

Helping Older Adults Select and Purchase Long Term Care

A Report to the Minnesota Legislature

Minnesota Department of Human Services
Aging and Adult Services

March 23, 2009

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I. INTRODUCTION

Laws of Minnesota, 2007, Chapter 147, Article 7, Section 73, directs the Department of Human Services (DHS) to bring recommendations to the Legislature regarding “how the State of Minnesota can most effectively assist persons 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.” This report is submitted to the Legislature in response to this requirement.

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Executive Summary

The 2007 Minnesota Legislature directed the Department of Human Services (DHS) to conduct a study to address the question “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.” In January 2008, the Continuing Care Administration of DHS contracted with Wilder Research to conduct a study to answer this question with specific focus on housing with services, assisted living, and in-home services.

DHS convened a stakeholder group in August 2007 including representatives from AARP, Minnesota Department of Health, Minnesota Department of Commerce, Minnesota Office of Ombudsman for Long-Term Care, Alzheimer’s Association, Blue Cross, Care Providers of Minnesota, Aging Services of Minnesota, Minnesota Home Care Association, Eldercare Rights Alliance, Minnesota Senior Federation, Senior LinkAge Line®, hospital discharge planners, Arrowhead Area Agency on Aging, Eldercare Development Partnership, Medica, Ramsey County, Chisago County, Hennepin County, the Central Minnesota Council on Aging, and Bloomington Public Health. The Minnesota Department of Health and the Minnesota Board on Aging were also represented at the meetings. Members of the diverse stakeholder group provided valuable input on all study activities. However, the findings and recommendations of this study and reports do not represent a consensus of the stakeholder group, nor do they necessarily represent the views of the organizations participating in the group.

Generally, long-term care refers to the full spectrum of services needed by older adults due to physical and/or mental impairments, and includes both nursing facility care and home and community-based services. In this study, the focus is specifically on housing with services, assisted living, and in-home services such as home care, transportation, companion services, home delivered meals, etc.

The study sought information about two key areas: 1) the factors that influence long-term care choices and decision making, and 2) the factors that enable long-term care consumers to maintain financial self-sufficiency as long as possible. Wilder Research completed four in-depth reports on the major activities of the study: 1) a literature review; 2) a report on interviews with key informants, on-line surveys of providers and decision-support staff; 3) a secondary data analysis; and 4) a report on surveys and focus groups of consumers and their family members.

Themes Throughout the Study

There were several themes that cut across all of the issues examined within this study. These issues must be considered in light of the current economic crisis, which has had a negative impact on the retirement savings of many older adults, and certainly will affect the ability of some to remain financially self-sufficient for as long as they might have, if retirement savings were stable. While some of the recommendations in this report will require additional investment, there are many which focus on better targeting of existing resources.

1. Consumers need good information about long-term care options that is readily available and easy to use.

Consumers need to be provided with accurate, reliable information that allows them to easily compare options. The complexity and lack of standardization in terminology used in the long-term care industry creates challenges for consumers, their family members, and professional decision support staff. It is difficult for consumers to discern which services and which providers offer the most appropriate and cost-effective services to meet a particular need. Work is needed to develop more standardized terms, definitions, and pricing information across all long-term care services and settings. The Uniform Consumer Information Guide (UCIG) could be used as a model for this effort with some modifications, e.g., separating rent from service costs and providing specific price information on all services.

Consumer-friendly quality report cards for home and community based services could be developed. Since consumers value word-of-mouth as a method of obtaining long-term care information, more consumer satisfaction quality measures that are trusted and reliable should be developed and made available to older adults.

2. A multi-pronged, targeted approach to long-term care information is required to meet the varying needs and situations of consumers.

The Minnesota Department of Human Services, the Minnesota Board on Aging, and their partners are now using a multi-pronged approach, through the MinnesotaHelp Network, to provide long-term care information and decision support using telephone, Internet, print materials, and face-to-face supports. This approach provides several options for how consumers receive information, and this approach needs to continue, based upon our findings in this study. Individuals use a variety of sources to obtain

information, and in order to maximize the reach of this information, several options are needed. Consumers typically make a series of long-term care decisions as their needs and resources change. It is important that appropriate information be provided at the “right time.” The Survey of Older Minnesotans or comparable instruments could incorporate items to determine which types of consumers and family members use/don’t use various sources including Senior LinkAge Line® , Long-Term Care Consultation, or the Office of Ombudsman for Long-Term Care. This information could then be used to address their information and assistance needs more effectively.

3. We need to increase the capacity of individuals to finance (more) of their own long-term care.

The State should ensure that adequate tools exist for advance financial planning for long-term care. While there are limited private financing options from which consumers can choose, those that are available need to be presented and described to consumers before retirement age. The Long-Term Care Partnership with its financial incentives for consumers and the State could be more heavily promoted. Employers could be encouraged to offer their employees a Health Care Savings Plan (HCSP). A program comparable to AARP’s 55 Alive could be developed to encourage older adults to learn more about long-term care services and financing and discuss preferences and decisions with family and friends in order to receive a discount on their Medicare supplemental insurance premium.

Recognizing the desire of most older adults to stay financially self-sufficient, consumers need good information about how they can use their own income and assets most effectively and all the strategies they can employ to address risk factors for long-term care.

4. More detailed information is needed to project future demand for Medical Assistance (Medicaid).

The Minnesota Department of Human Services does not have adequate information to project the financial resources the State will need to cover the cost of future long-term care in Minnesota. The Minnesota State Demographer and Minnesota Department of Revenue might be able to assist the Minnesota Department of Human Services in gathering information about the financial circumstances of current older adults using private or third-party resources to pay for long-term care. The State could then make more accurate projections about future demand and eligibility *and* develop and implement strategies to promote prolonged financial self-sufficiency of individuals.

5. More emphasis is needed on the role of informal caregiving.

There should be more emphasis placed on the role of informal caregivers in maintaining the financial self-sufficiency of older adults. Because of their close relationship with their older relative, these caregivers are in a good position to know the financial situation of the older relative, and be able to assist in their financial decisions related to long-term care.

Part I. Long-term care decision making

This portion of the study sought to answer the following questions:

1. What factors influence the long-term care choices and the decision-making process of consumers and those who make decisions on their behalf?
2. Which of these factors can the State influence to more effectively help persons age 65 and older in Minnesota select services that meet their needs and reflect their preferences?

Key findings:

- **Reasons people need long-term care.** The most common reasons people need long-term care services include lack of family caregivers, physical limitations, cognitive impairments, and limitations in mobility and/or home maintenance.
- **Lack of advance planning.** There is a significant lack of advance planning for long-term care needs among older adults. Professionals are limited in their ability to provide assistance to consumers in crisis situations, because there is not enough time to gather complete information and because services are difficult to access immediately, particularly in Greater Minnesota.
- **Proxy decision makers (family members) are very involved in long-term care decisions.** Consumers make decisions about long-term care on their own in only about one out of five cases. In the majority of cases, consumers' adult children or other family members are the primary decision makers. Often, these proxy decision makers do not solicit input from the older adult in need of long-term care, and also they may have different values that can lead to conflict. Consumers report, however, that they feel their preferences have been taken into account by their family members when decisions are made. Other important sources of influence are physicians and other professionals.
- **Key information sought by consumers.** Consumers and their family members value information regarding what services are available and when services are available, information on costs of services, and information on service quality.
- **Available information is underutilized, and when sought, is perceived as difficult to use and unreliable.** While there is a lot of information available about different long-term care options, few consumers or their families seek it out. Those that do seek out information from a variety of sources report that it is often difficult to use. The lack of standardization of service definitions makes it hard to

compare options. Price information is typically available only through direct contact with the provider. And, information is quickly outdated, both on the Internet and in print materials. Quality information, such as reports from licensing surveys, is not always consumer-friendly.

- **Location, race/ethnicity and family situation affect decision making.** Long-term care decision-making approaches and preferences differ by location, race/ethnicity, gender, and family situation. Many minority elders, particularly those who are immigrants or refugees, are concerned about more basic immediate needs such as food, shelter, and immigration status. Planning for future long-term care is therefore a lower priority. Minorities are often further challenged by language and the lack of culturally appropriate services.
- **Word-of-mouth is the source of information most used by consumers.** While a growing number of consumers and their family members use telephone-based or in-person assistance to obtain long-term care information, they rely primarily on information from friends and peers. Word of mouth is the most frequently used source of information on long-term care services for both consumers and their family members. State resources, particularly Senior LinkAge Line® and Long-Term Care Consultation, as well as the Long-Term Care Choices Navigator tool on MinnesotaHelp.info® are valuable and useful sources of information for consumers, but there is limited awareness of these supports.

Recommendations on long-term care decision-making supports

1. **Target long-term care decision-making supports.** Our goal should be to provide the right information, in the right format, in the right location, in the right amount at the right time.
 - A. **Provide targeted crisis intervention and support.**
 1. Develop services that better address the needs of older adults and their family members who are in a crisis situation when they begin their long-term care search.
 2. Make contact information for the Office of Ombudsman for Long-Term Care available at critical transition points such as termination of services or tenancy so that the consumers know they are available to assist with problem-solving.

B. Provide tools and services that support advance long-term care planning.

1. Partner with providers of the long-term care services typically used first, such as transportation and chore, to engage consumers in earlier planning for their long-term care.
2. Develop additional Internet and paper self-help tools that enable consumers and family members to compare long-term care options and to make informed decisions.
3. Publicize the availability of advance planning tools and encourage consumers to communicate with their families about their decisions. Assure that tools are available to facilitate advance planning between consumers and family members. These tools should be designed for consumers to clearly indicate their preferences in the event they are no longer capable of making decisions on their own behalf. Tools and supports also need to reflect the impact of family dynamics on decision-making and vice versa.

