This research was supported in part through a contract with the Kansas Department on Aging and the Kansas Department of Social and Rehabilitation Services
Topeka, Kansas 66612
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Appendix A:

Client Assessment, Referral, and Evaluation (CARE) Assessment
**I. Identification Information**

A. Client Social Security # (optional)

B. Client Name

  - First: __________  
  - Last: ____________

C. Address

  - Street: ____________________________  
  - City: ____________________________  
  - County: ______  
  - State: ______  
  - ZIP: __________

D. Birth date

  - Month: ______  
  - Day: ______  
  - Year: ______

E. Gender

  - 1. Male  
  - 2. Female

F. Date of Assessment

  - Month: ______  
  - Day: ______  
  - Year: ______

G. Assessor ID#__________

H. Primary Language

  - 1. English  
  - 2. German  
  - 3. Spanish  
  - 4. Other: __________

I. Ethnic Background (code for the correct response)

  - 1. Black (non-Hispanic)  
  - 2. White (non-Hispanic)  
  - 3. American Indian/Alaskan Native  
  - 4. Hispanic  
  - 5. Asian/Pacific Islander  
  - 6. Other: ____________

**II. PASARR**

A. Have you or anyone else suggested you need to move to a nursing facility?

  - 1. Yes  
  - 2. No (skip to section III)

B. MM/IR Screen

  1. Client has been diagnosed as having a serious mental disorder
     
     - 1. Yes  
     - 2. No

  2. What psychiatric treatment has the client received in the past 2 years (check all that apply)

     - 1. Partial hospitalization  
     - 2. Inpatient hospitalization  
     - 3. Supportive services/Intervention  
     - 4. None

  3. Has the client been diagnosed with one of the following conditions prior to age 22 AND the condition is likely to continue indefinitely (check all that apply)

     - 1. Mental retardation  
     - 2. Related condition  
     - 3. None

  4. What resources of information were used for the MM/IR screen (check all that apply)

     - 1. Client  
     - 2. Family  
     - 3. Health care professional  
     - 4. Clinical record

  5. Referred for level II assessment?

     - 1. Yes  
     - 2. No

**III. Functional Assessment**

Enter the code in the box to indicate the client's level of self performance at the time of the assessment:

1. Independent  
2. Supervision needed  
3. Physical assistance needed  
4. Unable to perform

A. Activities for daily living

  1. Bathing  
  2. Dressing  
  3. Toileting  
  4. Transfer  
  5. Walking, mobility  
  6. Eating

B. Instrumental Activities for daily living

  1. Meal preparation  
  2. Shopping  
  3. Money management  
  4. Transportation  
  5. Use of telephone  
  6. Laundry, housekeeping  
  7. Management of medications, treatments

C. Bladder continence (code current performance for client)

  1. Continent  
  2. Usually continent  
  3. Occasionally incontinent  
  4. Frequently incontinent  
  5. Incontinent

D. Cognition

  1. Composed, persistent vegetative state

     - 1. Yes (skip to section VI)  
     - 2. No

  2. Memory, recall

     - 1. Short-term memory  
     - 2. Long-term memory  
     - 3. Memory/Recall  
     - 4. Decision making  
     - 5. Total Score

Continued on next page
### IV. Current or Recent Problems and Risks

Check all the current or recent problems and risks the patient has had:

1. Falls, unsteadiness
2. Impaired vision
3. Impaired hearing
4. Wandering
5. Socially inappropriate, disruptive behavior
6. Self-neglect
7. Neglect, abuse, or exploitation experienced
8. None

### V. Support

A. Lives alone
   1. Yes
   2. No

B. Support, caregiver available
   1. Full time
   2. Part time—routine
   3. Part time—intermittent
   4. Not available

### C. Possible sources of payment for support services (check all that apply)

1. Self pay
2. Medicare
3. Private insurance
4. VA
5. Medicaid
6. Senior Care Act
7. Other: ____________________________

### D. Primary person for legal and financial matters (check all that apply)

1. Self
2. Spouse
3. Son, daughter, or other relative
4. Guardian
5. Durable Power of Attorney for health care
6. Durable Power of Attorney for financial matters
7. Other legal oversight
8. Friend
9. Other: ____________________________

### E. Primary person who manages care and financial matters, if other than client

Name: ____________________________

Street: ____________________________

City: ______________________________

State: [ ] ZIP: ______________________

Phone: ____________________________

### VI. Referral Information

A. These services are needed to assist client to remain in community care

<table>
<thead>
<tr>
<th>Service</th>
<th>Selected</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ] Self pay</td>
<td></td>
</tr>
<tr>
<td>[ ] Medicare</td>
<td></td>
</tr>
<tr>
<td>[ ] Private insurance</td>
<td></td>
</tr>
<tr>
<td>[ ] VA</td>
<td></td>
</tr>
<tr>
<td>[ ] Medicaid</td>
<td></td>
</tr>
<tr>
<td>[ ] Senior Care Act</td>
<td></td>
</tr>
<tr>
<td>[ ] Other: ____________________________</td>
<td></td>
</tr>
</tbody>
</table>

### B. Client, family choice for long-term care services (code for correct response)

1. Client's or family member's home without services
2. Client's or family member's home with services
3. Personal, residential, or boarding care
4. Nursing facility
   a. Name of facility: ____________________________
   b. Is the client's stay in the nursing facility anticipated to be less than 3 months?
      1) Yes 2) No

### VII. Address where client can be contacted for further information and referral services

(if different from Section I)

| Street: ____________________________ |
| City: ______________________________ |
| County: [ ] State: [ ] |
| ZIP: ____________________________ |
| Phone: ____________________________ |

Comments:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Appendix B:

Data Source Descriptions
Care Assessment

The CARE Assessment is the primary data source for the project. The CARE Assessment (Appendix B) is used with all individuals seeking/considering NF admission. It collects comprehensive data regarding the following: 1) demographics; 2) functional status; 3) cognitive status; 4) problems or risks; and 5) support available. As part of the CARE process, a follow-up contact is made by AAA-based CARE staff to determine which customers remained in the community and whether they received services. Staff also determine who is living in board and care facilities (diverted) and who entered a NF (non-diverted). Follow-up is conducted within twenty-five to thirty-five days following the initial CARE Assessment. This information makes it possible to compare the diverted and non-diverted customers. In addition, it provides a baseline for comparison of the two groups since the CARE data were collected uniformly and during the same time frame for both groups.

CARE assessors include staff and contract staff of the eleven Planning and Service Areas (PSA’s), nursing home staff and hospital discharge planning staff. A criterion for being a CARE assessor is either a nursing or social work background. The CARE assessors participate in a CEU accredited training program before conducting CARE assessments. The training by KDOA CARE Program staff offers a level of assurance that all CARE assessors are trained uniformly. In addition, KDOA offers CARE assessor update training, and, if necessary, mandated training when substantial changes are made in the CARE Assessment instrument or process.

The KDOA training allows the trainees to complete a sample assessment and then shares results within the group for feedback and discussion. The CARE Assessment data definitions are provided to the trainees in written form and the trainee has a handbook/manual to take into the field. The data definitions provide clear and specific objective measures, which help maintain reliability among CARE assessors. An important aspect of the CARE Assessment instrument and process is its consistency over time.

Uniform Assessment Instrument (UAI)

The UAI component of the Client Assessment and Referral System (CARS) database at KDOA has been the primary data source for diverted customers service use, source of funding (with the exception of Medicaid-HCBS/FE), and duration of service use until April 2000 when KAMIS was piloted in three PSA’s and then implemented in the other eight PSA’s in July 2000.

Supplemental Questions at 30-days after the CARE Assessment

The CARE Coordinators asked a series of questions when the completed the CARE 30-day follow-up in September 2000. The questionnaire was developed by OALTC and sought to obtain additional information about the types of formal and informal support diverted older adults were receiving. In addition, information about funding sources and whether CARE customers applied for Medicaid-HCBS/FE and state general fund services was also requested. The questionnaire is in Appendix G.

Medicaid Management Information System

The Medicaid-HCBS/FE service utilization and duration for diverted customers is obtained from the Medicaid Management Information System (MMIS) database.
**MDS 2.0**

The OALTC submitted a Data Use Agreement (DUA) to HCFA and has been approved to use of the Minimum Data Set 2.0 (MDS). This dataset will be used to identify date of entry and functional status upon admission of those individuals who entered nursing facilities.

**KDHE Vital Statistics**

A request was submitted to the KDHE Center for Health and Environmental Statistics to verify deaths and dates of death for individuals diverted in May 1999, March, April, and August 2000. The data request information covered the period from May 1, 1999 to January 31, 2002.

**Qualitative Interviews**

Qualitative interviews were the data source for decision-making, service-related quality of life (SRQOL), and informal support. The OALTC staff trained three project staff to conduct the interviews to obtain this information. Staff conducting the interviews had previous social work experience with older adults. The interview guide is in Appendix F.

**Informal Support Surveys**

In the fall, 2001, OALTC completed a phone survey of diverted customers (or their primary caregiver if the customer could not be interviewed) to learn more about the types, frequency, and amount of informal support diverted customers were receiving. The data gathered for the survey was used in the Legislative Brief *an Expanded analysis of Diverted Customers: August 2000*. The survey is in Appendix H.

**Case Manager Surveys**

Prior to conducting interviews, it was important for the OALTC research staff to determine whether the customer or a primary caregiver should be interviewed. A case manager survey was developed for this purpose (see Appendix E). Criteria for interviewing the primary caregiver were that cognitive or functional problems would prevent the customer from participating in an interview. Also, case managers were asked for their opinion about the customer’s ability to remain in the current setting without in-home services. In addition, information about the services currently being received and the funding sources was verified via the survey. Finally, the case manager updated primary caregiver information.

**OALTC Database**

The OALTC created a database to incorporate and merge the data obtained from the sources listed above. The database used the Statistical Package for Social Sciences (SPSS) for data entry and analysis.
Appendix C:

30-Day CARE Follow-up Form
CARE PROGRAM
30-DAY FOLLOW-UP

Client Name ___________________________ AAA # ____________________

Date of Initial Assessment ____________ Date 30 Day Followup done by caller ____________
Date 30 Day Followup Rec’d at AAA ____________ Date of Data Entry ____________

1. Client’s choice for LTC services?
   1. Client is in the community with no services.
   2. Client is in the community with services.
   3. Client is in a personal residential or boarding home.
   4. Client prefers to remain in a nursing facility.

2. If client is in the community without services, why?
   1. Necessary services do not exist.
   2. Client chose not to have services.
   3. Client cannot afford needed services.
   4. Client is waiting for services.
   5. Client has informal support services in home.
   6. Client does not need services.

3. If additional help at home had been available, could you have stayed in your home?
   Yes _____ No _____

4. Did you have any help at home before you went to the nursing facility? _____ Yes _____ No

5. Does the client want further assistance? _____ Yes _____ No

6. List services needed by client in order to return to the community. In addition to what is on the original assessment, add services needed now to function in the community. (Use service and availability codes for listing).

