



PEOPLE TALKING TO PEOPLE

ANNUAL REPORT

for

January 1- December 31, 2010

Prepared

by

Frank R. Meeuwis, Project Director

EXECUTIVE SUMMARY

People in America with certain disabilities depend upon different supports that our society often provides. One of the ways Tennessee and the other states support people is through collaboration with the U.S. federal government—in the form of Medicaid. Medicaid is a healthcare program where funding comes from state dollars matched by federal dollars. In Tennessee, one state dollar is matched with approximately two federal dollars. For their matching share, the federal government requires that states provide certain services through their Medicaid programs.

In addition to providing certain services mandated by law—like hospital care—the state may also provide therapies, medications, or dental, optometric, and/or nursing home services. Many of these services for people with disabilities are delivered through Medicaid waiver programs. The services are provided in their homes and communities by state agencies or private organizations. The federal government monitors these Medicaid waiver programs through the Centers for Medicare and Medicaid Services (CMS). CMS works with Tennessee’s Division of Intellectual Disabilities Services (DIDS) to provide these services to people with intellectual disabilities (ID).

The Arc Tennessee is a non-profit statewide organization on intellectual and developmental disabilities. Founded in 1952, it is affiliated with The Arc United States and is a membership organization composed of

people with intellectual, developmental and other disabilities, their parents, family members, friends, professionals and others. The People Talking to People (PTP) grant to The Arc Tennessee is just one part of what DIDS does to monitor customer satisfaction from people who receive supports through DIDS. The state of Tennessee uses these surveys to document with CMS that it properly administers its Medicaid Waivers for people with ID.

Recently, PTP finished 2010 working as an independent quality-assurance project for DIDS. PTP assures the quality of the services and provides quality improvement measures based on interview responses. PTP interviews are collected across Tennessee from a random sample of people receiving services from over 300 non-profit and for-profit agencies providing home and community-based services. PTP’s assistance allows for faster responses and follow-up from DIDS on specific issues uncovered during the interview process.

Since 2002, the interviews that PTP collects are a part of quality indicators that reflect Tennesseans’ general increase in satisfaction with their services. PTP is an integral part of the state moving from several quality assurance measures to a quality-assurance project led by the voices, priorities and choices of people receiving services. Tennessee and the people who receive services here continue to benefit from PTP’s work.

ACKNOWLEDGEMENT

The People Talking to People project first offers special acknowledgement to the Division of Intellectual Disabilities Services, specifically Brenda Clark and Annie Bernard for their support and assistance.

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:

	Region		Region
Holly Newingham, Project Assistant	n.a.	Cheryl Coleman, Interviewer	5
Danny Reaves, Interviewer	1	Gail Compton, Interviewer	6
Dianna Barrett, Interviewer	1	Mary Dale Greene, Interviewer	6
Jean Smith, Interviewer	2	Michael Robinson, Interviewer	6
Carol Smith, Interviewer	2	Brenda Lackey, Interviewer	6
Heather Wilson, Interviewer	2	Angie Snider, Interviewer	7
Linda Wilson, Interviewer	2	Judy Sparks, Interviewer	7
Melody Jacobs, former Interviewer	3	Tom Griffin, Interviewer	8
Amy Rutherford, Interviewer	3	Darryl Newsome, Interviewer	8
Larry Jacobs, Interviewer	3	Patrick Sanders, Interviewer	8
Holly Kirby, Interviewer	4	Sondra Loveless South, Interviewer	9
Cassie Frantz, Interviewer	4	Nadine Loveless, Interviewer	9
Woody Cade, Interviewer	5	Melissa Allen, Data entry	n.a.
Josh Turner, Interviewer	5	Linda Roberson, Data entry	n.a.

The Arc Tennessee staff

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

Frank R. Meeuwis, Project Director

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PEOPLE TALKING TO PEOPLE PROJECT OVERVIEW

The People Talking to People project has successfully completed collecting and reporting its interviews for 2010. The PTP operates through a grant from the Division of Intellectual Disabilities Services to The Arc Tennessee, a statewide organization on intellectual and developmental disabilities. PTP's Director and Administrative Assistant are headquartered in Nashville while it employs nine teams of part-time interviewers across Tennessee's 95 counties.

PTP interviewing teams include a family member of a person with a disability who has access to reliable transportation and a partner with a disability. Each team member is interviewed and trained by the Director, and is hired following a successful background check and verification of professional and personal references. Occasionally, training is reinforced with assistance from another seasoned interviewer, and a conference call held by the Director every other week encourages teams to share wisdom and experiences.

PTP interviewing teams receive a randomly-selected list of individuals who receive financial support from DIDS. This is done using an Internet-based random-number generator, assuring equal probability of selection and allowing for accurate statistical inferences to be drawn from the completed results. These results are what DIDS may show to CMS to reflect legal compliance and to justify continued matching federal dollars.

Additionally, PTP offers opportunity for people with disabilities to participate in meaningful and gainful employment. Meaningful because people may constructively influence the lives of the people they interview by bringing official attention to a problematic issue or unjust circumstance. PTP work is also meaningful because, by working in the community, team members raise the visibility and awareness of people with disabilities actively participating in and contributing to their communities—to be a valued and paid resource within his or her community. This is one of the very important, yet unheralded benefits of PTP—while PTP's efforts continue to better the support service system as a whole.

When they are interviewing, PTP team members are observed—not only by the people being interviewed but also by any staff that supports the interviewee—working in the community collecting valuable data for Tennessee and bringing specific attention to certain situations. Although funding currently exists for only part-time PTP interviewers, a position with PTP is gainful because starting pay exceeds the hourly minimum wage and staff may be eligible for yearly raises based on the organization's budget.

Critically important to PTP's function is the responsibility placed on PTP interviewers to bring attention to independent advocates and internal quality assurance teams of DIDS. PTP interviewers are trained to initiate a procedure whenever a situation meriting

further investigation is uncovered or shared during an interview. The procedure involves electronically submitting a Survey Notification Form—containing relevant contact information and an explanation of the issue or specific complaint.

In the year 2010, PTP interviewers produced 96 Survey Notification Forms sent by email simultaneously to DIDS, to the PTP Director, and to the Assistant Executive Director of The Arc Tennessee. A Survey Notification Form alerts to a response other than a positive was provided during an interview to any of four questions selected by DIDS in conjunction with CMS in advance of the 2009 calendar year.

The four questions used as performance indicators for CMS in the approved PTP interview tool—to which any other response than “yes” immediately prompts PTP teams to send in a Survey Notification Form—are:

30. Do your direct support staff treat you well or with respect?

34. Do you know how to report a complaint?

40. Were the things that are important to you included in your service plan?

48. Are you satisfied with the amount of privacy that you have?

Of these 96 Survey Notification Forms sent to DIDS in 2010, 42 were for interviews with people who were non-verbal or non-communicative. This automatically triggers the interview team to fill out and submit a Survey Notification Form for their interview because valid responses were not able to be collected for the questions. This is the second year that PTP has a formalized and direct Survey Notification Form and procedure. PTP still follows a protocol with Protection From Harm in DIDS Central Office whereby allegations of abuse, neglect, or exploitation are immediately shared with their investigators.

PTP experienced some turnover and some changes to interviewing teams in 2010 but still continues to employ—on a part-time basis—27 individuals with disabilities and family members of a person with a disability.

Across Tennessee, the nine PTP teams arrange, conduct, and record interviews from a random-selection of individuals receiving services through the DIDS system. The interview and interviewers ask questions about self-determination and choice while respecting each person's right to privacy. Confidentiality is very important for all interviews by all PTP teams and is part of PTP Policies and Procedures, as well as mandatory training.

The interview instrument initially used by PTP was based on the CMS-approved Participant Experience Survey. Over the years, following constructive feedback from people interviewed and from the interviewing teams, the instrument has been adapted to

increase applicability and clarity. A graphically enhanced version of the interview questions with matching pictures, as well as a large-type version, are available and are shared with PTP teams, enhancing participation of all team members in the interview process. Furthermore, at each interview opportunity, teams distribute DIDS

pamphlets on ‘Protection From Harm’ and ‘Equal Opportunity is the Law in Tennessee.’

Teams also share a brochure describing the PTP project, including contact information for the project Director Frank Meeuwis. Copies of the pamphlets, brochure, or PTP Policies and Procedures manual are available upon request.

2. METHODOLOGY

Results from the interviews are used to determine overall and category-specific satisfaction with services received. The interview may reveal a level of self-determination afforded to people. Results are analyzed by Medicaid waiver program—in 2010 in Tennessee, there are three waiver programs:

1. **Statewide Waiver** – also called the Home & Community Based (HCBS) or main waiver, it provides a comprehensive array of services, including residential services, day services, personal assistance, health and therapy services, and other services
2. **Arlington Waiver** – provides the services available through the Statewide Waiver plus some additional services; available to “at-risk” people and to “class members” of a lawsuit against the Arlington Developmental Center.
3. **Self Determination Waiver** – provides a self-directed component to the individual allowing them to control and select from a set of services with an annual limit per person of \$30,000; does not include residential services

In addition to interviews with people who receive services through the Medicaid waivers, PTP interviewed 81 people residing in one of the state’s Developmental Centers. All interview results are reported yearly corresponding with the calendar year. PTP has completed collecting interview data for 2010, again reflecting responses to questions in these four areas:

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

The people interviewed in 2010 came from a list of 5,641 people actively receiving services as of July 24, 2009. The list included people’s contact and address information as they appeared in the CS Tracking database—the electronic system used by DIDS.

People selected randomly may be interviewed by PTP every 12 months. People randomly selected in 2010 are assigned to be interviewed by each of the nine PTP interviewing teams, corresponding to the 9 Developmental Districts in Tennessee (http://www.tn.gov/tacir/PDF_FILES/Infrastructure/Infra07_ddmap.pdf).

The list of information regarding the person receiving services is put into a Microsoft Excel file, filled in with the information provided by DIDS, and then is assigned a number through an internet-based random number generator. A selection and region-specific list is sent to the team in each

of the nine regions across Tennessee. As each team finishes their list, the comprehensive list is used to fill the lists with more randomly selected potential interviewees.

Teams contact the individual (or family member or contact person) from the information on their Region's list to set up an interview. Each interview is set up at a time and place that is convenient for the person to be interviewed. Anybody being interviewed has the right to decline to answer or skip questions and also to stop the interview at any time. A phone log as well as the interview date is recorded on the list and is regularly sent by secure email to the Director. The Project Assistant with the Director reviews these lists to note any missing information or to determine why an interview is missing in the online database. When an interview is complete, each PTP team enters the responses into a secure internet database called SurveyMonkey (www.surveymonkey.com).

The PTP Director as well as people from DIDS, using password-protected access, periodically check the SurveyMonkey database to verify individual and demographic accuracy, to remove duplicate interviews, and if necessary to follow up with a team for a Survey Notification Form in the instances that one has not yet been received for any other response than a positive—a “Yes”—for any of the four performance measures. In 2010, 96 Survey Notification Forms were submitted by PTP.

In 2010, one thousand six hundred seventy one (1671) individuals were successfully interviewed and recorded into

the Survey Monkey collection platform. These valid interviews collected by PTP again surpass the 1,200 that were asked for by DIDS—exceeding the goal by 40%! However, the statistical accuracy and representativeness (relevancy) of the interview data presented in this report varies between waiver populations and is subject to the following important considerations of statistical validity.

2.1 2009 PTP waiver-combined participant interviews

For the 5,641 possible people to interview from the master list provided by DIDS in July, 2009, the confidence level is 95% at a confidence interval (sometimes also called margin of error) of 2.0 (i.e. +/- 2.0%). This means that with 1671 interviews collected and recorded in SurveyMonkey, it is possible to statistically predict, for 95 of the next 100 people interviewed, how these people would answer a question with an accuracy of plus or minus 2.0%. Statistically speaking, this is a very high level of relevancy and representativeness for these results across the different waivers for services in Tennessee.

The questions, methods, calculations, and procedures for the PTP interview in 2010 are the same as in 2009, and so the results are comparable. The findings in this 2010 report come from 82 more interviews than in the 2009 PTP report (<http://www.tn.gov/didd/PeopleTalkingToPeople/PTP%20Year%206%202009%20report%2010-28-10.pdf>). The relevancy of the PTP findings is somewhat lower when the

different populations' interview answers are analyzed by waiver program. The relevancies of the findings are indicated below for each specific waiver population.

2.2 2010 PTP Main waiver interviews

The master list provided by DIDS in July 2009 contains 4,073 participants in the Medicaid Home and Community Based Services waiver (Main waiver). In 2010 the PTP collected and reported the interview results for 1,260 of these participants. Statistically speaking, the confidence level is 95% at a confidence interval (also called margin of error) of 2.3 (i.e. +/- 2.3%). That is, with 1,260 valid interviews with Main waiver recipients, it is possible to statistically predict, for 95 of the next 100 people receiving Main waiver services, how these people would answer a question with an accuracy of plus or minus 2.3%. (See pages 14-20).

2.3 2010 PTP Self-Determination waiver interviews

For the 1020 participants in the Self-Determination waiver on the list from DIDS the confidence level is 95% at a confidence interval of 5.9 (i.e. +/- 5.9%). This means that with 215 interviews with Self-Determination waiver recipients, it is possible to statistically determine, in 95 of the next 100 people interviewed receiving Self-Determination waiver services, how these people would answer a question with an accuracy of plus or minus 5.9%. (See pages 14-20).

2.4 2010 Arlington Waiver interviews

For the 310 participants in the Arlington waiver (master list provided by DIDS in July 2009) the confidence level is 95% at a confidence interval of 7.2 (i.e. +/- 7.2%). This means that with 115 valid interviews with people receiving service through the Arlington waiver, it is possible to statistically determine, in 95 of the next 100 people interviewed receiving Arlington waiver services, how these people would answer a question with an accuracy of plus or minus 7.2%. (See pages 14-20).

2.5 2010 Developmental Center interviews

For the 310 people receiving supports at one of Tennessee's Developmental Centers on the July 2009 master list, the confidence level is 95% at a confidence interval of 9.4 (i.e. +/- 9.4%).

This means that with 81 interviews with people residing at any one of Tennessee's Developmental Centers, it is possible to statistically determine, in 95 of the next 100 people interviewed at Developmental Centers, what these next people would respond to a particular question with an accuracy of plus or minus 9.4 percent. (See pages 14-20).

3. PTP STAFF

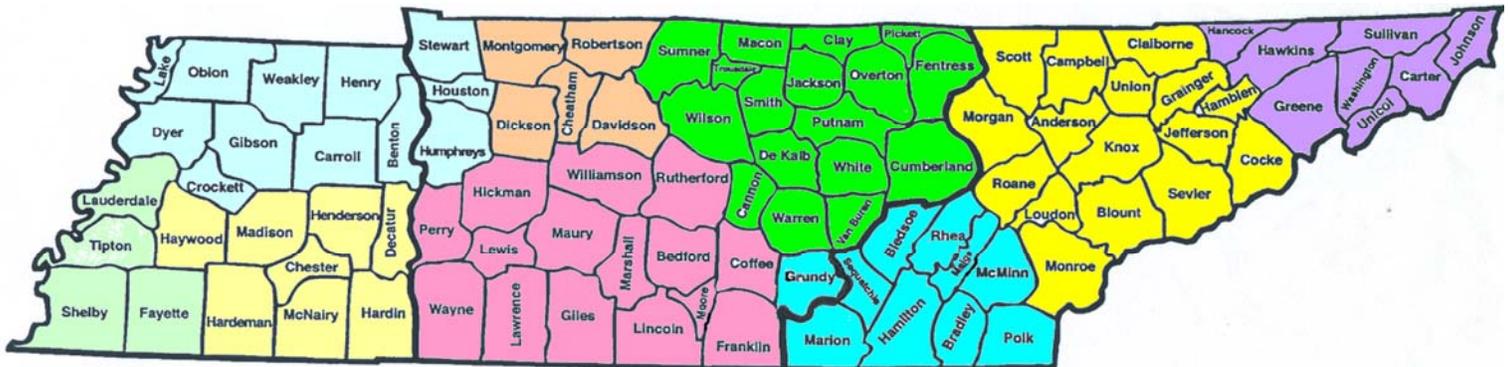
The Arc Tennessee's office is located in Nashville. Frank Meeuwis is the PTP Director and Holly Newingham is the PTP Assistant.

PTP employed 27 people in 2010 across Tennessee to serve as part time interviewers. The people on the interview teams arrange and do interviews in their region. Two people are assigned in each of nine regions. Regions 2, 5, 6 and 8 have additional people helping as substitute interview partners.

There are three interview teams for each grand region in Tennessee; East, Middle, and West. PTP's regions, the counties included in them, and interview team members are shown in the table and map below:

Region		Counties	Interviewing Team
East	1	Carter, Greene, Hancock, Hawkins, Johnson, Sullivan, Unicoi, Washington	Diana Barnett and Danny Reaves
	2	Anderson, Blount, Campbell, Claiborne, Cocke, Grainger, Hamblen, Jefferson, Knox, Loudon, Monroe, Morgan, Roane, Sevier, Scott, Union	Jean and Carol Smith; Heather and Linda Wilson serve as substitute team.
South-east	3	Bledsoe, Bradley, Grundy, Hamilton, Marion, McMinn, Meigs, Polk, Rhea, Sequatchie	Larry and Melody Jacobs
Upper Cumberland	4	Cannon, Clay, Cumberland, DeKalb, Fentress, Jackson, Macon, Overton, Pickett, Putnam, Smith, Sumner, Trousdale, Van Buren, Warren, White, Wilson	Holly Kirby and Cassie Frantz
Mid Cumberland	5	Cheatham, Davidson, Dickson, Montgomery, Robertson	Woody Cade and Josh Turner Cheryl Coleman is a substitute partner.
South Central	6	Bedford, Coffee, Franklin, Hickman, Lawrence, Lewis, Lincoln, Marshall, Maury, Moore, Perry, Rutherford, Wayne, Williamson	Mary Dale Greene and Gail Compton. Michael Robinson and Brenda Lackey are substitute partners.

Region		Counties	Interviewing Team
North-west	7	Benton, Carroll, Crockett, Dyer, Gibson, Henry, Houston, Humphreys, Lake, Obion, Stewart, Weakley	Angie Snider and Judy Sparks. Tom Griffin and Shawn Flowers are substitute partners
South-west	8	Chester, Decatur, Hardeman, Hardin, Haywood, Henderson, Madison, McNairy	Tom Griffin and Darryl Newsome. Patrick Sanders is substitute partner.
Delta	9	Fayette, Haywood, Lauderdale, Tipton, Shelby	Sondra Loveless-South and Nadine Loveless. Linda Roberson and Melissa Allen work as data-entry specialists when needed.



