

**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
2004 Survey**

MAY 31, 2004

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

**BY
SWS, INC.
COLUMBIA, SC**

EXECUTIVE SUMMARY

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 the relationship between the services provided and consumers remaining in their homes. The second purpose is to determine the consumer's satisfaction with the services. A survey instrument with seven questions regarding the first purpose and seven regarding the second was used to gather information. This survey was designed in 2002-2003.

An initial sample of 652 records was randomly selected by computer at SC DHHS. From these, 15 consumers were interviewed in their homes, 234 responded by mail to a written survey and 127 were administered the survey by telephone for a total of 376. The confidence interval for this data is 4.99 points at a 95% confidence level. The respondents appear to be demographically representative of the CLTC population.

Over 70% of the respondents believe they (or those for whom they care) would not be able to stay in their home or were not sure they would be able to remain in their home without CLTC services. Virtually all respondents state that they (or those for whom they care) want to stay in their homes as long as they can. These are almost exactly the same findings as from last year.

About 51% 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 33% believe other services will help them (or those they are caring for) remain in their homes. The need for more of the same help is 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 their homes. Also among caregivers, about 44% believe that they sometimes are near the end of their ability to provide care. Last year, 38% reported a need for more of the same services and 32% of caregivers reported that they sometimes are near the end of their ability to provide care. There has been a negative change since 2002-2003 in these two areas.

An overwhelming majority of the respondents are satisfied with their services. Only 7% of all respondents had a complaint they feel was not handled properly. Four and three tenths percent of respondents reported they cannot speak freely with the helpers provided by CLTC. Similarly, only 5.6% reported they cannot depend on these helpers. These reports are very similar to those of last year. There has been an improvement since last year in respondents being unclear about their rights. Last year, 18.6% reported they did not know who to notify if they have a complaint. This year, that figure was 8.5%. Unfortunately, there are more than twice as many respondents this year who made a complaint (29.8%) and are unhappy with the results of the complaint than there were last year (12.1%).

It is recommended that: the number of CLTC slots be increased to at least the number of people on the present waiting list; the amount and type of services provided to selected consumers be increased; additional and more flexible respite services be provided for caregivers, and; that the data from this study continue to be analyzed.

TABLE OF CONTENTS

EXECUTIVE SUMMARY	i
TABLE OF CONTENTS	ii
TABLE OF FIGURES	iii
INTRODUCTION.....	1
SOUTH CAROLINA COMMUNITY LONG TERM CARE.....	1
PURPOSES OF THIS STUDY	2
METHODOLOGY.....	3
SURVEY FINDINGS.....	5
INSTRUMENT RELIABILITY	5
SURVEY RESPONDENTS AND REPRESENTATION OF THE POPULATION	5
DEMOGRAPHIC CHARACTERISTICS.....	6
SURVEY RESPONSES.....	11
<i>Themes Questions.....</i>	<i>11</i>
<i>Satisfaction and Compliance Questions</i>	<i>15</i>
OTHER SIGNIFICANT FINDINGS OF THE SURVEY	17
COMPARISON TO PREVIOUS YEAR.....	22
<i>Themes Questions.....</i>	<i>22</i>
<i>Satisfaction and Compliance Questions</i>	<i>26</i>
CONCLUSIONS	30
OTHER CONCLUSIONS	31
RECOMMENDATIONS	32
APPENDIX ONE: SURVEY QUESTIONNAIRE.....	33
APPENDIX TWO:	36
LETTERS SENT TO CONSUMERS.....	36
INITIAL LETTER TO CONSUMERS.....	37
LETTER ACCOMPANYING SURVEY	38

TABLE OF FIGURES

<i>Table 1: Person Responding to the Survey</i>	5
<i>Table 2: Consumers Responding to the Survey by Service Status</i>	6
<i>Table 3: Consumers Responding to the Survey by Region</i>	6
<i>Table 4: Consumers Responding to the Survey by Rural or Urban</i>	7
<i>Table 5: Gender of Consumers Surveyed</i>	7
<i>Table 6: Ethnicity of Consumers Surveyed</i>	7
<i>Table 7: Age Group of Consumers Responding to the Survey</i>	8
<i>Table 8: Marital Status of Consumers Surveyed</i>	8
<i>Table 9: Education of Consumers Surveyed</i>	9
<i>Table 10: Total Number of Informal Supports to Consumers Surveyed</i>	9
<i>Table 11: Reasons for Referral of Consumers Surveyed</i>	10
<i>Table 12: Services Received by Consumers Surveyed</i>	10
<i>Table 13: Responses to Themes Question 1</i>	11
<i>Table 14: Responses to Themes Question 2</i>	12
<i>Table 15: Responses to Themes Question 3</i>	12
<i>Table 16: Responses to Themes Question 4</i>	13
<i>Table 17: Responses to Themes Question 5</i>	13
<i>Table 18: Responses to Themes Question 6</i>	14
<i>Table 19: Responses to Themes Question 7</i>	14
<i>Table 20: Responses to Satisfaction and Compliance Question 1</i>	15
<i>Table 21: Responses to Satisfaction and Compliance Question 2</i>	15
<i>Table 22: Responses to Satisfaction and Compliance Question 3</i>	16
<i>Table 23: Responses to Satisfaction and Compliance Question 4</i>	16
<i>Table 24: Responses to Satisfaction and Compliance Question 5</i>	16
<i>Table 25: Responses to Satisfaction and Compliance Question 6</i>	17
<i>Table 26: Responses to Satisfaction and Compliance Question 7</i>	17
<i>Table 27: Relationship between the Respondent and Themes Question 2</i>	18
<i>Table 28: Relationship between the Survey Distribution Method and Themes Question 2</i>	19
<i>Table 29: The Relationship of Themes Question 2 to Themes Question 1</i>	20
<i>Table 30: The Relationship of Themes Question 3 to Themes Question 1</i>	21
<i>Table 31: Comparison of Themes Question 1 to Previous Year's Responses</i>	22
<i>Table 32: Comparison of Themes Question 2 to Previous Year's Responses</i>	23
<i>Table 33: Comparison of Themes Question 3 to Previous Year's Responses</i>	23
<i>Table 34: Comparison of Themes Question 4 to Previous Year's Responses</i>	24
<i>Table 35: Comparison of Themes Question 5 to Previous Year's Responses</i>	24
<i>Table 36: Comparison of Themes Question 6 to Previous Year's Responses</i>	25
<i>Table 37: Comparison of Themes Question 7 to Previous Year's Responses</i>	25
<i>Table 38: Comparison of Satisfaction and Compliance Question 1 to Previous Year</i>	26
<i>Table 39: Comparison of Satisfaction and Compliance Question 2 to Previous Year</i>	26
<i>Table 40: Comparison of Satisfaction and Compliance Question 3 to Previous Year</i>	27
<i>Table 41: Comparison of Satisfaction and Compliance Question 4 to Previous Year</i>	27
<i>Table 42: Comparison of Satisfaction and Compliance Question 5 to Previous Year</i>	28
<i>Table 43: Comparison of Satisfaction and Compliance Question 6 to Previous Year</i>	28
<i>Table 44: Comparison of Satisfaction and Compliance Question 7 to Previous Year</i>	29

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 thirteen 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; and
- 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; and
- 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 qualify 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.

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 2002-2003, CLTC served 15,421 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. As of May 16, 2004, the number on the waiting list is 2,970. 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.

During FY 2000-2001, among the consumers of Elderly/Disabled services, about 13% were white males, 33% white females, 39% African-American females, and 15% African-American males. About 12% of Elderly/Disabled clients were 49 years old or younger. About 28.4% were between the ages of 50 and 69. The remaining 59.6% were 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 the relationship between the services provided and consumers remaining in their homes. The second purpose is to determine the consumer's satisfaction with the services.

METHODOLOGY

Instrument Design

A two-page self-administered survey comprised of 14 questions was developed and used with a representative sample of elderly and disabled consumers in 2002-2003. Seven of the questions are responded to with a five point Likert scale, including the one question designed for caregivers only. The remaining seven questions require dichotomous responses. The same survey was used for this study. A copy of the survey may be found in Appendix One.

Sampling Strategy

The initial sample held 652 records randomly selected by computer at SC DHHS. From these, seventy were pulled for in-home interviews using the survey and an observation instrument. (The findings from the observation instrument will be reported separately.) Fifteen of these seventy consumers/caregivers agreed to be interviewed at home. The remaining 582 were sent the survey instrument by mail. In a cover letter that accompanied the survey instrument, caregivers were asked to complete the survey if the consumer was unable to do so.

Of the possible 582 responses, a total of 224 surveys were returned by mail. An additional 137 surveys were then completed by telephone which, including the 15 in-home surveys, produced a total N of 376. 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 survey form. A cover letter explained what the survey was for, assured confidentiality, and informed the consumer that a family member or other person familiar with their situation could fill out the survey on their behalf. (A copy of the letter may be found in Appendix Two.) 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 themes identified in a qualitative study in 2002-2003. One of the questions is specific to caregivers. The self-administered questionnaire was constructed to find out how widely the concepts represented by the themes 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 information entered in Microsoft Access. Separate, but related, tables were used for each of the three types of data. The three types of data are: 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 Statistical Package for Social Sciences (SPSS) file to conduct the statistical analysis. Several different analyses were performed on the data in order to determine statistical importance; including reliability, confidence interval, frequencies, crosstabs, and chi-square. These analyses were then exported from SPSS to an Excel spreadsheet to ease editing and printing.

SURVEY FINDINGS

The findings for this survey were analyzed using a series of steps. First, the survey respondents were identified and statistical analyses were run to determine the extent to which the sample is representative of the population. To verify that the sample is representative of the population, the demographic characteristics of the sample were reviewed and reported. Survey responses were then analyzed and reported. Finally, further statistical tests of significance were conducted to determine if any relationships exist between the data sets.

Instrument Reliability

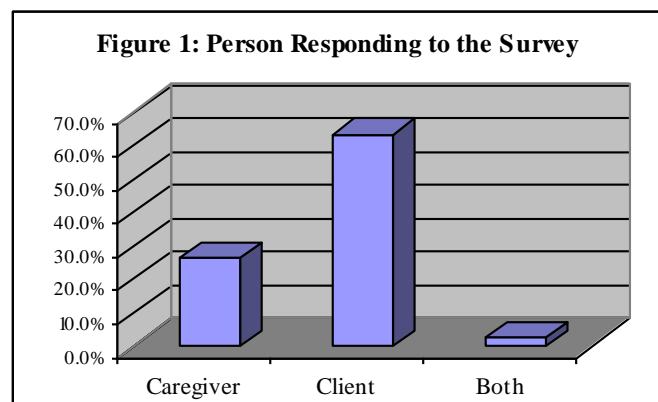
A test of reliability was conducted to determine if respondents would respond the same way to the questions if they were surveyed again. The reliability scale was estimated using a measure of internal consistency, coefficient alpha. This test based on the responses from the 2004 survey, establishes a reliability of 76%. The combination of 2003 responses with the 2004 responses demonstrates a reliability of 79%. This means that almost 80% of the sample would respond in the same manner if they were administered this survey again. Due to the tendency of this population to not respond to certain questions, a “No Response” was considered as a response for this analysis.

Survey Respondents and Representation of the Population

A total of 376 respondents out of the possible 652 responded to the survey, which is a response rate of 57%. The total population of consumers receiving services from CLTC in 2003 was 15,421. Based on this information, the confidence interval for this data is 4.99 points at a 95% confidence level. Therefore, there is a very high probability that the survey findings presented in this report represent the responses that can be expected from all elderly disabled and HIV/AIDS consumers of CLTC services (plus or minus 5 percentage points).

