



PEOPLE TALKING TO PEOPLE

ANNUAL REPORT

for

January 1- December 31, 2013

Prepared

by

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EXECUTIVE SUMMARY

People with disabilities in the United States of America depend on different supports from society. One of the ways Tennessee and the other states support people is through collaboration with the U.S. federal government—the program called Medicaid. Medicaid is a healthcare program funded by state dollars plus a matching number of federal dollars. In Tennessee, one (\$1) state dollar is matched with approximately two (\$2) federal dollars. For their contribution, the federal government requires that states provide certain quality services through their Medicaid programs.

In addition to providing mandatory health services—like hospital care—a state may also offer additional health benefits such as dentistry, medications, optometry, and/or therapies. Medicaid plans are also required to provide certain long-term supports and services (LTSS) such as nursing homes, but may choose to provide other LTSS through programs called Medicaid Waivers. Many people with disabilities benefit greatly from Medicaid Waiver services, which are often provided in community settings by private organizations or state agencies. The Centers for Medicare and Medicaid Services (CMS) works with Tennessee’s Department of Intellectual and Developmental Disabilities (DIDD) to provide services to people with intellectual disabilities. The federal government also monitors these Medicaid Waiver programs through CMS.

The Arc Tennessee is a statewide non-profit organization on intellectual and

developmental disabilities. Founded in 1952, it is affiliated with The Arc United States and is a membership organization composed of people with intellectual, developmental and other disabilities, as well as their parents, family, friends, and others. The People Talking to People (PTP) project, funded by a grant to The Arc Tennessee, is just one part of what DIDD does to assure peoples’ satisfaction with the supports they receive. Tennessee uses PTP interview findings to show CMS that it administers quality services under the Medicaid Waivers for people with intellectual disabilities.

In 2013, PTP completed its eleventh year as an independent quality-assurance project for DIDD. PTP’s consistent presence across the state ensures that people experience the best possible services, and provides statistical measures for quality improvement, based on confidential PTP interview responses. Interviews are collected all across Tennessee from a random selection of people who receive services. People are supported by more than 470 non-profit and for-profit agencies that provide home and community-based services. PTP’s interview findings can prompt follow-up from DIDD on specific issues.

Beginning in 2002, PTP is an especially important part of the state moving toward a quality-assurance project led by the priorities and choices of people receiving services. Tennessee and the people who receive supports and services here continue to benefit from the presence and function of PTP.

ACKNOWLEDGEMENT

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

This report would not be possible if it were not for the effort of each person in the People Talking to People teams, including:

	Region		Region
Ashley Brookshire, Interviewer	1	Jennie Isaacs, Interviewer	5
Jimmy Gillenwater, Interviewer	1	Josh Turner, Interviewer	5
Rocky Henley, Interviewer	1	Mary Dale Greene, Interviewer	6
Danny Reaves, Interviewer	1	Heather Henderson, Interviewer	6
Jean Smith, Interviewer	2	Brenda Lackey, Interviewer	6
Heather Wilson, Interviewer	2	Doris Price, Interviewer	6
Linda Wilson, Interviewer	2	Tom Griffin, Interviewer	7
Melissa Crouch, Interviewer	3	Sean Flowers, Interviewer	7
Larry Jacobs, Interviewer	3	Jessica Hatley, Interviewer	8
Holly Kirby, Interviewer	4	Patrick Sanders, Interviewer	8
Brandy McCauley, Interviewer	4	Judy Sparks, Interviewer	8
Debra McCauley, Interviewer	4	Suzanne Colsey, Interviewer	9
John Blake, Interviewer	5	Nadine Loveless, Interviewer	9
Cheryl Coleman, Interviewer	5	Sondra Loveless-South, Interviewer	9
Woody Cade, Interviewer	5		

The Arc Tennessee staff, including Valerie Jephson, Project Assistant.

All of those who 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 operates through a grant from the Department of Intellectual and Developmental Disabilities to The Arc Tennessee. PTP has nine teams of part-time interviewers that have successfully completed collecting and reporting interviews for 2013 across Tennessee's three major regions, covering 68 of the state's 95 counties.

PTP interview teams include a family member of a person with a disability and a person with a disability. Each team member is interviewed and trained by the Project Director, and is hired following a successful background check and verification of professional and personal references. Occasionally, training is supplemented with assistance from a local, experienced interviewer. Bi-weekly conference calls with the Project Director encourage teams to share their skills, or to discuss issues that they have encountered.

PTP interviewing teams receive a list of randomly-selected individuals who receive supportive services from DIDD. This is done using an Internet-based random-number generator, guaranteeing an equal probability of selection to be interviewed. Results may be confidently used for statistical inferences by DIDD to demonstrate efficacy of services, compliance with legal rules, and justification for continued matching federal dollars for its waiver services.

PTP's nine teams arrange, conduct, and report interviews with people receiving DIDD

services. The interviewers ask questions about self-determination and personal choice, while always being respectful of each person's right to privacy. PTP policies, procedures, and training mandate the confidentiality of all interviews.

The interview instrument used by PTP is based on the CMS-approved Participant Experience Survey. Over the years, constructive feedback from people interviewed and from the interviewing teams has been used to increase instrument clarity and applicability (see pages 70-73). An enhanced version of the interview questions including corresponding pictures, as well as a large-type version, are also available to PTP teams, enhancing participation of each team member in the interview process.

While continuing to improve the system of DIDD supports for people with disabilities is a primary goal of PTP, especially important is the identification of specific problems or issues that people are having. Whenever PTP interviewers receive unfavorable responses—especially to certain key interview questions—notification of the unsatisfactory response is sent simultaneously to the PTP Project Director, the Director of DIDD's Office of Civil Rights and the Assistant Executive Director of The Arc Tennessee. If a situation or issue requiring investigation is revealed during an interview, interviewers submit by e-mail a Survey Notification Form (SNF) containing an explanation of the specific issue. A Survey Notification Form identifies any negative response to the four

key questions selected as indicators by DIDD in conjunction with CMS prior to 2009. PTP interviewers may also submit an SNF if they identify other problems or needs during the interview. This is the fifth year that PTP is following this procedure, and the results are detailed on page 13.

Additionally, PTP follows DIDD's protocol regarding protection from harm. "Protection from harm is a legal and moral commitment to support, respect and value the dignity and worth of a person" (DIDD Provider Manual Ch. 18). Whenever PTP learns of any allegations of abuse, neglect, or exploitation, that information is immediately shared with DIDD through a phone call to the Investigations hotline.

At each interview opportunity, PTP distributes DIDD pamphlets on 'Protection From Harm' and 'Equal Opportunity is the Law in Tennessee'. Copies of the pamphlets, previous reports, and the PTP Policies and Procedures manual are also available upon request.

PTP offers opportunities for people with disabilities to be employed and to constructively influence the lives of others by bringing attention to specific issues or complaints with DIDD services. PTP interviewers' visibility in the community raises awareness of people with disabilities actively participating in and contributing to their communities through their gainful employment.

During interviews, PTP team members are in their communities doing important work collecting information for Tennessee and they are helping to change others' perceptions of people with disabilities' contributions and value to our community. Interviewers inspire and motivate people they meet who want to help improve the lives of others. Most importantly, interviewers are essential eyes and ears for DIDD, able to bring undesirable or critical situations to immediate attention.

2. METHODOLOGY

Interview results are used to determine overall and category-specific satisfaction with the support services received. The interview responses and the results in this report also reveal the level of self-determination that people have. Results are analyzed separately according to the interviewee's Medicaid waiver program.

1. **Main (or statewide) Waiver** – also called the Home & Community Based Services (HCBS) waiver, provides residential services, day services, personal assistance, health and therapy services, and other services.
2. **Arlington Waiver** – provides the services available through the Main Waiver plus some additional services; available to “at-risk” people and to “class members” of a lawsuit against the now-closed Arlington Developmental Center in Memphis, TN.
3. **Self Determination Waiver** – provides a self-directed component, allowing people to control and select from a set of services with an annual limit of thirty thousand dollars (\$30,000) per person. This waiver program has not included residential services in the past. However, the waiver was recently amended and a semi-independent living component will be available in future years.

In addition to interviews with people who receive services through the Medicaid waivers, PTP interviewed thirty-five (35) people residing in East Tennessee's Greene Valley Developmental Center or in Middle

Tennessee's Clover Bottom Developmental Center. All interview results in this report were completed in 2013 and reflect responses to questions in these four areas:

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

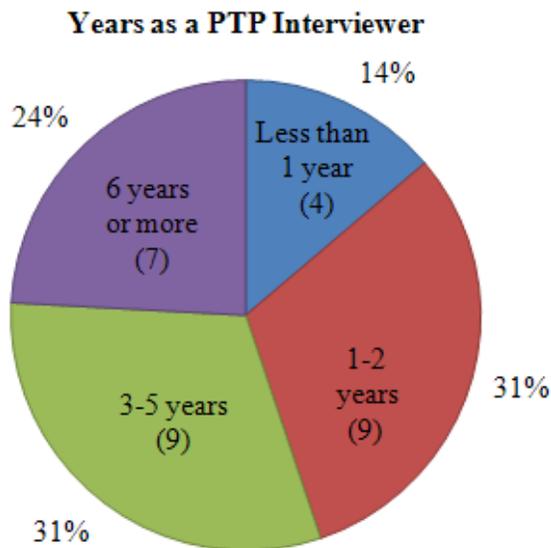
People receiving supports are randomly selected to be interviewed, and may be interviewed only once during a twelve-month period. The list exists as a Microsoft Excel file, filled in with the information provided by DIDD, and each individual is assigned a number through an internet-based random number generator (www.randomizer.org/form.htm).

People selected in 2013 were assigned to each of the nine PTP interviewing teams, corresponding to the nine Developmental Districts in Tennessee (www.tn.gov/tacir/PDF_FILES/Infrastructure/Infra07_dd_map.pdf).

The teams contact the individuals (or their families or other named contacts) to

arrange for private interviews. Each is set up at a time and place convenient for the person being interviewed. Persons being interviewed have the right to decline to answer or skip questions, and also to stop the interview at any time. When an interview is complete, the PTP team enters the responses into SurveyMonkey, a secure internet database (www.surveymonkey.com).

Additionally, the face-to-face interviews conducted by PTP teams provide a meaningful point of contact for individuals served by DIDD. Of the twenty-nine interviewers that have helped carry out the project across the state in 2013, twenty-five have been working for the project for more than a year.



Through years of experience in the project, PTP interviewers develop significant rapport with the individuals they interview and with the workers assisting those individuals. This familiarity creates a

comfortable zone in which the interviewees can feel at ease sharing thoughts and opinions that might otherwise be difficult to share. PTP interviewers take on the status of regularly expected visitors at many of the agencies and workshops at which they meet with individuals, so even those responding to interview questions for the first time are able to feel comfortable.

The PTP Director as well as staff from DIDD, using password-protected access, regularly checks the SurveyMonkey database for verification.

In 2013, 1401 individuals were successfully interviewed, and their responses were recorded in SurveyMonkey. The statistical accuracy and representativeness (relevancy) of the interview data presented in this report varies among the waiver populations and is subject to important considerations of statistical validity.

The questions, methods, calculations, and procedures for the PTP interview in 2013 are the same as in 2012, 2011, 2010 and 2009, making the results comparable. The relevancies of the findings are indicated below for each specific waiver population.

2.1 2013 Main waiver interviews

The master list provided by DIDD in December 2012 includes 5,975 people in the Medicaid Home and Community Based Services waiver (Main waiver). In 2013, PTP collected and reported interviews for 1,119 of these people. Statistically speaking, the confidence level for a sample this size is 95% at a confidence interval (also called margin of error) of 2.6 (+/- 2.6%). That is, with 1,119 valid interviews with Main waiver recipients, it is possible to statistically predict, for ninety-five (95) of the next one hundred (100) people receiving Main waiver services, how these people would answer a question, with an accuracy of plus or minus 2.6%. (See pages 15-20).

2.2 2013 Self-Determination waiver interviews

For the 1,131 people in the Self-Determination waiver on the list from DIDD, the confidence level is 95% at a confidence interval of 7.3 (+/- 7.3%). This means that given 154 PTP interviews with Self-Determination waiver recipients, it is possible to statistically determine for 95 of the next 100 people interviewed receiving Self-Determination waiver services, how these people would answer a question, with an accuracy of plus or minus 7.3%. (See pages 15-20).

2.3 2013 Arlington waiver interviews

For the 565 people in the Arlington waiver on the list from DIDD the confidence level is 95% at a confidence interval of 9.3 (+/- 9.3%). This means that given 93 completed PTP interviews with people receiving service through the Arlington waiver, it is possible to statistically determine for 95 of the next 100 people interviewed receiving Arlington waiver services, how these people would answer a question, with an accuracy of plus or minus 9.3%. (See pages 15-20).

2.4 2013 Developmental Center interviews

For the 275 people receiving supports in state Developmental Centers or a private intermediate care facility on the list from DIDD, the confidence level is 95% at a confidence interval of 15.5 (+/- 15.5%). This means that given 35 interviews with people residing at Greene Valley Developmental Center or the Clover Bottom Developmental Center, it is possible to statistically determine for 95 of the next 100 people interviewed in this population, how these people would respond to a particular question, with an accuracy of plus or minus 15.5%. (See pages 15-20).