PTP Region 9	PTP Region 8	PTP Region 7	PTP Region 6	PTP Region 5	PTP Region 4	PTP Region 3	PTP Region 2	PTP Region 1
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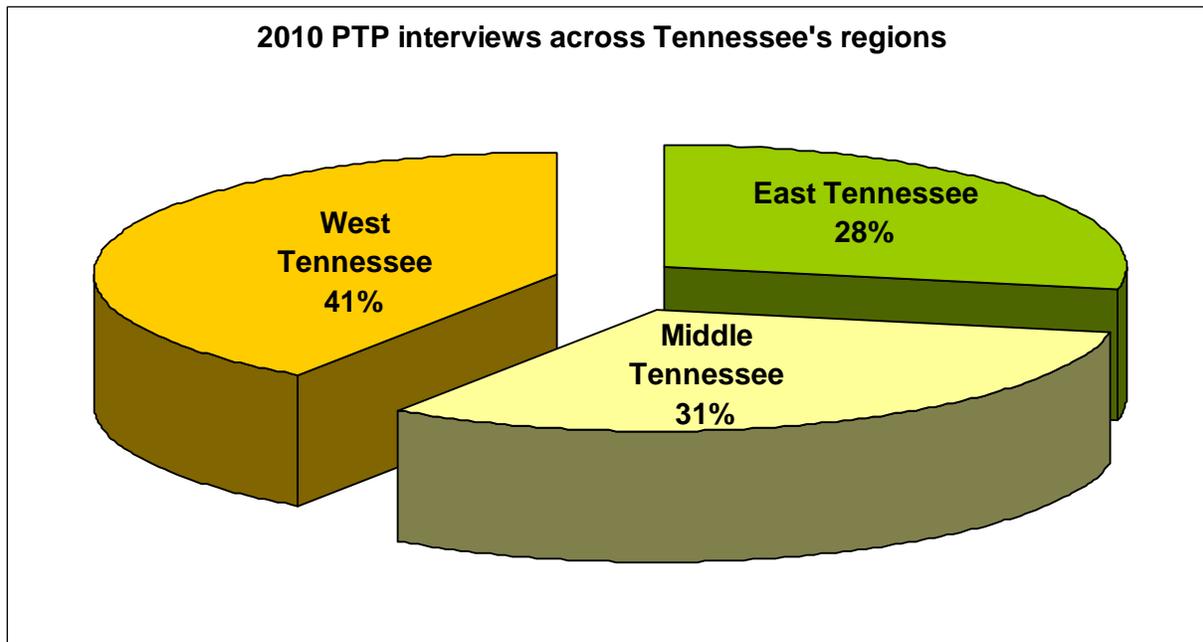
4. INTERVIEWEE DEMOGRAPHICS

The interviews scheduled, completed, and entered into SurveyMonkey in 2010 came from a DIDS master list. As mentioned above; on July 27, 2009, DIDS shared with the PTP Director four lists—one for each of Tennessee’s three waiver programs and a list of individuals at the various Developmental Centers in Tennessee—of people and relevant

contact information. These lists did not reveal the sex, race, or date of birth of the individual.

Below is the regional distribution of the 2010 PTP interviews completed by each team. The chart below this table shows the distribution of PTP interviews completed in 2010.

EAST TN			MIDDLE TN			WEST TN			Jan-Dec 2010 total
1	2	3	4	5	6	7	8	9	
86	204	178	56	309	157	202	268	211	1671
5.1%	12.2%	10.7%	3.3%	18.5%	9.4%	12.1%	16.0%	12.6%	100.0%
468			522			681			1671
28.0%			31.3%			40.7%			100.0%



5. PTP INTERVIEW RESULTS

PTP completed 5%—or 82—more interviews this year. These results may be compared with the PTP 2009 report because the questions, methods, calculations, and procedures are identical. The pie-charts on pages 14-20 show the answers to interview questions—separated by waiver. These pie-charts show the “Yes” or “No” or “Unsure/Not Applicable” answers to a selection of questions in each of these areas; Choice and Control, Respect and Dignity, Access to Care, and Community Inclusion.

“Yes” and “No” answers are positive or negative responses to interview questions. “Unsure/Not Applicable” means when the person interviewing—not the interviewer—was unsure of their answer or when the question did not apply to their situation. The confidence level (or confidence interval) is 95% for each question and for each waiver population. This is the predictive power or strength of the results. This means they are 95% reliable to represent what another PTP interviewing team would find at a similar interview.

The four questions also being used for performance indicators to CMS are starred and highlighted in bright yellow.

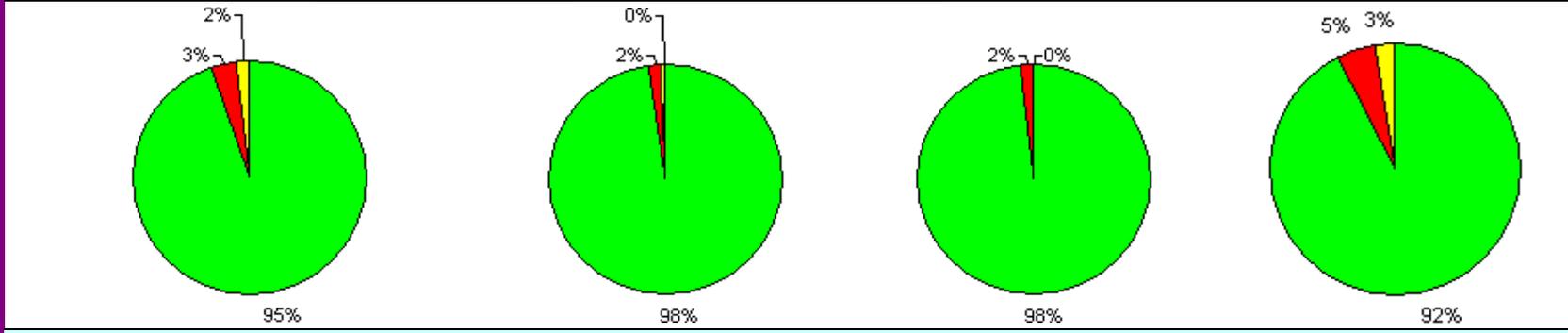
It is important to understand that the answers shown in the pie-charts each have different statistical strengths for each waiver-specific category. The pie-charts are therefore a useful visual aid for interpreting *approximate* response distribution within each waiver program in Tennessee.

Comparison to PTP’s 2009 interview (<http://www.tn.gov/didd/PeopleTalkingToPeople/PTP%20Year%206%202009%20report%2010-28-10.pdf>) findings reveal a significant decrease in the percentage of “Unsure/Not Applicable” responses collected—especially from people receiving services at one of Tennessee’s Developmental Centers. This likely reflects increased comfort with the interview questions, and increased understanding of the PTP Policy & Procedures—specifically that for interviews with individuals who may not communicate effectively, interviewers are instructed to consult a person who is familiar with the individual—a staff person or a family member. Interviewers are trained to only record answers from people who really know and do not accept responses from people who are unfamiliar with the interviewee.

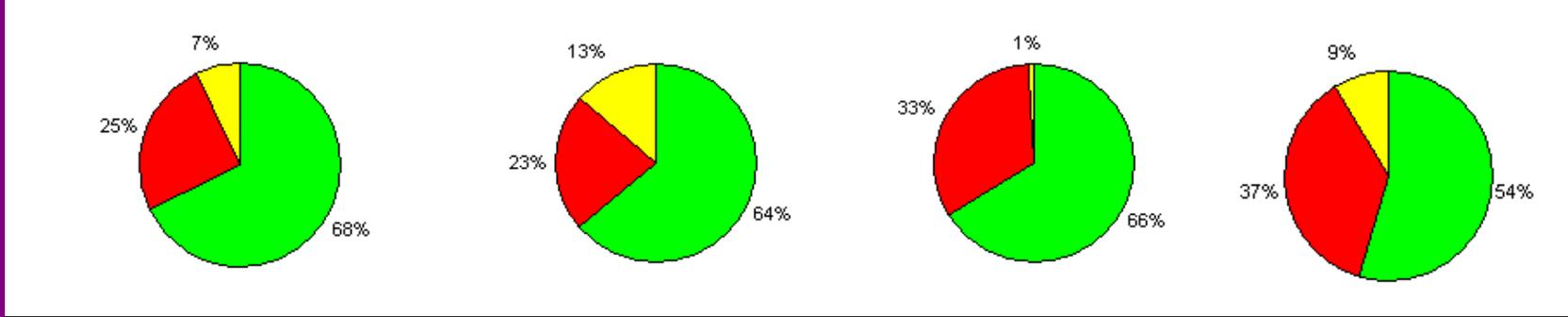
PTP 2010 Choice and Control

Main waiver 1260 interviews; +/- 2.3%	Self-Determination waiver 215 interviews, +/- 5.9%	Arlington waiver 115 interviews, +/- 7.2%	Developmental Centers 81 interviews, +/- 8.4%
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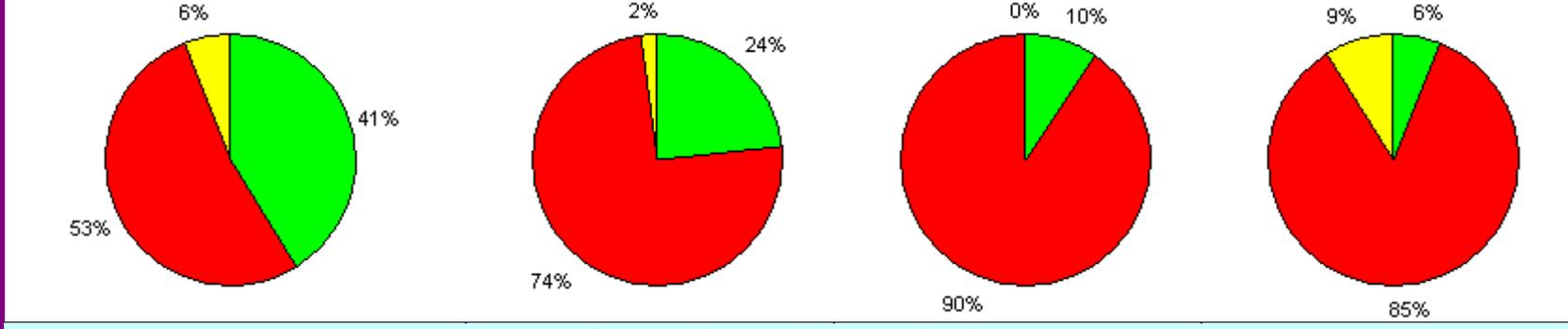
FAVORABLE / YES	UNFAVORABLE / NO	DON'T KNOW / N.A.
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Do you like where you live?



Did you know you have the right to change your support staff?



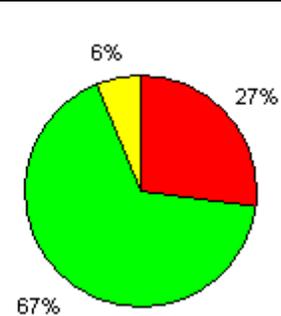
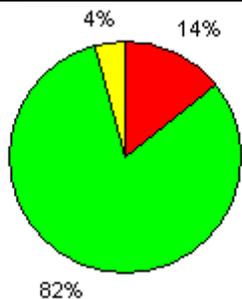
Do you choose where you live?



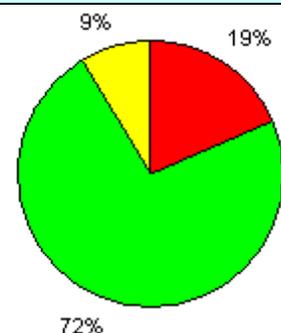
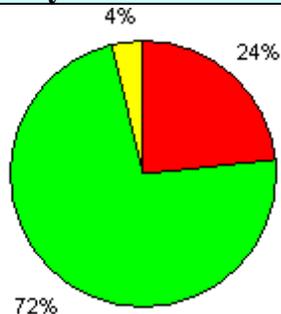
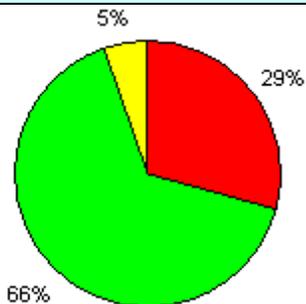
PTP 2010 Choice and Control

Main waiver 1260 interviews; +/- 2.3%	Self-Determination waiver 215 interviews, +/- 5.9%	Arlington waiver 115 interviews, +/- 7.2%	Developmental Centers 81 interviews, +/- 8.4%
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FAVORABLE / YES	UNFAVORABLE / NO	DON'T KNOW / N.A.
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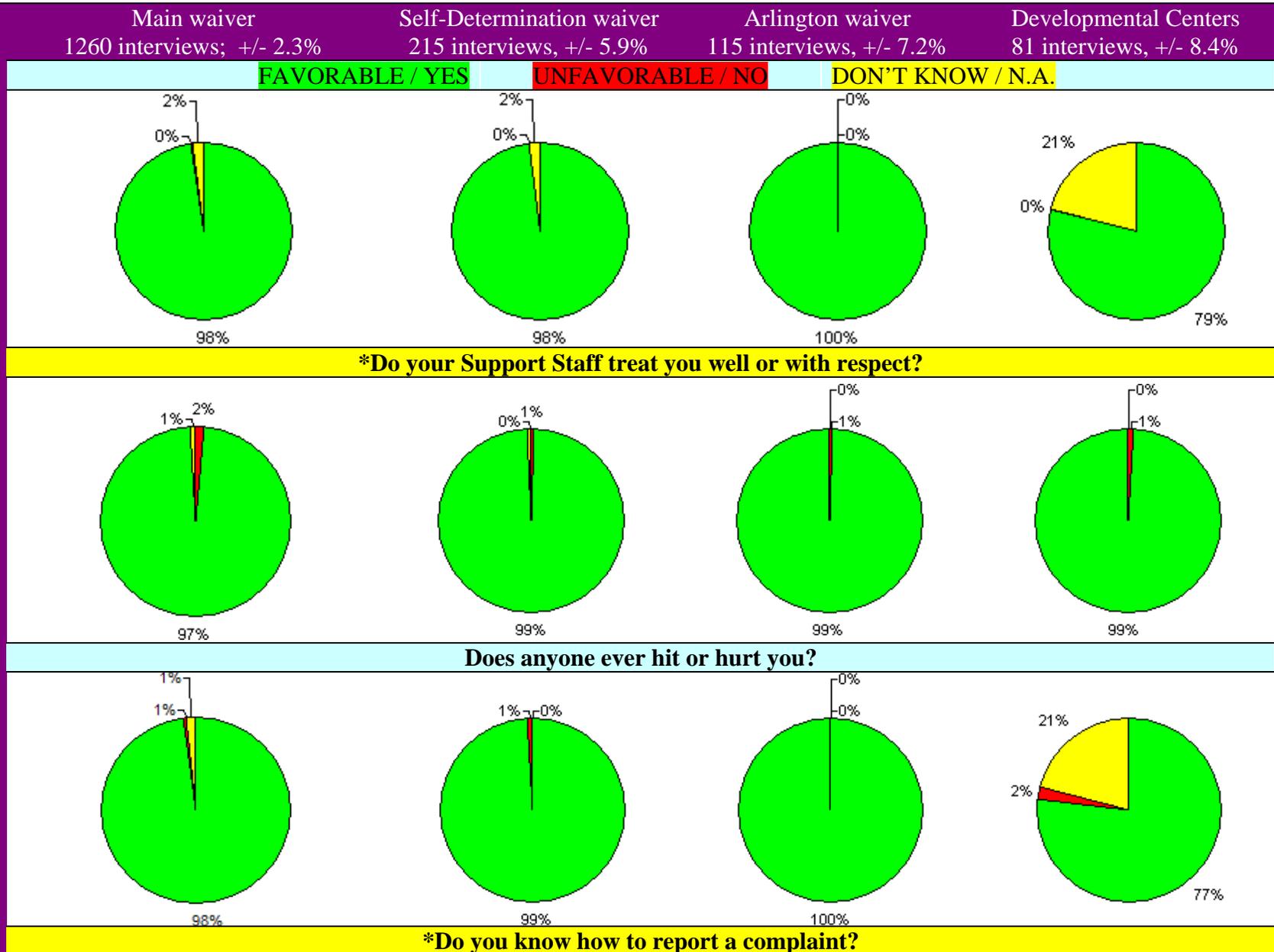


Would you rather live somewhere else or alone?