C. Ensure that good information is readily available and easy to use.

1. Consumers *and* their family members, especially adult children, should have access to complete and useable information about long-term care options including cost information.
2. Ensure that long-term care service options and pricing information are presented in a common format with standardized definitions of services for ease of comparison.
 - a. Use the Uniform Consumer Information Guide in all housing with services establishments. Develop and use a comparable format and list of services for other home and community-based licensed services to provide information to consumers and the State.
 - b. Research additional ways to standardize consumer satisfaction and service quality measures and make these available to older adults in Minnesota. Develop a consumer report card comparable to the existing Nursing Home Report Card for housing with services, assisted living, and licensed in-home services.

- 2. Leverage high quality decision support across health and long-term care service networks.**
 - A. Engage health and long-term care professionals as part of MinnesotaHelp Network and encourage use of the MinnesotaHelp.info® database.
 - B. Offer “informed choice training” for clinicians and other health care providers who are involved in long-term care decision making, to increase the patient-centeredness of professional consultation. Offer no- or low-cost training that meets professional continuing education requirements and use technology such as video conferencing to increase access and participation.
 - C. Provide education to health and long-term care professionals to increase their knowledge of how long-term care services are labeled and marketed, so they can provide accurate comparisons across available options to their clients.
- 3. Plan for and monitor the anticipated growth of older adult populations from diverse backgrounds.**
 - A. Ensure that decision-making supports are culturally and linguistically appropriate for all groups of older adults, and monitor the supply of culturally appropriate long-term care services/supports available for the increasingly diverse population of older adults in Minnesota.
 - B. Create incentives to encourage service providers to offer culturally appropriate long-term care services, and track demographic and cultural differences in long-term care preferences, decision-support needs, and service use in Minnesota.

Part II. Long-term care consumers and their financial self-sufficiency

This portion of the study sought answers to the following questions:

1. What factors enable long-term care consumers to maintain financial self-sufficiency as long as possible?
2. What factors contribute to increasing or decreasing the cost-efficiency of State-paid long-term care services?
3. What service substitution options would prolong financial self-sufficiency?

4. Which of these factors can the State influence to more effectively help persons age 65 and older in Minnesota maintain financial self-sufficiency as long as possible and ensure the State is using its limited resources in the most cost-efficient manner possible?

Key findings

- **Older adults prefer to remain financially independent.** In general, older adults prefer to remain financially independent and avoid use of State-paid services. However, in some cases, this means that older adults choose to go without services they need rather than paying out-of-pocket, which can result in more demand for crisis-based services.
- **Consumers and family members are not aware of the cost of long-term care services.** There is a lack of health care financial literacy, in general, and long-term care financial literacy, in particular.
- **Most consumers do not understand payment options for long-term care.** For example, they do not know:
 - Which long-term care services can/cannot be paid for by public programs such as Medicare and Medical Assistance.
 - The income and asset eligibility standards for Medical Assistance.
 - That their Social Security may be inadequate to pay for their long-term care.
 - That Elderly Waiver (EW) and Alternative Care (AC) pay for services, not housing or food, and that a recipient's personal needs allowance is limited.
- **Financial planning for future long-term care needs is limited.** Many consumers believe that long-term care is a public entitlement. The private financing options that are available are not well understood by most consumers.
- **New patterns of Medical Assistance use are emerging within housing with services and assisted living.** A significant portion (66 percent) of EW recipients receive Customized Living services in assisted living facilities in their first month on Medical Assistance. However, there is not enough information on these individuals to forecast future demand for EW. The State does not have information on:
 - When EW recipients moved into the housing with services establishments.

- How close consumers living in various settings and using long-term care services are to depleting their personal resources resulting in eligibility for Medical Assistance.
- **EW recipients in Greater Minnesota generally use higher cost services than their counterparts in the Metro area.** About 35 percent of EW recipients in Greater Minnesota were authorized for Customized Living services in assisted living facilities as opposed to 24 percent of EW recipients in the Metro area.

Recommendations to increase consumer financial self-sufficiency

1. Increase consumer literacy about long-term care financing.

- A. Assure that good financial literacy education programs are available across the state.
 - 1. Content should include: a) the range of long-term care services available, b) costs associated with different housing and service options, c) eligibility for and limitations of public funding sources, d) financial implications for consumers and their families, and e) vehicles for financial planning.
 - 2. Partner with education programs such as University Extension to assure that curriculum has appropriate content, is easy-to-use and readily available, and partner with existing community groups to deliver training where seniors and adult children already congregate, e.g., faith communities.
- B. Develop a program based on the model of AARP's 55 Alive/Safe Driver Program to encourage older adults to learn about long-term care services and financing and discuss preferences and decisions with family and friends in order to receive a discount on their Medicare supplemental insurance premium.

2. Make tools and decision support services available that enable easy cost comparisons among housing and service options.

- A. Develop Internet and paper tools for consumers, their family members and decision support professionals to easily compare costs of different housing and service options.
- B. Encourage MinnesotaHelp Network decision support staff to discuss the use of non-State-funded solutions with consumers whenever possible and appropriate.
 - 1. Provide consumers with information on how Medicare benefits can be used to meet their needs and reduce their risk for long-term care, e.g., access Medicare benefit for physical therapy to reduce risk for falls instead of moving to a place that has staff available to respond to a fall after the fact.
 - 2. Encourage informal caregivers to access decision supports and other services to prolong the duration and quality of care they provide.

3. Increase the capacity of individuals to finance their own long term care.

- A. Continue to promote Health Care Savings Plans through employers.
- B. Promote the Minnesota Long-Term Care Partnership, which enables Minnesota residents who purchase certain long-term care insurance policies to have more of their assets protected if they later need the State to help pay for their long-term care.
- C. Expand the availability of federally credentialed counseling to older adults regarding reverse mortgage options.

4. Promote the use of lower-cost preventative services.

- A. Assure that services needed for older adults to stay in their own homes and communities, e.g., transportation and chore services, are readily available.
- B. Develop messages and strategies that encourage earlier use of limited help, e.g., transportation or chore services, in order to prevent or delay the need for more expensive services.

- C. Monitor and implement evidence-based practices that have proven cost-to-benefit ratios, e.g., specific caregiver module that increases the duration of caregiving and delays nursing home placement.
5. **Gather more information about the financial circumstances of older adults.** Utilize the county-by-county data recently made available through the Minnesota Elder Economic Security Index (EESI) to describe the current cost of living for persons age 65 and over including housing, food, transportation, health care and long-term care, compared to the average income for older people in that county. Disseminate this information widely to providers, elected officials, and policymakers.

Contents

Background.....	2
Glossary.....	3
Part I. Factors affecting long-term care decision making.....	6
Part II. Long-term care consumers and their financial self-sufficiency.....	20
Appendices.....	28
A. Study Methods.....	29
B. Increasing older adult population in Minnesota.....	35
C. Endnotes.....	37

Background

The 2007 Minnesota Legislature directed the Minnesota Department of Human Services (DHS) to conduct a study to determine “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.”¹ In January 2008, the Continuing Care Administration (DHS) contracted with Wilder Research to conduct the study, with specific focus on housing with services, assisted living, and in-home services.

DHS convened a stakeholder group in August 2007 including representatives from AARP, Minnesota Department of Health, Minnesota Department of Commerce, Minnesota Office of Ombudsman for Long-Term Care, Alzheimer’s Association, Blue Cross, Care Providers of Minnesota, Aging Services of Minnesota, Minnesota Home Care Association, Eldercare Rights Alliance, Minnesota Senior Federation, Senior LinkAge Line®, hospital discharge planners, Arrowhead Area Agency on Aging, Eldercare Development Partnership, Medica, Ramsey County, Chisago County, Hennepin County, the Central Minnesota Council on Aging, and Bloomington Public Health. The Minnesota Department of Health and the Minnesota Board on Aging were also represented at the meetings. Members of the stakeholder group provided valuable input on all study activities. However, the findings and recommendations of this study and reports do not represent a consensus of the stakeholder group, nor do they necessarily represent the views of the organizations participating in the group.

This study sought to answer questions in two areas:

Part I. Long-term care decision making

1. What factors influence the long-term care choices and the decision-making process of consumers and those who make decisions on their behalf?
2. Which of these factors can the State influence to more effectively help persons age 65 and older in Minnesota select services that meet their needs and reflect their preferences?

Part II. Financial self-sufficiency

1. What factors enable long-term care consumers to maintain financial self-sufficiency as long as possible?
2. What factors contribute to increasing or decreasing the cost-efficiency of State-paid long-term care services?

3. What service substitution options would prolong financial self-sufficiency?
4. Which of these factors can the State influence to more effectively help persons age 65 and older in Minnesota maintain financial self-sufficiency as long as possible and ensure the State is using its limited resources in the most cost-efficient manner possible?

This report is a summary of the key findings on both parts of this study. Wilder Research completed four detailed reports on the core study activities:

- A literature review
- Web-based surveys and key informant interviews of providers and professional decision support staff
- Secondary data analysis
- Surveys of and focus groups with consumers and their proxy decision makers (called “family members” throughout this report)

All of the detailed research reports from each study activity can be downloaded from http://www.dhs.state.mn.us/main/dhs16_144477. The methods used for all parts of the study are summarized in Appendix A. Appendix B includes some background information about changing demographics in Minnesota that will affect long-term care services and funding in the future.

Glossary

Assisted living: A service or package of services advertised, marketed, or otherwise described, offered, or promoted using the phrase “assisted living.” “Assisted living” providers must meet the requirements of Minnesota Statute 144G. Assisted living is a subset of “housing with services.”

Consumers: Older adults who have recently purchased or are looking into purchasing long-term care services. See Appendix A for a more detailed description of the sub-group of consumers who were interviewed for this study.

Customized living: A bundle of services paid for by Elderly Waiver (EW) that can only be provided in a housing with services establishment. Customized living does not include rent or raw food. This EW service was formerly called assisted living.

