



Report of

**2008 Annual Survey of  
Community Long Term Care (CLTC)  
Consumer Experience and Satisfaction**

For

South Carolina DHHS

Bureau of Long Term Care and Behavioral Health Services  
Sam Waldrep – Bureau Chief

Survey conducted under contract by  
Center for Social Welfare Research & Assessment  
of the  
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## **INTRODUCTION**

In October 2007, partnering with the Bureau of Long Term Care and Family Services, Center staff again started the process of assessing the experience and satisfaction of participants in the three distinct waiver populations of the Community Long Term Care program (CLTC).

Based upon consultation with State CLTC staff, a preliminary instrument was developed. CLTC staff in the Area 4 office provided input and testing. The decision was made to replicate the 2007 survey, modifying as necessary, and adding questions to examine additional areas of interest. From these efforts a final sixty item instrument was constructed [Appendix A]. As many questions as possible were pre-coded to facilitate data collection and analysis. Minor modifications were made for the Ventilator Waiver [Appendix B]. As we anticipated substantial effort in securing responses from the HIV Waiver population, the instrument was modified and open-ended questions were added for additional research. [Appendix C].

## **OBJECTIVES**

The study was designed to explore the nature and extent of CLTC participant experience and satisfaction with the services received from CLTC. Consequently, the instrument included as many issues involved as could be covered with limited contact with participants. Given the potential for limited understanding from a percentage of the participants, the questions had to be relatively straight-forward and to the point.

As survey respondents tend to respond positively to 5-item Likert scales, “satisfaction” was measured on a 9-point scale. To tie-in to another study, we included items on complaints and the process of dealing with them. The role and importance of the case manager was explored through a number of questions, particularly given the recent program changes around case management choice and increased providers. We also searched for validation of the staff’s view of the importance of various services to the participants. Additionally, sections were included to look at paid family caregivers, and the impact of isolation upon participants.

## **SAMPLING**

Because the active population size in each waiver is dynamic, the populations were sampled as they were on December 31, 2007. Based upon the experiences in 2007, statewide surveys of the three waiver populations were conducted with differing methods. In line with the decision to over-sample all service areas on a three-year rotating basis, five areas were included for valid comparisons to statewide data and examination of results for each service area.

Sample sizes were chosen to guarantee a bound on the error of estimation of no more than  $\pm 4.5\%$  with a 95% confidence interval. Table 1 summarizes the situation.

Table 1

Waiver	Population Size	Method
Community Choice	11,567	Telephone interviews of a <b>statewide</b> random sample of participants
	Telephone interviews of a random sample of participants in:	
	503	Area 6
	435	Area 6A
	651	Area 10
	332	Area 10A
	1018	Area 11
HIV	980	A random sample of participants: 1. Face-to-face interviews in oversample areas 2. Telephone interviews in other areas.
Ventilator Dependent	31	Face-to-face interviews with all participants

## METHODOLOGY

Every Community Choice participant chosen as part of the sample received a letter of introduction to the survey from Sam Waldrep, Bureau Chief. Additionally, every respondent was to be contacted by their case manager to alert them to the possibility of being called. Over a three week period, interviewers from the Winthrop University **Social & Behavioral Research Lab** called participants until the desired number of interviews was obtained. During the interview, data were entered into the Lab's computerized survey system.

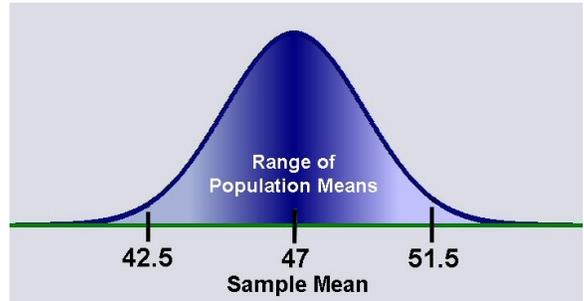
Every HIV and Ventilator Dependent Waiver case manager/nurse consultant was contacted with instructions for participant notification. The case managers then briefed the Center's Director of Operations on their participants – giving information necessary to insure the Research Assistant interviewers would be prepared and aware of each participant's individual situation. This both helped the interview process, as well as it also assured the case managers that their participants would be respected. participant interviews were arranged by telephone – including time and location. For the Face-to-face interviews, under the direction of the Director of Operations and Project Manager, a pair of Research Assistants interviewed each participant. The HIV and Ventilator Dependent telephone interviews were carried out by Research Assistants from the Center for Social Welfare Research and Assessment. Research Assistants entered the data into a Microsoft Access database.

All data for all waivers were analyzed using the SPSS statistical package.

**Sample Parameters**

**Figure 1**

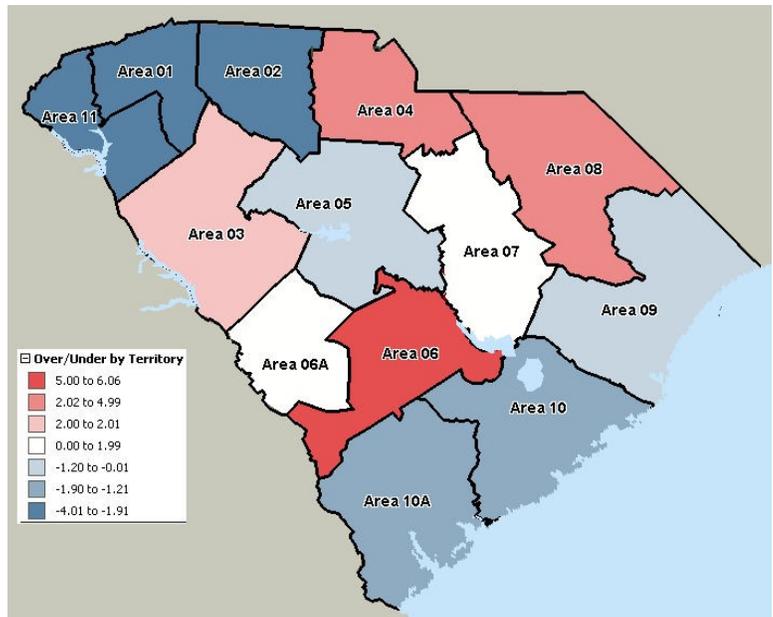
As noted above, sample sizes were chosen to guarantee a bound on the error of estimation of no more than  $\pm 4.5\%$  with a 95% confidence interval. For example, if the sample mean of a variable was 47, the mean of the population would be within the range of  $\pm 4.5\%$ , with values close to 47 being more likely. As shown in Figure 1, the distribution of errors should approximate a normal curve, so values close to the mean are more likely than those farther away. The smaller the interval, the more confidence you can have in the survey results.



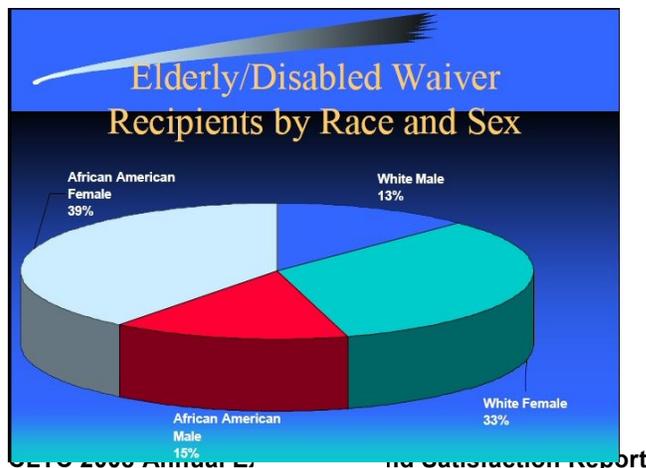
As expected, rather than  $\pm 4.5\%$ , the 423 statewide respondents actually gave a better range —  $\pm 2.1\%$ . The following charts show that the sample is representative of the population of participants in the state.

**Figure 2**

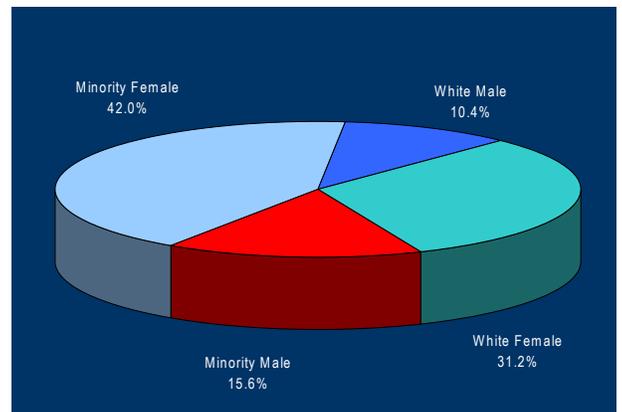
Figure 2 shows the extent to which the sample over or under-represents the areas in the population. As shown, there is less than a  $\pm 6.1\%$  variation statewide.



The next two charts compare CLTC Historical Data (from CLTC website) to Community Choice survey respondents by Race and Sex



**Figure 3**



**Figure 4**

Table 2 shows that the area over-samples were similarly representative – a much better bound on the error of estimation was obtained than the worst-case estimate used to select sample size.

**Table 2**

Population Size	Area	Final Sample Size	Differs From Population
11,567	Statewide	423	± 2.1 %
503	Area 6	92	± 2.7 %
435	Area 6A	131	± 2.8 %
651	Area 10	126	± 3.1 %
332	Area 10A	106	± 3.8 %
1018	Area 11	218	± 3.1 %

It is clear that the samples represent their respective populations extremely well. The implication is that any conclusions reached in the analysis of sample data can confidently be applied to the populations of CLTC Community Choice participants.

**FINDINGS - COMMUNITY CHOICES**

This section is divided into three parts:

1. 2008 specific findings
2. 2008 – 2007 comparisons.
3. Area oversamples.

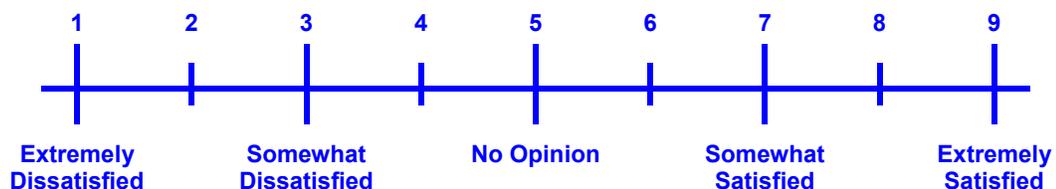
**2008 Specific Findings**

*Satisfaction*

Satisfaction with CLTC services is of paramount importance, and is also a reasonable gross indicator of participant experience with the program. Participant satisfaction is the bottom line for everyone involved with CLTC services; every Support Person, Nurse, Case Manager, Aide, Administrator, and Administrative Assistant. Without each contributing, there can be no ‘satisfaction’ with services.

As mentioned, a nine-point scale was used to measure satisfaction. After a number of questions about the program, participants were asked:

Q17 Now, thinking about your entire experience in the program, generally, are you satisfied or dissatisfied with the CLTC services you receive. Probe: How satisfied or dissatisfied.

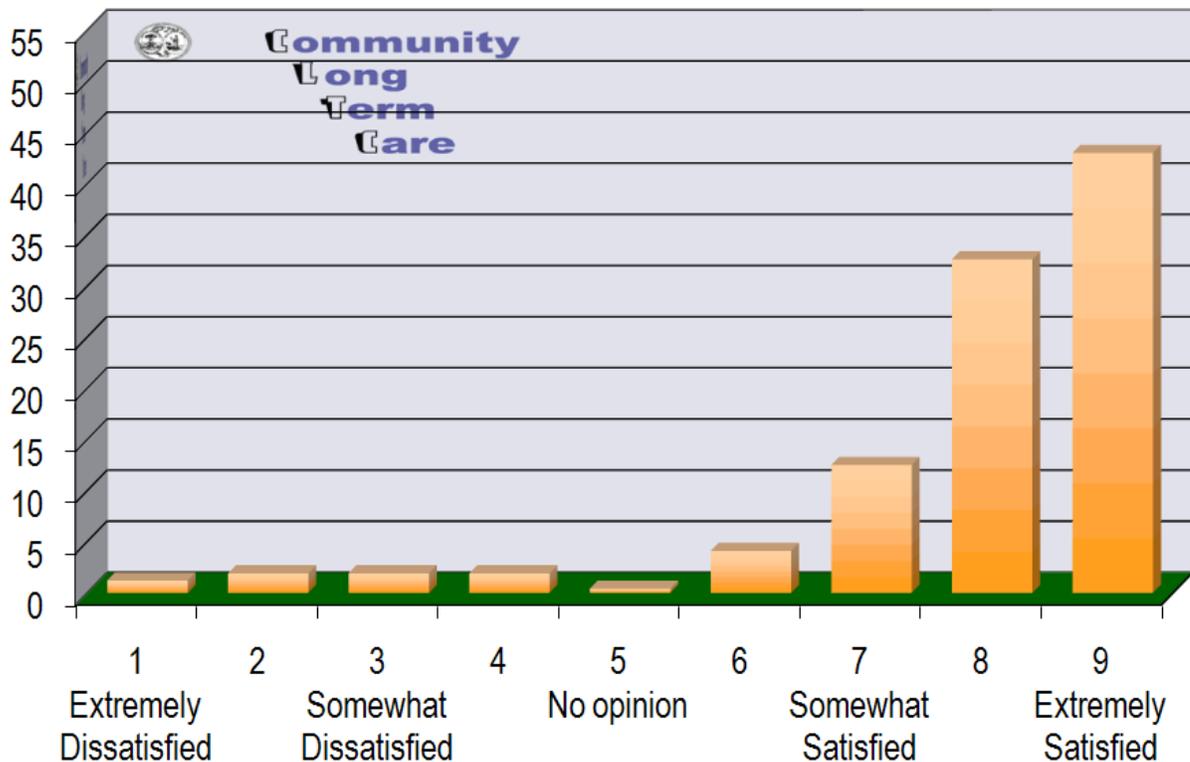


Using this nine-point scale, the expected distribution should have most participants responding between 3 and 8. However, the actual distribution of “satisfaction” was surprisingly different.