7. Client was in hospital at time of call _____ Yes _____ No

8. Client has moved out of the state. _____ Yes _____ No

9. Unable to locate client. _____ Yes _____ No

10. Client is deceased. _____ Yes _____ No (If yes, please change client status in CARS from "active" to "dead")

11. Follow-up completed by ____________________________
Appendix D:

Medicaid Long-term Care Services Threshold Guide
## HOME & COMMUNITY BASED SERVICES FE/PD WAIVERS
### MEDICAID LONG TERM CARE SERVICES THRESHOLD GUIDE

<table>
<thead>
<tr>
<th>ACTIVITIES OF DAILY LIVING</th>
<th>SCORES FROM CARE MODULE OF THE UI</th>
<th>WEIGHT</th>
<th>MULTIPLIER</th>
<th>WEIGHT X MULTIPLIER TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>BATHING</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DRESSING</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOILETING</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TRANSFER</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MOBILITY</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EATING</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>INSTRUMENTAL ACTIVITIES OF DAILY LIVING</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>MEAL PREPARATION</td>
<td>5</td>
</tr>
<tr>
<td>SHOPPING</td>
<td>3</td>
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<td>MONEY MANAGEMENT</td>
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<td>3</td>
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<td>TELEPHONE USE</td>
<td>3</td>
</tr>
<tr>
<td>LAUNDRY/HOUSEKEEPING</td>
<td>3</td>
</tr>
<tr>
<td>MEDICATION MANAGEMENT</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>RISK FACTORS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>BLADDER CONTINENCE (if UIA score 2-5, enter ✓ in next column)</td>
<td>5</td>
</tr>
<tr>
<td>COGNITION (see back for instruction)</td>
<td>4</td>
</tr>
<tr>
<td>FALLS (if checked on UIA enter ✓ in next column)</td>
<td>3</td>
</tr>
<tr>
<td>ABUSE/NEGLECT/EXPLOITATION BY OTHERS (if checked on UIA enter ✓ in next column)</td>
<td>5</td>
</tr>
<tr>
<td>SUPPORT (enter ✓ in next column if adequate support is lacking)</td>
<td>4</td>
</tr>
</tbody>
</table>

**TOTAL:**

<table>
<thead>
<tr>
<th><strong>YES</strong></th>
<th><strong>NO</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>✔️</td>
<td>❌</td>
</tr>
</tbody>
</table>

Does this individual meet the ADL criteria requirement?:

Does this individual meet the IADL criteria requirement?:

Does this individual meet the total weight criteria requirement?:

Does this individual meet the functional criteria for Medicaid long term care threshold?:

Does this individual meet the functional criteria for Medicaid nursing facility threshold?:

threshold.opp 11/7/06
<table>
<thead>
<tr>
<th>MULTIPLIER</th>
<th>PHYSICAL ASSISTANCE (UI Score 1) = 0</th>
<th>UNABLE TO PERFORM (UI Score 3) = 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>INDEPENDENT (UI Score 2) = 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SUPERVISION (UI Score 3) = 1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

With the exception of the risk factor for impairment of cognition, multipliers are applied only to ADL's and IADL's.

A Multiplier of 2 is applied to the risk factor of impaired cognition if, through assessment, the case manager/independent living counselor detects any level of cognitive impairment which, in the judgment of the case manager/independent living counselor, substantially impairs functional ability.

<table>
<thead>
<tr>
<th>ACTIVITIES OF DAILY LIVING</th>
<th>MINIMUM NUMBER OF IMPAIRMENTS</th>
<th>MINIMUM WEIGHT</th>
</tr>
</thead>
<tbody>
<tr>
<td>INSTRUMENTAL ACTIVITIES OF DAILY LIVING</td>
<td>3</td>
<td>9</td>
</tr>
</tbody>
</table>

**FRAIL ELDERLY & PHYSICAL DISABILITIES LONG TERM CARE THRESHOLD:**

Individuals must meet the minimum number of impairments;
AND
the minimum level of care weight of 15;
(OR)
the IADL weight must be equal to or greater than 2 with a minimum total weight of 15.

**NURSING FACILITY THRESHOLD:**

Individuals must meet the minimum number of impairments;
AND
the minimum level of care weight of 26;
(OR)
the IADL weight must be equal to or greater than 2 with a minimum total weight of 26.
Appendix E:

Case Manager Survey
Customer’s Name: ______________________________________
Today’s Date: ___________________
Case Manager’s Name: __________________________________
Case Manager’s phone number: (        ) _______-___________

1. Please enter the date of your last contact with this customer- Date: ______/_____/______

2. Please describe the method of your last contact with this customer: (circle one)
   a. In-home visit  b. Phone call  c. Other, please explain: ____________________________

3. On average, how many hours per month do you have contact with this customer? _______________

4. Did you conduct the CARE Assessment in April 2000 for this customer? (circle one) a. Yes b. No

5. Has the cognitive status of this customer changed since the April 2000 CARE Assessment? (circle one)
   a. Yes, please explain ↓  b. No  c. Do not know, please explain ↓
   __________________________________________________________________________

6. Has the functional status of this customer changed since the April 2000 CARE Assessment? (circle one)
   a. Yes, please explain ↓  b. No  c. Do not know, please explain ↓
   __________________________________________________________________________

7. After reviewing the attached project description, please answer the following question. Is this customer
   appropriate/able to be interviewed for this study? (circle one) a. Yes  b. No, please explain ↓
   __________________________________________________________________________

8. Please identify all publicly funded in-home services this customer is currently receiving. Please include
   funding source (i.e. HCBS/FE) as well as service type (i.e. Attendant Care):
   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________

9. In your opinion, would this customer be able to remain in their home/current setting without the in-home
   services they currently receive? (circle one)
   a. Yes  b. No, please explain (e.g. Would they have to enter a NF or AL/RHC facility?
     Would they move in with family?) ↓
   __________________________________________________________________________

10. Has this customer been involved in a report of abuse, neglect or exploitation? (circle one)
    a. Yes, please explain ↓  b. No or Unknown
    __________________________________________________________________________

11. Who is primary caregiver for this customer? Phone #: __________________________

12. What is the relationship of the primary caregiver to this customer (i.e. daughter, neighbor)?: __________

13. Does this customer have a court-appointed legal guardian? (circle one)
    a. Yes, Please enter their name: ____________________________  b. No
Appendix F:

Kansas Longitudinal CARE Diversion Study Customer Interview Guide
Before the interview begins, have the customer sign the consent to conduct the interview.

ACTION REQUIRED:
☐ Consent Obtained

As part of the warm up, let customers know we are interested in their views about the services they are receiving and we want their own words - hence we will audio-tape the interview. Remind them that nothing they say will have any impact on the services they currently receive.

This interview guide is set-up so that the questions can be asked in the sequence provided. In the course of the interview, the customer may provide information that answers a question that appears later in the interview guide. Be sure all numbered questions are asked.

In addition to audio-taping the interview, 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. *It is important to remember that despite the audio recording, equipment failures can occur therefore making the written notes the ONLY source of data from the interview.* Directions for each question are noted throughout the interview guide.

☐ Start tape recorder

Preliminary Interview Questions

I would like to begin the interview with a couple of preliminary questions.

P.1. How long have you lived in Kansas?
   # of years: _______ (If less than 20 years, please answer question P.1 (A)

P.1 (A) Where else have you lived in the last 20 years? please explain: _______________________________]

P.2. Do you have someone you rely on the most (e.g., someone who helps you with your day to day tasks, handles your finances, the first person you’d call in an emergency)? (circle one)

   NO

   Yes, please provide the following information:

   Name: _______________________________ Relationship: _______________________________
Decision Making Process

Is the tape recorder running? (This part will be audiotaped, and notes will be taken as well.)

The first section of the interview focuses on decision-making and I will begin with some general questions followed up by some specific questions.

D.1. Do you remember someone asking you questions at the time you were thinking about or considering nursing facility placement? (You might be recall it was called a CARE Assessment.) Please describe the events in your life that led up to that point (requesting of nursing facility placement). What factors were most important in leading up to this event?

The customer should go through the chronology of what happened.
Record key points made as the story is told and use the space to record notes.

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

(Use the following shaded area to code only; do not ask the customer about them however you may have to probe for specific details. Check all that apply.)

Was the customer hospitalized, then went into NF:  __ Yes;  __ No.

Was it the customer’s expectation that the NF stay would be 30 days or less:  __ Yes;  __ No.

If in the hospital, probe about diagnosis or medical condition.

Record on the back, if more space is needed.
Decision Making Process Continued

Now I am going to ask some specific questions, still focusing on decision making.

➤ **Note:** If customer does not discuss the factors printed in bold, specifically address them. If this was a factor that led to consideration of NF placement, circle it, and ask the customer how it was a factor; **if it was not a factor, cross it out.**

- bathing
- cooking
- housework
- changes in health of caregiver
- laundry
- dressing
- incontinence
- changes in your health
- cognitive impairment (memory, recall, and decision making)
Decision Making Process Continued

NOTE TO INTERVIEWER: If the customer did not address questions D.1 (A) and D.1 (B) listed below when answering D.1, ask them now.

D.1 (A) Where were you when the decision to seek nursing facility placement was made?
_____________________________________________________________________________________
(Use the following shaded area to code only; do not ask the customer about them. Check one.)

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>home</td>
<td>hospital</td>
<td>AL/RHC</td>
</tr>
<tr>
<td>other, please specify:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
_____________________________________________________________________________________

D.1 (B) Please describe other concerns, if any, that influenced your decision to seek nursing facility placement during this time?
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Decision Making Process Continued

D.2. In thinking about this process of deciding what was best for you at that time, can you recall what and who was most helpful in the process?
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

(Use the following shaded area to code only; do not ask the customer about them. Check all that apply.)

<table>
<thead>
<tr>
<th>What</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>information</td>
<td>advice</td>
<td>support</td>
</tr>
<tr>
<td>other:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Who |  |  |  |  |
|---|---|---|---|
| family | physician | home health nurse | hospital nurse |
| hospital discharge planner | other: |  |  |

D.3. What was the most difficult part of the decision-making process when you were considering nursing facility placement?
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
Decision Making Process Continued

D.4. What in particular influenced you to choose in-home services over nursing facility placement?  
(What factors affected your decision?)
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
(Use the following shaded area to code only; do not ask the customer about them. Check all that apply.)
__ desire to remain in own home/community
__ the cost of NF services compared to CBS
__ nursing facility services were unavailable in your community
__ desire to avoid nursing facility placement
__ other, please specify: ________________________________

D.5. How did you first hear about these in-home services?
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
(Use the following shaded area to code only; do not ask the customer about them. Check all that apply.)
__ advertisement __ family member __ CARE Assessment __ friend
__ hospital __ social worker __ don’t remember __ doctor
__ other: ____________________________________________

D.6. Are there other in-home services that you need/want but are not receiving?  
(circle one and record customer’s comments.)

NO, please explain: ________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

YES, please explain: ________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________


Service-Related Quality of Life

The next set of questions is about the services you are receiving, based on the information I have received from your case manager at the AAA. These questions are about how your life has been improved or enhanced as a result of receiving these services. *(Remind the customer that their responses will not have an impact on the services they currently receive. Their response will be used to describe the benefit of these services for older Kansans).*

Q.1. Please describe how the services you receive have been of benefit to you. (If customer receives more than one service, probe about each service, i.e. night support and attendant care)

Service: ______________________________________________________________________________

Benefits of service: ____________________________________________________________________
_____________________________________________________________________________________

➢ If you did not receive this service, how would the services be provided?
_____________________________________________________________________________________

*(Use the following shaded area to code only; do not ask the customer about them. Check all that apply.)*

___ family member ___ volunteer ___ friend/neighbor ___ wouldn't get done
___ other: ______________________________________________________________________

Service: ______________________________________________________________________________

Benefits of service: ____________________________________________________________________
_____________________________________________________________________________________

➢ If you did not receive this service, how would the services be provided?
_____________________________________________________________________________________

*(Use the following shaded area to code only; do not ask the customer about them. Check all that apply.)*

___ family member ___ volunteer ___ friend/neighbor ___ wouldn't get done
___ other: ______________________________________________________________________

Service: ______________________________________________________________________________

Benefits of service: ____________________________________________________________________
_____________________________________________________________________________________

➢ If you did not receive this service, how would the services be provided?
_____________________________________________________________________________________

*(Use the following shaded area to code only; do not ask the customer about them. Check all that apply.)*

___ family member ___ volunteer ___ friend/neighbor ___ wouldn't get done
___ other: ______________________________________________________________________

Service: ______________________________________________________________________________

Benefits of service: ____________________________________________________________________
_____________________________________________________________________________________

➢ If you did not receive this service, how would the services be provided?
_____________________________________________________________________________________

*(Use the following shaded area to code only; do not ask the customer about them. Check all that apply.)*

___ family member ___ volunteer ___ friend/neighbor ___ wouldn't get done
___ other: ______________________________________________________________________
**Service-Related Quality of Life, Continued**

Q.2. Which service that we just talked about helps you the most? (If only one service, skip this question)

Service: _______________________________________________________________________________

Please explain: _________________________________________________________________________
_____________________________________________________________________________________

Q.3. Would your primary caregiver (identified in question P.2 on page 1) agree with you? *circle one* If only one service or no primary caregiver, skip this question.