Housing with services establishment: A housing establishment, registered with the Minnesota Department of Health, which offers two or more supportive services or one or more health-related service. Establishments in which 80 percent of residents are 55 and over must register.

Registration is optional for establishments in which less than 80 percent of residents are 55 or older.

Key informants: Individuals who were identified by this study's stakeholder group as experts on the issues of long-term care decision making and/or financial planning for long-term care. See Appendix A for a more detailed description of the key informants who were interviewed for this study.

Long-term care services: Generally, long-term care refers to the full spectrum of services needed by older adults due to physical and/or mental impairments, and includes both nursing facility care and home and community-based services. In this study, the focus is specifically on housing with services, assisted living, and in-home services such as home care, transportation, companion services, home delivered meals, etc.

Long-Term Care Consultants (LTCCs): Professionals who aid older adults and their helpers in making decisions about long-term care services through provision of Long-Term Care Consultation, a service provided through counties, Indian Tribes or health plans.

Long-Term Care Partnership: A public/private arrangement between long-term care insurers and Minnesota's Medical Assistance program. Minnesota residents who purchase certain long-term care insurance policies have a fixed amount of their assets protected if they later need the State to help pay for their long-term care.

MinnesotaHelp.info®: An online tool (web application) that provides community resource information and interactive decision support tools that facilitate informal assessment and community support planning to consumers and the persons involved in assisting them.

MinnesotaHelp Network: The MinnesotaHelp Network has four channels of service delivery to Minnesota citizens. The phone service is provided by the Senior and Disability Linkage Lines. Online distribution of information is done through the www.MinnesotaHelp.info web site. Online chat is also offered through this site, and informational materials and connections to the linkage lines are offered through "outreach sites" across the state.

Nursing Home Diversion Project: A Minnesota initiative designed to: 1) promote earlier identification of older adults at risk of nursing home placement and Medical Assistance spend-down; 2) develop and implement a triage process; and 3) target interventions to better manage and reduce risk factors.

Professional decision support staff: Any professional who assists older adults and their helpers in making long-term care decisions. For this study, LTCCs, Senior LinkAge Line® staff, and nursing home and hospital discharge planners were the primary groups included. See Appendix

A for a more detailed description of the professional decision support staff who were surveyed for this study.

Proxy decision makers: Individuals (non-professionals) who help older adults to make long-term care decisions. These are typically adult children but could also be spouses, other relatives, or friends. See Appendix A for a more detailed description of the proxy decision makers who were interviewed for this study. Throughout this report, these individuals are referred to as “family members.”

Senior LinkAge Line®: Operated by the Minnesota Board on Aging and its seven Area Agencies on Aging, the Senior LinkAge Line® is a phone-based service that offers information and assistance to older adults and their family caregivers in a variety of areas. The areas include information on local long-term care supports, Medicare counseling, assistance with access to public programs, and connecting people to home and community-based service programs in their local community.

Service providers: Organizations or individuals that provide long-term care services to older adults. See Appendix A for a more detailed description of the sub-groups of service providers that were surveyed for this study.

Part I.

Factors affecting long-term care decision making

An important goal of this study was to better understand those factors that affect long-term care decision making. Most individuals do not plan ahead for their long-term care needs. This means that all too often individuals and their families are caught unprepared when an incident or health crisis occurs. The older person and/or their family member must make major decisions within a few hours or days that will affect them the rest of their lives: decisions on whether to move or stay in their home, how to meet long-term care needs, how to pay for needed services, etc.

In order to better understand these factors, the study included surveys and focus groups with consumers and their “proxy decision makers” (usually family members) to find out what process they use to obtain information to make decisions on how to meet long-term care needs. The factors that affect this process and our findings from this part of the study are described below.

A. Characteristics and circumstances of the consumer

Certain characteristics and circumstances of older consumers strongly influence their need for long-term care services. Some of the most important risk factors for needing long-term care services include:

- The lack of informal caregivers
- Physical impairments
- Cognitive impairments
- The need for transportation and home maintenance assistance²

Informal caregivers. Research has found a strong correlation between the degree to which consumers receive informal care and support from relatives and the extent to which nursing home care and other long-term care services are utilized.³ About 42 percent of long-term care service providers that participated in this study reported that caregiver stress or burnout or lack of a family caregiver were “frequently” reasons why consumers inquired about their services. Most professional decision support staff who participated in this study reported referring consumers to long-term care options across the continuum because of family caregiver issues. Compared with the professionals who were surveyed, fewer family members and consumers who participated in this study cited family caregiver issues as a reason for needing long-term care services. This can be at least partially attributed to the fact that the consumers who participated in this study tended to be receiving more informal long-term care services. In addition, the family

members who help with decision making tended to also fill the role of caregiver. Therefore, consumers who do not have family caregivers are likely to be under-represented in this study.

Physical limitations and cognitive impairment. Physical limitations, usually measured by limitations in Activities of Daily Living (ADLs) or risk for falls, and cognitive impairment, typically measured by limitations in Instrumental Activities of Daily Living (IADLs) or diagnosis of dementia, are also significant predictors of long-term care service use.⁴ Among groups participating in this study, professional decision support staff were *more* likely than all other respondent groups to report physical impairment and cognitive impairment as reasons for recommending long-term care services, while consumers were *least* likely to indicate that they needed services due to physical limitations or cognitive impairment. This could be due to the sample of consumers in this survey, since they were able to participate in telephone interviews, and may have been higher functioning than consumers who were not able to do this.

Limitations in mobility and need for home maintenance. Finally, need for assistance with transportation and home maintenance are commonly cited reasons for needing long-term care services, particularly among the consumers and family members who participated in this study. These limitations are often the first signs that an older adult is having problems with day-to-day tasks. (See Figure 1.)

Figure 1. Factors associated with the need for long-term care services

Family caregivers

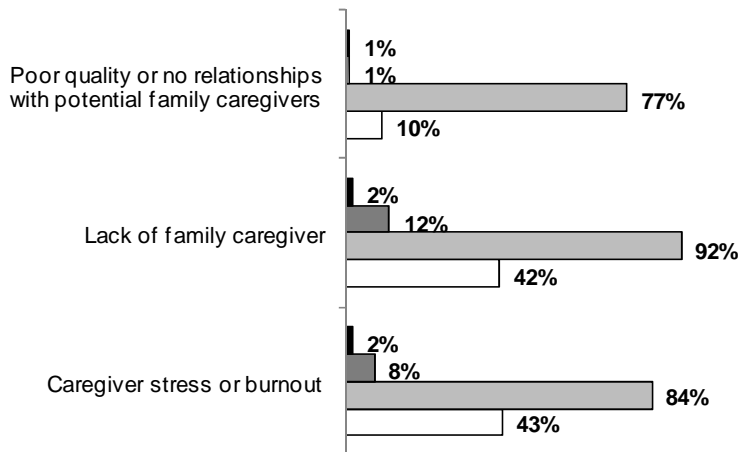
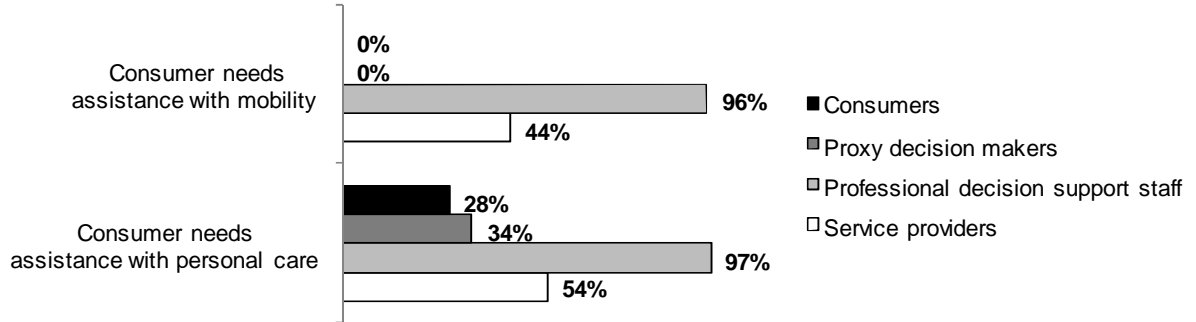
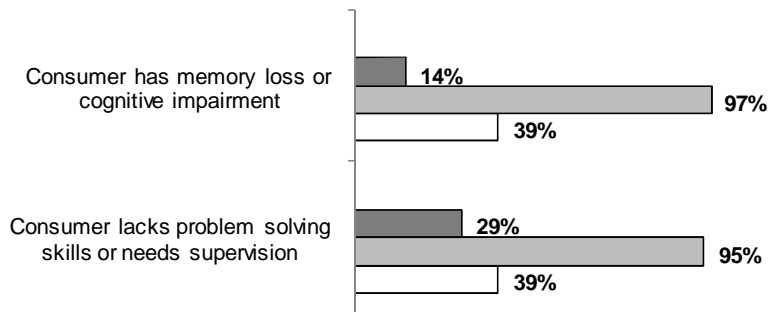


Figure 1. Factors associated with the need for long-term care services (continued)