As shown in Figure 5, **statewide**, the participants are **overwhelmingly satisfied** with CLTC services. Only **7.3 %** of the respondents indicated satisfaction less than **6**.

**Obviously, something is being done right.**

**Figure 5**



Without doubt, this is the **most significant finding** of this effort. While the study examined many of the services and attitudes that could impact ‘satisfaction,’ their net effect is shown in the answers to this question. It would seem difficult to have a more overall positive rating without being suspect. One interesting finding is that time participating in the program makes no difference to how respondents rated the program, i.e., those in the program for years rated it no differently than those who were new to the program.

**Other Findings**

The 2008 survey included a number of new questions included to explore issues that became evident in the analysis of the 2007 data.

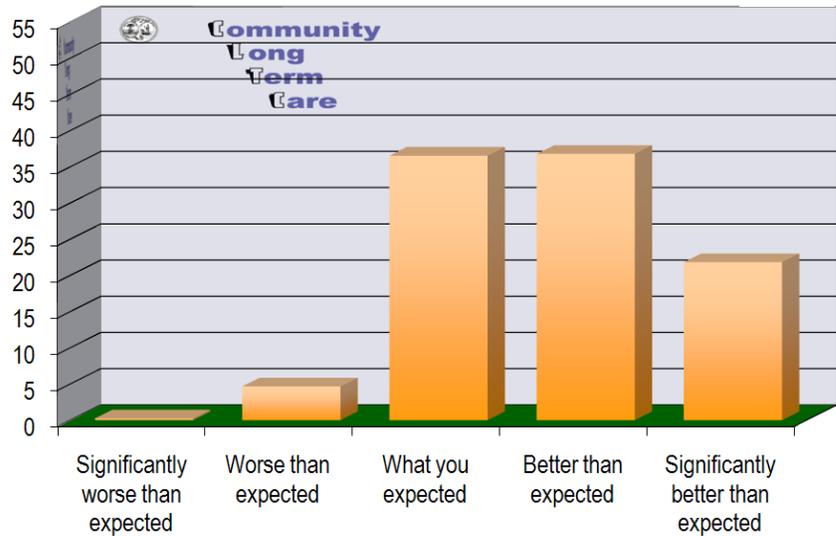
Given a similar positive ‘satisfaction’ response in 2007, one of these questions raised was whether or not participants were responding positively mainly out of a fear of losing benefits.

As noted above, responses to the nine-point scale would be expected to approximate a normal curve. Obviously, it didn't happen.

To test the 'fear of losing benefits' hypothesis, the following question was asked:

“Compared to what you thought CLTC services would be, how would you rate them now.”

Figure 6

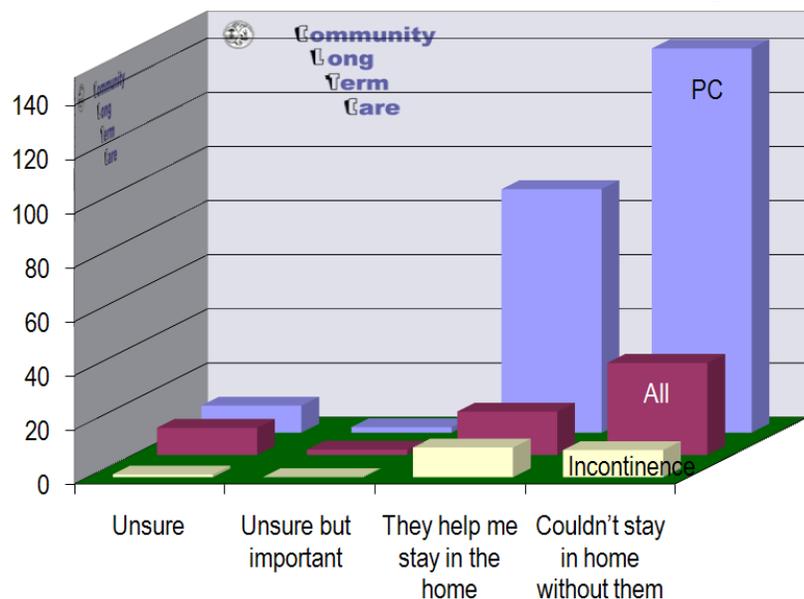


This response pattern in Figure 6 lends credence to the 'satisfaction' findings, as they are much less 'agreeably' positive, and they fit what would be expected. These responses show that respondents **did**

**not seem to be afraid** to rate their program experience as something other than extremely positive. Given that all participants are certified nursing home eligible, it is no surprise to find that for almost all of them, this program which allows them to stay in their home would be a good experience. And, as was the case above, time in program makes no difference to the responses.

In order to examine the CLTC experience, respondents were asked: “Which ONE of these services would you say most helps you stay in your home.” As shown in Figure 7, **Personal Care** services are overwhelming seen by participants as the most important service they receive from CLTC.

Figure 7

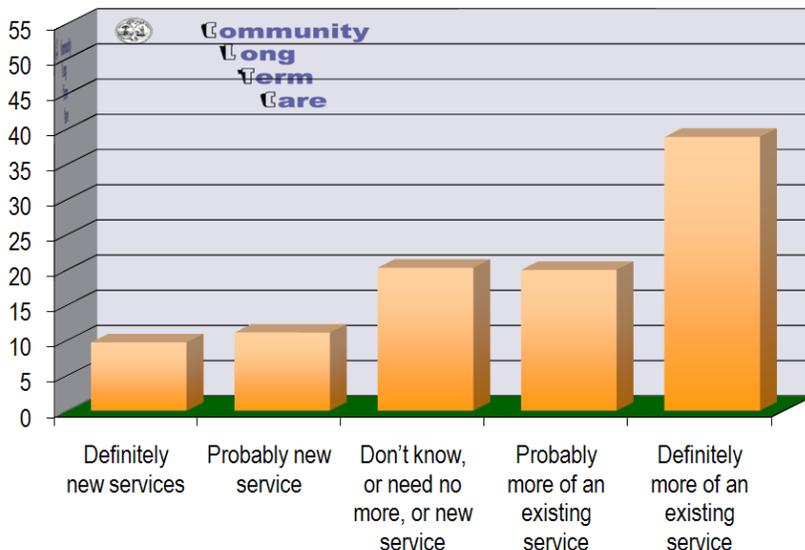


Curiously enough, the fact

that the second most chosen 'service' was "All services" only goes to further the importance of Personal Care services to these participants.

Figure 8

Respondents were asked: “If the CLTC program had additional money to spend on services, based upon your situation, where would the money be better spent – on a new service, or more of a service you now receive.” Perhaps not surprisingly, as Figure 8 shows, the responses favored more of an

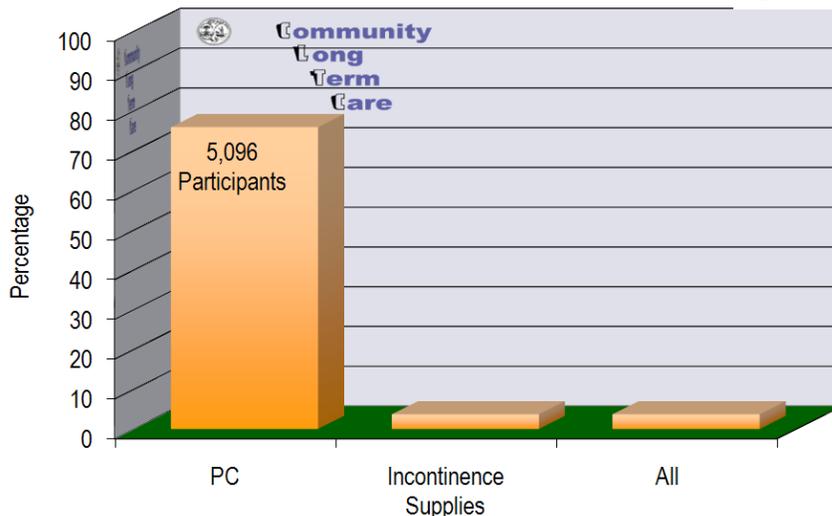


existing service. Once again, as almost 80% of the respondents said they were unsure, or didn't need anything different, or wanted more of an existing service, this could further imply satisfaction with the CLTC program at its foundation, but a desire to enhance or strengthen what currently exists.

The question arises: which existing services do they want more of? There is absolutely no doubt which services they would like more of, as shown in Figure 9. Almost 50% of the total of program participants

Figure 9

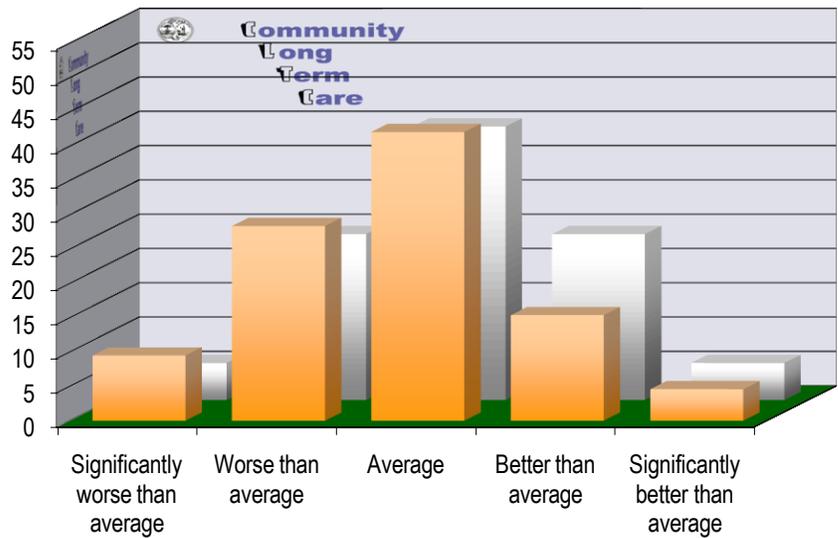
would like more 'Personal Care' services. As respondents overwhelmingly said, the 'Personal Care' services were the most important services keeping them in their homes. As the previous charts highlight, the expressed need for



more personal care hours also relates back to a core principle of CLTC of supplementing family care and support. This begs the question – What level of supplementation is “enough” given the needs of the population?

One somewhat surprising answer was to the question of their health. They were asked: “Compared to others your age, how would you rate your current state of health.” Considering all participants are certified as being nursing home eligible, one could expect that their overall level

of health would be generally below average, and that participants' perceptions would mirror this. Figure 10 shows the results, and they are most surprising. The silver columns show the percentages associated with a normal distribution (the normal or 'bell shaped' curve), which is the



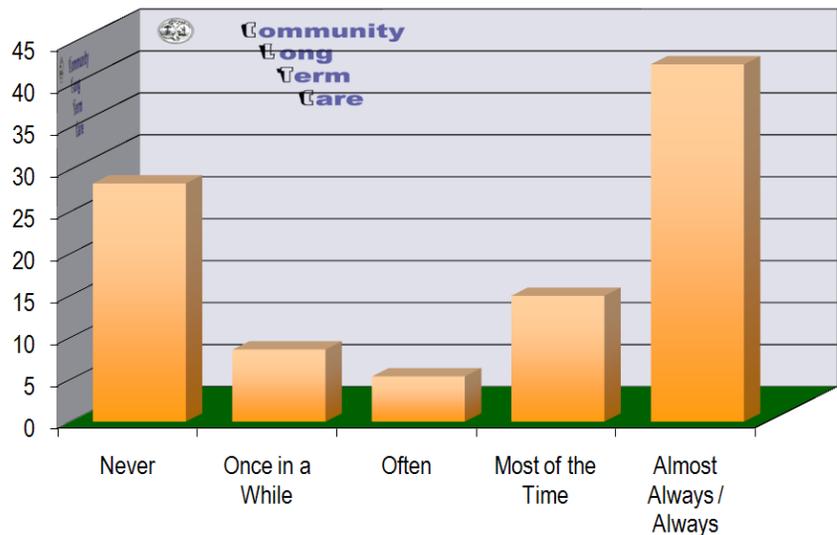
distribution associated with a general population. While the respondents see themselves as only slightly less healthy than their peers, they obviously seem at least mildly optimistic.

### Case Managers

As was done in 2007, the importance of the case manager to the CLTC program and participant satisfaction was examined.

Figure 10

Participants were asked: “Does your case manager tell you about new services or providers being offered.” As participant ‘choice’ in guiding services is an important variable, ‘informed choice’ would be a needed aspect. Figure 11 shows an undesired – almost



bimodal – distribution. The fact that close to 4 out of 10 respondents answered “Never” is disconcerting. Analysis of this relationship showed that it is **not an area specific issue**, in that all areas have approximately the same percentage of ‘Never’ and ‘Once in a While’ responses.

The relationship could have several causes, such as case managers actually not informing participants; participants not remembering they were told. In fact, hearing the question could

have made some participants feel there must be services they hadn't been told about. In any case, these data cannot explain why – but the issue should be further explored.

An important aspect of 'choice' is control over services and service providers. There is a small, but statistically significant, relationship between 'choice' and 'control' and 'satisfaction' with CLTC services – shown in Table 3.

