



PEOPLE TALKING TO PEOPLE

ANNUAL REPORT FOR YEAR 5
July 1, 2007- June 30, 2008

Prepared by:

Frank Meeuwis, Project Director

Authors

This report would not be possible if it were not for the effort of each and every person on the *People Talking to People* team, including:

Frank Meeuwis, Project Director
Holly Newingham, Project Assistant
Mary Turner, Interviewer, region 1
Dianna Barrett, Interviewer, region 1
Jean Smith, Interviewer, region 2
Carol Smith, Interviewer, region 2
Melody Jacobs, Interviewer, region 3
Larry Jacobs, Interviewer, region 3
Gatha Logan, Substitute Interviewer, region 3
Monica Gardner, Former Interviewer, region 4
Paula Gardner, Former Interviewer, region 4
Rebekah Sieber, Substitute Interviewer, region 4
Josh Turner, Interviewer, region 5
Woody Cade, Interviewer, region 5
Cheryl Coleman, Substitute Interviewer, region 4 & 5
Mary Dale Greene, Interviewer, region 6
Gail Compton, Interviewer, region 6
Patrick Sanders, Interviewer, region 7
Don DeVaul, Interviewer, region 7
Tom Griffin, Interviewer, region 8
Darryl Newsome, Interviewer, region 8
Sondra Loveless South, Interviewer, region 9
Nadine Loveless, Interviewer, region 9
Melissa Allen, Former Interviewer, region 9

The Arc of Tennessee staff

The People Talking to People project also offers special acknowledgement to DMRS, specifically Brenda Clark for her support and assistance.

All of those that have helped along the way that are not mentioned...thank you!

Table of Contents

| | |
|---|-------|
| 1. People Talking To People Grant Overview | 4 |
| 2. Methodology | 5-6 |
| 3. PTP Staff | 7-9 |
| 4. Demographics of randomized list for PTP interviewers | 10 |
| Gender | |
| Primary Means Of Expression | |
| Class Vs Non Class | |
| Competency | |
| Diagnosis | |
| 5. Interview Results | |
| Choice and Control | 11-20 |
| Respect and Dignity | 21-26 |
| Access to Care | 26-30 |
| Community Integration | 30-35 |
| Additional Comments | 35-42 |
| 6. Goals | 43 |
| 7. Recommendations | 44-48 |
| 8. Unanticipated Outcomes | 49 |
| 9. Future Plans | 50 |
| PTP Answers by Year | 50-51 |
| Survey | 52-55 |
| Works Cited | 56 |

1. PEOPLE TALKING TO PEOPLE PROJECT OVERVIEW

The People Talking to People project (PTP) has successfully completed the fifth year (2007-2008) of operating as an independent quality-assurance mechanism for Tennessee's Department of Finance & Administration's Division of Mental Retardation Services (DMRS). The PTP is a system of quality assurance and quality improvement measures based on a representative number of service recipients and their families providing objective and opinionated interview responses that result in expedited remediation, increased customer satisfaction, and system wide quality improvement. Over the past five years, PTP survey data indicates a general rising level in satisfaction with the services received through Tennessee's support service providers. The PTP helps to accomplish a paradigm shift, moving from a series of overlapping quality assurance systems to a system that is powered and led by the voices, priorities and choices of people receiving services and their families.

The Arc of Tennessee employs 18 individuals with disabilities and people familiar with disabilities (such as a family member of a person with a disability) to work as interview teams across the state. The People Talking to People project has selected and trained teams of two to conduct and collect interviews from randomly selected people receiving services from the DMRS, paying special attention to respecting each person's right to privacy and encouraging self determination and choice. The survey tool utilized by PTP is based on the Center for Medicaid and Medicare Services' (CMS)-approved Participant Experience Survey, altered to increase the survey's applicability and clarity after receiving constructive feedback and suggestions from both the people interviewed and those doing the interviews. A graphically enhanced version of the interview questions with matching pictures, as well as a large-type version, is also shared with PTP teams, enhancing participation of all team members in the interview process.

2. METHODOLOGY

The People Talking to People project has recently completed its fifth year of collecting and analyzing survey data, again providing indicators in four primary areas:

- **Choice and Control:** Do participants have input into the services they receive? Do they make choices about their living situations and daily activities?
- **Respect/Dignity:** Are participants being treated with respect by others?
- **Access to Care:** Are needs such as personal assistance, equipment, and community access being met?
- **Community Integration / Inclusion:** Do people receiving services participate in activities and events outside their homes when and where they want?

A simple random sampling method is used to select the people to be interviewed. After separation of the individuals into nine geographical regions in Tennessee, a single-stage random selection by computer ensures that each recipient of services has an equal chance of being chosen to be interviewed by one of our nine PTP teams. The sampling frame is a list of 8,250 individuals provided by DMRS for the Year 5 PTP project. It is comprised of individuals receiving supportive services, whether through a waiver program, through the state, or through other funding sources. This list is divided randomly to give equal representation to family members' and to individuals' interviewed. Their feedback is used to determine their satisfaction with services received and with the level of self-determination afforded to individuals.

This information regarding the person receiving services is then put into a Microsoft Excel file, filled in with the information provided by DMRS, and sent to the team in each corresponding region. Each interviewing team corrects or fills in missing information and sends it electronically to the Project Assistant through a secured server. A phone log as well as the interview date is recorded in the file. The Project Assistant with the Director reviews these files to note any missing information, the number of telephone calls needed for each interview, or why an interview is missing.

The sample size is assigned by DMRS along with providing the list of 8,250 potential interviewees. The sample size for Year 5 was originally 1000. These 1000 requested interviews were completed with contentious supervision and administration, rigorous hiring practices in regions experiencing high turn-over of PTP interviewer teams, and sound fiscal oversight of program budgetary constraints. The nine PTP teams collected 1,776 surveys from the 1,901 potential people receiving services or their families contacted between July 1, 2007 and June 30, 2008. The statistical accuracy and the representativeness (or relevancy) of the data is enhanced by exceeding the requested number of interviews. For the 8,250 'units of analysis,' the confidence level is 99% at a confidence interval (sometimes also called margin of error) of 2.7 (i.e. +/- 2.7%). That is, with 1,776 valid surveys collected, it is possible to statistically determine, in 99 of the next 100 people interviewed, what these next people would respond to a particular question with an accuracy of + or - 2.7%. Methodologically, this confidence level qualifies the Year 5 PTP data as highly representative, although some interviewers came across people that acquiesce to each question or for people that had difficulty answering questions, answers may have been provided by a family member, or a person providing direct support to the individual (Direct Support Professional-DSP). Confidentiality is well respected by all interview teams and is part of PTP Policies and Procedures, as well as mandatory training. Brochures explaining the PTP are distributed and copies of the PTP manual are available for anyone requesting it.

PTP STAFF

PTP Interviewers

This past year the PTP has employed 22 people to serve as part time interviewers. The people on the interview teams are assigned to conduct interviews in the region in which they live. Two people are assigned in each of nine regions. Regions 3, 4 and 5 have an additional person as a substitute interview partner. As stipulated in the original grant, there are three interview teams for each more expansive regions; East, Middle, and West Tennessee. The regions utilized by the PTP, and the counties included in them, are as follows:

Region 1; Carter, Greene, Hancock, Hawkins, Johnson, Sullivan, Unicoi, Washington

Mary Turner and Diana Barnett are the interview team for region 1 (Northeast). Mary has been working for the PTP since March, 2005. Diana has been working for the PTP since December, 2005.

Region 2; Anderson, Blount, Campbell, Claiborne, Cocke, Grainger, Hamblen, Jefferson, Knox, Loudon, Monroe, Morgan, Roane, Sevier, Scott, Union

In region 2 (East) Jean and Carol Smith are the interview team. They have both been working for the PTP since September 2004.

Region 3; Bledsoe, Bradley, Grundy, Hamilton, Marion, McMinn, Meigs, Polk, Rhea, Sequatchie

Region 3's (Southeast) interview team is Melody and Larry Jacobs. They have been working for the PTP since January, 2008.

Region 4; Cannon, Clay, Cumberland, DeKalb, Fentress, Jackson, Macon, Overton, Pickett, Putnam, Smith, Sumner, Trousdale, Van Buren, Warren, White

PTP Year 5 saw a high turn-over rate in region 4 (Upper Cumberland). Monica and Paula Gardner were an interviewing team for several months, and Rebekah Sieber and Cheryl Coleman

step in intermittently to collect interviews for this region. Rebekah has been substituting as needed since June, 2007. Cheryl has been working for The Arc since September, 2004.

Region 5; Cheatham, Davidson, Dickson, Montgomery, Robertson, Wilson

Region 5's (Mid Cumberland) interview team is Woody Cade and Josh Turner. Josh has worked for the PTP since August, 2005. Woody has worked for the PTP since June, 2007. Occasionally, Cheryl Coleman also substitutes as a team member in region 5.

Region 6; Bedford, Coffee, Franklin, Hickman, Lawrence, Lewis, Lincoln, Marshall,
Maury, Moore, Perry, Rutherford, Wayne

Region 6's (South Central) interview team is Mary Dale Greene and Gail Compton. Mary Dale has worked for the PTP since January, 2007. Gail has worked for the PTP since April, 2007.

Region 7; Benton, Carroll, Crockett, Dyer, Gibson, Henry, Houston, Humphreys, Lake,
Obion, Stewart, Weakley

Region 7's (Northwest) interview team is Don DeVaul and Patrick Sanders. Don has worked for the PTP since August, 2007 and Patrick has worked for the PTP since May, 2007.

Region 8; Chester, Decatur, Hardeman, Hardin, Haywood, Henderson, Madison,
McNairy

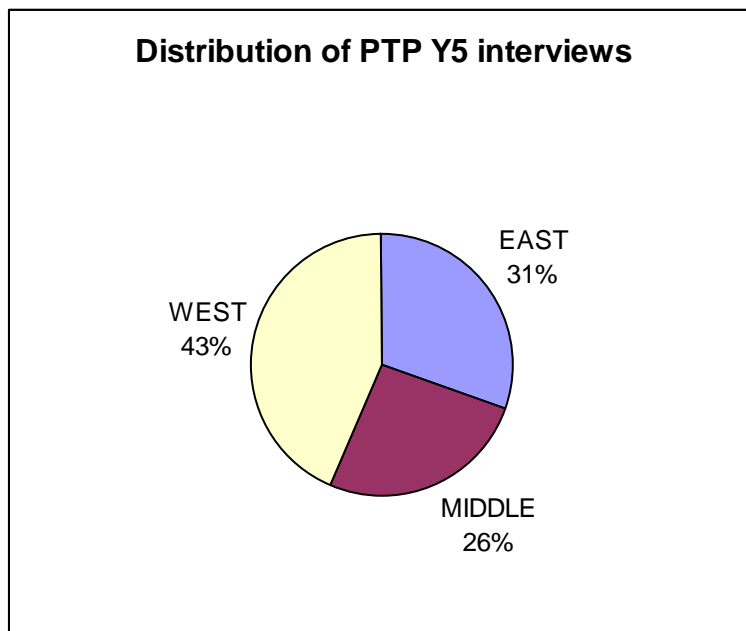
Region 8's (Southwest) interview team is Tom Griffin and Darryl Newsome. Tom and Darryl have worked for the PTP since March, 2005.

Region 9; Fayette, Haywood, Lauderdale, Tipton, Shelby

Region 9's (Delta) interview team is Sondra Loveless-South and her mother Nadine Loveless. Sondra has worked for the PTP since July, 2006 and Nadine has worked for the PTP since September, 2007.

