

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

For  
South Carolina DHHS  
Bureau of Long Term Care Services  
Sam Waldrep – Bureau Chief

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

Starting in October 2006, Center and Bureau staff 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 previous surveys, previous experience and consultation with State CLTC staff, a preliminary instrument was developed. CLTC staff in Area 4 office provided input and testing. From these efforts a final twenty-five item instrument was constructed [Appendix A]. All the questions 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 next year [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 decision was made to cover 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 generally respond positively to 5-item Likert scales, “satisfaction” was measured on a 9-point scale – to allow for more negative responses. 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 with a number of questions. We also searched for validation of the staff’s view of the importance of various services to the Participants.

## **SAMPLING**

Because the active population size in each waiver is dynamic, the populations were sampled as they were in November 2006. Early in the process, the decision was made by Center staff, and approved by the Bureau, to conduct statewide surveys of the three waiver populations with differing methods. The decision was also made to over-sample all service areas on a three-year rotating basis. Such over-sampling allows 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  $\forall 4.5\%$  with a 95% confidence interval. The table summarizes the situation.

**Table 1**

Waiver	Population Size	Method	Final Sample Size
Community Choice	9,758	Telephone interviews of a <b>statewide</b> random sample of Participants	495
	Telephone interviews of a random Sample of Participants in		
	1,114	Area 1	388
	633	Area 2	297
	659	Area 3	298
HIV/AIDS	1,024	Face-to-face interviews of a random sample of Participants	
Ventilator Dependent	29	Face-to-face interviews with all Participants	29

**METHODOLOGY**

Every Community Choice Participant chosen as part of the sample received a letter of introduction to the survey from Director Waldrep. Additionally, every respondent was contacted by their Case Manager to alert them to the possibility of being called. Over a 3-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 was contacted. 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, and it also assured the Case Managers that their Participants would be respected. Participant interviews were arranged by telephone – including time and location. Under the direction of the Director of Operations, a pair of Research Assistants interviewed each Participant. At the end of each day of interviewing, the Research Assistants entered the data into a Microsoft Access database.

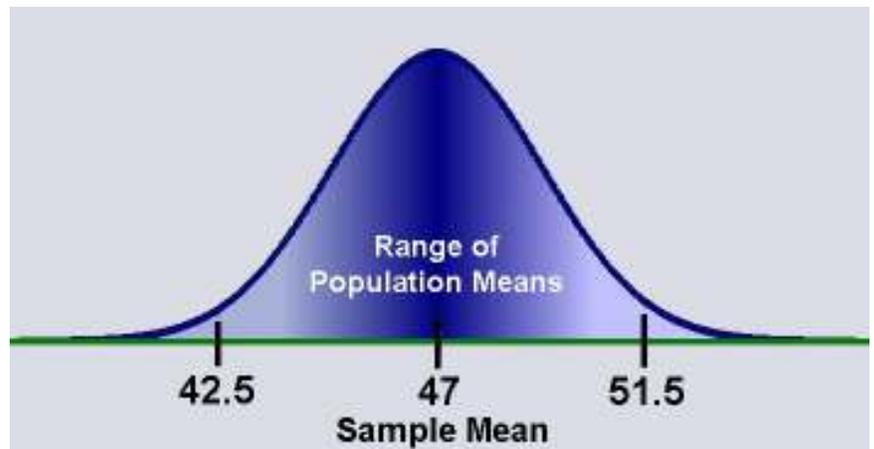
All data for all waivers were analyzed using the SPSS statistical package.

## FINDINGS - COMMUNITY CHOICE

### Sample Parameters

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.

Figure 1



As expected, rather than  $\pm 4.5\%$ , the 495 respondents actually gave a better range —  $\pm 1.8\%$ .

That the sample is representative is clearly shown by the following charts.

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  $\pm 3.1\%$  variation statewide.

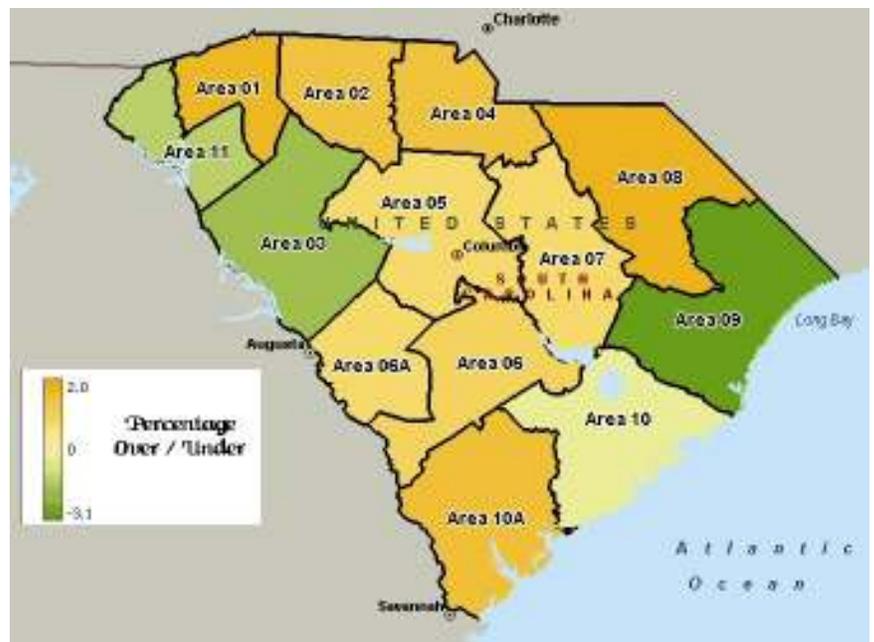


Figure 2

The next two charts compare  
CLTC Historical Data (from CLTC website)

with Community Choice survey Recipients  
by Race and Sex

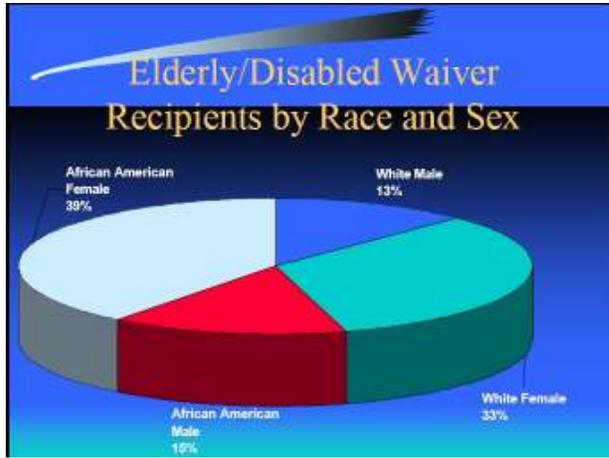


Figure 3

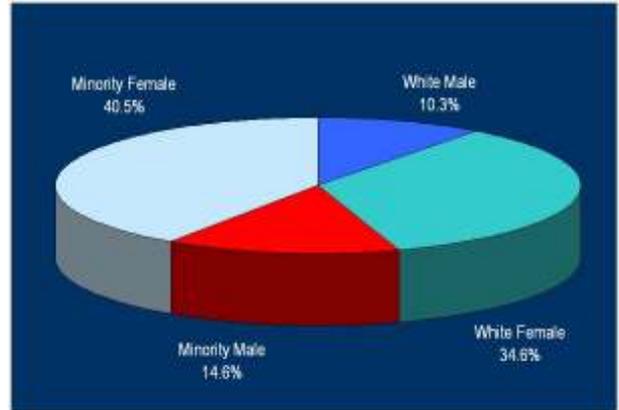


Figure 4

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
9,758	Statewide	495	± 1.8 %
1,114	Area 1	388	± 1.65 %
633	Area 2	297	± 1.85 %
659	Area 3	298	± 2.35 %

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. To reiterate, the survey results are a **valid and reliable measure** of this aspect of the CLTC program.

**Satisfaction**

Satisfaction with CLTC services is of paramount importance, and is also a reasonable gross indicator of Participant experience with the program. 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.

