al. 2007; Nichols et al. 2008).*

### **Information currently available through the State of Minnesota**

Most of the approaches that will be used for this study to assess the information currently available through the State of Minnesota will be derived from the original data collection activities included in other phases of this study. However, limited secondary information is available on this topic. For example, the literature documents an important new online system to support long-term care decision-making that has been recently implemented in Minnesota.

Kane et al. (2007) describe how the Long-Term Care Choices tool (which has become part of the MinnesotaHelp Network) provides structure, information, and expert opinion to long-term care consumers. This is a two-stage information matching process. In the first stage, the system determines what types of long-term care are best suited to the individual based on their needs. In the second stage the system finds the potential providers best able to meet the individual's needs and preferences.

This process fails to address several problems. First, in previous research, it was found that expert opinion on the best type of care is biased by the expert's area of interest (Kane et al. 2006). While not surprising, this has potentially serious implications for those seeking decision support from care giving professionals and made creating an automated system more difficult. Second, decision-making typically involves more than just the elder and “[s]uch a decision is not easy, nor is there necessarily unanimity...Family members may not agree among themselves and may have different priorities from the older client” (p. 244). The authors point out that “some sort of decision support facilitator is often needed to help families sort out their priorities” (p. 247).

These researchers also report that “the system [the MinnesotaHelp Network] has been well accepted, and most users find it easy to use” (p. 244). Further development is recommended in a two-track approach to allow more options for professionals “who would be familiar with the tool from repeated use” and for consumers “who...need a more detailed tool with many prompts and explanations” (p. 247).

“MinnesotaHelp.info is a search tool developed for all Department of Human Services agencies and programs” that allows users to enter a zip code to search for a wide range of service providers (Mollica 2006, p. 80). Online searches of long-term care providers

yields various providers and includes each provider's contact information, descriptions of services offered, enrollment or subscription services, and basic costs associated with the service (Mollica 2006, p. 80).

The State of Minnesota also provides information to consumers through the website of the Department of Human Services. On the website of the Department of Human Services, consumers can find information about various state programs, partnerships, and coalitions that serve to enhance long-term care. One such program that provides information to consumers via the Internet is the Minnesota Long-Term Care Partnership, which outlines the eligibility requirements and gives strategies on how to become eligible, provides information on determining the appropriate level of services to meet an individual's needs, how to research an insurer, and tax, relocation, and coverage information. Also included on this website is a link to the Federal Department of Health and Human Services' National Clearinghouse of Long-Term Care Information where consumers can request long-term care information to be sent to them through regular mail.

In addition to the above mentioned resources, the website of the Minnesota Department of Health offers resources on provider licensure information, grievance procedures, various provider inspection and survey findings, and nursing home report cards for nursing facilities across the state. The Office of Health and Facility Complaints maintains an online database that "[i]ncludes information on all resolved complaints and a description of the issue, investigative findings, and conclusions" (Mollica 2006, p. 80). This site also provides a mechanism for the online lodging of complaints. However, one apparent shortcoming is the fact that the Internet is not accessible to many seniors. Besides Kane et al. (2007) and Mollica (2006), no literature was found specifically on seniors' access to information provided by the State of Minnesota. With the notable exception of the phone-based Senior LinkAge® line, obtaining long-term care information appears to be difficult without Internet access.

### ***Long-term care consumers, financial independence, and the State***

This section focuses on financial planning and financial impact related to long-term care decision-making. Areas considered:

- Incentives affecting long-term care decision-making;
- Incentives reflected in long-term care insurance;
- Gaps in information and knowledge that prevent financial self-sufficiency;

- Financial implications of selecting a level of service;
- Demographic differences in long-term care financial planning;
- Consumer awareness of housing options; and
- Conditions that lead to depletion of personal assets.

