

**SUPPORT FOR THE ELDERLY,
DISABLED AND PERSONS WITH
HIV/AIDS TO REMAIN AT HOME AS
EXPERIENCED BY THE CONSUMERS**

**SOUTH CAROLINA COMMUNITY LONG
TERM CARE PROGRAM**

MAY 31, 2003

**PREPARED FOR THE UNIVERSITY OF SOUTH CAROLINA
COLLEGE OF SOCIAL WORK**

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EXECUTIVE SUMMARY

The participants in this study were consumers of Community Long Term Care services for the elderly and disabled and persons diagnosed with HIV/AIDS. The purpose of the study was to determine the experience of the consumers with CLTC around five issues. The issues are: Do the services provided have the desired affect of allowing consumers to remain at the lowest possible level of care (that is, remain in their home and not enter a nursing facility)? What would consumers do if the services were not provided? Is the social functioning of consumers reasonable given their situation, and has it improved since they began receiving services? What changes might be made in the services provided that would make it more likely consumers will not move to a higher level of care? Are the consumers satisfied with their services?

There were three parts to the methodology used in the study. First, a sample of 29 CLTC service consumers were interviewed in-depth on the telephone regarding their ideas about the issues. These interviews were analyzed, and a written survey was designed using the analysis and sent out to about 500 consumers and their caregivers. The 268 responses to the survey were entered into a database. The resulting information was analyzed, a report developed and recommendations for programs and further study made.

Almost 70% of the respondents believe they (or those for whom they care) would not be able to stay in the home or were not sure they would be able to remain in the home without CLTC services. The issue of what to do if the services were not provided turned out to be such a stressful question, it was not pursued in the quantitative survey. Questions about social functioning were not among the top issues to be pursued in the interviews, and therefore were not in the survey. An overwhelming majority of the respondents are satisfied with their services.

About 38% of respondents believe that more of the same services they (or those they are caring for) are now receiving will help them remain in their homes. About 31% believe other services will help them (or those they are caring for) remain in their home. These two figures are especially prominent among caregivers. Approximately 60% of caregivers believe that more of the same services will help the people they are caring for stay in the home. About 61% of caregivers replied that they need other services for those they are caring for to stay in the home. These numbers are almost twice the overall percentage. Also among caregivers, about 32% believe that they sometimes are near the end of their ability to provide care.

The following recommendations are made. 1) The number of CLTC slots be increased to at least the number of people on the present waiting list. 2) The amount of services provided to selected consumers be increased. 3) The types of services provided to selected consumers be increased. 4) Additional and more flexible respite services be provided for caregivers. 5) An organization of caregivers be developed to support caregivers in sharing knowledge about community resources and to support one another. 6) A group of caregivers, consumers and CLTC workers determine how best to encourage the communications to consumers who do not understand their rights and responsibilities. 7) The data gathered for the study continue to be analyzed, particularly as it relates to services for aging persons who have not as yet entered CLTC services.

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INTRODUCTION

South Carolina Community Long Term Care

The mission of Community Long Term Care (CLTC) is "... to provide a cost effective alternative to institutional placement for eligible clients with long term care needs, allowing them to remain in a community environment if they choose." CLTC has a state headquarters, but services are provided through 13 area offices.

Medicaid law requires that long term care services be provided in nursing facilities. However, waivers to the law can be obtained to provide these services in one's home, and states routinely obtain such waivers. South Carolina was among the early states to do so, establishing a state-wide Community Long Term Care (CLTC) program in 1983. CLTC is located in the South Carolina Department of Health and Human Services (SC DHHS) and operates three different waiver programs. These programs cover the following groups of people:

- The elderly and/or disabled;
- Those with HIV/AIDS;
- Those dependent on a mechanical ventilator.

CLTC administers two other waiver programs that are operated by the SC Department of Developmental Disabilities. These cover the following groups of people:

- Those with mental retardation and related diseases;
- Those with head and spinal cord injuries.

In addition to the waiver programs, CLTC also operates the pre-admission screening programs for all Medicaid sponsored long term care services, including nursing facility services. Pre-admission screening is conducted through assessments by registered nurses to determine medical eligibility based on established level of care criteria. The criteria are classified as either skilled or intermediate. Once a person is classified at either of these levels, they become eligible to receive Medicaid-sponsored long term care services (either in their home or in a nursing facility) in South Carolina.

In order to classify under the skilled level of care, a person must have a need for a skilled service and have at least one functional deficit. Skilled services include, but are not limited to: daily monitoring or observation due to an unstable medical condition, administration of medications, and treatment of disease or other medical disorder. Functional deficits, or activities of daily living (ADL's) are the everyday activities involved in personal care such as feeding, dressing, bathing, moving from a bed to a chair (also called transferring), toileting and walking (sometimes called locomotion). A person can also classify for skilled level of care if they are totally dependent in all ADL's.

A person can classify under the intermediate level of care in one of two ways. The first way is to require at least one intermediate service and have one functional deficit. The second way is if that person has at least two functional deficits. Intermediate services include supervision of the following: overall healthcare planning, moderate/severe memory loss, moderately impaired cognitive skills, and moderate problem behavior. Functional deficits are the ADL's such as feeding, dressing, bathing, transferring, and locomotion.

To enter the elderly/disabled waiver program, applicants must meet: nursing facility level of care criteria; be 18 years old or older; and be Medicaid eligible. To enter the HIV/AIDS program, applicants must be diagnosed with HIV/AIDS; be at risk of hospitalization; and be Medicaid eligible. To enter the mechanical ventilator program, the applicant must be 21 years old or older; meet nursing facility level of care criteria; and require mechanical ventilation.

Once an applicant is found to be eligible, he or she is enrolled in the program and assigned a case manager. The case manager develops a comprehensive plan of care in coordination with the new consumer and his or her primary caregivers. The case manager also monitors the consumer and the services provided to the consumer; coordinates services; authorizes the services; and re-evaluates the consumer regularly.

The number of people who can be served by CLTC is limited by the amount of funding made available by the Legislature. Costs for CLTC services are less than half the costs of serving someone in a nursing facility. The average total cost (long term care and other Medicaid costs) for an elderly/disabled consumer in FY 2000-2001 was \$10,257, while that of a consumer placed in a nursing facility was \$21,452.

In FY 2000-2001, CLTC served 14,431 consumers. However, due to limits in the amount of funds provided by the Legislature, a number of consumers had to go on a waiting list. In April of 2002, the number on the waiting list was 3,417. Since the time necessary to wait for a nursing facility bed is quite short, or there is no wait at all, many consumers choose to enter nursing facilities in order to receive needed services rather than wait for an opening in CLTC.

Among the consumers of Elderly/Disabled services, about 13% are white males, 33% white females, 39% African-American females and 15% African-American males. About 12% of Elderly/Disabled clients are 49 years old or younger. About 28.4% are between the ages of 50 and 69. The remaining 59.6% are over 69.

Purposes of this Study

The participants in this study are consumers of the services being provided by the Community Long Term Care program to the elderly and disabled and persons diagnosed with HIV/AIDS. There are two purposes to the study. The first purpose is to determine the experience with and perceptions about five issues among the consumers. The second purpose is to provide recommendations on how the information gathered can be used to improve the program. The five issues are:

- Do the services provided have the desired affect of allowing consumers to remain at the lowest possible level of care (that is, remain in their home and not enter a nursing facility)?
- What would consumers do if the services were not provided?
- Is the social functioning of consumers reasonable given their situation, and has it improved since they began receiving services?
- What changes might be made in the services provided that would make it more likely consumers will not move to a higher level of care?
- Are the consumers satisfied with their services?

To accomplish these purposes, the study has five objectives:

- To assess the knowledge, beliefs, attitudes, and assumptions held by consumers regarding the five issues (their *mental models* about the issues).
- To assess how widely these mental models are held by CLTC consumers and how demographic variables influence mental models.
- To understand how specific events (such as turnover in service providers) influence mental models among CLTC clients.
- To identify demographic predictors of differences in these mental models that can be used to effectively stratify and target audiences for particular service interventions.
- To use the knowledge gained in the previous objectives to develop specific recommendations to the program.

METHODOLOGY

Phase One - Understanding How Consumers Think about the Five Issues

Phase One was designed to assess the knowledge, beliefs, attitudes, and assumptions held by consumers about the five issues; to assess how widely these mental models of the five issues are held; and to assess how these mental models have been influenced by the consumers' experiences with the program. As part of this assessment, predictors of differences in these mental models were identified that could be used to effectively stratify and target audiences for particular interventions. To accomplish these objectives, both qualitative and quantitative research methods were used.

Qualitative Study - Mental Modeling

The mental modeling research methodology was used for the qualitative portion of the study. Mental modeling is a qualitative research approach that uses in-depth semi-structured interviews with individuals to help uncover their understanding and perceptions of an issue. Though labor-intensive, mental modeling provides several advantages. It allows for in-depth analyses of not just *what* people know about an issue, but also *how* they think about an issue. That is, advanced forms of mental modeling permit the mapping of constructs and their relationships to one another. So, in addition to cataloging the beliefs people have about a particular issue, it is also possible to examine the source of those beliefs and how those beliefs are connected together to form a cognitive mental model of that issue.

Sampling Strategy

To get a sense of the diversity of mental models held by consumers about the five issues, a multi-level, stratified, purposive sampling approach will be used. Fifty consumers were chosen from a randomly selected sample of 507. The fifty were chosen to provide a representative group by age, race, gender, geographic location and reason for services (elderly, disabled or HIV/AIDS). The interviews were conducted by telephone. If the consumer was unable to take part in an interview, the primary caregiver was substituted. The goal was to interview twenty individuals who met the sampling schedule and an additional ten only on items that related to CLTC service satisfaction and compliance issues. A total of 29 were interviewed, 21 on all questions and eight on items related to CLTC service satisfaction and compliance issues. An initial letter of introduction was sent about one week prior to the telephone call.

Procedure

1. Mental Modeling Interviews

The interviews were conducted by a group of specially trained graduate students. Participation was voluntary and respondents were notified as such. Identifying information was kept strictly confidential. Interviews were tape-recorded and transcribed. Interviews lasted an average of about 70 minutes. The Interview Schedule may be found in Appendix One.

2. Data Entry

The interviewer's case notes and recorded interviews were transcribed by the interviewer or by a professional transcriber. In addition, the responses to the service satisfaction and compliance issues, which lent themselves to dichotomous answers, were entered into a quantitative database.

3. Analyses

A set of coding criteria were developed by two SWS investigators (See Appendix Two). These were developed through an iterative process, in which each investigator read each of the first five interviews conducted and determined what themes presented themselves. These themes were defined and placed in a coding book. All of the transcriptions were then read by the two investigators twice each. During these readings, the mentions of the themes were identified and noted. The two investigators "staffed" each transcript to reach consensus on the identifications.

The investigators determined the number of mentions of each theme, and the number of people who mentioned each theme. This information was entered into an Excel spreadsheet classified by reason that the consumer was receiving services. The themes were ranked using a combination of mentions and number of persons mentioning the theme. Two types of themes were identified, Affective and Cognitive. A final list of top ranked themes (six for the Affective Themes and seven for the Cognitive Themes) were identified as candidates for the quantitative instrument. (See Appendix Three for the four spreadsheets concerning this analysis.)

The service satisfaction and compliance issues were examined based on the percent of times a particular negative response was made. All issues that were mentioned more than once were candidates for the quantitative instrument.

A final decision on the themes and issues to be tested in the quantitative instrument was made after consultation with staff at SC DHHS. Hypotheses were then developed based on the themes and issues, and questions developed based on the hypotheses.

Hypotheses

The hypotheses developed through the qualitative process are:

1. Many consumers believe that they would not be able to remain at home if they did not receive the CLTC services.
2. Many consumers believe they need other kinds of help besides what they are receiving in order to remain in their homes.
3. Many consumers believe they need more of the help they are already receiving in order to remain at home.
4. Consumers believe they can speak freely with the people who come to their home to help them.
5. Consumers believe they can depend on the people who come to their homes to help them.

6. Consumers want to stay in their homes as long as they can.
7. Many caregivers feel so overwhelmed at times that they don't believe they can continue providing care as they presently are.
8. Consumers know who to notify if they have a complaint about a service.
9. Consumers are notified if a service is not going to be delivered when it is supposed to be.
10. Consumers are given a choice of services.
11. Consumers' rights and responsibilities were explained to them before they started receiving services.
12. Someone talked to consumers about a plan for their services before the services started.
13. If consumers made a complaint, they were satisfied with the action that took place.

Quantitative Study

Instrument Design

A single, two page self-administered survey including 14 questions was developed to test the themes and issues. Use of a questionnaire with a statistically representative group of consumers also allowed variations in responses among diverse demographic groups to be examined. Seven of the questions are responded to with a five point Likard scale, including the one question designed for caregivers only. The remaining seven questions require dichotomous responses. A copy of the survey may be found in Appendix Four.

Sampling Strategy

The initial sample held 507 records randomly selected by computer at SC DHHS. Twenty nine were used for the qualitative study. During the qualitative study, an additional 30 consumers were discovered to be deceased, moved to a nursing home, or otherwise unable to participate in the study. The remaining 448 records were then sent the survey questionnaire. During this quantitative phase of the study, an additional 35 consumers were discovered to be deceased, moved to a nursing home, or otherwise unable to participate in the study. As a result, only the remaining 413 consumers could possibly respond to the survey questionnaire.

In order to achieve a confidence level of 95% and confidence interval of 6, a total of 262 responses were necessary. In the cover letter, caregivers were asked to complete the survey if the consumer was unable to do so. Of the possible 413 responses, twenty were pulled from the sample for in-home interviews using the survey. Twelve of these consumers/caregivers agreed to be interviewed at home. A total of 169 surveys were returned. An additional 87 surveys were then completed by telephone to produce a total N of 268. Each survey was coded so that the survey could be tied back to the demographics of the consumer to whom it was sent without identifying the consumer by name.

Procedure

1. Self-Administered Survey

The surveys were distributed by mail to the sample. A stamped, self-addressed envelope was included with the form. A cover letter explained what the survey was for, assured confidentiality and informed the consumer that they could have a family member or other person familiar with their situation fill out the survey on their behalf. (A copy of the letter may be found in Appendix Five.) Persons filling out the form for a consumer are called “caregivers” for the remainder of this report. Approximately two weeks after the surveys were mailed, telephone calls were made to persons who had not returned their forms. The consumers were asked to give their answers by telephone. The questionnaires were expected to take no more than 10 minutes to complete.

2. Content of Survey

- A. Themes Questionnaire: The first section of the questionnaire contains seven questions derived from the themes, one of which is specific to caregivers. The self-administered questionnaire was constructed to find out how widely the concepts identified most often are held within the consumer population and what demographic variables influence who holds these concepts.
- B. Satisfaction and Compliance Questionnaire: The second section of the questionnaire contains seven questions regarding satisfaction and compliance issues that are problematic for the consumers. The self-administered questionnaire was constructed to find out how widely the problems identified most often are held within the consumer population and what demographic variables influence who holds these concepts.

3. Data Entry

A database was constructed and entered in Access. Separate, but related, tables were used for each of the three types of data: contact information, demographics, and survey responses. This allowed the researchers to maintain the integrity of the data while still being able to correlate survey responses to demographics.

4. Analysis

The Access database was imported into a SPSS file to conduct the statistical analysis. Several different analyses were performed on the data in order to determine statistical importance, including frequencies, crosstabs, t-test, and chi-square. Tables and graphs were also developed in SPSS, then exported to an Excel format to ease editing and printing.

Focus Groups

A series of five focus groups were planned for the study to add more depth to the findings around how the services might be improved to keep consumers from moving into a higher level of care.

One of these focus groups was held with Bureau of Senior Services and Long Term Care personnel to develop focus group questions. Three of the other four were conducted with Elderly/Disabled consumers and/or their primary caregivers in the Upstate, Low Country and PeeDee regions of the state. Initially, a similar group with HIV/AIDS consumers was to be held in the Midlands. However, it was found that these consumers were without transportation and too ill to travel to a central location. A series of telephone interviews was substituted for the HIV/AIDS focus group.

Phase Two- Development of Report and Recommendations

Subsequent to the analysis of the data, a series of discussions were held among the study team members. The discussions centered around the interpretation of the findings of the study. Upon the completion of these discussions, a draft report was completed with the following elements:

- Executive Summary
- Introduction
- Methodology
- A presentation of the findings
- A discussion of the findings
- Conclusions based on the findings
- Specific recommendations based on the conclusions

Methodology Summary

QUALITATIVE PROCESS

1. Develop interview instrument.
2. Identify sample.
3. Conduct interviews.
 - a. Conduct interviews, while
 - b. Identifying themes (iterative process)
 - c. Sample to fill cells
4. Analyze interviews.
 - a. Identify mentions of themes
 - b. Determine instances of mentions and number of persons mentioning
 - c. Classify themes
 - d. Rank Themes
 - e. Determine top rankings

QUANTITATIVE PROCESS

1. Develop surveys based on qualitative information.
2. Identify sample.
3. Conduct survey.
 - a. Mail out
 - b. Follow-up phone calls
 - c. Home interviews
4. Analyze surveys.
 - a. Input data
 - b. Transfer database to SPSS
 - c. Conduct statistical analysis

FOCUS GROUPS

1. Determine place and makeup
2. Develop questions
3. Conduct focus groups
 - a. Greenville, Charleston, Florence, Columbia
 - b. Three elderly/disabled, one HIV/AIDS
4. Analyze information
 - a. Identify mentions of themes
 - b. Determine instances of mentions and number of persons mentioning
 - c. Classify themes
 - d. Rank Themes
 - e. Determine top rankings

FINAL REPORT DEVELOPMENT

1. Integrate data
 - a. Qualitative
 - b. Quantitative
2. Prepare Report
 - a. Findings
 - b. Discussion of Findings
 - c. Conclusions
 - d. Recommendations

PRESENTATION AND DISCUSSION OF THE FINDINGS

Survey Findings

Introduction

The data gathered for this study is rich in detail and depth. No single report could do justice to all the information that can be derived from the data. The findings presented below and the conclusions and recommendations at the end of the report will focus on answering the initial questions proposed by CLTC and go somewhat beyond those. Further, specific uses to be made of the data will also be provided at the end of the report.

For purposes of the report, the Themes Questions responses “yes definitely” and “yes I think so” were combined, as were “no I don’t think so” and “no definitely not” responses. Also, missing values are included in the percentages presented to provide an idea of how many people did not respond to a particular question.

Response Rate, Confidence Level, and Confidence Interval

A total of 158 consumers and 81 caregivers responded to the survey. An additional 29 people did not identify of which group they are a part, a total of 268. This constituted a response rate of 66.5%. The confidence interval for this data is 6%, at a 95% confidence level. Therefore, there is a very high probability that the responses to the survey represent the responses that can be expected from all elderly disabled and HIV/AIDS consumers of CLTC services (plus or minus 6%).

Demographic Characteristics

The demographic description of the population surveyed is portrayed in Tables I – VII and Figures I – VII. These demographics parallel those of the general CLTC consumer population.

Table I: Consumers by Region		
	#	%
Coastal/PeeDee	92	34.3%
Midlands	93	34.7%
Upstate	83	31.0%
Total	268	100.0%

Figure I: Consumers by Region

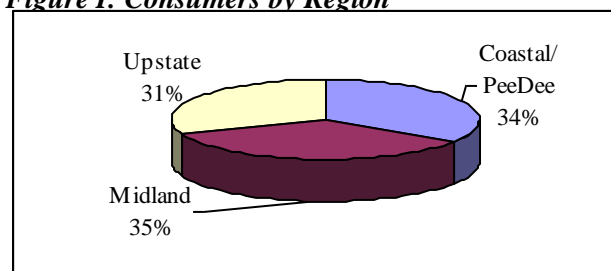


Table II: Consumers by Reason for Services		
	#	%
Elderly/Disabled	185	69.0%
Disabled	61	22.8%
HIV/AIDS	18	6.7%
Unknown	4	1.5%
Total	268	100.0%

Figure II: Consumers by Reason for Services

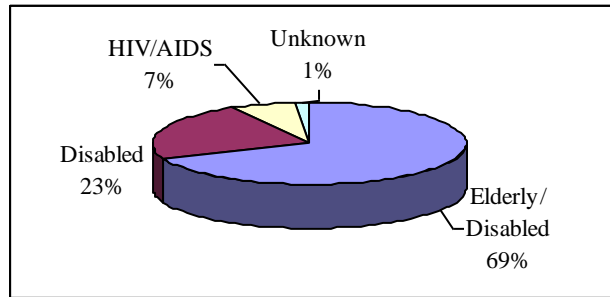


Table III: Consumers by Age Range		
	#	%
20 to 29	6	2.2%
30 to 39	6	2.2%
40 to 49	26	9.7%
50 to 59	38	14.2%
60 to 69	50	18.7%
70 to 79	55	20.5%
80 to 89	61	22.8%
Over 90	23	8.6%
Unknown	3	1.1%
Total	268	100.0%

Figure III: Consumers by Age Range

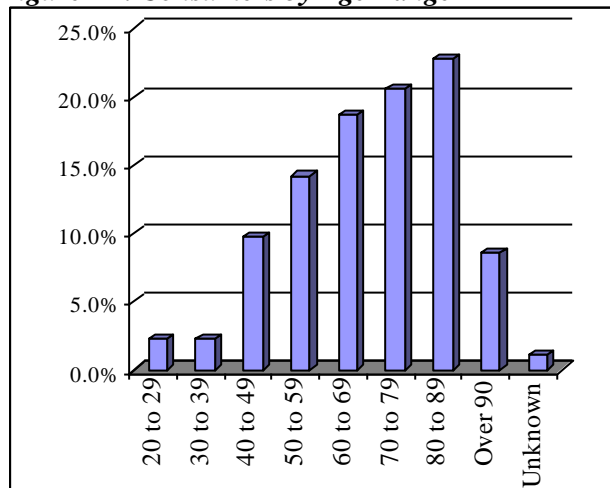


Table IV: Consumers by Ethnicity		
	#	%
Black	133	49.6%
White	130	48.5%
Unknown	5	1.9%
Total	268	100.0%

Figure IV: Consumers by Ethnicity

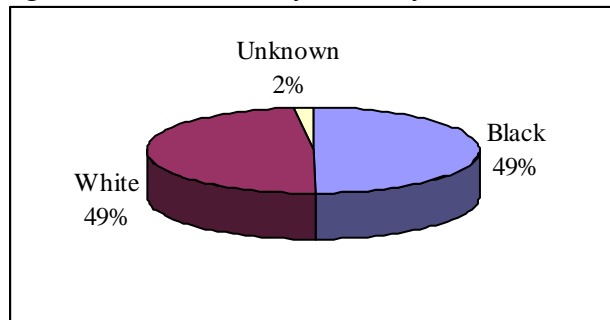


Table V: Consumers by Gender		
	<u>#</u>	<u>%</u>
Female	179	66.8%
Male	86	32.1%
Unknown	3	1.1%
Total	268	100.0%

Figure V: Consumers by Gender

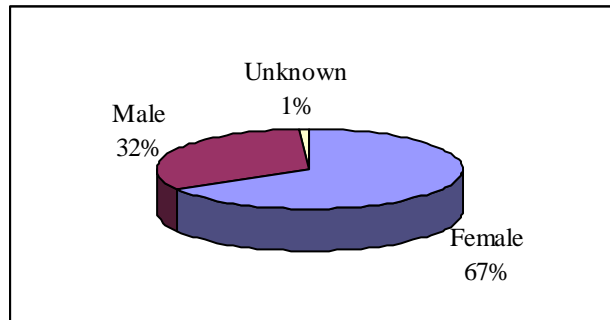


Table VI: Consumers by Education		
	<u>#</u>	<u>%</u>
Less than Third Grade	28	10.4%
Third through Eighth Grade	96	35.8%
Some High School	59	22.0%
High School Graduate	56	20.9%
Some College	14	5.2%
College Graduate	7	2.6%
Unknown	8	3.0%
Total	268	100.0%

Figure VI: Consumers by Education

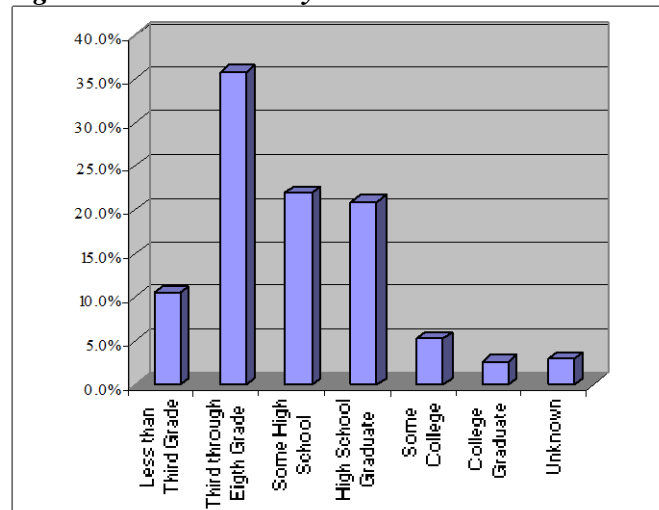
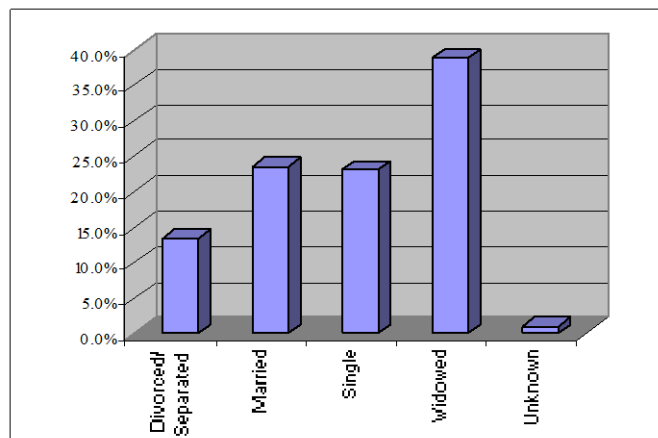


Table VII: Consumers by Marital Status		
	<u>#</u>	<u>%</u>
Divorced/Separated	36	13.4%
Married	63	23.5%
Single	62	23.1%
Widowed	104	38.8%
Unknown	3	1.1%
Total	268	100.0%

Figure VII: Consumers by Marital Status



Consumers versus Caregivers

There was some concern that the answers given by caregivers would differ from the answers given by consumers. A chi square analysis was therefore conducted on each question to determine if any such differences occurred. There were only two statistically significant differences.