Of the 376 respondents, 63.3% were consumers, 26.3% were the consumers’ caregivers, and 2.7% were completed by both the consumer and the caregiver. The remaining 7.7% did not respond to the question regarding who was completing the survey. (See Table 1 and Figure 1.)

Table 1: Person Responding to the Survey		
	#	%
Caregiver	99	26.3%
Consumer	238	63.3%
Both	10	2.7%
Unknown	29	7.7%
Total	376	100.0%

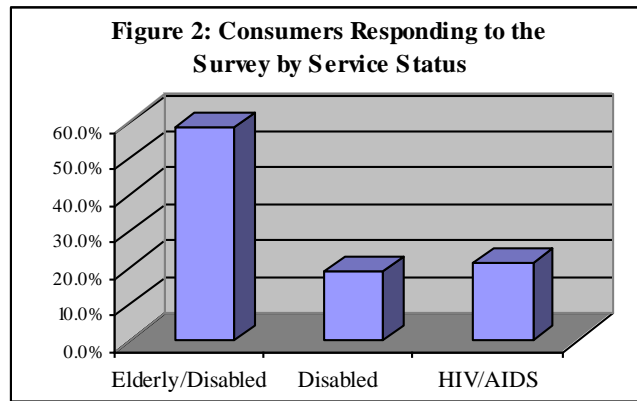


Demographic Characteristics

The following demographic characteristics describe the consumer who either responded to the survey or whose caregiver responded to the survey. This information was gathered from the records on each consumer at CLTC.

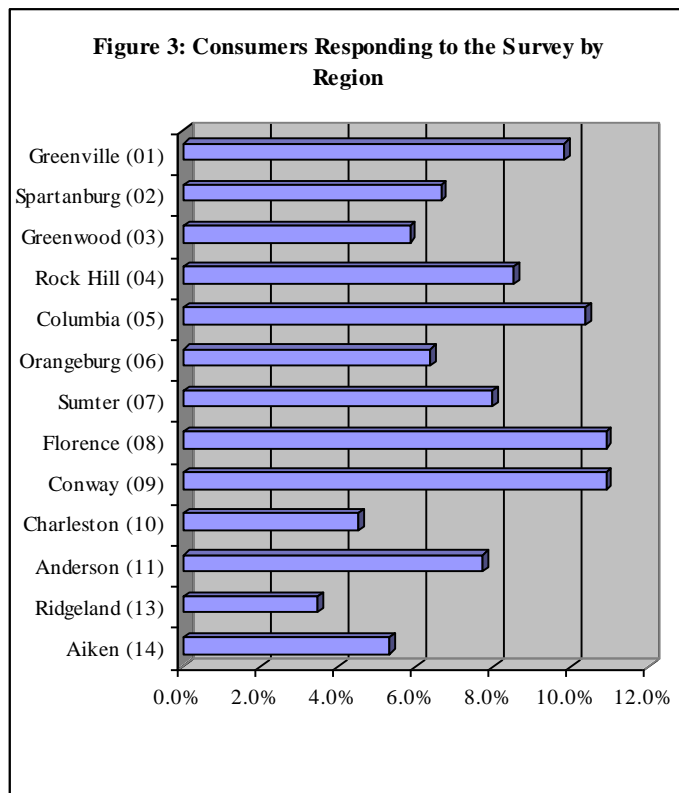
Out of the 376 consumers responding to this survey, 58.2% are elderly/disabled, 18.9% are disabled, and 21.3% are HIV/AIDS patients. (See Table 2 and Figure 2.)

	#	%
Elderly/Disabled	219	58.2%
Disabled	71	18.9%
HIV/AIDS	80	21.3%
Unknown	6	1.6%
Total	376	100.0%



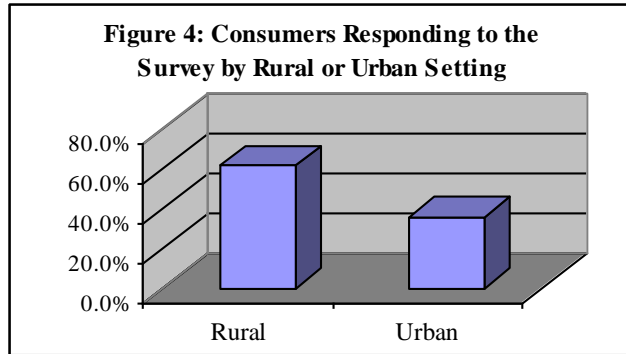
The percentage of surveys from each region ranges between 3.5% and 10.9%. The largest portion of responses came from the Florence and Conway regions at 10.9%. The smallest portion of responses came from the Ridgeland and Charleston regions at 3.5% and 4.5%, respectively. (See Table 3 and Figure 3.)

	#	%
Greenville (01)	37	9.8%
Spartanburg (02)	25	6.6%
Greenwood (03)	22	5.9%
Rock Hill (04)	32	8.5%
Columbia (05)	39	10.4%
Orangeburg (06)	24	6.4%
Sumter (07)	30	8.0%
Florence (08)	41	10.9%
Conway (09)	41	10.9%
Charleston (10)	17	4.5%
Anderson (11)	29	7.7%
Ridgeland (13)	13	3.5%
Aiken (14)	20	5.3%
Unknown	6	1.6%
Total	376	100.0%



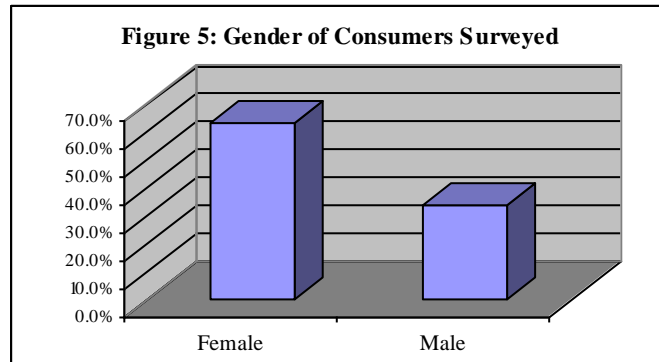
A large majority of respondents (62%) live in a rural setting. Another 35.6% live in an urban setting. (See Table 4 and Figure 4.)

Table 4: Consumers Responding to the Survey by Rural or Urban		
	#	%
Rural	233	62.0%
Urban	134	35.6%
Unknown	9	2.4%
Total	376	100.0%



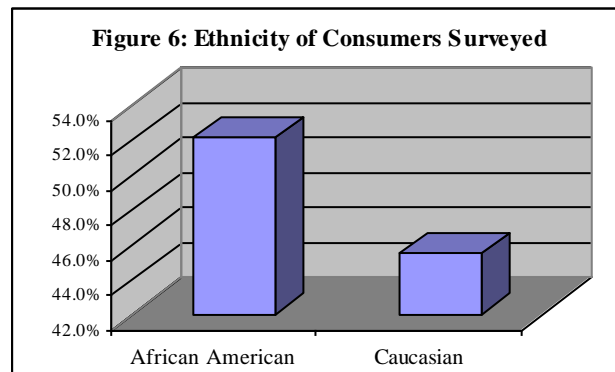
Of those consumers responding to the survey, 63.3% were female and 33.8% were male. (See Table 5 and Figure 5.)

Table 5: Gender of Consumers Surveyed		
	#	%
Female	238	63.3%
Male	127	33.8%
Unknown	11	2.9%
Total	376	100.0%



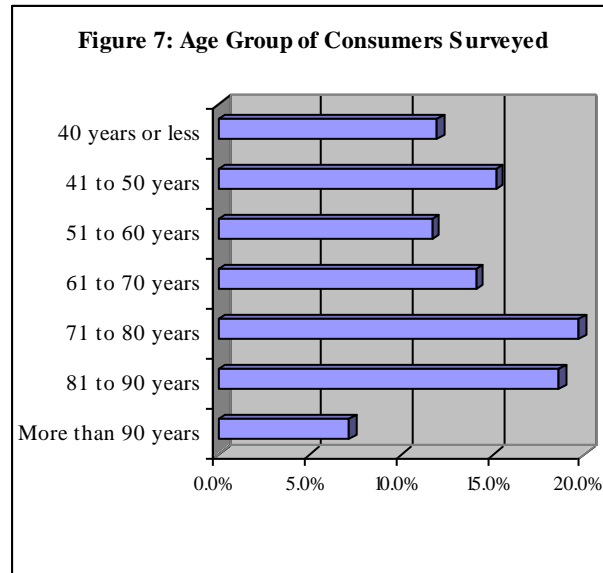
The ethnicity of respondents is almost evenly split between African American (52.1%) and Caucasian (45.5%). (See Table 6 and Figure 6.)

Table 6: Ethnicity of Consumers Surveyed		
	#	%
African American	196	52.1%
Caucasian	171	45.5%
Unknown	9	2.4%
Total	376	100.0%



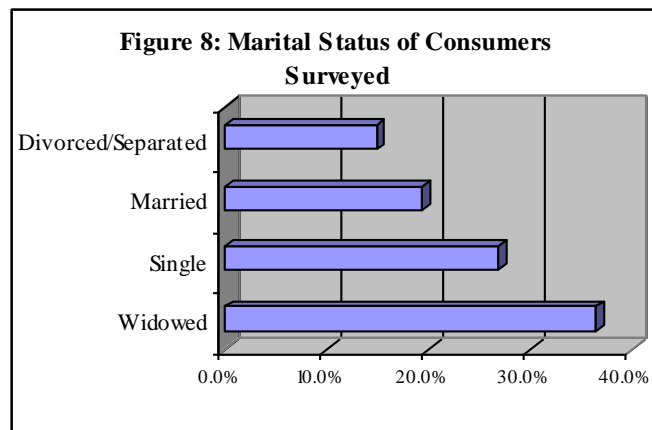
The age ranges of respondents are fairly evenly divided among age categories, in that 12% are 41 years old or younger, 15.2% are 41 to 50 years old, 11.7% are 51 to 60 years old, 14.1% are 61 to 70 years old, 19.7% are 71 to 80 years old, 18.6% are 81 to 90 years old, and 7.2% are older than 90 years. (See Table 7 and Figure 7.)

Table 7: Age Group of Consumers Responding to the Survey		
	#	%
40 years or less	45	12.0%
41 to 50 years	57	15.2%
51 to 60 years	44	11.7%
61 to 70 years	53	14.1%
71 to 80 years	74	19.7%
81 to 90 years	70	18.6%
More than 90 years	27	7.2%
Unknown	6	1.6%
Total	376	100.0%



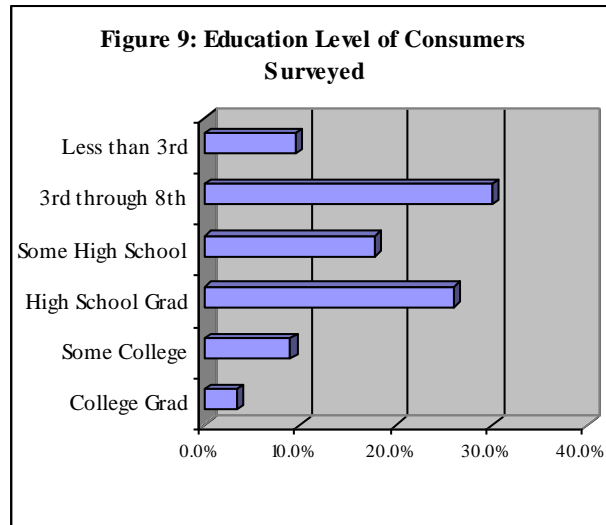
The marital status of respondents is 36.4% widowed, 26.9% single, 19.4% married, and 14.9% divorced or separated. (See Table 8 and Figure 8.)