**Table 3**

Issue	Relationship
Do you feel you have control over how your services are provided	<b>Less choice / control – less satisfied with CLTC</b>
How much choice do you feel you had in choosing your Case Manager?	
How much choice do you feel you had in choosing your service providers - other than your Case Manager?	<b>More choice/ control – more satisfied</b>
Do you feel you have control over how your services are provided	<b>Less control – CLTC is worse than I thought it would be</b> <b>More Control – CLTC is better</b>

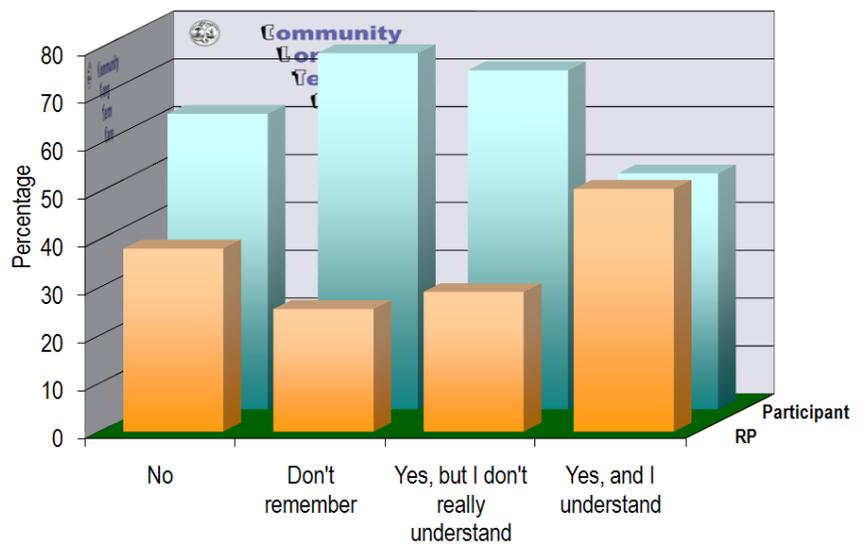
An interesting question in the area of choice – as noted above – is whether or not the participants perceive the options they are presented with, and the manner in which they are offered, as choice. These data provide at least a partial answer. If the

participant was not able to answer the questions, the Responsible Party (RP) was asked to answer the questions – as though they were the participant. Not unexpectedly, one area RPs and participants did answer differently was the area of informed choice.

participants' and RPs'

answers to: “[Did someone explain to you – and did you understand -- how you go about choosing the CLTC people paid to help you?](#)” are shown in Figure 12. The data strongly and significantly suggest that one answer for the question of whether or not the case manager informed them of new services is that, at least some of the time, the participants did not recall. However, a significant number of participants reported having been offered choice but did not understand it. This mirrors, in many ways, what case managers anecdotally report, which is that participants

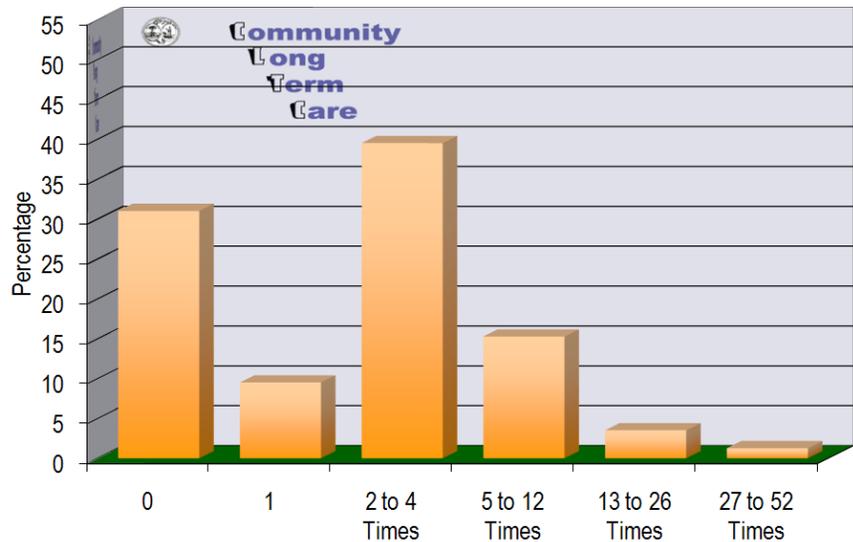
**Figure 11**



are uncomfortable choosing a provider from a list that has options all of which are unknowns to them. Many case managers report that participants ask them to choose for them, even though they are unable to do so. While this is purely speculative, the difference in responses between participants and RPs could be related to the fact that choice and control in care and health-related needs seems to be something that younger generations (such as adult children of the elderly) are more empowered to engage in and, in fact, may have come to expect. This could be both generational as well as due in part to education level. A question was added in 2008 that

asked: “About how many times in the last year have you needed to talk to your case manager.” The responses were wide ranging. Figure 13 shows a summary of the responses. Of special note is that 31% of respondents say they **never** needed to talk to their case manager

Figure 12



within the last year would be equivalent to **3,397 participants**. At the other end of the spectrum are the estimated 137 participants who needed to talk to their case manager at least once every two weeks or more often. Several of the new questions that were included in 2008 could indicate that at least some of the reasons for needing to talk to the case manager are not because of a weakness in the CLTC program, but rather, a characteristic of the participant’s situation.

Several potential situations could be involved. Questions were included to examine three potential explanations. They are, the extent to which the participant:

1. is isolated.
2. feels lonely

Isolation was examined using the following questions:

1. “About how many social activities did you participate in, at or outside your home.”
2. “Other than for medical reasons, how many times last month did you get out of house.”
3. “About how many times did you communicate with others using a telephone, cell phone, email, or Internet.”
4. “About how many people are there who provide you with social support on a weekly basis or more often.”

The data show an extremely isolated population.

Table 4

Activity	Percentage Responding		
	0 Times per Month	1 to 4 Times	5 to 8 Times
Social Activities	46.2	27.5	6.9
Get out of House	31.7	33.9	12.9
One or the other of these	25.7	23.2	17.3
Electronic Communication	18.7	6.3	10.9
At least one of the above	6.5	5.5	8.2
Social Support	No One	1 Person	2 People
People providing weekly support	4.9	15.8	20.4

As can be seen, electronic communication (telephone, email, Internet) is the only activity preventing many of these participants from being totally alone. More than 1 in 4 has no social activity or time out of the house a week, and 50% have less than one of these a week. Counterbalancing this, many of the participants who have little social or outside activity, do have someone providing weekly social support. Consequently, a very small percentage of participants are totally isolated and have a bleak social life.

The construct of “loneliness” was measured by the shortened ten item version of the UCLA Loneliness Scale, (Russell, 1996) which is generally considered the standard scale for measuring loneliness. Table 5 shows the range of ‘loneliness’ of the participants.

Table 5

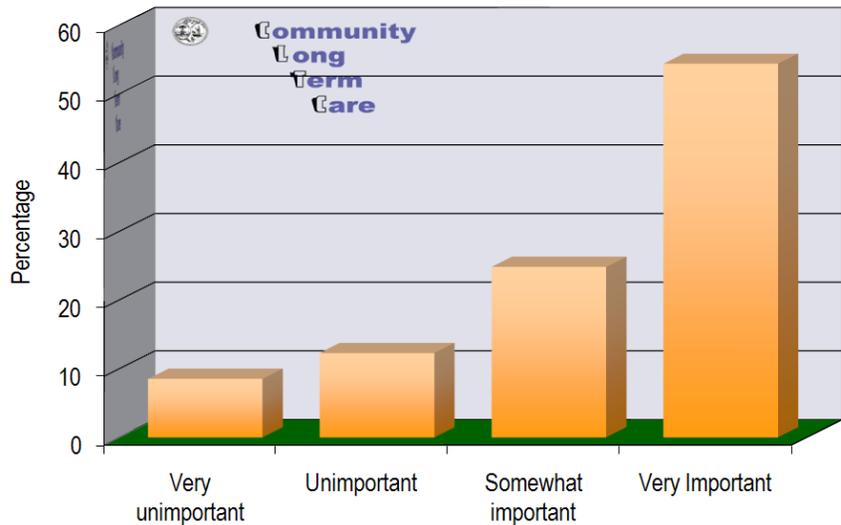
Degree of Loneliness	Percentage Responding		
	Normal Loneliness	Above Normal	Severe Loneliness
Degree of Loneliness	29.1	18.5	2.6

While only a small percentage of participants scale as ‘severely lonely,’ this small percentage represents more than 300 CLTC participants. With over 20% of the participants being at least ‘Above Normal’ loneliness, it would seem as though these respondents would welcome any meaningful connection or social contact.

As a test of the idea that their case manager may be that social contact – and as tangential indication of why some participants need to contact their case manager so often, respondents were asked: “How important is your case manager in providing you social support - not just services.”

Figure 13

While the expectation was that the case manager would be a social support provider, the distribution in Figure 14 was unexpected. The clear indication is that with these participants, the case manager fills an important role in their lives.



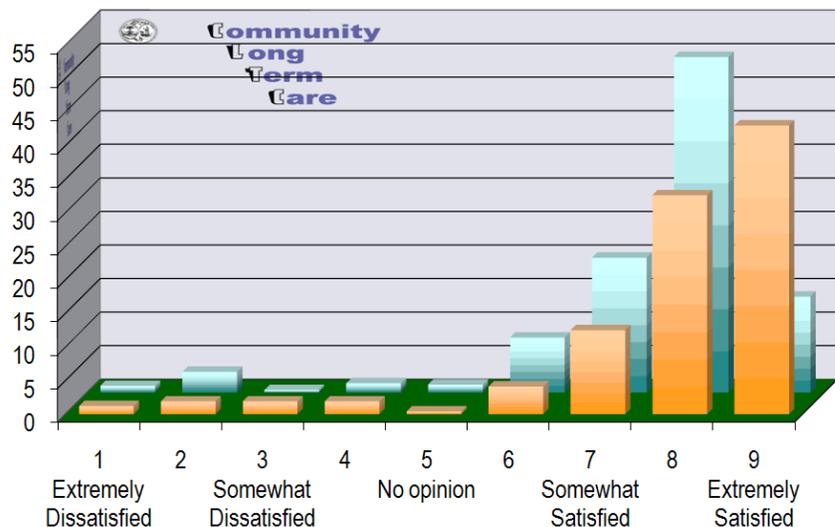
Obviously, case managers will have a difficult balancing act – they must be efficient in providing effective services, while at the same time case managers cannot be hurried and officious, but rather must be aware of their importance in providing social support. For a substantial number of the participants, it would seem that the case manager may be their most important or only means of social support.

### Comparisons to 2007

As shown in Figure 15, the overwhelming level of participant satisfaction with the CLTC program is not an anomaly. It is obvious that the CLTC program being experienced in an extremely positive way, and all CLTC staff are doing an exemplary job.

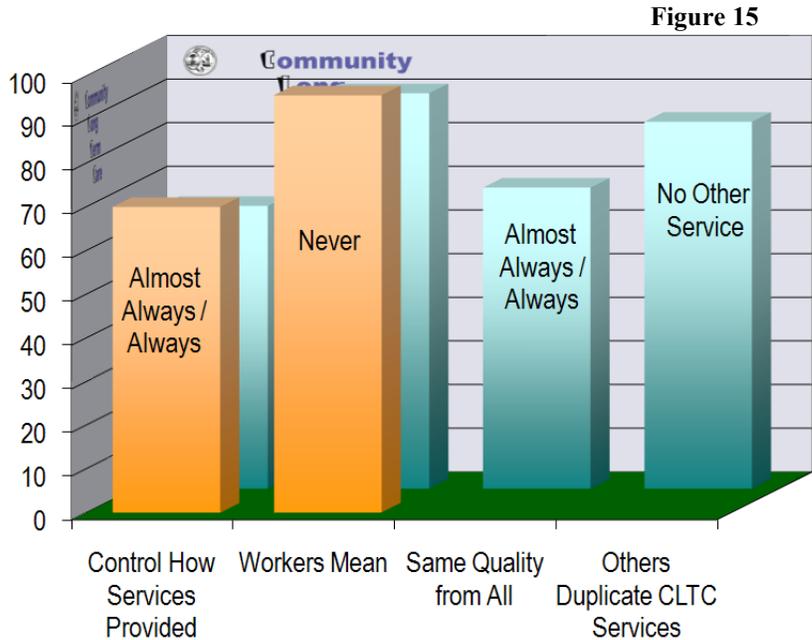
There are several interesting differences between the results from the two years. In 2007 (in blue), 64.3% responded with an ‘8’ or ‘9’. In 2008 (in orange), 75.6% responded ‘8’ or ‘9’. In fact, there was a 28% increase in the percentage responding

Figure 14



with a ‘9’. In sum, the overall level of satisfaction **increased** substantially in 2008. As noted above, it would seem difficult to have a more overall positive rating, that is, CLTC may have reached a ‘satisfaction ceiling.’

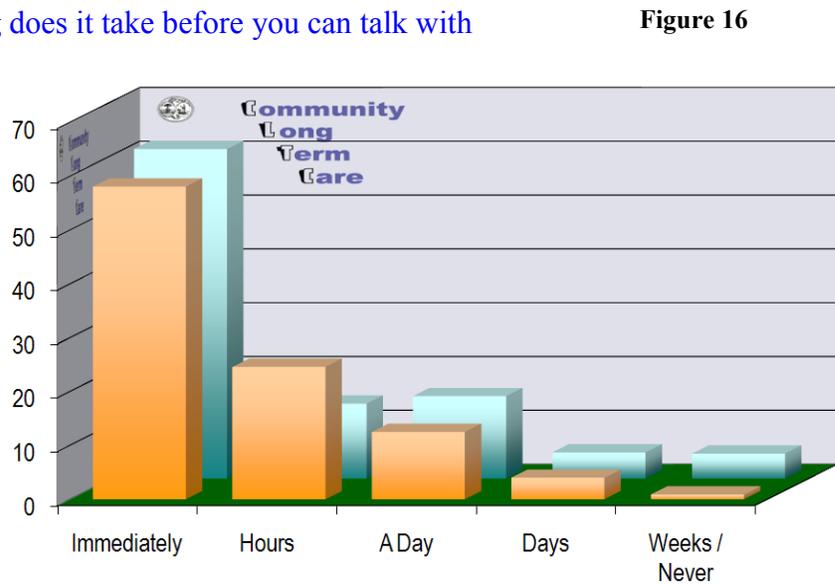
Figure 16 shows a comparison between two variables asked in both 2007 and 2008. As there is no substantial difference between the percentages for the two years, this gives confidence that there would probably be no significant difference in consistency of services or duplication of services in 2008.



There were two measures of case manager responsiveness asked in both years. The answers show a consistent pattern – across questions and years.