The Arc of Tennessee’s office is located in Nashville. Frank Meeuwis is the Director of the project, and has been with The Arc since April 2007. Holly Newingham (formerly Rossmailer) is the Project Assistant for PTP and has worked for the PTP since August, 2002. The PTP is a success because of the dedication and patience of all the partners of the interviewing teams. Below is the regional distribution of PTP Year 5 interviews attempted.

| Region: | EAST TN | | | MIDDLE TN | | | WEST TN | | | Y 5 Total |
|-----------------------|---------------|-------|-------|---------------|--------|-------|---------------|--------|--------|-----------------|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | |
| Individual | 186 | 95 | 54 | 21 | 158 | 65 | 76 | 214 | 149 | 1018 |
| Family member | 135 | 71 | 42 | 21 | 161 | 64 | 81 | 174 | 134 | 883 |
| Total | 321 | 166 | 96 | 42 | 319 | 129 | 157 | 388 | 283 | 1901 |
| % | 16.89% | 8.73% | 5.05% | 2.21% | 16.78% | 6.79% | 8.26% | 20.41% | 14.89% | 100.00% |
| Region total % | 583 30.67% | | | 490 25.78% | | | 828 43.56% | | | 1901 100.00% |



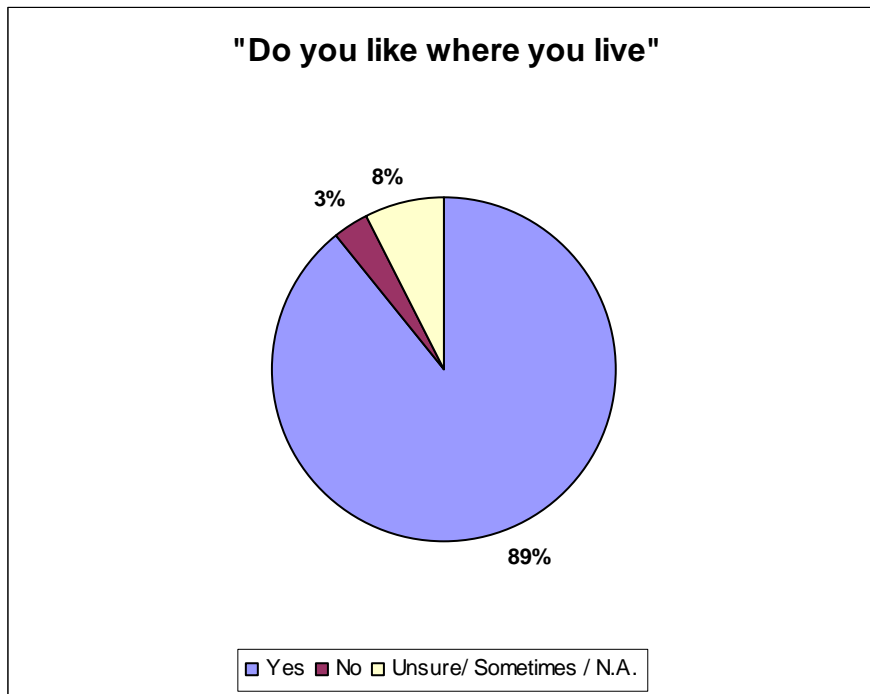
3. DEMOGRAPHICS OF INTERVIEWEES, PTP YEAR 5

| Region | 1 | % | 2 | % | 3 | % | 4 | % | 5 | % | 6 | % | 7 | % | 8 | % | 9 | % | Total | |
|------------------------|------------|-------|------------|-------|-----------|-------|-----------|-------|------------|-------|------------|-------|------------|-------|------------|-------|------------|-------|-------------|-------|
| Gender | | | | | | | | | | | | | | | | | | | | |
| Male | 169 | 52.6% | 95 | 57.2% | 51 | 53.1% | 25 | 59.5% | 170 | 53.3% | 67 | 51.9% | 88 | 56.1% | 217 | 55.9% | 174 | 61.5% | 1056 | 55.5% |
| Female | 152 | 47.4% | 71 | 42.8% | 45 | 46.9% | 17 | 40.5% | 149 | 46.7% | 62 | 48.1% | 69 | 43.9% | 171 | 44.1% | 109 | 38.5% | 845 | 44.5% |
| Total: | 321 | | 166 | | 96 | | 42 | | 319 | | 129 | | 157 | | 388 | | 283 | | 1901 | |
| Diagnosis | | | | | | | | | | | | | | | | | | | | |
| Mild | 73 | 22.7% | 64 | 38.6% | 16 | 16.7% | 14 | 33.3% | 84 | 26.3% | 44 | 34.1% | 47 | 29.9% | 168 | 43.3% | 60 | 21.2% | 570 | 30.0% |
| Moderate | 56 | 17.4% | 45 | 27.1% | 19 | 19.8% | 16 | 38.1% | 101 | 31.7% | 42 | 32.6% | 56 | 35.7% | 113 | 29.1% | 69 | 24.4% | 517 | 27.2% |
| Severe | 101 | 31.5% | 34 | 20.5% | 28 | 29.2% | 8 | 19.0% | 74 | 23.2% | 29 | 22.5% | 33 | 21.0% | 45 | 11.6% | 41 | 14.5% | 393 | 20.7% |
| Profound | 80 | 24.9% | 20 | 12.0% | 6 | 6.3% | 4 | 9.5% | 57 | 17.9% | 14 | 10.9% | 19 | 12.1% | 52 | 13.4% | 105 | 37.1% | 357 | 18.8% |
| Mental | 6 | 1.9% | 3 | 1.8% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 1 | 0.6% | 10 | 2.6% | 6 | 2.1% | 26 | 1.4% |
| Unknown | 5 | 1.6% | 0 | 0.0% | 27 | 28.1% | 0 | 0.0% | 3 | 0.9% | 0 | 0.0% | 1 | 0.6% | 0 | 0.0% | 2 | 0.7% | 38 | 2.0% |
| Total: | 321 | | 166 | | 96 | | 42 | | 319 | | 129 | | 157 | | 388 | | 283 | | 1901 | |
| Competency | | | | | | | | | | | | | | | | | | | | |
| Competent | 115 | 35.8% | 86 | 51.8% | 54 | 56.3% | 28 | 66.7% | 122 | 38.2% | 83 | 64.3% | 109 | 69.4% | 257 | 66.2% | 113 | 39.9% | 967 | 50.9% |
| Guardian/Cons. | 171 | 53.3% | 62 | 37.3% | 28 | 29.2% | 11 | 26.2% | 144 | 45.1% | 32 | 24.8% | 34 | 21.7% | 106 | 27.3% | 119 | 42.0% | 707 | 37.2% |
| Minor | 16 | 5.0% | 13 | 7.8% | 6 | 6.3% | 0 | 0.0% | 5 | 1.6% | 4 | 3.1% | 8 | 5.1% | 17 | 4.4% | 31 | 11.0% | 100 | 5.3% |
| Unknown | 19 | 5.9% | 5 | 3.0% | 8 | 8.3% | 3 | 7.1% | 48 | 15.0% | 10 | 7.8% | 6 | 3.8% | 8 | 2.1% | 20 | 7.1% | 127 | 6.7% |
| Total: | 321 | | 166 | | 96 | | 42 | | 319 | | 129 | | 157 | | 388 | | 283 | | 1901 | |
| Class/Non-class | | | | | | | | | | | | | | | | | | | | |
| Class | 116 | 36.1% | 24 | 14.5% | 9 | 9.4% | 2 | 4.8% | 69 | 21.6% | 10 | 7.8% | 14 | 8.9% | 51 | 13.1% | 105 | 37.1% | 400 | 21.0% |
| Non-class / Unknown | 205 | 63.9% | 142 | 85.5% | 87 | 90.6% | 40 | 95.2% | 250 | 78.4% | 119 | 92.2% | 143 | 91.1% | 337 | 86.9% | 178 | 62.9% | 1501 | 79.0% |
| Total: | 321 | | 166 | | 96 | | 42 | | 319 | | 129 | | 157 | | 388 | | 283 | | 1901 | |
| Expression | | | | | | | | | | | | | | | | | | | | |
| Verbal | 163 | 50.8% | 121 | 72.9% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 64 | 49.6% | 84 | 53.5% | 243 | 62.6% | 96 | 33.9% | 771 | 40.6% |
| Non-verbal | 87 | 27.1% | 5 | 3.0% | 3 | 3.1% | 9 | 21.4% | 0 | 0.0% | 24 | 18.6% | 22 | 14.0% | 62 | 16.0% | 119 | 42.0% | 331 | 17.4% |
| Sign-language | 4 | 1.2% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 1 | 0.3% | 0 | 0.0% | 5 | 0.3% |
| Gestures/limited | 25 | 7.8% | 1 | 0.6% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 24 | 18.6% | 11 | 7.0% | 53 | 13.7% | 29 | 10.2% | 143 | 7.5% |
| Comm. Device | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% | 3 | 1.1% | 3 | 0.2% |
| Unknown | 42 | 13.1% | 39 | 23.5% | 93 | 96.9% | 33 | 78.6% | 319 | 100% | 17 | 13.2% | 40 | 25.5% | 29 | 7.5% | 36 | 12.7% | 648 | 34.1% |
| Total: | 321 | | 166 | | 96 | | 42 | | 319 | | 129 | | 157 | | 388 | | 283 | | 1901 | |

1. INTERVIEW RESULTS

Results from Year 5 may be compared to interview results of the previous years, and more precisely with those from last year. Several answers to interview questions, separated by PTP Year, can be found at the end of this report on page 51. The pie-charts below represent selected interview responses from Year 5 (fiscal year 2007-2008) within each of these areas; Choice and Control, Respect and Dignity, Access to Care, and Community Integration.

A. Choice and Control



Eighty nine percent of people that responded said they liked where they lived. Almost everyone that stated they were unhappy where they lived did not choose that place to live. Following are both positive and negative examples of comments recorded during the survey.

Do you like where you live?

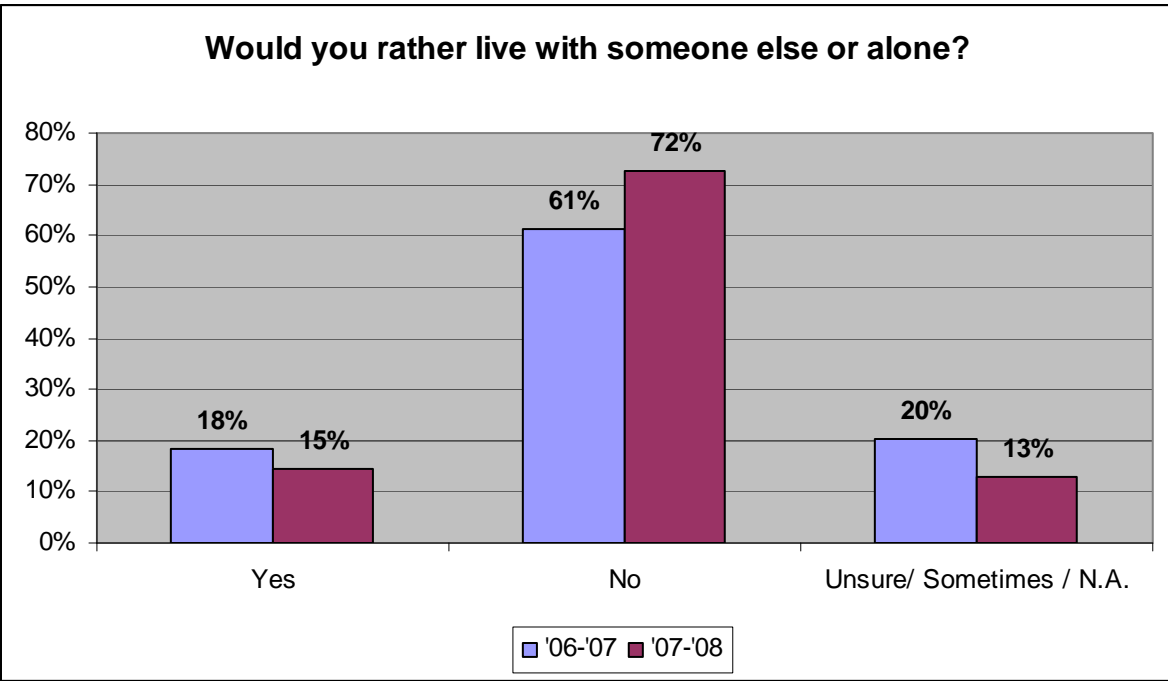
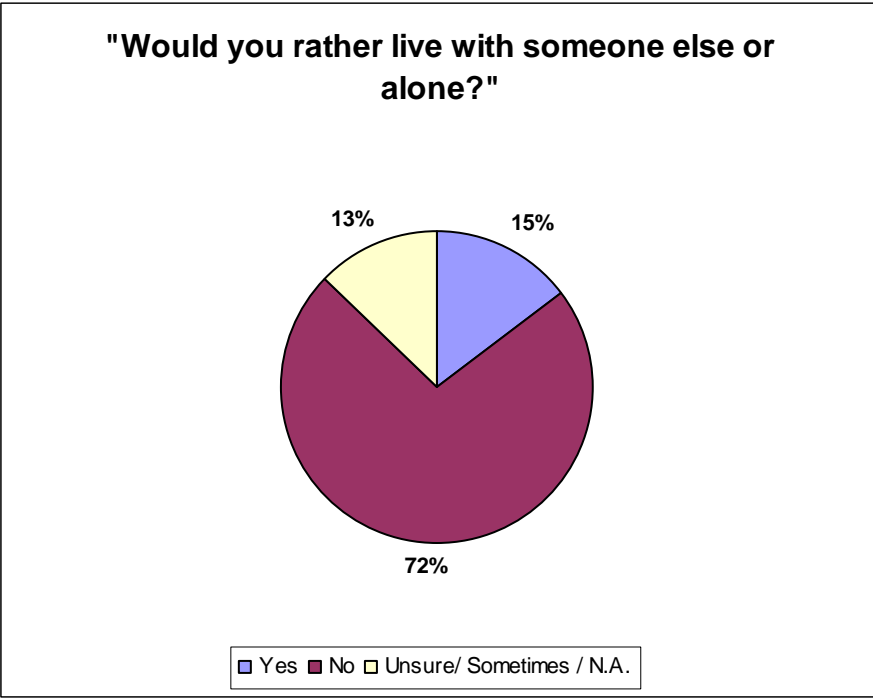
Positive:

- "Jennifer likes living in a gated community. It has a swimming pool, exercise room and free movies.
- She is non-verbal and signs she is happy.
- They have lived together for 30 years. They were roommates at GVDC. (per staff)

- “It's great.”
- He likes his home.
- Loves this place, goes to church every Sunday.
- “I like my apartment.”
- She loves it.
- "We are real satisfied with where he lives and the way he is treated."
- "He loves living here because he knows just about everybody and they are very good to him. We left the farm to move here because he wanted to,"
- "Likes having his own housemate"

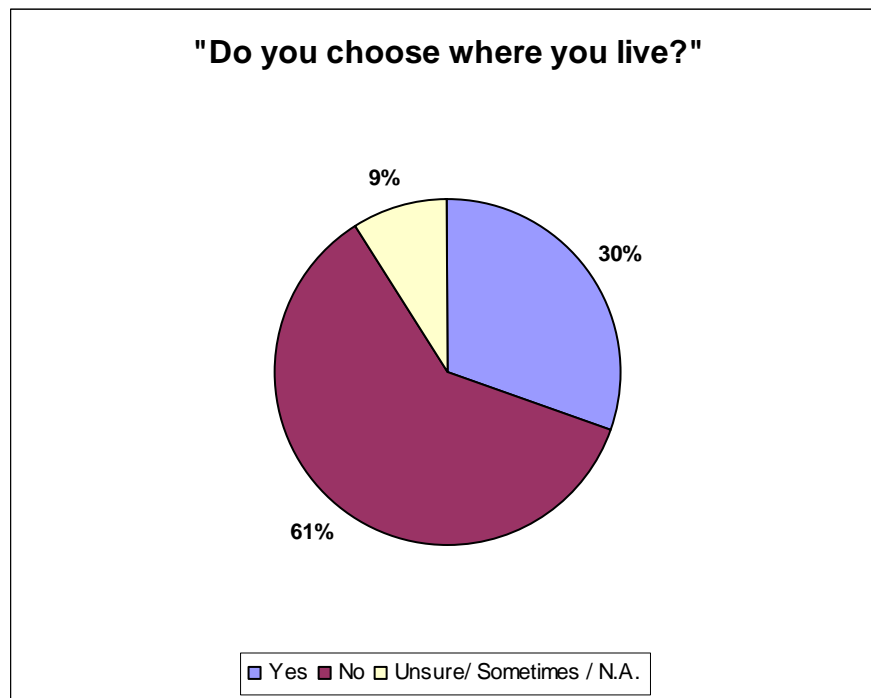
Negative:

- She wants to live with her father; the State removed her from him.
- “I hate it.”
- The agency got together and moved him. The family was not happy about the situation. He liked where he was, but they moved him anyways.
- Lives alone with 24 hour support, doesn't get time alone with roommates.
- Mother and father in bad physical health, wants to move in with twin brother in residential home 1/2 block away.
- “It’s not accessible.”
- "Where I live is too small."
- She doesn't like where she lives because when we bring her home, she is not happy."
- "There is a big drug problem in my neighborhood. It is very dangerous there. I want to move as soon as possible."
- "I hate where I live. All the house manager and the staff members do is sleep all day. [The person serving as my independent support coordinator (ISC)] says they're not supposed to do that. The house manager throws food away. The house manager threw me up against the wall and put a hole in it (he showed me the alleged wound where he says he was thrown up against the wall. He definitely had head trauma.) He also said it was the second time he had been thrown against the wall. He said he has told his agency but he says they've done nothing about it."
- Feels not safe, projects are near.



When this question is compared with the previous year's interview data the graph reveals increasing satisfaction that people receiving services have with their current living situation. Similar improvements over the previous year have also been made for at least 9 other of the

interview questions. (Please refer to the color-coded chart on page 51 for a break down of select answers and comparison with responses from the previous PTP Year.)



Did you choose the place you live?

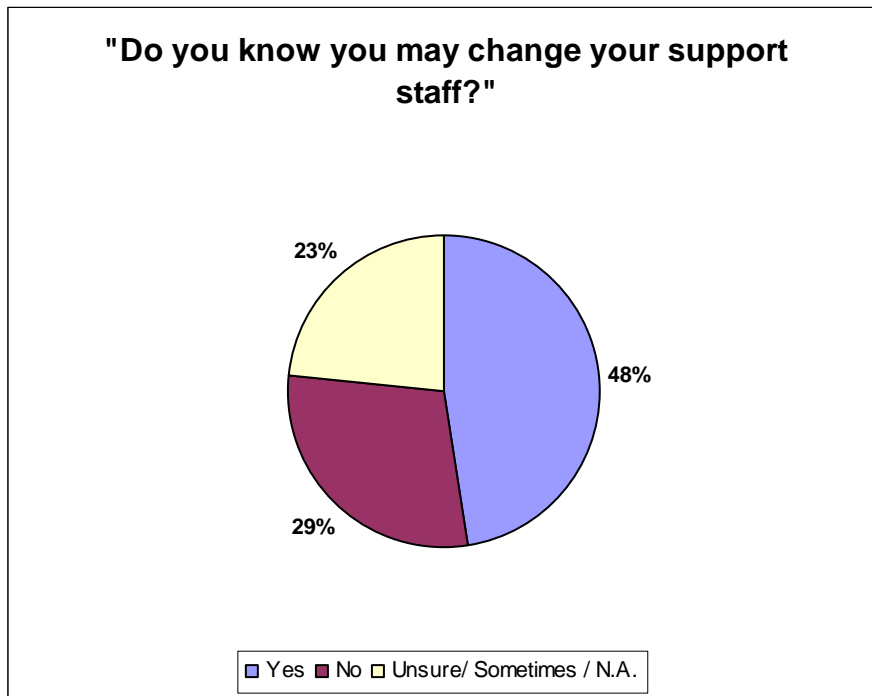
Positive:

- Agency and parents chose place to live.
- Roommate & client chose place.
- Lives w/ family.
- Me and my family.
- It was a process where we would come and visit her first.
- Family was the first in Bristol to get a grant to build the first group home.
- They took him around and let him look.
- Helped pick it out.
- Family home turned into residential group home.
- ISC Helped.
- "He spent one night there and decided he wanted to stay."

Negative:

- Agency chose.

- Church Leader recommended. Service recipient has tried to escape. His mom is unhappy with the residence, has many problems. Mother has conservatorship and is currently trying to get him out of there.
- State chose.
- Chosen for me.
- The developmental center just moved him there. They did not give him a choice.
- The workers took his choice away.
- They just took me there.
- House is unsafe because trees could fall on the house.
- She came to us in a crisis situation; there really wasn't a choice.



Many people were pleased with their case manager or ISC. The number of people responding to the interview that said they knew they could change their support staff increased from 35% in Year 4 to 48% in Year 5—an increase of 37% in the proportion of affirming responses. However, the number of people responding to the interview that said they did not know they could change their support staff also increased from 24% in Year 4 to 29% in Year 5—a significant 20% change in the proportion of individuals knowing they could change their support staff. Most notably, the number of people

responding to the interview that were unsure, replied “sometimes,” or for whom the question did not pertain, fell by nearly half from 41% in Year 4 to 23% in Year 5.

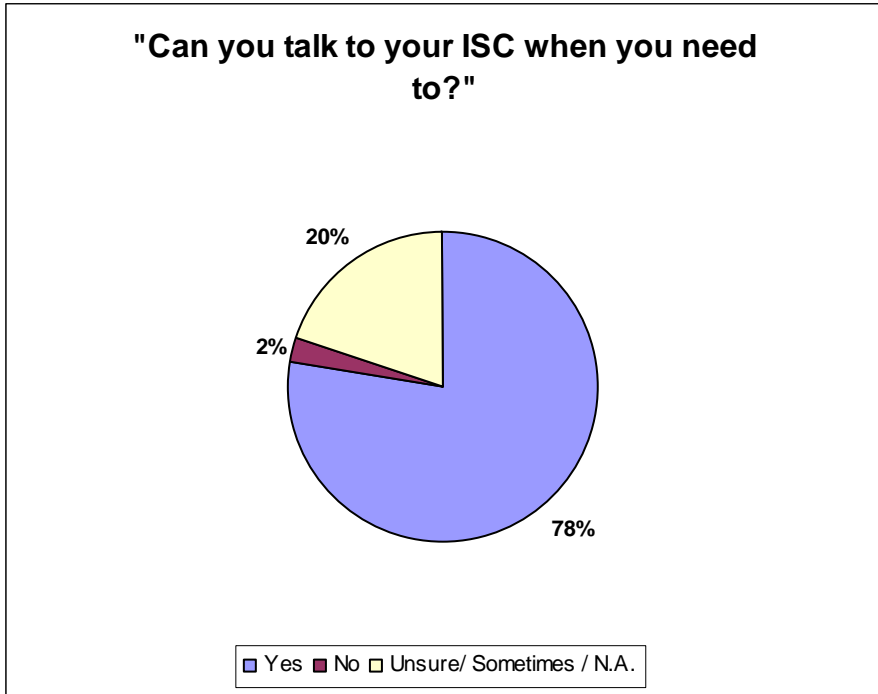
Do you know that you may change your support staff?

Positive:

- He picked who he wanted.
- Thought she knew that, but don't want to fuss.
- There was a staff member that was mistreating him, and mom called and reported it to agency.
- I never had any problem with any of them.
- Have had an incident where he was hit and the staff was removed.
- Learn that in training.
- I know my rights.
- We've changed staff several times

Negative:

- We leave messages, but they rarely call back.
- I didn't know I had that right.
- I am not happy with one staff person because she stays on the phone and does not help me. I told the office, but nothing is done.
- They don't listen to me.
- There is one staff that is mean and rude. They have talked to her about it.
- "Jack has expressed negative things about some of the PAs he has had in the past."
- I don't know about that.
- "No one told me I had the right to change my support staff."



The proportion of people interviewed that responded that they could talk with their ISC when they needed to increased from 57% in Year 4 to 78% in Year 5. The relevancy of this positive result is also strengthened because people responding to the interview who answered neither negatively nor positively decreased by more than half when compared with PTP Year 4's (2006-2007) 42%.

Can you talk to your ISC when you need to?