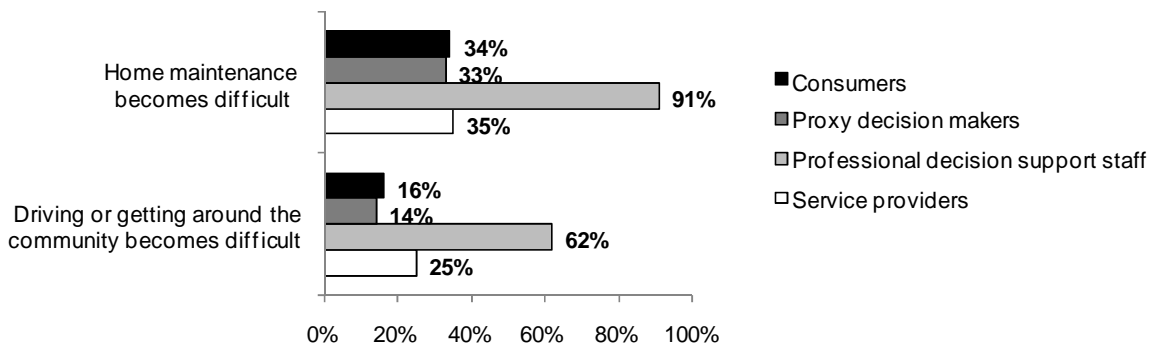
Physical limitations



Cognitive impairment



Transportation/Home maintenance



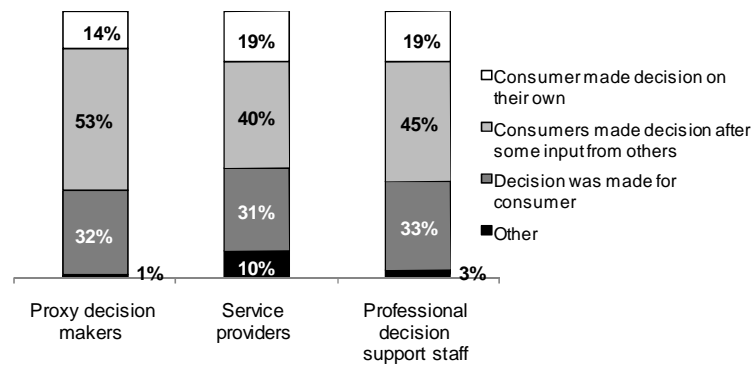
*** Note.** For providers, this is percent who said these are “frequently” reasons why consumers inquire about their services; for professional decision support staff, this is the percent who said they would recommend nursing homes, assisted living or housing with services, or other formal services to consumers in these situations; and for proxy decision makers and consumers, this is percent who said “yes” this was a main reason to seek long-term care services. Consumers and proxy decision makers were asked about mobility assistance and assistance with personal care in one combined question. Consumers were not asked about memory loss.

B. People involved in long-term care decisions

This study found that about 20 percent of older consumers make decisions about long-term care on their own. However, in the majority of cases (80 percent), consumers' adult children or other family members are the primary decision makers, with or without input from the older adult. Related research on this topic has found similar results. Decisions about long-term care services are made *for* the consumer by others for up to two-thirds of older consumers.⁵

Over three-quarters (78 percent) of the consumers who participated in this study felt that their opinions were considered "a lot" in deciding which long-term care services they should receive and another 18 percent felt that their options were considered "a little" in making the decision. Only 4 percent felt that their opinion was "not at all" considered. It is likely that the consumers in this study were better able to participate in decision making than many consumers with cognitive or memory challenges, since they were able to participate in a telephone interview for this survey. Most of the professional decision support staff and service providers who participated in this study felt that most consumers they know either made their decisions after some input from others (about 46 percent), or had decisions made for them about which long-term care services to select (about 32 percent). (See Figure 2.)

Figure 2. Consumer's role in long-term care decisions



Role of Adult Children

Adult children and other informal support persons have significant influence over consumers' long-term care decisions. Service providers and professional decision support staff who participated in this study reported that adult children of consumers have more influence over consumers' decisions than any other group. Consumers themselves were also very likely to report being influenced by adult children and other family members.

These family members are often the primary investigators of housing and long-term care services for their older relatives. The investigator role is especially important since much of the information available about long-term care options is available on the Internet, and use of the Internet is lower among older age groups. They also act as intermediaries between the older adult and the professionals who provide much of the information on long-term care services. This intermediary role is also powerful because it puts the family member in the position of interpreting the complex range of service options to their older relative. The older consumer often needs support from others to sift through and prioritize the key long-term care options, understand the pros and cons of each, and choose among them.

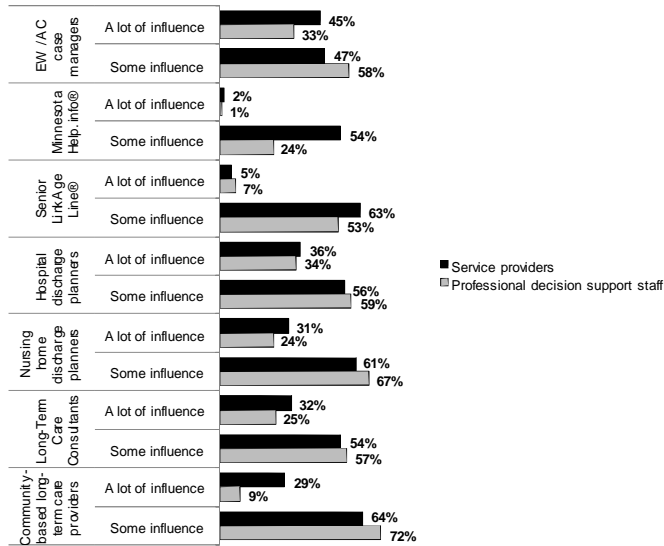
However, there is a more negative aspect to this level of influence. These family members often have different values or priorities than their older relative, the actual consumer, and this can lead to conflicts. For example, adult children tend to value safety and prolonged life for the older adult, whereas consumers often place higher priority on independence and maintaining the familiarity of their own home.⁶

Role of Health and Other Professionals

Physicians and other professionals are also important sources of influence regarding long-term care decisions. The providers and professional decision support staff who participated in this study reported a high degree of influence by physicians and other professionals. About 25 percent of consumers reported being influenced by their doctors or other health care provider. The involvement of the physician was ranked higher in Greater Minnesota than in the Metro area. Physicians are in a good position to provide many of the considerations that an older adult needs to think about when deciding on a long-term care option. Beefing up their knowledge of long-term care options in their communities, training their staff, connecting their clinics to the information sources in their communities, providing written materials in their offices are all ways to maximize the role that they can play in long-term care decision making.

As Figure 3 indicates, many groups are thought to have some influence in the long-term care decision making process, but few are considered to have a lot of influence. For example, both service providers and professional decision support staff perceived that EW/AC case managers had the greatest proportionate influence on this process (45 percent and 33 percent, respectively). Others perceived as having more influence include hospital discharge planners, nursing home discharge planners, and Long-Term Care Consultants (LTCCs).

Figure 3. Degree of influence of professional decision support staff and long-term care service providers



Note: Decision support staff were asked, “How much do you think ____ influences long-term care decisions? Long-term care service providers were asked, “How much influence do you think the following have on prospective customers in selecting your program or service?”

C. Timing of long-term care decisions

There is a significant lack of advance planning for eventual long-term care needs among older adults. Studies have found that most older adults in the U.S. do not begin planning for their long-term care needs until it is absolutely necessary, mainly due to a lack of education and lack of awareness about the consequences of not planning ahead.⁷

When respondents who participated in this study were asked about the reasons why older adults and their proxy decision makers inquire about their services, crisis-based reasons were among the top reasons reported. A full 77 percent of housing providers indicated that a crisis event was the reason for older adults and their families to seek their help, and 67 percent of other service providers said a crisis was the reason for seeking help. Much lower proportions of all the groups indicated that safety or caregiver burnout were the reasons for seeking help. (It is important to note that the consumers and family members who participated in this study are likely to under-represent those consumers who have family caregiver issues.) (See Figures 4a and 4b.)

Figure 4a. Reasons why older adults seek long-term care services as reported by stakeholders included in this study

	Consumers	Proxy decision makers	Assisted living, other housing with services providers	Other formal service providers	Informal providers
Crisis event (e.g., injurious fall, hospitalization, short-term nursing facility use, health decline)	37%	59%	77%	67%	43%
Family member expresses concern about the safety of the older adult	2%	12%	57%	59%	37%
Family caregiver stress and/or burnout	2%	12%	42%	46%	32%

Note. For consumers and proxy decision makers, these percentages represent the proportion of respondents who indicated that this was a main reason for consumers/proxies to seek long-term care services. For service providers, these percentages represent the proportion of respondents who said this is a main reason that consumers inquire about their program or services.

Figure 4b. Types of services recommended by professional decision support staff in various situations

Older adult's situation	In-home services	Services in the community	Assisted living or housing with services	Nursing home	None of these services
Crisis event (e.g., injurious fall, hospitalization, short-term nursing facility use, health decline)	81%	71%	78%	70%	2%
Family member expresses concern about the safety of the older adult	83%	74%	81%	58%	2%
Family caregiver stress and/or burnout	75%	85%	56%	36%	2%

Note. Respondents were allowed to recommend more than one type of service, so row totals add up to more than 100 percent.

Professionals are limited in their ability to provide assistance to consumers in crisis situations. This is true both because there is not enough time to gather complete information and because services that can be provided and made available immediately are in short supply and difficult to access, particularly in Greater Minnesota. Research has shown that professional long-term care decision-making support requires time for a relationship to develop with the consumer. Good relationships promote better assessment of the consumers' needs and preferences, which is essential for quality professional consultation.⁸

When faced with an older adult and their family member looking for help after a crisis event, professionals are more likely to refer the family to a nursing home (70 percent). They are less likely to refer the family to a nursing home for safety or caregiver burnout concerns (58 percent and 36 percent, respectively). There are also high levels of referrals to in-home services and assisted living or housing with services providers.

The reluctance or refusal of the older adult to accept services is also a challenge. A majority of the key informants in this study indicated that older adults do not adequately plan for their future long-term care needs. Older adults may save for retirement, but not specifically with long-term care expenses in mind. Of those respondents who felt people did plan, most felt that this planning started around the time of retirement, not before.

D. Types and sources of information used in decision-making

This study asked a number of questions about the types and sources of information that consumers and their family members now use for long-term care decision making, and what would be most helpful for them.

