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

APPENDICES

December 2003

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Appendix 1: Interview Guides
Appendix 1a: Older Adult in the Community (Recent Diversion)
Older Adult in the Community (Recent Diversion)

Date_____/_____/________  Interview ID:  C - A - _____ - M - M - D - D - ___

(Record the month and day in “M” and “D”, followed by the interviewer’s initials)

Before the interview begins, have the respondent sign the consent to conduct the interview. Leave a copy of the consent with them.

ACTION REQUIRED:  
☐ Consent obtained

This interview guide is arranged so that the questions can be asked in the sequence provided. However, in the course of the interview, the respondent may provide information that answers a question that appears later in the interview guide. The question does not need to be repeated in those instances.

Be sure all numbered questions are asked.

The interviewer must record key comments and notes onto this document. The interview guide has been developed for ease in recording directly onto the document. Directions for each question are noted throughout the interview guide.

Use the interview process to have the older adult provide details as they tell their story. After hearing the story from the older adult, consider using the probes if they did not discuss the specific topic or theme noted in the probe.

MAKE SURE THE TAPE RECORDER IS RECORDING/WORKING

Background information-opening the interview

As part of the warm up, let the respondent know “we are interested in how you were able to remain in the community and I would like you to tell me about this in your own words. Nothing you say will have an impact on the services or benefits you currently receive or any services or benefits you may receive in the future.”

This first section of the interview focuses on your situation immediately before you were considering the NF application. Do you remember someone asking you questions at the time you were thinking about or considering nursing facility admission? You might recall it was called a CARE Assessment. I would like you to think back to the time of the CARE Assessment because I am going to ask you about what was going on at that time.
1.) Please describe the events in your life that led up to that point of considering applying for NF admission.

PROMPT: Why was the CARE Assessment done?

2.) What influenced the decision for you to remain in the community?

NOTE: The older adult may have had a short NF stay, then returned home.

PROBE: The older adult’s assessment of what they could and could not handle.
3.) How was the CARE Assessor/case manager helpful in evaluating your situation and exploring potential community resource options? Such as help from a personal care attendant, home delivered meals, Lifeline, etc.

4.) You told me about several circumstance that influenced the decision for you to remain at home. What was the most important influence?
Background information-opening the interview (continued)

NOTE TO INTERVIEWER: the older adult may NOT have required assistance from a caregiver prior to the CARE Assessment – adjust prompts/probes accordingly.

5.) Despite any challenges you faced at that time (of the CARE Assessment), you have been able to continue living in your home. Please tell me how you have been able to accomplish this.

PROMPTS:
- strategies to remain in the community
- mobilization of resources (public or private services)
- Role of physician
- informal support from family/friends/neighbors (availability and perception of availability)
- do you prefer this person or someone else?

6.) You have told me about several challenges that you faced at the time of the CARE Assessment to stay at home. What is the most important one?
7.) Please describe the challenges you have continued to face in order to stay at home.

PROMPTS: What were the challenges you’ve experienced to stay at home? How did you deal with the challenges?
   lack of money
   transportation
   caregiver(s)
   difficulty accessing & using resources

8.) You have told me about several challenges you faced. What was the most difficult one?
9.) If circumstances were to change, and you were no longer receiving assistance or support, how would your needs be met?

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10.) Thank you for telling me about your experiences since the CARE Assessment. Please tell me, overall, how do you think you are doing?
If the older adult has mentioned a PCG, then ask: How do you think <name of family member> is doing?
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8
The older adult’s report of their current situation

I have some additional questions that are designed to gain information that is more specific. It is important that I ask these questions because there are some details we want to be sure we discuss with you. The next questions are about your health and how your day goes.

11.) How would you describe your health today? (physical, emotional, social)

a.) Probe by asking the respondent to compare his/her health to other people the same age, e.g.: excellent / good / fair / poor / bad.

b.) Probe for emotional well-being and social well-being: excellent / good / fair / poor / bad.

12.) What are some of the activities that have helped you live on your own?

Probe for health promoting behaviors (e.g. immunizations, exercise, nutrition)
13.) Please describe a typical day for you.

Tasks you perform for yourself.
Are there tasks you need help to accomplish?
What kinds of things are difficult for you to take care of (do) alone?

14.) Are there ways in which you help others in the community?
PROBE: volunteer, care for family members, peers, etc.

The next questions are about care or assistance you might receive.

15.) When you need help with something, to whom might you turn?

What types of tasks do the other caregiver(s) perform? (physical, emotional and social)
What is their relationship to you and what is their availability to help?
Information about the caregiving experience (continued)

16.) Who else provides assistance for you?

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17.) Of the people/person you mentioned, who would you identify as the key person who helps to care for you the most? How would you describe the relationship with that person? Do you prefer this person to help or is there someone else? Has the relationship with the PCG changed from the way it was prior to the PCG assisting you?

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Older adult’s perspective on service use and service needs

18.) How do you and <name of family member/PCG> work it out to arrange your care?

PROMPTS: How is it decided when <name of family member> would come over? How is it determined how often they help?

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Older adult’s perspective on service use and service needs (continued)

19.) When you need outside assistance, how are the social service arrangements made? (case management, social work help, other)

PROMPTS: How are telephone calls to arrange services made? How is it decided if <name of family member> will accompany you to the doctor, clinic?
Older adult’s perspective on service use and service needs (continued)

This set of questions is to learn how you have been able to benefit from formal help and services and what may be helpful if available.

20.) Take a moment to think about who provides other supports and services that you receive. Please tell me about the other services and supports you receive and who provides them.

PROMPTS:
Use of social programs
Volunteers or church support
Respite
Meals
Case management
Day care
Support groups
Other (tangible, informational, emotional) Caregiver Hotline

How did you find out about the service (Explore Your Options Booklet, computer)?
Who set up the services/support?
What prompted you or others to inquire about and set up services?
If you used the services/supports, how were they helpful?
What would make it more helpful to you?
If the service is available, but not used, what are the barriers to receiving the service?
21.) Who does <name of family member/PCG> turn to for support?
   Probe by having the older adult describe the kinds of support the PCG receives.
   What community agencies does <name of family member/PCG> turn to for support?
   Do you know about support programs for caregivers offered by the Area Agency of Aging?

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22.) What services are needed to enable you to continue to live at home?

   PROMPTS:
   What is missing or unavailable in the community that would make a difference for you to continue to live at home?
   Are there any tasks/needs that are not addressed in the care you receive?

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Wrap up and summary

These questions give you an opportunity to summarize our discussion today and you can respond with whatever you would like to say.

23.) Considering your experience as an older adult living at home, what advice might you give to other people in situations similar to yours?

24.) What has the experience of growing older been like for you?

PROMPTS: What are your thoughts about growing older: What kinds of adjustments have you had to make?

25.) What are your personal hopes and goals for the future?
**Demographic Questions**

I have a few questions I will ask that provide specific information about you. You may decline to answer any question.

A.) What is your marital status?  __________________________
    If widowed, how long?  

B.) Number of children  _________________

Do they live in the same town as you?
    Approximately how far is their house from yours?
    Next door/a few blocks away (within one mile)
    1-5 miles away
    6-10 miles away
    If more than 10 miles, approximate number of miles from you:    _______
    Different town: Specify ________________

C.) Who visits and how often?  __________________________

D.) What is your former occupation?  __________________________

E.) What is your spouse’s former occupation?  __________________________

F.) What is your race, ethnic, or cultural identity?  __________________________

G.) This question is about your income from all sources (excluding spouse)
   Is your monthly (annual) income from all sources $738 or less ($8,856) Yes __ No __
   Is your monthly (annual) income from all sources between $739 ($8,856) and $1,130 ($13,560) Yes __ No __
   Is your monthly (annual) income from all sources greater than $1,130 ($13,550) Yes __ No __ 

**Follow-up contact**

If you, the interviewer, observe a situation or identify a problem that needs immediate attention, notify the Area Agency on Aging or Social and Rehabilitation Services.

**IS ACTION REQUIRED?**

NO _____
YES _____

If yes, date AAA or SRS contacted (CIRCLE ONE): _____/_____/_______
Appendix 1b: Caregiver for Older Adult in the Community (Recent Diversion)
Before the interview begins, have the respondent sign the consent to conduct the interview. Leave a copy of the consent with them.

**ACTION REQUIRED:**
- Consent obtained

This interview guide is arranged so that the questions can be asked in the sequence provided. However, in the course of the interview, the respondent may provide information that answers a question that appears later in the interview guide. The question does not need to be repeated in those instances.

Be sure all **numbered** questions are asked.

The interviewer must record key comments and notes onto this document. The interview guide has been developed for ease in recording directly onto the document. Directions for each question are noted throughout the interview guide.

Use the interview process to have the caregiver provide details as they tell their story. After hearing the story from the caregiver, consider using the probes if they did not discuss the specific topic or theme noted in the probe.

**MAKE SURE THE TAPE RECORDER IS RECORDING/WORKING**

**Background information-opening the interview**

As part of the warm up, let the respondent know “**we are interested in how <name of family member> was able to remain in the community and I would like you to tell me in your own words. Nothing you say will have an impact on the services or benefits <name of family member> may currently receive or any services or benefits <name of family member> may receive in the future.**”

This first section of the interview focuses on <name of family member's> situation immediately before you and <name of family member> were considering the nursing facility application. Do you remember someone asking you questions at the time you and <name of family member> were thinking about or considering nursing facility admission? You might recall it was called a CARE Assessment. I would like you to think back to the time of the CARE Assessment because I am going to ask you about what was going on at that time.
Background information-opening the interview (continued)

1.) Please describe the events in <name of family member’s> life that led up to the point of considering applying for NF admission.
   PROMPT: Why was the CARE Assessment done?

2.) What influenced the decision for <name of family member> to remain in the community?
   NOTE: The older adult may have had a short NF stay, then returned home.
   PROBE: The caregiver’s assessment of what <name of family member> could or could not handle.
3.) How was the CARE Assessor/case manager helpful in evaluating the situation and exploring potential community resource options? Such as help from a personal care attendant, home delivered meals, Lifeline, etc.

4.) You have told me about several circumstances that influenced the decision for <name of family member> to remain at home. What was the most important influence?
Background information-opening the interview (continued)

NOTE TO INTERVIEWER: the older adult may NOT have required assistance from a caregiver prior to the CARE Assessment – adjust prompts/probes accordingly.

5.) Despite the challenges faced at that time (of the CARE Assessment), <name of family member> was able to continue living in his/her home. Please tell me how you and he/she have been able to accomplish this.

PROMPTS:
- strategies to remain in the community
- mobilization of resources (public or private services)
- Role of physician
- informal support from family/friends/neighbors (availability and perception of availability)
- Caregiver’s part in helping the older adult stay in the home.

6.) You have told me about several strategies <name of family member> faced at the time of the CARE Assessment to stay at home. What is the most important one?
7.) Please describe the challenges you and <name of family member> continue to face for <name of family member> to stay at home.

PROMPT: What were the challenges you’ve experienced for <name of family member> to stay at home? How did you deal with the challenges?

- lack of money
- transportation
- caregiver(s)
- difficulty accessing & using resources

8.) You have told me about several challenges you and <name of family member> faced. What was the most difficult one?
9.) If circumstances were to change, and *<name of family member>* was no longer receiving assistance or support, how would *<name of family member’s>* needs be met?

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10.) Thank you for telling me about your experiences since the CARE Assessment. Please tell me, overall, how do you think *<name of family member>* is doing?

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11.) How do you think you are doing?

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Information about the caregiving experience

I have some additional questions that are designed to gain more specific information. It is important that I ask these questions because there are some details we want to be sure we discuss with you.

The next questions are about care or assistance provided to <name of family member>. These questions focus on any care or assistance you provide to <name of family member>.

12.) Tell me a little about how you came to be a caregiver for <name of family member>?

PROBE: Have the caregiver elaborate on their role as caregiver.
How long have they been the caregiver?
(NOTE TO INTERVIEWER: Keep in mind, there may be several caregivers.)

13.) In addition to yourself, who else provides assistance to <name of family member>?

PROBES:
What types of tasks do they perform?
What is their relationship with <name of family member>?
What is their availability to help?
Who is your back up? Do you prefer this back-up person or someone else?
14.) Please describe a typical day for you, as a caregiver, for `<name of family member>`.

**PROMPTS:**
- Tasks you perform in the caregiving role.
- Are there tasks `<name of family member>` needs help to accomplish?
- On average, how many hours per day (or week depending on the role/tasks)?

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15.) How do you work out the arrangements with and for `<name of family member's>` care?

**PROMPTS:**
- How is it decided when you will come over?
- How is it determined how often you help?

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16.) When `<name of family member>` needs outside assistance, how are the social service arrangements made? (case management, social work help, other)

**PROMPTS:**
- How are telephone calls to arrange services made?
- How is it decided if you will accompany `<name of family member>` to the doctor, clinic?

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<th>How is it decided if you will accompany <code>&lt;name of family member&gt;</code> to the doctor, clinic?</th>
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**Information about the caregiving experience (continued)**

17.) How does *name of family member* participate in her/his care?

PROMPT:
- Types of health promoting behaviors (e.g. immunizations, exercise, nutrition)
- What are some ways *name of family member* cares for her/himself (maintain or improve health)?

18.) Do you provide emotional support to *name of family member*?

Probe about their thoughts and/or feelings about providing emotional support.

**Difficulties / problems associated with caregiving**

The next questions are about your experience assisting or supporting *name of family member* and how this affects you. There are no right or wrong answers and we are not making a judgment about you as a caregiver.

19.) Please describe what it is like being a caregiver.

PROMPTS:
- As a result of caregiving, how is your life different?
- As a result of caregiving, how are you different?
- Probe the economic (e.g. cut back in work hours), emotional (e.g. stress, depression), physical, and social (time with family or friends) problems experienced by the caregiver.
Difficulties / problems associated with caregiving (continued)

PROBE: What would you be doing if you weren’t a caregiver?

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20.) Has your relationship with <name of family member> changed from the way it was prior to being her/his caregiver?

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21.) Knowing that caregiving can be a challenging job, are there ways that you care for yourself?

PROMPT: Are there things you do to maintain your physical / emotional / social health?
PROBE: Ask the PCG to describe her/his health.
**Difficulties / problems associated with caregiving (continued)**

PROBE: Are there any health problems that developed for you since you became a caregiver. If yes, what have they done to address the health problem?


PROBE: If the health problem persists, would this problem eventually result in nursing facility placement (terminating caregiving in the home)?


22.) Who do you turn to for support for yourself?

PROBE:
Describe the kinds of support s/he/they provided to you. Who do you talk to about this?
What community agencies do you turn to for support?
Do you know about support programs for caregivers offered by the Area Agency on Aging?
Caregiver’s perspective on service use and service needs of the care recipient

23.) What other services and support does <name of family member> and/or you receive? Please tell me about the other services and supports you receive and who provides them.

PROMPTS:
Use of social programs
Volunteers or church support
Respite
Meals
Case management
Day Care
Support Groups
Other (tangible, informational, emotional)  Caregiver Hotline
How did you find out about the service (Explore Your Options Booklet, computer)?
Who set up the services/support?
What prompted you or others to inquire about and set up services?
If you used the services/supports, how were they helpful?
What would make it more helpful to you?
If the service was available, but not used, what were the barriers to receiving the service?
24.) What services are needed to enable <name of family member> to continue to live at home?
PROMPT: What is missing or unavailable in the community that would make a difference for
<name of family member> to continue to live at home?
Are there any tasks/needs that were not addressed in the care <name of family member> received?

Wrap up and summary

This question gives you an opportunity to summarize our discussion today and you can respond
with whatever you would like to say.

25.) Considering your experience as a caregiver with a family member at home, what advice
might you give to other people in situations similar to yours?
### Demographic Questions

I have a few questions that ask for personal information regarding you. You may decline to answer any question.

A.) What is your marital status? ________________
   If married, spouse’s (partner’s) occupation. ________________

B.) Do you have children living at home? ________________
   Ages: ________________

C.) How close do you live to <name of family member>? ________________

D.) What is your occupation? ________________

E.) Do you work full time/part-time in paid employment (CIRCLE ONE)?

F.) What is your age? ________________

G.) What is your race, ethnic, or cultural identity? ________________

H.) Gender of the caregiver (CIRCLE ONE): Female    Male

### Follow-up contact

If you, the interviewer, observe a situation or identify a problem that needs immediate attention, notify the Area Agency on Aging or Social and Rehabilitation Services.

IS ACTION REQUIRED?

NO _____
YES _____

If yes, date AAA or SRS contacted (CIRCLE ONE): __/__/_______
Appendix 1c: Older Adult Living in the Nursing Facility
Older Adult Living in the Nursing Facility

________________________________________       Date_____/_____/________

Interview ID: _N_-_A_-______-_____-____-____-

(Record the month and day in “M” and “D”, followed by the interviewer’s initials)

Before the interview begins, have the respondent sign the consent to conduct the interview. Leave a copy of the consent with them.

ACTION REQUIRED:

☐ Consent obtained

This interview guide is arranged so that the questions are asked in the sequence provided. However, in the course of the interview, the respondent may provide information that answers a question that appears later in the interview guide. The question does not need to be repeated in those instances.

Be sure all numbered questions are asked.

The interviewer must record key comments and notes onto this document. The interview guide has been developed for ease in recording directly onto the document. Directions for each question are noted throughout the interview guide.

Use the interview process to have the older adult provide details as they tell their story. After hearing the story from the older adult, consider using the probes if they did not discuss the specific topic or theme noted in the probe.

MAKE SURE THE TAPE RECORDER IS RECORDING/WORKING

Background information-opening the interview

As part of the warm up, let the respondent know “we are interested in your experiences and circumstances around the time you were considering the NF admission. Also, I would like you to tell me in your own words about assistance or help you received from others. Nothing you say will have an impact on the services or benefits you currently receive or any services or benefits you may receive in the future.”

This first section of the interview focuses on your situation immediately before the NF admission at <name of nursing facility>. Do you remember someone asking you questions at the time you were thinking about or considering the nursing facility admission? I would like you to think back to <date of CARE Assessment> and tell me about what was going on at that time.
Background information-opening the interview (continued)

1.) Please describe the events in your life that led up to that point (*requesting of nursing facility placement*).
PROMPT: Why was the CARE assessment done?

2.) What factors influenced the decision for you to go to *<name of nursing facility>*?
PROBE: The older adult’s assessment of what they could or could not handle.

3.) How was the CARE Assessor/case manager helpful in evaluating your situation and exploring potential community resource options?
Such as help from a personal care attendant, home delivered meals, Lifeline, etc.
4.) What was the most important factor that influenced the decision for you to go to <name of nursing facility>?

NOTE TO INTERVIEWER: the older adult may not have required assistance prior to the CARE assessment – adjust prompts/probes accordingly.
We were discussing what was occurring for you immediately prior to the CARE Assessment.

5.) Please describe the challenges you faced at the time of the CARE Assessment when you were considering NF admission.
PROMPTS: What were the challenges you experienced to stay at home? How did you deal with these challenges?
PROBES:
Strategies to remain at home
Mobilization of resources (public or private services)  Role of physician
Informal support from family/friends/neighbors (availability and perception of availability)

6.) You have told me about several challenges you faced. What was the most difficult one?
**Older adult’s experience of care when in the community BEFORE the NF**

The next questions are about tasks or assistance you might have received prior to admission to `<name of nursing facility>`. The next questions are about the help or assistance provided to you by others.

7.) How would you describe your health before admission to `<name of nursing facility>`? (physical, emotional, social)

PROBE: “Compared to other people my age, my health was: excellent / good / fair / poor / bad.”

Also, probe for emotional & social well being: excellent / good / fair / poor / bad.

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8.) What were some of the activities that helped you live on your own?

Probe for health promoting behaviors (e.g. immunizations, exercise, nutrition)

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9.) Please describe a typical day for you before your admission to `<name of nursing facility>`.

PROMPT: Tasks you performed for yourself.

Were there tasks you needed help to accomplish?

What kinds of things were difficult for you to take care of (do) alone?

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36
10.) When you needed help with something, to whom might you turn?
PROBE: What types of tasks did the caregiver(s) perform? (physical, emotional and social)
What is their relationship to you and what was their availability to help?

11.) Who else provided assistance to you?
PROBES:
What types of tasks did the other caregivers perform?
What is their relationship to you?
What was their availability to help?
Who was their backup? Did you prefer this back-up person or someone else?

12.) Of the people you mentioned, whom would you identify as the key person who helped to care for you the most?
PROBE:
How would you describe the relationship between you and your primary caregiver?
Is this the person who you’d prefer to help you, or is that person someone else?
13.) How did you and *name of family member* work it out to arrange your care?

**PROBE**

How was it decided when *name of family member* would come over?

How was it determined how often *name of family member* would help?


14.) When you needed outside assistance, how were the social services arrangements made? (case management, social work help, other)

**PROMPTS:** How were telephone calls to arrange services made?

How was it decided if someone would accompany you to the doctor, clinic?
Older adult’s perspective on service use and service needs BEFORE the NF admission

Do not repeat these next questions if they were covered at the beginning of the interview or if the older adult did not have service prior to the NF admission.

15.) Take a minute to think about who provided other services and support to you before admission to <name of nursing facility>? Please tell me about the other services and supports you received and who provided them.

PROMPTS:
Use of social programs
Volunteers or church support
Respite
Case management
Day care
Meals
Support groups
Other (tangible, informational, emotional) Caregiver Hotline
How did you find out about the service (Explore Your Options Booklet, computer)?
Who set up the services/support?
What prompted you or others to inquire about and set up services?
If you used the services/support, how were they helpful?
What would make it more helpful to you?
If the services were available but not used, what were the barriers to receiving the service?

16.) What services would have enabled you to continue to live at home?

PROMPT: What was missing or unavailable in the community that would make a difference for you to continue to live at home?

Were there any tasks/needs that were not addressed in the care you received?
Older adult’s perspective on service use and service needs BEFORE the NF admission (continued)

17.) Who does <name of family member/PCG> turn to for support?  
Probe by having the older adult describe the kinds of support the PCG receives.  
What community agencies does <name of family member/PCG> turn to for support?  
Do you know about support programs for caregivers offered by the Area Agency of Aging?

Older adult’s experience of care in the NF

The next questions are about care or assistance you received after going to the nursing home.  
The questions focus on any care or assistance provided to you at this time.

18.) Compared to other people your age, would you say your health is: excellent / good / fair / poor /or bad?  
PROBE:  
Emotional health?  Social health?  (to get at prevailing health, MH, & social health status – masked depression)

19.) Are there ways in which the person who was your primary caregiver at home still helps you today?  If yes, please describe.  How did you and your caregiver work out to arrange your care?