3. PTP STAFF

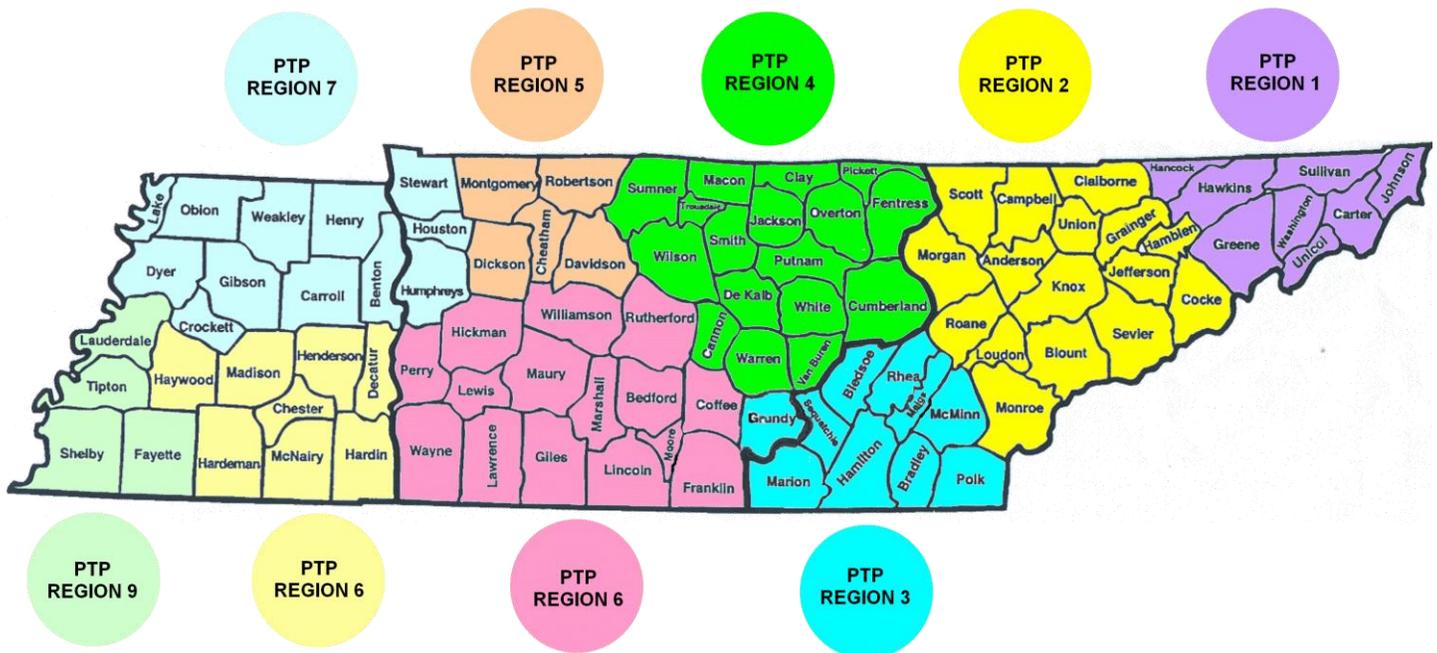
The Arc Tennessee's office is located in Nashville. Frank Meeuwis is the Project Director working with Project Assistant Valerie Jephson to supervise and support twenty-seven part-time interviewers across Tennessee. The PTP teams schedule and conduct face-to-face interviews in their regions. There are three interview teams for each grand region in Tennessee: East, Middle, and West.

A minimum of two people are assigned in each of the nine regions. Regions 1 in East Tennessee, 4, 5 and 6 in Middle Tennessee, and 8 and 9 in West Tennessee each employ additional alternate interview partners.

PTP's regions, the counties included in them, and interview team members are shown in the table and map below:

Region		Counties	Interviewing Team
East	1	Carter, Greene, Hancock, Hawkins, Johnson, Sullivan, Unicoi, Washington	Ashley Brookshire and Danny Reaves; Jimmy Gillenwater, replaced by Rocky Henley, serves as an alternate interviewing partner.
	2	Anderson, Blount, Campbell, Claiborne, Cocke, Grainger, Hamblen, Jefferson, Knox, Loudon, Monroe, Morgan, Roane, Sevier, Scott, Union	Heather and Linda Wilson; Heather and Linda also work as telephone interviewers for a TennCare Select program for certain persons with Intellectual Disabilities.
South-east	3	Bledsoe, Bradley, Grundy, Hamilton, Marion, McMinn, Meigs, Polk, Rhea, Sequatchie	Melissa Crouch and Larry Jacobs.
Upper Cumberland	4	Cannon, Clay, Cumberland, DeKalb, Fentress, Jackson, Macon, Overton, Pickett, Putnam, Smith, Sumner, Trousdale, Van Buren, Warren, White, Wilson	Holly Kirby and Brandy McCauley; Brandy's mother, Debra McCauley, replaced Holly Kirby in April.
Mid Cumberland	5	Cheatham, Davidson, Dickson, Montgomery, Robertson	Woody Cade and Josh Turner; Jennie Isaacs serves as an alternate interviewing partner. Cheryl Coleman and John Blake work as telephone interviewers for a TennCare Select program for certain persons with Intellectual Disabilities.

Region		Counties	Interviewing Team
South Central	6	Bedford, Coffee, Franklin, Hickman, Lawrence, Lewis, Lincoln, Marshall, Maury, Moore, Perry, Rutherford, Wayne, Williamson	Heather Henderson and Mary Dale Greene; Brenda Lackey and Doris Price both serve as an alternate interviewing partner.
North-west	7	Benton, Carroll, Crockett, Dyer, Gibson, Henry, Houston, Humphreys, Lake, Obion, Stewart, Weakley	Tom Griffin and Shawn Flowers.
South-west	8	Chester, Decatur, Hardeman, Hardin, Haywood, Henderson, Madison, McNairy	Jessica Hatley and Patrick Sanders. Tom Griffin replaced Jessica in April; Judy Sparks is an alternate interviewing partner.
Delta	9	Fayette, Haywood, Lauderdale, Tipton, Shelby	Sondra Loveless-South and Nadine Loveless. Suzanne Colsey is an alternate interviewing partner.



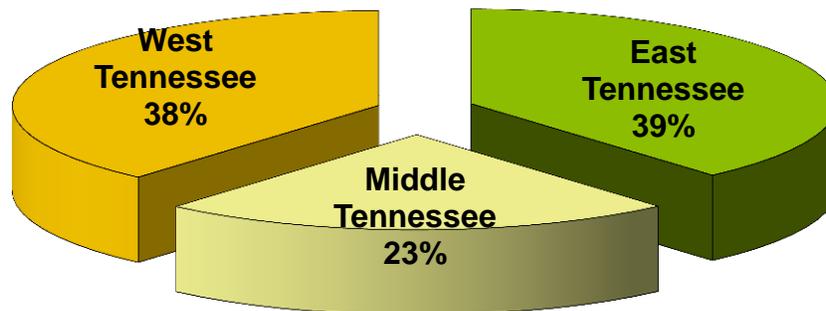
4. INTERVIEWEE DEMOGRAPHICS

The names of the persons interviewed in 2013 came from a random selection from lists provided by DIDD in December 2012.

Below is the regional distribution of the PTP interviews completed by each team in 2013. The chart below this table shows the geographical distribution of these interviews.

Region:	EAST TN			MIDDLE TN			WEST TN			2013 total
	1	2	3	4	5	6	7	8	9	
Total	116	75	350	101	131	88	255	197	88	1401
%	8.28%	5.35%	24.98%	7.21%	9.35%	6.28%	18.20%	14.06%	6.28%	100.00%
Region total	541			320			540			1401
%	38.61%			22.81%			38.54%			100.00%

2013 PTP interviews across Tennessee's regions

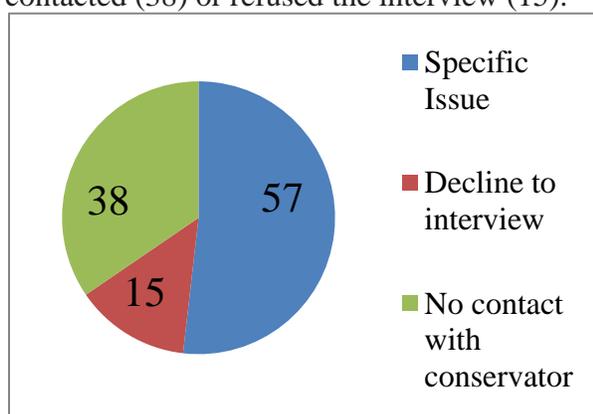


5. INTERVIEW RESULTS

Across the PTP interview, four questions are used as key performance measures for CMS. 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?**

Any response other than “yes” requires PTP to submit an SNF. In 2013, PTP interviewers generated 110 (one hundred ten) SNFs. Of these, fifty three (53 or 48%) were automatically submitted because valid responses were not collected for the four key questions. These interviews were attempted again by a phone call to the conservator of record. Some conservators were unable to be contacted (38) or refused the interview (15).



The remaining fifty seven (57 or 52%) SNFs directly address complaints or concerns of people interviewed during the 2013 calendar year. Thirteen (13 or 23% of 57)

SNFs followed negative responses to the question “Do your support staff treat you well or with respect?” Twelve (12 or 21% of 57) SNFs followed negative responses to the question “Were the things that are important to you included in your service plan?” Ten (10 or 18% of 57) SNFs followed negative responses to the question “Are you satisfied with the amount of privacy you have?” Nine (9 or 16% of 57) SNFs followed negative responses to the question “Do you know how to report a complaint?” Two (2 or 4% of 57) SNFs followed negative responses to the questions “Do you know how to report a complaint?” and “Were the things that are important to you included in your service plan?”

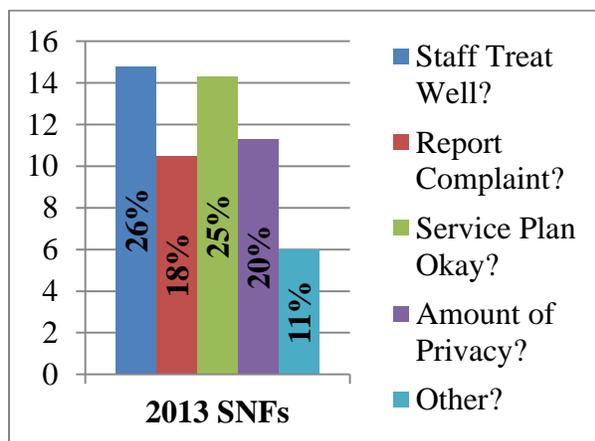
One SNF followed negative responses to both questions “Were the things that are important to you included in your service plan?” and “Are you satisfied with the amount of privacy you have?” Also, one SNF followed negative responses to both questions “Do your support staff treat you well or with respect?” and “Do you know how to report a complaint?”

One SNF followed negative responses to both questions “Do your support staff treat you well or with respect?” and “Were the things that are important to you included in your service plan?” and one SNF followed negative responses to both questions “Do your support staff treat you well or with respect?” and “Are you satisfied with the amount of privacy you have?”

One SNF followed negative responses to each of three questions “Do your support staff treat you well or with respect?” and “Do you know how to report a complaint?” and “Are you satisfied with the amount of privacy you have?”

The remaining six (6 or 11% of 57) SNFs do not directly pertain to a negative response to any of the four key questions, but related to issues with staff, ISCs, or lack of equipment/home-modifications.

This chart below depicts the number of times, and percentage, for each specific issue raised following negative responses to each of the key performance measures for the 57 SNFs in 2013.



Interview results are also comparable to previous reports because the questions, methods, calculations, and procedures are identical. The pie charts on pages 15-20 show the answers to a selection of interview questions, separated by waiver type. These pie charts show the “Yes,” “No” and “Unsure/Not Applicable” answers to questions addressing each of these areas:

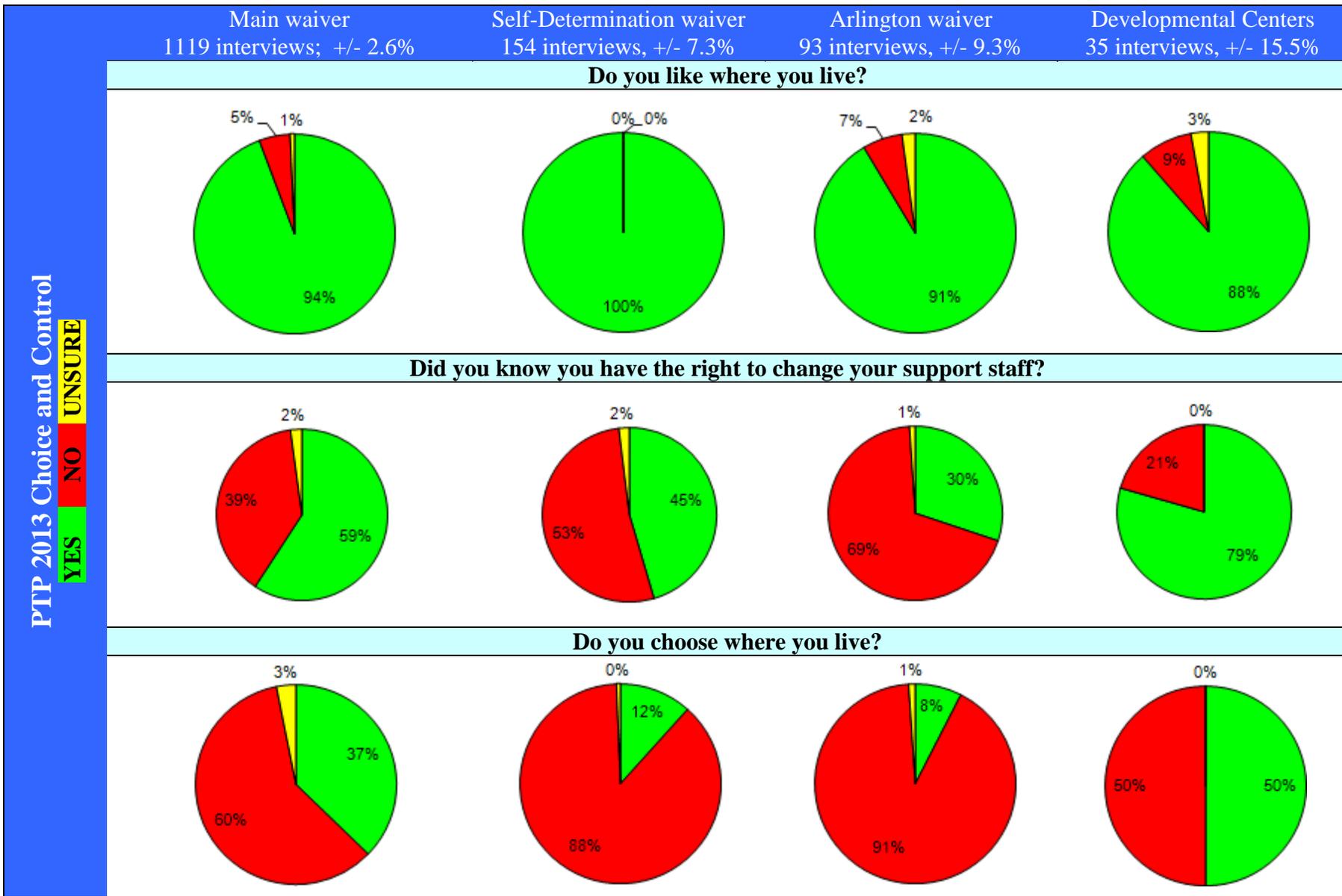
- Choice and Control
- Respect and Dignity
- Access to Care
- Community Inclusion.

