

**The University of Kansas
School of Social Welfare
Office of Aging and Long Term Care**

**Examination of the Use of Medicare Home
Health Services and Informal Caregiving and Their
Relationship to Successful Community Tenure**

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Examination of the Use of Medicare Home Health Services and Informal Caregiving and Their Relationship to Successful Community Tenure

Executive Summary

Purpose

The Kansas Department on Aging (KDOA) and the Kansas Department of Social and Rehabilitation Services (SRS) contracted with the Office of Aging and Long Term Care (OALTC) at the University of Kansas School of Social Welfare to conduct the *Examination of the Use of Medicare Home Health Services and Informal Caregiving and Their Relationship to Successful Community Tenure* study. This study, referred to here as the Community Tenure Study (State Fiscal Year 2003), builds on previous research completed as part of *The Longitudinal Study of Customers Diverted through the CARE Program*, referred to as the Diversion Study (SFY 2002). The overall purpose of this project was to examine the use of Medicare Home Health Services and informal caregiving and their relationship to community tenure. The OALTC staff continued to track the diverted customers represented in the Diversion Study for an additional 6 months. The Community Tenure Study tracked additional information about Medicare Home Health utilization as well as community tenure status and publicly funded community-based services utilized over a 24 month period. Interviews were also conducted to explore the role of informal support and the relationship to community tenure.

The Community Tenure Study Report (SFY 2003) is divided into three sections. Each section in this report begins with the policy related questions that guided the study methodology and analysis, a brief summary of the findings and then a presentation of detailed findings. Section I provides the study background, purpose, and a summary of the relevant literature on caregiving. Section II reports on the community tenure of diverted customers and community based service utilization, including Medicare Home Health Services use data. Section II also includes the analysis of state publicly funded services (SPFS) costs and a cost-benefit analysis of SPFS compared to nursing facility (NF) costs. In addition, Section II includes a multi-variate analysis to identify NF risk factors for diverted customers, building on the one conducted for the Diversion Study (SFY 2002). Section III presents the analysis of interviews with older adult and caregiver dyads and analysis of other factors that contribute to community tenure or NF admission. The Report concludes with a presentation and discussion of the implications for policy makers and legislators.

Study Methodology

Both quantitative and qualitative methods were used in the Community Tenure Study (SFY 2003). Section II is based primarily on quantitative analysis of data and Section III is based on qualitative analysis of interview data. Section II reports the findings of the analysis of community tenure, risk factors for a NF admission, and cost benefits of SPFS compared to NF. These analyses are based on the same methodologies used in the Diversion Study (SFY 2002).

Section III reports findings from the analysis of interviews with older adults who had a CARE Assessment and their caregivers conducted for the Community Tenure Study (SFY 2003). These

interviews illustrate the perceptions of older adults and caregivers. The interview population was divided into three groups of caregiver-care recipient dyads based on these criteria: 1) long-term community residents who had a CARE Assessment 2-3 years prior to August 2002 and continued to remain in the community and their caregivers; 2) recently diverted customers living in the community who had a CARE Assessment in March of 2002 and their caregivers; and, 3) customers who have recently entered a nursing facility on a permanent basis following a CARE Assessment in March of 2002 and their caregivers.

Overall Community Tenure Study Implications

This section provides a summary of key policy findings and implications for policy makers. These findings and implications are based on quantitative and qualitative data collection and analyses.

➤ State Publicly Funded Services (SPFS) are Cost Effective

The annual savings gained by providing SPFS for diverted older adults in our sample during 24 months of tracking in lieu of NF services is \$202,968.96 for diverted CARE customers who received SGF services, \$441,524.16 for diverted CARE customers who received OAA services and \$2,010,888.30 for diverted CARE customers who received HCBS/FE services, including TCM. The total savings was \$2,665,381.42 for 24 months.

Diverted customers' use of SPFS in lieu of a NF admission continues to be cost effective. Most diverted customers use SPFS for a limited time and were able to successfully maintain community tenure. The SGF services were used for an average of approximately 2 months, OAA services were used on average for slightly over 1 month and the Medicaid-HCBS/FE and TCM services were used for an average of approximately twelve and one-half months. For every month a diverted service customer in the sample remained in the community with SPFS, the state saved \$671.46 if SGF services were provided, \$924.00 if OAA services were provided and \$597.32 if Medicaid-HCBS/FE and TCM services were provided. The cost benefit analysis was conducted with actual SPFS cost data for diverted customers for 24 months. This is an additional 6 months of service use data for the analysis compared to the analysis conducted for the Diversion Study (SFY 2002).

➤ Diverted Customers Continue to Have High Rates of Community Tenure

After 24 months of follow-up, 40.7% (n=244) of the diverted customers remained in the community.

These findings are even more remarkable when the number of living diverted customers residing in community settings is compared to living diverted customers who are permanent NF residents. There are 244 (65.9%) or nearly two-thirds of the living diverted customers residing in community settings 24 months after the CARE Assessment compared to the 126 (34.1%) living diverted customers who are permanent NF residents. Also, 165 (27.5%) diverted customers were residing in the community when they died and only 64 (10.7%) were permanent NF residents at the time of their death. Our understanding of how diverted customers and caregivers were able

to remain in the community was enhanced by the qualitative findings from interviews. Diverted customers and caregivers told us that determination and their ability to uniquely combine informal support and formal services were important factors in considering permanent NF admission.

- **New Data Confirm that State Publicly Funded In-Home Services, Medicare Home Health Services and Informal Support Play an Important Role in Diversion and Community Tenure**

Diversion and the maintenance of community tenure by diverted customers require the integration of publicly funded state and Medicare in-home services in combination with informal support.

Analysis of SPFS and Medicare Home Health Service use suggest these publicly funded programs have the greatest impact in the first three months following the CARE Assessment. Interview findings reveal that immediately following the CARE Assessment diverted customers' needs were greater because they are often recovering from acute health episodes, but they can remain in the community with support from formal and informal sources. Effective case management was instrumental in helping older adults and caregivers identify and mobilize the formal services.

Diverted customers who indicated Medicaid as a potential source of payment for support services are at greater risk of entering a NF permanently. However, using SPFS, especially Medicaid-HCBS/FE, reduces the risk of permanent NF admission.

In a statistical analysis that included all diverted customers, the variable “Medicaid as a potential payment source for support services” (a proxy variable for low-income) was a statistically significant risk factor for permanent NF admission. However, diverted customers who used SPFS did not have an increased risk of permanent NF admission. Since these service customers are generally, by definition, lower-income, it appears that using state publicly funded services mitigates their risk of a NF admission. The cost analysis for diverted customers using SPFS demonstrates that diverting and maintaining older adults in the community with SPFS as an alternative to a NF is cost effective for the state. In addition, qualitative findings from interviews with CARE Assessment customers and caregivers, including CARE Assessment customers who permanently entered a NF, found they lacked awareness of these services and programs. Increased outreach to low-income customers with encouragement to apply for Medicaid-HCBS/FE would help them to access services promptly, reducing their vulnerability to a NF admission.

Analysis of SPFS and Medicare Home Health data in addition to the interviews with diverted and non-diverted customers identified two types of CARE Assessment customers with distinct care needs.

Both quantitative and qualitative findings suggest there are two categories or types of diverted customers. One group of older adults experienced an acute health crisis that resolved with skilled nursing care and community based services such as Medicare Home Health and

HCBS/FE. Many of these individuals do not have an on-going need for community-based services. Approximately two-thirds of the diverted customers did not use SPFS and/or Medicare Home Health anytime after their CARE Assessment. The second category of diverted customers have an acute health crisis or episode that is resolved; however they have on-going chronic health conditions that require community based services such as Medicaid-HCBS/FE and/or SGF and OAA services. These customers use unique combinations of publicly funded and informal support in order to remain in the community.

Similarly, there are two categories of non-diverted customers. First, there are non-diverted customers whose acute care needs resolved; however they remained in a NF because they were unaware of community based services and/or they did not have a caregiver or case manager to advocate on their behalf for a discharge. Case management services would be a likely resource for these individuals to help them transition back into the community. Second, there are non-diverted customers with chronic on-going needs that would most appropriately be addressed in a NF setting. They will likely remain as permanent NF residents.

- **Medicare Home Health Services Provide Needed Skilled Levels of Care in a Home Setting Immediately Following the CARE Assessment.**

Diverted customers utilized Medicare Home Health Services to address complex health needs at higher rates in the first three months following the CARE Assessment.

There were 178 diverted customers who used Medicare Home Health at any time during the 24 months of follow-up, 73.0% of whom (130) used them only for three months. During interviews, diverted customers and caregivers reported their needs were greater following a discharge from the hospital or a NF. Interview data also revealed that many diverted customers and caregivers often were unfamiliar with community-based services, including Medicare Home Health Services. This suggests that a valuable opportunity exists for AAA staff to assist diverted customers in securing Medicare Home Health Services. Once diverted customers' post hospital care needs decrease, they can be transitioned to SPFS if they have continued chronic health problems.

Utilization of Medicare Home Health Services can offset state expenditures for community-based services.

The state accrues additional savings when considering the cost avoidance for diverted customers who use Medicare Home Health Services alone or in combination with SPFS. The cost reduction due to Medicare Home Health has potential implications for the referral of CARE Assessment customers to these services. When a CARE Assessment customer's assessed needs suggest Medicare Home Health Services may be appropriate, the assessor or case manager could make a Medicare Home Health referral recommendation to the attending physician. In addition to the state avoiding or reducing expenditures for in-home service, another important benefit for CARE Assessment customers is the receipt of a skilled level of care provided by Medicare Home Health agencies.

➤ **CARE Assessment Customers and Caregivers Exhibit Resilience and Creative Use of Resources to Achieve Diversion and Maintain Community Tenure.**

Interviews with diverted customers and caregivers identified strategies used to maintain community tenure after being diverted.

Three groups of CARE Assessment customers were interviewed. One group had been identified during the Diversion Study (SFY 2002) and was selected because they have been in the community for over two years following their CARE Assessment. The other two groups were recent CARE Assessment customers (March of 2002); one group was diverted and the other was non-diverted. The two groups of recently diverted and non-diverted customers were selected for interviews based on their Long Term Care Threshold score of 66 or less. This selection criterion was important for discussion regarding similarities and differences in the interview findings between recently diverted and non-diverted CARE Assessment customers because their impairment levels and care needs would be similar.

Recently diverted customers revealed their determination to remain in the community and not become permanent NF residents. Another key to their successful community tenure was a caregiver who would support the diverted customer's goal to remain in the community. These committed care receiver-caregiver relationships were established with family members, neighbors, other informal support and paid caregivers. Regardless of the familial relationship, the determination and commitment was a shared attribute of the diverted customer and caregiver. When factoring out non-diverted customers with extensive care needs that could only be provided for in a NF, this determination, commitment and an instrumentally supportive caregiving relationship typically distinguished the recently diverted customers from the recently non-diverted customers.

Diverted customers' ability to sustain their mental health and creatively utilize limited resources were important traits that helped them overcome the challenges they faced in order to remain in the community.

Many people who were initially diverted managed to continue residing in the community for long periods of time. Data from interviews with diverted customers illustrated how sustained mental health was important for older adults, enabling them to creatively identify solutions to the challenges they faced. Diverted customers found novel and efficient ways to use the limited resources available to them. These diverted customers were not discouraged by health problems and continued to take care of themselves to the best of their ability. In contrast, non-diverted customers reported depression and powerlessness when facing decisions about options to remain in the community. Their depression and discouragement contributed to their inability to undertake problem solving and develop plans to return home. The finding that sustained mental health is a vital part of community tenure highlights the need for adequate evaluation and treatment of problems such as depression.

Diverted older adults reported security and safety were important factors that enabled them to live in the community. Older adults and caregivers want the assurance that the older adult can get help when they need it.

Both diverted and non-diverted older adults and their caregivers reported that they could accept the risks, such as a fall or sudden illness that come with living alone, but did need support in order to feel safe. Personal emergency communication services are one way that diverted customers and their caregivers were able to develop a sense of security. Neighbors and family members also monitor older adult's home and situation to reassure them. In a few situations, non-diverted customers continued to reside in the NF despite improvement in their health and functioning because they did not have a sense of safety and security to live independently. Other options to provide a secure and safe environment include supported housing options such as assisted living.

➤ **Some Older Adults and Caregivers Reported They Encountered Barriers When They Attempted to Access Community Based Services.**

Many older adults and caregivers utilized informal networks to identify community based services to assist the older adult and caregiver. Even if they were aware of the Area Agency on Aging, many older adults and caregivers did not actively request assistance to learn about community-based options.

One barrier identified during interviews with diverted and non-diverted older adults and their caregivers was that many of them did not have a single person or agency they would contact for information or assistance. These CARE Assessment customers did not understand that the AAA was a single point of entry for community-based options, information, and referral. This meant that they did not have someone providing case management to assess and coordinate services as needed in response to changes in the older adult's condition. The single point of entry concept at the Area Agency on Aging and KDOA provides the older adult and caregiver with a connection to the agency and potentially a case manager. This finding points to the need for outreach and community education programs around the single point of entry concept.

➤ **The Importance of Case Management was a Consistent Theme in the Interviews with Diverted and Non-diverted Customers.**

Older adults reported that responsive, on-going, and resourceful case management was effective and helpful to them. When older adults and their caregivers had a case manager working with them, they could learn about services and gain access to services that would help them resolve caregiving needs.

One challenge older adults face is unmet care needs when their care needs become too great for the available informal support alone. Without a consistent and direct link to formal services through case management, most older adults and their caregivers lacked awareness about available services, believing that services were not available or that they would be insufficient or difficult to arrange. Many of the interviewed older adults and caregivers were not even aware of case management services. Older adults are at risk for nursing facility placement if they are unaware of services, service eligibility, and accessibility. While a number of older adults had successfully pieced together informal services to meet existing needs, they were at risk for nursing facility placement when their needs increased. Without case management services, some

older adults and their caregivers saw NF placement as the only possible next-step rather than NF as one choice among several options for formal assistance.

Effective case managers develop a positive working relationship with older adults and caregivers.

Case management requires well trained and qualified case managers to deal with a multitude of interpersonal and practical needs of older adults as they attempt to achieve their goal of remaining in the community. Older adults and caregivers reported during interviews that positive working relationships with their case manager included a shared commitment to the goal of remaining in the community. Once a trusting relationship was established, older adults and caregivers utilized the expertise of the case manager when facing new challenges. What was helpful to these diverted customers and caregivers was knowing they could turn to one person, such as the AAA case manager, to help them as needed. In addition, case managers need to be able to maintain contact with older adults as a means to ensure their care plan is continuing to meet their needs.

As noted earlier, chronic health problems and disability are frequently accompanied by depression. Case managers need to be attentive to signs that older adults are experiencing mental health problems that will interfere in their successful community tenure. In addition to the professional counseling and support of the case manager, referrals to mental health resources may also be required. The case manager needs to be professionally trained and qualified to detect these mental health problems and then proactively respond. A positive working relationship between the case manager and older adult will promote the identification and amelioration of these mental health problems. The interviews clearly pointed out that the maintenance of the mental health of older adults and caregivers was key to community tenure.

- **The Significant and Important Contributions to Community Tenure Provided by Informal Caregivers were a Consistent Theme that Emerged During Interviews with Diverted and Non-diverted Customers and Their Caregivers.**

The interviews with older adults and caregivers provided valuable information and insight regarding caregiving from both the older adults' and caregivers' perspectives.

The Community Tenure Study (SFY 2003) confirmed other research findings that caregiving is complex, stressful, and also rewarding. When caregivers are available and have support for themselves, caregiving helps older adults remain in the community. Caregivers reported that when older adults were appreciative of the care they provided this gave the caregiver the encouragement and impetus to continue in the caregiving role. When interpersonal relationships between the older adult and caregiver were strained or difficult, this made the caregiving relationship too stressful and in some cases contributed to the loss of community tenure. Overall, diverted and non-diverted customers and caregivers reported they were unaware of caregiver support programs and in some instances caregivers expressed their need for such programs. In addition, the AAA could develop special recognition programs to encourage caregivers and acknowledge their valuable role as a caregiver.

The forms of assistance provided by caregivers varied widely and reflected the particular skills and abilities of the caregiver.

Caregivers demonstrated phenomenal tenacity and expertise in the types of assistance they provided to older adults. The variability in the skills and abilities of caregivers has implications for policy. Caregivers who provide significant types and amounts of physical caregiving were able to help older adults remain at home for long periods of time. When caregivers did not believe they had the skills or emotional fortitude to continue to support the older adult at home, the older adult was unable to remain in the home. In these instances, caregiver and older adults had not developed a case manager connection and relationship that could have been used to marshal support for the older adult and the caregiver.

The hazards model analysis also confirmed the importance of support from caregivers. In this analysis, increased levels of caregiving support, both informal and formal, reduced the risk of permanent NF admission. Interviews with diverted and non-diverted customers provided rich details regarding the frequency, extent, and types of caregiving required for older adults to remain in the community. Many caregivers reported it was difficult to know when caregiving would be too much for them to continue. Based on interviews with non-diverted customers in a NF, when the older adult required 24-hour care and two caregivers to assist the older adult with transferring, they entered a NF.

Conclusion

This study indicated that people who applied for an NF admission can be diverted and maintain community tenure for more than 24 months, which continues to be a cost effective alternative for the state. In order to maintain community tenure, state publicly funded services, Medicare Home Health Services and informal supports all play an important role. Diverted customers, who are at increased risk of permanent NF placement due to lower incomes, can maintain community tenure with the assistance of SPFS, especially Medicaid-HCBS/FE.

Through interviews with older adult and caregiver dyads, it was evident that informal supports play a critical role in maintaining community tenure. Diverted customers had many strategies they used to remain in the community including older adult and caregiver determination to avoid the NF, sustained mental health, intervening in order to feel safe and secure in their home, getting connected to formal services, and effectively working with case managers. When some of these strategies were not effective, older adults were at increased risk for NF placement.