One of the primary reasons for conducting research on home and community based long-term care services is to examine the financial impact of long-term care on individuals and on the State. Medicaid, which is the single largest payer of long-term care services for older adults, is increasingly devoting resources to home and community based care rather than institutional care. In 2002, about one-fifth of all Medicaid long-term care funding for older people, totaling \$7.3 billion, was used for home and community based services and assisted living (Wiener et al. 2004). Medicare contributes slightly more than half of what Medicaid contributes to long-term care services for older adults, but a larger proportion of Medicare funds (47%, or \$11.3 billion) was used for home and community based care. In general, Medicare is intended to be used for acute or short-term care needs, whereas waiver programs that have been a part of Medicaid since 1981 allow states to provide a wider range of longer-term services to recipients. Other government programs involved in the funding of long-term care services include Aging Networks that were established through the Older Americans Act, and the Social Services Block Grant. Many states also fund their own home and community based services outside of any federal funds or programs (Wiener et al. 2004).

In Minnesota, seniors who are 65 and older who are at risk for nursing home placement and have low levels of income and assets can qualify for Alternative Care. The Alternative Care program helps defray the costs of such assistive services as adult day care, homemaker services, home health aides, case management, assisted living, transportation services, chores services, and other care related services. The application process includes a long-term care assessment with a social worker and/or nurse from the county. If eligible, the long-term care consultant works with the senior on the development and implementation of a community support plan to meet their long term care needs. At this time no literature that specifically addresses the Alternative Care program in Minnesota has been identified.

A primary assumption (which is not necessarily supported by research in all cases) is that home and community based services are less expensive than nursing home care. Specifically, it is difficult to determine the impact of home and community based services on the public cost of nursing home expenditures. When home and community based services are offered to older adults who would otherwise have gone without any services, these individuals end up receiving services that they otherwise would not have (i.e., the

increase in number of people receiving services tends to offset the reduction in nursing home expenditures) (Wiener et al. 2004). Further, researchers assert that these findings may no longer be relevant given that much of this research was conducted with earlier generations of people with different needs, preferences, and demographic compositions. Further, the range of services and costs associated with these services has changed significantly over time (Wiener et al. 2004). No literature was found that specifically compares various home and community based services against each other (i.e., most of the literature in this vein compares nursing home care to home and community based care).

### **Incentives and disincentives affecting long-term care decision-making**

*Financial self-sufficiency is not regarded as a stand-alone decision, rather a factor in making long-term care plans and a consequence of health status, prior income and savings, and the availability of informal service providers.* Stum (1998) used interviews and qualitative analysis to describe the experiences of families and elders prior to and in the process of requesting medical assistance. This study suggests consumers try very hard to maintain financial self-sufficiency. *The main motive this study identified for seeking government financial assistance appears to be maintaining a sense of financial responsibility.*

Evidence suggests elders value personal freedom, independence, and other quality of life characteristics, in some cases more than their own safety, and more than the ability to make bequests to their relatives (Kane and Kane 2001; Kane and Wilson 1993; Kane et al. 1998; Mattimore 1997).

Disincentives for self depletion of personal financial resources identified in one focus group study included losing control of one's assets, Medicaid stigma, and perceived immorality of strategies to deplete personal assets. Incentives included preservation of one's estate and protection of a spouse (Curry et al. 2001).

According to Stum (1998) and Lee et al. (2006), when wealth transfers to family members occurred prior to Medicaid eligibility, the amounts transferred were often modest – averaging less than a month's nursing home expenses in total. Stum (1998) found that these transfers were often used by family members to pay for elder care not covered by Medicaid.

Stum (1998) indicates that families and decision-makers are well aware of their depleting assets, though this work was not specifically focused on consideration of future housing options. Other research (Bassett 2004, p. 20) found that "households and individuals with a higher subjective probability of future nursing home use are more likely to have made inter-vivos transfers in the past 12 months." This effect was small – regression results indicated that overall, the probability of making an asset transfer was less than 2

percent greater for those with a positive subjective probability of entering a nursing home in the next 5 years than for those with a zero subjective probability. Nevertheless, this indicates at least minimal awareness of the overall financial situation at some stages of long-term care use for some elders.

Lee et al. (2006) looked specifically at a representative sample of elders that became eligible for Medicaid and found that family wealth transfers actually took place more often among those using community based care than among those eventually entering a nursing home. This was a secondary analysis and, therefore, was not able to measure whether elders expected to enter a nursing home or were aware of housing implications before becoming eligible for Medicaid. Couples were found to transfer greater amounts than singles, the amount of transfer was typically modest, and transfers actually occurred in only a small number of cases.