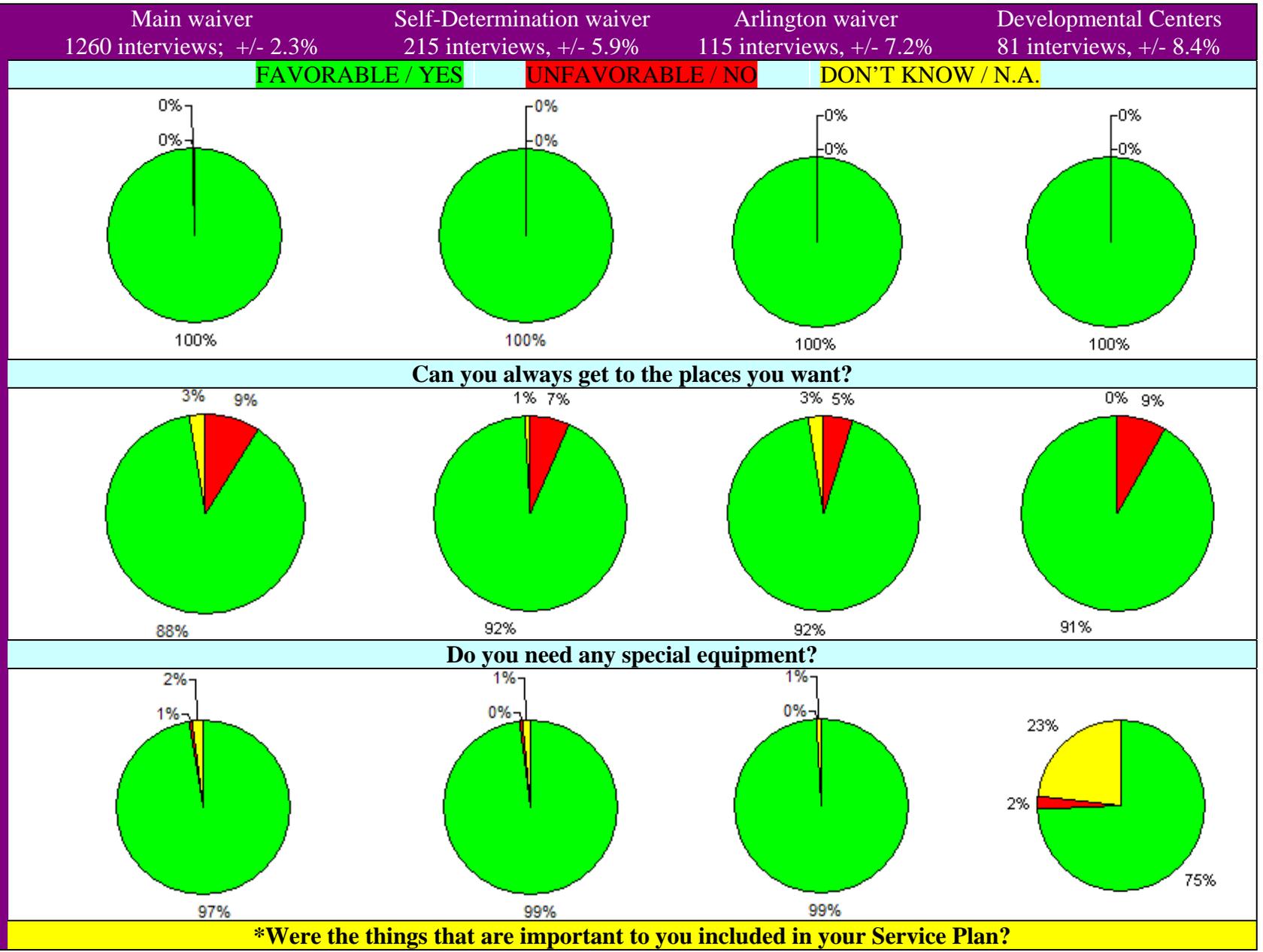


Would you like to work somewhere else?

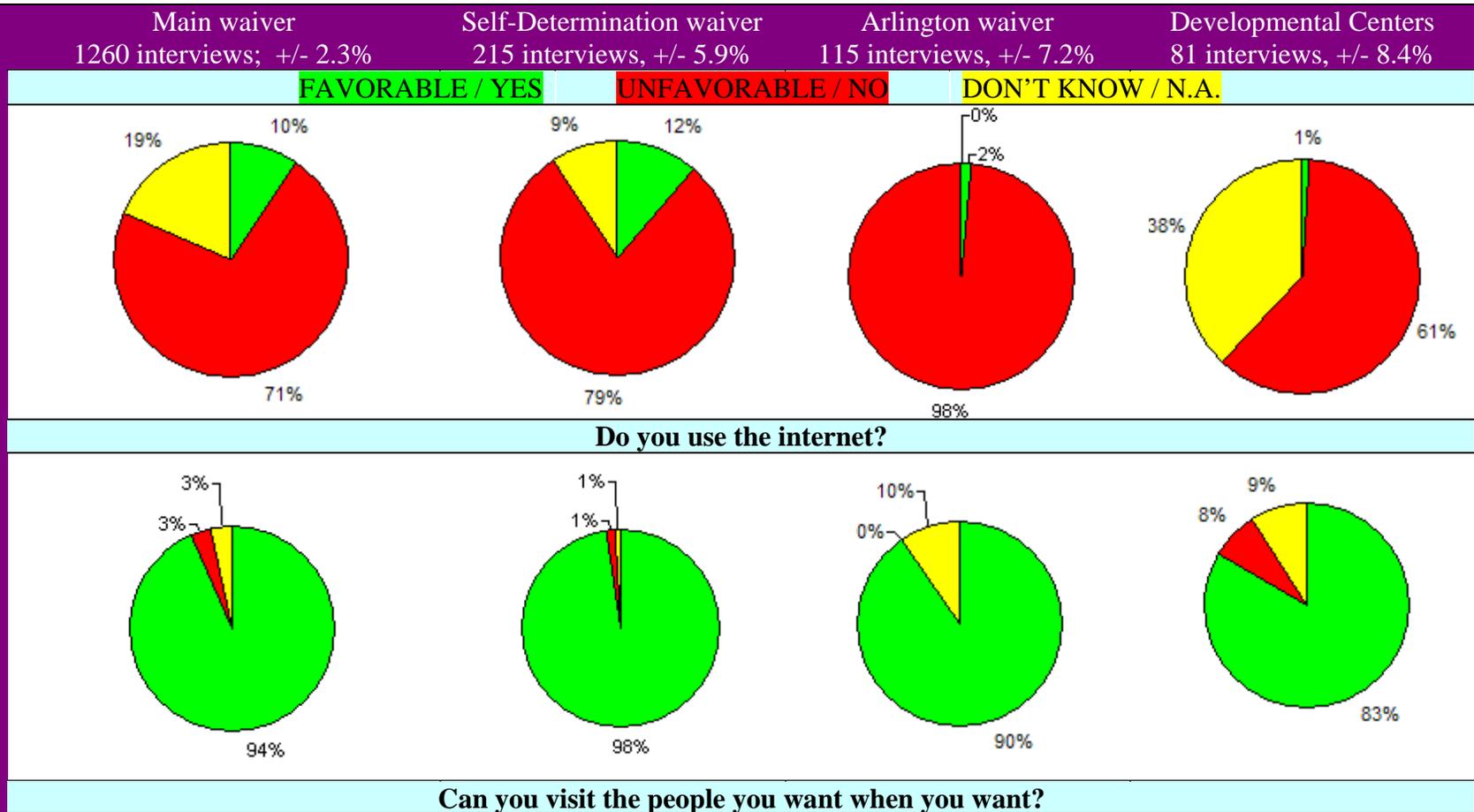
PTP 2010 Respect and Dignity



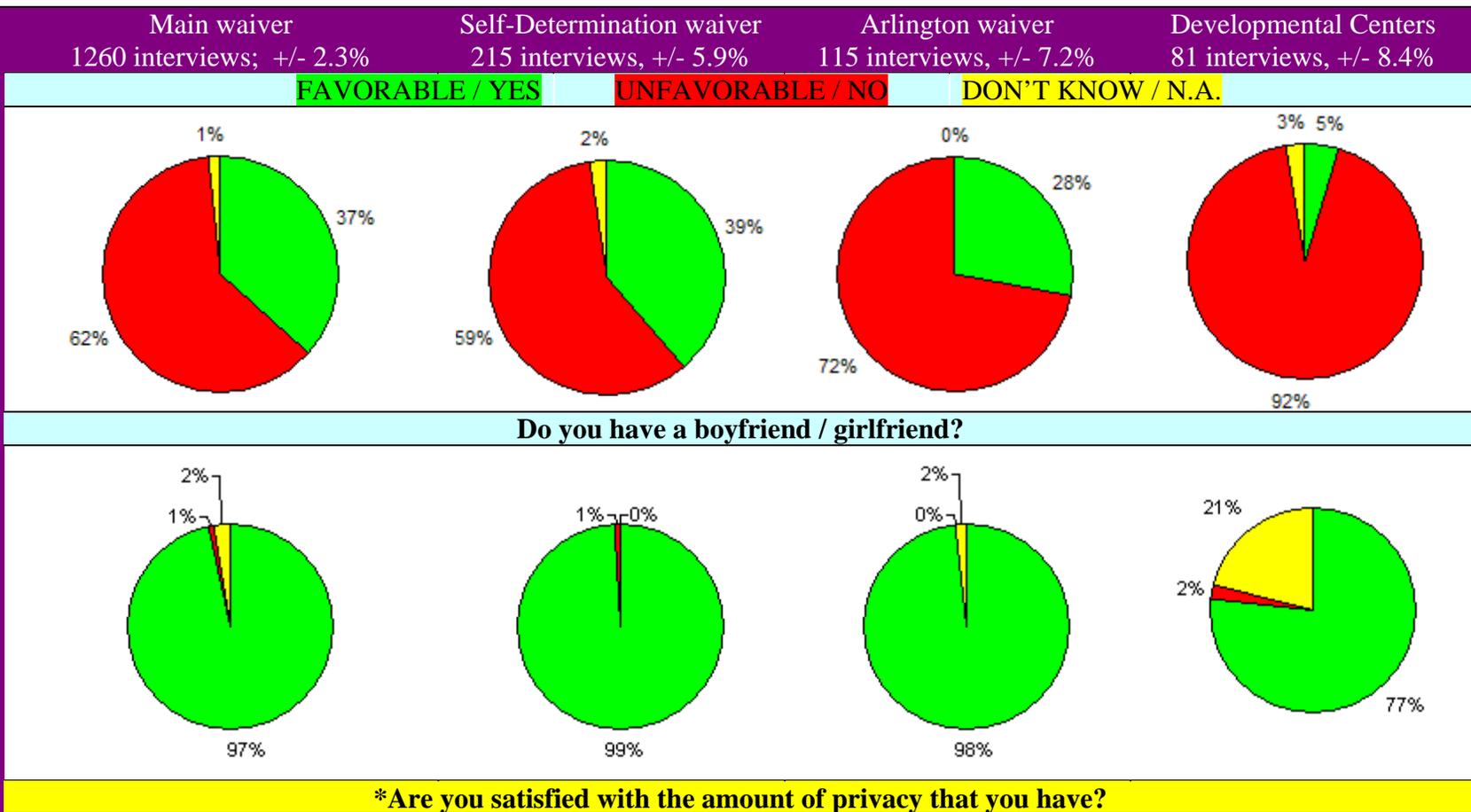
PTP 2010 Access to Care



PTP 2010 Community Inclusion



PTP 2010 Community Inclusion



6. PTP INTERVIEW COMMENTS

The PTP interview for 2010 includes identically formatted and worded questions as last year. Following are examples of comments taken during interviews with participants in the each of the waiver programs in Tennessee, including previously identified questions to which any response other than a positive one triggers the Survey Notification Form procedure, detailed on page 9.

A. Choice and Control for Main waiver

Do you like where you live?

Positive:

- A little bit, I guess. I like it alright except it gets a little noisy sometimes.
- Although Joseph said he likes where he lives, he is looking forward to moving into a three-bedroom, two-bath home.
- Bernice just moved to a new house. There was an accident and a vehicle plowed into the house she was in. So she had to move to a new house suddenly.
- Brian formerly lived in a duplex but now lives in a larger place (bungalow) because he roams throughout the house and needed more room. In addition, he needed a larger place due to his behavioral problems.
- But I like the new house where I'm moving better. (Staff said he'll be moving in 3 weeks - address is noted on survey list)
- Client is in the process of moving to Cleveland to be with mom.
- Danielle likes living in rural areas. Currently lives in a trailer but moving into a house in September, 2010.
- Debbie likes where she lives but her home is not handicapped accessible. Her health is declining and next year she will be in a new home.
- Doris lives with his niece, who is in the process of trying to gain conservatorship over him. He has lived in his home his entire life.
- Dustin lives with his mother, who is asking the state's permission to build a separate residence for him on her property. Dustin's father died of cancer in May of 2010.
- He moved out of his parent's house and when his care giver comes to pick him up he couldn't be happier.
- He's got a good relationship with his neighbors.
- I didn't at first, but now I got used to it.
- I just moved in and everything is going fine so far!
- I LOVE where I live.

A. Choice and Control for Main waiver (continued)

- I said no at first, but then I changed my mind and said yes. It's just too noisy around here. I'm concerned about that. (Staff said his ISC knows about it)
- I used to live in a mental institution, Middle Tennessee. I love where I live now.
- I'm lovin' it to death!
- It's a townhouse and I own it.
- It's haunted, but other than that, it's pretty cool.
- John just moved into a new home.
- moved back home to live with parents
- Peggy likes where she lives because "it is quiet."
- Prior to moving to her new home two years ago, Mary lived with her mother, who transitioned into a nursing home.
- She seems happy there.
- She's got good neighbors and they try to take care of her.
- Staff Comment: "Anita loves where she lives. She laughs all day. She hugs staff and her housemate."
- The house burned down several years ago, so the new house is much more wheelchair accessible. It's all open and there's no barriers. She loves her new home!
- Lives with parents

Negative:

- Barbara says she does not like where she lives "because the driveway has a crack in it."
- Doesn't like the small apartment
- He shook his head no, though he was smiling and staff said they felt he was happy.
- I don't always get along with my roommates.
- I don't like my housemate.
- I live too far away from any place. I do not like it here.
- I want a bigger bedroom!
- I want to live with my family.
- I want to move somewhere else.
- I've lived there too long - I'm moving.
- Jerry says he would rather live in his old home but can't because of health issues
- Lots of arguing from his sister Mindy and her husband.
- moving because of domestic violence incident (Janice was not hit or involved)
- My girlfriend don't come to see me. Too much talking. (Staff said he actually did live in his apartment.
- No I don't! Momma and daddy – no! Want to live with Jerry (he's another individual at the Center – staff said he wants to move away from his parents)
- Staff Comment: "Theresa's present home is not sufficient for her," a staff member said, "because her health has declined. It is too far for her to walk down the driveway, and there are too many steps on the back porch."

A. Choice and Control for Main waiver (continued)

- Rex says he has a bad roommate
- Ricky wants to live with his mother in Memphis.
- She thinks she is paying too much in rent
- The house is old.
- They only got one bathroom. I don't like using the same bathroom.
- Too noisy.
- Wants a bigger house
- Wants to get married
- Would like to live in his old house.

Did you choose the place you live?

Positive:

- Amy got to choose which house was most suitable for her.
- Big boss took me to see it.
- Brady helped choose place to live.
- Companion helped build the house.
- He actually looked around some houses with me, and he liked it.
- He chose it – he requested to live as “Three's Company”. He likes having 2 female housemates.
- He moved out of his parent's house and when his care giver comes to pick him up he couldn't be happier.
- He moved there when he was a young boy and he's never wanted to live anywhere else.
- He moved with his family, but he wouldn't want to live with anyone else.
- He went around with us looking for the house and his conservator took a look and agreed.
- He wouldn't be happy nowhere else.
- Her mom found it, but she usually has some input – we kind of go off her behaviors to let us know if she likes something or not.
- Her parents helped her pick this house.
- Her sister helped her find it.
- He's never showed any interest in living anywhere else. He lives with mom and dad.
- Has been there all his life.
- His mom moved him in with his brother.
- I been trying to get out of my old house for years. I couldn't stand my old house!
- I decided to move out of my apartment and move in the townhouse.
- I just looked in the paper and I found it.
- I moved in with my mom.
- I moved to this house with my mom. The name of the street is the same as mine!
- In a way I did. My cousin, who was over me, saw the house and wanted me to look at it.
- Jerry had to move to a new home because of the 2010 Nashville Flood.
- Lives with parents

A. Choice and Control for Main waiver (continued)

- Lives with relatives
- Melissa chose among several homes.
- Mother helped, but I did pick it.
- My cousin took me over there to look at it, and since there was no place else for me to go, I had to live somewhere.
- My family put me here in this group home with all my dolls. I wanted to go, I sure did.
- My sister helped me find this house I live in.
- [Agency] helped me.
- She got to go and look at the house before she moved in.
- She moved in with her sister when her momma passed away.
- She wants to be with her mommy.
- [Agency] policy is placing individual temporarily in a situation to see if they like it. If they aren't comfortable with living situation, another home is found for them.
- Somebody helped me pick the house. They told my family that it was alright for me to come over and live.
- They always show the houses before they move in.
- They're always placed in homes on a trial basis to see if they like it - nobody is ever just placed some place permanently unless they like it.
- We talked about it, me and my momma and my sister decided I would live with my sister after my momma passed away.
- Well kind of, well kind of not. Staff said there were some limited selections of homes and she got to pick the one she wanted.
- His parents say he couldn't be happier when he moved.
- Father helped.
- He came from Cloverbottom and he was the first one to move into this house - it was brand new. His parents are really active in his care.

Negative:

- Agency chose.
- Aunt chose
- Barry picked his own room but did not choose the home.
- Brother (conservator) chose.
- Cheryl said she has some problems with her housemate "because one day she is happy and the next days she is upset. She does not want to go anywhere or do anything. I'm the type person who must do things. I want new friends to talk to. I want to have dinner and play games with them. I get bored and stressed out if I don't have enough to do. I want more time with other people."
- Conservator chose.
- Dad chose.
- Family chose.
- Foster parents chose.

A. Choice and Control for Main waiver (continued)

- Grandparents chose.
- He came from Cloverbottom. His sister picked this house for him.
- I had no choice, I had no other place to live. I was living with my momma and daddy but they moved into a nursing home, so I had to have a place to go. But I like living there.
- I live with family.
- Legal guardian chose
- Lives with parents.
- Mom and dad own the house he lives in.
- Mom chose.
- My mom and my grandmom found it for me.
- Terrence has lived with his parents in the same house his entire life.
- [Agency] told me it was the only house available at the time.
- We got her when she was a baby, 10 months old.
- We had to make that choice for her - she was only 2 at the time.

Did you know you have the right to change your support staff?

Positive:

- A long time ago I didn't like a staff. She was always making fun of me so I told a staff over her and she got talked to. But she kept on doing it, so they fired her.
- According to staff member interviewed, Bobby can't verbalize his preferred staff but, if there is a problem with a staff person(s), Bobby has "behavior issues." He will hit himself in the head if he's upset.
- And there have been instances where the chemistry between him and staff have resulted in changes.
- As far as I know I can.
- But I haven't ever changed my staff.
- But I like 'em, I don't want to change 'em.
- But often has trouble getting the change made
- Companion Comment: "If Thomas does not like a staff person(s), he will not shake their hand."
- He does have his own sign language to let you know if he's not happy.
- He doesn't know, but his parents know. The family knows all that.
- He doesn't really understand his "rights" but it's been explained to us that if he has a problem with us, the agency will get someone else.
- He doesn't understand the right, but he would let you know if he wasn't happy.
- He really does like older ladies, and his caregiver right now is an older woman, so he's very happy with her.
- He's not capable of understanding but he has a way of expressing his dislikes. I'm sure his family understand his rights.
- I ain't got no problem with none of the staff there.
- I don't got a problem. I don't want to change.