The Community Tenure Study (SFY 2003) has been a successful collaboration between state policy makers and state university researchers. The findings indicate that older adults who planned to enter the NF were able to remain in the community through the use of SPFS, Medicare Home Health Services and informal supports. The implications of this study highlight areas where policy and program enhancements to state community-based services can improve the percentage of older adults that remain in the community and the length of time that permanent NF placement is avoided.

“Examination of the Use of Medicare Home Health Services and Informal Caregiving and Their Relationship to Successful Community Tenure”

I. Introduction

A) Background and Purpose

This report presents the results of the *Examination of the Use of Medicare Home Health Services and Informal Caregiving and Their Relationship to Successful Community Tenure* study, referred to here as the Community Tenure Study completed in State Fiscal Year 2003. The Community Tenure Study builds on previous research completed as part of The *Longitudinal Study of Customers Diverted through the CARE Program*, referred to here as the Diversion Study completed in SFY 2002. The Diversion Study was a three-year study that provided valuable insight into factors that contributed to the community tenure of diverted CARE Assessment customers. The Diversion Study Report is available on the Office of Aging and Long Term Care’s website: www.oaltc.ku.edu.

1.) Background: Diversion Study Findings

A number of important findings emerged from the Diversion Study (SFY 2002). These findings also pointed to areas in need of further examination. Through our interviews conducted for the Diversion Study with 69 diverted customers (or their primary caregiver), it was learned that State Publicly Funded Services (SPFS) were an important contributing factor in the community tenure of these diverted customers. The quantitative analysis of the 599 diverted customers in our Diversion Study sample also found that approximately 25% of the diverted customers used SPFS, such as Medicaid-HCBS/FE, Senior Care Act Services funded through State General Funds (SGF), and/or Older American Act (OAA) services. Older adults interviewed for the Diversion Study also reported using Medicare Home Health Services, however, data regarding diverted customers use of Medicare Home Health Services were not collected for analysis in the Diversion Study (SFY 2002).

In addition, our interviews with the diverted customers and caregivers for the Diversion Study (SFY 2002) provided a basic understanding of the role informal support plays in the community tenure of diverted customers. Diverted customers and caregivers reported that the combination of state publicly funded services and informal support was essential for diversion and maintaining community tenure. Support availability contributes to the community tenure of diverted customers and the risk of a nursing facility (NF) admission is reduced by 16% when part time intermittent support is available. The support can include any combination of formal services and informal support. Information about diverted customers’ and caregivers’ perspectives on caregiving, length of caregiving careers, and the impact of caregiving were unknown.

As part of the Diversion Study (SFY 2002) we also tracked a cohort of 599 diverted customers at 3-month intervals after the CARE Assessment to determine who was still in the community, who had been admitted to a NF, and who had died while residing in the community. We found that

nearly half (289, 48.2%) of the diverted customers remained in the community for at least 18 months post-CARE Assessment. Because client tracking ended, it was not known how much longer the 289 customers who were residing in the community upon completion of the Diversion Study remained there.

2.) Purpose of the Community Tenure Study (SFY 2003)

In order to further examine the issues identified in the Diversion Study (SFY 2002), the Kansas Department on Aging (KDOA) and the Kansas Department of Social and Rehabilitation Services (SRS) contracted with the Office of Aging and Long Term Care (OALTC) at the University of Kansas School of Social Welfare to conduct the Community Tenure Study (SFY 2003).

The overall purpose of the Community Tenure Study (SFY 2003) was to examine the use of Medicare Home Health Services and informal caregiving and their relationship to community tenure.

The goals of the Community Tenure Study were:

- 1.) To analyze factors not previously measured in the Diversion Study (SFY 2002), in particular Medicare Home Health utilization, and their relationship to the community tenure status of CARE Assessment customers;
- 2.) To track the community tenure status and publicly funded community-based service utilization of customers diverted from a NF over a period of 24 months following their CARE Assessment; and
- 3.) To explore the role of informal support, especially from family, and the relationship to maintaining community tenure for diverted older adults in Kansas.

The Community Tenure Study (SFY 2003) builds on findings from the Diversion Study (SFY 2002) in several ways. First, the 599 diverted customers were originally tracked for 18 months. The Community Tenure Study Report presents findings for this population of diverted customers for a total of 24 months following the CARE Assessment. This includes the community tenure status of diverted customers, their use of community-based services and the actual service costs and cost-effectiveness of state publicly funded services (SPFS) compared to a NF admission. It is important to keep in mind that all of these customers had applied for nursing facility placement. The total length of diversion and the number of diverted customers that remain in the community until death have important policy implications related to the cost effectiveness of case management and SPFS, particularly Medicaid HCBS/FE.

The Diversion Study (SFY 2002) also included information about state publicly funded services (SPFS), such as Senior Care Act, and other State General Funded (SGF) services, and Older American Act services (OAA), but not Medicare Home Health Services. This current report includes a descriptive analysis of Medicare Home Health Service use for the 599 diverted customers and a multi-variate analysis of Medicare Home Health Services impact on length of community tenure.

Finally, the Community Tenure Study Report (SFY 2003) includes an analysis of interviews with older adults and their caregivers regarding factors that led to a NF admission or continued residence in the community. The interview population (N=61) for the Community Tenure Study all had a CARE Assessment. The analysis of how the combined care receiver – caregiver relationship contributes to the community tenure of diverted customers is a unique perspective that has not been previously studied. In addition, topics that were explored in-depth through interviews for the Community Tenure Study included perceptions of older adults and caregivers about the older adults’ need for assistance, the self-care behaviors of diverted customers, and the availability, knowledge of, and caregivers’ use of support services and programs.

The findings from the Community Tenure Study (SFY 2003) are reported as answers to the policy related questions that guided the Community Tenure Study analyses. Policy related research continues to take on increased significance in light of the waiting list for community-based services in Kansas. The community tenure of diverted customers was examined based on the following six policy-related questions.

- How many diverted customers have remained in the community 24 months after their CARE Assessment?
- How many diverted customers use State Publicly Funded Services (SPFS) and Medicare Home Health Services?
- What factors contribute to community tenure?
- What are the utilization patterns for SPFS?
- What are the actual costs of SPFS for the state?
- What are the actual cost savings for the state for SPFS received by diverted customers?

The life experiences and perceptions of diverted and non-diverted customers and caregivers were examined based on the following policy-related questions.

- What are the successful strategies used by older adults and their caregivers to maintain community tenure? What barriers do they encounter?
- How do older adults and caregivers initiate and maintain informal and formal supports? How are these helpful in contributing to community tenure?
- What factors play a role in a NF admission compared to older adults who are able to maintain community tenure?

B) Format and Content of The Report

The Community Tenure Study Report (SFY 2003) is organized into three sections. Section I provides the study background, purpose, and a summary of the relevant literature on caregiving. Section II and III provide a statement of the major study questions and related findings. Section II reports on the community tenure of diverted customers and community-based service

utilization. This year, building on findings from the Diversion Study (SFY 2002), Medicare Home Health Service use data are included in the analysis of publicly funded services used by diverted customers. Section II will also include the analysis of SPFS costs and a cost-benefit analysis of SPFS compared to NF costs. The cost benefit analysis is conducted to compare the costs of state funded community based services to the state share of NF costs in order to identify cost savings for the state. In addition, Section II will include a multi-variate analysis to identify NF risk factors for diverted customers. This analysis builds on the one conducted for the Diversion Study, by including Medicare Home Health Service data and tracking diverted customers for a total of 24 months.

Section III presents the analysis of interviews with older adult and caregiver dyads and analysis of other factors that contribute to community tenure or NF admission. An interview dyad is the older adult and their primary caregiver. The analysis of the older adult and caregiver dyads is based on face-to-face interviews conducted with a sample of CARE Assessment customers (N = 61) for the Community Tenure Study (SFY 2003). The interviews were conducted with older adults and their caregiver in order to provide an understanding of their life situations, perceptions and the circumstances that played a role in the decision to remain in the community or enter a NF. Most existing research has relied on a single interview either with the older adult or the caregiver. This analysis of interviews with caregiver – care receiver dyads is unique because both are interviewed and the combined perspectives are taken into account when analyzing the interviews and reporting findings in order to understand how community tenure is maintained.

In addition, some of the findings from the interviews are integrated into the discussion of findings about community tenure status, use of publicly funded services, and the hazard model analysis that are presented in Section II. This method of reporting quantitative and qualitative findings permits a comprehensive understanding and explanation of findings. For example, the Diversion Study (SFY 2002) reported that, based on quantitative findings, older adults that lived alone were more likely to be diverted. The qualitative findings helped to understand that although diverted customers lived alone, they also reported they had daily contact with family and caregivers. This explained in part how an older adult living alone could have a lower risk of NF admission. In addition, the finding pointed to the fact that living alone does not necessarily mean the older adult is socially isolated.

Each section in this report will begin with the policy related questions that guided the study methodology and analyses, a brief summary of the findings and then a presentation of detailed findings. The Report concludes with a presentation and discussion of the implications for policy makers and legislators.

C) Summary of Literature on Caregiving

Research conducted by the Office of Aging and Long Term Care in partnership with the Kansas Department on Aging and Kansas Social and Rehabilitative Services revealed that nearly half of older adults who were diverted from nursing facility placement following application for nursing facility placement were still in the community 18 months after the CARE Assessment (Chapin et al., 2002). Findings from that multi-year study and national studies indicate that the availability

and use of supports, both informal and formal, overall functional ability and health status, and the influence of older adults' social network members are influential in the decision to remain in the community or move into a nursing facility when faced with an episode of increased care needs.

Still, little is known about ways in which older adults and their support providers/caregivers negotiate the circumstances beyond the identified decision point. The purpose of this study is to examine the relationship of formal service use and informal caregiving to successful community tenure. An important contribution of this study to the understanding of community tenure is to identify how the older adult/care recipient and caregiver relationship or dyad is instrumental to maintaining community tenure. It can be assumed that there are several factors related to long-term community tenure. An overview of the literature on caregiving reveals a wide-range of these factors, with the most important falling under the categories of caregiving, caregiving supports, environment, and illness/chronic disease/disability.

1.) Caregiving

The experience of caregiving from the care recipient's point of view is largely based on their relationship with a caregiver and their involvement in self-care. A positive relationship between the older adult and their caregiver is based on clear and honest two-way communication (Gallagher, 1999; Katz, Conant, Inui, Baron, & Bor, 2000), which can enhance the older adult's quality of life (Mahoney, 1999; Lawton, Moss, & Duhamel, 1995). However, the older adult recipient may view caregiving as a negative experience if this communication with the caregiver breaks down (Newsom, 1999); a possible result of a communication breakdown is depression for both the caregiver (Lyons, Zarit, Sayer, & Whitlatch, 2002) as well as the care recipient (Newsom, 1999).

The older adult's involvement in self-care can also affect their view of the caregiving experience. Research shows that it is important for elders to participate in activities that would make them feel useful, regardless of physical impairment (Katz, Conant, Inui, Baron, & Bor, 2000). It is important that older adults' voices are heard so that they can contribute to their own care (Gallagher, 1999; Russell, Bunting, & Gregory, 1997). Without the ability to participate in their own care, the older adult may consider their caregiving experience in a negative manner, which could lead to depression and other psychological distress (Newsom, 1999).

Findings from research on caregiving suggest the experience of caregiving from the caregiver's point of view is based on the amount of burden they experience as a result of caregiving for an older adult. In regards to physical burden, some studies claim that active caregivers have health problems that cease after their caregiving experience ends (Grasel, 2000), while other studies find no evidence that caregivers have poorer health outcomes (Scharlach, Midanik, Runkle, & Soghikian, 1997).

While there are conflicting findings concerning the amount of physical burden a caregiver experiences, a higher level of burden experienced by caregivers is directly related to the level of caregiving responsibilities (Lee, Walker, & Shoup, 2001; Pot, Deed, & Van Dyck, 1997). Caregivers reporting higher levels of burden also report and experience greater levels of

depression and deterioration in measured psychological well being (Lee, Walker & Shoup, 2001; Pot, Deed, & Van Dyek, 1997), as well as more difficulty doing tasks (Zarit, Todd & Zarit, 1986). Conversely, higher levels of support lead to less burden (Stoller & Pugliesi, 1989a), with subsequent lower levels of depression (Atienza, Stephens & Townsend, 2002; Stoller & Pugliesi, 1989b).

2.) Caregiving Supports

There are three forms of caregiving supports for the older adult: personal, informal, and formal. A recent study found that older adults often experience personal support through their religious faith, relying on their spiritual advisors to comfort them when they are feeling sad or depressed (Dobbs, Chapin, Reed, Hickey, & Ellman, 2002). Furthermore, the study found that religious faith served “an important role in coping with life challenges” the older adult faced (p.17).

Spirituality and religious beliefs are “sources of strength” that aid in the resilience process (Felten, 2000, p.109). Resilience, or the “ability to bounce back from adversity and go forward” (Felten, 2000, p.103), is multidimensional and encompasses physical, emotional, social, spiritual, and cognitive domains (Bauman, Harrison Adams, & Waldo, 2001). A significant part of resilience is self-care (Bauman, Harrison Adams, & Waldo, 2001; Felten, 2000), which, as was noted earlier, is important in combating depression in older adults.

Informal caregiving supports play an important role in the older adult’s life. Research shows that there has been an increase in care provided for older adults from friends, a trend that will continue to increase over the coming years; however, friends provide care for fewer hours than family members (Himes & Reidy, 2000). Family members continue to view caregiving for an older adult as the family’s responsibility (Piercy & Blieszner, 1999; Barrett & Lynch, 1999; Bond, Farrow, Gregson, Bamford, Buck, McNamee, & Wright, 1999), with research showing that more formal support is needed for families in this position (Yeh, Johnson, & Wang, 2002; Noelker & Bass, 1989).

Older adults with chronic conditions or poor levels of health often used formal support (Penning, 1995; Noelker & Bass, 1989). Furthermore, older adults with stronger social ties utilize formal support far more than socially isolated older adults (Penning, 1995). The connection between caregiver burden and formal service use is less clear. While some research has found that there is no significant difference in caregiver strain and depression between those who receive formal support services and those who do not (Schwarz & Blixen, 1997), other research claims that caregiver need or stress is “predictive of in-home service use” (Noelker & Bass, 1989, p. 69).

3.) Environment

An older adult who lives in the community with either a spouse or a child has a reduced risk for a nursing facility placement (Kersting, 2001). The success of this community dwelling is based on the relationship between the caregiver and the older adult (Feeney & Hohaus, 2001; Miller & Weissert, 2000), though other factors are involved in the success of community dwelling. Research shows that being nonwhite, having greater familial support, and greater social activity

are factors that predict successful community dwelling, while being older, living alone, and having informal care predict nursing home placement (Miller & Weissert, 2000).

4.) Illness/Chronic Disease/Disability

Decision making during an episode of illness or disease is grounded in the “personal and social context of people’s lives” (Paterson, Russell, & Thorne, 2001); as one study shows, older adults with a physical illness often reduce their desire or ability to connect socially with others (Dobbs et al., 2002). Furthermore, the caregiver of the older adult is also affected by the older adult’s illness, disease, or disability. Caregiver support can and does fill the gap even when disease is advanced for some older adults, while in other cases, this rather fragile care set-up is taxed beyond its means with needs of an elder who is relatively healthy. After receiving information about the disease (the progression and effects on daily living), caregivers are more likely to realize the limitations of what they can do for the older adult (Hepburn, Thornatore, Center, & Ostwald, 2001). However, older adults with stronger caregiver support are found to “make less use of health services at higher levels of illness and disability” than those with less caregiver support (Penning, 1995, p. 338).

D) Overview of Methodology

This section presents a brief summary of the methodologies used for conducting the analyses for the Community Tenure Study (SFY 2003). Section II is based primarily on quantitative analysis of data and Section III is based on qualitative analysis of interview data.

Section II reports the findings of the analysis of community tenure, risk factors for a NF admission, and a cost analysis of state publicly funded service costs compared to NF costs for the diverted customers. These analyses are based on the same methodologies used in the Diversion Study (SYF 2002). The specific methodologies are reported in the Technical Addendum to the Diversion Study report, which is available at: www.oaltc.ku.edu. The findings presented in this report should be read and interpreted keeping in mind the specific characteristics of the dataset they are based upon and the specific focus of the study.

First, predictors for length of community tenure in this dataset were derived from data collected at the time of the CARE Assessment. Functional status and availability of caregiver support at the time of the CARE Assessment were the measures used. Data to reflect *changes* in these factors that occurred after the CARE Assessment were, for the most part, unavailable. However, SPFS data and residential status were collected and updated continually over the 24 months of follow-up, so that patterns of use of these services and place of residence could be included in the analysis. The analyses in the Community Tenure Study (SFY 2003) included Medicare Home Health Service use data (OASIS) and an additional six months of SPFS data, Minimum Data Set (MDS) data, and death data. KDOA provided the SPFS data, Myers and Stauffer provided the MDS and OASIS data through a Data Use Agreement, and KDHE provided the death data.

Section III reports findings from the analysis of interviews with older adults who had a CARE Assessment and their caregivers conducted for the Community Tenure Study (SFY 2003). The interview population was divided into three groups of caregiver-care recipient dyads based on these criteria: long-term community residents and their caregivers, recently diverted customers living in the community and their caregivers, and customers who have recently entered a nursing facility on a permanent basis and their caregivers. The first group had the CARE Assessment 2-3 years prior to August 2002 and continued to remain in the community. This interview sample was selected from the original Diversion Study (SFY 2002) sample of 599 diverted customers. The second group of dyads had a CARE Assessment in March of 2002 and had been diverted. They continued to reside in the community at the time the interview was conducted. The third group had a CARE Assessment in March of 2002, however they were not diverted and had been residing in a NF on a permanent basis (in the NF 100 days out of 120 days) at the time the interview was conducted. Comparison of these last two groups provided a way to examine the circumstances that may have contributed to either a NF admission of non-diverted CARE Assessment customers or continuing community residence of diverted customers. Separate interview guides were developed for caregivers and for older adults in each of the three groups. These six interview guides are included in Appendix 1.