A notable, very detailed study of productivity in home and community-based care in the United Kingdom found that *productivity gains had a greater potential for cost savings and care improvement than service targeting* (Davies and Fernandez 2000). This study literally attempts to draw a map between the “inputs of standard community services” and the “effects on some of the outcomes most valued by users, caregivers, and policy-makers” by estimating the production function for community care. The impetus for this major study of long-term care was evidence in the early 1980s that “consumers who received larger amounts of services seemed not to be much better off... as a result of receiving the larger quantities [of service]” (p. xxv). Taking into account risk factors of the users of services and the necessarily incomplete coverage of services, the results of this study show, for example, how inputs such as the presence of a primary informal caregiver affect the extent to which users feel in control over their own lives. By studying the issues at this level of detail, the researchers want to show (1) where some of the greatest opportunities for improvement exist, (2) the collateral impact on other outcomes (e.g., length of stay in the community) from “unconstrained optimization” of one outcome (e.g., extent to which users feel in control over their own lives), and (3) the potential for substitution among inputs.

There are many significant differences between health care systems in the U.K. and the U.S. Nevertheless, we believe the framework of Davies and Fernandez (2000) is worth studying for applications in Minnesota. Ideas from this framework may prove useful in our secondary data analysis.

A recent AARP survey and accompanying report (AARP 2005; Kochera et al. 2005) finds that 83 percent of people over 50 want to stay in their current community for at least five years. “This is slightly less true of 50 to 64 year olds (79% compared to 88% of those 65+)

... [T]hose who want to stay where they are still represent a solid majority, indicating social engagement and attachment with their communities” (AARP 2005, p. 85).

### **Incentives reflected in long-term care insurance**

**In 2002, about 9 percent of adults 55 or older had some type of long-term care insurance.** The likelihood of having private insurance increases with both income and wealth. Only 3 percent of elders with incomes below \$20,000 and 4 percent with assets below \$20,000 had coverage, compared with 14 percent with incomes above \$50,000 and 18 percent with financial assets above \$100,000. More than half of policyholders had incomes exceeding \$50,000 or financial assets exceeding \$100,000 (O’Brien 2005).

**In 2005, about 7 million long-term care insurance policies were in force in the U.S. (AHIP 2007).** The typical purchaser was age 61. Almost half of purchasers had incomes over \$75,000 and more than three-fourths of purchasers had over \$100,000 in liquid assets (AHIP 2007).

When asked the *most important reason for buying long-term care insurance*, about 1 in 3 say “to protect assets or leave an estate.” Avoiding dependence is most important to 25 percent, guaranteed affordability is most important to 18 percent, and being able to protect living standards is most important to 14 percent (AHIP 2007, p. 33).

Interestingly, if this type of question is asked in terms of degree of importance, protecting assets and avoiding dependence are almost equally important, while protecting family resources is somewhat secondary. Avoiding Medicaid use is actually more important than leaving an estate (AHIP 2007, p. 34).

Among those *not buying long-term care insurance*, cost was by far the most important reason given (83% said very important or important). Interestingly, less than 20 percent of respondents said that Medicare/Medicaid coverage was an important or very important reason not to buy private long-term care insurance (AHIP 2007, pp. 45-46). Between 14 and 25 percent of non-buyers would, under some circumstances, be willing to pay the premium level for policies being sold to their age group (AHIP 2007, p. 9).

Those with prior health problems have difficulty purchasing private coverage – about 15 percent of applicants may be denied insurance due to health problems. And affordability may be the biggest barrier. The GAO (2000) estimates that only 10 to 20 percent of older adults can afford long-term care coverage. If this is true, we would expect the long-term care insurance market to remain near current levels regardless of Medicaid policies.

There is a small literature in finance that suggests Medicaid or other government programs may “crowd-out” private long-term care insurance (for example Brown and Finkelstein 2004; Cutler and Gruber 1996; Sloan and Norton 1997). By “crowding-out”

they mean that the existence of social support programs acts as an economic substitute for long-term care insurance, reducing demand for the insurance. These papers focus on the theoretically sufficient conditions for crowding-out, rather than empirical investigations of insurance buying decisions. Empirical studies to date show little or no “crowding out” (Shore-Sheppard 2005; Shore-Sheppard et al. 2000). Despite this, the theoretical “crowding-out effect” has been used by the insurance industry to explain why demand for insurance is less than some had expected.