20.) In what ways are others (besides the NF staff) involved in your care now? (meeting physical, social, emotional needs)?
### Wrap up and summary

21.) Considering your experience as an older adult in a NF, what advice might you give to other people in a similar situation?

---

**What has the experience of growing older been like for you?**
**What are your thoughts about growing older?**
*(Prompt: What kinds of adjustments have you had to make)*

---

**What are your personal hopes and goals for your future?**

---
**Demographic Questions**

I have a few questions I will ask that provide specific information about you. You may decline to answer any question.

A.) What is your marital status? __________________________
   If widowed, how long?

B.) Number of children __________________________

   Do they live in the same town as you?
   Approximately how far is their house from yours?
   Next door/a few blocks away (within one mile)
   1-5 miles away
   6-10 miles away
   If more than 10 miles, approximate number of miles from you: ______

   Different town: Specify: __________________________

C.) Who visits and how often? __________________________

D.) What was your former occupation? __________________________

E.) What was your spouse’s former occupation? __________________________

F.) What is your race, ethnic, or cultural identity? __________________________

G.) This question is about your income from all sources (excluding spouse)
   Is your monthly (annual) income from all sources $738 or less ($8,856) Yes ___ No ___
   Is your monthly (annual) income from all sources between $739 ($8,856) and $1,130 ($13,560) Yes ___ No ___
   Is your monthly (annual) income from all sources greater than $1,130 ($13,550) Yes ___ No ___

**Follow-up contact**

If you, the interviewer, observe a situation or identify a problem that needs immediate attention, notify the Area Agency on Aging or Social and Rehabilitation Services.

**IS ACTION REQUIRED?**

NO ___
YES ___

If yes, date AAA or SRS contacted (CIRCLE ONE): ____/____/_______
Appendix 1d: Caregiver for Older Adult Living in the Nursing Facility
Caregiver for Older Adult Living in the Nursing Facility

Interview ID: _______P-____-____-____-M-____-____-D-____-____

(Record the month and day in “M” and “D”, followed by the interviewer’s initials)

Before the interview begins, have the respondent sign the consent to conduct the interview. Leave a copy of the consent with them.

ACTION REQUIRED:
☐ Consent obtained

This interview guide is arranged so that the questions can be asked in the sequence provided. However, in the course of the interview, the respondent may provide information that answers a question that appears later in the interview guide. The question does not need to be repeated in those instances.

Be sure all numbered questions are asked.

The interviewer must record key comments and notes onto this document. The interview guide has been developed for ease in recording directly onto the document. Directions for each question are noted throughout the interview guide.

Use the interview process to have the caregiver provide details as they tell their story. After hearing the story from the caregiver, consider using the probes if they did not discuss the specific topic or theme noted in the probe.

MAKE SURE THE TAPE RECORDER IS RECORDING/WORKING

Background information-opening the interview

As part of the warm up, let the respondent know “we are interested in your experiences and circumstances at the time you and <name of family member> were considering the nursing facility admission. Also, I would like you to tell me in your own words about assistance or help <name of family member> received from others. Nothing that you say will have an impact on the services the <name of family member> may currently receive or any services <name of family member> may receive in the future.”

This first section of the interview focuses on the situation for <name of family member> immediately before the admission to <name of nursing facility>. Do you remember someone asking <name of family member> and/or you questions at the time you were thinking about or considering nursing facility admission? I would like you to think back to <date of CARE Assessment> and tell me about what was going on at that time.
1.) Please describe the events in <name of family member’s> life that led up to that point (requesting of nursing facility admission).

PROMPT: Why was a CARE Assessment done?

2.) What influenced the decision for <name of family member> to go to <name of nursing facility>?

PROBE:
The caregiver’s assessment of what <name of family member> and they could or could not handle.
Background information-opening the interview (continued)

3.) How was the CARE Assessor/case manager helpful in evaluating the situation and exploring community resource options with <name of family member> and you?
Such as help from a personal care attendant, home delivered meals, Lifeline, etc.

4.) What was the most important factor that influenced the decision for <name of family member> to go to <name of nursing facility>?
NOTE TO INTERVIEWER: the older adult may not have required assistance from a caregiver prior to the CARE Assessment – adjust prompts/probes accordingly.

We were discussing what was occurring for you immediately prior to the CARE Assessment.

5.) Please describe the challenges you and <name of family member> faced at the time of the CARE Assessment when you were considering <name of nursing facility> for <name of family member>.

PROMPT: What were the challenges to stay at home (if they were a caregiver before NF)?

PROBES:
- strategies to remain at home
- mobilization of resources (public or private services)
- Role of physician
- informal support from family/friends/neighbors (availability and perception of availability)

How did you deal with the challenges?

-Caregiver’s part in helping the older adult stay in the home.

***IF PCG MENTIONS HEALTH/WELL-BEING AS A PROBLEM FOR THEM, EXPLORE IT IN DETAIL HERE.

6.) You have told me about several challenges you faced. What was the most difficult one?
Information about the caregiving experience in the community BEFORE the NF

The next questions are about tasks or assistance provided to <name of family member> prior to going to the nursing home (while in the community). The questions focus on any help or assistance you or others provided to <name of family member>.

7.) Tell me a little about how you came to be a caregiver for <name of family member>?

PROBE: Have the caregiver elaborate on their role as caregiver.
How long have you been the caregiver?
(NOTE TO INTERVIEWER: Keep in mind, they may be one of several caregivers.)

8.) In addition to yourself, who else provided assistance to <name of family member>?

PROBES:
What types of tasks did the other caregivers perform?
What is their relationship with <name of family member>?
What was their availability to help?
Who was your back up? Did you prefer this back-up person or someone else?
9.) Please describe a typical day for you as a caregiver for *<name of family member>* prior to the admission to *<name of nursing facility>*.

PROMPTS:
- Tasks you performed in the caregiving role.
- Were there tasks *<name of family member>* needed help to accomplish?
- On average, how many hours per day (or week depending on the role/tasks)?

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10.) How did you and *<name of family member>* work it out to arrange their care?

PROMPTS:
- How was it decided when you would come over?
- How was it determined how often you would help?

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<th>Decision on when</th>
<th>Frequency of help</th>
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Information about the caregiving experience in the community BEFORE the NF (continued)

11.) When <name of family member> needed outside assistance, how were the social service arrangements made? (case management, social work help, other?)

PROMPTS: How were telephone calls to arrange services made? How was it decided if you would accompany <name of family member> to the doctor, clinic?

-----------------------------------------------

12.) How did <name of family member> participate in her/his care?

PROMPT:
Types of health promoting behaviors (e.g. immunizations, exercise, nutrition)
What were some ways <name of family member> cared for her/himself (maintain or improve health)?

-----------------------------------------------

13.) Did you provide emotional support to <name of family member>? Prove about their thoughts and/or feelings about providing emotional support.

-----------------------------------------------
Difficulties / problems associated with caregiving

The next questions are concerned with your experience assisting or supporting <name of family member> BEFORE THE ADMISSION TO <name of nursing facility> and how this affected you. There is no right or wrong answer and we are not making a judgment about you as a caregiver.

14.) Please describe what it was like being a caregiver when <name of family member> lived in the community before admission to <name of nursing facility>?

PROMPTS:
- As a result of caregiving, how was your life different?
- As a result of caregiving, how are you different?
Probe the economic (e.g. cut back in work hours), emotional (e.g. stress, depression), physical, and social (time with family and friends) problems experienced by the caregiver.

PROBE: What would you be doing if you hadn’t been a caregiver?

15.) Has your relationship with <name of family member> changed from the way it was prior to being her/his caregiver?
Difficulties / problems associated with caregiving (continued)

16.) Knowing that caregiving can be a challenging job, were there ways that you cared for yourself?

PROMPT: Were there things you did to maintain your physical / emotional / social health?
PROBE: Please describe your health,

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PROBE: Were there any health problems that developed for you while being a caregiver for <name of family member> before the nursing facility admission?

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If this health problem persisted, did the problem eventually result in nursing facility placement?

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17.) Who did you turn to for support for yourself?

PROBE:
Describe the kinds of support s/he/they provided to you. Who do you talk to about this?
What community agencies did you turn to for support?
Did you know about support programs for caregivers offered by the Area Agency on Aging?
**Caregiver’s perspective on service use and service needs of the care recipient**

These questions are to learn how you and *<name of family member>* benefited from formal help and services before the admission to *<name of nursing facility>*.

**NOTE TO INTERVIEWER:** Do not repeat if they were covered at the beginning of the interview or if no caregiving/services were provided before the CARE Assessment.

18.) Take a minute to think about who provided other services and support to *<name of family member>* before admission to *<name of nursing facility>*? Please tell me about the other services and supports received and who provides them.

**PROMPTS:**
- Use of social programs
- Volunteers or church support
- Respite
- Case management
- Day care
- Meals
- Support groups
- Other (tangible, informational, emotional)
- Caregiver Hotline
- How did you find out about the service (Explore Your Options Booklet, computer)?
- Who set up the services/support?
- What prompted you or others to inquire about and set up services?
- If you used the services/support, how were they helpful?
- What would make it more helpful to you?
- If the services were available but not used, what were the barriers to receiving the service?
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<td><strong>19.) What services would have enabled &lt;name of family member&gt; to continue to live at home?</strong></td>
<td>PROMPT: What was missing or unavailable in the community that would have made a difference for &lt;name of family member&gt; to continue to live at home? Were there any tasks/needs that were not addressed in the care &lt;name of family member&gt; received?</td>
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<td><strong>20.) How has the nursing facility been able to meet those needs?</strong></td>
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### Information about role of caregiver AFTER NF admission of older adult (continued)

21.) How would you describe <name of family member’s> needs today (in the NF)?
Prompts: physical, emotional, social?
Who cares for those needs currently?

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22.) Please describe your role as a caregiver after the NF admission?
PROMPT: How has a “typical day” as a caregiver changed for you?
PROBES: What challenges do you experience in caregiving now?

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23.) What has it been like for you to have the nursing facility take care of many of the tasks you had done before the admission?

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<td>Information about role of caregiver AFTER NF admissions of older adult (continued)</td>
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<td><em>(Ask only if not mentioned by now)</em> In what ways are you involved in the care of <em>&lt;name of family member&gt;</em> now? (meeting physical, social, emotional needs)?</td>
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<td><em>(Ask only if not mentioned by now)</em> How do you and <em>&lt;name of family member&gt;</em> work out to arrange care? How are arrangements for doctor’s visits, etc. negotiated now?</td>
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<td>How are you different now from the time when you provided care to <em>&lt;name of family member&gt;</em> in the community?</td>
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Information about the experience of caregiving AFTER NF admission of older adult

These next sets of questions are about your experience as a caregiver and how caregiving affects you after the NF admission. There are no right or wrong answers and we are not making a judgment about you as a caregiver.

24.) Please describe your health and any health problems that developed since the NF admission. (Ask if respondent indicated health problems)
   PROBE: Are there things you do to maintain your physical / emotional / social health?
   If yes, what do you do to address the health problem?
   If the problem persists, how are you managing the problem?

25.) Who do you turn to for support now that <name of family member> has been in the nursing facility?
   Describe the kinds of support s/he/they provide to you.
   What community agencies do you turn to for support?
   Do you know about support programs for caregivers offered by the Area Agency on Aging?
Caregiver’s overall impressions

This question gives you an opportunity to summarize our discussion today and you can respond with whatever you would like to say.

26.) Considering your experience as a caregiver with a family member in a NF, what advice might you give to other people in situation similar to yours?
Demographic Questions

I have a few questions I will ask that provide specific information about you. You may decline to answer any question.

A.) What is your marital status? ____________________________

If married, spouse’s (partner’s) occupation ____________________________

B.) Do you have children living at home? ____________________________

Ages? ____________________________

C.) How close do you live to <name of nursing facility>? ____________________________

D.) What is your occupation? ____________________________

E.) Do you work full time/part-time in paid employment (CIRCLE ONE) ?

F.) What is your age? ____________________________

G.) What is your race, ethnic, or cultural identity? ____________________________

H.) Gender of caregiver (CIRCLE ONE): Female Male

Follow-up contact

If you, the interviewer, observe a situation or identify a problem that needs immediate attention, notify the Area Agency on Aging or Social and Rehabilitation Services.

IS ACTION REQUIRED?

NO ____

YES ____

If yes, date AAA or SRS contacted (CIRCLE ONE): ____/____/_______
Appendix 1e: Older Adult in the Community (Long-Term)
Before the interview begins, have the respondent sign the consent to conduct the interview. Leave a copy of the consent with them.

ACTION REQUIRED:

☐ Consent obtained

This interview guide is arranged so that the questions are asked in the sequence provided. However, in the course of the interview, the respondent may provide information that answers a question that appears later in the interview guide. The question does not need to be repeated in those instances.

Be sure all numbered questions are asked.

The interviewer must record key comments and notes onto this document. The interview guide has been developed for ease in recording directly onto the document. Directions for each question are noted throughout the interview guide.

Use the interview process to have the older adult provide details as they tell their story. After hearing the story from the older adult, consider using the probes if they did not discuss the specific topic or theme noted in the probe.

MAKE SURE THE TAPE RECORDER IS RECORDING/WORKING

Background information-opening the interview

As part of the warm up, let the respondent know “we are interested in how you were able to remain in the community and I would like you to tell me about this in your own words. Nothing you say will have an impact on the services or benefits you currently receive or any services or benefits you may receive in the future.”

We are interviewing older adults who had a CARE Assessment.

I understand that you considered a NF admission several years ago. The Area Agency on Aging indicated the CARE Assessment was completed in __/__/___. (For the long term CT dwellers, it was May, 1999, March, April or August 2000- we will supply the CARE Assessment date). A decision was made for you to remain at home in the community.
Background information-opening the interview (continued)

1.) Despite any challenges you faced over the last couple of years, you have been able to continue living in your home. Please tell me how you have been able to accomplish this over the last couple of years.

PROMPTS:
- strategies to remain in the home
- mobilization of resources (public or private services)
- Role of physician
- informal support from family / friends / neighbors (availability and perception of support)
- do you prefer this person or is there someone else?

2.) You have told me about several circumstances that helped you remain at home over the last couple of years. What was the most important one?

________________________________________________________________________

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Background information-opening the interview (continued)

3.) Please describe the challenges you have faced to remain at home.

PROMPTS: What were the challenges you’ve experienced to stay at home? How did you deal with the challenges?
   lack of money
   transportation
   caregiver(s)
   difficulty accessing and using resources

4.) You have told me about several challenges you faced. What was the most difficult one?

5.) If circumstances were to change, and you were no longer receiving assistance or support, how would your needs be met?
6.) Thank you for telling me about your experiences over the last couple of years. Please tell me, overall, how do you think you are doing?

If the older adult has mentioned a PCG, then ask: How do you think <name of family member> is doing?

The older adult’s report of their current situation

I have some additional questions that are designed to gain more specific information. It is important that I ask these questions because there are some details we want to be sure we discuss with you. The next questions are about your health and how your day goes.

7.) How would you describe your health today? (physical, emotional, social)

a.) Probe by asking the respondent to compare their health to other people their age, e.g.: excellent / good / fair / poor / bad.
b.) Probe for emotional well-being and social well-being: excellent / good / fair / poor / bad.
The older adult’s report of their current situation (continued)

8.) What are some of the activities that have helped you live on your own?

Probe for health promoting behaviors (e.g. immunizations, exercise, nutrition)?

9.) Please describe a typical day for you.

PROMPTS: Tasks you perform for yourself.
Are there tasks you need help to accomplish?
What kinds of things are difficult for you to take care of (do) alone?

10.) Are there ways in which you help others in the community?
PROBE: volunteer, care for family members, peers, etc.
Information about the caregiving experience

The next questions are about care or assistance you receive.

11.) When you need help with something, to whom do you turn?

PROBE: What types of tasks do the other caregiver(s) perform? (physical, emotional and social).
What is their relationship to you and what is your availability to help?

12.) Who else provides assistance for you?

13.) Of the people/person you mentioned, who would you identify as the key person who helps
to care for you the most? How would you describe your relationship with that person?

PROBE: Do you prefer this person to help or is there someone else?
Has the relationship with the PCG changed from the way it was prior to the PCG
assisting you?
### Older adult’s perspective on service use and service needs

14.) How do you and *name of family member* work it out to arrange your care?

**PROMPTS:** How is it decided when *name of family member* will come over? How is it determined how often they help?

<table>
<thead>
<tr>
<th>Prompt</th>
<th>Answer</th>
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<tbody>
<tr>
<td>How is it decided when <em>name of family member</em> will come over?</td>
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<td>How is it determined how often they help?</td>
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</table>

15.) When you need outside assistance, how are the social service arrangements made? *(case management, social work help, other)*

**PROMPTS:** How are telephone calls to arrange services made?

How is it decided if *name of family member* will accompany you to the doctor, clinic?

<table>
<thead>
<tr>
<th>Prompt</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>How are telephone calls to arrange services made?</td>
<td></td>
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<tr>
<td>How is it decided if <em>name of family member</em> will accompany you to the doctor, clinic?</td>
<td></td>
</tr>
</tbody>
</table>
Older adult’s perspective on service use and service needs (continued)

This set of questions is to learn how you have been able to benefit from formal help and services and what may be helpful if available.

16.) Take a moment to think about who provides other support and services that you receive. Please tell me about the other services and supports you receive and who provides them.

Do not repeat any question if it was covered at the beginning of the interview.

PROMPTS: Use of social programs
Volunteers or church support
Respite
Meals
Case management
Day care
Support groups
Other (tangible, informational, emotional) Caregiver Hotline
How did you find out about the service (Explore Your Options Booklet, computer)?
Who sets up the services/support?
What prompted you or others to inquire about and set up services?
If you used the services/support, how were they helpful?
What would make it more helpful to you?
If the service was available, but not used, what were the barriers to receiving the services?

17.) Who does <name of family member> turn to for support?

Probe by having the older adult describe the kinds of support the PCG receives.
What community agencies does <name of family member/PCG> turn to for support?
Do you know about support programs for caregivers offered by the Area Agency on Aging?
Older adult’s perspective on service use and service needs (continued)

18.) What services are needed to enable you to continue to live at home?

PROMPT:
What is missing or unavailable in the community that would make a difference for you to continue to live at home?
Are there any tasks/needs that were not addressed in the care you receive?

19.) How has the case manager been helpful for you to continue to live at home?
PROMPT: such as help form a personal care attendant, home delivered meals, Lifeline, etc.
Wrap up and summary

These questions give you an opportunity to summarize our discussion today. I will ask some questions and you can respond with whatever you would like to say.

20.) Considering your experience as an older adult living at home, what advice might you give to other people in situations similar to yours?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

21.) What has the experience of growing older been like for you?

PROMPTS: What are your thoughts about growing older: What kinds of adjustments have you had to make?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

22.) What are your personal hopes and goals for the future?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
**Demographic Questions**

I have a few questions I will ask to obtain specific information about you. You may decline to answer any question.

A.) What is your marital status? __________________________
   If widowed, how long? __________________________

B.) Number of children __________________________
   Do they live in the same town as you?
   Approximately how far is their house from yours?
   Next door/a few blocks away (within one mile)
   1-5 miles away
   6-10 miles away
   If more than 10 miles, approximate number of miles from you: ______
   Different town: Specify: __________________________

C.) Who visits and how often? __________________________

D.) What was your former occupation? ________________

E.) What was your spouse’s former occupation? ________________

F.) What is your race, ethnic, or cultural identity? ________________

G.) This question is about your income from all sources (excluding spouse)
   Is your monthly (annual) income from all sources $738 or less ($8,856) Yes __ No __
   Is your monthly (annual) income from all sources between $739 ($8,856) and $1,130 ($13,560)
   Yes __ No __
   Is your monthly (annual) income from all sources greater than $1,130 ($13,550) Yes __ No __

**Follow-up contact**

If you, the interviewer, observe a situation or identify a problem that needs immediate attention, notify the Area Agency on Aging or Social and Rehabilitation Services.

**IS ACTION REQUIRED?**

NO _____
YES _____

If yes, date AAA or SRS contacted (CIRCLE ONE): ____/____/________
Appendix 1f: Caregiver for Older Adult in the Community (Long-Term)
Caregiver for Older Adult in the Community (Long-Term)

________________________________________       Date_____/_____/________

Interview ID: _L_ - _P_ - ___ - ____ - _M_ - _M_ - _D_ - _D_ - ___

(Record the month and day in “M” and “D”, followed by the interviewer’s initials)

Before the interview begins, have the respondent sign the consent to conduct the interview. Leave a copy of the consent with them.

ACTION REQUIRED:
☐ Consent obtained

This interview guide is arranged so that the questions are asked in the sequence provided. However, in the course of the interview, the respondent may provide information that answers a question that appears later in the interview guide. The question does not need to be repeated in those instances.

Be sure all numbered questions are asked.

The interviewer must record key comments and notes onto this document. The interview guide has been developed for ease in recording directly onto the document. Directions for each question are noted throughout the interview guide.

Use the interview process to have the caregiver provide details as they tell their story. After hearing the story from the caregiver, consider using the probes if they did not discuss a specific topic or theme.

MAKE SURE THE TAPE RECORDER IS RECORDING/WORKING

Background information-opening the interview

As part of the warm up, let the respondent know “we are interested in how <name of family member> was able to remain in the community and I would like you to tell me about this in your own words. Nothing you say will have an impact on the services or benefits <name of family member> may currently receive or any services or benefits <name of family member> may receive in the future.”

We are interviewing caregivers of individuals who had a CARE Assessment.

I understand that <name of family member> considered a NF admission several years ago. The Area Agency on Aging indicated the CARE Assessment was completed in ____/____/____. (For the long term CT dwellers, it was May, 1999, March, April or August 2000- we will supply the CARE Assessment date). A decision was made for <name of family member> to remain at home in the community.
1.) Despite the challenges faced over the last couple of years, <name of family member> has been able to continue living in their home. Please tell me how you and s/he have been able to accomplish this over the last couple of years.

PROBE:
Strategies to remain in the home?
- mobilization of resources (public and private services)  
- informal support from family / friends / neighbors (availability of and perception of support)
- Caregiver’s part in helping elder stay in the home

2.) You have told me about several circumstances that helped <name of family member> remain at home. What was the most important one for <name of family member> to remain at home over the last couple of years?
3.) Please describe the challenges you and *<name of family member>* have encountered for her/him to remain in the community.

