



PEOPLE TALKING TO PEOPLE

ANNUAL REPORT

for

January 1- December 31, 2012

Prepared

by

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EXECUTIVE SUMMARY

People with disabilities in America depend on different supports than our society often provides. 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 quality 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 received. Tennessee uses PTP interview findings to show CMS that it administers quality services under the Medicaid Waivers for people with intellectual disabilities.

In 2012, PTP completed its tenth 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. Supported people are served by more than 470 non-profit and for-profit agencies that provide home and community-based services. PTP’s interviews 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 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	Gail Compton, Interviewer	6
Jimmy Gillenwater, Interviewer	1	Mary Dale Greene, Interviewer	6
Danny Reaves, Interviewer	1	Allison Miller, Interviewer	6
Jean Smith, Interviewer	2	Michael Robinson, Interviewer	6
Heather Wilson, Interviewer	2	Brenda Lackey, Interviewer	6
Linda Wilson, Interviewer	2	Tom Griffin, Interviewer	7
Melissa Crouch, Interviewer	3	Sean Flowers, Interviewer	7
Larry Jacobs, Interviewer	3	Judy Sparks, Interviewer	7
Holly Kirby, Interviewer	4	Jessica Hatley, Interviewer	8
Cassie Frantz, Interviewer	4	Patrick Sanders, Interviewer	8
Brandy McCauley, Interviewer	4	Sondra Loveless-South, Interviewer	9
Woody Cade, Interviewer	5	Nadine Loveless, Interviewer	9
Josh Turner, Interviewer	5	Linda Roberson, Interviewer	9
John Blake, 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 has successfully completed collecting and reporting interviews for 2012. PTP operates through a grant from the Department of Intellectual and Developmental Disabilities to The Arc Tennessee. PTP has nine teams of part-time interviewers across Tennessee's three major regions, covering all 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 67-70). An enhanced version of the interview questions including corresponding pictures, as well as a large-type version, are also available to PTP teams, enhancing full 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 for PTP interviews is the identification of specific problems and unfavorable situations. Whenever PTP Teams 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 containing an explanation of the specific issue. A Survey Notification Form (SNF) 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 fourth year that PTP is following this procedure.

These four questions are used as key performance measures for CMS in the PTP interview:

- 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 2012, PTP interviewers generated 454 (four hundred fifty-four) SNFs. Of these, 273 involved interviews with individuals who were not able to communicate responses. These interviews are automatically followed by the submission of an SNF because valid responses were not collected for the four key questions. In addition, 95 SNFs were submitted for interviews that were incomplete or were declined by the individual, a family member, or staff. The remaining 86 Survey Notification Forms directly address complaints or concerns of people interviewed during the 2012 calendar year.

Additionally, PTP adheres to 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 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 with disabilities are in their communities doing important work collecting information for Tennessee and helping to change perceptions of people with disabilities. Interviewers are inspirational and motivational for those who want to work to better 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-two people residing in the Greene Valley Developmental Center or in an Intermediate Care Facility (ICF). All interview results in this report were

completed in 2012 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 available at: (www.randomizer.org/form.htm).

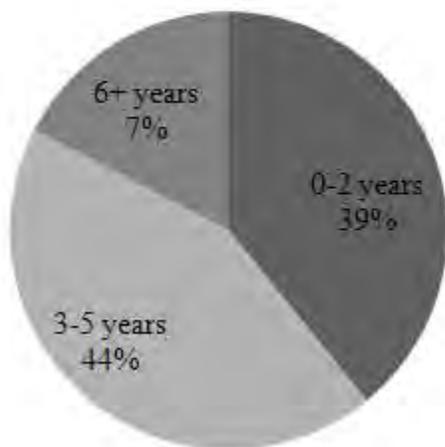
People selected in 2012 were assigned to each of the nine PTP interviewing teams, corresponding to the nine Developmental Districts in Tennessee (www.tn.gov/tacir/PDF_FILES/Infrastructure/Infra07_ddm_ap.pdf). When a team exhausts its list, more randomly-selected people are added from the master list.

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-seven interviewers carrying out the project across the state, twenty-two have been working for the project for more than a year.

Years Working as a PTP Interviewer



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 2012, 1379 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 2012 are the same as in 2011, 2010 and 2009, making the results comparable. The relevancies of the findings are indicated below for each specific waiver population.

2.1 2012 Main waiver interviews

The master list provided by DIDD in June 2012 includes 5,935 people in the Medicaid Home and Community Based Services waiver (Main waiver). In 2012, PTP collected and reported interviews for 1,136 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 1,136 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 14-19).

2.2 2012 Self-Determination waiver interviews

For the 1,141 people in the Self-Determination waiver on the list from DIDD, the confidence level is 95% at a confidence interval of 7.1 (+/- 7.1%). This means that given 165 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 7.1%. (See pages 14-19).

2.3 2012 Arlington waiver interviews

For the 587 people in the Arlington waiver on the list from DIDD the confidence level is 95% at a confidence interval of 13.9 (+/- 13.9%). This means that given 46 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 13.9%. (See pages 14-19).

2.4 2012 Developmental Center interviews

For the 278 people receiving supports at Greene Valley Developmental Centers or a private intermediate care facility on the list from DIDD, the confidence level is 95% at a confidence interval of 16.3 (+/- 16.3%). This means that given 32 interviews with people residing at Greene Valley Developmental Centers or a private intermediate care facility, 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 16.3%. (See pages 14-19).