**NO.** They would have a different opinion. Please explain: ______________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

**YES**

---

**Service-Related Quality of Life, Continued**

Q.4. Would you be able to remain in your home without all the current services your currently receive? *circle one*

**NO,** please answer Q.4 (A)

**YES**

Q.4 (A) Where would you live?

_____________________________________________________________________________________
_____________________________________________________________________________________

(Use the following shaded area to code only; do not ask the customer about them. Check one.)

__ family  __ assisted living facility  __ nursing facility
__ other, please specify: _________________________________________________________________

Q.5. Do you feel like you are safer in your home because you receive these services? *circle one*

**NO,** please explain: __________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

**YES,** please explain: __________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

Q.6. Do you think you are generally better off, worse off or the same as a result of in-home services? *circle one of the bold words in the sentence above and record customer’s comments below:*

Please explain: ______________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

**Informal Support**

This final set of questions is about the informal support you receive.

I.1. Is there anyone else living with you or staying with you at this time? *(circle one)*

- **NO**

- **YES,** please explain: ____________________________________________
  ____________________________________________
  ____________________________________________
  ____________________________________________

I.2. I asked you earlier for the name of your primary caregiver. How often do you have contact with them?

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

*(Use the following shaded area to code only; do not ask the customer about them. Check one.)*

- **daily**
- **biweekly**
- **weekly**
- **bimonthly**
- **monthly**

I.3. Is this contact usually by **phone** or **face-to-face**? *(circle one):*

I.4. Other than your in-home service workers and your primary caregiver, who else provides you with assistance?

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

*(Use the following shaded area to code only; do not ask the customer about them. Check all that apply.)*

- **family**
- **neighbors**
- **church/synagogue**
- **volunteer**
- **other, please specify:** _______________________________________________________________

I.5. Do you have family (siblings, children, and grandchildren) that lives in the same community as you? *(circle one)*

- **NO**

- **YES**

I.6. Where does your closest family member live? (How far away is that?)

Relation: __________________ Location: __________________ Distance: ________________

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________

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**Informal Support, continued**

**I.7.** How often do you get out of the house?

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________  

(Use the following shaded area to code only; do not ask the customer about them. Check one.)

__ daily __ biweekly __ weekly __ bimonthly __ monthly __
__ other _____________________________________________________________________________

**I.8.** For what purpose do you generally get out of the house?

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________  

(Use the following shaded area to code only; do not ask the customer about them. Check all that apply.)

__ shopping __ visiting __ medical appointment __ exercise __
__ other _____________________________________________________________________________

**I.9.** Generally, when you get out of the house, does someone accompany you? (**circle one**)

NO

YES, describe relationship(s)? __________________________________________________________

(Use the following shaded area to code only; do not ask the customer about them. Check all that apply.)

__ family __ friend __ volunteer __ worker __ other _____________________________________________________________________________

**Follow-up Contact**

We also have some questions related to caregiving issues we would like to ask your primary caregiver. Would you mind if we contacted her or him? (**circle one**)  

NO

YES, please obtain phone number: 

Phone: (   ) _____-___________ Alternate Phone: (   ) _____-____________

If you, the interviewer, observe a situation or identify a problem that needs immediate attention, notify the customer’s Case Manager or the Area Agency on Aging.

**IS ACTION REQUIRED?** (**check one**)  

NO _____

YES _____

If yes, date of Case Manager or AAA contact: ________/_______/_______
Appendix G:

30-day Supplemental Questions
Customer Name: _____________________________________________________

Please ask the following questions for anyone NOT in a nursing facility at the time of the 30-day CARE Follow-up.

1) If you are receiving formal in-home services, what is the funding source of the services provided? (Check ALL that apply)
   a) □ Medicare (Medicare is the red, white, and blue card)
   b) □ Medicaid (HCBS/PD or HCBS/FE). (Medicaid is the green card)
      If the person is not currently getting Medicaid/HCBS services, then ask this question:
      Did you apply for Medicaid/HCBS in-home services? (Check one)
          □ Yes; but not eligible
          □ Yes, they are pending
          □ No; why not (Check all that apply):
              □ Do not believe I am eligible
              □ Do not want Medicaid/HCBS services because: (i.e. estate recovery, paperwork, privacy, independence)
              Please explain:
                  □ Plan to apply later because: (i.e. currently receiving Medicare services, moving, spending down assets)
              Please explain:
                  □ Other:
   c) □ AAA/KDOA (such as SCA, IE, OAA, case management, delivered meals, etc.) (Were your services arranged by a staff person who came from the AAA office?)
      If the person is not currently getting AAA/KDOA in-home services, then ask this question:
      Did you apply for AAA/KDOA in-home services? (Check one)
          □ Yes; but not eligible
          □ Yes, they are pending
          □ No; why not (Check all that apply):
              □ Do not believe I am eligible
              □ Do not want AAA/KDOA in-home services because: (i.e. paperwork, privacy, independence)
              Please explain:
                  □ Plan to apply later because: (i.e. currently receiving Medicare services, moving)
              Please explain:
                  □ Other:
   d) □ Other funding source (i.e. private pay): ________________________________________________

2) Are you receiving informal services from family, neighbors, church, or other source?
   □ Yes, Please Explain: ________________________________________________________________
   □ No

3) If you are not getting formal or informal services, how are your needs being met at home?
   Please explain: ....................................................................................................................

Additional Comments: ........................................................................................................
Appendix H:
Informal Support Survey Questions
Informal Support Survey Form for Customer

Name of interviewer: ____________________________ Date of Interview: ____________

Name of the CARE assessment recipient: __________________________________________

1. I have explained the purpose of this telephone survey and before I proceed, I would like to confirm that I have your consent to conduct this interview with you. (Circle one)
   No    (GO to 1-A below)
   Yes    (proceed to question 2)

1-A. If no, reason ______________________________________________________
________________________________________________________________________
________________________________________________________________________

STOP

2. Do you have someone you rely on the most (e.g., someone who helps you with your day to day tasks, the first person you'd call in an emergency)?
   (Circle No or Yes)
   No    (proceed to question 3)
   Yes    (GO TO 2-A and 2-B below)

2-A. If yes, who ______________________________

2-B. Relationship to you (Circle one):
   1-  Spouse
   2-  Daughter
   3-  Son
   4-  Grandchild
   5-  Nieces/nephews
   6-  Sibling
   7-  Other (specify; include ex-spouse here) _______________________

3. Do you live alone?  (Circle No or Yes)
   No    (GO TO 3-A, below)
   Yes    (proceed to question 4)

3-A. If No: with whom do you live? (Circle all that apply)
   1-  Spouse
   2-  Daughter
   3-  Son
   4-  Sibling
   5-  Other (specify) _______________________

4. Where do you live? (Circle one)
   1.  Your own house
   2.  An apartment (such as a high-rise, but NOT Assisted Living)
   3.  Home of family (specify) _______________________
   4.  Assisted Living
   5.  Other (specify) _______________________

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5. What is your marital status? (Circle one):
   1- Married
   2- Divorced
   3- Widowed
   4- Partnered/live-in
   5- Single/Never married

6. How many adult children do you have? _____ (If none, go to question 8)

7. **Next, I am going to ask a series of questions about your children.**

   7-A. Child1
     i. Name _____________________________
     ii. Gender (Circle one)  F M
     iii. Do they live in the same town as you?: (circle one)
       1- Same town
       2- Different town: Specify: ____________________________
     iv. Approximately how far is their house from yours?: (Circle one)
       1- Next door/a few blocks away (within one mile)
       2- 1-5 miles away
       3- 6-10 miles away
       4- If more than 10 miles, approximate number of miles from you: ______

   7-B. Child2
     i. Name _____________________________
     ii. Gender (Circle one)  F M
     iii. Do they live in the same town as you?: (Circle one)
       1- Same town
       2- Different town: Specify: ____________________________
     iv. Approximately how far is their house from yours?: (Circle one)
       1- Next door/a few blocks away (within one mile)
       2- 1-5 miles away
       3- 6-10 miles away
       4- If more than 10 miles, approximate number of miles from you: ______

   7-C. Child3
     i. Name _____________________________
     ii. Gender (Circle one)  F M
     iii. Do they live in the same town as you?: (Circle one)
       1- Same town
       2- Different town: Specify: ____________________________
     vi. Approximately how far is their house from yours?: (Circle one)
       1- Next door/a few blocks away (within one mile)
       2- 1-5 miles away
3- 6-10 miles away
4- If more than 10 miles, approximate number of miles from you: _____

7-D. Child4
i. Name _____________________________
ii. Gender (Circle one)   F    M
iii. Do they live in the same town as you?: (Circle one)
   1- Same town
   2- Different town: Specify: ____________________________
iv. Approximately how far is their house from yours?: (Circle one)
   1- Next door/a few blocks away (within one mile)
   2- 1-5 miles away
   3- 6-10 miles away
   4- If more than 10 miles, approximate number of miles from you: _____

7-E. Child5
i. Name _____________________________
ii. Gender (Circle one)   F    M
iii. Do they live in the same town as you?: (Circle one)
   1- Same town
   2- Different town: Specify: ____________________________
iv. Approximately how far is their house from yours?: (Circle one)
   1- Next door/a few blocks away (within one mile)
   2- 1-5 miles away
   3- 6-10 miles away
   4- If more than 10 miles, approximate number of miles from you: _____

7-F. Child6
i. Name _____________________________
ii. Gender (Circle one)   F    M
iii. Do they live in the same town as you?: (Circle one)
   1- Same town
   2- Different town: Specify: ____________________________
iv. Approximately how far is their house from yours?: (Circle one)
   1- Next door/a few blocks away (within one mile)
   2- 1-5 miles away
   3- 6-10 miles away
   4- If more than 10 miles, approximate number of miles from you: _____
8. As I mentioned earlier, this survey is about the help that people receive from family, friends, neighbors and churches. All of the questions that I am going to ask now will be about the help you receive from these sources. If someone does help you, I will ask some additional questions.