**PROMPT:** What were the challenges you’ve experienced for *<name of family member>* to stay at home? How did you deal with the challenges?

**PROBE:** lack of money, transportation, caregiver(s), difficulty accessing and using resources

4.) You have told me about several challenges *<name of family member>* and you faced. What was the most difficult one?

---

5.) If circumstances were to change, and *<name of family member>* was no longer receiving support or assistance, how would *<name of family member’s*> needs be met?
6.) Thank you for telling me about your experiences over the last couple of years. Please tell me, overall, how do you think <name of family member> is doing?

<table>
<thead>
<tr>
<th>Name of Family Member</th>
<th>Response</th>
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7.) How do you think you are doing?

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<tr>
<th>Name of Caregiver</th>
<th>Response</th>
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**Information about the caregiving experience**

I have some additional questions that are designed to gain more specific information. It is important that I ask these questions because there are some details we want to be sure we discuss with you.

The next questions are about care or assistance provided to <name of family member>. The questions focus on any care or assistance you provide to <name of family member>.

8.) Tell me a little about how you came to be a caregiver for <name of family member>?

**PROBE:** Have the caregiver elaborate on their role as caregiver.

**NOTE TO INTERVIEWER:** Keep in mind, there may be several caregivers.

How long have you been a caregiver?

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<thead>
<tr>
<th>Name of Caregiver</th>
<th>Response</th>
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### Information about the caregiving experience (continued)

**9.)** In addition to yourself, who else provides assistance to <name of family member>?

**PROBE:**
- What types of tasks do the other caregiver(s) perform?
- What is their relationship with <name of family member>?
- What is their availability to help?
- Who is your back-up? Do you prefer this person or someone else?

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship</th>
<th>Availability</th>
<th>Back-up</th>
<th>Preference</th>
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**10.)** Please describe a typical day for you as a caregiver for <name of family member>.

**PROMPTS:** Tasks you perform in the caregiving role.
- Are there tasks <name of family member> needs help to accomplish?
- On average, how many hours per day (or week depending on the role/tasks) do you spend caregiving?

<table>
<thead>
<tr>
<th>Task</th>
<th>Frequency</th>
<th>Notes</th>
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**Information about the caregiving experience (continued)**

11.) How do you and <name of family member> work it out to arrange their care?  
**PROMPTS:** How do you work out the arrangements with and for <name of family member’s> care?  
How is it decided when you will come over?  
How is it determined how often you help?

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12.) When <name of family member> needs assistance, how are the social service arrangements made? (case management, social work help, other?)  
**PROMPTS:** How are telephone calls to arrange services made?  How is it decided if you will accompany <name of family member> to the doctor, clinic?

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13.) How does <name of family member> participate in her/his care?  
**PROMPT:** types of health promoting behaviors (e.g. immunizations, exercise, nutrition…)  
What are some ways <name of family member> cares for her/himself (maintain or improve health)?

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14.) Do you provide emotional support to <name of family member>?

**Probe about their thoughts and/or feelings about providing emotional support**
**Difficulties / problems associated with caregiving**

The next questions are about your experience assisting or supporting <name of family member> and how this affects you. There are no right or wrong answers and we are not making a judgment about you as a caregiver.

15.) Please describe what it is like being a caregiver.

PROMPTS:

- As a result of caregiving, how is your life different?
- As a result of caregiving, how are you different? How do you feel about the caregiving role?

Probe the economic (e.g. cut back in work hours), emotional (e.g. stress, depression), physical, and social (time with family or friends) problems experienced by the caregiver.

PROBE: What would you be doing you weren’t helping <name of family member>?

16.) Has your relationship with <name of family member> changed from the way it was prior to being her/his caregiver?

17.) Knowing that caregiving can be a challenging job, are there ways that you care for yourself?

- Are there things you do to maintain your physical / emotional / social health?

PROBE: Ask the caregiver to describe their health.
Difficulties / problems associated with caregiving (continued)

PROBE: Are there any health problems that developed for you since you became a caregiver. If yes, what have they done to address the health problem?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

PROBE: If the problem persists, would this problem eventually result in nursing facility placement (terminating caregiving in the home)?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

18.) Who do you turn to for support for yourself?

PROBE:
- Describe the kinds of support s/he/they provided to you. Who do you talk to about this?
- What community agencies have you turned to for support?
- Do you know about support programs for caregivers offered by the Area Agency on Aging?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
Caregiver’s perspective on service use and service needs of the care recipient

This set of questions is to learn how you and <name of family member> have been able to benefit from formal help and services and what may be helpful if available.

Do not repeat any question if it was covered at the beginning of the interview.

19.) Take a minute to think about who provides other services and support to <name of family member>. Please tell me about the other services and supports <name of family member> receives and who provides them.

PROMPTS:
Use of social programs
Volunteers or church support
Respite
Case management
Day care
Meals
Support groups
Other (tangible, informational, emotional) Caregiver Hotline
How did you find out about the service (Explore Your Options Booklet, computer)?
Who set up the services/support?
What prompted you or others to inquire about and set up services?
If you used the services/support, how were they helpful?
What would make it more helpful to you?
If the service was available but not used, what were the barriers to receiving the service?
### Caregiver’s perspective on service use and service needs of the care recipient (continued)

20.) What services are needed to enable <name of family member> to continue to live at home?
PROMPT: What is missing or unavailable in the community that would make a difference for <name of family member> to continue to live at home? Are there any tasks/needs that were not addressed in the care <name of family member> received?

<table>
<thead>
<tr>
<th>Service Needed</th>
<th>Missing or Unavailable in Community</th>
<th>Additional Details</th>
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<tbody>
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</table>

21.) How has the case manager been helpful for <name of family member> to continue living at home?
PROMPT: Such as help from a personal care attendant, home delivered meals, Lifeline, etc.

<table>
<thead>
<tr>
<th>Case Manager Help</th>
<th>Details</th>
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### Wrap up and summary

This question gives you an opportunity to summarize our discussion today and you can respond with whatever you would like to say.

22.) Considering your experience as a caregiver with a family member in the community, what advice might you give to other people in situations similar to yours?

<table>
<thead>
<tr>
<th>Advice</th>
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</table>
Demographic Questions

I have a few questions I will ask to obtain specific information about you. You may decline to answer any question.

A.) What is your marital status? ____________________________
    If married, spouse’s (partner) occupation? ____________________________

B.) Do you have children living at home? ____________________________
    Ages? ____________________________

C.) How close do you live to <name of family member>? ____________________________

D.) What is your occupation? ____________________________

E.) Do you work full time/part-time in paid employment (CIRCLE ONE)?

F.) What is your age? ____________________________

G.) What is your race, ethnic, or cultural identity? ____________________________

H.) Gender of caregiver (CIRCLE ONE): Female  Male

Follow-up contact

If you, the interviewer, observe a situation or identify a problem that needs immediate attention, notify the Area Agency on Aging or Social and Rehabilitation Services.

IS ACTION REQUIRED?
NO  __________
YES  ________

If yes, date AAA or SRS contacted (CIRCLE ONE): _____/_____/_______
Appendix 2: Individual Demographic Data on Interviewees
Appendix 2a: Recently Diverted Community Tenure
### Older Adults – Recently Diverted Community Tenure

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Marital Status</th>
<th>Race</th>
<th>Income</th>
<th>Number of Children</th>
<th>Urban/Rural Code</th>
<th>Urban/Rural Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>CA402</td>
<td>Dorothy</td>
<td>Female</td>
<td>81</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>1</td>
<td>2</td>
<td>1 1 = 5</td>
<td></td>
</tr>
<tr>
<td>CA407</td>
<td>Alice</td>
<td>Female</td>
<td>91</td>
<td>Widowed</td>
<td>African American</td>
<td>1</td>
<td>-deceased 1</td>
<td>2 2 = 2</td>
<td></td>
</tr>
<tr>
<td>CA420</td>
<td>Catherine</td>
<td>Female</td>
<td>89</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>3</td>
<td>4</td>
<td>3 0 = 3</td>
<td></td>
</tr>
<tr>
<td>CA424</td>
<td>Frank</td>
<td>Male</td>
<td>79</td>
<td>Married</td>
<td>Caucasian</td>
<td>3</td>
<td>4</td>
<td>4 0 = 4</td>
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<tr>
<td>CA428</td>
<td>Karen</td>
<td>Female</td>
<td>78</td>
<td>Married</td>
<td>Caucasian</td>
<td>-declined</td>
<td>1</td>
<td>5 9 = 1</td>
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<tr>
<td>CA430</td>
<td>Bea</td>
<td>Female</td>
<td>93</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>1</td>
<td>2</td>
<td>6 6 = 1</td>
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</tr>
<tr>
<td>CA431</td>
<td>Laura</td>
<td>Female</td>
<td>68</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>2</td>
<td>2</td>
<td>7 3 = 3</td>
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<tr>
<td>CA437</td>
<td>Janice</td>
<td>Female</td>
<td>80</td>
<td>Married</td>
<td>Caucasian</td>
<td>3</td>
<td>4</td>
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<td></td>
</tr>
<tr>
<td>CA439</td>
<td>Allen</td>
<td>Male</td>
<td>73</td>
<td>Widowed</td>
<td>Caucasian</td>
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<tr>
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<td>97</td>
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<tr>
<td>CA454</td>
<td>Ethel</td>
<td>Female</td>
<td>77</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>3</td>
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</tr>
<tr>
<td>CA455</td>
<td>Lily</td>
<td>Female</td>
<td>87</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>-unknown</td>
<td>2</td>
<td>7</td>
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<td>CA470</td>
<td>Marian</td>
<td>Female</td>
<td>85</td>
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Average Age: 82.92

### Caregivers – Recently Diverted Community Tenure

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Marital Status</th>
<th>Relationship to Older Adult</th>
<th>Employment outside of the home: Yes/No</th>
<th>Race</th>
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</thead>
<tbody>
<tr>
<td>CP402</td>
<td>No caregiver</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>CP407</td>
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</tr>
<tr>
<td>CP420</td>
<td>Gina</td>
<td>Female</td>
<td>52</td>
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<td>Daughter</td>
<td>No – retired</td>
<td>Caucasian</td>
</tr>
<tr>
<td>CP424</td>
<td>Sue</td>
<td>Female</td>
<td>69</td>
<td>Widowed</td>
<td>Friend</td>
<td>No – disabled (paid cg)</td>
<td>Caucasian</td>
</tr>
<tr>
<td>CP428</td>
<td>Fred</td>
<td>Male</td>
<td>?</td>
<td>Married</td>
<td>Husband</td>
<td>No – retired</td>
<td>Caucasian</td>
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<tr>
<td>CP430</td>
<td>Sarah</td>
<td>Female</td>
<td>69</td>
<td>Married</td>
<td>Daughter-in-law</td>
<td>Yes – full time</td>
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<tr>
<td>CP431</td>
<td>Julie</td>
<td>Female</td>
<td>38</td>
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<td>Medical Assistant</td>
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<td>American Indian</td>
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<tr>
<td>CP437</td>
<td>Nick</td>
<td>Male</td>
<td>78</td>
<td>Married</td>
<td>Husband</td>
<td>No – retired</td>
<td>Caucasian</td>
</tr>
<tr>
<td>CP439</td>
<td>Vickie</td>
<td>Female</td>
<td>45</td>
<td>Divorced</td>
<td>Daughter</td>
<td>No – workman’s comp</td>
<td>Caucasian</td>
</tr>
<tr>
<td>CP441</td>
<td>Molly</td>
<td>Female</td>
<td>68</td>
<td>Widowed</td>
<td>Home Health Aide</td>
<td>Yes – part time (paid cg)</td>
<td>Caucasian</td>
</tr>
<tr>
<td>CP454</td>
<td>Nicole</td>
<td>Female</td>
<td>53</td>
<td>Married</td>
<td>Daughter</td>
<td>Yes – full time</td>
<td>Caucasian</td>
</tr>
<tr>
<td>CP455</td>
<td>Amy</td>
<td>Female</td>
<td>54</td>
<td>Married</td>
<td>Daughter-in-law</td>
<td>Yes – full time</td>
<td>Caucasian</td>
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<tr>
<td>CP470</td>
<td>No caregiver</td>
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<td></td>
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Average Age: 58.44
Appendix 2b: Recent Nursing Facility Admission
### Older Adults – Recent Nursing Facility Admission

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Marital Status</th>
<th>Race</th>
<th>Income</th>
<th>Number of Children</th>
<th>Urban/Rural Code</th>
<th>Urban/Rural Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>NA518</td>
<td>Mabel</td>
<td>Female</td>
<td>73</td>
<td>Widowed</td>
<td>Caucasian-little NA</td>
<td>2</td>
<td>7</td>
<td>1 = 1</td>
<td></td>
</tr>
<tr>
<td>NA535</td>
<td>Luella</td>
<td>Female</td>
<td>98</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>-unknown</td>
<td>8</td>
<td>2 = 0</td>
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</tr>
<tr>
<td>NA560</td>
<td>Shirley</td>
<td>Female</td>
<td>83</td>
<td>Single</td>
<td>Caucasian</td>
<td>2-Medicaid</td>
<td>0</td>
<td>8</td>
<td>3 = 0</td>
</tr>
<tr>
<td>NA577</td>
<td>Edward</td>
<td>Male</td>
<td>89</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>3</td>
<td>2</td>
<td>7</td>
<td>4 = 0</td>
</tr>
<tr>
<td>NA586</td>
<td>Nancy</td>
<td>Female</td>
<td>93</td>
<td>Married</td>
<td>Caucasian</td>
<td>3</td>
<td>6</td>
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<td>5 = 0</td>
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<tr>
<td>NA622</td>
<td>Helen</td>
<td>Female</td>
<td>84</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>6 = 0</td>
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<tr>
<td>NA628</td>
<td>Andrew</td>
<td>Male</td>
<td>79</td>
<td>Single</td>
<td>Caucasian</td>
<td>3</td>
<td>0</td>
<td>8</td>
<td>7 = 2</td>
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<tr>
<td>NA636</td>
<td>Betsy</td>
<td>Female</td>
<td>95</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>-Medicaid</td>
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<td>8</td>
<td>3 = 0</td>
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<tr>
<td>NA516</td>
<td>Marlene</td>
<td>Female</td>
<td>91</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>2</td>
<td>7</td>
<td>9</td>
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<tr>
<td>NA620</td>
<td>Lillian</td>
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<td>-declined</td>
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Average Age: 87.7

### Caregivers – Recent Nursing Facility Admission

<table>
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<th>Participant Number</th>
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<th>Age</th>
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<th>Employment outside of the home: Yes/No</th>
<th>Race</th>
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</thead>
<tbody>
<tr>
<td>NP518</td>
<td>Cindy</td>
<td>Female</td>
<td>52</td>
<td>Married</td>
<td>Daughter</td>
<td>Yes – part time</td>
<td>Caucasian</td>
</tr>
<tr>
<td>NP535</td>
<td>Anthony</td>
<td>Male</td>
<td>77</td>
<td>Single</td>
<td>Son</td>
<td>No</td>
<td>Caucasian</td>
</tr>
<tr>
<td>NP560</td>
<td>Marlene</td>
<td>Female</td>
<td>91</td>
<td>Widowed</td>
<td>Sister</td>
<td>No</td>
<td>Caucasian</td>
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<tr>
<td>NP577</td>
<td>Sandra</td>
<td>Female</td>
<td>58</td>
<td>Divorced</td>
<td>Daughter</td>
<td>Yes – full time</td>
<td>Caucasian</td>
</tr>
<tr>
<td>NP586</td>
<td>James</td>
<td>Male</td>
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<td>Married</td>
<td>Son</td>
<td>Yes – part time</td>
<td>Caucasian</td>
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<tr>
<td>NP622</td>
<td>Mindy</td>
<td>Female</td>
<td>79</td>
<td>Single</td>
<td>Sister</td>
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<td>Caucasian</td>
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<tr>
<td>NP628</td>
<td>No caregiver</td>
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<td></td>
</tr>
<tr>
<td>NP636</td>
<td>Stephen</td>
<td>Male</td>
<td>78</td>
<td>Married</td>
<td>Son-in-law</td>
<td>No</td>
<td>Caucasian</td>
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<tr>
<td>NP516</td>
<td>Barbara</td>
<td>Female</td>
<td>49</td>
<td>Married</td>
<td>Daughter</td>
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<tr>
<td>NP620</td>
<td>Cynthia</td>
<td>Female</td>
<td>78</td>
<td>Married</td>
<td>Family Friend</td>
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Average Age: 69.89
Appendix 2c: Long-Term Community Tenure
### Older Adults – Long-Term Community Tenure

<table>
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<th>Participant Number</th>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Marital Status</th>
<th>Race</th>
<th>Income</th>
<th>Number of Children</th>
<th>Urban/ Rural Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>LA103</td>
<td>Ellen</td>
<td>Female</td>
<td>85</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>2</td>
<td>1</td>
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<tr>
<td>LA110</td>
<td>Not interviewed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LA120</td>
<td>Jennifer</td>
<td>Female</td>
<td>87</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>3</td>
<td>1</td>
<td>2 = 2</td>
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<tr>
<td>LA 122</td>
<td>Gregory</td>
<td>Male</td>
<td>80</td>
<td>Divorced</td>
<td>-unknown</td>
<td>1</td>
<td>2</td>
<td>3 = 1</td>
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<tr>
<td>LA174</td>
<td>Marian</td>
<td>Female</td>
<td>98</td>
<td>Widowed</td>
<td>-unknown</td>
<td>3</td>
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<tr>
<td>LA184</td>
<td>Walt</td>
<td>Male</td>
<td>72</td>
<td>Married</td>
<td>-unknown</td>
<td>3</td>
<td>9</td>
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</tr>
<tr>
<td>LA213</td>
<td>Martha</td>
<td>Female</td>
<td>80</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>2</td>
<td>1</td>
<td>7 = 0</td>
</tr>
<tr>
<td>LA300</td>
<td>Esther</td>
<td>Female</td>
<td>76</td>
<td>Widowed</td>
<td>-refused</td>
<td>2</td>
<td>5</td>
<td>8 = 3</td>
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<tr>
<td>LA313</td>
<td>Anna</td>
<td>Female</td>
<td>89</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>1</td>
<td>2</td>
<td>9 = 1</td>
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<tr>
<td>LA315</td>
<td>Not interviewed</td>
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<tr>
<td>LA305</td>
<td>Harvey</td>
<td>Male</td>
<td>86</td>
<td>Widowed</td>
<td>Caucasian</td>
<td>3</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>LA296</td>
<td>Susan</td>
<td>Female</td>
<td>87</td>
<td>Divorced</td>
<td>-unknown</td>
<td>-unknown</td>
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</table>

Average Age: 84

### Caregivers – Long-Term Community Tenure

<table>
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<tr>
<th>Participant Number</th>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Marital Status</th>
<th>Relationship to Older Adult</th>
<th>Employment outside of the home: Yes/No</th>
<th>Race</th>
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<tbody>
<tr>
<td>LP103</td>
<td>Not interviewed</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LP110</td>
<td>Alex</td>
<td>Male</td>
<td>80</td>
<td>Married</td>
<td>Cousin</td>
<td>No – retired</td>
<td>Caucasian</td>
</tr>
<tr>
<td>LP120</td>
<td>No caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LP122</td>
<td>Gloria</td>
<td>Female</td>
<td>43</td>
<td>Divorced</td>
<td>Home Health Aide</td>
<td>Yes – full time</td>
<td>Caucasian</td>
</tr>
<tr>
<td>LP174</td>
<td>Melanie</td>
<td>Female</td>
<td>67</td>
<td>Married</td>
<td>Daughter</td>
<td>No – retired</td>
<td>Caucasian</td>
</tr>
<tr>
<td>LP184</td>
<td>Beverly</td>
<td>Female</td>
<td>70</td>
<td>Married</td>
<td>Wife</td>
<td>No – never worked</td>
<td>Caucasian</td>
</tr>
<tr>
<td>LP213</td>
<td>No caregiver</td>
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<td></td>
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<td>LP300</td>
<td>Debra</td>
<td>Female</td>
<td>56</td>
<td>Married</td>
<td>Daughter</td>
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<td>Caucasian</td>
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<td>LP313</td>
<td>Fred</td>
<td>Male</td>
<td>62</td>
<td>Married</td>
<td>Son</td>
<td>No – retired</td>
<td>Caucasian</td>
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<tr>
<td>LP315</td>
<td>Sam</td>
<td>Male</td>
<td>64</td>
<td>Married</td>
<td>Son</td>
<td>No – retired</td>
<td>Caucasian</td>
</tr>
<tr>
<td>LP305</td>
<td>Steve</td>
<td>Male</td>
<td>60</td>
<td>Married</td>
<td>Son</td>
<td>No – retired</td>
<td>Caucasian</td>
</tr>
<tr>
<td>LP296</td>
<td>Rachael</td>
<td>Female</td>
<td>?</td>
<td>Divorced</td>
<td>Daughter</td>
<td>Yes – part time (paid cg)</td>
<td>Caucasian</td>
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</tbody>
</table>

Average Age: 62.75
Appendix 3: Synthesis and Integration of Interview Findings
Synthesis and Integration of Findings From All Three Groups

This section presents a more detailed discussion of the qualitative interview findings, using the policy related questions (see main report) as the basis for organizing the analysis. The analysis is presented in two major parts.

First, findings are presented and compared from the two groups of moderately functioning (LTC of 66 or less) older adults who received a CARE Assessment in 2002 and their caregivers. One group was diverted and was residing in the community at the time of the interview (referred to as “recently diverted”); the other was not diverted and had entered a nursing facility within 30 days following the CARE assessment (referred to as “recent NF admissions”). Interviews with each of these two groups and their caregivers are presented separately below, along with an explanation of who was interviewed—i.e., selected socio-demographic characteristics of the interview group and a list of each older adult with a description of their living situation. Following presentation of the separate analyses, similarities and differences in findings between the two groups will be compared. Comparative analysis is intended to provide in-depth understanding of the specific circumstances that allowed one group of moderately impaired older adults to remain in the community while the other similarly functioning group permanently entered a nursing home.

The second part of this section follows a similar format to present data from longer-term diverted customers and their caregivers. These individuals have resided in the community, maintaining their diversion, for a period of 24 months or longer. They provide examples of highly successful diversion. Data from interviews with these older adults and their caregivers can provide insight into the circumstances that have allowed them to remain in the community for an extended period of time.

The analytic themes identified and discussed here represent the dominant trends in the interview data. They are illustrated with quotations, which also indicate some of the variations through which these themes are expressed. Findings from the analysis of the unpaired elders are presented at the end of each of the sub-sample sections in order to illustrate variances that emerged through interviews completed with individuals who did not identify a caregiver. These findings must be interpreted cautiously due to the small number of participants interviewed that did not identify a caregiver.