The confidence level is 95% for each question and for each waiver population. This is the predictive power or strength of the results. The four questions selected by CMS as key performance indicators are starred (*) and highlighted in yellow. Positive or “Yes” responses are segments colored green in the pie charts. Yellow segments represent responses of “Unsure” or “Not Applicable.” The segments in the pie charts colored red represent “No” or negative responses.

Comparison to PTP’s 2012 interview findings reveal more than a five-fold decrease (85 total in 2012 to 17 total in 2013) in the number of “Unsure/Not Applicable” responses collected from people receiving services at the Greene Valley Developmental Center or at the Clover Bottom Developmental Center.

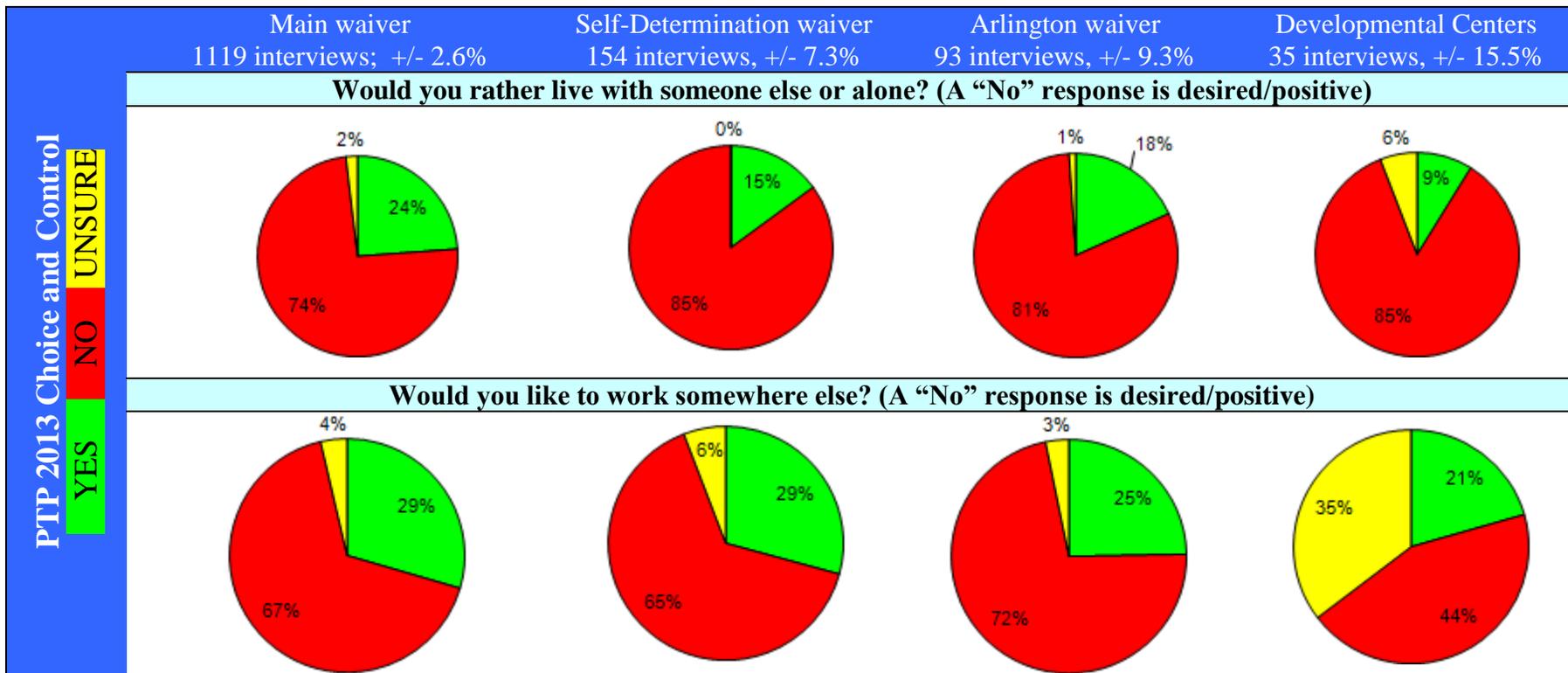
<http://www.tn.gov/didd/PeopleTalkingToPeople/FINAL%20PTP%202012%20report.pdf>

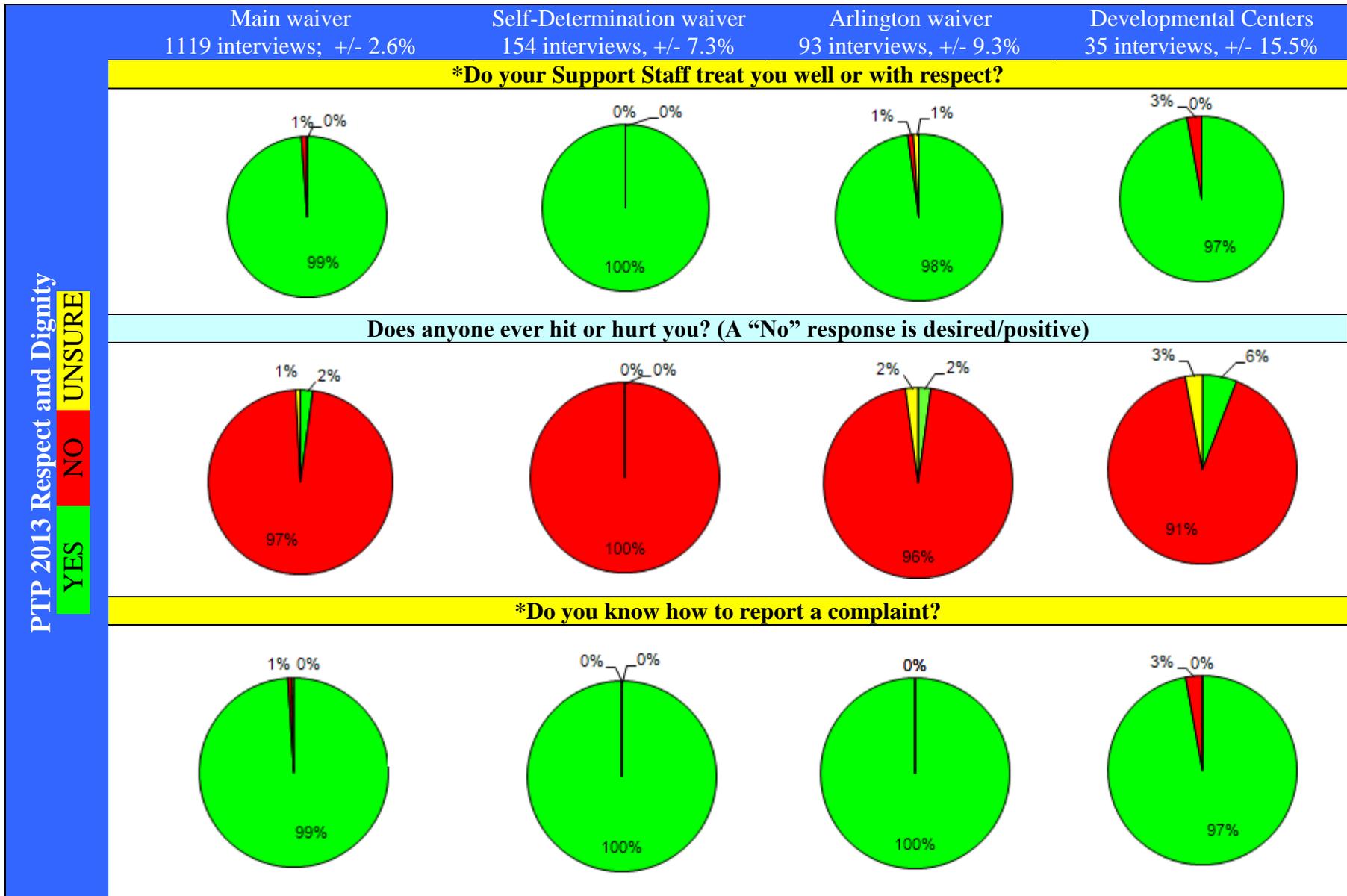
The lower rate of “Unsure/Not Applicable” for people served at a Developmental Center results from an additional procedure in 2013; PTP interviewers are contacting as a proxy individual the conservators for people who were unable or unwilling to communicate a response at the time of the face-to-face meeting.