II. Community Tenure of Diverted Customers: Use of State Publicly Funded and Medicare Home Health Services

Introduction

The section on community tenure reports findings for the entire cohort (all four waves) of diverted customers (N=599¹) tracked over a 24-month period. The Community Tenure Study (SFY 2003) builds on the policy related questions, methodology, and findings for the Diversion Study (SFY 2002). The Diversion Study was unique because it tracked the community tenure and state publicly funded service (SPFS) utilization of older adults who had applied for nursing facility (NF) placement, received a CARE Assessment² and were diverted³. This year's study builds on the community tenure and service tracking of the diverted customers. It adds information about Medicare Home Health Service use by diverted customers and an additional six months of data regarding community tenure status and SPFS use.

The diverted customers were tracked for 24 months beyond the CARE Assessment. This section reports on:

- 1) The community tenure status of diverted customers in 3 month intervals;**
- 2) The actual services used during the 24-month tracking period;**
- 3) An analysis of risk factors for permanent NF admission of diverted customers; and,**
- 4) A cost analysis of actual SPFS costs for diverted customers compared to NF costs.**

The community tenure of diverted customers was examined based on six policy-related questions.

- How many diverted customers have remained in the community 24 months after their CARE Assessment?
- How many diverted customers use State Publicly Funded Services and Medicare Home Health Services?
- What factors contribute to community tenure?
- What are the utilization patterns for State Publicly Funded Services?
- What are the actual costs of State Publicly Funded Services for the state?
- What are the actual cost savings for the state for State Publicly Funded Services received by diverted customers?

¹ There were 600 cases of diverted customers; however there were only 599 unduplicated diverted customers.

² The CARE Assessment gathers information about the person's potential need for specialized services, functional ability, available support systems, and recent problems and risks at the point they are applying for NF admission. It also provides the older adult with information regarding their LTC options. The CARE Program tracks diversion status of customers at the 30th and the 90th day.

³ Diversion occurs when "individuals who have been assessed for potential nursing facility placement are residing in community settings with services or are living in board and care facilities when the 30 Day Follow-Up contact is made" (CARE Annual Report, December 30, 1998, page 5).

This section on community tenure is organized to provide answers to the above policy-related questions and includes detailed data analysis and interpretation. First, there is a summary of the community tenure status of the diverted customers reported in 3-month intervals for a 24-month period. Next, the Medicare Home Health Service use is reported and discussed, followed by a composite summary of Medicare Home Health Service and SPFS use for the diverted customers reported in 3-month intervals for a 24-month period. The multivariate analysis of factors that contribute to community tenure is reported along with the interpretations of these analyses. Finally, the section concludes with the cost-benefit analysis of SPFS compared to NF costs.

A) Outcomes Following 24 Months of Tracking Diverted Customers

- **How many diverted customers have remained in the community 24 months after their CARE Assessment?**
 - **When the tracking of diverted customers ended 24 months after their CARE Assessment, 244 (40.7%) diverted customers were still in the community.**
 - **There were 190 (31.7%) diverted customers who became permanent NF residents or died subsequent to permanent NF admission.**
 - **There were 165 (27.5%) diverted customers who died while still residing in the community.**
 - **After about the 9th month, diverted customers were more likely to lose community tenure due to death than permanent nursing facility placement.**
 - **Almost twice as many diverted NF applicants (244) were still living in the community 24 months after their CARE assessment than were permanently living in a nursing facility (126).**
 - **Of the diverted customers living at the 24 month after the CARE Assessment, 244 (66%) were residing in the community.**

The Office of Aging and Long Term Care (OALTC) identified the community tenure status of diverted customers at three-month intervals after the CARE Assessment to determine who was still in the community, who had been admitted to a NF, and who had died while residing in the community. The results for each three-month interval up to 24 months of follow-up are presented in Table 1 below and in Chart 1.

Table 1
Community Tenure Status of Diverted Customers
Tracked for 24 Months, Reported in Three-Month Intervals
N = 599

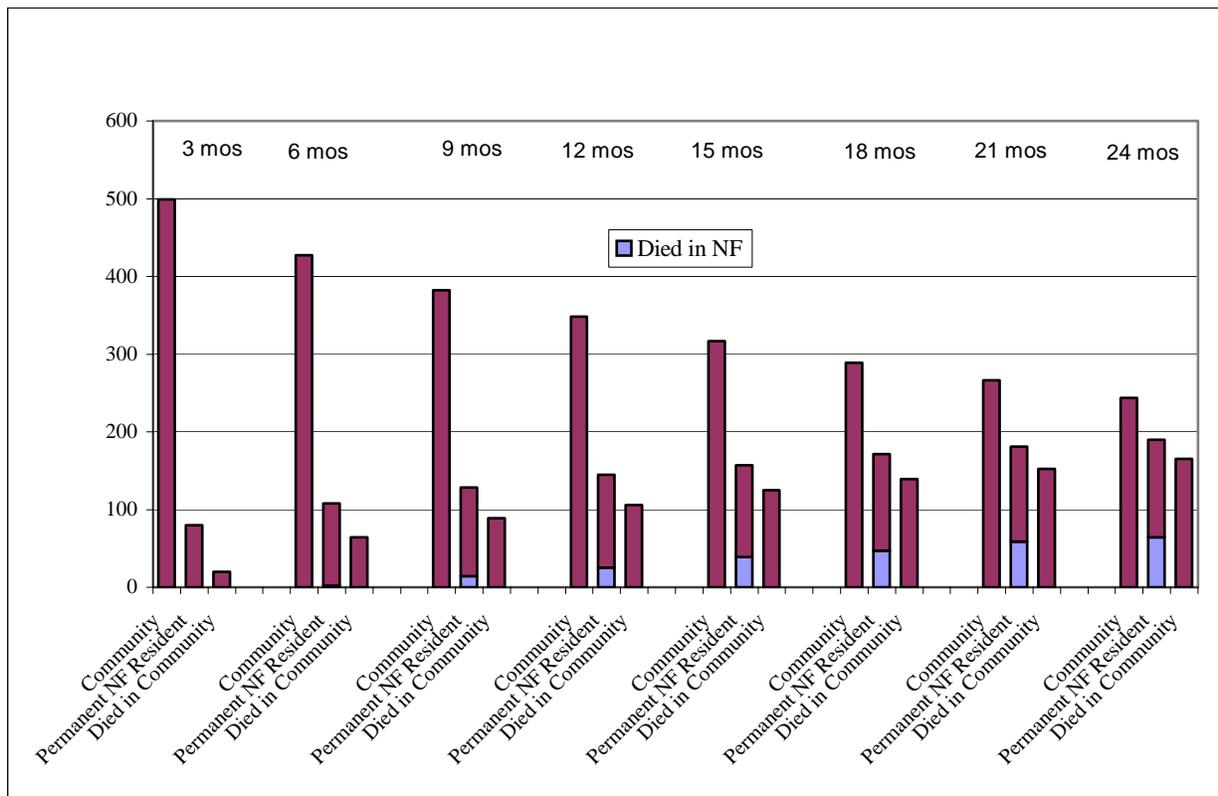
Time Interval after the CARE Assessment	In the Community	Permanent NF Resident	Died While Permanent NF Resident	Died While Living in Community
3 months	499 (83.3%)	80 (13.4%)	0 (0%)	20 (3.3%)
6 months	427 (71.3%)	106 (17.7%)	2 (0.3%)	64 (10.7%)
9 months	382 (63.8%)	114 (19.0%)	14 (2.3%)	89 (14.9%)
12 months	348 (58.1%)	120 (20.0%)	25 (4.2%)	106 (17.7%)
15 months	317 (52.9%)	118 (19.7%)	39 (6.5%)	125 (20.9%)
18 months	289 (48.2%)	124 (20.7%)	47 (7.8%)	139 (23.2%)
21 months	266 (44.4%)	122 (20.4%)	59 (9.8%)	152 (25.4%)
24 months	244 (40.7%)	126 (21.0%)	64 (10.7%)	165 (27.5%)

As Table 1 shows, over 40% (244) of the diverted customers were still in the community 24 months after their CARE Assessment. In addition, only 21% of diverted customers were residing in a NF at the 24th month, and 38.2% (229) of the originally diverted group had died (combining 10.7% (64) died while permanent NF resident and 27.5% (165) died while living in the community). Overall, only 190 (31.7%) of the diverted customers had been permanently admitted to a NF by the 24th month of follow-up (combining 126 permanent NF residents and the 64 died while permanent NF residents). This finding is particularly noteworthy in light of the finding 366 (61%) of the diverted customers had a short NF stay after the CARE Assessment, and had returned to the community by the 30-day CARE Assessment Follow-Up. In the past, traditional thinking has been that older adults who enter a NF were unlikely to return home. Our data clearly show that older adults are using nursing facilities in a different manner and do in fact return to successful community living without becoming a permanent nursing facility resident.

Within nine months of the CARE Assessment, the proportion of permanent NF residents in the study plateaued at approximately 20%. New admissions were being balanced by deaths of previously diverted customers who had been admitted and subsequently died in a NF. These findings are consistent with other research findings regarding death following a NF admission. NF admission and death are both correlated with functional impairment and age (Miller and Weissert, 2000).

As follow-up has progressed, an increasing number of diverted customers have died in the community. The rate of death of diverted customers residing in the community increased incrementally by approximately three percentage points every three months from the 9th month to the 24th month. This information is also graphically displayed in Chart 1 below.

Chart 1
Community Tenure Status of Diverted Customers Tracked for 24 Months,
Reported in 3-Month Intervals After the CARE Assessment
N = 599



As Chart 1 shows, the largest drop in community tenure occurred in the first 6 months following the CARE Assessment. After about the 9th month the rate of older adults residing in the community continued to decline but at a much smaller rate than previously was observed. In addition, the proportion of diverted older adults who were current permanent NF residents stayed relatively constant after the 9th month following the CARE Assessment. At the same time, diverted customers were most likely to lose community tenure due to death in the community as opposed to permanent nursing facility placement. In the Community Tenure Study (SFY 2003),

those diverted customers who died were nearly three times more likely to die in their own home than a NF.

The following table displays the community tenure status of living diverted customers at 3-month intervals after the CARE Assessment.

Table 2
Community Tenure Status of Living Diverted Customers
Tracked for 24 Months, Report in 3-Month Intervals

Time Interval after the CARE Assessment	In the Community	Permanent NF Resident	Living Diverted Customers
3 months	499 (86.2%)	80 (13.8%)	579
6 months	427 (80.1%)	106 (19.9%)	533
9 months	382 (77%)	114 (23%)	496
12 months	348 (74.4%)	120 (25.6%)	468
15 months	317 (72.9%)	118 (27.1%)	435
18 months	289 (70%)	124 (30%)	413
21 months	266 (68.6%)	122 (31.4%)	388
24 months	244 (66%)	126 (34%)	370

Table 2 shows that by the time tracking ended after 24 months more than half (370) of the diverted sample (599) was still alive. Almost twice as many diverted NF applicants (244) were still living in the community 24 months after their assessment than were permanently living in a NF (126). Throughout the 24 months of tracking, at least 66%, or two-thirds, of the living diverted customers were residing in the community and no more than 34% were permanently residing in the nursing facility at any time. This finding is remarkable considering that all of the diverted customers had in fact applied for nursing facility placement and more than 60% had a short NF stay following their CARE Assessment. The data show that if a customer gets through the first 6 months following the CARE Assessment, they are likely to stay in the community.

- **How many diverted customers use Medicare Home Health Services and/or State Publicly Funded Services (SPFS)?**
- **There were 178 (29.7%) diverted customers who received Medicare Home Health during the 24-month tracking period.**
 - **The Medicare Home Health Services were most often provided in the first 3 months following the CARE Assessment.**
 - **157 (31.4%) diverted customers received Medicaid-HCBS/FE or SGF and/or OAA services 3 months after their CARE Assessment.**
 - **Out of the diverted customers still in the community 24 months after the CARE Assessment, 52 (21.3%) were receiving Medicaid-HCBS/FE and SGF and/or OAA services.**
 - **Of the 102 diverted customers who were receiving SPFS one month after the CARE Assessment, 33 (32.4%) were still in the community at the 24th month.**
 - **Very few diverted customers received both Medicare Home Health Services and State Publicly Funded Services during the same time period. No more than 17 customers received both Medicare Home Health Services and State Publicly Funded Services at any time interval.**

When the Diversion Study (SFY 2002) was planned, an assumption was that most of the services were SPFS, such as Medicaid-HCBS/FE and State General Fund and/or Older American Act services. However, one of the Diversion Study findings was that only 32% of the diverted customers used SPFS. The types of services the additional 68% of diverted customers received was unknown at the conclusion of the Diversion Study. Therefore, Medicare Home Health OASIS data were used to identify the diverted customers who utilized Medicare Home Health Services. The inclusion of this dataset analysis in the Community Tenure Study (SFY 2003) is described next.

The Medicare Home Health benefit provides for skilled nursing and rehabilitation services in the home setting. The benefit is approved initially for sixty days and then can be re-authorized for additional sixty-day periods provided that the individual is improving and still requires a skilled level of services. Table 3 below provides a summary of diverted customers' use of Medicare Home Health Services reported in monthly intervals for the first twelve months after the CARE Assessment.

Table 3
Medicare Home Health Service Use by Diverted Customers
Reported Monthly for the First 12 Months after the CARE Assessment
N = 178

Time Interval After the CARE Assessment	Medicare Home Health Use
1 month	64
2 months	80
3 months	57
4 months	34
5 months	31
6 months	30
7 months	33
8 months	28
9 months	17
10 months	17
11 months	15
12 months	13

Sixty-four diverted customers used Medicare Home Health within the first month following the CARE Assessment. This had increased to 80 diverted customers using Medicare Home Health by the second month and then decreased to 57 diverted customers by the third month. The next greatest decrease in Medicare Home Health Service utilization occurred in the 9th month with only seventeen diverted customers receiving the service. The number of diverted customers receiving the service began to decrease in the 12th month and at the end of the 24-month tracking period, only one diverted customer received Medicare Home Health Services. Overall, there were 178 diverted customers who used Medicare Home Health Services at some time during the 24 months following the CARE Assessment.

The finding regarding Medicare Home Health Service use is consistent with the criteria for service eligibility. The individual must have a skilled care service need to receive Home Health Services and this is typically the result of an acute health condition, which corresponded to the timing of the CARE Assessment. As expected, the majority of diverted customers received Medicare Home Health during the first three months following the CARE Assessment. Over time, their condition improved and the Medicare Home Health was discontinued. The short-term use of Medicare Home Health is illustrated in Table 4 below.

Table 4
Number of Months Diverted Customers Used
Medicare Home Health Services
N = 178

Diverted Customers who used Medicare Home Health Services		Number of Months Services Received
Number	Percent	
62	34.8%	One
56	31.5%	Two
12	6.7%	Three
15	8.4%	Four
7	3.9%	Five
6	3.4%	Six
7	3.9%	Seven
5	2.8%	Eight
8	4.6%	Nine to Twenty

Table 4 illustrates that more than sixty-five percent of the diverted customers who used Medicare Home Health Services had the services for only 2 months. The range of Medicare Home Health Service utilization was one month to twenty months and the average number of months diverted customers used Home Health Service was 3.1 months.

As part of the community tenure analysis, we analyzed and tracked the state publicly funded services being received by diverted customers at 3-month intervals during their community tenure through 24 months after their CARE Assessment. The following service funding sources are displayed in Table 5: Medicaid-HCBS/FE and Targeted Case Management (TCM);⁴ State General Fund (SGF) services (which would include Senior Care Act services) and/or Older Americans Act (OAA) services; and Medicare Home Health Services. Service customers could begin and discontinue services at any time after the CARE Assessment. Please note that “Other Services” could include medical insurance, veterans’ benefits and/or private pay services⁵. The information in each column for the funding source is mutually exclusive.

⁴ In this report, Case Management funded as a Medicaid Administrative cost (MedAdmin) is included in TCM.

⁵ In the Diversion Study (SFY 2002), Medicare Home Health was included as one of the “Other Services”.

Table 5
Community Tenure Status of Living Diverted Customers
at Three Month Intervals and by Funding Source ^a

Time Interval After the CARE Assessment	Medicaid-HCBS/FE, TCM ^b	SGF and/or OAA	Medicare Home Health Only ^c	Other or No Services	Number of Diverted Customers
(3 months)	84 (16.8%)	73 (14.6%)	40 (8.1)	302 (60.5%)	499
(6 months)	70 (16.4%)	46 (10.8%)	20 (4.7%)	291 (68.1%)	427
(9 months)	68 (17.8%)	41 (10.7%)	10 (2.6%)	263 (68.9%)	382
(12 months)	41 (11.8%)	42 (12.1%)	12 (3.4%)	253 (72.7%)	348
(15 months)	38 (12.0%)	37 (11.7%)	9 (2.8%)	233 (73.5%)	317
(18 months)	33 (11.4%)	37 (12.8%)	9 (3.1%)	210 (72.7%)	289
(21 months)	32 (12.0%)	20 (12.8%)	8 (3.0%)	206 (72.2%)	266
(24 months)	29 (11.9%)	23 (9.4%)	1 (0.4%)	191 (78.3%)	244

^a All categories are mutually exclusive.

^b Diverted customers who received both Medicaid-HCBS/FE and SGF and/or OAA were categorized as Medicaid-HCBS/FE customers.