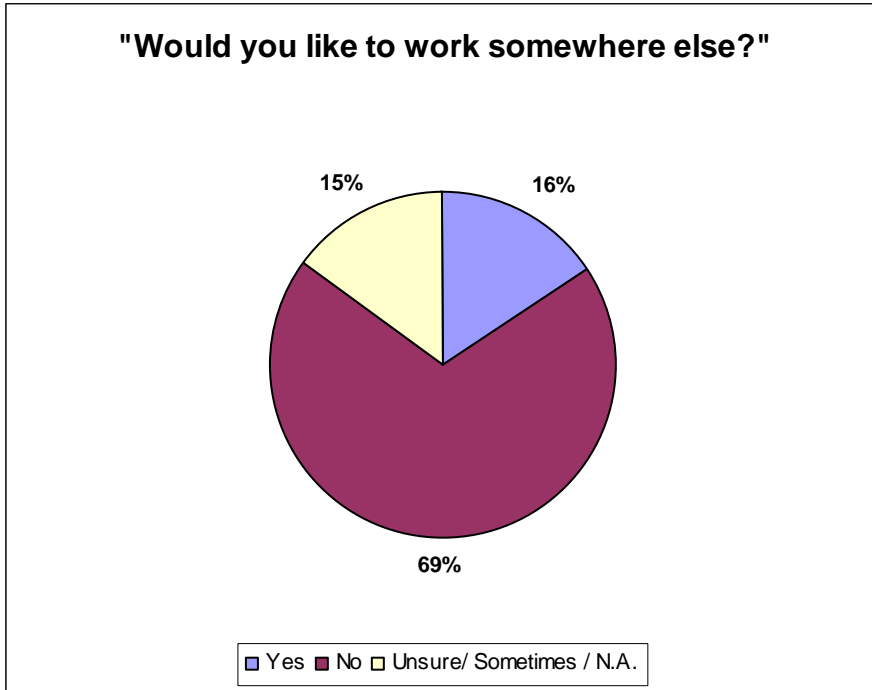
Positive:

- He visits once a month.
- My ISC does a great job 110%!
- She is great.
- At times, they say they will call back but it takes a while.
- He is dependable.
- She checks on him often.
- She is my friend.
- We hear from her within 3 days.
- "The staff does a great job in meeting his needs."

- “They do a good job and those that have been there for a very long time are very devoted.”
- She's pretty responsive.
- He has her phone number and he uses it.

Negative:

- ISC has been changed three times this year.
- He has a toll free number but I can't get him
- Doesn't know, new guy took over case.
- We're supposed to get a new case manager but no one's told us; right now we just talk to the support coordinator at the agency.
- She is hard on me. Won't let me have my ways. She won't let me do what I want to do. I am 33 years old and I am old enough to know what I want.
- She has not bonded with him.
- Doesn't feel like the ISC worker is doing her job and wonders why she is not following up with certain problems.
- I can't reach him half the time.
- She don't always return my calls.
- Haven't had him long enough. They keep changing them around.
- "There is a lot of turnover. Many of the staff are recent college graduates and the job just does not pay enough.
- Individual did not know her ISC's name and neither did the staff. Staff said the entire year she'd been working with the individual she'd never seen the ISC - but it was possibly the ISC came only to the individual's house; interviewers had to give staff ISC name.



Year 5 also reveals increased satisfaction in current work placement because of a greater than 60% decrease in the proportion of people responding affirmatively to the question as to whether they would like to work somewhere else—from 27% in Year 4 to 16% in Year 5. The number of Unsure / Sometimes / N.A. responses also decreased from 24% of respondents unsure in Year 4 to 15% of respondents unsure in Year 5, indicating greater accuracy in the answers collected to this question. Many people stated they liked where they worked but were not given much choice in the matter. Many stated that they wanted to work out in the community:

Would you like to work somewhere else?

Positive:

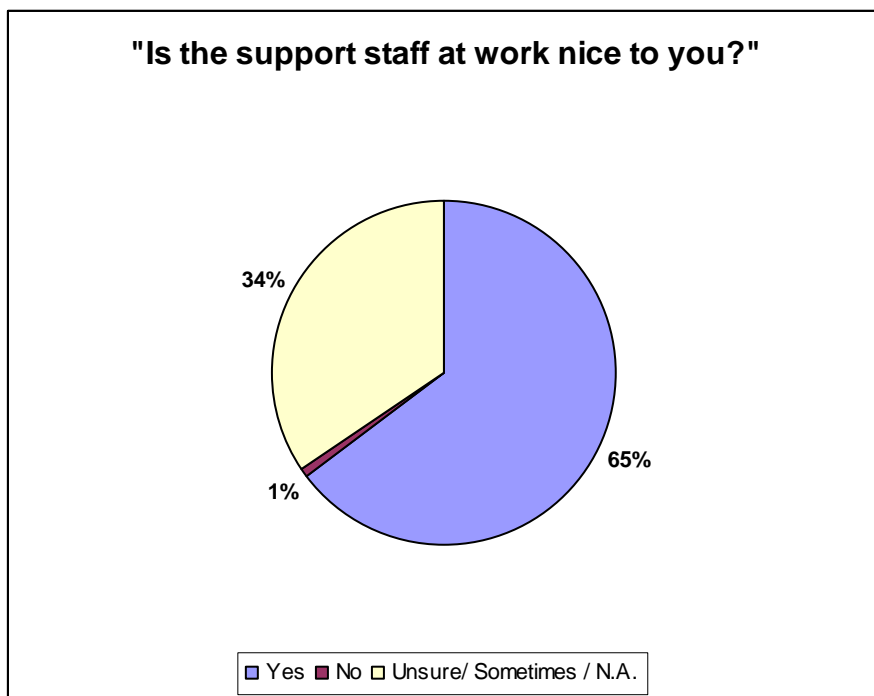
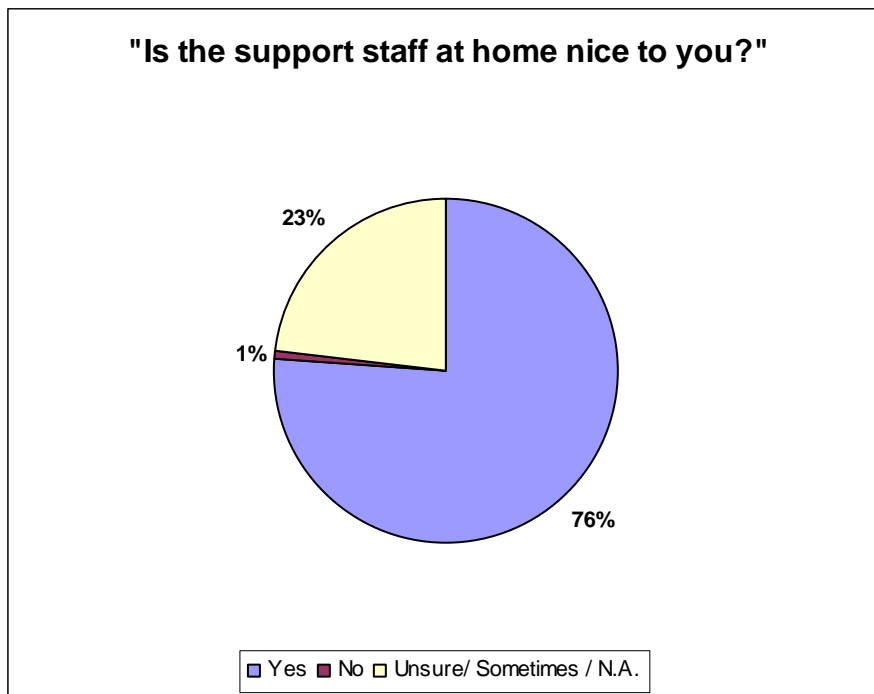
- Loves working at Walgreens
- Like to work at Wal-mart
- Shreds paper & greets people. Loves his job.
- Loves working at Pizza Hut.
- “I love my Goodwill job. I don't want to go nowhere else.”

Negative:

- “I want to mow yards.”
- “I want to work with babies.”

- “I want to be a pro-wrestler.”
- “I want to go to a day program, but there is no transportation.”
- “I want to work at Wendy’s.”
- Like to work as a bagger.
- "I would like to be a DJ on a country radio station."
- “I would like to work at Kentucky Fried Chicken...I like fried chicken and French fries.”
- “I’d like to work in food services.”
- “I’d like to work with cattle or at a sale barn.”
- “I’d like a job as a door greeter.”
- Like to baby sit
- “I’d like to work at PetCo.”
- “I’d like to work as a janitor.”
- “I’d like to work as a car mechanic.”
- Machinist.
- Wash the vans.
- Wants to work at subway.
- Fishing.
- Fold towels.

2. Respect and Dignity



Comparing Year 4 and Year 5 responses to this question, there is a statistically significant shift of more than an 18% increase in the proportion of people responding that the staff at home is

nice to them, (from 64% responding affirmatively in Year 4 to 76% responding affirmatively in Year 5). Between Year 4 and Year 5, there is an insignificant difference in the proportion of people responding that the staff at work is nice to them.

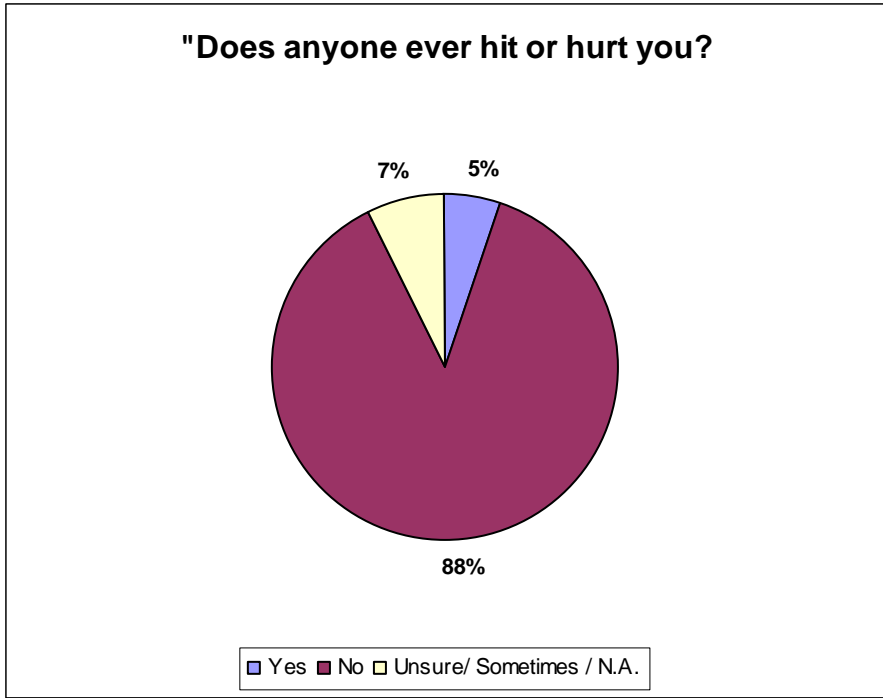
Is the support staff at home / work nice to you?

Positive:

- “He loves all the staff, they treat him just like family; I couldn't be happier with them.”
- Staff is very supportive and encouraging.
- "We are very happy with the support staff we have now."

Negative:

- “We have had trouble in the past, thought they were rude to her and impatient with her.”
- "I (the mother) am a trained PA, but I need more help. We have trouble getting good PAs because the pay is low. Quite frankly, we have gotten some "slugs" in the past. I would like to know why it takes so long to do background checks on PAs. With the internet, it should just take 1-2 hours. I have a PA who wants to start soon. I would like to know what a reasonable time to train a PA is."
- “Two staff members have had to be let go because of abuse issues; when I go over there now they seem to be nice to him but I worry about him all the time-I'm just not sure.”
- "The weekend person(s) that stay at her home tend to be not as dedicated as those who stay with her during the week."
- "He chooses not to go to a certain agency because there would be trouble if he went there."
- "I am not all that happy with my agency."
- “He has been physically abused by many non-caring persons at the developmental center on several occasions. There is an investigation going on right now.”
- “Support staff gets mad at me sometimes.”
- Teasing home staff.



Does anyone ever hit or hurt you?