Sources of Information

Both consumers and their family members used word-of-mouth from family, friends, and others as their primary information source, with 51 percent of both of these groups mentioning this source. This is likely a preferred source of information because it comes from a credible and trusted source, and it provides real examples of what benefits or difficulties a consumer has experienced when receiving particular long-term care services or assistance. A full 93 percent of professionals use word-of-mouth information as a source. Word-of-mouth can also extend to the tools now available that report and rate services based upon consumer feedback. Tools such as report cards that display and report consumer satisfaction are gaining popularity.

Other sources used frequently by consumers included Senior LinkAge Line® (35 percent) and other community-based resources (19 percent). Family members used other community-based resources (24 percent), Senior LinkAge Line® (20 percent) and the Internet (15 percent). For these family members, "other resources" were the largest source at 60 percent, which illustrates

the wide diversity of sources that people use for information. When asked which information source was most helpful in their search for long-term care services, consumers found word-of-mouth and Senior LinkAge Line® most helpful; their family members mentioned community-based resources and word-of-mouth as most helpful. (These figures are likely to over-represent actual use in the population since a majority of the sample for this study was drawn from a list of Senior LinkAge Line® callers.)

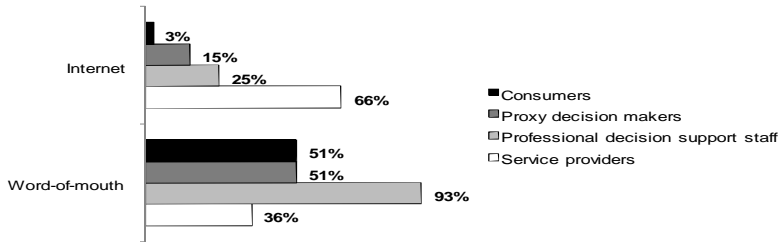
Information about long-term care is widely available to consumers and their family members on the Internet.⁹ However, very few consumers and their family members reported using the Internet as a source of information about long-term care. Ironically, the majority of service providers indicated that the Internet is a marketing strategy used by their organizations, and 66 percent use the Internet as a source of information. Most health care professionals and service providers who participate in decision-making do have ready access to the Internet, and may therefore assume that consumers (and especially their family members) have easy access to and familiarity with computers and online formats, but this is not necessarily true. (See Figure 4.)

Types of Information

Both professional decision support staff and service providers who participated in this study indicated that consumers and their family members are most interested in what services are available and when. They are also very interested in price, impact of service on quality of life, payment sources accepted, safety and security, location, and staff qualifications.

Most long-term care information is not standardized, making it difficult for consumers to compare across services types and among providers. A review of resources available, including MinnesotaHelp.info® and private sector sources, found inconsistent and/or complex terminology among and across provider types. Other research completed on this topic draws a similar conclusion.¹⁰ Because so many sources of information exist, different names for the same types of services abound, e.g., home care, home health care, in-home services. The use of taxonomy codes by MinnesotaHelp.info® has increased the consistency in the use of terminology throughout the system.

Figure 5. Sources of information and influence regarding long-term care information



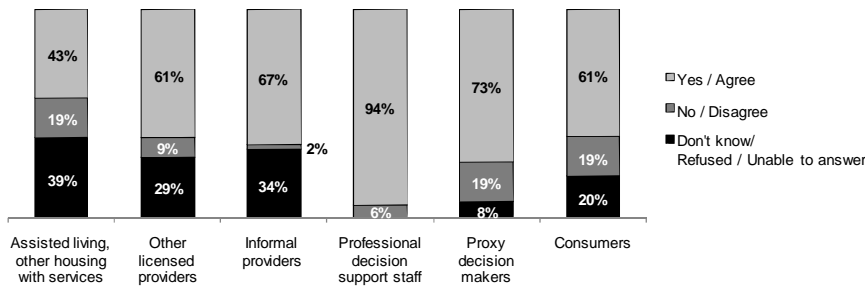
*** Note.** For consumers and proxy decision makers this is the percent of respondents who said this was a source of information for them when they were looking into getting long-term care services. For service providers, this is the percent who said that word-of-mouth has “a lot of influence” over their consumers and the percent who said that the Internet is a primary or secondary marketing strategy used by their organization. For professional decision support staff this is the percent of respondents who said these sources have “a lot of influence” or “some influence” over long-term care decisions, and for the Internet, this is the percent who said specifically that *MinnesotaHelp.info*® was the source (these respondents were not asked more generally about the Internet as a source of information).

While there is a difference of opinion about consumer and professional awareness of long-term care service options, all agree that clarity about options and organization of information for ease of comparison is lacking. Nearly 80 percent of the professional decision support staff who participated in this study agree that older adults are not aware of existing services in their community, and 65 percent indicated that *other professionals* are not aware of existing services. A full 46 percent think that it is hard for older adults to find information about available services, and 66 percent think it is hard or very hard for older adults to find cost information about long-term care services in their community. While only about 10 percent of the family members in this study said that it was “not at all easy” to get information about available services in their area, these respondents also reported having difficulty getting information about price, criteria under which services might be discontinued, and coordination of care across providers.

E. Additional information and formats that would be helpful

High proportions of non-housing service providers, professional decision support staff, consumers and family members who responded to the surveys believe that the State should ensure that standard price and quality information is available for housing with services, assisted living, and in-home services. A smaller proportion (43 percent) of assisted living and housing with services providers believe that the State has a role in making this information available. (See Figure 6.)

Figure 6. The State should make long-term care price and quality information available to consumers



There are some efforts already underway to provide more standardized, user-friendly information on housing and services for both consumers and their family members and professionals in the system. These are described below.

Efforts at Standardizing Information

The Uniform Consumer Information Guide (UCIG). This guide provides a model for the provision of standardized, reliable information about long-term care services for consumers and professional decision support staff. The UCIG, developed by the Minnesota Department Health in consultation with a stakeholder group, contains a standard list of 43 services as well as a variety of housing features presented in a uniform format. These services fall into three categories: 21 are support services (such as meals, low sodium and diabetic diets, laundry, assistance with bills, activities and socialization, transportation, and access to community resources); eight are personal care services (such as help with dressing, grooming, bathing, and transferring); and 14 are health-care related services (such as availability of registered nurse on-site, medication set-ups, insulin injections, wound care, and oxygen management). In addition, facilities may list “other” services in each category and indicate whether they are part of the base rate. Assisted living programs must make the UCIG available to all current and prospective residents.

Rates for “base packages” offered (which may include meals, supportive services or health services in addition to rent) are included in the UCIG. The type and amount of services included in the base rates vary by provider. Virtually all providers include some services, such as activities or meals in addition to rents in their base rate. Providers indicate which services, but not the amounts or the specific costs, that are included in the base rate. Base rates range from \$120 to \$10,000 per month. (It is assumed that the lowest rate reflects a subsidized apartment.) The middle half of the range has maximum base rates of \$1,775 to \$3,775 per month.

A full 72 percent of housing with services establishments indicated that they offer services in addition to those included in the base package. Price information on these additional services is

not included in the UCIG. About 12 percent of housing with services establishments indicated that a list of additional services available along with a fee schedule is posted on MinnesotaHelp.info® and 14 percent of housing with services establishments indicated that this information is posted on their own website. The cost of “rent only” is not delineated in the UCIG.

Only assisted living providers are required to complete the UCIG. Other housing with services providers and other home and community-based care providers do not have a standard format for providing such information to current and prospective consumers.

The Minnesota Department of Health (MDH) and the Minnesota Board on Aging (MBA) are collaborating to improve the reliability of information in MinnesotaHelp.info®. Housing with services establishment registration submitted to MDH has been “streamed” into MinnesotaHelp.info®, and MDH is currently working with the MBA to make the information from the UCIG available through MinnesotaHelp.info®. This will allow consumers to more easily compare assisted living programs. Consumers will be able to view a side-by-side comparison of assisted living providers for specific features by accessing this database on the Internet and will also be able to print the complete UCIG for providers of interest. This improvement, which is anticipated by summer 2009, will greatly enhance the reliability and comparability of information and ease of access.

The Long-Term Care Choices Navigator tool on MinnesotaHelp.info®. This tool was designed to help Internet-savvy consumers, family members, and professionals identify providers that offer appropriate services in the consumer’s preferred geographic location. This tool asks the user a series of questions about location, service needs and preferences, and then generates a list of service providers from the MinnesotaHelp.info® database that offer services in the consumer’s preferred location. The consumer or family member must then contact each provider individually in order to obtain complete information about current availability, cost, etc. While MinnesotaHelp.info® uses taxonomy codes to classify services, much information is still provided in narrative form which makes it difficult to compare this information among providers and across services, or to use this information if a language other than English is required.

The Nursing Home Report Card. This report card provides quality information about nursing homes in Minnesota and incorporates dimensions of quality that are important to consumers and their family members. It is web-based (www.health.state.mn.us/nhreportcard) and interactive, allowing the user to select three measures most important to them and obtain the ratings for three nursing homes at once to compare. The report card uses a five star rating system within each of the quality indicators. The information is updated either quarterly or annually, depending on the data source/measure. It includes information for 383 nursing homes in the state that are certified to participate in the Medical Assistance program. Seven quality measures are included:
1) resident satisfaction and quality of life; 2) clinical quality indicators; 3) hours of direct care;

4) staff retention; 5) use of temporary nursing staff; 6) proportion of beds in single bedrooms; and 7) state inspection results. It receives 50,000 hits per year. Comparable information is not yet available for assisted living, housing with services, or in-home services, but this offers a good model for replication.

With regard to housing providers, some private market resources exist that provide some indication as to what type of quality information might be obtained. In some cases, private marketing firms help providers compare their services to a peer group of other providers with which they compete. One such service is utilized by many providers in Minnesota to assess their senior housing programs. Each provider administers a customer satisfaction questionnaire and then receives its tabulated results compared to a group of other programs surveyed by the company. This information is kept private and providers are not given the names of the other organizations in their peer group, but they are able to compare their organization's results to a "benchmark" of similar providers. It is unlikely that such private information will be available to consumers, but the state can take cues from the type of information collected and analyzed by these sources, and use it as another model (in addition to the nursing home report card and the UCIG) for developing a public report card for the rest of the state's long-term care services and settings.