The responses to the question “When you need to talk with your case manager, generally, how long does it take before you can talk with him/her?” are as excellent

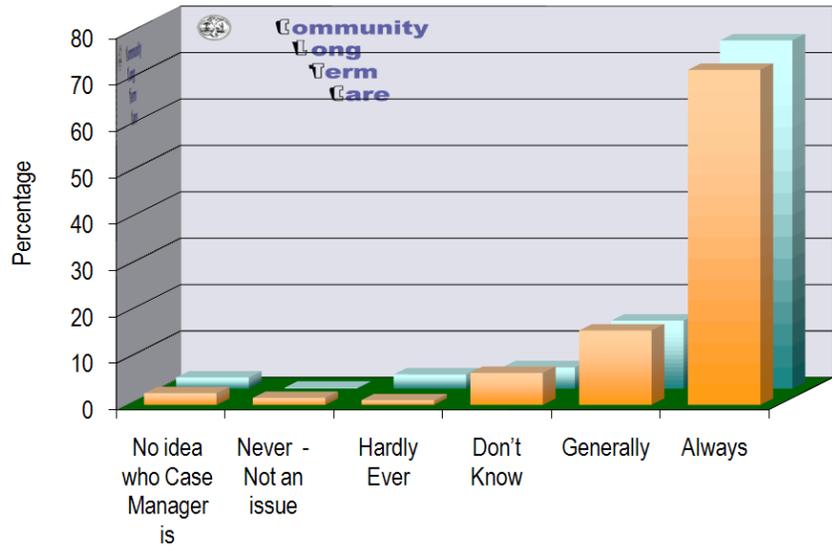
in 2008 as they were the year before. It would appear that case managers are incredibly available to their participants, and, more importantly, the participants perceive that case managers are readily available. Both are positive factors in participant experience.



The second case manager issue of interest is “How often do you feel your case manager listens to you and responds to your concerns and needs?”

Figure 17

Ideally, a case manager should always do so. Figure 18 show just how consistently the participants view their case managers as being responsive. The fact that in both years a small percentage of the

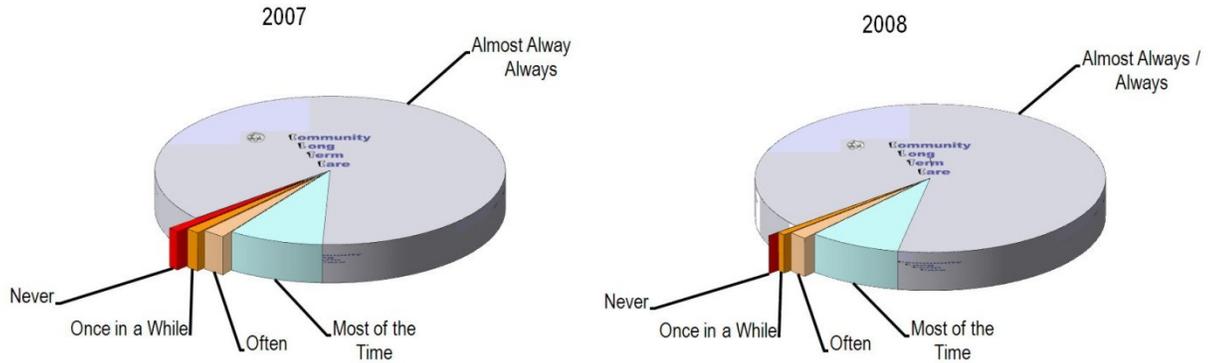


respondents have ‘no idea who their case manager is’ shows that this is a system artifact, unrelated to case managers. Not knowing their case manager seems a normal result of case manager turnover and when in that process the participant was interviewed. The peculiar fact is that greater than 70% of the participants continue to perceive their case manager in an almost saintly manner. Case Manager training and supervision should definitely continue its current approach.

There is a relatively strong, statistically significant – but not perfect - relationship between a case manager’s listening and responding and participant “satisfaction.” That is, respondents who felt that their case manager did listen and respond were more likely to be satisfied with CLTC services. In short, case managers – as the focal point of CLTC services – are again confirmed as “**the**” touchstone for service satisfaction.

Participants continue to feel as though they are treated with respect and dignity. As shown in Figure 19, if anything, while the differences are not significant, participants perceive the CLTC people paid to provide them services as doing even a better job in 2008.

**Figure 18**



The findings consistently show participants’ satisfaction with CLTC – staff, programs and services. As CLTC staff members were aware of the results from the 2007 survey, where many were pleasantly surprised to see that participants overwhelmingly valued their services, it seems as though every staff member made a consistent effort to do even better this year – and it shows.

**General Themes**

Several questions elicited open-ended responses. Center Research Assistants examined the responses and found the following common themes.

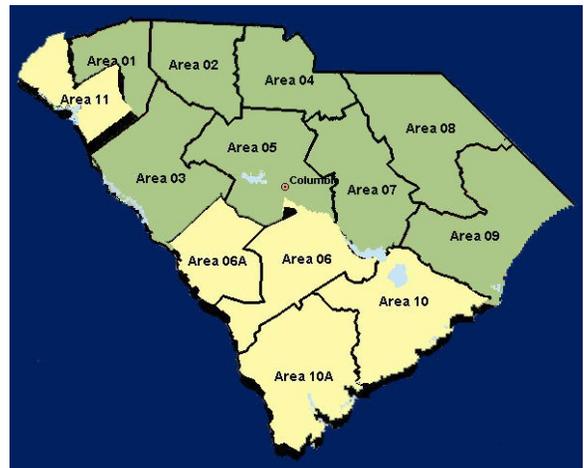
Question	Most Common Themes	Number Responding
Do you think there is a service you do not receive that will help you stay in your home longer or help you have a better life.	More Aid Hours/Daycare Night/Weekend Hours Physical Therapy Transportation Services	14 11 10 8
Why not share this need with case manager.	Did not know about Services Available Case Manager Issue	10 8

## Area Oversamples

### Satisfaction

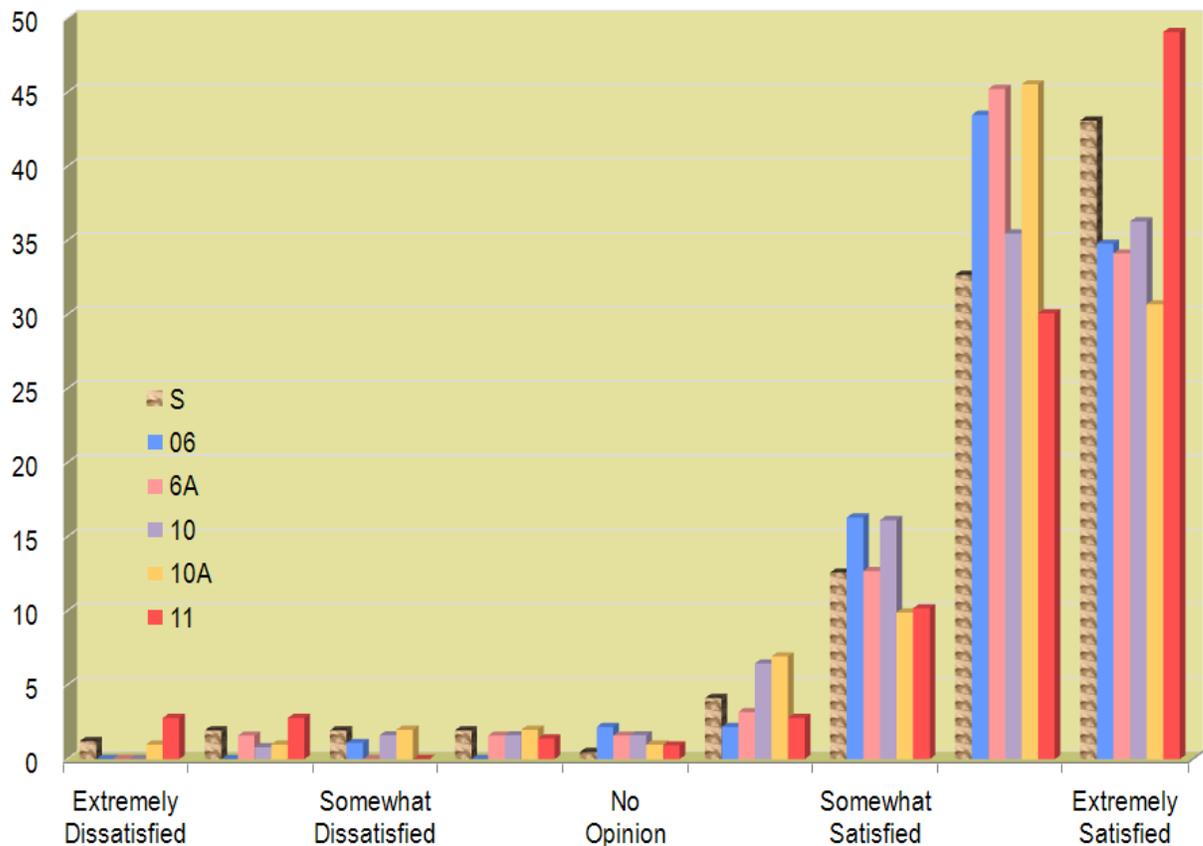
Figure 19

The five Areas that were oversampled in 2008 are shown in Figure 20. They obviously differ in geography and demographics – from each other and from the state as a whole. They contain just over 25% of the CLTC participants. This report will examine the level of participant satisfaction and compare it to state levels. Also, results will be reported on every question where Areas differ significantly from either the State as a whole or the other oversample Areas.



The most important finding is that on satisfaction with CLTC, the oversample Areas do not differ significantly from the State levels.

Figure 20



Obviously, Areas differ from each other and from the state, but the overall ‘satisfaction’ is not significantly different.

Note that while Area 11 has a somewhat larger percentage of ‘dissatisfied’ participants, this Area also has the highest level of ‘Extremely Satisfied.’ Figure 22 illustrates the ‘non-difference’ quite dramatically. The average level of satisfaction is almost an 8 - out of 9.

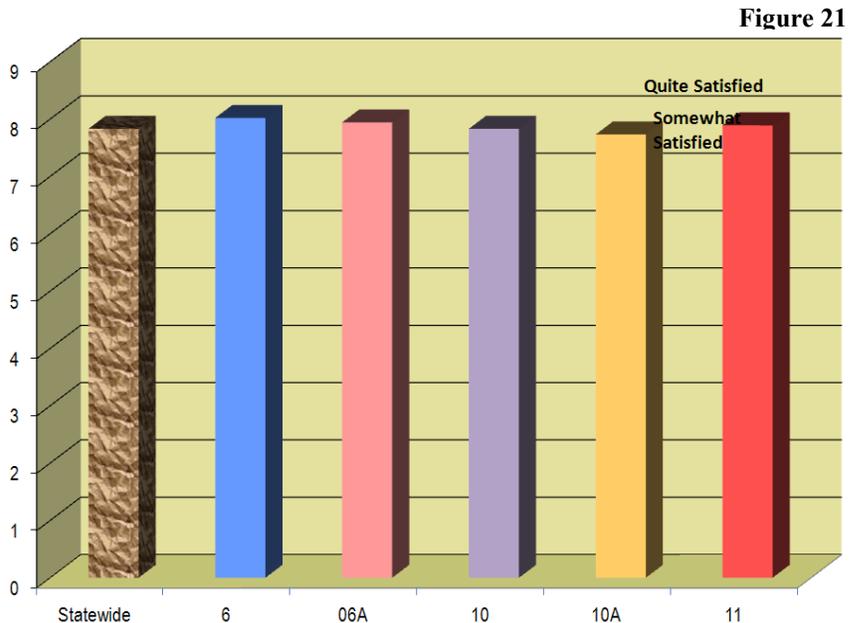


Figure 21

In fact, the average ‘satisfaction’ for all the oversample Areas is equal to or greater than the statewide average.

**Significant Differences**

On a number of factors, the Areas differ significantly and some, quite interestingly:

- From State levels.
- From each other.

Figure 23 shows the percentage of each service received by participants. Not only do the

services received in each Area differ from the statewide levels, they differ considerably between Areas. A tentative reason for these differences is the diversity in geography, resources, and

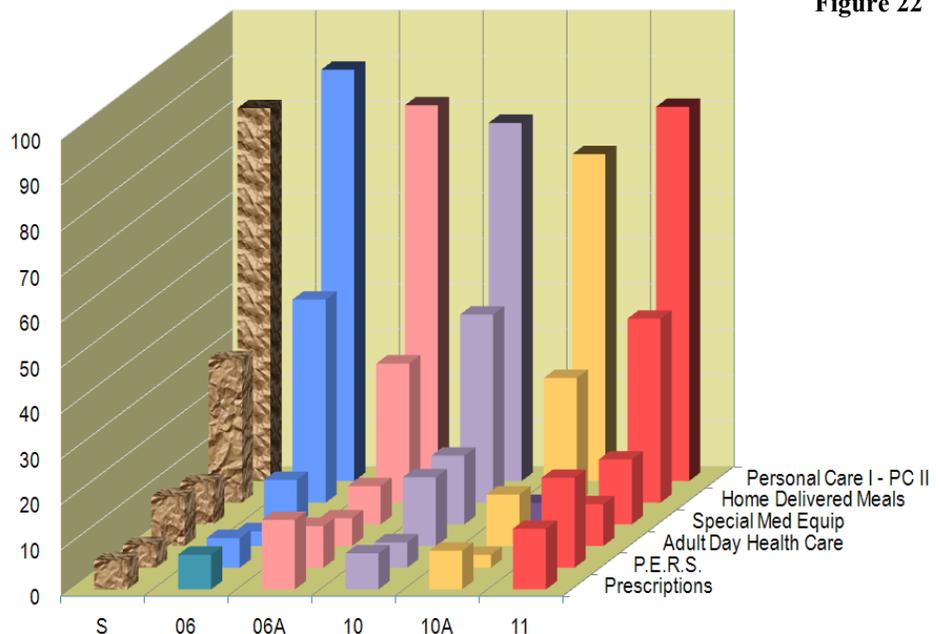


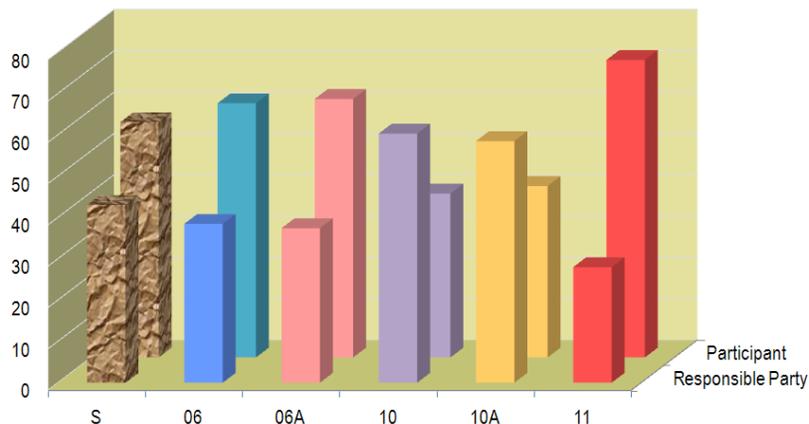
Figure 22

participant demographics. As participants from the individual Areas are all quite satisfied, the

lesson is quite clear. Although CLTC is a very successful program statewide, its success in each Area depends upon how well it is tailored to local conditions.