This question has occasionally stirred-up past events and accompanying emotions for the person being asked. PTP interviewers note that people receiving services and / or their family members felt uncomfortable calling the abuse or complaint hotlines, and had several times asked the interviewer to do it for them. The PTP has a protocol with Protection from Harm staff at DMRS Central Office. Each interviewer notified of a possible situation immediately informs the Project Director of any situation by phone or email. The director then calls in the situation to the complaint or investigations departments within DMRS where from corrective action should shortly follow. In collecting the survey responses to this question, people interviewing are encouraged to help the people responding to use their own words, thought patterns, and values when answering questions. There is a significant increase in the number of people receiving services responding negatively to this question with 88% denying being hit or hurt compared with 80% in Year 4. The qualitative answers are the best way to describe a few of the incidents:

Positive:

- "He has been hit in the past, but those staff who hit him were fired."
- "In the past, there was some verbal abuse and one staff member pushed her down, but this is not happening at all now."

- A staff member hit an individual at the workshop. “He threw screws and hit me in the face. I talked to a man, like a judge, and they took him out of the workshop.”
- -Another individual “gets frustrated and sometimes will smack everyone else, she doesn't really hurt anyone, though.”
- -“Some time ago we had an incident with one of his caregivers, but I let the agency know I didn't want to see him again ever, and he was replaced; things are fine now.”
- -“Defend myself.”
- -Individual doesn't get along with another. The staff watches and keeps them separated.
- -“D. hits staff sometimes; he would also let you know if somebody hit him.”
- -He got scratched yesterday but that was just a classmate having some problems, it wasn't on purpose.
- -“He was abused in the past but not now.”
- -His housemate sometimes hits him, but it's infrequent
- -“I would tell.”
- -Father said she has fallen and hurt herself and is self-abusive, but nobody has ever hurt her.
- -“No siree. Nobody will ever hit me cuz I'd backfire em!”
- -“She understands that if anyone does anything to her she could verbalize it and knows that if someone does something to her she's to tell us.”
- -Staff indicated that she could take "good care of herself", that she would and could defend herself; individual stated "sure could!"
- -Was abused by a worker years ago and the worker was dismissed.
- -“Never have hurt me here before.”

Negative:

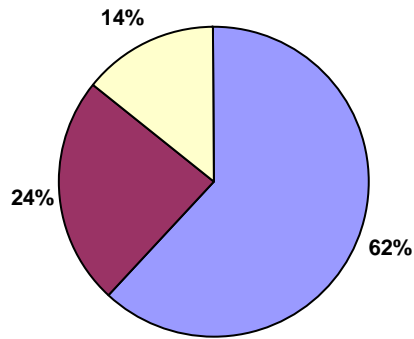
- -"A member grabbed him by the arm and assaulted him. He had a few bruises."
- "C. and S. hit me with a blue chair and I had to go to the hospital. He still yells in my ear."
- "My Dad hits me."
- “He sometimes kicks others, they might hit back.”
- He hits himself.
- “He was very abused at his home before; he ended up in the hospital for days and our doctor said he wouldn't release my son back to that place.”

- “I had a boyfriend who done that.”
- In the past her birth father used to beat her so bad he caused her to be blind.
- Last housemate assaulted him.
- “My uncle.”
- She got knocked down last week hurt left arm & wrist.
- “She sometimes hits her roommates and they hit back... it never amounts to much.”
- Was raped by staff.
- Was spanked by her special Ed. Teacher.
- “Yes, I have been hit on and raped.”

There are two questions on the survey that pertains to abuse, which are *Has anyone ever hit or hurt your body?* and *Does anyone ever yell at you?* Approximately 14.8% answered yes to *Does anyone ever yell at you* during Year 3. In Year 4, this measured 13.7%, and this dropped again to 8.0% (127/1,579) in Year 5. In Year 3, the number of people answering yes to *Has anyone ever hit or hurt your body?* is 9.5%. In Year 4 this decreased to 8.2%, and in Year 5 the number of people answering yes to this question fell to 5.6%. Occasionally, older cases were brought up during the interview due to the question (“*Have you ever been hurt or hit?*”). It is sometimes difficult to discern the alleged time of abuse unless a specific time was given. The Civil Rights and Protection From Harm departments of DMRS has changed their procedures attempting to make incident reporting more timely, reliable, and reportable, in part due to the work of the PTP. In compliance with new assurance standards set forth by the Centers for Medicare & Medicaid Services (CMS), in Year 6 the PTP and DMRS is implementing a more direct and official notification process intending to accelerate remediation in situations that warrant correction or other action.

When people were asked if they knew how to file a complaint in case of an abusive situation, in Year 4, more than half (55%) knew the complaint filing process. In Year 5, this measure has increased to 62% of people responding to the interview.

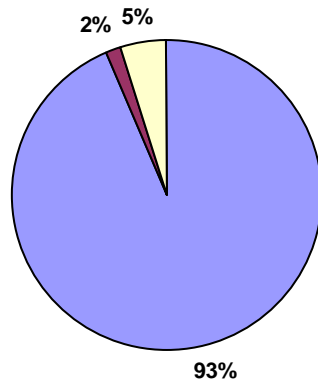
"Do you know how to file a complaint if someone hits/hurts/yells/steals from you?"



■ Yes ■ No □ Unsure/ Sometimes / N.A.

3. Access to care

"Can you always get to the places you want?"



■ Yes ■ No □ Unsure/ Sometimes / N.A.

For the question “Can you always get to the places you want,” Year 5 shows a 4.5% increase in the proportion of affirmative responses—from 89% in Year 4 to 93% in Year 5. Although statistically an insignificant shift, the positive variation is encouraging in light of recent increasing transportation costs.

Can you always get to the places you want?

Positive:

- "Her housemate takes her to the grocery store to buy food and hygiene items."
- "It's hard to get him to go to the doctor, but his caregiver does a great job with him" the mother says.
- "He limits his driving to short distances, but he is able to get to where he needs to go."
- "The new van has a lift which works real well."
- "Always."
- Bus or cab.
- Family (father / mother / sister / brother / cousin / children / neighbor) always help transport.
- Case manager or staff takes her / him.
- "During the week I have a van that's always accessible for me, but on the weekends and nights my housemate and I have to share."
- Has own van / car.
- Loves to go to church.
- Companion takes her when and where she needs to go.
- "I want to go Christmas shopping but that's not yet!"
- "Just got a new van."
- "Let me tell you something, right now I just walk, but I'm going to get my driver's license pretty soon; I took the test and I already passed it; when I need to go to the doctor a lady here takes me."
- One of the requirements for this job is that all staff have a car and are willing to transport the individual to wherever she needs to go, so yes.
- Regular trips.
- Agency staff transports the individual.
- "She can't get around too well but she has the help she needs."

- “She loves to go to the flea market.”
- “She's taken out frequently and goes when she wants.”

Negative:

- "Because we can not pay for a van to have a wheelchair lift, I have to take off from work to take him places. Sometimes, a nurse helps us."
- "The van is not working now which makes it hard for him, so, currently, he is using Access Ride."
- “Absolutely she can, but it has to be done by ambulance.”
- “The staff has been cut, so it is harder to get out.”
- “She is seldom taken out because of her violence & destructive behavior. She undressed 1st time she was taken to the mall.”
- “Don’t always have gas!”
- I want to go fishing but I can’t get staff to take me. They just go riding around.”
- “If we have gas money!”
- “If I walk!”
- “Our support isn't always here and we can't always take off of work.”
- Staff does not always have gas to take him to places.
- “There are so many people, it's hard to go when you want to; it's just hard.”
- There is not a van for him to use to get him out into the community.
- Vehicles were not accessible for persons with disabilities.

Is there equipment to make your life easier?

Nearly 11% of the people interviewed in Y4 answered yes to needing special equipment that would make their life easier. This measure of need fell by more than one fifth to 9% in Year 5. The PTP interview does not place equipment in specific categories. Of the 150 requests, 38 were for accessibility accommodations / maintenance to their homes including; ramps, railings and grab bars for in bathrooms, 25 were for wheelchairs, 13 were for medical devices including an insulin hand pump, new eye glasses,

hearing aides, or services like PT and OT, 8 for communication devices, and 5 for vans or personal vehicles. A new bed, new computer software, and a computer were each requested 4 times.



Some people interviewed reported waiting too long for important items. The “Other” category includes a variety of responses such as; “a grab-belt, a bicycle, a blender, a cell phone, a new recliner, a pool lift.” The following are some examples of answers, by category, to this interview question:

[Do you need any special equipment?](#)

Medical:

- New hand splints.
- Crutches.
- A breathing machine.
- A hearing aid.
- A lift for shower / bed, a commode chair, and a transfer board.
- A portable suction machine.
- New eye glasses and shoes.

Technology:

- A computer.
- A communication device / board.

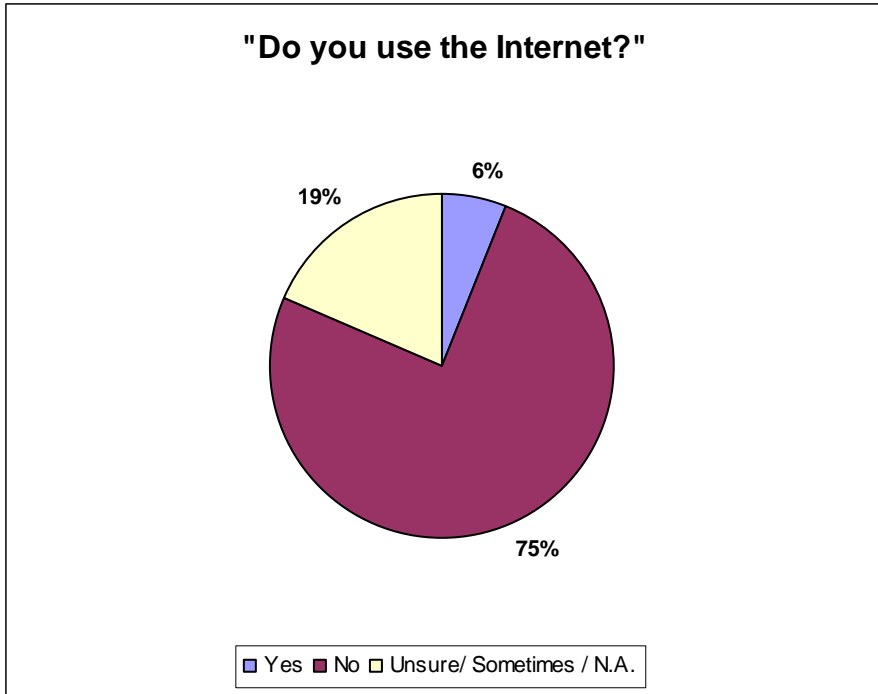
- Computer software.
- A magnifying screen for the computer.

Access and other:

- Grab-bars in shower and bathroom.
- A ramp for access to the building.
- A wheelchair lift for our van.
- A headrest for my wheelchair.
- A power-wheelchair.
- A scooter would be nice.
- A bicycle.
- A blender.

4. Community Integration

Research on community integration is lacking in terms of clear definitions for what constitutes “community integration.” Many researchers consider the use of media to be highly correlated with what is accepted as a general definition for community integration (McLeod, et. al.). Several people interviewed by the PTP are working directly in their communities at Wal-Marts, Pizza Huts, Sonics, Mobile Meal programs, and other service sector jobs. There is a great number of people with a disability surveyed by the PTP in Year 5 that are still not using the internet even though nearly three out of four U.S. households with a phone line have access to the Internet, according to a February 2004 Nielsen / NetRatings survey. In the entire United States, 204.3 million people have access to the Internet, or 74.9 percent of the population. Another study during the first three months this year found that of 1,088 adult heads of households in the United States 79% had used the internet to look at a website or to search for information, and / or had used email for communication. Excluding the Unsure / sometimes / N.A. responses in Year 4, 7% of people interviewed responded that they use the internet. In Year 5, the same measure has declined slightly to 6% (see page 51). This population continues to lag behind the national trend, indicating another barrier to community inclusion and participation.



Additional questions related to and under the heading community inclusion are; *Can you visit with the people you want to when you want?* and *Do you have a boyfriend / girlfriend?* Year 5 interview responses are charted in the following pages. The boyfriend / girlfriend question is important in light of a prevailing tendency to judge people with disabilities as asexual (Milligan & Neufeldt, 2001). The population served by DMRS faces this issue in their daily lives, and more discussion of relationship issues with staff and families needs to be embraced and will lead to an increased range of opportunities and experiences for self determination for people with disabilities.



This measure for Community Integration statistically changed insignificantly, though falling from 73% in Year 4 to 69% in Year 5.