In fact, there are reasons other than a theoretical “crowding-out effect” to expect long term care insurance to be problematic. One reason is that there are “multiple dimensions” of private information issues (Finkelstein and McGarry 2006). Another is that employers have been slow to get involved (Johnson and Uccello 2005). O’Brien (2005, p. 4) suggests that since “Medicaid is not a major barrier to the purchase of private long-term care insurance ... potential purchasers may reject [private policies] because they question the value of policies with thin coverage and rigorous exclusions.”

### **Gaps in information impacting financial self-sufficiency**

One of the recurring themes throughout various strains of literature is that *long-term care decisions suffer from a lack of consumer knowledge and skills, not a lack of raw information*. Still, many people in the process of making long-term care decisions cite a lack of information as a hindering factor in the decision-making process. No study we are aware of has attempted to differentiate between lack of information, information complexity, and lack of basic financial skills in the context of long-term care decisions.

Arthur Levitt, former chair of the Securities Exchange Commission, is quoted in Vitt et al. (2000): “Years ago the problem was lack of information. Today there is a glut of information. But the irony is: Do people have the foundation in the financial basics that will allow them to use that information?” Levitt was talking about general financial planning. Cutler (1997), after surveying middle-aged people, especially baby-boomers, for levels of financial literacy, found that *basic literacy was lowest in areas of health care and long-term care*.

*Basic information about the cost of long-term care services may also be lacking*. A longitudinal study of long-term care insurance buyers and non-buyers concludes that “while only 14 percent of those who purchase long-term care insurance underestimate the cost of nursing home care, 70 percent of non-buyers” do (AHIP 2007, p. 9).

In a 2008 survey (N=121) of chronic maintenance, long-stay residents in eight southern California nursing facilities receiving Medi-Cal (California’s Medicaid program), Nishita (2008) finds that, after counseling about housing and services available, the percentage of nursing home residents (or their proxies) who believe the elder can return to the

community rises from 23 percent to 33 percent. *As returning to the community may prolong financial self-sufficiency, this result demonstrates the potential for improvement through knowledge and help applying that knowledge.* Interestingly, in a study of physician-patient information sharing, improving information was not found to increase the demand for health care in general (Kenkel 1990). Even if many people tend to underestimate their health care needs or the effectiveness of health care intervention, it is not known if the same is true for long-term care.

### **Financial implications of selecting level of service**

Although many authors suggest that the decision to enter an institution is one of the most difficult in the entire process of long-term care, up to 1 in 3 elders admitted to nursing homes either return or could return to a home or community-based setting at some point (Newcomer et al. 2001; Spector et al. 1996; Nishita 2008). This suggests that, *in some cases, a higher level of services than is needed may persist after the period of need is over.* It is not clear from the literature which variables influence these decisions. Clearly, the high cost of unnecessary residential care would tend to decrease the chances of continued financial self-sufficiency. Due to the high costs associated with residential care, services that help long-term care consumers to examine possible routes to return to the community from nursing home care would seem to be suggested.

What is not known is the extent of unnecessarily high levels of service in home and community based care settings. Han et al. (2007) studied length of service among elders receiving home care with differing payment sources – for-profit and nonprofit agencies. These authors found there was a period prior to 1998 during which time Medicare patients with for-profit agencies had longer lengths of service than Medicare patients with nonprofits. These researchers had previously proposed a profit motive for the differences (Han et al. 2004). After the 1997 Balanced Budget Act, this disparity seems to have disappeared. Interestingly, “[l]ength of service among patients with Medicaid did not change significantly from 1992 through 2000” (Han et al. 2004). After adjusting for other agency and patient characteristics, however, the earlier noted disparities in length of service were not significant. Overall, this seems to suggest that *home and community based care service levels may not often be higher than what is needed by the consumer.*

In one study of 224 high-risk older adults enrolled in a Medicare managed care plan, researchers showed that when home based services are separated and consumers are given greater freedom of choice than in the typical prepackaged format, the associations between elder characteristics and service utilization were complex and not always easily explained (Alkema et al. 2006). Use of care was related to medical condition and impairment level, but also to age, gender, social support, living situation, and education. Whether these choices represent higher or lower levels of service than needed is not clear.

