



PEOPLE TALKING TO PEOPLE

ANNUAL REPORT FOR  
January 1- December 31, 2009

Prepared by:

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# Authors

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:

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

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# 1. PEOPLE TALKING TO PEOPLE PROJECT OVERVIEW

The People Talking to People project (PTP) has successfully completed 2009—its first year of reporting on a calendar-based time-frame—operating as an independent quality-assurance mechanism for Tennessee’s Department of Finance & Administration’s Division of Intellectual Disabilities Services (DIDS.) PTP is a system of quality assurance and quality improvement measures based on a representative number of people who receive services, their families and staff providing objective and opinionated interview responses that result in faster resolution of identified issues, increased customer satisfaction, and system wide quality improvement. PTP interview data, since 2002, indicates a general rising level in satisfaction with the services received through Tennessee’s support service providers. PTP helps to accomplish a paradigm shift, moving from a series of overlapping quality assurance systems to a system that is powered and led by the voices, priorities and choices of people receiving services and their families.

There is additional value to PTP by offering an opportunity for people with disabilities to participate in meaningful and gainful employment. Meaningful for several reasons; in that there has been consistent overall greater satisfaction with DIDS services received across Tennessee since PTP began, and in that people with disabilities are observed, not only by people being interviewed but also by support staff that may be present, working in the community speaking with other people to bring attention where needed and to better the support service system as a whole. Gainful in that with each year of successful employment with PTP, part-time interviewing team members are eligible to receive a raise to their hourly pay-rate.

Robert B. Nicholas, Ph.D. coordinates the research agenda for the U.S. Department of Labor, Office of Disability Employment policy as well as provides technical assistance to the Tennessee Employment Consortium. In November 2009’s issue of *Breaking Ground* by the Tennessee Council on Developmental Disabilities, Dr. Nicholas notes “Many people served by DIDS do not have the experience to know what employment is about or the possibilities for a life in the community that could result from employment. As a result, employment is often dismissed as an option because people ‘do not want to work.’” PTP offers meaningful employment, in their communities, for people with disabilities, which Dr. Nicholas states is a “core component” to

support people to be employed. He states that “employment provides a person the opportunity to be a valued and paid resource to a community business.” This is one of the very important, yet unheralded benefits of PTP.

Perhaps most importantly, PTP interviewers bring attention to independent advocates and internal quality assurance teams of DIDS. PTP initiates the process whenever a situation merits further investigation by electronically submitting what is termed a Survey Notification Form. The year 2009 encompassed 101 Survey Notification Forms sent by email simultaneously to DIDS, to the PTP Director, and to the Assistant Executive Director of The Arc of Tennessee. A Survey Notification Form alerts to a response other than a positive was collected during an interview to any of four questions selected by DIDS in conjunction with the Centers for Medicare and Medicaid Services (CMS) in advance of the 2009 calendar year. There are four 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. They 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 101 Survey Notification Forms sent to DIDS in 2009, 56 were for interviews with people who were non-verbal or non-communicative thereby automatically triggering 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 performance indicating questions. This is the first 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 grew in 2009 and its interviewing teams across the state are now employing—on a part-time basis—27 individuals with disabilities and people familiar with disabilities (such as a family member of a person with a disability). PTP has selected and trained teams of two people to conduct and collect interviews from a random list of individuals receiving services through the DIDS system. Interviews pay special attention to self determination and choice while respecting each person's right to privacy. Importantly, confidentiality is respected for all interviews by all PTP teams and is part of PTP Policies and Procedures, as well as mandatory training.

The interview instrument utilized by PTP is based on the CMS-approved Participant Experience Survey. Over the years, following constructive feedback and suggestions 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. Per request from DIDS, at each interview opportunity, the interviewing teams distribute DIDS pamphlets on 'Protection From Harm' and 'Equal Opportunity is the Law in Tennessee.' The teams also share a brochure describing the PTP project, including contact information for Frank Meeuwis. Copies of the PTP Policies and Procedures manual are available for anyone requesting it.

## 2. METHODOLOGY

Results from the interviews are used to determine overall and category-specific satisfaction with services received and with the level of self-determination afforded to individuals. Instead of PTP reports following the fiscal year schedule (from July 1<sup>st</sup> through June 30<sup>th</sup> of the subsequent year), DIDS and PTP are now reporting interview results on a basis that corresponds with the calendar year. PTP has completed collecting interview data for 2009, again providing indicators in these four primary areas:

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

The people interviewed in 2009 came from two lists. The first list provided on September 12, 2008 containing a pre-selected random list of 1,315 people receiving services through the DIDS. The second list was provided on July 27, 2009 and included records of persons actively receiving services as of July 24, 2009 with contact and address information as they currently appear in the CS Tracking database—the electronic system used by DIDS.

The list is comprised of individuals receiving supportive services, whether through a waiver program or through the state. 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 corresponding regions across Tennessee. As each team exhausts their list, the comprehensive list is used to replenish the lists with more randomly selected potential interviewees.

Each interviewing team is charged with setting up a time and place to do the interview—convenient to the interviewee. An individual being interviewed has the right to decline to answer or skip questions and to stop the interview at any point. The team contacts the individual (or contact person) from the information on that PTP Region's list to set up an interview. A phone

log as well as the interview date is recorded on the list. The Project Assistant with the Director reviews these lists to note any missing information or to determine why an interview is missing. After completing an interview, each PTP team enters the interview responses into a secure internet-based collection platform—SurveyMonkey ([www.surveymonkey.com/](http://www.surveymonkey.com/)).

The PTP Director as well as representatives from DIDS, using secure password-protected access, periodically check the SurveyMonkey interview-collection platform 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 performance indicating questions. In 2009, 101 Survey Notification Forms were submitted by PTP.

One thousand five hundred eighty nine (1,589) individuals were successfully interviewed from the 5,642 people on the DIDS master list received in July 2009. This number of valid interviews collected by PTP again surpasses the 1,200 that were asked for by DIDS—exceeding the goal by nearly one third (32.4%). The master list included individuals on the Arlington, the Self-Determination, and the Home & Community Based Services (Main) waivers. The list also includes individuals receiving supports at each of the Developmental Centers in Tennessee, including Arlington, Clover Bottom, the Harold Jordan Center, and Greene Valley. These completed interviews serve to provide the data for analysis in this report. The statistical accuracy and representativeness (relevancy) of the data presented in this report varies between waiver populations and is subject to the following important considerations of statistical validity.

## **2009 PTP waiver-combined participant interviews**

For the 5,641 ‘units of analysis’ (master list of all waiver and service recipients provided by DIDS on July 27, 2009) the confidence level is 95% at a confidence interval (sometimes also called margin of error) of 2.1 (i.e. +/- 2.1%). That is, with 1,589 valid interviews collected and recorded in the online SurveyMonkey, it is possible to statistically determine, in 95 of the next 100 people interviewed, what these next people would respond to a particular question with an accuracy of + or – 2.1%. Statistically speaking, this is a very high level of relevancy and representativeness for the PTP interview results across the differing waivers for services in Tennessee. The relevancy of the PTP findings is somewhat lower when the differing waiver populations’ interview results are flushed out by waiver. The relevancies of the findings are indicated below for each specific waiver population.

## **2009 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 2009 the PTP collected and reported the interview results for 1,235 of these participants. Statistically speaking, the confidence level is 95% at a confidence interval (sometimes also called margin of error) of 2.3 (i.e. +/- 2.3%). That is, with 1,235 valid interviews with Main waiver recipients collected and recorded in SurveyMonkey, it is possible to project or statistically determine, in 95 of the next 100 people interviewed receiving Main waiver services, what these next people would respond to a particular question with an accuracy of plus or minus 2.3 percent. (See pages 14-20).

## **2009 PTP Self-Determination waiver interviews**

For the 1020 participants in the Self-Determination waiver on the list supplied by DIDS the confidence level is 95% at a confidence interval of 6.7 (i.e. +/- 6.7%). That is, with 179 valid interviews with Self-Determination waiver recipients collected and recorded in the online SurveyMonkey, it is possible to statistically determine, in 95 of the next 100 people interviewed receiving Self-Determination waiver services, what these next people would respond to a particular question with an accuracy of plus or minus 6.7 percent. (See pages 14-20).

### **2009 Arlington Waiver interviews**

For the 310 ‘units of analysis’ (master list provided by DIDS in July 2009) the confidence level is 95% at a confidence interval of 8.1 (i.e. +/- 8.1%). That is, with 91 valid interviews with Arlington waiver service recipients collected and recorded in the online SurveyMonkey, it is possible to statistically determine, in 95 of the next 100 people interviewed receiving Arlington waiver services, what these next people would respond to a particular question with an accuracy of plus or minus 8.1 percent. (See pages 14-20).

### **2009 Developmental Center service recipient interviews**

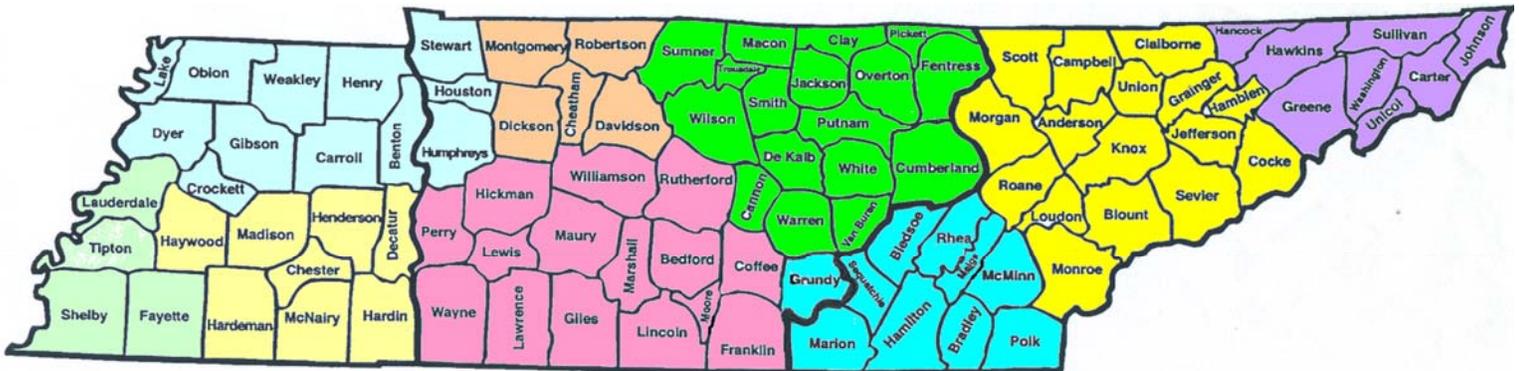
For the 310 ‘units of analysis’ (master list provided by DIDS in July 2009) the confidence level is 95% at a confidence interval of 9.1 (i.e. +/- 9.1%). That is, with 84 valid interviews with people residing at any one of Tennessee’s Developmental Centers collected and recorded in the online SurveyMonkey, 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 9.1 percent. (See pages 14-20).

### 3. PTP STAFF

#### *PTP Interviewers*

The Arc of Tennessee’s office is located in Nashville. Frank Meeuwis is the Director of the project and Holly Newingham is the Project Assistant. PTP employed 27 people in 2009 all across Tennessee to serve as part time interviewers. The people on the interview teams are assigned to conduct interviews in the region in which they live. Two people are assigned in each of nine regions. Regions 2, 5, 6 and 8 have additional persons employed as substitute interview partners. As stipulated in the original grant, there are three interview teams for each more expansive regions; East, Middle, and West Tennessee. PTP is a success because of the dedication and patience of all the partners of the interviewing teams. The regions utilized by the PTP, and the counties included in them, are as follows and depicted in the map below:

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

Diana Barnett, Abby Counts, and Mary Turner were the interviewing team in region 1 (Northeast). Now, Diana works with interviewing partner Danny Reaves..

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

Region 2 (East) has Jean and Carol Smith for the interview team, and Heather and Linda Wilson as a substitute team.

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

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

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

Region 4's (Upper Cumberland) interview team is Terry Votaw, Holly Kirby, and Cassie Douglas.

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

Region 5's (Mid Cumberland) interview team is Woody Cade and Josh Turner. Cheryl Coleman is a substitute interview partner for the team.

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

Region 6's (South Central) interview team is Mary Dale Greene and Gail Compton. Michael Robinson and Brenda Lackey serve as substitute interviewing partners.

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

Region 7's (Northwest) interview team is Angie Snider and Judy Sparks.

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

Region 8's (Southwest) interview team is Tom Griffin and Darryl Newsome. Patrick Sanders is a substitute interviewing partner.