^c To illustrate the extent to which state dollars were funding community in-home services, a diverted customer receiving both Medicaid and Medicare Home Health Services was classified as a Medicaid customer. Customers who received Medicare Home Health Services and SGF and/or OAA were categorized as SGF and/or OAA.

Table 5 illustrates that 157 (31.4%) diverted customers received Medicaid-HCBS/FE or SGF and/or OAA services 3 months after their CARE Assessment. Of the diverted customers still in the community 24 months after the CARE Assessment, 52 (21.3%) were receiving Medicaid-HCBS/FE or SGF and/or OAA services. Forty diverted customers received only Medicare Home Health Services at the 90th day after the CARE Assessment. The Medicare Home Health Services were most often provided in the first 3 months following the CARE Assessment.

Very few customers received both Medicare Home Health Services and State Publicly Funded Services during the same time period. No more than 17 customers received both Medicare Home Health Services and State Publicly Funded Services at any time interval. This suggests that some diverted customers' medical/health conditions improved and they no longer required

Medicare Home Health Services. These same diverted customers, as well as others, may have gone onto SPFS due to continued chronic health conditions or a disability as suggested by findings from interviews with older adults and caregivers (As noted in the introduction, follow-up assessments of functional capacity that would reflect changes were unavailable. Therefore, we have relied on anecdotal evidence from interviews). These interviewed diverted customers reported that once they recovered from any acute health conditions, they continued to need support and assistance due to chronic conditions or disabilities. In addition, only 40 diverted customers received both Medicaid-HCBS/FE and SGF and/or OAA services during the 24 months of tracking. Both of these findings illustrate that there is very little simultaneous use of services across funding sources.

Table 5 also illustrates how the number of Medicaid-HCBS/FE customers falls slightly below the number of SGF and/or OAA customers at the 12th and the 18th months. Table 5 also illustrates that overall, more diverted customers received SPFS than Medicare Home Health at any measurement point. Chart 2 graphically illustrates the funding sources of services received by diverted customers in three-month intervals.

Chart 2
Community Tenure Status of Diverted Customers at
Three Month Intervals by Funding Source
N = 599

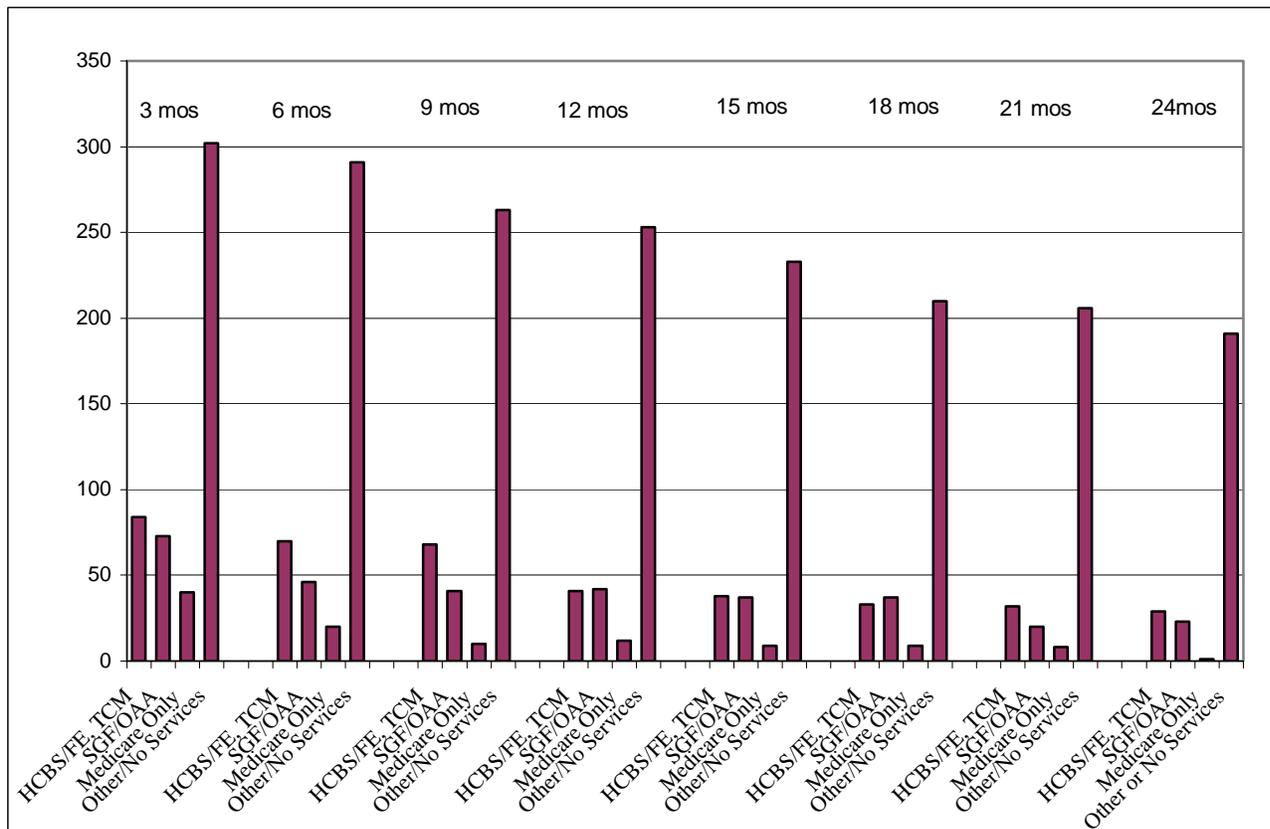


Chart 2 illustrates how the number of diverted customers receiving Medicaid-HCBS/FE and SGF and/or OAA services decreased from 157 to 52 over 24 months, but the percentage rate only declined from 31.4% to 21.3% in the same time period. Chart 2 also shows how the number of diverted customers receiving SPFS remains relatively stable after the 12th month following the CARE Assessment while the number who received Medicare Home Health Services declined steadily. The chart also shows that, in general, diverted customers receive services from the major public long-term care funding sources shortly after their diversion but do not continue to receive these services throughout the 24 months. In other words, their need for these services is limited and once they receive them and their condition stabilizes they are able to remain in the community.

The preceding Table 5 and Chart 2 do not show whether the diverted customers continued to receive services at the 3-month intervals from the same funding source as the 30th day. Therefore an additional analysis was conducted to examine service utilization from this perspective. **Of the 102 diverted customers who were receiving SPFS one month after the CARE Assessment, 33 (32.4%) were still in the community at the 24th month.** In addition, 19 (26.0%) of the 73 who were receiving Medicaid-HCBS/FE services at the 30th day were still in the community receiving these services at the 720th day.

B) Factors that Contribute to Community Tenure

An analysis was conducted to identify factors that contributed the most to the community tenure of diverted customers (N = 599). Two quantitative methods, the Cox Proportional Hazards Model Analysis and Logistic Regression Analysis, were used to analyze this question. Both methods measure the length of community tenure in the number of days diverted customers lived in the community until either they died or were permanently admitted to a NF. Since both methods achieved similar results, only the Cox Proportional Hazards Model Analysis results are presented.

➤ What factors contribute to community tenure?

- The more support available, as indicated at the time of the CARE Assessment, the less likely the diverted customer was to enter a NF permanently.**
- In an analysis of all diverted customers, diverted older adults who indicated Medicaid as a potential payment source for support services (a proxy for poverty) were approximately twice as likely to have a permanent NF admission.**
- In a separate analysis of low-income diverted customers only, risk factors for permanent NF admission for low-income older adults have less to do with functional or cognitive impairments compared to other factors, such as location of CARE Assessment or living alone. Services and case management interventions could likely reduce the impact of these risk factors.**

- **Diverted customers whose CARE Assessment took place in the hospital appeared to be less at risk of permanent NF placement compared to diverted customers whose CARE Assessment took place in the community.**
- **Diverted customers who resided in an assisted living facility were more likely to permanently enter a NF. However, residing in assisted living was not a risk factor for low-income customers.**
- **Low-income diverted customers who live alone in urban areas are at an increased risk of a permanent NF admission.**

Most factors examined for their contribution to community tenure were measured at the time of the CARE Assessment: age in years, degree of rurality (of county of residence), gender, LTC threshold score⁶, support availability, Medicaid as a potential payment source for support services, location where the CARE Assessment was conducted (community, hospital or NF), and whether the CARE customer lived alone. Also, whether the customer was in residential care or assisted living (AL) at the time of the 30-Day CARE Follow-Up was included in the analysis. Two types of service usage during the 24 months of tracking following the CARE Assessment were included in the model: a) hours of Medicaid-HCBS/FE and TCM, and SGF and/or OAA service used during the 24 months after the CARE Assessment, and, b) hours of home health assistance, mostly funded through Medicare. Only diverted customers (N=599) were included in these analyses.

The hazards model, a type of regression analysis, was used to analyze the probability that diverted customers would permanently enter a NF at any time after the 30-Day CARE Follow-Up through 24 months later. The hazards model was appropriate for this analysis because it allowed for several risk factors to be included when analyzing time to permanent NF admission (Gaugler et al., 2000). The results of the hazards model show the odds ratio or “relative risk” associated with each factor of losing community tenure (e.g. entering a NF) at any time period.

The results in Table 6 show the risk of **losing** community tenure and permanently going into a NF were associated with a series of explanatory factors. Table 6 below includes the odds ratio and significance level of each variable.

⁶ Summed ADLs and IADLs were originally included in the analysis and showed results consistent with the overall LTC threshold score. Therefore, the composite LTC threshold score was included in the final analyses.

Table 6
Proportional Hazards Model Results: Assessing Risk Factors
for Permanent NF Placement of all Diverted Customers
N = 550^a

Variables Measured	Odds Ratio ^b	<i>p</i> -value ⁷
Age in years	1.016	0.17
Degree of rurality (9 = most rural)	0.974	0.72
Gender (1 = male)	1.006	0.85
LTC score	0.992	0.10*
Support availability (0= none, 3 = full time)	0.861	0.01***
Medicaid as potential payment source of support services	1.964	0.001†
CARE Assessment location hospital ^c	0.650	0.02**
CARE Assessment location NF ^d	0.668	0.18
Customer lives alone	1.330	0.12
Customer lives in assisted living	1.420	0.06*
Hours of Medicaid-HCBS/FE and TCM, and SGF and/or OAA service use	1.001	0.75
Hours of Medicare Home Health	.975	0.39

^aThe N is less than 599 because of missing values.

^b Effect of variable on probability of going into a NF permanently. An odds ratios of > 1 indicates increased risk, <1 indicates reduced risk.

^c CARE Assessment completed in the hospital compared to CARE Assessment completed in the community.

^d CARE Assessment completed in the NF compared to CARE Assessment completed in the community.

* Statistically significant at $p \leq 0.10$

** Statistically significant at $p \leq 0.05$

*** Statistically significant at $p \leq 0.01$

† Statistically significant at $p \leq 0.001$

Table 6 displays the results of the hazards model analysis. In the analysis, an odds ratio greater than 1 indicates the variable increased the chance that the diverted customer would enter a NF for a permanent stay. An odds ratio less than 1 indicates the diverted customer is less likely to enter a NF with the variable present. Age, degree of rurality, and gender were not significant in this analysis. The results in Table 6 show that diverted customers with higher LTC scores were actually **less likely** to permanently enter a NF (odds ratio less than 1).

Support availability was statistically significant. The more support available, as indicated at the time of the CARE assessment, the **less likely** the customer was to enter a NF permanently. For diverted customers, part time intermittent support as opposed to no support reduced the risk of entering a NF permanently by about 14 percent. Medicaid as a potential payment source for

⁷ The *p*-value associated with each factor indicates the extent to which the result could be due to chance as opposed to any true finding in the data. Ideally, *p*-values should be low. A *p*-value of less than .05 indicates that the statistical relationship in question could have occurred less than 5 times out of 100 by chance alone. A *p*-value as high as .10 may be considered by researchers to indicate statistical significance.

support services was highly significant. This variable is a proxy for poverty. Low-income older adults in the sample of diverted customers were approximately twice as likely to have a permanent NF admission (odds ratio greater than 1).

One of the variables indicating the location of the CARE Assessment was statistically significant.⁸ Older adults whose CARE Assessments took place in the hospital compared to older adults whose CARE Assessments took place in the community appeared to be at less risk of permanent NF placement. It is hypothesized that diverted customers assessed in this setting were experiencing an acute disabling episode from which they recovered after a short rehabilitation stay and/or acquisition of appropriate services that lead to maintenance of community tenure. Living alone was not statistically significant in this analysis. Diverted customers who live in an assisted living (AL) facility were more likely to permanently enter a NF and the results were statistically significant. AL Residents may end up entering a nursing facility permanently because they run out of resources and can no longer afford AL. Finally, hours of Medicaid-HCBS/FE and TCM, and SGF and/or OAA service use and hours of Medicare Home Health Services were not significant.

When comparing the analysis results of 18 months of tracking compared to 24 months of tracking of diverted customers there were some differences. Age was statistically significant at 18 months, but not at 24 months. This suggests that advanced age would have contributed to loss of community tenure for diverted customers closer to the time of the CARE Assessment. Once diverted customers had been in the community for long periods of time, age was no longer a contributing factor in the loss of community tenure.

A second hazards model analysis was conducted that limited the analysis to only those diverted customers who were known to be low-income, (e.g. indicated Medicaid as a potential source of payment for support services). These results are shown in Table 7 below.

⁸ CARE Assessments are conducted by hospital CARE Assessors or AAA Care Assessors in an NF and the community.

Table 7
Proportional Hazards Model Results for Low Income^a
Diverted Customers: Assessing Risk Factors for
Entering a NF Permanently for Diverted Customers
Who Indicated Medicaid as a Potential Payment Source
N = 124

Variables Measured	Odds Ratio ^b	p-value
Age in years	1.042	0.06*
Degree of rurality (9 = most rural)	0.684	0.01***
Gender (1 = male)	1.059	0.35
LTC score	1.001	0.95
Support availability (0= none, 3 = full time)	0.915	0.41
CARE Assessment location hospital	0.376	0.003***
CARE Assessment location NF	0.566	0.37
Customer lives alone	2.149	0.03**
Customer lives in assisted living	1.560	0.34
Hours of Medicaid-HCBS/FE and TCM, and SGF and/or OAA service use	1.001	0.88
Hours of Medicare Home Health	0.961	0.37

^a Customers who indicated Medicaid as a potential source of payment for support services.

^b Effect of variable on probability of permanently going into a NF. An Odds Ratios of > 1 indicates increased risk, <1 indicates reduced risk.

* Statistically significant at $p \leq 0.10$

** Statistically significant at $p \leq 0.05$

*** Statistically significant at $p \leq 0.01$

As Table 7 shows, there were a few notable exceptions in this analysis of low-income diverted customers compared to the analysis of all diverted customers. First, age became a significant factor for the low-income group. Second, the degree of rurality became highly significant with low-income customers. The finding indicates that the more rural the diverted customer, the **less likely** the diverted customer was to permanently enter a NF. This finding suggests that the low-income, urban dwelling diverted customers are at greater risk of permanent NF admission than their low-income, rural counterparts. Another difference is that living alone is a significant finding in this analysis. Low-income diverted customers who lived alone were more than twice as likely to permanently enter a NF as low-income diverted customers who lived with someone. In summary, the analyses of risk factors of low-income diverted customers suggests low-income diverted customers who live alone in urban areas are at an increased risk of a permanent NF admission.

Another notable finding is that while the LTC threshold score was significant in the first analysis that included all diverted customers, it does not show up as significant for the low-income diverted customers. This finding indicates that the risk factors for permanent NF admission for low-income older adults have less to do with functional or cognitive impairments compared to other factors such as living alone or location of CARE Assessment. Services and case management interventions could likely reduce the impact of these risk factors. In the first analysis, living in an assisted living facility was a risk factor for permanent nursing facility

admission. However, in the analysis for low-income customers it was not a risk factor for permanent nursing placement. This suggests that assisted living for low-income older adults may help mitigate the risk of permanent nursing facility placement. Overall, the findings for the analysis of low-income diverted customers at 18 months were the same as the analysis of low-income diverted customers at 24 months.

C) State Publicly Funded Service Utilization Patterns, Costs and Savings

The actual costs associated with the use of SPFS were analyzed and the cost savings accrued by the state is provided next. As noted earlier, of the 599 older adults who were diverted, 31.4% received State Publicly Funded Services (SPFS) by the third month after their CARE Assessment (Table 5). In addition, of the diverted older adults that were receiving SPFS at the time of the 30-Day Follow-Up, 32.4% were still in the community at the 24th month. One of the purposes of this project was to identify services that help older adults remain in their homes and analyze related costs and savings in order to assist policy makers in developing effective state policies and practices. This section examines actual service use by diverted customers and costs of SPFS during the 24-month period. This analysis is placed within the context of key policy questions.

- **What are the utilization patterns for State Publicly Funded Services by diverted customers?**
 - **One hundred and forty diverted customers (23.4%) used SGF and/or OAA services while in the community at some time during the 24 months they were followed.**
 - **Ninety-four diverted customers (15.7%) used Medicaid-HCBS/FE and TCM services while in the community at some time during these 24 months.**
 - **Forty diverted customers (6.7%) received SGF and/or OAA and Medicaid-HCBS/FE services, including targeted case management, simultaneously during the 24 months examined.**

Table 8, below, displays the most frequently used services in terms of the units received, the length of service use and the cost of services received.

