



People Talking to People: Building Quality and Making Change Happen
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Report Year One

Sample and Collection

A collective initial sample of 75 surveys was all scheduled by October twelfth. This sample will include 73 surveys (4 surveys were scheduled to be completed after this report was due). The surveys came from three regions: West, Middle, and East. Twenty five surveys were collected or attempted from each region from teams of two in each region, the majority coming from Madison, Davidson, and Knox counties. Names were chosen from 6,644 consumers receiving services from waivers and/or state funds throughout the state of Tennessee. The consumer list was split into counties and then randomized with an online randomizer (through Javascript random number generator). Additional names were chosen (30 total for each region) in the case that consumers originally chosen could not be contacted.

It was the Co-Directors' responsibility to make the initial contact and schedule interview times, dates, and locations. A face sheet with information regarding the interviewee was then sent to the corresponding team. Seven percent of the 75 survey participants refused, due to hospitalization (40%), being uncomfortable with the survey (40%), or no longer receiving services (10%).

Each interview team would then go to interview the consumer, using the survey on paper format (computer surveys were not yet available). The overwhelming majority (71%) felt more comfortable in interviewing at home. The rest met at their place of work or day center (28%) or an open area outside of their work or home (1%). The surveys were each kept in a safe contained area and sent in entirety to the Co-Directors via mail using return receipt as soon as the majority of the interviews were completed. The surveys were then entered into a survey database and thus analyzed utilizing access and excel. Some percentages may not look accurate; this report will be focusing on positive and negative answers only and thus the remainder may be no answer, unclear response, or no response. Those questions where 40% or more were not answered are considered analytically unusable and will thus not be counted in this report.

Demographics

The age range was quite varied, with the youngest being 14 and the oldest 82. The average age was 44. Gender was almost split down the middle (42% male, 58% female). Class and non-class members were also almost even (52% non class, 48% class).

Approximately Twenty five consumers were represented in each region (22 west, 25 middle, 26 east).

The Answers

Almost half (45%) of the participants answered all of the questions by themselves. It was mostly staff (43%) or Families (24%) that helped answer questions for those who could not give all of the answers themselves. All interviewers explained to the consumers that they had a choice whether they wanted staff and/or family present when the survey was taking place.

Choice and Control

The majority (75%) answered that they liked where they lived. Those that answered no or sometimes (15%) had a mix of living situations, but 60% were in housemate situations and the majority of those that answered no (66%) did not choose their place to live. None of those living with housemates shared a room.

Almost half (40%) stated that they helped pick their support staff. All of those that didn't would like to help pick their staff. Almost half (45%) of those that stated they didn't pick their staff said they were aware they could change their support staff if they wanted. Two thirds (66%) stated they tell support staff what to help them with. Every consumer answered that they could eat, watch TV, go to bed, and be by themselves whenever they wanted. The majority go to their support staff (47%) or family or friend (22%) when they need help. Fifty four percent could name their case manager or ISC; Sixty eight percent total feel they can go to their case manager or ISC when they need help and that same percentage feel they help when the consumer needs something.

About two-thirds (60%) responded that they like their day program; half (50%) of those that reported they didn't like their day activity stated they didn't chose it. Forty eight percent of those that answered said they did not choose the day program/job/volunteer work they do now.

Respect/Dignity

Over two-thirds (68%) responded that the support staff in the home respect them. Those that answered "yes" to this question answered "yes" to the following questions (Whether the staff say please and thank you and whether they listen carefully).

Fifty Six percent of the consumers used a van to get to places they need to go. Almost all (98%) answered that the people on the van respect them, and, like the previous question,

all that answered “yes” to respect answered “yes” to the two questions that follow (Whether the staff say please and thank you and whether they listen carefully).

Twenty five percent stated that people sometimes go into their room without permission and 21% say that people have taken things without asking first. Of those that have had items taken, half of the culprits have been housemates (50%) followed by staff at home (21%). Twenty eight percent have stated that people have done mean things to them. Those people that have been mean to them include support staff at home or support staff elsewhere (53%), or housemate (11%). Twelve percent have stated that people have hit or hurt their body. Of that 12%, 25% were staff other than home staff and 50% were housemates. The rest were categorized as “other”. All of the incidents were reported in some way to either family or staff, but it is unclear in the data how it was resolved.