The first difference was on Themes Question 2, “I need more of the help I am already getting if I am going to stay at home.” Consumers were almost twice as likely to answer that they do not need more help as caregivers were likely to answer for the consumer (62.6% versus 39.7% after removing missing values and those who responded as neutral). This difference is highly statistically significant (Chi-square = 9.468, p less than or equal to .002). (See Tables VIII a and VIII b and Figure VIII.)

The second difference was on Themes Question 3, “I need other kinds of help besides what I’m getting now if I am going to stay at home.” Consumers were more likely to answer that they do not need other help as caregivers were likely to answer for the consumer (61.8% versus 39.1% after removing missing values and those who responded as neutral). This difference is statistically significant (Chi-square =9.045, p less than or equal to .003). (See Tables IX a and IX b and Figure IX.)

Table VIII a : Themes Question 2														
I need more of the help I am already getting if I am going to stay at home.														
	Yes Definitely		Yes I Think So		Maybe Yes Maybe No		No I Don't Think So		No Definitely Not		No Response		Totals	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Consumer	39	24.7%	10	6.3%	20	12.7%	59	37.3%	23	14.6%	7	4.4%	158	100.0%
Caregiver	26	31.7%	15	18.3%	9	11.0%	16	19.5%	11	13.4%	5	6.1%	82	100.0%
Total	65	27.1%	25	10.4%	29	12.1%	75	31.3%	34	14.2%	12	5.0%	240	100.0%

Table VIII b: Themes Question 2 Summarized						
(Missing Values and Neutral Responses Removed)						
	Yes		No		Total	
	#	%	#	%	#	%
Consumer	49	37.4%	82	62.6%	131	100%
Caregiver	41	60.3%	27	39.7%	68	100%
Total	90	45.2%	109	54.8%	199	100%

Figure VIII: Themes Question 2

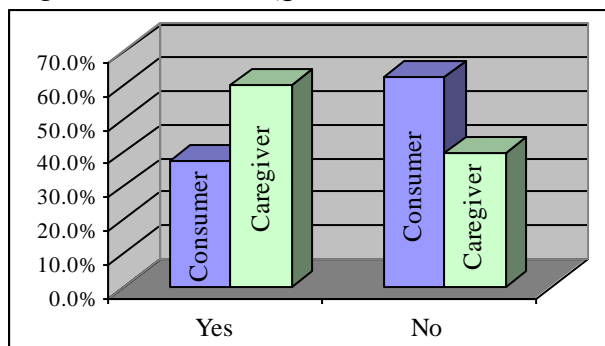
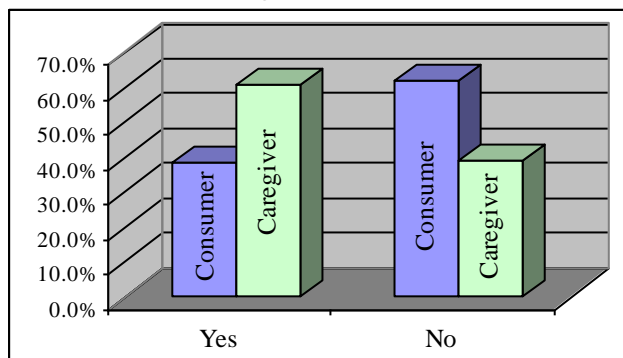


Table IX a : Themes Question 3														
I need other kinds of help besides what I'm getting now if I am going to stay at home.														
	Yes Definitely		Yes I Think So		Maybe Yes Maybe No		No I Don't Think So		No Definitely Not		No Response		Totals	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Consumer	28	17.7%	24	15.2%	15	9.5%	53	33.5%	31	19.6%	7	4.4%	158	100.0%
Caregiver	19	23.2%	20	24.4%	13	15.9%	7	8.5%	18	22.0%	5	6.1%	82	100.0%
Total	47	19.6%	44	18.3%	28	11.7%	60	25.0%	49	20.4%	12	5.0%	240	100.0%

Table IX b: Themes Question 3 Summarized (Missing Values and Neutral Responses Removed)						
	Yes		No		Total	
	#	%	#	%	#	%
Consumer	52	38.2%	84	61.8%	136	100%
Caregiver	39	60.9%	25	39.1%	64	100%
Total	91	45.5%	109	54.5%	200	100%

Figure IX: Themes Question 3



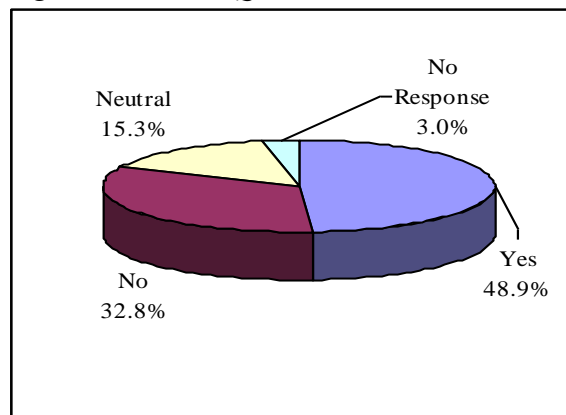
Themes Questions

1. "If I didn't have these services, I would not be able to stay at home."

Forty-eight and nine tenths percent of the respondents stated that the consumer would not be able to remain at home without the CLTC services. Another 15.3% were not sure and 3% did not respond. Thirty-two and eight tenths percent of the respondents stated that they could remain at home without these services. (See Table X and Figure X.)

Table X: Themes Question 1 If I didn't have these services, I would not be able to stay at home.		
	#	%
Yes Definitely	99	36.9%
Yes I Think So	32	11.9%
Maybe Yes Maybe No	41	15.3%
No I Don't Think So	37	13.8%
No Definitely Not	51	19.0%
No Response	8	3.0%
Total	268	100.0%

Figure X: Themes Question 1



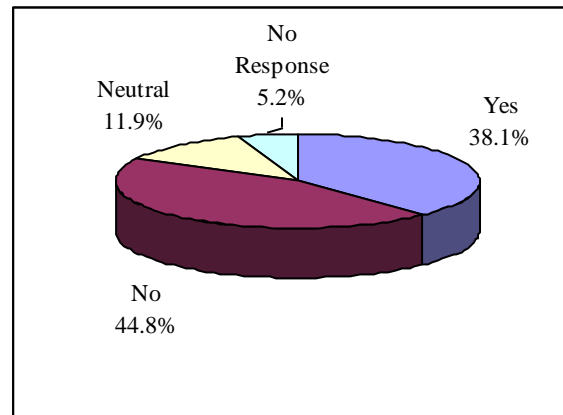
2. *“I need more of the help I am already getting if I am going to stay at home.”*

As mentioned previously, there were significant differences between consumers’ responses to this question and the responses of caregivers. The responses were almost exactly the opposite of each other. Of the caregivers, 53.9% said more help was needed and 34.2% said more help was not needed. Among the consumers, 54% said more help was not needed and 32.9% said more help was needed. Among the caregivers, 11.8 % were not sure, as were 13.2% of the consumers. Four point nine percent of caregivers and 4.4% of consumers did not respond. (Please refer to Tables VIII a and VIII b and Figure VIII in the Consumers versus Caregivers section of this report.)

Overall, 38.1% of all respondents stated that they need more of the help they are currently receiving in order to stay in their home. On the opposite side, 44.8% of all respondents stated that they did not need more help in order to stay in their home. The remaining 11.9% and 5.2% were either unsure or did not respond, respectively. (See Table XI and Figure XI.)

Table XI: Themes Question 2 I need more of the help I am already getting if I am going to stay at home.		
	#	%
Yes Definitely	71	26.5%
Yes I Think So	31	11.6%
Maybe Yes Maybe No	32	11.9%
No I Don't Think So	84	31.3%
No Definitely Not	36	13.4%
No Response	14	5.2%
Total	268	100.0%

Figure XI: Themes Question 2



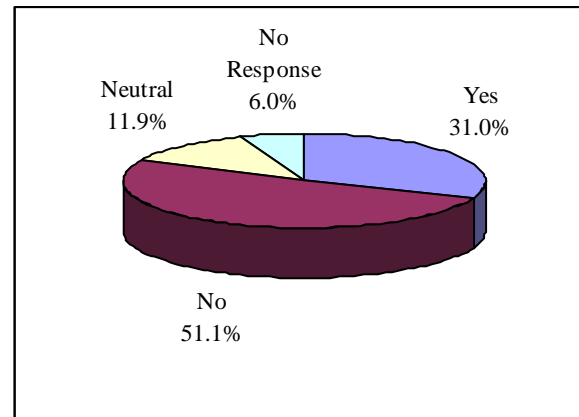
3. *“I need other kinds of help besides what I’m getting now if I am going to stay at home.”*

This was the second question the answers to which were significantly different between consumers and caregivers. The responses of caregivers were almost evenly divided between those who believe other kinds of help are needed (40.3%) and those who don’t (42.9%). Among consumers, 29.6% believe they need other kinds of services and 60.5% do not. Caregivers were more ambivalent than the consumers, with 16.9% were not sure how to answer while 9.9% of consumers were not sure how to answer. Four point nine percent of caregivers and 3.8% of consumers did not respond. (For the breakdown of responses comparing the two different respondents, please refer to Tables IX a and IX b and Figure IX in the Consumer versus Caregiver section of this report.)

Overall, 31% of all respondents stated they need other kinds of help in order to stay in their homes. An additional 51.1% stated they do not need additional help in order to stay in their homes. The remaining 11.9% and 6% of respondents were either unsure or did not respond to the question, respectively. (See Table XII and Figure XII.)

Table XII: Themes Question 3		
I need other kinds of help besides what I'm getting now if I am going to stay at home.		
	#	%
Yes Definitely	51	19.0%
Yes I Think So	32	11.9%
Maybe Yes Maybe No	32	11.9%
No I Don't Think So	87	32.5%
No Definitely Not	50	18.7%
No Response	16	6.0%
Total	268	100.0%

Figure XII: Themes Question 3

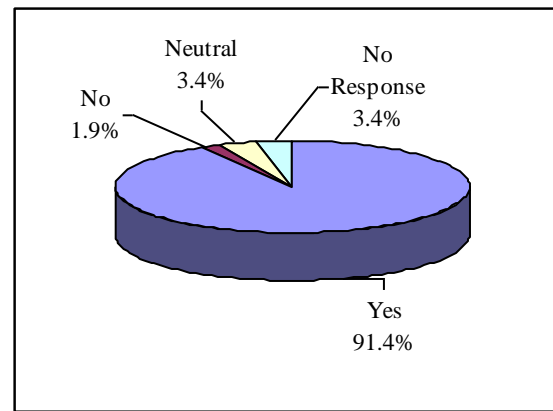


4. I can speak freely with the people who come to my home to help me.

Only five respondents (less than 2%) did not believe they can speak freely to the people who come to their home to help them. Three and four tenths percent were not sure and 3.4% did not answer the question. That leaves 91.4% of respondents who clearly stated they can speak freely to those who come to their home to help them. (See Table XIII and Figure XIII.)

Table XIII: Themes Question 4		
I can speak freely with the people who come to my home to help me.		
	#	%
Yes Definitely	207	77.2%
Yes I Think So	38	14.2%
Maybe Yes Maybe No	9	3.4%
No I Don't Think So	1	0.4%
No Definitely Not	4	1.5%
No Response	9	3.4%
Total	268	100.0%

Figure XII: Themes Question 4



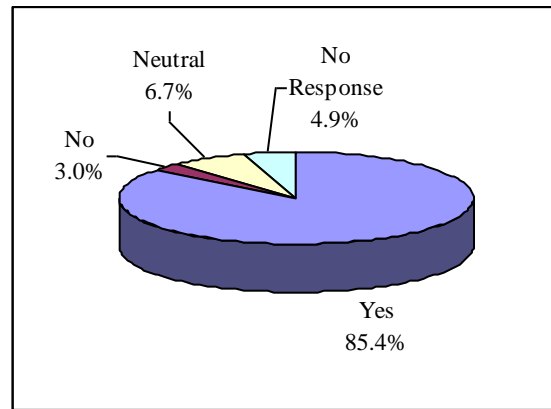
5. I can depend on the people who come to my home to help me.

Just eight respondents (3%) did not believe they can depend on the people who come to their home to help them. Another 6.7% were not sure how to answer and 4.9% did not answer the question. That leaves 85.4% who clearly stated they can depend on those who come to their homes to help them. (See Table XIV and Figure XIV.)

Table XIV: Themes Question 5		
I can depend on the people who come to my home to help me.		

	#	%
Yes Definitely	198	73.9%
Yes I Think So	31	11.6%
Maybe Yes Maybe No	18	6.7%
No I Don't Think So	3	1.1%
No Definitely Not	5	1.9%
No Response	13	4.9%
Total	268	100.0%

Figure XIV: Themes Question 5



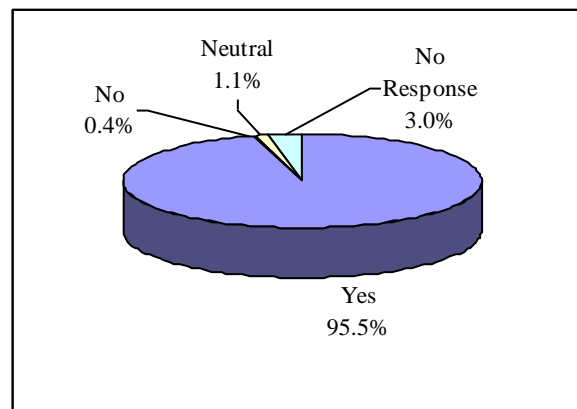
6. I want to stay in my home as long as I can.

As might be expected, just one respondent (0.4%) did not agree with this statement. Another three respondents (1.1%) were not sure how to answer and 3% did not answer the question. That leaves 95.5% who clearly stated they want to stay in their homes as long as possible. (See Table XV and Figure XV.)

This question was a test of the instrument, in that it was expected that virtually all respondents would respond positively. That did, indeed, happen, assuring that the questions on the instrument were being answered accurately.

Table XV: Themes Question 6 I want to stay in my home as long as I can.		
	#	%
Yes Definitely	245	91.4%
Yes I Think So	11	4.1%
Maybe Yes Maybe No	3	1.1%
No I Don't Think So	0	0.0%
No Definitely Not	1	0.4%
No Response	8	3.0%
Total	268	100.0%

Figure XV: Themes Question 6

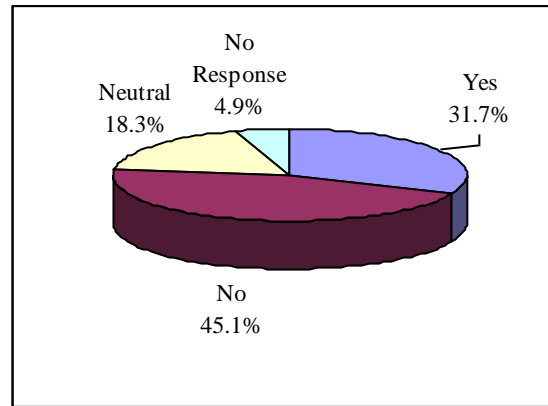


7. Sometimes I feel so overwhelmed I think I can't continue providing care like I am now.

This question was asked only of caregivers. Of the caregivers, 31.7% agreed with the statement. Another 45.1% disagreed, 18.3% were not sure how to answer, and 4.9% did not respond. (See Table IVX and Figure IVX.)

Table XVI: Themes Question 7		
Caregivers Only: Sometimes I feel so overwhelmed I think I can't continue providing care like I am now.		
	#	%
Yes Definitely	15	18.3%
Yes I Think So	11	13.4%
Maybe Yes Maybe No	15	18.3%
No I Don't Think So	10	12.2%
No Definitely Not	27	32.9%
No Response	4	4.9%
Total	82	100.0%

Figure XVI: Themes Question 7



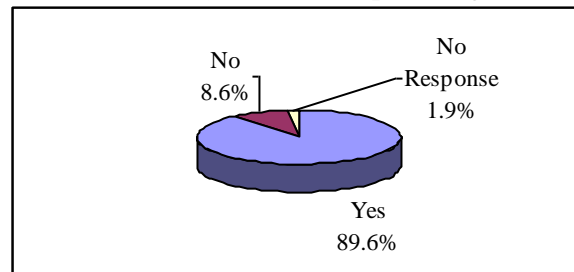
Satisfaction and Compliance Questions

1. *I know who to notify if I have a complaint about a service.*

Eighty-nine and six tenths percent of respondents answered yes to this question. Eight point six percent answered no and 1.9 % did not respond. (See Table XVII and Figure XVII.)

Table XVII: Satisfaction & Compliance Question 1		
I know who to notify if I have a complaint about a service.		
	#	%
Yes	240	89.6%
No	23	8.6%
No Response	5	1.9%
Total	268	100.0%

Figure XVII: Satisfaction & Compliance Question 1

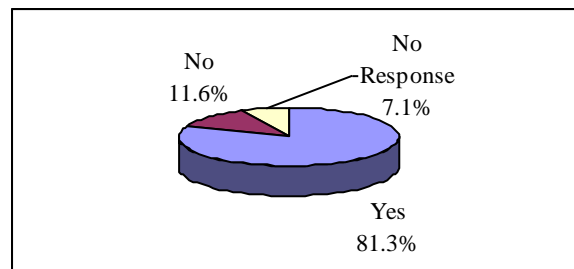


2. *I am notified if a service is not going to be delivered when it is supposed to be.*

Eighty-one and three tenths percent of respondents answered yes to this question. Eleven and six tenths percent answered no and 7.1% did not respond. (See Table XVIII and Figure XVIII.)

Table XVIII: Satisfaction & Compliance Question 2		
I am notified if a service is not going to be delivered when it is supposed to be.		
	#	%
Yes	218	81.3%
No	31	11.6%
No Response	19	7.1%
Total	268	100.0%

Figure XVIII: Satisfaction & Compliance Question 2

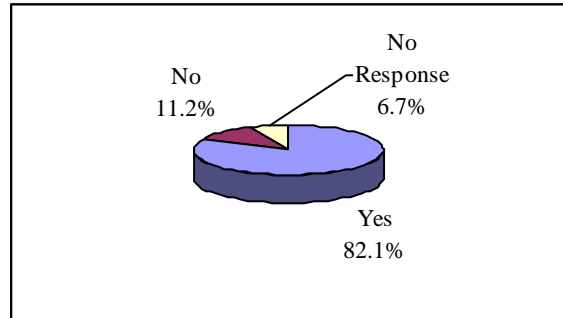


3. *When I first started the program, I was given a choice of services I could receive.*

Eighty-two and one tenth percent of respondents answered yes to this question. Eleven and two tenths percent answered no and 6.7% did not respond. (See Table XIX and Figure XIX.)

Table XIX: Satisfaction & Compliance Question 3 When I first started the program, I was given a choice of services I could receive.		
	#	%
Yes	220	82.1%
No	30	11.2%
No Response	18	6.7%
Total	268	100.0%

Figure XIX: Satisfaction & Compliance Question 3

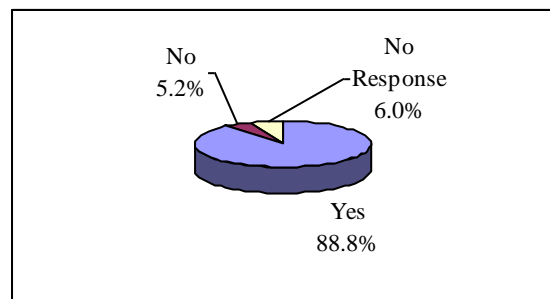


4. *My rights and responsibilities were explained to me before I started receiving services.*

Eighty-eight and eight tenths percent of respondents answered yes to this question. Five and two tenths percent answered no and 6% did not respond. (See Table XX and Figure XX.)

Table XX: Satisfaction & Compliance Question 4 My rights and responsibilities were explained to me before I started receiving services.		
	#	%
Yes	238	88.8%
No	14	5.2%
No Response	16	6.0%
Total	268	100.0%

Figure XX: Satisfaction & Compliance Question 4

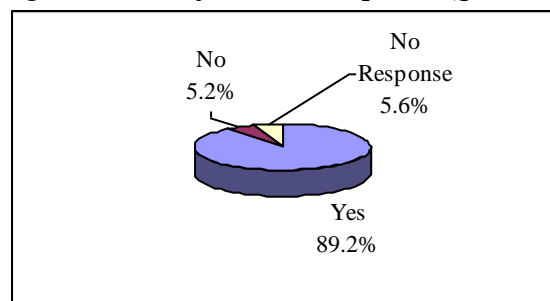


5. *Someone talked to me about a plan for my services before I started getting them.*

Eighty-nine point two tenths percent of respondents answered yes to this question. Five point two percent answered no and 5.6% did not respond. (See Table XXI and Figure XXI.)