A. Choice and Control for Main waiver (continued)

- I don't want to change them. I like them all and I like to get along with everybody.
- I know, but we don't want to.
- If he don't like you, he'll beat up on you. Staff have actually quit - he can get pretty wild. If they happens, then staff will change.
- I'm happy with 'em.
- I've heard that but it's not true. It's not true at all. I tried to get new staff, daytime and nighttime.
- Lisa, in the past, has changed support staff.
- Of course she does! Individual said "I don't got no problem with them."
- Once I had a staff and we didn't see eye to eye. So I said something ugly to her. I was thinking about changing her, but now we get along better.
- Really likes the woman that works with her.
- "Robert was at Clover Bottom for many years. With Rochelle, he can make more of his own decisions."
- She doesn't really understand but we know if someone is not working well with her and change them.
- She doesn't, but her parents do.
- She's actually changed her staff before.
- Sister's Comment: "I pretty much picked Willie's support staff, but her decision was the final factor. Willie has had her present PA for 10 years, and that's a long time. She's had some PA's she wasn't happy with. I told one of the PA's to leave because she was ineffective."
- Staff said he complains if there's ANYTHING he doesn't like. Individual said, "That's right! I do!"
- That's right!
- We try to give him choices but he pretty much goes with the flow. But if there was a conflict, we'd switch up staff. He's very good at calling out who he wants.

Negative

- [He] does not like male support staff.
- He really doesn't understand this concept, but if he was visibly uncomfortable with staff, they would be changed.
- I didn't know that. If they discussed that with me I can't remember it. (Interviewers explained she had the right to change staff.)
- I didn't know. (Interviewers explained right.)
- I don't want to have anybody else. I didn't know that, but I don't want nobody else. I just want Theresa and Veronica as my staff in my brand new group home.
- If they told me I forgot.
- Individual said "no," but staff said she gets that explained to her but she just doesn't get it. She will let you know if she's not happy though."
- She doesn't understand that at all, so [Agency] puts them in place. We've had many staff changes - staff would come in and then quit. Staff we have now are consistent and stable.

A. Choice and Control for Main waiver (continued)

- No, I didn't know that.
- This right was explained to her.
- We explained this right to him, but he got a little stressed thinking about it.
- Staff Comment: "Sometimes some of the support staff is not sensitive when Thomas is undergoing medication(s) changes."

Can you talk to your ISC when you need to?

Positive:

- According to the staff member interviewed, to assess if Lamont has problems, "you have to learn to know him." He will lie down if he's not feeling well.
- Any time we raise a concern to her she's very thorough.
- Brian has a Circle of Support Meeting once per month and his ISC attends.
- brother and his wife can
- Conservator communicates with ISC
- He doesn't really have much that comes up in the way of needs, but she makes regular visits.
- He loves Donna.
- He's a real good fellow
- He's been switching and I think he's getting ready to get switched again. We don't know who the new ISC will be.
- I guess I could but I never have thought about it.
- I have a brand new ISC. I only had her a couple of months.
- I never have to call her. She comes to see me all the time at the workshop or at home.
- I think I can, I've never had to call.
- If I need to, I can. I got her number but I only call her when it's really important.
- If she's up here I can talk to her. If she ain't here I guess I could call her. Sometimes she's hard to catch.
- If something happened to me, she'd care about me.
- If there's a problem, we can ALWAYS call.
- ISC phone numbers are kept in George's home.
- Jeanetta talks to her ISC once monthly at the bowling alley.
- Parents can.
- She comes down twice a month.
- She comes every now and then. I like her.
- She comes for her birthday parties and special activities. She even comes to the hospital. We are thankful to have her, she's great!
- She gets the job done.
- She lost her 2 previous ISCs and she's got a brand new one now. We just met her for the first time just recently.
- She makes visits every 21 days.
- She talks a lot! (Individual made a sign to indicate she talks all the time)

A. Choice and Control for Main waiver (continued)

- She's always available. She's a good one.
- She's always on call. She's on my speed dial.
- She's been out sick for awhile, but even with her condition, she makes time to come - she misses her guys.
- She's nice, she's great. She gives us all the information we need.
- She's very helpful - every time you can her, she's there.
- Staff does.
- Staff leaves message for ISC; she returns call
- Staff wasn't sure if he understood this right, but his parents do.
- They're wonderful!
- We just got a new one, but they're gonna change this one, so I'm not sure who we have right now. But the ones we've got I feel like they're very responsive. I can get on the phone right now and I know they'll talk to me.
- When he knows Kyle – that's his case manager - is coming to see him, he gets really excited. And Jaylene is very responsive and helpful.
- When I call her and leave a message she'll call me back.
- Whenever I need anything she's right on it! She comes to see Mike regularly.
- Willie has had Deion as her PA for the last four years. Willie's sister said Fisher "is wonderful."

Negative:

- by appt. only
- I used to have Nancy Tallant but she moved and they haven't given me a new one.
- I don't really know who she is.
- Ms. Johnson said, at times, communication with Andrea's ISCs has not been very good. "Some of them are very hard to contact," she said. "I wish Andrea had one ISC who would stay in her position for a longer period of time."
- She has "availability issues." We have a hard time getting a hold of her and it's impossible for Elsie.
- Staff used said she used to be his ISC, but she wasn't sure Lisa still was his ISC. Individual couldn't really remember speaking with her.
- "The ISC does not respond to us. They don't take the time to address Lorenzo's needs."
- We just got her so we really don't know her.

Would you like to work somewhere else?

Positive:

- A pizza place.
- Alice would like to work at McDonald's cleaning up, sweeping, washing tables, taking out trash

A. Choice and Control for Main waiver (continued)

- Answer phones.
- Any job!
- Be a hospital nurse
- Brady said he might want to become a painter.
- Brian's mother said an assessment had been completed regarding Brian's work aptitudes. Brian said he wants to work at McDonald's cleaning tables. Brian said he would like to attend New Horizons. His mother, who responded to some of the interview questions, said she's attempting to enroll Brian at Rochelle Center so he can "pick the job he wants."
- Cars and trucks. Plant. (Staff said that was the first she'd heard of it. He used to do contract work here when we had it, but we lost the contract. When questioned further, individual said he wanted to work a plant located nearby the Center, but there was no shop that staff knew of.)
- Charles said he would like to work for Tennessee State University or The Tennessee Titans. Staff Comment: "We have been looking seriously for jobs online. Charles has filled out applications for Burger King, Taco Bell and Wal-Mart."
- Chris said he wants to be in the Progress day program. He has visited there once. He has attended New Horizons during the holiday season, going to dances.
- Christopher would like to work at Taco Bell.
- Cleaning cages at a pet store
- Client would like to be a police man.
- Construction
- Doing landscaping
- Evan has had contact with Voc Rehab concerning his artwork.
- Formerly, Bryan did kitchen work, helping homeless individuals. Also, he worked with Goodwill for around four years, started working there at age 16.
- Grocery store, bagging groceries, cleaning job
- Hard to stand on feet. would have to have a job sitting most of the time
- has a job but would like another one part time
- He nodded his head when asked about volunteering, but staff said he wouldn't be able to hold a job. Staff wasn't sure what he might want to volunteer at.
- He used to work at vocational rehab but then he had his stroke. We've been talking to Nancy about seeing whether he can get back on with them. Individual indicated he would be interested in working at the animal shelter.
- He does have some little jobs here at the center and he does some contract work when we have it. He's not able to hold a job or volunteer outside because of safety issues.
- Helping elderly people and taking care of children.
- I applied for a cook or pick-up dishes at Logan's Roadhouse.
- I have a job at the bowling alley. I want to work someplace else - but I want to keep my job. I want more. Staff also said he volunteers at Hospice.
- I put in an application at Goodwill and I'm waiting to hear from them. I can't take much more of here. There's nothing to do. I don't come every day. I couldn't stand it if I did - they don't pay me anymore.

A. Choice and Control for Main waiver (continued)

- I used to have a job at the big house, but there ain't nobody there. I'd like to have anything.
- I used to work at Vanderbilt. My mom wants me to work. I'd like to be staff, take Jessica's place (Jessica is staff). Staff said they weren't aware that individual's mother was wanting her to work.
- I used to work for the City of Franklin in the grounds keeping. I worked at Publix but I quit because there was a guy who was getting on my nerves. I'd like to work somewhere. Staff questioned what he might want to do and he couldn't really settle on anything. He's not really big on crowds or people he doesn't really know.
- I volunteer at Meals on Wheels. I volunteer at Water Park. I want a job at the grocery.
- "I would like to work at Vanderbilt University in some sports capacity. I like many sports.
- I want to work at pizza hut. Staff said he did have a job once at Goodwill for about 3 months, but it didn't work out for him. Right now he volunteers at the food pantry at her church 2 days a week. Sebastian said "I help out with cleaning and maintenance at the church."
- I was going to school majoring in social work, but I'm taking a break now. I'd like to volunteer somewhere, but I think I'd like to do what Brenda (one of the interviewers) is doing.
- I was trying to get me a job at this restaurant, Wendy's. I filled out an application and I'm waiting to hear.
- I work at McDonald's right now but I want to work at Publix, too, so I can make more money.
- I work at the tax office, and I clean there 5 days a week; and I work here at [Agency]. I'd like to volunteer someplace. And I'd like to work another place. I hadn't talked to anyone about it. (Interviewers suggested he speak with his ISC and talk about what he'd like to do.)
- I work part time at Ace Hardware. I'd like to work more days.
- I would like to have a job. Maybe go up and pick up papers, clean up the streets. I'd like to work and have money hanging out of my pockets. I used to work hard.
- I'd like a job washing cars.
- I'd like a job working outside in the open and the woods.
- I'd like to have a job. I'd like to work at the animal shelter.
- I'd like to have a job. It don't matter where, just different places.
- I'd like to work at a Dollar Store.
- I'd like to work as a mechanic one day. And I want 40 grandchildren.
- I'd like to work as a repairman fixing things.
- I'd like to work as a receptionist.
- I'd like to work as a waitress.
- I'd like to work at a Night Club
- I'd like to work at an Art Store

A. Choice and Control for Main waiver (continued)

- I'd like to work in a BINGO Hall calling out numbers!
- I'd like to work at a car lot. But I don't work because I'm retired. I'm old enough to retire. When they have work here I work.
- I'm gonna get a job. Connie's helping me. The job coach is trying to help him get a job.
- I'm looking for a job right now. I've been applying at difference places, and I think I'm going to apply at TJ Maxx. I volunteer here at [agency].
- I used to work here but not no more. I'd like to have another job here.
- Joe formerly worked at TGI Friday's at Opry Mills Mall but the Nashville May Flood forced him out of the job. He has recently submitted four job applications, one each with Longhorn and Friday's.
- Mary would like to own a bookstore. Has done Meals On Wheels in the past
- Michael, who said he wants to work for a florist, dropped out of high school at age 17 but feels he is very)qualified to work. Michael, who formerly worked at Tony's Garden Center in Portland, Tn., said he has talked with his residential program about getting a job as a florist but "I am afraid to talk to my staff further. They are not helping me get a job."
- Previously, Mary worked wiping tables and sweeping floors; also worked at Long Jon Silvers and Goody's.
- Previously, Mary was a secretary at [an agency] six hours per week and wants to do the same job again.
- She would possibly want to volunteer. Previously, Debbie helped with Meals on Wheel. She worked in the [agency] workshop but that was not a good fit for her.
- Sheila said she formerly worked at Pizza Hut but got into an argument with someone.
- Staff Comment: "Barry has been trying to work through Voc Rehab to get a job, but their job coach, after we contacted him in August, 2009, has not returned one of our calls. Barry's ISC, Marissa Woodley, has also tried to get in touch with Lee Qualls (Voc Rehab Job Coach). Barry needs a work resume. He wants to work at a fast food or full-service restaurant (Shoney's) probably busing tables."
- Staff Comment: "The Job Corps pretty well indicated they would get Susan a job; we have left messages but the job corp. has not returned our calls. Susan would like to work with animals."
- Staff member interviewed said it is hard for Joe to obtain suitable employment "because he finds it hard to trust new people." She said Joe, while at Rochelle Center participating in its job search program, didn't make as much progress towards finding work as he did when someone works with him one-on-one.
- Staff said he volunteers at the Senior Citizens' Center and at Graymere Church. Individual said "I'd like to volunteer other places, too."
- Staff said the VR did an assessment for him, trying to get him a job, but because it's such a small town there's very little available at this time. But they're still trying.
- She wants to work in a nursing home for the elderly after high school graduation.
- They did some job training with him at Kroger's and Taco Bell, but it was too hard for him. They're working on something else for him.
- Stocking at Target.

A. Choice and Control for Main waiver (continued)

- They've previously looked into finding him a job but his attention span is so short that it's difficult to find something suitable for him to do. We're looking at maybe doing something in the yard next spring.
- Waiting until done in court to look for a job, going to court so she can stay with her boyfriend
- Want a real job like being a nurse
- Was working due to budget cuts was let go would like another job
- Willie says she wants to work at a funeral home and likes visiting graveyards.
- Works at TGI Friday's in Opry Mills Mall filling up ice, washing trays (12 hrs. per week, 3 days a week)
- Would like to have a sit down job
- Would like to work for The Arc!

Following are jobs mentioned more than once:

- Bag groceries.
- Burger King
- Child care
- Cracker Barrel
- Daycare
- Flower shop
- Hospital
- Janitorial
- Kmart
- Meals-On-Wheels
- McDonald's
- Mowing
- Nursing Home
- Paint
- Pizza Hut
- Recycle center
- Taco-Bell
- Wal-Mart
- Washing dishes

Negative:

- At her last ISP meeting she said she did NOT want to work or volunteer.
- Brian had a job shredding paper but do to seizures had to resign.
- Formerly, Darren volunteered for Meals On Wheels but had to quit because he was eating the food. He also attended [agency] but left because of inappropriate sexual behavior.

A. Choice and Control for Main waiver (continued)

- He is retired.
- He can if he wants to, but he has no desire.
- He can't work or volunteer anywhere, he's just not able to.
- He couldn't work or volunteer anywhere because of behavioral issues.
- He couldn't work. He has a very short attention span and has got to be moving. He also is in diapers and has a colostomy, so that makes things even more difficult.
- He does meals on wheels. He can't hold a job.
- He doesn't like to be outside his comfort zone. He did used to have a job at a sheltered place but he doesn't show any interest here.
- He goes to St. Clair's and does Meals on Wheels. He does it 3 times a week. He couldn't hold a job – his attention span prevents him. We tried to get him to work on recycling, but it just didn't work out.
- He has no motivation to work anywhere.
- He isn't capable of holding a job or volunteering.
- He likes it here, and I don't think he'd be happy anywhere else.
- He picks up trash at the park, and he just got a new job at the nursing home cleaning the bingo chips, but he's been going to the nursing home for awhile. His day is pretty full and he gets upset if he doesn't get to come to the day program. He wouldn't want to do anything else.
- He really couldn't work. He's deaf and non-verbal.
- He seems very content here, and I don't think he'd even understand the concept of working outside the Center.
- He shook his head "yes," but didn't seem to really understand the question. Staff said he showed no real interest.
- He used to work here when they had contract work, but that's gone. He seemed to really enjoy so I think he'd like to have some kind of work, but I think it'd have to be here.
- He volunteers at Meals on Wheels, and he gets out in the community 2 times a week. He's happy with what he's doing.
- He volunteers at the Auction Barn and he works on the cleaning crew here.
- He works a couple of days at Taco Bell, and he does some odd jobs here. He'd like to quit but he really wants to keep that paycheck!
- He works at [agency] packing sponges when he feels like it. He also goes out in the community, and he's happy with that.
- He's not really capable of working or volunteering - he's not comfortable around a lot of people or strangers.
- He works in our cafeteria right now, and when transportation is available, he has job sites at the library, PetSmart, YMCA. He also works at the Cookie Store here at school and delivers coffee to the teachers. He doesn't necessarily want to work, but he really likes the social interaction.
- His parents – and they're his conservators – have said they don't want him to work. I think it's because of his history with behaviors. But I've never heard him express a desire to work anyway.

A. Choice and Control for Main waiver (continued)

- I been working at Kroger's for 15 years and I like it. I bag groceries and take them out to the car.
- I don't think so – unless it would have something to do with computers.
- I can't. I can't hardly stand because I've had 2 knee replacements and my back really hurts me.
- I don't know that she even has the physical skills to work or volunteer.
- I don't like working - I don't like job working! Staff said she has phobia issues and it's difficult to get her out.
- I don't think I want a job. I do meals on wheels. I like that.
- I don't think she's ever had a job. She used to go to a day program, but for some reason - maybe behavioral issues - she doesn't go there anymore.
- I don't think so because I can't hardly get around too much.
- I DON'T WANT TO WORK
- I hadn't really thought about it. I'm a diabetic so I have to watch it.
- I have 2 jobs. I work at the bowling alley and I work for the PTP. I like my jobs and I don't want to change them. I don't volunteer anywhere, and I don't want to.
- I never volunteered. I'm getting too old to work. Staff said he had gone for assessments and qualified for jobs, but when he was offered the job, he didn't want it. They had a hard time getting him to do much of anything - "he likes to SLEEP!"
- I used to have a job but not no longer. I'm just happy here.
- I volunteer at Meals on Wheels, it's the closest one I can get to. I used to work at the hospital, and I when I lived with my daddy I'd do babysitting. But I don't want to do that anymore - I don't like changing diapers.
- I volunteer Wednesdays and Fridays at the Food Bank. I'm a janitor here (the agency's bldg.)
- I work at Goodwill 2 days and I really like it. I've been there over 2 years. I don't volunteer anywhere.
- I work at Meals on Wheels. I'm on the cleaning crew here. I love that. I wish I could work every day.
- I work at the TPA office shredding paper. I'm happy right now.
- I work at Wendy's 5 days a week. I don't want to volunteer; I got to make that cash.
- I work on the contract line and do meals on wheels. I go to this day program and out in the community.
- I work at Wal-Mart as a Courtesy Associate, and I come to this day program. I work about 4 days a day. (He volunteers at people first and meals on wheels. He's also a person-centered trainer - that's a volunteer position. He's a certified trainer and he's putting everybody here at the Center through training.) I won the self-determination from The Arc. I went through all the classes.
- I work Tuesday, Thursday and Friday at Good Will. I clean here. I get paid. I want to stay at Goodwill.