3. PTP STAFF

The Arc Tennessee's office is located in Nashville. Frank Meeuwis is the Project Director and supervises 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 TN, 4, 5 and 6 in Middle TN, and 8 in West TN 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:

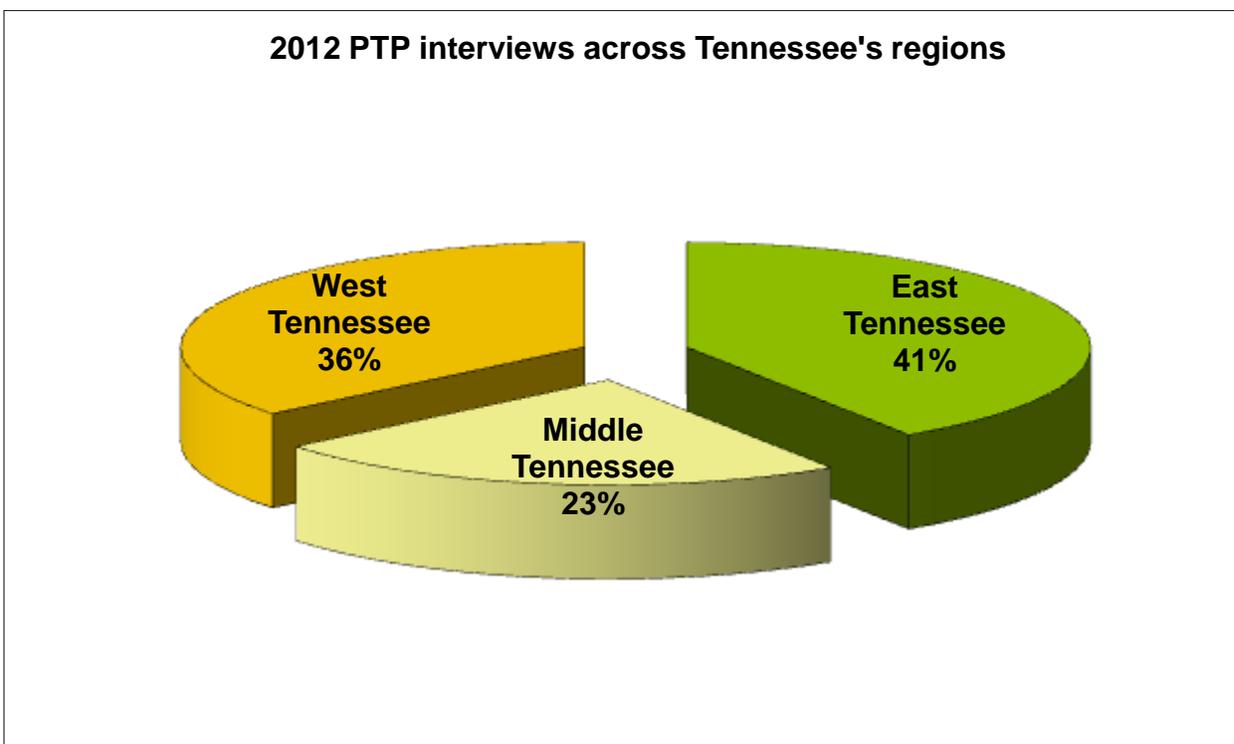
Region		Counties	Interviewing Team
East	1	Carter, Greene, Hancock, Hawkins, Johnson, Sullivan, Unicoi, Washington	Ashley Brookshire and Danny Reaves; Jimmy Gillenwater is an alternate interviewing partner.
	2	Anderson, Blount, Campbell, Claiborne, Cocke, Grainger, Hamblen, Jefferson, Knox, Loudon, Monroe, Morgan, Roane, Sevier, Scott, Union	Heather and Linda Wilson; Jean Smith works as a telephone interviewer 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 Cassie Frantz; Brandy McCauley replaced Cassie Frantz in August.
Mid Cumberland	5	Cheatham, Davidson, Dickson, Montgomery, Robertson	Woody Cade and Josh Turner; John Blake is an alternate interviewing partner.
South Central	6	Bedford, Coffee, Franklin, Hickman, Lawrence, Lewis, Lincoln, Marshall, Maury, Moore, Perry, Rutherford, Wayne, Williamson	Gail Compton and Mary Dale Greene; Allison Miller, Michael Robinson and Brenda Lackey are alternate interviewing partners.

4. INTERVIEWEE DEMOGRAPHICS

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

Below is the regional distribution of the PTP interviews completed by each team in 2012. The chart below this table shows the geographical distribution of these interviews.

Region:	EAST TN			MIDDLE TN			WEST TN			Jan-Dec 2012 total
	1	2	3	4	5	6	7	8	9	
Total	77	127	358	93	182	46	329	30	137	1379
%	5.58%	9.21%	25.96%	6.74%	13.20%	3.34%	23.86%	2.18%	9.93%	100.00%
Region total	562			321			496			1379
%	40.75%			23.28%			35.97%			100.00%



5. PTP INTERVIEW RESULTS

The PTP interview results are comparable to previous reports because the questions, methods, calculations, and procedures are identical. The pie charts on pages 14-19 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.

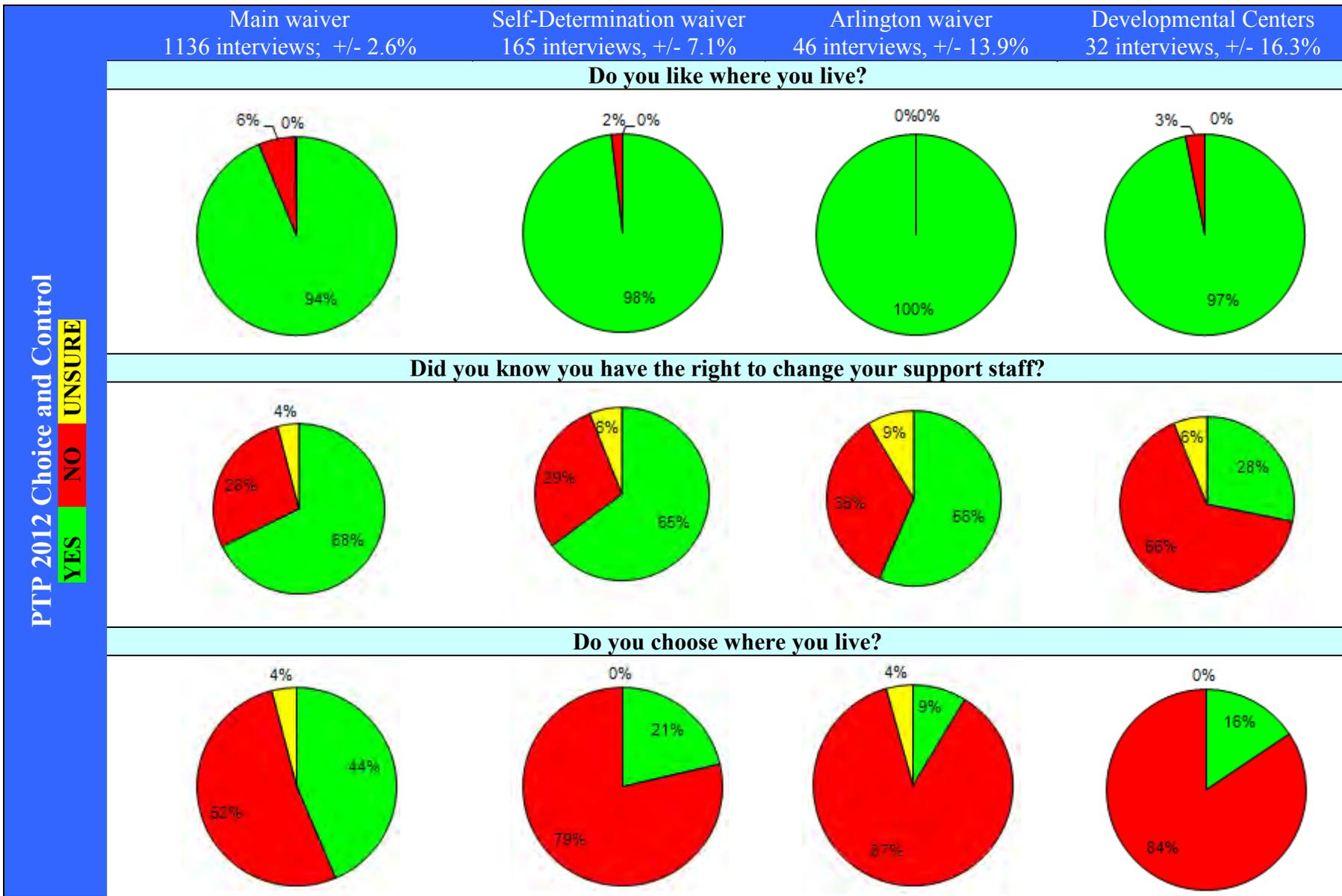
The confidence level (or confidence interval) is 95% for each question and for each waiver population. This is the predictive power or strength of the results.