Table XXI: Satisfaction & Compliance Question 5 Someone talked to me about a plan for my services before I started getting them.		
	#	%
Yes	239	89.2%
No	14	5.2%
No Response	15	5.6%
Total	268	100.0%

Figure XXI: Satisfaction & Compliance Question 5

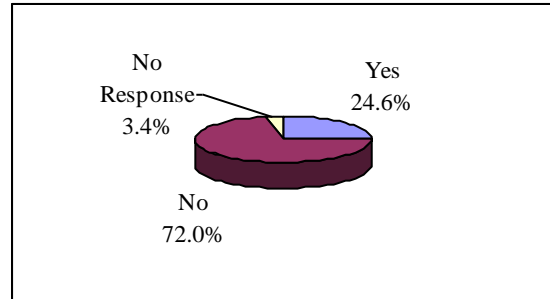


6. *I have written or called someone to make a complaint about my services.*

Twenty-four and six tenths percent of respondents stated they had made a complaint. An additional 72% stated that they had not. The remaining 3.4% did not respond. (See Table XXII and Figure XXII.)

Table XXII: Satisfaction & Compliance Question 6 I have written or called someone to make a complaint about my services.		
	#	%
Yes	66	24.6%
No	193	72.0%
No Response	9	3.4%
Total	268	100.0%

Figure XXII: Satisfaction & Compliance Question 6

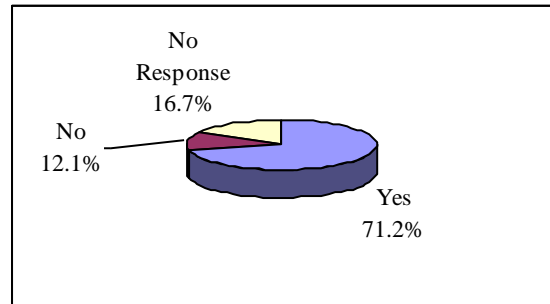


7. *If you made a complaint, were you satisfied with what was done about it?*

Seventy one and two tenths percent of those who made a complaint were satisfied with the result. Twelve and one tenth percent were not satisfied, and 16.7% did not respond. (See Table XXIII and Figure XXIII.)

Table XXIII: Satisfaction & Compliance Question 7 If you made a complaint, were you satisfied with what was done about it?		
	#	%
Yes	47	71.2%
No	8	12.1%
No Response	11	16.7%
Total	66	100.0%

Figure XXIII: Satisfaction & Compliance Question 7



Other Significant Findings of the Survey

The key question in the Themes section of the survey is Question 1, *“If I didn’t have these services, I would not be able to stay at home.”* An examination of how the responses to this question interact with responses to other questions was conducted. Tests of significance were conducted for the responses to all of the other Theme Questions in regards to question 1. Statistically significant differences were found for two of the questions, questions 2 and 3. The tests were then repeated for the consumer sample and the caregiver sample. It was found that the differences lay entirely in the consumer group.

Question 2 asked, “I need more of the help I am already getting if I am going to stay at home.” If a consumer answered yes to this question, they were more than twice as likely to answer yes to question 1 than to answer no to question 1. If they answered no to question 2 then their chances of answering yes or no to question 1 were much closer to even. The differences among responses to these two questions are significant at the .01 level. It can be surmised that about 25% of all consumers not only believe they need CLTC services to remain in the home, but also believe that they need more of these services to remain in their home. See Tables XXIV a and XXIV b and Figure XXIV.

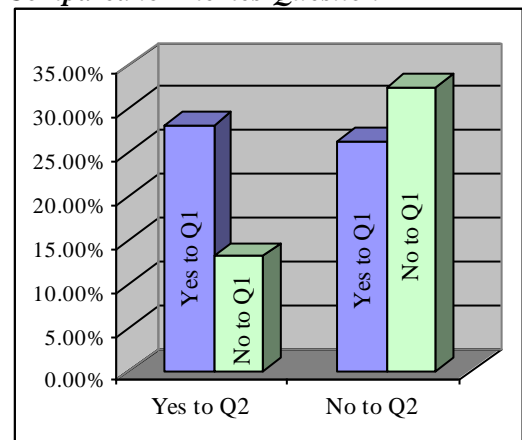
Table XXIV a: Themes Question 2 Compared to Themes Question 1								
Response to Question 1	Response to Question 2							
	Yes			No			Total	
	#	% within Q2	% of Total	#	% within Q2	% of Total	#	% of Total
Yes	32	68.1%	28.1%	30	44.8%	26.3%	62	54.4%
No	15	31.9%	13.2%	37	55.2%	32.5%	52	45.6%
Total	47	100.0%	41.2%	67	100.0%	58.8%	114	100.0%

Table XXIV b: Chi-Square Tests for Comparison					
	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	6.425 ^b	1	.011		
Continuity Correction ^a	5.497	1	.019		
Likelihood Ratio	6.529	1	.011		
Fisher's Exact Test				.014	.009
Linear-by-Linear Association	6.369	1	.012		
N of Valid Cases	114				

a Computed only for a 2x2 table

b 0 cells (.0%) have expected count less than 5. The minimum expected count is 21.66.

Figure XXIV: Themes Question 2 Compared to Themes Question 1



Question 3 asked, “I need other kinds of help besides what I’m getting now if I am going to stay at home.” If a consumer answered yes to this question, they were almost twice as likely to answer yes to question 1 than to answer no to question 1. If they answered no to question 3 then their chances of answering yes or no to question 1 were much closer to even. The differences among responses to these two questions are significant at the .03 level. It can be surmised that about 25% of all consumers not only believe they need CLTC services to remain in the home but

also believe that they need other kinds of services to remain in their home. See Tables XXV a and XXV b and Figure XXV.

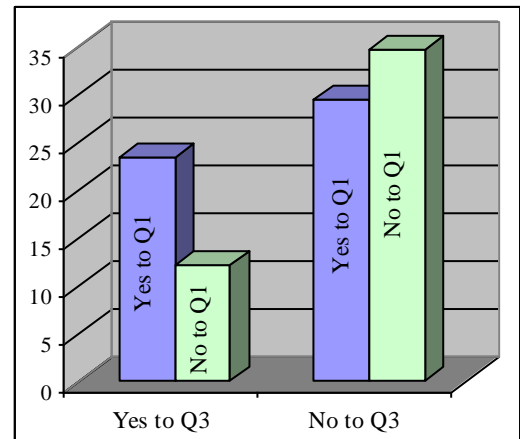
Table XXV a: Themes Question 3 Compared to Themes Question 1								
Response to Question 1	Response to Question 3							
	Yes			No			Total	
	#	% within Q3	% of Total	#	% within Q3	% of Total	#	% of Total
Yes	27	65.9%	23.5%	34	45.9%	29.6%	61	53.0%
No	14	34.1%	12.2%	40	54.1%	34.8%	54	47.0%
Total	41	100.0%	35.7%	74	100.0%	64.3%	115	100.0%

Table XXV b: Chi-Square Tests for Comparison					
	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	6.425 ^b	1	.011		
Continuity Correction ^a	5.497	1	.019		
Likelihood Ratio	6.529	1	.011		
Fisher's Exact Test				.014	.009
Linear-by-Linear Association	6.369	1	.012		
N of Valid Cases	114				

a Computed only for a 2x2 table

b 0 cells (.0%) have expected count less than 5. The minimum expected count is 21.66.

Figure XXV: Themes Question 3 Compared to Themes Question 1



Findings of the Focus Groups

The focus groups generally confirmed the results of the surveys. The focus group guiding questions and the transcripts of the focus groups and individual interviews with consumers who have HIV/AIDS may be found in Appendix Six.

Six matters were especially clear in the focus groups.

- The services provided by CLTC are greatly appreciated and case managers are highly regarded.
- Consumers and caregivers are quite satisfied with the services themselves and with the CLTC offices.

- People want to remain in their homes and their caregivers want them to remain there also.
- Caregivers are heavily stressed and are asking for help with that stress.
- There are community resources which some caregivers and consumers are not aware of.
- The amount and type of services available just barely make the difference between institutionalization and remaining in their homes for many consumers.

CONCLUSIONS

Conclusions Regarding Initial Purposes

There were five purposes for the study initially. The conclusions regarding these initial purposes are discussed below. For ease of statement, responses from consumers and caregivers are totaled and referred to as “respondents.”

1. *Do the services provided have the desired affect of allowing consumers to remain at the lowest possible level of care (that is, remain in their home and not enter a nursing facility)?*

Almost 70% of the respondents believe they (or those for whom they care) would not be able to stay in the home or were not sure they would be able to remain in the home without CLTC services. Just 33% believe they (or those for whom they care) would be able to remain in the home without the services. Moreover, virtually all respondents state that they (or those for whom they care) want to stay in their homes as long as they can. The amount and type of services available make the difference between institutionalization and remaining in their homes for many consumers.

2. *What would consumers do if the services were not provided?*

A clear picture of the alternatives consumers envision if they lose services did not emerge from the study. The qualitative interviews indicated that some individuals have made plans about what to do if they lose services. But a larger number either avoided the issue entirely, denied having thought about losing services or were unaware of alternatives to remaining at home. Since this is a distressful question for most consumers, it was not pursued in the quantitative survey.

3. *Is the social functioning of consumers reasonable given their situation, and has it improved since they began receiving services?*

Information on the social functioning of the consumers was difficult to ascertain through the qualitative interviews. In fact, since their social functioning was not of a great deal of interest to the consumers, questions about social functioning did not appear among the top issues to be pursued in the quantitative survey, and therefore were not.

4. *What changes might be made in the services provided that would make it more likely consumers will not move to a higher level of care?*

Three changes were very apparent in the findings of the study. First, about 38% of respondents believe that more of the same services they (or those they are caring for) are now receiving will help them remain in their homes. About 31% believe other services will help them (or those they are caring for) remain in their home. These two figures are especially prominent among caregivers. Approximately 60% of caregivers believe that more of the same services will help

the people they are caring for stay in the home. About 61% of caregivers replied that they need other services for those they are caring for to stay in the home. These numbers are almost twice the overall percentage. Also among caregivers, about 32% believe that they sometimes are near the end of their ability to provide care. Caregivers are heavily stressed and are asking for help.

5. Are the consumers satisfied with their services?

An overwhelming majority of the respondents are satisfied with their services. About 25% of the respondents had made a complaint at some time, and, among these, 88% were either satisfied with the results or did not respond to the question asking them about their satisfaction. Therefore, only about 3% of all respondents had a complaint they did not feel was handled properly.

Just 1.9% of respondents reported they can not speak freely with the helpers provided by CLTC. Similarly, only 3% reported they can not depend on these helpers. The services provided by CLTC are greatly appreciated and case managers are highly regarded.

Other Conclusions

1. Many respondents are unclear about their rights and responsibilities. The proportion includes 18.6% who do not know who to notify if they have a complaint and 11.6% who say they are not notified when a service is not going to be delivered. In addition, a number of respondents report they were not given a choice of services (11.2%), did not have their rights and responsibilities explained to them (5.2%) or did not have anyone talk with them about a plan for services (5.2%).
2. Additional analysis of the data indicates that about 25% of respondents believe they are in imminent danger of having to leave their homes without more of the services they are presently receiving and/or additional services.
3. As indicated in the focus groups and in the qualitative interviews, there are community resources that some caregivers and consumers are not aware of.

RECOMMENDATIONS

A recent study by the Legislative Audit Council¹ concluded that CLTC services cost much less than nursing facility costs and additional funding for CLTC slots could save the state a good deal of money. Another recent study conducted by the American Association of Retired People² concluded that most people who are elderly and disabled would rather stay at home than go to an institution.

The findings of this study support both of the above mentioned studies. People do want to stay at home rather than go to an institution. As stated in the introduction, it is also clear that it costs less to keep people in their home than to place them in an institution. Therefore, increasing funding for CLTC would be a much more efficient use of long term care money than the current system. **It is recommended that the number of CLTC slots be increased to at least the number of people on the present waiting list.**

To increase the amount of time some CLTC consumers could remain at home, four changes are recommended. These are:

- 1. The amount of services provided to selected consumers be increased.**
- 2. The types of services provided to selected consumers be increased.**
- 3. Additional and more flexible respite services be provided for caregivers.**
- 4. An organization of caregivers be developed to support caregivers in sharing knowledge about community resources and to support one another.**

There are a substantial number of consumers and caregivers who do not understand their rights and responsibilities. **It is therefore recommended that a group of caregivers, consumers and CLTC workers be formed to determine how best to encourage the communications necessary to increase those who do understand their rights and responsibilities.**

This study generated considerable data that has not been thoroughly explored. **It is recommended that the data continue to be analyzed, particularly as it relates to consumers of services for aging persons who have not as yet entered CLTC services.**

¹ "Options for Medicaid Cost Containment." (Jan 2003) Legislative Audit Council. Retrieved from: <http://www.state.sc.us/sclac/>

² Gibson, MaryJo et al. "Beyond 50.03: A Report to the Nation on Independent Living and Disability." (Apr 2003) American Association of Retired People. Retrieved from: http://research.aarp.org/il/beyond_50_il.html

**APPENDIX ONE:
INTERVIEW SCHEDULE FROM PHASE I**

INTERVIEW SCHEDULE

Instructions to Interviewer

This interview schedule is designed for consumers (and/or their primary caregivers) of services provided or arranged for by the Community Long Term Care program that help keep the elderly, disabled and persons with HIV/AIDS in their homes and communities. The purpose of the study that this interview is a part of is to determine if the necessary quantities of the right services are being provided to these consumers in order to maximize the length of time they can comfortably remain in their homes and communities without going into more intensive services such as nursing facilities.

You will receive the following information for each consumer in the sample.

- Case number
- Name, address, telephone number
- Services being received
- Name, address and phone number of primary caregiver
- Regional office providing services
- Functioning level of consumer
- Case Manager

The consumer will receive a letter from the University of South Carolina College of Social Work notifying the consumer that a telephone call is going to be made to them. The consumer will also be given a telephone number to call and an e-mail address to contact if they should have questions about the interview. If the consumer or primary caregiver indicates that the consumer is unable to carry out the interview, the primary caregiver will be asked to carry out the interview on behalf of the consumer.

About one in five consumers and/or primary caregivers will be interviewed in their homes. There are two purposes for these home interviews. First, they will help determine if there are any systematic errors in the telephone interviews. Second, they will allow an opportunity to observe the consumers in their environment. Interviewers will be asked for comments on these observations using an observation form.

Some information discussed in interviews, such as bathing and toileting, are personal. The interviewer must be sensitive to this, and make sure that the consumers understand they do not have to discuss any matters they don't want to discuss, that their responses will be strictly confidential and that they can end the interview at any time they choose. Interviewers are reminded that the information gathered is indeed strictly confidential and will be treated as such. When asking the questions that involve what consumers would do if they were not getting the CLTC services, be very careful to do this gently. *Not receiving services may be a traumatic prospect for many of the consumers.*

There are six main questions on this interview schedule. Under each are prompting questions. These questions are to be used to prompt the client to provide this information if it doesn't come

up on its own. *The prompting questions don't have to be asked if they do come up.* In asking the questions, remember that the consumer or their primary caregiver may not know or remember that CLTC is arranging for certain of their services. The consumers may be getting services from other organizations. CLTC case managers can arrange for several different services for consumers, depending on what they need and what is available. *It is important to establish at the beginning of the interview exactly what services are being talked about so we are sure we are getting information about services arranged for by CLTC case managers.*

Interviewers are to make three attempts to reach consumers and/or primary caregivers. After three attempts, we will not make any further attempts.

Immediately following the interview, the interviewer will transcribe the interview.

INTERVIEW SCHEDULE

COMPLETE THE FOLLOWING INFORMATION BEFORE TALKING TO CUSTOMER/PRIMARY CAREGIVER

Client case # _____ Region _____

ED or HIV/AIDS (Check One) ED _____ HIV/AIDS _____

Service(s) Customer Receives 1. _____ 2. _____
3. _____ 4. _____

Interviewer _____

Attempt 1 Date and Time _____

Attempt 2 Date and Time _____

Attempt 3 Date and Time _____

Hello, my name is _____ and I am from the University of South Carolina. You should have recently received a letter saying you would be getting a call from someone from the University. Did you get a letter?

(If no read letter to the consumer.)

Is this a good time to talk?

(If no) Is there a better time to call? When would that be? (Record time and day.)
_____ That's great. We'll call back then.

(If yes) Good. Before I ask any questions, I'd like to let you know a few things. First, this conversation will be held in strict confidence. No one except for me and the staff who will write the report will know what you said. All of the information from the different people we are talking to will be put together and no one will be able to tell who said what. Do you understand that this will be confidential? Do you have any questions about that?

If you don't want to answer a question, please just say that. You can also stop the interview anytime you want to. If you get tired, I can always call you back another time. Do you understand that you don't have to answer any questions you don't want to and that you can stop at any time? Do you have any questions about that?

Answering this questionnaire will not affect your services in any way. Taking part will not get you more services, and the answers you give will not reduce your services. Do you understand that answering this questionnaire will not affect your services in any way? Do you have any questions about that?

The reason that we are doing this survey is to find out if the services being provided to you and other people are as good as they need to be. We also want to find out what else can be done to help people stay in their homes when they have the kinds of physical difficulties you are having right now.

My memory is not as good as it should be, and I don't want to miss any of the things you have to say. I would like to tape record this telephone call. The tape will help me write up what you say. You do not have to agree to this. If you don't, I will take notes. May I tape record this call?

(If yes) I am turning on the tape machine. Could you please repeat that it is OK with you for me to tape this conversation?

Thank you. I am going to ask you some questions. You just answer them in your own words and we'll have a conversation about them. If there is anything you don't understand, just ask me about it.

1. I want to make sure that I have the services you are receiving right. My information says that you are getting (describe services). Is that correct?

2. The reason you are receiving these services is so you can stay in your home and be as independent as you can be. Are the services helping you to do that?
 - a. Can you tell me how they are helping you to stay in your home?

- b. Are you receiving any other help to stay in your home?
 - c. What kind of help is that? Who gives it to you?
3. Do you think you could still stay in your home without these services?
- a. What would you have to do to stay in your home without the services?
 - b. If you couldn't stay in your home, where would you go?
4. Since you started getting these services, have you been able to socialize more (like talk to your friends or relatives or get out of the house sometimes)?
- a. What are you able to do that you couldn't do before?
 - b. How have the services made that possible?
5. What other services could be provided to make it easier for you to stay in your home?
- a. Are there new or different services that would help?
 - b. Would more of the same services help?
 - c. Are there changes in the services you are now getting that would help?

6. Can you tell me about what your case manager is doing for you and if you are satisfied with what he or she is doing?
 - a. Do you know who your Community Long Term Care case manager is?
 - b. Do you have your case manager's phone number?
 - c. What is it your case manager is supposed to do for you?
 - d. Are you satisfied with the services arranged by your case manager?
 - e. Does your case manager call or visit you at least once a month?
 - f. Does your case manager visit you at least once every three months?
 - g. Do you feel comfortable talking to your case manager?
 - h. Did your case manager give you a choice in what services you get?
 - i. Did your case manager ask your choice about the days and times you would get your services?
 - j. Has your case manager ever done anything you did not want him or her to do?
 - k. Have you ever made any complaints to your case manager about the services you are receiving?
 - l. (If yes to k) Were you satisfied with the results of making the complaint?
 - m. Did your case manager explain or discuss with you the Community Long Term Care service plan of care with you?
 - n. Do you or your family understand the purpose of the service plan of care?
 - o. Did your case manager explain the CLTC Client's Rights Statement and Responsibilities to you?
 - p. Did you sign a copy of the CLTC Client's Rights Statement and Responsibilities?

REPEAT THE FOLLOWING FOR EACH CLTC ARRANGED SERVICE BEING RECEIVED BY THE CLIENT.

7. Can you tell me about _____ service and how satisfied you are with it?
 - a. Is the _____ service done the way you like?
 - b. Do the people providing _____ service respect you wishes and beliefs?
 - c. Has the person delivering _____ service ever done anything you did not want them to do?
 - d. If the _____ service cannot be delivered for some reason, does the agency providing the service call you and let you know?
 - e. Do you know who to call if your _____ service is not delivered, or if you have a complaint about the service? Who is that?
 - f. Have you ever had to make a complaint about _____ service?
 - g. (If yes) Were you satisfied with the way the complaint was handled?
 - h. (For personal care services) Before the personal care aide started working did the personal care aide's nurse supervisor explain to you what the personal care aide's duties for you would be?
 - i. (For personal care) Has the personal care aide's nurse supervisor ever visited while the personal care aide was working in your home?

**APPENDIX TWO:
CODING CRITERIA USED DURING PHASE I**

CODEBOOK FOR CLTC CONSUMER INTERVIEWS

Code: STAY
Brief Definition: services help stay in home
Full Definition: The services provided by CLTC are necessary (although not necessarily sufficient) to allow the consumer to remain in their home rather than having to be placed in a higher level of care.
When to Use: Apply this code when the consumer or their primary caregiver is able to describe how the services support the consumer in remaining in their home.
When Not to Use: Do not use this code when the consumer or the primary caregiver does not believe the services help them remain in their home.
Example: “I can’t move without my wheelchair and the aide helps me get into it.”

Code: MOREHELP
Brief Definition: other services that would help stay in home
Full Definition: Other help or services that the consumer or primary caregiver believes would make it more likely that the consumer will not have to move to a higher level of care.
When to Use: Apply this code when the consumer or their primary caregiver is able to describe specific help or services that would make it more likely that the consumer will not have to move to a higher level of care.
When Not to Use: Do not use this code when the consumer or the primary caregiver cannot specify help or services
Example: “If they would buy me a walker, I could do more for myself around the house.”

Code: OTHERHELP
Brief Definition: support for consumer not provided by CLTC
Full Definition: Support or services, paid or unpaid, provided to the consumer to help them to remain in their home and not move to a higher level of care and is not provided by CLTC.
When to Use: Apply this code when the consumer or their primary caregiver is able to describe specific support or services that are being received in the home and are not provided by CLTC.
When Not to Use: Do not use this code when the service or support is provided by CLTC.
Example: “My two children come in every day and clean my house and take care of me.”

Code: NEEDMORE
Brief Definition: other services needed by consumer
Full Definition: Other help or services or a modification of existing services that the consumer or primary caregiver believes would be helpful, but not necessary, for the consumer to remain in their home.
When to Use: Apply this code when the consumer or their primary caregiver is able to describe specific services, or modification of existing services, that would be useful or helpful, but not necessary to remain in their home.
When Not to Use: Do not use this code when the consumer or the primary caregiver believes the service is necessary for them not to move to a higher level of care.
Example: “It would really be a help if I could get more pads.”