A. Does someone help you with laundry?
   i. Circle one: No (proceed to question B) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Agency or paid caregiver: (Circle one)
       1. No (go to iv below) Yes (SKIP to vii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   v. How many times per week? ______
   vi. How much time does it take? _____
       Interviewer will calculate the number of hours per week ______
   vii. Does anyone else help you with laundry?
   viii. No (proceed to question B) Yes (GO to ix below)
   ix. If yes, who ________________
   x. Agency or paid caregiver: (Circle one)
      No (go to xi below) Yes (proceed to question B)
   xi. Specify relationship: (Circle one)
      1. Spouse
      2. Daughter
      3. Son
      4. Grand child
      5. Sibling
      6. Other family (specify) __________
      7. Friend
      8. Neighbor
      9. Church
      10. Other (specify) ______________
   xii. How many times per week? ______
   xiii. How much time does it take? _____
       Interviewer will calculate the number of hours per week ______
B. Does someone help you with housekeeping?
   i. Circle one: No (proceed to question C) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Agency or paid caregiver: (Circle one)
        No (go to iv below) Yes (SKIP to viii below)
   iv. Specify relationship: (Circle one)
        1. Spouse
        2. Daughter
        3. Son
        4. Grand child
        5. Sibling
        6. Other family (specify) __________
        7. Friend
        8. Neighbor
        9. Church
        10. Other (specify) ________________
   v. How many times per week? ______
   vi. How much time does it take? _____
        Interviewer will calculate the number of hours per week ______
   vii. Does anyone else help you with housekeeping?
   viii. No (proceed to question C) Yes (GO to ix below)
   ix. If yes, who ________________
   x. Agency or paid caregiver: (Circle one)
      No (go to xi below) Yes (proceed to question C)
   xi. Specify relationship: (Circle one)
      1. Spouse
      2. Daughter
      3. Son
      4. Grand child
      5. Sibling
      6. Other family (specify) __________
      7. Friend
      8. Neighbor
      9. Church
      10. Other (specify) ________________
   xii. How many times per week? ______
   xiii. How much time does it take? _____
        Interviewer will calculate the number of hours per week ______
C. Does someone help you with meal preparation?
   i. Circle one: No (proceed to question D) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Agency or paid caregiver: (Circle one)
        No (go to iv below) Yes (SKIP to viii below)
   iv. Specify relationship: (Circle one)
        1. Spouse
        2. Daughter
        3. Son
        4. Grand child
        5. Sibling
        6. Other family (specify) __________
        7. Friend
        8. Neighbor
        9. Church
        10. Other (specify) __________
   v. How many times per week? ______
   vi. If everyday, how many times per day? ______
   vii. How much time does it take? _____
        Interviewer will calculate the number of hours per week ______
   viii. Does anyone else help you with meal preparation?
      ix. No (proceed to question D) Yes (GO to x below)
      x. If yes, who ________________
     xi. Agency or paid caregiver: (Circle one)
          No (go to xii below) Yes (proceed to question D)
     xii. Specify relationship: (Circle one)
          1. Spouse
          2. Daughter
          3. Son
          4. Grand child
          5. Sibling
          6. Other family (specify) __________
          7. Friend
          8. Neighbor
          9. Church
          10. Other (specify) __________
     xiii. How many times per week? ______
    xiv. If everyday, how many times per day? ______
     xv. How much time does it take? _____
          Interviewer will calculate the number of hours per week ______
D. Does someone help you with grocery shopping?
   i. Circle one: No (proceed to question E) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Agency or paid caregiver: (Circle one)
       No (go to iv below) Yes (SKIP to vii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ________________
   v. How many times per week? ______
   vi. How much time does it take? ______
       Interviewer will calculate the number of hours per week
   vii. Does anyone else help you with grocery shopping?
   viii. No (proceed to question E) Yes (GO to ix below)
   ix. If yes, who ________________
   x. Agency or paid caregiver: (Circle one)
      No (go to xi below) Yes (proceed to question E)
   xi. Specify relationship: (Circle one)
      1. Spouse
      2. Daughter
      3. Son
      4. Grand child
      5. Sibling
      6. Other family (specify) __________
      7. Friend
      8. Neighbor
      9. Church
      10. Other (specify) ________________
   xii. How many times per week? ______
   xiii. How much time does it take? ______
       Interviewer will calculate the number of hours per week
E. Does someone help you with household maintenance? (e.g., repairs, mowing, etc.)
   i. Circle one:   No   (proceed to question F)   Yes   (GO to ii below)
   ii. If yes, who ________________
   iii. Agency or paid caregiver: (Circle one)
      No   (go to iv below)   Yes   (SKIP to viii below)
   iv. Specify task: ________________________________________
   v. Specify relationship: (Circle one)
      1. Spouse
      2. Daughter
      3. Son
      4. Grand child
      5. Sibling
      6. Other family (specify) _________
      7. Friend
      8. Neighbor
      9. Church
      10. Other (specify) __________
   vi. How many times per week? ______
   vii. How much time does it take? _____
      Interviewer will calculate the number of hours per week ______
   viii. Does anyone else help you with other household maintenance?
      ix. No   (proceed to question F)   Yes   (GO to x below)
      x. If yes, who ________________
      xi. Agency or paid caregiver: (Circle one)
         No   (go to xii below)   Yes   (proceed to question F)
      xii. Specify task: ________________________________________
      xiii. Specify relationship: (Circle one)
         1. Spouse
         2. Daughter
         3. Son
         4. Grand child
         5. Sibling
         6. Other family (specify) _________
         7. Friend
         8. Neighbor
         9. Church
         10. Other (specify) __________
      xiv. How many times per week? ______
      xv. How much time does it take? _____
         Interviewer will calculate the number of hours per week ______
F. Does someone help you with financial matters? (e.g., going to the bank, paying bills)
   i. Circle one: No (proceed to question G) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Agency or paid caregiver: (Circle one)
       No (go to iv below) Yes (SKIP to vii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   v. How many times per week? ______
   vi. How much time does it take? _____
       Interviewer will calculate the number of hours per week
g. Does anyone else help you with financial matters?
   vii. Yes (GO to ix below) No (proceed to question G)
   viii. If yes, who ________________
   ix. Agency or paid caregiver: (Circle one)
      No (go to xi below) Yes (proceed to question G)
   x. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   xi. How many times per week? ______
   xii. How much time does it take? _____
       Interviewer will calculate the number of hours per week
G. Does someone help you with using the telephone (e.g. actually making the calls, looking up numbers, dialing the phone)?
   i. Circle one: No (proceed to question H) Yes (GO to ii below)
   ii. If yes, who ______________
   iii. Agency or paid caregiver: (Circle one)
       No (go to iv below) Yes (SKIP to viii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   v. How many times per week? ______
   vi. If everyday, how many times per day? ______
   vii. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
   viii. Does anyone else help you with using the telephone?
   ix. No (proceed to question H) Yes (GO to x below)
   x. If yes, who ______________
   xi. Agency or paid caregiver: (Circle one)
       No (go to xii below) Yes (proceed to question H)
   xii. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   xiii. How many times per week? ______
   xiv. If everyday, how many times per day? ______
   xv. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
H. Does someone help you with reading/writing (e.g. reading mail, writing notes or letters)?
   i. Circle one: No (proceed to question I) Yes (GO to ii below)
   ii. If yes, who ______________
   iii. Agency or paid caregiver: (Circle one) 
         No (go to iv below) Yes (SKIP to vii below)
   iv. Specify relationship: (Circle one) 
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) __________
   v. How many times per week? ______
   vi. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
   vii. Does anyone else help you with reading/writing?
   viii. No (proceed to question I) Yes (GO to ix below)
   ix. If yes, who ______________
   x. Agency or paid caregiver: (Circle one) 
      No (go to xi below) Yes (proceed to question I)
   xi. Specify relationship: (Circle one) 
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) __________
   xii. How many times per week? ______
   xiii. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
I. Does someone help you with transportation? (Errands, dine out, medical appointments, church)
   i. Circle one: No (proceed to question J) Yes (GO to ii below)
   ii. If yes, who ______________________
   iii. Agency or paid caregiver: (Circle one)
       No (go to iv below) Yes (SKIP to vii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) __________
   v. How many times per week? ______
   vi. How much time does it take? ______
   Interviewer will calculate the number of hours per week
   vii. Does anyone else help you with transportation?
   viii. No (proceed to question J) Yes (GO to ix below)
   ix. If yes, who ______________________
   x. Agency or paid caregiver: (Circle one)
      No (go to xi below) Yes (proceed to question J)
   xi. Specify relationship: (Circle one)
      1. Spouse
      2. Daughter
      3. Son
      4. Grand child
      5. Sibling
      6. Other family (specify) __________
      7. Friend
      8. Neighbor
      9. Church
      10. Other (specify) __________
   xii. How many times per week? ______
   xiii. How much time does it take? ______
      Interviewer will calculate the number of hours per week
J. Does someone help you with emergencies and crises (e.g. the water heater breaks, other home emergencies, medical emergencies, etc.)?
   i. Circle one: No (proceed to question K) Yes (GO to ii below)
   ii. If yes, who ____________________________
   iii. Agency or paid caregiver: (Circle one)
        No (go to iv below) Yes (SKIP to vii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) ___________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ________________
   v. What kind of help is this? ____________________________________________
      ________________________________________________________________
   vi. How often? ________________________________________________________
   vii. Does anyone else help you with emergencies and crises?
   viii. No (proceed to question K) Yes (GO to ix below)
   ix. If yes, who ____________________________
   x. Agency or paid caregiver: (Circle one)
      No (go to xi below) Yes (proceed to question J)
   xi. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) ___________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ________________
   xii. What kind of help is this? __________________________________________
       ________________________________________________________________
   xiii. How often? ______________________________________________________
K. Does someone help you with taking medication?
   i. Circle one: No (proceed to question L) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Agency or paid caregiver: (Circle one)
       No (go to iv below) Yes (SKIP to viii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) _____________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) _____________
   v. How many times per week? ______
   vi. If everyday, how many times per day? ______
   vii. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
   viii. Does anyone else help you with taking medication?
   ix. No (proceed to question L) Yes (GO to x below)
   x. If yes, who ________________
   xi. Agency or paid caregiver: (Circle one)
       No (go to xii below) Yes (proceed to question L)
   xii. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) _____________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) _____________
   xiii. How many times per week? ______
   xiv. If everyday, how many times per day? ______
   xv. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
L. Does someone help you with medication setup?
   i. Circle one: No (proceed to question M) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Agency or paid caregiver: (Circle one)
        No (go to iv below) Yes (SKIP to viii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) __________
   v. How many times per week? ______
   vi. If everyday, how many times per day? ______
   vii. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
   viii. Does anyone else help you with medication setup?
      ix. No (proceed to question M) Yes (GO to x below)
      x. If yes, who ________________
     xi. Agency or paid caregiver: (Circle one)
         No (go to xii below) Yes (proceed to question M)
    xii. Specify relationship: (Circle one)
        1. Spouse
        2. Daughter
        3. Son
        4. Grand child
        5. Sibling
        6. Other family (specify) __________
        7. Friend
        8. Neighbor
        9. Church
        10. Other (specify) __________
    xiii. How many times per week? ______
    xiv. If everyday, how many times per day? ______
    xv. How much time does it take? ______
        Interviewer will calculate the number of hours per week ______
M. Does someone help you with coordinating services, treatments, in-home visits, etc.?
   i. Circle one: No (proceed to question N) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Specify what kind of help: ____________________________________________
   iv. Agency or paid caregiver: (Circle one)
       No (GO to v below) Yes (SKIP to viii below)
   v. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) _________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   vi. How many times per week? ______
   vii. How much time does it take? _____
       Interviewer will calculate the number of hours per week ______
   viii. Does anyone else help you with coordinating services, etc.?
      ix. No (proceed to question N) Yes (GO to x below)
      x. If yes, who ________________
      xi. Specify what kind of help: ____________________________________________
      xii. Agency or paid caregiver: (Circle one)
          No (go to xiii below) Yes (proceed to question N)
      xiii. Specify relationship: (Circle one)
          1. Spouse
          2. Daughter
          3. Son
          4. Grand child
          5. Sibling
          6. Other family (specify) _________
          7. Friend
          8. Neighbor
          9. Church
          10. Other (specify) ______________
      xiv. How many times per week? ______
      xv. If everyday, how many times per day? ______
      xvi. How much time does it take? _____
          Interviewer will calculate the number of hours per week ______
N. Does someone help you with eating?
   i. Circle one: No (proceed to question O) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Agency or paid caregiver: (Circle one)
       No (go to iv below) Yes (SKIP to viii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) _________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   v. How many times per week? ______
   vi. If everyday, how many times per day? ______
   vii. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
   viii. Does anyone else help you with eating?
   ix. No (proceed to question O) Yes (GO to x below)
   x. If yes, who ________________
   xi. Agency or paid caregiver: (Circle one)
       No (go to xii below) Yes (proceed to question O)
   xii. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) _________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   xiii. How many times per week? ______
   xiv. If everyday, how many times per day? ______
   xv. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
O. Does someone help you with bathing/taking a bath?
   i. Circle one:  No (proceed to question P) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Agency or paid caregiver: (Circle one)
       No (go to iv below) Yes (SKIP to vii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   v. How many times per week? ______
   vi. How much time does it take? _____
       Interviewer will calculate the number of hours per week
   vii. Does anyone else help you with bathing/taking a bath?
   viii. No (proceed to question P) Yes (GO to ix below)
   ix. If yes, who ________________
   x. Agency or paid caregiver: (Circle one)
      No (go to xi below) Yes (proceed to question P)
   xi. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   xii. How many times per week? ______
   xiii. How much time does it take? _____
       Interviewer will calculate the number of hours per week
P. Does someone help you with dressing/undressing?
   i. Circle one: No (proceed to question Q) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Agency or paid caregiver: (Circle one)
       No (go to iv below) Yes (SKIP to viii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) __________
   v. How many times per week? ______
   vi. If everyday, how many times per day? ______
   vii. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
   viii. Does anyone else help you with dressing/undressing?
   ix. No (proceed to question Q) Yes (GO to x below)
   x. If yes, who ________________
   xi. Agency or paid caregiver: (Circle one)
       No (go to xii below) Yes (proceed to question Q)
   xii. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) __________
   xiii. How many times per week? ______
   xiv. If everyday, how many times per day? ______
   xv. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
Q. Does someone help you with using the toilet (e.g. helping onto and off the commode, cleaning up urine, or bowel accidents)?
   i. Circle one: No (proceed to question R) Yes (GO to ii below)
   ii. If yes, who ________________
   iii. Specify what: ________________________________________________
   iv. Agency or paid caregiver: (Circle one)
       No (go to v below) Yes (SKIP to ix below)
   v. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) _________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   vi. How many times per week? ______
   vii. If everyday, how many times per day? ______
   viii. How much time does it take? _____
       Interviewer will calculate the number of hours per week ______
   ix. Does anyone else help you with using the toilet?
   x. Circle one: No (proceed to question R) Yes (GO to xi below)
   xi. If yes, who ________________
   xii. Specify what: ________________________________________________
   xiii. Agency or paid caregiver: (Circle one)
       No (go to xiv below) Yes (proceed to question R)
   xiv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) _________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) ______________
   xv. How many times per week? ______
   xvi. If everyday, how many times per day? ______
   xvii. How much time does it take? ______
       Interviewer will calculate the number of hours per week ______
R. Does someone help you with transfers (e.g. from bed to chair, etc.)?
   i. Circle one: No  (proceed to question S)  Yes  (GO to ii below)
   ii. If yes, who ____________________
   iii. Agency or paid caregiver: (Circle one)
        No  (go to iv below)  Yes  (SKIP to viii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) _________
       7. Friend
       8. Neighbor
       9. Church
       10. Other  (specify)
   v. How many times per week? ______
   vi. If everyday, how many times per day? ______
   vii. How much time does it take? ______
       Interviewer will calculate the number of hours per week
   viii. Does anyone else help you with transfers?
   ix. No  (proceed to question S)  Yes  (GO to x below)
   x. If yes, who ____________________
   xi. Agency or paid caregiver: (Circle one)
        No  (go to xii below)  Yes  (proceed to question S)
   xii. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) _________
       7. Friend
       8. Neighbor
       9. Church
       10. Other  (specify)
   xiii. How many times per week? ______
   xiv. If everyday, how many times per day? ______
   xv. How much time does it take? ______
       Interviewer will calculate the number of hours per week
S. Does someone help you with walking?
   i. Circle one: No (proceed to question T) Yes (GO to ii below)
   ii. If yes, who ______________
   iii. Agency or paid caregiver: (Circle one)
        No (go to iv below) Yes (SKIP to viii below)
   iv. Specify relationship: (Circle one)
        1. Spouse
        2. Daughter
        3. Son
        4. Grand child
        5. Sibling
        6. Other family (specify) __________
        7. Friend
        8. Neighbor
        9. Church
        10. Other (specify) ______________
   v. How many times per week? ______
   vi. If everyday, how many times per day? ______
   vii. How much time does it take? ______
        Interviewer will calculate the number of hours per week ______
   viii. Does anyone else help you with walking?
   ix. No (proceed to question T) Yes (GO to x below)
   x. If yes, who ______________
   xi. Agency or paid caregiver: (Circle one)
        No (go to xii below) Yes (proceed to question T)
   xii. Specify relationship: (Circle one)
        1. Spouse
        2. Daughter
        3. Son
        4. Grand child
        5. Sibling
        6. Other family (specify) __________
        7. Friend
        8. Neighbor
        9. Church
        10. Other (specify) ______________
   xiii. How many times per week? ______
   xiv. If everyday, how many times per day? ______
   xv. How much time does it take? ______
        Interviewer will calculate the number of hours per week ______
T. Does someone stay with you at night, all night (night support)?
   i. Circle one: No (proceed to question U) Yes (GO to ii below)
   ii. If yes, who __________________
   iii. Agency or paid caregiver: (Circle one)
       No (go to iv below) Yes (SKIP to vii below)
   iv. Specify relationship: (Circle one)
       1. Spouse
       2. Daughter
       3. Son
       4. Grand child
       5. Sibling
       6. Other family (specify) __________
       7. Friend
       8. Neighbor
       9. Church
       10. Other (specify) __________
   v. How many times per week? ______
   vi. How much time does it take? _____
       Interviewer will calculate the number of hours per week ______
   vii. Does anyone else stay with you at night?
   viii. No (proceed to question U) Yes (GO to ix below)
   ix. If yes, who __________________
   x. Agency or paid caregiver: (Circle one)
      No (go to xi below) Yes (proceed to question U)
   xi. Specify relationship: (Circle one)
      1. Spouse
      2. Daughter
      3. Son
      4. Grand child
      5. Sibling
      6. Other family (specify) __________
      7. Friend
      8. Neighbor
      9. Church
      10. Other (specify) __________
   xii. How many times per week? ______
   xiii. How much time does it take? _____
       Interviewer will calculate the number of hours per week ______
U. Does someone help you with other tasks or activities that we have not discussed already?