A. Choice and Control for Main waiver (continued)

- I'm through working. I worked through the 50's, 60's and 80's. I used to work at the Columbia carwash and other places I can't remember. I volunteer at the nursing home, just singing you know.
- I'm working part time now with PTP!
- Linda has attempted working on freelance projects but hasn't been successful.
- Lorenzo works at Dell Computer part-time and gets a check which is put into his account.
- Melisa's parents don't want her to work.
- No ma'am, I want to stay at my brand new group home.
- No ma'am. I want to stay here. I want to sing and dance.
- Oh heavens no, he couldn't work. He's at high risk in so many areas.
- Rosemary can't read or write so working somewhere else might prove to be very difficult.
- She does volunteer some at the park, but she's pretty much content with what she has.
- She goes once a month to the hospice and bag things for them. She used to have a job somewhere but nothing right now. Individual didn't really respond to this question.
- She seems content with all her activities, coming here and going out in the community. And I doubt she could volunteer or have a job because of her physical limitations. Someone would have to do for her.
- She used to pack scrubbers when we had the contract, but as far as getting a job in the community, no I don't think so.
- She was in school, but I had to take her out because they called every day, she was having so many seizures. Now we just take her out in the community - we can go out everyday. She just isn't capable of working, besides the seizures she has the attention span of about 3 seconds.
- She would not be able to work anywhere.
- Shelton's mother (conservator) wants him to stay retired; He worked in the past.
- She's very helpful here, but she would not want to go out in the community to work.
- Staff Comment: "Brian has autism and can't stay on task very long. He has a short attention span."
- Staff leaned in and asked "Hey, Mike, you want a job?" Individual smiled and said "Nooo. I hurt my back!"
- Staff member interviewed said Susan "is available to work but she doesn't want to."
- Staff said he used to work at Crockett's Restaurant until it closed down. Now he works at Save A Lot 3 days a week. He absolutely loves his job. The rest of the time he goes out in the community. He's a very busy guy.
- Terry lost his last job because he was late to work two consecutive times.
- When we have contract work she'll work in the workshop here. She has to have constant supervision.
- We've tried to do it before but she's just not interested.
- Works at Humane Society where she accepts donations

B. Respect and Dignity for Main waiver

Do your direct support staff treat you well or with respect?

- Always! A+!
- Anita prefers female staff.
- Billy has 24-hour staff. One of Billy's staff members is his great nephew.
- Chris: "My staff gives me very good support."
- Heck, yeah, they treat me right!
- He's always well dressed and clean and is SO happy when he sees his care giver.
- He's spoiled. We treat him like he's the baby of the house!
- His sister is his PA – she works for TPA. I think she's good. (When staff asked if he liked her, he got a HUGE smile on his face and spread out his arms and said “This much!”)
- I know they do - I can't take any bad behavior!
- I love them all. They are so good to me, and I wouldn't change one of 'em.
- I try to get along with everybody.
- Individual grabbed staff's hand and kissed it, and she continually waved at her staff.
- Individual had a clearly responsive and fond relationship with her staff. Staff obviously took excellent care of individual.
- Individual kept on kissing staff and leaning on her.
- Leroy has no PDI support staff at home, but is treated well and with respect at PDI day program.
- Ms. Hollis is upset about the DIDS PA cuts. She says that Dustin's three PAs sometimes work 16 hours per day and travel long distances (30 miles or more) to come to the Hollis home. Ms. Hollis says she feels Tennessee Personal Assistance, whom Dustin receives services from, is very misguided because she fears, due to the PA's long hours, they will suffer burnout and quit. Ms. Hollis says she is very pleased with Dustin's present staff. She said if Dustin dislikes a PA, "He will push them away and have nothing to do with them."
- Oh they're wonderful. I love them.
- She didn't eat her breakfast - I'm going to put her on a diet! No more chips & dip! If she left I'd miss her. (Comments by individual regarding her staff)
- She's got us wrapped around her finger!
- Staff member said Rose has "zero tolerance" for poor staff treatment.
- That's what's wrong – she's spoiled!
- They are VERY good to him!
- They treat me good. I like 'em. I LOVE 'em!
- They treat me right here. Everybody loves me here, and that's the truth.
- They're good to me at my home.
- VERY nice! They're VERY nice!
- Well, let me see. Well ... yes (big smile)!

B. Respect and Dignity for Main waiver (continued)

Negative:

- Although Danielle's support staff treats her pretty well, Danielle says sometimes staff "treats me like a baby."
- Although Rhonda's sister, Carolyn Coatwell, said most of the [agency] staff "is very attentive and takes good care of Rhonda. Ms. Coatwell said Rhonda has had past problems with some [agency] staff "because some employees were hostile towards her." Due to this, Rhonda went to [other agency] (also in Clarksville) then back to [original agency]. Recently, Darlene said [agency] staff person took away her baby dolls because she urinated on herself. Ms. Coatwell confirmed Rhonda's story by going over to Rhonda's home, finding the baby dolls and gave them back to her. "Rhonda sleeps with her baby dolls," so it really upset her when staff took them away from her," Ms. Coatwell said. In a second incident, Rhonda said staff took away her puzzles from her "and told me to sit on my hands because I urinated on myself." Once again, Ms. Coatwell went to Rhonda's home, retrieving the hidden puzzles.
- Rex made the statement that one staff member did not treat him with respect. This staff member insisted on buying off brand food at the store and not name brand food that Rex asked for.
- She had a staff member recently that did not respect her. She is not at the house anymore.
- Staff member says she can "only speak for herself" but feels night staff PA gives Roger's housemate "preferential treatment." Daytime staff PA who was interviewed says nighttime PA "treats the other housemates better than Roger; this makes Roger mad." "We (my wife and I) have found Lorenzo in bed lying in his urine. When he goes to school, teachers say he smells like urine. The staff is not properly trained. Many of them are foreigners and have little conception of what it means to be clean. When they bathe Lorenzo, they pour cold water over his head. We are not happy with Evergreen at all, and we are looking at other agencies. The staff sits around and watches TV most of the time. The doctor does not take good care of Lorenzo. There have been bruises and rashes on Lorenzo which I think are suspicious. I can't prove it, but there may be things going on that should not be. The staff does not feed Lorenzo enough food which causes him to be hungry. He does not get enough to drink, making him foam at the mouth."

C. Access to care for Main waiver

Can you always get to the places you want?

Positive:

- Agency provides all transportation.
- Billy drives himself to appointments.
- Companion transports.
- friends and staff provide transportation
- Good places I like to go, uh huh.
- House Manager transports.

C. Access to care for Main waiver (continued)

- I can get where I need to go but the places I want to go only sometimes.
- I don't hardly go places. Staff said she has phobia issues and it's hard to get her out in the public. They're working on it.
- I'm always on time wherever I need to go.
- I've got my own driver's license.
- Mother transports.
- My brother will take me if I need a ride.
- My nephew and my dad and sisters, public transportation - I get everywhere I need to go. I notify them when I need a ride.
- Our van isn't the best, but we get around.
- Parents and Aunt transport.
- parents and staff transport
- Personal assistants transport.
- Shares a car with housemate.
- Shelton has transportation availability for shopping but does not like shopping or going to public places.
- Staff or mother transports.
- Staff take him everywhere he needs to go, and places where he wants to go.
- Staff transports.
- Sometimes it is very difficult to take Joseph to places because we have three wheelchair-bound individuals in the house and, for the most part, when we take one person out somewhere, we have to take the other two. It is unsafe to take three persons in a van.
- Takes Bus to [agency]; parents take Johnnie to doctor's appointments.
- Van transports.
- We transport him here and back home. He always needs assistance.

What special equipment would make your life easier? *(by category)*

Medical

- 6 foot 5 inches tall, needs a longer bed
- Get van/lift for van fixed. Lift for house, track to help get in shower.
- has OT and needs PT again but funds were cut
- Joseph wants a way to carry his tray in the cafeteria independently and he cannot use his right hand.
- Needs a new hospital bed mattress and the bathroom floor needs a better slope. The water is coming out onto the floor and mold is growing. Also needs an elevating recliner chair.
- Needs special clothes that are not easy to rip
- New CPAP mask
- Outdoor hammock, helps with sensory skills
- Plastic cup holder on wheelchair tray.

C. Access to care for Main waiver (continued)

- Roger leaned on wash basin, causing the basin to come loose from the wall. Staff says he needs "something to lean on" near the basin.
- Shower Chair
- speech therapy but it was cut from services last year
- Weights for working out
- Wheelchair
- Would like a table that rolls and goes up and down to help carry ceramic molds that she makes at the CP center.

Technology

- Better communication device
- Communication device
- Floyd has difficulty communicating with words and needed help from staff answering. He was able to make gestures and express like or dislike to questions. Floyd could benefit from a communication device.
- Hearing aid
- I-Pad
- Needs different switches for her Dyna Vox communication board and a Hoyer lift
- Ronnie says he would like his own phone. He is very capable of this with the use of a headset but stated he would "be in trouble with his brother" for asking.
- Speech machine.
- Touch screen computer
- Wants a computer and a telephone in her room so she can call her brother.
- Would like to have a laptop computer

Access

- Andrea's mother said her daughter needs a bath chair, shower railings, a stander, Locomat, a rail to pull herself out of her wheelchair so she can use the bathroom easier....She also needs an adaptive tricycle and a walker.
- A special strap for the overhead lift & a new wheelchair.
- Hoyer lift.
- His house shares a car with another house and when the housing split, the car went to the other house. He needs a car so he can go out in the community more.
- Jeremiah is in the process of getting a designer bed to more effectively cope with his muscle spasms. The Clover Bottom Assistive Technology Center is making the bed, needs doctor's orders.
- Like to have a bar in her bathroom and a shower chair.
- Michael needs a ramp at both exits of his house because he has a bone and seizure disorder and falling would cause serious injury.
- Maybe a walker. Wants to learn how to walk again.

C. Access to care for Main waiver (continued)

- Needs a new house. They are renting and can't modify. Hallways are very narrow and they are having difficulties giving [her] a bath. Also need a ramp off of the back porch.
- Needs a new manual wheelchair.
- Needs a new walker.
- Needs a ramp on their house, needs a pulse and oxygen meter and also needs a lift.
- Needs a special bath tub so he can take a bath.
- Needs a bath tub lift but insurance is being slow.
- Power wheelchair is in the shop for repairs and she hates the loaner because it gives her bruises and is manual and she can't get away from her housemate.
- Power wheelchair.
- Power wheelchair and transportation for it. Also needs a ramp on the house and maybe a portable one.
- Portable light weight ramp & threshold ramp.
- Portable light weight wheelchair.
- She needs a better wheel chair or repair done on the current one.
- The lift on the van is too small, causing injury really needs something bigger she really needs a bigger van
- Van with a lift.
- Walk-in shower.

More than 8.9% (113 affirmative responses) of the 1260 people interviewed who receive services through the main waiver in 2010 answered yes to needing special equipment that would make their life easier. The PTP interview does not place equipment in specific categories but of the 113 equipment requests; 22 were for wheelchairs, 14 were for general equipment including shower chairs, 12 were for modifications to their shower or bath or hand rails, 11 for communication devices, 10 for a van or a car, 10 for lifts including Hoyer lifts, 8 were for ramps, 6 were for walkers, 5 were for a new bed, 2 requests for hearing aids, 2 for therapies like Occupational, Physical and Speech, 1 for exercise equipment, and 1 for a new medical breathing mask (CPAP).

Were the things that are important to you included in you service plan?

Positive:

- Being in her room, making her own choices, she gets to bowl on the ladies league when she chooses to. And working with meals on wheels. The most important thing is her ability to make choices, and that's all written up.

C. Access to care for Main waiver (continued)

- Bowling - he loves to go bowling! Community outings and special events, he loves those and they're included in his service plan.
- Bowling is a big thing for him. He loves to hear gospel singing. He loves going out to eat, he especially loves fish. Also very important to him is feeling safe – especially during thunder and lightning storms.
- Brady's mother (conservator) makes sure his service plan follows his choices.
- Cheryl has been interviewed twice for her ISP. Because Cheryl said she has memory problems, it's important to her to have a "Memory Board" in her home which has appointments written on it.
- Church, bowling, going out to eat are all in her plan. Arts and crafts are also in her plan.
- Cigarettes are non-negotiable. It's very important for him to be able to call his mother and grandmother daily.
- Coloring, community events and getting out are very important to her - that's all in her plan.
- Coming here everyday - I don't like to stay home! Going out - I like to go out.
- Community outings, time to himself and sleep - that's all in his plan.
- Cooking - pizza! (Staff said cooking is very important for her and she has expressed a desire to have even more offered to her)
- Cooking and watching TV. I love to watch TV.
- Cooking, cleaning, doing laundry, reading and being out in the community are important to Linda.
- David's brother said bowling and bingo were added to David's ISP recently.
- Dolls are the most important thing to her, and her shows, rocking in her rocking chair. And that's all in her plan.
- Dustin's mother said Dustin had his first Circle of Support meeting in a year on July 12, 2010.
- Exercise, dancing is very important to her. Going out to eat is important to her.
- Fishing, wrestling and helping at the Auction Barn - those are all very important to him and put in his book.
- Four Important Items in Vicky's ISP: Activities to "strengthen her mind," walking, exercising at swimming pool, go out into the community once weekly.
- Getting to go to church every Sunday and going to see my mom. These are very important to me and I get to do them.
- Go fishing, go bowling. Goin' to see Momma every Tuesday. They put that in my book.
- Going "bye-bye" is at the top of her list. She loves to get out.
- Going home to spend time with her son, going to church, group meetings - those are all in her plan.
- Going out on dates with my boyfriend; seeing my family (staff said her family has quit coming to see her and they don't answer the phone when she calls. The ISC has tried to find out why they don't come see her anymore, but hasn't gotten an answer. But even though she can't see her family the way she wants to, it's still in her ISP. She loves her family, but they're not responding.)

C. Access to care for Main waiver (continued)

- Going bowling, horseback riding, and meals on wheels are in my plan.
- Going out to eat I like to do and I know that's in my plan. I can't remember the other stuff right now.
- Going shopping and going to camp is important to me.
- Going to church on Sundays and being part of different programs in the community are very important to her.
- Going to movies, sensory things and listening to music are in his plan.
- Going to the farm to see animals is written up in his plan; going to church and church functions are very important and that's included.
- Going to the Titans games, going out to eat and concerts – that's all in his plan.
- Got to have my diet cokes. Karaoke and music and having my own place.
- Having family around me is VERY important.
- Having his Mountain Dew and visitation with his father.
- Having his own space, his privacy, is very important. His activity room with his toys is important to him.
- He has to go on rides and listen to the music.
- He has to have a set place to sit every day, he has a sturdy chair made specifically for him that he wants to sit in - these are all in his ISP.
- He has to have his keys – he's always waving them at everybody. And he's got to have his ring and watch.
- He has to wear western shirts – absolutely no shorts. He has to have his John Wayne items, and he wants his fish tank.
- He loves coming here to the Center; he loves his toys and going to his momma's.
- He LOVES puzzles. He doesn't put them together, he just likes to hold them. That's in his plan.
- Her dolls and her mother are VERY important to her and they're both in her plan. She also loves music and going on rides.
- Her magazines, going out to eat and getting her nails done are important to her, and that's all written up.
- Her reading, writing and learning skills are very important to her and they're put in her plan. She's also going to take Taekwondo.
- His church is very important to him – especially spending time with his church family. And he loves sporting events. That's all in his plan.
- His country music, his guitars and getting out, being active - it's all in his plan.
- His job is very important to him, and going out in the community shopping is also important to him.
- His magazines, his love of motors, everything he likes is written up in his service plan - absolutely.
- His markers and his computer are VERY important to him. His parents use the computer as a means to achieve proper behavior.
- His music, his hand massager and sounds machine are all in his ISP - pretty much everything he likes and has to have he's got.

C. Access to care for Main waiver (continued)

- He's got to watch his weather channel and have his TV.
- I got a bird. Take care of the bird. Her name Noel. Staff said he takes great care of that bird – he even had to get surgery for the bird, which is a cockatiel. Since she means so much to him, they put her in his ISP.
- I got to have a job, and that's in there. I also want to walk by myself and that's in my plan. I want to cook, but because I'm blind they're scared to let me. When I get my companion she's going to help me.
- I'm going to Las Vegas! (Contact with his family and losing weight is very important to him - he's lost almost 50 lbs.)
- Included in Timothy's service plan is emptying dishwasher, helping staff, take care of his home, take out trash.
- Getting everything that she needs and having lots of love and family, that's all written up.
- Keeping busy and taking care of the yard - that's in my plan.
- Listening to music and watching videos. Her family told us that's what she enjoys doing.
- Living on my own, losing weight and getting in better shape - that's something that is important to me and I had it put in my plan. Going to church is very important. I'm an usher, and I do security for them at special events.
- Making money! I got to have a job. Going shopping by myself, going to the mall by myself - I get to do that.
- Music stuff, taking trips to Memphis, going to concerts and bowling
- My purse and my toothpaste and toothbrush in my purse - that's very important to me. I brush my teeth every time I eat
- My tapes and my TV, my ring and necklace. Staff said all those things are put in his plan.
- Picking out her own clothes is very important to her - she gets to pick out all her own clothes, and her closet is set up so she can do that.
- Privacy and playing video games are his most important things.
- Robert must be able to chew tobacco and be out in the community.
- Sensory things, arts and crafts, things we see she really likes - those are in her plan. Also community outings.
- She goes to yard sales and goes out to eat when she wants to - that's in her plan.
- She loves to have everything in place, especially the blinds - it's in her plan that she gets to open the blinds. She has to have her drinks, too. That's not an option.
- She loves to have magazines, and we always bring her magazines. Also, dolls.
- Social gatherings, like playing Bingo, and going to church are in her plan. Her artwork and jewelry making are included in her service plan, too.
- Spending time with mother, coming to the day program and sports are important to him.
- Spending time with my nieces and nephews. Playing with the babies. Seeing my sister.
- Staff consistency and family involvement are very important to her.
- Staff said he gets time on his computer and the internet. He has to spend time with his friends and listening to music, and also physical activities.
- Staff said talking to her mom and being with family, going out to eat, and working are in her plan.

C. Access to care for Main waiver (continued)

- Taking fishing trips, going to concerts and going bowling.
- The circus. He absolutely loves the circus and has been going since he's a little boy. His brother just took him last month. He's got to be able to go to the circus. He also likes being with his brothers.
- The YMCA is important to me - they put in that in my service plan for me.
- Titans clothes and sports stuff – he's really into the Titans. He likes to be well dressed, his appearance is very important to him. His visits with his mom are also very important.
- Visiting his mother; he likes to go to church and he likes to be let alone and watch TV.
- Visiting pet shops - she loves holding snakes! Calling and visiting her mom is very important. That's in her plan, and having her coffee.
- Watching ballgames with her dad, bowling, and she especially needs to know about her transportation. She needs to know what's happening with the vans. That's all in her plan.
- Working in the enclave and learning the value of money is important to him.
- Working in the workshop is important. The job is REALLY important to me. Going out in the community is very important to me.