Code: RAPPORT
Brief Definition: confidence in paid helper
Full Definition: The consumer or primary caregiver expresses a belief that he/she can talk openly with and/or have confidence in a helper paid through CLTC, such as the case manager or aide.
When to Use: Apply this code when the consumer or their primary caregiver is able to clearly state their belief that he/she can talk openly with and/or have confidence in a helper paid by CLTC.
When Not to Use: Do not use this code when the consumer or the primary caregiver does not clearly state these beliefs.
Example: “My case manager always tells me what is going on. I can tell her anything.”

Code: NONRAPPORT
Brief Definition: lack of confidence in paid helper
Full Definition: The consumer or primary caregiver expresses a belief that he/she cannot talk openly with and/or have confidence in a helper paid through CLTC, such as the case manager or aide.
When to Use: Apply this code when the consumer or their primary caregiver is able to clearly state their belief that he/she cannot talk openly with and/or have confidence in a helper paid by CLTC.
When Not to Use: Do not use this code when the consumer or the primary caregiver does not clearly state these beliefs.
Example: “It’s like talking to a brick wall.”

Code: DEPEND
Brief Definition: belief paid helper will do what supposed to
Full Definition: The consumer or primary caregiver expresses a belief that he/she can depend on the timely delivery of promised services by a helper paid through CLTC, such as the case manager or aide.
When to Use: Apply this code when the consumer or their primary caregiver is able to clearly state their belief that he/she can depend on the timely delivery of promised services by a helper paid by CLTC.
When Not to Use: Do not use this code when the consumer or the primary caregiver does not clearly state these beliefs.
Example: “She is always here right after breakfast”

Code: NODEPEND
Brief Definition: belief paid helper will not do what supposed to
Full Definition: The consumer or primary caregiver expresses a belief that he/she cannot depend on the timely delivery of promised services by a helper paid through CLTC, such as the case manager or aide.
When to Use: Apply this code when the consumer or their primary caregiver is able to clearly state their belief that he/she cannot depend on the timely delivery of promised services by a helper paid by CLTC.
When Not to Use: Do not use this code when the consumer or the primary caregiver does not clearly state these beliefs.
Example: “She is never here when the weather is bad.”

Code: HONEST
Brief Definition: belief paid helper can be trusted
Full Definition: The consumer or primary caregiver expresses a belief that he/she can depend on a helper paid through CLTC to tell the truth, not steal from them or exploit them.
When to Use: Apply this code when the consumer or their primary caregiver is able to clearly state their belief that he/she can depend on a helper paid through CLTC to tell the truth, not steal from them or exploit them.
When Not to Use: Do not use this code when the consumer or the primary caregiver does not clearly state these beliefs.
Example: “I don’t have to hide my jewelry when he’s here.”

Code: DISHONEST
Brief Definition: belief paid helper cannot be trusted
Full Definition: The consumer or primary caregiver expresses a belief that a helper paid by CLTC has or intends to mislead, steal from or lie to them.
When to Use: Apply this code when the consumer or their primary caregiver is able to clearly state their belief that a helper paid by CLTC has or intends to mislead, steal from or lie to them.
When Not to Use: Do not use this code when the consumer or the primary caregiver does not clearly state these beliefs.
Example: “I don’t dare leave anything laying around.”

Code: FEAR
Brief Definition: feeling of lack of personal security
Full Definition: The consumer or primary caregiver expresses a feeling of apprehension or anxiety about personal security or living situation.
When to Use: Apply this code when the consumer or their primary caregiver is able to clearly state their belief that he/she has a feeling of apprehension or anxiety about personal security or living situation.
When Not to Use: Do not use this code when the consumer or the primary caregiver does not clearly state these beliefs.
Example: “ I don’t really know what is going to happen to me.”

Code: AUTONOMY
Brief Definition: desire to live independently
Full Definition: The consumer (on their own or through their primary caregiver) expresses a desire to do things for themselves to the extent possible, to make their own decisions and to live independently.
When to Use: Apply this code when the consumer (on their own or through their primary caregiver) makes a clear statement expressing such a desire.
When Not to Use: Do not use this code when the consumer (on their own or through their primary caregiver) does not clearly state this desire.
Example: “I plan to stay right here in my house as long as I can.”

Code: NO BURDEN
Brief Definition: desire to not be a burden
Full Definition: The consumer (on their own or through their primary caregiver) expresses a desire to not be a burden to others, including their family members.
When to Use: Apply this code when the consumer (on their own or through their primary caregiver) makes a clear statement expressing such a desire.
When Not to Use: Do not use this code when the consumer (on their own or through their primary caregiver) does not clearly state this desire.
Example: “My children have their own families to take care of. I don’t want to bother them.”

Code: COMMUNICATION
Brief Definition: believe informed
Full Definition: The consumer or his/her primary caregiver believes he/she is informed and is confident that the case manager gives timely and complete information about services and changes.
When to Use: Apply this code when the consumer or primary caregiver clearly states such a belief.
When Not to Use: Do not use this code when the consumer or primary caregiver does not clearly state this belief.
Example: “My case manager really tells me what is going on. I know what my options are.”

Code: RESPONSIVE
Brief Definition: conviction listened to
Full Definition: The consumer or his/her primary caregiver is convinced that when he/she complains or questions something, there will be results.
When to Use: Apply this code when the consumer or primary caregiver clearly states such a conviction.
When Not to Use: Do not use this code when the consumer or primary caregiver does not clearly state such a conviction.
Example: “If I call the supervisor, I know that she will find me another aide that will do the job right.”

Code: SOCIAL
Brief Definition: social connection
Full Definition: The consumer or his/her primary caregiver believes the services provided by CLTC have allowed the consumer to have more social connections.
When to Use: Apply this code when the consumer or primary caregiver clearly states such a belief.
When Not to Use: Do not use this code when the consumer or primary caregiver does not clearly state this belief.
Example: “I have more energy now to make phone calls to my friends.”

Code: CARE
Brief Definition: believe others will help
Full Definition: The consumer or his/her primary caregiver believes consumer will be “looked out for” by others in the community or neighborhood.
When to Use: Apply this code when the consumer or primary caregiver clearly states such a belief.
When Not to Use: Do not use this code when the consumer or primary caregiver does not clearly state this belief.
Example: “My neighbors always get my mail, especially when the weather is bad.”

Code: AVOID
Brief Definition: does not respond appropriately
Full Definition: The consumer or his/her primary caregiver does not respond to the question or topic, changes the subject, or otherwise avoids the question or topic.
When to Use: Apply this code when the consumer or primary caregiver exhibits this behavior.
When Not to Use: Do not use this code when the consumer or primary caregiver takes a round-about direction, but does finally respond.
Example: “I can’t think about that right now.”

Code: CONTROL
Brief Definition: believes in control
Full Definition: The consumer states directly or through his/her primary caregiver that he/she is in control of what happens, rather than other people having control over him/her. Has an internal locus of control.
When to Use: Apply this code when the consumer directly or through his/her primary caregiver clearly states such a belief.
When Not to Use: Do not use this code when the consumer directly or through the primary caregiver does not clearly state this belief.
Example: “I may be in a wheelchair, but I can still decide what is best for me.”

Code: NEEDY
Brief Definition: admits need for help
Full Definition: The consumer states directly or through his/her primary caregiver admits that they need to have help with personal care.
When to Use: Apply this code when the consumer clearly admits to this need directly or through his/her primary caregiver.
When Not to Use: Do not use this code when the consumer states directly or through his/her primary caregiver or primary caregiver does not clearly state this need.
Example: “I hate waiting to have someone get me dressed. It is frustrating not to be able to do it myself.”

Code: KNOWNOT1
Brief Definition: doesn’t know meets nursing home level of care
Full Definition: The consumer states directly or through his/her primary caregiver that they can’t go into a nursing facility.
When to Use: Apply this code when the consumer clearly makes this statement directly or through his/her primary caregiver.
When Not to Use: Do not use this code when the consumer does not make this statement directly or through his/her primary caregiver.
Example: “I don’t have money to go to a nursing home.”

Code: KNOWNOT2
Brief Definition: doesn't know what would do if lose services
Full Definition: The consumer states directly or through his/her primary caregiver that he/she doesn't know what to do if they lose services.
When to Use: Apply this code when the consumer clearly makes this statement directly or through his/her primary caregiver.
When Not to Use: Do not use this code when the consumer does not make this statement directly or through his/her primary caregiver.
Example: "I don't know what I'd do if I didn't have PCA services."

Code: WHAT
Brief Definition: knows consequences of losing services
Full Definition: The consumer states directly or through his/her primary caregiver that he/she has a concept of what would happen to him/her if he/she lost services.
When to Use: Apply this code when the consumer clearly describes the consequences for him/her of a loss of services.
When Not to Use: Do not use this code when the consumer does not give a clear description directly or through his/her primary caregiver.
Example: "If I didn't have these services I would have to leave my home."

Code: TURNOVER
Brief Definition: personnel turnover
Full Definition: The consumer states directly or through his/her primary caregiver that turnover among CLTC provided helpers causes a degradation in their care.
When to Use: Apply this code when the consumer clearly makes this statement directly or through his/her primary caregiver or primary caregiver.
When Not to Use: Do not use this code when the consumer does not make this statement directly or through his/her primary caregiver.
Example: "Just when an aide knows what to do, they send a new one."

Code: PLAN
Brief Definition: ready if services lost
Full Definition: The consumer states directly or through his/her primary caregiver that he/she has a plan in the event that CLTC supported services are lost.
When to Use: Apply this code when the consumer clearly makes this statement directly or through his/her primary caregiver.
When Not to Use: Do not use this code when the consumer does not make this statement directly or through his/her primary caregiver.
Example: "If I lose the services, my family in Alabama has agreed to take care of me."

Code: CONFUSION
Brief Definition: lack of program/service/other knowledge
Full Definition: The consumer or the primary caregiver makes statements that indicate confusion about where services come from, who authorizes the services, what services he/she are eligible for, or something similar.
When to Use: Apply this code when the consumer or the primary caregiver clearly makes such statements.
When Not to Use: Do not use this code when the consumer or the primary caregiver does not make such a statement.
Example: “I can’t get some health care because I don’t qualify for Medicaid.”

Code: OVERWHELMED
Brief Definition: feeling of being overpowered by situation
Full Definition: The consumer or the primary caregiver makes statements that indicate their lives are being submerged entirely by the client’s physical problems and the response necessary to deal with the problems.
When to Use: Apply this code when the responses of the consumer or the primary caregiver give a strong sense of this feeling.
When Not to Use: Do not use this code when the consumer or the primary caregiver does not give this sense.
Example: “I just can’t keep doing what I’m doing. It’s just too much.”

**APPENDIX THREE:
SPREADSHEETS FOR QUALITATIVE ANALYSES**

MENTIONS AND NUMBER OF COMMENTS OF QUALITATIVE THEMES

	ELDERLY DISABLED (9)		YOUNGER DISABLED (8)		HIV/AIDS (4)		TOTAL (21)	
	MENTIONS	NUMBER	MENTIONS	NUMBERS	MENTIONS	NUMBERS	MENTIONS	NUMBERS
AFFECTIVE THEMES								
Rapport	11	7	3	3	38	4	52	14
Non-Rapport							0	0
Depend	18	7	9	4	16	3	43	14
Nodepend	7	4	20	1			27	5
Honest							0	0
Dishonest			3	3			3	1
Fear	3	1	5	3			8	4
Autonomy	2	2	22	3	1	1	25	6
No Burden	3	2					3	2
Responsive	11	5	4	2	2	1	17	8
Care	7	2	1	1	2	2	10	5
Control	1	1	2	2			3	3
Overwhelmed	14	4	8	3			22	7
TOTAL	77	9	77	8	59	4	213	21
	ELDERLY DISABLED (9)		YOUNGER DISABLED (8)		HIV/AIDS (4)		TOTAL (21)	
	MENTIONS	NUMBER	MENTIONS	NUMBERS	MENTIONS	NUMBERS	MENTIONS	NUMBERS
COGNITIVE THEMES								
Stay	35	9	23	7	26	4	84	20
MoreHelp	20	5	23	7	1	1	44	13
OtherHelp	18	6	23	7	11	3	52	15
NeedMore	8	3	8	4	1	1	17	8
Communication	15	6	2	2	14	3	31	11
Social	16	5	5	2	12	2	33	9
Avoid	7	2	3	1	2	2	10	5
Needy	16	4	19	4			35	8
KnowNot1	1	1	1	1			2	2
KnowNot2	1	1	7	5	7	3	15	9
What	16	8	4	4			20	12
Turnover			1	1			1	1
Plan	12	5	11	2			23	7
Confusion	6	2					6	2
TOTAL	171	9	130	8	74	4	373	21

RANKINGS OF THEMES					
	MENTIONS	RANK	NUMBERS	RANK	OVERALL RANK
AFFECTIVE THEMES					
Rapport	52	1	14	1	1
NonRapport	0		0		
Depend	43	2	14	1	1.5
NoDepend	27	3	5	5	4
Honest	0		0		
Dishonest	3	9	1	9	9
Fear	8	8	4	6	7
Autonomy	25	4	6	4	4
No Burden	3	9	2	8	8.5
Responsive	17	6	8	2	4
Care	10	7	5	5	6
Control	3	9	3	7	8
Overwhelmed	22	5	7	3	4
TOTAL	213		21		
COGNITIVE THEMES					
	MENTIONS	RANK	NUMBERS	RANK	OVERALL RANK
Stay	84	1	20	1	1
MoreHelp	44	3	13	4	3.5
OtherHelp	52	2	15	3	2.5
NeedMore	17	9	8	7	8
Communication	31	6	11	5	5.5
Social	33	5	9	6	5.5
Avoid	10	11	5	9	10
Needy	35	4	8	7	5.5
KnowNot1	2	13	2	10	11.5
KnowNot2	15	10	9	6	8
What	20	8	12	2	5
Turnover	1	14	11	11	12.5
Plan	23	7	7	8	7.5
Confusion	6	12	2	10	11
TOTAL	373		21		

TOP RANKINGS				
AFFECTIVE THEMES			COGNITIVE THEMES	
Rapport	1		Stay	1
Depend	1.5		OtherHelp	2.5
NoDepend	4		MoreHelp	3.5
Autonomy	4		What	5
Responsive	4		Needy	5.5
Overwhelmed	4		Communication	5.5

SATISFACTION AND COMPLIANCE ISSUES – NEGATIVE RESPONSES		
	NUMBER	PERCENT
CASE MANAGEMENT		
Rights and Responsibilities Explained	6	22.20%
Sign Rights and Responsibilities	6	22.20%
Given Choice of Services	5	18.50%
Satisfied if Complain (of Complainants)	2	18.50%
Know What Case Manager Does	4	14.80%
Plan of Care Discussed	4	14.80%
PERS CARE AIDE		
Notice When No Service	4	21.10%
Who To Call	4	21.10%
Pers Care Aide Work Explained	3	15.80%
Nurse Supervisor Visited	3	15.80%
HOME DELIVERED MEALS		
Notice When No Service	2	33.30%
Who To Call	2	33.30%
ADULT DAY SERVICES		
Notice When No Service	3	50%
Who To Call	3	50%
Done Anything Not Want To Do	2	33.30%
INCONTENENCE SUPPLIES		
Satisfied if Complain (of Complainants)	2	50.00%
Notice When No Service	7	41.10%
Who To Call	4	23.60%

**APPENDIX FOUR:
SURVEY QUESTIONNAIRE USED IN PHASE II**

Please Return this Survey by April 16.

PLEASE PUT A CHECK NEXT TO THE ANSWER THAT APPLIES TO YOU

I Receive Services

I Provide Care for Someone Who Receives Services (Caregiver)

PLEASE CIRCLE THE NUMBER THAT BEST DESCRIBES WHAT YOU THINK

	Yes Definitely	Yes I Think So	Maybe Yes Maybe No	No I Don't Think So	No Definitely Not
1. If I didn't have these services, I would not be able to stay at home.	1	2	3	4	5
2. I need more of the help I am already getting if I am going to stay at home.	1	2	3	4	5
3. I need other kinds of help besides what I'm getting now if I am going to stay at home.	1	2	3	4	5
4. I can speak freely with the people who come to my home to help me.	1	2	3	4	5
5. I can depend on the people who come to my home to help me.	1	2	3	4	5
6. I want to stay in my home as long as I can.	1	2	3	4	5
(TO BE ANSWERED BY CAREGIVER ONLY)					
7. Sometimes I feel so overwhelmed I think I can't continue providing care like I am now.	1	2	3	4	5

Please Return this Survey by April 16.

PLEASE CIRCLE YOUR ANSWER TO THESE STATEMENTS

1. I know who to notify if I have a complaint about a service.	Yes	No	
2. I am notified if a service is not going to be delivered when it is supposed to be.	Yes	No	
3. When I first started the program, I was given a choice of services I could receive.	Yes	No	
4. My rights and responsibilities were explained to me before I started receiving services.	Yes	No	
5. Someone talked to me about a plan for my services before I started getting them.	Yes	No	
6. I have written or called someone to make a complaint about my services.	Yes	No	
7. If you made a complaint, were you satisfied with what was done about it?	Yes	No	Does Not Apply to Me

PLEASE LET US KNOW IF YOU HAVE ANY ADDITIONAL COMMENTS

**APPENDIX FIVE:
COVER LETTER ACCOMPANYING SURVEY
QUESTIONNAIRE IN PHASE II**

March 31, 2003

«First_Name» «MI» «Last_Name»
«Street_Address»
«City», «State» «Zip»

Dear «Last_Name»:

The Community Long Term Care program provides the services that help you in your home. These are things like meals delivered to your home. Another service is aides who come in to help you with your normal activities, such as dressing, bathing, and housework.

The program would like to know what you think of the services you receive. They have asked the University of South Carolina to help find out.

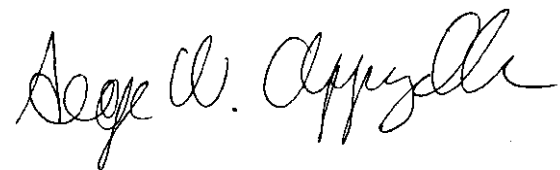
Could you please complete the survey that came with this letter? Hundreds of other people are being asked to do the same thing. It should take just five or ten minutes of your time. A family member or someone else who knows about your situation can complete the survey for you.

Every thing you tell us will be confidential. No one will be identified when we write our report. The services that you receive will not be affected in any way by what you say.

Thank you for reading this letter and thank you for helping us make the services you receive even better. **Please use the enclosed self-addressed stamped envelope to return the survey to us by April 16, 2003.**

If you have any questions, please call me at (803) 771-6663.

Sincerely,

A handwritten signature in black ink that reads "George W. Appenzeller". The signature is written in a cursive style with a large, prominent initial "G".

George W. Appenzeller, MSW
Project Coordinator

**APPENDIX SIX:
FOCUS GROUP GUIDING QUESTIONS
TRANSCRIPTIONS FROM FOCUS GROUPS
TRANSCRIPTIONS FROM HIV/AIDS INTERVIEWS**

QUESTIONS FOR FOCUS GROUPS

You or someone you are responsible for, is receiving services from Community Long Term Care. These services are to help you or the person you are responsible for, to stay at home. We would like to ask you some questions about those services so that we can improve the chances of you or the person you are responsible for staying at home as long as possible.

1. Would you or the person you are responsible for have to leave home if these services weren't provided?
2. Would more of the same services help you or the person you are responsible for stay at home longer?
3. Would different services help you or the person you are responsible for stay at home longer?
4. What would those services be?
5. Where would you or the person you are responsible for go if staying home wasn't possible?

Community Long Term Care Focus Group

Location: Greenville, South Carolina
Facilitator (F): Sarah Meadows
Participants (P): (3) Caregivers of Parents & Focus Group Host (H)
Date: 3/25/03

F: Thank you all for-for being here this evening as an invitation of CLTC folks here in the office. We're involved with this project as I think I told a couple of you earlier, um – working under contract with the University of South Carolina. And they gotten some funding to find out more about the Community Long Term Care program and how it's working for people and what, um, what do they need to know specifically to help them improve the program and, uh, to keep the things that are most valuable for people and to really understand what those are. Um, and we have been talking – we've done some telephone surveys so far with clients and caregivers, we're meeting at four different places in the state, like we are with you, um, here tonight ...to hear from either clients or caregivers and we're going to be sending out a written survey to clients and caregivers to find out more about what they're-they're, uh, feelings and thoughts are about the program, so that we can get some good information to people who fund and manage it, and uh . . . So we thank-you for coming out tonight, I know that it is hard to get away in the situations you're in. Are-are you all caregivers?

P's: (Group Quiet Response)...Yes to my mother...my mom...my father.

F: So that's a parent? ... thank-you. Uhm . . . we are going to ask you some questions and mostly just have a conversation amongst ourselves about, uh, your response to those questions. And uh . . . We are going to developing a report for Health and Human Services, the people who operate the Community Long Term Care Program. No-ones name will be in the report. So anything that you or other people say will-will not be quoted, so, uh, I hope you'll feel free to say what you think. Uhm, so anyway we will... I've got four or five question and we will talk about that, and you all are – feel like you've said what you need to say or want to say, then uh, we're done and you can uh, go home so. . . . If you would like to have apple juice or anything else that you'd like, please feel free to . . .

P: Do you have water?

F: Huh...

P: Do you have any water?

F: I don't have water but there are cups. Is there a water fountain or anything? ... little cups are over there too and you may have your refreshments.

(pause while participants get refreshments and settle)

P: May I ask you a question?

F: Sure.

P: How are you involved with the CLTC?

F: Well, we are doing the research for this, yes. uh I-I have not been invo – I am not employed by CLTC program, don't provide any services. We are working under a contract with the University to do this, to get the information together for the, uh, Human and Health services. Actually, (Name & I) both work for a small consulting company in Columbia.

P: Oh, thank-you.

F: We do a lot of work for the government and non-profit agencies of different kinds.

H: You think they would be more comfortable if I wasn't in here, so they can say what they want to say? I mean I don't want...

P: It doesn't bother me because I don't know who you are (laughter)... I have only nice things to say so . . .

H: Okay...

F: ok, well, we'll ask-ask-ask questions and you say whatever is on your mind. The first thing that we need to say is that the intent of the – the information that we are getting is to find out about the services, so that, uh, the people responsible for the program can improve those services and keep the person that you are caring for in their home as long as possible, which is the purpose of the program. Um, The first thing I would like to ask you is: Would the person that you caring for, uh, have to leave home if these services were not available? ...they were not provided by Community Long Term Care? Would have to be somewhere else other than where they are now?

P1: I just don't think I could do by myself...I did not have help for four weeks and I did not know I was so stressed out until this wonderful person by the name of (name) came and I told my husband I didn't realize I was so stressed out but he knew (laughs) and my brothers knew, but I-I just couldn't do it. Cause I'll will be 70 in May and a lot of people 70 aren't able to do what I do, I'm healthy and I am proud of that-but stress can get to you.

F: uh huh. These are all parents that you all are responsible for or caring for, is that correct?

P2: My mother passed away last February but uhm...Community Long Term Care had been helping my father I guess for the last 10 years and helped my mother ...

F: care for you father?

P2: uh huh. and that gave her a little break. And when she died suddenly in February, its was up to me and my two brothers, to try and take care of my dad and CLTC were still helping and we had um . . . companion

F: companion, uh huh.

P2: and then we had, um, a person come in the morning and then we had companion care also. but without that-because all of us work and have children at home too, we couldn't – couldn't of been able to do it, you know without all of the assistance that we've had.

F: So the first year-your father then is getting a personal care aide and a companion?