The four questions selected 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 2011 interview findings reveal more than a sixteen percent (16%) decrease in the number of “Unsure/Not Applicable” responses collected from people receiving services at the Greene Valley Developmental Center or an intermediate care facility.

<http://www.tn.gov/didd/PeopleTalkingToPeople/FINAL%20PTP%202011%20report.pdf>

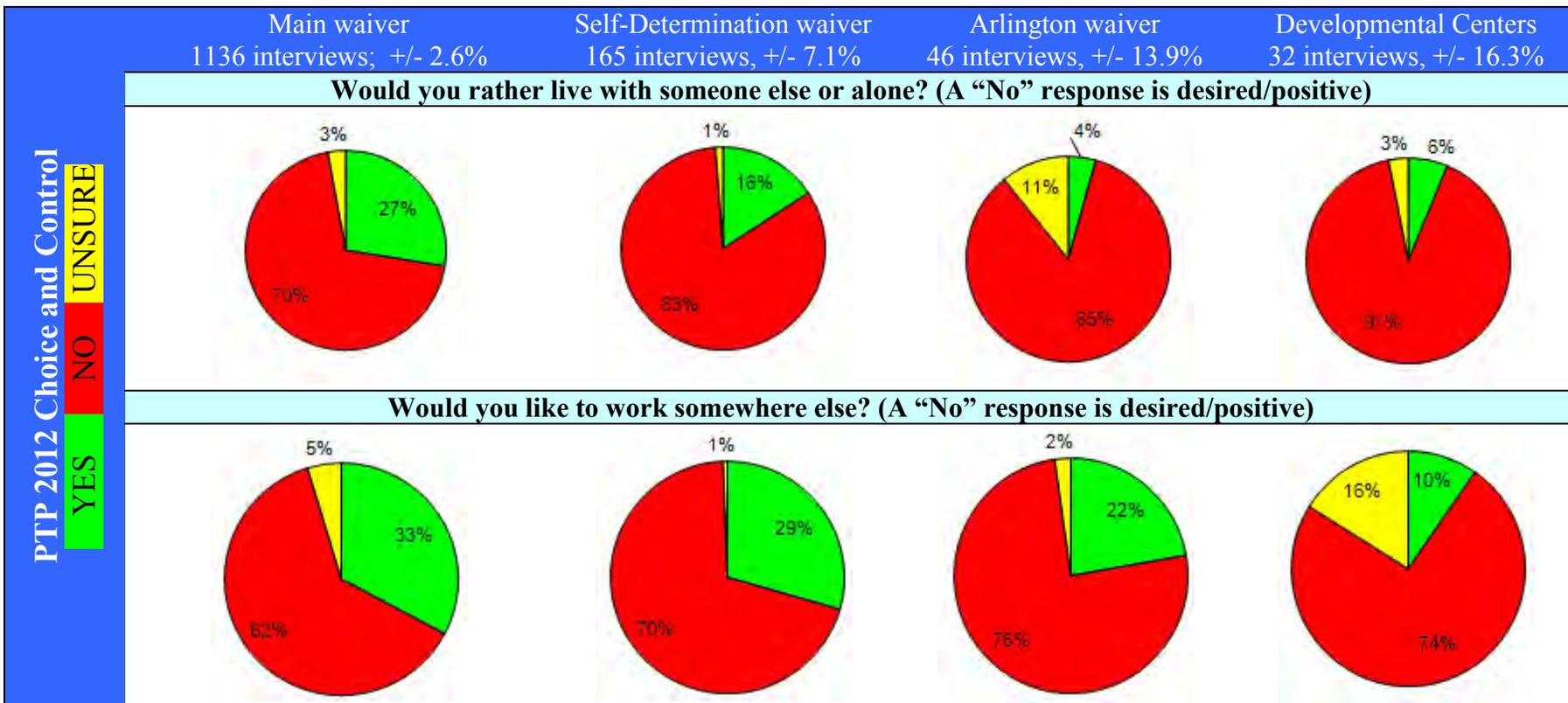
The lower rate of “Unsure/Not Applicable” responses naturally increases the number of valid responses and should therefore be a more useful measurement to DIDD.