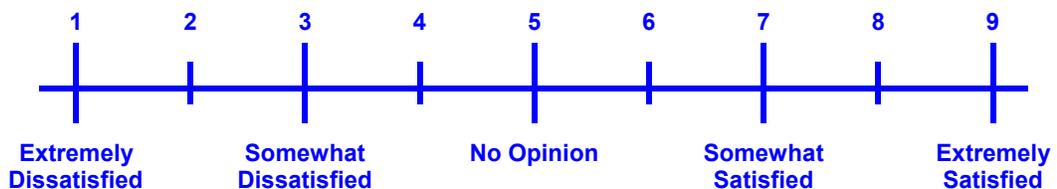
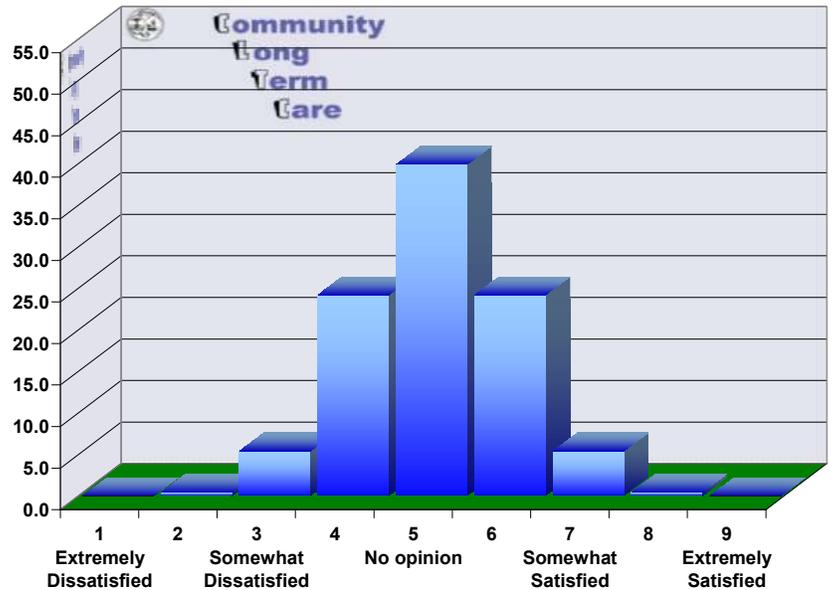


Figure 5

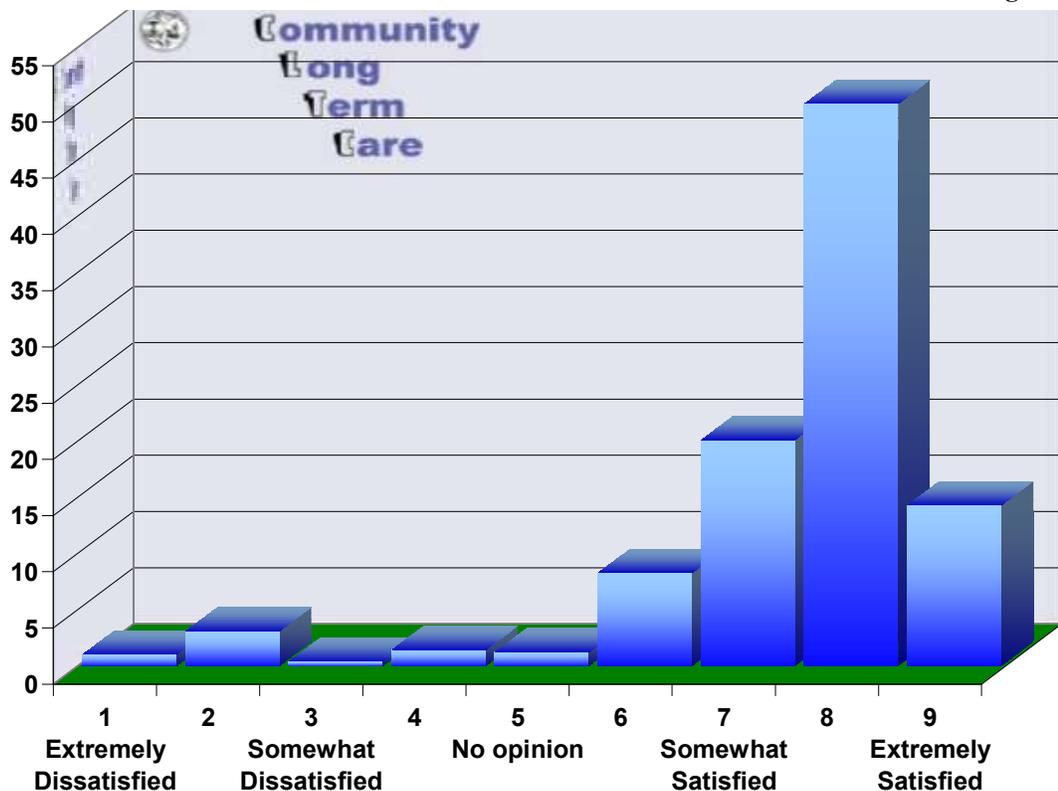
Using this scale, the expected distribution should have most Participants responding between 3 and 8, as shown in the chart. However, the actual distribution of “satisfaction” was surprisingly different – as shown next.



### Statewide

As shown in Figure 6, 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.

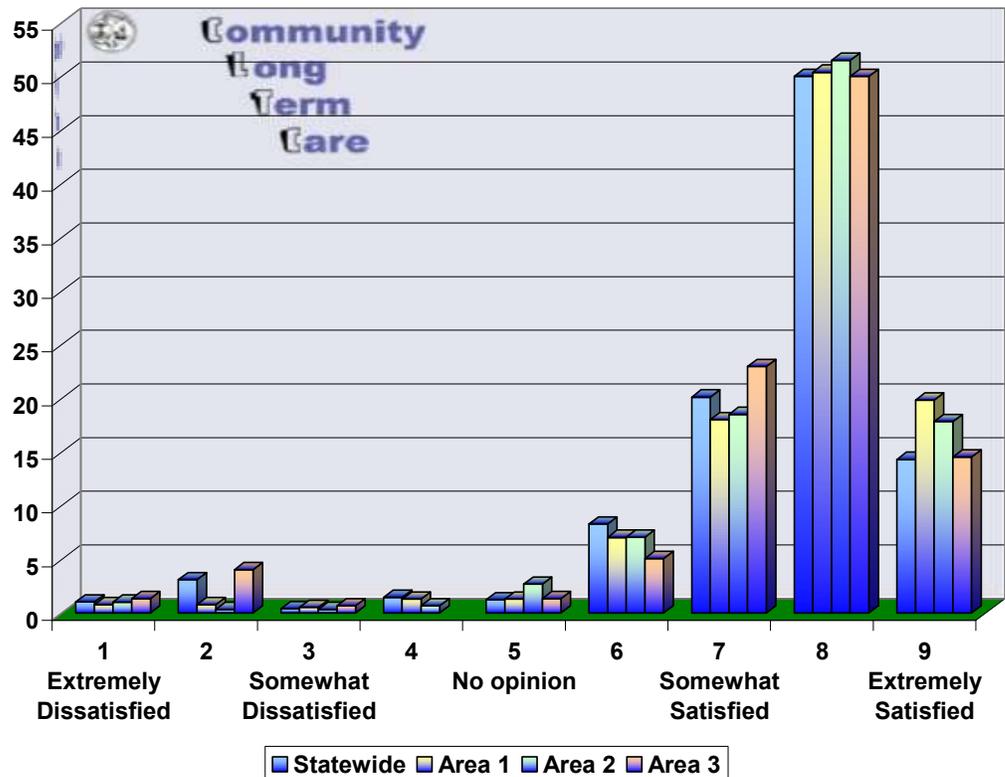
Figure 6



## Area Over-samples

The area over-samples reveal an interesting situation. Given the varied geography and demographics of the state, differences in “satisfaction” with services might be expected. However, the differences between the statewide sample and Areas 1, 2 and 3 were inconsequential.