Considerable research has been done that documents high burdens on family caregivers when informal care options are used (Arnot et al. 1999). These costs are not just economic, but also affect mental and physical health.

Although it is difficult to determine how often lower-than-needed services are chosen, given the desire of elders not to be institutionalized (Kane and 2001; Kane and Wilson 1993; Kane et al. 1998; Mattimore 1997) and not to “go on the dole” (Stum 1998), the situation where a consumer receives less care than what is needed, or less care than what is optimal in terms of maintaining financial self-sufficiency seems likely to be occurring more often than we know.

### **Demographic differences in long-term care financial planning**

A significant amount of work has been done on differences in long-term care services by various demographic and situational groups. Several researchers focus on the differences between urban and rural use of long-term care by elders (Bolin et al. 2006; Coward et al. 1994; Greene and Ondrich 1990; Phillips et al. 2003; McAuley et al. 2004; Ghelfi and Parker 1997; Coburn 2002; Reeder and Calhoun 2002; Coward and Cutler 1989; Poley et al. Slifkin 2003). This work is suggestive without directly addressing the question of attitudes toward use of personal resources.

For example, higher use of rural nursing homes by less impaired elders has been found (Bolin et al. 2006). The authors suggest that lack of resources in rural areas, particularly medical specialists, may play a role in this phenomenon. Their hypothesis is that nursing home care substitutes – although imperfectly – for more specialized medical treatment in areas where that treatment is not available.

A significantly smaller proportion of newly admitted rural elders used Medicare than urban elders. Taken together with structural facts of higher poverty and lower earnings in rural areas, this would suggest greater reliance on personal resources (including personal finances and informal support from family and friends) in rural areas (Ghelfi and Parker 1997; Reeder and Calhoun 2002). Rural elders are also significantly more likely than urban elders to use formal home care services (McAuley et al. 2004). This might be taken to support the hypothesis of greater reliance on personal resources in rural areas.

Similarly, much research has been done on race/ethnicity, gender, family situation, and type of long-term care services needed (Penning et al. 2006; Stallard 2006; Blake and Simic 2005; Angel and Angel 2006; Angel et al. 1996; Burr 1990; Himes et al. 1996; Mor et al. 2004; Mui et al. 1998; Shea et al. 1996; Wallace et al. 1995; Stone 2006; Alexcih et al. 1997; Spillman and Lubitz 2002; Spillman et al. 1997). Much of this work focuses on financial disparities. Given the lower lifetime earnings of women and racial/ethnic minorities, these groups are found to have lower assets and be more likely to

be eligible for state assistance than white males. Some research focuses on specific needs while others focus on trends in the populations of various groups. Yet, we found nothing directly related to attitudes toward use of personal resources for payment that also considered differences in attitudes by social group.

### **Consumer awareness of housing options**

We found no studies that specifically addressed this issue. Given the research on financial literacy discussed above (Vitt et al. 2000; Cutler 1997), we expect that few elders or long-term care decision-makers have more than an intuitive sense of a risk to future housing choices when spending assets.

The overall lack of affordable housing does not appear to drive long-term care demand, based on the relative stability of elder housing statistics in the Census and American Community Survey data. However, this stability applies only to Minnesota as a whole – data for individual communities may show a different story. One of the issues we will be addressing in our secondary analysis is the proportion of rural Minnesota residents living in housing “with conditions.” This designation by the Census Bureau includes cost burdening as well as physical inadequacies of the property. Further, one of the major issues faced by older adults who have been institutionalized for a period of time is that they lose their housing. This constitutes a major barrier for those wishing to return the community.

According to a recent study (Bayer and Harper 2000), nearly 1 in 4 respondents over age 45 thought it was likely that someone in their household would have difficulty getting around in the home within the next 5 years. Kochera et al. (2005) report that “people age 50 and older who said they lived in a home that is not able to meet their physical needs as they age scored lower on several key indicators of successful aging” (p. 55). They also note that “cost was the primary reason respondents did not make the home improvements they felt they needed to age in place.” It appears that those elders already experiencing physical challenges are more likely to see financial challenges with home adaptation.