Table 8: Marital Status of Consumers Surveyed		
	#	%
Divorced/Separated	56	14.9%
Married	73	19.4%
Single	101	26.9%
Widowed	137	36.4%
Unknown	9	2.4%
Total	376	100.0%



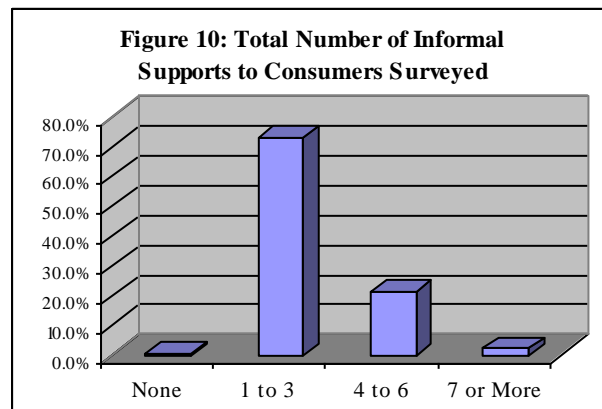
The majority of respondents have either a 3rd through 8th grade education (30.1%) or a high school education (26.1%). Other respondents have taken some high school, but not finished (17.8%), have less than a 3rd grade education (9.6%), have taken some college courses, (9%), or have graduated college (3.5%). (See Table 9 and Figure 9.)

Table 9: Education of Consumers Surveyed		
	#	%
Less than 3rd	36	9.6%
3rd through 8th	113	30.1%
Some High School	67	17.8%
High School Grad	98	26.1%
Some College	34	9.0%
College Grad	13	3.5%
Other/Unknown	15	4.0%
Total	376	100.0%



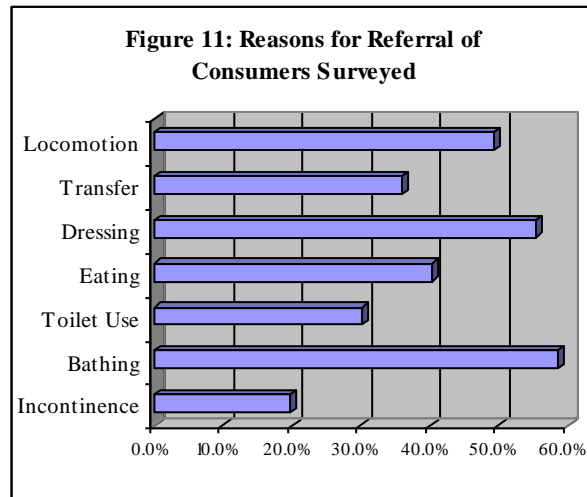
The majority of respondents (72.9%) have between one and three informal supports. Another 21.3% have between four and six informal supports, and 2.1% have seven or more. Only two of the respondents (0.5%) did not have any informal supports. (See Table 10 and Figure 10.)

Table 10: Total Number of Informal Supports to Consumers Surveyed		
	#	%
None	2	0.5%
1 to 3	274	72.9%
4 to 6	80	21.3%
7 or More	8	2.1%
Unknown	12	3.2%
Total	376	100.0%



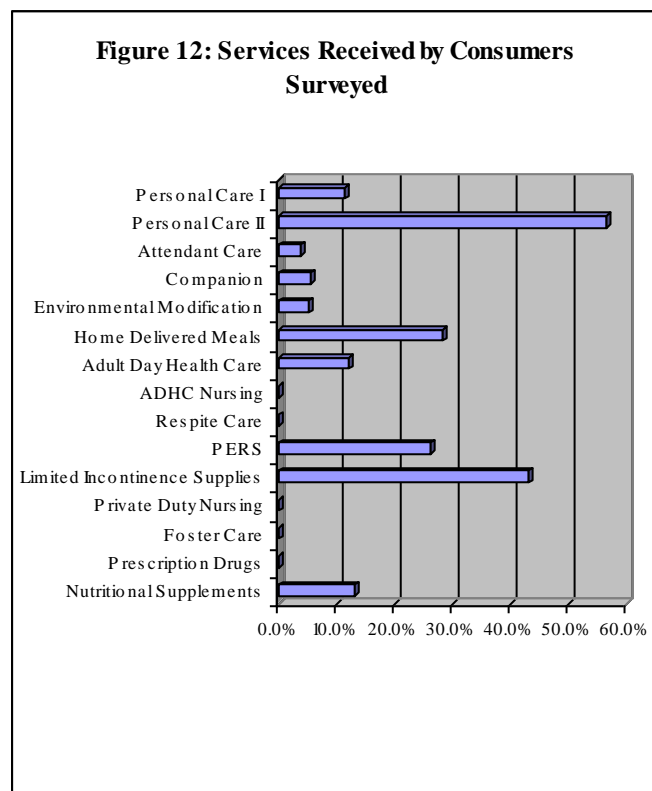
Consumers are referred to CLTC in order to receive help with their ADL's. The items they need assistance with are known as Reasons for Referral. Of the survey respondents, 58.5% need assistance with bathing, 55.3% need assistance with dressing, 49.2% need assistance with locomotion, 40.4% need assistance with eating, 35.9% need assistance with transfer, 30.1% need assistance with toilet use, and 19.7% need assistance with incontinence. (See Table 11 and Figure 11.)

Table 11: Reasons for Referral of Consumers Surveyed			
	N=376	#	%
Locomotion	185	49.2%	
Transfer	135	35.9%	
Dressing	208	55.3%	
Eating	152	40.4%	
Toilet Use	113	30.1%	
Bathing	220	58.5%	
Incontinence	74	19.7%	



Consumers of CLTC have a wide variety of services available. The services that are most utilized by the survey respondents are Personal Care II (56.6%), limited incontinence supplies (43.1%), and home delivered meals (28.2%). The following services are not being used: ADHC Nursing, respite care, private duty nursing, foster care, and prescription drugs. (See Table 12 and Figure 12.)

Table 12: Services Received by Consumers Surveyed			
	N=376	#	%
Personal Care I	43	11.4%	
Personal Care II	213	56.6%	
Attendant Care	14	3.7%	
Companion	21	5.6%	
Environmental Modification	20	5.3%	
Home Delivered Meals	106	28.2%	
Adult Day Health Care (ADHC)	45	12.0%	
ADHC Nursing	0	0.0%	
Respite Care	0	0.0%	
PERS	99	26.3%	
Limited Incontinence Supplies	162	43.1%	
Private Duty Nursing	0	0.0%	
Foster Care	0	0.0%	
Prescription Drugs	0	0.0%	
Nutritional Supplements	49	13.0%	



Survey Responses

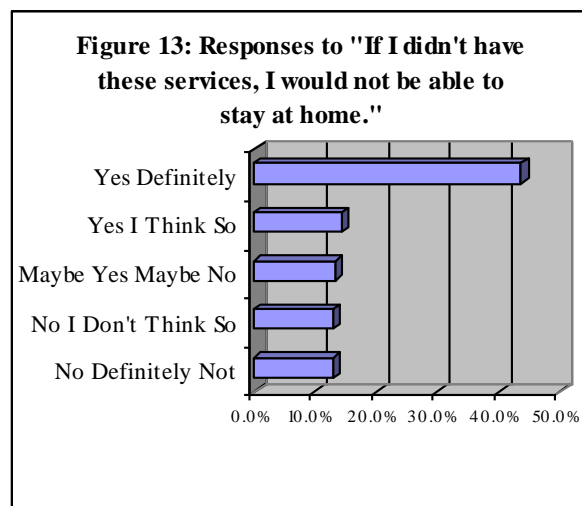
The survey responses are divided into two sections: 1) Themes Questions and 2) Compliance and Satisfaction Questions.

Themes Questions

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

The majority of respondents (58%) stated that they would not be able to stay at home without the services they receive. An additional 25.8% responded that they would still stay at home without the services, and 13.3% were unsure if the services were helping them stay in their homes. The remaining 2.9% did not respond. (See Table 13 and Figure 13.)

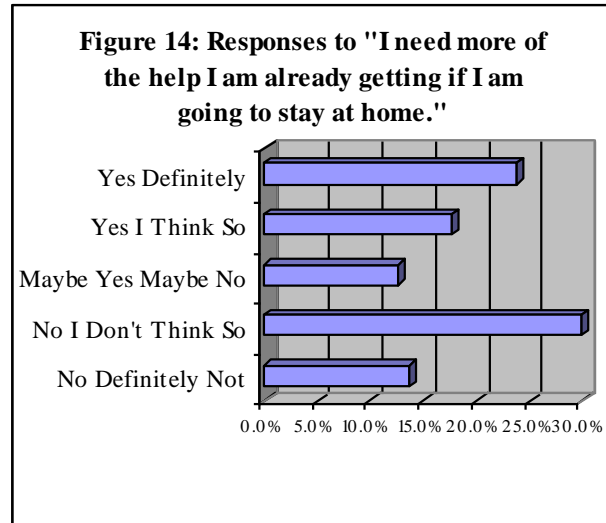
	#	%
Yes Definitely	164	43.6%
Yes I Think So	54	14.4%
Maybe Yes Maybe No	50	13.3%
No I Don't Think So	48	12.8%
No Definitely Not	49	13.0%
No Response	11	2.9%
Total	376	100.0%



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

Respondents were fairly evenly split on whether or not they need more help in order to stay at home, with 51.3% stating that they need more help and 44.4% stating that they do not need more help. An additional 12.5% were unsure if they need more help to stay in their home and 2.9% did not respond. (See Table 14 and Figure 14.)

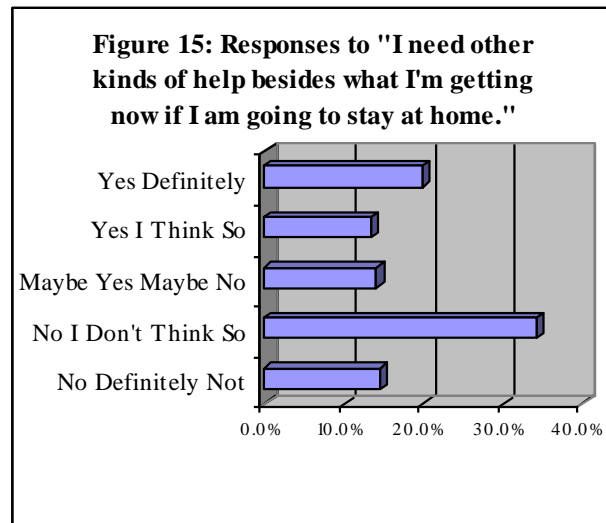
Table 14: Responses to Themes Question 2		
	#	%
Yes Definitely	89	23.7%
Yes I Think So	66	17.6%
Maybe Yes Maybe No	47	12.5%
No I Don't Think So	112	29.8%
No Definitely Not	51	13.6%
No Response	11	2.9%
Total	376	100.0%



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

More respondents (48.9%) stated that they do not need other kinds of help in order to stay in their homes. On the other hand, 33.2% stated that they do need other kinds of help. An additional 14.1% were unsure if they need other help and 3.7% did not respond. (See Table 15 and Figure 15.)