Table 8
Most Frequently Used SPFS Services by Diverted Customers Over a 24-Month
Period by Units of Use, Months Received & Cost per Customer (Average)

		Average Total Units ^b Per Customer	Average Total Months Received Services Per Customer	Average Total Cost of Service Per Customer
SGF and/or OAA^a (n=140)				
	n			
Home Delivered Meals	79	100.28	5.10	\$383.74
Assessment	55	10.82	1.07	\$205.28
Case Management	37	16.72	3.95	\$180.23
Homemaker	25	65.31	7.0	\$939.99
Attendant Care	22	43.04	5.68	\$638.41
Congregate Meals	18	73.89	5.94	\$305.91
Medicaid-HCBS/FE^c (n=94)				
Targeted Case Management ^d	93	105.01	9.99	\$420.05
Health Care Attendant II	75	743.59	12.00	\$4,122.31
Personal Emergency Service	44	11.67	11.64	\$112.34
Wellness Monitoring	32	3.25	3.22	\$47.59
Health Care Attendant I	25	133.30	6.92	\$673.77

^a SGF and/or OAA services (e.g., ASMT, AASMT and IAASMT), case management services (e.g., CMGT, CMGTS and CMGTJ), and congregate meals (e.g., CMEL and CMELH) are presented as composite indicators of their service type. These services are based on the KDOA taxonomy.

^b All units represent one-hour increments except for ASMT. One unit of ASMT is equivalent to fifteen minutes.

^c Medicaid-HCBS/FE services have been calculated at 40% of the actual cost to account for 60% matching funds.

^d One customer received MedAdmin at the end of the tracking period (24th month) and had not gone onto TCM.

- Of the SGF and/or OAA services, home delivered meals and assessment were used by the greatest number of customers, followed by case management, homemaker, attendant care and congregate meals. Homemaker, congregate meals, and attendant care services were used, on average, longer than other SGF and/or OAA services.
- Of the Medicaid-HCBS/FE and targeted case management (TCM) services, TCM and health care attendant II were used by the greatest number of customers, followed by personal emergency service, wellness monitoring and health care attendant I. The Medicaid-HCBS/FE and TCM services used the longest were health care attendant II, personal emergency service, and TCM.

Next, OALTC completed a cost analysis of the cost of SPFS used by diverted CARE customers compared to the cost of NF had these diverted customers entered the NF instead of being diverted and remaining in the community. The first cost analysis presented is for the cost of SGF and OAA services used by diverted CARE customers compared to the cost of NF had these diverted customers entered the NF instead of remaining in the community. In order to complete the analyses, actual SGF and OAA service cost data for the May 1999 diverted CARE customers

was calculated for 24 months.⁹ These actual SGF and OAA cost data for the May 1999 diverted CARE customers were used to estimate the cost of SGF and OAA services for the March, April and August 2000 diverted CARE customers.

- **What are the cost savings for the state when SGF and OAA services are received by diverted CARE customers in lieu of NF care?**
 - **For every month that an older adult was diverted from NF care and able to remain in a community setting with community-based services, the state saved \$671.46 if SGF services were provided and \$924.00 if OAA services were provided.**
 - **The estimated total cost savings achieved through four waves of diverted CARE customers in our sample tracked over 24 months was \$67,656.32 for SGF service customers and \$147,174.72 for OAA service customers.**

The next segment of this report details the basis for the cost calculations. Table 9 provides the total average and monthly average service costs for SGF and OAA services.

Table 9
Average SGF and OAA Service Use by Diverted CARE
Customers^a Over a 24-month Period for Each Funding Source

SGF Services^b (n=26 customers)	Average
Total Number of Services Used (Range/SD, 1.00-5.00/1.07)	1.89
Total Months of Service Use (Range/SD, 0.58.00/2.07)	2.29
Total Cost of Service Use (Range/SD, \$15.75-2,127.34/\$634.81)	\$578.31
Average Monthly Cost	\$252.54
OAA Services^c (n=34 customers)	Average
Total Number of Services Used (Range/SD, 1.00-4.00/0.62)	1.26
Total Months of Service Use (Range/SD, 1.00-12.00/2.61)	3.62
Total Cost of Service Use (Range/SD, \$6.40-2,481.38/\$453.98)	\$303.80
Average Monthly Cost	\$83.92

^a There were 49 diverted CARE customers who received SGF and/or OAA services in the May 1999 wave of diverted CARE customers. The number of customers in each funding category is not mutually exclusive.

^b The state share of SGF is 100%.

^c The state does not share in the cost of OAA services.

- For the May 1999 diverted CARE customers, the mean number of SGF services used was 1.89. On average, these customers' service use extended 2.29 months and cost \$578.31 over the 24 months of tracking. The average monthly cost of these services was \$252.54.

⁹ Due to data availability, OALTC was unable to calculate the cost analysis for all four waves of diverted CARE customers using actual cost data. At this time OALTC used actual SGF and OAA cost data for the May 1999 diverted CARE customers. OALTC will complete the full cost analysis for the other three waves later.

- For the May 1999 diverted CARE customers, the mean number of OAA services used was 1.26. On average, these customers' service use extended 3.62 months and cost \$303.80 over the 24 months of tracking. The average monthly cost of these services was \$83.92.

The actual May 1999 service cost data for diverted CARE customers tracked for 24 months were used to estimate the March, April, and August 2000 service cost data. The average monthly cost of NF care is \$2,310.00.¹⁰ To reflect an accurate estimate of SGF and OAA costs, diverted CARE customers who received services from multiple funding sources were identified and categorized as an SGF customer if they did not receive HCBS/FE and categorized as an OAA customer if they did not receive HCBS/FE or SGF.¹¹

In addition, OALTC assumed that approximately 50% of the service customers in the sample who used SGF or OAA would have been Medicaid eligible upon entry to a NF. Based on the actual number of unduplicated SGF and OAA diverted CARE customers in May 1999, the figure in Column A of Table 10 reflects the 50% Medicaid eligibility rate. Finally, the number of SGF and OAA diverted CARE customers were mutually exclusive.¹² The following methodology was used to calculate the savings reported in Table 10.

- The average length of service use (Column B) was calculated by summing the total number of months in which each customer received one or more services, and computing a mean value of this figure.
- The average monthly state share of services (Column C) was derived by totaling service costs and dividing by the average number of months customers received services (Column B). SGF state share of services was calculated at 100% of their cost and OAA state share of services was calculated at 0% because the state does not share in the cost of these services.
- In calculating the average monthly state share of NF cost (Column D), the NF cost is calculated at 40% of the statewide monthly average of \$2,310.00 since the state receives 60% federal matching funds.
- The state savings achieved by use of SGF and OAA (Column F) was calculated by multiplying the average monthly savings (Column E) by the number of persons that received SGF and OAA (Column A), and this figure was then multiplied by the average months of service use (Column B).

¹⁰ This SFY 2002 NF cost information was provided by KDOA. The SFY 2002 NF cost information was used for the cost analysis of NF compared to SPFS. SFY 2003 NF costs may be slightly higher and then cost savings would be greater.

¹¹ There were 94 HCBS/FE customers. Three HCBS/FE customers also received SGF only, two HCBS/FE customers received SGF and OAA and one HCBS/FE customer received OAA only. These duplicate customers were removed from the customer totals in Table 10.

¹² There were 26 SGF and 34 OAA diverted CARE customers. There were 11 diverted CARE customers who received both SGF and OAA services. Customers were categorized as SGF if they received both SGF and OAA services. Therefore, there were 26 SGF and 23 OAA, mutually exclusive, diverted CARE customers in the May 1999 wave.

Table 10
Actual State Cost Savings for State General Fund
and Older American Act Customers Diverted in
May 1999 Based on 24 Months of Community Tenure Tracking

(A) Number of customers by Service	(B) Average months of service use	(C) The average monthly state share of services	(D) The average monthly state share of NF costs	(E) Average monthly savings (column D less column C)	(F) State savings (Multiply Columns A, B, & E)
SGF (n=11) ^a	2.29	\$252.54	\$924	\$671.46	\$16,914.08
OAA (n=11) ^b	3.62	\$0.00	\$924	\$924.00	\$36,793.68

^a There were 26 SGF customers. Five of the 26 SGF customers also received HCBS/FE; these customers were removed from the total for the calculation of the actual cost savings for SGF because these customers' cost savings are included in HCBS/FE calculations that follow. In addition, it was assumed only 50% of the SGF customers would be eligible for Medicaid upon permanent entry into an NF. The calculation was: $26 - 5 = 21$ divided by $2 = 11$.

^b There were 23 OAA customers. One of the 23 also received HCBS/FE and/or SGF; this customer was removed from the total for the calculation of actual cost savings; this customer's cost savings are included in the HCBS/FE calculations that follow. In addition, it was assumed only 50% of the OAA customers would be eligible for Medicaid upon permanent entry into an NF. The calculation was: $23 - 1 = 22$ divided by $2 = 11$.

To estimate the savings for all four waves of diverted CARE customers, the figures in column F (\$16,914.08 and \$36,793.68) were multiplied by 4. The estimated savings for four waves of diverted CARE customers in our sample tracked for 24 months are \$67,656.32 for SGF service customers and \$147,174.72 for OAA service customers.

Finally, the cost analyses presented above is based on the estimate of 4 months of CARE Assessment data. The findings can be extrapolated to one year by multiplying the number of customers (Column A) by twelve. The total annual state cost savings is estimated to be \$202,968.96 for SGF diverted customers and \$441,524.16 for OAA diverted customers.

The second cost analysis is presented for Medicaid-HCBS/FE diverted customers.

- **What are the actual cost savings for the state when Medicaid-HCBS/FE services and TCM are received by diverted CARE customers in lieu of NF care?**
 - **For every month that an older adult in our sample was diverted from NF care and was able to remain in a community setting with Medicaid-HCBS/FE services the state saved \$597.32 if Medicaid-HCBS/FE and TCM services were provided.**
 - **The actual total state cost savings achieved through four waves of diverted CARE customers in our sample tracked over 24 months was \$670,296.13 for Medicaid-HCBS/FE service customers, including TCM.**

The next segment of this report details the basis for the cost calculations. Table 11 provides the total average and monthly average service costs for Medicaid-HCBS/FE services, including TCM.

Table 11
Average State Publicly Funded Service Use by
Diverted Customers over a 24-month Period
for Each Funding Source

Medicaid-HCBS/FE Services (n=94 customers)	Average
Total Number of Services Used (Range/SD, 1.00-7.00/1.22)	3.13
Total Months of Service Use (Range/SD, 1.00-24.00/8.37)	12.35
Total Cost of Service Use ^a (Range/SD, \$130.00-43,636.85/\$10,222.38)	\$10,086.10
Average Monthly Cost ^a	\$816.69

^a The total cost of service use and average monthly cost are reported at 100% of cost before the 40% state match has been computed.

- The mean number of Medicaid-HCBS/FE and TCM services used was 3.13 services over 12.35 months and cost \$10,086.10 over the 24 months of tracking. The average monthly cost of these services was \$816.69.
- Comparing the Medicaid-HCBS/FE and TCM service use at the 18th month to the 24th month, the total number of services increased from 3.02 to 3.13, and the total months of service use increased from 10.72 to 12.35, an increase of slightly more than 1.6 months. In addition, the total cost of Medicaid-HCBS/FE and TCM service use increased from \$8561.68 at the 18th month to \$10,086.10 at the 24th month.

OALTC staff conducted a cost analysis using actual Medicaid-HCBS/FE and TCM service data and NF cost data. The average monthly cost of NF care is \$2,310.00.¹³ A major consideration in evaluating the effectiveness of Medicaid-HCBS/FE is the cost of providing community-based services in lieu of NF care. It is important to note that service customers in this sample would have likely qualified for Medicaid upon entry to a NF based on their eligibility for Medicaid-HCBS/FE, and TCM. The following information was used to derive the results presented below in Table 12.

- The average length of service use (Column B) was calculated by summing the total number of months in which each customer received one or more Medicaid-HCBS/FE service, and computing a mean value of this figure.
- The average monthly state share of services (Column C) was derived by totaling service costs and dividing by the average number of months customers received services (Column B). Medicaid-HCBS/FE and TCM were figured at 40% of costs since the state receives 60% federal matching funds.
- In calculating the average monthly state share of NF cost (Column D), OALTC assumed that customers who received Medicaid-HCBS/FE and TCM services would have likely qualified for Medicaid upon entering a NF. Thus, the NF cost is calculated at 40% of the

¹³ This SFY 2002 NF cost information was provided by KDOA. The SFY 2002 NF cost information was used for the cost analysis of NF compared to SPFS. SFY 2003 NF costs may be slightly higher and then cost savings would be greater.

statewide monthly average of \$2,310.00 since the state receives 60% federal matching funds.

- The state savings achieved by use of Medicaid-HCBS/FE and TCM (Column F) was calculated by multiplying the average monthly savings (Column E) by the number of persons that received Medicaid-HCBS/FE services (Column A), including TCM, and this figure was then multiplied by the average months of service use (Column B).

**Table 12:
Actual State Cost Savings for Medicaid-HCBS/FE Customers Based on
24 Months of Community Tenure Tracking Following the CARE Assessment**

(A) Number of customers by service	(B) Average months of service use	(C) The average monthly state share of services	(D) The average monthly state share of NF costs	(E) Average monthly savings (Column D less Column C)	(F) State savings (Multiply Columns A, B, & E)
HCBS/FE (n=94)	12.35	\$326.68	\$924.00	\$597.32	\$693,428.79

Based on the actual service utilization of the diverted adults in our sample, for every month that an older adult is diverted from NF care and is able to remain in a community setting with Medicaid-HCBS/FE and TMC services, the state saves \$597.32.

To complete the calculation of savings for Medicaid-HCBS/FE customers diverted from NF, OALTC included the costs of SGF services for diverted CARE customers who received both HCBS/FE and SGF. There were 40 diverted CARE customers who received HCBS/FE and other SPFS. SGF customers used services for an average of 2.29 months and the average cost was \$252.54 per month. Therefore, the costs for the 40 diverted CARE customers who received SGF services were an additional \$23,132.66. The \$23,132.66 was subtracted from the HCBS/FE savings calculated in Table 12.

The actual total state cost savings achieved through the diverted CARE customers in our sample was \$670,296.13 for Medicaid-HCBS/FE service customers, including TCM. While tracking ended at 24 months, many of these customers are still in the community and the benefits of Medicaid-HCBS/FE and TCM are still accruing. Refer to **Table 1** of this report for data on the community tenure status of these customers during the 24-month period and **Table 5** for information related to the payment source(s) of SPFS diverted customers used during their community tenure.

Finally, the cost analysis is based on our sample of four months of CARE Assessment data. The findings can be extrapolated to one year by multiplying the number of customers (Column A) by three. **The total annual state cost savings is estimated to be \$2,010,888.30 for diverted CARE customers in our sample who received HCBS-FE services, including TCM.**

In summary, savings to the state when diverted CARE customers use community-based services in lieu of NF placement are:

- **\$670,296.13 for diverted CARE customers in our sample receiving Medicaid-HCBS/FE and TCM services. Annually this savings could potentially equal \$2,010,888.30 for diverted CARE customers receiving Medicaid-HCBS/FE and TCM services.**
- **\$67,656.32 for diverted CARE customers in our sample receiving SGF services. Annually this savings could potentially equal \$202,968.96 for diverted CARE customers receiving SGF services.**
- **\$147,174.72 for diverted CARE customers in our sample receiving OAA services. Annually this saving could potentially equal \$441,524.16 for diverted CARE customers receiving OAA services.**

These calculations are based on unduplicated (mutually exclusive) customer counts. Therefore, if all the potential annual savings are added together the potential savings to the state to maintain diverted customers in the community in lieu of permanent NF placement is \$2,665,381.42 annually.

D) Summary

In summary, the community tenure data show that high rates of diverted older adults are able to remain in the community over time. Less than one-third of the diverted customers received state publicly funded services at any one point during the 24 months of tracking. An even smaller percentage received Medicare Home Health Services. However, the state publicly funded services that diverted customers did receive were extremely cost effective for the state. In our analysis of the risk factors for losing community tenure, indicating Medicaid as a potential source of payment for services (a proxy for low-income) was found to be a significant risk factor for permanent nursing facility placement. In addition, low-income customers who live alone in urban areas were at an increased risk of permanent nursing facility placement. The findings reported in this section suggest that service interventions could help reduce the risk of nursing facility placement and yield cost savings for the state. In the implications section of this report these findings are discussed and integrated with the qualitative findings and implications for policymakers are offered.

III. Qualitative Analysis: Perceptions of Older Adults and Caregivers Regarding Community Tenure and NF Avoidance.

A) Introduction

This section of the Community Tenure Study (SFY 2003) reports the findings from the analysis of sixty-one (61) in-depth, face-to-face interviews with CARE Assessment customers and their caregivers and a discussion of implications based on the findings. The section includes specific details of the caregiving and care-receiving experiences of older adults who applied for nursing facility admission. As described in greater detail in Section I, three non-random groups of older adults and caregivers¹⁴ were selected for interviews. All older adults in the three interview groups had a CARE Assessment.

CARE Assessment data for March 2002 were used to identify two groups of recently diverted customers and customers recently admitted to a NF. A non-random sample of diverted and non-diverted customers with LTC threshold scores of 66 or less was selected for an interview. Previous findings in the Diversion Study (SFY 2002) suggested diverted customers with a LTC threshold score of 66 or less could maintain community tenure. This selection criterion was important for discussion of findings regarding similarities and differences in the interview findings between recently diverted and non-diverted CARE Assessment customers because their impairment levels and care needs would be similar. A third group of diverted customers had their CARE Assessment conducted in May 1999, March, April or August 2000. All interviews for the three groups were conducted from December 2002 to June 2003.

As soon as interview groups were identified, staff contacted the older adults and caregivers to request an interview. Interviews were conducted with all older adults and caregivers who consented to an interview. Interviews are a qualitative methodology that is appropriate to explore a situation or set of circumstance in-depth. The interview approach guides the interviewees into topic areas and lets them make the comments they think are important (Refer to Appendix 1 for the interview guides). For this study, the interviewers asked the older adults and caregivers to describe their experiences, perceptions, and interpretations of their situation around caregiving and maintaining community tenure. These self-reported experiences, perceptions, and interpretations are analyzed and the findings are reported based on policy related questions.