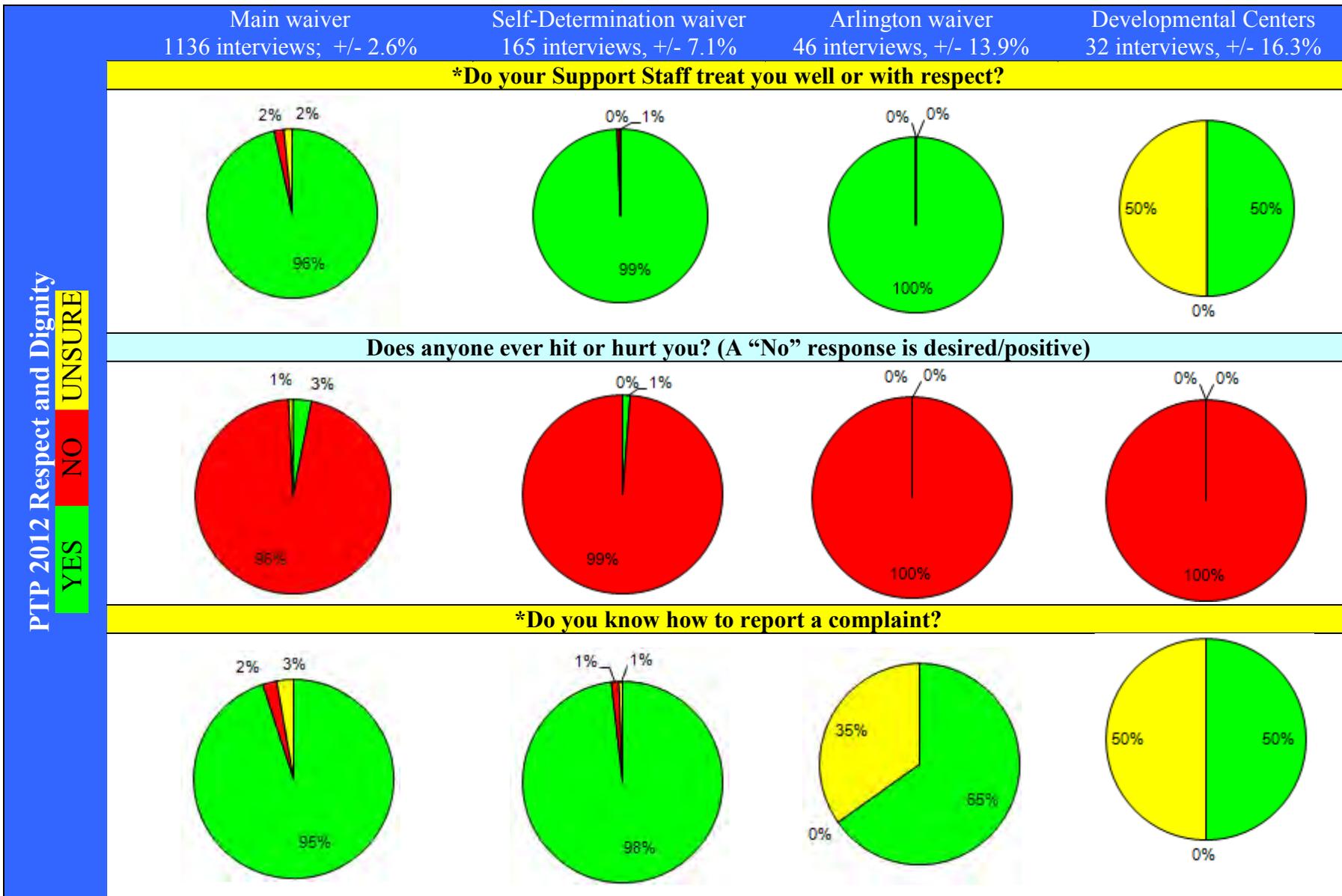


PTP 2012 Choice and Control

YES NO UNSURE

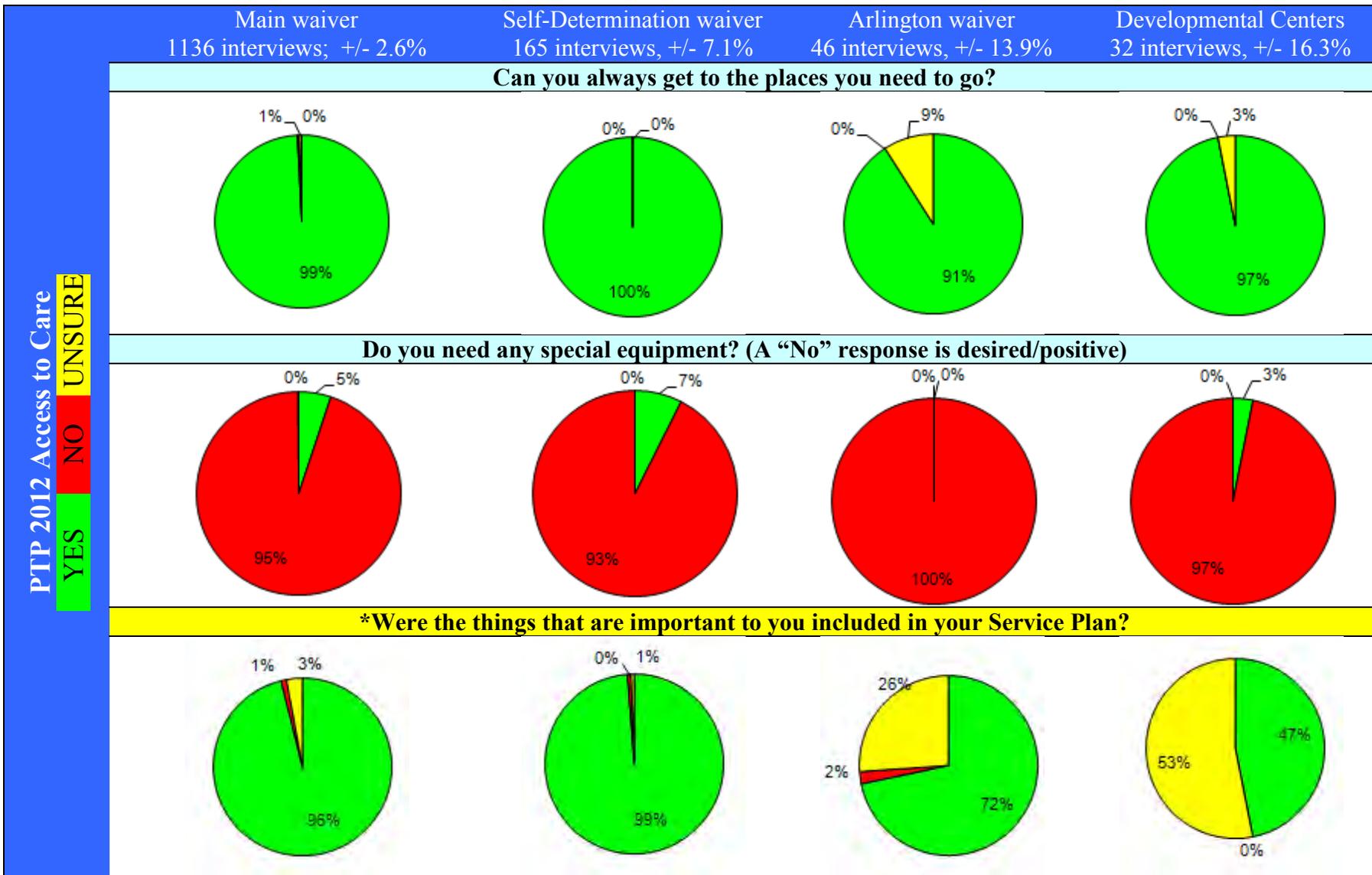






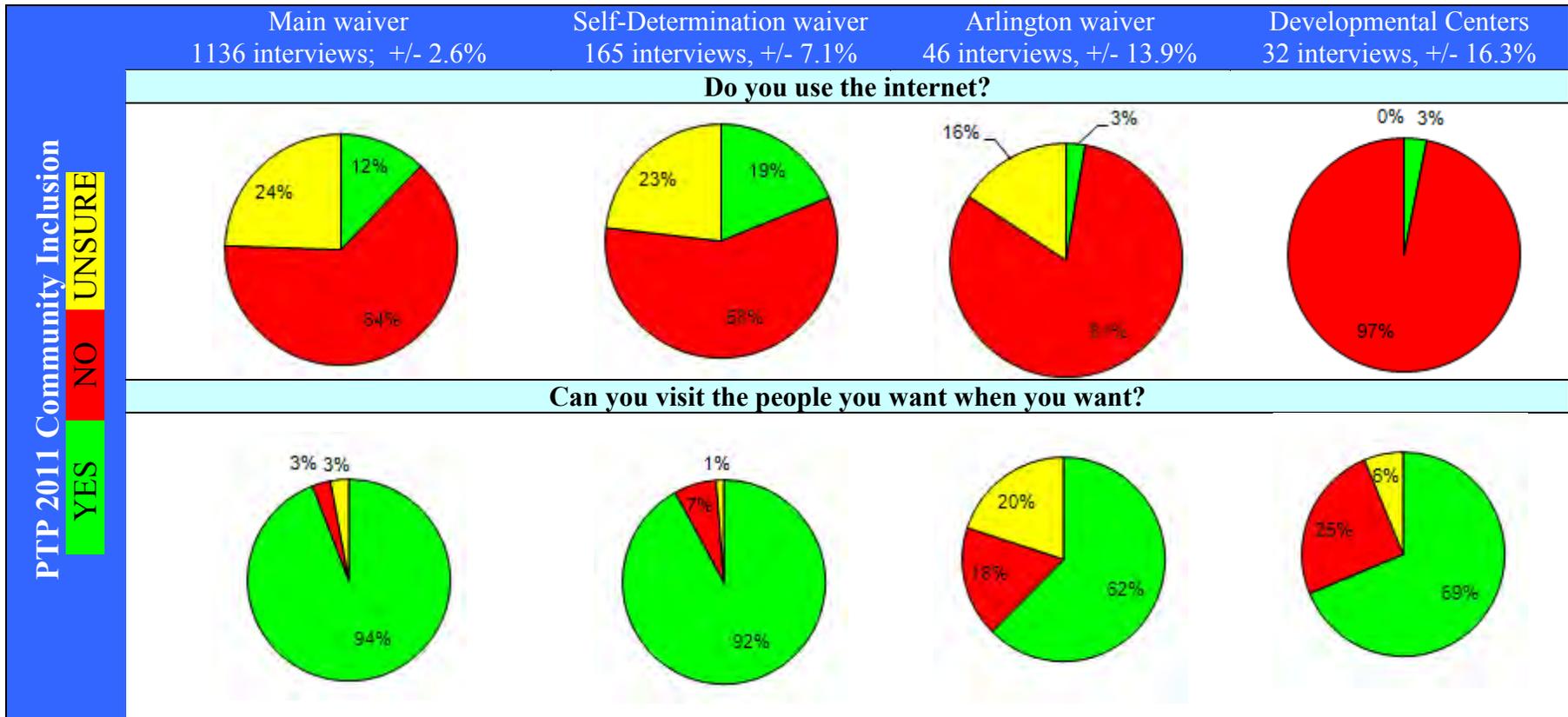
PTP 2012 Respect and Dignity

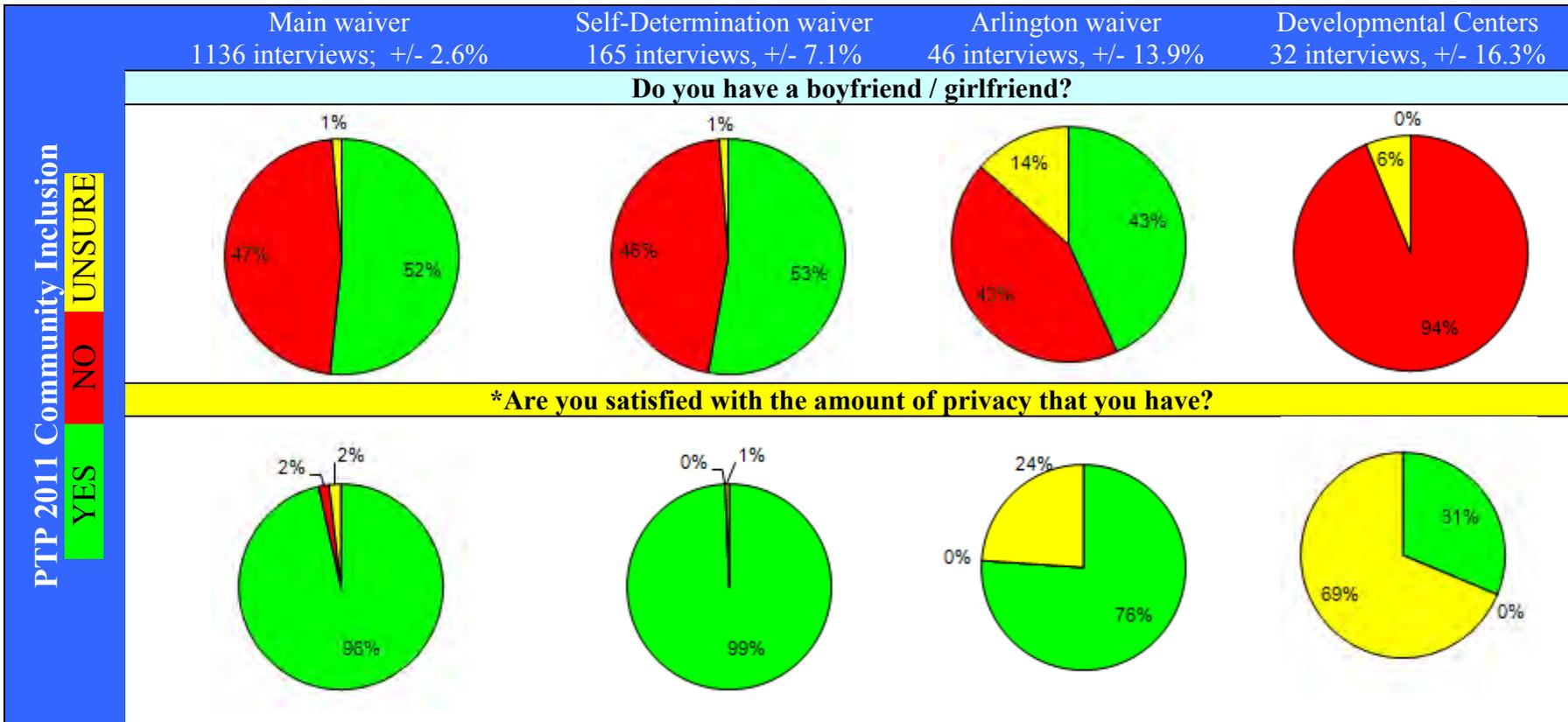
YES
NO
UNSURE



PTP 2012 Access to Care
 YES NO UNSURE







5. PTP INTERVIEW COMMENTS

The PTP interview for 2012 includes the same questions as the previous three 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 page 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:

- But moving soon.
- Gets along well with his 3 housemates.
- [He] has lived in several group homes.
- [He] lives in a foster home.
- [He] said his new home is "superior" to his previous home.
- [His] staff member said his new home "is a lot nicer than the other [previous] place."
- He says that he would like to have more room to store all of his stuff.
- He would like to live with family.
- Housemate is incapable of keeping house like [she] is accustomed to.
- In the past, [she] lived at [a different] developmental center.
- Individual said his new home is much better than the duplex he formerly lived in because it has more living space.
- Individual said she wants to move to another home if possible.
- Individual said there is a lot of crime where he lives and he wants to move.
- "It's different."
- Likes roommates.
- Likes current house and staff but doesn't like housemate.
- Lives with mom and brother.
- Love it.
- Moving again soon.
- She could not remember how long she has lived in her new home, but she likes it because she got the bigger bedroom and her own bathroom.
- She said she likes her present apartment better than her previous residence, which didn't have sufficient walking space.
- With mother.

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