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

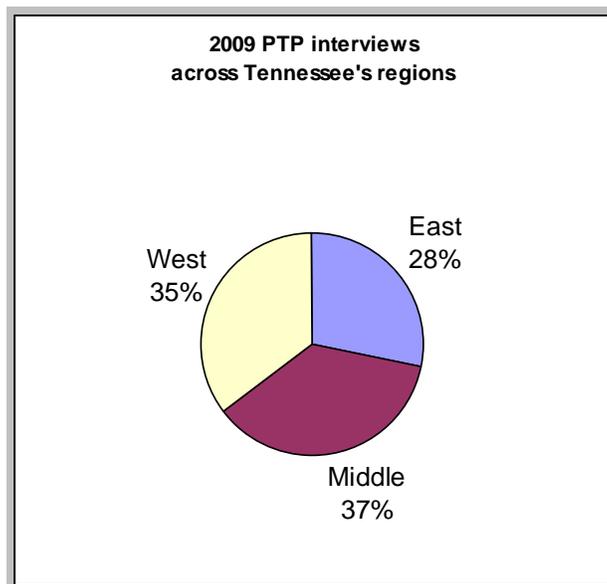
Region 9's (Delta) interview team is Sondra Loveless-South and Nadine Loveless. Additionally, Linda Roberson and Melissa Allen serve as data-entry specialists to work part-time as needed.

## 4. INTERVIEWEE DEMOGRAPHICS

The interviews scheduled, completed, and entered into SurveyMonkey are come from two DIDS master lists sent to the PTP Director for distribution to the interview teams. The initial pre-randomized list of potential interviewees was assigned by DIDS September 12, 2008. As mentioned above; on July 27, 2009, the 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 2009 PTP interviews completed by each team. The East, Middle, and West Tennessee designations below do not correspond precisely to the DIDS assigned designations for the interviewees. The pie-chart below this table depicts the distribution of PTP interviews completed in 2009.

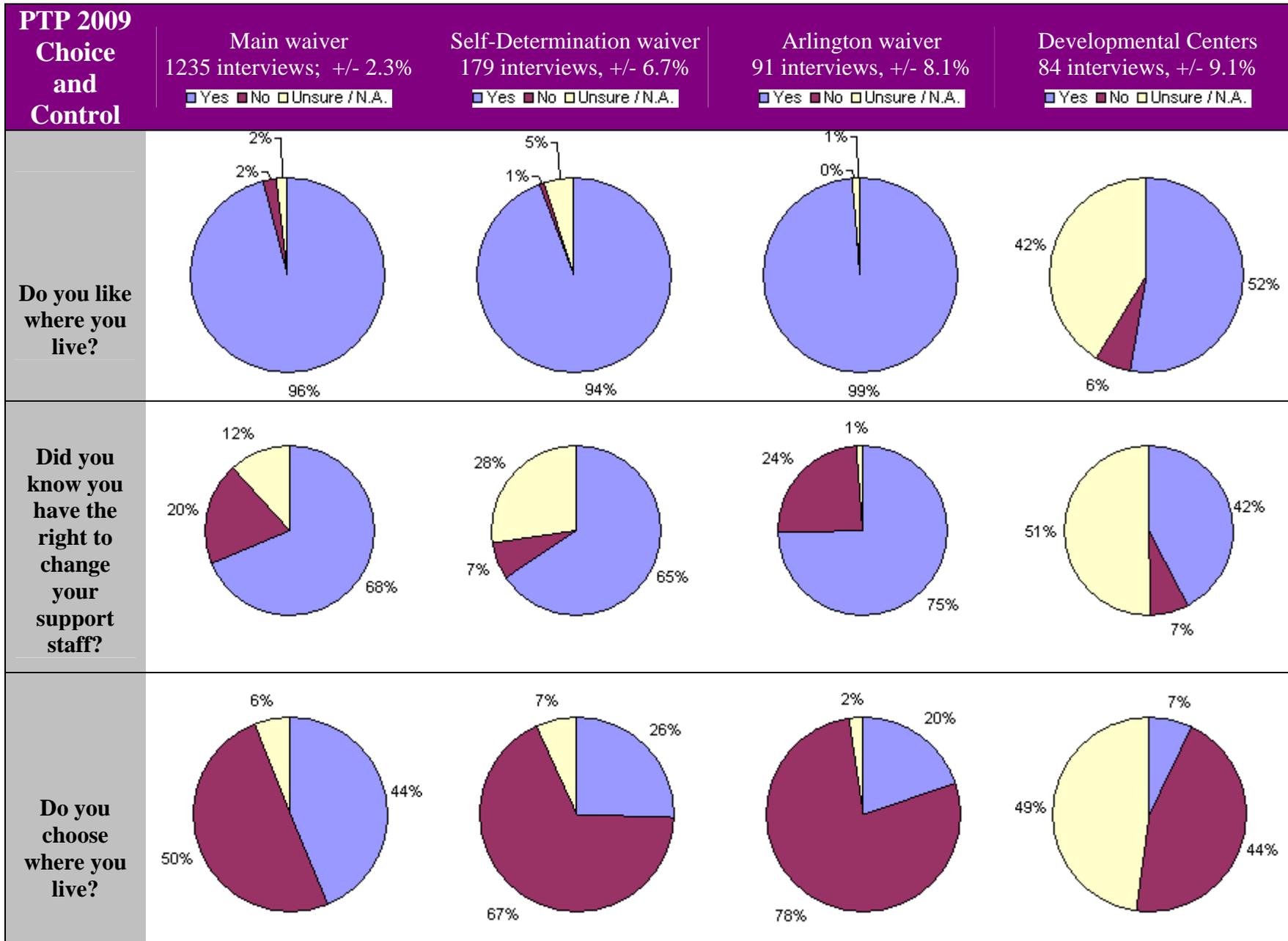
Region:	EAST TN			MIDDLE TN			WEST TN			2009 total
	1	2	3	4	5	6	7	8	9	
<b>Total</b>	126	123	201	189	233	153	46	326	192	1589
<b>%</b>	7.93%	7.74%	12.65%	11.89%	14.66%	9.63%	2.89%	20.52%	12.08%	100.00%
<b>Region total</b>	450			575			564			1589
<b>%</b>	28.32%			36.19%			35.49%			100.00%



## 5. PTP INTERVIEW RESULTS

The subsequent pie-charts for 2009 represent selected interview responses—separated by waiver—within each of these areas; Choice and Control, Respect and Dignity, Access to Care, and Community Inclusion. These pie-charts represent the Yes or No or Unsure/Not Applicable responses to a selection of questions from each of the four areas of the interview. Yes and No indicate a positive and a negative response respectively. Unsure/Not Applicable indicates when the interviewee—not the interviewer—was unsure of their response or when the question did not apply to the situation. The confidence level (or confidence interval) is 95% for each question and particular waiver population. This indicates the predictive power or strength of the reported results—indicating their reliability. The four questions also being used for performance indicators to CMS are starred and highlighted in bright yellow.

A very important consideration before interpretation of the results shown in the pie-charts is to recognize the differing statistical strengths (or representativeness) of each waiver-specific results. For example, when comparing the pictured responses to the question “Can you visit with the people you want to when you want?” between Main waiver service recipients and Self-Determination waiver service-recipients, a difference of 4 % is apparent (93%-89%) in people responding affirmatively. Yet, recognizing that the percentage pictured for the Main waiver service recipients has a 2.3% margin of error, and that the percentage pictured of Self-Determination waiver service recipients has a 6.7% margin of error, should tell the reader that the next Main waiver service recipient interviewed would statistically be 91%-95% (93% +/- 2.3%) likely to respond affirmatively, whereas the next Self-Determination waiver service recipient might be 82%-96% (89% +/- 6.7%) likely to respond affirmatively—and one can only be 95% statistically certain of those approximations—rendering statistical comparison between waiver populations very complex. The pie-charts therefore are merely an approximate visual aid for interpreting response distribution within a waiver program.



**PTP 2009  
Choice  
and  
Control**

Main waiver  
1235 interviews; +/- 2.3%

■ Yes ■ No ■ Unsure / N.A.

Self-Determination waiver  
179 interviews, +/- 6.7%

■ Yes ■ No ■ Unsure / N.A.

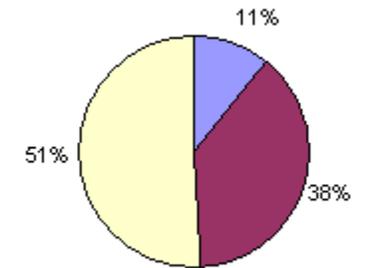
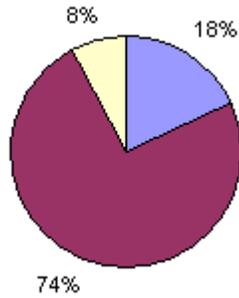
Arlington waiver  
91 interviews, +/- 8.1%

■ Yes ■ No ■ Unsure / N.A.

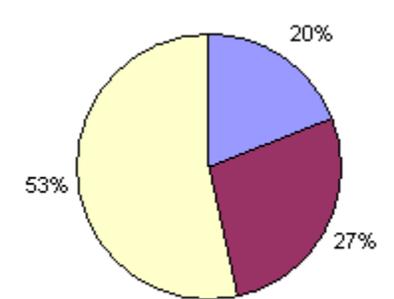
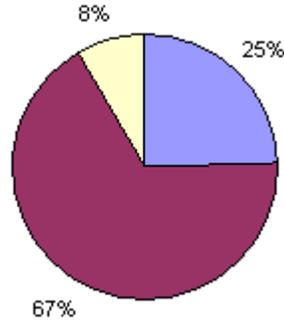
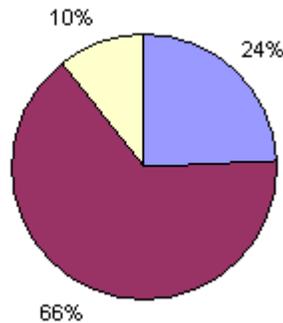
Developmental Centers  
84 interviews, +/- 9.1%

■ Yes ■ No ■ Unsure / N.A.

**Would you rather live with someone else or alone?**



**Would you like to work somewhere else?**



**2009 PTP  
Respect  
and  
Dignity**

Main waiver  
1235 interviews; +/- 2.3%

■ Yes ■ No □ Unsure / N.A.

Self-Determination waiver  
179 interviews, +/- 6.7%

■ Yes ■ No □ Unsure / N.A.

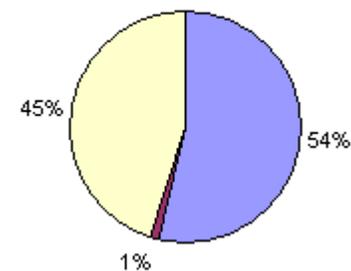
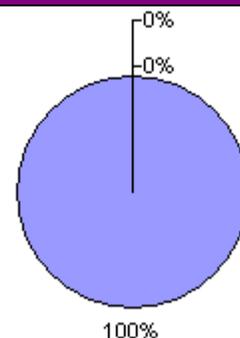
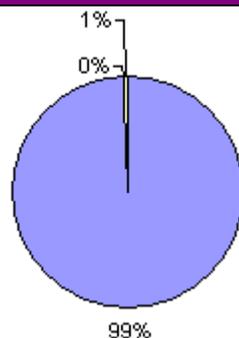
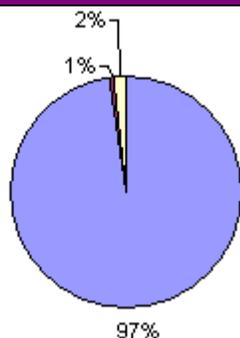
Arlington waiver  
91 interviews, +/- 8.1%

■ Yes ■ No □ Unsure / N.A.

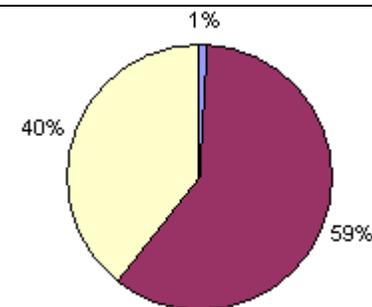
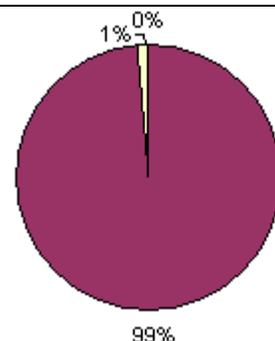
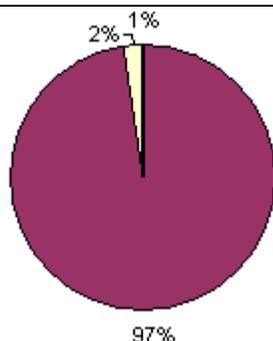
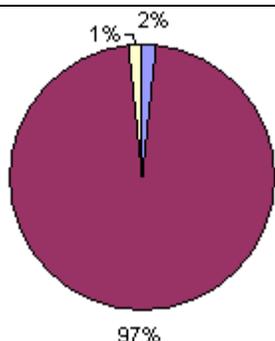
Developmental Centers  
84 interviews, +/- 9.1%

■ Yes ■ No □ Unsure / N.A.