The interviews provided a variety of perceptions. Customer's experiences and perception of effective case management provide valuable feedback to policy makers regarding what works. Timely intervention, exploration of all options, referral to needed services and availability of services were crucial. It is important to keep in mind the issues that arose were the perceptions of the experiences for older adults and caregivers. Also, older adults and caregivers identified

¹⁴ For the purposes of this study initial consideration was given to those caregivers listed by older adults at the time of their CARE Assessment. We asked the older adults to confirm this information or provide updated information. The persons identified as "primary caregiver" were interviewed. Caregivers included paid and non-paid caregivers as well as caregiver who were and were not family members.

barriers to community tenure such as ineffective or unhelpful case management, lack of community-based service information, or failure of health providers to explore options besides NF. This is not to say case management was always ineffective or unhelpful and community-based service information was always unavailable.

The benefit of a qualitative methodology is that when a study participant describes their experience and perception of ineffective case management for instance, researchers and policy makers can learn what would help to increase case management effectiveness for the customer from the perspective of the consumer. A policy implication would be development of quality management criteria for case management that each AAA could then use to evaluate their own case management program effectiveness. For example, using effective case management strategies as benchmarks permits the AAA to evaluate their agency's practice. Furthermore, identification of barriers provides policy makers and the AAA with specific information that can be used to amend or enhance policies.

This section begins with the background that lays the foundation for this study of older adults and caregivers. The interviews with CARE Assessment customers and caregivers provided detailed and rich stories about their experiences prior to and following the CARE Assessment. Although it is not possible or practical to provide all the detail, the stories can be summarized and reported in a format that honors the challenges and successes of the interviewed older adults and caregivers. In order to make this section reader friendly, the findings based on the analysis of the interviews with diverted and non-diverted CARE Assessment customers and their caregivers will be divided into two sub-sections. The findings are first summarized and organized as responses to policy related questions. Next, the findings are interpreted based on a policy-focused data analysis.

Appendix 2 includes a summary of the demographic characteristics of the older adults and caregivers for all three groups. The in-depth qualitative interview data are presented in Appendix 3. This appendix includes a brief description of each older adult-caregiver situation and a summary of the findings for the interviewed group.

B) Background

The Diversion Study (SFY 2002) presented several key findings from interviews with diverted CARE Assessment customers regarding the decisions they faced about a NF admission and managing in the community 30 days after the CARE Assessment and beyond. First, the decisions and the sequence of events that followed the CARE Assessment were based on the unique combination of the customer's health and functional status, the caregiver's capacity to provide care, and the availability of in-home services. For instance, care arrangements were made in response to the needs of diverted customers as they transitioned from one setting to another if they were hospitalized. This was illustrated by the variety of patterns that some diverted customers followed in transitions between home, acute care, and rehabilitation settings. This pattern of transition is in contrast to the traditional linear continuum of care model.

Second, community tenure was established and maintained because diverted CARE Assessment customers, caregivers, and professionals believed that disability is a dynamic process that is amenable to adaptation. Instead of a view of older adults declining and eventually needing permanent NF admission, older adults are using NF care for rehabilitation and then moving to a less restrictive level of care.

Third, diverted CARE Assessment customers remained in the community for long periods of time. The Diversion Study reported nearly 50% of the diverted customers remained in the community for 18 months. As reported in Section II of this report, over 40% of the diverted CARE Assessment customers are still in the community 24 months after the CARE Assessment. What is not well understood is how older adults, with the assistance from informal caregivers and formal services, are able to remain in the community following the CARE Assessment.

Finally, only diverted CARE Assessment customers were interviewed for the Diversion Study (SFY 2002) to learn about their experiences at the time of the CARE Assessment. These findings lead to important and valuable policy implications, although it was not possible to compare the experiences of diverted and non-diverted customers because non-diverted customers were not interviewed for the Diversion Study. This prompted KDOA and SRS to contract with OALTC staff to interview a purposive sample of diverted and non-diverted CARE Assessment customers to learn more about their experiences to inform policy makers. Study participants were selected in order to better understand the factors that led to community tenure or permanent nursing facility placement.

The Community Tenure Study (SFY 2003) analysis of interviews regarding the perceptions of diverted and non-diverted customers and caregivers was based on the following policy-related questions.

- 1.) What are the successful strategies used by older adults and their caregivers to maintain community tenure? What barriers do they encounter?
- 2.) How do older adults and caregivers initiate and maintain informal and formal supports? How are these helpful in contributing to community tenure?
- 3.) What factors play a role in NF admission compared to older adults who are able to maintain community tenure?

C) Summary of Major Themes From Interview Findings

The findings presented below are succinct answers to the policy related questions. These answers capture the essence of the responses given by older adults and caregivers to the interview questions (Refer to Appendix 1 for the interview guides).

The findings will be presented in a table format first, followed by a narrative summary that provides further details about the findings in Table 13.

Table 13
Summary of Findings from Interviews
Office of Aging and Long Term Care

QUESTION 1. What are the successful strategies used by older adults and their caregivers to maintain community tenure? What barriers do they encounter?

Strategies	Barriers
Steadfast determination and commitment on the part of older adults and paid and informal caregivers to remain in the community Active paid and informal caregiver relationships	Delay in service Lack of caregiver support Cost of care
Sustained mental health Creative use of resources	Lack of advocacy on behalf of older adults Lack of service awareness <ul style="list-style-type: none"> ○ Customer ○ Family ○ Service provider

QUESTION 2. How do older adults and caregivers initiate and maintain informal and formal supports? How are these helpful in contributing to community tenure?

Older adults adapted the environment to meet their needs.
 Older adults and caregivers actively sought out ways to remain self-sufficient by seeking out information on their own and creatively using assistance and services.
 Older adults and caregivers established connections with case managers and community resources.
 Recovery (as a result of) from an acute health event prompted the utilization of formal and informal supports to meet current and future needs.

QUESTION 3. What factors play a role in NF admission of non-diverted customers with low LTC threshold scores compared to diverted customers with low LTC threshold scores who are able to maintain community tenure?

Lack of caregiver network
 Diminished sense of security
 Decreased mobility
 Negative influence of others in a NF decision
 Lack of personal connection to in-home services
 Lack of service awareness

QUESTION 1. What are the successful strategies used by older adults and their caregivers to maintain community tenure? What barriers do they encounter?

STRATEGIES:

- Resistance to NF. Older adults who maintained community tenure were highly motivated to avoid permanent nursing home placement and expressed strong determination to achieve this goal, compared to those who were admitted to a NF.
- Active caregiver relationship. Older adults remaining in the community had mutual agreement and collaboration with their caregiver to assist them to remain in the community. This mutual resolve and commitment between the older adult and caregiver to work together to avoid permanent NF placement distinguished diverted from non-diverted customers. Paid caregivers were as committed to avoiding permanent NF placement as family members.
- Sustained mental health. Older adults with community tenure were mentally strong and optimistic. They did not manifest outward signs of depression. Depression frequently accompanies chronic health problems and disability and interferes with the motivation and proactivity required to maintain community tenure.
- Creative use of resources. Compared to their counterparts who permanently entered a NF, older adults remaining in the community were resourceful and creative in managing and utilizing the limited resources available to them.
 - Identifying and mobilizing personal aids, such as ramps, canes, and Lifeline helped them to achieve a sense of safety and security in their living environment.
 - Caregivers also helped older adults identify creative solutions to the challenges they encountered in an effort to remain at home.
 - Diverted customers reported case management could be effective in identifying community resources.

BARRIERS:

- Delay in service. Older adults reported that receiving too little service too late was a barrier. Older adults had to wait for a case manager to follow-up with them regarding requests for assistance or they were told services were available only on a waiting list basis.
- Lack of caregiver support. Caregivers lacked support and this was identified as a barrier because it led to caregiver burden and stress. Many caregivers did not have a backup person to relieve them so they were unable to take a break from caregiving. Caregivers were unaware of caregiver support programs offered by Area Agencies on Aging.
- Financial circumstances create a barrier. Older adults and caregivers expressed concern that costs of care exceeded their resources. In one instance, the older adult needed daily supervision due to sensory impairments and the caregiver was unable to afford hiring someone to be with the older adult throughout the day. In other instances the amount of

care needed was beyond the means of the older adult. Older adults and caregivers were aware that Medicaid did not cover some needed services and in some instances they lacked information about Medicaid coverage in general.

- Role of service provider. Service providers (e.g. hospital case manager and discharge planners, physicians, and home health agency staff) were not always aware or informed about community-based care options. For instance, physicians may recommend a NF and not be aware of community based in-home services. This is compounded by the fact that physicians' recommendations are influential and older adults may not consider other reasonable options because of the medical authority of physicians.
- Lack of advocacy on behalf of older adults. Service providers were not effective advocates to assist older adults in leaving a NF or to avoid a NF. For example, a physician had recommended the older adult could manage in the community however the caregiver was not provided assistance to identify and utilize community-based resources for the older adult. In another instance, an older adult was told unless they went to a NF, the physician would no longer provide medical care for them.
- Lack of service awareness. Older adults and caregivers' lack of awareness about community-based services may create a barrier to leave a NF or limit the older adult's ability to remain in the community. Older adults and caregivers did not always know what services are available, they did not always know how services can be combined to address needs and/or that services can address a significant level of care needs.

QUESTION 2. How do older adults and caregivers initiate and maintain informal and formal supports? How are these helpful in contributing to community tenure?

- Older adults adapted the environment to meet their needs. This includes building ramps to enter and exit their homes, and use of assistive devices such as canes, and walkers.
- Older adults and caregivers exhibited self-sufficient behaviors. Older adults and caregivers sought out information on their own, and relied on their own means to remain in the home. A number of older adults described creative ways of meeting their nutrition needs, including purchasing frozen prepared foods and saving leftovers from the Meals On Wheels for use on the weekend.
- Older adults and caregivers established connections. Older adults and caregivers were aware of services and/or had an established connection with the AAA or a hospital discharge planner that they would seek out if assistance were needed. In these instances, the AAA/case manager was helpful to older adults by arranging services.
- Recovery from acute health events. Older adults could remain in the community once they recovered from the immediate health event or crisis that precipitated the CARE Assessment. The formal services and informal support helped the older adult until the need subsided when:

- Older adults and caregivers received the help they needed;
- There was reciprocity and cooperation between the older adult and the caregiver;
- There was a mutually agreed upon commitment or a promise to avoid a NF placement between the older adult and the caregiver.

QUESTION 3. What factors play a role in NF admission of non-diverted customer with low LTC threshold scores compared to diverted customers with low LTC threshold scores who are able to maintain community tenure?

- Lack of caregiver network. The older adults who entered a NF lacked a caregiver network that they could rely on to meet all of their needs, while the older adults who remained in the community had either a familial caregiver or paid caregiver who provided care for the older adult. Caregivers of older adults in a NF were often willing to provide instrumental assistance, but they were not willing or able to commit to more hands-on personal caregiving. This lack of a caregiver network to draw from limited the older adults' ability to remain in the community.
- Diminished sense of security. The older adult and/or caregiver needed a greater sense of security or supervision than was available when the older adult lived in the community, usually alone. However, the older adults who remained in the community as opposed to entering a nursing facility had either informal or formal supports that enabled them to feel a greater sense of security as well as providing reliable assistance in case of emergencies.
- Decreased mobility. The older adult needed more physical assistance than informal caregivers were able or willing to provide and/or than formal home-based services were able to provide due to the older adults' decreased mobility following a major health event. Those older adults who remained in the community needed physical assistance from their caregivers, but the majority of them were still mostly mobile and not wheel chair or bed bound. For the older adults in the community, if the older adult needed more physical assistance than was being provided by informal caregivers, more home-based services were obtained to fulfill their need. For some older adults that entered a NF, 24-hour care was necessary and the older adult and/or caregiver decided that a NF would be the best option to provide that care.
- Negative influence of others in a NF decision. An older adult's belief in their capacity to live in the community could be negatively influenced by the perspectives of caregivers and health care providers. Even some of the older adults who were diverted to the community instead of going to a nursing facility were told they should be in a nursing facility and should not return to the community.
- Lack of personal connection to in-home services. In some instances the older adult and/or caregiver had awareness of services but had not perceived that the existing home-based services would have been personally beneficial and thus, did not acquire the services for the older adult while they were living in the community. For those adults

who live in the community, home-based services were perceived to be one of the primary reasons why the older adults were able to remain in the community versus entering a nursing facility.

- Lack of service awareness. The older adults and/or caregivers knew about or were familiar with AAA or senior center services yet the agency staff was not helpful in offering services for the older adults and/or caregivers. This disconnect between finding services that were provided and knowing the services that were needed was also evident in the cases of diverted older adults. Yet older adults in the community often found ways to meet their needs if the agency they contacted for help was not helpful.

D) Policy Focused Interpretation of Findings

In this next sub-section of the report, the synthesis and integration of findings for all three groups of interview data are presented based on a policy-focused analysis of the interview data. This policy-focused interpretation of findings of the data identified two overarching themes or categories discussed below. These themes or categories, *service related needs* and *caregiver and context related needs*, are discussed in relation to factors associated with community tenure or a NF admission. In addition, the roles of informal support and services as well as specific barriers or conditions that contributed to the various patterns of community tenure of CARE Assessment customers are discussed.

In the presentation of these findings, it is important to emphasize that the broader categories can influence each other and the key findings may overlap with other key findings within the same category or across categories. The order in which these categories and key findings are presented does not suggest greater importance or value of one over the other.

The first group of findings is categorized as *service related needs* and KDOA policy can be developed or revised to resolve many of these needs. The category includes a set of key findings that are generally classified under the headings of 1) case management, 2) service awareness, and 3) supported housing. The second group of findings is categorized as *caregiver and context related needs*. The older adult, the caregiver, other sources of informal support, and formal support mutually and individually contribute to these findings. This category includes a set of key findings that can generally be classified under the headings of 1) reciprocal care, 2) environmental circumstances, and 3) health. The *service related needs*, and *caregiver and context related needs* suggest implications for policy. After each key finding is presented and discussed, policy implications are offered.

The findings will be presented in a table format first, followed by a narrative summary that provides further details about the findings in the Table 14 and 15. The table format will include recommendations for potential enhancement of services.

Table 14
Policy Focused Interpretation of Interview Findings
Office of Aging and Long Term Care
Theme: Service Related Needs

Key Finding	Potential Options for Service Enhancements
1) Case management	<ul style="list-style-type: none"> ➤ Case managers can play an important preventive role by educating older adults and their caregivers regarding strategies to support community tenure and sufficient case management time needs to be allocated to this function. ➤ Effective case management was crucial for some diverted customer to remain in the community and effectiveness can be enhanced by training and increased allocation of professional time spent with older adults ➤ Case managers need to establish strong and positive working relationships to help orient older adults and their caregivers to state programs and services. ➤ Case managers need to assess the social environment that supports the older adult as well as assess their social and emotional well being. ➤ Case managers need to re-assess older adults frequently throughout the year to identify needed changes in the care plan. This is cost effective because unneeded services can stop and services can be increased in lieu of NF to deal with episodic health events.
2) Service awareness	<ul style="list-style-type: none"> ➤ Education of older adults and caregivers is critical to prevent NF admission. <ul style="list-style-type: none"> ○ Education should ideally take place outside of a crisis situation. ○ Education should include development and implementation of specific plans in addition to written information because older adults can be overwhelmed with only written information. ➤ Public awareness programs need to occur in settings where family members of older adults are involved, such as schools, worksites, community settings, etc. <ul style="list-style-type: none"> ○ Public education programs need to identify AAA as the single point of entry. ○ Family members of older adults need to learn about LTC services before a crisis.
3) Supported housing	<ul style="list-style-type: none"> ➤ Cooperative ventures between KDOA and HUD are needed to develop additional low-income senior housing as a supportive environment for older adults with long term care needs. <ul style="list-style-type: none"> ○ The housing provides privacy as well as a community environment. ○ AAA staff could visit senior housing centers weekly to assist older adults in getting connected with services. ➤ State agencies and AL providers need to increase public awareness of AL as a LTC option for low-income older adults. Many older adults and caregivers are unaware of this option.

Table 15
Policy Focused Interpretation of Interview Findings
Office of Aging and Long Term Care
Theme: Caregiver and Context Related Needs

Key Finding	Potential Options for Service Enhancements
1) Reciprocal care	<ul style="list-style-type: none"> ➤ Case management roles can be expanded. Training needs to include information focused on the importance of relationship and reciprocity between the older adult and caregiver. <ul style="list-style-type: none"> ○ Case managers need to encourage older adults and caregivers to discuss expectations related to caregiving. ○ Case managers can mediate between older adults and caregivers when problems arise. ➤ The AAA and KDOA should help to create ‘substitute’ reciprocity for caregivers. <ul style="list-style-type: none"> ○ Acknowledge the challenges of caregiving as well as the commitment and dedication of caregivers. ○ Establish community programs to recognize caregivers. This can include the AAA, services providers, and business and professional associations. ○ Increase opportunities for caregivers to receive support. Caregivers may be reluctant to attend support groups; however training programs around caregiving needs provide valuable information as well as informal support.
2) Environmental circumstances	<ul style="list-style-type: none"> ➤ Case managers need to assess the older adult’s social environment for strengths, supports, and weak areas. Mobilizing resources can be included in the care plan. <ul style="list-style-type: none"> ○ In some instances, case managers will need to develop networks for social support. ○ Older adults need opportunities and support to stay socially connected. This can include friendly visitors, telephone support, and outings. ○ Developing housing options near services and shopping help older adults to remain active and involved despite functional disabilities. ○ Adapting the environment helps to foster self-sufficiency of older adults as well as promoting security and safety for older adults and family members. ➤ The development and promotion of community volunteer programs should continue. Match those who need support with programs that provide support.
i) Finances	
ii) Living arrangements	
iii) Social support	
3) Health	<ul style="list-style-type: none"> ➤ Older adults do not perceive functional disability as an indication of poor health. Building on their sense of wellness requires services and support so they can maintain community tenure. ➤ Older adults and caregivers need to understand how NF and other LTC services can support their well being in the least restrictive environment.