Negative:

- Fussing and fighting going on all the time.
- She would like to move back to Walnut Street. She commented that someone was mean to her because she wanted a second cup of coffee and they said no.
- Her roommate gets mad and starts yelling sometimes.
- Trying to move into another apartment.
- Would rather live at home with mom.
- Does not like the area.
- Doesn't like it because it is too crowded.
- [He] said drugs are a problem at his apartment complex.
- He wants to change to a different group home.
- He would like to move to where he doesn't have to go up or down stairs.
- House design is not good; looking for a new one.
- House manager keeps jumping on her.
- "I don't always get along with my housemates."
- "I don't like the house."
- "I liked my other house better, but I didn't want a housemate so this was all I could get."
- Indicated that he was happier in his previous home.
- Individual said she wants to live in another home.
- Maintenance problems with the house.
- Moving in one week because of rats and termites.
- Moving to another house.
- Not without cable.
- Rather live in Oak Ridge than Clinton.
- Rather live on Duck Pond Road. That's where she was raised.
- She does not like her housemate. She thinks he is too slow,
- "There are older people there. They're like in their 50's and I'm only 25!"
- Too many people.
- Too much confusion.
- Would like to live in a house instead of apartment because neighbors are noisy upstairs.

Did you choose the place you live?

Positive:

- Agency helped.
- Agency let individual visit several homes before he decided where to live.
- Brother helped.
- Chose the new place.

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

- [He] lives with her brother and sister-in-law.
- [He] was assisted by his mother in looking for their home.