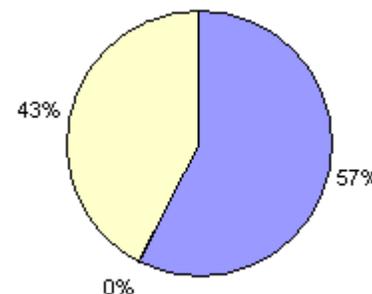
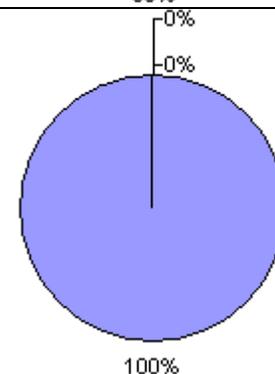
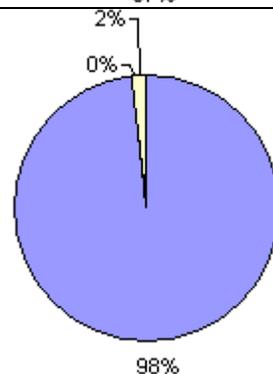
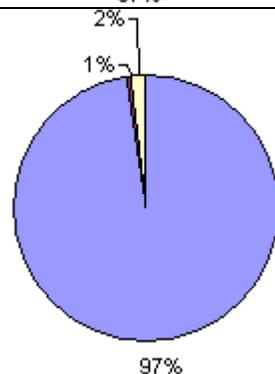
**Do your  
Direct  
Support  
Staff treat  
you well or  
with  
respect?**  
\*

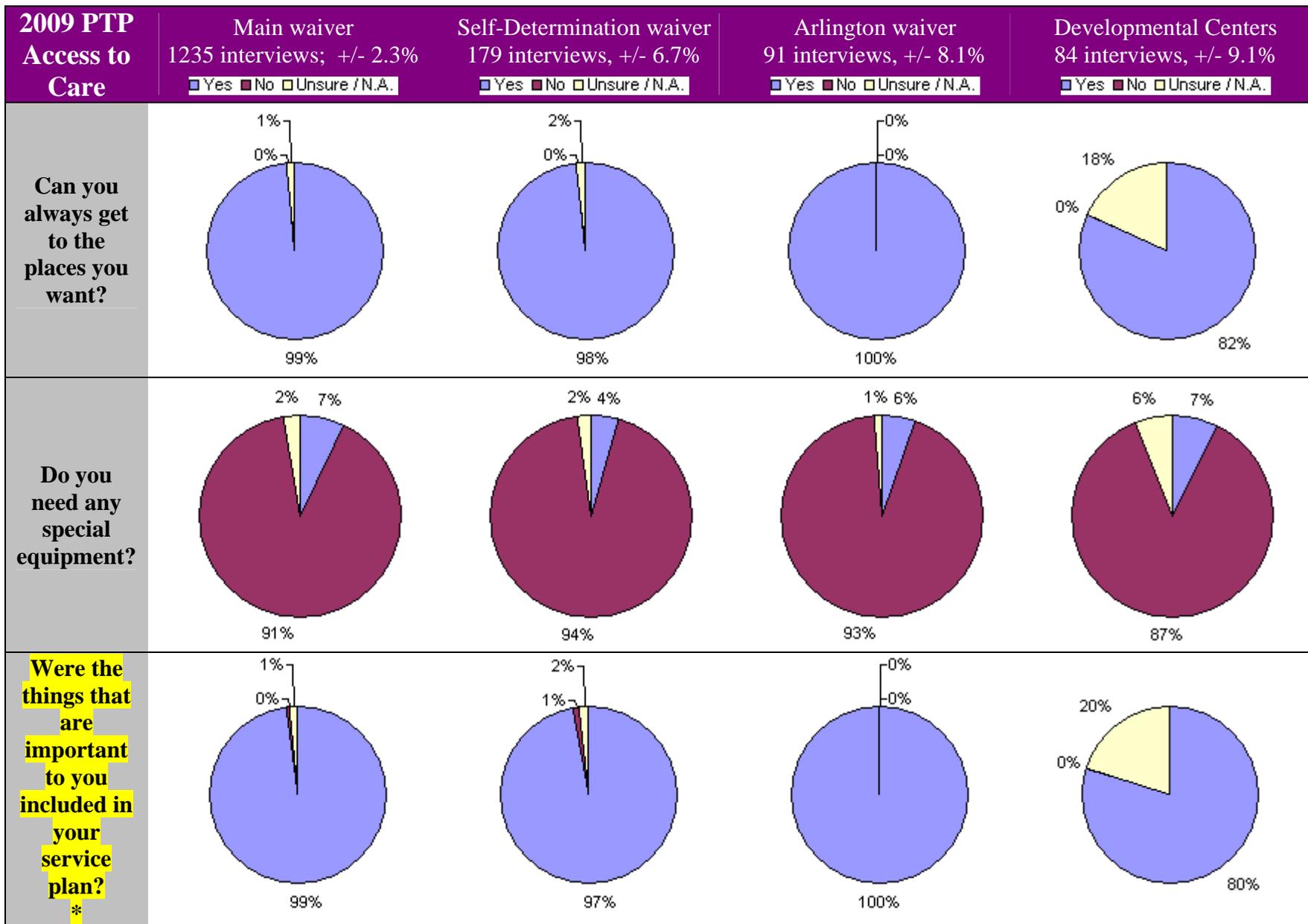


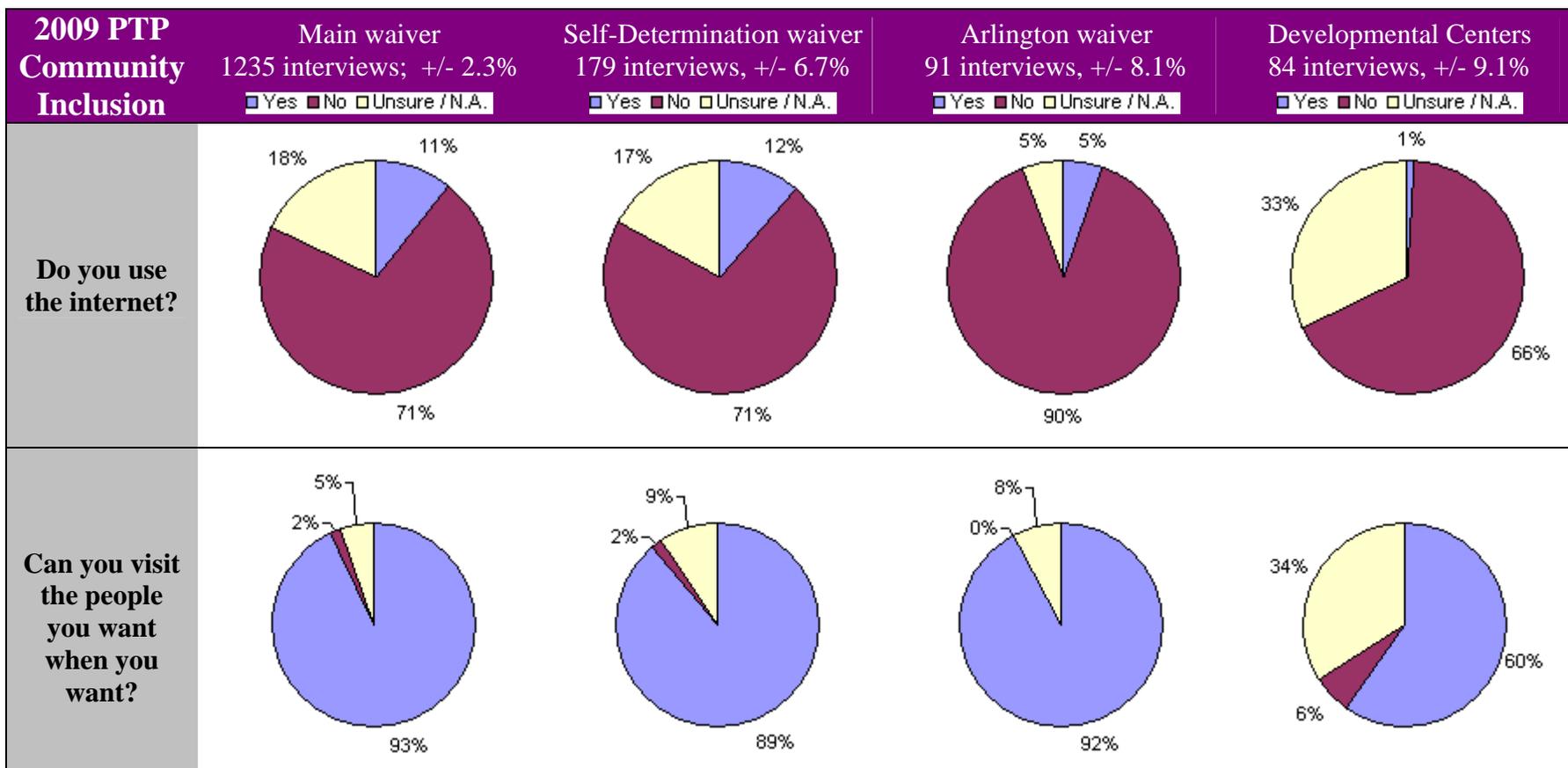
**Does  
anyone ever  
hit or hurt  
you?**

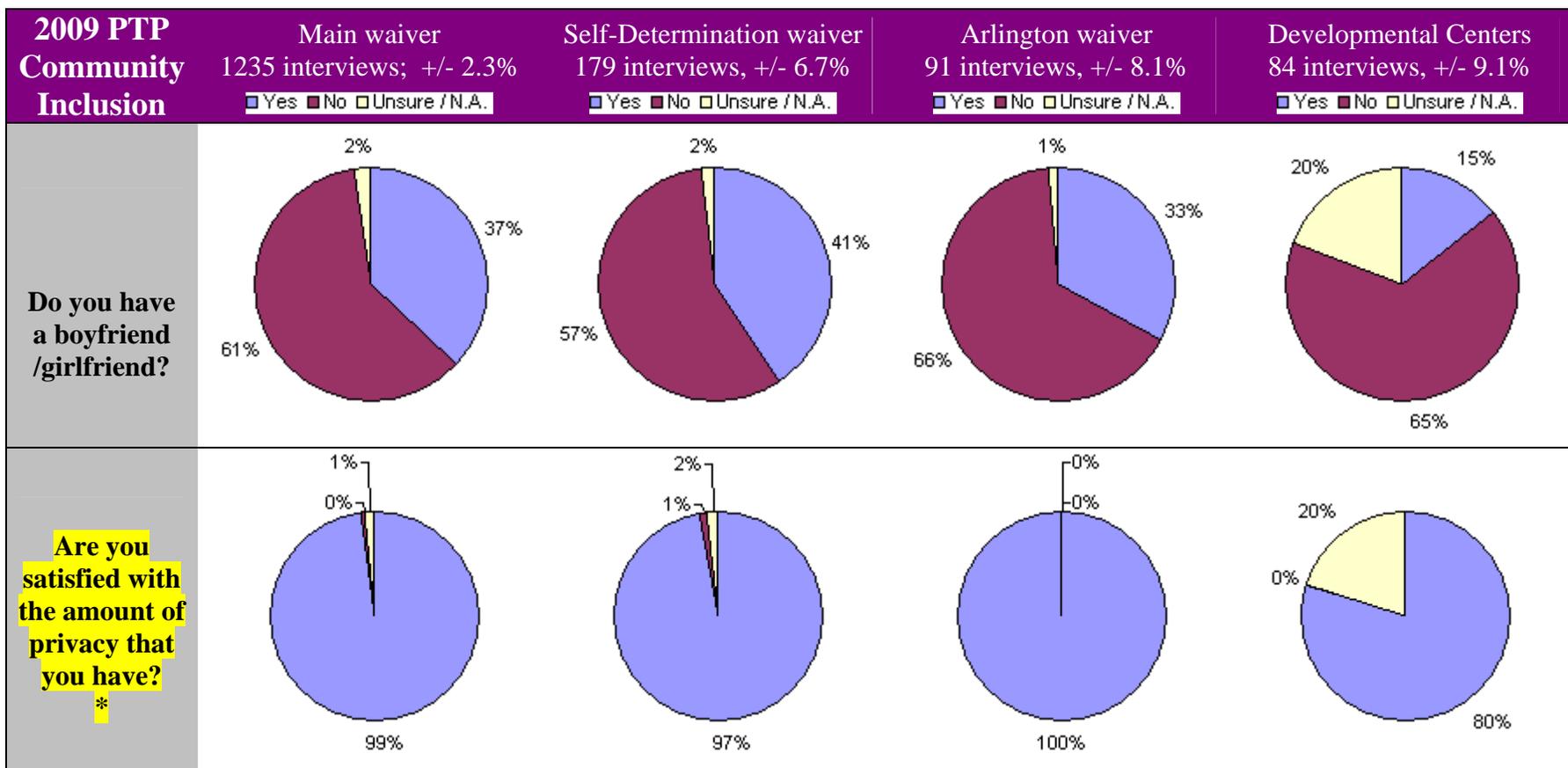


**Do you  
know how  
to report a  
complaint?**  
\*









# PTP INTERVIEW COMMENTS

The PTP interview for 2009 includes newly formatted questions and wording. This renders the interview results unique and incomparable to previous years' interview results. PTP, responding to a request from DIDS, will report interview results according to the waiver program of an individual. Following are both positive and negative examples of comments recorded 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 5.