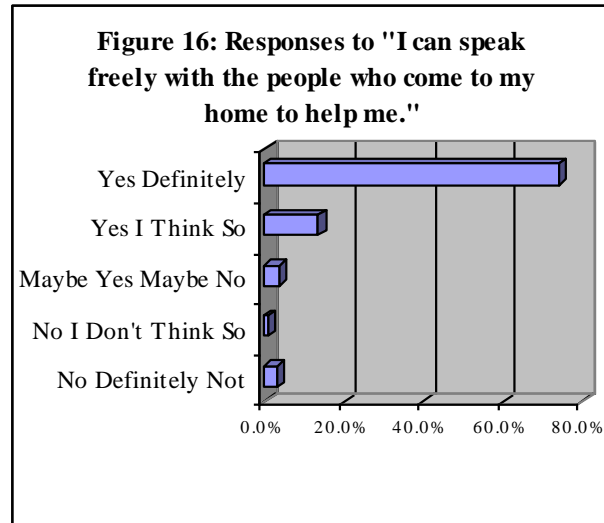
Table 15: Responses to Themes Question 3		
	#	%
Yes Definitely	75	19.9%
Yes I Think So	50	13.3%
Maybe Yes Maybe No	53	14.1%
No I Don't Think So	129	34.3%
No Definitely Not	55	14.6%
No Response	14	3.7%
Total	376	100.0%



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

Almost all of the respondents (87.8%) stated that they can speak freely with the people who come to their home to help them. Only 4.3% stated that they could not, and 3.7% were unsure. The remaining 4.3% did not respond. (See Table 16 and Figure 16.)

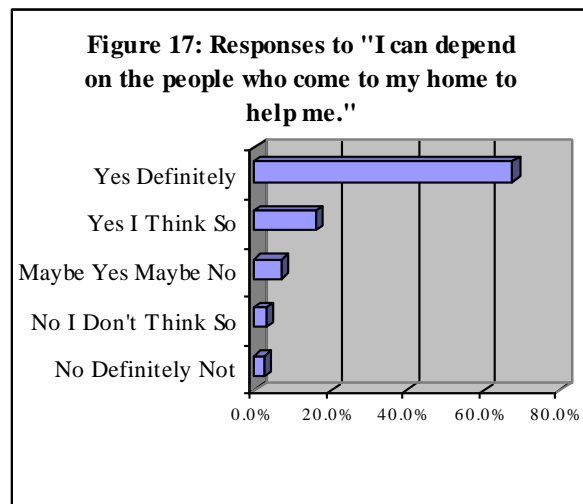
Table 16: Responses to Themes Question 4		
	#	%
Yes Definitely	279	74.2%
Yes I Think So	51	13.6%
Maybe Yes Maybe No	14	3.7%
No I Don't Think So	4	1.1%
No Definitely Not	12	3.2%
No Response	16	4.3%
Total	376	100.0%



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

Almost all of the respondents (83.8%) stated that they can depend on the people who come to their home to help them. Only 5.6% stated that they could not, and 6.9% were unsure. The remaining 3.7% did not respond. (See Table 17 and Figure 17.)

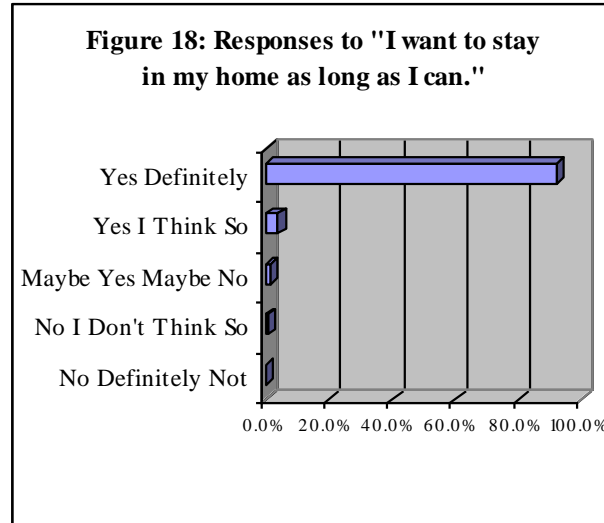
Table 17: Responses to Themes Question 5		
	#	%
Yes Definitely	254	67.6%
Yes I Think So	61	16.2%
Maybe Yes Maybe No	26	6.9%
No I Don't Think So	12	3.2%
No Definitely Not	9	2.4%
No Response	14	3.7%
Total	376	100.0%



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

Almost all of the respondents (96%) stated that they want to stay in their home as long as they can. Only two people (0.5%) stated that they do not, and 1.3% were unsure. The remaining 2.1% did not respond. (See Table 18 and Figure 18.)

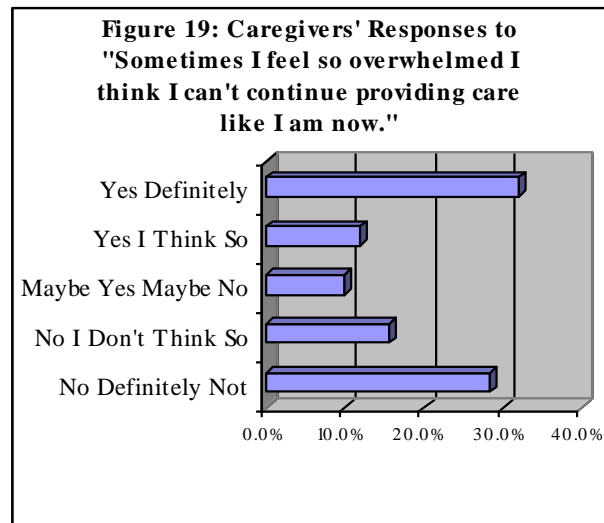
Table 18: Responses to Themes Question 6		
	#	%
Yes Definitely	346	92.0%
Yes I Think So	15	4.0%
Maybe Yes Maybe No	5	1.3%
No I Don't Think So	2	0.5%
No Definitely Not	0	0.0%
No Response	8	2.1%
Total	376	100.0%



7. *(Caregivers Only) Sometimes I feel so overwhelmed I think I can't continue providing care like I am now.*

Caregivers' responses to this question were evenly split, with 44% agreeing that they sometimes feel overwhelmed and 44% disagreeing with the statement. An additional 10.1% were unsure, and 1.8% did not respond. (See Table 19 and Figure 19.)

Table 19: Responses to Themes Question 7		
	#	%
Yes Definitely	35	32.1%
Yes I Think So	13	11.9%
Maybe Yes Maybe No	11	10.1%
No I Don't Think So	17	15.6%
No Definitely Not	31	28.4%
No Response	2	1.8%
Total	109	100.0%

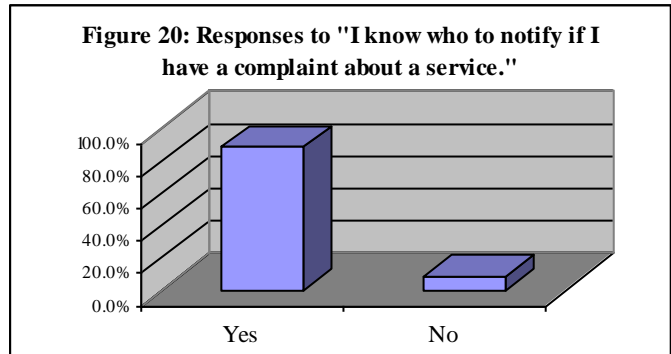


Satisfaction and Compliance Questions

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

The majority of respondents (88.3%) stated that they do know who to notify if they have a complaint about a service, and only 8.5% stated that they do not know who to notify. The remaining 3.2% did not respond. (See Table 20 and Figure 20.)

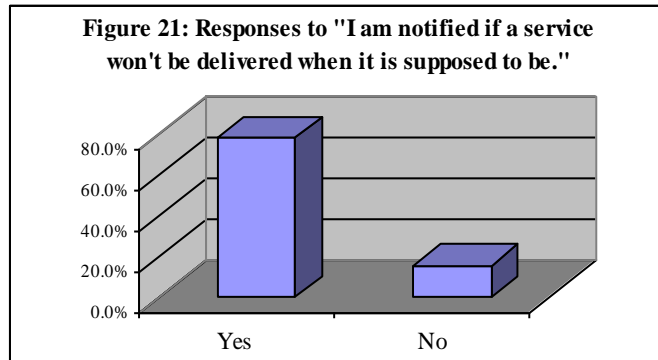
	#	%
Yes	332	88.3%
No	32	8.5%
No Response	12	3.2%
Total	376	100.0%



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

The majority of respondents (78.5%) stated that they are notified if a service is not going to be delivered when it is supposed to be, and 15.4% stated that they are not notified. The remaining 6.1% did not respond. (See Table 21 and Figure 21.)

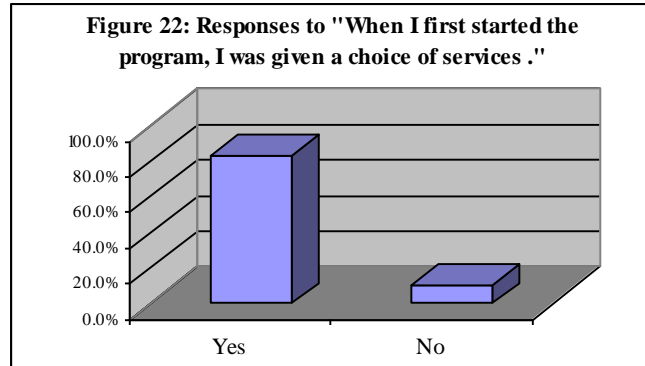
	#	%
Yes	295	78.5%
No	58	15.4%
No Response	23	6.1%
Total	376	100.0%



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

The majority of respondents (83%) stated that they were given a choice of services, and 10.6% stated that they were not given a choice. The remaining 6.4% did not respond. (See Table 22 and Figure 22.)

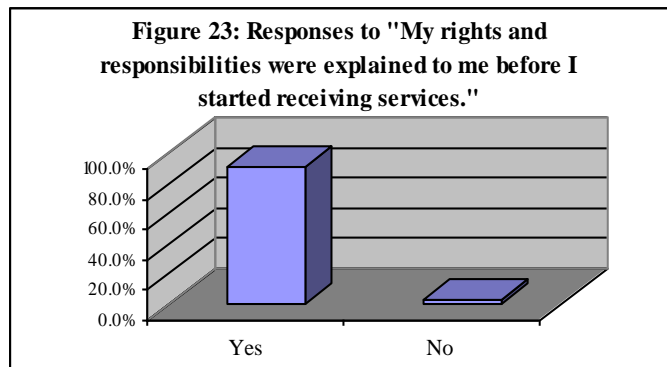
Table 22: Responses to Satisfaction and Compliance Question 3		
	#	%
Yes	312	83.0%
No	40	10.6%
No Response	24	6.4%
Total	376	100.0%



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

Almost all respondents (91%) stated that their rights and responsibilities were explained to them, and only 3.5% stated that they were not. The remaining 5.6% did not respond. (See Table 23 and Figure 23.)