PTP 2013 Choice and Control

YES NO UNSURE



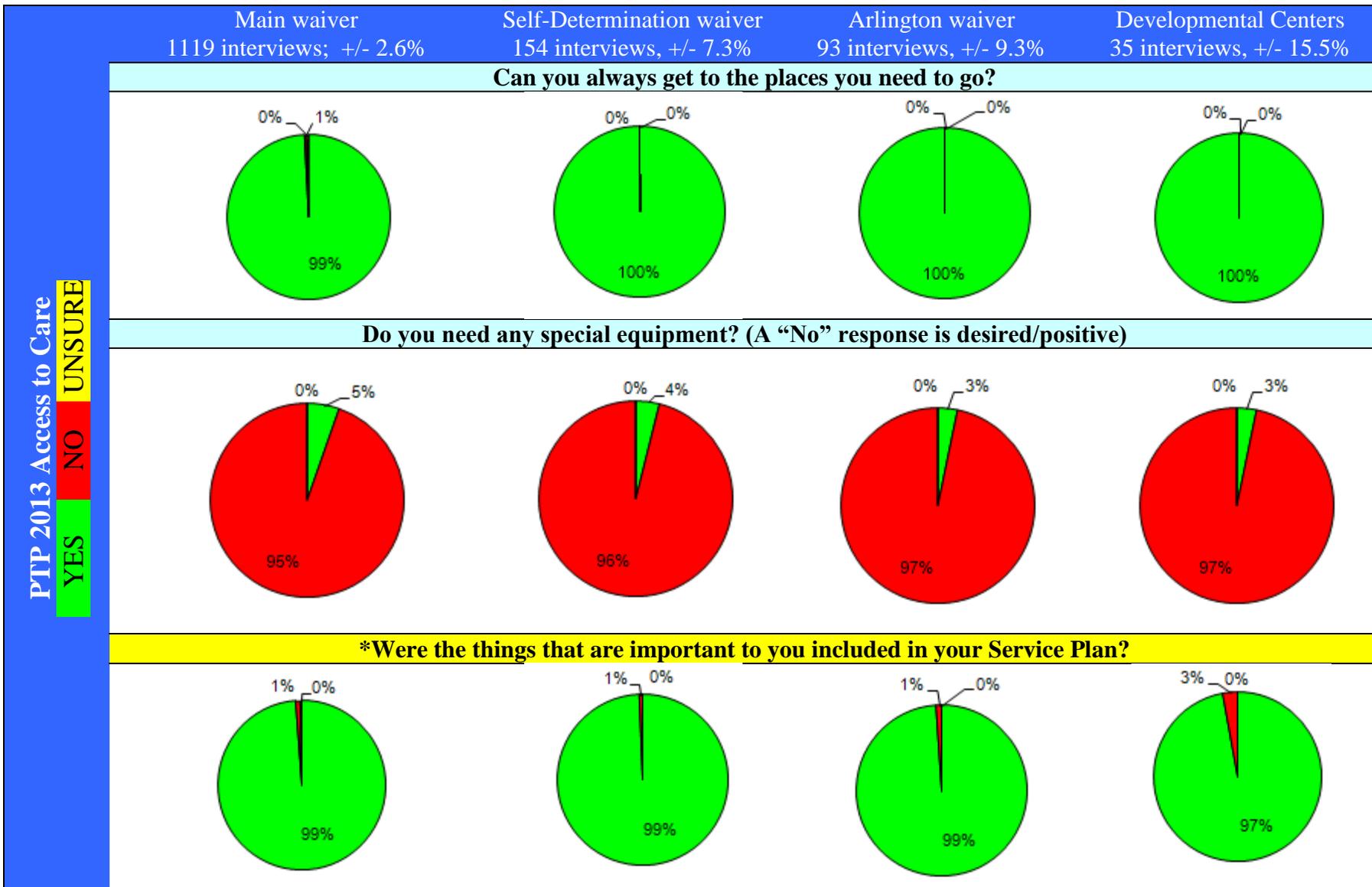


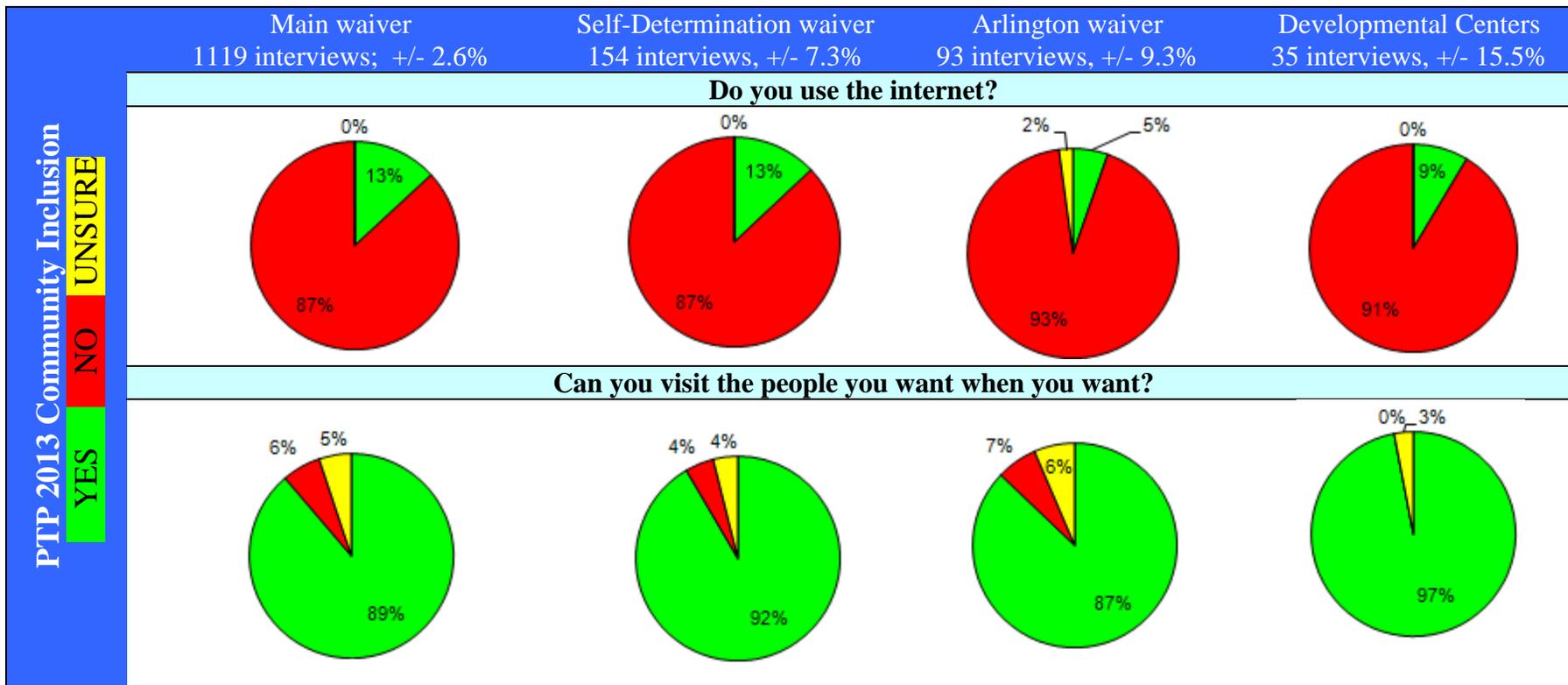
PTP 2013 Respect and Dignity

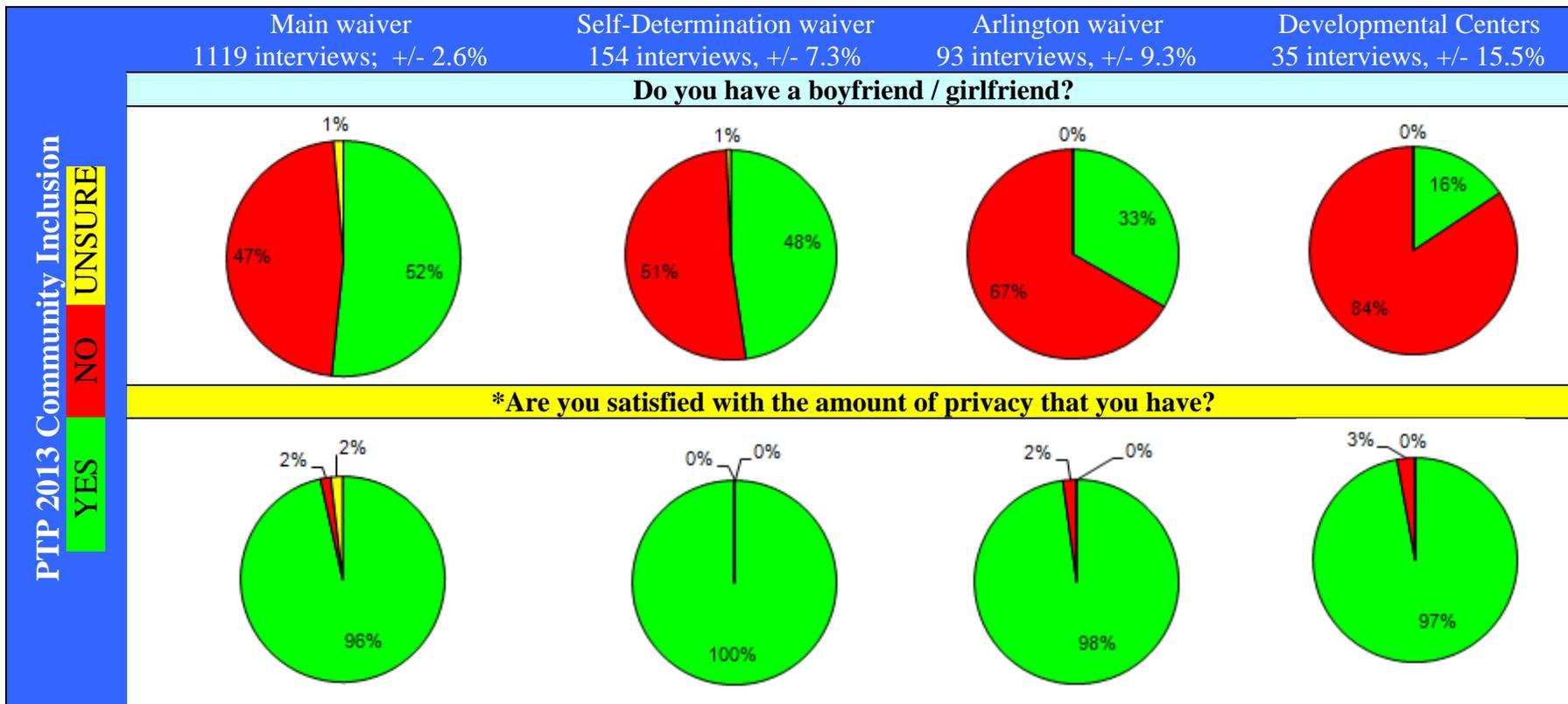
UNSURE

NO

YES







5. INTERVIEW COMMENTS

The PTP interview for 2013 includes the same questions as the previous four years. Following are examples of comments taken during interviews with people in the each of the waiver programs in Tennessee, including the four questions to which any response other than a positive one triggers the Survey Notification Form procedure, as detailed on pages 5 and 6. The ‘positive’ comments are those comments that followed a “yes” answer to a question. ‘Negative’ comments are those that followed a “no” answer to a question.

A. Choice and Control for Main waiver, comments

Do you like where you live?

Positive:

- Except for the people upstairs-- they make too much noise!
- He has lived here all his life.
- He likes his new apartment, and likes living by himself [has 24/7 staff].
- He likes it, but is moving back to Memphis to be closer to family.
- He said that he loves his house and had a smile on his face when he talked about it.
- He seems to love it.
- Her parents had the home built to accommodate her needs.
- He's lived there since his dad died.
- I like it.
- I like living upstairs.
- I live with my brother.
- I love it.
- I used to live in Columbia [Tennessee].
- I will be moving April 7th.
- I would like to move to a new place.
- I'm happy here.

Negative:

- Has problems with roommate & staff.
- I don't like it. (3)
- I don't like the house, because of the raccoons.
- I don't like the agency I am at.
- I sometimes don't get along with my housemates. (5)
- I sometimes would like to live alone.
- I want to be closer to my mother.

A. Choice and Control for Main waiver, comments (continued)

- I want to get married and move somewhere else.
- I want to live in Memphis, TN.
- I want to live with my husband.
- I would like to return to my previous home.
- I'm ready for something new. I'm moving when the lease is up.
- Individual said he would like to live in his previous residence.
- It floods.
- It's not big enough.
- Likes his roommates and the home but because he has lived there so long, he said, "I'm bored with it, I'm just ready for a change."
- Person is getting married in two days.
- She liked it at first, but is moving/changing agencies in April
- The house is old and falling apart.
- There are not enough staff to take her places, and too many roommates.
- There is too much violence in the area.
- They are too fussy.

Did you choose the place you live?

Positive:

- Agency assisted.
- He had help.
- His family placed him.
- Housing was chosen with assistance from individual's mother.
- I had help. (2)
- Individual chose the house with assistance from sister/ conservator.
- Individual said he has lived with his sister since he was 18 years old.
- It was either that house or another one at the time.
- I've always had my own choice where I have lived.
- Lives with family. (2)
- Mama and Daddy helped.
- Me and my dad looked, and we picked the apartment I wanted to live in.
- Ms. [] helped.
- My conservator chose.
- My daughter helped.
- My parents helped.
- [Her] roommate, asked her come live with her.
- She has lived there almost her whole life.
- She likes location and says it's good for riding her bike.
- She owns the home she lives in.
- She visited several homes before deciding on her current residence.

A. Choice and Control for Main waiver, comments (continued)

- She wouldn't live someplace else; likes it here.
- Sister assisted.
- Someone helped move the nightstand, bed, and dresser.
- Staff helped.
- With mom and [another family member].

Negative:

- Agency chose house and roommate.
- Dad chose. (2)
- [She] helped--she works for the state.
- I live with my family. (86)
- I live with my foster family. (4)
- My agency chose. (26)
- My agency helped. (2)
- My brother chose. (2)
- My conservator and agency chose.
- My conservator chose. (37)
- My family did. (53)
- My parents chose. (2)
- Parents bought the house.
- Lives with family. (26)
- Individual, staff and conservator had a meeting to help her pick.
- Individual's mother chose the house. (9)
- Previous companion chose.
- Sister helped.
- Staff helped Individual and his wife select a location.
- The state chose it. (2)
- They just moved me here.

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

Positive:

- Conservator is very happy with his care and living situation.
- Conservator said she knows.
- Conservator said that if [the individual] does not like his staff, he will display this through behaviors.
- Conservator said that she knows.
- Currently in the process of changing staff.
- Doesn't want to change his current support staff. (4)
- Doesn't want to change them.
- Guardian chose staff but the family met them beforehand.

A. Choice and Control for Main waiver, comments (continued)

- He knows he has the right to change staff but says his current agency is strict about allowing it.
- He wants to keep his current support staff.
- He will grab his DSP's hand when he wants to eat.
- His mother can tell by the way he acts, and she will change staff if needed.
- I get along with her.
- I like the staff I have.
- I make decisions for my brother based on feedback from him.
- I'm happy with them.
- Individual reported problems with day staff.
- Pleased with his current support staff.
- She said one of her staff is too emotional.
- She said she wouldn't change them, she loves them.
- Yes, but she loves them.
- Yes, I like my staff.

Negative:

- He [the individual] can communicate if he's unhappy with someone.
- He didn't know he had the right to change his staff, however he does feel he has more freedom in his current living situation.
- I didn't know that.
- I like my staff.
- I like my staff. I don't want to change.
- If I was told, I forgot.
- Individual was confused by this question; it took a while for him to understand that we were not asking him to change his staff. β interviewer's comment, wasn't sure if you'd want to keep it
- She said she didn't know she had the right to change her staff. β there are some of these throughout, where the comment is basically restating the question and answer.
- They were already there but she likes her staff.

Can you talk to your ISC when you need to?

Positive:

- Conservator has ISC's email address and phone number.
- Conservator said the ISC is great to work with and has helped the participant and the conservator very much.
- He could not remember the ISC's name.
- He likes who he has.
- He sees his ISC at least once a month.
- Her brother is very happy with communications with his staff, but she is leaving.

A. Choice and Control for Main waiver, comments (continued)

- I call and she comes and sees me. I stop by sometimes.
- I don't want to talk with [my ISC].
- I have a hard time getting a hold of him.
- I like her.
- I talk to her when I have problems.
- I think I can; I've never had to call. (22)
- I've never had to call.
- Mother can.
- Individual sees the ISC during visits.
- Respondent was under the impression she does not have an ISC so was uncertain how to answer the questions.
- Sees ISC once a month. (2)
- Sees the ISC around often.
- She can't remember the ISC's name, but says the ISC can be reached.
- She does not know ISC by name.
- Sometimes the ISC comes over on the weekend.
- Staff can get a hold of them if he needs them.
- Staff can help me.
- The ISC takes care of things.
- Yes. I like her.

Would you like to work somewhere else?

Positive:

- Any job is fine as long as I can make some money. (38)
- He described himself as a quick learner and said he would like to do stock work. Previously, he has done construction work, roofing, and worked at Denny's Restaurant.
- He does not want to work too many hours because it might jeopardize SSI payments.
- He is looking for work, and hopes to find a job loading trucks at Wal-Mart.
- He is looking into getting a job at Goodwill on Saturdays.
- He said McDonald's was going to hire him but did not because there were too many kids around. He might want a job unloading trucks.
- He wants to work at Goodwill hanging up clothes, and will have a job soon growing plants and vegetables at his sponsoring agency.
- He would like to work at the Ford place but has to work on some personality issues.
- I am in the process of getting that worked out. (2)
- I like doing flower arranging and cutting hair.
- I like my job at Goodwill.
- I want a job out in the community.
- I want to volunteer with Meals On Wheels. (2)
- I want to work at H.H. Gregg or Sears because my hours have been cut at my current job.