## A. Choice and Control for Main waiver

### Do you like where you live?

#### *Positive:*

- “I love my place.”
- She likes her friends there.
- She likes living with family.
- Lives with brother.
- Staff says she cried once when she tried living elsewhere.
- Lives by himself.
- Chose same housemate because he has lived with him many years.
- "At first, [he] had a rough time adjusting to a roommate but things have smoothed out.”
- Staff explained that he lives in a condo that his parents bought, specifically designed and built just for him.
- [He] formerly lived in a group home. He now lives in a house in [city removed] where he can walk outside. [He] likes to take care of his buddy, who is one of his roommates.
- I like where it is, but I'd like to live closer to my mom. I mean, I like it, but it's mostly older women and I'd like a place where there are people closer to my age.
- Parents live “around the corner.”
- “It’s alright.”
- “I like where I live cuz there's all kind of good neighbors there and when I need help, they're always there to help me.”

## A. Choice and Control for Main waiver (continued)

- “Much better than old address.”
- He's lived with his family all his life. He lives on a farm, and he's got animals and a little pond. He loves living there.
- Dad built home.
- Used to live at [Developmental Center].
- Likes his two roommates.

### *Negative:*

- He is moving.
- House has no steps.
- She is in transition and she'll be moving to a new home within the month.
- “I like the inside of the house, but I don't like living in the city.”
- Will probably move in with sister.
- Only one bathtub for three people. Staff's mom owns it.
- Jealous of housemate.
- “I want to live out in the country where I will not be bothered by people, where it is quiet.”
- I want to move to residential and have housemates that are my age.
- [She] would like to be closer to town.
- Place has bugs.
- [She] said her roommate hit her sometimes.
- Wants to live with mom.
- “I'd like to live somewhere there's an elevator.” (Staff said she doesn't like to climb stairs.)
- “I want to live in the city.”
- “Guy upstairs hates me.”
- "There is not enough traffic around here. I would like to see more females."
- It's not the nicest place and the complex managers aren't very responsive.
- I want to go back to [city removed].

## A. Choice and Control for Main waiver (continued)

- There's too much noise and racket. (Staff said he was asked to move from his previous apartment because the people that visited him made too much noise. He's in a new apartment now, and staff believes he misses his old place and the people that came to see him.)
- I'm not very happy there. They're always jumping on my case.
- Wants to live with her sister.

## Did you choose the place you live?

### *Positive:*

- "Sure did."
- "I could went somewhere else. Didn't want to."
- He helped pick it out.
- "I went to visit and stayed."
- Visited and picked colors.
- With assistance from [agency]. They looked at 3 houses before [he] made his selection.
- My momma helped me move, she found the house.
- Chose because of [agency] and her roommate.
- His sister helped him get in the house.
- He would get upset when it came time to leave his group home, and we realized it was a bad place, so we brought him back home.
- We got a level house because [she] is afraid of heights.
- "[He] does not have a conservator so that person was not involved in selecting where he lives. He used to live in Portland. [Agency] is strongly involved with [him]."
- "I used to live in a group home with [agency] and I did NOT like it; I found out through a lady that worked there that a new agency was opening up, so I asked to go with them and my parents and [advocate] helped me find this house. They had this house built for me."
- Yes, just has one roommate.
- Lives with sister.

## A. Choice and Control for Main waiver (continued)

- Lives with brother and staff assistance.

### *Negative:*

- Conservator chose.
- His mom placed him there, but she always asks him and gets his input, so I'm sure he had a little to do with it.
- The state put me here, but I like where I live. (Staff said she came from another agency and she decided she wanted to live in her current house.)
- He was moved from his old home to his new home due to "medical reasons."
- Sister chose.
- State did.
- "My parents built me a home."
- Someone picked it for him.

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

### *Positive:*

- "Yes, I have already done that due to staff falling asleep, claiming that took her places, but lied and stayed home instead."
- "ISC told me I could refuse anyone."
- "[She] told me if I didn't like someone to tell them."
- "Yes, and I have too."
- "[He] helps me with things like that."
- Have had bad staff removed.
- Case manager told me.
- "I tell ISC, she get it taken care of."
- His family does know that.
- "There use to be a lot of staff turnover. If [she] does not like a staff member, she will let you know."
- Although [he] is non-verbal, he gestures if he does not like staff.

## A. Choice and Control for Main waiver (continued)

- Changes support staff often; of the three support staff in house only likes one.
- (staff) “He doesn't understand the right, but if he didn't like us, he wouldn't cooperate with us.”
- (staff) “His mom talks to him all the time and questions him, so if he has a problem with anyone, he'll tell her and she'll come to us.”
- Her parents requested a staff change because they felt [she] didn't like her previous staff and wasn't doing well.
- (staff) “He'd exhibit negative behaviors if he had a problem with you. His sister knows, too.”
- His mom understands all of his rights and [he] will sure let you know if he don't like you.
- Two former support staff "were not very nice."
- “I'm glad I got [her].”
- Sometimes if somebody's late, I call! (Staff said if he's not happy with staff, he'll call the office and inform them.)
- (staff) “I think if he had a problem with someone, he'd come in here and point until I figured it out. And he'll rub his eyes to tell us ‘cry-baby’ which is his way to tell us someone is on his nerves. His family knows they can change staff, too.”
- “I do now.”
- "If [she] wanted to change her support staff, she would 'act out'".
- “I don't want to change anybody, I like everybody here. But I'd talk to somebody here if I had a problem.”
- That happens with great frequency. There are some pretty serious behavior issues.
- “You mean, if I don't get along with them or something like that? Yeah, I can do that.”
- “I love them.”
- [He] uses a communication device. Mother says she understands.
- Staff said he knew. He only gestures.
- “Don't need to.”
- He's not capable of making those decisions for himself - his mom makes those for him. But, oh gosh yes, if he didn't like you he has a way of letting you know!

## A. Choice and Control for Main waiver (continued)

- When staff asked [her] she hummed and staff said that was a yes answer.
- [He] nodded his head in confirmation of his sister's verbal answer–yes.

### *Negative*

- “Yes, but it caused trouble with agency and they turned us in for delayed services because we were not satisfied with the services of the DSP.”
- “They would get mad at me.”
- “I just let [her] know when [I] don’t like someone.”
- Mom has always done that for him.
- (staff) “He doesn't understand his rights, but he'll let you know if he doesn't like you. It will usually trigger a behavior.”
- “No, I sure didn't.” (Interviewers explained to her and gave her brochure on her rights.)
- (staff) “[He] is a real good person but if he does not like a support staff person, he will not be pushed around.”
- “I don't want to change my staff.” (Individual didn't seem to really understand the question - she seemed to think we were going to change her staff for her. We assured her she could keep her staff.)
- “[Agency] tells us we can't change our staff. We have no say in who’s hired and if we're not happy we can't change them.”
- “I didn't know that, but I've never had a problem with them.” (Interviewers explained this right to him.)

## Can you talk to your ISC when you need to?

### *Positive:*

- “Yes, she is good.”
- “Within two or three days.”
- “Most of the time.”
- “Case manager gets back that day, ISC within two days.”
- Family can. They always come in for a Circle of Support meeting.
- “They always get back to me.”

## A. Choice and Control for Main waiver (continued)

- One visit per month by ISC.
- ISC visits twice monthly.
- "[She] communicates to the ISC and others through her actions. If she tugs on her pants, she needs to use the bathroom. If she throws her fist, that means she is mad."
- "She comes like she's supposed to."
- "[She] would do anything she could for us."
- She sends him cards, picks him up, and comes to see him.
- "She's great. Anytime we've had a problem, she gets right to work on it. She always has."
- He doesn't really know her, but she visits regularly.
- "I send her email and she answers me pretty quickly. I email her once a week and she responds back."
- "She would help me if I had a problem."
- "If I wanted to, yes. If something's bothering me I'd call ahead and tell her something's going on and she'd call me right back."
- She's very responsive, very, very responsive. They have a good relationship.

### *Negative:*

- "No, she's in Chattanooga."
- "She don't return her calls like she should."
- "Called and left a message to call me, but have not heard back from her yet."
- "She never answers the phone when we need her. My mom calls her and she can't reach her."
- (Father) "I don't think [he] works as hard as he should. [The individual] only sees him once every three months. I guess [he] is very busy and just does not have the time."
- (Parent) "I haven't seen the woman in the 9 months [the individual] has been here. I haven't even talked with her. I tried calling her once when [the individual] was in the hospital, but she never called me back."
- "Every time we try to get a hold of him, it takes forever before we can talk to him."
- "We don't have one at the moment."

## A. Choice and Control for Main waiver (continued)

### Would you like to work somewhere else?

#### *Positive:*

- Like to have an outside job.
- Church.
- Would like to try animal shelter.
- Wants to work at a grocery store.
- Same location, different duties.
- Go out in community.
- “Cut grass.”
- Her mom says [she] needs something to make her feel like she was contributing to the world.
- (Staff) “If she doesn't do how she wants to, she'll start cussing and acting out. All she wanted to do is get her free meal and if we tried to encourage her, she'd start cursing and I'd have to take her out. Then she got sick and she just couldn't go back.”
- “I quit. I'm retired. I quit like a hot potato!”
- “My dad would shoot me.” (Staff said that was a joke - he actually works for his dad who is an executive at [agency], the individual's workplace. He LOVES working there where he hands out mail.)
- (Staff) "She formerly worked in the community packaging and repackaging items."
- “I like Meals on Wheels and the nursing home.”
- “I have 2 jobs already. If I had one more, it would kill me.”
- “I work at [agency] every day from 8 to 12 then I come here and go out in the community.”
- “Drive a big truck!”
- Would like to wash dishes.
- "William likes to take out the trash, especially in parks. He is near the end of his one-year service plan, but [agency] still has not been able to find a job for him."
- He is on the [agency] board of directors, volunteers at a nursing home.

## A. Choice and Control for Main waiver (continued)

- “He really likes to interact with people, but it's not something that's really ever been brought up. Maybe we should think about it. He really is very smart- the way he handles his games and mercury board is amazing!”
- “He used to work when he was in school and really enjoyed the different jobs. I think he's kind of fallen through the cracks here because nothing is happening in that regard and I think he'd do very well with a job.”
- “[The individual] works at the church and formerly worked at [restaurant] but they eliminated her job. She folded silverware and washed trays for three or four months. She gave everybody hugs. Her job coach told us not to call about a job for her; I'm not sure why.”
- “I'd like to work more hours and make more money at [restaurant].”
- Would like to work in a nursing home.
- “Like to work at hospital, nursing home.” (Staff said she wanted to volunteer at the hospital where her mom was, but after her mom passed away, she lost interest in volunteering.)
- “I'd like to work. I don't want to volunteer.” (Staff said she works at [organization]. Staff explained that what [she] really wants is to make more money - more money than she can make in the workshop - so any time there is an opportunity outside the workshop to make more money, she jumps at it.)
- “I would like to work at [restaurant] and fill up ice machines.”
- Loves animals—think he would be good for the animal shelter.
- “One of [his] ISP goals is to get involved with Vocational Rehabilitation. Somebody would need to work with him. He gets upset when he's alone.”
- “I wouldn't mind doing the group home clean-up. I was doing contract work but they don't got it now. I'm waiting for some work to do to make some more money.”
- (Parent) “We would like for [her] to work at [agency] but, due to budget cuts, they are no longer taking anyone new. We would like her in a day program around twice weekly four hour daily.”
- “I'd like to work at [restaurant]. They're working on it for me.”

## A. Choice and Control for Main waiver (continued)

- “Any job!”
- Would like to work in a hotel/motel.
- “I’d like to work at [store].”
- “I’d like to work as a truck driver.”
- “I’d like to work at a car lot.”
- Like to work at a hospital.
- Like to do child care.
- Any stocking job in a store.
- “I’d like to work as a bus boy.”
- He is very nervous not working. He will be happy when they find him a job.
- “Any job where I can talk to people.”

### *Negative:*

- Work with Mobile Meals.
- Currently, [he] cleans the Tennessee Drivers Facility 4-5 days per week, two hours a day.
- “I’m concerned that if I did, it would mess up my Social Security. I don’t want anything else at this time.”
- Happy with [agency].
- Enjoys working at [agency].
- (Staff) “He wouldn’t be able to hold a job or volunteer anywhere. He can’t be anywhere by himself. We have to do just about everything for him.”
- Doesn’t want a job anymore.
- “My daughter does not want me to work anywhere else due to my age.”
- Happy there.
- “I’m happy I have work.”
- “[Agency] doesn’t pay me enough money. I call it ‘dirt money.’ I clean the dirty bathrooms and get paid very little, therefore it’s ‘dirt money.’”
- Tried workshop and day program, but did not work.