1. Moderately functioning older adults recently diverted from a NF admission and their caregivers in comparison to moderately functioning non-diverted older adults admitted to a NF.

This section first provides descriptive details regarding the CARE Assessment customers who were recently diverted from a NF and their caregivers. A table with the demographic description of the older adults and caregivers is provided. Then, a description of the older adult’s circumstances is presented to provide the background and the context for the CARE Assessment and the caregiving. Finally, findings from the interviews are presented in a format based on the policy related questions. In order to facilitate understanding of the findings, quotes that illustrate
the data are used throughout the section. This section also provides descriptive details regarding customers who received their CARE Assessment at a similar point in time and with similar levels of impairment who, instead of being diverted, permanently entered a nursing facility. Data from interviews with their caregivers is also included. Similar demographic and contextual descriptions are provided.

a) Recently diverted customers and caregivers

Who was interviewed?

Of the twenty-three interviews involving recently diverted customers, most (20) came from the 10 dyadic relationships between an older adult and caregiver. The remaining 3 interviews were with elders who did not identify a caregiver.

Seven of the caregivers were related to the older adult in some way (three daughters, two daughters-in-law, and two spouses), while three of the caregivers were non-related and paid. All but two of the caregivers were women. Two of the older adults were men. Seven of the older adults lived in their own homes, one lived in low-income housing for older adults and four lived with their caregiver. All of the caregivers lived within five miles of the older adults they cared for at the time of the CARE Assessment. All ten of the older adults had been in a nursing facility for rehabilitation services and had been discharged after a short time.

The three elders who did not identify a caregiver were all women. Two lived in their own homes and the other lived in an assisted living facility. All three older adults without a caregiver had been discharged from temporary rehabilitation in a nursing facility.
Table 11 gives selected demographic information about this group.

**Table 11**  
**Demographic Characteristics of Recently Diverted CARE Assessment Customers and their Caregivers**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Older Adults N=13</th>
<th>Caregivers N=10</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Average Age: 82.92 Age Range: 68-97</td>
<td>Average Age: 58.44 Age Range: 38-78</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Females: 11 Males: 2</td>
<td>Females: 8 Males: 2</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td>Caucasian: 12 African American: 1</td>
<td>Caucasian: 9 American Indian: 1</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td>Single: 0 Married: 3 Widowed: 10 Divorced: 0</td>
<td>Single: 0 Married: 7 Widowed: 2 Divorced: 1</td>
</tr>
<tr>
<td><strong>Caregiver Relationship to the Older Adult</strong></td>
<td>Not Applicable</td>
<td>Child: 3 (Daughter = 3) Spouse: 2 Other relative: 2 Non-related: 3 No caregiver: 3</td>
</tr>
<tr>
<td><strong>Urban/Rural Residence of the Older Adults a</strong></td>
<td>1: 7 2: 1 3: 1 4: 4</td>
<td>Not Applicable</td>
</tr>
<tr>
<td><strong>Income Level (Monthly)</strong></td>
<td>&lt; $738: 3 $739-1130: 2 &gt; $1130: 5 Unknown: 3</td>
<td>Not Applicable</td>
</tr>
<tr>
<td><strong>Does caregiver work outside the home?</strong></td>
<td>Not Applicable</td>
<td>Work full-time: 4 Work part-time: 1 Not working: 5</td>
</tr>
</tbody>
</table>

*a The legend below explains the classification of urban-rural used:
1 Urban* Country (1,2)
2 Adjacent to an Urban Area with a city of at least 10,000 (3,5)
3 Adjacent to an Urban Area without a city of 10,000 (4,6)
4 Not adjacent to an Urban Area (7,8,9)

*Used Urban as equal to Metro*
**Brief narrative description of the older adult’s situation** (care-recipients are denoted with an asterisk)

*Ethel* and *Nicole*
Ethel is an older adult who lives with her daughter, Nicole, and Nicole’s husband and daughter. Nicole acts as Ethel’s caregiver.

*Frank* and *Sue*
Frank and Mary are husband and wife and live in their own home. While Sue is the couple’s paid caregiver, Frank sometimes takes on the responsibilities of caregiving for his wife. However, he needs a caregiver as well.

*Janice* and *Nick:*
Janice and Nick are husband and wife and live in their own home. Nick is Janice’s caregiver, and Nick removed Janice from a nursing facility where Janice was receiving rehabilitative treatment because he was not confident in the type of care she was receiving.

*Nina* and *Molly*
Nina is an older adult who lives in her own home, and Molly is Nina’s paid caregiver.

*Allen* and *Vickie*
Allen is an older adult who lives in his own home, and Vickie, his daughter, is his caregiver. Vickie removed Allen from a nursing facility after a short time because both were concerned that the nursing facility was taking all of Allen’s Social Security.

*Laura* and *Julie*
Laura is an older adult who lives in low-income senior housing. Julie is Laura’s paid caregiver, and is paid by the State.

*Catherine* and *Gina*
Catherine is an older adult who lives in her own home. Gina is her daughter and acts as her caregiver, though Catherine needs very little help to live on her own.

*Bea* and *Sarah*
Bea is an older adult who lives on her own in her own home. Sarah is Bea’s daughter-in-law and caregiver, and she lives with Bea’s son across the road from Bea.

*Lily* and *Amy*
Lily is an older adult who lives with her daughter-in-law Amy and Lily’s son. Amy acts as Lily’s caregiver, and claims that Lily has dementia and early onset Alzheimer’s.

*Karen* and *Fred*
Fred and Karen are a married couple who live on their own. While Fred is considered Karen’s caregiver, they provide reciprocal care for each other.
Dorothy*  
Dorothy is an older adult who lives on her own in an apartment. While she claims she doesn’t have a caregiver, she does have a housekeeper and someone who bathes her.

Alice*  
Alice is an older adult who lives on her own in an apartment. She also claims she doesn’t have a caregiver, but has a “telephone pal” who fixes her medications for her and helps her to get dressed.

Marian*  
Marian is an older adult who has lived in an assisted living since her husband died. She does not have a caregiver who performs tasks for her.

Strategies used to remain in the community

Recently diverted older adults and their caregivers used a number of strategies in order to remain in the community, as opposed to returning to the nursing facility for care. These strategies, discussed below, include:

- resistance to placement in a nursing facility,
- older adults’ orientation toward autonomy,
- utilization of formal services,
- reliance on caregiver assistance, and
- reciprocal care between the older adult and caregiver.

Resistance to placement in a nursing facility

Of the ten recently diverted older adults who have a caregiver, all resisted returning to a nursing facility for permanent placement. Several of the older adults used the word “determination” when describing their experience of resisting nursing facility placement, and one older adult claimed to be “aggressively” (Frank, older adult) against placement.

In some instances, the issue of leaving the nursing facility centered on the older adult’s lack of certainty that the nursing facility was adequately providing care. One older adult left the nursing facility because she lacked confidence in the care provided by the nursing facility staff and felt that she would fare better getting care at home:

My cousin is my power of attorney, he and his wife come and got me out. I don’t think I would have been alive if they hadn’t of. (Nina, older adult)

The cost of placing an older adult in a nursing facility was also an issue for both elders and their caregivers. A daughter, who acted as a caregiver for her parent, removed the older adult from a nursing facility because his entire Social Security check went to the nursing facility to cover the cost of nursing facility care.
I think nursing homes are a rip-off. They are. People work their whole lives for their social security, and you know, VA and stuff and when you go into the nursing home, they take all your money. (Vickie, caregiver)

Several older adults and their caregivers expressed concern that money would become an increased problem if the older adult were placed in a nursing facility. One older adult claimed that he and his wife would be broke within a year if they were placed in a nursing facility. However the same older adult gave the advice of living within your financial means and not accepting money from others.

Well, live within your income. Get out of debt and live within your income. If you are careful, you can do it. We’ve got enough money to live on. I don’t feel penny pinched, buy whatever you want. Something we wasn’t able to do before. Always had to save up for your old age. (Frank, older adult)

Furthermore, when a woman from the local Area Agency on Aging visited the older adult at home, he assumed that she was there to offer financial help, which he would not accept.

There’s a lady came to call on us once and I was favorably impressed with her. She just visited and told me pretty soon we can’t do much for you, they’ve cut our budget way down. I guess she figured I was wanting some financial help, but I never figured on any of that. I don’t think my fellow citizens owe me… (Frank, older adult)

It is evident from the interviews with both older adults and their caregivers that money plays a part in the determination to stay in the community as opposed to entering a nursing facility for permanent placement.

Strong determination for the older adult to stay in the community was displayed throughout the interviews. One older adult even expressed the need for more education on how older adults could remain in the home instead of being placed in a nursing facility:

If I could contribute anything positive, I would like it to be how people could take care of themselves in their homes. (Frank, older adult)

Not all caregivers expressed the same level of determination, however. While the paid caregivers enthusiastically supported the decision to keep the older adult in the community, not all of the family members shared the same enthusiasm. Several of the older adults had family members who supported permanent nursing facility placement, yet the older adults remained in the community. Of the familial caregivers, a number expressed feeling burdened, stressed, or felt they had sacrificed their own personal lives to care for the older adult. One exception was a daughter who cared for her father and felt as though it was “[her] turn to take care of him” (Vickie, caregiver). This was the only instance of a daughter caring for a father (as opposed to a mother), and it is possible that this might have had some impact on the lack of expressed burden or strain.
Older adults’ orientation toward autonomy

Research shows that older adults who adopt autonomous strategies thrive more than those who do not (Katz et al., 2000). All ten of the older adults who were discharged into the community as opposed to remaining in the nursing facility as a permanent resident used walkers and were able—to an extent—to perform different tasks (i.e. making a meal, cleaning their room/home, fixing their own medications, etc.) on their own. Several of the older adults mentioned using different gadgets or equipment that would make their lives easier, and some even had home modifications done in order to make going to the bathroom or walking up steps easier, for example. Some of the older adults were quite aware of their physical limitations, even going so far as to claim that they would enter a nursing facility if they couldn’t walk or get out of bed anymore; however, their physical limitations did not, in their minds, affect their ability to stay in the home versus entering a nursing facility. Some felt they did not need help at all:

_I didn’t see any need for help. I was plenty capable of taking care of myself and my home._ (Catherine, older adult)

The older adult’s perception of his or her own autonomy sometimes differed from the caregiver’s perception. For example, a couple of the older adults claimed to be independent, yet their caregiver would claim the opposite. Ethel, an older adult who lives with her caregiver daughter, said she was very independent and may need help someday; however, her daughter Nicole claimed that Ethel needs so much help walking that it would be easier for Ethel to be in a wheelchair, which Ethel protests against. Another older adult said that she can do things on her own, and does not understand why she was sent to a daycare for older adults. Her caregiver explained that the older adult attends a daycare because she is suffering from dementia and early-onset Alzheimer’s, and needs constant supervision.

Utilization of formal services

Research shows that older adults with chronic conditions or poor levels of health utilize formal support more often than those with better health (Penning, 1995; Noelker & Bass, 1989). For the 10 recently diverted older adults—whom all have some type of lingering or chronic illness or medical problem that began before the CARE assessment—the formal supports and services include hired caregivers, home health care, and meal delivery services. Along with their primary caregivers, seven of the older adults have home health care services and six of the older adults have additional hired caregivers/housekeepers. One older adult received daycare services.

Reliance on caregiver assistance

The success of community tenure for the older adult is primarily based on the relationship between the caregiver and the older adult (Feeney & Hohaus, 2001; Miller & Weissert, 2000). Caregivers provide physical, social, and emotional care for older adults. Physically the caregiver provides assistance to the older adult when the older adult reaches his or her physical limitation. Examples of physical caregiving include housekeeping, assisting the older adult bathe or dress, and helping the older adult with health care treatments. One caregiver who looked after her mother-in-law rubbed her mother-in-law’s legs daily in order to combat swelling. It is this
physical assistance that supports the older adult’s ability to stay in the community versus being placed in a nursing facility, as is exemplified by an older adult who is cared for by her daughter-in-law:

_Somebody asked me awhile back if I was still living out here by myself. I said yes, with the home health and my family taking care of me, I can do it._ (Bea, older adult)

The older adults interviewed also relied on their caregivers for social and emotional assistance. The three paid caregivers each viewed the older adult they cared for as a member of their own family, and the feeling from the older adult was mutual.

_She treats me like a member of her family and I treat her like a member of mine._
(Molly, paid caregiver)

_She always tells me that I’m that daughter that she lost and you know she says well I feel like you’re the daughter._ (Julie, paid caregiver)

_[My caregiver] is very good to me. I feel fortunate._ (Laura, older adult)

_They have been so good to me. She is a doll, I just love her dearly._ (Sue, paid caregiver)

The three paid caregivers are so devoted to the older adults they care for that they will call and check in with the older adults on their days off, or call just to chat with the older adult. Social and emotional interaction is very important for the older adult. Dobbs and colleagues (2002) found that older adults indicated that they experienced positive benefits from social contact and the maintenance of close social ties. This was the case for the older adults interviewed, some of who voiced that they were lonely when their caregiver was not around.

The familial caregivers did not express the same emotional involvement as the paid caregivers reported. Of the familial caregivers, several stated that they felt overwhelmed or guilty for not spending enough time with the older adult. For example, a woman who cared for her mother in the home felt a sense of guilt for not focusing enough on her mother:

_I feel bad that I don’t include her enough or just the usual daughter guilt stuff._
(Nicole, caregiver)

Furthermore, several of the familial caregivers claimed that they did not provide any emotional support for the older adult.

*Reciprocal care between the older adult and caregiver*

Several of the older adults provide social support in addition to receiving social support. According to Spaid (1998), this reciprocation of support is often overlooked in older adults due to the idea that elders’ physical and emotional needs are too great to allow them to offer any type
of support to their caregivers. However, the reciprocation of care between the older adult and the caregiver—particularly the paid caregiver—was evident in the interviews. For example, the three paid caregivers all expressed a sense of gratitude towards the older adult for including the caregiver in his or her life.

*And they’ve done things for me and I appreciate it.* (Sue, paid caregiver)

*I would say we lean on each other.* (Julie, paid caregiver)

*Being with Nina helps us both.* (Molly, paid caregiver)

Among the familial caregivers, reciprocal care was less evident. A woman who cares for her father expressed gratitude for her father taking care of her when she was young, and she is now returning the favor:

*Well, I mean, he’s my dad. He took care of me when I was younger and, you know, supported me and took care of me and everything and now it’s my turn to take care of him. Too bad more people didn’t think that way.* (Vickie, caregiver)

However, the theme that was most apparent among familial caregivers—both spouses and children—was a sense of duty or obligation for caring for the older adult. This is consistent with recent literature that claims family members view caregiving for an older adult as the family’s responsibility (Piercy & Blieszner, 1999; Barrett & Lynch, 1999; Bond et al., 1999). One example of this is a caregiver who described caregiving for his wife as a duty that accompanied marriage. Many of the familial caregivers talked about the burden and sacrifice associated with caregiving, a subject that will be discussed in more detail later.

**Participation in health and caregiving**

Recently diverted older adults took an active role in maintaining their own health in order to remain in the community, in lieu of returning to the nursing facility for care. The role of self-care, the perception of health and needs, and mobilization of resources all factored into the capacity to maintain the older adult in the community.

**Self-care**

The older adult’s involvement in self-care can also affect their view of the caregiving experience. Research shows that it is important to let the older adult’s voice be heard in order for the older adult to participate with the caregiver in the regulation of their own physical and mental development (Gallagher, 1999; Russell, Bunting & Gregory, 1997). As far as health-related self-care, several of the older adults monitor their health with the help of home health care services. One older adult even went so far as to learn how to administer his own breathing treatment in the home, while another older adult treats her legs for swelling. Furthermore, some of the older adults do some kind of exercising, whether it is traditional exercising or something physically active, such as housework.
Church participation was also important to half of the older adults interviewed. Based on several older adults’ common complaint of not being able to leave their home for social events like they used to, church attendance may be the only source of social interaction with other older adults:

_Well if I could just, I wish I could get out more. And my girlfriend at the church says anytime that I think that I want to go well she’ll come get me._ (Janice, older adult)

Other self-care activities that promote emotional health and well-being are hobbies, including knitting and crocheting for a non-profit organization, and a few older adults use the computer to play games or e-mail their friends:

_I play computer, I keep my mind active and I play computer games; I feel like that helps with my reflexes._ (Ethel, older adult)

_I write lots of letters. I have an e-mail list you wouldn’t believe!_ (Catherine, older adult)

**Perception of health and needs**

Caregivers who are made aware of the older adult’s physical health are more likely to realize the limitations of what they can do for the older adult, and what the older adult can physically do (Hepburn et al., 2001). However, this does not necessarily mean that the older adult has realized his or her own physical limitations. For example, one older adult feels as though she is capable of caring for herself while her caregiver and the caregiver’s family leaves for a vacation.

_Like they’re going off for spring break, I’m trying to convince them that I can stay here by myself but they don’t see it that way and I don’t want them to worry so I mean there are just some things like heavy stuff I can’t do._ (Ethel, older adult)

Her caregiver sees the situation differently:

_And now I don’t like to leave Mom, I mean she can’t stay at home by herself. She can do the daily things but if she fell or got sick, she shouldn’t be there alone all the time._ (Nicole, caregiver)

Another older adult who described her own health as “excellent” had a daughter-in-law as her caregiver; the daughter-in-law claimed the older adult doesn’t need a lot of help. However, the same caregiver proceeded to provide a long list of services that she provides for her mother-in-law, and later discussed how burdened and overwhelmed she was from caregiving. Thus, the perception of the older adult’s health and needs was intangible to even the caregiver.

Several of the older adults described their health as “good” or “excellent,” yet either they or their caregivers admitted they had some physical limitations. For example, an older adult who describes his health as “good” also admits to having severe leg problems; his caregiver claimed that the older adult admitted his physical limitations to her, but yet “he’s a very determined man
and you’ve got [to] give him credit for what he does” [tries to overcome his physical limitations] (Sue, caregiver). Another older adult who said she could do things for herself has a caregiver who reported that the older adult cannot see or walk very well, but she does what she can. A final example is an older adult who described her health as “pretty good for her age,” yet her caregiver revealed that the older adult is suffering from dementia and early onset Alzheimer’s.

**Mobilization of resources**

As previously stated, older adults with chronic conditions or poor levels of health more often use formal support (Penning, 1995; Noelker & Bass, 1989). However, the only way older adults can mobilize resources and formal support is if they have been given information concerning what is available to them. The interaction that older adults had with their case manager ranged from positive and helpful for the older adult to negative in nature.

For example, one older adult has a case manager who set up home health services for her, and found funding for her services. Another older adult is working with a case manager to find assistance in paying for her medications, which take up a bulk of her monthly income. A third older adult receives assistance from an Area Agency on Aging, but his daughter (who acts as his caregiver) had to actively seek out assistance.

While several of the individuals do not recall having a case manager contact them, some had negative experiences with their case managers. One older adult claimed that a case manager visited her once, but said that she couldn’t do anything for the older adult. Another older adult had a more drastic negative experience with a case manager; after calling her case manager for assistance, the case manager claimed that he or she could not talk on the phone to the individual and instead set up an appointment to visit the older adult’s home. However, the case manager never showed up—it had been three weeks past the date when the older adult was interviewed—and the older adult lost her transportation services.

> Well, I call her. But the way I understand it and I hate it cause I like [the case manager] but she told me about a year ago that they were going to have to come to the house. That they weren’t supposed to call you on the phone to see how things are going. And I called her, she was supposed to have been here three weeks ago today with some papers for me on this new changeover [to find new transportation services, because she lost hers]. See. But, I haven’t seen or heard from her. I will call her until she calls me back. (Laura, older adult)

Another couple that share caregiving responsibilities for each other had trouble getting along with their case manager and are subsequently not receiving services they so desperately need. Their home health services were cut, and they had continuing problems with the area’s case manager.

> Terrible when I say this, but it’s true. The person that was at the head of it was just wanting to promote herself. And she wanted everything for her and not too much for the clients. (Fred, caregiver)
Finally, an older adult who claimed a case manager never visited her asked if there were other services available that she could receive, because she was not aware of what was available. If the older adult has a case manager who is either not available or is not helpful in finding services, the older adult may lack essential services that would allow for he or she to live in the community with more ease. While a case manager can be a resource in showing older adults how their needs can be met, they could also be a deterrent in obtaining resources if they are not involved with the older adult.

**Challenges for remaining in the community**

Recently diverted older adults and their caregivers face challenges in an attempt to remain in the community. Financial determinants, the task of finding services, and caregiver burden and sacrifice all factor into the decision to keep the older adult in the community.

**Financial deterrents**

Several of the older adults interviewed expressed concern for their financial well-being. While a couple of the older adults had enough money to either hire a caregiver (if the state did not pay for such a service), many of the older adults had financial problems that resulted in their caregivers—both paid and familial—providing supplies for them, or paying the costs of additional services for the older adult.

*We won’t take Ms. Laura’s money. I can’t do that when she doesn’t have enough anyway. And I don’t care, she needs toilet paper, I don’t care if it’s salt, pepper, sugar, whatever...they are necessities as general as a community is life that we go and why should she not be entitled to these?* (Julie, paid caregiver)

*They did cut her back to two baths a week and so we asked, she gets most of these services, I don’t know if it’s through Medicare or she pays a minimum anyway. So then we said we’d pay for the third bath.* (Sarah, caregiver)

The cost of placing an older adult in a nursing facility was also an issue for both elders and their caregivers. In one instance, a daughter who acted as a caregiver for her parent removed the older adult from a nursing facility because the facility was costing the older adult his entire Social Security check.

*Oh, yeah. They [the nursing facility] were talking about taking all of his money.*

(Vickie, caregiver)

Several older adults and their caregivers expressed concern that money would become an increased problem if the older adult were placed in a nursing facility. One older adult claimed that he and his wife would be broke within a year if they were placed in a nursing facility. Another older adult said that she would need financial assistance if she were placed in a nursing facility, because she had no money for emergencies or a nursing facility placement. Finally, a caregiver found that placing her mother-in-law in a nursing facility or assisted living would cost too much money:
And I was going to put her in assisted living but when I found out he [the older adult’s son] cancelled all her burial insurance and so I thought Oh Lord, we can’t do that. We can’t afford that so we just had her move in with us and the food, board, everything we just pay for. (Amy, caregiver)

It is evident from the interviews with both older adults and their caregivers that money plays a part in the determination to stay in the community as opposed to entering a nursing facility for permanent placement.