Figure 7



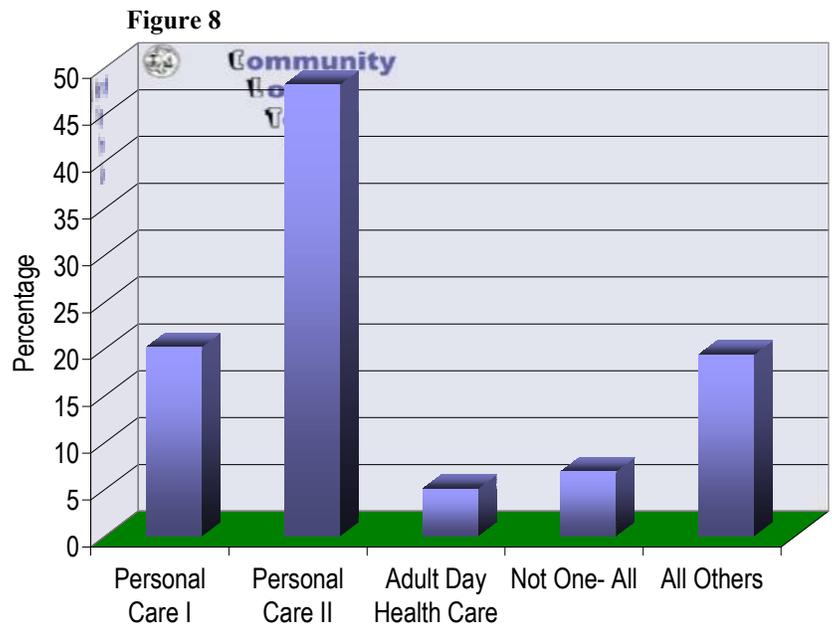
This section started with the statement that “Satisfaction with CLTC services is of paramount importance, and is also a reasonable gross indicator of Participant experience with the program.” By every indication, Participants are **overwhelmingly satisfied** with the CLTC program and its ability to keep them in their homes. This conclusion holds statewide and in the three areas studied.

## Other Findings

The data revealed interesting findings related to program experience. One of the most undeniable is that Participants had no trouble judging which services are important to them. They were asked to specify **the ‘one service you receive that most helps you live in your home.’** They were **not** given a list of CLTC services; rather the interviewer just recorded their answer. The important advantage of this approach is that respondents were not influenced by how the interviewer presented a list of services; or could not have their memory refreshed by a list; rather, they had to rely on their experiences.

Not including the six respondents who gave a non-CLTC service or who could not understand the question, the results shown most likely reinforce CLTC staff impression.

None of the services included in “All Others” was named by more than 3.3 % of the respondents as “**most**” important.



The “All Others” category includes:

- ADHC Nursing
- Companion
- Incontinence Supplies
- Respite Care
- Attendant Care
- Environmental Mods
- Nutritional Supplements
- Respite in an Institution
- Can't think of any
- Home Delivered Meals
- PERS
- Specialized Medical Equipment

Additionally, it must be noted that the data do not support the idea that services that were not judged “**most**” important are non-important. As approximately 5% of the respondents insisted, ‘they all are.’ This technique, however, allows for comparisons of felt worth.

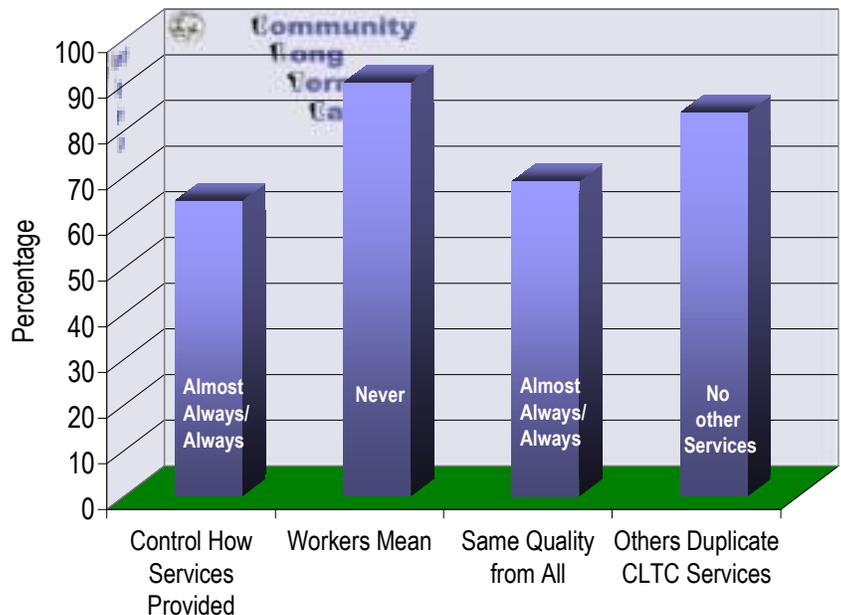
Several service issues are noteworthy in that they show the expected experiences Participants **should** have in a consumer directed program. While not maximal, they do show the extent to which the program achieves its goal. In particular, as program services are contracted from others, it is impressive that 64 % of the Participants feel they receive the same level of

**Figure 9**

quality from every worker.

The issues are:

- Does Participant feel control over how services are provided.
- Are workers mean or yell at Participant
- Does Participant feel all workers deliver the same quality of service.
- Is someone duplicating CLTC services.



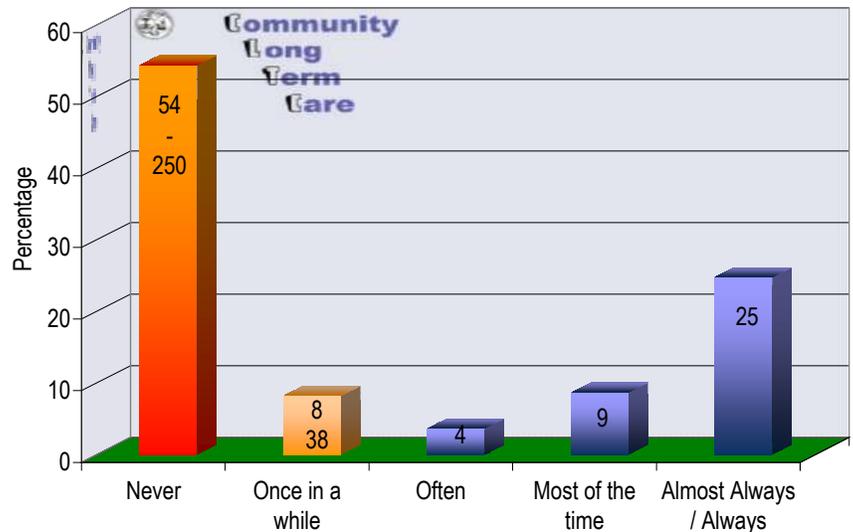
The issue of choice is extremely important. More than 60% of the respondents say they “always or almost always” have control over how their services are provided. A question then arises over the discrepancy between this sense of control and whether respondents feel that they were able to choose the CLTC people who provide them services. The answer is interesting and provides insight into the complexities of just what “choice” means. Figure 10 would seem to

indicate that participants have little choice in selecting service providers – 62% say “Never” or “Once in a while.” This speaks to the challenges that are often echoed by case managers in initial choice, particularly given the relatively low education level and disempowerment of many CLTC consumers. Staff often discuss, and this seems to be reflected in this data, that the way that the system is set up when consumers enter the program does not really give them a choice. Figure 11 includes only those respondents who said “Never” or “Once in a while.”

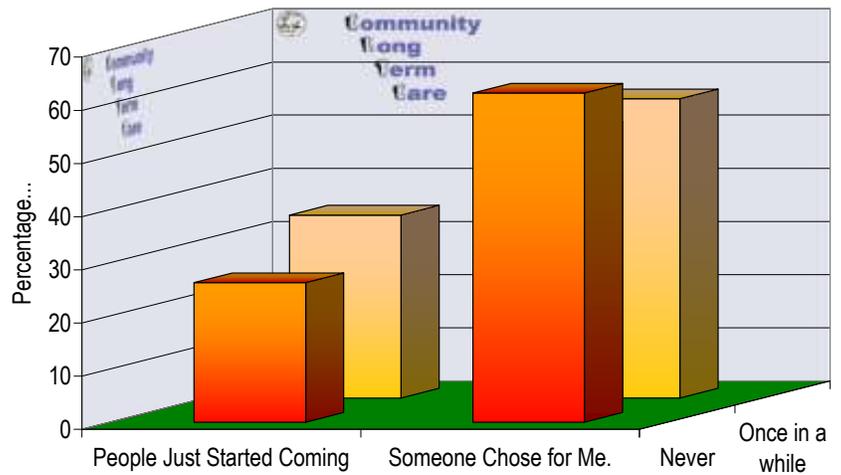
The 26% of the “Never”, and 34% of the “Once in a while” respondents indicated that “People just started coming and providing services.” Again, many consumers may not feel that they made the choice, even when they technically may have selected a provider from a list. The 61% “Never” and 56% “Once in a while” respondents who report that someone chose for them could indicate a number of scenarios, at least some of which could indicate an active — albeit limited — participation in the process. For example, the question remains, did a family member choose for the Participant, or did the CLTC Case Manager choose, or appear to choose.