## B. Respect and Dignity for Main waiver

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

*Positive:*

- “Yes, they are nice.”
- Staff at Day Program look out for her.
- “They treat me good.”
- Worked with her at least twelve years.
- “We are satisfied with the DSP that we have now, but have had staff that did not.”
- “Staff treats me right. They don’t mistreat me. I love them.”
- “Staff at [developmental center] were mean to me, but now staff is fine.”
- He’s spoiled rotten!
- (Staff) “I treat him better than my kids!”
- “They're on time.” (Staff said if staff is late, he holds a grudge. He's REAL big on being on time.)
- “Some of the staff are hysterical.”
- (Staff) “He's been here for 30 years and he's really part of the establishment. We consider him part of ‘management’ really. Nobody mistreats him!”
- “Oh yes, they do. You couldn't ask for better staff than I have. They're really caring and if something's wrong, they're there to help you in any situation.”
- Individual gave his staff a big hug.
- “[Individual] has a top-notch support staff. They are very kind, very respected. We are very blessed to have them.”
- “The five we had before were all fired. We had a lot of trouble with them, but the staff we have now are good.”
- (Staff) “There's no doubt about it - he loves them! They go on all kinds of outings, they even go to [other state], and car races.”
- Individual first said a resounding "no" and then began giggling at her staff. She started poking her staff in the stomach and started laughing. They clearly had a very good relationship, and individual really enjoyed messing with staff.

## B. Respect and Dignity for Main waiver (continued)

- [Parent] responded that [individual's] staff treat him well.
- Foster family at [agency] is very kind.
- [She] is very happy with her direct support staff.
- [Parent] says yes.

### *Negative:*

- [Staff member] on awake shift is mean to her and she is scared of her and indicated that she twisted her wrist.
- “Some staff does not treat me with respect. [They] come into my room and shake me and shake my bed and tell me to get up to take my meds. I take my meds when I want. No one can make me get up. I tripped one staff and she came back from the hospital on crutches. You don't disrespect me.”
- (Parent) “She needs to be moved into a different home. I get the impression that the people she's living with aren't nice to her at all. ‘You'll get your medicine when I decide to give it to you.’ I might have misremembered exactly what was said... but I know that medicine needs to be given at the proper time.”
- “They treat me like a two-year-old, I do not like it. I'm looking for a good group to go out with. Staff does not care about me.”
- “Goes to [agency] and does not like it there.”
- “They (staff) never take me anywhere. They disrespect me. The third shift sleeps all the time when I'm awake, as far as I'm concerned, the staff are just babysitters.”
- “My staff at my house treat me right, but some here don't. I'm tired of being ignored.”

## Does anyone ever hit or hurt you?

### *Positive:*

- “A staff member, but [they] are no longer here.”
- He stated that a former staff had grabbed him in wrong place. It was investigated.
- [His] roommate will sometimes hit according to staff.
- Once in a while sister hit him.

## B. Respect and Dignity for Main waiver (continued)

- There are some peers that he has issues with; they grab, hit, scratch, and pinch. But certainly no staff.
- “[Housemate] hit me in the back and it's been hurting me a lot lately, but other than that, no.”
- “Everyone is nice to me.”
- In the past when [he] was at [Developmental Center] he was hurt, but not since leaving there.
- “I would tell staff.”
- (Staff) “He was in a bad situation about 4 years ago, but no one hurts him now.”
- “When I was little, Mrs. [name removed] drowned me, shoved a pipe down my throat and she threw me against the wall. I was one years old. Nobody hits me now.”
- “I'd call the police on them!”
- Staff and conservator check [individual] often for bruises, but conservator says there is no evidence of them. However, before [individual] was ten, she was abused. I don't think she's gotten over that.
- “They'd better not - I'd whip 'em back!”
- 
- We won't let that happen - not here, it won't. It's never going to happen.
- “One of my housemates came up behind me this morning and kind of choked me, but I told staff and he was written up.”

### *Negative:*

- “Was knocked around as a teenager, no one hurts me now.”
- “Staff hit me with a shoe. I filed a complaint, but have not heard what happened to it.”
- There are bruises on her right arm where she was talking about.
- “I might hit back.”
- Would be upset.
- “My mom would be mad.”
- “Nobody but my brother, but he died. He couldn't keep his hands off me, that was the reason I had to move.”

## B. Respect and Dignity for Main waiver (continued)

- [Individual] claims his companion has hit him. The staff member we interviewed did not dispute there was not a problem. She said his behaviors were worse when she was around the companion than around her.
- [Individual's] father did not like the above question and said emphatically he would not answer it on [individual's] behalf.
- "In the past housemate did."

## Do you know how to report a complaint?

### *Positive:*

- "Tell staff."
- She complained to her house manager and the staff is no longer in her home. Participant did not know if the staff was fired or not.
- Mother has numbers.
- "ISC says always tell."
- Didn't understand to start with. We ask a question in a different way then he understand.
- Family knows. Dad came in while we were there.
- "911!"
- Would tell her mother.
- (Staff) "[Individual] is non-verbal but movements and gestures complaints through eye movement."
- (Staff) "She will gesture if she has something to complain about."
- "Staff makes me upset. They will not let me do anything on my own."
- (Staff) "He doesn't understand, but his behavior would let us know that something had happened. We'd know to investigate and we know his rights and his brother knows. His brother isn't in the same city, but he's very much involved."
- (Staff) "He will let you know if you hurt him, but he won't remember the next day if he got hurt the day before. He doesn't understand "right to change," but his conservator knows what to do. We sure know and nobody hurts [him]!"

## B. Respect and Dignity for Main waiver (continued)

- (Staff) “He's usually happy all the time, so if he's not, we'll know. He also uses his mercury board and he can let us know if something is wrong on that. And his mother checks on him regularly and he'd let her know if something was wrong. She knows all [his] rights!”
- (Staff) “[She] complains by covering her face, crying, and, on rare occasions, throws herself onto the floor.”
- (Staff) “She'll act out if she doesn't like someone, and she won't come close if she doesn't like you. Her mother knows exactly what to do.”
- “Would call law enforcement or [agency director].”
- “Oh yeah! The state has definitely heard from us!”
- “I'd talk to my staff, but I have the number to call if I had a problem.”
- (Staff) “I doubt he does but I do. We have the numbers and I've been trained. But as far as he goes, he doesn't really talk and he's very much to himself, so we just watch him carefully and you have to know his facial and hand gestures, his body language.”
- “I'd call the Department of Services for Abuse - I have the number at my house. I can call 911, but I've never had to call it. I'd talk to staff.”
- Staff knows how to report.
- [Individual] is non-verbal. His family and staff know how.

### *Negative:*

- She doesn't understand question. [She] stated that she had complained to central office and nothing had been done.
- Staff does not think she would be able to communicate to anyone that she was hit or yelled at.
- She didn't share any concerns with anyone outside of the PTP interview. [Staff member] said the staff asked her how her weekend was, and she responded "just fine", but then only later shared with me what really happened--that 'they' (the people around her over the weekend) were mean to her. I explained to her who to tell and call.
- “But when we did, it got us in trouble, so we are going to keep our mouths shut.”
- Parents were very puzzled when told they were told it was their right to file a complaint.

## C. Access to care for Main waiver

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

#### *Positive:*

- House manager and [transportation service] provide transportation.
- Companion transports.
- Staff takes
- Family or staff takes.
- "The dentist office in Dickson is not handicap accessible so I have to go to Nashville."
- Sister and PA transport.
- "I go to [restaurant], to my dad's, and to the mall."
- "Yes, but I'm either too early or not on time."
- "I've got my driver's license, but I don't have a car. My PA people and [agency] staff take me places I need to go.
- Parents do. "There's no trouble transporting [him], but once he gets somewhere, he has a hard time entering the building. He will not enter a church. To see the doctor, he/she must come out to the car but not all of them will do that. [He] has had dental work done in the car with anesthesia."

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

#### *Medical*

- A manual wheelchair.
- Bathroom needs some kind of lift to help him get in and out of the tub.
- Bathroom set up so she can be safe. A smaller wheelchair.
- She could use a closet shower.
- Need a better wheelchair and bath chair but nothing happens when I ask staff about this matter.
- New bed, his bed hurts his back he sleeps in recliner a lot because of it.
- Special mattress that can be wiped down with a cloth.
- Needs PT and OT; not available in the area.
- New wheelchair.

### *Technology*

- The family has been waiting on a communications device for almost six years.
- We're waiting on a voice-output device to help with initiation.
- Communication device.
- A box for communicating.
- Says he would really like a [portable stereo] to listen to music and he would like to learn to use a computer.

### *Access*

- Shower chair and handrail
- Really need a lift for van.
- Lift system, ramps, modified van.
- Portable ramp.
- Needs railing for front porch and ramp for back door.
- "New van with wheelchair access, or old one fixed. Getting to old to lift her."
- Needs a car.
- Bars in bathroom.

Nearly 6.6% of the 1235 people interviewed who receive services through the main waiver in 2009 answered yes to needing special equipment that would make their life easier. The PTP interview does not place equipment in specific categories but the 81 equipment requests were as follows; 16 were for wheelchairs, 13 were for ramps, 11 were for modifications/accommodations to their shower or bath including shower benches or hand rails, 11 were for bath or van lifts, 8 for communication devices, 6 were for equipment including walkers and a helmet, 6 were for exercise equipment, 4 for home repairs or maintenance, 2 for a van or a car, 2 were for a new bed, 1 request for a new hearing aid and 1 for services like PT and OT which are unavailable in the area.

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

#### *Positive:*

- They do what she wants done.
- "If I didn't understand something it was explained to me."
- "I'm happy with my life."

### C. Access to care for Main waiver (continued)

- “I can do what I like to do.”
- Circle of Support meeting made sure what he wanted was included.
- “Yes, I’m happy.”
- Speech class, computer and exercise.
- “I like alarm clocks. [Staff] is going to get me some batteries.” (Spoke with staff and they said his outcomes in the day program were music therapy and going out in the community - both of which were included in his service plan.)
- Privacy was a big issue, and he gets all the privacy he desires.
- “I like to walk every morning, 10 laps, and work inside the workshop.”
- (Staff) “Community based things, like going out, personal shopping and such, are all part of his outcomes. Sending his brother cards is one of his outcomes, too.”
- (Staff) “He can make purchases out in the community with his credit card, and he spends time out in the community socializing as he chooses- and these are part of his ISP. He feeds his fish and plans an outing once a week.”
- She goes to the beauty shop twice a month, visits stores at least once a month and she'll go out to eat twice a month and to the movies once a month. These things she really enjoys and they're in her service plan.
- (Staff) “Watching [T.V. show], bowling, and movies are all part of his outcomes and part of his service plan. The most important things to him are watching [local television channel] and he definitely gets to do that.”
- (Parent) “She enjoys animals so being able to interact with animals, watching them, is most important to her. Also, she can't stand hamburger, so no hamburgers for her!”
- Case manager sees to it that [individual] receives needed services. Family not involved.
- ISC works closely with [him] and makes sure he is receiving what he needs.
- Mother sees to it that [he] receives all services he needs.
- Mother is satisfied.
- Mother is very happy and satisfied with the services.

#### *Negative:*

- When communicated with her ISC, she said that she felt like her rights were being invaded.

### C. Access to care for Main waiver (continued)

- [Individual] says sometimes he doesn't get what's important. He is wanting to live at home with is family and to have more things to do. He is high functioning and could easily hold a job.
- “I want to go back to school part-time but staff does not care. I graduated from high school in 1992.”
- [Individual] was asked by staff and PTP interviewers many times the above question. The question was also paraphrased several times, and [individual] could not answer the question. He said he had never had a Circle of Support meeting while the staff said he had.

### 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. There is a disproportionately few number of people receiving services through the main waiver that were interviewed by the PTP in 2009 using the internet (11%) even though nearly three out of four (74.9 %) U.S. households with a phone line have access to the Internet, according to a February 2004 Nielsen/NetRatings survey. 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 89% of those interviewed 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). Nearly 60% of people interviewed 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.

## D. Community Inclusion for Main waiver (continued)

### Do you have a boyfriend / girlfriend?

#### *Positive:*

- Have friends.
- “Might get married one day.”
- One of her housemates.
- “We go out on dates.”
- She works in the shop with him.
- Has ring from him.
- “Mary has been his girlfriend for 20 years”
- Girlfriend from the workshop, they talk on the phone a lot.
- Very outgoing & sociable, has many friends, has had a special girlfriend the last 2 weeks, which is about the length of time he keeps a girlfriend.
- At this question, she started to laugh and laugh and got very excited.
- “I pretty much see him when I want to.”
- “I see her every day just about! Me and her been dating for a long time.”
- He pointed to his [staff member] and he immediately gave her a hug.
- “I’m going to marry [him]. He’s my best friend. We’re talking about getting married. He wants me to be his fiancée and everything else. He’s blind, but we’d be a lovely couple, if you want to know the truth about it.”
- He is married.
- “He works at the ambulance service, and he’s cute, my lover boy.”
- “I see her two times a week and in the summer.”
- “I did have [her], but she dumped me - just like a hot potato. I wanted to marry her, but she wanted to go her own way. I got a new one now, but if [she] decides to come back to me she’s more than welcome to. I’d just like to get married.”