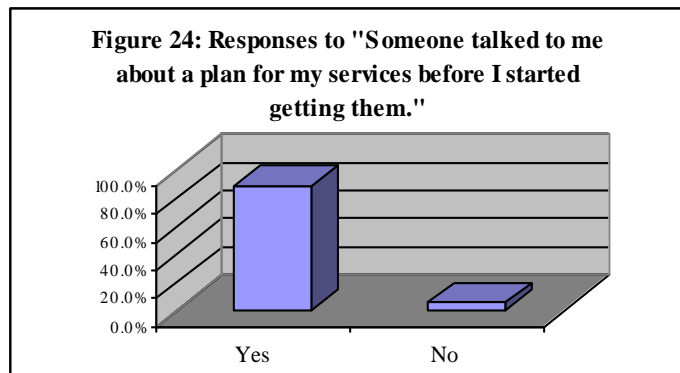
Table 23: Responses to Satisfaction and Compliance Question 4		
	#	%
Yes	342	91.0%
No	13	3.5%
No Response	21	5.6%
Total	376	100.0%



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

The majority of respondents (89.1%) stated that someone talked to them about a plan for services, and only 5.6% stated that they had not been spoken to about the plan for services. The remaining 5.3% did not respond. (See Table 24 and Figure 24.)

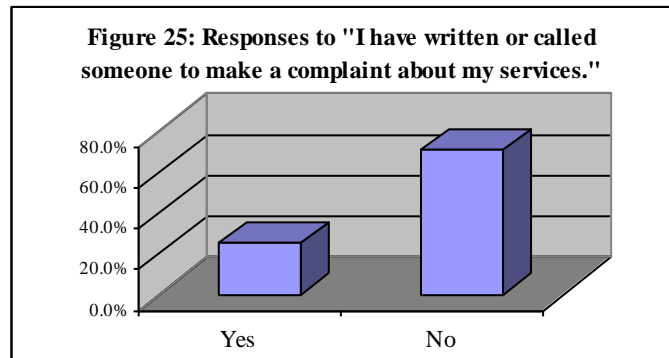
Table 24: Responses to Satisfaction and Compliance Question 5		
	#	%
Yes	335	89.1%
No	21	5.6%
No Response	20	5.3%
Total	376	100.0%



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

Almost all respondents (70.7%) stated that they have not made a complaint about their services, and 25% stated that they have made a complaint. The remaining 4.3% did not respond. (See Table 25 and Figure 25.)

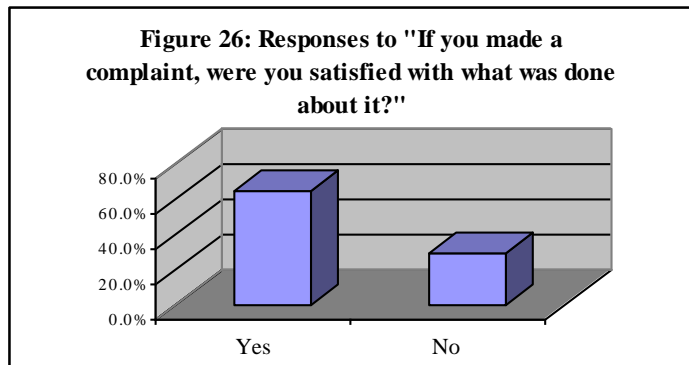
Table 25: Responses to Satisfaction and Compliance Question 6		
	#	%
Yes	94	25.0%
No	266	70.7%
No Response	16	4.3%
Total	376	100.0%



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

Of those 94 people who stated that they had made a complaint, 64.9% stated that they were satisfied with what was done about it and 29.8% were not satisfied. The remaining 5.3% did not respond. (See Table 26 and Figure 26.)

Table 26: Responses to Satisfaction and Compliance Question 7		
	#	%
Yes	61	64.9%
No	28	29.8%
No Response	5	5.3%
Total	94	100.0%



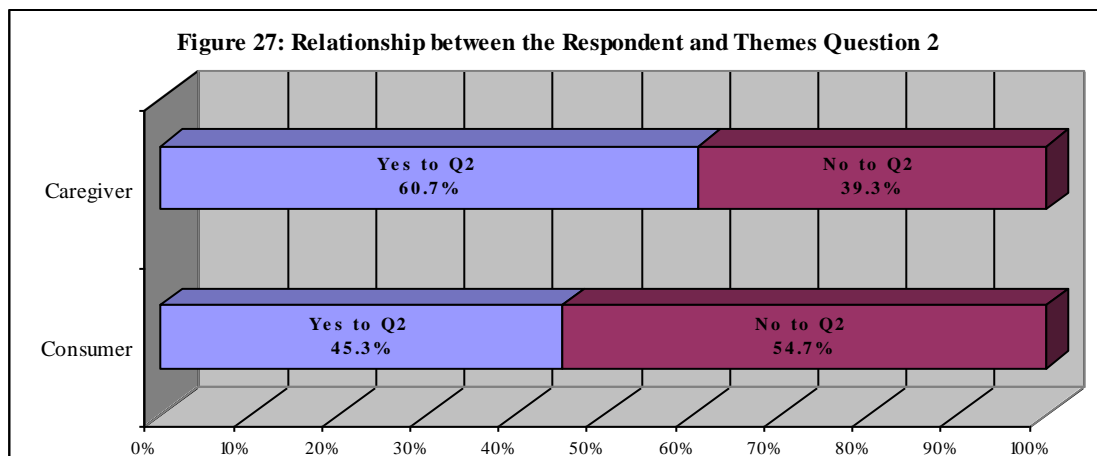
Other Significant Findings of the Survey

Tests of significance were conducted to determine if any relationships existed in the data that would affect responses. For purposes of this portion of the study, 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. In addition, all missing values and "Maybe Yes Maybe No" responses were removed to provide a more accurate picture of the differences between responses.

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 was only one statistically significant difference.

The only difference on responses was to Themes Question 2, “I need more of the help I am already getting if I am going to stay at home.” Consumers were more likely to respond that they do not need more help in order to stay at home, and caregivers were more likely to respond that the consumer they are answering for does need more help in order to stay at home. This difference is highly statistically significant (Chi-square =5.85, p = 0.016). (See Table 27 and Figure 27.)

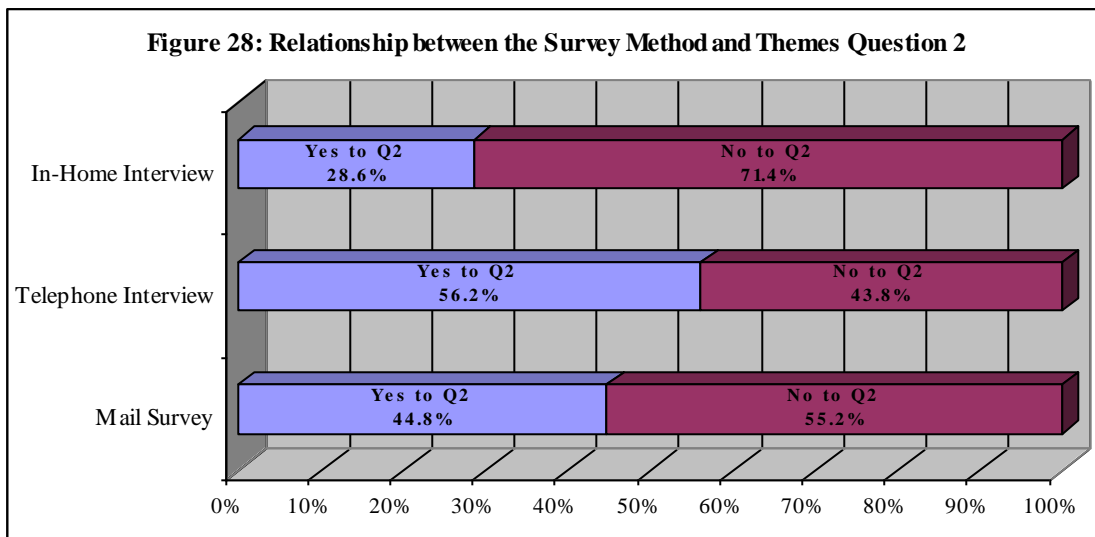
Table 27: Relationship between the Respondent and Themes Question 2						
	Yes to Q2		No to Q2		Total	
	#	% of Respondent	#	% of Respondent	#	%
Consumer	91	45.3%	110	54.7%	201	100.0%
Caregiver	54	60.7%	35	39.3%	89	100.0%
Total	145	50.0%	145	50.0%	290	100.0%



There was some concern that responses would differ according to how the survey was administered, whether the survey was returned by mail, completed in-home, or completed via telephone interview. A chi square analysis was therefore conducted on each question to determine if any such differences occurred. There was only one statistically significant difference.

The only difference on responses was to Themes Question 2, “*I need more of the help I am already getting if I am going to stay at home.*” Respondents interviewed in-home were more likely to answer that they do not need more help in order to stay at home (71.4%) than respondents surveyed by either of the other two methods. Respondents surveyed over the telephone were slightly more likely to answer that they do need more help in order to stay at home (56.2%) than respondents completing the survey by mail (44.8%). This difference is statistically significant (Chi-square =6.21, p = 0.05). (See Table 28 and Figure 28.)

Table 28: Relationship between the Survey Distribution Method and Themes Question 2						
	Yes to Q2		No to Q2		Total	
	#	% of Type	#	% of Type	#	%
Mail Survey	78	44.8%	96	55.2%	174	100.0%
Telephone Interview	73	56.2%	57	43.8%	130	100.0%
In-Home Interview	4	28.6%	10	71.4%	14	100.0%
Total	155	48.7%	163	51.3%	318	100.0%

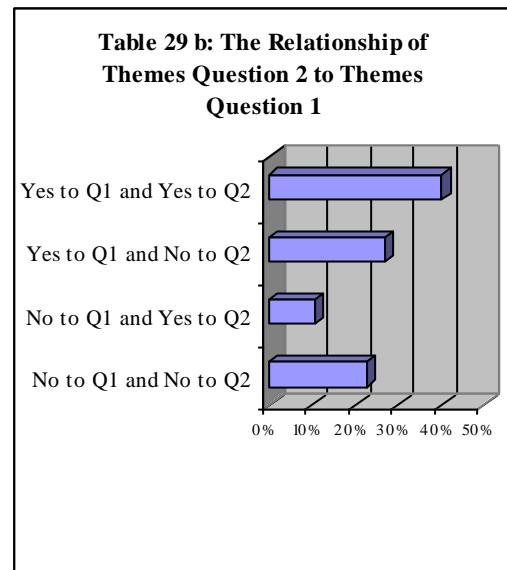
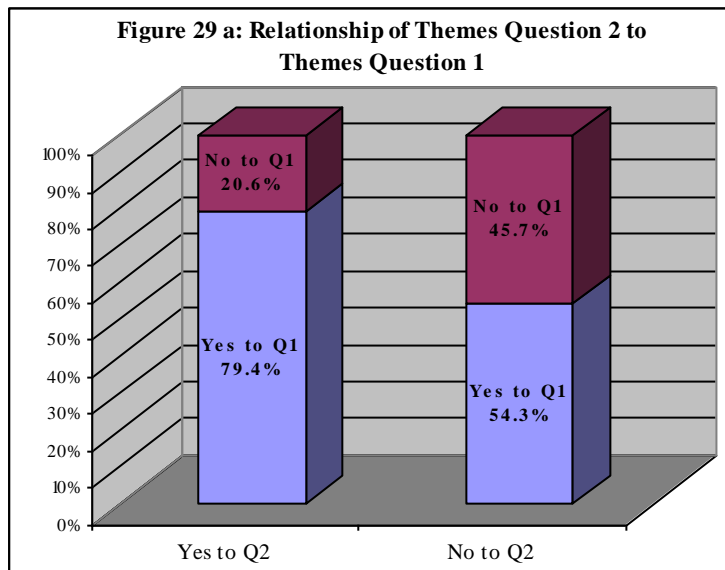


The key question in the Themes section of the survey is question 1: “*If I didn’t have these services, I would not be able to stay at home.*” An examination of how the responses to this question interact with responses to other questions was conducted. Statistically significant differences were found for two of the questions, questions 2 and 3.