SERVICE RELATED NEEDS

Case Management

All older adults and caregivers were asked during the interview if they received case management services. Some individuals mentioned the CARE Assessor and some discussed their case manager. However, not all older adults received, and many were unaware of the availability of case management services prior to or after the CARE Assessment. An important finding is that older adults and caregivers had contact with case managers from multiple settings. Although the role of case managers may vary from setting to setting, for this report, we rely on the KDOA Field Service Manual definition of case manager. “Case management consists of assistance in access and coordination of information and services to older customers and/or their caregivers to support the customers in the living environment of their choice.”¹⁵ For older adults and caregivers who received case management, several reported it was a helpful service and others reported it was unhelpful.

Analysis of the interviews illustrated how a case manager was helpful to older adults. First, case managers who kept in touch with the older adults and/or caregiver were perceived as helpful. Second, case managers who responded promptly to requests for services or information were perceived as helpful. Finally, case managers who put together those services that supported the older adult and caregiver’s efforts to keep the older adult in the community were perceived as helpful.

Also, the role of case managers was considered by older adults and caregivers to be very important. This is illustrated with two examples. When case managers did not respond promptly to requests for assistance, older adults and caregivers were unable to identify and access services on their own. A second example occurred for several interviewed pairs of older adults and caregivers in the recent NF admission group. These older adults and caregivers were unaware of case management and struggled with identifying and accessing services in a timely manner to prevent a NF admission. Also, had case managers followed up with these same older adults in a NF, it is likely that they would have been discharged from a NF after a 45 or 60 day stay.

When the older adult and caregiver identified one case manager as the person they could contact whenever a problem arose, this on-going relationship was beneficial. For example, one older adult and caregiver team were connected with social work services in the hospital and they relied on that helper from “rehab” as a contact person for assistance negotiating service connections at the time of crisis and at later points.

Older adults and caregivers found case management to be unhelpful when the case manager recommended the older adult consider entering a NF. These older adults and caregivers wanted to explore all possible options before making a decision regarding a plan that would ultimately be implemented. Older adults and caregivers found case management unhelpful when they only had contact with the older adult during the annual care plan review. Older adults and caregivers described how their circumstances changed, their needs changed and this would be overwhelming for them. Older adults and caregivers needed to know that case managers would

¹⁵ Kansas Department on Aging, Field Services Manual, effective date March 1, 2001.

advocate for them if asked. However, the greater danger is that older adults and caregivers lose the connection with the case manager unless there is periodic contact initiated by the case manager.

Implications:

- Establishing a strong and positive working relationship with a case manager is an important first step to helping orient older adults and their caregivers to state-programs and services that are both cost effective alternatives to a NF and community tenure oriented.
- Case managers could play an important role educating older adults and their caregivers about LTC service options and also about strategies that support community tenure. This could be seen as a prevention intervention.
- Case managers need to assess the social environment that supports the older adult in addition to the assessment of the older adult's physical and emotional needs when developing care plans.
- Providing case management assessments with increased frequency is likely to be of great benefit to many older adults and their caregivers for whom changes in care needs occur throughout the year.
 - This saves money because the state-funded service care plan would change as the needs change. The flexible and adaptable care plan would provide services as needed and this would prevent funding for a service that is no longer needed.
 - It is also cost effective because long term care community based services help to keep older adults out of the nursing facility or for shorter stays.

Service Awareness

Older adults' and caregivers' awareness of services also varied. One older adult's story illustrates the basic lack of service awareness. The older adult lived in a senior high-rise apartment and was talking to other residents about meals the other residents were receiving. The older adult was unaware of the meal program, but did express an interest in the meal program. The older adult reported in the interview that eventually he began to receive home delivered meals, but he did not know who had arranged for them to be delivered. As a result, this older adult did not have knowledge about how to request other services in the event his needs increased.

In another situation, the lack of service awareness was the result of a misunderstanding when the older adult and caregiver requested AAA/KDOA services. An older adult/caregiver described in the interview how they had contacted the AAA for help at home. The older adult/caregiver reported that AAA staff indicated the only service that would pay for was a NF; they also reported the AAA case manager did not explore other options with the older adult/caregiver. As a result, the older adult/caregiver believed there were no community-based services available at all, regardless of funding sources. This older adult went without services.

Older adults and caregivers were also specifically asked if they knew that caregiver support programs were available. One caregiver noted she had seen a billboard with information about caregiver support and the 800 number to call for more information. She did not request services however. Another caregiver described the stress and burden she experienced. She had talked to a senior center director about the need for support services for caregivers, however she was not informed that there were caregiver support programs available. For the most part, caregivers were unaware of caregiver support programs and services available through the AAA and none of the caregivers received or participated in caregiver support programs.

Finally, very few older adults and caregivers have personal computers and when they own one, the computer is primarily used for sending email to family and friends. A typical reason for not having or using a computer was older adults and caregivers believed they were too old to learn how to use one. Yet, in an age of easy access to information via the Internet, policy makers and service providers need to remember many older adults and caregivers are not part of the electronic information network.

Implications:

- Education of older adults and caregivers (potential caregivers, current caregivers, former caregivers) is a critical intervention to prevent permanent nursing facility placement.
 - Preferably the education should take place outside a crisis situation. However, it may be a helpful first step to begin with a formal education component at the time of the CARE Assessment process. Education will need to be provided episodically.
 - Education programs should include information giving as well as assisting in the development of specific plans and follow through with referrals to agencies. Older adults and caregivers become overwhelmed and may not benefit exclusively from written information.
- Public awareness programs need to occur in settings where family members of older adults are involved— such as schools, worksites, and churches.
 - Public information campaigns could help to establish the AAA as the single point of entry for services for older Kansans.
 - Family members could begin to learn about community-based LTC services before a need arises.

Supported Housing

Supported housing includes assisted living and congregate housing. Both settings provide older adults with a less restricted environment, and the support and supervision that could help them avoid a NF admission. The Diversion Study (SFY 2002) presented findings last year that suggested low-income older adults in assisted living were at a reduced risk of a NF admission than their private pay counterparts. Very few of the older adults interviewed in the Community Tenure Study (SFY 2003) used assisted living. None of the individuals who were permanent NF residents were in assisted living prior to a NF admission, although it might have been an appropriate setting for some of them after a short NF stay. Key factors that prevented older adults from using this option were their inability to afford to private pay for the assisted living and/or the availability of assisted living in or near their community.

Congregate housing options include older adult high-rise apartment buildings or a Continuing Care Retirement Community (CCRC). For the older adults in a CCRC, their choice of this setting was based on the availability of multiple levels of care depending upon their temporary or permanent need for care. In one instance, an older adult with memory deficits was able to successfully remain in a senior apartment. While the housing did not offer formal care services, a great deal of informal care occurred between residents and family members. During one interview, the researcher observed a caregiver being greeted by her mother's neighbor. The interaction revealed a trusting and supportive relationship that included mutual assistance.

Implications:

- State financial support for more low-income assisted living options would be beneficial for older adults. Low-income senior housing can be a supportive environment under certain conditions, if:
 - The architectural design provides a community environment, yet with privacy;
 - There are natural opportunities for interaction; and,
 - AAA staff member could visit the high rise apartment once a week or have a satellite office in a low-income senior housing complex.
- State agencies, in partnership with assisted living providers and other LTC service providers, could join forces to increase public awareness about a variety of options. Many older adults and caregivers are unaware of the availability of HCBS/FE services in an assisted living setting.
- Assisted living facilities are admitting older adults with greater physical care needs and/or keeping residents longer despite increased needs. If the HCBS/FE services in assisted living can be provided at less cost than NF, the state saves money over time. Older adults can age in place and have the security of a supervised living environment, which is important to older adults.

CAREGIVER AND CONTEXT RELATED NEEDS

The next findings that will be discussed are those categorized as *caregiver and context related needs*. It must be emphasized that the three classifications in this category may overlap with each other. In addition, one of the classifications may influence or be influenced by another. Finally, the classifications for the *service related needs* influence each other and there is interaction between the classifications in the two categories.

Reciprocal Care

An important finding from the analysis of the interviews was the reciprocity between older adults and caregivers. The literature on this topic debates the presence of reciprocal care. The Community Tenure Study (SFY 2003) findings clearly demonstrated that reciprocal care exists and that it is important. Two examples of reciprocal care were identified. The first we describe

as “here and now” reciprocal care. An example is the simple expression of appreciation that is basic to human interaction and relationships. The second example is “banked” reciprocal care. Some caregivers described how the impetus and reason they became a caregiver was because the parent had been their caregiver when they were young. Although a sense of appreciation existed between the older adult and the caregiver, the banked reciprocity was a powerful and strong inspiration that sustained adult offspring in the caregiving role.

The first example of the “here and now” reciprocal care illustrates what an older adult and caregiver did for each other. The older adult described how her daughter’s support and assistance made it possible for her to remain in the community. In return, the older adult would tell her daughter she could finish up the caregiving and leave early for the day. Or, the older adult would ask the caregiver to call and let her know she had made it home safely after leaving the older adult’s home. During interviews with both the recent and long term community tenure groups, older adults and caregivers reported the reciprocal care sustained them. Many of the caregivers reported fatigue, even exhaustion, and stress. However, at the same time, they also described feelings of being appreciated by the older adults for their efforts and dedication.

This was not the case for one older adult and caregiver pair in the recent NF group; this example illustrates how the lack of reciprocity took a toll on the caregiver. The motivation for this caregiver was guilt. That is, she provided the care and support for the older adult because it was her mother. The caregiver reported she did not feel the older adult appreciated her efforts and support, an example of lack of reciprocity. In fact, both the older adult and caregiver reported stress and conflict in their relationship. Following an acute health crisis for the older adult, the older adult was admitted to a NF. Neither the older adult nor the caregiver made attempts for the older adult to leave the NF and return to the apartment although the older adult continued to rent the apartment for several months. Had reciprocity existed between the older adult and caregiver, it is likely this older adult might have returned to the community.

There were older adults in the recent NF group for whom reciprocity did exist. The circumstances for the older adult’s admission were the presence of a severe physical impairment that prevented them from transferring from the bed to a wheelchair without the assistance of two individuals or a mechanical lift. The fact that these older adults and caregivers persisted in the community as long as they did attests to the importance of reciprocity.

These findings have implications for social policy that can enhance caregiver support programs. For example, the AAA may work with community social service agencies and local businesses to sponsor a semi-annual caregiver appreciation banquet or a caregiver of the month. Caregivers do not directly ask for the expression of appreciation, but they reported how they valued the expression of appreciation. Some of the older adults may not be able to express their appreciation possibly due to dementia,. Community recognition of caregivers would be one way to provide the support and encouragement needed in this situation. Also, case managers may need to refer older adults and caregivers to CMHCs for counseling and support to work through the stressful and difficult family relationships that occur because of caregiving.

The other example of reciprocity was the banked reciprocal care. Some caregivers stressed the impetus to take on the caregiving role and responsibility was because they could pay back the

parent for being their caregiving when they were young. One daughter reported how this had inspired her to be her father's caregiver.

Implications:

- The education and training for case managers needs to include discussion of this idea of reciprocity – in essence the CM could help older adults and their caregivers think about this idea early on in the process.
 - This initial information could include a discussion of expectations on the part of older adults and caregivers.
 - If needed, CMs could counsel the dyads or refer them to CMHCs if problems arise.
- The AAA and KDOA and other service providers assisting older adults can be helpful in creating “substitute” reciprocity for caregivers
 - Increase the social status of the care work provided to older adults by unpaid and paid caregivers. This acknowledges the informal caregiver's experience of caregiving as challenging and hard work that is done out of love and concern for the well being of the older adult.
 - Provide formal opportunities for caregiver recognition in the community. This could involve a cooperative recognition program sponsored by the AAA, local service providers, and business associations.
 - Provide more formal opportunities for engagement, support, and socialization for caregivers. Caregivers may be hesitant to attend a support group, but a training program provides valuable information and the opportunity to learn from other caregivers and exchange support.

Environmental Circumstances

Environmental circumstances represent a broad and diverse set of factors that played a role in the older adult's quest to remain in the community. Those factors identified were: 1) finances, 2) living environment; and, 3) social support.

Finances

Older adults and caregivers cited availability of financial resources as a factor that limited their ability to live safely in the community. For example, financial resources were used to provide older adults with needed care. The financial resources could be private or public sources. Some caregivers arranged for housekeepers and paid caregivers to assist older adults. One older adult stated all she needed was a chair with a seat that would rise so she could get in and out of the chair safely. She commented she did not have the financial means to pay for this. She was frustrated because she believed this chair was the only “caregiving support” she needed and yet Medicare and Medicaid would not pay for this.

Living Environment

In addition, older adults' living environments were modified to accommodate their special needs. One older adult had the microwave set up at a lowered level near a table so she did not have to carry food from the microwave to the table. Other older adults had ramps built to help them get in and out of their home.

Social Support

Older adults also discussed their need for social support. Some older adults have frequent visitors in their home or even a NF. Some older adults used the telephone to keep in touch with friends, neighbors, family, and church members. There were also instances when the older adult reported that they were lonely because they were unable to leave their home for socialization and other activities in the community. The implication is that these older adults' social isolation will lead to depression, hopelessness, and despair.

Caregivers talked about their need for relief from the responsibility of caregiving. There are examples of caregivers providing daily and consistent caregiving for the older adult, sometimes eight or more hours per day. Caregivers reported there was not a person they could call upon to temporarily relieve them. Caregivers consistently reported a lack of awareness of caregiver support programs and services. In addition, caregivers reported their feeling of burden because they also had responsibilities to their spouse and children and/or they worked outside the home in addition to being a caregiver. Research literature regarding caregiving has sufficiently described the risks and negative outcomes related to caregiver burden.

The achievements of older adults and caregivers to overcome some of these environmental barriers are noteworthy. For instance, one older adult in a very small rural community was able to network with neighbors and church members to have others provide instrumental activities. This older adult needed to wear "depends" but was unable to manage disposal of them. Remarkably, she arranged for one person to take the "depends" from her bathroom to the front porch. Then, once a week, on the way to work, another person would take the refuse from the front porch to the curb for pickup by sanitation workers.

Implications:

- Assessment of the strengths and weaknesses of the older adult's environment could reveal elements that could be mobilized, supported, or added to an older adult's environment in support of community tenure.
 - Social connection – friendly visitor, telephone support, transportation to a social event;
 - Physical environment – housing near services (shopping, medical, etc.);
 - Adapted environments to foster self-sufficiency;
 - Financial support for older adults to buy foods that are prepared / packaged in such a way that they can handle their own nutrition needs (e.g. Wyandotte Co AAA used to deliver frozen meals for a week.)
 - Personal emergency services, such as Lifeline, provide a great deal of comfort to older adults and caregivers. Currently HCBS/FE pays for this service, however other funding mechanisms are needed to pay for this service.
 - Informal support resources
 - Mobilize latent supporters – case managers could attempt to strengthen older adults' social network contacts and involve an array of supporters rather relying primarily on the caregiver.
 - Involve community volunteer programs like the Shepard Center in Kansas City to encourage linking volunteers with older adults.

Health

Typically we objectively consider health on a continuum of healthy to unhealthy. The older adults in the Community Tenure Study (SFY 2003) would not meet the criterion of healthy, however their subjective perception of their own health was positive. Older adults and caregivers viewed the challenges to remaining in the community based on the impact of functional disability on their independence. Older adults were willing to accept a reduced level of independence as long as they could remain in the community in what they perceived as a safe and secure environment. And caregivers were equally accepting of the older adults' limited independence and did what they could to support the older adult to remain in the community.

Older adults and caregivers reported a severe, sudden, or new health condition prompted a hospitalization. The health condition improved, yet the older adult needed rehabilitation and this prompted the CARE Assessment. Older adults who needed skilled nursing care or rehabilitation then went to a NF for a short stay. This changes some aspects of the nursing home role in the provision of care for older adults. One change in expectation is that if the older adult enters a NF, they cannot leave. There needs to be community education, especially physician education, to promote the idea of a NF as a place to achieve wellness. We believe that a focus on wellness is consistent with older adult's perceptions of his or her own health and it also promotes the idea that a NF can play a role in achieving wellness.

Implications:

- Older adults' experiences of health and functioning are unique and individual; they also tend to subjectively rate their health as good despite functional disability. The analyses of CARE Assessment data suggest health and functioning alone aren't the determinants of a NF placement. Avoiding NF placement is also based on mobilizing sufficient support to offset the challenges of functional disability.
- The use of a NF should be presented as a strengths based approach that promotes the older adult's return to wellness.
 - Health care providers can encourage short term NF care for rehab and encourage older adults to think about needs after a NF stay.
 - KDOA communication with the public and legislators can reflect this emphasis on wellness and recovery.
 - KDOA health facilities licensure surveys and re-certification processes need to emphasize a wellness model.
 - CARE Coordinators could complete the 90-Day CARE Follow-Up on all customers.
 - AAA case managers could track the status of non-diverted customers in a NF for potential discharge to community settings.
 - Nursing facilities could foster their role in supporting the wellness and recovery of older adults following a health episode.

IV: Implications Based on Quantitative and Qualitative Findings

This section of the report provides a summary of key policy findings and implications for policy makers. This section is based on key quantitative and qualitative findings from Section II and III. These findings are organized based on key policy issues.

➤ State Publicly Funded Services (SPFS) are Cost Effective

The annual savings gained by providing SPFS for diverted older adults in our sample during 24 months of tracking in lieu of NF services is \$202,968.96 for diverted CARE customers who received SGF services, \$441,524.16 for diverted CARE customers who received OAA services and \$2,010,888.30 for diverted CARE customers who received HCBS/FE services, including TCM. The total savings was \$2,665,380.80 for 24 months.