#### *Negative:*

- “Not interested.”
- “Too much trouble.”
- Would like a girlfriend.

#### D. Community Inclusion for Main waiver (continued)

- “They just want my money.”
- “Don’t want one either.”
- “I had a girl friend one time that was too old for me. My momma broke us up. I’d like to find me a young, pretty girlfriend one day.”
- “Girls are too expensive. They want your money.”
- (Staff) “[He] presently does not have a girlfriend, but he is a big flirt. He loves ladies.”
- (Staff) “He’ll blow kisses to some of the staff here, but he doesn’t have a girlfriend.”
- “I have ‘ex’s’ - Do I want a boyfriend? Yes, but right now all I have are ‘ex’s.’”
- (Staff) “I think a few girls here claim him, but he doesn’t claim any.”
- “And I don’t want to.” Staff said she was married to the same man for 29 years.

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

##### *Positive:*

- “If I have money.”
- “Usually during holidays.” Family visits her.
- Visits with girlfriend.
- “I like to do things with the family.”
- He can see his mom when he wants to, but he only sees his brother and niece at his mom’s house.
- His natural support comes to see him regularly. That’s written in his plan.
- His family lives in [other state], and if he really wanted to go back, they would make arrangements for him to come.
- His momma will take him whenever he wants.
- He is very close to his brother with whom he visits several times a month.
- If he wants to go, he’ll take his dad by the hand and his dad will take him.
- They are VERY active in his life - he goes home about three times a week, and spends one night a week at home.
- “If I feel like I need to go home, they say pack your bag and I’ll go. They live here just down the street.”

## D. Community Inclusion for Main waiver (continued)

### *Negative:*

- “Don’t always have gas.”
- “If we have a car.”
- Every other weekend.
- “If they come to see me.”
- Staff would like to spend more time with her but isn't allowed to.
- She always has something to do.
- We are trying to set up visits where she can see her boyfriend.
- His brother lives in [other state], but he's very active in [individual's] life and checks in regularly.
- It depends on [individual's] health and church is on Sunday.
- Her mom chooses when she wants to see [her]. [She] would like to see her mom every day - in fact, she'd like to live with her. Many of her behaviors happen because she can't live with her mom.
- It depends on mom's schedule.
- He can see his ISC only a little.
- “I stay busy, my friends and parents stay busy, so it's hard to coordinate schedules.”
- “I can go home for special holidays and I get to go home once a month. Sometimes I'll stay for two weeks, but I can't go all the time because staff can't get me there.”
- “They have to come to me, it's too hard for me to go to them.”

### *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 98% (1212 of 1235) of the interviews collected in 2009.

### *Positive:*

- “If I need to be alone I just go to my room.”
- (Staff) “Yes, but there are monitors in her room in case she falls.”
- Has own apartment within the house that his parents built for him.
- Loves her bathroom time.

#### D. Community Inclusion for Main waiver (continued)

- Stays by himself most of the time except for staff.
- Mother says yes.
- “Have no complaints.”
- However, [individual] has seizures and must be watched.
- “I like to walk around the neighborhood and come back to my house. I like staying busy.”
- “The things that are important to [individual] like health and family are included in her service plan. She has direct care staff. [Individual] is treated with respect and feels safe.”
- (Staff) “[She] will let you know if she does not have enough privacy.”
- (Staff) “If he wants to be alone, he just goes into his room or he'll cover his face.”
- (Staff) “He would say he gets way too much ‘alone time,’ - he does NOT like to be alone!”
- “She has been with [the agency] since the very start. But the best agency in the world does not substitute for good staff. That's why I moved back here from [other state]. I could not stand to worry about how [individual] was doing. I know it sounds like bragging, but her poor behaviors have become minimal in the months I have been here.”
- (Staff) “At his house, he'll just get up and get in bed or he can get up and go in the sensory room here.”
- (Staff) “She'll push you away if she wants to be by herself.”
- (Parent) “It's actually in his ISP that he gets his privacy.”
- “All I got to do is take off walking. If I want to be by myself or I don't want to be by myself, I can do it.”
- Her privacy is extremely important to her - it's written up in her service plan. And she expects her privacy to be respected!

#### *Negative:*

- Has no door on his bedroom. Door will be installed.
- [Individual] is often non verbal and uses movement to respond. PA said her reaction to the question implied a no.
- Wants a lock to bedroom door.
- “My momma comes and checks on me and I don't want her in my room.”
- “I do not like having third shift present. They invade my privacy.”

#### D. Community Inclusion for Main waiver (continued)

- His medical condition requires him to have CONSTANT supervision. His seizures are so bad, he can't be alone, so he doesn't really get privacy, but also doesn't even understand the concept of privacy.
- “I do not get enough privacy. I would like to be able to see my friends or go to clubs with staff around me all the time.”
- “To tell the truth, no, I'm not satisfied. I can't just go in stores and stay by myself or in my room. I have a BA I'm working with right now and we're working through everything. Hopefully, pretty soon I won't need her services, and she thinks so, too.” When questioned whether she felt that this lack of privacy was a good thing for her, individual replied, “Yeah, probably so.”

#### 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 have not been separated by geographic region and are both positive and negative:

##### *Positive:*

- “I can't think of anything. I'm happy with my life right now.”
- Likes to go to animal shelter.
- Likes fishing and swimming likes to feel wind in his face.
- “I like to help my mom wash dishes by hand.”
- “I would like to go to metro parks to swim and do other exercises. I am happy here. The staff is very nice. It is much better than the last place. The staff is like family to me. They look after my health real well.”
- [Individual] loves going to the workshop—unhappy if he has to miss a day.

##### *Negative (by category):*

###### *Choice*

- “I want to have more baths in our house.”
- “I think the state hates me. I keep changing apartments. I want to change my apartment.”

#### D. Community Inclusion for Main waiver (continued)

- She said it was in her goals to dust her room, but the staff would do it for her. She wants to do it herself. She was upset about the foods they fixed her for supper; she said they fixed pizza all the time. She was very upset that when it was snack time at her house, she was left in her bedroom while her roommates ate. There have been times when she had a problem and wanted to talk to her house manager, but they would not let her. [Interviewer] asked her if she wanted me to get her ISC worker on the phone and talk to him about these issues. She stated that she did. She tried to talk to him over the phone but she was upset. He told her he would come by today and discuss these issues with her and help her with them.

#### *Economics*

- [Agency] had questions about the pay there. Said staff did not get paid to take her to the doctors.
- “Yes, I’d like to make some money. So I can buy me a radio. I miss my radio. My radio tore up.”
- “Staff cutbacks concern me.”
- [Individual] goes to food banks for food. Staff was concerned that the mother was not spending his money appropriately.
- "I'm concerned about the budget cuts. I think [my son's] future is pretty secure, but, with the cuts, I can't be sure. [My son] is a pioneer. He is the first person with an intellectual and developmental disability to graduate from this county's high school.

#### *Employment*

- (Father) "I have felt humiliated by the agencies I have dealt with. I could go on and on about that but I won't. [My son] had encephalitis when he was four. It damaged [his] impulse control. So he is not able to think of the consequences his actions have. He was at the Harold Jordan Center for one year because he got into trouble. [My son] has a behavioral analyst and a psychiatrist at [local university hospital]. [He] really needs to get a job. We have gone through Voc. Rehab. but they have not helped any. [He] will always need somebody to look after him.”

## D. Community Inclusion for Main waiver (continued)

### *Medical*

- “Yes, I’m really concerned with [her]. She comes in some times in dirty clothes and her hair not comb. She always acts hungry. She eats good here. I don’t think she is getting enough food at home because she should weigh more than sixty nine pounds. I’ve reported it but there hasn’t been a thing done about it.”

### *Services*

- She was not happy with a certain staff member, because she would yell at her.
- Very frustrated with DIDS for not helping get the communication device.
- Mother says she wants PT for daughter.
- Mom feels [agency] seldom returns her calls.
- “We were turned in for delayed services because some of the staff they sent stole from us, sat on the couch and watch TV, talked on their cell phones. We had 84 hour of service, but got cut back to 40 hours. This makes it difficult due to our health (both parents). This week [individual] had a seizure, which caused her to bite her tongue, mom fell and cut her leg and it took 12 EMS people to get mom up off the floor and deal with [individual’s] injuries.”
- (Mother) “We (parents) would not have [individual] live anywhere else but home, but we are concerned about what will happen to him while we are gone. DIDS does not follow protocols and does not do anything to make day agencies safe for consumers. They do not do anything in these day centers. If we put [him] in a group home, we are afraid he would be treated horribly by staff. If we put him in a day program, he would be just sitting in a corner doing nothing. In the past, DIDS officials blamed us for staff getting kicked out of our home even though they did not do anything. DIDS needs a better monitoring system. The state does [not] do enough to help consumers in society.”
- “My biggest concern is there is no day program for [individual]. She went to [agency] for 27 years but it closed.”
- Mom feels threatened that if she does any complaining that her 40-year-old son could be removed from home.
- (Father) “Her OT dropped her; I didn’t understand why.”

#### D. Community Inclusion for Main waiver (continued)

- Mom is afraid with the new service plan in May of this year that her PA hours will be cut and she needs a PA 24 hours because she can't work unless she has a PA that many hours. She and [individual] live alone. [Individual] has seizures.

##### *Transportation*

- “We just really need to get van fixed or help to get a new one. [It is] getting to old to pick her up.”

##### *Other*

- “Yes my mom is sad sometimes. We miss Dad—he passed away and we miss him so bad. I try real hard to help mom.”
- Wants to feel safe. Roommate gets aggressive and mean.

## A. Choice and Control for Self-Determination

### Do you like where you live?

#### *Positive:*

- It's nice
- I live 2 weeks with Netta and Jimmy, sometimes I live with Willard and Jeanette - they're my guardians - for 2 weeks and I live with Stella and Moe. (Staff explained that individual alternates between his 3 sisters, spending 2 weeks with each, which he seems to really enjoy.)
- It's not too far. (She likes living close to her day program.)
- Heck, yeah, I do. Shoot, yeah - that's my favorite.
- Mother says she's well adjusted in her environment

#### *Negative:*

- "Area is not safe"

### Did you choose the place you live?

#### *Positive:*

- Lives with family
- He's always lived with his mom and dad.
- My sisters helped me with where I live.
- His mom and dad picked the house he lives in, but he wanted to live there.
- Use to live with dad.
- I was living in 2 group homes at the time and that was enough to drive me nuts. I wanted to live with my family. They asked me when I was going to come home. (Staff said she and her sister have the same mom, different dads, and when their mom passed away, the sister stepped in and had her move in.)
- My sister, Robin, helped me. I live with my sister.
- Mother says she kissed the wall
- Somebody helped me, Patty. (One of her caregivers.)

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

### *Negative:*

- Mom choose.
- Agency choose.
- Mother and Dad did.

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

### *Positive:*

- If there is some one I can't get along with, I let ISC know.
- Sister helps with him.
- He has a P,A. that he helps interview
- I like my group leader. I only got my family at home.
- Staff said he doesn't have any support staff at his house, but at the Center he picks who he likes.
- Me and my sister went out looking and we found her. She likes me anyway.
- “[My staff] always told me that.”
- Mother is aware.
- He uses facial expressions to let you know when he's not happy, and his family knows.
- “I'm happy with her. I don't want to change her.”
- "I like them here." We understand her rights and we're very involved with the program here.
- “I didn't know that, but I do now! I do have the right to change!”

### *Negative*

- Staff said they're assigned to staff here, but if she has any problems with any staff, she can certainly change them.
- Most people were working at [the service provider] when he came there.
- Mom says no.

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

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

#### *Positive:*

- Always.
- Mom takes care of that.
- I call her.
- They get to us with in two days.
- They get back with in three days.
- She doesn't check on a monthly basis or anything, but if we need her, she does respond.
- Sister said Support Broker was wonderful, they couldn't ask for anyone better. They are absolutely thrilled with her.

#### *Negative:*

- Mother says she can't depend on them to call back or even show up at scheduled times.

### Would you like to work somewhere else?

#### *Positive:*

- “Would like to in day care.”
- “Would like to work at Wal-Mart as a greeter.”
- “I’d like to work as a janitor.”
- “Would like to work in the food pantry again.”
- ““I use to be at [agency name removed], They didn't have much to do. I like being busy.”
- “Make boxes.”
- “I like to cut grass.”
- “Drive truck.”
- I’d like to work at Wal-Mart.”
- If I volunteered, it would be at Salvation Army.”
- “Work at the school.”
- “Work in recycling.”
- “I’d like to work for Meals on Wheels.”