Negative:

- He does not comprehend the service plan question. Workshop staff did not know either.
- Needs a good speech therapist.
- Suzanne said "They don't do what I want them to do."

D. Community Inclusion for Main waiver

Several people receiving services through the main waiver that were interviewed by the PTP are working directly in their communities at Wal-Marts, Pizza Huts, Sonics, Mobile Meal programs, and other service sector jobs. Fewer than 1 in 10 (9.6%) people receiving services through the main waiver that were interviewed by the PTP in 2010 are using the internet. In stark contrast, more than eight in ten (80%+) Americans go online according to a 2009 report by the Center for the Digital Future at the USC Annenberg School for Communication. Similarly, calculations from June 2010 by Nielsen Online, the International Telecommunications Union, and the U.S. Census Bureau estimate that more than 77% of the population of North America goes online. Research on community integration is lacking in terms of clear definitions for what constitutes community inclusion or integration, however 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). With 72% (900 of 1254) of those interviewed who answered this question and clearly responded that they do not use the internet, this population continues to lag behind the national trend, and is another barrier to their 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?* The interview comments to this question are below. The boyfriend/girlfriend question is important in light of a prevailing tendency to judge people with disabilities as asexual (Milligan & Neufeldt, 2001). Just over 62% (775 of 1248) of people interviewed who answered this question and are receiving main waiver services responded “No” that they did not have a boyfriend or girlfriend. The population served by DIDS 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.

Do you have a boyfriend / girlfriend?

Positive:

- A boy comes and visits her on sat & sun. she met him in one of the centers. They are good friends.
- Another one of the little students here at school just loves him.
- At the center/agency/workshop.
- At the bowling alley. Staff said he had just met a girl at the bowling alley and they made arrangements to meet the next Monday. But he decided not to go – he stood her up. He's probably in the dog house now.
- Barbara – she's here at the Center. She hugs on him, even though he ignores her a lot of the time.
- Boyfriend.
- Calls a girl at church his girlfriend.
- Calls boyfriend daily.
- Donnie is her boyfriend.
- Elvis Pressley! (big smile)
- Fiancée.
- Friends at church/school/workshop
- He and Sherry have been friends for quite some time. They always sit next to each other and they actually communicate pretty well.
- He has a love/hate relationship with one of the individuals here.
- He has several, but he has a special friend - Emily - who works at the local store.
- he is a people pleaser, very outgoing person, adores going to church, has many friends
- He smiled and pointed to the lunchroom.

D. Community Inclusion for Main waiver (continued)

- Her name is Patty Baker. Her idea is to get married. That's just her idea. I just like her, that's all. I take her out when I have money.
- He's got a ton of girlfriends. He likes the good lookin' ladies.
- I do got a friend, but she's not my girlfriend yet.
- I do love Bobby. We get along real well with each other. We're engaged.
- I got one that the Lord give me. We're supposed to get engaged this month. She's in Alabama.
- I'm going to marry her and kiss on the red lips!
- Individual began to clap and smile.
- Individual is married and lives with her husband.
- Many friends.
- My girlfriend is a mess all the time.
- Right before we began the interview her boyfriend came and gave her a big hug.
- Shane – he's here at the Center. Man, they get to flirting when they go bowling. He'll give her the eyebrows, and she'll just smile.
- She ain't here. She's at [agency]. I see her sometimes. Sometimes I call her.
- Somebody calls me now and then. But I'm not saying no names.
- Staff said he really like the ladies - everyone was his girlfriend.
- Used to be my girlfriend, but now she's my wife!
- Very social, many friends.
- We been together a long time. I call her on the phone all the time.

Negative:

- Don't want one! After the last one, no!
- He doesn't really have any concept of boyfriend, girlfriend.
- He doesn't see any difference between men and women. It just doesn't register.
- He don't know what a girlfriend is.
- He'd say yes and give you the names of 500 people. Oh yeah honey, he's got a bunch of them. All make believe.
- I been thinking about getting married. I'd like to get me a girlfriend but my family don't want me to.
- I can't find a boyfriend. I don't want one.
- I did but at this moment I'm single.
- I don't got enough money!
- I don't want one! They're too much trouble.
- I hadn't had one since I got here. Staff said "he's looking!"
- I talk to some boys but they're not my boyfriends.
- I'm married. I got 6 children. My husband died in 2002 and he's in heaven. (Staff said to her knowledge individual had never been married, nor did she have children.)
- I'm still looking; I want a girlfriend my own age. I'll have one day.
- Looking for a boyfriend.

D. Community Inclusion for Main waiver (continued)

- No ma'am, I don't want a boyfriend.
- Not now. I gave her a ring but she's not mine no more.
- Oh Lord, no. NOOO! I'm cute lookin', but I don't want no girlfriend.
- She doesn't have one but she has aspirations for a relationship. There is a prospect!
- She's just a big flirt!
- Staff said "He's too cheap!" He laughed and agreed.
- Staff said this question is off limits; individual began to be very upset as he wants very BADLY to have a girlfriend. We had to immediately redirect his attention.

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

Positive:

- Every chance I get.
- He can call his mom anytime and if he needs her, she'll come and get him. For the most part, she comes to get him once a week.
- He comes to see us just about every weekend.
- He faxes his parents a letter every week.
- His family live about an hour ½ away but they come to see him a lot and he goes there for holidays.
- I can see 'em when I want to, but I usually don't. I got to plan ahead - I just usually like to go on holidays.
- I see her just about every day. If I don't see her she calls me.
- I see them every day!
- Most of my friends come to the center. I see them there.
- Sees mother in Goodlettsville every two weeks.
- She goes home every other weekend.

Negative:

- Boyfriend lives at a distance.
- Client has had some legal limitations placed upon him.
- Doesn't like to anymore.
- He really doesn't go visit anyone. It's really just agency and staff that visit him. No friends or family come to see him.
- He really likes to be with his family, but there's financial and health problems - so he can't see them that often.
- Her aunt lives in Maryland.
- Her family come every now and then, but she never gets to go see them. On special occasions she'll go home with staff.
- His folks live in Alabama so we can't see them all the time.
- Housemate is restricted from female contact so Adam's girlfriend can't visit.

D. Community Inclusion for Main waiver (continued)

- It's at her momma's schedule, but she does see her every week for hours at a time. And they talk frequently. Her mom helps her out a whole lot.
- It's at their decision. Some of his behaviors are as a result because he thinks his mom is coming and she doesn't show up. He sees his housemates every day.
- It's pretty much when they determine to come get him, but they come every holiday.
- It's sometimes hard to find the time to get together.
- My family won't see me much.
- My family lives too far away to see when I want to.
- Only sees girlfriend at work.
- She can't come much cuz she has a husband. But my other sister comes every Saturday.
- She only sees him when he comes to see her. She goes to her family reunions and she can go on holidays, but her time with them is VERY limited. When her family come to see her it's like hi, how are you, a walk around the block and good-bye.
- She sees him twice a week and takes him home for holidays, but she isn't able to have him on a regular basis.
- Sister is a doctor & lives in Nashville.
- They don't live here, but within reason she can see them. We do see them quite a bit.
- They see him on their own schedule. He'd really like to see them much more. He used to spend a week or so on holidays with family. But now it's down to one day here and there. And I think that's where some of his behaviors come from. He LOVES his family.
- Would like to have transportation to see her friend Alice.

Are you satisfied with the amount of privacy that you have?

The following question for main waiver service recipients was answered positively in more than 97% (1228 of 1260) of the interviews collected in 2010.

Positive:

- As much as we can give him. Because of all his medical issues we have to really keep a close watch on him. He doesn't like to be by himself – he loves people.
- Because of Brian's self-injurious behaviors, his bedroom door "isn't totally closed."
- Believe me, when he goes in his room, he closes the door and we don't bother him.
- Dustin's mother said he "becomes insecure if there isn't somebody around him."
- For medical and safety reasons he really can't be alone, but we try to give him his space. He doesn't really show he cares one way or another though.
- He can go in his room anytime and close his door.
- He doesn't like to be by himself.
- He has a recliner in his room, and he loves to watch TV there.
- He really doesn't ever say he wants to be by himself, but he has times where he's to himself - like when he watches TV.
- He sits on the front porch all the time. He loves to sit out by himself.

D. Community Inclusion for Main waiver (continued)

- Her privacy is very important to her - finding the balance between allowing her all the privacy she wants and the need to socialize her is sometimes hard.
- I get PLENTY of time by myself.
- I get too much alone time!
- If I want to be alone I go in my room and close my door.
- In my room, or go outside and sit on the swing- yeah, I can do that.
- Mother says yes.
- Rachel, since the state enlarged her room, feels "more of a sense of privacy."
- Robert has great regard for his privacy. "There is one specific chair at [agency] he sits in. Nobody else is to sit in that chair."
- His mother says, although he has privacy when he wants it, "he does not like to be alone."
- She doesn't really like to be alone. If she's left alone in the living room, she'll say "what are you doing? Come in here!"
- She enjoys her room a lot more now that she has a double bed!
- Sometimes when I'm home I go in my room and close my door.
- Staff member interviewed said David has privacy when he wants it but likes talking "one-on-one" with persons.
- That is one of his most important issues – having his own privacy.
- When he's had enough of me he goes in his room and closes the door.

Negative:

- "Lorenzo has no privacy when he gets out of the tub," his mother said. "There have been females in the area when he's left the tub. They (staff) undress Lorenzo on his bed in front of everybody."
- Michael says he does not have enough privacy because "my two housemates knock on my bedroom door and try to come in without permission." I have told the staff about it but they have not done anything about it."
- Need more personal space away from staff.
- Sheila said, "There are not enough people around," she still answered "No."
- Sherry does not like her roommate Mary Jane.
- Wants to get married. Staff and house mates are nosey.

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

This final qualitative question is an opportunity for individuals and family members to share additional comments or concerns that would not have otherwise appeared through the interview. Following are both positive and negative comments made by people interviewed in 2010 all across Tennessee.

D. Community Inclusion for Main waiver (continued)

Positive:

- Christine wants someone to help her get married.
- Client's family is having trouble with the state right now, due to the changing of agencies as well as changing from the SD Waiver to the Main Waiver.
- Companion Comment: "I am teaching Thomas self-help skills so he can live independently. For example, he has learned to pay his own way into movies."
- Courtney's mother Mrs. Hawkins is very happy with the services.
- David's sister is very happy & satisfied with Support Solutions
- Father's Comment: "Lorenzo is a very intelligent person. He knows what is going on. Lorenzo is a very likeable person. I know you would like him."
- He is doing really well goes to the moose hall and dancing once a month.
- I am very happy with the services I am receiving.
- I would love to have gone to the TN Disability MegaConference.
- Marilyn's Sister Comments: "Marilyn has been attending Rochelle Center since 1972. The staff there is friendly and great."
- Mother is very happy with services.
- Mrs. Hayes (mother) is very happy with services. Robert prefers to be called Andy.
- No, I'm happy.
- Parents would like assistance on getting legal guardianship.
- Ronnie says he would like his own phone. He is very capable of this with the use of a headset but stated he would "be in trouble with his brother" for asking.
- Ruby has been depressed. Her good friend died. She is beginning to feel better.
- She has come a long way from being in an institution and abused. She is doing great.
- Staff Comment: "Eric has had trouble with obesity, but he's lost over 50 pounds."
- Staff Comment: "Mary will often assign people names. Her power of attorney is very active in Mary's life. The POA will do things like straighten up Mary's closet." In regard to People Talking To People, she said, "It is awesome what you are doing."
- Staff Comment: "This was a very helpful interview."
- Staff Comment: "I have two children with Downs Syndrome and have been working in this field for 41 years. I worked twice at Clover Bottom. Troy is mostly a happy person. He hums when he's happy. On outings, we go to the same areas and stores so people will know Troy there. He and his house mate (Wayne) have been together for 18 years and get along very well together. The same staff has been together with Troy for 8-9 years. It's great when employees are more concerned with individuals than a paycheck."
- Staff Comments: "Because Samantha is under 21, she can't have a physical therapist at home but at school she gets PT. "Samantha's health is good. Her ISC visits her several times a month and is very helpful."
- Staff Comments: "Larry was involved in an auto accident in 1972 and was in a coma for five years. He has short-term memory, and remembers only up to 1972."
- Staff Comments: Barry is enjoying his Friday dating class very much. The class teaches him appropriate ways to approach females, especially in public places. We want Barry to be as independent as possible."

D. Community Inclusion for Main waiver (continued)

- Staff Comments: "Lamont's staff has been very consistent. He likes to eat out with friends. He has an OT and a PA."
- The mother mentioned that Tammy was in stage 5 kidney failure--the last stage.
- Very happy
- Wants to get a job and be happy. Wants to work at movie theater, IHOP, or Shoney's.
- Works one day a week at McDonald's mom is very involved with her.

Negative (by category):

Choice

- "I do not like my housing situation because I want to live independently. [Residential agency] does not want me to live by myself. I would like to get my GED, then go to school at ITT Tech to learn more about computers. I can fix a computer in five minutes."
- I would like another housemate.
- She said she feels better in her own home and not in the group home she is in now.
- Ms. Johnson's Comments: "We are trying to get an advocate for Andrea," she said. "It's hard to get [agency] to implement the ISC's recommendations. "We want Andrea to be as independent as possible." Ms. Johnson added: "We are trying to get Andrea on the SD Waiver where we can have more control over her treatment."
- Sister in law/conservator would like the provider agency to include her in decisions they make for Jill.
- Would like to have an apartment with an assistant and live next to her sister Phyllis. Does not like where she is living now at Ramona Ave.

Economics

- Concerned about the impact funding cuts from DIDS will have on her.
- There is a worry about abandonment by the family due to legal and services problems.

Employment

- Ronald wants a job badly and is very capable of working

Medical

- Client's family is worried about having not been told about medicine change and about getting conservatorship paid for.
- "If I die of a heart attack they'll wish they had took me to the doctor"
- Ms. Posey is concerned about Marvin gaining too much weight. She has talked to the advocate and they are trying to monitor his eating patterns.
- Dustin's Mother's Comments: She said the state has given her three options regarding his living status: Staying in her home, assisted living, and supportive living. During a meeting on August 11, 2010, she said she was told there "was a good chance Dustin can

D. Community Inclusion for Main waiver (continued)

continue living with her due to medical reasons." Ms Hollis said, "I could not stand to have Dustin move out. I don't know what I'd do if the state made him move." She said the recent death of her husband, Jim, is wearing on her and Dustin. "Dustin was a daddy's boy," she said. He cries because he misses his father. Jim was the center of our lives. With Jim's death and the possibility of Dustin moving, it's been almost too much to bear." Ms. Hollis said Dustin, who has had up to 20 seizures per day, takes up to 20mg of valium by injection to calm him down. She said Dustin, who has traveled to Memphis and Nashville to see if his seizures can be reduced, often suffers pain due to seizures. Ms. Hollis said Dustin takes 18 medications daily. Due to his seizures, Dustin wears a helmet and a gait belt. In addition to his seizures, Dustin has other medical problems. He must sleep on his stomach, saying he "could suffocate if he used a pillow." Also, Mrs. Hollis said she feels pretty sure that when Dustin "was 6 or 7, he was abused at school. We never could prove that, but had bruises on him." Ms. Hollis said a psychiatrist told her it was obvious that Dustin's behavior had changed due to abuse.

Services

- Client and family have asked for there to be a way to be guaranteed the number of times that Sarah will be able to go into the community. Right now the ISP process only tells them that she will but not how often.
- Mother's Comments: "We currently have 98 hours of staff coverage per week but, if Gov. Bredesen goes through with these budget cuts in July, he takes 50 hours a week from us."
- Mother is upset with DIDS because she said she was contacted by them and said Shannon's PA services would be reduced to 12 hours daily. Currently, he receives 24-hour nursing care. "There are 56 hours during the week that Shannon may lose if these cuts occur," she said. "I can't be with him 24 a day. If he does not receive 24-hour nursing care, it would amount to a death sentence because he has so many medical problems. Shannon is legally blind, has drainage problems, sleep apnea.
- Need more funding and angry at the Governor.
- Says the staff at [agency] is disrespectful.
- Sister's Comments: "Eula helps everybody at [agency]." Eula's sister feels [agency's] services for individuals have declined in recent years.
- Sonya's mother says she would like the staff to keep Sonya's blankets, pillows, and bibs with her. They are often shared with other clients and misplaced.
- They are having difficulty getting everything in order due to the fact that they are changing agencies, from the The Arc TN to The Arc Hamilton County and switching from the SD Waiver to the Main Waiver.

Transportation

- Joseph would like to go to church at Kingdom Hall but has no transportation. Wants some way to carry tray to cafeteria because he drops his tray and food goes everywhere.
- Worries about exit ramp for wheelchair in the back. In case of fire.
- Would like to get out more in the community but need more support

D. Community Inclusion for Main waiver (continued)

Other

- Client is concerned about the level of noise in the house.
- Client says area he's in is too noisy.
- Mrs. Domm reports the family is in their 2nd mediation fight. The state continues to try and reduce services down to 1 person rather than 2 people. Stephanie needs 2 staff people to lift her. Patty Hall from the Knoxville Arc office is assisting with this mediation.

A. Choice and Control for Self-Determination

Do you like where you live?

Positive:

- I live with my family.
- It's better than last home.
- It's an assisted living situation, not a group home.

Negative:

- Jeffrey wants to live in a group home.
- Nosey neighbors
- I don't like the house
- Susan wants to move into a bigger (3 bedrooms, 3 baths, den) because her mother died July 3, 2009 and her housecleaner also died last year, causing her to want to move somewhere else to escape the memories. Her stepfather said Susan had suffered "a lot of significant losses in recent years.

Did you choose the place you live?

Positive:

- I was 2 when my 2nd cousin adopted me and I've been with them ever since.
- His momma found it and bought it, and they all moved in.
- We were all in agreement with it, especially because it's just one floor.
- Lynn did (she is center director). She helped me.
- He had his brother's help.

Negative:

- Father built house.
- Jeremy, 18, was placed in foster care to Mr. Britton. He and his wife are now legal guardians. "Jeremy is my best friend," Mr. Britton said.
- Jessica has lived in the same house her entire life (23 years)
- Linda lives with her sisters and brothers in a housing project.
- Live with family.
- My dad did. But it's o.k. with me because it's got everything I want and need.
- My brother and my guardian did it, not me.
- Too young

A. Choice and Control for Self-Determination (continued)

Did you know you have the right to change your support staff?