P2: Yes actually 'companion' that what it is. Now he is in a nursing home now as of a week but I don't know if that is involuntary or not he really needs to be in a hospital but that year we would had been able to make it without the assistance throughout the day. At night what we had to do is switchin of takin care of him. But he was able to live back home. And we just . . . were there for a couple of hours.

F: ok . . . so What about your situation?

P3: Lets see I am trying to think about when my mother been with us, I think about 6 or 7 years, I lost track and uh, has been very independent, she's 94, and has been just marvelous, mentally she is still alert, she can't see to well and she cannot, does not go out but except to go to the doctor and that type of thing. But um, um I was asking a nurse friend from church, uh, about some help and just wondering if we could get some she had the direction to get me to the people that got us involved in this and it has just been a 'Godsend' I mean really I could not make it without it. I mean, it just lifts it off and I am going to be 70 next year

F: uh huh

P3: not this uh, a year from June – and see I am already losing it... (laughs)

P1: We can't tell. I have to make long notes... (Laugh)

P3: ...and uh...this year, we have – we were granted 12 hours a week, and uh it’s actually been cut back to ten because of the weekend help. We had a nurse friend who came in and still does often sometimes but since she can’t be consistent with it, she felt that she had to give up being under the program and far as getting paid from them. But she still comes and see my mother because they developed this friendship and I think she may pay her independently, but um . . . The other girl that is there now, (name) I just – I mean – I just could not say enough about her. She’s absolutely – she love – you know able to do the work and she’s – herself – has had physical problems and has children to raise, but has just been um . . . she has been just a gem, she’s been so kind and good and caring and, uh, I-I mean I just can’t say enough for her. But I told her I was going to tell you all that too. (*group laughs*) But she’s – oh, we had a couple that have not been – they have come and gone very quickly. Every one of em seemed to be nice, but just one, but did – it was – it looked like it was difficult to get off the chair for her, but you know . . . This gal is, (same name as above) is just marvelous. And, uh, she’s there five days a week for a couple of hours. And it just – It takes – It gives my mother the social interaction that she needs, uh, which is just extremely helpful, cause if she didn’t come, she would be dependent on the family for that. And this way I got a lot of f- of freedom during the day, and plus the physical stress, she’s downstairs and getting older, going up and down stairs...and, that type of thing. . .

F: yeah, well, the essential question I think we are trying to listen from you is: “If these service were not there, were not available, would the person you care for would be able to remain in their home?”

P1: My mother is totally is bedridden, we feed her and diaper her and she is absolutely totally bedridden. For a long time she was able to hold her piece of toast. Uh, she loves cheese toast in the morning, but she can’t even do that now. Um, she’s just – uh – she could not live by herself. She’s lived with us four and a half years now.

F: But even living with you what your are saying is that – if you did not have that, it would not be possible?

P1: uh huh...and I’ve held up better than my husband has. Um, (husband’s name) is 74 and he developed shingles about a year and a half ago and I think it was stress because he was lifting mother a lot then. Mother has no cartilage in her left shoulder at all and the Hoyer lift we tried, the man from the air care came and he tried several seats and it just – she just screamed with pain. And you could not put any – you just can’t put any pressure on that right shoulder. So (husband) was lifting her 8 or 10 times a day. And uh, he developed shingles...they are still there, they still pop out and he is really...I held better than he has...with it cause he hates to see me, uh, having to do what I have to do.

F: Yeah, so it-it sounds like you’re saying that you could not manage that...if you didn’t have those services?

P1: If she didn’t come. And I believe we got 13 hours and we had some – the last three, I think it’s gone over about a three year period, and have been very competent, really, I mean, they knew what they were doing and watched mothers skin so carefully, took really good care of her.

F: yeah, we’re trying to get at the essential- is this making a difference?

P1: It makes the difference! I think I would be ill-and (name) has said that all along, “I’m not going to let you get sick.”

F: Okay. It sounds like for at least you two-it really is essential, so because...

P3: There are bad times too; there seems to be more need of the care which put demands on us and so on. so really, I know that we're getting – we could be going into that place where we'd have to find someplace for her.

F: yeah, that – right. Well, you know, that's kind of the-the essential question that we're trying to find out more about, so that

P2: I can last for a while but it would not be for very long.

F: and your situation, what do you . . . ?

P2: It's the same, like I said with-with mother gone and father he can't stay by himself he had a stroke fourteen years ago so he's been paralyzed; he's in a wheelchair. So therefore, he can't be left alone...and like I said, we all work. If it weren't for the people who come in and take care him and put his food on the table and, you know, do different things, there would be no way that he would be able to stay at home.

F: ...And he has been able to stay in his – and this is his house that he's staying in?

P2: since his stroke for 14 years. Otherwise, you know fourteen years ago he would have to've been put in a nursing home or whatever because mother – for that amount of time would not have been able to take care of him by herself completely 24 hours a day. . . . and Like I said after she died there was no way we could have done without the assistance that we've been receiving. Cause we did, like I said, get the companion, um, care. You know. They were like sitters that stayed with em. Put his food on the table, turn the TV, read to him, you know whatever; but he just could not be at home alone.

F: right.

P2: So then, you know, that left us free to work and do what we needed to do, whereas, if we would have to hire a sitter or a nurse or whatever, you know, we wouldn't been able to afford someone cause we checked into that, and the rates were at 15-20 dollars an hour. You know anybody that you wanted to get that was competent, you know, to-to stay with him.

F: ok, um, ok. So it sounds like it's pretty essential to keep your parents in the situation they're in now to have those services. If you could get more of the same services that your parent is getting now, rather that be with an aide a personal care aide or companion or whatever the service they are getting; Would more of, more hours, more availability of that uh, help, that person that you are responsible for stay home longer or could you see more out into the future that that would make it possible for them to maintain in their current situation for a longer period of time?

P3: Yes, I can definitely see that because now mother would love to be tucked in at night and, you know, the whole – the whole thing and maybe her situation when she has to do it by herself when I'm not there keeps her doing it longer. I don't know what that is, but I think that uh, these you don't know when it's gonna get – I don't know when the ax is going to fall and I'm going – she's not going to be able to do anything more. And so therefore at that time to have someone come in and take some of the other load and more hours would be helpful, right now it's – I can – you know, it's fine.

F: Right, now you're saying there's a balance but if you knew the availability before you can say I could project a longer time for your father or mother.

P3: Right. And otherwise, we're going to have to look for some place to put her because I-I just, I know physically, I'm not...I'm on that edge myself; I just have to do so much. My husband is going to be 80 in September so. Even though he's still working...he has stress too, so this is really helps. It just – it allows her to be there, and to have the care that we can give her and that security, and be, um, independent, but without undue stress on us, or the elderly also.

F: yeah, ok.

P3: and so . . . I am not sure if I am answering you questions.

F: Yeah, you did – you did. . . I don't know what – if either of the other two. . .

P1: oh I'm just wishing I could have two more hours. (laughs) so I can have somebody for three hours each day. . . . um, we have a new caretaker now. She is really good and the one we had before was really good but she would not come for two hours. Uh, the way the schedule was first set up she was to be there everyday, but-but one day it was two hours. And she would not come. She told me she doesn't work on Fridays. So um, the schedule set up for, um, four hours on Friday. Um, three hours . . . it was so nice on the day that-that we had four hours that (husband) and I would go out for lunch. Because even – when I had my little shop here in Greenville, he used to come over for lunch. And we enjoyed that part of it. But now just the physical. It-takes nearly three hours to do everything you have to do for mother. Because she is – she – in the morning sometimes she can hardly even talk. It takes nearly three hours to do it. And we're trying now to get the scheduling changed so that she'll be there three hours Monday, Wednesday, and Friday and two on Tuesday and Thursday. I could have my stress relieved better.

F: So you're saying that more time or more availability would make that possible?

P3: It will, it will help.

P2: And the other thing is, the way it is now, our Saturdays and Sundays are literally taken away, if it would be something that will allow some weekend work because otherwise if you wanted to do – you know – go out and if you have something planned with the family, then one of you have got to sacrifice that cause it's – you know couldn't work it out. Somebody will have to come in and take care. You just can't send a substitute in and expect the person to know how your mother or father – what they need. Cause my father's speech is impaired because of his stroke, so you really gotta know what he's trying to tell you. So just someone coming in and breezing in an hour here, or once a month or something substituting, they don't know. So the consistency in our case would, you know, consistent sitters is another key to it. Being able to understand what that person's needs are and how to take care of that person's needs. But the weekend, you know, just something like that to give you a relief there, cause you gotta think, you do have family and other things other than just your parents. You need that break then as well as during the week. Usually during the week, you're working so you still don't have a break.

F: You are kind of leading to the next area I was going to ask you about, which was -“Would different services not just more of the same thing you're getting now; more hours of a care aide or more companion time -would different services be helpful to maintain the parent in the home longer?” You were talking about a substitute or a sitter, or a – some kind of respite service for you and your sibling; I guess that you are not getting it, you don't have that now. Is that correct?

P2: Right, right. Like I say, it's during the week but the weekends your on your own.

F: So some kind of services on the weekend occasionally would be – would be helpful.

P1: I don't know if this is the time or if you are going to bring up the question or what. . .but I wish that the hours could be varied sometimes, like if it wasn't such a absolute, so many hours today and so many hours on Monday, Wednesday, and Friday. If it is agreeable between me and the caretaker, it could be a little flexible. I have – for instance – my husband had an appointment with the doctor and I had an appointment with the doctor, and it was – we-we wasn't going to be able to get back – we knew we wouldn't get back before she had left. And I had a terrible time trying to find somebody to come. But if she could come in – could've come in that day a little earlier, just so she got her three hours in. I wish the hours could be a-a little flexible. In my situation – I've worked-worked out weekends with my brothers. I-I have one sister-in-law that

would do anything for mother. She doesn't mind the diaperin, nothing. But my other sister-in-law, she is not able. She's ill herself. She has more things wrong with her than mother. Mother's just old. She doesn't have heart problems, or cholesterol problems or anything like that. But, um, we got our little time off worked out real well and my brothers say they pray daily for my health. It even bothers one brother, one of my sister-in-law's and I used to have a lil shop here in Greenville together, and every now and then – and we still do a little bit of work for private people but we went out of town together a few weeks ago and my o-other brother said he just worried to death. He was so afraid something was going to happen. He said he and (name) would be in terrible, terrible fixin. But the things that (husband) and I have to do sometimes, if we could just – if the caretaker hours could be just a little flexible, would help so much. If it w – if it was alright with her, something that could be worked out with her and it looks like with that phone-in number thing they have to do just so that they got their hours in.

(group talking over each other)

P3: Ours was pretty much tied because she had two other patients.

F: ...two other patients and she had to balance her schedule.

P3: her schedule, yeah, you know so she couldn't do a lot of . . .

P1: I said if it could be work out and if it was agreeable with the-the caretaker, it would help.

F: So I-I-I've heard at least that some assistance on the weekend, which is not something that you're getting now would be very helpful. Are there other services that would benefit your parent or help them in some way that you can see that would be helpful – that would make it more possible for them to stay at home?

P1: First, I think mother has been apart of this for about four years – a lil over about four and half years – and the respite – the first two years she was able to go. She thoroughly enjoyed it, they had a Jacuzzi, she thoroughly enjoyed it the first time and was – it was great for all of us – just great. Did not have to worry. But the second time, mother wasn't herself, and I had sent a dress for every day, you know how you – they hadn't even put a dress on her. She hadn't wanted to get dressed so, she hadn't been – she didn't even know who we were when we got back. So we don't get much into that anymore.

F: so that-that

P3: the respite was wonderful, for us.

F: yeah, well, ok. Are there any other, um, ideas you have about different services for your parent or the person that you take care of that you think would be helpful to keep them at home longer other than what you're getting now? And having perhaps more hours or more availability, some of those services. Are there some things that you can think of that might make that possible?

P2: It just seems, just you know . . .

P1: It's just wonderful to have what we have, I'm so grateful.

P2: Yes, I'm grateful for that. And we- when we – we haven't used the respite because, um, um, we've had the nurse come in and she stays at our house. She works full time but she stays there with her at night. And so we used her and usually pay her for that. It would be just so nice if-if that – instead of leaving mother out someplace – which I haven't tried it because the battle is so difficult to try to get her to go someplace. And-and I just – I-I . . .

F: the change in routine...

P1: mother thoroughly enjoyed it.

P2: I think she probably would enjoy it after she got there but it's just, you know, I'm just so . . . sometimes to go to the doctor it's just – you know it's like you have to put your foot down and then she . . .

P1: I can't – I'd make her.

P2: oh she's just – oh her responses, she doesn't wanna take – I don't want to take away her right to make those choices either, but sometimes when it's a doctor's appointment, you, you know, you're not – they're not as – she just decides at the last minute she doesn't wanna go, so . . . I have to come in and be a mean daughter and say “you are going” you know and that type of thing. So to move that up to a respite and say “you're going to go away for a week or two . . . For us” . . . If somebody were able to come, I mean if they could do something like that, and I don't – I can't even believe that would be possible for somebody to come in and stay overnight or something.

P1: You know, it looks that would be cheaper than the respite. That nursing home that-that we went to in Columbus, North Carolina. It was like that would be cheaper way to go to spend the government's money then-then . . .

P2: Someone locally can come and stay at you house.

F: You mean to have a sitter kind of thing, . . . I-I-I can't say. They don't let me make those decisions, I'm sorry.

P1: I-I had thought about that because that had to be a pricey thing, her staying there.

P3: Well, maybe that's something that could be added instead of – have a choice – instead of sending your parents off for a week or two – having someone come there if you know, at your home, or wherever they're staying for that week or two or whatever. Someone qualified to do the same thing that they would be doing

P1: just a sleepover, essentially.

P3: right, if it's one night, two nights or whatever. You know, give that option . . . Because by the time you load them up, pack all their stuff, shape them up mentally and physically to cart them off somewhere, and then the shock of that. By the time they get used to all these new people and surroundings it just horrifies you.

P2: or horrifies them. It's a terrible experience . . .

P3: and then to bring them back in and you know get them re-adjusted and then they'll be scared of thinking they gotta go again, if they didn't have a good experience. It's just like a child - taking them out of that environment they feel safe in is not . . . trauma.

F: So you're-you're saying that-that going out to a respite kind of experience you found to be more, uh, upsetting to your parents than helpful . . . at least . . . ?

P3: I-I-I heard that.

F: cause you were talking about fearful or being upset. Ok, so you're – sounds like at least, uh, the thing I heard you mention is respite care in your home – in other words, a relief person on the weekend kind of thing occasionally – would be a very helpful thing to kind of, uh, maintain a continuity of them being in their home but also to give you and other caregivers a little time. Are there other services that you can think of that might be helpful that would maintain them in their home?

P1: I don't know where this service lies, but, um, I was talking with (name), um, I think between the underpants and pads and they say you can have one of each. And if they don't use the pads could they get – change that over to panties and have two panties instead of pads?

F: oh, you mean the incontinence supplies?

P1: incontinence.

F: to have choice if they're getting incontinence supplies...?

P1: yes, if they're going to offer two . . . cause I don't see my mother using the pad, but she has started to use the panty. And um, um, I-I would think that would be . . .

P2: Fortunately, we can buy them for mother but the 72 every three months is just absolutely not enough for . . . and that's what we get. That does about a-a month. A good month. That's about a month. But I know there're some people – I've had some caretakers who take care of people who . . . they just find terrible situations, you know, where they just have the same one on and I just – I know they're getting bed sores and all sorts of things.

F: So-so you mentioned having at least an option on choosing which-which of those you get – if you can only get a limited amount, to choose which kinds and what's best for your situation.

P1: right. That would be a help. And they have taken – I think the shower stalls-er stools out. We tried to get a-a stool to put in the shower and-and they no longer are available but they used to be. Cause that would be something that would . . . because mother doesn't stand up, you know, and she needs to sit on that stool with a hand wash where she could get in the shower and have something to sit on. And-and actually I tried the potty chair in there but it collects water and then we (laughs) I mean, not the potty but in the legs. So you're dripping water and carrying it, and that's-that's difficult. So if that would be a possibility. That would – that would help.

F: that would be a-a . . . so an-an-an uh, an appliance, so to speak. Okay, are there other things that-that . . . ?

P3: I know the um, there was, um, the nursing program, when the nurse would come out, you know, every 3 months or every month or whatever and I think they kind of cut back I think the government or whomever cut that back or cut it out, unless you had a critical need. Again in my father's case, it's very difficult to get him in a car, get him out of a car, lifting him. I can't do it so that means my brother has to get off work to do that, um, whereas if a nurse, you know, on call nurse, if that was all there was. You just call and they come out, check is it necessary that thy go to a doctor. You know just-just set up an appointment, like, you know, can you come out today, can you come out tomorrow. But not, you know, have to take them to the doctor, if that is . . .

P2: That's a good idea . . . my mother has not been – last March was the last time she went to the doctor. Of course we had to get an ambulance. And it absolutely exhausted her. And so Dr.(name) had home health come out. I was very concerned about a few things and it was just – she just – I just don't believe she could have stood out there, riding in that ambulance. And the home health nurse evaluated her and reported back to Dr. (name). But it made me feel so much better, um, that we were doing the right thing and-and she maybe it was just – good for this it was. And mother was just as alert as she could be that day, answered questions. And Dr. (name) got a really good report and . . . 30 minutes after the nurse left, mother was telling me to get out of the bed. And I asked her what did she mean, and she says well you're in my bed. And your legs are too big. And so . . . (laughs) but she was just as alert as she could be when that nurse was there; answered every question. But I would feel better . . .

F: Having some in home help nursing service . . .

P2: oh, just to take her blood pressure and mother's blood pressure has always been low and just to reassure me that – now she is getting strangled a lot and I-I'm beginning to wonder what in the world they're gonna do about that, and I hate to bother the doctor, calling, calling, calling.

P1: It's a blessing. I've had a nurse who has been so good and we have been fortunate . . .

(group talking over each other)

P2: and she was a friend of yours that you got qualified . . . ?

P1: no, she was – we go to the same church, and she was

P2: I didn't know that you could do that kind of thing.

P1: I didn't know you could have a nurse. Uh, we're-we're – we just got a different qualification for it. I don't know

H: It is usually the Medicaid program you have to have a skilled need. (*muffled description of a skilled need and qualifications.*)

P1: She qualified for that advance need. . . . You pay more but you get higher – I mean, that's part of your hours. And then response, you know once a month or once a week for a couple hours they come in . . . it really helps me when-when they can evaluate her. And I – you know – I don't know how she's doing, but she-she looks at all of her vitals and things and weighs her and sees how she's responding, and that gives reassurance to me, so

F: and what you mentioned was so you would know whether anything was going on that would require you to transport them to . . . a doctor.

P3: yes ma'am. If you get scared and you think something's wrong and there's not. So you've wasted all that time taking the trip, you know, in and out, and then

P's: (group discussion)...discussion of personal care aides.

P3: . . . that's what they did with my father. They did that – makin it easier. Pickin up stuff that he needs for shakes for what the doctor prescribed.

P2: I-I just wondered if there was anything that could be done, like cause (name)'s mother is all about pleasure. And she loves food. And she'll eat. But she does not even – she won't even – she doesn't even have an appetite sometimes. And I would so hate for her to have to have bland food. (*muffled discussion about mother's diet*)

P1: I thought it was just my mother that was so wild about food.
(*continued discussion about food and diet*)

F: Okay we are just getting closer to the end of what we need to find out about. Um, where would the person that you're responsible for go, if staying home was not possible? If they could not stay at home, where-would they go?

P2: That really, really worries me because I understand that you can't get anybody into a nursing home unless it is out of a hospital, unless you got money to pay for it. And we spent everything mother had keepin her in her own home until she was 92. She stayed there until she was 92. So.

P3: There needs to be some kind other help to get a person that you have been caring for at home into a nursing home, some assistant to get them into a nursing home without having to place them in a hospital and say here take care of it. . . .

P2: I have put in applications, and the lady told me that should mother, should put his mother in the hospital – that I just had to absolutely say, I can't do it, you can't – I just can't do it. That she said, now you must say that. But, um, but everybody has said you can't – you have to go from a hospital. I just absolutely don't agree.

P1: that seems so sad.

P3: See the men beds, cause that's what we've been havin to go through now, there are hardly no men beds. There are women beds because the women live longer than the men, and there's a limited amount of men spaces, so until one dies or recuperates enough to go home, there is no bed. And trust me, I've been going through this trying to find a place for him to be rehabilitated and finally found one in downtown Greenville and we're all the way down in Fountain Inn - below Fountain Inn. And because there's limited beds all over, here and there, they're fillin up like the next day. But there are no men – no men beds. So there've been - like I's sayin, you know the assistance of getting from a home environment. Cause if-if we're willing to keep them

at home and do everything possible and do everything possible to keep them in their environment – out of the nursing home, then we need some kind of assistance just as if, you know, we sent em to the hospital and they had to help, you know. We need someone to help us close that gap up there.

F: uh huh, so that's important infor – that's the kind of thing we need to be hearing.

P3: It's just as important for us to get them to a home close to us instead of just putting them off somewhere that you can visit them once or twice a week, cause you have to drive forever to get there. It needs to be, you know, somewhere around your community and someone to help us get them into a facility.

P2: (name)'s mother is in Camden. It's the closest we could find. She's in a coma-type state, but all – we still gotta go down and see about her. Can't . . .

P1: That was one of my questions because I-I just talked with one of our, uh, another lady at church works at a retirement home or some health care type of thing and when I was talking with (name) she said um, if you need to start working on what you would do or where you would go now. And I didn't realize that it was – everybody's filled up.

P2: I put in applications, but I probably need to go back because I think they say you have to do it every six months just about. But uh, I-I-I'm a – I don't know what my brothers would do if I broke my leg or something. I just don't know what they would do. Cause my brother's wife, well, she won't even help diaper mother. And (name) has to find somebody to come in and help them when he comes to our house. Because of the problems he's having, we haven't been going out of town quite as much for the last six months, because it-it's really hard for a man to have to help diaper his mother. You know it's really, really. . . really hard.

P1: I was doing my stepfather and I thought – I didn't think in this world I would ever be able to do that and take care of him and give him enemas and all sorts of things, but I just thank the Lord, you deal with what you have, and um . . .

P2: My husband's mother lived with us the last year she was alive, and she was – kept strangling. And Dr. (name) said – oh, no Dr. (name) said, yes that's from . . . I just can't do that. He said, oh, baby, you will be able to when you have to, you will. And I was.

F: sounds like the-the things that you two have mentioned have been what you would see if you were not able to keep your parent at home with you with their condition or if your circumstances changed so you weren't able to keep them at home that you would see the – where they would have to be would be in some sort of nursing facility.

P2: It would have to be. . . neither one of my brother's could not take mother into their family. They could not.

F: so, what you're saying is that-that even knowing that and having dealt with that fairly recently that it's very difficult first of all with the bed and second of all how to manage that. Has-has anyone been assisting you in trying to find a slot?

P3: The social worker at the hospital.

F: the social worker at the hospital, ok.

P3: uh huh, and if you don't have them in the hospital then you are on your own.

F: I don't know what role the case managers in Community Long Term Care – what their role would be with that, I don't know.

P3: Basically, you have to go to the nursing home, put in the application and call them daily, weekly, whatever to try your best to get them in. If you go to the hospital which we had a choice because my father was really sick,

F: uh huh. So he was admitted to the hospital right?