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

### *Negative:*

- Would like to try something else but is worried about his hand coordination problems.
- She's in with the VR program and they've done 3 assessments with her and they're currently taking her on job applications. She's looking for something janitorial, but there are transportation problems, so she's going to have to work during the day. Her family live way out in Hickman County and combined with funding problems, they're not able to get her out in the evening for that kind of job.
- "I'd like to be a policeman, but they won't let me. I help my sister fold towels."

## B. Respect and Dignity for Self-Determination

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

#### *Positive:*

- They are very nice.
- The mother said "when they're here they treat her fine."
- "Everyone here is very nice."
- "They are great."
- Parents say yes.
- Staff at work is a big help.
- "Very good."
- She doesn't really have any direct support staff – [the service provider] is a privately owned company and doesn't have "staff" per se. But the people and volunteers here are wonderful!

#### *Negative:*

- Wish she had support staff at home.

### Does anyone ever hit or hurt you?

#### *Positive:*

- "Would tell."

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

- “I get along well with others.”

### *Negative:*

- He would fight back.
- Said emotional hurt.

## Do you know how to report a complaint?

### *Positive:*

- Kim always told us what to do about that.
- Sisters knows how to.
- “His family would report if [he] was hurt, and his facial expressions would let us know if something was wrong. And I know what to do! I watch out for [him,] he's a sweetheart!”
- Call 911. I'd call the police. I'd talk to my family. (Staff also explained that his sisters, who are extremely active in his care, are well aware of all his rights.)
- “I filed a complaint many years ago.”
- She'd tell her sister or she'd come tell us. It's explained in the body of her ISP and I know [she] knows what to do. She's always with family and they've been explained all their rights.
- If there was a fire, I'd probably get out of the house or something. I'd tell my teachers or somebody if something bad happened. (Her sister knows her rights fully.)
- Mom knows.

### *Negative:*

## C. Access to care for Self-Determination

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

- “Staff takes me.”
- “Dad takes me.”
- “Family don't allow us to do her medical, so family take her where she needs to go. We take her on community outings.”

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

- [The agency] takes me. My sister takes me to the doctor's.
- Allen drives his moped to places he wants to go

### What special equipment would make your life easier?

- Communication device, home modifications.
- [Eye] glasses.
- Could use help paying for diapers.
- A Dynavox communication board.
- A lift and a better ramp getting into the house.
- New wheelchair.
- Would like to expand his room and get mold problem under control. We need insulation installed in house.
- Walker, because he stumbles a lot and falls.

Nearly 5.6% of the people receiving services through the Self-Determination waiver that were interviewed in 2009 answered yes to needing special equipment that would make their life easier. The PTP interview does not place equipment in specific categories. Of the 179 Self-Determination waiver participants interviewed, there were ten requests. Three were for accessibility accommodations/maintenance to their homes including; ramps and insulation, two for wheelchairs, two for communication devices, one new eye glasses, and a personal vehicle. A new laptop computer was also requested once.

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

#### *Positive:*

- I'm happy with my services.
- Dad made sure.
- Yes most of it.
- He likes to go bowling, to the Special Olympics and Wal-Mart - Wal-Mart is nonnegotiable - They're all listed in his service plan.
- Mom always helps with that.

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

- [Father] is very satisfied and happy with the services received.
- When asked this question, individual said, "I don't know." When we asked what kinds of things were important to him, he said, "My tapes are important to me, especially my Elvis tapes." Staff said getting out in the community, going bowling and movies, all of which are very important to him, are all outcomes listed in his ISP.
- Socializing, trips to the store and mall, doing stickers and workbooks are all things she likes to do and they're part of her service plan.
- Getting out into the community and doing volunteer work at the nursing homes and animal shelter - these are all in his service plan.
- She wants to be up at a specific time and have a specific breakfast, very specific foods. She's had spaghetti for lunch for the last 7 years - and she's got to have her coke. And she has to watch TVland, AMC, and Dancing With the Stars. These are all written in her service plan.
- Staff said, "She loves to go out in the community, bowling, and the library - loves going to the library. Her favorite job here is ceramics, but she's also very proud of her work in the kitchen. These are all included in her plan for her day program. At home, I know she has to spend some time working with her doodle board."
- I love to go bowling, visiting with my mom - she's important to me! And my sister and brother is important to me! The nursing home, my job is important to me. That's in there.

#### *Negative:*

- [The individual] has not had a PA since December 2008. [The agency that was] sending a PA, said they couldn't help her anymore. [The case manager] visited January 31 said they were trying to find someone but no one seemed to want the job. [The case manager] said they might get a PA at [DIDS, and] is trying everything she knows to get help, but nothing has happened yet. The program participant lives at home with her mother [name and phone number removed]. She is DESPERATE for help.

## D. Community Inclusion for Self-Determination

Several people interviewed by the PTP are working directly in their communities at Wal-Marts, Pizza Huts, Sonics, Mobile Meal programs, and other service sector jobs. There is a disproportionately few number of people with a disability interviewed by the PTP in 2009 using the internet (13%) even though nearly three out of four (74.9 %) U.S. households with a phone line have access to the Internet, according to a February 2004 Nielsen/NetRatings survey. 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 87% of those interviewed 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:*

- A boyfriend sometimes but her mom told her long ago before she died that she couldn't have a boyfriend, so she still remembers
- "I'm married."
- [To interviewer] "You're my boyfriend! You want to go on a date?"
- Has been with boyfriend for five years.

#### *Negative:*

- No. Too Much trouble
- [He] has many friends, but a special friend [name removed] died recently.
- No. Divorced.

## D. Community Inclusion for Self-Determination (continued)

- “No! Don't want one neither.”

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

#### *Positive:*

- [She] loves to see her aunt who does not live nearby.
- Mom takes her.
- I always go when Dad goes.
- He sees his friends here every day, but he can only see his friends in Chattanooga when his folks go.
- He likes getting in the car with mom and riding.

#### *Negative:*

- If I have gas money.

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

This question was answered positively in 98% (174 of 179) of the interviews collected with Self-Determination waiver participants.

#### *Positive:*

- “I always go to my room.”
- Usually, he's not wanting to sit by himself, he likes to be with others. He has the choice, but he usually chooses to be with us.
- She never wants to be alone. She wants to have people around her all the time. If she needed privacy, we have a room here where she can go and lay and have some privacy. And she has her own room at home.
- I want my sister to be there. (Staff tried to explain this question, but individual clearly didn't like the idea of being "alone.")
- Mother says yes.

#### *Negative:*

- Mother is unsatisfied with PA services through [service provider].
- “Too much traffic [at my home].”

## 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:*

- [The mother] said she paid [the service provider] a \$50 deposit for [her daughter] to go to camp. They said she couldn't go & did not return her money. The interviewers asked that [the mother] call [the service provider] and speak to the director regarding this concern. [The mother] will call The Arc of Tennessee if nothing is resolved.
- Sister says [she] loves to work, [and] doesn't understand or care about the money. [She] is very outgoing and just wants to be with people. Sister doesn't know what she would do if she became unable to work.
- "Yes I like coming here. I will keep coming here. I like my job too."
- "I just want to keep my PA and keep going into the community."
- "I am planning on getting married [this summer]. I would like to be a cross-country truck driver."

#### *Negative (by category):*

##### *Choice*

- "The area is not safe to live in. Needs help finding a safer place to live. Away from drug dealers and gun shots. Next door people shoot at cars and the cars shoot back!"
- Expressed desire to live on his own away from dad's place. Presently lives in a camper behind dad's house.

##### *Medical*

- Yes [comment from mother]. The transition program that [she] attends is way out of control. [She] broke her foot [and the service provider] didn't have her medicine list in the community with her. They called me at home to come to the hospital to tell them the [medications she] was on. That is real frightening. What if I hadn't been home?

## D. Community Inclusion for Self-Determination (continued)

### *Services*

- Sister [name removed] has asked that [she] be changed to [different service provider.] It's closer to home. [The sister] hasn't heard anything yet.
- [Mother] has asked for a behavioral assistant. [She] hasn't heard back yet.
- [Father] doesn't like [service provider], too many people coming to there house...wants to change agencies, says he is going to start checking on getting another agency
- [Mother] is very unhappy [with the service provider.] She has no idea when they will come and can't depend on them. [Her daughter] can't do anything for herself [and the mother] can't depend on the PA to be there when she's supposed to be there; when [her daughter] gets off the bus from school to help get her in the house etc. Therefore [the mother] can't work which she needs and wants to do. She is unhappy with the services of [the service provider.]

## A. Choice and Control for Arlington waiver

Do you like where you live?

*Positive:*

- Father built home.
- Lives with mother.
- Likes both roommates.

Did you choose the place you live?

*Positive:*

- “Momma” (He and his mother choose it.)
- Lives with mom.

*Negative:*

- No, lives with family.
- No, mom chose.

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

*Positive:*

- His mom would know better than anybody if something was wrong, but he'd let you know if he wasn't happy.
- “With assistance.”
- Mother knows.

*Negative:*

Can you talk to your ISC when you need to?

*Positive:*

- Mom Knows what to do.
- “We have in the past.”
- “I don't need to.”
- I'm sure his parents know that. They're informed of everything.

## A. Choice and Control for Arlington waiver (continued)

- “Mom said if she don't do good job then we get another one.”
- “If we didn't like someone, we know we can change them.”
- Staff said this right had been very clearly explained to client at their meetings. Her sister knows they can change their Case Manager.
- His momma knows, but I don't think he really knows that.

### *Negative:*

- [Mother] is very unhappy with [service provider] because the PA seldom shows when scheduled [and the service provider] says they can't send anyone else when this person is a no show.

## Would you like to work somewhere else?

- “I'd like to work at Popeye's.”
- “Newspaper stand.”
- “Any job!”
- “I'd like to work as a janitor.”
- “I'd like to work at a bank.”
- “I'd like to work at Wal-Mart.”

## B. Respect and Dignity for Arlington waiver

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

- “Recently the house manager changed.”

### Does anyone ever hit or hurt you?

PTP interviewers did not interview any Arlington waiver participants that responded in any way but negatively (“No”) to this question.

### Do you know how to report a complaint?

- Mother [name removed] is very assertive and gets things changed when needed.

## C. Access to care for Arlington waiver

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

There were no comments to this question with all 91 people interviewed responding affirmatively (“Yes”).

### What special equipment would make your life easier?

- Bath tub rails.
- “Hand rail for the shower.”
- Portable ramp.
- “A full-size bed.”
- “Positioning equipment.”

Nearly 6% of the people receiving services through the Arlington waiver that were interviewed in 2009 answered yes to needing special equipment that would make their life easier. The PTP interview does not place equipment in specific categories. Of the 91 Arlington waiver participants interviewed, there were five requests. One for a new bed and the rest for accessibility accommodations or modifications to their homes including; rails in bath rooms and a ramp

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

#### *Positive:*

- Would like to learn to cook.
- Brothers and parents are much happier with [new service provider].
- Working and making some money are important to [him] and both of those are in his service plan.
- [He] is very happy with all the services.

## 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 very few people receiving services through the Arlington waiver that reported using the internet in 2009 (6%). 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.

### Do you have a boyfriend / girlfriend?

#### *Positive:*

- Girlfriends in the home where she lives.

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

#### *Positive:*

- He lives with his mother with whom he has a very close relationship, but his brother and sister live out of state. He sees them about once a year.

### 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:*

- He is a wonderful person who loves to talk and play pranks.
- She's 30 years old, loves her family
- Never meets a stranger, is happy go lucky.
- Very happy with services
- Mrs. [name removed] cooks every Thursday for [her and] her roommate. They go to Mrs. [name removed]'s home. [Name removed] did have two roommates. Agency is trying to get another roommate.

#### D. Community Inclusion for Arlington waiver (continued)

- No, I am very happy with services, says Mrs. [name removed].
- Smiles all the time and seems happy.
- His sister is very happy with services.
- The brother and guardian says he is on a first name basis with [the DIDS Deputy Commissioner] and they have everything they need. [The brother] visits [his sister] twice a week.
- [He] can only respond with a smile or frown. He has to wear extra clothes because of his body temperature.
- [He] moved from Arlington two years ago, seems much happier at new location says his conservator.
- [Mother] says she is very happy with services, especially the physical therapy they have started to give [her daughter].

#### *Negative:*

- [She] has only 1 living relative, a sister in Colorado. No one visits her.

## A. Choice and Control for Developmental Centers

### Do you like where you live?

#### *Positive:*

- “Enjoy it.”
- “It’s Alright!”

#### *Negative:*

- “It’s okay.”
- Wants to buy a house after leaving [Center].
- "Can't leave campus, took a 'judge test' and thought I did pretty well."

### Did you choose the place you live?

#### *Positive:*

- Family chose.
- Mother chose.

#### *Negative:*

- “Would like to be with my family back in Memphis.”
- Court ordered.
- Unsure who chose.

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

Thirty five of the eighty four (42%) 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. Thirty eight of the interviews (45%) were unable to record a response to this question because the person interviewed is not able to communicate a response.

#### *Positive:*

- "There would be a meeting with [name removed] and staff if he were to change his support staff."