Resolution of this issue will require more targeted questions in future work.

**Figure 10**



**Figure 11**



There were two measures of Case Manager responsiveness. They were not asked sequentially in the interview, so they would not cross-contaminate. The answers show a consistent pattern.

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 surprising. Either Case Managers are incredibly available to their Participants, or, perception is reality, and the Participants perceive that Case Managers are readily available. Either way is a positive indication of 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?” Ideally, a Case Manager should always do so.

The fact that 2.4% of the respondents have ‘no idea who their Case Manager is’ is interesting. At any one time, 240 Participants out of 10,000 not knowing their Case Manager seems a normal result of Case Manager turnover or Participant abilities. The peculiar fact is that greater than 70% of the Participants perceive their Case Manager in an almost saintly manner. Case Manager training and supervision should definitely continue its current approach.

While this distribution looks similar to the “Satisfaction” distribution, and they are significantly the same, the relationship is not identical. About 3 % — a non-trivial number — of respondents who say their Case Manager always listens and responds, are somewhat or extremely dissatisfied.

Figure 10

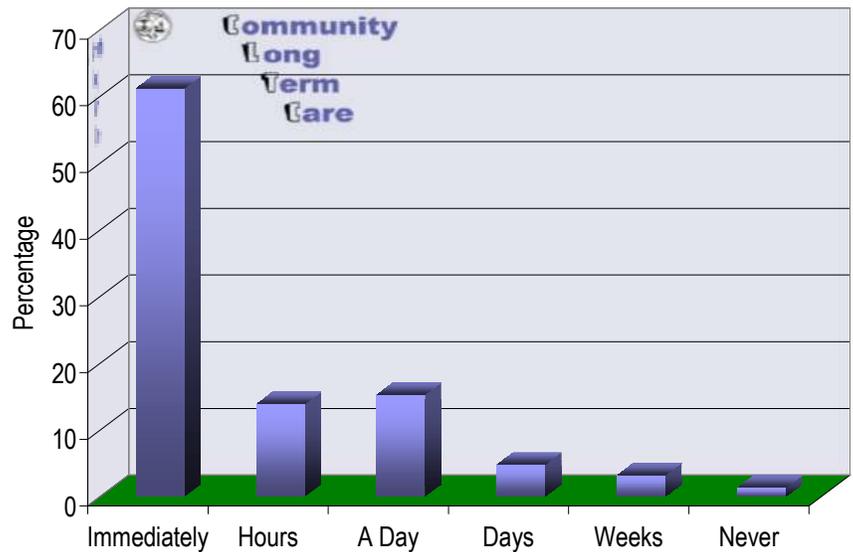
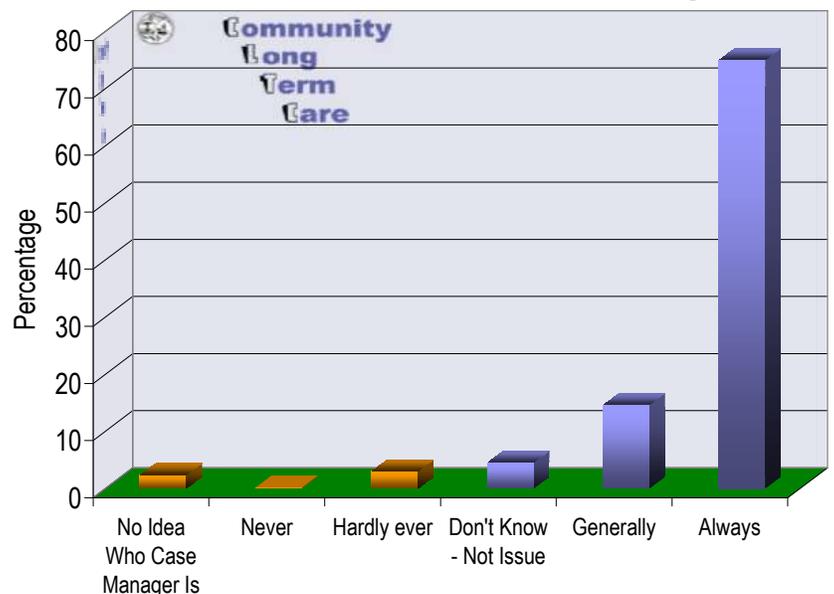


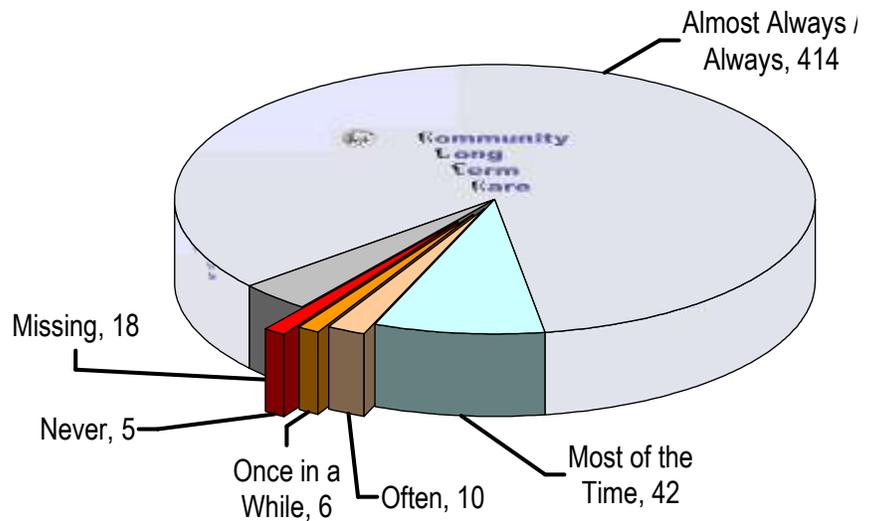
Figure 11



An important issue is whether the Participants are treated with ‘respect’ and ‘dignity.’ “Respect” was defined as **“People value your opinions and wishes,”** while “dignity” was defined as being **“Treated as an important human being, not a piece of furniture.”** As both are important aspects of responsive consumer driven services, they were combined for analysis.

**Figure 12**

Figure 12 shows the number of respondents, not percentages for each category. The vast number of Participants are treated well. Although the 5 ‘Never’ treated well are but 1.2 % of the sample, they represent about 100 program Participants. Likewise, the 6 ‘Once in a While’ represent about 120. Given the implications of this kind of treatment, this issue deserves further investigation.



**Explaining Satisfaction**

As noted, Participants are exceedingly ‘satisfied.’ In fact, the distribution is so skewed towards the positive end that it makes analysis very complicated – it is difficult to explain why people were ‘dissatisfied’ if almost no one is.

However, it is undeniable that there is one factor that explains “satisfaction” with the CLTC program better than any other, i.e., the most important factor explaining satisfaction with CLTC is:

**Being a CLTC Participant.**

That is, apparently Participants feel that the CLTC program is so much more desirable than the alternatives available to them, that just having the services is itself extremely satisfying.

Understanding the limitations of the distribution — very few people are dissatisfied — we nonetheless looked for factors associated with satisfaction with CLTC. Unfortunately, as the distribution was so skewed, the “satisfaction” variable had to be collapsed from a 9 point scale to a dichotomous scale — every response less than ‘6’ became a ‘1,’ and ‘6’ and above became a ‘2.’ Although this recoding causes significant loss to the richness of the data, it allows statistical tests to examine the relationships. Other variables also had to be collapsed for analysis.

The results of the explanatory analysis should therefore be examined with this limitation in mind. Specifically, these results should be considered “suggestive,” not definitive. Future research

may be able to better explore these relationships. In terms of developing program policy, these results should only be used as confirmation of other data.

Having said the above, the following factors might be thought to be significantly (.05 level) related to “satisfaction,” but **were not**.