One of the more interesting ‘local conditions’ was quite unexpected; a difference in who was interviewed. Looking at the distribution in Figure 24, the most immediate difference is that in Areas 10 and 10A. RPs answered the questions at a much higher percentage than statewide or any of the other Areas. Again, a likely explanation is the uniqueness of these Areas.

Figure 23



Respondents were asked: ““Compared to what you thought CLTC services would be, how would you rate them now.”” There were significant differences between the Areas. The respondents from Area 6 rated the experience more negatively than the other areas. This pattern of Area 6 being different from the other Areas – **including Area 6A** – repeats on other questions. There is a likely answer, beyond just gross differences in Areas.

Figure 24

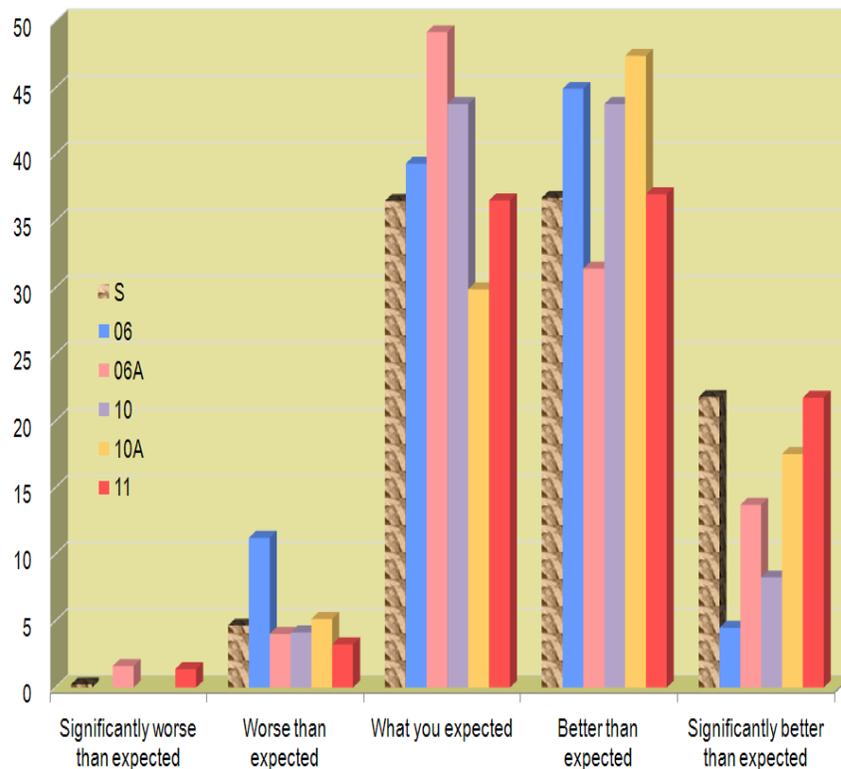


Figure 26 provides an area of inquiry for what makes Area 6 different – on this and several other questions. The distribution of the educational level of participants is most revealing. As might be expected with an older population, most participant’s education ranged from 3<sup>rd</sup> grade to being a High School graduate. However, it is Area 6 that is most interesting. Although Area 6A is a satellite of Area 6, the educational levels are radically different.

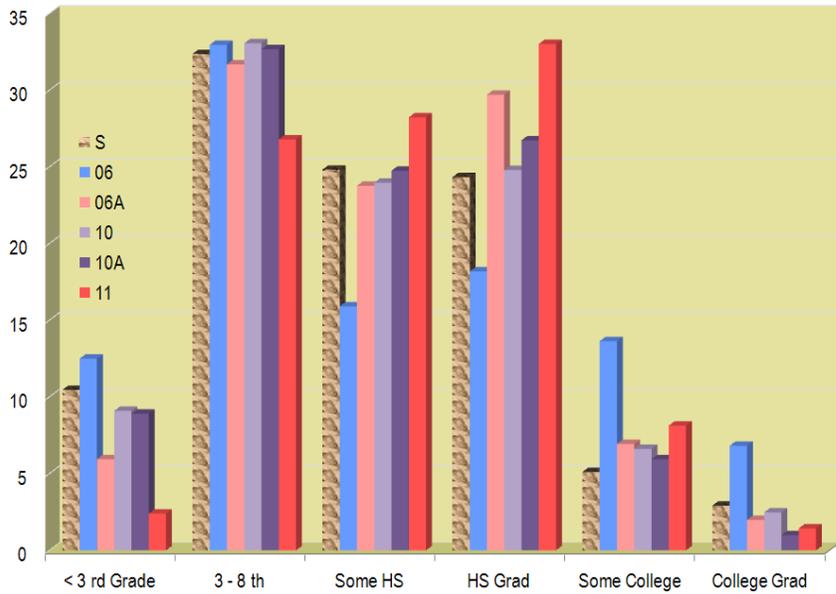


Figure 25

In order to see the differences more clearly, Figure 27 shows statewide and Area 6 alone. It can be seen very clearly that Area 6 participants differ from those statewide. More directly, Area 6 participants represent two distinct populations. That is, Area 6 has greater than expected less educated participants, in addition to having a great many more participants with education levels beyond high school. Does this explain why Area 6 participants have a mixed view of whether or not CLTC met their expectations? The trend exists, but there is not a statistically significant difference between the educational levels. In short, while education may be an important factor, it is too simplistic an explanation for the differences.

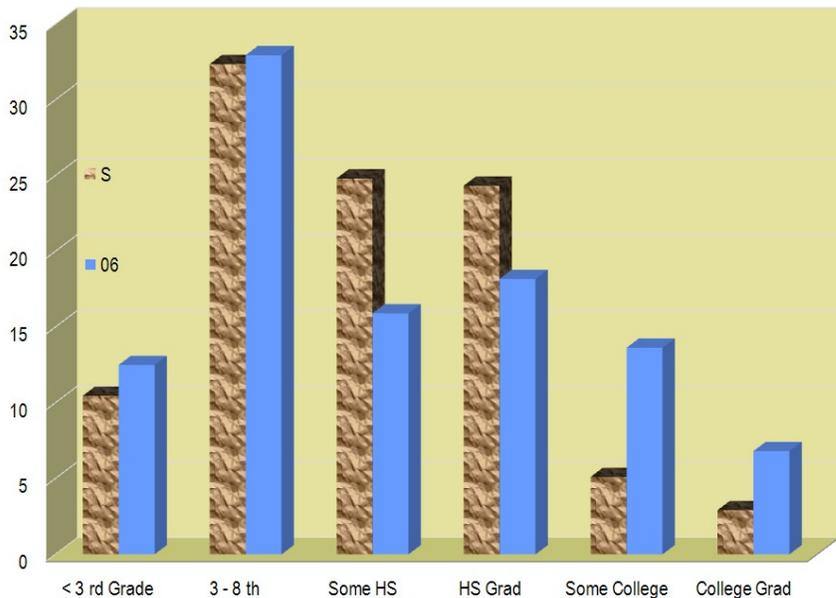


Figure 26

Another significant difference between Areas is shown in Figure 28 – showing how long it takes the participant to talk to her/his case manager when they need to. First, note

that every oversample Area has a lower percentage than statewide on “Immediately.” As ‘statewide’ data includes these Areas, other Areas must be substantially higher on “Immediately.” Again, notice the distributions of Areas 6 and 6A. Most directly, note that they have the

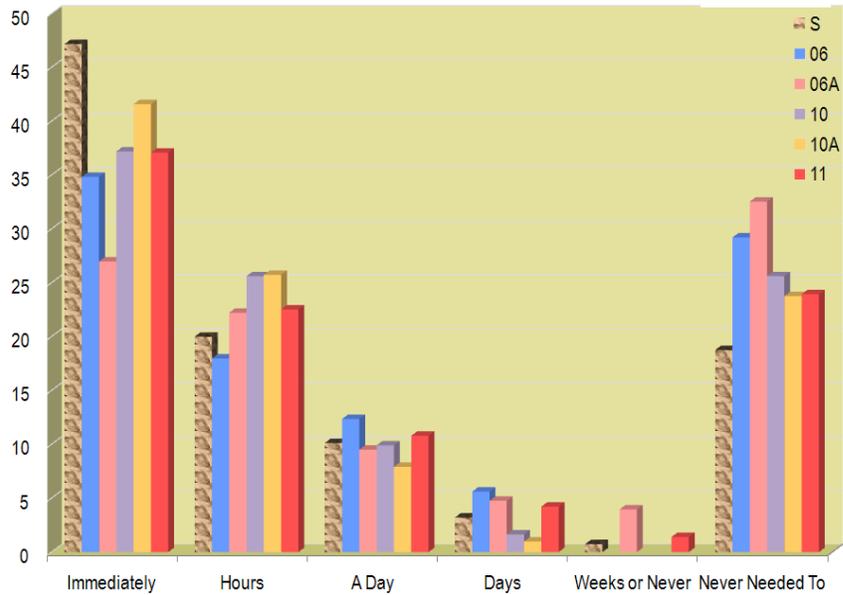


Figure 27

highest percentage of “Never Needed To.” In fact, all these Areas are substantially higher on this response than the statewide level. However, it should also be noted that all the Areas’ case managers show a remarkably quick responsiveness to participants needs.

Continuing the pattern, Figure 29 shows the pattern of answers to the question of how important the case manager is in providing ‘social support’ – not just services.

Quite apparently, in all of the oversample Areas, the case manager seems to be an important social support. Note that Area 6 responses are somewhat bi-modal. Again, the influence of education could be a factor in this distribution. The percentage of participants with a high school

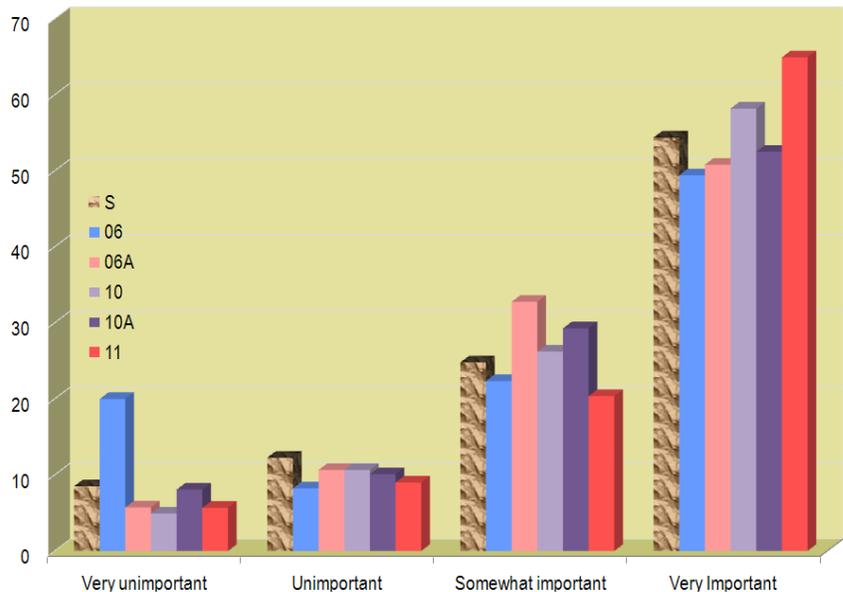


Figure 28

education or more in Area 6 is approximately the same as those who say the case manager is “Very Unimportant” as a provider of social support. It is tempting to assume that education would explain that choice. Yet, that is not the case.

Obviously, the Areas differ on several – not unexpected variables – such as percentage minority and marital status. However, there is one difference that is extremely

difficult to understand. As noted above, all CLTC Community Choices participants are certified as being nursing home eligible. So, the answers to the question: “If you didn’t have these CLTC services, what are the chances that you could still live in your home” are surprising to the point of wondering if a large percentage of the participants fully understand their level of care needs. Note the statewide distribution also seems quixotic.