i. Circle one: No (proceed to question 9) Yes (GO to ii below)

ii. If yes, who _________________

iii. What task: _______________________________________________________

iv. Agency or paid caregiver: (Circle one)
   No (go to v below) Yes (SKIP to viii below)

v. Specify relationship: (Circle one)
   1. Spouse
   2. Daughter
   3. Son
   4. Grand child
   5. Sibling
   6. Other family (specify) ______
   7. Friend
   8. Neighbor
   9. Church
   10. Other (specify) __________

vi. How many times per week? ______

vii. How much time does it take? _____
   Interviewer will calculate the number of hours per week ______

viii. Does anyone else help you with other tasks or activities?

ix. No (proceed to question 9) Yes (GO to x below)

x. If yes, who _________________

xi. What task: _______________________________________________________

xii. Agency or paid caregiver: (Circle one)
   No (go to xiii below) Yes (proceed to question 9)

xiii. Specify relationship: (Circle one)
   1. Spouse
   2. Daughter
   3. Son
   4. Grand child
   5. Sibling
   6. Other family (specify) ______
   7. Friend
   8. Neighbor
   9. Church
   10. Other (specify) __________________

xiv. How many times per week? ______

xv. How much time does it take? _____
   Interviewer will calculate the number of hours per week ______
9. We have just finished talking about specific help you receive from others. I am going to ask about other people who might be helping you that we have not talked about already. *(Do not mention anyone we have already discussed.)*

9-A. Do your grandchildren help you?  
(Circle one) Not Applicable  No  Yes  
If yes, specify who, task, frequency and duration:

9-B. Do your siblings help you?  
(Circle one) Not Applicable  No  Yes  
If yes, specify who, task, frequency and duration:

9-C. Do your nieces/nephews help you?  
(Circle one) Not Applicable  No  Yes  
If yes, specify who, task, frequency and duration:

9-D. Do other relatives help you?  
(Circle one) Not Applicable  No  Yes  
If yes, specify who, relationship, task, frequency and duration:

9-E. Do friends help you?  
(Circle one) No  Yes  
If yes, specify who, task, frequency and duration:

9-F. Do neighbors help you?  
(Circle one) Not Applicable  No  Yes  
If yes, specify who, task, frequency and duration:

9-G. Do members of faith organizations help you?  
(Circle one) No  Yes  
If yes, specify who, task, frequency and duration:

9-H. Does your apartment manager help you?  
(Circle one) Not Applicable  No  Yes  
If yes, specify who, task, frequency and duration:

9-I. Does anyone else we have not mentioned help you?  
(Circle one) No  Yes  
If yes, specify who, relationship, task, frequency and duration:
10. Is there anything you could suggest that would help to improve the ability of your primary caregiver to provide care for you? (PROMPT: For example, services, resources such as training, paid time off from work, etc.) EXAMPLES: Is it difficult for your primary caregiver to take off from work to take you to appointments? Does your primary caregiver have to juggle their time between their other family obligations and doing things for you?

___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

Remind the person that they can contact Dr Rosemary Chapin or Kelley Macmillan at 785-864-4720 if they have any questions.
Appendix I:

Community Tenure Decision Rules
Rules for the Community Tenure Analysis

For the purpose of this study, these are our decision rules: The dependent variable is the number of days in the community before the permanent NF admission.

1.) When calculating the number of days in the community, start the count with the day of the CARE Assessment.

2.) An older adult’s community tenure ends when admitted to NF for a period of 100 out of 120 days (do not have to be consecutive days) regardless of subsequent discharge to the community. At this point they will be considered a permanent NF resident and their community tenure has ended.

3.) Community tenure ends at the time an older adult has had four or more NF admissions. At this point they will be considered a permanent NF resident.

4.) If a person has four or more NF admissions and discharges OR is in NF 100 days out of 120, the date to use for the end in community tenure is the admission date that begins the 100-day (out of 120 days) stay.

5.) If the person dies in the NF, but their stay is less than 100 days before their death, they will not be considered a permanent NF admission.
Appendix J:

Advisory Committee on Human Experimentation Approval Letter
Contract Negotiations and Research Compliances

July 13, 1999
ACHE #11667

Rosemary Chapin
School of Social Welfare
Twente Hall
University of Kansas

The Advisory Committee on Human Experimentation has received your response to its expedited review of your research project.

11667 Chapin/Macmillan/Reehlm (SOC WEL) Longitudinal Study of Customers Diverted Through the CARE Program Long Term Care Project

and found that, as described, it complied with all the requirements and policies established by the University for protection of human subjects in research. The proposal is exempt from the usual Committee review under category (b)(2) of 45 CFR part 46.46.101. Participants will not be at risk. The Committee assumes that voluntary participation and confidentiality of individual responses is understood. Unless renewed, approval lapses one year after approval date.

Please follow the procedures listed below:

1. At designated intervals until the project is completed, a Project Status Report must be returned to the ACHE office.
2. Any significant change in the experimental procedure as described should be reviewed by this Committee prior to altering the project.
3. Notify ACHE about any new investigators not named in original application.
4. Any injury to a subject because of the research procedure must be reported to the Committee immediately.
5. When signed consent documents are required, the primary investigator must retain the signed consent documents for at least three years past completion of the research activity. If you use a signed consent form, provide a copy of the consent form to subjects at the time of consent.