A. Choice and Control for Main waiver, comments (continued)

- I work at Goodwill.
- I'd like to be in the workshop.
- I'd like to get a job.
- I'd like to work at handing out coupons.
- I'd like to work in a bowling alley.
- I'll take any job so I can make some money and go out and do something.
- I'm getting a job soon.
- I'm getting help finding a job.
- I'm looking for work.
- I'm thinking about it.
- I'm working on getting a job. (2)
- I've tried for jobs in the past.
- I'd like to cut grass.
- I'd like to do office work.
- I'd like to work as a babysitter.
- I'd like to work as a fireman.
- I'd like to work as a house cleaner.
- I'd like to work as a janitor.
- I'd like to work as a mechanic. (2)
- I'd like to work at a clothing store.
- I'd like to work at a donut shop.
- I'd like to work at a factory. (2)
- I'd like to work at a Family Dollar store.
- I'd like to work at a grocery store.
- I'd like to work at a gun shop.
- I'd like to work at a hospital.
- I'd like to work at a Lowe's store.
- I'd like to work at a nursing home. (3)
- I'd like to work at a restaurant. (9)
- I'd like to work at a store. (3)
- I'd like to work at a veterinarian's office.
- I'd like to work at an arts and crafts store. (2)
- I'd like to work at Barnhill's [restaurant].
- I'd like to work at Burger King.
- I'd like to work at Cornerstone.
- I'd like to work at Food Lot.
- I'd like to work at K-Mart.
- I'd like to work at McDonald's. (15)
- I'd like to work at Pizza Hut, making chicken wings in the back. Or tacos at Taco Bell.
- I'd like to work at Taco Bell.
- I'd like to work at Toys-R-Us.
- I'd like to work at Wal Mart. (13)

A. Choice and Control for Main waiver, comments (continued)

- I'd like to work in construction.
- I'd like to work in law enforcement.
- I'd like to work outside.
- I'd like to work with animals.
- Individual formerly worked at another workshop.
- Individual has talked to a friend about working at the volunteer Fire Dept.
- Individual is looking for work in the community, but finds most of it too difficult. She has worked at McDonald's wiping down tables.
- Individual said he is starting to work at [Agency] as soon as all the paperwork is done. (2)
- Individual used to volunteer at Meals On Wheels.
- Individual volunteers at [School].
- Individual volunteers at Mobile Meals.
- Individual wants a job in Memphis.
- Individual wants a job, but does not want to volunteer.
- Individual wants to be a vet tech assistant, but doesn't know if her sharps/glass/chemicals restrictions can be lifted for her to try to get that type of job. She would also like to work at Kroger.
- Individual wants to change.
- Individual wants to volunteer. (7)
- Individual wants to watch TV.
- Individual wants to work at a plant, but is recovering from hip surgery and can't work right now.
- Individual wants to work at Wal-Mart in the baby dept.
- Individual wants to work with [friend].
- Individual works at [the agency] and likes her job; she does not want to volunteer.
- Individual would clean houses.
- Individual would like a better paying job.
- Individual would like a job but is unsure if she would like to volunteer.
- Individual would like an outside job.
- Individual would like to do something different for a change.
- Individual would like to find more places to mop.
- Individual would like to have a job at McDonald's. Previously volunteered with Meals On Wheels.
- Individual would like to have a job.(3)
- Individual would like to make more money.
- Individual would like to take courses in welding but it's too far to travel.
- Individual would like to volunteer in a hospital and help with children.
- Individual would like to volunteer, but hasn't talked to anyone about it.
- Individual would like to work and volunteer, used to babysit two sisters' children.
- Individual would like to work at a pet store, Security or desk greeter, Greeter at church.
- Individual would like to work at a restaurant or movie house.

A. Choice and Control for Main waiver, comments (continued)

- Individual would like to work at Bi-Lo.
- Individual would like to work at Kroger and volunteer at mobile meals.
- Individual would like to work at Logan's Steak House.
- Individual would like to work at the sea side
- Individual would like to work at Vanderbilt.
- Individual would like to work for pay.
- Individual would like to work for the Tennessee Titans.
- Individual would like to work in a day care or a job working with kids. Also would like to volunteer.
- Individual would like to work in a hospital.
- Individual would like to work in a work shop.
- Individual would like to work in recycling.
- Individual would like to work in retail store doing stock or folding clothes.
- Individual would like to work in the hospital.
- Individual would like to work in workshop.
- Individual would like to work outside.
- Individual would like to work somewhere else.
- Individual would like to work somewhere he could clean tables.
- Individual would like to work somewhere.
- She had a job at Taco Bell and would like another. They were very happy with her work, but couldn't handle her behaviors.
- She has been an assistant secretary, and did janitorial work at The Air National Guard of Nashville.
- She said she might be getting a job working with her conservator.
- She wants to be an artist and used to work as a Program Coordinator.
- She wants to go out [in the community].
- She would consider doing office work, and shared her previous work experience. She has volunteered as a housekeeper at a hospital clinic. She worked at Taco Bell, picking up trash. In Cookeville, she worked at [Agency]. In Clarksville, she put labels on boxes. She has also sold Avon Products.
- She would like to do office work.
- Wants to attend school, but formerly volunteered with Meals On Wheels and hopes to volunteer soon with Second Harvest Food Bank.
- Wants to work out in the public.
- Would like to work at fast food restaurant.
- Would like to work at Orange Grove [Developmental Center].

Negative:

- Folded silverware and emptied trash at a motel.
- He gets to work on cars and likes that.
- I don't want to volunteer. (5)
- I don't want to change anything.
- I have a job.

A. Choice and Control for Main waiver, comments (continued)

- I like going to the retirement home.
- I like it here at the agency.
- I like it here but wish I could work somewhere else on days they don't have work for me.
- I like working here at the workshop. (2)
- I love it at work.
- I volunteer at Meals On Wheels.
- I volunteer for hospice and Meals On Wheels.
- I work at McDonald's now part-time.
- I work at Taco Bell.
- I worked in a nursing home.
- I'm enjoying my retirement.
- I'm happy working here at the workshop.
- I'm working part-time now at the library.
- Individual already volunteers at park and museum.
- Individual does a work-based training program at school.
- Individual is not able to work due to physical limitations.
- Individual likes to volunteer at [the agency].
- Individual likes working at [the agency].
- Individual prefers to stay at the developmental center.
- Individual volunteers already. (3)
- Individual volunteers at a hospital and works at [an agency].
- Individual works part-time now. (13)
- Individual would like to work in the community but has physical limitations.
- She is happy with what she already does. (3)
- She is happy with what she does and doesn't have time to do anything else. She has received an award for the work she does.
- She likes her job.
- She loves working at Pizza Hut. She used to volunteer and would like to again.
- Worked as a cook.
- Worked at McDonald's.

B. Respect and Dignity for Main waiver, comments

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

Positive:

- A lot better than the one I had in the past.
- Always, but they are overworked with house mates that need more care.
- Individual reports current staff is great, but prior staff was not.
- Individual says the current staff treats her well.
- Individual enjoys staff and gets a lot of attention.
- Individual loves his staff. (2)
- I stand up for myself.
- I like them.
- I try to respect my support staff as much as I can.
- My trouble is getting them to believe I can do stuff.
- They are nice.
- Oh yeah!
- I make sure I get respect.
- My staff is fine but my roommate yells sometimes.
- Individual says the staff that did not treat him well has been changed.
- They cook for me, and do laundry.
- Conservator believes they do.

Negative:

- Individual said her staff arrives drunk.
- Nothing major.
- Individual reports staff sometimes yell at her.
- Individual says his housemate comes into his room without permission, and DSPs are unable to stop him. They have been roommates in a prior home.
- They hurt my feelings.
- They make fun of me.
- Individual says that her evening staff doesn't treat her well, seems to favor her roommate and even told her once that she likes the roommate better.
- Individual said she has an issue with 2 staff members.
- [One staff] doesn't respect me. She called me a liar and asked if I wanted to fight.
- Individual reported that two female staff put her in a chair and pulled her legs forward and backward on separate occasions in April 2013.

B. Respect and Dignity for Main waiver, comments (continued)

Does anyone ever hit or hurt you?

Positive:

- A long time ago, someone hit me when I was [a different agency].
- [She] threatened me.
- Individual stated that she had been struck and yelled at by a staff member at her group home in the recent past, and that she had not reported it because she was afraid.
- Guardian does not feel it is safe for the participant with her roommate in the house. [The Agency] only informed guardian of past problems involving the roommate and a knife after the participant had already been placed in the home.
- His cousin used to hit him, but the man has passed away.
- Individual said his housemate scratches him but he tells staff and they take care of the situation.
- Housemate does. (5)
- Individual says her housemate has some behaviors and the two have a love/hate relationship, but she has no problems to report.
- Housemates are mean to me.
- Individual said her housemate has hit her.
- My ex-boyfriend did. Now I don't see him.
- My roommate.
- Individual reports his roommate hits him sometimes when she gets upset.
- Saturday before last.
- She said someone on her weekend staff hits her.
- Staff has to watch my roommate.
- [She] hit me.

Negative:

- Conservator said her son has never been hurt by staff, to the best of her knowledge. She added, "Sometimes my son is very violent and has to be restrained. He is a self-mutilator."
- Hurts her feelings.
- Not to the best of our knowledge.
- Individual said no, but later told a story about a co-worker hitting him, and said he hit back. Said it has happened twice and the person no longer hits him because he takes care of it.
- People are sweet to me.
- Roommate has SIB and [he] thinks he is being yelled but really his roommate is trying to communicate.

B. Respect and Dignity for Main waiver, comments (continued)

Do you know how to report a complaint?

Positive:

- Call 911. (3)
- Call the agency.
- Call the agency. "[He] will not be mistreated," his sister said, adding, "If I think he's being mistreated, they'll know I'm coming."
- Call an ambulance.
- Call DIDD.
- Call [the agency] and document the complaint.
- Call ISC and agency director.
- Call ISC or The State has on Speed Dial.
- Call [him].
- Call Mama.
- Call police. (2)
- Call Police. The neighbor is the police.
- Call the case manager.
- Case Manager. Police.
- Conservator does.
- Contact the state.
- Definitely!
- Family does.
- Go to the office.
- He said when he has a complaint, he tells his staff or his Dad.
- He will tell his mom and she will report it.
- He would tell the staff.
- Head nurse and parents file complaints as determined necessary
- [Her] mother is not sure that [she] would know how to report a complaint. Heidi's mother knows how to file a complaint.
- Her Niece.
- His Aunt knows how to report a complaint and [he] nodded 'yes' to the question.
- His mother is with him all the time and she knows how to file a complaint
- House manager.
- I call a social worker.
- I don't usually have to.
- I tell staff or would tell somebody.
- I'd tell [friend].
- Initially, father would go to manager at the agency and if that didn't work he would elevate all the way to the state level if necessary.
- Knows to tell someone.
- Main office and staff.
- My brother would take care of it!

B. Respect and Dignity for Main waiver, comments (continued)

- My supervisor. If someone takes my word search, they have to ask my permission. I would also report to my companion or coordinator. If you don't want the person you are working with, you can tell your supervisor.
- Parents do.
- Individual said he would call his mother.
- Individual said: "If somebody stole from me, I would talk to him about it because I would want the situation handled in a proper way. I stay cool calm and collected and I will walk away if someone tries to confront me, but, if somebody 'gets up in my face," I might do something about it."
- Respondent would speak to staff.
- She says she has regular contact with staff at the residence where her sister lives but as far as the state is concerned she needs new number in case something were to happen.
- Signals aide
- Sister would contact staff at [agency].
- Staff does. (3)
- Tell companion.
- Tell friend.
- Tell home staff or agency office staff.
- Tell House Manager. (3)
- Tell ISC.
- Tell mom and dad. (4)
- Tell mother. (2)
- Tell my sister. (2)
- Tell staff. (36)
- Tell staff or call the police.
- Tell staff, my ISC, my job coach.
- Tell staff, tell my mother.
- Tells administrator.
- Tells people at the agency, called Nashville, got runaround got replacement when [staff] could no longer care for her.
- With assistance.
- Would report to director at agency, and if that didn't work he would escalate to his ISC or advocate.
- Would talk to my staff, program manager, or call family
- Would tell [support staff], would not tell roommate.

Negative:

- I don't know who I would call.
- Said he "sometimes" knows how to report a complaint. He also said there was something he did not want to talk about, so I moved on with the rest of the interview.
- [She] shrugged her shoulders each time this question was asked.

C. Access to care for Main waiver, comments

Can you always get to the places you want?

Positive:

- I love my great staff.
- My mother and my aunt take me.
- Individual's foster mother takes him.
- Individual is hoping to go shopping for church clothes later.
- Individual likes going to Wal-Mart and Shoney's.
- Individual likes to go grocery shopping but does not like to cook.
- Individual needs a lift van, as staff struggles over the transfer.
- Individual says he gets out a lot
- Individual says his boss takes him to and from work.
- Individual's staff transports him and [roommate] at home.
- Individual's sister and [Agency] transport.
- Individual takes access ride to the agency, and staff takes him other places.
- Individual uses Access Ride to go to workshop, and staff transportation.
- Individual uses uni-car.
- Staff take me. (57)
- Van takes her places.
- We have a van. (5)
- Yes, now that I got my own van.

Negative:

- I have to call an ambulance.
- I want to go shopping but now we don't get to go nowhere.

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

Of the 1101 people receiving services through the Main waiver who responded to this question in 2013, nearly 5.4 % (60 affirmative responses) answered yes to needing special equipment that would make their lives easier.

Medical:

- 22 wheelchair requests.
- 7 walker requests.
- 2 Lift chair/recliners
- A urinal for use from the bed.
- A 'stander.'
- New eyeglasses.

C. Access to care for Main waiver, comments (continued)

Technology:

- 3 speech/communication devices.
- 1 cell phone.
- 1 I-Pad.
- 1 assistive technology device “to help keep up with notes.”
- 1 ‘tracking’ system.

Modifications:

- 6 accessible bath requests (5 shower chairs, 1 grab bar).
- 1 ramp request.
- Hand rails for the bathroom.