F. Demographic differences in long-term care use

Long-term care needs and preferences differ by location, race/ethnicity, gender, and family situation. Most older adults prefer to age in place in the community where they have spent their lives. This means that communities need to have available a range of long-term care service options for their residents.¹¹ Older adults in rural areas are more likely to have less education, fewer financial resources, and more health problems compared to their urban counterparts,¹² so there may be a need for a different blend of services and settings in rural areas. This may also mean that the type and sources of information and assistance in choosing long-term care options need to be rethought to better meet the needs of older adults in rural areas.

One of the significant differences in service utilization between Greater Minnesota and the Metro area can be seen in the use of assisted living services. In 2008, 35 percent of EW recipients from Greater Minnesota were authorized for customized living services (a bundled package of services provided in an assisted living or housing with services setting), compared with 24 percent of recipients from the Twin Cities Metro area. This is likely related to the general lack of home health services in rural areas to provide service in people's homes. For example, 73 percent of all professional home health agencies in Minnesota (those holding Class A licenses) are registered in the Twin Cities. In other words, older adults who live in Greater Minnesota do not have as many home-based service options available to them, e.g., night care, weekend care.

There are also gender differences in the use of EW services. In 2008, female EW recipients in Minnesota were more likely than male recipients to be authorized for customized living (32 percent

vs. 27 percent). Men are more likely to receive care from family and friends and are less likely to use formal long-term care services, 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.

Widowed older adults or those who have never married have a greater probability of using long-term care services, whereas married individuals are less likely to use any services because caregiving responsibilities tend to fall on spouses.¹³ Older adults with children are more likely to rely on an informal system of care (typically adult daughters) rather than depending on formal long-term care.¹⁴ Due to changing demographics, formal long-term care could be in higher demand in the future. Families have provided most of the care needed by older adults in the past, yet one-third of baby boomers do not have children and, therefore, may not have a traditional informal care network available.¹⁵

Differences Among Elders in Ethnic, Immigrant and Tribal Communities

There are also substantial differences in service utilization between White elders and elders in ethnic, immigrant, and tribal communities. Whites are more likely to leave their own homes/families and move into assisted living than are minority elders.¹⁶ In 2008, 36 percent of White EW recipients in Minnesota were authorized for customized living compared with only 11 percent of minority elders receiving EW services.

Many elders in immigrant communities have concerns regarding basic needs such as money for food and shelter, citizenship and immigration, and other issues related to previous traumatic experiences. Planning for long-term care necessarily becomes a lower priority for these individuals. Focus group participants in this study, who represent African American, American Indian, Hmong, Latino, Russian, and Somali elders, described a variety of cultural factors that influence or limit their ability to plan for or use long-term care services. Factors that influence their attitudes and decision making include language and citizenship barriers, cultural isolation, desire for traditional food, and preference for long-term care and social services that support or acknowledge their religious traditions. Several of the elders mentioned immigrant or citizenship status as a barrier to getting the long-term care services they need.

Hmong, Somali, Latino, and American Indian elders mentioned that an inability to read and write in English limits their ability to obtain information and to communicate with providers and professionals. Several American Indian elders noted that there is a lack of services that are specific to the American Indian community. African American elders mentioned that someone of their background might not use services because of fear that caregivers would steal from them. Latino elders provided several reasons that a Latino elder may not use long-term care services such as pride, the perception that children should take care of their parents in old age, and the fact that some may feel they will not get help because they are Latino.

Furthermore, 41 percent of professional decision support staff who participated in this study felt that it is “somewhat hard” and another 18 percent feel it is “very hard” for minority members of their community to get information about the cultural appropriateness of various services. Participants in each elder cultural group mentioned that older adults of their backgrounds may not use long-term care services because they do not know about them.

Part II.

Long-term care consumers and their financial self-sufficiency

The second part of this report provides more detailed findings related to the financial aspects of long-term care decision making. It also looks at the State's potential role in extending the self-sufficiency of older adults who use long-term care services. Part II examines:

- A. Information available to consumers and family members regarding long-term care financing
- B. Gaps in information and services that affect financial self-sufficiency
- C. Consumer awareness of housing options
- D. Demographic differences in long-term care financial planning

A. Consumer and family member knowledge of and access to information about long-term care financing

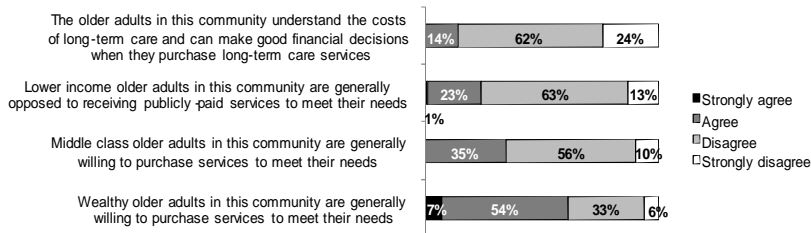
In general, older adults prefer to remain financially independent and avoid use of State-paid services. However, in some cases, this means that the older adult chooses to go without services they need rather than paying out-of-pocket, which can result in subsequent higher demand for crisis-based services.

Research on the topic of attitudes toward personal responsibility for long-term care costs vs. public responsibility for these costs is inconclusive. Some research suggests that older adults value personal freedom, independence, and quality of life more than their ability to make bequests to their relatives.¹⁷ *Disincentives* for depletion of personal financial resources identified in one study included losing control of one's assets, Medicaid stigma, and perceived immorality of strategies to deplete personal assets in order to qualify for publicly funded long-term care. *Incentives* for maintaining financial self-sufficiency included preservation of one's estate and protection of a spouse.¹⁸ Two other studies found that when wealth transfers to family members occurred prior to Medical Assistance (Medicaid) eligibility, the amounts transferred were often modest, and these transfers were often used by family members to pay for elder care not covered by Medical Assistance (Medicaid.)¹⁹

In our study, most consumers and family members did *not* believe that the government should pay for both nursing home and in-home services needed by disabled older people. However, most professional decision support staff reported that older adults in their community do not understand

the costs of long-term care and therefore are not able to make good financial decisions when they purchase long-term care services. (See Figure 7.)

Figure 7. Professional decision support staff: Consumers' awareness of and willingness to pay for long-term care services



Most family members who participated in this study said that they had considered how services would be paid for when they were searching for long-term care for the consumer. Most consumers stated that they had originally planned to use personal savings or Social Security to pay for their long-term care needs. These plans did not vary much by income, although higher income consumers were slightly more likely to have long-term care insurance. Several consumers also reported that they had no plans for how to pay for long-term care services, had not looked into it or thought about it, or were still considering it. This is a concern, since all of the consumers and family members who participated in this study were either currently receiving services or seriously looking into obtaining services for imminent needs.

Although some Internet resources are available to aid in financial planning for long-term care, these issues are so complex that the appropriateness and accuracy of Internet-based individualized recommendations are questionable. For example, the federal government offers a Long-Term Care Planning Tool (www.longtermcare.gov) that guides consumers through care planning and financial planning. However, the financing plan only describes a few different service options and what the potential cost might be to the consumer, based on their geographic location. The Minnesota Department of Human Services website also offers an eligibility calculator that can help consumers determine if and when they may become eligible for Medical Assistance, but this site does not offer consumers any advice regarding how to maintain their financial self-sufficiency.

Efforts to provide consumers with information about all options are at odds with recommending only the most cost-effective options. In some cases, the professional decision support staff who participated in this study reported discussing higher cost services such as assisted living, housing with services, or nursing homes with older adults who were experiencing specific needs that could potentially be met with informal and/or community-based services. The options that professionals discussed with consumers did vary by type of situation. Presumably they did this

in order to provide all the options available to the consumer and their family members. (See Figure 8.)

Most of the key informants who participated in this study indicated that in-home and community-based services--especially chore and homemaker services, transportation, and home modifications or supports--are the most overlooked of all long-term care services. Other overlooked services are case management and advocacy. Informants also reported that services for caregivers, such as respite and caregiver coaching, are under-utilized due to limited availability in certain communities, a general lack of awareness about these services, and/or lack of caregiver interest.

Figure 8. Types of services professional decision support staff discuss with consumers in various situations

Older adult's situation	In-home services	Services in the community	Assisted living or housing with services	Nursing home	None of these services
Difficulty with home maintenance	83%	50%	50%	20%	3%
Wants to move to be ready for future needs	37%	43%	88%	33%	3%
Wants to move to be closer to friends / for socialization	32%	70%	72%	24%	6%
Prefers to pay for services than do it themselves	80%	66%	51%	16%	7%
Spouse/partner passes away	80%	76%	58%	23%	7%
Wants a smaller place	27%	39%	79%	17%	11%

Note. Respondents were asked, "Which long-term care service options do you typically discuss given each of the following situations?" Respondants replied, "yes" or "no" to each of the options.

B. Gaps in information and services affecting financial self-sufficiency

Planning for future long-term care needs is limited, often because older adults and their family members are overwhelmed by the complexity of the long-term care system and their lack of preparation to make such decisions. One of the recurring themes throughout the literature is that long-term care decisions suffer from a lack of consumer knowledge and skills, not a lack of raw information. After surveying middle-aged people, mainly baby boomers, for levels of financial literacy, one study found that basic literacy was lowest in areas of health care and long-term care.²⁰ Another study found that "over 40 percent of Americans mistakenly believe that long-term care is an entitlement that all Americans are eligible for at retirement."²¹

Awareness about the cost of long-term care services is lacking among consumers and their family members. A longitudinal study of long-term care insurance buyers and non-buyers concluded 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.²²

Consumers and their family members who participated in this study were asked how much they believed staying in a nursing home in their area would cost if they had to pay the entire cost out-of-pocket. Many consumers (31 percent) and their family members (21 percent) stated that they did not know. Of those consumers who did venture a guess, they offered monthly estimates ranging from \$500 to \$9,000 with a mean of about \$3,309. Family members, however, tended to estimate a lower mean monthly cost of \$2,700 (with a range from \$1,200 to \$10,000).