OALTC staff conducted a cost analysis using 24 months of actual SPFS cost data for diverted customers. This represents an additional 6 months of service use data for the analysis compared to the analysis conducted for the Diversion Study (SFY 2002). Diverted customers' use of SPFS in lieu of a NF admission continues to be cost effective. Most diverted customers use SPFS for a limited time and were able to successfully maintain community tenure. The SGF services were used for an average of approximately 2 months, OAA services were used on average for slightly over 1 month and the Medicaid-HCBS/FE and TCM services were used for an average of approximately twelve and one-half months. For every month a diverted service customer in the sample remained in the community with SPFS, the state saved \$671.46 if SGF services were provided, \$924.00 if OAA services were provided and \$597.32 if Medicaid-HCBS/FE and TCM services were provided. The cost benefit analysis was conducted with actual SPFS cost data for diverted customers for 24 months.

➤ Diverted Customers Continue to Have High Rates of Community Tenure

After 24 months of follow-up, 40.7% (n=244) of the diverted customers remained in the community.

These findings are even more remarkable when the number of living diverted customers residing in community settings is compared to living diverted customers who are permanent NF residents. There are 244 (65.9%) or nearly two-thirds of the living diverted customers residing in community settings 24 months after the CARE Assessment compared to the 126 (34.1%) living diverted customers who are permanent NF residents. Also, 165 (27.5%) diverted customers were residing in the community when they died and only 64 (10.7%) were permanent NF residents at the time of their death. Our understanding of how diverted customers and caregivers were able to remain in the community was enhanced by the qualitative findings from interviews. Diverted customers and caregivers told us that determination and their ability to uniquely combine

informal support and formal services were important factors in considering permanent NF admission.

- **New Data Confirm that State Publicly Funded In-Home Services, Medicare Home Health Services and Informal Support Play an Important Role in Diversion and Community Tenure**

Diversion and the maintenance of community tenure by diverted customers require the integration of publicly funded state and Medicare in-home services in combination with informal support.

Analysis of SPFS and Medicare Home Health Service use suggest these publicly funded programs have the greatest impact in the first three months following the CARE Assessment. Interview findings reveal that during this time diverted customers are often recovering from acute health episodes and can remain in the community with support from formal and informal sources. Diverted customers reported that their needs were greater immediately following the CARE Assessment because they were recovering from an acute health crisis. Effective case management was instrumental in helping older adults and caregivers identify and mobilize the formal services.

Diverted customers who indicated Medicaid as a potential source of payment for support services are at greater risk of entering a NF permanently. However, using SPFS, especially Medicaid-HCBS/FE, reduces the risk of permanent NF admission.

A hazards analysis was conducted using 24 months of data for all diverted customers. “Medicaid as a potential payment source for support services” (a proxy variable for low-income) was a statistically significant risk factor for permanent NF admission. However, diverted customers who used SPFS did not have an increased risk of permanent NF admission. Since these service customers are generally, by definition, lower-income, it appears that using state publicly funded services mitigates their risk of a NF admission. The cost analysis for diverted customers’ using SPFS demonstrates that diverting and maintaining older adults in the community with SPFS as an alternative to a NF is cost effective for the state. In addition, qualitative findings from interviews with CARE Assessment customers including those who permanently entered a NF, and caregivers found they lacked awareness of these services and programs. Increased outreach to low-income customers with encouragement to apply for Medicaid-HCBS/FE would help them to access services promptly, reducing their vulnerability to a NF admission.

Analysis of SPFS and Medicare Home Health data in addition to the interviews with diverted and non-diverted customers identified two types of CARE Assessment customers with distinct care needs.

Both quantitative and qualitative findings suggest there are two categories or types of diverted customers. One group of older adults experience an acute health crisis that resolves with acute, skilled nursing home, and community based services such as Medicare Home Health and HCBS/FE. Many of these individuals do not have an on-going need for community-based services. Approximately two-thirds of the diverted customers did not use SPFS and/or Medicare Home Health anytime after their CARE Assessment. The second category of diverted customers have an acute health crisis or episode that is resolved; however they have on-going chronic health conditions that require community based services such as Medicaid-HCBS/FE and/or SGF and OAA services. These customers use unique combinations of publicly funded and informal support in order to remain in the community.

Similarly, there are two categories of non-diverted customers. First, there are non-diverted customers whose acute care needs resolved; however they remained in a NF because they were unaware of community based services and/or they did not have a caregiver or case manager to advocate on their behalf for a discharge. Case management services would be a likely resource for these individuals to help them transition back into the community. Second, there are non-diverted customers with chronic on-going needs that would most appropriately be addressed in a NF setting. They will likely remain as permanent NF residents.

- **Medicare Home Health Services Provide Needed Skilled Levels of Care in a Home Setting Immediately Following the CARE Assessment.**

Diverted customers utilized Medicare Home Health Services to address complex health needs at higher rates in the first three months following the CARE Assessment.

There were 178 diverted customers who used Medicare Home Health at any time during the 24 months of follow-up, 73.0% of whom (130) used them only for three months. During interviews, diverted customers and caregivers reported their needs were greater following a discharge from the hospital or a NF. Interview data also revealed that many diverted customers and caregivers often were unfamiliar with community-based services, including Medicare Home Health Services. This suggests that a valuable opportunity exists for AAA staff to assist diverted customers in securing Medicare Home Health Services. Once diverted customers' post hospital care needs decrease, they can be transitioned to SPFS if they have continued chronic health problems.

Utilization of Medicare Home Health Services can offset state expenditures for community-based services.

The state accrues additional savings when considering the cost avoidance for diverted customers who use Medicare Home Health Services alone or in combination with SPFS. The cost reduction due to Medicare Home Health has potential implications for the referral of CARE Assessment customers to these services. CARE assessors and case managers are involved when customers are examining options for care and services, based on the assessment of their needs.

When a CARE Assessment customer's assessed needs suggest Medicare Home Health Services may be appropriate, the assessor or case manager could make a Medicare Home Health referral recommendation to the attending physician. In addition to the state avoiding or reducing expenditures for in-home service, another important benefit for CARE Assessment customers is the receipt of a skilled level of care provided by Medicare Home Health agencies.

- **CARE Assessment Customers and Caregivers Exhibit Resilience and Creative Use of Resources to Achieve Diversion and Maintain Community Tenure.**

Interviews with diverted customers and caregivers identified strategies used to maintain community tenure after being diverted.

Three groups of CARE Assessment customers were interviewed. One group had been identified during the Diversion Study (SFY 2002) and was selected because they have been in the community for over two years following their CARE Assessment. The other two groups were recent CARE Assessment customers (March of 2002), one group was diverted and the other was non-diverted. The two groups of recently diverted and non-diverted customers were selected for interviews based on their Long Term Care Threshold score of 66 or less. This selection criterion was important for discussion regarding similarities and differences in the interview findings between recently diverted and non-diverted CARE Assessment customers because their impairment levels and care needs would be similar.

Recently diverted customers revealed their determination to remain in the community and not become permanent NF residents. Another key to their successful community tenure was a caregiver who would support the diverted customer's goal to remain in the community. These committed care receiver-caregiver relationships were established with family members, neighbors, other informal support and paid caregivers. Regardless of the familial relationship, the determination and commitment was a shared attribute of the diverted customer and caregiver. When factoring out non-diverted customers with extensive care needs that could only be provided for in a NF, this determination, commitment and an instrumentally supportive caregiving relationship typically distinguished the recently diverted customers from the recently non-diverted customers.

Diverted customers' ability to sustain their mental health and creatively utilize limited resources were important traits that helped them overcome the challenges they faced in order to remain in the community.

Many older adults who were initially diverted managed to continue residing in the community for long periods of time. Data from interviews with diverted customers illustrated how sustained mental health was important for older adults, enabling them to creatively identify solutions to the challenges they faced. Diverted customers found novel and efficient ways to use the limited resources available to them. For instance, one diverted customer with mobility problems used remote control devices to operate electronic equipment such as an air conditioner, a ceiling fan,

and his television. This enabled him to remain independent without much assistance from others. These diverted customers were not discouraged by health problems and continued to take care of themselves to the best of their ability. In contrast, non-diverted customers reported depression and powerlessness when facing decisions about options to remain in the community. Their depression and discouragement contributed to their inability to undertake problem solving and develop plans to return home. The finding that sustained mental health is a vital part of community tenure highlights the need for adequate evaluation and treatment of problems such as depression.

Diverted older adults reported security and safety were important factors that enabled them to live in the community. Older adults and caregivers want the assurance that the older adult can get help when they need it.

Both diverted and non-diverted older adults and their caregivers reported that they could accept the risks, such as a fall or sudden illness that come with living alone, but did need support in order to feel safe. Personal emergency communication services are one way that diverted customers and their caregivers were able to develop a sense of security. Neighbors and family members also monitor older adult's home and situation to reassure them. In a few situations, non-diverted customers continued to reside in the NF despite improvement in their health and functioning because they did not have a sense of safety and security to live independently. Other options to provide a secure and safe environment include supported housing options such as assisted living. The statistical analysis demonstrated that assisted living facilities might mitigate the risk of a NF admission for low-income diverted customers.

- **Some Older Adults and Caregivers Reported They Encountered Barriers When They Attempted to Access Community Based Services.**

Many older adults and caregivers utilized informal networks to identify community based services to assist the older adult and caregiver. Even if they were aware of the Area Agency on Aging, many older adults and caregivers did not actively request assistance to learn about community-based options.

One barrier identified during interviews with diverted and non-diverted older adults and their caregivers was that many of them did not have a single person or agency they would contact for information or assistance. These CARE Assessment customers did not understand that the AAA was a single point of entry for community-based options, information, and referral. This meant that they did not have someone providing a case management role to assess and coordinate services as needed in response to changes in the older adult's condition. The single point of entry concept at the Area Agency on Aging and KDOA provides the older adult and caregiver with a connection to the agency and potentially a case manager. This finding points to the need for outreach and community education programs around the single point of entry concept.

➤ **The Importance of Case Management was a Consistent Theme in the Interviews with Diverted and Non-diverted Customers.**

Older adults reported that responsive, on-going, and resourceful case management was effective and helpful to them. When older adults and their caregivers had a case manager working with them, they could learn about services and gain access to services that would help them resolve caregiving needs.

One challenge older adults face is unmet care needs because the care needs become too great for the available informal support alone. Without a consistent and direct link to formal services through case management, most older adults and their caregivers lacked awareness about available services, believing that services were not available or that they would be insufficient or difficult to arrange. Older adults are at risk for nursing facility placement if they are unaware of services, service eligibility, and accessibility. Many of the interviewed older adults and caregivers were not aware of case management services. While a number of older adults had successfully pieced together informal services to meet existing needs, they were at risk for nursing facility placement when their needs increased. Without case management services, some older adults and their caregivers saw nursing facility placement as the only possible next-step rather than a NF as one choice among several options for formal assistance.

Effective case managers develop a positive working relationship with older adults and caregivers.

Case management requires well-trained and qualified case managers to deal with a multitude of interpersonal and practical needs of older adults as they attempt to achieve their goal of remaining in the community. Older adults and caregivers reported during interviews that positive working relationships with their case manager included a shared commitment to the goal of remaining in the community. Once a trusting relationship was established, older adults and caregivers utilized the expertise of the case manager when facing new challenges. What was helpful to these diverted customers and caregivers was knowing they could turn to one person, such as the AAA case manager, to help them as needed. In addition, case managers need to be able to initiate contact with older adults as a means to ensure their care plan is continuing to meet their needs.

As noted earlier, chronic health problems and disability are frequently accompanied by depression. Case managers need to be attentive to signs that older adults are experiencing mental health problems that will interfere in their successful community tenure. In addition to the professional counseling and support of the case manager, referrals to mental health resources may also be required. The case manager needs to be professionally trained and qualified to detect these mental health problems and then proactively respond. A positive working relationship between the case manager and older adult will promote the identification and amelioration of these mental health problems. The interviews clearly pointed out that the maintenance of the mental health of older adults and caregivers was key to community tenure.

- **The Significant and Important Contributions to Community Tenure Provided by Informal Caregivers were a Consistent Theme that Emerged During Interviews with Diverted and Non-diverted Customers and Their Caregivers.**

The interviews with older adults and caregivers provided valuable information and insight regarding caregiving from both the older adults' and caregivers' perspectives.

The Community Tenure Study (SFY 2003) confirmed other research findings that caregiving is complex, stressful, and also rewarding. When caregivers are available and have support for themselves, caregiving helps older adults remain in the community. Caregivers reported that when older adults were appreciative of the care they provided this gave the caregiver the encouragement and impetus to continue in the caregiving role. When interpersonal relationships between the older adult and caregiver were strained or difficult this made the caregiving relationship too stressful and in some cases contributed to the loss of community tenure. Overall, diverted and non-diverted customers and caregivers reported they were unaware of caregiver support programs and in some instances caregivers expressed their need for such programs. In addition, the AAA could develop special recognition programs to encourage caregivers and acknowledge their valuable role as a caregiver.

The forms of assistance provided by caregivers varied widely and reflected the particular skills and abilities of the caregiver.

Caregivers demonstrated phenomenal tenacity and expertise in the types of assistance they provided to older adults. The variability in the skills and abilities of caregivers has implications for policy. Caregivers who provide significant types and amounts of physical caregiving were able to help older adults remain at home for long periods of time. When caregivers did not believe they had the skills or emotional fortitude to continue to support the older adult at home, the older adult was unable to remain in the home. In these instances, caregiver and older adults had not developed a case manager connection and relationship that could have been used to marshal support for the older adult and the caregiver.

The hazards model analysis also confirmed the importance of support from caregivers. In this analysis, increased levels of caregiving support, both informal and formal, reduced the risk of permanent NF admission. Interviews with diverted and non-diverted customers provided rich details regarding the frequency, extent, and types of caregiving required for older adults to remain in the community. Many caregivers reported it was difficult to know when caregiving would be too much for them to continue. Based on interviews with non-diverted customers in a NF, when the older adult required 24-hour care and two caregivers to assist the older adult with transferring, they entered a NF.

Summary

The Community Tenure Study (SFY 2003) provides numerous examples of strategies diverted customers and caregivers utilized to maintain community tenure. These findings suggest how the Kansas Department on Aging and local Area Agencies on Aging can develop, enhance, and promote programs and services that will support older adults and their caregivers' efforts to remain in the community.

The Kansas Department on Aging and local Area Agencies on Aging could consider public information programs regarding the AAA single point of entry concept in order to support older adults as well as CARE Assessment customers who were diverted. It is crucial that older adults and their caregivers come away from the CARE Assessment understanding they have some place to turn if they want to remain in or return to the community from a NF. Primarily, older adults, but also their caregivers would benefit from learning how the single point of entry would be valuable to them when facing an acute health crisis as well as dealing with chronic health problems resulting in functional disability. The single point of entry needs to be a system that consistently connects the older adult and/or caregiver with one person at the AAA who can provide services and support as needs change.

Also, older adults and caregivers would benefit by seeing and hearing examples of older adults who have managed to age in the community. The information needs to impress upon older adults that changes in long term care services to provide community-based services have assisted many older Kansans to remain in community settings. Older adults and caregivers need to understand that a NF is only one option in an array of long term care service options and for many older adults NF care is used for rehabilitation and/or short NF stays and not permanent admissions. Also, public information should inform older adults and caregivers about how community-based services could make a difference for them.

Public education programs also need to be extended to physicians, hospital staff, such as case managers and discharge planners, and Home Health nurses and social workers. These health care professionals are on the front line when older adults experience an acute health crisis and are also influential in developing discharge plans with older adults. In-service education regarding the role of community-based services, such as Medicaid-HCBS/FE, and the short-term role of nursing facility care can help these health care providers make recommendations for post-hospital care. They would benefit from in-service education programs that illustrate how older adults and caregivers effectively manage to marshal resources in order to remain in the community.

In order to make permanent NF placement less likely, the state could consider programs and services that build on the successes of diverted customers as well as utilize technology to support older adults. Older adults frequently utilized personal emergency communication systems that provide older adults and caregivers with a sense of security and safety should an emergency arise for the older adult. Other ideas include building on neighborhood watch programs. These programs would identify at risk and vulnerable older adults in neighborhoods. A key person in the neighborhood could be a contact for the older adult if they needed assistance or had an

emergency. The key person could also be available if neighbors became concerned about the safety and well being of the older adult.

KDOA has already implemented the Lifelong Communities Initiative that may provide a foundation for developing a neighborhood watch program to ensure the safety and well being of older adults. The program would not have to be restricted to older adults and could include children and other at risk and vulnerable populations.

These ideas require money to fund them and state and local budget-makers are already looking for ways to trim expenses. However, as demonstrated in the cost analysis, the state saves money when low-income CARE Assessment customers are diverted onto SPFS instead of entering the NF permanently. As noted in the hazards analysis, low-income diverted customers are twice as likely to permanently enter a NF. In addition, many diverted customers only used SPFS for a short time following the CARE Assessment. Medicare Home Health potentially offers savings to the state by avoiding or reducing SPFS utilization and avoiding permanent NF admission. Other options include supported housing options for diverted customers who need supervision or are concerned about security and safety. Assisted living is effective in reducing the risk of low-income diverted customers entry into a NF.

The interviews with CARE Assessment customers and caregivers provided examples of their resourcefulness, determination, and creative problem solving to successfully overcome the challenges to maintaining community tenure. Analyses of community tenure data indicated that many diverted customers were able to remain in the community for extended periods of time with little or no use of Medicare Home Health, Medicaid-HCBS/FE, SGF, and/or OAA services. For those diverted customers who did use these SPFS, they used them for a limited time and were able to successfully maintain community tenure when the services were available in a timely fashion.

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