Other:

- 2 requests for a van with a lift.
- 2 new bed requests.
- 1 coffee cup.
- 1 tray for a wheelchair.
- 1 electric razor.
- Weights.
- Boxing equipment (bag and gloves.)
- “Someone that knows sign language.”
- “Would like something that makes beds.”

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

Positive:

- Conservator helps with plan.
- Conservator (sister) says she gets regular reports.
- I’m trying to think of new things to put in it.
- Individual said a monthly calendar is now in her ISP plan.
- Likes to buy watches.
- Losing weight is important to the individual.
- She recently got a bigger bed which she needed very badly.
- She recently got a new chair.
- Sister helps.
- Support and conservator help him with this.
- Taking several trips this year.
- Wants a man included in her plan!

C. Access to care for Main waiver, comments (continued)

Negative:

- Didn't get everything he wanted on his ISP. Said that he felt that at his last ISP, false information was on it. Feels he has been improperly labeled and is in type of house he doesn't want to be in.
- Doesn't like people to talk about him. More one on one.
- Except for control over his money.
- Family is not being notified of meetings and receiving notification after the fact.
- I don't know.
- I think so.
- She wants to get out into the community, but they don't call me when the meeting is.
- They don't listen to her.
- Wants more time with mom.
- Wants to be own conservator.
- Wants to live with husband. This has been brought up at the ISP meeting.

D. Community Inclusion for Main waiver, comments

PTP interviewed many people receiving services through the Main waiver who are working or volunteering in their communities at convenience stores, cinemas, libraries, mobile meal programs, nursing homes, restaurants, superstores, and other jobs.

There is more to community inclusion than just working or volunteering, and many researchers consider the use of mass media to be highly correlated with what is accepted to define community integration (McLeod, et. al, 1996). Computer technology and the Internet also broaden lives and increases the independence of people with disabilities (Kaye, 2000). Clearly now, with the familiarity and common use of Facebook, YouTube and other social networking sites, use of the Internet is an important part of connecting people with their communities.

Yet among those interviewed receiving services through the Main waiver in 2013, only slightly more than one in ten (13%) are using the Internet, whereas, according to a 2013 report by the Center for the Digital Future at the USC Annenberg School for Communication, more than eight in ten (85%) of all Americans are going online. This measure has been consistently at least 70% below the national average since the inception of PTP, prompting the question, “Why are people with intellectual disabilities not accessing the internet more often?”

Two key factors impacting Internet usage in the general population are socioeconomic status (SES) and level of education (Hargittai, E., and A. Hinnant. 2008)—which may also be factors for people with intellectual disabilities. However, since so many public spaces offer free access to the internet, there is little reason for this percentage to be so

low. With over 67% (736 of 1096) of those interviewed who receive services through the Main waiver in 2013 responding that they do not use the Internet, access and use of the Internet—in addition to typically lower SES and level of education—continues to be an obstacle to full community inclusion and participation. People receiving DIDD services need support and encouragement to access the Internet.

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 boyfriend/girlfriend question is important in light of a prevailing tendency to judge people with disabilities as asexual (Milligan & Neufeldt, 2001).

Forty eight percent (48% or 525 of 1096) of those interviewed who receive services through the Main waiver responded “Yes,” that they have a boyfriend or girlfriend. The people served by DIDD would benefit from more discussion of relationship issues with staff and families. Healthy relationships will increase the differing opportunities and experiences for self-determination for people with disabilities.

D. Community Inclusion for Main waiver, comments (continued)

Do you have a boyfriend / girlfriend?

Positive:

- All of them.
- Apparently he decided it was me.
- Best friend lives in the next apartment complex.
- Boyfriend.
- [Friend’s name].
- Eight.
- Four.
- [Friend’s name].
- Has 3 girlfriends—all know about each other.
- Has a girlfriend—“Wants to marry her up.”
- Has a husband but they don't live together.
- Has a picture of them as his background on his phone.
- Has too many—about 78.

D. Community Inclusion for Main waiver, comments (continued)

- Have lots of friends.
- He finds out Tuesday what her name is.
- He has 3.
- He has 2.
- He is married.
- He likes [Friend's name] who also works here like he does.
- He was all smiles when he talked about [her].
- Her name is [Friend's name].
- Her name is [Friend's name]. He really likes her.
- His girlfriend lives in Fairview where he used to live.
- His name is [Friend's name].
- His name is [Friend's name].
- I don't know how many I have.
- I have about two!
- I have a few friends.
- I'm married. (6)
- [Friend's name] and they have been together for 20yrs.
- [Friend's name].
- Kind of.
- [Friend's name].
- Likes [Friend's name] at the other Skills.
- Lots of friends. (5)
- Many church friends.
- Many friends. (6)
- Many friends on bus she rides to [agency.]
- Many friends, a special male friend [Friend's name].
- Many girlfriends at workshop.
- [Friend's name].
- [Friend's name].
- More than one.
- [Friend's name].
- No girlfriends, lots of boyfriends.
- One is enough for me.
- [Friend's name] who lives in Lewisburg.
- [Friend's name]. They have been together for 14yrs. He plans on marrying her; he has his suit and has been looking at houses.
- Individual said he has had a girlfriend for 2.5 years, but staff reported after interview that he does not have a girlfriend.
- Individual reports having has 5 or 6 girlfriends at Church.
- Individual has a few friends, and a sister.
- Individual has all kinds of friends and is very outgoing.
- [Friend's name] (she is at the day program also).

D. Community Inclusion for Main waiver, comments (continued)

- [Friend's name].
- [Friend's name] at Fairview.
- [Friend's name].
- Said she's married to someone named [Friend's name].
- Saw him at the Valentine's dance.
- Says he has 3 but only could remember one's name.
- Says he has a girlfriend at the center.
- Says he has two secret girlfriends.
- Says that he is too short for her, but she likes him anyway.
- Several.
- Several friends at church and nearby.
- [Friend's name].
- She loves everyone.
- She's my only best friend.
- She passed away very recently.
- She's crazy about him and she's crazy about me: "We are good to each other"
- She's got married Wednesday 4/24.
- Three and they all know about each other.
- [Friend's name] the boyfriend.
- Two boyfriends. (3)
- [Friend's name].
- Very friendly.
- Wife [Friend's name].

Negative:

- Conservator said "He has no concept of that".
- [She] is a loner and doesn't like to be around anyone but family.
- Does have a girl he talks to that a friend introduced him to.
- Doesn't have time for one.
- Doesn't like men.
- Doesn't want one. (7)
- He wants one.
- I did.
- Individual said he doesn't want a girlfriend because "they cost money."
- Just a lot of friends.
- Looking for a girlfriend.
- Married.
- My sister don't want me to go with one.
- Not right now.
- Not very social or outgoing, mostly a loner.
- Said that [agency] does not allow girlfriends in his categorization.

D. Community Inclusion for Main waiver, comments (continued)

- Says she not interested.
- She is a loner.
- She loves everyone.
- That is kind of hard, but I'm looking for one.
- They broke up. It was [Friend's name].
- Used to have one, don't want another.
- Wants a boyfriend with black hair.
- Wants a girlfriend.
- Working on it. I wish I could.

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

Positive:

- Around her friends all the time.
- As long as she schedules visits first.
- Can see [Friend's name] the most because she is in the same house.
- He comes home three times a month.
- If they come to see me I can't go to them.
- It's sometimes hard to find the time when we can get together.
- Likes to eat lunch with them.
- Make a appointment.
- Mostly when she is at school.
- My mom is not able to take care of me.
- On special occasions.
- Individual said he can, as long as he makes arrangements ahead of time.
- She sees them often.
- Usually once a month.
- Weekends.
- When they come and pick him up.

Negative:

- Because of travel it can be a little difficult. (2).
- I used to visit her more but her husband died and it's too far for her to drive alone.
- I have no one to see. (14)
- It's sometimes hard to find the time when we can get together. (18)
- It's limited.
- Mom is busy.
- No, because they live in Memphis.
- Individual would like to move closer to her mom.
- She sees them on holidays.
- Sister lives in California.

D. Community Inclusion for Main waiver, comments (continued)

- Someone has to be with her.
- The amount of care the other house mates need make it hard.
- They live at a distance. (19)
- They live in Florida.
- They live in Oregon.
- They live too far away. They see [each other] only a few times a year.
- They work every day.
- I went to Michigan last year for a birthday.
- When I can.

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

The preceding question for people receiving Main waiver services was answered positively in more than 99% (1111 of 1119) of the interviews collected in 2013. Most responded ‘Yes’ with no comment. Following are the few comments that PTP did collect.

Positive:

- Has privacy in her room but not in other parts of the house.
- He has a big screen TV in his room and he can go watch that by himself.
- I can do whatever I want to!
- I got two radios; I can shut the door and listen to the gospel.
- Like to sit in my bedroom and watch my TV.
- She is in her room and I’m in mine.

Negative:

- Has to leave door open when he has visitors no matter what the gender.
- He does not get enough privacy.
- [She] stated that she feels that her staff sometimes yells at her and she feels that she doesn't have enough privacy.
- She wishes she had more privacy.
- They want to be in your business all the time -- my staff and my roommate.

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

This final qualitative question is an opportunity for people we interview and their family members to share additional comments or concerns that do not otherwise come up during the interview. Following are both positive and negative comments made by people receiving Main Waiver services interviewed in 2013 across Tennessee.

D. Community Inclusion for Main waiver, comments (continued)

Positive:

- [Conservator] seems very well informed regarding procedures, etc. Very glad that we checked on [her] and wished someone had back in 2010.
- Conservator says they are both very happy since he had her removed from [agency] where she was very badly abused in 2010. Conservator says complaints were filed and all paperwork was done according to procedure regarding the abuse in 2010.
- Going to "Rehab your Place", learning to make her bed, etc.
- Has a cat that she owns and is responsible for the care of, and she does a great job.
- Has a toy poodle that follows her around everywhere.
- [He] and his mother are very happy & satisfied with all his needs being met.
- [He] and his roommate are each other's best friend.
- [He] and his twin brother are very happy living together, next door to their dad.
- [He] can nod head yes/no. Uses a computer to point to some answers. His brother helped [him] understand the questions. [He] seems happy and content. His brother says everything is going well and he is happy with all services. Definitely knows how to file a complaint.
- [He] has a new communicative device he is learning to use. His guardian/mother helped the team understand his answers.
- He is enjoying marriage, and enjoyed talking to us.
- [He] is healthy and happy, his sister said.
- [He] is part Cherokee Indian and proud of his heritage. He loves his job and wants us to come and eat at [restaurant]. [He] says there are bad people in the apartment complex, but he stays home and only goes out to get his mail or visit [his friend].
- [He] is somewhat verbal and seemed to understand most all of the questions. He says he is fine and everything is fine.
- [He] is very active in Special Olympics and showed us his ribbons and medals. Good interview with a happy family.
- [He] is very verbal, very outgoing and eager to talk to us. Said he was so glad that we came, that he will miss us and wants us to come again to talk to him.
- [He] loves going to the [center] to the Friday night dances!!
- He talked about how much he likes cars and motorcycles.
- [He] was a very good interview. He communicated very well. He can read and write. Loves National Geographic. [He is] happiest when in his workroom fixing things.
- He was very happy with his services.
- He was very personable. He is a very strong self-advocate in our opinion.
- He was very proud of his job. He was happy.
- I got great news, I got my hair cut.
- I love pool and to eat!
- Individual likes to swing on the porch.
- Love going to thrift store, fixing things.

D. Community Inclusion for Main waiver, comments (continued)

- Loves to go to eat at O' Charley's and Five Guys!!! And also goes swimming!!!
- [She] is friends with everyone. Her sister wants her to have more to do to keep busy!
- [She] is very happy with services. [Mother] says she loves attending church.
- [She] loves taking care of her roommate. She is very mobile herself and helps out a lot.
- [She] said things couldn't be better. She is happy & satisfied with all the services. [Her son] is 25 years old and in very good physical health.

Negative (by category):

Choice

- Doesn't have anyone to interact with at home.
- [He] is not allowed to live with mother.
- He wants his own place.
- I just wish I could change agencies or something.
- I want to see my friend more.
- I would like to move back to Chicago or go back and visit there.
- I'd like to go to Dolly Wood but I ain't got no money.
- Like to have a roommate.
- My sister took my cell phone away, and she said she will not give it back to me unless I lose weight.
- [She] has a problem with one or two of her staff. An SNF will be completed.
- [She] said she would like to give her own medicines to herself and would like to have her own cell phone.
- [She] was concerned about getting a housemate she does much better alone.
- [She] would like to live with someone her own age and likes to do the same things she does. She has seizures and someone with high pitch voices really gets to her.

Medical

- Change pills because they are too big.
- He has trouble sleeping.
- He is having problems with colonoscopy supplies.
- He is ill and may have to be hospitalized.
- Her knee is hurting because of recent surgery.
- Mother: I need to go into hospital for surgery and need a PA to be with [my son] around the clock while I am in hospital.
- [She] needs a product called Thick It but hasn't been able to buy it because it is very expensive and it is not covered by her insurance.

Services

- [Guardian] was contacted by phone and she complained that she was informed about the verbal abuse on 6/26/13 and tried unsuccessfully to obtain any additional information.

D. Community Inclusion for Main waiver, comments (continued)

- Has multiple problems with roll in shower installed by the state.
- [He] said his ISC—who has been his ISC for 8-9 years—treats me like a baby and babies me. She talks baby talk to me. I'm getting tired of her. She has got to go. He said [ISC] is critical of his in-home staff. The staff are doing their job well, he said. He said [his ISC] is trying to stop him from getting a new job. I formerly worked at Sears, and she does not want me to work there again because she said I have 'issues' with them. I have no issues with them. He said his in-home staff is aware of his dilemma. He said his problems with [his ISC] are getting worse year-by-year.
- If [he] is not out in the community at least four hours each day, he becomes very unhappy.
- [She] is limited in her outings because she does not have a lift van. Staff struggles to transfer her from her wheelchair to a car.
- [She] stated that a day shift staff hollered at her and she didn't like it.