Please inform ACHE when this project is terminated. You must also provide ACHE with an annual status report to maintain ACHE approval. Unless renewed, approval lapses one year after approval date. If your project receives funding which requires an annual update approval, you must request this from ACHE one month prior to the annual update. Thanks for your cooperation. If you have any questions please contact me.

Sincerely,

David Harin
ACHE Coordinator

cc: CNRC, Youngberg Hall
Faculty Supervisor:
Department: SOC WEL
Appendix K:

Consent Form for Interviews
Kansas Longitudinal CARE Diversion Study
Consent Form

The following information is provided to you so you can decide whether you wish to participate in the Kansas Longitudinal CARE Diversion Study being conducted by the University of Kansas, School of Social Welfare, Office of Aging and Long Term Care. You should be aware that even if you agree to participate, you are free to withdraw at any time without penalty.

You are being asked to participate in an interview that will help to identify what was important in your decision to choose community services or nursing facility placement. We are also interested in your perception of how the services you chose helped to improve the quality of your life. It is estimated that this interview will take approximately one hour of your time. We believe that the information gathered in this study will be useful in evaluating the benefits of in-home services for persons diverted from nursing facility placement throughout the state.

Your participation is strictly voluntary. We assure you that your name will not be associated in any way with the research findings. A code number will identify the information. Interviews will be tape-recorded. Access to the tapes will be restricted to the researchers and research assistants. Tapes will be destroyed immediately upon completion of the study.

If you would like additional information concerning this study before or after it is complete, please feel free to contact Kelley R. Macmillan, Research Assistant, at 785-864-3738. A copy of this consent form will be given to you.

Sincerely,

Dr. Rosemary Chapin
The University of Kansas
School of Social Welfare
Twente Hall
Lawrence, KS 66045-2510

With my signature I acknowledge that I have received a copy of this consent form to keep.

_________________________________________  _______________________________________
Customer’s Signature or Responible Party’s Signature  Interviewer’s Signature

____________________________________  ______________________________________
Date  Date
Appendix L:

State Community Tenure Questionnaire and State Responses
Community Tenure Questionnaire

Hello, my name is __________, and I’m calling from the University of Kansas School of Social Welfare. We are working with the Kansas Department on Aging & Social and Rehabilitation Services to set up a project in which we track older adults who have been diverted from nursing facility admission to see how long they are able to remain in the community. We’re talking with other states to learn whether they have tracked community tenure, how they have done it, and what they have learned. Would you have 10-15 minutes to answer a few questions?

1. First, do you measure nursing facility diversion rates?

   IF NOT, do you have some other way of tracking diversions?

2. How do you define a diversion?

3. Do you measure community tenure—i.e., how long diversions remain in the community?
   IF YES, how long have you been monitoring it? Why did the State decide to monitor it?
   IF NOT, do you have some informal way of tracking it? (If they don’t do anything formal, and it seems appropriate, end interview here.).

4. How do you define community tenure?
5. Can you describe how your tracking process works? For instance, when do you start and stop counting the person as a diversion? (Is there a particular event, such as pre-admission screening or the beginning service date that triggers the process?)

6. Do you track community tenure by individuals, or do you track only aggregate numbers? If individuals, how long do you track them? (e.g., calendar year, from beginning to end of services, etc.). What happens if there is a break in service because the person loses eligibility temporarily or enters a hospital or NF before returning to the community?

7. Who (what department, division, etc.) is responsible for gathering statistics, and where do they get their numbers? (MMIS, AAAs, etc., one source or several?).

8. Have you measured the average length of time people stay in the community after they begin HCBS and what eventually happens to them—e.g., what percentage of adults eventually enter NFs, what percentage die while on HCBS, etc.?

9. Who in your state is interested in community tenure data and how do they use it?

10. Is there anything we have not covered that is important to know about how you track community tenure?
11. Finally, do you know of any other states it might be good for us to contact?

12. Additional comments:

13. Number of people on FE waiver:

We would appreciate receiving any forms, reports, or other written material about how you track community tenure. Please address it to Kelley Macmillan, School of Social Welfare, Rm. 306 Twente Hall, University of Kansas, Lawrence, KS 66045.
<table>
<thead>
<tr>
<th></th>
<th>Missouri</th>
<th>Connecticut</th>
<th>Minnesota</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do they measure NF diversion rates?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
| 2. How do they define a diversion? | Customer’s expressed intent to accept HCBS in lieu of NF at time of pre-admission screening | Preadmission screened, 65+, meet financial eligibility requirement, and come onto Home Care program | 1) Found to be at high risk of NF placement during preadmission screening  
2) Care plan is cost-effective  
3) Client chooses HCBS |
| 3. Do they measure community tenure? | Yes, have done so since program began in 1992                            | Yes, have since program began in 1987                                                        | No, though probably could if asked |
| 4. How do they define community tenure? | Anyone who hasn’t chose NF                                                | Begin services and remain on program without long-term placement                              | N/A                                                                                           |
| 5. How does the tracking process work? | The preadmission system (“ELTACS”) contains client status codes that are updated whenever a significant change occurs, such as increase in level of needs or hospital admission. This system also tracks the state-funded “personal care” program. They feel this system is archaic because codes don’t tell them much about client functional status. Only tracks level of care in 9 areas and services received (by procedure code) | Start counting on beginning service date. Count until client dies, is admitted for long-term NF care (> 90 days), moves out of state, chooses to discontinue services for whatever reason, or cost of care becomes excessive. | N/A                                                                                           |
| 6. Do they track tenure by individuals or in aggregate? | 1) Both, but only look at aggregate numbers  
2) They track from beginning to end of services, spanning fiscal years  
3) Breaks in service are handled various ways, depending on length | Individuals                                                                      | If they did, would do aggregate                                                                  |
<p>| 7. Who gathers statistics? | Research &amp; Evaluation unit in DSS, by matching PAS data with MMIS         | Dept of Social Services. Have a MMIS designed to generate the numbers                          | Have staff of 3 with statistical backgrounds                                                        |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer 1</th>
<th>Answer 2</th>
<th>Answer 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Have they measured average length of stay in community?</td>
<td>Yes, but doesn’t know numbers off top of her head. Will send copy of Community Options report</td>
<td>Yes, it’s 35 months. Most common reasons for discharge are death and entering an NF.</td>
<td>Not sure but doesn’t think so</td>
</tr>
<tr>
<td>9. Who in the state is interested in community tenure data and how is it used?</td>
<td>Mostly the Legislature because of the allocation process</td>
<td>Legislature, Medicaid administration (as a justification for shifting resources from institution to community)</td>
<td>Everyone/no one. Program managers are too busy to sit down to plan this sort of research that could be done by their staff</td>
</tr>
<tr>
<td>10. Is there anything else important about how they track community tenure?</td>
<td>No</td>
<td>No, just that they have their own MMIS and have had to provide this information from day one.</td>
<td>No</td>
</tr>
<tr>
<td>11. Can they recommend other states to contact?</td>
<td>Tennessee and Iowa</td>
<td>Mass, Vt, NH, Maine (PAS binding)</td>
<td>No</td>
</tr>
<tr>
<td>12. Additional comments</td>
<td></td>
<td></td>
<td>They have an aggressive community reentry program. Case managers maintain contact with those admitted to NF to see if they can be discharged</td>
</tr>
<tr>
<td>13. Number of people on waiver</td>
<td>30,000 (40,000 including state program)</td>
<td>7,163</td>
<td>7,000</td>
</tr>
</tbody>
</table>
| Official Interviewed:                                                    | Sallianne Sestak  
Coordinator, Missouri Options Program  
9/29/99  
573/526-8531 | Michelle Parsons  
Manager, Home Care Unit  
10/8/99  
860/424-5177 | Pat James  
Director, Community Alternatives Program (past waiver director)  
10/1/99  
651/296-2213 |
<table>
<thead>
<tr>
<th></th>
<th>Iowa</th>
<th>Wisconsin</th>
<th>Michigan</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do they measure NF diversion rates?</td>
<td>No, but are trying to develop a way to do it</td>
<td>No</td>
<td>No. Track those on waiver admitted to NF and from NF to waiver.</td>
</tr>
<tr>
<td>2. How do they define a diversion?</td>
<td>N/A</td>
<td>When accepted into waiver program</td>
<td>N/A</td>
</tr>
<tr>
<td>3. Do they measure community tenure?</td>
<td>They track average time on program</td>
<td>No, but would be possible to do so by tracking back to waiver start date.</td>
<td>Only on an ad hoc basis. 1) Recently completed a study of all who left waiver through death or NF admission in 1996. Looked at community tenure for this group. 2) Monitor how long someone remains on waiver within a given fiscal year. Could accumulate years but currently don’t.</td>
</tr>
<tr>
<td>4. How do they define community tenure?</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>5. How does the tracking process work?</td>
<td>N/A</td>
<td>System records start date. If services are interrupted by period of institutionalization or ineligibility, the episode restarts. However, they could go back and capture original start date.</td>
<td>N/A</td>
</tr>
<tr>
<td>6. Do they track tenure by individuals or in aggregate?</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A. End of life study tracked individuals</td>
</tr>
<tr>
<td>7. Who gathers statistics?</td>
<td>N/A</td>
<td>N/A. They have only one staff member who keeps statistics.</td>
<td>Variety of sources</td>
</tr>
<tr>
<td>8. Have they measured average length of stay in community?</td>
<td>Only average time on program. She is faxing us the report.</td>
<td>Yes. The average time on HCBS is 3 years. However, they have a few who have been on as long as 12 years. They track on annual basis (not cumulatively). These statistics are included in the legislative report.</td>
<td>Yes, for those who left waiver through death or NF admission. Average for those who died while on waiver was 404 days, for those admitted to NF 83 days. Overall average 356 days.</td>
</tr>
<tr>
<td></td>
<td>Iowa</td>
<td>Wisconsin</td>
<td>Michigan</td>
</tr>
<tr>
<td>---</td>
<td>------</td>
<td>-----------</td>
<td>----------</td>
</tr>
<tr>
<td>9. Who in the state is interested in community tenure data and how is it used?</td>
<td>N/A</td>
<td>Mainly the legislature because it is used in the HCBS budgeting allocation process. The Dept. of Administration in the Governor’s office looks at the numbers in budgeting.</td>
<td>Only budget division. For everyone else, the issue is not even on the radar screen because of the program’s popularity. Budget staff attempted recently to cut waiver and were forced to back down for political reasons.</td>
</tr>
<tr>
<td>10. Is there anything else important about how they track community tenure?</td>
<td>N/A</td>
<td>Tenure has increased as services have expanded. They now have 17-18 services to choose from. She believes that if proposed plan to capitate HCBS is ever implemented, the menu will be cut.</td>
<td>No</td>
</tr>
<tr>
<td>11. Can they recommend other states to contact?</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>12. Additional comments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Number of people on waiver</td>
<td>Judy White: 13,000</td>
<td>Irene Anderson: 9,800</td>
<td>John Peterson: 9,800</td>
</tr>
<tr>
<td>Official Interviewed:</td>
<td>Title</td>
<td>Title</td>
<td>Title</td>
</tr>
<tr>
<td>Judy White</td>
<td>Case Management Coordinator, CMFE (waiver program)</td>
<td>Irene Anderson [not asked]</td>
<td>John Peterson Director, Research, Policy &amp; Program Development</td>
</tr>
<tr>
<td>Date: 10/28/99</td>
<td>10/4/99 10/29/99</td>
<td>603/266-3884</td>
<td>517/373-8562</td>
</tr>
<tr>
<td>Telephone number: 515/281-8621</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Ohio</strong></td>
<td><strong>Oregon</strong></td>
<td><strong>Washington</strong></td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1.</td>
<td>Do they measure NF diversion rates?</td>
<td>Yes, but it’s very small</td>
<td>No. Used to track where people admitted and discharged from, but no longer do.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No &amp; don’t have an informal way of tracking either</td>
</tr>
<tr>
<td>2.</td>
<td>How do they define a diversion?</td>
<td>Not asked</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>3.</td>
<td>Do they measure community tenure?</td>
<td>No</td>
<td>No. However, they would be interested in replicating our efforts.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bob Applebaum of the Scripps Institute at Miami University has done some</td>
<td>No, never have</td>
</tr>
<tr>
<td></td>
<td></td>
<td>studies in the past.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Referred me to him for further analysis.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>How do they define community tenure?</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>5.</td>
<td>How does the tracking process work?</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>6.</td>
<td>Do they track tenure by individuals or in aggregate?</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>7.</td>
<td>Who gathers statistics?</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>8.</td>
<td>Have they measured average length of stay in community?</td>
<td>No. However, they could compute if necessary.</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Applebaum’s work with the waiver showed that approx. ¼ disenrolled in</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>very short period, ½ entered NF, and 29% died.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td>9.</td>
<td>Who in the state is interested in community tenure data and how is it</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>used?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Is there anything else important about how they track community tenure?</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>11.</td>
<td>Can they recommend other states to contact?</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
</tr>
</tbody>
</table>
12. Additional comments

The state has had a demographic dip over the past few years, and number of elders on waiver has declined.