- Age
- Sex
- Marital status
- Race
- Education
- Time in CLTC program
- Number of medical conditions
- Degree of ‘isolation’
- If they picked CLTC staff
- If family care has changed since receiving CLTC services
- Amount of Social Activity
- If they are treated respectfully
- If they are treated with dignity
- If workers are mean or yell at them
- Number of major complaints with CLTC

A number of the relationships may actually be curvilinear rather than linear, which makes interpretation difficult. One unfortunate effect of the necessary data manipulations is that the collapse of data categories may mask those relationships. Considering those limits, the following factors did have a statistically significant relationship with “satisfaction,” although the percentage of the variance explained (the power of the explanation), shown in Table 3, is quite small:

**Table 3**

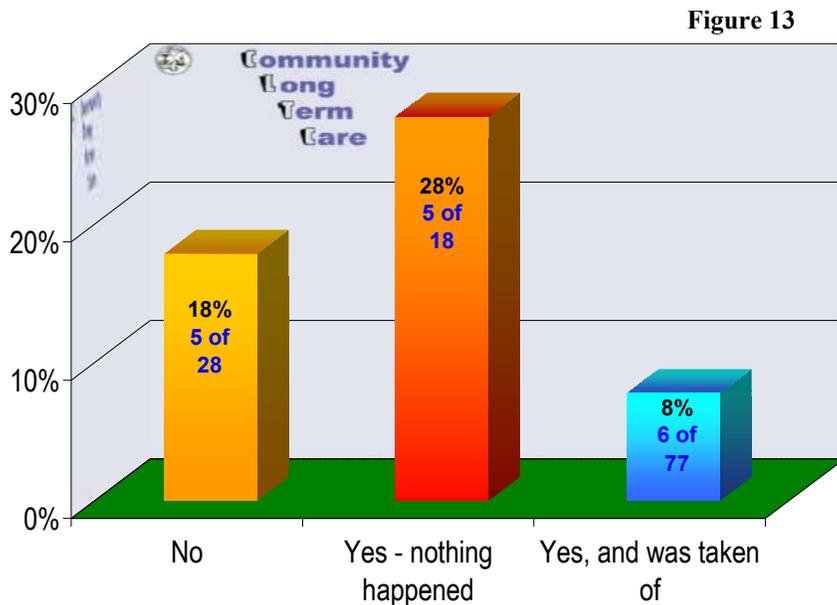
Factor	Relation To “Satisfaction”	% Variance Explained
Service that would help live in home longer	If you think there is - more likely to be not-satisfied	6
Participant Control service provision	More control - more satisfaction	18
Same quality service from all workers	Yes - More satisfied	14
Time it takes to talk to Case Manager	Quick response - more satisfied	6
Formally file a major complaint	The real irritation is when someone is told & nothing happened	11
Case Manager listens and responds	Yes - More satisfied	8

Assuming a Participant driven service model, these relationships present few surprises.

The relationship between ‘filing a major complaint’ and ‘satisfaction’ is quite interesting and demonstrates a curvilinear nature and the hazards of data analysis. Note that Figure 13 shows only the “Not-Satisfied” respondents (**100- Not-Satisfied= Satisfied**). The “No” response includes:

- No, afraid to - fear of retribution
- No, didn't know how to
- No, did before and nothing happened
- No, was told that's how things are
- No, didn't know that I could
- No, told worker - nothing happened

First note the curvilinear nature of the relationship – a straight line from “No” to “Yes, and was taken care of” does not “fit” the “Yes, but nothing happened” category. Obviously, once a Participant makes a complaint, their unhappiness will increase if nothing happens. These data show that unhappiness may not disappear even when they perceive action has been taken,



Next, note the difference in comfort level when the number of respondents is used rather than percentage of respondents. All three categories only included 123 people total. The 18% and 28% are somewhat misleading because of small numbers. For example, consider that the 28% ‘Not-satisfied’ would become 22% or 33% if only one respondent answered “Satisfied.”

### Interesting Findings

Several findings were interesting in the sense they suggest interesting situations – not easily explained.

The relationship between ‘satisfaction’ and ‘Other than for medical reasons, how many times last month did you get out of house’ shows an interesting trend.

The small graphic shows this relationship as it actually exists. Notice that almost every respondent is ‘satisfied.’ The number of respondents in each category is sufficient to make generalizations – as opposed to the last graphic.

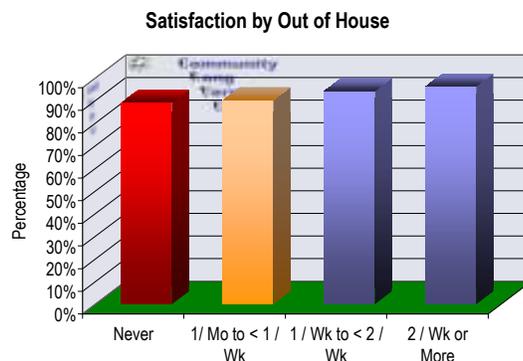
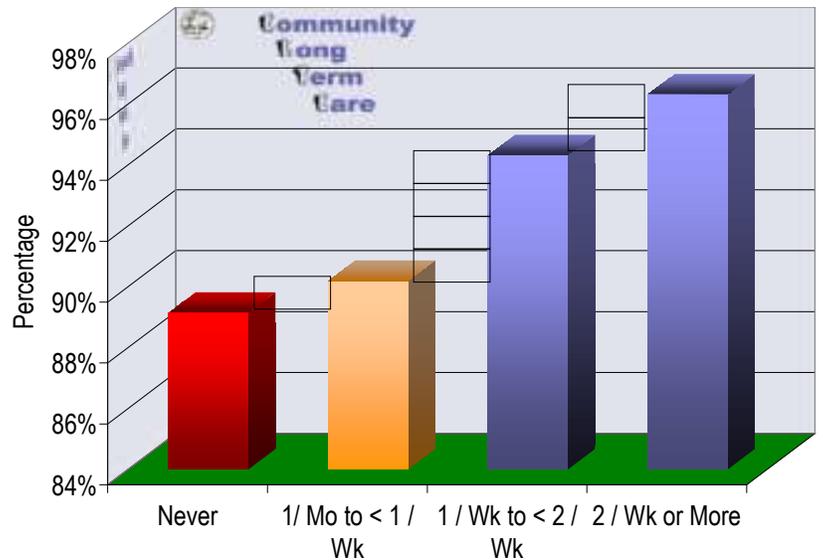


Figure 15 shows an enlarged section to show details. What is important to

Figure 14

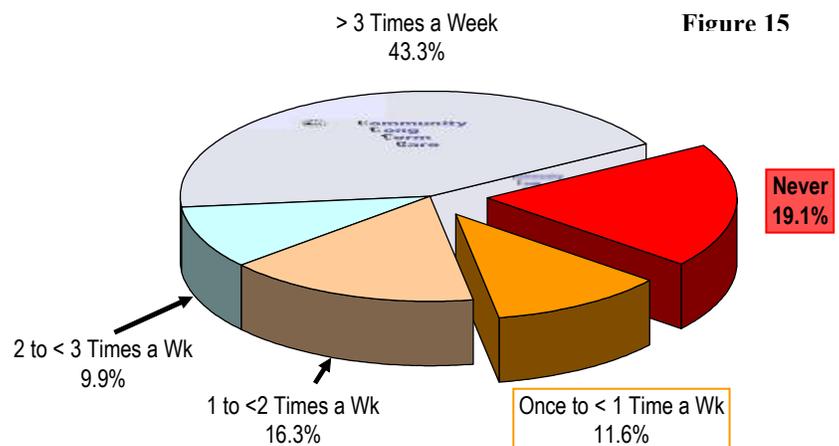
notice here is the degree of change in level of satisfaction. If the change from ‘Never’ to ‘Less than once a month’ is seen as one unit of positive change, then going from ‘Less than once a month’ to ‘Once a week’ is associated with four (4) units of positive change. Going from ‘Once a week’ to ‘Two or more times a week’ is associated with almost two (2)



units of positive change. The relationship is not linear, and would take a higher order mathematical function to describe. The implication that arises is that there may be **something “magical”** about getting out of the house at least once a week. As over 88% of the ‘Never’ respondents are satisfied anyway, this may be ‘gilding the lily.’ However, it may also suggest that for the ‘Never’ people, getting out of the house for medical reasons fulfills both a medical and a social need.

A similar concern is social isolation in general. Three questions on the instrument touched on this area: “Within the last month, about how many social activities did you participate in, at or outside your home? (A “social activity” is any time you are meeting or talking with others for enjoyment.)”; “Other than for medical reasons, how many times last month did you get out of house?”; and “About how many times did you use the internet, or cell phone to connect with others last month?” As shown above, individually they do not contribute substantially to understanding. However, together they provide an interesting statistic of the population. The responses to these three questions were combined into a scale of “isolation.” If a Participant never got out of the house except for medical reasons, never had any social activities, and never contacted others by cell or internet, the person could surely be seen as fairly isolated.