When asked how much they thought an assisted living in their area would cost if they had to pay the entire cost out-of-pocket, many consumers (39 percent) and family members (29 percent) stated that they did not know. Consumers who ventured a guess offered monthly estimates ranging from \$200 to \$10,000 with a mean of about \$2,390. Family members tended to provide higher monthly estimates than consumers, which ranged from \$700 to \$10,000 with a mean of about \$4,340.

There are currently a few private financing options but none have experienced major take-up rates. Long-term care insurance is not utilized as a mechanism for older adults to maintain their financial self-sufficiency. Cost of the premiums and existing health issues are the primary barriers to purchasing long-term care insurance. In 2005, about 7 million long-term care insurance policies were in force in the U.S. The typical purchaser was age 61. Almost half of purchasers had incomes over \$75,000 and more than three-quarters of purchasers had over \$100,000 in liquid assets.²³ It is estimated that only 10 to 20 percent of older adults in the U.S. can afford long-term care coverage.²⁴ Furthermore, older adults with prior health problems have difficulty purchasing private coverage: about 15 percent of applicants may be denied insurance due to health problems.²⁵

When asked the most important reason for buying long-term care insurance, about one-third of participants in one study said “to protect assets or leave an estate.” Avoiding dependence was most important to 25 percent, guaranteed affordability was most important to 18 percent, and being able to protect living standards was most important to 14 percent of participants.

Some researchers have hypothesized that government programs create incentives for consumers to avoid financial planning. There is a small literature in finance that suggests Medicaid or other government programs may “crowd-out” private long-term care insurance.²⁶ In other words, the existence of Medicaid acts as an economic substitute for long-term care insurance, reducing demand for the insurance. Empirical studies to date show little or no “crowding out.”²⁷

At the State level, information is not available about the financial situation of consumers who are using assisted living, housing with services, or in-home long-term care services until these individuals become eligible for State-paid services. This is in contrast to consumers who live in nursing homes, for whom the State has regulatory authority to obtain information about both public-pay and private-pay consumers directly from their service providers. This information about nursing home consumers enables the State to predict with some degree of accuracy what proportion of private-pay consumers can be expected to become eligible for State-paid services within various time periods.

C. Consumer awareness of housing options and their costs

A majority of consumers and family members who participated in this study reported that they would rather stay in their own homes than move to nursing homes, assisted living, or other senior housing, even if that meant they would pay more to stay in their homes. Because of this stated preference for remaining in their “own homes,” education about home and community-based services--seen as an alternative to nursing home care--is more readily accepted by consumers.²⁸

The professional decision support staff who participated in this study reported that older adults in assisted living (or other housing with services which charge a “package rate” or base rate) do not understand how much they are paying for rent versus how much they are paying for services, or even understand that they are paying for both housing and services. Because Medicaid does not pay housing costs for low-income persons (unless they are in nursing home settings), the separation of pricing for rent versus services is a critical factor for consumers and professional decision support staff to understand if and how the consumer will be able to stay in that location once their private assets are depleted. “Special Income Standard” Elderly Waiver (EW) recipients are allowed to keep \$860 per month for their “Maintenance Needs Allowance” (MNA) to cover room and board costs and personal needs. The EW (Medicaid) does not cover housing or raw food costs. Therefore, anyone who is at risk of depleting their personal assets needs to know what their rents and raw food costs will be, in order to determine whether their MNA will be adequate to cover their rent and food in the current housing if they rely on EW to pay for their services.

Services are typically bundled into the base rate along with rent. This may result in consumers paying for services that they do not need or use. This bundling also results in consumers having less real choice among possible service providers, since they would have to pay twice for the services they need if they decide to purchase services included in their base rate from another provider. While it is helpful for consumers and their families to anticipate their long-term care needs by moving to environments that have the capacity to meet future needs, it is problematic if they deplete personal resources more quickly due to purchase of unneeded or unwanted services.

There are indications that this situation is causing problems for consumers. In 2008, of the 384 complaints handled in home and community residential settings by the Office of Ombudsman for Long-Term Care that assists consumers with problem-solving in these settings (housing with services including assisted living, adult foster care settings, and residential hospice), 16 percent were related to termination of tenancy, transfer, or moves into the setting.

At the State level, data on EW recipients indicates that consumers may be spending down to public program eligibility more quickly in assisted living than if they were receiving in-home services. In 2003, less than half of new EW recipients using Medicaid for the first time were authorized for customized living during their first month on the program, compared with two-thirds of EW recipients in 2008 (using data through August). While in-home services may not have been appropriate for all of these consumers, it is likely that at least some of these individuals could have been supported in their own homes for lower cost, thereby saving the State's resources.

D. Demographic differences in long-term care financial planning

Changes in the population of older adults who are receiving the EW over the past five years indicate that there are some demographic differences in financial planning. However, caution should be used when interpreting these results. Since older adults from certain demographic groups (rural, minorities, etc.) are more likely to be lower income before reaching the age of 65, it is important to note that any differences observed in these characteristics of the EW population could be due to pre-existing differences in financial status rather than differences in financial planning per se.²⁹

For example, “young-old” (age 65 to 69) individuals, males, and Twin Cities residents made up a higher proportion of the EW population in 2008 compared with 2003. This may indicate that these demographic groups are struggling more financially today than they were five years ago. These changes might also point to groups that the State could potentially focus on for increased financial planning to prevent or delay eligibility for State-paid services.

Use of higher cost services among older adults in Greater Minnesota versus the Twin Cities may indicate a lack of lower cost service options in these areas. One study found that a lack of resources in rural areas, particularly medical specialists, may play a role in this phenomenon. The hypothesis is that nursing home care substitutes for more specialized medical treatment in areas where that treatment is not available.³⁰

Older adults in ethnic and immigrant communities report differences in their attitudes toward payment of long-term care services and face unique challenges in paying for long-term care services. All of the focus groups conducted with ethnic and immigrant elders in Minnesota for this study included some discussion of their reliance on public programs such as Supplemental Security Income, Medicaid, Medicare, Food Stamps, or MinnesotaCare. The elders consistently

stated that they felt that these programs did not provide enough money to meet their cost of living or sustain their self-sufficiency. Many African American elders mentioned the fear that if a crisis occurred or if they did not have help from family, entering a nursing home would result in the majority of their income going to pay for those services. African American and Latino elders stated that the practice of linking the cost of many services to an elder's income often results in the elder having very little money left over at the end of the month. Latino, African American, and American Indian elders discussed the high cost of transportation as a barrier to elder mobility. Also, many of these elders discussed the lack of citizenship or refugee status as a barrier to programs that can help pay for services. Latino elders remarked that without public assistance many elders could not afford a nursing home, while Hmong elders noted that many had to enter nursing homes because they did not have enough money to sustain their own household.

Appendix

A. Study methods

B. Increasing older adult population in Minnesota

Appendix A. Study methods

This Appendix briefly describes the methods used for each phase of this study. See the full study reports (links provided) for more detailed information about the methods used.

Research plan

The research plan is the primary document that describes the specific methods and approaches the study team used to complete the study. Staff members from DHS, Wilder Research, and other stakeholder organizations participated in various aspects of this project. While developing this plan, the researchers from Wilder met with the study's stakeholders to further specify the research questions that guided the study design and implementation, to increase our knowledge of all of the systems and organizations that are involved in long-term care planning and service provision, and to learn about the sources of data that already exist that could inform this study.

See the full research plan at http://www.dhs.state.mn.us/main/dhs16_144477.

Literature review

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 study's research questions were included. Most of the items included in the 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. See the literature review report http://www.dhs.state.mn.us/main/dhs16_144477 for a complete bibliography – studies referenced in this report are cited in footnotes.

Provider and professional decision support staff web surveys and key informant interviews

During April and May 2008, Wilder Research interviewed 52 key informants who were identified by DHS and this study's stakeholder group to qualitatively examine key issues related to long-term care decision making and financial self-sufficiency of older adults. These interviews were used to develop the surveys used in this and other phases of the study. Key informants include long-term care providers, professional decision support staff, advocates or representatives from health plans, legal services, or financial planners.

In September and October 2008, Wilder Research administered a web-based survey to long-term care service providers to examine, from their perspective, how long-term care decisions are

made, what resources are used to make these decisions, who is involved in the decision, and how the costs of long-term care affects the financial self-sufficiency of consumers. Overall, 433 providers completed part or all of the survey, for a response rate of 38 percent.

In September and October 2008, the DHS administered a web-based survey to professional long-term care decision support staff to examine, from their perspective, how long-term care decisions are made, what resources are used to make these decisions, who is involved in the decision, and how the costs of long-term care affects the financial self-sufficiency of consumers. Overall, 409 professional decision support staff completed the survey. It was not possible to determine response rates for this survey since unique identifiers were not used in the invitation (lead agency staff was used to distribute the survey more widely to other professional decision support staff).

See the Appendix of the provider and professional decision support staff web survey report for detailed information about the characteristics of participants in this phase of the study http://www.dhs.state.mn.us/main/dhs16_144477.