<table>
<thead>
<tr>
<th>Ohio</th>
<th>Oregon</th>
<th>Washington</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Number of people on waiver</td>
<td>15,600</td>
<td>25,000</td>
</tr>
</tbody>
</table>
Appendix M:

Amendment 1: An Expanded Analysis of Diverted Customers: August 2000
This legislative brief is based on work completed as part of the “Longitudinal Study of Customers Diverted through the CARE Program,” a three-year longitudinal study of older Kansans who have received a CARE Assessment. The overall purpose of this multi-year study is to examine publicly funded community based services and their relationship to diversion and community tenure of people assessed for nursing facility (NF) placement. During the course of this study, a number of findings with implications for policy makers have emerged, including the following:

- **Publicly funded services play a role in diversion of older adults from NF admission, by providing a combination of services that complement each other as well as the informal support of family.** Customers and primary caregivers reported that each service they received was equally essential and that without the services they would have to go to a NF.

- **The difference in the mean long-term care threshold score of the diverted and non-diverted groups is small.** In addition, more than half of the diverted customers in our sample had a NF admission directly after the CARE Assessment and were back in the community with services when the 30-day CARE Follow-up was completed. The quantitative and qualitative data both show that older adults are using NFs for short-term rehabilitative care and that older adults can and do come in and out of nursing facilities. In general, older adults no longer receive care in a linear progression beginning in the home and progressing to the nursing facility. It has become more of a “circle of care” with many different paths.

Based on these findings, additional analyses were conducted during this fiscal year in order to: 1) determine the source of in-home services diverted customers received; 2) examine rates of community tenure of diverted customers; 3) analyze the reasons why diverted customers didn’t apply for Medicaid or state funded community based services, particularly those customers who entered NFs with Medicaid as a payor source; and 4) learn more about the informal support received by diverted customers.

**Source of In-home Services Received at the Time of the CARE 30-Day Follow-Up**

In the first year of the study, it was learned that more than 75% of the diverted older adults assessed in May 1999 were getting services from sources (i.e. Medicare, private pay, etc.) other than state publicly funded services, including Medicaid HCBS/FE (SPFS). Diverted older adults who received the CARE Assessment in August 2000 were asked by CARE Coordinators during the CARE 30-Day Follow-up to identify the funding sources of any community-based services that they were receiving. The results are reported in Chart 1.

---

1 Diversion is defined as individuals who have been assessed for potential nursing facility placement, and who were residing in community settings with services or were living in board and care facilities when the 30 day follow-up contact was made. (CARE Annual Report, December 31, 1999, page 1).

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Chart 1: Source of In-home Services Received at the Time of the CARE 30-Day Follow-up (N = 86)

<table>
<thead>
<tr>
<th>Sources of In-home Services</th>
<th>In the Community</th>
<th>In the Community</th>
<th>In the NF</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Customers</td>
<td><strong>86</strong></td>
<td><strong>58 (67.4%)</strong></td>
<td><strong>13 (15.1%)</strong></td>
</tr>
<tr>
<td>SPFS Only</td>
<td>3</td>
<td>2 (66.7%)</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td>Informal Support Only</td>
<td>8</td>
<td>5 (62.5%)</td>
<td>None</td>
</tr>
<tr>
<td>Medicare and/or Private Pay</td>
<td>19</td>
<td>14 (73.7%)</td>
<td>2 (10.5%)</td>
</tr>
<tr>
<td>SPFS and Informal Support</td>
<td>8</td>
<td>4 (50.0%)</td>
<td>3 (37.5%)</td>
</tr>
<tr>
<td>SPFS and one or both Medicare and Private Pay</td>
<td>6</td>
<td>5 (83.3%)</td>
<td>None</td>
</tr>
<tr>
<td>Informal Support and one or both Medicare and Private Pay</td>
<td>27</td>
<td>19 (70.4%)</td>
<td>3 (11.1%)</td>
</tr>
<tr>
<td>SPFS, Informal Support and one or both Medicare or Private Pay</td>
<td>15</td>
<td>9 (60.0%)</td>
<td>4 (26.7%)</td>
</tr>
</tbody>
</table>

Combinations of Services

As Chart 1 indicates, the majority of diverted customers received a combination of services. Through the in-home interviews conducted during Phase II of the study, diverted CARE customers and primary caregivers reported that it was the combination of services that helped them maintain community tenure. In order to examine the relationship between the sources and combinations of services received by diverted customers and their community tenure\(^2\), an analysis of diverted customers status on the 180\(^{th}\) day after the CARE 30-Day Follow-up was conducted. Table 1 illustrates the community tenure status in relation to the source of in-home services received.

Table 1: Number and Percent of Diverted Customers in the Community 180 Days After the CARE 30-Day Follow-up Based on Source of In-home Services

\(^2\) Once a CARE customer is diverted, they are considered to have maintained community tenure until they die or move into a NF permanently (for a period greater than 100 days).
Table 1 illustrates that diverted customers receiving SPFS and one or both of Medicare and private pay had the highest community tenure rate (83.3%). For those diverted customers receiving informal support only, none entered an NF, and although they had a lower community tenure rate (62.5%), older adults in this group remained in the community until their death. Based on additional analysis, we found that those diverted customers with SPFS only and those with SPFS, informal support and one or both of Medicare or private pay are the most impaired. These services are going to the frailest older adults and helping them to remain in the community.

State Publicly Funded Services (including Medicaid HCBS/FE)

The data in Chart 1 show that 37% (N= 32) of the diverted customers received some type of SPFS. These services could include Medicaid HCBS/FE, Senior Care Act, Income Eligible or Older Americans Act services. The vast majority of customers receiving SPFS were also receiving some other type of service. In order to examine why more diverted customers were not receiving SPFS, customers were asked if they had applied for SPFS and if not, why not. This information is important to policy makers since these customers may enter NFs and spend down to Medicaid. Customers who entered an NF but may have been eligible for SPFS represent a potential cost savings/avoidance for the state if they are able to remain in the community rather than entering a NF and subsequently going on Medicaid.

Diverted customers did not apply for SPFS primarily because they believed they were not eligible (N = 17). The other major reason was that they did not want SPFS (N = 11). Of those customers who had not applied for SPFS by the time of the 30-day follow-up (N=26), 38% had received SPFS by the 180th day after the follow-up. Although they may eventually receive the services, consumer education about the services and eligibility are warranted. One of the findings from interviews conducted with diverted customers last year was that they did not have enough information about community-based services that would have helped them prepare for sudden health problems or changes.

Informal Support Services

As Chart 1 shows, 68% (N=58) of the diverted customers were receiving informal support at the time of the 30-day follow-up. In order to learn more about the informal support received, phone interviews were conducted with diverted customers in the fall, 2001. Thirty-one people participated in the survey. Twenty-three respondents were older adults who received a CARE Assessment in April or August 2000, and eight were primary caregivers interviewed in place of the customer when the customer was unable to complete the interview. Since a convenience sample was used to conduct this informal support survey, findings are not necessarily indicative of all older Kansans. Nonetheless, we can glean the sources of informal supports that frail older adults in Kansas rely on, and how their informal support system strives to assist these older adults to maintain community residence.

Over 90% (N=27) of these older adults were found to have someone they relied on for their day-to-day tasks and emergencies. With the exception of five respondents, all of the other respondents identified primary caregivers as relatives. The majority of family caregivers were identified as a spouse (N = 5) or an adult child (N = 12; 6 daughters and 6 sons). Table 2 shows the types and sources of informal support by respondents. 13 areas of assistance that aid frail older adults’ activities of daily living (ADLs) and instrumental activities of daily living (IADLs) were identified. Although social, emotional and financial supports are types of supports that are extremely important for older adults, this list includes only instrumental tasks.
Table 2: Type and Source of Informal Support Provided to Customer

<table>
<thead>
<tr>
<th></th>
<th>Family</th>
<th>Friends or Neighbors</th>
<th>Church</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal care</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administration of medication</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coordination of in-home services &amp; medical treatment</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Handling financial/business matters</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Night support</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication (using telephone, reading, &amp; writing)</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housekeeping</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Household maintenance</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Grocery shopping</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Emergency contact</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>“Checking on” regularly</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

Older adults received a wide variety of assistance from their informal support network. However, the type of support provided varied by the source. Families took care of different types of tasks than friends or neighbors. Most frail older adults rely on a few people who provided a wide variety of assistance to help them to stay in the community. In many cases primary caregivers took responsibility to provide all assistance including personal care and housekeeping tasks with very little help.

Given the fact older adults have few sources of informal support, primary caregivers are providing a substantial portion of caregiving hours needed for the care recipients. The amount of informal support that individual older adults received varied greatly from less than one hour to over 40 hours per week depending on their needs and available formal and informal supports. The informal caregiving system is very fragile because it is often based on both the health and availability of one caregiver.

In response to the question what would help people who provide informal supports to improve their ability to care for frail older adults, caregivers who provided a high level of care most vocally expressed their needs for respite, night support, and housekeeping services. A number of respondents (N = 14) utilized paid services for some tasks, such as laundry (N = 10), housekeeping (N = 14) meal preparation (N = 10), household maintenance (N = 14), and this included five diverted customers who lived in assisted living facilities. The majority of older adults seem to be satisfied with the kinds and quality of care they received from both formal and informal support system.

It is important to note that 18 of the 31 older adults interviewed were receiving SPFS in addition to the informal support. The fact that these older adults were residing in the community a year or more after their CARE Assessment points to the beneficial impact the SPFS have in supporting informal caregivers.
Summary

These findings highlight the importance of the combination of services older adults receive in maintaining community tenure. Also, informal support, by and large provided by one family member, is complementing the community-based services received. Any changes in services provided must be carefully considered in light of the impact the change would have on the formal and informal caregiving system that helps older adults maintain community tenure and delay NF admission.
Appendix N:

Amendment 2: Community Based Service Utilization Prior to Nursing Facility Admission
Legislative Brief:
Community Based Service Utilization Prior to Nursing Facility Admission

This legislative brief is based on work completed as part of the “Longitudinal Study of Customers Diverted through the CARE Program,” a three-year longitudinal study of older Kansans who have received a CARE Assessment. The overall purpose of this multi-year study is to examine publicly funded community based services and their relationship to diversion and community tenure of people assessed for nursing facility (NF) placement. During the course of this study, a number of findings with implications for policy makers have emerged, including the following:

- **Eighty percent of persons who had a CARE Assessment were in a nursing facility (NF) when the CARE 30-day follow-up was completed.** Care Coordinators and Directors of the AAAs reported that Medicaid and state administered/publicly funded services were provided for a significant number of non-diverted older Kansans, prior to NF placement (referred to as ‘early diversion’). AAA staff believes that early diversion might have played a key role in helping these persons to maintain community tenure before being admitted to the NF.