Question 2 asked, “I need more of the help I am already getting if I am going to stay at home.” Of the respondents who answered ‘yes’ to this question, 79.4% also answered ‘yes’ to question 1 and only 20.6% answered ‘no’ to question 1. For respondents who answered ‘no’ to question 2, responses are almost evenly split between answering ‘yes’ to question 1 (54.3%) and ‘no’ to question 1 (45.7%). Therefore, respondents who feel they need more services are also more likely to feel that they need the services they are receiving in order to remain in their home. In addition, about half of the respondents who do not need more services are likely to believe they need the services they are currently receiving in order to stay in the home. This difference is statistically significant (Chi-square = 19.86, p = .000). (See Table 29 and Figure 29 a.)

It can also be surmised that about 40% of all consumers believe they need the CLTC services they are currently receiving and need more of these services in order to stay in their home. This belief is held by more consumers than any other combination of the two questions. (See Table 29 and Figure 29 b.)

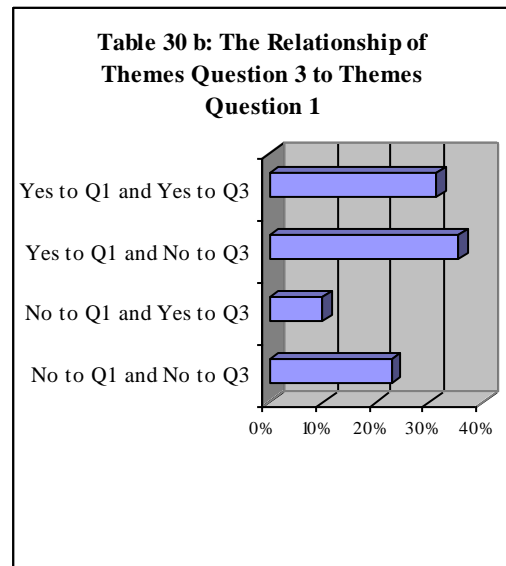
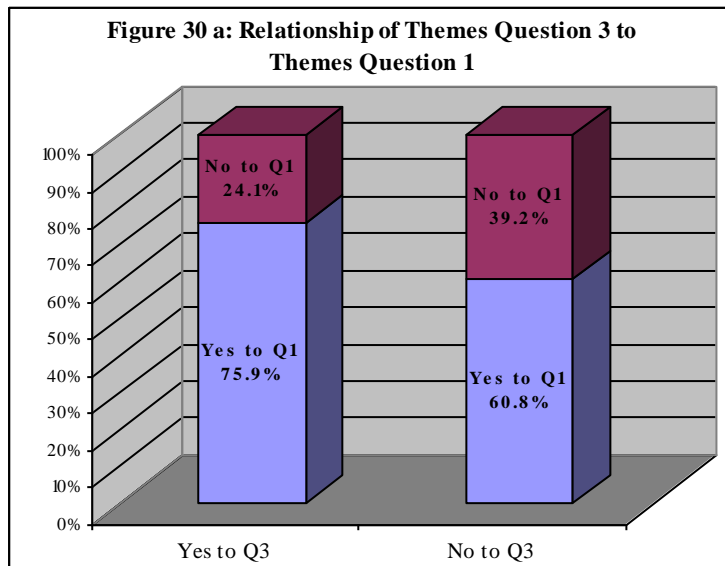
Table 29: The Relationship of Themes Question 2 to Themes Question 1								
	Yes to Q2			No to Q2			Total	
	#	% of Yes to Q2	% of Total	#	% of No to Q2	% of Total	#	%
Yes to Q1	112	79.4%	40.1%	75	54.3%	26.9%	187	67.0%
No to Q1	29	20.6%	10.4%	63	45.7%	22.6%	92	33.0%
Total	141	100.0%	50.5%	138	100.0%	49.5%	279	100.0%



Question 3 asked, “I need other kinds of help besides what I’m getting now if I am going to stay at home.” Of the respondents who answered ‘yes’ to this question, 75.9% also answered ‘yes’ to question 1 and only 24.1% answered ‘no’ to question 1. Respondents who answered ‘no’ to question 2 were also more likely to answer ‘yes’ (60.8%) than ‘no’ (39.2%) to question 1. Therefore, people who answer ‘yes’ and ‘no’ to question 3 were both more likely to answer ‘yes’ to question 1. This difference is statistically significant (Chi-square = 6.793, p = .009). (See Table 30 and Figure 30 a.)

It can also be surmised that the majority of consumers holds one of two beliefs. The first belief, held by approximately 30% of consumers, is that they need both the services they are already receiving, and other services in order to stay in their homes. The other belief, held by approximately 30% of consumers, is that they need the services they are currently receiving, but do not necessarily need other services in order to stay in their homes. (See Table 30 and Figure 30 b.)

Table 30: The Relationship of Themes Question 3 to Themes Question 1								
	Yes to Q3			No to Q3			Total	
	#	% of Yes to Q3	% of Total	#	% of No to Q3	% of Total	#	%
Yes to Q1	85	75.9%	31.5%	96	60.8%	35.6%	181	67.0%
No to Q1	27	24.1%	10.0%	62	39.2%	23.0%	89	33.0%
Total	112	100.0%	41.5%	158	100.0%	58.5%	270	100.0%



Comparison to Previous Year

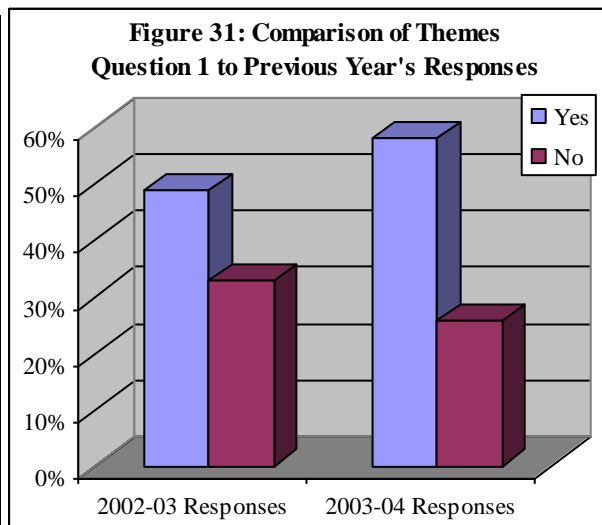
Responses to this year's survey were compared to the responses from the 2002-2003 CLTC survey to determine if there were any changes in beliefs or satisfaction with services. For purposes of this comparison, the Themes Questions responses "Yes Definitely" and "Yes I Think So" were combined, as were "No I Don't Think So" and "No Definitely Not" responses. In addition, all missing values and "Maybe Yes Maybe No" responses were combined into "other" responses.

Themes Questions

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

Compared to last year, there was an increase in persons responding that they need their services in order to remain in their homes from 48.9% last year to 58% this year. There is a corresponding decrease in persons stating that they do not need these services to stay in their homes from 32.8% last year to 25.8% this year. (See Table 31 and Figure 31.)

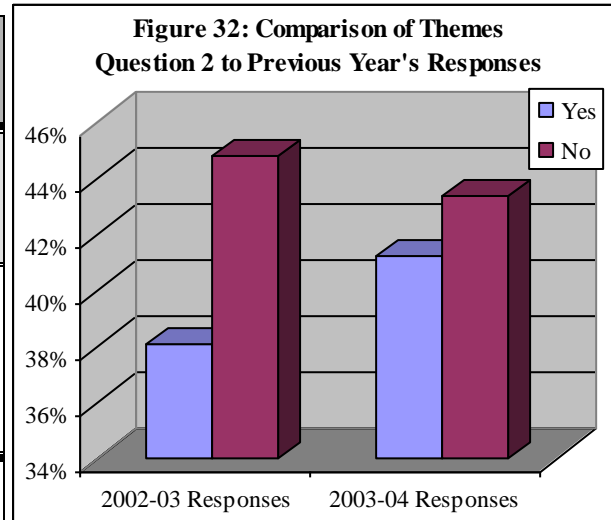
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	131	48.9%	218	58.0%
No	88	32.8%	97	25.8%
Other	49	18.3%	61	16.2%
Total	268	100.0%	376	100.0%



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

There was a slight increase from 38.1% last year to 41.2% of respondents this year stating that they need more of the services they are already receiving in order to stay in their homes. There was also a corresponding decrease in persons stating that they do not need more help. However, more persons responded to this question this year than last year. (See Table 32 and Figure 32.)

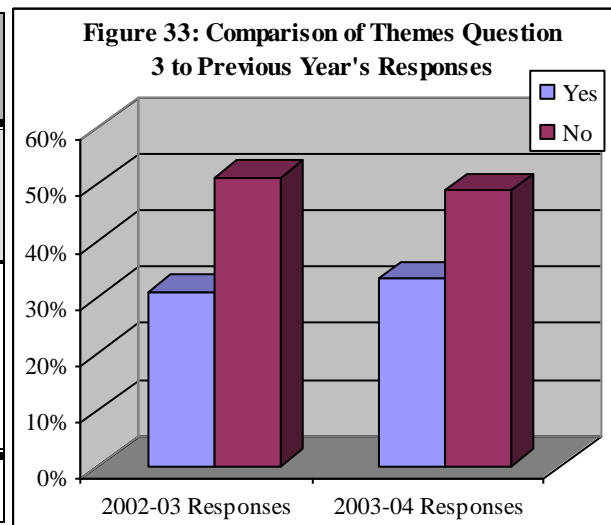
Table 32: Comparison of Themes Question 2 to Previous Year's Responses				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	102	38.1%	155	41.2%
No	120	44.8%	163	43.4%
Other	46	17.2%	58	15.4%
Total	268	100.0%	376	100.0%



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

The distribution of responses for this question is very similar to the distribution of last year. Approximately half of the respondents in both years felt that they did not need other kinds of services, and one third in each year felt that they did need other kinds of services in order to stay in their homes. (See Table 33 and Figure 33.)

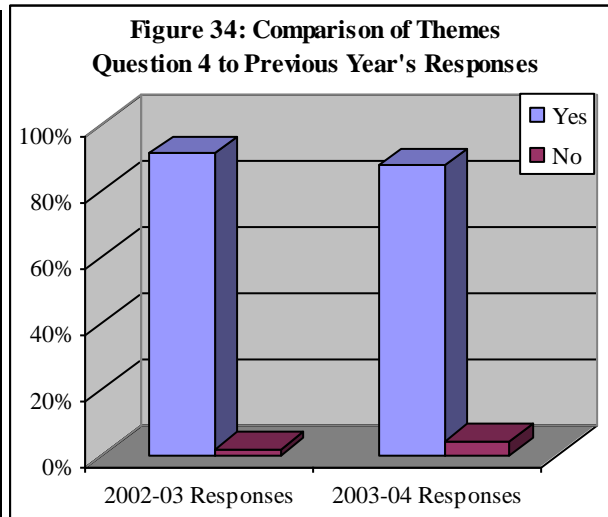
Table 33: Comparison of Themes Question 3 to Previous Year's Responses				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	83	31.0%	125	33.2%
No	137	51.1%	184	48.9%
Other	48	17.9%	67	17.8%
Total	268	100.0%	376	100.0%



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

The distribution of responses for this question is very similar to the distribution of last year. Almost all of the respondents in both years (91.4% last year and 87.8% this year) felt that they could speak freely with the people who come to their homes to help them. There is only a slight increase from 1.9% last year to 4.3% of respondents who reported this year that they could not speak freely with the people who help them. (See Table 34 and Figure 34.)