Seen in this light, the very high proportion of elders expecting to stay in their current homes (83%, AARP 2005), may reflect overly optimistic expectations, both in terms of physical challenges and financial challenges. Still, 62 percent of residents who felt their home would not meet their physical needs wanted to remain in their current homes (Kochera et al. 2005). There does seem to be a disconnect between many elders’ evaluations of their physical needs and their expectations of remaining in their homes.

### **Conditions that lead to the depletion of personal assets**

To be eligible for Medicaid and have assets to transfer, elders have to be reasonably well-off (probably middle class), but not wealthy enough to expect to pay their health care costs on their own. Sloan and Shayne (1993) used data from the national long-term care survey of 4,600 disabled elders who lived in the community in 1989. They constructed simulations of the extent of Medicaid eligibility, finding about 59 percent were eligible and another 6 percent would become eligible within six months. They estimated that about 19 percent of the participants were actually on Medicaid, indicating that many elders are avoiding Medicaid even when eligible. Thus, Sloan and Shayne (1993) argued that the *fraction of elders for whom transfers make sense is small*.

Lee et al. (2006) used longitudinal data from the Health and Retirement Study to track a sample of elders who began the study in the community and not on Medicaid. For the elders who became Medicaid beneficiaries over the following 10 years, about 18 percent self-reported transferring wealth to family members with cash gifts. The amount of the gifts was relatively small – the average was about \$8,500 and the median was even lower. These researchers also found that elders who remained in the community were less likely to receive Medicaid (16.4%) than those who entered a nursing home (26.3%). However, when community based elders did receive Medicaid, they were more likely to report transferring assets to family members and the transfers were greater. Similarly, elders who were members of a couple were less likely to become Medicaid recipients than singles, but when couples did become recipients, they had larger transfers to family members. A consistent finding is that more married couples transfer assets than singles.

Burwell and Crown (1995) estimate 5 to 10 percent of unmarried applicants and 20 to 25 percent of married applicants transfer wealth to qualify for Medicaid. Lee reports transfers by 64 singles averaged about \$6,700 with a median of \$2,400. This paper also reports transfers by 68 couples averaged about \$10,100 with a median of \$2,000 (Lee et al. 2006, p.10).

One of the shortcomings of this study is that the authors did not consider the more exotic forms of wealth transfer currently being used – testaments, annuities, etc. These instruments generally require a lawyer or estate planner to execute and, thus, are generally used for larger transfer amounts. Nor do these authors consider exempt assets, including housing and businesses. One question of interest might be whether exempt assets are transferred as often as cash, adjusting for availability. If so, motives other than Medicaid eligibility would have to be considered.

Others who have studied Medicaid estate planning have noted that it seems to occur less frequently and in smaller amounts than might be expected. For example, Wiener (1996)

used data from a 1993 GAO study of applicants for Medicaid nursing home care in Massachusetts to show that only 49 applicants had transferred assets out of 403 total applicants. This author also used the Survey of Income and Program Participation (SIPP) to argue that most elders did not have enough non-housing assets to be worth paying for expensive estate planning. Most had less than \$12,000, enough for less than 6 months of nursing home care. The Minnesota Department of Human Services (1996) estimated 22 percent of elders receiving Medicaid had transferred assets to become eligible. Norton (1995) found that some elders in nursing homes receive transfers from their children or sell housing assets to avoid Medicaid eligibility.

A recent change in federal law, the Deficit Reduction Act of 2005 ('DEFRA' 2005 - Public Law 109-171), mandates more stringent eligibility criteria with respect to gifting, the homestead exemption, and protection of assets for the community-based spouse when one spouse is institutionalized. In particular, DEFRA lengthens the "look back" period to establish eligibility from 36 months to 60 months for many people applying for Medicaid. This may or may not have a significant impact on asset transfers.

There are exceptions to the findings of low rates and amounts of transfer. Walker et al. (1998) estimated that 25 to 50 percent of elders transfer assets with an average value of \$50,000 just before applying for Medicaid. This study primarily interviewed attorneys and financial planners who are paid to execute elder estate plans; these respondents could have biased perceptions due to their typically wealthier clientele. But the study participants also did not all agree about the extent or frequency of transfers. And the GAO (1993) estimated a rate of 54 percent, though they included asset transfers from "countable" to "uncountable" categories as well.