**Finding and arranging services**

Just as the older adults’ experiences with case managers influenced whether or not the older adult received services or mobilized resources and formal supports, the caregivers also relied on the case managers for locating information concerning services. Two of the caregivers stated that they had positive experiences with their case manager, and the case manager was helpful in arranging services for the older adult.

*Yes, I think she [case manager] is helpful because, I think that’s the one home health turns to and she’s always worked well to get the services they recommend that she needed. And she’s always had those services, so I’d say she worked very well for her.* (Sarah, caregiver)

*And um, she [case manager] she come out and she was very helpful. She’s the one that got us hooked up with [adult daycare] and had them come out. She’s also the one I would contact if I needed to get Lily into assisted living. We just did a review this year.* (Amy, caregiver)

Other caregivers either claimed that the case manager who performed a CARE Assessment was not helpful at all, or they approached a case manager for help and received none, which forced the caregiver to become their own case manager and seek out information themselves.

*Because you don’t have, you got [to] have a good social worker to give you the info and if it isn’t, if we don’t find it amongst ourselves the social workers and the state itself will not give it to you unless you’re a state employee.* (Julie, paid caregiver)

*I just went up to the Area Agency on Aging, cause I knew that that’s where they [services] was. I would have found out [about additional services]. I find out what I need to know to make sure that Dad’s okay.* (Vickie, caregiver)

Previous experience with the state and case managers also influence how caregivers view case management. For example, a daughter who is the caregiver for her mother had previous experience taking care of her mother-in-law. In the previous instance, the caregiver approached the state for financial help; they offered to pay for nursing home placement, but would not provide money for at-home care.
It just didn’t make any sense that we couldn’t get any assistance with paying a caregiver. It would have been a fraction of what a nursing home cost. If we put her in a nursing home, she has no money, so obviously the state’s going to be paying for it. (Gina, caregiver)

In this instance, a case manager would have been helpful in finding additional resources, but the caregiver received no guidance from a case manager.

Caregiver burden and sacrifice

As previously stated, 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 caregivers have health problems that cease after their caregiving experience ends (Grasel, 2000), while other studies find no evidence that caregivers have poorer health practices (Scharlach et al., 1997). While none of the caregivers interviewed claimed to have poorer health as a result of caregiving, several of the familial caregivers felt burdened, stressed, and that they had sacrificed their own lives in order to care for the older adult. However, the level of burden the caregiver feels does not always match up to the amount of services they provide for the older adult; perhaps the fact that familial caregivers do not necessarily choose to care for their older family member, but feel a sense of obligation plays a part in this phenomenon.

While two of the paid caregivers expressed that they sometimes felt tired after caregiving, they did not feel burdened by their caregiving job. On the other hand, a large majority of the familial caregivers expressed feelings of burden, strain, and sacrifice; one caregiver even described caregiving as “very boring” and “very confining” (Nick). For example, one daughter who cares for her mother felt so burdened and tired that she used the nursing facility as a temporary placement for her mother:

The doctor recommended it I think as much for my sister and me as for her because we were just exhausted from the hospital stay and just worried about her. And he said, “I think you guys need a break.” (Nicole, caregiver)

This particular caregiver felt so burdened that doing a simple errand for her mother—mailing letters—essentially overwhelmed the caregiver.

Sometimes I feel kind of overwhelmed by how much I have to do with just what she needs. And as you get older, you just focus on, all you have to think about is what you need. She knows I’m busy and have a lot to do, and a lot of demands and a lot of things to worry about, but it’s “oh, you’re going out, mail my letters.” So it’s one more thing I have to do, remember the letters and find a mailbox. (Nicole, caregiver)

As noted earlier, the level of burden for caring for an older adult does not always coincide with the amount of services the caregiver performs. However, the caregivers who expressed feelings
of being overwhelmed also happen to be caring for their own children, and, in some instances, for sick spouses and grandchildren. While it is dangerous to assume that caring for an older adult is not as overwhelming service-wise as the caregivers make it out to be, it is possible that the caregivers feel burdened because they are also caring for other members of their family without outside help, and working outside of the home at the same time.

Another interesting theme that emerged from the caregiver interviews is the idea of the caregivers being confined in their role. For example, three of the caregivers provided specific examples of how they had to give up their hobby of traveling, because they had to make arrangements for someone to care for the older adult.

And when you want to take a trip you have to...you can’t take a trip. Or you take her along. (Amy, caregiver)

The other big thing too, is we used to travel a lot. And now I don’t like to leave Mom, I mean she can’t stay at home by herself. My activity is more restricted. I mean we would travel more. (Nicole, caregiver)

You know you can’t leave—that’s kind of a priority you know. You just can’t leave unless there’s some definite arrangements there. (Sarah, caregiver)

This personal sacrifice of freedom from the caregiver’s point of view affects the experience of caregiving for the older adult, and could lead to feelings of burden that do not necessarily coincide with the services they provide for the older adult.

Recent tenure older adults without caregivers

For the three older adults who claimed that they did not have a primary caregiver, two themes emerged from the interviews. First, while the older adults did not perceive that they had caregivers, they did have people who cared for them and performed specific caregiving tasks. For example, one older adult had both a housekeeper and someone who regularly helped her to bathe, yet claimed “people haven’t got time to do for you” (Dorothy, older adult). Another older adult referred to her “telephone pal” who checked in on her, helped “fix up” her medications, and assisted her in dressing. However, she believes that she is “pretty much on her own” (Alice, older adult). Finally, one older adult says that she is on her own and does not have any help, yet she lives in an assisted living facility where she regularly receives assistance when she needs it.

A second theme among older adults without caregivers is the fact that they did not have case managers or social workers that set up services for them. One older adult said that she was not even offered any options while she was in a nursing facility for rehabilitation:

No, there is no options...you, you know if you can live by yourself, you do. (Dorothy, older adult)

Another older adult contacted the state directly to request a reclining chair that would make it easier for her to stand up, but her request was turned down.
Summary of recent community tenure findings

Among the older adults, there was a consensus of resisting nursing facility placement, regardless of whether or not their family members felt the same. In order to resist this placement, several of the older adults adopted strategies—such as gadgets and home modifications—that would make living at home easier for them. While their perceptions of autonomy and reliance on their caregivers sometimes differed from how the caregiver viewed the situation, most caregivers admitted that the older adult does what they can with the limitations they face.

Reciprocal care between the older adult and paid caregiver was important, with the relationship becoming familial in nature. However, other caregivers did not express the same level of reciprocity that the paid caregivers did. Self-care of some sort was important to fill the older adult’s time, as well as to combat loneliness and depression. As far as case managers are concerned, some older adults had contact with one, while others claimed they never had. The level of case manager involvement ran the gamut, as did the older adults’ concerns with financial issues. Paid caregivers expressed a low level of caregiver burden, while familial caregivers expressed feeling overwhelmed, burdened, and had other caregiving responsibilities they were struggling with at the same time they were caring for the older adult.

b) Older adults recently admitted to a NF and their caregivers

Who was interviewed?

Nine older adults residing in a NF were interviewed along with their primary caregivers. One additional interview included an older adult who had no primary caregiver. The ten older adults had a CARE Assessment in March 2002 and at that time, a decision was made that the older adult would enter a NF and they have remained in a NF since that time. Eight older adults in the study were female and two were males.

The identified caregivers of the nine older adults include two sons, one son-in-law, three daughters, two sisters and one non-familial couple that had grown up next door to the older adult. At the time of the CARE assessment, two older adults lived with their caregivers and four older adults were either neighbors or lived in the same town as their caregivers. Two older adults lived within 40 miles of their caregiver and one older adult-caregiver dyad lived in different states. This section focuses on the analysis of the dyadic relationship narratives of older adults and their caregivers, followed by a brief discussion of the one older adult without a caregiver.
Table 12 provides demographic information about this group.

### Table 12
Demographic Characteristics of CARE Assessment Customers Recently Admitted to a NF and their Caregivers

<table>
<thead>
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<th>Characteristics</th>
<th>Older Adults N=10</th>
<th>Caregivers N=9</th>
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</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Average Age: 87.7</td>
<td>Average Age: 69.89</td>
</tr>
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<td>Age Range: 73-98</td>
<td></td>
<td>Age Range: 49-91</td>
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<tr>
<td><strong>Gender</strong></td>
<td>Females: 8</td>
<td>Females: 6</td>
</tr>
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<tr>
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*The legend below explains the classification of urban-rural used:
1 Urban* Country (1,2)
2 Adjacent to an Urban Area with a city of at least 10,000 (3,5)
3 Adjacent to an Urban Area without a city of 10,000 (4,6)
4 Not adjacent to an Urban Area (7,8,9)

*Used Urban as equal to Metro*
**Brief narrative description of the older adult’s situation** (care recipients are denoted with an asterisk)

**Betsy* and Stephen**

Betsy lived in Texas until she was admitted to a NF in Kansas due to her declining health. Her son-in-law, Stephen, was her caregiver because she trusted him to take care of her more than she trusted her children. Stephen also lives outside of Kansas and had to contact nursing facilities by phone and take a few short trips to Texas to try and sell his mother-in-law’s possessions during the month prior to her NF placement.

**Edward* and Sandra**

Prior to a NF placement, Edward was living in an apartment owned by a NF complex. He had utilized the NF for his noon meals as well as socialization. His caregiver, Sandra, was his daughter. She helps her father manage his finances and pay his bills as well as going to the doctor with him. She visits the NF every weekend and provides a lot of social support. Edward had pneumonia and fell precipitating his entry in a NF.

**Helen* and Mindy**

Helen and Mindy are sisters. Helen relocated to Kansas City a few years prior to her placement in a NF so that she would live in the same area as her sister. The sister dyad live in the same complex, only Mindy is still living in an apartment and Helen has moved into a NF in part due to a heart condition and her use of a wheelchair. The caregiving relationship involves daily visits to the older adult for socialization, and prior to a NF placement Mindy was helping Helen around her apartment, managing her finances and doing the majority of Helen’s shopping.

**Lillian* and Cynthia & Charles**

Cynthia and Charles are a married couple that have known Lillian since she was very young. They grew up as neighbors and naturally Cynthia and Charles began to take care of Lillian when she was in need of assistance. Previously, they had also cared for Lillian’s parents. Lillian fell and broke her hip prior to a NF placement and the doctor informed her that she could not return home without 24-hour care. Cynthia and Charles were supportive in Lillian’s NF admission, assisting her with selling her house and continue to manage her finances.

**Mabel* and Cindy**

Mabel entered a NF following a fall that resulted in a fractured hip and her inability to get out of bed. A few years prior Mabel fractured her arm and Cindy began caring for her mother. At that time, Cindy and Mabel made adjustments to the home in order to make community tenure feasible for her. Prior to Mabel’s NF placement, Cindy was providing 8-16 hours a day of direct personal care to her mother.

**Margaret* and Barbara**

Margaret moved from her lifetime home into an apartment due to finances and chronic health problems. Her daughter, Barbara, was instrumental in assisting her with this move along with the support of her siblings that live out of town. Barbara provided her mother hands on personal care such as changing her dressings as well as instrumental tasks such as shopping and cooking meals. Following multiple hospitalizations, Margaret was admitted to a NF after getting
pneumonia. The NF was intended to be a short-term stay for recuperation and now that Margaret’s health has stabilized, leaving the NF is not an option due to finances.

**Nancy* and James**

Nancy made the decision with her son, James, that she was going to enter a NF. Nancy’s husband had been recently admitted to a NF due to dementia. Following a fall and fractured hip, Nancy realized that she needed assistance with cleaning and cooking. James hired people to provide these services, but Nancy was reluctant to have them in the home for long periods of time. She and James decided that a NF placement would allow her to not have to care for her husband in the NF while caring for herself at home, making it easier on Nancy if she also were in the NF.

**Shirley* and Marlene**

Marlene had her sister, Shirley, move in with her following the death of the previous sister she was living with. Shirley had never lived on her own due to a developmental disability and the older sister felt that she could care for her. Marlene needed emergency surgery and time to recuperate, so her two children decided that Shirley would be placed in a NF. Marlene brings her sister home once a week and visits every weekend. She misses having her around the house, but there is no thought about bringing the sister back to live with Marlene.

**Luella* and Anthony**

When Luella was widowed 53 years ago, her oldest son, Anthony, moved back home to farm and provide economic support for his mother and younger siblings. He has resided with his mother since that time assuming responsibility of the farm. Then, ten years prior to Luella’s placement in a NF, Luella began to experience functional difficulties due to her health. At that time, Anthony began caregiving for his mother.

**Andrew***

Andrew was unable to identify a caregiver. He mentioned that he had social supports that he was able to lean on for certain tasks, though nothing extensive. He lived alone prior to a NF placement.

**Factors that play a role in a NF admission**

The decision to enter a NF was based on a number of factors. These factors, discussed below, include:

- decision to go to a NF was often times a joint decision between the older adult and their family, physician, or case manager,
- financial factors,
- needing more services than caregivers could provide, and
- caregiver burden
Decision to go to a NF was often times a joint decision between the older adult and their family, physician, or case manager

The decision to enter a NF was often a long and protracted process. For three older adults the decision was made following a period of time where the older adult and caregiver resisted advice from the older adult’s physician to enter a NF. Six out of ten older adults that went into a NF claimed that their doctor or another health professional was the decision maker in the situation and most caregivers agreed with this assertion as well. There was a sense of passivity that occurred in the decision making process that will be examined briefly.

Three of the NF residents actively resisted a NF placement for varied lengths of time despite their doctor’s recommendations that they should go to a NF.

*Her doctor mentioned to her that she think about a home you know.* (Stephen, caregiver)

Both the older adult and the caregiver worked together to ensure that the older adult could remain in the community for as long as possible before a NF placement. For instance, Margaret’s doctor recommended to her and the family that a NF would be a good idea due to frequent hospital admissions. During the second to last hospitalization subsequent to a NF placement, a daughter, Barbara, recounts her comments to the doctor, “I said no, I don’t think she’s quite ready for that [the nursing home].”

Three older adults and/or caregivers whose physicians recommended a NF placement expressed the desire to avoid going into a NF as well as one other older adult until it was the last possible option.

*The doctor had mentioned nursing home care to her prior, but my mom absolutely refused.* (Cindy, caregiver)

*She did not want that [NF] at all.* (Cynthia, caregiver) *She didn’t, that was the last resort.* (Charles, caregiver’s husband) *She just always said, I just want to live here until I die.* (Cynthia, caregiver)

For these dyads, there was a sense that the older adult and the caregiver would not consider a NF until there were no other available options.

For these individuals as well as the four other older adults, that idea of a NF as the last resort/last option actually became the reality following a major health event. At that point, the older adult and caregiver passively agreed with physicians or health care teams about the decision to enter a NF. Five of the nine older adults-caregiver dyads indicated that a doctor, hospital personnel, or a health care team made the decision to move the older adult into a NF. In some instances, the caregiver and older adult had objections or disagreement about the decision of the health care professional, but they went along with the doctor’s recommendation at that particular time due to the older adults’ health.
Dr. L over there said that I could not go home. I resented that. It didn’t really give me any choice. (Margaret, older adult)

I didn’t decide, they [doctor at the hospital] brought me here. (Lillian, older adult)

With Helen’s inability to walk, why it was, the committee decided that she should go. It was sort of decided for her. (Mindy, caregiver)

Another caregiver expressed his opinion that NF placement was inevitable due to hospital policies that only allowed the older adult to stay in the hospital three days following a broken hip. Due to this, the caregiver expressed that there was “no place for her to go but the nursing home” (Anthony, caregiver). One other older adult-caregiver dyad also had little input into the placement of the older adult in a NF because other family members made the decision due to the health care needs of the caregiver.

Two of the older adult-caregiver dyads indicated that the decision to go to a NF was really their own to make. One caregiver mentioned that for a year the older adult lived in the community against the desires of her doctor until eventually she decided that she was ready to enter a NF.

That’s when [following a hospitalization] she finally realized that she no longer could take care of herself. It was, the decision was hers about going into the nursing home. (Stephen, caregiver)

Another had a husband residing in a NF and decided that instead of being separated from him, things would be easier if she also was at the NF.

So during the night it came to me, why don’t I just shove everything off at my house and come up here and stay with Henry. “It’s up to you to decide what you want to do.” (Nancy, older adult)

There was disagreement between one of the pairs about how a NF was selected. Sandra, the caregiver, explained that her father was supposed to move into an assisted living from his apartment due to recent health concerns.

When it came time to move he said, no, I want to be on the nursing floor. That was his decision to go there. (Sandra, caregiver)

The older adult in this dyad explained that it was the doctor that had made the decision for him to move to a NF so that he could recuperate from a recent fall, but that he now prefers to be in the NF and has decided to stay.

Financial factors

Overall, financial factors that would prevent the older adults from receiving needed care were not factors resulting in a NF placement among this population. They all had adequate money to
make minor modifications to their home and hire any needed assistance for minimal hours during the week. Yet, upon NF placement some older adults sold their home in order to pay for their stay and then financial factors became a barrier to leaving the NF once admitted. Older adults and caregivers reported they did not have the financial resources needed to return to the community.

One older adult did take financial circumstances into consideration when making her decision to go to a NF. Nancy’s husband was already residing in the NF while Nancy remained at home with the assistance of privately paid help. Nancy decided that she did not want to have the double expense of paying for her husband’s NF stay and the assistance needed by herself in the home and thus, decided that she would enter the NF. Yet, in this situation it was not that the older adult could not afford the NF and private help, but she chose to go to the NF and in essence only pay “one” bill for both her and her husband’s care.

I’ve been going to double expenses of paying his keep and paying all that $10 an hour fee. (Nancy, older adult)

Older adults, after staying in a NF for a period of time, often spend a considerable amount of their income and assets. In one instance, an older adult went into a NF in April and by October had depleted her assets and went on Medicaid. Two older adults sold their homes in order to have the funding needed to stay at a NF. The same two older adults are now in a NF indefinitely partly because they no longer have the resources to move back into the community despite their improved health.

Needing more services than caregivers could provide

These older adults relied extensively on their caregivers for many of their needs, though their needs were often more instrumental than direct personal care assistance. Prior to their major health event, the majority of the older adults still felt that they were primarily independent, not really needing the assistance of the caregiver as much as the caregiver perceived the older adult having needs. Two caregivers talked about not wanting to infringe on the older adults’ independence. One of these caregivers felt it was important for the older adult to continue cooking meals although it took her an extended amount of time. He expressed the importance of “letting people do things as long as they can, as much as they can” (Anthony, caregiver). The other caregiver stated,

My theory was keep her independent as she could be. That was my theory. I did not want her to be dependent. I wanted her to remain independent. (Barbara, caregiver)

Prior to a NF placement, seven of the older adults utilized their caregiver primarily for instrumental support, such as going to the store, picking up mail, doing the laundry, cooking meals and taking care of financial matters for the older adult. Only two older adult-caregiver dyads reported that there had been a need for more hands-on personal assistance, which included bathing, dressing wounds and completing blood work.
Instead of providing this direct personal assistance, two male caregivers decided that they would be more comfortable hiring outside assistance and supervising the process.

*I thought I couldn’t give my mother a bath and I didn’t want to give my father a bath. But we hired people to do that. Anyway, as for that work, we did fine by hiring people to do it, why it made my load lighter and I didn’t mind doing that. What it did was make me a supervisor.* (James, caregiver)

For these caregivers, they were able to overcome personal limitations and perceptions about the caregiving role through the use of formal supports, which delayed the older adults’ need for a NF.

All nine of the caregivers in the study began their caregiving role prior to the older adults’ placement in a NF. As health problems began to interfere with the older adults’ ability to be independent, caregivers began assisting the older adults with specific tasks. The caregiver-older adult relationship began to evolve. The lengths of the caregiving relationships prior to the older adult entering a NF ranged from 14 years to one month. Two relationships lasted for two years, two lasted for five years, one caregiving relationship lasted approximately seven years and another lasted for ten years. A brief explanation of the longest and shortest caregiving relationship is provided next because they are exceptions to typical caregiving relationships.

Shirley and Marlene are sisters and their caregiving relationship began 14 years prior to Shirley’s placement in a NF. Shirley is developmentally delayed and has always lived with family members. Shirley had lived with another sister until her death. Marlene moved Shirley into her own home and provided 24-hour care including supervision and offering verbal prompts. Marlene did Shirley’s laundry, cooking and most of the housework. Although she was not helping her sister with baths at the time of the older adult’s NF placement because the AAA provided a personal care assistant to bath Shirley, Marlene had assisted Shirley with baths for the first ten years that she lived with her.

The shortest caregiving relationship involved Betsy and her son-in-law, Stephen. For the month preceding Betsy’s placement in a NF, Stephen became very involved with instrumental tasks that he could take care of over the telephone due to the distance between their two homes. Betsy was living in Texas and following a hospitalization she stayed with a neighbor until her son-in-law could arrange a NF admission in Kansas. He located a NF and took care of his mother’s-in-law belongings including selling the house and discarding of her possession after she entered a NF.

Although the older adults entered the NF, the caregiving relationships have not ended for any of these dyads. Due to the nature of tasks completed by the caregivers prior to NF placement, the caregivers have for the most part kept similar caregiving roles with some small modifications. The eight family caregivers have continued seeing the older adult as often as prior to a NF placement. The non-familial caregiver, despite less frequent formal visits to a NF, says that their role in caregiving still has not changed.

*It hasn’t changed any. It’s the same, she’s just living in a different place.*
(Cynthia, caregiver)
In addition to their roles lessening slightly, the caregivers reported a sense of assurance about NF placement due to the 24-hour coverage and supervision. For one caregiver this has allowed her to stay away for longer periods of time compared to the two years prior to the older adult going into a NF.

_I just know someone’s there 24 hours with her. And she still knows how to reach me by phone if she needs anything._ (Cindy, caregiver)

Just prior to their NF placement, eight of the nine older adults experienced a major health event. Four of these major health events involved broken bones, which resulted in the older adults’ reliance on the use of a wheelchair. The other older adults experienced pneumonia and heart problems, which again decreased their mobility requiring them to use a wheelchair and/or needing assistance from two people to get in and out of bed.

One older adult did not go to a NF as the result of her own major health event, but was admitted due to her caregiver’s need for surgery and recovery. The older adult needed a place to stay during the caregiver’s operation and recovery because she was living with her caregiver at the time. Following the caregiver’s recovery, the older adult continues to remain in the NF.

Due to the severity of health conditions that arose during these health incidents, the caregivers admitted that they were unable to handle the physical needs of the older adult.