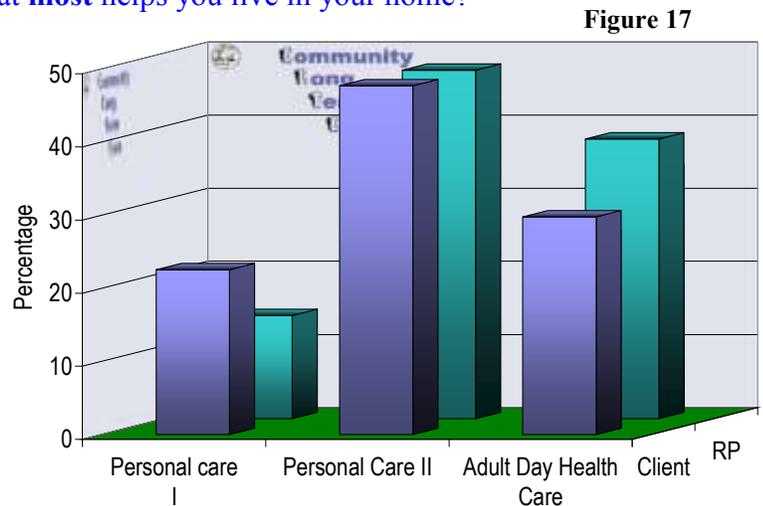
Over 19% of the CLTC Community Choice Participants **Never** have any of the three



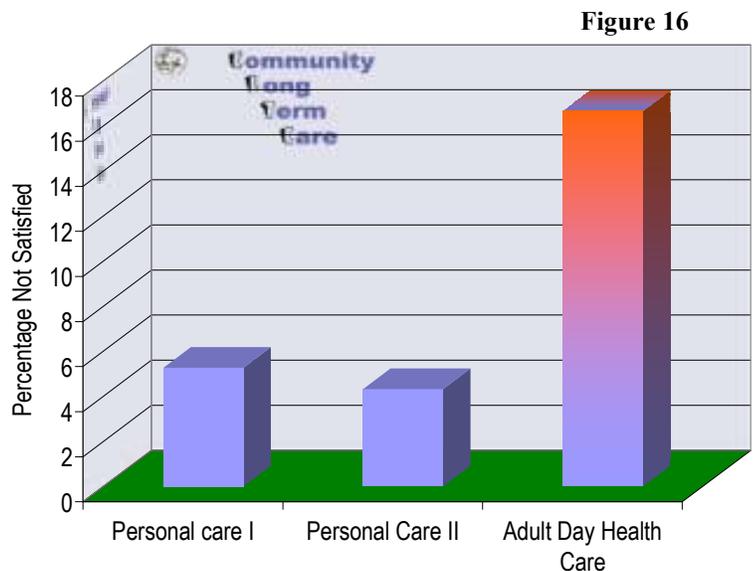
types of social interaction in a month. Almost 31% have less than one of these activities a week. Given the relationship between isolation and mental illness / deterioration, this is an issue that should be pursued further. Even so, while it may not be the direct responsibility of the CLTC program to provide, it seems that there is an obligation on society or family to insure Participants have something other than a lonely, isolated life. As one respondent put it, what she needs is “just somebody to talk to.”

There were two quite curious findings. The first involves the perception of the most needed services. Surprisingly enough, Participants and Responsible Persons see a difference. On the question: the ‘**one service you receive that most helps you live in your home?**’

Responsible Persons saw “Adult Day Health Care” as more important than “Personal Care I.” These data provide no indication of why this is so. One might hypothesize that PC I brings someone into the house – and provides social interaction – whereas ADHC takes the Participant out of the house – and provides some relief for the Responsible Person.



The other curious relationship involves differences in ‘satisfaction’ by perceived program importance. Once again, this relationship involves a very small number of respondents and a small difference in ‘satisfaction.’ Nonetheless, the question would be why Participants (Not RPs) who chose ADHC as the ‘**one service you receive that most helps you live in your home?**’ be less satisfied.



General Themes – compiled by Vivian Shannon-Ramsey

**Is there a service that would better meet your needs? What service would that be?**

- Over half the survey participants indicated that they would like more assistance:
  1. More hours with nurse
  2. Help on the weekends and nights from attendant
  3. More Personal Care II hours
  4. Assistance 5 days a week instead of 3

- Generally the survey participants stated the need for environmental modification and home repairs. Examples Include:
  1. Pest control
  2. Bed ramps
  3. Help with yard work
  4. Repairs to porch and refrigerator
- Generally the survey participants stated the need for medical equipment or services. Examples Include:
  1. Lifeline system in home in case of emergencies.
  2. Lifts to get in and out of bed
  3. Physical therapy
  4. Shower chair
  5. Walker/Cane
  6. Rails in tub
  7. Wheelchair
- Several survey participants stated the need for transportation

**Is there a service that would improve the quality of your life? What service would that be?**

(Responses were mostly a repeat of the previous.)

- Several survey participants stated the need for transportation for such things as:
  1. Groceries
  2. Doctor visits
  3. Attendance to social activities
  4. Attendance to church
  5. Getting groceries
  6. Picking up medication
- Most of the survey participants indicated that they would like more companionship or have the nurse check in more regularly
  1. More hours with aid
  2. More personal care I and II
- Over 90 percent of survey participants said they wanted more social activities and community involvement by:
  1. Getting out of the house
  2. Having someone to walk and share with
  3. Day program
  4. Transportation to activities
  5. Vocational rehab
- A large number of survey participants said there was a need for respite care.
- Most of the survey participants stated they would like cleaning services.

**Why not?**

- The majority of participants that didn't report their issues failed to do so because:
  1. Didn't want services affected
  2. Didn't feel like issue would be resolved
  3. Didn't feel like their issues were worth reporting
- Some of the complaints made by participants were not addressed or no action was taken that the client could measure as any noticeable change.
- The majority of the complaints made were in regards to the persons paid to help client. Most of the survey participants stated after reporting problem, that issue was resolved.
- Generally complaints made by survey participants were concerns of:
  1. Not having medical equipment/supplies

2. Endangerment of client or family member
3. Attendant not performing work duties

## Region Specific Findings

As expected, there were statistically significant differences between the statewide sample and the Areas on several variables.

However — most importantly — regardless of their general differences, there were no significant differences between the statewide sample and the over-sampled areas on “satisfaction” with CLTC.

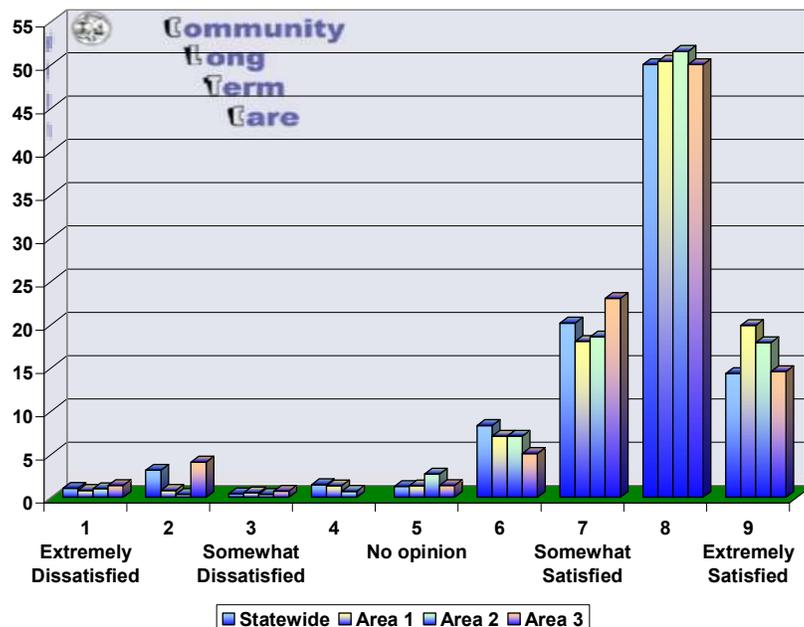
Figure 18 again shows the level of satisfaction for each Area compared to the statewide sample.

Acknowledging that the differing characteristics do not apparently influence the level of satisfaction, it is interesting to see how the Areas differ. Table 4 shows several of the statistically significant differences.