Can you visit with the people you want to when you want?

Positive:

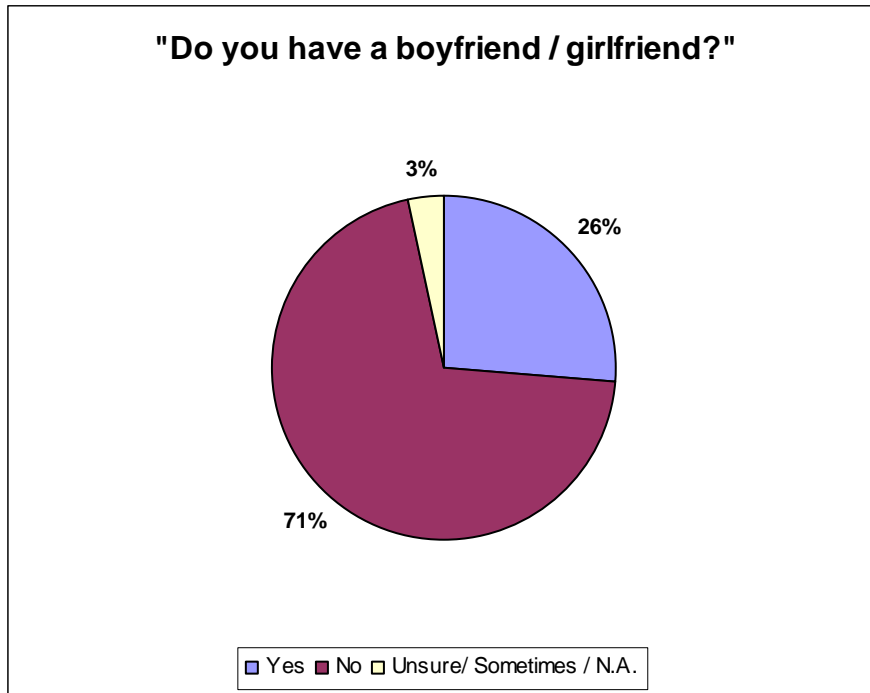
- Aunt that visits regularly and the sister visits.
- Besides his teacher, there isn't anyone in particular he likes to visit; he just likes to get out and go places.
- Her mother's niece and comes up about once a week to check on her.
- Every three weeks.
- Every other weekend.
- Family pick him up on Friday & keep until Monday.
- Has friends in other apartments he likes to visit.
- He can pretty much visit who he wants to when he wants to and he likes a lot of people
- He has pictures of his family and when he wants to see them he'll bring out his pictures, and when he does that staff call and his mom will come right and get him; his family is very responsive.

- His family pick the time when they want to see him; they see him about every other week, but they are very active in his life; he also likes to visit with staff.
- “I see 'em when I want to, uh huh. We get together all the time.”
- “I'm going to see him this coming Christmas.” (staff said his dad calls and makes appointments; they do talk to each other a lot and see each other for every holiday).
- “My church family takes me to see my family whenever I want; they're wonderful to me.”

Negative:

- Her family doesn't seem to want her and aren't open to her coming - but she can visit her neighbor when she wants.
- Aunt works so it is hard to go see her when she wants her to.
- Family lives too far away.
- Can't afford it.
- Don't have money.
- “I am not allowed to go into other people's houses.”
- “I don't get to see my family.”
- “I can't get out.”
- “My dad will not let me see my sister.”
- "I don't get to see my dad much, he is very sick"
- "I would like to know more about the persons that are helping [my family member]. I had her in a program/home in Waverly, and I was very disappointed about her conditions there and moved her to Dickson. Dickson is much improved."
- "It's hard to visit my mother because she is very busy.”
- No contact with birth family except mom once a year.
- No one has visited him in over six years.
- Not any more; she can't because of her medical condition.
- Parent calls when she wants to see him; [individual] can only see family when they choose.
- She isn't always able to see her friends at the center but she always sees her housemate.
- Staff indicated she is unable to visit family without their approval and they often refuse.

- They live too far away.
- Staff indicated she never sees her children; she also has grandchildren that she's never seen.



Do you have a boyfriend / girlfriend?

Positive:

- "Several girlfriends."
- "A girl at the restaurant."
- At church.
- At learning center.
- "We're going to get married in April. He asked me to marry him a week ago."
- "Eat lunch at the workshop with her. We go on dates to the movies / dances."
- "Go bowling and go out to eat with me."
- Has a Friday social night, no girlfriend yet.
- "He comes over to the house and we watch movies."
- "I get to see her once in a while. I want to marry her and settle down."
- "Indiana Jones."

- “Johnnie Depp.”
- Likes a girl at Wendy’s.
- Many girlfriends, none special. He likes dancing.
- “Sometimes I do, sometimes I don't; I prayed to find me a fella that will be good to me and do things for me and my family who will love on me and keep my company.”
- “We go out and go to the prom.”
- “Yes, I do. He lives right next door to me. He has a light blue car. I ain't saying his name.”

Negative:

- "I hit my boyfriend once. I have a fear of being written up even though he hit me first. Some people say I am abusive.”
- "She has a lot of boys that are friends, but we want nothing serious to develop. We are afraid and watch for that."
- When she was at the developmental center, she complained that boys came into her room and teased her.
- Can’t see him all she wants.
- Don’t go out.
- Family thought this question should not be asked.
- “My dad don’t let me have one. He don’t want me to get married.”
- “No Ma'am, I don't have nothin!”
- “Same one I been with. She used to work here, but it's been a long while since I saw her. With me working I don't have time to do nothing.”
- Staff feels like it would be unsafe situation.

Is there anything else you would like to add?

This final qualitative question creates an opportunity for individuals and family members to express additional comments or concerns that would not have otherwise appeared through the interview process. Following are brief examples of comments made by people interviewed. Comments are both positive and negative:

Positive:

- "He has a behavioral problem, but the people at his job let him work up to 6 days a week because they understand him."
- "I have enough privacy."
- "She is doing real well. The support staff treats her very well."
- "He loves a strict schedule. He is meticulous with his work habits. He really doesn't have any problems."
- "I am satisfied with the amount of privacy I have."
- "I have nothing but praise for [the agency]."
- "I like the way he is taking care of himself," his father says.
- "The case manager is great at getting [our daughter] what she needs."
- "The support staff is just great. She has a better life than she would if she lived with me."
- "All is good except case workers need to spend more time talking to me."
- Dream is to save his money to live on the river.
- Everything is fine.
- The developmental center is the best. Not interested in community living at all.
- He is involved in many activities and loves the group home.
- Likes where he lives.
- She is very happy. The services are great. The family is happy that all her needs are being met.
- The mother received a letter [from The Arc] and appreciates that.
- "No, we are very pleased with what we're receiving right now."
- "Not at this time. Can I call you if I think of anything?"
- She was glad to meet us.
- Sometimes I am satisfied with the amount of privacy I have.
- There are things in the system that could be improved, but in her life all is well.
- Very happy.

- Very thankful for where she's at.
- We are pleased with [the developmental center.] I think sometimes the meetings get a little silly with "[He] wants to do this and [he] wants that." We know that [he] doesn't voice his opinion, but that's okay. We are satisfied with their work and their care of our brother.
- We are very happy & proud of the services [he] receives.
- "Well-satisfied with staff services."
- Yes, he is happy with services.
- Loved [the developmental center.] Only place she wasn't abused until current home. Front teeth knocked out in 1 location, raped in Bolivar. All the other places she was abused with the exception [the current center]. She is treated good here.

Negative (by category):

- Does not have enough time to himself.
- He says too much red tape to get anything done.
- His mom believes that there are issues of gross misconduct, neglect, etc. Also has worries about possible sexual misconduct due to condoms being found outside the building.
- If she had not received the letter from [The Arc in] Nashville, she would not have interviewed. She likes the name with retarded in it because that's what they are & the doctors diagnosed it & it should not ever be politically changed.
- "Some of the funding was cut from [the agency] and that really concerns me. The things they enjoy is being taken away. The fun stuff adds so much more to the quality of life. The therapy that she gets is very important."

Choice

- "I want [my child] to be self-sufficient. A lot of parents won't fight for their kids, but I will. Our family does not support us very well. There are a lot of persons who call but don't support us."
- "I don't trust the staff here. I don't mind having staff in the house first or second shift, but I want to be alone on the third shift. The staff is an invasion on my privacy. I want to live alone. The house manager has to approve of my friends before I can go out with them."
- Can't get out as much because roommate doesn't want to go and since the cut back there is only one staff member.

- I do not want him moved out of the developmental center to a group home.
- She wants to change agencies. She is very unhappy with service / staff.
- Wants to go back to mom's (foster mother.)

Economics

- "I feel the state should pay me for being her caregiver."
- \$145 bill for a pap smear, Medicare won't pay, recover the \$28,000 her other payee stole from her, they do not pay her for her dental, pay for her eye-exams.
- "Agencies need to pay more to the [individuals] so the [individual] can have a better life. They have to pay for some of their own medicine. The state needs to take care of their medicines."
- I get 4 pair of medical panty hose a year. After that I have to pay \$100 a pair. My home needs home improvement and upkeep. The carpet is really old and needs replaced.
- Mother became conservator without my permission. She has it where I can't do anything like go places without women staff going or go into my neighbor's home. I want to work somewhere else. I don't like people asking me about my bowel movements or where I am going. I want to be my own conservator. I am a 33 year old married woman.

Employment

- "I really do not know what [he] does all day. He just sits there and stares and responds very little to anything."
- "I'd really like to move, and I'd like to get a job."

Medical

- "I am getting older, and my biggest concern is to have an advocate for my loved one when I die. I want to be sure he has his own place. I am concerned for his well-being."
- "The state does not really have a finger on the pulse on what's going on because they should look at the whole family's needs, not just the needs of the individual."
- Concern about medicine—thinks it is messing with her speech. Wants staff to communicate with family for any doctor's visits, any problems she is having, wants staff to follow instructions about calling nursing home before they take her to see her 91 year mother.
- He has to pay for his own hearing aid. We think the state needs to help out with hearing aids.

- He pays for his own dental and some medicine. He likes to go fishing but there is no one to take him.
- “I need more money, a bigger home, and I need a hearing aid.”
- “It would be nice for the state to help out with glasses and dental and help with money so I can go on a nice trip.”
- Mother says "I'm concerned there is only one staff person at the home at times because there are major issues. She is incontinent, blind, has seizures and can't walk on her own because she could very easily fall. She lives alone so, as you can see, there are major problems.
- “The state should pay for dental care.”
- First, and by far the most important, is that [the executive director] of an agency / center, is responsible for his brother's being bedridden because [the executive director] 'forced' him to use a walker. He walked very well without a walker with the aid of a physical therapist. I want [the executive director] fired. He added "[he] looks down on southerners because he is from Chicago and treats everybody rudely. Second, he is not happy with the Arc. Third, he's upset that personal assistants are not bonded because he thinks, in the past, they have stolen things from his brother [individual receiving DMRS services]. Third, Nashville police do not enforce the handicapped parking space law [and he is] upset, according to him, that Metro told him it was hard to enforce the law "because it is too ambiguous." He added that Tennessee is a horrible place for disabled persons!
- The state needs to help me pay more on my doctor bills. I am partially blind, I need rails on my porch and in my bathroom.
- The state needs to help pay for glasses and dental care. The state has deducted pay of foster parents. The state should not cut the home rates. It is cheaper for the state to send the individuals to a foster home [than to a developmental center.] Steve Norris said that he has to do what the governor said to do.
- The state needs to help pay more on dental costs. She is needing a larger place to live. The apartments are too small for two of them. How can parents and staff protect her against grown men sexually and financially without taking her rights away? We are talking about men that have been in jail and have a drinking / drug problem.

- They have dropped her nutritionist program which she needs due to being a diabetic. The program is helping her and she has lost 11 pounds. The cutback hurt for her diet / nutritionist care. Wants to be able to take off from work and go places with foster mom. Afraid they may lose their job if they take off. Was told that foster mom was the only one allowed to give meds. Foster mom concerned about who will give them their meds when she is in the hospital.
- Yes, I'm frustrated that they won't help get an accessible bathroom in the house so I can take care of him like he needs to be cared for.