- “I had a little bit of a problem with some of the people where I lived, so I asked to move.”
- “I had to have help - my Aunt.”
- Individual lives with three housemates.
- Individual said she chose her present apartment because she loves to swim and the apartment complex has several swimming pools and a hot tub which she also enjoys.
- Individual was given a choice of several homes to live in by her agency.
- Mother and her sister chose.
- Mother passed away, moved in with sister.
- “My companion helped.”
- “My sister and brother-in-law helped me find it.”
- Parents chose.
- Part of [his] home was made to accommodate his special needs (wheelchair, etc.).
- [She] lives with a female caregiver and the caregiver's ex-husband. Previously, [she] lived with the caregiver's grandmother.
- [She] had help from [Agency], her Circle of Support and her sister (conservator).
- She looked at several homes before deciding on her present residence.
- Sister-In-Law and brother helped.
- They had 2 apartments that were available and I got to choose which one I wanted.
- With agency assistance.
- With staff's help.

Negative:

- “Actually, somebody chose it for me. I found out when [my assistants] came.”
- Agency chose.
- Aunt chose.
- Companion chose it.
- Conservator chose.
- Dad placed when she was a baby.
- Did not choose to live there.
- [Developmental Center] chose.
- Foster mother chose.
- [He] has lived with his mother all of his life.
- He is unsure who chose for him.
- He lives with his family.
- [His] family is very involved in his care.
- “I live with my foster family.”
- “I told them I didn't want to move there. I told them it wouldn't work, but I didn't have a choice. I try to stay out of the house.”
- “I wanted to go back to my brother's house.”