**Table 4**

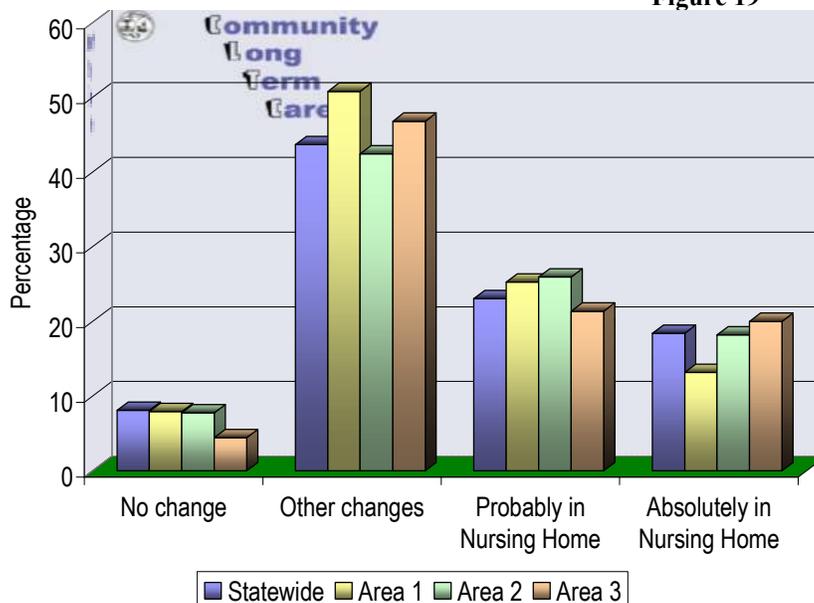
As shown, Area 1 has fewer minority Participants, somewhat younger and somewhat higher educated Participants. While the data do not provide definitive support, there is a suggestion that Area 1 Participants also have greater supports than the other Areas. Figure 19 shows the answers for the question of what would happen to them without CLTC services. This suggests Area 1 Participants believe they have access to other services to keep them from a nursing home.

**Figure 18**



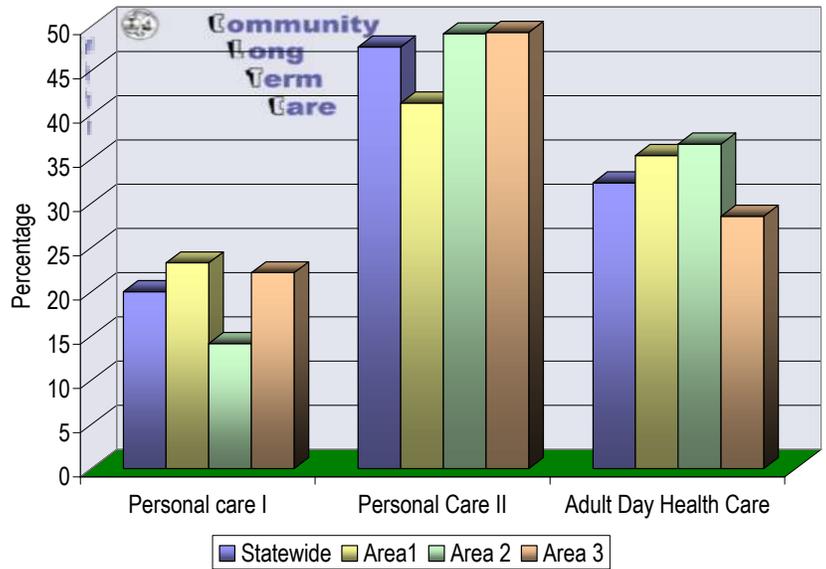
Factor	State	Area	Area	Area
% Minority	55.1	27.3	37.4	46.8
% Male	24.8	27.3	34.0	24.8
% with < H.S. education	70.9	65.7	67.0	74.8
% who can talk to CM < a day	75.2	76.7	84.0	81.7
Median age	72	68	73	73

**Figure 19**



One further difference between Areas is interesting, and could indicate a difference in service provision – and Participants. On the question the ‘one service you receive that most helps you live in your home,’ there were substantial differences between the Areas. The data do not provide answers as to why Areas 1 and 2 Participants have substantially differing views on which service is most important to them.

Figure 20



## FINDINGS - HIV

The Participants of the HIV and Community Choice waiver obviously have quite different characteristics as shown in Figures 22 and 23.

Figure 22 - Community Choice

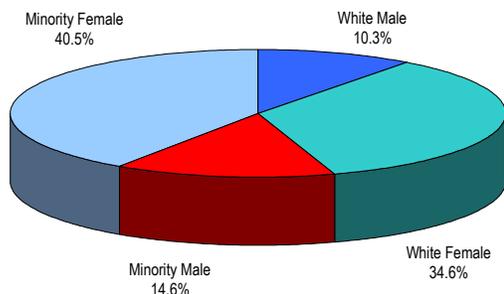
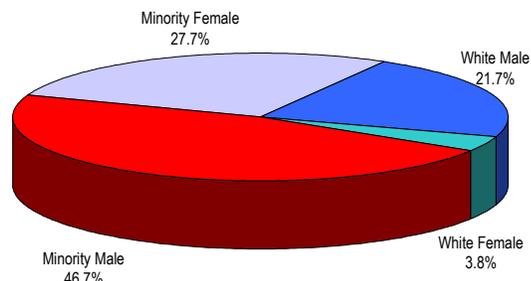


Figure 21 - HIV



Yet, in terms of satisfaction with CLTC, they are not so different. Figure 24 shows the percentage of satisfaction of the statewide Community Choice sample in blue, and the HIV sample in yellow. The most noticeable finding is that the HIV Participants are substantially more satisfied than the Community Choice Participants. Again, by every indication, Participants are **overwhelmingly satisfied** with the CLTC program and its ability to meet their needs. As might be expected, the HIV Waiver Participants differ in both background and view of CLTC from Community Choice Waiver Participants as shown in Table 5.

Figure 23

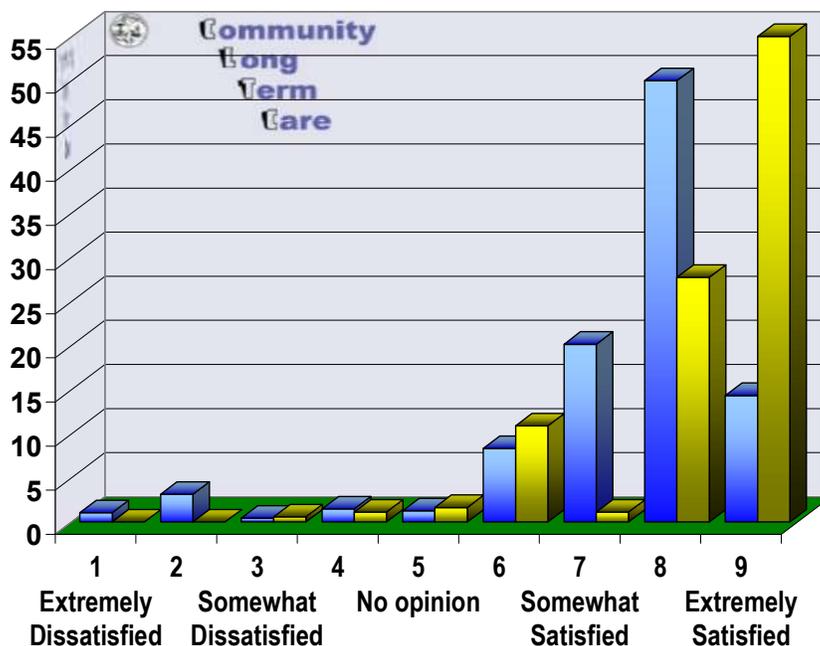
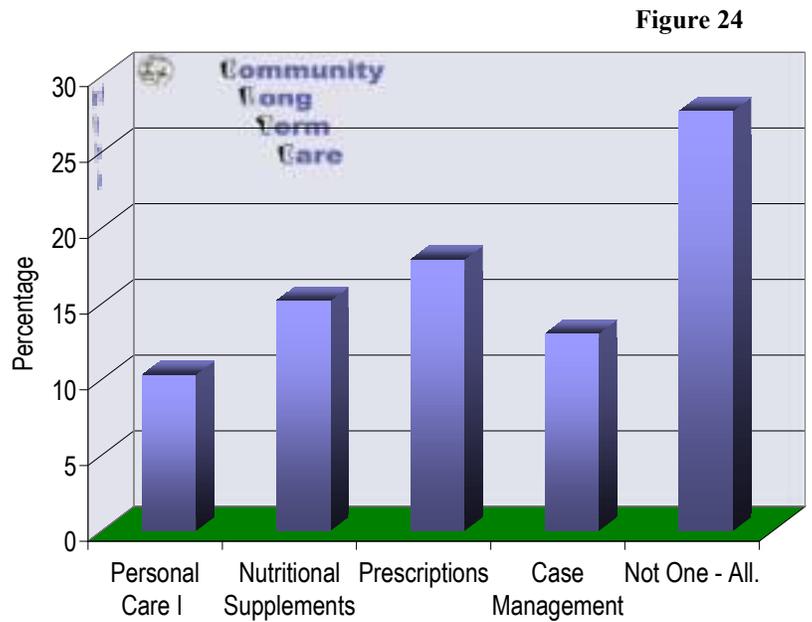


Table 5

Factor	Difference
Education	Generally more educated.
Age	Younger – Median age is 50.
Relation to CM	91% say CM “Always” listens and responds to them.
Treated with Respect and Dignity	Greater Percentage say “Always/Almost Always.”