- **Publicly funded services can help delay NF admission, by providing a combination of services that complement each other.** Customers and primary caregivers reported that each service they received was equally essential and that without the services they would have to go to a NF.

Based on these findings, additional analyses were conducted during this fiscal year in order to: 1) calculate the ‘early diversion’ rate; 2) document the occurrence of early diversion and identify state administered/publicly funded services, including Medicaid HCBS/FE and State General Fund/Older American Act services that non-diverted customers received prior to NF admission; and; 3) explore whether individuals who received services in the six months prior to their CARE assessment were more impaired upon entry into the NF than persons who did not receive services. The potential to delay NF placement and thereby save state Medicaid dollars is of primary interest in all these analyses.

There were 2,056 non-diverted older adults from the four months of data (May 1999, and March, April and August 2000) used for these analyses.

**Service Utilization Prior to NF Admission (Early Diversion)**

- **Out of the 2,056 older adults who were admitted to a NF, 514 used publicly funded services during the six months prior to admission. This corresponds to an early diversion rate of 25%. These individuals used HCBS-FE (n=165; 8%) and SGF/OAA (n=349; 17%) services.**

Also, Medicaid was the payment source for the NF stay of 489 of these 2,056 persons. Seventy-four of the 489 persons (15.1%) were considered short-term NF Medicaid residents (e.g., they were discharged from the NF in 120 days or less). There were 415 individuals (84.9%) who were long-term or permanent

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3 Diversion is defined as individuals who have been assessed for potential nursing facility placement, and who were residing in community settings with services or were living in board and care facilities when the 30 day follow-up contact was made. (CARE Annual Report, December 31, 1999, page 1).

4 These 489 persons for whom Medicaid was listed as a payment source during the first 120 days of NF admission would have likely qualified for services (Medicaid-HCBS/FE and SGF/OAA) and are referred to as service eligible in this brief.

5 We queried 120 days instead of 100 days (the Medicare limit for rehabilitation per occurrence) to allow for brief interruptions in service delivery (e.g., short hospital stays).
Medicaid NF residents (e.g., their stay exceeded 100 days or they died while in the NF, which may have occurred sooner than 100 days).

- The early diversion rate of the 415 permanent Medicaid NF residents was 42.9%. In the six months prior to their NF admission, 178 of them used services.
- The use of services before NF admission appears to have an impact on length of stay. For example, among the 74 short-term NF residents, 64.9% (n=48) used services compared to 42.9% (n=178) of the 415 permanent Medicaid NF residents. This suggests that prior knowledge and involvement with services facilitates coordinating discharge and re-entry in the community.

Profile of Permanent Medicaid NF Residents

Table 1 illustrates the demographic distribution of the 415 permanent Medicaid NF residents by the source of funding for services received prior to NF admission.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Used Services (n=178)</th>
<th>Did Not Use Services (n=237)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Medicaid-HCBS/FE (n=125)</td>
<td>SGF/OAA (n=53)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>1 (1.9%)</td>
<td>12 (5.1%)</td>
</tr>
<tr>
<td>65-74</td>
<td>24 (19.2%)</td>
<td>45 (19.0%)</td>
</tr>
<tr>
<td>75-84</td>
<td>41 (32.8%)</td>
<td>87 (36.7%)</td>
</tr>
<tr>
<td>85 &amp; Older</td>
<td>60 (48.0%)</td>
<td>93 (39.2%)</td>
</tr>
</tbody>
</table>

Gender *  
- Male 35 (28.0%) 19 (35.8%) 81 (34.3%)  
- Female 90 (72.0%) 34 (64.2%) 155 (65.7%)

*These do not total the n because of missing values.

- Forty-eight percent of the NF residents who used Medicaid-HCBS/FE prior to admission were age 85 or older, compared to about 39% of the SGF/OAA recipients. The Medicaid-HCBS/FE services helped to maintain a greater proportion of the oldest-old in the community. This group is at the greatest risk of NF placement and generally lacks informal support.

- The vast majority of permanent Medicaid NF residents, regardless of prior service utilization, were women and age 75 and older.

Types of Services Used Prior to NF Admission

One hundred seventy-eight of the 415 permanent Medicaid residents used at least one Medicaid-HCBS/FE (n=125) or one SGF/OAA service (n=53) in the six months prior to their CARE assessment.
• Health Care Attendant II was used by 80.0% of the 125 HCBS/FE service customers--nearly twice as often as the next most frequently used service, wellness monitoring (37.6%). This illustrates that Health Care Attendant II is a core service for many older adults, and is used in combination with other services. The use of this service may have played an important role in delaying NF admission.

• Home delivered meals were used by about half of the 53 SGF/OAA service customers (49.1%). SGF case management and attendant care (non-medical) services were used by approximately 33.0% of services recipients.

• It was found that Medicaid-HCBS/FE services were used an average of 5.8 months and SGF/OAA services were used an average of 3.3 months during the seven months that were queried (e.g., the month of the CARE assessment plus six months prior).

Comparison of LTC Threshold Scores by Service Utilization Prior to NF Admission

The mean LTC threshold score for permanent Medicaid NF residents who used and did not use services prior to NF admission was compared. These data indicated that there were no significant differences in level of impairment between permanent Medicaid NF residents who entered the NF with prior service utilization and those who did not utilize services before being admitted to the NF. In the FY2001 Diversion Study Report, the mean LTC threshold score of the diverted individuals was 65.8, and the non-diverted individuals mean LTC threshold score was 74.0. This data is also helpful in comparing the permanent Medicaid NF residents LTC scores.

• Permanent Medicaid NF residents (non-diverted individuals) who entered the NF after receiving services were more impaired (LTC score = 73.8), on average, than diverted customers (LTC score = 65.8).

An additional sub-analysis of LTC threshold scores of permanent Medicaid NF residents was conducted to discern differences between older adults that used services and those that did not use services. There were 149 permanent Medicaid NF residents whose LTC threshold score was at the diverted group mean of 66 or below. It was found that the 74 people who did not receive services were entering the NF with less impairment than those who received services. Targeting services to these people prior to permanent NF placement could have potentially delayed their NF admission.

Summary

These analyses document that ‘early diversion’ is frequent among non-diverted individuals, and appears to play an important role in helping these individuals maintain community residence prior to NF placement. A significant number of less impaired non-diverted permanent Medicaid NF residents did not receive services before their NF admission. Targeting services to individuals with lower impairment levels may potentially delay their NF admission. Additionally, Medicaid NF residents who used services prior to NF admission were more likely to have shorter stays and re-enter the community than Medicaid NF residents with no prior use of services. Cost savings could have accrued to the state had services been provided to these customers to delay permanent Medicaid NF placement. This analysis documents that the use of services prior to NF placement delays permanent Medicaid NF placement.
Appendix O:

Glossary
Glossary

Andersen Social-Behavioral Model of health care use - The Andersen Model is widely used to understand patterns of health services use for older adults. Introduced in the 1970’s, it serves to categorize personal and environmental factors, which in concert lend to the use of healthcare resources by older adults (Andersen, 1995; Andersen & Newman, 1973). Andersen’s model is comprised of three categories of factors influencing service use: predisposing, enabling and need factors. These factors ultimately predict service use.

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

CARE Program - The Client Assessment, Referral, and Evaluation (CARE) Program is administered by KDOA. In Kansas, all older adults seeking admission to a nursing facility (NF) must have a CARE Assessment prior to NF admission.

CARE 30-Day follow-up - AAA CARE Program staff confirmed the diversion status of the CARE customers at the 30th day after the CARE Assessment when they completed the CARE 30-day Follow-up. This method identified the 600 diverted customers being tracked for community tenure. Thereafter, the status of diverted customers at 3-month intervals after the CARE Assessment was confirmed through several data sources.

Community Based Services - In this report, community-based services include case management, wellness monitoring, home delivered and congregate meals, personal emergency service, homemaker, and personal care. In this report, the funding sources for these services include Medicaid-HCBS/FE, Senior Care Act, Income Eligible, and Older Americans Act. In this report, in-home community-based service programs are also referred to as State Publicly Funded Services (SPFS).

Community Tenure - the community tenure of an individual is calculated from the day the diverted customers received the CARE Assessment. Although diversion status is determined when the 30-day CARE Follow-up is completed, the time between the CARE Assessment and the 30-day follow-up is considered community tenure for any days the customer is not in an NF. If a diverted customer enters a NF at any time after the 30-day follow-up, and is discharged in 100 days or less, they are still considered to have maintained community tenure. Diverted customers have maintained community tenure until they die or move into a NF permanently (for a period greater than 100 days).

Diversion - Diversion in this project is defined as “those individuals who have been assessed for potential nursing facility placement, and who were residing in community settings with services or were living in board and care facilities when the 30 day follow-up contact was made” (CARE Annual Report, December 30, 1998, page 5).
**Enabling Factors** - Personal, family, and community characteristics that must exist in order for elders to make use of services. Andersen (1995) writes that not only must the services be available to the elder, but that the elder must be able to make use of the services. Recognition of service need enables service utilization to occur. “Health personnel and facilities must be available where people live and work. Then, people must have the means and know-how to get those services…income, health insurance, a regular source of care” (Andersen, 1995, p.3).

**Informal Services** - in this project, informal services are those unpaid services or assistance provided by family, friends, and neighbors to older adults. In addition, the voluntary efforts provided by churches, and service organizations and associations are also informal services.

**Long Term Care Threshold Score (LTC Score)** - A weighted, composite score calculated based on assessment of ADL, IADL, cognitive, bladder continence, support, abuse, neglect, exploitation by other, and falls. The LTC score is used to assess the appropriateness for NF and CBS.

**Need Factors** - The need for care and services perceived as a need by the older adult or evaluated by health service providers. “Perceived need is largely a social phenomenon…. Evaluated need represents professional judgment about people’s health status and their need for medical care” (Andersen, 1995, p.3).

**Permanent Nursing Facility Admission** - An older adult’s community tenure ends when admitted to NF for a period of 100 out of 120 days (these do not have to be consecutive days) regardless of subsequent discharge to the community. At this point they will be considered a permanent NF resident and their community tenure has ended. If the person dies in the NF, but their stay is less than 100 days before their death, they will not be considered a permanent NF admission.

**Predisposing Factors** - characteristics such as demographic status, social structure, and the elders’ beliefs about health. The “broad array of factors that determine the status of a person in the community, his or her ability to cope with presenting problems and commanding resources to deal with these problems” (Andersen, 1995, p.2)

**Service Customer** - For the purposes of this report, a service customer is a person, who after the CARE Assessment, is receiving services funded by any or all of the following sources: 1) The Older Americans Act (OAA) funds; 2) state general funds (SGF), including Senior Care Act (SCA) and Income Eligible (IE), 3) Medicaid Targeted Case Management, 5) Medicaid Administration Case Management, and 5.) Medicaid HCBS/FE, funded through a match of state and federal dollars.

**State Publicly Funded Services (SPFS)** - In this report, state publicly funded services include Medicaid-HCBS/FE, Medicaid TCM, Medicaid Case Management, services funded by state general funds such as the Senior Care Act Program, Income Eligible program, and nutrition programs funded by state funds and the Older Americans Act.