Bassett (2004) considered some of the private information/moral hazard issues with estate planning decisions. Elders who regard themselves as more likely to enter a nursing home have a greater incentive to transfer assets. While this study found a positive correlation, it estimated the overall effect to be only about \$1 billion per year, which is about 3 percent of Medicaid nursing home expenditures in the study year. As noted earlier, other researchers have found that elders tend to overestimate their chances of entering a nursing home within months.

### **Information available through the State of Minnesota regarding depletion of assets, and characteristics of older Minnesotans who are receiving Medicaid**

At this time, no literature is available to address these issues. However, the original data collection and secondary data analysis components of this study will address these questions directly.

# Conclusions

This literature review examined the topics related to how the State of Minnesota can most effectively help older adults to select the long-term care services that meet their needs and preferences and that help them maintain their financial self-sufficiency as long as possible. Home and community based services are an increasingly popular alternative to institutional long-term care, and these services are growing in terms of the proportion of public funds (from Medicare, Medicaid, the Older Americans Act, and the Social Services Block Grant) that are used for these types of services versus institutional care. This study is examining housing with services, assisted living, and in-home services like home care, chore, nutrition, transportation, companion, and other services that enable older adults to stay in the community.

One important aspect of determining the impact of home and community based services on older adults and on the State is the long-term care decision-making process. Specifically, we set out to investigate what factors affect long-term care decision-making and the depletion of personal resources resulting in Medicaid eligibility and what role the State can have in influencing these factors. The literature indicates that an individual's personal health and general wellness tend to have an impact on who they involve in their long-term care decision-making. Several different decision-making models have been identified. A pivotal factor in decision-making paradigms appears to be who makes the decision, which in turn is impacted by the capacity of the senior.

Most older adults rely heavily on their adult children and other relatives to aid in the decision on which services to purchase. It appears that consumers and those who help consumers make long-term care decisions also seek advice from professionals, mainly the older adult's physician. Ultimately, most older adults want to feel that their values of autonomy, privacy, and dignity are maintained regardless of who makes the final decision about which long-term care services to use. Families are often limited in their ability to select services that honor their loved one's wishes, because the older adult had never clearly communicated their wishes before becoming impaired, because the family's desire to ensure their loved one's safety may override concerns about maintaining independence, or because they are unable to obtain the desired services on short notice in the case of a health crisis. Professionals also struggle to provide high quality consultation and advice to consumers and families when no advance planning has occurred, which is a common situation.

The primary factors that influence selection of long-term care services are, not surprisingly, physical and mental health status. Specifically, falls and inability to perform ADLs are the main physical health factors and dementia is the main cognitive

factor that predicts need for long-term care services. A consumer's status in these areas is used to determine which type of long-term care service is most appropriate. Long-term care preferences and use also differ by age, gender, race, and geographic location. Finally, the older adult's financial situation plays a role in determining which long-term care services are ultimately used, but the literature is mixed as to whether Medicaid eligibility increases or decreases use of home and community based services. The literature is also mixed regarding the extent to which long-term care consumers select services that are either a lower or higher level than what they really need. More research is needed in this area.

Decision aids are a common tool used in the health care decision-making arena to aid consumers and those who make decisions on their behalf to make the best and most informed choice only after considering all the possible options and the implications of selecting those options. However, these types of tools are most often available on the Internet, which may limit accessibility for some older adults. The Internet will most likely be a much more appropriate format for presenting long-term care information to older adults from the baby boom generation and beyond, due to these cohorts' increased familiarity with computers and the Internet, and increased Internet accessibility in general. Some clinicians and other professionals have participated in informed choice training, which has helped them to provide better advice to long-term care consumers and their families to select the most appropriate services.

It appears that a system of screening information for quality, standardizing the information, and providing it to consumers in accessible formats is a much needed service that the State could provide. The amount of information, or non-standard formats or complicated and highly technical aspects of the information, about long-term care service and financing options can be daunting to consumers and those who make decisions on their behalf. Further, consumers need information about assistive technology and other services available to help them stay in the community. Information about private sources of long-term care financing and money management related to long-term care planning is also warranted, including policy costs, coverage areas, and important implications of lapses in coverage.