Positive:

- But it doesn't work like that here
- He doesn't know but his parents know.
- Mom does
- Mother says there is not enough funding
- Recently did change

Negative

- I didn't know that, but I do now.
- Joseph would show aggression towards staff if he did not like them.
- Right was explained to him.

Can you talk to your Support Broker when you need to?

Positive:

- I think I can I've never had to call.
- Staff does.
- We used to have some case managers we never even met. This is the first case manager we've actually met and has stayed with us.

Negative:

- Non verbal

Would you like to work somewhere else?

Positive:

- Any job is fine.
- Any job that is inside. I'm working part time at the high school now.
- I'd like to work as a janitor at a school.
- I'd like to work as a secretary.
- I'd like to work at a car body shop.
- I'd like to work at a movie theater.
- I'd like to work at a pet store.
- I'd like to work with computers.
- Robert says he would like to work for the police department filing papers.

A. Choice and Control for Self-Determination (continued)

Negative:

- Formerly, Joshua worked at Tennessee School for the Blind where he picked up mail, communicating with his voice box.
- Has seizures
- He used to volunteer at his church but then he had health problems come up, so his parents requested that he not volunteer anymore. He can't hold a job.
- I don't think he's got the energy. (Individual was falling asleep while we were talking to him!)
- I used to work at Pizza Hut. I can't work now. I got arthritis in my legs and my doctor said don't work.
- I work at Pizza Hut now.
- I work at the landfill now.
- I work at the Lewis County Chamber Office - I mop, sweep, clean offices. I do meals on wheels, and water the flowers downtown, and I grow vegetable and plants and we take 'em and sale 'em. I like what I'm doing.
- I'm working now part time at E.W.JAMES AND SON'S
- Likes where he is at
- Lord, no! She wouldn't be able to hold a job.
- Mary formerly worked as a janitor at Dickson County High School, but can't work now due to physical problems.
- Michael can't stay on task.
- Mom says she has hard time focusing
- We're retired.
- William worked at Kroger in 2008 washing tables.

B. Respect and Dignity for Self-Determination

Do your direct support staff treat you well or with respect?

Positive:

- But to tell you the truth I'm always aggravating them up here. I do it as a joke.
- Center staff indicated the only staff she had was her during the day. At home she has natural supports, and they're not paid.
- Christine's paid support staff consists of her sister, mother and brother. Her mother indicated the family needed more help. Christine's brother is a student at MTSU and works Wednesday-Saturday. Christine's mother was off work for some time due to two surgeries so Christine's father took time off from his job to help at home.
- Doesn't have staff at home but at day program
- He has no staff at home, just here.

B. Respect and Dignity for Self-Determination (continued)

- Michael's two direct support persons have been with him a total of 13 years (8 years, 5 years).
- Staff said his computer is broken and he's mad that it's not fixed. Center director said that fixing the computer may cost far more than he's able to afford. She has tried to get staff who are computer savvy to help, but no luck so far.
- The first ones I had weren't, but after I reported it to the supervisor, they switched 'em and I do like them now.

Does anyone ever hit or hurt you?

Positive:

- Client hit her one time
- Jeffrey said he had a fight recently with a HATS individual. "He hit me and I hit him," Jeffrey said. I gave him a bloody lip."
- Lauren who is a client.

Negative:

- Michael is a self-mutilator who slaps himself and bangs his head, his mother said.
- No one hits me.
- Pamela said her feelings were hurt in the past.
- She's had some things happen in the past when she was younger. That's all gone now and we're past that.

Do you know how to report a complaint?

Positive:

- Call 911
- Call police. Tell staff.
- Go tell someone. I'd tell my brother.
- He would come to staff. He'll tell you when someone is bothering him.
- I can go to one of my staff members or my ISC. I got the emergency number right here (showed us his cell phone)!
- I think he'd probably tell his parents, but oh yeah, his parents know what to do!
- I'd talk to Sheila, but if she wasn't here I'd talk to Leah (both staff). I'd call 911. I'm kin to a policeman.
- Joshua's aunt would call his case manager.
- Mom does
- She'd probably scream her head off, maybe even hit 'em back. But I know how to file a complaint.
- She will point to her pain or show her sister any problems that she's having.

B. Respect and Dignity for Self-Determination (continued)

- Staff does.
- Tell ISC/mother/parents.
- Tell Supervisor
- We know to call the TN Department of Health
- With assistance.
- With mom's help.
- With some help, I could file a complaint. I'd talk to Miss Rosie. I know the emergency number is 911. The number is posted at the house.
- Would tell the ISC or the agency.

C. Access to care for Self-Determination

Can you always get to the places you want?

- Agency transports.
- Cab driver and staff transport
- Caregiver or aunt transports.
- Gregory's sister takes him to the dermatologist; uses Access Ride
- I'm working on getting my driver's license - I have my learners permit right now. When I get my license I'll be driving myself. I've driven a couple of times with my momma and step-sister.
- In my family car.
- Mother transports.
- Parents or staff take.
- Rides bus
- We have a car/van.
- We pretty much go wherever we want to go. We do Special Olympics 3 times a year, and we stay in motels.
- With assistance

What special equipment would make your life easier?

- A device that shows random pictures to identify. Bored with magazines
- A shower chair.
- Christine's mother says her daughter needs a new wheel chair, a ramp at the front door, and improvements made to the bathroom.
- His mother says a gated area around their home would "keep Michael from eloping which he does."
- Home set up for the deaf with bed vibrator for fire alarm etc
- Maybe a computer to help her learn to read and enter her journal writings.
- Needs a bath tub lift but insurance denied. Would like a stander and parallel bars.

C. Access to care for Self-Determination (continued)

- New bed.
- New wheelchair.
- New voicebox (hiptalker).
- Susan wants a bath with tub bars which she will have in her new home.
- Will need a wheelchair soon

Nearly 7% (15 of 215) of the people receiving services through the Self-Determination waiver that were interviewed in 2010 answered “yes” to needing special equipment that would make their life easier. The PTP interview does not place equipment in specific categories. Of the 215 Self-Determination waiver participants interviewed, there were fifteen requests. Three were for accessibility accommodations/maintenance to their homes including; ramps and bars for the bathroom, three for communication devices, three for equipment like a shower chair, three for wheelchairs, and three for new beds.

Were the things that are important to you included in you service plan?

Positive:

- Being with my husband and family is very important to me. It's important to me to have a job and to have choices. Her staff said her ISP is a perfect model of what person-driven ISP should be.
- Getting me another job is very important, and my horse.
- Going shopping, going to church are both important to her.
- Going to the Rec Center, bowling and movies are important to him.
- His computer is important. He likes dancing, and socializing, and he likes chewing gum.
- Tossing his ball, shaking hands are important to him and those are written up in his plan.
- Well one thing is I got to have my cell phone. I need to keep me informed. They put that in my book.

Negative:

- Mom says she wishes her staff could give Alisha feedings and perform respiratory treatments without clocking out.

D. Community Inclusion for Self-Determination

Many 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. In the

population of people interviewed receiving Self-Determination waiver services are a few number of people using the internet—less than 12% (25 of 215). In stark contrast, more than eight in ten (80+%) Americans go online according to a 2009 report by the Center for the Digital Future at the USC Annenberg School for Communication. Similarly, calculations from June 2010 by Nielsen Online, the International Telecommunications Union, and the U.S. Census Bureau estimate that more than 77% of the population of North America goes online. Research on community integration is lacking in terms of clear definitions for what constitutes community inclusion or integration, however 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.). With 79% of those interviewed receiving Self-Determination waiver services responding that they do not use the internet, this population continues to lag behind the national trend, and is another barrier to their 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? The interview comments to this question are below. 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 DIDS 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.

Do you have a boyfriend / girlfriend?

Positive:

- At church.
- At workshop.
- Every pretty girl
- Has many friends
- Individual pointed to interviewer and said "hold your hand" - staff said he had no girlfriend.
- I'm married.
- Many friends.
- The only time I see him is when I play bingo.
- Very good friend Eric.

D. Community Inclusion for Self-Determination (continued)

Negative:

- He passed away.
- Not looking for one.
- Women are trouble! Women are nothin' but trouble!

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

Positive:

- *As much as I can!*
- Living there right now.
- Some out of state.

Negative:

- It's sometimes hard to find the time when we can get together.
- Most of my friends went to college so I can't see them.
- No one I care to see.
- Scheduling with a PA is a problem.
- They live too far away.

Are you satisfied with the amount of privacy that you have?

This question was answered positively in 99% (213 of 215) of the interviews collected in 2010 with Self-Determination waiver participants.

Positive:

- As much as we can give him
- Her sister said she can go to her room and spend time when ever she wants
- If I want to be alone I go in my room and close my door.
- Jessica does like to spend time alone but has privacy when she wants it.
- Too much privacy and he will masturbate 20 times a day.
- Whitney is non verbal and her Mom answered all questions

Negative:

- As to the "No" answer, Shannon said, "My mother takes care of me."
- Younger sister always walks in on her.

D. Community Inclusion for Self-Determination (continued)

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

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:

- Brother's Comments: "In addition to her intellectual disability, Jessica is bipolar and also has schizophrenia. She is not a self-mutilator, but constantly says she must not cut herself. Jessica is very smart and very capable."
- Church means a lot to him.
- In process of getting a house built so he can learn to take care of himself.
- Like to horse around with people.
- Likes flowers.
- Loves Hawaii and Elvis.
- Loves to hear a baby cry and the phone ring.
- Mother's Comment: Lewis has many physical problems, including seizures, severe diabetes, sinus problems and sleep apnea. Lewis uses an oxygen machine, a C-Pap (sleep apnea), and a "medicine tube. He has two hearing aids. Lewis has an exercise bike and ropes so he can do pull-ups."
- Mrs. Thornton is happy & satisfied with all the services.
- Pamela's Comments: "I'm part Native American and my dad is part Cherokee."
- Sister's Comments: "Randall is on a set routine. If he deviates from him it, it 'throws him off.'"
- We are very happy with services.

Negative (by category):

Choice

- Ms Lowe's Comments: "In the future, I may want to have conservatorship of William. I would like to get it at a low cost."
- Robert's mother says she is strict with Robert & doesn't let him go out alone because she doesn't approve of the neighborhood. She takes Robert to church and SRVS workshop, but bus brings him home from workshop.

Medical

- Mr Britton's Comments: "The biggest issue with Jeremy is his safety. He once swallowed some glass but fortunately was unhurt. One of the things that affected Jeremy was that he had real bad teachers at Hillwood High. Hillsboro High worked out much better for him."

D. Community Inclusion for Self-Determination (continued)

Services

- Parents' Comments: "We have been trying to enroll Nichole in [agency's] residential housing program but to no avail. [Agency] is supposed to be helping us. We are very frustrated right now."
- Vida's family feel that their support broker does not listen to Vida and her needs.
- Would like a day center in Monroe County. Joe goes to [agency] which serves Monroe, McMinn, and Meigs counties and is overcrowded.

A. Choice and Control for Arlington waiver

Do you like where you live?

Positive:

- Delich has limited communication skills and her staff answered all questions
- Recently moved to new address.

Negative:

- I don't always get along with my housemates.
- I sometimes would like to live alone.
- I want to live someplace else.
- The house costs too much. Not a lot of money left to do what I want.

Did you choose the place you live?

Positive:

- Yes.

Negative:

- It was picked for me.
- Lives with family.

Did you know you have the right to change your support staff?

Positive:

- Yes.

Negative:

- No I didn't know that.

Can you talk to your ISC when you need to?

Positive:

- Emily Kearney doesn't keep M/M Wilson as informed as they would like to be, but she does return their phone calls.
- I think I can. I've never had to call.

Negative:

- Sometimes.

A. Choice and Control for Arlington waiver (continued)

Would you like to work somewhere else?

- Any job is fine.
- I'd like to work as a janitor.
- I'd like to work at a day care center.
- I'd like to work at a sporting goods store.
- I'd like to work at Popeye's.
- I'd like to work at Wal-Mart.
- I'd like to work with animals.

B. Respect and Dignity for Arlington waiver

Do your direct support staff treat you well or with respect?

All answers to this question were positive.

Does anyone ever hit or hurt you?

Among the interviews with people receiving services through the Arlington waiver, interviewers received a single response of “sometimes” to this question. This was immediately reported to the state according to the notification procedure described on page 6 under section 1; People Talking to People project Overview. Further investigation revealed that the incident referred to happened over 1 year ago, and an official investigation and appeal proceeding already had been completed. This experience teaches that the wording of questions could prompt previously resolved issues or long unresolved memories to be brought up. Discrepancies like this are explained by research studies, like the work done at the University of Michigan's Institute for Social Research (Schwarz, 1996).

Do you know how to report a complaint?

Positive:

- By way of his staff.
- I'll tell someone, staff, family, friends, someone!
- I would let someone know.

C. Access to care for Arlington waiver

Can you always get to the places you want?

There were no comments to this question with 114 people responding affirmatively (“Yes”). Compared to 91 in 2009, there are 25% more interviews collected with people receiving services through the Arlington waiver. This increases the same measure of confidence level (accuracy or relevancy of the statistic) from +/- 8.1% in 2009 to +/- 7.2% in 2010.

What special equipment would make your life easier?

- New prosthesis for leg.
- Better ramp and/or hand rails.
- Communication device.
- Wheelchair.

Of the people receiving services through the Arlington waiver that were interviewed in 2010, only 5 people (4%) answered “yes” to needing special equipment that would make their life easier. The PTP interview does not place equipment in specific categories. Of the 115 Arlington waiver participants interviewed, there were five requests. Two for wheelchairs, one for a new leg prosthesis, one communication device and one for a better ramp and hand rails.

Were the things that are important to you included in you service plan?

Positive:

- Yes, but would like to have more meetings/communications.

D. Community Inclusion for Arlington waiver

Most people served by the Arlington waiver that were interviewed by the PTP are working in workshops or are generally participating in the community. There are still too few people receiving services through the Arlington waiver that reported using the internet in 2010 (only 2 of 115.) For the questions *Can you visit with the people you want to when you want?* and *Do you have a boyfriend / girlfriend?* The interview comments are below.

D. Community Inclusion for Arlington waiver (continued)

Do you have a boyfriend / girlfriend?

Positive:

- At workshop.
- Has many friends.
- several friends, likes people
- very outgoing, many friends

Negative:

- doesn't get along with people
- doesn't like to be around anyone, likes to be alone
- very reserved

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

Positive:

- I see them when I can.

Negative:

- I have no one to see.
- They live too far away to see as much as I want!

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

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 all positive.

Positive:

- Can't think of anything!
- David is happy.
- Gerald would like to work. Mrs. Morris is checking with voc rehab on a job for him.
- Linda goes to therapy twice per week. Mrs. Madison(Linda's) mother is very happy with current services.
- Ms. Huggins says all of Mary's needs are being met. She is doing fine and thriving. Losing weight. Just returned from a mini vacation and is very happy.
- No, Maggie's brother Alford Donald is satisfied with all services. He says they treat Maggie like a queen.
- No, we are very satisfied and happy with all the services.

A. Choice and Control for Developmental Centers

Do you like where you live?

Positive:

- "It seems David is very happy at Clover Bottom. He smiles if he is happy. If familiar with someone's voice, David will laugh. He is very aware of his surroundings."
- Arvie (61) came to Clover Bottom when she was 10. Staff Comment: "I have been with Arvie for nine years and she is very intelligent."
- Norman has been at CB since he was 10.
- Ronald moved from the Magnolia House (Clover Bottom) four months ago.

Negative:

- No.
- Staff Comment: "Nancy talks about leaving Clover Bottom."

Did you choose the place you live?

Positive:

- Yes.

Negative:

- Family did. When Lynn became 18, she became too big for her parents to handle at home.
- I lived at Harold Jordan Center for 15 years.
- Mother chose. Staff Comment: "Steven's mother is very involved in his life. She will call us (staff) any time day or night if she's not happy with something. She has been known to cuss staff out but I love her to death because she is well-intentioned towards Steve. I will call his mom at home if necessary. His mother hung the pictures next to Steven's bed. If just one of those pictures were removed, she would know it. She numbers his shirts and takes inventory of his clothes. One time she found one of Steven's shirts in another roommate's closet and was very unhappy about it. If there were to be any scratches on Steven's body, the nurses are to immediately call his parents. We (techs) tell management immediately if there is anything out of line."
- Parents, grandmother chose.
- Ready to leave CBDC
- Staff Comment: "Ronald's parents felt CBDC was the safest place for him."
- There were people in her home that fought so she was moved to CBDC.
- Unsure who chose.

A. Choice and Control for Developmental Centers (continued)

Did you know you have the right to change your support staff?

Forty four of the eighty one (54%) interviews with people being served at one of Tennessee's four Developmental Centers revealed that the person knew they had the right to change their support staff. Seven of the interviews (8.6%) were unable to record a response to this question because the person interviewed is not able to communicate a response. That PTP only had seven interviews indicating that a response was unable to be obtained may reflect increased experience in the teams doing interviews at Developmental Centers and their ability to gather responses from staff who are present during the interview.

Positive:

- Forty four "Yes" responses.

Negative:

- Thirty "No" responses.

Can you talk to your Case Manager when you need to?

Only two interview respondents replied no to this question and without comment. More than 90% (73 of 80) of interviewees residing in Developmental Centers responded that they could talk with their Case Manager when they needed to.

Would you like to work somewhere else?

Positive:

- Bag groceries; take them out to customers' cars.
- Community job.
- Needs direction to work.

Negative:

- David likes his job at Critters.
- Empties trash.
- Has two community jobs: Bull's Eye, Steak n' Shake. Previously worked at Dollar Store.
- Retired.
- Would not be able to work because Annie tires easily.

B. Respect and Dignity for Developmental Centers

Do your direct support staff treat you well or with respect?

Positive:

Of the eighty one interviews, there were sixty four positive responses (79%) to this question without comment.

- "The staff and patients are like my family. We are like brothers. Because this (Clinch) is a medical building, the staff was specially chosen for it.
- "The staff is very close to Steven. He has had one of his technicians for 30 years. I have been here for six years."

Negative:

- Anthony said, "The techs make fun of me."
- He said some of the technicians "try to get me into trouble."

Does anyone ever hit or hurt you?

This question only got one positive response among the eighty one interviews completed in 2010 with people residing in one of Tennessee's Developmental Centers. This year, the PTP did not have any interviews indicating that a response was unable to be obtained because the person being interviewed was unable or unwilling to communicate a response to this question. This may reflect increased experience in the teams doing interviews at Developmental Centers and their ability to gather responses from staff that are present during the interview.