P3: yeah. And um, three times actually. And those first two time we told them no, we were gonna take him home, which he was getting better. And then something else happened, which caused him to get even worse, and something else happened. So the last time, we had to make the decision that when we send him this time, we're going to have to put him in a nursing home. Because we cannot change diapers 24 hours a day. It was never until February, we had never had to deal with that. And like you said it's very hard, especially for me to have to change my father's diaper from constant diarrhea. That-that takes away from him, you know. Mother is bad enough, but your father. . . . that's horrible.

P1: yeah, stepfather is . . .

P's: *(discussion about parent's dignity)*

P3: It would be – it would be nice if they could include um, from this, a transition. If they could include that or work on that, particularly as you all said that people have been under their care for a long time and have used this facility. If you could bridge that gap –

P3: with a social worker from – even if it's from a local hospital if it's not affiliated with Long Term health care, or whomever – a social worker who has that skill and knows those people at those nursing homes. If it had not been for the social worker (name) at Hillcrest Hospital, you know, working diligently, daily calling these nursing homes, telling me you call this person or you check on this, and I'm going to go and do this, and this is what we got available but it's here, you know. This is your only chance. And what you're told is – if you don't take something close by when the bed comes available he could be moved all the way to Henderson, North Carolina. Because as I understand they have this magnificent nursing home up there that's very large, but – do you know how detrimental that would be to the family and to the parent?

P's: *(agreement)*

P3: So people not knowing all the different nursing homes and the level of skills that they have – which a social worker does – you're lost. And I-I did not know where to start or what to even do...if it had not been for her.

F: so what you're saying is that it took a crisis in your father's health to get you connected with someone so that you could make the plan for the next thing that you had to do – that you had to do with him.

P3: right

F: and that – what your suggestion was that if you could have some service or some education or some, you know, learning about keeping mom or dad at home as long as we can, but if we can't, what are our options, how do plan for that, how do we begin set the stage for that, is what you're saying?

P's: *(agreement)*

P1: it's almost – yes – it's almost like I know it's going to come where we – you know – where we're gonna make that-that. And certainly, you know, we've proved the fact that we want to keep our parents in our – in their-their environment as long as we can but to have an option or some direction that c-could probably come easier with the group like you are doing...

F: yeah, uh, well, the object of, you know, the goal of CLTC is to keep people in their homes and in the community for as long as it is feasible. You know to keep them in the level of care that is in the community. Um, and what I-I think part of what they're trying to gather by talking with people that are the clients and the caregivers is what is it that they could put in place that could help do that but also – what you're saying is that if you could manage that a little more planfully it might not end up being as confusing or even possibly as expensive. Because if you're not making bad decisions then you don't have to do it three or four times.

P1: right, I would think that if they established through the people that were servicing our people and administrating and they could – as they evaluate it, they see this crisis coming, that there could be a plug in to let's prepare them for the next step, I think that could be a good transition here that would it could be recognized and then you could start communicating and start the search for a facility

F: and not have to put them through . .

P1: right, right.

P's: *(more discussion reiterating need for transition services. Tape is muddled)*

P2: I don't know what in the world would happen to mother, if . . . I fell the last two steps down the stairs about three weeks ago, and I just knew my ankle was broken. And my first thought was what on earth, how in the hell . . . so it would just be awful.

P3: yeah, the caregiver could not be able – what if you were hospitalized and you were the person who took care of . . . who could help step in and start helping getting the help or putting them in the home, because you're-you're not actively able to do that anymore.

P2: and I'm too worn out – just *(muffled)*

(group talking over each other)

F: so a lot of what you're talking about is you know that what you're doing is really important to keeping that person in the home too. Not just the services, but you – what happens if something happens to you and you can't do that.

P3: right. What-where will it be picked up and how? Is there someone there at that facility that can be the go-between. Even though you're being taken care of by the hospital or whomever, you know what-what's going to happen here. . . .

F: so you're talking about a care plan that has some what-ifs things, not just how many hours is somebody going to be here to help bathe or do whatever, but something about . . .

(group talking all at once)

P2: I just – mother's – I don't know. She has absolutely – I had to call 911 one time because she absolutely passed out not breathing. And you know, if you – you just get panicky. And she was on Evercare, we'd been doing Evercare. *(muffled comment)* but *(laughs)* my husband was there, he said, well she's gonna go to the hospital. She came around before he even got the ambulance there. They took her out to the hospital anyway. He said she could not say that she couldn't breathe. But everything about her was normal when they got there. She could tell him how old she was, where she was born, and he they're not gonna keep her. But she was passed out.

P's: *(muffled group discussion on hospital and doctor experiences)*

P2: One thing hasn't been mentioned that mother did and Dr. (name) suggested was daycare. Years ago. Mother went three days a week. And, now we'd had a neighbor who went and I just thought it was the awfulest thing in the world that she sent her mother out there. But then here mother was at my house and it was – she was a little demanding in the beginning. . . and it turned out she really enjoyed it. She really – she kept crocheting things and mother would bring me things home. She stayed about four hours three times a week. And it was – it was so good for her socially. She just really enjoyed it.

(group talking)

P3: it is more – more nursing homes or more whatever. Cause I know when we checked into that, it was like in West Greenville, or wherever like that, was I think the closest one which would've been like an hour drive for my father to travel, you know.

P2: my mother went to the one in Liberty which was just like four miles, and for a while they talked about closing that. And well, of course mother couldn't ride all the way to the old Shriner's Hospital, is where it was. She-She couldn't stand it, sitting in a wheel chair. You know they rolled her on. She could not. And I said, no mother could not do that. And they changed their minds about moving the one from Liberty and have added space, but that was the best thing. As long as she was able to go. She uh, wanted her hair done and her lipstick and she insisted on carrying a purse, so that she could have her lipstick. But they started feeding her, she had a friend she talked about so much, um, and his name is George. And, um, then she said one day, "Have I told you that my best friend is black?" And I said no, mother you hadn't told me. He had been feeding her cause she had . . . and he had been feeding her and it turned out he was one of the patients. . . . and her best friend was George.

F: Well you've mentioned a lot things that are um, some different services or different appliances or different aids that would help. Uh, and you mentioned some, uh, suggestions about options about what the person that you care for, whether that you recognize that uh, if they were not able to stay home that the nursing facility would probably be where they would need to be but you're having some difficulty either arranging for that or knowing what you have to do to arrange that when that moment arrives. When you know that this is the choice that you have and you're asking for some additional help and systems and planning for . . .

P1: If when they go on the program that there could be almost a-a fill in so that – we'll do this as long as you can do this and keep them at home. And it would lift the stress if you knew, should anything happen, these are the options, a very directive type of thing. And have that already open. Because I-I what I sense in myself, is as we're talking – I didn't realize I was having stress over it but I guess I am – is those things, and you're always just living on, when is it gonna happen, you know and . . .

F: So you're saying - seems that you're saying that some planning and some information and kinda helping managing that would be helpful. And you're saying it's harder than you think so you **are** gonna need some help with it. Based on your own experience.

P3: Nothing against it but these ladies are older than I am and I just don't see how they could possibly...Cause' I am running two households and I am taking care of – you know my brother...(*group talkover*). . . as far as, you know, just knowing like you said, if it came to the point where I'd just call em and say, we're to the point where we cannot go on any longer, whether it's we can't stretch to handle it because of the situation we have encountered to this point and then they just took off with it. Let us take care, let us start turn it over to whomever that would start feeding us the information that we needed. Like, ok we've contacted this home. All you gotta do is just go there, fill out an application, and talk to them. You know, things like that. Because if they don't go to the hospital, they're gonna be doing this on their own.

F: I think those are very practical things about managing the continuity things that-that make it not an emergency. And I think when you deal with disabled people and elderly people it's hard to deal with emergencies.

P1: And if the social worker that does that work through the hospital could do – it could be one then I think they could have, you know they would be familiar with it. It could be . . .

F: The mechanism, I can't speak to but it sounds like what you're asking for is something that would be planning to keep them at this level of care as long as you can and when you can't what do you do. And what are the options that you've got so that you can be thinking about it

P3: and help that you don't have to try to – cause if you're out trying to take care of that person and you're also trying to work and take care of your family, you don't have a lot of time left to

run around here and try to visit all the nursing homes and continually – like I said if I didn't have that social worker that was constantly on the phone, visiting and doing whatever, and calling me and saying, this is the update today. I'll call you in two days. If I hear anything this is the – I'd still be out there running around. Not knowing what I was doing.

F: So you need sort of a planning and some advocacy about how you would...

P3: Yes. Because they know exactly the points they have to make and exactly what they looking for whereas we don't.

P2: If I understand it nursing homes have just a certain number of Medicaid patients

P's: yes.

P2: and uh, they don't get paid, I understand, enough to cover the care.

P3: no they don't. Your social security check and your Medicaid

P2: doesn't totally cover it?

P3: um, in some cases it depends on what type of room you get, depends on if you want a private room, depends on, you know – private room you have to pay for on your own – you know and . . . it just goes, there's just a lot of details that-that you really need to look into.

F: ok, well, we-we are done with what we came to ask you and we appreciate you sharing your situations and your thoughts about it with-with us. And uh, and . . .

P1: Just on my personal experience and you sound like it too... I am just so personally grateful for the program and um, for the-the helpful people that we have dealt with who have just been so perfect to help me through it and if it wasn't for (name) listening to the occasional, you know, *my mother says I couldn't make out her checks anymore, you know, she thinks I'm stealing from her.* She said my mother did that too, you know. I mean, just it really is a help too, you know as you go through all of those-those stresses and . . .

P2: And my mother never - that's never been a problem, at all

P1: I must have a (*laughter*)

P2: ...if my mother had exercised, she would not be in quite the shape she is now. And that all – that was a thing that uh, daycare wanted to try one more time – I think they tried two more times. But mother had her knee replacement about 17 years ago. And um, she was doing just great, but then her back started turning her off. And her family doctor just kept giving her something stronger and stronger and stronger. Oh, I went by one Saturday morning and she couldn't get her medication, and he said, well you can take her to the emergency room, but I know it's just that ol' arthritis. Well, it was a crushed vertebrae. And she had been in terrible, terrible pain. But um, I guess that all happened about twelve years ago and that was really when I had to really start taking-taking care of her. But um, she didn't mind me writing checks or anything like that. She's been easy about things like-like that. But she did want to stay in her own home. But she started having a lot of little TIA's. and uh, I don't know how many times she-she could think of my telephone number, because she'd be in the den

(*Group discussion*)

F: Well Thanks you all for coming ...

Transcription end 4/19/03.

Community Long Term Care Focus Group

Location: Florence, South Carolina – Pee Dee Active Day Care (Adult Day Health)
Facilitator (F): Sarah Meadows
Participants (P): (3) Female clients (1BF, 1WF)
Date: 4/14/03

Two clients used a walker; one had a leg amputated and was in a wheelchair. One of the clients had severely impaired speech, apparently due to a stroke. She was oriented and nodded or shook her head to indicate agreement or disagreement to questions. The other two clients were oriented, alert and articulate. All three had been attending this day care program for at least two years.

F: I have your permission to tape this conversation - is that correct? Say yes or no, so we have it on the tape.

P1: Yes

P2: (nods)

P3: Yes

F: Um. As I said before, we're talking to people who are getting Community Long Term Care services. Like you're in Adult Day Care right now. And you get some other services at home, is that right? Somebody comes to your home?

P3: Yes

P2: nods

F: What kinds of services do you get at home?

P3: Like on Monday, Wednesday and Friday, they come and help you to get your water, take your bath. Clean up and everything.

F: So, it's personal care?

P3: Uh Huh.

F: And do you get personal care at home also, someone comes into your home?

P1: Yeah, somebody comes out.

F: That's in the morning?

P1: Yeah every morning.

F: So they come and help you get ready to come here to the program?

P1: Every morning except for Saturday and Sundays.

F: OK. And then your family helps you on the weekend?

P1: My daughter.

F: All right. (turns to P2) And you get help at home also?

P2: nods yes.

F: Uh, the first question I have for you is "Would you have to leave your home, the place you are living right now, if these services were not provided for you?" In other words, if you did not have that kind of help. Would you have to leave home?

P1: I would, if I didn't have some kind of home care.

F: Uh Huh. You'd have to leave?

P1: If I didn't have some of the services.

F: Because there's no one who could do that for you?

P1: My, uh, my daughter works.
F: Your daughter works, so she wouldn't be able to stay and do all of the ...
P1: (nods) yes
(Pause --- Background noise as other clients enter building)
F: (to P2) What about your situation? Would you be able to stay at home if these services were not available?
P2: I did _____(unintelligible)
F: You did before? Stay at home before you got services?
P2: nods yes
F: (turns to P3) What about your situation?
P3: I would definitely stay at home, but it's just my son and I live there. But --- They come in and get your water and everything straight. I get my clothes up at night, you know.
F: But the person coming in and helping you now makes it a lot easier?
P3: Uh Huh.
F: And you said, uh that the person you live with is your son?
P3: Uh Huh
F: So the personal care might be difficult for him, right?
P3: Yes.. (Nods)
F: Uh, the second question I have is "Would more of the same services you are getting now help you stay in your home longer?" For longer out into the future. More of the same thing you are getting now.
P3: Like I get an hour of the mornings. I come by here [adult day care]. If I wasn't coming here, I would get two hours. Like I don't get any afternoon, any help like that.
F: OK
P3: I been coming and do for myself.
P1: If I could get somebody for two hours, it would be better.
F: If you could get more time, is that what you're saying?
P1: You mean, if I had more help?
F: Like if you had more of the same kind of service, but more of it.
P1: Uh Huh. That would *really* help me.
F: Would there be some different kind of help that you could get in your home - not the same things you are getting now - something different - that would help you to stay at home and manage?
P3: I couldn't stay by myself. Because my leg has been amputated. So it would be difficult to stay by myself.
F: So your son provides some of that help, helping you move around

P3: I can move and ---my prosthesis, but the walker. I still have to have somebody stay with me.
F: Uh Huh. Ok.
P3: They don't want you to stay by yourself.
F: Right, OK. (to P2) Would something different be helpful to you to help you stay at home or with a family member?
P2: I don't stay at home (unintelligible)
F: You don't stay at home ?
P2: (shakes head no)
F: Who do you live with?
P2: I tay, I tay by ee (unintelligible)

F: OK. (to P1) Would something different help you?
P1: If I had more help.
F: And what kind of help would that be?
P1: Help get my food.
F: Getting your food, getting your meals? You mean like preparing it?
P1: Uh Huh.
F: Cooking it and such?
P1: Uh Huh.
F: And you don't get that now?
P1: No.
F: Do you mean like someone coming in to prepare food or delivering it made?
P1: Delivering a meal.
F: You don't have a delivered meal now?
P1: No.
F: That would be helpful to you?
P1: Yeah. Especially on the weekends.
F: Uh Huh, OK. (Clears throat.) "If it were not possible for you to stay at home with your health and the things you have to have done, where would you be living? If you could not stay where you are now?"
P1: I'd have to go to a nursing home.
F: Uh Huh.
P1: And that's where I don't want to go.
F: Uh Huh. You are living with a family member now...
P1: My daughter
F: (turns to P3) Do you have any thoughts about ... So if it were not possible for you to manage at home with the services you are getting, where would you be living?
P3: I'd have to live with someone else. Now, my son is there with me. So that he gives me time and everything.
F: Uh Huh.
P3: But things change and I would have to let them know, "Things have changed."
F: So you are saying, if it were not possible for you to be with your son, if there was some difficulty, then you would look for some other family member or someone else that you know.
P3: If he were not there with me I would have to stay with some other family member or something like that...another place where you can do things for yourself, some place like that.
F: You mean like assisted living?
P3: (can't hear on tape)
F: I'm sorry I didn't hear that - they were singing loud.
P3: Like these other homes. Like you can get around and do for yourself.
F: Like assisted living. Like you are in you own space.
P3: Like they come in and help you and change the linens on your bed and everything. Scrub the floors. Keep the kitchen up and like that.
F: Uh Huh.
P3: She comes in the morning time.
F: Well, those are most of the things that I had to ask you. The people that are wanting to know the answers to these questions want to know how important it is to keep people in the community and keep people in their homes or with a family member.

P3: Very important. Because for me they do a good job, they are real nice. Now *here*, it's ... (background noise)

F: I'm sorry I can't hear.

P3: At home. You know coming here (adult day care), you have somebody to be with, to talk to.

F: OK. Did any of you have anything else you wanted to say about the services?

P2: I did ... I have some to talk to

F: And you like having somebody to talk with?

P2: Yeah.

F: That's what's important for you about coming together with other people?

P2: (nods.)

F: OK. Thank you for taking the time to answer my questions today. I appreciate it.

Tape ends

Community Long Term Care Focus Group

Location: Charleston, South Carolina
Facilitator (F): George Appenzeller
Participants (P): (7) 2 Caucasian Females / 5 African American Females
Date: April 17, 2003

F: Ok, well, I'm gonna repeat again that it's...it's ok with ya'll if I tape record this?

P: Yes (entire group)

F: Okay. Ok, great. Ma'am?

P: You actually.....?? (unintelligible)

F: oh, ok.

P: ...and I live by myself....

F: uh-huh...

P: I live by myself and that's the reason why I got this ?? phone and I could call for help.

F: ah, okay.

P: I need more than...on Friday, on Saturday and Sundays, when I need somebody.... cause' when the aide go out Friday mornings, she work two hours and I don't have nobody else to uh...to cook for me and I always seem to burn myself or I end up sitting out there on porch.

F: Okay.

P: I...I take care of my mother and um....she...she's 88 and uhm...

F: That'll, that'll be fine for right now

P: Okay.

P: My name is (P3) I take care of my son. I have taken care of him since, well...he is 41, and I have been taking care of him since he was six, when he was hit by a car.

F: Okay. Well, I really appreciate ya'll coming here today...ah, to... ah talk with me and what we are trying to do...well first let me say if anyone would like to come up here and get a cookie or get some uh...something to drink, uh...crackers or whatever, please...please do so, whenever you want to.

P: We appreciate it.

F: Okay, would you like for me to pass some to you, ma'am?

P: No, thank-you

F: Okay, Please go right ahead. What...uh...what we're trying to do is to gather some information that will help us in improving the program. Because I'm sure ya'll know the people in CLTC are trying real hard to do a good job, ah...they, of course, could use help in doing that and uh...I've been asked along with some other people to hold some meetings like this and to uh...uh...do some surveys. You'll may have gotten a survey in the mail. I don't know if you have or not. Probably not because we tried to keep the people who we were going to be talking with and the people who were getting surveys to be different from one another, uhm, but we're trying to get information and...and hopefully that...that'll help us in improving the program. Uhm, and I guess that the, of course... the thing the CLTC is about, this whole program is about, is helping people stay in their homes.

P's: Right, Right...I'm so glad.

F: So, the...the first question I would have to ask ya'll, if you could...could tell us ah, would be if you or the person that you are responsible for, ah would they have to leave home or go some place else if these services were not available?

P: Yes, he would I guess, because uh...we've been with LTC for 12 years and uh...I really appreciate them, and the only thing that I would have as a suggestion is on the Respite. Add to providers for the caregivers, especially when it's the family and I have a suggestion, it would be nice if they could have it where they could have it in the home. Because I have a bad experience with the nursing home for his...5 years ago when he was on a respite. And you know when you leave your love one, you want to be sure they're gonna' be taken well care of...

F: sure...

P:and...and uh...in the home they would be in their surroundings and it just would be much easier. Uh...because you have to deal with moving them out and moving them back and that's...that's a great, you know, ordeal for that person that's having to be taken out of their home.

F: sure...

P: Yes, so and uh...I've always have felt that ...be nice if they would have where you have a month, where you can take two weeks intervals, where that maybe in the fall or in the spring or summer and winter, you know...because it...and it **still** would be much cheaper than having them go into a facility. Because you can have someone qualified enough that if they's on medication and that, that they will be able to assist with that and still not cost what it costs what to put them in that nursing home or the hospital or whatever they use for respite, now... you know. And that's, my suggestion....one of 'em (laughs).

F: Okay.

P: That's.....that's very sure because I had a experience, because I actually live in two different states. I live in Georgia and here and I commute back and forth because my husband and other children are in Georgia and then I have two.... my smaller babies are here with me. And I have to commute back and forth because I have to take her back and forth and-well, their sometimes out of their environment. It's even more difficult because everybody becomes a prisoner to a dead bolt lock. (group laughs) And uh, I had a bad experience also with respite. The fact that I needed a break and needed to come home to my family. And she was supposed to remain for two weeks and I gave them little tidbits, you now, that the first opportunity she was gonna make a break for it and two days later, my sister called me....

P: ..she can't hear you, excuse me.....

P: Oh, I'm sorry....two days later, my sister called me in Atlanta, saying that uh....they had called and said to come and get her because there were confrontations. One incidence where she left, she almost got hit by a car and they didn't really know that she had left the facility.

F: I see....how about some others?

(A discussion ensues among the participants)

P1: What do you call a respite?

P2: That's.....that's where once a year they give you the opportunity – two weeks, where they can be placed in a place where they will take care of them for you. It gives you a break.

P1: Okay, do you have to take it all at two weeks? Cuz I mean,

P2: Well you have to take a...it's either a week at a time, you know...and they have to have a opening, so you could be able to take them into that place because so many facilities are closed.

F: So what...what would you like to have?

P1: I just need someone to help me every now and again, you know...at least once or twice a week, so I could just get, you know, a full nights rest.

P2: Well, that's what's nice about respite. You could have it...if they would have it, if they would have it in the home!

P1: But you only get it for two weeks...you know....

P2: Well, you could take a week....

P1: ...no matter where! Um...like with me (clears throat) it would just be nice if I knew there was goin' to be two nights out of one - out of seven days...that I could get a good nights rest. Cause it's either eleven or twelve, two or three, or five or six and then from nine on through the day. And it's just about to whip me and I am really getting worried now because if something was to happen to me, what...where would she go?! If I got sick right this minute... where she stay? What would she do? She can't even get and go to the bathroom by herself. She can't get herself a drink of water (pauses) and if I didn't get up all night long and keep changing her and make sure she's fine, then she might try it herself, which she did on the 11th and fell over her potty chair and broke one of her ribs. Now I've got that much more, see...that was with her thinking she was giving me a little break, which you know, it wasn't a break, it just made it worst. It was a break of course, but it made it worse! And um....as far as the other siblings you can forget them! (group laughs) I mean, you're like...I call and told them, you know, they need to come see momma, she's hurt her ribs, so she needed a little pampering you know? So, they came in and seen her for about a hour a piece, twix the two of 'em, poof! We ain't seen 'em since! But...that makes me feel like I need to give her more attention to keep her from being depressed. Cuz when you get depressed, then you got more problems. Then if the Red Cross falls apart on me, there I'm left two weeks without an aide. And with her right now, you have to watch her real close because she could easily get bed sores. Even with aide with her, I have double check. I uh...checked here a while back and told the aide, "lookey here, you're not doing your job right cuz there is a bed sore fixin' to come on her hiney, it already blistered." So the we got that straightened out but I mean it's um...it's to the point where I just need...*I need*...

P3: More 'I care'...(laughs)

P1: I need...I can't go to the grocery store, you know. What happens with us, is...is my husband has to stay or I go or I stay while he goes...but now because she's so dependant on someone to help her with the pot, you know, and things like, that my husband can't do that! So then, now it's left up to where he has to do *all* the going. And like for instance the other evening, he said "you just go ahead and go and I will stay here with Mimi, you done got her in the bed." So I went to the drug store, got her medicine; went to Wal-Mart just to get her diapers and things and I got back and she was so upset, "she said, what are you doing! You must be got a man out there somewhere." (group laughs)well, that upset me so bad, I didn't know what to do. So I haven't been nowhere since until right now.