_It was a little more than I could handle when she couldn’t walk._ (Mindy, caregiver)

_I knew that I couldn’t stay at home with her, she needed to be you know watched and I knew I wasn’t going to be able to do it._ (Barbara, caregiver)

The caregivers’ inability to care for the older adult at home for health reasons or personal choice was only one of the factors in the older adults’ placement in a NF.

Prior to a NF placement, many caregivers talked about the possibility of hiring 24-hour assistance for the older adult in order to keep them in the community. This did not appear to be a viable option for two primary reasons. The first reason was a sense that 24-hour care was equivalent to or more expensive than a NF.

_I figured it would cost just as much to have somebody at home as it was here [NF]. So, I decided I’d just as well stay here._ (Luella, older adult)

More importantly, it was seen as an unpredictable option due to dependability and availability of this kind of help. Caregivers reported that the option was ruled out because it puts the older adult at risk of being without care and this would be a worry and source of stress for the caregiver. The nursing facility is seen as more reliable when there is extensive need for care. One individual stated that
It is almost impossible to hire qualified people there that you could depend on.
(James, caregiver)

The necessities of 24-hour care, the costs of the service and/or the unpredictability in the service were only a few of several reasons older adults went into a NF instead of staying in the community. Caregiver burden is another important factor that influenced the decision to enter a NF.

**Caregiver burden**

Few caregivers reported a sense that they were feeling burdened by their responsibilities and roles undertaken on behalf of the older adult. One individual reported that this burden, which was present prior to the NF placement, did not lessen following the older adults’ NF placement. There was a sense that she was unappreciated and had feelings of guilt associated with not being able to do enough as well as for the fact that the older adult was in a NF.

*It’s total guilt-laden, I just uh have so much guilt that uh, I have my independent strong-willed Mother in a nursing home and she is so – praise the Lord – her mind is so strong and vibrant still but her body is to the point where she can’t continue as she used to. I think I worry almost constantly about her mental frustrations of being in the nursing home. And there again I think it falls into guilt.* (Barbara, caregiver)

*Is it going to be 20 percent with that person, you know you can’t ever put a percentage on it because you have no idea until you live it what is the need.* (Barbara, caregiver)

Barbara’s mother had a sense that her daughter might be stressed in her role as the caregiver. The mother reported that Barbara also felt obligated to care for the older adult’s sister and brother-in-law that moved into the same NF. The older adult reported that her daughter often was aggravated with her during this caregiving role.

*She gets aggravated with me once in a while but that’s understandable.* (Margaret, older adult)

Another caregiver expressed his burden in caregiving, which occurred across state boundaries prior to his mother-in-law’s placement in a NF.

*It wasn’t easy and I would say it was stressful yes. Uh, because we knew she was a long ways away, things had to be done and we had to forget about some of the things that we ordinarily would be thinking about to go and take care of ’em.* (Stephen, caregiver)

Two caregivers reported that they have health conditions that began after they started caregiving.
I don’t see any difference in my health I mean I think I’ve put weight on but not my health. (Barbara, caregiver)

I’ve gotten diabetes in the last two years and high blood pressure. But it runs in my family. But I’m sure the added stress contributed to that. (Cindy, caregiver)

Cindy reported that despite her developing health condition and exhaustion caused by the work, she is glad that she can help as a caregiver. She reported that she sought out methods of relieving stress such as aquacise, tai chi, and yoga in order to avoid burnout.

I’m glad I can help her and I’m glad I can do it. (Cindy, caregiver)

Other caregivers also reported taking care of themselves both currently and prior to a NF.

I’d see to it I’d get my rest. I’d rest during the day. And go places. (Marlene, caregiver)

Although some caregivers report feelings of burden, there are other caregivers that have emotions that deviate from that. One caregiver reports her feeling of being lucky due to the older adult’s placement in a NF.

I do realize how lucky I am because I have friends that, friends my age who’s parents will not leave their homes and should leave their homes because they’re not able to care for themselves. I’m more at ease because there’s people there that are always available to him. (Sandra, caregiver)

Both prior to a NF placement and following a NF placement, other caregivers felt that they were easily able to complete the tasks involved with caregiving and it did not interfere with their lives in negative ways.

I did not mind it, I did what I could to help out. (James, caregiver)

Along with caregivers expressing burden due to the caregiving experience, older adults also expressed their desire not to be a burden on the caregiver. Three older adults mentioned their desire to avoid being a burden to their children. They didn’t want to add stress to their children’s lives because they were not used to it. This is instrumental for some older adults in their willingness to live in a NF.

This is the best place for me. I prefer to be here cause I don’t want to put a burden on my kids. That wouldn’t set right with me. (Edward, older adult)

[I] began to believe or think that I was a burden on my family and I kind of felt maybe it better if I came down here. (Margaret, older adult)
I was always satisfied to live at home because I was able to do things there with Anthony's help. After I couldn't do anything, I felt what's the use of burdening him? (Luella, older adult)

**Participation in health and caregiving**

An older adults’ placement in a NF was often prolonged by the elders’ participation in their health and the caregivers’ role in the relationship. The older adults’ ability to remain in the community was extended due to a variety of factors such as the reciprocal care between older adults and their caregivers, older adults’ participation in self-care, the older adults’ and caregivers’ perception of the older adults’ health and needs and the mobilization of services by older adults and their caregivers.

**Reciprocal care between the older adult and caregiver**

One of the important features in the older adult-caregiver dyads is the reciprocal nature of the relationship. Although the older adult received a greater measure of physical care and assistance from the caregiver, there are social and emotional features that enhance or diminish the relationship for both the older adult and the caregiver. One example is the degree to which older adults express appreciation for what the caregiver does for the older adult. One caregiver expressed her disappointment for not receiving thanks for her caregiving efforts.

[I feel] unappreciated and I think that's selfish. I wanted to be there for her but she is such a strong willed woman that I've always you know like I said tried to keep her independent and if she's going to do something she’s going to do it her way anyway no matter how you would talk about it, share about it and uh, keep her informed of what’s going on. (Barbara, caregiver)

The reciprocal nature of the relationship is best stated in these quotes by one older adult-caregiver dyad.

*I appreciate everything.* (Mabel, older adult)

*She appreciates everything.* (Cindy, caregiver)

The social needs of older adults and caregivers are also important, which is basic and true for all human relationships. One caregiver who resided with the older adult prior to a NF reported her loneliness due to her sister’s absence in her home.

*I still miss her and I have her come here once a week and then we see her on the weekends. I always look forward to have her visit me. What’s more, I call her every day about suppertime. Every day I get in touch with her.* (Marlene, caregiver)

One older adult-caregiver dyad expressed that there was a mutual feeling that the relationship improved due to their increased role with each other. The older adult had moved to the same town as her sister so that they would be near each other. The caregiver described part of her
typical day with the older adult as “mainly just visiting and being friends.” (Mindy, caregiver) She describes the closer friendship that has formed.

We’ve become very good friends and got to know each other much better. (Mindy, caregiver)

The older adult also expressed that the caregiver is very important to her.

I couldn’t live without her, she’s my confidant. (Helen, older adult)

Another caregiver mentioned that her mother wanted to have her friends do some housework for the older adult, but the caregiver refused and instead hired a housekeeper. This allowed the friends the opportunity to come visit her and provide her social support without being the caregivers as well as providing some relief to the daughter.

She didn’t want that [housekeeper] because it cost money. I just told her it would help me and she thought her friends could do it for her and I told her I would like her friends to come over and visit as a friend and not to have to clean for her and do things like that. (Cindy, caregiver)

Finally, one caregiver provided the most important and salient reflective comment when he said:

I think that people [who] are involved just [need to] remember that some day we [will] be old too. (Stephen, caregiver)

Self-care

Older adults that reside in a NF related their experience of being active and involved in health, social activities and hobbies both before and after the admission to a NF. Although some individuals are not as active in some areas, there is a sense that some attempt to continue their life as they enter a NF.

Caregivers reported that older adults actively participated in their health by going to the doctor regularly, taking vitamins, eating well and physical and mental exercise. One older adult felt that regular doctor’s visits were important. Her caregiver explains the mother’s frequency of doctor’s visits.

I’d say she’s not happy if she doesn’t go to the doctor once a week! Yeah, she goes to the doctor a lot. (James, caregiver)

One older adult takes natural herbs and vitamins in order to remain healthy; also she drove to the masseuse once a month until she was 86. One caregiver reported that the older adult had to eat balanced meals and that there was no snacking between the meals. Two older adults and two caregivers also mentioned that the older adult exercised or kept an active lifestyle, though another caregiver reported that due to health conditions exercise was not feasible. Another
element of health that was emphasized by one older adult and one caregiver was mental health. The older adult found a way to use her mind regularly so that she could maintain functioning.

*We’ll go to lectures and talks all the time so I can keep up with them. Of course they encourage you to do that.* (Helen, older adult)

One caregiver explained that the NF was a good place for people to live because of the mental stimulation.

*Nursing home care...keeps their minds busy.* (Sandra, caregiver)

Beyond caring for one’s health, older adults in a NF were also very connected to church, neighbors and other social supports. For all of the older adults, living in a NF has not affected their social activities to a great extent compared to prior to a NF. Permanent non-diverted NF residents have maintained their connections with the people outside of the NF, including both family, friends and for some church.

One older adult was able to remain connected to her church through the use of her phone. She has her own phone in the room and listens to the church service on the speakerphone. Her caregiver explains her phone use.

*Her telephone is her line to the outside world.* (James, caregiver)

Mabel indicated that her active social life has not changed much since moving into the NF. Her daughter still visits daily and her friends and people from church make regular visits to her in the NF. Another older adult who lived in an apartment under the same management of the NF explained that he would daily eat lunch in the NF and he would visit people when he came over for the meal. Now he is in the same building as many of his friends.

*I’m talking to somebody every day.* (Edward, older adult)

Three older adults reported that they were still doing their hobbies in a NF. Margaret was able to bring outdoor plants and plant them outside her window. She still cares for the plants herself. In another instance, Nancy sews, crochets, embroiders and has a pen pal. She was currently working on afghans that she will give to her great grandchildren. Marlene brings her sister, Shirley, home once a week to help her make noodles because Shirley has always enjoyed that task. Edward continues to consult with the person renting his farm so he can stay updated about how the crops and weather are during the year. Luella enjoys playing Bingo at the NF and gives the prizes she wins to her grandchildren when they visit.

Two older adults reported that they have either lost interest in their hobbies or are unable to do them due to physical limitations. One older adult used to draw, but does not do that any more.

*I’d like to do some more drawing before I go but I doubt if I do it. Kind of lost interest in it.* (Helen, older adult)
Another individual used to read, but now her eyesight if failing and she is unable to read anymore. One caregiver also mentioned that due to the older adult’s declining eyesight, she is no longer able to make quilts or afghans, which was common for her only a few years prior.

Although older adults are residing in a NF, they generally still have and participate in some of their own health and previous interests instead of becoming isolated. However, there were also two individuals that spent the majority of their time in their room due to their desire to not be in a NF.

**Perception of health and needs**

At the time of placement in a NF, both older adults and their caregivers had a sense that the older adults’ health was bad. Eight older adults had recently suffered a severe health event that required increased assistance, such as broken bones, pneumonia, and heart complications. Despite the agreement between caregivers and older adults at the time of placement, there was some degree of variance between the two perspectives of health leading up to the time when the older adult had a major health event.

In one instance, there is a real dichotomy between how the older adult perceived her health and need for caregiving as compared to her caregiving daughter’s perception of the health and need. The older adult, Mabel, reported that she was very independent prior to her fall. She reported that she did not have to ask others for assistance prior to her NF stay because she was able to do everything on her own.

*I could do anything. I never stumbled over anything or nothing. If I needed [something], I’d go get it.* (Mabel, older adult)

The caregiver in this dyad reported the situation completely different. Cindy mentioned that the older adult had frequent falls at home as well as required the ambulance to come and lift her off the floor several times.

*We did everything for her.* (Cindy, caregiver)

Cindy reported spending 8-16 hours per day with her mother providing care, yet her mother did not indicate that there was any need from her daughter for care.

**Mobilization of resources**

Prior to a NF placement, older adults with the assistance of their caregivers adapted their lifestyle, home and at times their neighborhood in order to remain in the community as long as feasible. Through the use of walking equipment, home adjustments and utilization of neighbors, there was an attempt to keep the older adult functioning in the community.

While living in the community, these older adults used canes, walkers, and wheelchairs in order to access greater mobility. Four older adult caregiver dyads reported that the older adult had used a cane as well as five older adults used a walker. Another way older adults tried to remain
autonomous was to make adjustments to their homes. One caregiver in particular got a lift for the older adult to get in and out of the house due to the older adult’s inability to maneuver steps. This caregiver also adjusted the height of the microwave in the kitchen to make it feasible for the older adult to continue to cook her own meals.

_We kept the microwave in a different position in the kitchen so she’d never have to carry a dish to the microwave._ (Cindy, caregiver)

Another caregiver discussed the adjustments made to the older adult’s bathroom including grab bars that allowed the older adult to get in and out of the bathtub and a toilet seat riser on the stool that raised it.

Neighbors could also be utilized as a means of staying in the community. One older adult set up a system with the neighbor so that when they both woke up, they would open their blinds to indicate that they were okay. When the blinds remained closed, the neighbor knew that the older adult was in need of assistance. Additionally, one caregiver mentioned that the older adult had neighbors check in on her periodically and that prior to the older adult’s admission to a NF, she was able to reside with the neighbor while arrangements were made.

Older adults and caregivers found formal supports useful in remaining in the community. Of the older adults interviewed, five had a homemaker to clean their homes and some cooked meals as well. Six older adults utilized home health services or a bath aide at some point. Two older adults utilized Meals On Wheels, additionally two older adults ate their noon meal in the NF of the CCRC where they lived. Lifeline was also seen as very useful for both older adults and caregivers in order to ensure a quick response when the older adult was in need.

Although all of the older adults had at least one formal service prior to entering a NF, only two older adult-caregiver dyads mentioned a case manager or the AAA. Cindy and Mabel both reported that the case manager visited with them prior to the NF placement. Mabel could not recount any specifics about the meeting with the case manager except that she remembers telling them that she wanted to go home. Her daughter, Cindy, reported that the case manager did a great job facilitating a discussion between the daughter and older adult, even though Mabel was resistant to going to the NF.

_She did a very good job. I was very impressed with her. She made it a positive experience._ (Cindy, caregiver)

Anthony also mentioned he and Luella used the AAA when setting up services for a bath aide. Although the AAA set up the service, he got tired of what he termed the “runaround” he experienced with the AAA and decided to hire someone independently.

Other older adults in the NF and their caregivers reported the lack of connection with outside sources. It was apparent through the caregivers’ perspective that the dyad had to already know about the services or seek out services on their own often without finding the resources and services that they need.
I guess the caregiver would have to search out those resources for themselves but there not just right there visible.

Nobody made any contact with us in that, with that – nobody made any contact with me to let me know what was available. (Barbara, caregiver)

One caregiver talked about how he had hired a couple of people that he knew from town to provide housekeeping and bathing services for his mother. He also was the person that contacted the assisted living and a NF when his mother was admitted to the NF.

I made that connection myself. (James, caregiver)

Another caregiver reported that the services she knew about from working in the hospital setting helped her to find needed services. Finally, one caregiver said that she utilized a nurse in the community for information.

I’ve got a connection about all the resources, a nurse in the community. (Cindy, caregiver)

In one instance, the caregiver reported that they had searched the internet for resources related to caring for an older adult.

**Perception of the NF following a year of residence**

For many, the NF is a situation that people want to avoid until it is absolutely necessary, yet after residing at the NF for a period of a year, caregivers and older adults reported that they were pleased with the NF and did not mind living there. Although both older adults and caregivers reported their like of the NF, the caregivers reported it more frequently than the older adult.

I’ve been here a year and don’t have a day of complaint. I’m happy with my arrangements and the nurses are okay. (Nancy, older adult)

Nursing home care is not the disaster that a lot of people think it is. Um, just the interaction with the nurses and the aides, I think is good for these people. I mean the social aspect beyond the care they get, I think is a major plus because you can’t be there all the time for them. (Sandra, caregiver)

We have been very pleased with the nursing home and the care she has received up there. They have done an excellent job. (James, caregiver)

For others, they were not satisfied with living in the NF; for some older adults, they expressed their anger and feelings of depression because they did not want to live in a NF. One older adult expressed her dissatisfaction with placement in the NF and due to being in a NF she had no personal hopes and goals for the future.
I don’t want to be in here all the time. I just feel like, I just want out of here.
(Margaret, older adult)

Another older adult was very angry about her NF placement because she does not want to be in a NF.

I don’t have experiences here. I eat breakfast, lunch and dinner. (Lillian, older adult)

One older adult expressed her desire to go home, despite the NF being an acceptable place. The NF placement is just not like home and that is what she wants instead of a NF.

This is a nice place. I have no complaints really, other than it’s not like home. I’d love to go home. (Mabel, older adult)

Recently admitted older adults to a NF without caregivers

As noted earlier, one male older adult did not have a caregiver. He was single and lived alone prior to entering the NF. He reported that he had been his mother’s primary caregiver until her death and he had been financially and instrumentally helpful to his younger sister. As a result of a fall at home that caused a fractured lower limb, this older adult was hospitalized and subsequently admitted to a NF for rehab.

The absence of a caregiver or a confidant to discuss returning home and helping to make arrangements has possibly resulted in his continued stay in the NF. For instance, he would go to his home for a few hours one time per week and sometimes even spend the night. He admitted he could care for himself and when asked the reason for his continued stay in the NF, he did not give a reason.

I’ve been discharged from here. All I need to do is pick up and go home. But I haven’t got that brave yet. (Andrew, older adult)

This statement made by the older adult highlights the feelings of being scared or reluctant to return to an environment. He was not the only older adult that mentioned his insecurity in living at home without supports and assistance. This older adult did not provide information in the interview that would contradict or provide additional insight to the research questions.

Summary of recently admitted NF findings

The older adult-caregiver dyads represented in this analysis provided a brief look at the reasons people are admitted to a NF and continue residing there. The decision to enter a NF is often a lengthy process due to the lack of desire to go. Yet, when a health care professional recommended a NF, many portrayed a sense of passivity and agreement with the doctor. Prior to entering a NF, caregiving dyads made home modifications, used neighbors and formal services as well as relying on the caregiver for increased support. The majority of caregivers in this sample provided instrumental assistance for the older adults. There was a mix between those
that felt reciprocity in their relationship and those that did not, which was one factor in the presence or absence of caregiver burden, a barrier to community tenure.

Prior to a NF placement, many older adults were very active in their physical health as well as social health. When entering a NF, older adults continued to remain active unless prevented by health factors. The health of the older adult at the point of admission to a NF was poor as described by both the older adult and caregiver. Most of the older adults experienced a major health event right before entering a NF, which often compounded upon more chronic health problems. Some caregiving dyads considered 24-hour care in order to keep the older adult at home, but there were barriers to this possibility. Only a few dyadic pairs mentioned case management, most older adults and caregivers expressed the need to be able to look for their own resources.

Although financial factors did not seem to hinder community tenure, it was an indicator of the need to remain in a NF despite improved health conditions. Also, the lack of explicit communication about entering and leaving the NF was another area that affected the older adults ability to remain in or return to the community. Following a year of placement in a NF, there were differences in the older adults’ desire to remain in the NF. For some the NF had become an acceptable place to live, though others desired the ability to leave the NF and return to the community.

c) Comparative analysis of diverted and non-diverted groups.

Decision to remain in the NF or return to the community

Older adults entered a NF because of a major health problem; however the older adult and caregiver dyads had two different expectations of the outcome. For instance, some older adults and caregivers did not anticipate the older adults would improve enough to discharge from the NF. Other older adults (and caregivers) entered a NF with the understanding that they were simply going to recover from their illness and return home. For these older adults that use a NF for recovery, it is important to reflect on the communication that was going on when the older adult entered the facility as well as continued communication about going home. The lack of explicit communication about going home and negotiation regarding roles and what the caregiver and older adult are willing and/or able to do in order to remain at home were important factors in the decision to keep the older adult in the NF versus returning to the community. The impact of others on the older adults’ perception of their own ability to remain in the community was instrumental in the older adult-caregiver decision around a NF placement and discharge. Caregivers, family members, physicians and other health care providers’ opinions about the older adults’ ability to live in the community could negatively impact older adults who felt they were able to return or remain at home. Often older adults would follow the caregiver and physician’s advice while disregarding their own thoughts because they did not think they could live in the community alone without supports.

For recently diverted older adults in the community, the NF was a place where the older adult could rehabilitate from their recent health problems. However the decision to return to the
community versus permanent placement in a NF was based on the older adult’s strong resistance to a NF placement, and explicit communication and understanding of this resistance to a NF placement was made clear to family members, physicians, case managers, and caregivers. After the older adult made the decision to return to the community, they negotiated with caregivers, service providers, or family members about what their needs were, and whether or not their needs would be met. Even with potential resistance from some of these people, the older adults in the community were able to live in the community due to their own determination and the support of some major players in their care, not necessarily all.

Need for more assistance and personal caregiving

Older adults who entered a NF lacked a caregiver network, or needed more hands-on personal caregiving than was being provided. Caregivers of older adults in a NF typically performed instrumental tasks for the older adults including such things as cooking meals, paying bills and shopping. Although they were generally willing to provide some forms of instrumental assistance, they were unwilling or not able to provide as much caregiving as the older adult needed due to the older adults’ decreased mobility following a major health event. At the time of the CARE Assessment, most of the older adults became dependent on a wheelchair or needed the assistance of two people to transfer due to broken bones or another health problem. With their decreased mobility, the older adults needed a drastic increase in care, which some caregivers could not or did not want to provide.

Older adults who remained in the community had either a familial or paid caregiver who provided as much assistance as the older adult needed. When the older adult needed more assistance, they either sought out the assistance themselves, or the caregiver helped to find more services for the older adult. Several of the older adults were able to perform self-care tasks, such as exercising or seeking out social activities. Other older adults utilized and mobilized services that would benefit their health. For example, all of the recently diverted older adults used a walker, and several used a wheelchair in a limited capacity. However, when they needed more help with their mobility, they received assistance from their caregiver.