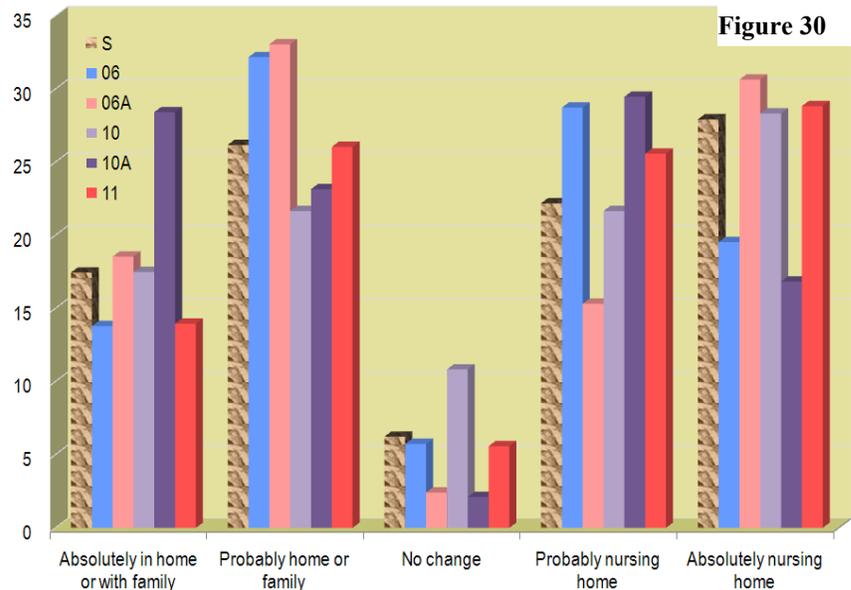
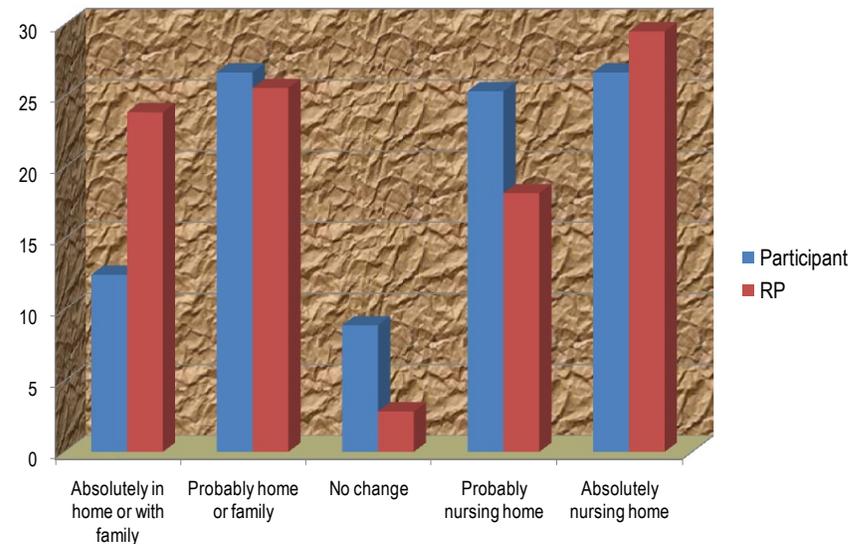


Figure 29  
Figure 30

Two interesting findings relate to this issue of what would participants and their families do if they didn’t have CLTC services. There were significant differences between the answers of the participant and the RP – but **only** statewide and in Area 10.

As shown in Figure 31, RPs are less likely to see ‘No change’, but somewhat more likely to see that the participant could stay at home or with family. Quite obviously, given the shape of the

Statewide - Participant v RP



distribution (almost a 50/50 split in the responses), there are major differences in the perceived ability of the participant to stay home and/or the family’s ability to take care of the participant without these services. It is curious that 12% of the participants think they would ‘Absolutely’ stay at home or with family, while twice as many RPs (24 %) say that the participant could stay

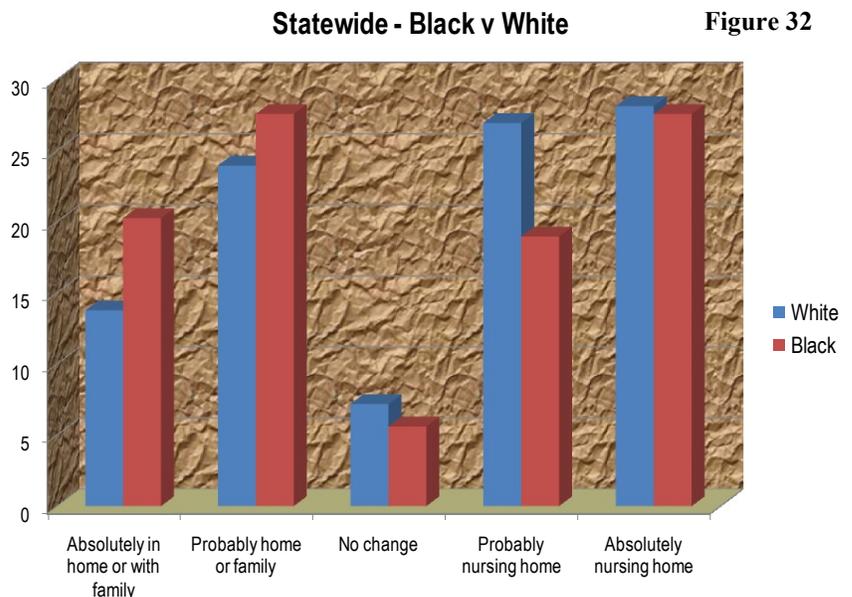
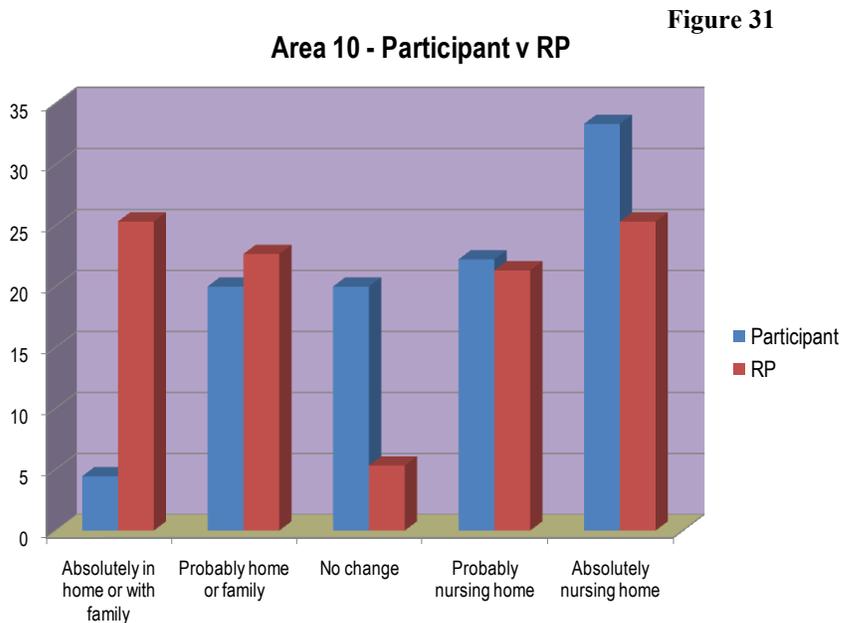
at home or that they could care for the participant. It is important to note that the RPs participating in the survey did so because the participant was determined to not have the capacity to take the survey. This may have been due, in part, to their higher levels of care needs. With this in mind, it is understandable that the RPs, who may also be caregivers, would on both hands see that the participant would have to go to a nursing home without CLTC services AND express a sense of willingness to do whatever it takes to keep their loved one at home.

In Area 10, this difference is even more evident. While virtually the same percentage of RPs think the participant could stay home or with family (25%), only 4% of the participants think so. These data cannot explain this difference, but it seems as though at least a substantial

portion of participants in Area 10 are more aware of their needs, as they see much less chance of staying home, and a substantially greater chance of having to live in a nursing home.

One ‘negative’ finding of this analysis concerns the belief that Black families — with what is often perceived as a cultural expectation to care for ones’ elders within the family or community — with a wider sweep of extended family — should be more supportive of an elderly relative, and less likely to see nursing homes as an option. Figure 33 shows that there was **not a significant difference** between the responses of Black and White

Black and White



respondents. That is, the presumed cultural difference is not supported by these data.

## Conclusion

As was the case in 2007, the results of this survey show a program that is providing needed services to the participants, and the participants are overwhelmingly satisfied with the services they receive. The people associated with CLTC obviously not only do their jobs, but it is undeniable that they are meeting the expected needs of the participant population. One indication is the fact that case managers are seen as providing important social support to the participants, not just services. The commitment to the participants is evident statewide and in the oversampled Areas.

The success of the CLTC program is further shown by the fact that 73.5% of the respondents had **no major complaint** within the last year. In detail, that means that services to more than 8,800 participants were delivered with no complaints. 19.5% had one complaint. 7% of the participants had more than one complaint. Of those who formally complained, 70% had their complaint successfully resolved. In sum, 92% of the participants had either no complaints with services or had their complaints attended to satisfactorily — which is congruent with the 92.5% of respondents who indicated they were satisfied with CLTC services.

## FINDINGS: HIV WAIVER

### Sample and Interviewing

As noted in the methodology overview, data from the population of HIV Waiver participants were gathered in two ways. Table 6 summarizes the methods and sample representativeness.

**Table 6**

Waiver	Population Size	Method	Sample Size	Confidence Interval
HIV	980	A random sample of participants: 1. Face-to-face interviews in oversample areas 2. Telephone interviews in other areas.	186 60 126	$\pm 2.8\%$ $\pm 3.3\%$ $\pm 3.8\%$

**Figure 33**

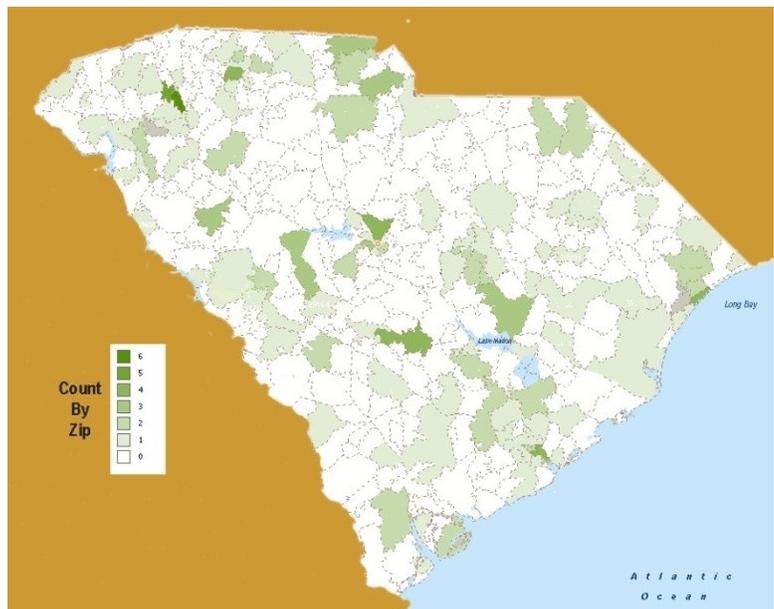
Figure 34 shows the statewide distribution of participants in the sample. As would be expected, given the small confidence interval, it closely mirrors the distribution HIV Waiver participants in the state.

Given the size of the geographic area to be covered, we tested the efficacy of telephone interviewing with this population. Previous experience with telephone interviewing for health studies lead Center researchers to believe that telephone interviews could be used for the HIV Waiver population.

There were differences between the responses gained between telephone and face-to-face — **with apparent support for telephone as a preferred method**. The median length of the Face-to-face interview was 43.5 minutes, and of the Telephone, 31.0 minutes.

Table 7 shows the results on questions where there were significant differences between the two methods.

Table 7 shows the results on questions where there were significant differences between the two methods.



**Table 7**

Question	Result
Other than for medical reasons, how many times last month did you get out of house.	Face-to-face say they get out more.
About how many people are there who provide you with social support on a weekly basis or more often.	Face-to-face say they have more.
Did you or someone in your family formally complain to someone in CLTC about a major complaint.	Face-to-face much more likely to say the 'Couldn't answer'. Telephone much more likely to say they complained and nothing came of it.
How often do you feel lack companionship.	Telephone more likely to say they do.

It seems as though the 'remoteness' of the telephone contact encouraged HIV Waiver participants to more freely respond to questions about loneliness and isolation, and to be willing to disclose problems with the program. The writings of Georg Simmel on "the stranger" touch on this, particularly: "... [the stranger who leaves] often receives the most surprising openness --confidences which sometimes have the character of a confessional and which would be carefully withheld from a more closely related person." (From Kurt Wolff (Trans.) *The Sociology of Georg Simmel*. New York: Free Press, 1950, p. 402)

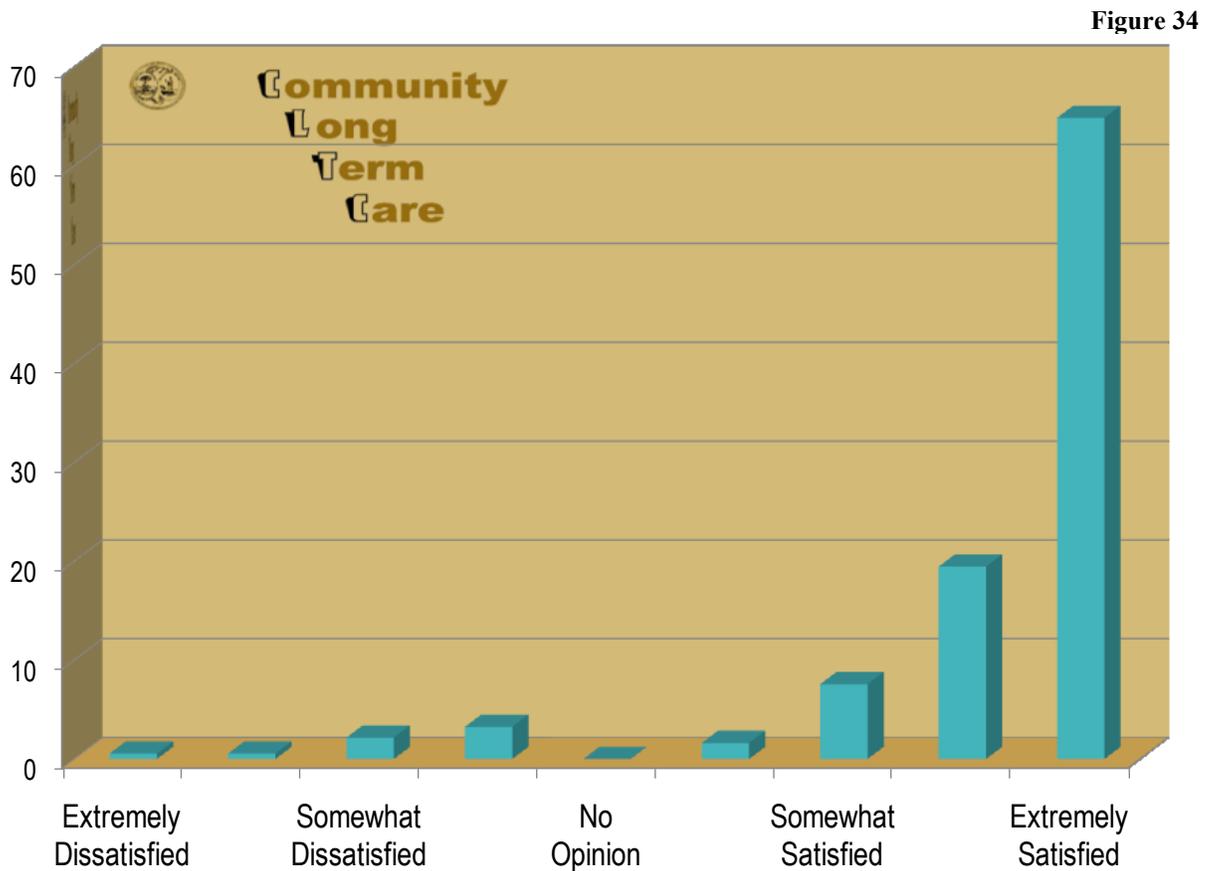
Demographic statistics are shown in Table 8.