Neutral:

- Can you come back to see me soon?
- Got a sinus infection, will feel better tomorrow, can ya'll come back again then?
- [He] didn't understand many of the questions. He answers 'yes' to everything. His mother/guardian helped with interview.
- [He] did not want to answer question 33, he said he might tell me sometime. I gave him several chances to elaborate on his answer but he chose not to. I didn't get any sense that there was an immediate problem.
- [He] did not want to sit for the whole interview.
- [He] had a hard time sitting still he would get up and walk out of the room so we just got him to answer the big four questions.
- He has a large cyst on his right arm.
- [He] stutters but we could understand his answers. He asked if he could come see when he went out into the community, and to come back to see him soon.
- He wants a boom box.
- [He] was not interested in answering all questions.
- I am crazy about boys!
- Individual enjoys opera, country and R&B music.
- Individual has speech and occupational therapists who work to improve his life skills.
- It was good to see him realize that he could ask for items after talking to me.
- It's hard to get this weight off.
- Mom's passed away—going to court to get a conservator.
- She doesn't talk very much. Likes to be alone in her room. Likes using her computer for Disney animation viewing. She has a twin sister and they are very close.
- [She] is deaf but she can read the questions and she gave us the answers.
- [She] seems to have a good memory. She is very possessive of her things and doesn't want anyone to go into her bedroom.

A. Choice and Control for Self-Determination waiver, comments

Do you like where you live?

Positive:

- I live with my mother.
- I love my family. [Friend's name] married me, and mom and I are sooo happy!
- We love our new house.
- Yes, now that they have added male staff

Did you choose the place you live?

Positive:

- Yes, with ISC's assistance.

Negative:

- Agency chose.
- Family chose. (115)

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

Positive:

- Individual likes his staff.

Negative:

- "If I was told, I forgot."

Can you talk to your ISC when you need to?

Positive:

- "I think I can; I've never had to call." (8)
- "She comes to see me at the workshop."

Negative:

- Person has new ISC and hasn't met her yet

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

Would you like to work somewhere else?

Positive:

- “Any job is fine as long as I can make some money.” (11)
- I'd like to work at Chattanooga bakery.
- I'd like to cut grass.
- I'd like to work at a dollar store.
- I'd like to work at a store.
- I'd like to work as a guard.
- I'd like to work as a janitor. (2)
- I'd like to work as a mechanic.
- I'd like to work as a teacher.
- I'd like to work at a store.
- I'd like to work at a body shop.
- I'd like to work at a day care center.
- I'd like to work at a grocery store.
- I'd like to work at a nursing home.
- I'd like to work at a pizza restaurant. (2)
- I'd like to work at Disney World.
- I'd like to work at Fred's.
- I'd like to work at McDonald's. (2)
- I'd like to work at Taco Bell.
- I'd like to work at the co-op.
- I'd like to work at Wal-Mart. (2)
- Would like to work in laundry room because he is good at folding.

Negative:

- I have a part-time job now. (5)
- I like working at the workshop.
- I work at E.W. James and Sons now, part-time.
- I work at McDonald's now-- part- time.
- In the past the person worked in a sheltered workshop doing contract work.

B. Respect and Dignity for Self Determination waiver, comments

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

(No comments.)

Does anyone ever hit or hurt you?

Positive:

- There were previous issues that had already been reported.

Do you know how to report a complaint?

Positive:

- Call 911 or mama.
- I would tell Staff.
- My mom will help me.
- The participant isn't sure, but his mother does know how.

C. Access to care for Self-Determination waiver, comments

Can you always get to the places you want?

Positive:

- The person takes Access Ride to and from the workshop; staff also transports.
- Staff transports.

What special equipment would make your life easier?

Nearly 4% (6 of 154) of the people receiving services through the Self-Determination waiver interviewed in 2013 answered “yes” to needing special equipment that would make their lives easier. Two (2) were for accessibility accommodations to their homes including a walk-in bath tub and a ramp, three (3) were for medical devices or communication aides including a breathing machine, a hearing aid and an electronic speech device. The remaining request for equipment was for an I-pad.

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

Medical:

- 1 Breathing machine
- 1 Hearing aide
- 1 Speech communication device

Modifications:

- 1 ramp request.
- 1 walk-in bath tub

Other:

- An I-Pad

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

Negative:

- Interviewers asked what he didn't get and he didn't know of anything but still stated that his service plan wasn't right.

D. Community Inclusion for Self-Determination, comments

PTP interviewed several people receiving services through the Self-Determination waiver who are working in their communities at restaurants or other service sector jobs. Several people also stated that they enjoy employment in a workshop.

There is more to community inclusion than just working or volunteering, however. Although precise definitions for what constitutes community inclusion or integration do not exist, many researchers consider the use of media to be highly correlated with what is accepted to define community integration (Mcleod, et. al, 1996).

Computer technology and the Internet also broaden lives and increases the independence of people with disabilities (Kaye, 2000). Clearly now, familiarity and common use Facebook, Twitter, YouTube and other social networking sites, use of the Internet is an important part of connecting people with their communities.

Yet among those interviewed receiving services through the Self-Determination waiver in 2013, fewer than two in ten (12.98%) are using the Internet! Yet, again recall that according to a 2013 report by the Center for the Digital Future at the USC Annenberg School for Communication, more than eight in ten (85%) of all Americans are going online!

This measure, although increasing, remains at least 70% below the national average since the inception of PTP, prompting the question, “Why are people with intellectual disabilities not accessing the

internet?” Two key factors impacting Internet usage in the general population are socioeconomic status (SES) and level of education (Hargittai, E., and A. Hinnant. 2008)—which may also be factors for people with intellectual disabilities. However, since so many public spaces (especially libraries) offer free access to the internet, there is little reason for this percentage to be so low.

With more than 87% (134 of 154) of those interviewed who receive services through the Self-Determination waiver in 2013 responding that they do not use the Internet, access and use of the Internet—in addition to typically lower SES and level of education—continues to be an obstacle to full community inclusion and participation. This suggests that people receiving DIDD services need support and encouragement to access the Internet.

Additional questions related to and under the heading of community inclusion are: *Can you visit with the people you want to when you want?* and *Do you have a boyfriend/girlfriend?* The boyfriend/girlfriend question is important in light of a prevailing tendency to judge people with disabilities as asexual (Milligan & Neufeldt, 2001).

Forty eight percent (48% or 73 of 153) of people who receive Self-Determination waiver services and who answered this question responded “Yes,” that they did have a boyfriend or girlfriend. People should also be encouraged and would benefit from more discussions with staff and families. Healthy relationships will increase the differing opportunities and experiences for self-determination for people with disabilities.

D. Community Inclusion for Self Determination waiver (continued)

Do you have a boyfriend / girlfriend?

Positive:

- Has five.
- Individual has many friends and “loves everybody.”
- I'm married. (2)
- Individual reports having many friends. (2)
- Individual has many friends at church.
- Mary is my girlfriend. I took her to the prom. (He showed his prom pictures.)
- Yes, three.
- Yes. He is very tall.

Negative:

- I am an honorary deacon at my church.
- I am looking for one.
- Family member interviewed says participant is a loner and doesn't like to be around people.
- Family member interviewed said socialization is a problem sometimes because of behavior issues
- Individual described himself as a loner.
- Not at this time.

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

Positive:

- I see most of my friends at the workshop every day.

Negative:

- “It's sometimes hard to find the time when we can get together.(6)
- My family lives too far away to see when I want to.

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

(No comments)

D. Community Inclusion for Self Determination waiver (continued)

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

This final qualitative question is an opportunity for people we interview and their family members to share additional comments or concerns that have not come up during the interview. Following are the very few positive and negative comments made by people receiving Self-Determination waiver services interviewed in 2013 all across Tennessee.

Positive:

- Has her own TV in her room, likes to go be by herself and watch Blues Clues
- [He] finished school last year in Bartlett High School.
- I have everything I need.
- I am very pleased with her staff. They have been wonderful with her.
- Likes to go out and eat more.
- Individual showed us the birdhouses he had made. He said he loves making them and doing arts and crafts.
- Said his sister and the entire family are very supportive & are constantly helping him with his learning & talking.

Negative

- Concerned about not having a hearing aide.
- Family member said the participant is in the hospital with a blood clot on his brain.
- Mother/guardian and [individual] are staying with [individual's] sister until they find an apartment. Sold their last home. It was in a dangerous neighborhood.

A. Choice and Control for Arlington waiver, comments

From 2012 to 2013, there were almost twice as many interviews conducted with people receiving services through the Arlington waiver, while the number of people receiving services through the Arlington waiver has dropped more than 3% (from 587 in 2012 to 565 in 2013). This increases the measure of confidence level (accuracy or relevancy of the statistic) from +/- 13.9% in 2012's report to +/- 9.3% in this 2013 report.

Do you like where you live?

Positive:

- He is so much happier in the group home than when he was at [Developmental Center].
- He said that he loves it.
- Individual likes the house much better than the [Developmental Center].
- When we talked about his home, his face lit up.

Negative:

- I want to live with my family.
- I sometimes would like to live alone.
- I don't like the house. (4)

Did you choose the place you live?

Negative:

- Family chose.
- It was chosen by (corporate conservator).
- Provider chose for him.
- Sister chose.

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

Positive:

- He said that he would tell his ISC if there are issues.
- His conservator was aware.
- His has favorite staff.

A. Choice and Control for Arlington waiver, comments (continued)

Can you talk to your ISC when you need to?

Positive:

- I think I can; I've never had to call.
- Conservator calls when needed.

Would you like to work somewhere else?

Positive:

- Any job is fine, as long as I can make some money. (9)
- I'd like to work at a store.
- I'd like to work as a landscaper.
- I'd like to work as a security guard.
- I'd like to work at a dollar store.
- I'd like to work at a bar.
- I'd like to work at McDonald's.
- I'd like to work at pizza hut.
- I'd like to work at Wal-Mart.
- I'd like to work in a warehouse.
- Person wants to get a job again.

Negative:

- I work at a day care center part time now.
- I work part-time now.
- I'm working now part time at pizza hut.
- Used to work at Goodwill.

B. Respect and Dignity for Arlington waiver, comments

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

Positive:

- He loves his staff especially [individual].
- He is happy with the staff.

Negative:

- Individual's mother says she doesn't think the staff has been treating her son well and is very concerned for his safety.
- Individual says he tries to talk to his staff, but he feels they ignore him.

Does anyone ever hit or hurt you?

Positive:

- Individual's roommate hit him last year. Staff member and individual's sister filed a complaint and everything has been worked out.
- Individual says a staff member pushed him and was suspended for one day.

Do you know how to report a complaint?

Positive:

- Tell [staff] but she is hard to get a hold of and is sometimes unresponsive or unavailable.
- Conservator does.

C. Access to care for Arlington waiver, comments

Can you always get to the places you want?

There were 93 of 93 positive responses to this question with a single comment.

Positive:

- We have a van.

C. Access to care for Arlington waiver, comments (continued)

What special equipment would make your life easier?

Slightly more than 3% (3 of 93) of the people receiving services through the Arlington waiver interviewed in 2013 answered “yes” to needing special equipment that would make their lives easier. One (1) request was for new eye glasses, one (1) request for mobility aides (supportive shoes and a walking cane), and one (1) request for a new lift.

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

There are ninety two (92) positive responses without comment. The single negative comment is below.

Negative:

- He says his old staff in Memphis used to buy him clothes and take him out more.

D. Community Inclusion for Arlington waiver, comments

For 2013, PTP interviewed 93 people receiving services through the Arlington waiver. Nearly one half of people served by the Arlington waiver (43, or 46%) were working in workshops or identified as participating in day programs. Thirty seven (37 or 40%) people interviewed responded that they participated in their communities. Nine (9 or 10%) people reported part-time jobs in the community, including McDonald’s, KFC, Wal-Mart, and a Recycling facility. Also, five (5 or 5%) people receiving services through the Arlington waiver reported using the internet. Below are the comments collected, corresponding to the questions *Can you visit with the people you want to when you want?* and *Do you have a boyfriend/girlfriend?*

Do you have a boyfriend / girlfriend?

Positive:

- [Boyfriend is named].
- Individual has a girlfriend at the center.
- Individual has several friends
- She has a boyfriend. She met him at the center. She sees him at the center and his staff brings him to visit her once or twice per week. They like to watch movies together.

D. Community Inclusion for Arlington waiver, comments (continued)

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

Sixty eight individuals (68 or 73%) replied positively with no comments to this question. Thirteen individuals (13 or 14%) indicated “Sometimes” with no comment. Six (6 or 6%) individuals said “No” because they claimed they had no one to see, or it was hard to find time to get together.

Negative:

- It’s sometimes hard to find the time when we can get together. (5)
- It’s hard to find the time when we can get together. Mostly around the holidays.
- I have no one to see. (4)

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

Positive:

- Individual has TV in her bedroom and likes to stay in bedroom alone a lot.

Negative:

- Individual says that she can't go in her room alone and have privacy.
- Individual says staff pesters him and does not pay attention to him.

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

This final qualitative question creates an opportunity for individuals to share any other comments or concerns.

Positive:

- Everything is fine.
- He talked about his subscription to Sports Illustrated. He loves to read it and see the girls' pictures.
- Individual just got back from doctor check-up in good health.
- Individual reports, “I’m just happy.”
- Individual told us he could read and tell time.

Negative:

- Conservator reported that staff isn’t giving the information [he] asks for. “I don't know if he is being mistreated. I am worried about him. I would like to have him moved closer to me so I can check on him more often.”

A. Choice and Control for Developmental Centers, comments

Do you like where you live?

Positive:

- [She] gets along very well with her staff and knows them interacts with them very well.
- I wish I had a bigger house.

Did you choose the place you live?

Positive:

- Conservator said the participant has always shared a room with someone, and she expects that the participant may have an easy transition if and when she is moved to a residence with her own room.