Awareness of services

Some older adults who entered a NF were not familiar with service agencies that may or may not be able to provide services to the older adult. Some had connections in the community to certain services, but this was not comprehensive knowledge that allowed the older adults and caregivers’ access to all the services needed and available. Other older adults might have been aware of services, but did not perceive how these services could be beneficial in keeping the older adult in the community as opposed to a NF. This was illustrated by the fact that only two of the older adults interviewed in a NF could think of services that might have helped them remain in the community. The other older adults felt that no services would have been beneficial because they were too independent, yet these older adults all had some level of services at the point of a NF placement. Finally, there were older adults who contacted service agencies for assistance, yet did not find it helpful in obtaining services.
Recently diverted older adults in the community dealt with the same issues of service awareness. While a few older adults in the community reported a strong relationship with a case manager, or a service provider such as an AAA, KDOA, or a senior center, several of the recently diverted older adults reported they either had little communication with their case manager, or simply were not aware of available services. While older adults did not experience a strong connection with community service providers, the older adults in the community were better able to remain in the community compared to those who entered a NF for several reasons. First, their care needs were not as great as those who entered NF. Second, in some instances, caregivers reported they were willing to manage community dwelling older adults care needs with limited or in some instances without formal services. This was accomplished through creative coping skills or informal services provided by friends or family.

2. Older adults who have remained in the community for 24 months or longer and their caregivers

This section provides descriptive details regarding long-term community tenure as represented by the CARE Assessment customers who were in the community for 24 months or longer and their caregivers. First, a table with the demographic description of the older adults and caregivers is provided. Then, a description of the older adult’s circumstances is presented to provide the background and the context for the CARE Assessment and the caregiving. Finally, findings from the interviews and selected quotes are presented in a format based on the policy related questions.

Older adults prefer to age in place rather than enter a more institutionalized and more costly setting, such as an assisted living or nursing facility. The elders whose situations are described in this section not only were diverted from nursing facility placement at the time of a CARE Assessment, but they have also remained in the community over time. Analysis of the data from this set of older adults and their caregivers sheds light on the creative coping and adaptation, negotiation of caregiving and care-receiving, and challenges associated with the provision of care in light of potential nursing facility placement.

Who was interviewed?

Seven older adults (three male and four female) who remained in the community long-term following their initial application to nursing home admission and their caregivers were interviewed. Four of the older adults experienced housing transitions following their application for nursing facility placement and two of the four moved twice. These transitions include a move to the town where an adult child lives, in one instance into the home of an adult child for a period of time, a move into low-income senior apartments, and one move into an assisted living facility. At the time of the interviews, three respondents lived in their own homes in the community, one resided in assisted living, and three lived in senior apartments (one of whom had been admitted to a hospital two weeks prior to the interview date and remained there at the time of the interview). Six of the seven caregivers live within 20 miles of the care recipients. As mentioned previously, the other caregiver moved his mother near him during an acute care need, but now she lives further away.
Five of the seven older adults returned to the community after a brief stay in a nursing facility while two returned to the community following hospital stays. For some respondents, the health problem precipitating application for nursing facility placement has since been resolved. However, all older adult respondents indicated that they experience some type of health challenges still today ranging from arthritis and heart disease to extreme low-vision and pervasive short-term memory problems.

Among the pairs, all but one of the caregivers is related to the older adult. Three caregivers are daughters, two are sons, one is the wife of a care-recipient and the paid caregiver is a home health aide. Both the non-related caregiver and one daughter are paid caregivers paid with private funds and as a self-directed caregiver through Home and Community-Based Services respectively. One family caregiver received specific training from health professionals and another family caregiver works as a healthcare provider. There is a wide range in the types and amounts of care provided by the identified caregivers. Caregiving experiences represented in this group include: 1) instances in which the caregiving is comprised of the multi-year provision of comprehensive care (i.e. assistance with multiple activities of daily living and instrumental activities of living); 2) instances in which the caregiving is comprised of assisting the older adult with small-scope assistance; and, 3) instances of intermittent provision of support (e.g. delivering groceries in inclement weather and occasional telephone contact). Table 13 gives selected demographic information about this group.
### Table 13
Demographic Characteristics of Long Term Community Dwelling CARE Assessment Customers and Their Caregivers

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Older Adults</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=10</td>
<td>N=9</td>
</tr>
<tr>
<td>Age</td>
<td>Average Age: 84</td>
<td>Average Age: 62.75</td>
</tr>
<tr>
<td></td>
<td>Age Range: 72-98</td>
<td>Age Range: 43-80</td>
</tr>
<tr>
<td>Gender</td>
<td>Females: 7</td>
<td>Females: 5</td>
</tr>
<tr>
<td></td>
<td>Males: 3</td>
<td>Males: 4</td>
</tr>
<tr>
<td>Race</td>
<td>Caucasian: 7</td>
<td>Caucasian: 9</td>
</tr>
<tr>
<td></td>
<td>Unknown: 3</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
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<td>Single: 0</td>
</tr>
<tr>
<td></td>
<td>Married: 1</td>
<td>Married: 7</td>
</tr>
<tr>
<td></td>
<td>Widowed: 7</td>
<td>Widowed: 0</td>
</tr>
<tr>
<td></td>
<td>Divorced: 2</td>
<td>Divorced: 2</td>
</tr>
<tr>
<td>Caregiver Relationship to the Older Adult</td>
<td>Not Applicable</td>
<td>Child: 6 (Daughter = 3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Spouse: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other relative: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Non-related: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No caregiver: 2</td>
</tr>
<tr>
<td>Urban/Rural Residence of the Older Adults*</td>
<td>1: 3</td>
<td>Not Applicable</td>
</tr>
<tr>
<td></td>
<td>2: 2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3: 0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4: 4</td>
<td></td>
</tr>
<tr>
<td>Income Level (Monthly)</td>
<td>&lt; $738: 2</td>
<td>Not Applicable</td>
</tr>
<tr>
<td></td>
<td>$739-1130: 2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; $1130: 2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unknown: 4</td>
<td></td>
</tr>
<tr>
<td>Does caregiver work outside the home?</td>
<td>Not Applicable</td>
<td>Works full-time: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Works part-time: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Doesn’t work: 7</td>
</tr>
</tbody>
</table>

*The legend below explains the classification of urban-rural used:
1 Urban* Country (1,2)
2 Adjacent to an Urban Area with a city of at least 10,000 (3,5)
3 Adjacent to an Urban Area without a city of 10,000 (4,6)
4 Not adjacent to an Urban Area (7,8,9)

*Used Urban as equal to Metro
**Brief narrative description of the older adult’s situation (care recipients are denoted with an asterisk)**

**Gregory* & Gloria**
Gregory lives in senior congregate housing apartments. Gloria, who describes herself and is described by Gregory as a housekeeper, is Gregory’s paid caregiver. Gloria has worked as his housekeeper for approximately two years. While the care Gloria typically provides is limited to housekeeping, she describes having a strong emotional attachment to Gregory.

**Marian* & Melanie / Carrie**
Marian is cared for by her two daughters. Marian moved from her very rural home to an apartment in the town where Melanie lives. Carrie drives approximately twenty miles several times a week to share caregiving duties with Melanie. Together, Marian’s daughters provide daily care for Marian. Over the last six years Marian’s care needs have increased. She is vehemently opposed to nursing facility placement and opposed to receiving care from someone other than her daughters.

**Walt* & Beverly**
Beverly first provided care for her husband Walt following a work-related accident that prompted the CARE Assessment. Since that time Walt has had other health problems that precipitated additional decision points for the couple regarding caregiving, home care, and nursing facility placement. Notably, Walt has also provided care to Beverly during two episodes of poor health in the time following his CARE Assessment.

**Esther* & Debra**
Esther identified Debra as her primary caregiver at the time of the CARE Assessment. Upon Esther’s discharge from the nursing facility (following an acute health problem), Debra made arrangements for Esther to receive paid care services in her home. At the time of the interview Debra says that she provides little care for her mother other than help with errands.

**Anna* & Fred**
Anna’s son Fred helped make arrangements for nursing facility care for her following an acute health problem. Subsequently, he assisted her in finding temporary housing near his home and was able to check on her and provide incidental assistance. When she felt able and when the temporary living situation came to a close, Anna returned to her rural home many miles from Fred. At the time of interview, the care he provided was strictly emotional.

**Harvey* & Steve**
As Harvey experienced increasing health problems, his son Steve provided assistance though he lived in a separate town. However, when this became cumbersome, Harvey moved from his home to live with Steve and his family. Both Harvey and Steve acknowledge challenges associated with this situation. Steve looked for and found an assisted living facility into which he vigorously encouraged Harvey to move. Currently Steve provides assistance to Harvey with transportation and emotional support.
Susan* & Rachael

Susan lives in congregate senior apartments and receives care from her daughter Rachael who is paid for the care she provides by the State of Kansas. Rachael routinely cares for her mother’s needs stopping by at least once per day. She helps with meal preparation, making financial transactions, bathing and a number of other tasks. Rachael is currently wrestling with the decision to continue providing care as she has a number of other life commitments.

Martha*

Martha lives independently in the community and has a very strong desire to avoid placement in a nursing facility. She relies on family, friends, and a number of formal services that enable her to live on her own. Notably, near the end of the interview, she expressed concern that the interviewer may, in some way, be able to influence that outcome based on the interview. It is likely that her concern about this colored her responses.

Jennifer*

Jennifer lives in an apartment complex for older adults that provides services similar to an assisted living facility. She identifies her son as her primary caregiver even though he lives out of state. Jennifer has most of her needs taken care-of by the apartment complex. She receives additional care, such as house cleaning and cooking, from a paid assistant. Jennifer is very active and believes that her social engagements are key to her ability to live on her own.

Ellen*

Ellen is able to continue living independently and does not rely on formal services for assistance. She is very motivated to remain at home, and she is committed to staying healthy by eating right and exercising. Ellen identifies her social and faith communities as being the most important structures in her life.

Alex

Alex was the last remaining relative to his cousin, Lola, and thus became her primary caregiver. Lola lived in Assisted Living before she died 2 weeks before the interview was conducted. Alex provides primarily emotional support to Lola, and he feels that the support is reciprocal. Alex is very committed to caregiving and feels that his life would not be fulfilled if he was not able to care for others.

Sam

Sam is a caregiver for his mother, Wanda. He lives 250 miles from her and provides primarily emotional support. Wanda has heart valve problems that have had life-threatening effects for her. She had two short visits to a nursing facility, but she now lives at home with the help of a nurse who visits regularly. Wanda is very motivated to live on her own. She also relies on several formal services, but Sam believes that the social supports of the small town have been the most important influence in her ability to live at home.
Strategies used to remain in the community

Long-term diverted older adults and their caregivers used a number of strategies in order to remain in the community, as opposed to entering a nursing facility for care. These strategies, discussed below, include:

- the determination to remain in the community,
- creative coping and adaptation skills,
- use of formal services and informal services, and
- reciprocal care between older adults and their caregivers.

Determination to remain in the community

Five of the seven older adults experienced short-term nursing facility placement before returning to the community following the health event that led to application for nursing facility admission. Of those five only two noted having a relatively positive experiences in the nursing facility (one of whom spent only a few days in the NF).

*This nursing home was real nice. Most of all the ladies were how do I want to say they weren’t quite have their minds. So I got special attention because I suppose I still had my mind. That’s a good a very good place. I’d recommend it to anybody.* (Anna, older adult)

*And they were awful nice people over there. And they worked toward me coming home.* (Esther, older adult)

More often, respondents indicated a strong desire to avoid nursing facility placement. The wish to age in place expressed by most participants is common among older adults (Dobbs et al., 2002). When both the older adult respondent and her/his caregiver shared this commitment, their mutual efforts supported the maintenance of community tenure. Walt and his caregiver Beverly, his wife, provide a powerful example:

*It was, it was tough to put him in there because I had promised him I’d never put him in the nursing home, it would just have to be the last resort. And I just, oh it just broke my heart to even think put him out there just for a couple weeks…It just makes you feel so guilty putting them in there even though it's for their own good and the doctor has ordered and everything. Just, and they fight and they turn against you and everything you know and uh, so we sort of promised each other that as long as we were able and had the, the uh presence of mind to do it we'd take care of each other at home. And not depend on our children or anybody else - the nursing home would have to be the very last resort.* (Beverly, caregiver)

Marian expressed great distaste regarding nursing facility placement. Her caregivers, her two daughters, indicated a clear understanding of her wishes and a commitment to honor their mother’s position.
She has consistently told us ‘I hope I never have to go to the nursing home, I hope I’m never in a nursing home’, and I think this has made it more difficult knowing how she felt. (Melanie and Carrie, caregivers)

One caregiver, Rachael, described her impressions that her mother did not experience success in the nursing facility; but rather that it was a negative experience for her. This understanding on the part of the caregiver then fuels the caregiver’s commitment to care for her mother in the community.

*I don’t think she’d last if she’d go to a nursing home. That three-week period when she was in a nursing home she totally isolated herself.* (Rachael, caregiver)

In some cases, the older adult and her/his caregiver differed in their commitment to community tenure. While Anna stated that she had a good experience in the nursing facility, her son Fred recounted the experience, as one that Anna strongly disliked, stating that her preference was to return to live independently.

*When she was at the rehab center she says, ‘get me out of here there is too many old people here.’* (Fred, caregiver)

Another case in which there were disparate views of nursing facility care was exemplified in Esther and Debra’s stories. While Esther noted that she did not mind the nursing facility she later stated that she preferred to live in her own home, receiving care at home if necessary. However, Debra, Esther’s daughter, advocated that her mother Esther return to facility care following what she believed to be a premature discharge. Debra cited her own inability to manage Esther’s care needs as the rationale for preferring that Esther remain in placement.

*Because we could see it was not going to work. Because I couldn't lift her; she couldn't get up at all. My aunt was over, and between the two of us, it took both of us to help lift her up, because she didn't have the strength to do it herself... And I was still working at the time, too. So that made a lot of difference there, because I was going to be at work all day. And there was no way she could spend nights by herself... We didn't really have a choice.* (Debra, caregiver)

*I was up in my room walking with the walker and the doctor and this nurse came in. And he says, "Well, it looks like you're about ready to go home." And I said, "Yeah." And he just dismissed me. Oh, I tell you, Debra was upset... And I knew I wasn't ready to come home. But he dismissed me, what are you going to do? So Debra called him on the phone and got onto him. And he let me go back. But I was home a day and a night. And then I was back in the hospital for a day and a night. And Debra told me, "You're probably going to have to go to the nursing home." And I said, "OK." It didn't bother me a bit to go.* (Esther, older adult)

Notably, Debra describes the care she provides at the time of the interview as minimal, with Esther’s direct care, such as house cleaning, being provided by a formal service. It is possible, given Debra’s statements about both nursing facility care and her own disinterest in providing
care for her mother, that if Esther’s care needs were to increase that she would have nursing facility care as her only option.

Respondent narratives revealed an overarching theme of awareness, on the part to the older adults, that nursing facility placement may be something that they would experience at some point in their lives. One respondent who had not been to a NF after the CARE Assessment stated resolutely that if he were not able to receive assistance from his caregiver (housekeeper) that he would “probably go to a nursing home” (Gregory, older adult).

_The Nursing Facility may be where we'll have to go... you know but it has to be the last answer._ (Walt, older adult)

_She’ll say, “You know, you may have to put me some place [indicating a nursing home]. ”_ (Rachael, caregiver)

_I'd say as long as he could walk, he will not go [to the Nursing Facility]. _ (Gloria, caregiver)

**Creative coping and adaptation skills**

Evidence of older adults’ functional abilities including coping and adaptation to physical health challenges, is linked with community tenure (Miller, Longino et al. 1999). A number of the older adult respondents indicated that they persisted in accomplishing tasks associated with daily living despite needing to do them more slowly or in new ways. Gregory proudly recounted that he is able to bathe himself and change into clean clothes every other day. The following exemplars show ways that older adult respondents perform household tasks and manage their personal care needs.

_So far, I've took care of myself pretty well... I do my own washing and do my own dishes and cooking... I pick up the papers and trash out of here. Carry my dishes into the sink and wash them out or whatever needs to be done. I will wash and hang my clothes up._ (Esther, older adult)

_[Gregory] vacuums every once in awhile._ (Gloria, caregiver)

_I can give myself a sponge bath and I don't have to get my whole body a sponge bath everyday._ (Anna, older adult)

_[Esther] does her cooking and she used Meals on Wheels for a while until she felt like she could do it herself._ (Debra, caregiver)

_I do my own washing and do my own dishes and cooking._ (Esther, older adult)

_[Gregory] lives a block and half away from his heart doctor. And if he's not feeling good or if he knows something's wrong, he'll just walk right down there and they'll get him in._ (Gloria, caregiver)
In addition to accomplishing daily tasks older respondents also demonstrated remarkable and creative approaches to problem solving and the implementation of coping strategies. Gregory “can’t drive anymore” yet he keeps his car and maintains vehicle insurance as he allows other residents in the assisted living facility to drive his vehicle when they help him run errands.

Anna’s narrative revealed multiple instances of creative problem solving and resource management.

\[ I \text{ get Meals-on-Wheels and ugh I usually have enough meat and stuff left that I can keep it and you can use it for Saturday and Sunday then for a sandwich.} \]

(Anna, older adult)

She also describes having difficulty lifting items that are very heavy such as her bathroom garbage, comprised primarily of used protective undergarments. To manage this need, Anna has arranged two-part assistance from her neighbor and from a woman from her church. Notably, the woman from church originally agreed to perform a one-time only help. Over a year later, she continues to help Anna weekly.

\[ \text{She [the neighbor] puts it all together and garbage goes on Tuesdays and she brings it, comes over Monday evening and puts it all together and sets it here by the door. And Tuesday morning another lady [affiliated with Anna’s church], as she goes to work at 8:00, stops and picks it up, carries it out.} \]

(Anna, older adult)

Anna’s resolve is also demonstrated in the way she approaches adapting to her physical health challenges. Despite recommendations from healthcare professionals, Anna follows her self-knowledge of her body.

\[ \text{I lean over when I like when I was in the hospital with my heart, the lady kept pushing my back end to walk straighter. I said well my head wants to pull me back and I don’t feel safe. So I lean over and I don’t look good but then that’s the only safe way.} \]

(Anna, older adult)

In addition to the creative mobilization of resources as a demonstration of self-efficacy, respondents also worked to improve their situations. Esther provides a poignant account regarding her perception of her limitations and her pursuit of self-efficacy.

\[ \text{I used [a walker] for a couple of months... Then one of the old men up there, he talked to me. And he told me “that walker is just a habit.” He said, “If you try real hard, you can get off that walker.” Well the next time I went over there, I walked by myself. There’s benches setting along the hallway to get back to the elevator and I just walked and whenever I got tired, I’d sit down on one of those benches! Sit a little bit and get up and go again. And I made it on my own. And each time I went it got easier.} \]

(Esther, older adult)
Use of formal and informal services

Over half of the older adults routinely used formal services. The two most commonly used were Meals on Wheels and a “Lifeline” type service. Additional services used by the older respondents following the CARE assessment include housekeeping (3 respondents – one in assisted living) and assistance with personal care (3 respondents – one of whom no longer receives the service).

The Meals on Wheels did come by and he didn't know about that. And I said, "Get it. You're old enough, it's $2 a week, and you can well afford it." (Gloria, older adult)

I got a housekeeper she comes in twice a month... I take that Meals on Wheels, just one meal a day though. (Gregory, older adult)

Three years ago she had fell two or three times and she had used it [Lifeline-type service] because she couldn't get up of course and then when she got confused here just before she went to the hospital she had used it and they called us that she had called in. (Melanie and Carrie, caregivers)

The older adult respondents received a variety of caregiving services from their caregivers. Four respondents received relatively little care from their identified caregivers. Three of the identified caregivers currently give emotional support primarily and all helped to arrange for services at the time of the application for nursing facility placement. One lives a great distance away from the older adult.

I just don't feel like I'm a caregiver as someone who does a lot more stuff than I do...because I know some people have a lot more stress and a lot more to do than this. (Debra, caregiver)

[She lived] right next door...She wanted to go back to her home. She felt more comfortable in her own home. (Fred, caregiver)

Notably, two of the four caregivers provided substantial amounts of tangible assistance to the older adult earlier in the community tenure. The types of services the caregivers performed in these cases included (but were not limited to) assistance with bathing, meal preparation, and medication management. In one situation the predominant health concerns of the older adult resolved while the other older adult moved to assisted living, thus reducing his need for assistance from the identified caregiver.

So I kind of pressured him to the fact that as you get older, it's going to get more serious all the time. So we got him to move to Council Grove and he had a sale, sold everything at Smithville and moved to Pleasant Hill Apartments, it's a federally operated thing for senior citizens. And that's worked real well until September of this last year, then he had the last bout we had to do something different. So what I'm saying is over the time, we've kind of geared toward this. If
he had any trouble, we made sure we made a point that we need to be closer so we can do something different. (Steve, caregiver)

Conversely, two older adults received consistent and substantial assistance with activities of daily living and instrumental activities of daily living. Their caregivers, notably all daughters, provided this type of care increasingly over the last few years.

And to be real honest I don't think she could have stayed by herself for the last six years if we hadn't of been helping. (Melanie & Carrie, caregivers)

In addition to providing significant amounts of personal care for her mother Rachael also described her use of creativity in providing care. When her mother expresses sadness about her failings and memory problems Rachael will distract her with a more pleasant long-term memory.

So I’ll start and say, “Okay mom, what are some of those songs you used to sing when you were growing up?”, and she’d remember some...It just, I, something that, that you know, works to get her [away from feeling down about her situation]. (Rachael, caregiver)

Similarly, Gregory’s caregiver, Gloria, noted that she attends to his emotional well-being in addition to doing housework. While the scope of her paid work is small, Gloria has even accompanied Gregory on a trip to visit family. While her companionship likely involved the provision of care, she described the trip in terms of mutual benefit.

We spend Christmas Eve together. We were good buddies, good friends. (Gloria, caregiver)

Reciprocal care between older adults and their caregivers

While much of the gerontology literature focuses on the care needs of elders and the services provided by burdened caregivers, some scholars document reciprocity in the caregiving and care-receiving experience (Dwyer, Lee et all. 1994; Spaid, 1998). In the cases of two respondents, the caregivers receive pay for their services. The paid caregiver who is not related to the older adult asserts that providing care in the form predominantly of housekeeping is not stressful or burdensome. The caregiver who receives payment for caring for her mother describes working well beyond the amount of time for which she receives pay and experiences considerable stress from her caregiving role.

I spend a lot more time with her than I get paid for but that still helps to make it easier for me financially since I am spending so much time with her. (Rachael, caregiver)

Dwyer and colleagues (1994) assert that familial caregiving and care-receiving relationships are commonly considered within a framework of responsibility and delayed reciprocation for care provided by the older adult in the past. However, they note that for caregiving dyads in which the older adult is able to engage in some type of contemporary reciprocity that caregiver burden
is mitigated (Dwyer et al., 1994). Study participants described reciprocity in the caregiving experience through financial assistance, gratitude, and caring provided by the older adults.