Access to Care

Twenty eight percent of those surveyed needed some form of help taking a bath or shower. Only one person (5%) of those that needed help answered that she sometimes goes without a shower when needed, and she said it was of her own choosing. Only Nine Percent needed help getting out of bed, and out of those 29% said they have gone without getting out of bed when needed, due to lack of staff. Thirteen percent needed help eating, and one person of those (11%) said they go without eating when needed. Almost half (49%) stated they need help making meals, all stating that they have never skipped a meal when needed. Fifty six percent of the consumers stated that they needed help getting groceries, with one person stating that they did not get groceries when needed due to finances. Thirty three percent needs help with housework, with one reporting that housework sometimes doesn’t get done just because she doesn’t want it to. Forty six percent need help with their laundry, with 10% of those 46% stating it sometimes doesn’t get done when needed. All stated that it doesn’t get done because of their own doing. Sixty four percent say they need help getting medication. Only one stated that they didn’t get medication when needed because she doesn’t want to. Fourteen percent needs help going to the bathroom, and done stated they were ever unable to go when needed.

Seven percent of consumers say the staff doesn’t spend all the time with them that they are supposed to. Nineteen percent of the consumers have spoken with their case managers or ISC’s about special equipment that would make their life easier. Only one person (8%) of those who requested actually received their request.

Not one consumer answered “no” to the following questions: “Do you like to go shopping?”, “Do you go shopping?”, “Do you help pick where to go shopping?”, “Do you like to go out to eat?”, “Do you go out to eat?”, “Do you help pick where you go out to eat?”, and “Are there people you like to visit with?” . Qualitative responses to the last question include friends, boy/girlfriends, neighbors, church friends, and family. Sixty one percent could see these people whenever they wanted.

What consumers like to do run across the gamut. Some like the more active lifestyle, and spend their time bowling, shopping, and playing with their pets. Others enjoyed

private activities, like coloring, reading, and writing. One or two said they preferred sleeping to anything else. Only 3% answered they could not do these things when they wanted.

Some interviewees felt comfortable enough to continue talking to the surveyor after the survey. A few mentioned specifically how happy they were with their current situation. Others discussed their desires that have not yet been fulfilled, such as marriage, jobs, or school. Quite a few talked about how they disliked the survey itself, saying some of the questions were stupid or how they didn't apply to them.

Surveyor Comments

The surveyors are asked to give comments at the end of each survey. These comments really give a better feel for how the interview went, how reliable the consumer's answers were, suggestions for improving the instrument and interview process, and concerns that should be addressed.

One concern that was repeated a number of times was communication. Often consumers were nonverbal and the interviewers had to rely on staff to help translate. There seemed to be many situations where the staff didn't know how to communicate at all with a consumer that spends 5 days a week at a particular program with staff that cannot understand them. Another concern was that consumers often answered "yes" to every question in order to please the interviewer. This makes the viability of the answers questionable. A few surveyor comments include:

-Consumer answered yes to every question. No support staff was able to communicate with her.

-consumer vocal but answered yes to many questions, leaving us wondering how accurate. Probably didn't help. Answers questionable.

-Went to interview but does not communicate with words and no support staff could communicate with her.

Another interesting subject that came up was the amount of family members that were unaware of services:

-Client is very independent; however, she and her mother are not aware of many services that are available to them.

-Family is unaware they can receive services for the client.

One positive that came out of the comments was the supportiveness of staff:

-Excellent survey. One in which we got substantive answers. Support staff very knowledgeable and innovative. He is a lucky guy.

- His support staff was polite and helpful. He wanted his staff to stay in the room. Bobby responded to all questions himself. He was relaxed and excited about the interview.

Observations

We have observed among our staff an increased sense of self-esteem and an ever growing expansion of their willingness and ability to handle more tasks with greater responsibility. Among our staff, half of the individuals never previously held competitive employment.

The surveyors have reported very few instances where participants were not willing and/or eager to participate in the survey.

Our surveyors have reported the great majority of staff and personal assistants have been helpful in the completion of survey interviews. They have stated, in most cases, staff appears to be patient, polite, and considerate in their interactions with consumers.

Initially, we discovered a significant percentage of the personal data sent to us by DMRS, provided to us for the purpose of identifying in locating survey participants, were inaccurate or outdated. Approximately 28% of the total addresses and 59% of the phone numbers originally given were wrong and/or missing. After bringing this to the attention of Tami Wilson, Ms. Wilson assisted in improving the system of information delivery and communication between the Arc and DMRS. We are working to continue to increase the efficiency of this process. We did note that there were instances where the DMRS database was not as up to date as the hardcopy consumer files.

We have learned the importance of employing strong teamwork involving ISC agencies and individual ISCs in the presentation and scheduling of surveys. In the future, The Arc staff will plan to attend monthly ISC and provider meetings in order to inform the community about the survey and survey results and to establish a strong working relationship with all the stakeholders in this program.