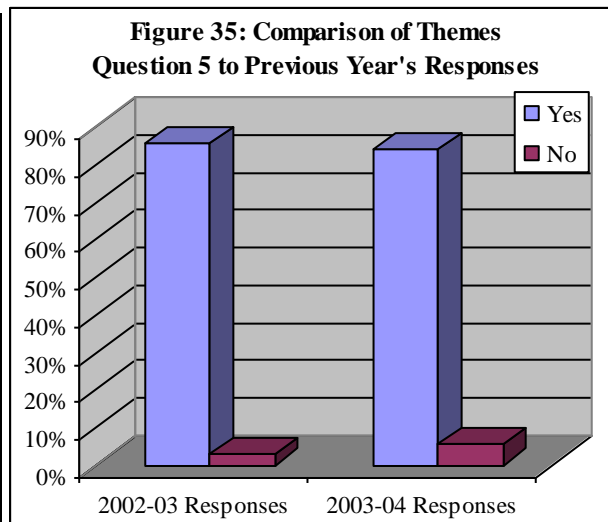
Table 34: Comparison of Themes Question 4 to Previous Year's Responses				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	245	91.4%	330	87.8%
No	5	1.9%	16	4.3%
Other	18	6.7%	30	8.0%
Total	268	100.0%	376	100.0%



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

The distribution of responses for this question is very similar to the distribution of last year. Almost all of the respondents in both years (85.4% last year and 83.8% this year) felt that they could depend on the people who come to their homes to help them. Only 3% of respondents last year and 5.6% of respondents this year stated that they could not depend on the people who come to their homes to help them. (See Table 35 and Figure 35.)

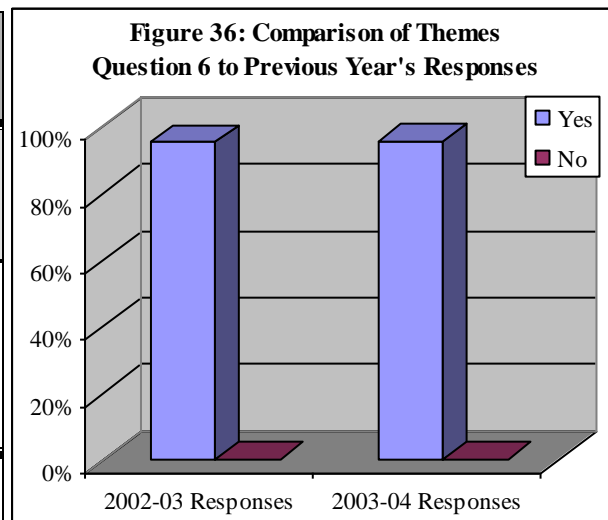
Table 35: Comparison of Themes Question 5 to Previous Year's Responses				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	229	85.4%	315	83.8%
No	8	3.0%	21	5.6%
Other	31	11.6%	40	10.6%
Total	268	100.0%	376	100.0%



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

Almost all of the respondents in both years (95.5% last year and 96% this year) stated that they want to stay in their homes as long as they can. Only 0.4% of respondents last year and 0.5% of respondents this year do not want to stay in their homes as long as they can. (See Table 36 and Figure 36.)

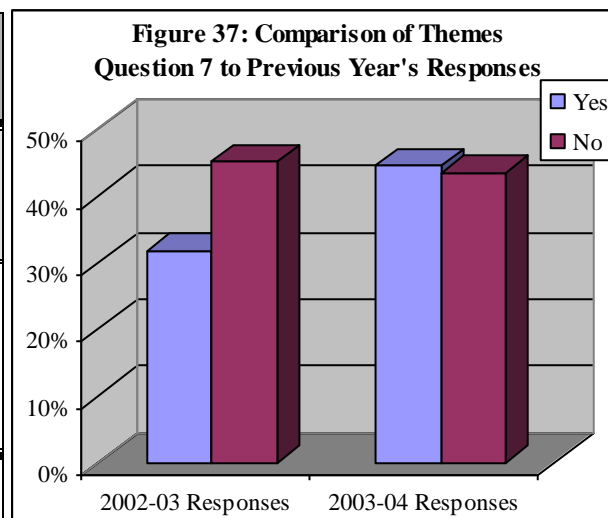
Table 36: Comparison of Themes Question 6 to Previous Year's Responses				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	256	95.5%	361	96.0%
No	1	0.4%	2	0.5%
Other	11	4.1%	13	3.5%
Total	268	100.0%	376	100.0%



7. *(Caregivers Only) Sometimes I feel so overwhelmed I think I can't continue providing care like I am now.*

Compared to last year, there was an increase in the percentage of caregivers who sometimes feel overwhelmed (44.4% this year compared to only 31.7% last year). However, there is approximately the same percentage of caregivers in both years (43.4% this year and 45.1% last year) who stated that they do not feel so overwhelmed that they think they can't continue providing care. This difference is due to the smaller percentage of caregivers who did not respond this year (12.1%) compared to last year (23.2%). (See Table 37 and Figure 37.)

Table 37: Comparison of Themes Question 7 to Previous Year's Responses				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	26	31.7%	44	44.4%
No	37	45.1%	43	43.4%
Other	19	23.2%	12	12.1%
Total	82	100.0%	99	100.0%

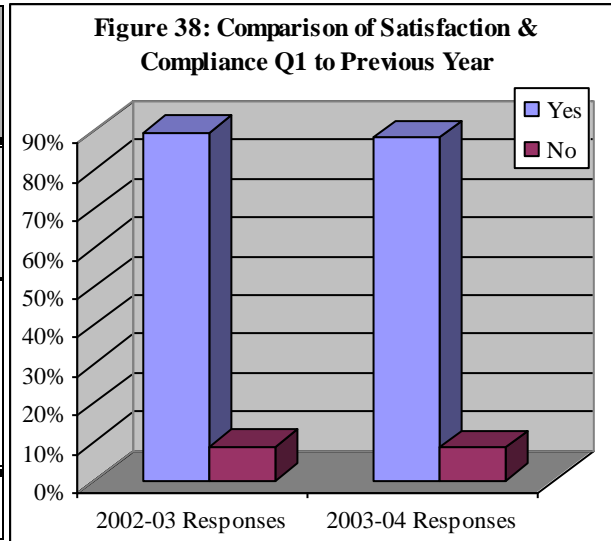


Satisfaction and Compliance Questions

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

Approximately the same percentage of respondents stated that they know who to notify with a complaint this year (88.3%) and last year (89.6%). (See Table 38 and Figure 38.)

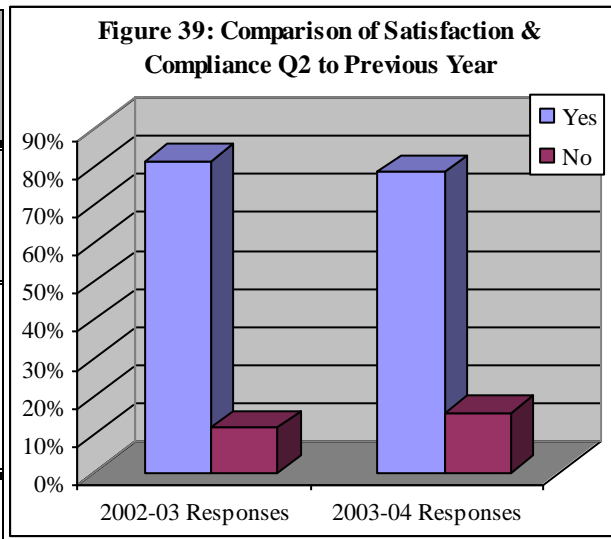
Table 38: Comparison of Satisfaction and Compliance Question 1 to Previous Year				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	240	89.6%	332	88.3%
No	23	8.6%	32	8.5%
No Response	5	1.9%	12	3.2%
Total	268	100.0%	376	100.0%



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

Approximately the same percentage of respondents last year (81.3%) and this year (78.5%) stated that they are notified if a service is not going to be delivered when it is supposed to be. A very small percentage of respondents in both years (11.6% last year and 15.4% this year) stated that they are not notified. (See Table 39 and Figure 39.)

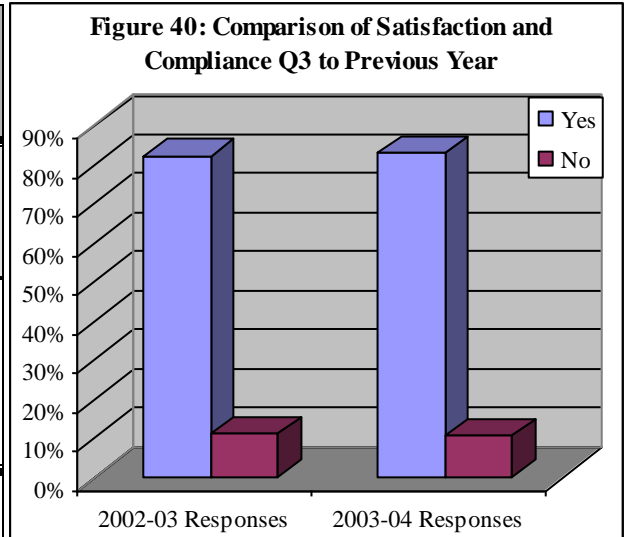
Table 39: Comparison of Satisfaction and Compliance Question 2 to Previous Year				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	218	81.3%	295	78.5%
No	31	11.6%	58	15.4%
No Response	19	7.1%	23	6.1%
Total	268	100.0%	376	100.0%



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

Approximately the same percentage of respondents last year (82.1%) and this year (83%) stated that when they started the program, they were given a choice of services. In addition, there was only a small percentage of respondents in both years (11.2% last year and 10.6% this year) who stated that they were not given a choice. (See Table 40 and Figure 40.)

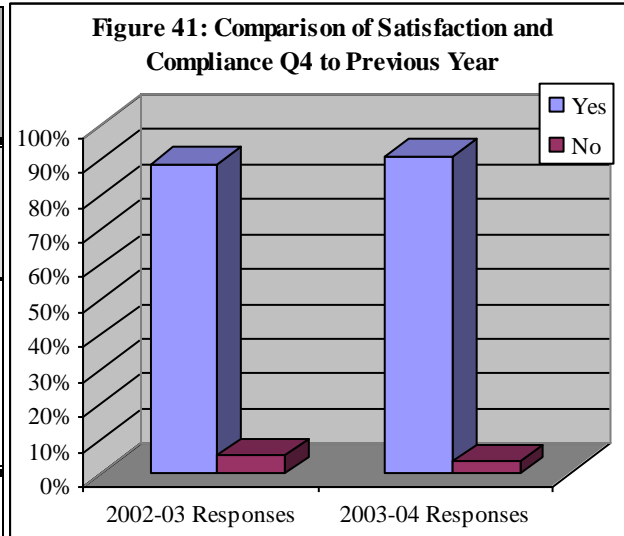
Table 40: Comparison of Satisfaction and Compliance Question 3 to Previous Year				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	220	82.1%	312	83.0%
No	30	11.2%	40	10.6%
No Response	18	6.7%	24	6.4%
Total	268	100.0%	376	100.0%



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

Almost all respondents last year (88.8%) and this year (91%) stated that their rights and responsibilities were explained to them. Only a small percentage of respondents in both years (5.2% last year and 3.5% this year) stated that their rights and responsibilities were not explained to them. (See Table 41 and Figure 41.)