P4: My problems is uh... it's hard for me to get out of my wheel chair to get into a regular chair so I can elevate my foot, cuz if I don't, my foot get all swelled up. And...um, wasn't nothing to wake up um...Friday mornings, I...I have to find food from Friday evenings, Saturday mornings, Saturday evenings, Sunday mornings and Sunday evenings, and I burn myself!

P1: Barefoot too!

P4: A bad burn on me when I burn myself and then I *fall* a lot! And then I can't remember to take all my medications on time, so more help would be beneficial for me. And then um...if I didn't have these...this little bit help I got now, I wouldn't have nowhere to go. I have no place to go, I live by myself. My kids have got their...I got a lot kids, and their homes is big enough for them, so I would have no place to go. But I'm 78 years old. Pretty soon I'll be 80!

P3: Do you...Now do you assist with her?

P5: We...she has quit a few grandchildren and...and children. So we all, you know, take turns. Coming over and visiting, doctors appointments, uh...errands to the store and that's how we've

been doing it. Um...I agree also with, you know, having someone in the home if that is possible because for her as strong minded and willed she is, to put her in a home, she's, you know, that's...that's so...so depressing!

P4: ..ain't it?!

P5: And that itself would, I think, deteriorate her health above and beyond a lot of other things because she is so used to doing things for herself. Putting her in a home would just, you know, it would change a lot of things for her health.

F: sure...

P5: So, I mean....it would definitely be in good health for her if she had someone that could, you know, dedicate more time to helping her and her home, where she's has been since I can remember.

F: sure...

P3: As far as her meals, I know there is a program meal on wheels...

Group converses: That's what she's talking about ...but you don't get 'em on weekends. No weekends.....you see, that's what I wondered, what are these people like...well, they have to make....they live alone...how do they manage? Isn't.....isn't that's what a homemaker's program is for?

F: I'm...I'm not sure what.....

P3: not sure?

Group: they have homemaker's programs.

F: I know there is a homemaker's program, I'm not sure if.....I'm not sure what they do on weekends, though.

P4: they don'tthey don'tI don't see nobody from Friday morning supper until Monday morning. And so I cook....they don't want me to cook because I burn myself so bad,....

F: sure, sure....

P4: and um...so that's what I need. And anyany kind of help you can give me, it's what I'd appreciate.

F: What...what I hear ya'll saying a lot of is...that you're getting are good service but you need more of 'em.

Group: Right...need a little booster...right

P6: Sir, I wanted to ask you on uh...in my situation is um...my concern is with lifting because my son is as big as I am and he's a quadriplegic ...is....if there's a program that would make provision for him to receive a lift, not a hooyer, but, you know, they have portable lifts now that can pick them up which would be a "God-Send". I've...I mean I've always taken care him, I'm just starting Monday to have that caregiver come in to help me to bathe him, I finally gave in, (laughs) but uh...if there would be someway thatbecause still again, that's gonna' this...Medicaid money! And with, you know, there's ways of getting around that if they could just lend out a little bit, then they're gonna get more from their families and the ones that's taking care of them because I believe we're all in here to support one another and help one another because we *don't* want our loved ones in the ah...I mean, my son is going to stay with me till I draw my last breathe. I mean I am determined on that. Because I feel that uh...one reason....my son that he's my responsibility and...and I know what's best for him and he **loves** being at home. And ah...if I just had the equipment that I need to help me with him, it would just make it easier.

F: Sure.

P3: That's the thing I don't understand about Medicaid. They would embrace you putting someone in a nursing home or facility, which could be much costly than just to have someone to come into the home and stay hours. You know, while she sleeps at night....

Group: um-hmmm...(many comments of agreement)

P3:have somebody to come eight hours twice a week...

Group: just once or twice a week...or have somebody to come in for four hours while you have to go shopping and run errands, and...and things of that nature.

P6: It's a worry because right now I'm by myself. My son's is in the bed and here I am and he's home. And so I go on a grand run to get back and forth, and you know as you get older, its harder. Thank-God, I'm still young enough that I can keep on going and...and God gives me the strength to do it! But I'm like the rest of them. I haven't ...I've not had any help for well since....really since he's been hurt. And so in the past twenty years, I've been on my own with him. So uh...and it's not complaining because like I said I wouldn't have it any other way and...and I can't say enough about Long Term Care, Community Care. And their...their people, they're...they're good people. I appreciate Medicaid, I appreciate everything they do. We just need a little more assistance. And if we just come up with the money. I mean, I know that's the big thing there but we've been saving them money. While they spend \$75,000 for a person in a nursing home...you know, half of that would go for what provisions were to take care of...helping in the home. It would save money!

(a cellular phone keeps ringing in the background)

P1: There again they have to be careful so many people abuse, you don't know what's going on...

P6: well, you should.....

P1: but I do know ...

P3: You have a caseworker, they screen everything else...if...if you are putting them into a facility, they go (someone coughs – phone rings louder) with to get the medical records, the go through your financial statements that that person has. It would be the same process, um...if you were to get uh...additional help...

P's: Right, Right.

P3...or the maximum amount of care that you possibly can.

P1: Well, like right now, I *know* I need a hospital bed, so how am I going to go out and get one of those?

P7: So your case manager will help you.

P1: They....well, Medicare don't pay for all of it now....

Group:Do you have Medicare...I mean....she...she gets Medicare..she has Medicare and Medicare... Well, why don't they go together? But still I don't...

F: Excuse me a minute, are you going to go ahead and go? Or do you....

P5: well, she'll....she'll stay here.

F: Okay...because if you had something you wanted to say, I wanted you to get a chane to say it before....

Group: They's organizations too that will help you because um...Yeah, I have..... I have sought many organizations, I don't know what I would've done without them, that has helped. If you go and you tell them... they, there is other agencies that will help when you have a need.....See, I don't know what's out there...

P4: They put in the hospital...I was in the hospital here... ohh, I don't even remember, times all gone so crazy in my head. Uhm and I guess they figured, it was part of just stress and strain and

someone or another, Susan, came into focus and started helping. That's when I got an aide then. And see I didn't know all that was out there or I was...and even now, I know there must be other things, but I just don't know what they are. Like one lady told me I really needed to get in touch with hospice. That you don't necessarily have to be cancer, you know, ...

Group: right.

P4: ...something terminal....that old age wouldn't be a factor. And uh...so I been thinking seriously on trying to contact them and to see what they can offer me, you know. I don't know, that's it, I don't know! I don't have notion what's out there.

F: So having more information about what services are available would be helpful?

Group: yeah, they would...yeah...that would help...

P3: It would have been good to have a...a caseworker in here now tosince everybody is um....saying exactly what they feel, then they would know what is needed of them.

F: Well, that....that would...I will definitely pass all this along. Yes, ma'am?

P7: Yes, I.I was....I was saying, you know, most of my problems are...similar terms. Right now I don't have anybody to um....you know, come and get my mom up...Red Cross came in and like I said, the young lady worked three days and she left. And you know it's between me and my brother.

Group: (cell phone goes off) can you get the phone? It's like, get her up and get her dressed and give her some breakfast. It's just a burden to um.... like I said that's my mom and I know I *need* to take care of her and I don't want to put her in a nursing home, you know. Well, so I struggle with her, but as far as a respite, I don't know anything about that! And I've been taking care of her eight years and I haven't had a vacation since eight years.

P1: I feel like if I was to put momma in somewhere like that for even a *few* days, she ...I don't know, she couldn't handle it! She *could not* handle it, she **would not** handle it!

P2: My mom's been to a respite. My name is ----, I take care of my mom. And I has been taking care of my mom for six years and um....the respite is just awful! I mean the people there, they don't care. When I put my mom in a respite, I might as well keep her home because I'm constantly there and I'm doing more work than they are. So I don't put her in there. My mom never use up her days and you took care of your mom for *eight years* and didn't know anything about respite?!

P6: Honey, I took care of my son for 27 years and didn't know it...just in the past seven years we had respite. I took care of him for 23.....

P1: Now, Susan told me about it...

Group: ...well, it just hadn't never been that long before....two weeks, you know you have to plan ahead for....and you know...my momma never would...yeah.....last thatexcuse me....there's a lot of things that are going on in this state, you know, for the older people? But it's like, you know, closed mouth, only they don't make it available....just like you talk about the respite. You know....it's...it's, you know, why is everything so secretive? That'sthat's my thought, if you're here to help, why...I mean, why not share? Why not the knowledge game...you share it. A lot of people around this general area...I can't believe what I hear later, you know? Just like now about a respite. All, I know is....I, I was told about it.... I just forgot the terminology of it...what about...what about...told me about it. ?? Why don't they make you, you know....You have to ask you...your case manager what...what form you fill out. They know...never! Never,like my case manager...my case manager tells me everything! That's one thing, I feel very good, I feel real good asking questions about everything....

F: So....so another thing then that I hear ya'll saying is that there's more public information is needed...on what services are available?

Group: Sure...sure. Um-hm....Because I mean, you know, we have our lives as well. We love our family members. I love my mom, I mean...it...I, you know, a lot of times, I put my husband to the side...Amen...mine...me too, it's unfair. I am young; too young for this. (laughs) But you can't just not take care of your mom...you know? But it's just so unfair. You know, like I said these old people have lived their lives and worked and paid taxes, you know and they need to be taken care of, so.....why not make the caretaker aware of what's available, you know? Why everything is so secretive? I mean, nobody...I've gotten into trouble if I ask a question at first....oh, this is my whole one's....when, when I came back and I was like you know, I wanted to know what was going on around the general area and everybody 'why you want to know that?' Well, I'm just the person that asks questions. You know, that's how I learn, you know.... but I never heard of respite.

F: Hm....

P7: I...I'm listening to everybody, I truly am, my heart goes out to you and I say again, I know that there is aa little gap between income, I've learn that much because... the Care...the Long Term Care people, they come, they come to interview you in your home every two or three months. They...they're at my home, to ask these questions about them and they bring this paper with them. It's a list of everything! I don't think nothing is left off. I mean even the um...the exterminator comes to the house and exterminates the house. I'mI'm not adding to it, I'm telling you, I took care of my mother, she died in 96' and I was taking care of her for years! And I've had Long Term Care. Whatever I needed, it was there, it was there! You understand? Like you say, if you ask them, just ask the right person. You got Medicaid gives you a booklet. Sometimes you don't these booklets.... and its there. And like he said, he's here to take in our, you know....what we need...

Group: yes!

P7: you know, a lot of time, I'm listening to everything right now. It's a lot of complaints, but we *need* to let them know right! Hosp...respite care, you only have a few facilities..

Group: yes, that's right...two....

P7: ..a few facilities...

Group: ...and they never....

P7: and the hospital...my brother, he even had respite at the hospital! They cut that out!

Group: yes...

P7: yes, you have respite at the hospital, they cut the hospital out, I don't know why. But they cut it out. Because some patients are more for needing the hospital than others. He has a trach, he has a feeding tube or he has to...you know, he can't talk for himself. He can't say nothing for himself. So they put him....I mean the nursing home that we've been using, they're pretty good. Because you have to find out what this nursing home ?? are. You know, people are there....Medicare's in there. Um...Community Long Term Care is *in* the nursing home where we use um...um....

(claps hands) Driftwood...they're in there. (Group discussion ensues) They got their wholeI know they ...explain to you what's going on. You read these papers to sign, what else? It's a state of them not giving us information. I don't know who's not doing, but maybe we need to investigate the people who are holding these positions. (cough in audience)

P7: yeah....even in the nursing home, you need to check on what's going on in the nursing home. So quit putting it off! hey, these people here are helping me! I'm telling you. I've had a

brother had AIDS, I had my mother and I got him still! So, I can't complain that I didn't get the help that I need. But if I need help, I pick up the telephone "hey, I holler!"

P5: ...well, I went there andwhat am I trying to say?.... I went there and they uh...and I investigate...I investigate every place I go because I'm very, very particular about my son and uh...they promised me this and that. When I went back to pick him up, we left right from there, went to the doctor's. We took photos. My son was bleeding, he was black and blue in the groin area. His...his ear was a mess...his...and...and he hadn't had his...and I had people checking on him!

Group: um-hm!

P5: he hadn't had his medication. We reported it immediately to the state...

Group: um-hm...

P5: ..they covered it up! The state went in there and they covered it all up. And they weren't not a fine for what they done! I'm sorry. I will not take my son back to...

P7: ...I'm not saying....

P5: ...the facility.

P7: no, no....I didn't say...I didn't say don't takethis is what I'm saying...

Group: I say, I'd rather have evening care.I know!

P7: he's asking us the goals...listen, he's taking this in for the information you're talking about! You know you say somebody didn't have a meal at home. Somebody had knocked on my door, we canright now here. We shouldn't even leave each other without having the telephone. Maybe I can come over with somebody that would be... my church people they....when I had implants and people been in my home for the last three weeks helping me. And I gotta do nothing! Implants. I'm supposed to be

Group: your church....

P7: yeah, church people and....and the neighborhood. You got to know the people around you.

Group: well, I'm all for that...I understand that...I've lived there for years....and most of these people around have problems themselves....they have not....I'm having (a very loud confusing discussion ensues among participants – unable to decipher)because you don't know who's there to help her?that's right....it's not worthchecking....

F: Do you have something you wanted to say, Ma'am?

P2: I think (name)...was very awful to my mom because they didn't um....they didn't feed her and my mom has Alzheimer's but she does eat and um....they didn't feed her. Um...my sister went there, she was soaking wet! I don't never keep my mom soaking wet because I am very picky and uhm, I had a problem with them. I went into my mom's room and my mom's roommate was on the floor. so I feel like when my mom goes to respite, I'm there helping my mom and I've gotta other people because I just can't *stand* to see other people hurting and I...I called the aide and they took their slow time and came and go that lady up off the floor, that's right! So I will never take my mom back to (name) or that one in MT. Pleasant. I will never take her to Charleston something....what is it, Charleston, it's like....Charleston, whatever. It's by, you know...

F: No, no....I don't know.

P2: Well, it's by the hospital there.... by East Cooper hospital, I will never take her there.

Group: Really?!

P2: no!

Group: (conversation ensues) what you mean.... I seen that place plenty of times and thought gee, that looks like a nice place...

P2: I would never take her there.

Group: ...near the hospital...I would think...it seems....

P1: Of course, there is no excuse for it, but I believe in the facilities there are just as we are...they are over worked, not enough help, (Group mumbles in the background in agreement) not enough money, you know and you have all of these patients that needs so much individual care and you may have one nurse assigned to twenty people.

P2: and that is true. They...they....

(loud crunching noise in background – making it hard to hear)

P1: You know, you're assigned to one person and you find how difficult it is.

Group: um-hm....

P1: So I mean maybe Medicare and or the government needs to step in (background 'tnak you') as far as the agencies are involved to, to hire people, to pay people because it is *not* an easy job, when someone needs um.... such care as...as an infant does but this person is full grown

P's: uhmm, that's true, um-hm....

P1: It's even harder at that point. You would rather take care of an infant.

P's: Yes, uhum...Yes ...I got a grandson that easier to take care of and he is 15 months old.

P1: Right, I think to talk to the workers, they would probably have the complaints that

Group: yes....

P1: we have and...and the other thing is on families um...that are caregivers. It's harder financially.

Group: yes, it is.....yes...

P: Because you have um....the...the individuals that are on a fixed income and....

Group: right...yes...

P: I mean fixed to the point that you know they're poverty level....

Group: yes...yes...that's the situation...

P:you know 500 hundred dollars... how take care of a home? Or....

Group: my momma says 'honey, let me hire somebody here'.....diapers.....and they only send it out every three months.....

P: Now, we appreciate it and it helps

Group: ...yes, sure...

P: but it is not even one per day.....

Group: yeah! Tell me about it.....

P: You go to the bathroom multiple times but the amount that is sent out isn't one per day and when you go to the less expensive stores that are cost-effective like Wal-Mart,

Group: yeah.....

P: ...even the store brand is \$10.00.

Group: That's Right...That's Right...hen you thicker one, which is the better one and you get better quality ones...that's right....and like ---- has a cap on his to where the...through the...got it through an alternative like food stamps...now listen who can live off of \$39.00 a month!and when I called about they said.... this is the story they gave me in Columbia, "because he cannot get up and cook for himself, that's all he deserves and really doesn't deserve that." And I asked to speak to that person's supervisor but it did not fly. But I mean, you know, it is, I mean it..it's....to... and we're not complaining. It's 24/7...and uh...as they get older there...there's more need there. The quality of life, it extends more care. And uh....I believe that we should take care of our families. I mean they took care of us and raised us. We should take care of them...

P2: I know ...and I feel so guilty some times...that's

P5: and ...and they have...I've not been able to work um...since (name) was hurt and uh, we are getting ready to loose income from my ex-husband. Which I feel, now this out of the state of Ohio which I think the courts have lost there senses or something of the other because there's a situation here that needs, you know. But that's neither here and now, but anyway there just needs to be little bit more provision, and help and understanding and ah...with uh...even in their care giving. When these client's girls come her, or guys which ever they have, that take car of these clients, don't talk at them - talk to them, they are human beings and they still have a little bit of dignity, you know what is left and ah.. you know, I think this way, I for one treat someone the way I would want them to treat me

Group: Yes!

P:and they come in and sometimes you know its just a job - get it done get over with! You know these folks are lonely and they could give them a little TLC. And uh...cuz you never know when where we're gonna be someday...

Group: that's true...

P2: They have....they need a lot of support in a lot of ways; I mean it's mental, physical and spiritual.

F: yes, ma'am?

P4: I need to home and take my medication. My sugar pill and my pressure pill....

F: Thank-you very much...

Group: ...I know what she is talking about though...it all stops from Friday until Monday....right....and she's home alone.....you know, she takes much of the responsibility...its scary for her...yeah...

P: I work and everybody else works and we have families and we all live different towns from where she lives. So we all commute to her, every other day somebody tries to go by or call, but she takes herself. And if we could have somebody that just can come in, just a little bit more or a couple of more hours

Group: yeah....

P: ... so...so she can you know, eat what she wants to eat and mean she does everything for herself but she needs help.

P2: On the weekends....

P5: Right, she's not mobile....

Group: seven days a week....yeah.....she needs help.... A couple....some help...I know....(a lot of discussion goes on)....

P: ...a hardship for the children...Emotionally, for the children it...it is really hard. They may not say, they're gonna go and they're gonna help but it.... it affects them. and we need to...to try to nurture or find ways of relieving them and caring for them, cuz they're not going to verbalize to us how they feel but we have to be conscientious of...of the children too. ASnd maybe it's...it's an area where families need counseling on um...caregivers and their families and the effect that has on husband, wives and children.

Group: Because my husband helps me with my mom mine does too..... and I thank God for him, yes...yes....he sets the clock every night and if I don't get up, he.....he pushes.....(laughs)....cuz you know you gotta change her! Yes.... And then if I go somewhere, he...he says 'you go ahead, I'll be here with her. You know I can change her diaper, you know.'yeah....yeah.....

P: My husband do everything, he change her, he feed her, he gives her all her medicine. She's fine....

Group: His tape ran out.....Group talks among theirselves...

F: let me make sure it's working...yep, it;s working...

P: I think the whole thing, for me, would be the bottom line which is that I just need a little bit of extra help. It might save my husband's sanity and mine too! (laughs) Group laughs.....

P: yeah, my husband helps a lot. He change her, he feed her when I have to go somewhere, and uh...I can't for ...with the PC aide that comes out, I have been blessed, because they have been good. And the ones that was not good with my mom, I got rid of them. Because I am not gonna let anyone come in my house and treat my mom any kind of way, so I just...you know, that God has been good with me on that because I had good aides that came in and they talk to her, they treat her with, you know, respect and...and all of my aides last for either three and four years.

F: really?

P: yes!

P: ...Really...mine always quit and go to better jobs...

P: the independent program ya'll have is great one. That where they send out an agency cuz then you're able to pay a little bit more to that independ....independent contractor that they hire throughout...that...that is a *fantastic* thing!

P: what is that that you're talking about?

P: It's where one thing that I like about if you know someone that is qualified to do this, you can send them and they'll interview them and hire them to come in and then you know who you are getting.

P2: How do I contact that agency?

F: how...

P5: It's through Community Long Term Care. It....it's independent uh...contractors. If any....they have to know how to uh...do uh...they have to be certified. You know someone certified and then they'll contact them....and it's *wonderful* because that way you **know** who's coming in....

Group: it's alright!...

P: and see it's through them....

F: rather than going through one of the companies...

P: right! Through an agency...right. Cuz see, through an agency,...

F: so it's an individual...

P: Yeah, it's an individual and they're private contractors.

Group: ...and you know your workers...better care...things....yeah....alternative care....

F: Medicaid...

P: yeah, Medicaid offers a little bit more than Medicare pays.

Group: yeah....I seen 'em...but I don't want to do that....for the...this man became his ex-wife's caregiver....

F: that is allowed in some states, it is not allowed in South Carolina.

P: ...and I wished it was because ...

F: ...because like the state of Florida, for example, allows that...but not the state of South Carolina.

Group: yeah...some of the aides, they want to come in and they want to look at tv...and they don't want to do any work....right...some drink coffee...yeah...right...drink coffee...

P: you know, hold conversations....when I first meet you, I want you and I don't talk to you. I just see what you're doing and they'll bark and...and I go in the room, I don't never leave my mom in the room by herself with them. I always go in the room to make sure that they're washing her correctly and...and you know, make sure they're catching every spot!

P: ...and you see, that's right...I hadn't done that. I hadn't done that...

P: ...that's right! I usually...I go in the bedroom...

P: you do that in the beginning until you get to know them? or....

P: ...hour....

P: I do it all the time. I *still* do it. Because my mom...

P: how do...how do you get.....

P: you don't never get no free time!

P: no, I don't never get nohow do I get.....

P: how do you get a break? How do you....

P: I don't get breaks.

Group: well, she could go out and the come back early....she....get someone...(discussion unintelligible) spot check.....

P: no! no! I don't leave them in my house. I'm not...

P: excuse me...I'm not that critical because you know, as far as should be...

Group: yeah, you should be...some of them are not going to wash and clean....

P: I...I...I just, you know...I just want somebody to be there in ways to get her up, to make sure she gets her breakfast.....get dressed while I'm gone....and you know, then when I go over there, you know, I may sure I take care of my mom.

Group: ...stay with your mom...huh....you don't stay with her?

P: no, I don't...

P: my mom stay with me.

P: well, I had her with me and she wanted to go back home.

Group: ...wanted to go back home....yeah...

P: so I took her back home. And my brothers...they are...my brothers, they are very good. He's disabled himself, but he's real...now today, that's why my husband called a few minutes ago. He's lying down because he has a disability *himself*, but I've never seen a brother or a person that so *devoted* to his mother! And I...you know, we work together. The other siblings, they come nowhere near my mom.

Group: um-hm....yeah...

P: they don't want that responsibility!

Group: ...responsibility...so they make excuses...so, I don't care. I just....yeah...you know...I don't care...that sort of thing....(laughter)....they don't want to help...you know, I'm.....

P: but all I need right now, is you know, I need a break. My brother needs a break, but he said he's not gonna take one.