Secondary data analysis

Various data sets produced by State agencies were identified and analyzed to see how they might shed additional light on the specific research questions being considered in this project. This phase of this study was designed to glean information from a variety of existing sources of information, primarily within the State, that bears on the study's key research questions. Four major sources of information were identified as having information of potential value to this analysis:

- **Senior LinkAge Line®** is a telephone information service operated by the Minnesota Board on Aging (MBA) to provide information to seniors and their representatives. Senior LinkAge Line® maintains a database of callers, types of questions and concerns, and referrals made.
- **MinnesotaHelp.info®** is an Internet site operated by the state of Minnesota Board on Aging. Information from housing with services establishment registration, home care licensing collected by the Minnesota Department of Health (MDH) is included in MinnesotaHelp.info®. Consumers can sort through a variety of search topics including help with care, adult day services, Medicare, senior housing, and prescription drug help. There is also a “Long-Term Care Navigator” feature which leads consumers through a series of questions and then indicates appropriate types of services. The system is also a resource for counselors of older adults and is used by the counselors of Senior LinkAge Line®.
- **Medicaid Management Information System (MMIS)** is the principal database used for administering Medicaid in Minnesota. The system includes information on individual recipients and their health and service needs and payments made. Information on approximately 40,000 EW recipients in 2008 and 2003 was inspected and compared statistically.
- **Uniform Consumer Information Guide (UCIG)**. By statute, assisted living facilities in the state are now required to provide this information in a standardized format to all current and prospective residents as of January 1, 2008. This information is being compiled by the Minnesota Department of Health and will be incorporated into MinnesotaHelp.info®.

In addition to these four primary sources, relevant information was received from the Office of the Ombudsman for Long-Term Care. This data consists of reports on the type of complaints received by the Office relating to housing and some additional data on the number of callers who call and receive information and consultation pertaining to home care and housing options.

A cursory investigation of some non-governmental sources of information available to consumers, chiefly through the Internet was also conducted in order to better ascertain what older adults and their proxy decision makers face when contemplating long-term care choices. In particular, various searches were done and approximately a dozen of the most promising websites and directories were explored in some detail to see what information would ultimately be available to the consumer looking to make decisions about long-term care choices.

Consumer and proxy decision maker surveys and focus groups

During November and December 2008, Wilder Research conducted phone interviews with 249 long-term care consumers in Minnesota. Consumers were identified in one of three ways. First, all individuals who became eligible for the EW or Alternative Care (AC) programs within the previous six months were sampled, except in cases where the consumer was listed as having a legal guardian. Second, all consumers who had called Senior LinkAge Line® in the previous six months were sampled. Finally, the Minnesota Department of Human Services sent letters to selected service providers who offer informal, community-based long-term care services such as transportation or companion services, asking these providers to recruit some of their clients for the study. These consumers were then invited by their service providers to contact Wilder Research directly if they were interested in participating. Overall, interviews were conducted with 177 consumers identified through Senior LinkAge Line®, 31 consumers receiving AC, 22 consumers receiving EW, and 19 consumers who opted-in after being invited by their service providers. All consumers who participated provided informed consent, through the process approved by the Minnesota Department of Human Services' Institutional Review Board.

In addition to consumers, interviews were conducted with 150 proxy decision makers associated with those consumers. Specifically, the Minnesota Department of Human Services sent email requests to the county case managers of all of the sampled EW and AC consumers asking that they provide some basic information about these consumers, including the names and contact information for any adult children or other individuals who helped that consumer with their long-term care decisions. Consumers were asked for permission before these proxy decision makers were contacted. Consumers who were surveyed were also asked to provide names and contact information for up to three people who helped them with their decisions. Through this process, one or two proxy decision makers were interviewed for some consumers, whereas other consumers were not able or willing to provide the names of any proxy decision makers (in some cases because they made their long-term care decisions completely on their own).

Finally, in October and November 2008, six focus groups were conducted with ethnic/ racial specific groups of older adults to examine the ways in which the awareness of, attitudes toward, and actual use of long-term care services varies by race/ethnicity. Groups were targeted based on their prevalence in Minnesota, mainly in the Twin Cities area, and included: African Americans, American Indians, Hmong, Latino, Russian, and Somali groups. To complete these focus groups,

Wilder Research partnered with six community-based organizations that provide services to the targeted racial/ethnic groups in order to facilitate recruitment and comfort level of participants. All participants completed informed consent. Groups were facilitated in the participants' primary languages.

Strengths and limitations of this study design

The primary strength of the methodology used for this study is that data is available from a variety of perspectives, which allowed observations of themes or trends that cut across groups and examination of areas in which differences in perspectives may contribute to or cause challenges or issues with regard to long-term care decision making or financial planning for long-term care. This approach makes this study unique, as most research on this topic (and others) rely on the perspectives of only one group, which can severely bias the findings toward that one group's opinions.

The primary limitation of the methods used for this study is that the samples of respondents from each group are not statistically representative of the populations for those groups (because random selection techniques were not used due to budget constraints and other feasibility issues), so caution must be used when interpreting the results. In all cases, the samples sizes obtained for each population are large enough that the findings can increase our understanding of areas of strength, areas that pose challenges, and areas in need of further research.

Specifically, the service provider and professional decision support staff web survey respondents and key informants are not necessarily representative of the entire population of providers or professional decision support staff in Minnesota. The providers were selected from the MinnesotaHelp.Info® database (including all providers who offer assisted living or other housing with services, and in-home services for older adults), so those providers that are not registered in this system were not eligible to be sampled for this survey. Also, the professional decision support staff were recruited in some cases by DHS through lead agency staff, and in some cases directly through their individual email addresses (for Senior LinkAge Line® staff), so it is even more difficult to determine the extent to which these respondents may or may not be representative of all professional decision support staff in Minnesota.

Also, it is important to note that the data reported here for consumers and proxy decision makers is not necessarily representative of these populations because: 1) only consumers who were cognitively and physically able to participate in the study (and legally allowed to consent for themselves) were surveyed, and it is likely that these consumers under-represent consumers who had long-term care decisions made for them; and 2) because the proxy decision makers interviewed were identified by the consumers' county case manager or the consumers themselves as people who helped the consumer, so these respondents are likely to over-represent the perspective of consumers who were influenced by others when making their long-term care

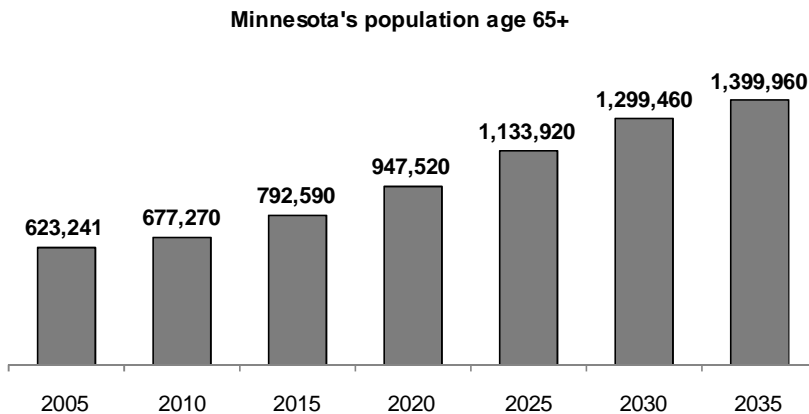
decisions. Based on the resources available to Wilder Research through the Minnesota Department of Human Services, identifying private pay consumers to participate in a study of this type is very challenging, since DHS does not have information on private pay consumers (other than those who have called Senior LinkAge Line® and/or those who live in nursing homes).

Appendix B. Increasing older adult population in Minnesota

The number of Minnesotans age 65 and older and the increasing proportion of older adults of color are expected to significantly impact the long-term care system:

Between 2010 and 2020, Minnesota's older adult population is projected to increase by 40 percent³¹ and by the year 2035, the Minnesota State Demographic Center projects the older adult population will approach 1.4 million. See Figure A1. A majority of this growth is expected from within the group of Minnesotans who are age 85 or older, increasing from just over 100,000 in 2010 to 250,000 by 2050.

A1. Projected growth of Minnesota's older adult population



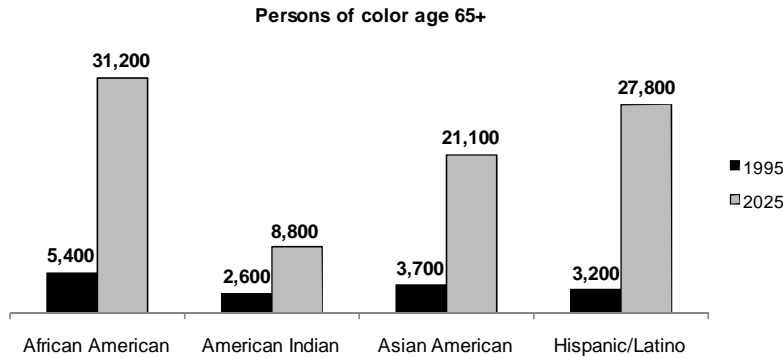
Source: *Minnesota State Demographic Center projections.*

The size of the older adult population is directly related to the demand for long-term care, since approximately 25 percent of older adults age 65 to 74 are disabled, in addition to 42 percent of older adults age 75 to 84, and 68 percent of older adults age 85 or older. Further, because the baby boom generation had fewer children per couple compared with the previous generations of older adults in Minnesota, this will result in: 1) fewer informal long-term care providers, 2) potentially fewer workers in the labor force available to the long-term care system, and 3) fewer earners to pay taxes to support the public long-term care support system.

Older adult populations of color have been growing rapidly over the past decade and will continue to expand significantly in the future. See Figure A2. Particularly in the Twin Cities metropolitan area, but also in certain pockets in Greater Minnesota, there are several immigrant/refugee communities that may present specific challenges to the long-term care system. The largest groups to consider are Latino, Hmong, Somali, and Russian. American-born

older adults of color, especially African Americans, Latinos, and American Indians are also growing populations with unique service needs and preferences.

A2. Growth in Minnesota's older adults of color populations



Source: *Minnesota Department of Human Services*

As described in the body of this report, older adults of color tend to have different long-term care service preferences, different needs, and different resources. Therefore, the State of Minnesota must consider not only the needs, preferences, and resources of the majority of older adults who are White, but also the supports and resources that will contribute to meeting the service needs and preferences and financial self-sufficiency of older adults of color.

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