It appears that there are some incentives and some disincentives for consumers to deplete their personal financial resources in order to become Medicaid eligible. Also, it seems that due to the lack of consumer understanding concerning the price and availability of various home and community based services, consumers confront difficulties during financial planning. There is not currently literature available that directly addresses the question of how one type of home and community based service compares to another in terms of the impact on depletion of consumers' financial resources.

The findings from the literature review will be used to design the data collection activities for future phases of this study. Specifically, several articles were found that included survey instruments or sample items that will be reviewed, and modified if needed, for the various surveys that will be conducted for this study, with consumers, friends/relatives, providers, and long-term care consultants. The findings from this literature review will also help focus the topic areas for both the original data collection and secondary data analysis and will be included in the study's final report.



# Appendix

*Works cited*

*Minnesota Legislation*



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## *Minnesota Legislation*

**Sec 73. HOUSING WITH SERVICES AND HOME CARE PROVIDERS STUDY; REPORT.** The commissioner of human services shall conduct a study of how the state of Minnesota can most effectively assist persons age 65 and older in selecting long-term care services that meet their needs, reflect their preferences, and enable them to maintain financial self-sufficiency as long as possible. The study shall include surveys of both consumers and providers of housing with services, assisted living, and in-home services, as well as an evaluation of what role the long-term care consultation program under Minnesota Statutes, section 256B.0911, does or could play in helping consumers to evaluate their options. Upon request of the commissioner, providers covered by the study shall provide data that the commissioner determines is reasonably necessary to achieve study outcomes. The preliminary results of this study shall be reported to the senate and house of representatives committees with jurisdiction over health and human services policy and finance issues by February 15, 2008, with a final report completed by December 15, 2008.

Sec 5, Minnesota Statutes, 2006, section 256.97, Subd. 7 is amended to read:

### **Consumer information and assistance: senior linkage.**

Incorporate information about housing with services and consumer rights within the MinnesotaHelp.info network long-term care database to facilitate consumer comparison of services and costs among housing with services establishments and with other in-home services and to support financial self-sufficiency as long as possible. Housing with services establishments and their arranged home care providers shall provide information to the commissioner of human services that is consistent with information required by the commissioner of health under section 144G.06, the Uniform Consumer Information Guide. The commissioner of human services shall provide the data to the Minnesota Board on Aging for inclusion in the MinnesotaHelp.info network long-term care database.

Sec. 14. Minnesota Statutes 2006, section 256B.0911, is amended by adding a subdivision to read:

Subd. 3c. **Transition to housing with services.** (a) Housing with services establishments offering or providing assisted living under chapter 144G shall inform all prospective residents of the availability of and contact information for transitional consultation services under this subdivision prior to executing a lease or contract with the prospective resident. The purpose of transitional long-term care consultation is to support persons with current or anticipated long-term care needs in making informed choices among options that include the most cost-effective and least restrictive settings, and to delay

spenddown to eligibility for publicly funded programs by connecting people to alternative services in their homes before transition to housing with services. Regardless of the consultation, prospective residents maintain the right to choose housing with services or assisted living if that option is their preference.

(b) Transitional consultation services are provided as determined by the commissioner of human services in partnership with county long-term care consultation units, and the Area Agencies on Aging, and are a combination of telephone-based and in-person assistance provided under models developed by the commissioner. The consultation shall be performed in a manner that provides objective and complete information. Transitional consultation must be provided within five working days of the request of the prospective resident as follows:

(1) the consultation must be provided by a qualified professional as determined by the commissioner;

(2) the consultation must include a review of the prospective resident's reasons for considering assisted living, the prospective resident's personal goals, a discussion of the prospective resident's immediate and projected long-term care needs, and alternative community services or assisted living settings that may meet the prospective resident's needs; and

(3) the prospective resident shall be informed of the availability of long-term care consultation services described in subdivision 3a that are available at no charge to the prospective resident to assist the prospective resident in assessment and planning to meet the prospective resident's long-term care needs.

**EFFECTIVE DATE.** This section is effective October 1, 2008.