Marian provides some financial remuneration to her daughters in order to ease the financial strain they incur in the course of providing care. Melanie noted that Marian gives money to Carrie to pay for her gasoline costs as she commutes to her mother’s home daily to provide assistance.

Mother had been very generous in giving us money the last few years you know too as far as that goes so you know. (Melanie and Carrie, caregiver)

Rachael describes a different type of reciprocity in her caregiving and care-receiving relationship with her mother. Despite inadequate pay for her caregiving services from the State, Rachael still finds satisfaction in providing the care.

She’s a very good encouragement to me. She’ll say to me, uh I know you’re tired. I know you don’t feel like being here right now, and I know. So there are times when she’s fully aware of my stresses. And she’ll say, why don’t you just go on home and, no we’ll do this now and then I’ll go home. So, she’s very supportive even in that. When I’m down. She can tell I’m exhausted sometimes and, and I just don’t even have enough energy to deal with, you know, some things. She’ll say, she’ll say something to me. She will see that. She’ll say, “Oh hone, I know you’re tired and you don’t have to stay here with me, you just go on home”, you know. And, no, I just, you know will stay for a while. And, and just, just that lifts me knowing that she’s there for me. She’s still there for me even when she doesn’t, you know, can’t remember other things. (Rachael, caregiver)

Walt and Beverly’s narrative presents unique information about reciprocal care. Not only does the caregiver describe her enjoyment in providing assistance to her husband but also their roles have reversed when she experienced illness two times following his application for nursing facility placement.

[Caring for Walt] I felt needed and I enjoyed doing it, felt sorry for him but uh yet at the same time I was so glad he was alive and here...I just couldn't do enough for him, I just wanted to do it you know. (Beverly, caregiver)

[Caring for Beverly] was a great pleasure to me, it was. It give me something to do, something to think about other then myself and I done whatever she wanted me to do. No, it didn't bother me. I've been through, I've taken five before you know, got burned. I've been through that nasty stuff. (Walt, older adult)
Participation in health and caregiving

Elders’ participation in caregiving and care-receiving

In the above sections many of the highlighted responses from older adults and their caregivers shed light on elders’ preference of avoiding nursing facility placement and their implementation of coping and adaptive strategies to realize their preference. In essence the preceding sections point to tangible behaviors that support elders’ desire to age in place such as negotiating immediate needs. Notably, the analysis of the caregiving and care-receiving narratives also revealed elements with distal connections to remaining in the community. These elements include elders’ participation in self-care, the elders’ and their caregivers’ understanding of the elders’ health situations and care needs, overarching attitudes of older adults about their situations, and elders’ participation in the mobilization of resources. These themes reflect somewhat more global processes than those described previously.

Self-care

Among the seven long-term community dwelling older adults who were interviewed, all indicated an awareness of their ability to influence their own health. In gerontology literature, self-care is linked in with prevention efforts for its potential to help reduce the incidence and or severity of disease and disability through direct prevention, early detection and treatment, and health enhancing practices.

Most noted that they visit their physician regularly and participate in primary prevention programming such as health screenings and influenza vaccinations. The use of home modifications assisted four of the older adults to function in their homes. The doorways and hallways were widened in Walt and Beverly’s home so that he could maneuver the wheelchair he used for a time after returning home from the hospital. Esther describes the living situation enhancing recommendations she received:

And they told me what to do to make the house safe. I had to get a riser for the toilet stool. And one of those seats you could slide in the shower. (Esther, older adult)

A number of older adult respondents engage in pro-health activities. The array of activities noted by respondents address physical health (e.g. exercise, routine medical screenings and immunizations), mental/cognitive health (e.g. reading, mental exercise games, and learning new skills such as computer skills) and social health (e.g. participating in social gatherings, maintaining friendships and volunteerism).

He says he walks on his treadmill, but I don't know. But I know he'll walk about a block a day. He doesn't sit there and look at four walls; he gets out and communicates with people. (Gloria, caregiver)
She does, uh, a couple of things to occupy her mind. She likes to read. She loves to read her paper and she will read other things, so I bring other things to her. She’ll read novels sometimes. Uh, she used to work crossword puzzles she watches TV and she plays old sol. She likes to play cards...and just go out and walk. (Rachael, caregiver)

She does have good vision so she can read and she likes to do these number puzzles and that kind of stuff. (Fred, caregiver)

My sister and I go shopping, we go around to the stores when I feel like it, when I don't hurt too bad. We go to Walgreen's and places. I have a computer. I have a sewing machine, I sew some, not much. (Esther, older adult)

We do lots of volunteer work...We're musicians and we play, we go down and entertain the Senior Citizen Center and...once in a while and I play at the church, the organ and the piano at the church...He's been such a hard worker and he just, he hates just sitting around with me in the house and giving him honey do things to do. (Beverly, caregiver)

Perception of health and needs

Older adult respondents were asked to rate their health overall in relationship to others their same age. Among those interviewed in this sub-sample 4 indicated that their health was good and 2 noted that their health was fair considering their existing health problems and one noted having poor health that had declined substantially over time. Anna reported the status of her health within the context of her existing health challenges: I’m doing ok as long as my heart don’t give out. (Anna, older adult) This global report does not necessarily correspond to an older adults health functioning or needs as it may reflect their perception of self and circumstances in addition to actual health problems. However, Idler, Hudson & Leventhal (1999) note that good self-appraised health is negatively associated with mortality.

The perceptions of the older adult respondents of their health and needs may also not match that of their caregivers. Underestimations could lead to a lack of understanding about the scope and intensity of caregiving whereas overestimations could lead to learned helplessness when more care than necessary is provided and/or risk for nursing facility placement when caregiving fails to meet the needs of the elder.

Melanie and Carrie described their caregiving regimen. It included multiple stops at Marian’s home throughout each day to care for her needs until such time as Marian experienced more acute needs requiring hospitalization. Despite her history of needing substantial daily care in her home and having needs that had increased to an even greater extent, when asked about the circumstances of her hospital admission Marian reported:

Well, I think I could have [stayed at home]. (Marian, older adult)
Fred noted that Anna did need assistance in order to remain in her own home. He further identified that a neighbor provided help to Anna yet Fred did not know specifically who Anna’s helpers were, the specific tasks with which she required assistance, nor the arrangements surrounding the assistance provision. Fred asserted that in Anna’s small community “…people just kind of take care of each other when they really need it.” Anna says of her neighbors’ help:

“He [the neighbor] mows the yard and I pay him... And she [the neighbor who helps Anna with housework and medication management] doesn’t require any pay, but I pay her anyway. I don’t know how I’m supposed to pay her but then I pay her... I just wanted to be independent... I’m too old to have surgery unless I have to have it.” (Anna, older adult)

A final example of this mismatch in perceptions of needs is illustrated in Rachael’s narrative. She asserts that her mother Susan inaccurately reports her needs due to pervasive short-term memory and cognitive problems. Susan reports that the washing machine and dryer do not function properly. Consequently, she has a need for assistance with laundry. However, Rachael is able to successfully utilize the appliances.

“I noticed uh, she wasn’t doing some of the things that she needed, like her bathroom, I’d have to, you know I would clean the floor for her and uh, she wasn’t able to remember that, uh, she knew she had a washer and dryer, but she didn’t know that they still worked. From then on she just didn’t think it worked so I always, you know, made sure that she had her clothes. I’d wash them and dry them while I was there.” (Rachael, caregiver)

**Mobilization of resources**

Older adult respondents and their caregivers who used formal resources described various ways in which those resources were mobilized. In two instances, the arrangements and ensuing provision of services appear to be almost serendipitous. A neighbor couple checked in on Anna and began assisting her. A beautician from a nearby town not only cuts and sets Anna’s hair but also provides Anna round trip transportation to the beauty salon. Both Anna and her son Fred attribute her good fortune in obtaining help to her rural, small-town locale.

“Cause a small town helps [in times of need]. Well you can get help when you need it. I get my groceries delivered and get Meals on Wheels.” (Anna, older adult)

“There is [a grocery store], and they deliver... She can order on the phone and they’ll deliver to her and they, they like that. Anna gets her hair fixed once every two weeks. And the beauty parlor operator comes by and picks her up.” (Fred, caregiver)

Similarly, when asked how his Meals On Wheels were arranged, Gregory said:
I just found out that they was doing [Meals-on-Wheels] and I just let them start. (Gregory, older adult)

Esther indicated that she was informed about the procedures she would follow to obtain additional homemaker services.

If I need more time for housekeeping [the service provider said] to call her to increase it. And she tells me if there's anything I need to call her [case manager]. (Esther, older adult)

Her daughter Debra arranged Esther’s case management service at the time of Esther’s health problem.

Including Esther, case managers worked to arrange services for four of the older adult respondents (Walt, Esther, Anna, Susan). While Rachael is Susan’s paid caregiver, her case manager is available to provide assistance such as delivering a shower chair to Susan’s home. The following quotes are exemplars of assistance provided by case managers.

And she has case management through the Area Agency on Aging? She comes by every year and evaluates [Esther] for the health...When we first started she was [helpful]. (Debra, caregiver)

And at that time, that's when uh, you know we looked around they [hospital and social services staff] found for us a health nurse to come out and she uh, assessed us and just did everything she could to help us out. Sent someone out to bathe him and uh, you know do his daily thing...every morning wasn't it for a couple weeks um, showered him. (Beverly, caregiver)

Challenges for remaining in the community

To better understand the elements that are positively linked with community tenure it is also important to consider the challenges to remaining in the community encountered by older adults and their caregivers. For some older adult respondents financial concerns made nursing facility placement undesirable. Financial resources played an important part in the community tenure of the older adult respondents.

Financial determinants

For some older adult respondents financial concerns made nursing facility placement undesirable. A number of older adult and caregiver respondents indicated an awareness of the cost of services and the ways their service choices were influenced by their financial circumstances.

There was no way she could spend nights by herself. And we really couldn't afford to hire a nurse to come and stay full time. (Debra, caregiver)
I've got some money. And I was saving it to give to the kids, but now that I had such a problem, they've all decided they'll just use it to get me where I could live. (Harvey, older adult)

While Walt and Beverly recounted that they did not have financial concerns regarding Walt’s care following his accident, they did point to a financial concern for older adults in general.

Well I know that’s the problem now, is seeing that we have better healthcare (Beverly, caregiver).

Like drug expenses. There isn’t enough money for older people to be able to stay home. I just feel so sorry for so many of them. That’s the biggest worry, I think, with elderly people. (Walt, older adult)

Similarly, Gregory claims that paying for prescription medication causes financial worry.

Money can be a challenge to living here... cause see you got to buy your own pills. (Gregory, older adult)

In addition to adding general worry, financial resources played an important part in the community tenure of the older adult respondents – framing the determination of service arrangements.

We are fortunate that that [the costs associated with helping their mother live at home] has not been a problem. She and Dad were pretty thrifty for years and invested well. (Melanie and Carrie, caregivers)

And at that time we still didn't have to worry about the expense because he was still on workman’s comp. That wasn’t the problem at all, the problem was making the decision to put him out there for a couple weeks or bring him or hiring help of some kind to bring him in here. (Beverly, caregiver)

Finding and arranging services

Successful arrangement of services hinges on awareness of their existence and negotiation of service eligibility requirements. For the community dwelling older adults and their caregivers accomplishing this was challenging at times. The narratives revealed two examples where respondents did not seek services. While Anna had a case manager who offered to arrange additional help for her in addition to Meals On Wheels, Anna stated that to contact the case manager and describe what might be helpful was “too much work.” Fred, Anna’s son, said he believed Anna could use more services but that he did not know how to help arrange assistance for her across the miles.

[She could use] somebody to check in on her more often. I think they come in and take her blood pressure I’m going to guess, she told me and I don’t remember but
there is a county nurse or somebody that comes by and I think it’s once, once a month and takes her blood pressure and trims her toenails maybe…Housework, just to dust and stuff like that. (Fred, caregiver)

Prior to caring for her mother, Melanie worked for a social service agency for many years. Despite this history of working within the system that could assist her mother, Melanie has not arranged for state services for her mother stating that the available services would provide too little assistance to be of any consequence.

Here the last few years I know they [formal service providers] couldn’t have gone in there enough times, you know, been in there long enough to have done any good – I mean, to help out that much. (Melanie, caregiver)

The Area Agency told us that what would be available was the meals. But we felt they would not be that helpful in our situation because basically they just drop 'em off and go on. Which is the same thing that the Meals on Wheels do. There is no - I mean you know, if the person is not able to come to the door or not up in their chair or something that way they might report that to someone but otherwise, you know there is no contact other than just then. I mean it's such a brief contact it really. We didn't feel it was anything that would help us that much when this last few months when mom really needed more than that. (Carrie, caregiver)

A number of the older adult respondents had contact with case managers. In some instances the case managers perform only an annual screening and in others instances respondents described ways case managers arranged assistance for the older adult and caregiver. Walt and Beverly made a connection with a case manager through staff at the hospital and rehab center. Beverly and Walt did not have to make any of the care arrangements on their own and were grateful for the assistance.

Care manager is what you call it. And, she’s the one that looked into it [care services provided in the home] for us. I was just thankful we had that much. Oh, I thought they were just wonderful. (Beverly, caregiver)

We had some good people. (Walt, older adult)

Susan also benefited from case manager services. However, neither Susan nor Rachael was aware of case management services save for a serendipitous conversation that took place between Rachael and contact of a friend. She recounted that without this chance encounter with the contact she would not have known about the services that were available.

My sister has a friend who worked for the SRS. And so I said, we wanted to get her into a different type of housing, you know, so it was less expensive for her. And she said well why don’t we check into this and see what she has, you know to say about it. And then she started telling me us that we could get in-home help for her you know, so that’s how the process began...Otherwise I wouldn’t have a
clue, you know, that this was even out there. And it wasn’t even at that time when I started helping mom. I mean I helped her before that...But when the council on aging told me I could get paid for the services I do anyway, then and that then helped me because at the time it was, you know, difficult financially for me to find the time to do all of this for her. (Rachael, caregiver)

In the absence of case management assistance, Debra alone made arrangements for Esther to receive care in her home. She did so hurriedly, in the midst of Esther’s acute health problem.

I made a lot of calls and got my forms through the Department of Aging to come out because we were going to need to help her get up and down, showers, and all that, and rented all the stuff because I thought we were going to stay at home. (Debra, caregiver)

Caregiver burden and sacrifice

Analysis of the caregivers’ narratives revealed themes of burden and sacrifice in addition to those of caring and commitment. The actual work of caregiving differed among the respondents, as did the amount of caregiving at which care providers felt overwhelmed. Gloria, a paid caregiver who is not a family member, did not report feeling burdened by her experience of caregiving. While Debra provided only occasional assistance with errands such as delivering groceries to Esther in bad weather, she indicated that she would not participate in Esther’s care to a greater extent were she to need more care. Debra has maintained this stance since Esther’s initial application for nursing facility placement.

[The doctor] dismissed me... So Debra called him on the phone and got onto him. And he let me go back. But I was home a day and a night... Debra told me, "You're probably going to have to go to the nursing home." And I said, "OK.” (Esther, older adult)

In some instances the provision of care proved to be overwhelming and/or disruptive to the caregivers life with her/his partner and/or children. Beverly described enjoying her role as care provider in the context of her happiness that Walt was alive following his negative health event. She reported that having the assistance from formal helpers was invaluable yet still struggled as a caregiver.

I had to be close by all the time. But until he could finally start walking and I used to feel kind of tied down with him at times. I’ll admit it. There were times that [I’d think] oh, I’d just give anything to have a day to myself. [It was] emotionally draining – and things just kind of add up to a breaking point. It has to go somewhere. (Beverly, caregiver)

When Steve realized that he may reach a “breaking point” with caring for his father he sought an alternative living arrangement for Harvey in supported housing. Steve revealed that caring for his father strained the relationship Steve had with his family.
It's tough being a caregiver. I did enough of that to know, because you're 24 hours a day. It's 24/7, and people laugh, and say I'm 24/7. But when you're caring for somebody, it's 24/7. And it taxes you really hard, it really does. (Steve, caregiver)

Now that Harvey lives in assisted living Steve’s participation in his care is limited to helping with errands and providing emotional support. Both Steve and Harvey report relative satisfaction with the situation and with their relationship.

Rachael described her current caregiving situation as one that is tenuous. With a number of personal responsibilities and suspended or slowed progress on personal goals, Rachael revealed that she is unsure whether she will be able to continue to provide care for her mother indefinitely.

I do feel responsible for her. I have let a lot of my own things go to take care of her. I put my life on hold a lot. I don’t know how to change that because I do love her.... It’s challenging for me. Because with [my other work] I don’t know how much time I’m going to be able to dedicate to her. And I’m trying to decide...I’m going to have to give up some things. ...as far as coming in and being in charge of her daily baths and things like that, I’m not sure I’m going to be able to. ...I may have to have someone else come in and take over part of the care for her. (Rachael, caregiver)

Whereas Rachael is currently assessing whether or not she will lose out on personal opportunities if she is to continue to provide care for her mother, Melanie and Carrie assert with certainty that their caregiving role has precluded them from engaging in other pursuits.

It's been we couldn't really go out of town for anything without checking to see if the other one you know would be available and just things like that and like she said you know I mean it just ruled our life for us and our husbands. (Melanie and Carrie, caregivers)

Melanie noted that she had not believed her mother would live to such an advanced age. She has been caring for her mother throughout much of the time her husband has been retired; such that they have not carried out many of their retirement plans.

The burden of caregiving for some respondents is linked to ways the caregivers themselves consider care options to utilize in older adulthood. Melanie stated that she and her husband are looking at purchasing long-term care insurance (both are over the age of 65) so as to avoid relying on their adult children in the event that they may need care. Beverly and Walt who promised to care for each other as spouses expressed similar sentiments about hoping to avoid burdening loved ones.

And not depend on our children or anybody else - the nursing home would have to be the very last resort. I don't want our children to feel that they have to take us in, to save us from the nursing home and things, you know I don't think it's right to do that on them, they have their own lives. (Beverly, caregiver)
Despite feeling burdened by providing care, respondents also noted things that assisted them in their caregiving role. Beverly said that if she were to need emotional support she would have people to whom she could turn. Notably, Beverly specified that only certain types of interactions would be helpful.

*I’d either go to my minister or my daughter [Sandra]. [Sandra], my daughter, is a wonderful person to talk to. We’re close [Beverly and her other daughter, Elaine] but she’s bossy. [Imitating Elaine] ‘You’re going to do this mother, you do it!’ [Elaine] talks to me like I’m an old lady and need to be bossed. Sandra says ‘Well mother, I suggest you do this. You do what you think...’* (Beverly, caregiver)

Melanie and Carrie looked to the example provided by their mother, now the care recipient, who once provided care for their father and to each other for support.

*I asked her one time, I says, ‘Mom, how in the world were you able to do that?’ She said, ‘Well, I just get up every morning and I’d ask God to help me to get, have the strength to do what I needed to that day.’ And I think that’s the only thing that got her through because otherwise I don’t know how she could do it...* (Carrie, caregiver)

*Well the number one thing that helped me the most was having a sister that helped too.* (Melanie, caregiver)

Rachael identified assisted living placement as a formal support that would allow her to engage in what she described as the best parts of caregiving, attending to her mother’s interests and emotional health while formal care providers undertook the provision of more practical daily care. However, Rachael reports that this assistance, the benefits that would be evident were her mother to live in an assisted living setting, is likely out of her and her mother’s reach.

*So, you know, you just have to weigh the positive things. They have an assisted living part there but I’m not sure my mother would even qualify for that. So, if, she could afford [it]. See, since she doesn’t, all she has is her social security and most of that was daddy’s. She didn’t work enough years at a good enough wage to make her own way there so she doesn’t have the finances to be able to live in assisted care. Because I think if I could do really what would be best for her, it would be to put her in assisted care where she would have people prepare her meals. They would have things going on for her to, to uh, include her in the activities. They would bring her into it because she doesn’t seek that. They would do her clothes for her, they would make sure that she had her bath you know and just oversee that and you know be firm with her.... What I would like would be to spend more time with my mom without the pressure [of caregiving]. To be able to just take her places and do more fun things. Spend more time with her in a setting where I’m not obligated to....* (Rachael, caregiver)
**Long-term tenure older adults without caregivers**

The findings indicate that older adults have a strong desire to avoid placement in a nursing facility. Likewise, caregivers indicate determination to prevent nursing facility placement and they perceive mutual determination with the older adult. The older adult respondents have a number of health problems, and they rely heavily on primary caregivers, formal and informal services that allow them to remain in the community. Additionally, older adults describe a commitment to maintaining physical, emotional and social health through a number of activities. Finally, having friends who provide informal caregiving tasks and social activity for the older adult is very important in helping the older adult remain in the community.

**Summary of long-term community tenure findings**

Findings from the analysis of long-term community dwelling older adults and their caregivers reveal a wide range of experiences. Both the older adult and caregiver respondents described experiences of resilience and overwhelming challenges. Attention to the total well-being of both parties is essential to the efficacy of this special exchange of care. Important distinctions appear between paid and unpaid caregivers, the amounts and types of care provided by caregivers (for varied lengths of time), in the health / functional capabilities of the older adults, and in the resources available to the older adults and caregivers (e.g. financial, time, physical strength, and social supports).

Overarching themes emerged that seem to transcend these distinctions. Formal services supplement assistance provided by caregivers; filling in care gaps, offering caregiver respite, and attending to more acute care needs. In order for formal services to fill this function however, older adults and their caregivers must be made aware of them and aided in negotiating service eligibility and delivery systems. Supported housing, with on-site formal services emerged as a potential “next step” after living independently in the community yet preceding nursing facility care. Mobilizing additional information supports also proved helpful to older adults and their caregivers. When available and mobilized, informal social support facilitated adaptive strategies implemented by elders and caregivers, buoyed the spirits of caregivers and reduced their care-loads, and filled in for family supports separated from the older adult by geographic distance.

Contrary to some gerontological scholarship the older adults in this study often participated in an exchange of care rather than simply receiving care in a one-way transfer from the caregiver. These exchanges included the reciprocation of esteem and affection, the interchange of support – some of which was in different forms and quantities, and the provision of support to elders who themselves, had provided support in the past. The social support exchanges within the caregiving process merit further attention for their potential to better inform social service policies and practices.