P: he won't take it either. ...you don't want to leave...he don't want me to take mom somewhere....to leave her somewhere, you know....he wants her to be at home, so...but I need a break! Because right now I'm going to the chiropractor....lifting, you know, constant...you know...

Group: yeah.....well, they have a hooyer lift....also, they can...help....she can...I did...I did....check....my mom is heavy and we used to lift her and then I got a hooyer lift and it makes *much* easier.right...yeah...I can put my mom in the chair by myself and everything.right....

P: Well, how do you get one?

P: Well how do you go about getting a hospital bed? They...a lot of people....

Group: Ask for his bed....no...your doctor needs to write a prescription.right, whatever you need....prescriptions for whatever you need....and you get to....but now she's having to pay that extra uh....what was it, last year that Medicare and Medicaid as a combination covered it?...I don't know....Um...but um.now this year, I went to get some bed railings, I think's how that went and they told me x amount of dollars I'd have to pay, you know....get a prescriptionI know....that's what I did, that's what I had, but they still did not pay it all this year...who was your person you dealt with? ...who was thethe uh..company?uh...Riser – no, it's out there on Highway 52, I think....Goosecreek, are you familiar with out there.....try CroMed in Summerville, uh...Debbie...she's the owner of a ...uh...medical company. And she's real good. She knows the ins and outs and how to help you to get the medical supplies that you need.....that's just like the other day, I get a bill for mama's wheelchair! But she's had that thing since about '95 and I guess.....Yeah....somebody, Medicare or Medicaid, wants to pay rent on this thing!so they...they....rent them until they buy 'em....yeah...yes....they didn't her the option to buy it...right!yes....well, they should have....that thing should have been bought!yeah....that's how....they...I think...but I think....(paper crumples, everyone speaks at same time)....they don't make this other wheelchair.....yeah...make it....check your bill, cuz I always check my bill....yeah....cuz I had a bill that came from one of those places that ...rental places, it was my mom – something...oh, her um...chair! They said um...my mom was renting two chairs and they had billed, you know, Medicaid. And I called them and I told them no and they had to take that off that bill. Because you...you need...you need to just check your bills all the time....yeah...and over...because they will make mistakes, I'm not going to say it....

F: We have about 2-3 more minutes.....

Group: Ok, well....I've got to go....you...gotta....So your position is.....to do what...to take information....?

F: Ok, well, let...let me explain that to you before ya'll go. I do *not* work for the state.

P: right.

F: I'm an independent contractor.

Group: oh....ok....um-hm....

F: and uh...I have a little company, my wife and I. uh...we're both retired and we started a little company that does this sort of thing. We do focus groups for health organizations and so...they hired us to do a series of focus groups and to do surveys. So we are....we are, um....we're not connected to the state, so we're objective. So, what we'll do is we'll write a report based on all this information. Uh...the report is due on July 1. We will then turn that over to CLTC. They will then make use of it. Uh...rather they will make that public or they provide a copy for you, ask for it. That...that has to be up to them. I can'tbecause I...

P: yes... now are you sending it to the Legislators too? Like we did, you know...

F: I'm sure this will end up going to the Legislators...um...we did one several years ago that went to the Legislature which resulted in...in a lot more money being added to the CLTC program. Uh...that's been about 5-6 years ago, I guess.

P: right...

F: and um...um...so I'm sure they're gonna make use of this

P: right...

F: ...in a similar kind of way...

P: so then when you present your information, it's gonna be based on what we're talking about today?

F: it's gonna be based on what ya'll were talking about and it's going to be based on the responses to a survey we've sent out where we've asked questions of people, like "what would you do without CLTC? Are you getting enough services? What other services would you like to have?" And things like that.

P: hm...

F: but it's always good to talk to people directly because you get a lot more information that way...

Group: yes...sure...good places....yes, you know good places. ...we need more respite. That we could feel comfortable to send our loved ones, you know..not no 'ring bell'...when you walk ...when you walk in a nursing ...me, for myself...this is how I case out the nursing home....when I walk in nursing home and I smell rankness or whatever...I felt cold not that long....she's not going! Because that means they're not keeping the place clean. and then I go...I go in the bathrooms and I check all the bathrooms out to see if they clean. because if they not, my mom not going because that mean they not keeping up!exactly...in two weeks...I know....two weeks is not enough...I'm sorry!....I've been telling them that for years. They need a month, a good month....cuz the first week, you're coming down. That...that caregiver is coming down. The second week when you just start to, you know, kind of get into you know...having this break, it's over with.... Yeah, It's over with!....so you know,I don't let my momma go for that long!....yeah, you know what you're talking about because ...about coming down....I mean, like while ago, uh...this morning when I just went out and got in the car and set down...yes!....it was a ...like, uh...but then I knew I couldn't ...I couldn't, I had to crank right up and get geared....you become, it...it's like being in prison, it really is. And you know, so we don't need furlough!...(loud laughter from group)...and I'm leaving on that one! (loud laughter and discussion)....thank you for ...

F: well, thank you and I'll definitely pass this along.

Group: (keeps talking and discussing things among themselves for about 45 seconds) thank you....goodbye...I just need somebody...yeah!...cuz I run over to my mom three times a day...you're right...and nobody pays me...for my gas but I, you know....I understand, yeah....yeah, you know...her property needs to be taken care of, you know, like the lawn...um-hm....my husband does all that, free of charge! ...you know, and like you say...I...I'd like spending more money on mine and I can't....um-hm.....I just can't keep affording that...you know, because like you said...she...she don't want, you know...

F: well, with my mother, she would not live with us...

Group: uh-huh!

F: ...and we went back and forth forever..

Group...um-hm..yeah...'I want to go back home'...

F: yeah...

Group: she's been there for what...sixty years or more...um-hm...yeah....my momma will not be by herself! She is a person, you got to be there....well, my mom, she...she ...you don't think you need the hospital back on this Respite care? ...well, I don't know anything about that....well, I would say by...yes, ...the computer already cut it off!....if it could be the special care people with special needs, right?...um-hm....they could stay over at your mother's....cuz the hospice....when I say the hospital used to have it...I didn't like county hospital....I didn't think they were good....well, I mean there's a lot of them, not just....that's the only one here...and in

South Carolina...well...why not in Charleston, you could go....I want one to come....on to my mom's house....for her care...take care of this...I understand that...you know, respite is only like two or three....

F: yes, ma'am?

P: What were you gonna say, I'm sorry?

P: uh....let's see....agencies...

P: oh, there is an agency that my um...my social worker....my mother's....

Group: (laughter) your worker...

P: ...told me about that will assist you with reimbursement um...up to \$400 a year.

Group:what?!...

P: ..for, you know, Depends or stockings or uh...

P: if you had somebody ...if you had to go out and you had somebody to come in and I am trying to think of the name...

P: yeah, before you leave this facility...

P: ...um-hm....my case worker is Florence Gilliard and she told me about ...she told me about this agency and I called them, but it has escaped me right now. But please before you leave here, just ask um....the director about it and let her know that you can contact them and they will help you...they will even help if you have to pay um....a family member that will come in for a couple hours to give you some relief or come in for a couple days...

P: is....is that a fact? You're saying....

P: yes!

Group: are you saying that they would reimburse you for Depends to help you?.....if you have a receipt....you have to have your receipt.....I have all of my receipts because I order my mom Depends from Medicine Man by the case. Because I found out going to WalMart to buy Depends and I was buying it like every three days....yeah....and you know, that was ridiculous! I was spending more money just doing it that way! So um...I started going to Medicine Man and I paid 70 something dollars for a case! And, you know, that's expensive but I don't have to ...um-hm...but I don't have to ...I don't have to run back and forth to WalMart for the last....yeah....you know cheaper thing that's not going to hold her. And get the thicker ones...I'd rather do that....where do you get the Medicine Man?.....The ...the Depends....No, I mean where are they....I have the number right here.....Well, I need to go!yeah....

F: ok, our...our time is up and ...and I really appreciate ya'll coming tonight. I apologize for being late, I had it on my calendar 10:30!

Group: (laughs)...this is early...you gotta eat!....I wanted to come so bad....and then I thought it was yesterday....you know then....

F: oh, really? But I do appreciate ya'll coming.

Group: ...if this helps...with equipment also.....because I um....everybody's needs are different, so if everybody could be evaluated based on that.um-hm...that's right....you know, like she...she needs somebody at night so she can get some rest. You may need somebody four hours during the day....that's what I need....everybody needs to be evaluated on um....their needs...um...their needs...Because I need to be something that's.....this is the way to do it...yeah....this is the way we have done it....that needs to be explained....I hear ya....it's just right now....Here is the number....good point...based on the needs....because like I say, it'sif someone could go over and just make sure she gets lunch...cuz she doesn't get her own meals on her own....yes, I don't need...they need to know that....meals on wheels...

F: well, talk to your case manager about that.

Group: yeah....like I said...some..some...the case manager that I have now, she...she's really good...most of 'em are really good...yeah...she's really good...but my momma had some and I didn't never really see her....yeah, call her...

F: ok, well, thank ya'll again..

G: ...nice meeting you too! And I'm glad that we ...you know, that we got a chance to share some of our needs. Yeah...ok....

F: well, you too. I appreciate it....

Group: who...who's your provider?....my caseworker?yeah...Rubell...who are you with.....(they keep talking, tape is turned off)

HIV/AIDS INTERVIEW TRANSCRIPTION

CONSUMER ONE (by Notes)

Major help receiving from program is the prescription benefit. Without this, not sure what would do because of the expense. Partner is very supportive with direct help. Has therefore not needed in-home care on the whole. However, did have nursing care at one point when on feeding tube.

Lost counseling when that was cut, but the case worker has stepped in and is available to talk when he needs that. Very comfortable with case worker. Very complimentary about case worker and program.

Also receives SSI, which helps great deal with money. Does not believe that other services would help him stay at home, because his intention is to die at home. If more services would be available to help him do that when the time comes, he will be grateful, but is going to die at home no matter what.

CONSUMER TWO (by Notes)

Primary help receiving is prescriptions and nutritional supplement. Lives with mother, who takes care of direct needs. Sees case manager as a great advocate and someone he can talk to, now that they don't have counseling services. Has helped with things like getting the house sprayed for insects. Makes staying at home possible.

If it was no longer possible to stay at home, he isn't sure what he would do. Doesn't want to be too much of a burden on mother. Would have to work with MD and case manager to work it out.

CONSUMER THREE (from Tape)

I: ...the purpose of the um, of the survey is to find out how people who are getting community long term care services um, think that they're doing, as far as, uh.... keeping them in their homes and being able to live independently. So that's, that's the purpose of it and no one's name is gonna be in the final report, I mean...none of the people we speak with. So, we appreciate you talking with us. Uh....the first question I have for you is uh....would you um..have to leave home or live somewhere else if these services were not provided for you?

C: Yes.

I: yes. okay, can you tell me a little bit more uh, about that and in what way it helps you stay in your...in your home?

C: Um, a lot of times, sometimes I have to be hospitalized and I don't....my doctor knows that I'm a person that um....don't particularly care for hospitals....so when I get sick....

I: um, hum.

C: ...they usually provide me with um....a home attendant to come in and like tape my bandages and stuff like that.

I: uh, hum. So you get...when..when you're not doing as well, you get some additional services..is that what you're saying?

C: yes.
I: ..a home attendant?
C: yeah, well she comes in....like I had a PIC line put it and every week she came out and cleaned the wound and everything....
I: uh, hum.
C: ...and uh...
I: So if that were not available to you, you would have to be in the hospital, is what you're saying?
C: that's right.
I: yeah, okay.uh, okay...well, that...that's really the essence of what we're trying to find out, you know...for people because the purpose of the program is to keep people at home to the extent they can be. Uh, would more of the same kinds of services you're getting right now uh...help you stay at home longer? ...for more of the time?
C: Now that's a hard question. Um, I can't really...I, I, I...really I couldn't say...
I: uh,hum.
C:...because um, it's only when I get like really, really sick and I can't take care of myself...
I: uh, hum.
C:...and I need help from community long term care.
I: uh, hum. Uh, tell me..in the periods when you are doing somewhat better and are able to take care of yourself, what services are you getting sort of on a long term basis from them?
C: Oh, um, my extra prescriptions that they give me.....
I: uh, hum.
C: ...they allow me to get instead of 4, what is it 3 or 4 that I think you can get.....I can get up to 6 medications...
I: uh, hum.
C: ...sometimes when I um, don't have enough food in my house, they might write me up referrals to Harvest Hope to, you know...to get some food....
I: uh, hum.
C: ...and they , they try their best to make sure that um, I get my nutrient drinks.
I: nutrient drink, so do....it's like...Ensure type of thing?
C: yes.
I: Uh, hum. Okay, would different services help you stay at home more of the time or longer?
C: Different services?
I: uh, hum. Things other than what they are able to offer you now?
C: well, um, different services....like, give me an example because I can think of a lot of things....I mean, it'll be nice if, if, if, if..they had a program that assists people with they light bill and they electric bill other than these AFO's....
I: um, hum.
C: ...out here...because they're not efficient.
I: uh, hum.
C: ...you know they, they, there's always red tape with them but, um... you know and then like sometime with the nutrient drinks..like I'm a person who can't tolerate um, milky products....
I: uh, hum.
C:...and they have other nutrient drinks out there that's not milky...you know what I'm saying....
I: uh, hum. Yeah, so you're lactose intolerant.

C: yes, ...and um, that would be nice if they could get that.
I: uh, hum. So..so a nutrient drink that...
C: yeah.
I:...would not uh, conflict with your, your, um....lactose intolerant.
C: right cuz when I drink that..when I drink that Ensure....
I: uh, hum.
C:...you know I spend most of my time in the bathroom....
I: uh, hum. Uh, hum.
C:...but I have to drink it because I gotta try to gain my weight back.
I: uh, hum. Right, right. Okay, so you're saying that uh, economic services or just money to help pay some of the basic bills because uh..would be helpful to h..keep you at home...um because some of the other programs that are around are more complicated or more difficult?
C: yes, you gotta, you know like for example, if I had got assistance with my light bill, I couldn't go back to them for.....(*sighs*)...for a while.
I: uh, hum.
C:to get assistance again. And when I try to make people understand that, you know, it's not the fact that a person is trying to be lazy or anything but sometimes they are just not able to get the resources that they need to maintain on they own.
I: uh, hum.
C: and...you follow what I'm saying?
I: uh, hum. Uh, hum.
C: ..and um, it's, it's you know, it's really, really, it's really, it can be really, really stressful cuz see I come from a big city....
I: uh, hum.
C: ..and where I was at in the big city, they had a program like community long term care but they just dealt with people who um...who was living with AIDS and...
I: uh, hum.
C:...they used to have someone that would come out to my house every other month, you know...
I: Uh, hum.
C: ...make a little inspection, you know make sure where I'm living at was efficient..
I: uh, hum
C: ...and um, they assist us in (*unclear as to what was said*)....I was able to get food stamps for my kids....see they don't have that kind of stuff here...
I: uh, hum
C:...but community long term care has always came through for me...
I: uh, hum
C: ..you know the best that they could...
I: yeah, well..what, what we're trying to find out is, you know is the program keeping people in their home and then if there were any other things that they could offer in the program what would the most important ones be...and that's sort of why we're trying to talk to more people to, to discover that...
C: Oh.
I: okay. Okay. um, if staying home was not possible because of, of your health, if your health was such that you could not stay at home, where would you...be? Where would you go?
C: well, I would have to stay with my mother.

I: stay with, with your mother?

C: uh, hum.

(silence)

I: ...and you um, have, you have children at home?

C: I have 2 kids.

I: ...and so they would have to be there as well....is what you're saying...

C: No, well the oldest one doesn't live with me...

I: oh...

C: ...but the youngest one....

I: oh, okay. But that would be the, that would be where you would have to go if you were not able to stay at home...

C: yes.

I:...over time....okay.

C: Yes, because when I get sick I have to stay..or I have to be around someone who can help me...

I: uh, hum.

C:...with certain things.

I: uh, hum.

C: ...and my son is not equipped to do that.

I: uh, hum. Okay. Well, those are the main things that uh, we wanted to ask, um....people and we appreciate your time to uh, to speak with me.

C: Oh..

I: So, I think I'm done. Is there anything else that you..need to say?

C: no, that's it.

I: okay.

C: alrighty.

I: okay, thanks so much.

C: bye, bye.

CONSUMER FOUR

I: I have your permission to tape this, is that right?

C: yeah.

I: okay. well, I have to have that on the tape so that registers when I turn it on...okay, um, as you know the community long term care program is...uh supposed to help people um, stay in their homes, uh, as long as possible...to provides services that allow that to happen. Uh, you are getting services from community long term care right now, is that correct?

C: yes, that's correct.

I: um, and what services are you currently receiving?

C: I receive uh, Ensure, uh supplements....

I: uh, hum

C: ..and um,..uh...diapers and uh...pads..

I: uh, huh.

C: ...for um, bed padding.

I: uh, huh. Okay. And are there other services that you get too?

C: no, there's...that's...well, they..the..they help out with my prescriptions.

I: oh, okay. So that you get the prescription benefit too.
C: yeah
I: Okay. Alright, um, would you uh, be able to stay at home if these services were not provided...through community long term care?
C: Um, that's a hard question to ask because you never know from day to day with HIV....
I: uh, hum
C: ...what um, how your systems gonna be.
I: uh, hum
C:... I mean, right now I'm functioning....
I: uh, hum.
C: .. I don't know...what's gonna be next month, or in the next few weeks...I, I...don't know.
I: Right, uh, huh. Um, would more of the same service you're getting now help you to stay at home? With more of what they are already providing be more helpful to you?
C: yes.
I: and uh, what, what would it be most helpful to have more of...I guess is a good question?
C: I'm, I'm really not real sure what they have to offer...I'm don't know if they have nursing...
I: Uh, hum. Well, those would be different services but what..you're not getting any nursing services.
C: no, I'm not getting, I'm not real sure what they do have to offer....
I: uh, hum.
C: ..um, as far as cleaning my house and things like that...do they offer that?
I: I, I am not sure what's available...I know that they have some..services of that kind. I'm not sure who is eligible to get them. But I think your case manager would be the person to ask.
C: okay.
I: ..the person that, that uh, coordinates the services you're getting right now, um, and I don't know all of the eligibility requirements for that, but I would say that's where I would start finding out...
C: I have, I have been uh, going to uh, the doctor back and forth to the doctor with the Medicaid van...
I: uh, hum.
C: ..um, I'm not sure if the community long term care offers that system of not but they....
I: uh, hum. Well, they work with with it. I think the uh, a lot of the Med..the services that Medicaid pays for uses the Medicaid van to get people to and from...
C: the doctor..Yes.
I: Um, but what, the Medicaid van is uh, something that you do use?
C: yes, I do use that.
I: uh, huh okay. And if you could get some different service to help you stay at home and be able to manage in your own place, uh, what would...what would that be that would be helpful to you? ..if they were able, I'm, I'm, like I said I'm not sure what they are able to offer but would different services be helpful to you?
C: well, um, actually if I could get Meals on Wheels. Um,..
I: uh, hum.
C:...I don't know whether they offer that or not but...
I: uh, hum.
C: ...that's, like, stuff that, I mean when you really feel, really wh...uh, fatigued...
I: uh, huh.

C: ..if you have a meal already prepared, it's so much easier.
I: uh, hum. So getting home delivered meals would be helpful to you if, if that were something that was able to be done and...
C: yeah, if that could be done that would be a really....a good...you know....
I: well, we're trying to talk to people to identify if there were funding, or if there were availability of things, what would the most important things be....to folks that are in a situation like yours....what, what would they want be..using that would uh...actually make a difference because you know, the people who need the service can obviously speak to that better than...
C: well, I have, I have no car. I, I depend on transportation through the Medicaid van.
I: uh, hum.
C: um, going to get groceries...um, I live close to the store but I..usually have my daughter come by and...
I: uh, hum.
C: ...she helps me out with getting groceries.
I: right, but um, the,..having the meals delivered or...
C:that would help...
I: Or having some way that you could get help with your groceries if your daughter were not able to sounds like it would be something that would be very helpful....
C: yes, uh, huh. And she has taken me over to the Harvest Hope...
I: uh, huh.
C:...to get extra food that..
I: uh, huh.
C: you know when I can't...my social security check does not stretch.
I: uh, hum.
C: you know with utilities and everything, it's very tough.
I: uh, huh.
C: ...to make it you know, so I go to the Harvest Hope too..
I: Uh, huh.
C: ...but if I could get the Meals on Wheels, I wouldn't even need to go...to Harvest Hope.
I: Uh, hum. Okay. So, that,..you think that meal..delivered meals would be very helpful...you said something earlier and asked a question about nursing services and as I said, I, I'm not certain whether that, you know, who is eligible to get that....
C: uh, hum.
I: .. you know under the current rules, but what I'm asking people is, if we could make up the rules, what would, what would be helpfulare you, will you, are you saying that or, or, or..
C: well..
I: ..nursing services might be...
C: yeah, I was asking that because I, I, I have...I don't get to see my doctor only...well....it's prob..it's probably gonna be 4 months between services...
I: uh, hum.
C: ..and you know I have to arrange to get to the doctor....
I: uh, hum.
C: and you know get the doctor to come out here... I mean....
I: uh, hum.
C:...it would be easier if I could get a nurse to just come out here and get my blood work done instead of me having to arrange...see I, I'm a thyroid person, I've also got um, cholesterol

problems and I've got HIV, andthese kind of things...she usually have me come 2 weeks before...my original follow up...

I: uh, hum.

C: ...just for, to get the blood work done.

I: So the doctor will have the results.

C: Yes, she has the results by the time I get there...

I: uh, huh.

C: and uh sometimes I, I just can't arrange transportation so it's like ..it goes to 4 months before I get to the doctor.

I: uh, hum. So having a nurse come in to do the bloodwork or other kind of nursing things....

C: that would be nice, yes.

I: and that, that would help you to remain in your home longer.

C: right....

I: ..is what you're saying...

C: I wouldn't have to make that trip...

I: Uh, hum.

C: you know, trying to get out and arrange transportation.

I: Uh, hum. Okay, well those are, I, I've tried to take notes on that and I've got the tape of what you had said now if...if staying at home was not possible...for you..if that were not possible for you to do, uh, because of your health..where would you go? Where would you be if you were not able to stay at home?

C: I would, I would probably have to go into an assisted living or...or into an HIV house...housing.

I: uh, hum. Uh, huh

C: They, they had a survey about HIV housing, whether HIV people would live in the same environment

I: uh, huh.

C: ..and uh, I filled out the survey but I never heard anything about that.

I: uh, hum. Now, I, I am not familiar with that. I don't know whether that was one of the HIV specific organizations uh....

C: I'm not quite old enough to go into uh, assisted living, um, that I know of...I am on disability social security...

I: uh, hum.

C: but um, if I had, if I were old enough, I guess assisted living would be the answer to that.

I: uh, hum. Uh, hum. Okay, well the object of the community long term care is to try to keep people...

C: ..living in their homes...

I: ...in their homes and in the community as long as possible and the reason we're talking with uh, consumers and caregivers uh, is to find out what are the most important parts of that um, to help people make decisions that, will, you know, will obviously do the most good so that's the object.

C: I understand.

I: yeah, Okay, well I think I finished the questions that I had to ask. Is there anything else that you, would like to say about....?

C: No, I think we pretty much covered everything.

I: okay, well I appreciate your time this afternoon and thank you.

C: thank you so much.
I: bye, bye.
C: bye.