**Table 8**

Statistic	Value		Comment
Respondent	96% were participants		Significantly different from Community Choice
Age	Range from <20 (1.1%) to >70 (1.2%)		Median = 48, but only 14% are < 40
Marital status	Married	14 %	42% are or have been married
	Widowed	4 %	
	Divorced/Separated	24 %	
	Single	58 %	
Race	Black	73%	Compared to Community Choice <ul style="list-style-type: none"> <li>• 20 % higher Black participants</li> <li>• Female / Male percents are reversed</li> </ul>
	White	27%	
Sex	Female	31 %	
	Male	70 %	
Education	High School or more.	63 %	As would be expected, HIV participants are younger, and they are more educated than Community Choice participants
	> High School	26 %	

## Satisfaction

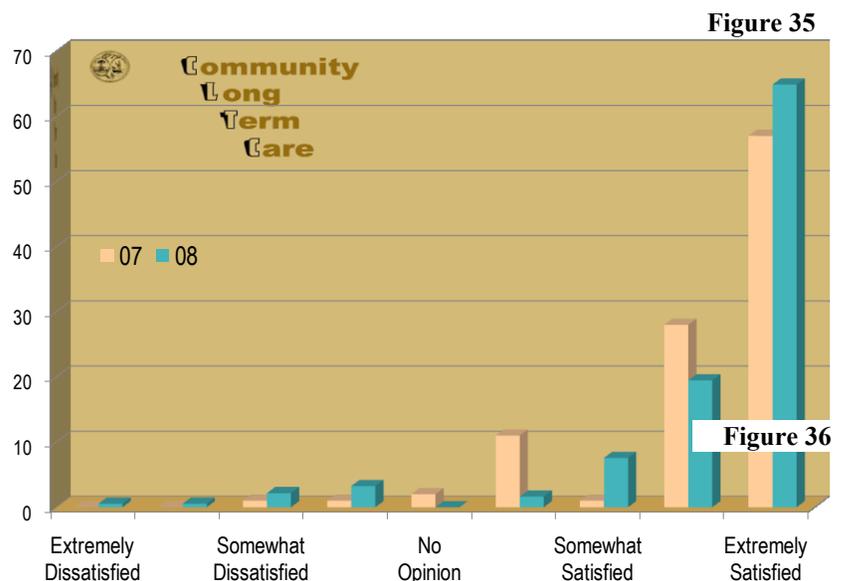
As can be seen in Figure 35, HIV Waiver participants are overwhelmingly satisfied with the CLTC program.



Again, obviously, something is being done right.

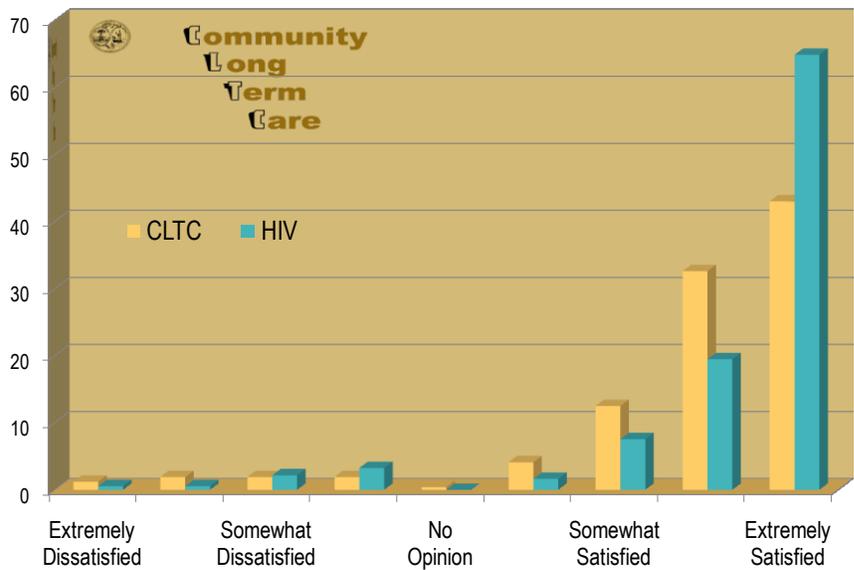
As can be seen in Figure 36, HIV Waiver participants are even more satisfied in 2008 with the program than in 2007.

In fact, it is difficult to imagine these respondents being any more satisfied. As the responses between the face-to-face and the telephone respondents are not significantly different, credibility must be given to this level of satisfaction.



**Figure 36**

As a comparison, Figure 36 shows the HIV Waiver responses compared to the Community Choice responses. Even more so than the Community Choice Waiver responses, CLTC may have reached a ‘satisfaction ceiling.’



### Other Findings

When asked “Compared to what you thought CLTC services would be, how would you rate them now,” the respondents had no difficulty forming an opinion. As 60% expressed that the services were better than they had expected, two points are clear:

1. Respondents were not just answering positively on ‘Satisfaction’ out of fear of losing services, or wishing to be accommodating to the interviewer.
2. CLTC should aggressively advertise this finding to people newly diagnosed with HIV, as newly diagnosed people often do not seek services.

Figure 37

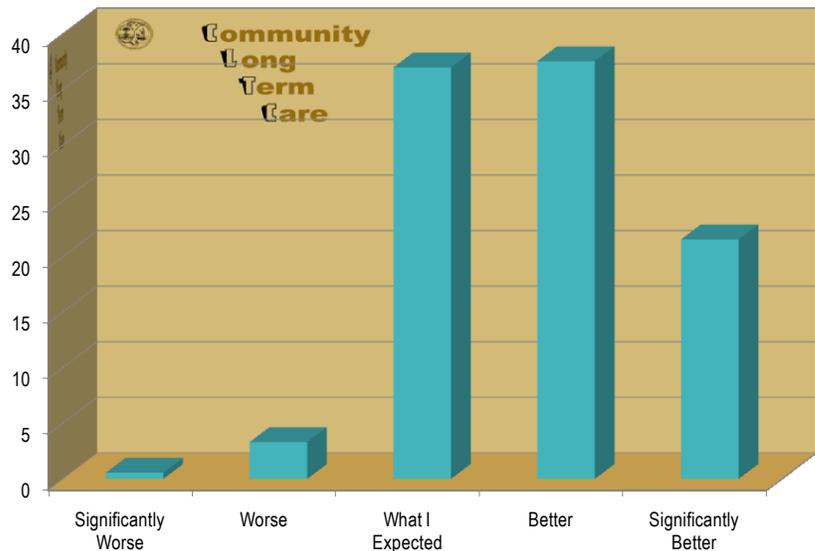
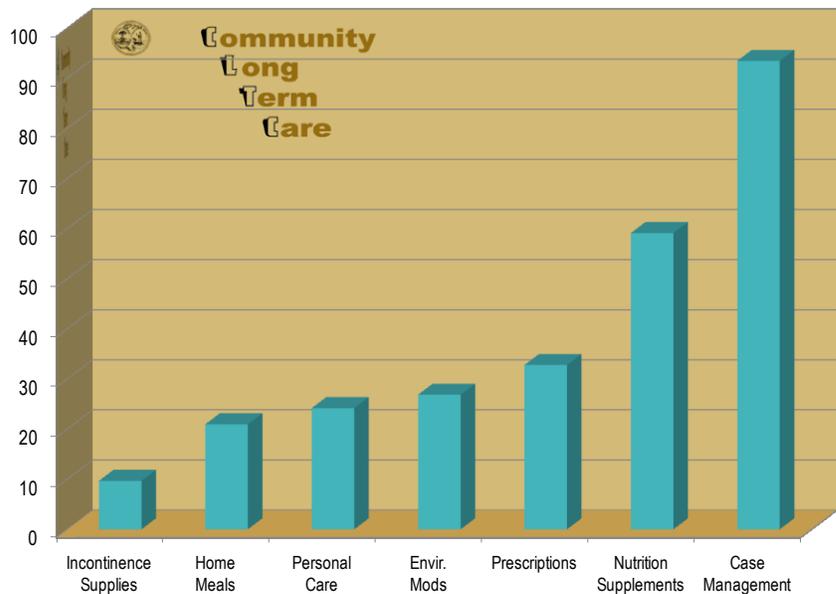


Figure 38

HIV Waiver participants receive varied services — the most received are shown in Figure 39. These data seem slightly incorrect, as all the participants should be receiving ‘Case Management,’ not 90%. However, participants may not immediately perceive case management as

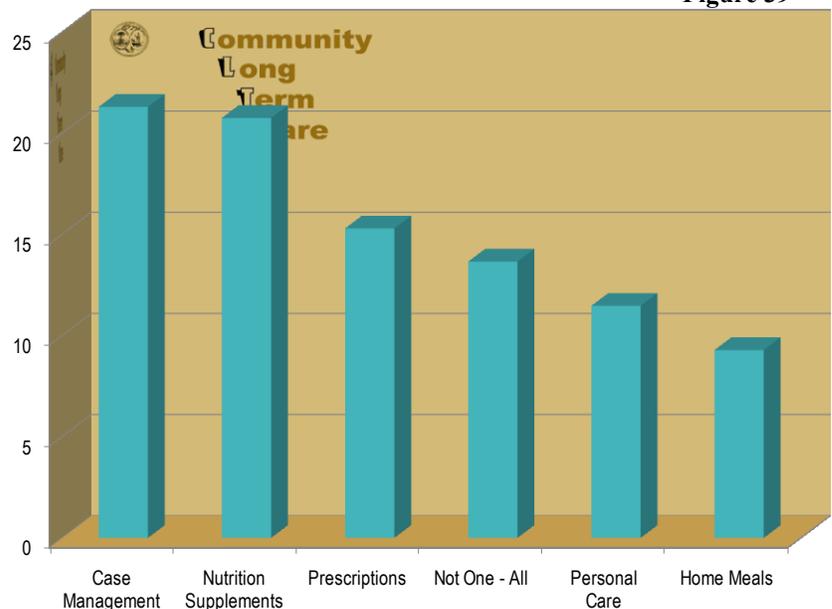


something they “receive”. Certainly, HIV Waiver services are not limited to just medication,

The answer to the question: “Which ONE of these services would you say most helps you stay in your home” is perhaps quite different from what would be expected. Figure 40 shows the top answers.

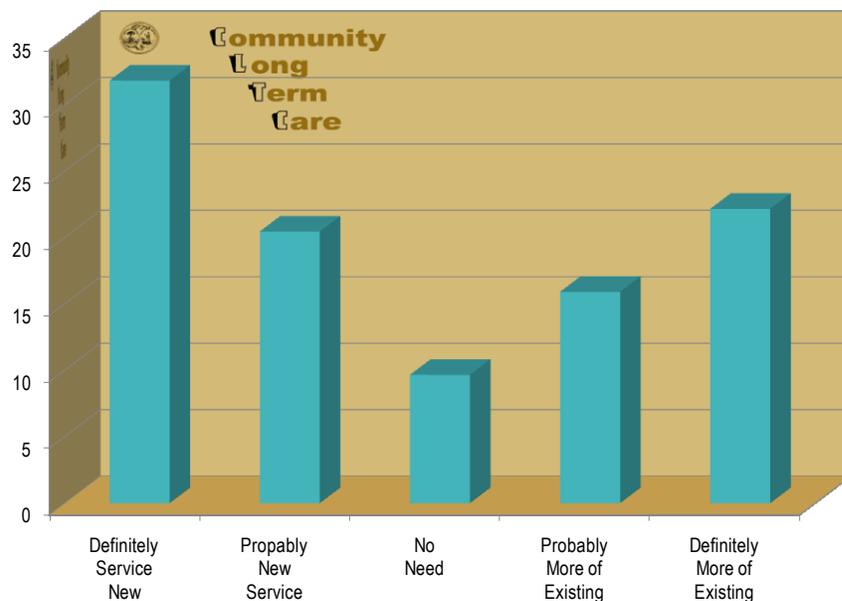
Similar to Community Choice, the case manager shows substantial importance. Respondents did not identify prescriptions as being the most important as might be expected. Home delivered meals and Personal Care could indicate the fragile state of a portion of these participants.

Figure 39



The issue of importance of services was explored by asking “If the CLTC program had additional money to spend on services, based upon your situation, where would the money be better spent – on a new service, or more of a service you now receive.” The answers are not homogeneous, and show that one cannot speak of a ‘typical’ HIV Waiver participant.