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

- Individual's mother put in her will that she wanted [a specific agency] to care for him. Individual lived at [a developmental center] for 30 years.
- Mom helped.
- Mom passed away. She came to live with her sister.
- “My daddy told me I had to move over there – I needed to go there.”
- “My family got this house for me”
- Parents picked it out. [Individual] was born there.
- Program Coordinator showed me the house but she picked it.
- Said case manager did because she wasn't taking medicine and couldn't make decisions.
- She came from [a developmental center] so she was just sent here.
- She had to move because she had some issues with a previous housemate.
- [She] was court-ordered to stay in her present home. She is from El Paso, Texas.
- She was sick in hospital before she moved in.
- “They did it for me - the State.”

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

Positive:

- But likes the people that work with her.
- Conservator (sister) does.
- Has before.
- [He] analyzes prospective staff members to gauge their ability to handle transferring him in and out of his chair.
- [Her] dad said she "gets along well with staff."
- In the past, has told some staff members he would not work with them anymore.
- “I know they can be changed at any time.”
- It is hard to adjust to new staff.
- “I've had to do that before. I always have a say so. If I don't like it I'll raise such a stink about it!”
- Likes her staff.
- Momma helps me change things.
- Mother chose.
- Mother knows.
- “Oh yes, if she doesn't like you, she will bite, she will scream. She will definitely let you know! She's not verbal, but she's very vocal.”
- “Once a year, we get all them together and explain their rights; and then he gets that explained during his ISP meetings.”
- She says yes. We think she understood the question.
- She doesn't understand this but if she doesn't like you, she won't have anything to do with you - then we'd change the staff.

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

- [She] would call her sister if she didn't like a staff member.
- Staff picked.
- “They told me that. We’ve been through all that.”

Negative:

- Agency picked.
- But family knows.
- But staff and family do [know].
- [He] lets staff know if he doesn't like them.
- [His] mother (conservator) knows [he] has the right to change his support staff.
- “I did not know that.” (This right was explained to her by PTP interviewers.)
- Individual says she would like to change her support staff.
- Likes her staff.
- Right was explained to him. Told him to talk to his PC or ISC if he was unhappy.
- She doesn't understand her rights but [the agency] would change staff if there were problems.
- Staff knows.
- [The] program manager doesn't listen to his requests.
- Was informed he had the right.

Can you talk to your ISC when you need to?

Positive:

- “As long as she isn't busy.”
- But can make a meeting with [him].
- [He] caregiver is one of the best ISC's around. She is a complete advocate for [her].
- [He] communicates with a DynaVox.
- [He] said he hasn't received a visit from his new ISC.
- Family does.
- “I can reach her by email but my phone can't call long distance so I can't reach her that way.”
- “I can't call her. She calls but I can't answer it.”
- “I haven't really needed her yet.”
- “I talk to her all the time.”
- “I think I can.”
- “If I need to.”
- Individual communicates by screaming, for example if he wants to stop eating, or screams if there are other problems bothering him, and enjoys being alone. If he is angry at staff, he has hit them.
- “Individual has ISC's phone number.”
- Mother can.

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

- Parents can.
- [She] talks with her ISC at [her agency].
- She could not remember her ISC's name, but she talk to her regularly.
- Staff can.

Negative:

- But staff can.
- [He] doesn't have her number
- He only sees [his ISC] when she comes to see him.
- "I do have a problem talking to her sometimes. She doesn't really talk to me too well. I'd really like to change my ISC."
- She said her ISC hasn't called her. She said her staff does not [let her] use the telephone
- [She] indicated that [her ISC] did not return her phone calls.
- Sister talks to them.

Would you like to work somewhere else?

Positive:

- Along with working at McDonald's, [he] helps clean at another restaurant.
- [He] wants to take food orders at McDonald's.
- "Any job is fine."
- "At any library."
- [He] would like to be a police officer.
- [He] has wide and varied work and volunteer experience. He worked as a bartender at People's Restaurant, has bussed tables, worked at Goodwill, McDonald's, Wendy's, K Mart, Food Lion, Flower Power. He also worked as a cook at El Palacio Restaurant, and formerly volunteered with Meals On Wheels.
- Burger King [would be a good place to work].
- But he can't lift heavy boxes.
- Cancun Mexican Restaurant [would be a good place to work].
- Different Nursing Home [would be a good place to work].
- Formerly [he] worked at Cracker Barrel one day a week for 2-3 hours.
- Formerly, [he] worked at Quebecor.
- Formerly, individual worked at a department store in Murfreesboro and at an agency day program.
- Hardees [would be a good place to work].
- [He] wants to work at a funeral home.
- [He] wants to work at Dairy Queen.
- He formally worked at an agency.

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

- He has been a busboy and a dishwasher and would like to do that again, and also wants to work at a grocery store.
- He has been having some difficulties at work and is thinking about retiring.
- He has previously mowed grass, and would like to be a stock clerk of some sort.
- He is working outside right now and says he likes to be outside but he would rather have another job.
- [He] plans to take a cooking class because he wants to work in a full-service restaurant, such as O' Charley's. Previously, [he] has worked at Green Hills Regal Cinemas, Crump Financial, and Ingram Publishers, where he put labels on books.
- [He] said he has to wait because he has to get his anger issues under control.
- [He] used to press clothes at Goodwill.
- He wants to vacuum.
- [He] wants to work with the fire department and has done stock work. He used to work at Save-A-Lot.
- He wants to work at Wal-Mart as a stocker and janitor.
- He would like to be in a workshop.
- He would like to drive a big rig.
- He would like to get a job as a janitor.
- He would like to help people.
- He would like to volunteer someplace.
- He would like to work at Erlanger Hospital.
- He would like to work at Krystal's.
- He would like to work at Tennessee Valley Authority.
- He would like to work at Wendy's.
- He would like to work in an office.
- He would like to work in recycling.
- He would like to work in the cafeteria.
- "I already volunteer but I want to work. I had a job interview yesterday. I'd like to work at Sonic. I used to before but I had some medical issues and they had to let me go. I'm a certified cook's assistant."
- "I had a job in Lebanon. I haven't looked [for another job]. I've just been lazy, but I do need a job. I have to work!"
- "I used to work at Sole Supports and I might be able to return in July. It's only two days a week, but that's what I wanted."
- "I want to get a job and they're working on it. I went to the office and talked to a lady at the Vocational Rehabilitation office and I'm hoping to get a job. I'm not so much wanting to volunteer."
- "I wish I could volunteer at Maury Regional Hospital with the newborns—change their diapers, sit with them. I'd like a job, maybe working here at the mall."
- "I work at the nursing home but my hours were cut and I'd like to be able to work more there. I also volunteer at the nursing home. I sing there every fourth Saturday."