We have observed some family members and conservators might be able to benefit from disability awareness training. There were numerous comments from some parents and conservators to the effect that the consumer "had the intelligence of a two -year-old or, "he/she will never be able to understand the questions or give you answers". As postulated in the premise of this program, we have found participants will often rise to the level of responsibility which is afforded to them.

Future Goals

Goal dates and statuses are as follows:

Goal	Original Date	New Date or status
Interview Instrument Amended	September 2004	February 2005 This must be done with the help of our advisory committee which is not yet comprised (in progress)
Identify/Recruit Sample of Persons to be interviewed	September 2004	Completed for First 75; Second year sample to be finished by November 2004
Develop Information Management System	September 2004	Completed
Seventy Five Interviews Scheduled and/or Completed	September 2004	Completed October 12, 2004
Develop Training Curriculum	October 2004	Completed
Procedures for Recruitment	October 2004	Completed
Confidentiality Procedures	October 2004	Completed
Identify Teams of Interviewers	October 2004	Completed for first 3 regions; remaining teams will be identified by March 2005.
Develop TQSC	End of year one	January 2005
Quality Improvement Report	December 2004	December 2004
Report Findings Year One	March 2005	Should be completed by November 2004
Amendments to Project Processes	March 2005	In progress
Add 2 additional teams of Interviewers	April 2005	All teams of interviewers to be hired at this time
Report to DMRS and TennCare	April 2005	April 2005
Add 2 additional teams of Interviewers	May 2005	All teams of interviewers to be hired by April 2005
Track System Follow Up on Remediation and Pursue	June 2005	June 2005
747 Surveys to be Completed	September 2005	635 to be Completed by July 2005, remainder (112) by September 2005

Report to DMRS and TennCare	October 2005	October 2005
Create Plan for Sustainability	November 2005	November 2005
Report Findings year 2	December 2005	December 2005
Track System Follow Up on Remediation and Pursue	December 2005	December 2005
Amendments to Project Processes	December 2005	December 2005
Implement Plan for Sustainability	March 2006	March 2006
1494 Surveys to be Completed	July 2006	1307 Surveys to be completed by July 2006, remainder (440) by beginning of September
Report Findings Year 3	September 2006	September 2006
Track System Follow Up on Remediation from December 2005 and Pursue	September 2006	September 2006
Report to DMRS and TennCare	September 2006	September 2006
FINAL REPORT	September 2006	September 2006

Recommendations

The initial 75 survey interviews have provided excellent feedback towards possible changes in the survey instrument which would deliver more accurate information. Each interviewer has written a report regarding changes and a master report is in progress. A few suggestions that have come in are:

-Concerns with validity of answers. Some people say yes to opposing questions that conflict each other, or may say yes to all questions to please the interviewer. Some questions are confusing as well, and may say yes without completely understanding or misinterpreting the question.

-Concerns with validity of certain questions such as:

Choice and Control (1-30)

-question 16 "Can you eat when you want to?"-does not reflect choice. If a consumer says no it may be due to lack of choice but to dietary restrictions.

-questions 27-30 Question 26 asks for all responses to skip these three questions and thus not enough valid information was achieved through these questions.

Respect and Dignity (30-52)

-question 41 “Does anyone take your things without asking you first?” This question needs to be clarified, for it was noted a few times consumers answered “yes” when, for example, staff took their laundry to wash and returned it clean a few hours later.

-question 46 “Is anyone mean to you?” Consumers misunderstand “mean”-may answer incorrectly.

-Group related questions regarding respect (30-32, for example) If the first question is answered “yes”, then all other questions are followed by yes, not giving much final information to PTP

Access to Care (53-99)

-Special help questions are not applicable to all, and many consumers become bored or agitated at the repetitiveness and/or inapplicability.

-Questions 88-93. These don't necessarily pertain to community inclusion but to community exposure.

-Questions 88-94 Every one of these questions were answered “yes” by those who answered them, not giving much information to PTP.

-Other recommendations include: adding questions about money issues, add “other” and “na” to questions, explain choice (choice not giving a choice of 2 items), and add more probing questions.

-Concerns regarding the lack of the voice of family members. This concern is being addressed and next round will attempt to include a larger percentage of family members.

In addition, the 75 interviews allowed us to put a protocol into place, giving us the policies and procedures needed to continue with the program more efficiently and effectively. The next round is already in its beginning stages, and will hopefully go much more smoothly after lessons learned from year one.