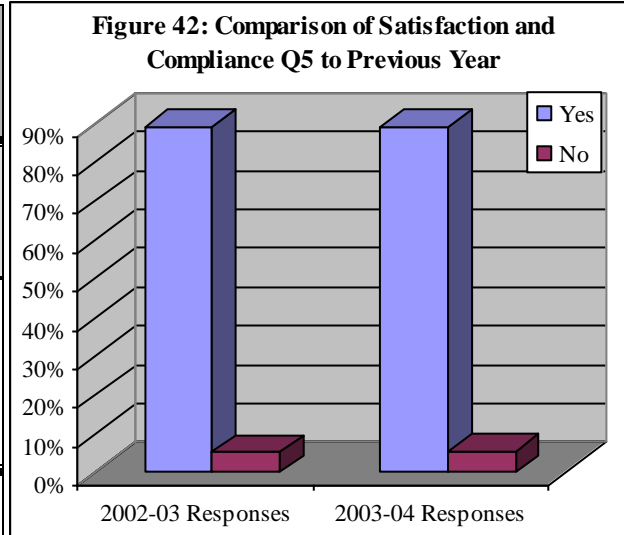
Table 41: Comparison of Satisfaction and Compliance Question 4 to Previous Year				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	238	88.8%	342	91.0%
No	14	5.2%	13	3.5%
No Response	16	6.0%	21	5.6%
Total	268	100.0%	376	100.0%



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

Almost all respondents last year (89.2%) and this year (89.1%) stated that someone talked to them about a plan for services. Only a small percentage of respondents in both years (5.2% last year and 5.6% this year) stated that someone did not talk to them about a plan for their services. (See Table 42 and Figure 42.)

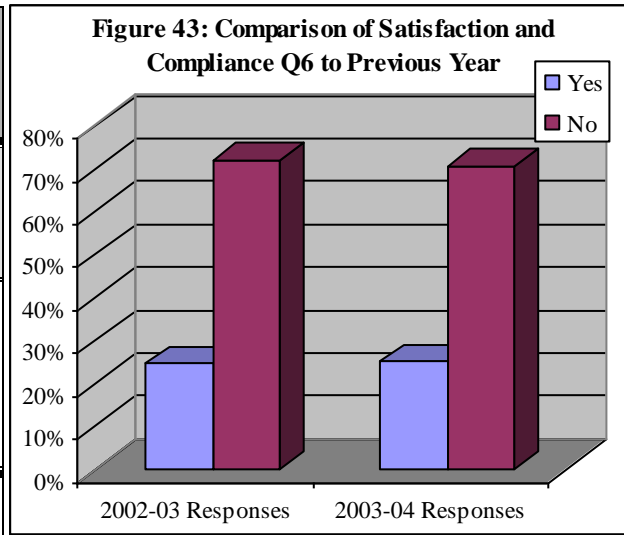
Table 42: Comparison of Satisfaction and Compliance Question 5 to Previous Year				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	239	89.2%	335	89.1%
No	14	5.2%	21	5.6%
No Response	15	5.6%	20	5.3%
Total	268	100.0%	376	100.0%



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

Approximately the same percentage of respondents in both years (25%) reported making a complaint about their services. (See Table 43 and Figure 43.)

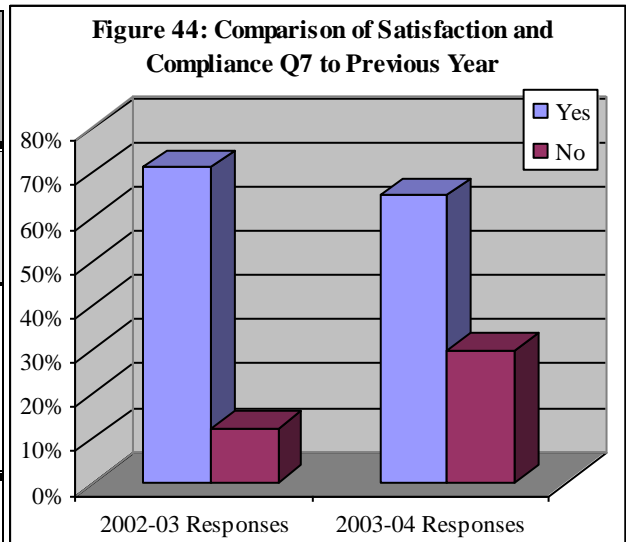
Table 43: Comparison of Satisfaction and Compliance Question 6 to Previous Year				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	66	24.6%	94	25.0%
No	193	72.0%	266	70.7%
No Response	9	3.4%	16	4.3%
Total	268	100.0%	376	100.0%



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

Compared to last year, there is an increase from 12.1% to 29.8% of respondents who responded that they were not satisfied with how a complaint was handled. However, there is also a smaller number of persons who did not respond this year (5.3%) compared to last year (16.7%). (See Table 44 and Figure 44.)

Table 44: Comparison of Satisfaction and Compliance Question 7 to Previous Year				
	2002-03 Responses		2003-04 Responses	
	#	%	#	%
Yes	47	71.2%	61	64.9%
No	8	12.1%	28	29.8%
No Response	11	16.7%	5	5.3%
Total	268	100.0%	376	100.0%



CONCLUSIONS

Of the 376 respondents, 63.3% were consumers, 26.3% were the consumers' caregivers, and 2.7% were completed by both the consumer and the caregiver. Of the respondents, 58.2% are elderly/disabled, 18.9% are disabled, and 21.3% are HIV/AIDS patients. The service status of the remaining 7.7% is unknown. The ethnicity of respondents is almost evenly split between African American (52.1%) and Caucasian (45.5%). A large majority of respondents (62%) live in a rural setting and another 35.6% live in an urban setting. More respondents (63.3%) were female than were male (33.8%). The age ranges of respondents are fairly evenly divided among age categories, in that 12% are 41 years old or younger, 15.2% are 41 to 50 years old, 11.7% are 51 to 60 years old, 14.1% are 61 to 70 years old, 19.7% are 71 to 80 years old, 18.6% are 81 to 90 years old, and 7.2% are older than 90 years. The marital status of respondents is 36.4% widowed, 26.9% single, 19.4% married, and 14.9% divorced or separated. The majority of respondents have either a 3rd through 8th grade education (30.1%) or a high school education (26.1%). Other respondents have taken some high school but not finished (17.8%), have less than a 3rd grade education (9.6%), have taken some college courses, (9%), or have graduated college (3.5%).

The majority of respondents (72.9%) have between one and three informal supports. Another 21.3% have between four and six informal supports, and 2.1% have seven or more. Only two of the respondents (0.5%) did not have any informal supports. Of the survey respondents, 58.5% need assistance with bathing, 55.3% need assistance with dressing, 49.2% need assistance with locomotion, 40.4% need assistance with eating, 35.9% need assistance with transfer, 30.1% need assistance with toilet use, and 19.7% need assistance with incontinence. The services that are most utilized by the survey respondents are Personal Care II (56.6%), limited incontinence supplies (43.1%), and home delivered meals (28.2%). the following services are not being used: ADHC Nursing, respite care, private duty nursing, foster care, and prescription drugs.

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

Over 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 26% 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.

These findings are very similar to those from last year. The only major difference was the increase of 9% in the percentage of respondents stating they need the services they are currently receiving to remain in their homes.

2. 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 41% 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 33% believe other services will help them (or those they are caring for) remain in their home. The need for more of the same help is 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. Also among caregivers, about 44% believe that they sometimes are near the end of their ability to provide care. Caregivers are heavily stressed and are asking for help.

Last year, 38% reported a need for more of the same services (an increase of 3%) and 32% of caregivers reported that they sometimes are near the end of their ability to provide care (an increase of approximately 12%).

3. 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, 70% were either satisfied with the results or did not respond to the question asking them about their satisfaction. Therefore, only about 7% of all respondents had a complaint they did not feel was handled properly.

Just 4.3% of respondents reported they can not speak freely with the helpers provided by CLTC. Similarly, only 5.6% reported they can not depend on these helpers. The services provided by CLTC are greatly appreciated and case managers are highly regarded.

Unfortunately, there are more than twice as many respondents who made a complaint this year (29.8%) who are unhappy with the results of a complaint than there were last year (12.1%).

Other Conclusions

There has been a slight improvement since last year in respondents being unclear about their rights. Approximately the same percentage of respondents know who to notify with a complaint this year (8.5%) as did last year (8.6%). The proportion who reported they are not notified when a service is not going to be delivered stayed about the same at 11.6% last year and 15.4% this year. The same was true of being given a choice of services, at 10.6% last year and 11.2% this year. The percent who reported that their rights and responsibilities were not explained to them changed from 5.2% last year and 3.5% this year. The reports of not having someone talk to them about a plan for services were about the same, at 5.2% last year and 5.6% this year.

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.**

This study generated considerable data that has not been thoroughly explored. **It is recommended that the data continue to be analyzed.**

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:
SURVEY QUESTIONNAIRE**

Please Return this Survey by _____.

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 _____.

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 TWO:
LETTERS SENT TO CONSUMERS**

Initial Letter to Consumers

November 5, 2003

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

Dear «Prefix» «Last_Name»:

You will receive a survey form in the mail from the University of South Carolina in about a month. The survey asks questions about the help you receive to stay in your home. We would appreciate your filling out the survey. If you would like, you can ask a friend or family member whom you trust to help you fill out the survey.

We are doing this survey to find out what you think about the services you receive. That will help the people who provide your services do a better job. Your answers on the survey will be strictly confidential. No one besides us will know what you say. The services that you receive will not be affected in any way by what you say. You don't have to take part in the survey if you don't want to. But your answers are important to helping improve services for everyone.

If you have any questions about the survey or this letter, please call Mr. George Appenzeller or Ms. Sarah Meadows. Their number is 1-866-660-8090. This is a toll free number.

Thank you for reading this letter. And thank you for helping us make the services you receive even better.

Sincerely,

A handwritten signature in blue ink, appearing to read "Leon Ginsberg for". The signature is cursive and somewhat stylized.

Leon Ginsberg, PhD
Acting Dean
College of Social Work

Letter Accompanying Survey

November 19, 2003

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

Dear «Prefix» «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.

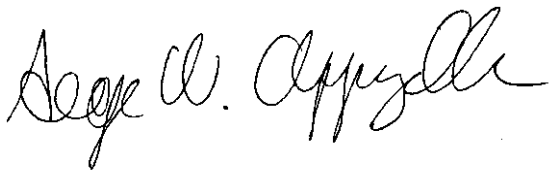
Could you please complete the survey that came with this letter? Hundreds of other people are being asked to do the same thing. It should take just five or ten minutes of your time. A family member or someone else who knows about your situation can complete the survey for you.

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 December 12, 2003.**

If you have any questions, please call me at (803) 771-6663 or toll-free at 1-866-660-8090.

Sincerely,



George W. Appenzeller, MSW
Project Coordinator