## A. Choice and Control for Developmental Centers (continued)

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

Only two interview respondents replied no to this question and without comment. Nearly half of the interviewees responded that they could talk with their Case Manager when they needed to.

### Would you like to work somewhere else?

#### *Positive:*

- Would be a good greeter at a store.
- Would like to play music somewhere.
- Take out trash.
- "Angela would make a good secretary." (Staff Comment)
- Stock work in grocery store.
- Factory.
- Fast food or hospital.

#### *Negative:*

- Wants to bag groceries. Was formerly a worker at K-Mart in Memphis.
- "Likes to be on the GO, would probably like to work."
- "I would like to work at Wal-Mart stocking on the third shift because there would be nobody there to bother me. I stay up all night, anyway. I find it easier to concentrate on third shift."
- Would like to help father with supply store.
- Would like to work with father in landscaping.

## B. Respect and Dignity for Developmental Centers

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

#### *Positive:*

Of the eighty four interviews, there were forty five positive responses (54%) to this question without comment.

## B. Respect and Dignity for Developmental Centers (continued)

### *Negative:*

- Staff hollers and screams at me
- [He] claims he has been written up too many times by staff. In a specific incident, he said an individual hit him, and, although [he] said he did not retaliate, he was written up and not the alleged perpetrator.

### Does anyone ever hit or hurt you?

This question only got one positive response among the eighty four interviews with people residing in one of Tennessee's Developmental Centers. Thirty two of the eighty four interviews (38%) did not get a response because the person being interviewed was unable or unwilling to communicate a response.

### Do you know how to report a complaint?

This question elicited forty eight positive responses from the eighty four interviews (57%). Comments are noted below.

### *Positive:*

- He would let you know if something is wrong. (Staff comment)
- Cries when upset.
- "I would report a complaint to my supervisor, the supervisor would report it to the nurse, the nurse would report the complaint to the building manager, the building manager would report it to the investigator." (Staff comment)
- "Robert is blind but hears well. To report a complaint, he would move his hand or when he gets mad he hits his head." (Staff comment)
- Would tell staff.
- "She would react to a staff she did not like or feared." (Staff comment)
- Call investigator.

## B. Respect and Dignity for Developmental Centers (continued)

### *Negative:*

- He would defend himself and act out, but is unable to tell staff if someone was abusing him.” (Staff comment)
- No family involved.

## C. Access to care for Developmental Centers

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

#### *Positive:*

- Most positive responses to this question were explained by staff as being their duty.

#### *Negative:*

- She does not like leaving [the Center]. According to staff, cries when she leaves the grounds.

### What special equipment would make your life easier?

- The arm rest on his chair needs readjustment.
- Communication device.
- Electric wheelchair.
- Her left shoe [to be] replaced per staff.
- Own wheelchair.
- Reclining chair.

Just over 8% of people receiving services at one of Tennessee’s Developmental Centers that were interviewed in 2009 answered yes to needing special equipment that would make their life easier. The PTP interview does not place equipment in specific categories. Of the eighty four residents interviewed, there were seven requests (8.3%). Four were for chairs (wheel, reclining or electric), one communication device, one request for new shoes, and an equipment adjustment was requested once.

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

#### *Positive:*

- Brother is involved.

### C. Access to care for Developmental Centers (continued)

- “[She] must watch T.V. It’s non-negotiable.”
- Dad and brother involved in his life.
- His family is involved in his ISP.
- “Leave here if I stay out of trouble!”
- Sister involved.
- Family involved.
- Parents involved.
- "I go to meetings with my social worker."

#### *Negative:*

- She is non-communicative and has no family involved in her life.
- Family is not involved and she is not able to communicate and express her wishes and thoughts.
- Family not involved. Grandmother lives in Chattanooga.
- No family involved.
- Was unable to respond to question.
- [He/she] is nonverbal.

### D. Community Inclusion for Developmental Centers

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:*

- [He] thinks every woman is his girlfriend!
- [He] showed a picture of a young lady [name removed]. She lives in Knoxville.
- Friends with guy in the home.
- Several friends.
- A few.
- Many friends.

## D. Community Inclusion for Developmental Centers (continued)

### *Negative:*

- Wants a girlfriend when [he] leaves [the Center].
- His room mates are his friends.
- Would like to have a boyfriend.
- “We are not allowed to have girlfriends.”

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

#### *Positive:*

- About every two weeks.
- Sister visits.
- Christmas and Easter.
- Family visits.

#### *Negative:*

- Sees parents three or four times monthly.
- [Her] father is elderly and has health problems and can't come see her as much as he used to.
- Need passes to visit; lived with grandparents when he was younger

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

This question was answered positively in forty eight of the interviews collected at Tennessee's Developmental Centers.

#### *Positive:*

- Staff stated that she is mobile and will go look out of the window.
- Respondent is mobile and can go when this person wants to.

#### *Negative:*

- “I won't answer that question!”
- [He] is nonverbal.
- She is unable to respond.
- She left the interview before the question could be asked.

## 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 or family members or staff 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:*

- “No, I am very happy with services” says parent.
- "Randy is a nice guy, a hard worker. Likes to eat."
- "Play games, play card games."
- “[He] is a very nice, easy-going person.” (Staff comment)
- "John loves to eat out." (Staff comment)
- "Nancy is doing well. She likes her own space. She does not want to be in a rush. She loves people, likes to shop and go out to eat." (Staff comment)
- "Janice is a great person. She is very quiet." (Staff comment)
- "[She] must be able to go out into the community and sleep by herself.” (Staff comment)
- He is nonverbal. His brother is involved in his life.
- Staff said it would be great if she had a recliner for her work place. Staff stated that the team leader was working on getting her one.
- He will be moving into a group home in July.

#### *Negative:*

- Staff stated that she is supposed to go to a group home soon. She needs 24 hour nursing support. They are concerned that where she goes, they will not have this nursing coverage. [Name removed] is supposed to be checking into this.
- Staff stated that when they closed another [home], they had taken on several more people in their [home]. It would be nice if they had more bedroom space.
- "My dad beat on me when I was small, but that was a long time ago."
- She is nonverbal. Her family is not involved in her life.

## 6. GOALS

In the year 2009, the PTP has been asked to collect 1,200 interviews with people receiving services through the various Waiver programs. At the end of 2009, the PTP has successfully collected and recorded 1589 interviews with individuals in 75 of Tennessee’s 95 counties, an impressive near-80% of the counties in Tennessee. The following counties—and number of interviews conducted—are represented in the 1589 interviews collected by the teams:

Anderson	17	Dickson	26	Lauderdale	2	Roane	17
Bedford	15	Dyer	5	Lawrence	3	Robertson	17
Benton	8	Fayette	11	Lincoln	12	Rutherford	17
Blount	8	Fentress	22	Loudon	18	Scott	6
Bradley	50	Franklin	16	Macon	4	Sevier	11
Campbell	7	Gibson	17	Madison	134	Shelby	180
Cannon	2	Greene	89	Marshall	6	Smith	3
Carroll	6	Grundy	20	Maury	33	Sullivan	12
Carter	3	Hamblen	4	McMinn	6	Sumner	11
Cheatham	2	Hamilton	112	McNairy	39	Tipton	2
Chester	10	Hardeman	51	Meigs	1	Trousdale	2
Clay	2	Hardin	24	Monroe	2	Unicoi	1
Cocke	1	Haywood	21	Montgomery	26	Warren	7
Coffee	17	Henderson	23	Morgan	1	Washington	21
Crockett	7	Henry	6	Obion	4	Weakley	7
Cumberland	38	Hickman	6	Overton	10	White	18
Davidson	146	Jackson	1	Pickett	1	Williamson	28
Decatur	7	Jefferson	4	Putnam	43	Wilson	3
DeKalb	2	Knox	57	Rhea	18	Total:	1589

## 7. RECOMMENDATIONS

Evaluation and monitoring of a program and the system within which it operates is essential to maintaining quality and effectiveness of services provided. Program evaluation seeks to gather information to help improve effectiveness, to assist administrators to make program-level decisions, and to enable interested parties to examine a program (Posavac and Carey, 10). In producing the report for the PTP's interviews in 2009, increasingly representative data and statistics about the population of people receiving services significantly contributes to improving the effectiveness of the services being rendered.

What does this analysis say about Tennessee's delivery system? Based upon the PTP interview data analysis for 2009, 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.*** It is well known that DIDS is attempting to employ more people with their *Employment First!* Initiative. This initiative does not include the word *gainful* in front of employment nor does it mention *choice*. Those people that receive services that mentioned what they would like to do for another job should be able to attempt to find employment in that field, whether it is with the help of *Employment First!*, ISCs, Case Managers, Vocational Rehabilitation or otherwise. People interviewed cited job desires that should be a viable option. DIDS' main concern is with the *quantity* employed and not necessarily with the *quality* and *choice* of employment.

### *Choice*

- ❖ **Teach the *meaning of choice* to providers and to people receiving services.** People interviewed in 2009 may reply they had choice in their selection of employment or living arrangement but further probing reveals that some interviewees do not know the difference. True choice of employment is not "this job or unemployment." True choice of

living situations is not “the bed on the left or the bed on the right.” The DIDS Quality Assurance program states that one of their ten domains for a positive performance factor is “choice and decision making” (*Quality Assurance Frequently Asked Questions*). How can DIDS assure that there is choice in an individual’s life if that person, as 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 would be able to be dispersed to people and their families with increased internet awareness and technology assistance, as well as enhancing community inclusion for people receiving services and their families and loved ones.

#### *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 their families when there is a long time for their calls to be returned, as well as with the length of time for an item/service/information requested to be provided.

- ❖ **Learn how to provide the equipment needed *in a timely manner*.** PTP finds that many people need certain items/devices to help their level of self determination flourish. Some items listed may not be easily funded or found. The person’s ISC/case manager needs to better help obtain needed items. 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 person interviewed needs.

## Program Recommendations

### *Maintain the instrument*

PTP is currently using a significantly modified *Participant Experience Survey*, an instrument 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 Schwartz (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 universally consistent across agencies and the state.

- 1) Individualized—many complaints from family members that DSPs do not have enough personalized training—some DSPs were unable to help the PTP interview teams with obtaining answers because they themselves had communication problems with the individual receiving services.
- 2) Emphasize importance of their jobs—make it more than “just a job” and emphasizing the increasing satisfaction with DIDS services throughout Tennessee over the last seven years.
- 3) Include job coaching training as required course—again in 2009 PTP uncovered issues with people who have DSPs that do not understand the importance of helping the person they support on their job.
- 4) Encourage family members, people serving as conservators, and others that receive DIDS funding to take training courses.
- 5) Connect with local community colleges and give partial credit to courses taken at DIDS and/or intern for credit—perhaps even incentives such as post-secondary education scholarships for DSPs.

## System Recommendations

The interviews completed in 2009 help to uncover and to identify the following recommendations to the DIDS system, including:

### *Use of technology*

- 1) Utilize technology in management—will save time and resources.
- 2) Share with the regional offices of DIDS any new address or contact information that PTP teams collect and record into SurveyMonkey so the current state-wide tracking system remains up to date.

### *Special Equipment*

At least 5% 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.

<b>2009 PTP interviews</b>	<b>1235 Main waiver respondents</b>	<b>179 Self-Determination waiver respondents</b>	<b>91 Arlington waiver respondents</b>	<b>84 Developmental Center respondents</b>
<b>People interviewed answering that they need special equipment to make their lives easier.</b>	6.4%	5.0%	5.5%	7.1%

### *Self Direction*

- 1) Staff and agencies respect and honor individual’s choices.
- 2) Consistently include person centered planning in the creation of the individual’s ISP by making sure an individual—and their support providers—understand their obligations, duties and rights to the ISP.

## 8. UNANTICIPATED OUTCOMES

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

- 1) The original interview project was written to help create flexible positions for those with disabilities, and that outcome was achieved. Those family members that are interviewers are also benefiting from the flexible schedules to allocate time needed with their family members with disabilities.
- 2) Those people that have worked for the PTP for some time have improved their skills greatly and are more equipped to answer questions and/or to give referrals to people needing them. They are refining their interviewing skills and are more efficient with the interview process, allowing for more precise answers and better information for analysis.
- 3) The information that the PTP receives from the state is compiled from the state's CS tracking database and is still may contain outdated and incorrect information. An online, password based, database where agencies can come online and change information more efficiently is still hoped for. The PTP is informing DIDS of changes of this sort on an individual's interview—recorded in SurveyMonkey—and should be used to update DIDS' database.

## 9. FUTURE PLANS

The grant has been approved through DIDS and will continue to provide independent quality assurance measures powered and led by the voices, priorities and choices of people receiving services and their families. The PTP project is reporting its findings on an annual basis matching the calendar year. This report examined PTP interview findings between January 1, 2009 and December 31, 2009. Subsequent PTP reports will reflect a similar calendar year schedule.

The following are some changes put into place:

- ✓ The DIDS requested number of interviews for 2010 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 has been reduced to 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 first 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.

# PTP interview instrument for 2009

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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