Do you know how to report a complaint?

This question elicited 77% (62 of 81) positive responses from the interviews. Comments are noted below.

Positive:

- Camille communicates through facial expressions.
- If someone took something from James he would get mad; He would show his anger by using simple expressions.
- Mother and staff know.
- Robert will yell if he's unhappy and will fight. His dad, a former boxer, killed his mother
- Staff knows.

C. Access to care for Developmental Centers

Can you always get to the places you want?

Positive:

- Robert is transported for shopping, movies and dinner.
- Staff transports.
- Technicians transport.
- We schedule trips 2-3 times per week for doctor's and dentist's appointments. All Kenneth's trips are planned, including recreational outings, etc. He buys toiletries once per week and does other shopping at the end of the week.

What special equipment would make your life easier?

- Better wheelchair.
- Could use a new helmet.
- Could use a new mattress.
- James is unable to speak, and needs a better communication device. Price is an obstacle.
- Needs new wheelchair. Staff checked with Assistive Technology at Clover Bottom.
- Possibly a communication device.
- Staff is currently looking for ways to get her a laptop that she can use.

Nearly 9% (7 of 81) of people receiving services at one of Tennessee's Developmental Centers that were interviewed in 2010 answered "yes" to needing special equipment that would make their life easier. The PTP interview does not place equipment in specific categories. Of the 81 residents interviewed, there were seven requests (8.6%). Two requests for new wheelchairs, two for a communication device, one request for a new helmet, one request for a new mattress, and one for a laptop computer..

Were the things that are important to you included in your service plan?

Positive:

- Anna wants to have her own house.
- Family has great input into ISP.
- Geneva would like to live with her family in Lebanon, TN
- Her goals are to work at Wal-Mart and staying active in the community.
- I attend the ISP meetings. What's important to Walter is that he has outlets for all his lamps. He has two VCRs and two or three DVD players.

C. Access to care for Developmental Centers (continued)

- Lynn's goals include being more independent, continue working, being around people but keeping her privacy.
- Not bothering Steven is part of his ISP.
- One of the "requirements" in Gregory's service plan is that he try to use sign language to communicate.
- Staff Comment: "James likes to be very independent, but he is also a very private person. If he's in a good mood, he likes to be taught. James can fold clothes and arrange them. If he wants to, he can shower pretty much by himself."
- Visiting Chattanooga is in his service plan.

Negative:

- Staff Comment: "It is impossible for most individuals here (Clover Bottom) to achieve everything in their ISP. The most you can do for them is feed and clothe them, maybe take them out to eat."
- Steve said, "They (staff) ignores me and gets mad at me."

D. Community Inclusion for Developmental Centers

As found in the PTP interviews in 2009, only one person interviewed at a Developmental Center said that they used the internet. Most comments collected to these other questions are below.

Do you have a boyfriend / girlfriend?

Positive:

- Four "Yes" responses.

Negative:

- Seventy two "No" responses.

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

Positive:

- Family lives in Chattanooga.

Negative:

- Feeding schedule limits when Kenneth can visit others.
- Long drive prohibits some visiting.

D. Community Inclusion for Developmental Centers (continued)

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

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 positive and negative.

Positive:

- Staff Comment: "[She] loves to hear her voice. She responds negatively when there's too much noise. She loves hot baths. Even though she is blind, she can take herself to the bathroom."
- Staff Comment: "Health is the biggest issue with Annie. If we could keep her stable on her medications rather than taking her off and on them, she'd do better. She recently had gall bladder surgery. If Annie is unfamiliar with something, she can get real frustrated. When she feels well, Annie can be very pleasant. I have been her primary caretaker for six months, and I would like to move in with her in her new residence when she leaves Clover Bottom. I worry that new staff would not be sensitive enough to her needs."
- Staff Comment: "John is very nice; He is easy to work with."
- Staff Comment: "Norman is very happy."
- Staff Comment: "Patricia really loves money. When she leaves Clover Bottom to go somewhere else, I hope she is happy. Patricia is very intelligent. She gets a lot of choices and makes decisions for herself."
- Staff Comment: "With the probable closing of Clover Bottom, David's parents are concerned with the possible increased distance between them and David. His parents are elderly and not in good health, which has been declining. From what I hear, David may move either to Greene Valley, Mercy-Homes or Guardian. I would like to make sure he, wherever he moves, is treated very well. I would like to continue to look after Walter after he leaves Clover Bottom."
- Staff Comments: "James is learning to use new machines in the work area. Although he can't speak, he understands what you are saying. He is a very good person, and I like to work with him. Sometimes you have to convince James to do things like eating. As far as we're concerned, the Clover Bottom staff and the individuals we care for are on equal footing. I am very pleased to work here. We are very strict on respecting the privacy of individuals." The staff member, who has assisted James for 10 years, worries what will happen when James and others leave Clover Bottom for other residences. "The lack of money the state has must not hinder the value of the people here."

D. Community Inclusion for Developmental Centers (continued)

Negative:

- Anthony Ellis: "I want to get out of here. I really miss my family. I pray to God I can get out of here."
- Staff Comment: "The biggest problem with Bryan is bedtime. He does not like going to bed. He screams and kicks. Then he listens to music all night long and finally sleeps."
- Staff Comment: "Steven has been in deteriorating health for around two or three years. He has so many health problems that his life is somewhat at stake, especially if one or more of these problems flares up at the same time. He is an aspiration risk. Steven is on pain medication. It is hard to make him comfortable. Steven is very intelligent. Although he can't acknowledge it, he understands exactly what you are saying. The staff that takes care of Steven and others keeps in constant touch with each other. When we're out away from Clover Bottom off work, we talk about the individuals we take care of. They need 24-hour care."
- Staff Comments: "I'm concerned about what will happen to Kenneth after he leaves Clover Bottom. His 'G' and 'J' feeding tubes come out very easily, and staff from another facility may not be very attentive to this situation. Many persons are hesitant to work with Kenneth because you have to be very careful because he can accidentally hurt you. He has gained weight since coming here. Kenneth has seizures but, unless you know the warning signs, you can't detect them."
- Step-dad, Chuck says Arlington is planning to move James (likes to be called Michael) to a house or apt. soon & his mother and step-father are unhappy about that, but they can't do anything about it.

GOALS

In the year 2010, the PTP was again asked to collect 1,200 interviews with people receiving services through the various Waiver programs. At the end of 2010, the PTP has successfully collected and recorded 1671 interviews with individuals in 74 of Tennessee's 95 counties, near-80% of the counties in Tennessee, and 82 (5%) more interviews than in 2009. The following counties — and number of interviews conducted — are represented in the 1671 interviews collected by the teams:

Anderson	11	Giles	7	Lauderdale	10	Robertson	26
Bedford	12	Grainger	5	Lewis	5	Rutherford	2
Benton	16	Greene	52	Lincoln	5	Sequatchie	4
Blount	17	Grundy	28	Loudon	32	Sevier	5
Bradley	24	Hamblen	9	Macon	2	Shelby	183
Carroll	26	Hamilton	81	Madison	106	Smith	1
Carter	4	Hardeman	46	Marion	6	Stewart	7
Cheatham	4	Hardin	26	Marshall	6	Sullivan	3
Chester	10	Hawkins	2	Mauy	46	Sumner	17
Cocke	9	Haywood	31	McMinn	21	Tipton	10
Coffee	22	Henderson	20	McNairy	28	Trousdale	3
Crockett	16	Henry	7	Meigs	1	Warren	4
Davidson	179	Hickman	3	Monroe	7	Washington	25
Dickson	54	Houston	2	Montgomery	46	Wayne	9
Dyer	28	Humphreys	8	Obion	20	Weakley	20
Fayette	9	Jackson	1	Overton	2	Williamson	31
Fentress	3	Jefferson	9	Polk	1	Wilson	14
Franklin	8	Knox	99	Putnam	9		
Gibson	51	Lake	2	Rhea	13	Total:	1671

7. RECOMMENDATIONS

Careful evaluation and monitoring of a program and the system within which it operates is important to maintain the quality and effectiveness of the services it provides. 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 report for the PTP's interviews in 2010, increasingly representative data and statistics about the population of people receiving services will contribute to improve the system and the services it delivers.

What does this analysis say about Tennessee's delivery system? Based upon the PTP interview data analysis for 2010, some of the following recommendations are being made within these categories:

Abuse/Neglect

- ❖ **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.** DIDS continues to help and employ more people with their *Employment First!* Initiative. Interviewees that mentioned what they would like to do for another job should be encouraged to try and find work in that field, whether it is with the help of *Employment First!*, ISCs, Case Managers, Vocational Rehabilitation or otherwise. DIDS' criteria for measuring success seems biased to the *quantity* of people employed and not necessarily with the *quality* and *choice* of that work.

Choice

- ❖ **Teach the *meaning of choice* to providers and to people receiving services.** Interviewees in 2009 may reply they had choice in their selection of employment or living arrangement but more questioning flushes out that some interviewees do not know the difference. True choice of employment is not "this job or no job." True choice of living situations is not "the bed on the left or the bed on the right." DIDS Quality Assurance program states that one of their ten domains for a positive performance factor is "choice and decision making"

8. RECOMMENDATIONS (continued)

(Quality Assurance Frequently Asked Questions). How can DIDS assure that there is choice in an individual's life if that person, as some PTP interviews show, does not know what choice is?

Information Dispersal

- ❖ **Implement internet awareness projects and trainings while also proving access.** Due to the relatively low numbers of people receiving services from DIDS that are using the internet, and in line with the DIDS Quality Assurance program, more information should be dispersed to people and their families with increased internet awareness and technology assistance. Increasing individuals' access to the internet should also enhance the level of community inclusion for people receiving services (Mcleod, et. al.).

Independent Support Coordination/Case Management

- ❖ **Improve the current ISC system by reducing each ISC's caseload.** People for the most part are satisfied with their ISCs but are upset with the frequency of staff changes and the workload. It is difficult to people receiving services and the people that support them when there is a long time for their calls to be returned, as well as a long time before anything requested is given.
- ❖ **Learn how to provide the equipment needed in a timely manner.** PTP found people needing devices or assistive technologies to increase their level of self determination. Some items listed may not be easily funded or found. Additional ISC/case management training in interagency communication and collaboration would benefit DIDS and the people receiving its services. There are more than a few situations that the PTP has encountered with individuals needing, for example, a new wheelchair. For a few of these situations, the PTP was able to contact United Cerebral Palsy which has access to pre-owned equipment to help get what the interviewee needs.

Program Recommendations

Maintain the instrument

PTP is currently using a significantly modified *Participant Experience Survey*, an instrument

8. RECOMMENDATIONS (continued)

designed by Medstat and approved by CMS. The interview tool has been revised to address shortcomings or ambiguity following feedback from the interviewing teams and people interviewed. The necessity for maintaining an updated and relevant interview instrument will serve to curb discrepancies stemming from what Schwarz (1996) noted—that seemingly innocuous differences in the phrasing of survey questions will affect how people report about their experiences and surroundings. The PTP interview instrument needs to ask the same questions over years in order for statistically accurate and meaningful comparisons may be made. After all, comparison across years is also subject to any individual interviewer biases or circumstances, so maintaining a consistent interview instrument will minimize any error of this sort. The interview tool, however, should remain flexible to practical adjustments or rephrasing.

DSP Training/Improvements:

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

- 1) Individualized training. Many complaints from family members that DSPs do not have enough person-centered training. Some DSPs were unable to help teams to get answers because they were also unfamiliar with the person being interviewed.
- 2) Emphasize importance of their jobs—highlight the increasing satisfaction with DIDS services throughout Tennessee since 2002.
- 3) Include job coaching as a required part of training—in 2010 PTP again revealed issues with people who have DSPs that do not help the person they support on their job.
- 4) Coordinate with local colleges to credit courses offered by DIDS.

System Recommendations

The interviews completed in 2010 help to identify these recommendations to DIDS, including:

Use of technology

- 1) Utilize available technology more in management.
- 2) Regional offices of DIDS need to regularly access and update new address and contact information that PTP teams record in the SurveyMonkey.

8. RECOMMENDATIONS (continued)

Special Equipment

Between 5% and 9% of the people interviewed within each waiver program—including those residing at a Developmental Centers—expressed needing special equipment. The percentage of completed interviews where people expressed a need for special equipment is in the following table.

2010 PTP interviews	1260 Main waiver respondents	215 Self-Determination waiver respondents	115 Arlington waiver respondents	81 Developmental Center respondents
People that needed special equipment to make their lives easier.	8.7%	6.9%	5.3%	8.6%

Self Direction

- 1) Staff and agencies honor individual's choices.
- 2) Use person-centered planning in making each person's ISP.

8. UNANTICIPATED OUTCOMES

PTP once again has encountered some instances not anticipated through the original grant process, both positive and negative:

- 1) PTP interviewers improve their interviewing skills as well as their level of comfort at interviewing, as well as their ability to ease any concerns of the interviewee. Individual interviewing skills are being sharpened and teams are more efficient with the interview process, allowing for more interviews, more precise answers, and fewer “false alarms.”
- 2) The information that the PTP receives from the state is compiled from the state’s CS tracking database and still contains inaccurate information. A secure online database where agencies can change information more efficiently is still needed. DIDS also has access to the SurveyMonkey interview collection site, and through that PTP securely shares changes in a person’s basic contact information.

9. FUTURE PLANS

Support from DIDS continues for PTP for its efficient and effective completion of at least 1,200 interviews per year. PTP continues to provide independent quality assurance measures powered and led by the voices, priorities and choices of people receiving services and their families. This report examines PTP interviews between January 1, 2010 and December 31, 2010. This report's data is collected, measured, and reported in a manner comparable to the 2009 PTP report.

(<http://www.tn.gov/didd/PeopleTalkingToPeople/PTP%20Year%206%202009%20report%2010-28-10.pdf>)

The following are some changes put into place:

- ✓ The DIDS requested number of interviews for 2011 will be at least 1,200 interviews, all conducted face-to-face with individuals receiving services.
- ✓ The maximum number of hours worked by any PTP interviewer is twenty hours per week and there is no full time interview staff; work limits remain fluid and are adjusted to remain within the allotted budget.
- ✓ The PTP Policy and Procedures manual has been edited to reflect these changes.

The program is also providing follow-up and referral for advocacy issues. The second year of PTP reporting on an annualized calendar-year schedule is complete and PTP hopes to expand more each year to better the lives of all of the individuals served and their families.

10. PTP INTERVIEW INSTRUMENT FOR 2010

1. Interview Date (mm/dd/yy):
2. Participant ID#:
3. First name:
4. Last name:
5. County:
6. Waiver type:
7. Region : EAST MIDDLE WEST
8. Team # and Interviewer(s):

PART ONE CHOICE AND CONTROL

9. How long have you lived in your home?
_____ months / years
10. Do you like where you live?
-yes -no -sometimes -unsure-n/a
Comments like where live?
11. Did you choose that place to live?
-yes -no -unsure-n/a
Comments choice?
12. Do you like who you live with?
-yes -no -some people -unsure-n/a
Comments like live with?
13. Would you rather live with someone else or alone?
-yes -no -unsure-n/a
Comments rather live with someone else?
14. Do you share a bedroom?
-yes -no -unsure-n/a
15. Do you like sharing a bedroom?
-yes -no -sometimes -unsure-n/a
16. Did you pick who shares your bedroom?
-yes -no -unsure-n/a
Comments share bedroom?

17. Did you help pick your support staff?
-yes -no -unsure-n/a
Comments help pick?
18. Did you know you have the right to change your support staff?
-yes -no -unsure-n/a
Comments right to change
19. Can you choose when you eat?
-yes -no -sometimes -unsure-n/a
Comments when eat?
20. Can you go to bed when you want to?
-yes -no -sometimes -unsure-n/a
Comments go to bed?
21. Who do you talk to when you have problems?
-family -friend -ISC -staff -other
22. Who is your Case Manager/ISC/Support Broker?
23. Can you talk to them when you need to?
-yes -no -sometimes -unsure-n/a
Comments?
24. Do you know you have the right to change your ISC?
-yes -no -unsure-n/a
Comments change ISC?
25. What do you do during the day?
-volunteer -job -workshop -day program -other
26. What do you like to do during your free time?
27. Can you do this when you want?
-yes -no -sometimes -unsure-n/a
Comments do what want?
28. Would you like to work or volunteer somewhere else?
-yes -no -unsure-n/a
Comments work somewhere else and why?
29. Do you open your own mail?
-yes -no -sometimes -unsure-n/a

PART TWO RESPECT AND DIGNITY

30. Do your direct support staff treat you well or with respect?

-yes -no -sometimes -unsure-n/a

Comments support staff?

31. Does anyone steal or take your things without asking?

-yes -no -sometimes -unsure-n/a

Comments take things?

32. Does anyone ever hit or hurt you?

-yes -no -sometimes -unsure-n/a

Comments hurt or hit?

33. Does anyone ever get angry and yell at you?

-yes -no -sometimes -unsure-n/a

Comments anger or yell?

34. Do you know how to report a complaint?

-yes -no -sometimes -unsure-n/a

Comments complain?

PART THREE ACCESS TO CARE

35. Can you get to places you need to go, like work, shopping, or your doctor?

-yes -no -sometimes -unsure-n/a

Comments get to places?

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

-yes -no -sometimes -unsure-n/a

Comments support staff?

37. What special equipment would make your life easier?

38. Have you spoken to anyone about this?

-yes -no -sometimes -unsure-n/a

39. Did you get the equipment needed, and how long did you wait?

-yes -no _____

Comments equipment?

40. Were the things that are important to you included in your service plan?

-yes -no

Comments services?

PART FOUR COMMUNITY INCLUSION

41. Do you decide what you do with your money?

-yes -no -sometimes -unsure-n/a

Comments money?

42. Do you have your own bank account?

-yes -no -unsure-n/a

Comments bank account?

43. Do you have a computer where you live?

-yes -no -unsure-n/a

44. Do you use the internet?

-yes -no -unsure-n/a

45. Do you (consumer) have a boyfriend or a girlfriend?

-yes -no -unsure-married)

Comments boyfriend or girlfriend

46. Who do you like to visit with?

47. Can you see these people when you want to?

-yes -no -sometimes -unsure-n/a

Comments visit?

48. Are you satisfied with the amount of privacy that you have?

-yes -no -sometimes -unsure-n/a

Comments privacy?

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

50. Amount of questions answered

-25% -50% -75% -100%

51. Who answered?

-consumer -family -guardian -staff

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