Services

- “Having two staff to deal with issues helps with his behavior. The state should not cut back on people who can't take care of self.”
- "I want more information and communication from [the agency.]”
- "Is marriage counseling available to her through waiver services or through another agency?”
- Funding for the agency—needs to have enough for their needs. Home staff needs more pay, the state needs to help more on her medicine. Need to investigate more into some of the agencies so they can see more of what is going on in some of the workshops.
- “Only problem is there is too much turnover in staff and ISC workers.”
- Because he has a job coach he is not allowed to have a Personal Assistant. If he had a PA on weekends, that would give him more freedom.
- “I think they should do good background checks on each employee, pop-in house checks on the staff and individuals, and make sure they have a good balanced meal due to his diets. Not a lot of soft drinks and fast foods.”
- “I want all staff to treat me nice and not to stay on the phone.”
- “If there were more money for staffing, then will have incentive to stay, but also to quench the urge to steal from consumers.”
- More checking on staff, pay not good, some of the staff are not able to take care of them. My son has been beaten, raped and jailed. He was jailed over throwing himself on the floor at Wal-mart over a candy bar. The police maced him, beat him and put him in jail. The state needs to be more involved in the agencies and their program. The mentors did not let him know all this had happened.

- Mom feels that staff at the home is inattentive.
- My child was abused by home staff. When confronted, the ordeal was sugar coated and nothing happened through the agency. I took my child out of school because the school and staff would not work with me with my child and was unfair to her. I had to continually fight the school and the system for my daughter. Finally, I took her home. She is a 16 year old girl that had a bad experience with abusive staff and an unfair school system.
- Not having the PAs to fill our hours. The PA we have now weighs 400 lbs. and his health is poor. He has been in the hospital 3 times since August. When he is out, we have no PA. The staff we have now is not CPI trained. With our son, you have to have one on one contact or he will hurt you. Schools need cameras in the classroom to protect the students from abuse and also to protect teachers if they are accused of hurting a student. Cameras in special education are important to protect teachers and students.
- “Staff needs to help take better care of me and keep me shaved and clean.”
- The state should not make it so hard to get services, such as the waiting list for the waiver is so long, the amount of things that you can actually get with the waiver services. With the PA that we get it takes all the money where we don’t have enough money left for behavior analyst.
- There are things out there but we have no idea what they are. We have to buy his clothes, the agency doesn’t. He has to pay his bills and there is no extra. It took two years for him to get a washer and dryer. Mom would take his clothes home and wash them. He has been in the system for 5 years. When the state did the reduction, they moved him in with a roommate. Why, when he has to pay for his own rent and bills? Why should this affect him? He needs new living room furniture.
- Too much turnover with the ISCs. Too much turnover with staff. I think, that if they pay the staff more money, they might not have so much turnover.
- Too much turnover. The state and agency needs to pay more to staff to keep the turnover down. The state might need to buy their sheets, pillows, blankets, etc. He has to buy his own furniture. The state needs to help on it. Agency does not want him to spend the night away from home because that is money out of their pocket.

- Train staff to put individual's needs before their own. After being in the hospital and almost dying, the staff took her car shopping the day she got out of the hospital. Staff needs to inform family anytime there is a change or illness in the individual's life.
- Turn over in staffing—she had 22 staff in the first year. I don't know how they do all the training and checking on all of them.
- When she was at [agency] in Nashville she got hurt and had to have surgery on her legs. She ended up with double pneumonia before they took her to the doctors. She was in a coma for a while. They sent her to [a developmental center], which was a rat hole, and they were supposed to help her learn to walk again. They didn't do anything for her. Sent her to [another developmental center] and they were supposed to help her learn to walk, but we feel they gave up on her and are not helping her. When we visit her she looks depressed. We are moving her back with a new agency, and they are willing to help her learn to walk. [The developmental center] was supposed to move her January 2 but they kept putting it off due to the expense. It is going to cost over \$1000 to move her here and [the developmental center] thinks it is [the new agency's] responsibility to move her and [the new agency] thinks it is [the developmental center's] responsibility to move her.
- "I don't understand why [the agency] don't pay overtime. Where would I find that answer?"

Transportation

- "A better van!!"
- Cuts in his funding has hurt him in getting to go places.
- He is not able to get out into the community due to [the agency] not having a van for wheelchairs. The ISC told her to talk to her agency and agency cannot provide a van so therefore, his [individual support plan (ISP)] plan is not being met. It states that he is to get out at least 3 times a month and do things he is not able to.

6. GOALS

PTP's personal goal was to complete at least 1000 PTP surveys for Year 5. With 1,776 completed interviews from the 1,901 potential people or their families contacted by the end of June, 2007 the statistical accuracy and the representativeness (or relevancy) of the data is the most it has ever been for the PTP. In Year 5, the PTP interview teams attempted to contact or interview people in 72 of Tennessee's 95 counties. This is a 76% increase in the number of counties in which interviews were collected when compared with Year 4's achievement of interviews in 41 of Tennessee's 95 counties.

The following counties were represented in the list of people contacted by the teams:

| | | | | | | | |
|------------|-----|-----------|-----|------------|-----|------------|--------|
| Anderson | 17 | Fayette | 9 | Knox | 61 | Scott | 4 |
| Bedford | 2 | Fentress | 4 | Lauderdale | 9 | Sevier | 7 |
| Benton | 19 | Franklin | 17 | Lawrence | 5 | Shelby | 258 |
| Bledsoe | 1 | Gibson | 17 | Lincoln | 10 | Stewart | 5 |
| Blount | 14 | Giles | 5 | Loudon | 13 | Sullivan | 42 |
| Bradley | 29 | Greene | 178 | Macon | 3 | Sumner | 28 |
| Campbell | 7 | Grundy | 11 | Madison | 175 | Tipton | 9 |
| Carroll | 17 | Hamblen | 10 | Marshall | 4 | Unicoi | 3 |
| Carter | 12 | Hamilton | 45 | Mauy | 52 | Union | 2 |
| Cheatham | 4 | Hardeman | 50 | McNairy | 38 | Warren | 5 |
| Chester | 9 | Hardin | 27 | Monroe | 3 | Washington | 70 |
| Cocke | 4 | Hawkins | 13 | Montgomery | 34 | Wayne | 11 |
| Coffee | 13 | Haywood | 26 | Obion | 18 | Weakley | 22 |
| Crockett | 7 | Henderson | 38 | Overton | 4 | White | 3 |
| Cumberland | 13 | Henry | 11 | Putnam | 10 | Williams | 4 |
| Davidson | 169 | Hickman | 1 | Rhea | 10 | Wilson | 33 |
| Decatur | 16 | Humphreys | 22 | Roane | 16 | Unknown | 3 |
| Dickson | 34 | Jefferson | 8 | Robertson | 17 | | |
| Dyer | 23 | Johnson | 3 | Rutherford | 5 | Total | : 1901 |

The total number of PTP interviews requested by DMRS, as well as those completed by the PTP, is represented by grant year in the chart below, along with a running total.

| Year | Total Requested | Total completed | Achievement rate |
|---------------|-----------------|-----------------|------------------|
| 1 | 75 | 75 | 100% |
| 2 | 635 | 613 | 97% |
| 3 | 1307 | 1456 | 111% |
| 4 | 1000 | 825 | 83% |
| 5 | 1000 | 1776 | 178% |
| Total: | 4017 | 4745 | 118% |

PTP interviews were declined at the average rate of 7.5% in Year 3, and 3.4% in Year 4. In Year 5, only 2.3% of people or their families declined to be interviewed. This is an excellent refusal rate when compared with national refusal rates, which are up to 45% (Jarvis 2002).

7. RECOMMENDATIONS

Evaluation and monitoring of a program and the system within which it operates is essential to maintaining quality and effectiveness of services provided. Program evaluation seeks to gather information to help improve effectiveness, to assist administrators to make program-level decisions, and to enable interested parties to examine a program (Posavac and Carey, 10). In producing the Year 5 report for the PTP, increasingly representative data and statistics about the population of people receiving services significantly contributes to improving the effectiveness of the services being rendered.

What does this analysis say about Tennessee's delivery system? Based upon the PTP survey data analysis for Year 5, some of the following recommendations are being made within these categories:

Abuse / Neglect

- ❖ **Do not assume that people within the system know about or want to call the hotline.** Some people that the PTP have interviewed stated they are afraid to call the hotline for fear of retaliation or other issues.
- ❖ **Address the needs of people that have been abused in the past.** Often times nothing can be done but to be aware that these individuals are bringing up past abuse and that they would benefit from counseling to help with these issues.

Employment

- ❖ **Increase number of *gainful employment* opportunities in the community.** It is well known that DMRS is attempting to employ more people with their *Employment First!* Initiative, and the DMRS 2004 report states that 23.9% of those people receiving day services are involved in community employment, and 12.9% of those that do not have a community job want one. Their goal is to have 25% of people receiving services in jobs in the community (Center on Disability and Employment: 2004; State of Tennessee DMRS Annual Report 2005). There are many reports that state numbers, but these do not

include the word *gainful* in front of employment nor do they mention *choice*. Those people that receive services that mentioned what they would like to do should be able to attempt to find employment in that field, whether it is with the help of *Employment First!*, ISCs, Case Managers, or otherwise. People interviewed cited job desires that should be a viable option. DMRS is narrowly concerned with the *quantity* employed and not necessarily with the *quality* and *choice* of employment.

Choice

❖ **Teach the meaning of choice to people receiving services.** This year it is again clear that people being interviewed may say they had choice but qualitative investigation reveals they do not really know the difference. True choice of employment is not “this job or unemployment.” True choice of living situations is not “the bed on the left or the bed on the right.” The DMRS Quality Assurance program states that one of their ten domains for a positive performance factor is “choice and decision making” (*Quality Assurance Frequently Asked Questions*). How can DMRS assure that there is choice in an individual’s life if that person, as PTP has shown, does not know what *choice* is?

❖ **Make sure an individual’s choice is acted upon.** The ISPs filled out for an individual is often very concise and specific. The goals stated look great on paper. The person receiving services did not always take part in the plan, nor was given choice and a voice.

Information Dispersal

❖ **Implement greater internet awareness projects and trainings.** Due to the relatively low numbers of people receiving services from DMRS that are using the internet, and in line with the DMRS Quality Assurance program, more information would be able to be dispersed to people and their families with increased internet awareness and technology assistance, as well as enhancing community inclusion for people receiving services and their families and loved ones.

❖ **Become aware of Tennessee’s increasing cultural diversity.** Tennessee’s foreign-born population is growing with lightning speed, especially people who speak primarily Spanish. While it is true that translations can be provided over the phone, how does a person speaking only English tell someone in another language to wait on the line while a person offering translation services is being contacted, or that they have that service at

all? There are still relatively low numbers of Spanish speaking individuals receiving DMRS services which may be indicative of the language barrier that still remains for these individuals and their families. If one looks at the amount of primarily Spanish speaking people with a disability and compares it to the Census increase of people identifying themselves as Hispanic in Tennessee, there will be approximately 45,000 Hispanic people with disabilities living in Tennessee by 2010 (U.S. Census, Tennessee Department of Health).

Independent Support Coordination / Case Management

❖ **Improve the current ISC system by reducing paperwork / documentation as well as each ISC's caseload.** People for the most part were pleased with their ISCs but were upset with staff change and workload. ISCs, like Direct Support Professionals (DSPs), are often overworked and underpaid. Most aggravating to people receiving services and their families is the long time for returned calls, as well as the length of time for an item / service / information requested to be provided.

❖ **Learn how to provide the equipment needed in a timely manner.** PTP finds that many people need certain items / devices to help their level of self determination. Some items listed may not be easily funded or found. The person's ISC / case manager needs to better help with the items needed. Additional ISC / case management training in interagency communication and collaboration would benefit DMRS and the people receiving its services.

Program Recommendations

Change the instrument

PTP is currently using a modified *Participant Experience Survey*, an instrument designed by Medstat and approved by CMS. The interview tool is lacking in several areas and has been revised at the conclusion of the project's Year 5 interviews to address shortcomings or ambiguity. As it is now, the interview questions used would benefit from rewording to communicate more clearly to the person being interviewed instead of relying on the PTP team's ability to probe deeper to get a clear response. The necessity for an updated instrument include; being too much of a medical model, focusing too much on negatives, the lack of questions regarding economics and sexuality, difficulty comparing results with other states, and questions

worded poorly. Schwartz (1996) noted how seemingly innocuous differences in the phrasing of survey questions will affect how people report about their experiences and surroundings.