Negative:

- Conservator said a social worker assisted in choosing where [he] lived.
- Individual's dad and grandmother chose.
- Individual's family chose. (6)
- Individual's family & the state chose.

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

Positive:

- Conservator knows. (3)
- Conservator understands his right to change anyone handling the Individual's care.
- Individual's brother does.
- Individual's family knows they can change support staff.
- Individual's family understands their rights and talks with [Developmental Center] staff regularly.

Negative:

- Conservator reports getting frequent calls from the developmental center.
- Conservator did not know he had the right to change support staff.
- She did not know until we told her and she has different staff.

A. Choice and Control for Developmental Centers (continued)

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

Positive:

- Individual's family says they are in regular contact with [Developmental Center] staff.

Negative:

- Sometimes.

For all but two conservators interviewed in 2013 on behalf of their ward residing in a developmental center, it was communicated that they could talk with the Case Managers when they needed to. Most people interviewed (19/35 or 54%) for this population resides at Middle Tennessee's Clover Bottom Developmental Center. In 2013, PTP did not complete any interviews at Private Intermediate Care Facilities.

Would you like to work somewhere else?

Positive:

- Individual would like to work at McDonald's.

Negative:

- Conservator says the participant can't work. (4)
- Conservator said participant is not able to work due to physical limitations.
- Depending on what his muscles would allow him to do.
- Due to medical issues participant is unable to work. (2)

B. Respect and Dignity for Developmental Centers, comments

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

Positive:

- Conservator says he is very pleased with participant's care at the developmental center.

Does anyone ever hit or hurt you?

Positive:

- Sometimes her roommates take things without asking.
- Someone hit him in the eye 4 or 5 years ago.
- [He] says he hits himself.

In 2013, this question received two affirmative responses and one response of "Sometimes" at Developmental Centers. In 2012 and 2011, there were no affirmative responses from people residing at Developmental Centers or at private intermediate care facilities. PTP did not have any interviews indicating that the person being interviewed was unable or unwilling to communicate a response to this question.

Do you know how to report a complaint?

Positive:

- Brother does.
- Conservator knows. (3)
- Conservator is in regular contact with developmental center staff and is happy with the participant's care. He does know whom to contact if he wants to change things.
- Father said he does know how.
- Mother said she knows.
- Individual said she would dial 911 and tell staff.
- Individual's family knows.
- Individual's sister is very involved in her care and knows how to take action if needed.
- Individual's sister said she does.
- Individual said she would tell staff.

Negative:

- [He] left the interview, so staff answered that he did not know how to report a complaint.

C. Access to care for Developmental Centers, comments

Can you always get to the places you want?

Positive:

- Conservator reports that staff takes [him] wherever he needs to go.
- Due to physical limitations, participant is transported is by ambulance in his bed wherever his wants to go.
- Individual said she likes to visit her mom and go to church on Sundays.
- Staff transports him. (8)

What special equipment would make your life easier?

One person responded “[s]he is in the process of getting a new wheelchair.”

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

Positive:

- Individual started at [one agency] in 2003 and now she would like a different job. She would like to work at a clothing store.
- Conservator says they have a meeting coming up soon and know they can change things.

D. Community Inclusion for Developmental Centers, comments

In 2012, one (1) person at a Developmental Center reported using the internet. In 2013, PTP interviewed three (3) people residing at a Developmental Center that used the internet.

Do you have a boyfriend / girlfriend?

Positive:

- [She] has a friend she likes at the center.
- [His] mother told us she is his best girl.
- [She] has friends at the center she is very fond of.
- Stephen.

D. Community Inclusion for Developmental Centers (continued)

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

Positive:

- Family said [she] visits with her brother and sister about once a month.

Negative:

- Without comments, one (1) “Sometimes” response.

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

This final qualitative question creates an opportunity for expression of additional comments or concerns that would not have otherwise appeared through the interview process.

Positive:

- Conservator has heard reports that the state will be closing down the workshop and moving the participant to another building.
- Conservator reports that participant has worked in sheltered workshops before and was very skilled at assembling pens. She loved to work for hours and would become agitated when she was told it was time to stop. She also loves to go to dog shelters to see and pet the puppies. She loves going to church and listening to church music, especially Tennessee Ernie Ford's Gospel music.
- [His] favorite thing to eat is cornbread and milk.
- I have a little dog.

6. GOALS

In the year 2013, PTP was again asked to conduct interviews with a minimum of 1,200 people receiving services through the various waiver programs. In 2013, PTP successfully conducted and recorded 1401 interviews with individuals in 68 (72%) of Tennessee's 95 counties.

The following table lists all Tennessee's counties and the number of interviews conducted in 2013 by PTP teams.

Anderson	17	Fentress	25	Lauderdale	5	Roane	0
Bedford	8	Franklin	4	Lawrence	7	Robertson	0
Benton	28	Gibson	57	Lewis	0	Rutherford	6
Bledsoe	1	Giles	3	Lincoln	5	Scott	2
Blount	10	Grainger	0	Loudon	13	Sequatchie	1
Bradley	22	Greene	79	Macon	7	Sevier	5
Campbell	0	Grundy	30	Madison	110	Shelby	74
Cannon	0	Hamblen	0	Marion	3	Smith	0
Carroll	30	Hamilton	216	Marshall	3	Stewart	23
Carter	1	Hancock	0	Maury	23	Sullivan	10
Cheatham	0	Hardeman	20	McMinn	38	Sumner	19
Chester	4	Hardin	15	McNairy	25	Tipton	7
Claiborne	0	Hawkins	0	Meigs	2	Trousdale	0
Clay	0	Haywood	14	Monroe	0	Unicoi	0
Cocke	9	Henderson	10	Montgomery	9	Union	0
Coffee	6	Henry	9	Moore	0	Van Buren	0
Crockett	10	Hickman	1	Morgan	4	Warren	0
Cumberland	20	Houston	6	Obion	17	Washington	17
Davidson	106	Humphreys	22	Overton	4	Wayne	14
Decatur	3	Jackson	0	Perry	1	Weakley	23
DeKalb	1	Jefferson	0	Pickett	0	White	3
Dickson	16	Johnson	0	Polk	0	Williamson	7
Dyer	26	Knox	24	Putnam	22	Wilson	0
Fayette	2	Lake	0	Rhea	37	TOTAL	1401

7. RECOMMENDATIONS

Consistent evaluation and monitoring of a program and the system within which it operates is important to maintain the quality and effectiveness of the services it provides. Program evaluation seeks to gather information to improve effectiveness, to assist administrators making program-level decisions, and to enable interested parties to examine a program (Posavac and Carey, p. 10). In producing the 2013 PTP report, using representative data and statistics about the people receiving services, the following recommendations are made within these categories:

Employment

- ❖ **Increase the number of *gainful employment* opportunities in the community.** DIDD seeks to promote employment of persons it supports through its *Employment First!* initiative. This initiative has shown improvement in moving the employment rate from 16.3% in September 2011 to nearly 22% in December 2012 (<http://www.tn.gov/didd/EmploymentFirst/documents/Employment%20Statistics%20-%2020130201.xlsx>). Numbers for employment for the calendar year 2013 have not been publicized as of the time of this report. Hopefully, this trend will continue and will soon surpass the high near-25% employment rate reported in December 2004. Employment data for May, 2013 shows 964 people receiving services that are also employed. As this statistic includes competitive, supported, and sheltered employment, the average wages works out to under \$5.09 per hour per person, and is still well below the high of 2004 with under 13% employment (<http://tn.gov/didd/EmploymentFirst/documents/Employment%20Statistics%20-%2020130701.xlsx>). With strong departmental emphasis on employing people with disabilities, the comments in this report—page 25-29 shows comments collected from people receiving Main waiver-funded support, page 46 shows comments collected from people receiving Self-Determination waiver-funded support—show clearly that many people want to work, and even know where they want to work.

Choice

- ❖ **Teach the *meaning of choice* to providers and to people receiving services.** People responding to the PTP interview may have replied they had choice in their employment or living arrangements, but after more questioning PTP has discovered that individuals

may not understand the meaning of the word *choice*. One of the ten domains for a positive performance as outlined by DIDD Quality Assurance program is “choice and decision making” (Quality Assurance Frequently Asked Questions www.tn.gov/didd/quality_management/faq.shtml). Understanding the concept of choice is prerequisite to the possibility of self-determination. National Core Indicators—which produces the survey tool that PTP will use beginning in 2014—proposes training in self-advocacy via the internet. As discussed below, internet use by people with disabilities lags behind national averages, and therefore requires training as well. Both of these trainings should be addressed by agencies as part of their services and programs (<http://www.nationalcoreindicators.org/blog/article/self-advocacy/>). Continued emphasis on person-centered planning will also further individual choice.

Information Dispersal

- ❖ **Implement internet awareness projects and trainings while also improving internet access.** Due to the still relatively low numbers of people receiving services from DIDD who are using the internet (under 12.5%), more information should be shared with individuals and their families about increased internet awareness and technological assistance. Increasing individuals’ access to the internet should also enhance the level of community inclusion and increase the level of independence for people receiving services (McLeod, et. al. 1996., Kaye. 2000.)

Independent Support Coordination/Case Management

- ❖ **Improve the current ISC system.** It is difficult for individuals and the people who support them when there is too little time and attention available from an ISC. There continues to be anecdotal evidence from people receiving services that calls are not returned promptly enough, and that there is a long wait before any decision or provision of assistance, devices, or service.
- ❖ **Improve the timeliness of providing needed adaptive equipment.** PTP identified several individuals needing special equipment to make their lives better. Some items listed may not be easily funded or found. Supplementary training in alternative funding sources to purchase adaptive equipment may benefit ISCs and the people who need the equipment.

Program Recommendations

Adjusting the instrument

In 2013, PTP continued to use a significantly modified *Participant Experience Survey*, an instrument designed by Medstat and approved by CMS. Over the years PTP has revised the interview questions to address shortcomings or ambiguity following feedback from the interviewing teams and people interviewed. A new PTP interview instrument (survey tool) will remove ambiguous questions, and should increase the rigor and applicability of statistical findings.

Subjective interpretation of the wording and phrasing of questions affects the answer and interferes with statistical inferences. Implementing a revised interview instrument will reduce discrepancies stemming from what Schwarz (1996) noted—that seemingly innocuous differences in the phrasing of survey questions will affect how people report about their experiences and surroundings. PTP will put a new interview instrument or survey tool into use beginning in 2014.

System Recommendations

Use of technology

- 1) The information that PTP receives is compiled from the state’s CS tracking database. For years now DIDD has struggled to upgrade its existing computer information systems. Project Titan is a new effort to replace DIDD’s system with a single, integrated solution. Upon complete implementation, Project Titan should provide for a database with demographic data, electronic Individual Support Plans, financial data, and any investigations data (<http://tn.gov/didd/TITAN/TITAN.shtml>)
- 2) It is recommended that DIDD consider implementing an initiative around internet usage and social networking for the people they serve—perhaps incorporated into the new staff training and educational online resources.

Special Equipment

- 1) Continue to address equipment needs of the people served. Reviewing this report’s comments from people we interviewed, there are mostly completely reasonable “equipment requests” for wheelchairs or walkers, shower chairs or grab bar modifications

to bathrooms. PTP recommends a review, and possible streamlining, of the procedures in place to provide people with requested special equipment.

The percentage of interviews in 2013 where people expressed a need for special equipment is in the following table.

2013 PTP interviews	1119 Main waiver individuals	154 Self-Determination waiver individuals	93 Arlington waiver individuals	35 Greene Valley Developmental Center or Clover Bottom Center individuals
People who needed special equipment to make their lives easier.	5.4%	3.9%	3.2%	5.7%

8. UNANTICIPATED OUTCOMES

- 1) Per the contract agreement with DIDD, PTP is to complete at least 1,200 interviews per reporting period. In 2013 PTP met with and successfully reported interview results for 1401 individuals, exceeding the goal by 17%. Increased numbers of successful interviews produces statistically more accurate results, and, more importantly, broadens the reach of the quality assurances that PTP may provide to the system in Tennessee.
- 2) PTP will begin implementing a different survey tool for conducting interviews in 2014. Using the National Core Indicators (NCI) Adult Consumer Survey for PTP interviews will make future results comparable to any or all the other 40 NCI member states (<http://www.nationalcoreindicators.org/>). Unfortunately, although many of the new questions are similar to questions in the interview tool used by PTP, the wording is often different, and questions in the NCI tool appear in a different order. This means that an “apples-to-apples” comparison with existing and past PTP data will be virtually impossible.

9. FUTURE PLANS

DIDD continues to support the PTP Project and the interviewers rise to the occasion by completing more than the project minimum of 1,200 face-to-face interviews annually. PTP continues to provide independent quality assurance measures powered and led by the voices, priorities and choices of people receiving services and their families. Moving forward, the following requirements, guidelines and changes are in place:

- ✓ For calendar year 2013, DIDD has requested a significant change in procedure for those individuals who are unable or unwilling to communicate responses to the interviewers. Rather than submit Survey Notification Forms in such situations, PTP interview teams will follow up with guardians, conservators, or other contact persons of those individuals for whom no responses could be recorded. Those guardians and conservators will be offered the opportunity to participate in the interview on behalf of the individual with a disability. This procedure is expected to continue for future interviews with individuals who are unable or unwilling to communicate responses to the interviewers.
- ✓ This new procedure has empowered PTP to include more comprehensive interview data, which has not previously included information relating to individuals unable or unwilling to participate in interviews. By allowing PTP to interview an interested party on behalf of those individuals rather than automatically submitting SNFs, the state can better focus its resources.
- ✓ Project Director will provide interviewers with the training and instruction needed to implement these changes.
- ✓ PTP hopes to continually expand its outreach for the betterment of the lives of all of the individuals who receive DIDD supports, as well as their families.

10. PTP INTERVIEW INSTRUMENT FOR 2013

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 Interviewers:

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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