In fact, the distribution is not linear, and contrasts with Community Choice where respondents generally wanted more of an existing service, only 38% of these respondents want more of an existing service. The new services desired by 53% of the respondents



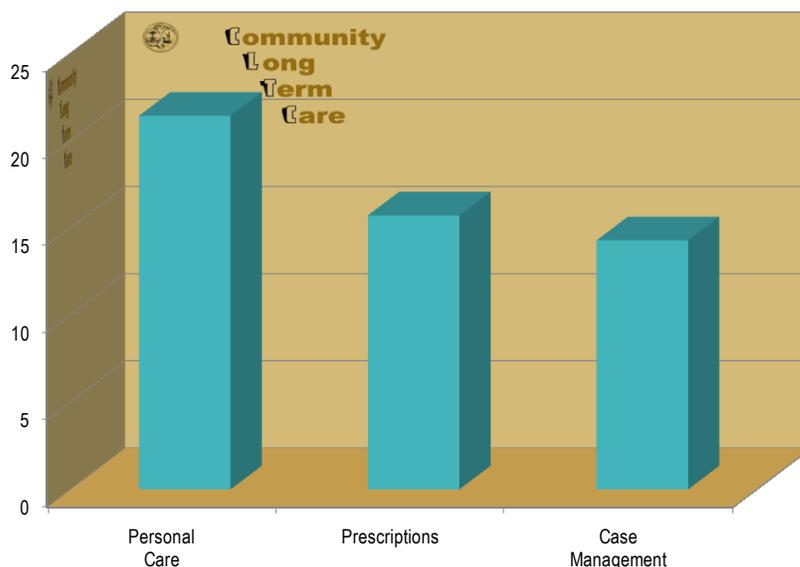
can be inferred from the question: “Do you think there is a service you do not receive that will help you stay out of the hospital longer or help you have a better life.” The top responses are shown in Table 9.

**Table 9**

Service
Financial/Brokering Assistance
Medical/Health/Counseling Services
Transportation/Home Delivery Services
Personal Home Care or Home Repairs/Modifications
Food/Nutritional Supplements

The 38% of the respondents who wanted more of an existing service were asked which service that would be. Interestingly, Figure 41 seems to indicate responses that differ from those given in the “most important service” category. A substantial portion of participants would like more money spent on these services to meet their needs.

**Figure 40**



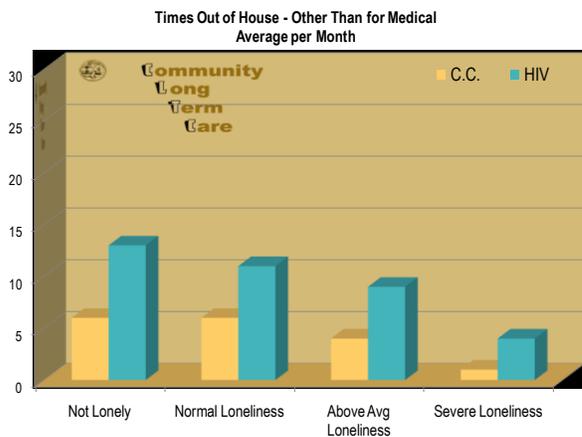
The HIV Waiver participants are quite lonely as shown in Table 10. Of note is the fact that isolation and loneliness are not significantly different between participants in rural verses urban areas.

**Table 10**

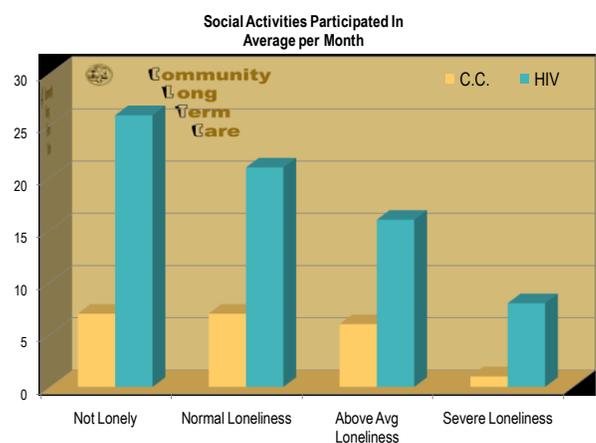
LA Loneliness Scale	Percent of Respondents
Not Lonely	28
Normal Loneliness	30
Above Average Loneliness	33
Severe Loneliness	8

However, there is a substantial difference between the HIV Waiver participants and the Community Choice participants. Figures 42 and 43 show that HIV Waiver participants are **less isolated, yet are lonelier**.

**Figure 41**

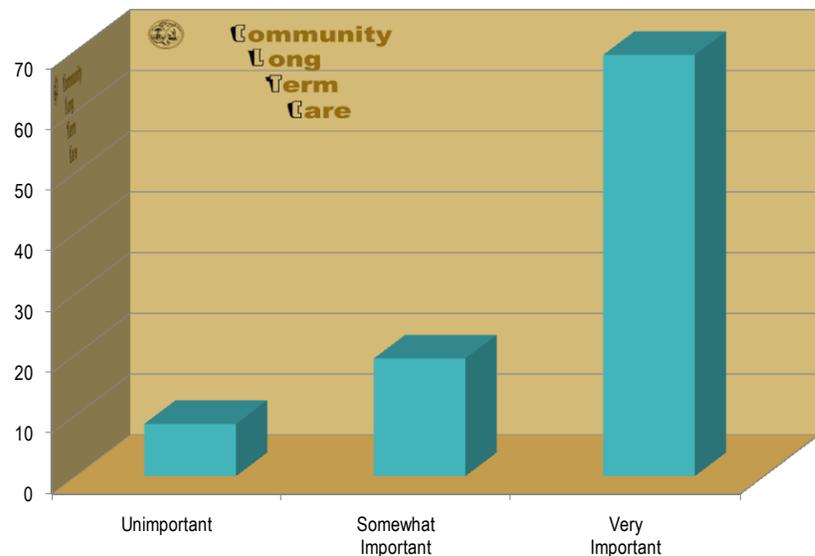


**Figure 42**



Contrary to the views expressed in the past, the case manager is seen as important to these participants, as noted above.

One finding that is becoming increasingly evident is the importance of the case manager in providing ‘**social support**, not just services.’ However, while ‘providing social support’ may not be a paid task, it is of extreme importance. Figure 44 shows just how important.



## **Conclusion**

As was the case in 2007, the results of this survey show that this waiver is providing needed services to the participants, and the participants are overwhelmingly satisfied with the services they receive. The people associated with CLTC obviously not only do their jobs, but it is undeniable that they are meeting the expected needs of the participant population. The participants are quite diverse, with diverse needs. They obviously rely on the program for many services, and would like to see several different new services. As is the case with the Community Choices waiver, participants report that ‘case management’ is important, and further, see their case managers as providing important social support, not just services.

## FINDINGS: VENTILATOR DEPENDENT WAIVER

### Sample and Interviewing

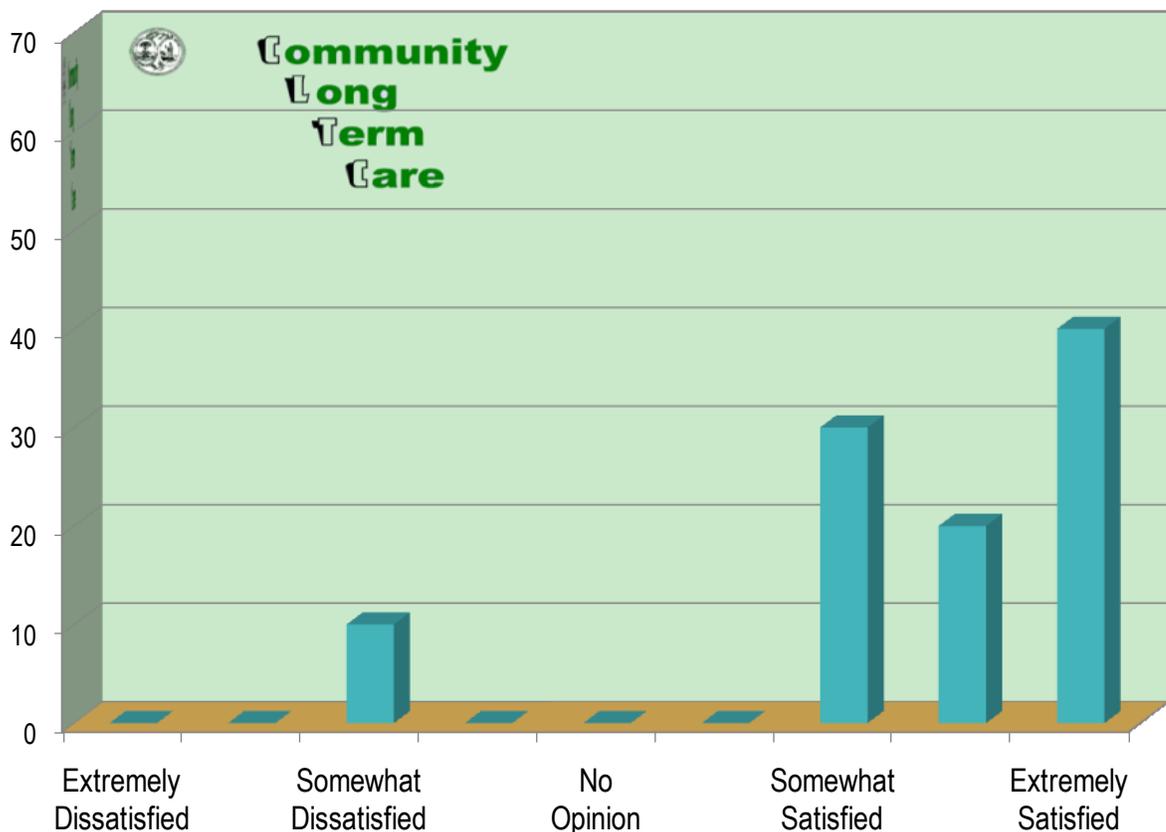
As noted in the methodology overview, data from the population of HIV Waiver participants were gathered by face-to-face interviews with all respondents. However, given the extremely small number of participants in this waiver (31), and with 15 interviews (approximately 50%), only the broadest conclusion can be reached.

### Finding

Caution must be exercised in viewing these findings, strictly because of the small population / sample size. Because of this, all percentages are rounded to the nearest 10%.

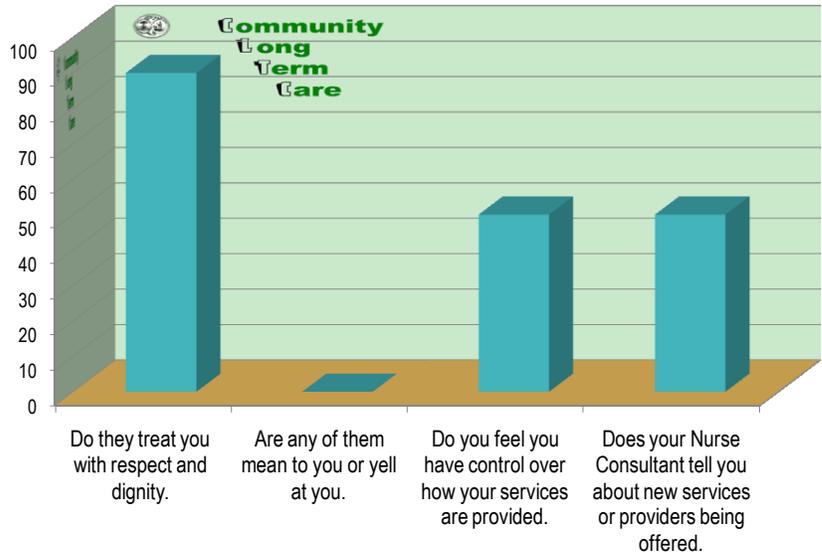
#### Satisfaction

The Ventilator Waiver population is generally satisfied with the CLTC program – 90% are ‘satisfied’.

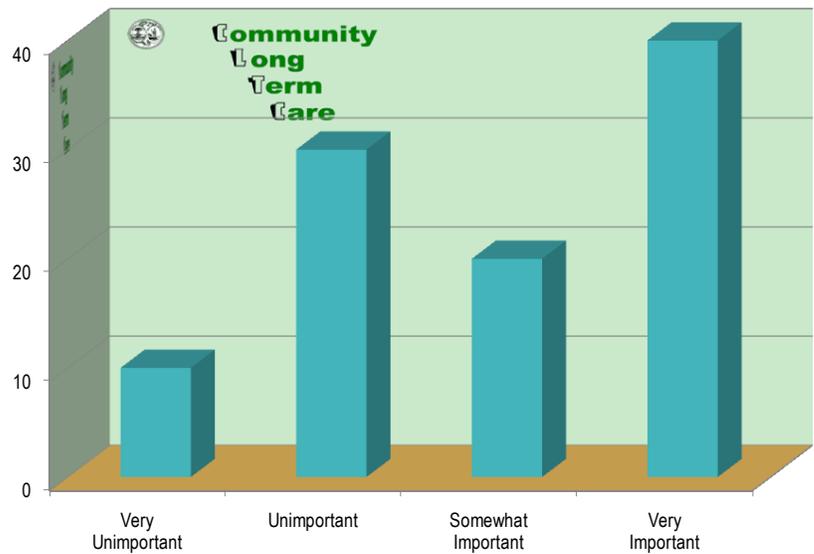


The responses to two additional questions are shown on the next pages. While not trying to make more of these responses that is prudent, the overall impression these answers give is a general satisfaction with the services and people paid to provide those services.

The ‘positive’ responses are shown in this table. In line with the other waivers, CLTC service providers are perceived as treating them respectfully and with dignity. They reported no one treating them meanly. The responses to the remaining two questions are comparable to the answers from the other waiver participants.



An interesting finding is the extent to which participants see the nurse consultant as important to providing social support, not just services. Compared to the other waivers, their perception of the nurse consultant’s social support role is much more limited.



This finding is may be related to differences in the population, the differing role of nurse consultant and case manager, and assuredly to the population size.

### Conclusion

Given available data, this population reports an overall level of satisfaction with the program. The most important finding is that there is no major dissatisfaction showing – which would show, even with the small number of respondents.