DSP Training / Improvements:

More consistent training and monitoring of training in agencies to make sure training is identical across agencies and the state.

- 1) Individualized—many complaints from family members that DSPs do not have enough personalized training—some DSPs were unable to help the PTP interview teams with obtaining answers because they themselves had communication problems with the individual receiving services.
- 2) Therapy conducted in and using the community vs. solely in the home.
- 3) Emphasize importance of their jobs—make it more than “just a job” and emphasizing the increasing satisfaction with DMRS services throughout Tennessee over the preceding five years.
- 4) Stagnation vs. advancement—allow for more job-mobility within an agency
- 5) Include job coaching training as required course—again in Year 5 PTP uncovered issues with people who have DSPs that do not understand the importance of helping the person they support on the job.
- 6) Encourage family members, people serving as conservators, and others that receive DMRS funding take training courses.
- 7) Connect with local community colleges and give partial credit to courses taken at DMRS and / or intern for credit—perhaps even incentives such as post-secondary education scholarships for DSPs.

System Recommendations

Gleaned from this year’s interviews are recommendations regarding the system including:

Rules and Regulations

- 1) Lessen paperwork on ISCs and reduce the caseload per ISC.
- 2) ISCs should have the power to change ISPs through agreement between the individual receiving services and agencies.
- 3) Give more education for families on the current and future changes to the ISC system.

- 4) Confidently ensure that an individual's ISC is completely educated about the individual needing supportive services.
- 5) Report and track sanctions or other actions enforced for an ISC's failure to implement a individual receiving services' ISP.

Dental

- 1) A waiver-based dental voucher, redeemable with any person licensed for dental treatment in Tennessee, to address the pain and costs of poor dental health.

Use of technology

- 1) Individuals should be evaluated for use of technology as a part of intake process.
- 2) Utilize technology in management—will save time and resources.
- 3) Share new address and contact information that PTP teams collect and provide with the regional offices of DMRS so that they might update the current state-wide tracking system.

Information

- 1) Utilize PTP teams to give out information to individuals.
- 2) Encourage more awareness and access for internet use by people receiving services, their families and loved ones.

Transportation

- 1) Appropriate transportation for people.
 - a. Proper safety equipment.
 - b. Staff training.
 - c. Verification of licensure and insurance.

Self Direction

- 1) Staff and agencies respect and honor individual's choices.
- 2) Creative alternative opportunities for individuals.
- 3) Include person center planning in the creation of the individual's ISP—make sure individual understands their rights to their new ISC and to their ISP.

Waiting List

- 1) Interview those people on waiting list like those already receiving services.
- 2) Provide additional and ancillary service opportunities for people still on the waiting list for DMRS services.

8. UNANTICIPATED OUTCOMES

PTP once again has had other outcomes not anticipated through the original grant process, both positive and negative:

- 1) The original survey project was written to help create flexible positions for those with disabilities, and that outcome was achieved. Those family members that are interviewers are also benefiting from the flexible schedules to allocate time needed with their family members with disabilities.
- 2) Those people that have been with PTP for a while have improved their skills greatly and are more equipped to answer questions and / or to give referrals to people needing them. They are refining their interviewing skills and are more efficient with the interview process, allowing for more precise answers and better information for analysis.
- 3) The information that the PTP receives from the state is compiled from the state's CS tracking database and is still rife with outdated and incorrect information. An online, password based, database where agencies can come online and change information more efficiently is still hoped for, and PTP is coordinating with DMRS to make better use of the corrected information supplied by the interview teams.

9. FUTURE PLANS

The PTP project has already begun Year 6. The grant has been approved through DMRS and will continue to provide independent quality assurance measures powered and led by the voices, priorities and choices of people receiving services and their families.

. The following are some changes put into place:

- ✓ The instrument has undergone a change at the end of Year 5;
- ✓ The DMRS requested number of interviews for Year 6 will be 1,200 interviews, all conducted face-to-face with people receiving services.
- ✓ The maximum number of hours worked by any PTP interviewer has been reduced to twenty five hours per week and there is no full time interview staff; work limits remain fluid and are adjusted to remain within the allotted budget.
- ✓ Policy and Procedures book will be revamped to reflect the above changes.

The program is also providing follow-up and referral for advocacy issues. Year six is now on its way and PTP hopes to expand more and more every year to better the lives of all of the individuals served and their families.

PTP Answers by Year

These percentages have all been calculated by determining the proportion of interview respondents who answered affirmatively. Numbers in the chart on page 51 in **black** (or slightly larger font) indicate the better year, and **grey** (or slightly smaller font) to indicate less favorable percentage over the previous two years. The selected questions in each category of the interview instrument are used to generate the subsequent, admittedly artificial, category-specific composite score.

| Category | Question | '06-'07 | '07-'08 |
|--|--|---|------------|
| Choice and Control | Do you like where you live? | 87% | 89% |
| | Did you choose that place to live? | 34% | 30% |
| | Would you rather live with someone else or alone? | 18% | 15% |
| | Did you help pick your support staff? | 23% | 22% |
| | Did you know you have the right to change your support staff? | 35% | 48% |
| | Can you talk to your ISC / Case Manager when you need to? | 57% | 78% |
| | Would you like to (volunteer/work/etc) somewhere else? | 27% | 16% |
| | Do you know how to file a complaint if someone hits/hurts/yells at or steals from you? | 55% | 62% |
| | Choice and Control composite | 50% | 54% |
| Respect and Dignity | Are support staff at home nice to you? | 64% | 76% |
| | Are support staff at work nice to you? | 66% | 65% |
| | Does anyone ever hit or hurt you? | 7% | 5% |
| | | Respect and Dignity composite | 74% |
| Access to Care and Community Inclusion | Can you always get to the places you need to go, like work, shopping, or the doctor? | 89% | 93% |
| | Do you need any special equipment would make your life easier? | 11% | 9% |
| | Do you use the Internet? | 7% | 6% |
| | Do you have a boyfriend / girlfriend? | 37% | 26% |
| | Can you see your friends / partner / family when you want to? | 73% | 69% |
| | | Access to Care and Community Inclusion composite | 59% |

Year 5 PTP Interview tool

PART ONE CHOICE AND CONTROL

How long have you lived in your home?
(Number, years or months)

Do you like where you live?
(Yes, no, sometimes, unsure, not applicable)

--Comments like where live

Did you choose that place to live?
(yes, no, unsure, not applicable)

--How choose (and any additional comments)

Do you like who you live with?
(yes, no, some people, unsure, not applicable)

--Like live with comments

Would you rather live with someone else (or alone)?
(Yes, no, unsure, not applicable)

--Comments rather live with someone else
(Alone? With family? With room mate?)

Do you share a bedroom?
(Yes, no, unsure, not applicable)

Do you like sharing a bedroom?
(Yes, no, sometimes, unsure, not applicable)

Did you pick who shares your bedroom?
(Yes, no, unsure, not applicable)

--Share bedroom comments

Did you help pick your support staff?
(Yes, no, unsure, not applicable)

--Help pick comments

Did you know you have the right to change your support staff?
(Yes, no, unsure, not applicable)

--Comments right to change

Can you choose when you eat?
(Yes, no, sometimes, unsure, not applicable)

--Choose when eat comments

Can you go to bed when you want to?
(Yes, no, sometimes, unsure, not applicable)

--Go to bed comments

Who do you talk to when you have problems?
(Mother, father, friend, ISC, DSP, other agency staff, no one, other)

Who is your case manager/ISC?
(Yes if knew plus name-make sure to write whether it is case manager or ISC)

Can you talk to them when you need to?
(Yes, no, sometimes, unsure, not applicable)

--Case manager comments

Do you know you have the right to change your ISC?
(Yes, no, sometimes, unsure, not applicable)

--Right to change ISC comments

What do you do during the day?
(Volunteer, job, workshop, day program, community participation, nothing, other)

Would you like to (volunteer/work/etc) somewhere else?
(Yes, no, sometimes, unsure, not applicable)

--Work somewhere else comments
(Anywhere in particular? Why?)

Do you open your own mail?
(Yes, no, sometimes, unsure, not applicable)

PART TWO RESPECT AND DIGNITY

Is support staff at home nice to you?

(Yes, no, sometimes, unsure, not applicable)

Is support staff at work nice to you?

(Yes, no, sometimes, unsure, not applicable)

--Support staff comments

Does anyone ever take your things without asking?

(Yes, no, sometimes, unsure, not applicable)

--Take things comments

Does anyone ever hit or hurt you?

(Yes, no, sometimes, unsure, not applicable)

--Hit comments

Does anyone ever get angry and yell at you?

(Yes, no, sometimes, unsure, not applicable)

--Angry and yell comments

Do you know how to file a complaint if someone hits/hurts/yells/steals from you?

(Yes, no, sometimes, unsure, not applicable)

--Complaint comments

PART THREE ACCESS TO CARE

Can you always get to the places you need to go, like work, shopping, or the doctor?

(Yes, no, sometimes, unsure, not applicable)

--Comments get to places

Does the support staff spend all the time they should with you?

(Yes, no, sometimes, unsure, not applicable)

--Comments support staff

What special equipment would make your life easier?

Have you spoken to anyone about this?

(Yes, no, sometimes, unsure, not applicable)

Did you get the equipment needed (try and get how long they waited or have waited thus far)?

Are you receiving all of the services you need?

--Services comments

PART FOUR COMMUNITY INCLUSION

Do you decide what you do with your money?
(yes, no, unsure, na)

Do you have your own bank account?
(yes, no, unsure, na)

--Money comments (i.e. they may have a bank account of their own but not control of it)

Do you have a computer?
NOTE computer questions for family as well as consumers

Do you use the internet (whether at home or other such as libraries)?

What do you like to do during your free time?

Can you do this when you want?
(Yes, no, sometimes, unsure, not applicable)

--Do what want comments
(if can't, why not? Lack of help? Lack of money? Etc)

Do you (consumer) have a boyfriend/girlfriend?
(Yes, no, unsure, married)

--Boyfriend/girlfriend comments

Who do you like to visit with?

Can you see these people when you want to?
(yes, no, sometimes, unsure, not applicable)

--Visit comment

Is there anything else you would like to talk to me about?

Amount of questions interviewee answered
(None, 25%, 50%, 75%, all)

Who else answered?

Works Cited

Center on Disability and Employment. 2005. *The Status of Employment Services for Tennesseans with Significant Disabilities as related to the Olmstead Decision.*

http://www.cde.tennessee.edu/products/state_report/executive_summary.htm. University of Tennessee, Knoxville.

Jarvis, S. 2002. *CMOR find survey refusal still rising.* American Marketing Association, Marketing Power, Inc.

No Name. 1995. *Valued Outcomes for Californians with Developmental Disabilities.*

<http://www.allenshea.com/outcomes.html> California Department of Developmental Services.

No name. 2008. *One in Five U.S. Households Has Never Used E-mail.*

http://newsroom.parksassociates.com/article_display.cfm?article_id=5067 Park Associates Research & Analysis for digital living technologies.

McLeod, J. M., Daily, K., Guo, Z., Eveland, W. P. Jr., Bayer, J., Yang, S., Wang, H. 1996. *Community Integration, Local Media Use, and Democratic Processes.* Communication Research, Vol. 23, No. 2, 179-209

Milligan M.S., Neufeldt A.H., 2001. *The Myth of Asexuality: A Survey of Social and Empirical Evidence.* Sexuality and Disability, 19 (2), p. 91-109.

Posavac, Emil J. and Carey, Raymond G. 2003. *Program evaluation methods and case studies-6th ed.* New Jersey: Prentice Hall,

Schwartz, N. 1996. *Cognition and communication: Judgemental biases, research methods, and the logic of conversation.* Mahwah, NJ: Erlbaum.

The State of Tennessee. 2005. *Annual Report Fiscal Year 2005.* DMRS, Department of Finance and Administration, Nashville.

U.S. Census. 2000. Tennessee. www.census.gov