In terms of program experience HIV Participants also had no trouble judging which services are important to them. They were asked to specify the ‘one service you receive that most helps you live in your home.’ As was the case with the Community Choice survey, respondents were **not** given a list of CLTC services; rather the interviewer just recorded their answer. These results shown in Figure 24 most likely reinforce CLTC staff impression.



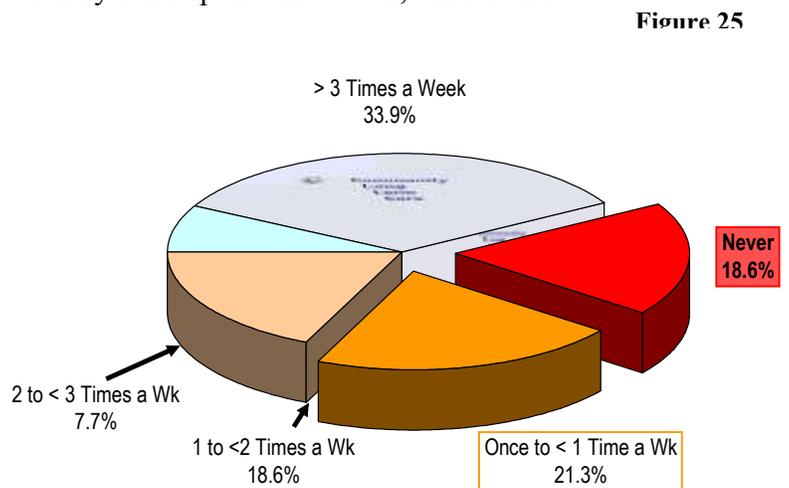
As with the Community Choices data, the same pattern is reflected in the HIV Waiver, which is that initial choice is not perceived as such by Participants. However, choice and

control over services seems to increase with the length of time on the program and the relationship established with the Case Manager.

HIV Waiver Participants are extremely socially isolated. The responses for the question:

“Within the last month, about how many social activities did you participate in, at or outside your home,” leave no room for doubt. We defined a “social activity” as “any time you are meeting or talking with others for enjoyment.”

Almost 40% of the Participants have less than one activity a week. Whether self-imposed or not, these respondents have become modern day lepers whose only social contacts is with their CLTC Case Manager.



General Themes – compiled by Vivian Shannon-Ramsey, Danielle Goulet and Pauline McCullough.

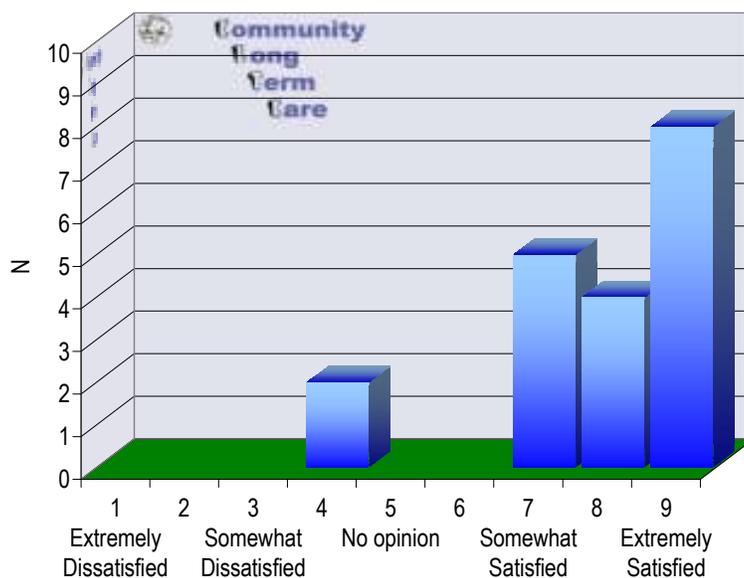
- Majority of participants not aware of what CLTC provided and wanted services that were already in existence but they didn't know about them.
  1. Environmental modifications (ramps and air conditioning)
  2. Personal Care I
  3. Emergency financial assistance
  4. Companions
  5. Home delivered meals
- Generally participants wanted help with mental/emotional support and therapy (not just physical)
  1. Support groups
    - In some areas, clients not aware if support groups exist
    - In many areas where support groups are available, clients expressed discomfort with the nature of the support group (more about sexuality) or with confidentiality issues (small town, people talk)
  2. Network with other persons living with HIV/AIDS.
    - Online or phone support
    - Possible option as support group for people concerned about confidentiality and anonymity
  3. Social activities to connect with other HIV/AIDS persons
- A large number of survey participants stated they would like assistance with services not directly offered by CLTC.
  1. Financial
    - Housing/utilities
    - Social welfare programs
    - Home repairs
  2. Quality of life improvements
    - Dental services
    - Eye glasses
    - Dietary programs/weight loss
    - Transportation to non-medical appointments
    - Exercise services
  3. Socialization and education
    - Vocational training
    - Community involvement
    - Mentoring programs for children and young adults
- Some clients are unaware that CLTC is a Medicaid service
  - They do not understand how CLTC and Medicaid are linked
- Most of the survey participants agreed with primary program goal but wanted to have the goal include a way for clients to learn about other community services through their case manager or the CLTC office.

***When participants were asked why they were not involved with other local agencies, the general response was, "I didn't know any other services existed."***

## FINDINGS - VENTILATOR WAIVER

The ventilator dependent waiver was a a shifting population. It was only possible to interview 19 Participants statewide. Nonetheless, these Participants also show – as shown in **Figure 26**

Figure 22 – a general overall satisfaction with CLTC services. The Ventilator Dependent Waiver Participants have a surprising number of activities, yet they get out of the house seemingly less than Community Choice Participants.



Given the medical needs of this population, it is not surprising that CLTC services

are extremely important and relied upon. Consequently, the Participants and their Responsible Persons are quite passionate both about the program and when they perceive a service gap. To illustrate, one Participant noted a nurse that yelled at him/her, and s/he complained and the problem was fixed – something that occurred **seven (7)** years ago.

### General Themes – compiled by Danielle Goulet:

There were twenty ventilator surveys that were completed so it is difficult to draw any general themes; however, these are some issues and concerns brought up in many of the twenty surveys:

- **NURSES**
  - Many clients need more hours from the nurses but not authorized
  - Some complained of high turnover rate
  - Most noted the shortage of nurses, especially among third shift
  - No backup nurses for when one calls out—hours lost are never made up
  - A few clients complained nurses and aides were inexperienced and not knowledgeable about the ventilator population
  - Need more respite nurses with more availability
    - In SC no nursing homes or facilities take in vent. cases for respite
- **ENVIRONMENTAL MODIFICATIONS/ACCESSIBILITY**
  - A quarter or more of the clients complained that they need either wheelchair, lift for van, handicap-accessible bathroom, ramp etc.
    - Some clients have asked CLTC with no results
  - Many clients also noted a desire to have more mobility/help with transportation

- OTHER
  - A couple wished for physical and speech therapy
  - One client expressed need for help paying utility bills because of high cost of vent. expenses

**OVERALL:**

Of the twenty ventilator clients interviewed, only about one quarter reported complete satisfaction with the program, having no complaints. There were about nine formal complaints clients had in the past year, which is nearly half of those surveyed. Clients seemed dissatisfied with the lack of response they receive from CLTC, with the majority of the problems involving nursing issues and environmental modifications. Interestingly enough, however, when asked whether they felt their nurse consultants listened to them and responded to their concerns and wishes, most clients answered “generally” or “always.”

Given the small size of this population and the sample, there is little else that can be confidently reported about their responses.