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

- “I work at the tax office three days a week but I'd like to have another job, too.”
- “I work here two days a week, Tuesdays and Thursdays, but I wouldn't mind having another job like this.”
- “I'd like to get a job like putting shoes in boxes, like a stocker. I'd like to get out and go to Franklin.”
- “I'd like to work as a baby sitter.”
- “I'd like to work as a bus boy.”
- “I'd like to work as a fireman.”
- “I'd like to work as a house cleaner.”
- “I'd like to work as a landscaper.”
- “I'd like to work as a mechanic.”
- “I'd like to work at a nursing home.”
- “I'd like to work at a restaurant washing dishes.”
- “I'd like to work at Goody's department store.”
- “I'd like to work at [Agency] again. A lady is helping me try to find another job.”
- “I'd like to work at the Arc in Tullahoma.”
- “I'd like to work in an office.”
- “I'd like to work in child care.”
- “I'd like to work with animals.”
- “I'd like to work with my brother and get free stuff.”
- ‘I'd like a job but no one's helping me right now. (Encouraged her to talk to her ISC)
- In the past [he] has worked as a courier carrying supplies to the Hospital. He has also put labels on pizza boxes. He is currently looking for work at Goodwill.
- Individual formerly volunteered with Meals On Wheels.
- Individual formerly worked at a truck stop.
- Individual would like to volunteer at a daycare center for children.
- Individual would like to work in a factory or warehouse.
- Individual said he would like to be a car mechanic or work cooking chicken at KFC, Church's Chicken, or Cracker Barrel. He also likes to cook pork chops. Previously, he worked at Friday's at Opry Mills mall, where he folded silverware, swept and mopped floors, cleaned tables, took out trash, washed dishes, stocked the ice machine and cleaned baseboards.
- Individual wants to be a car mechanic or fold silverware in a restaurant.
- Individual wants to work at Goodwill sorting clothes, and would like to participate in a workshop program.
- Individual wants to work in the technology field.
- Individual would like to work at a restaurant cleaning tables and bathrooms.
- Individual said he would like to shred paper and stick labels onto different items.
- Individual wants to work at McDonald's cooking hamburgers.
- “Like my job but I'm open to a new job. I'd like to make more money!”

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

- Likes working at the day program but would like to work at the church.
- McDonald's [would be a good place to work].
- Needs a job coach.
- Parts store [would be a good place to work].
- Person stated he wanted to work in Jackson TN because that's where the big money is.
- Possibly would like to work as a greeter at Wal-Mart.
- Previously, she worked at Tennessee Christian Hospital.
- Previously, she worked for two years at Shoney's.
- Previously, he did stock work at a food store.
- Previously, [he] bussed tables at Shoney's.
- Previously, individual has had factory experience (crane operator, order picker, stacking car parts) and would now like to do landscaping.
- Says he would like to work at Logan's, and also would love to try out for the Titans.
- She is unsure where she would like to work.
- She likes what she does but would like to have another job.
- She said she would like to be a cook or maybe an actress.
- [She] said she wants to continue her employment with [Agency] "if they give me more hours." She previously worked at Wendy's, where she cleaned tables and bathrooms and took food orders.
- [She] worked for five years at Goody's and five years at Long John Silver's, can't work anymore due to seizures.
- She would like to be in a workshop or something because she is bored.
- She would like to do some volunteer work.
- She would like to work at Burger King refilling drinks and wiping tables.
- She would like to work at Walgreens.
- She would like to work in a hospital.
- Somewhere working with fresh produce.
- Unsure.
- With assistance; individual would like to work, but has behavioral issues.
- Work somewhere else.
- Would like an additional job so he could have some spending money because he uses his current job to pay bills.
- Would like a job at a movie theater or fast food.
- Would like another job but not a morning person.
- Would like to attend a workshop or day center.
- Would like to work at a bank. Now volunteers at Meals On Wheels.
- Would like to work in daycare or in fast food.
- Would like to work on the line in the workshop.

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

Negative:

- Already works and is happy with her job.
- Formerly, [he] worked at [an agency] packing boxes.
- Formerly, [he] folded boxes at Pizza Hut.
- Happy [with current situation].
- Has worked at D.O.T. and Pizza Hut.
- [He] hasn't worked in several years because he's been very ill. At home, he does laundry and makes beds. It is hard to get [him] to wash clothes but he will put them in his closet.
- [He] has some behavioral problems which keep him from working.
- [He] only has use of his right hand. It would depend on the type of work it is.
- "I don't want to work or volunteer right now."
- "I really don't want another job. I like working here."
- "I work at a hat store now."
- "I work at Ace Hardware now, part-time."
- "I work at McDonald's now."
- "I work part-time now."
- "I'm happy working here."
- "I'm working part-time now."
- "I'm working part-time now at Backyard Bar-B-Q."
- "I'm working part-time now at the library."
- In January he will start work helping in a local parts factory.
- In the past [she] worked part-time at Goodwill, where she helped stack books, along with other duties.
- Individual previously worked at Goodwill.
- Likes her job and has been there about 15 years.
- "Lord, no! She hates to work! She only shows up here when there's a party or she has to. She loves to chill and relax."
- No, not really--individual is happy.
- Previously, individual worked at Krystal where he cooked and swept the parking lot.
- Previously [she] working in a sheltered workshop.
- Previously worked at Shoney's folding silverware; also scanned time cards for another company. "Every time I start doing well on a job I get fired," [he] said.
- Previously worked at The Pancake House.
- Previously, she picked up trash at [the developmental center].
- Previously, she did janitorial work for Metro Water Services for two years.
- Previously volunteered at Loaves and Fishes.
- She has a job at Belk's as a greeter every Saturday. She also asks customers if they'd like to open up a credit account. She works about 3 hours per week.
- "She just likes to get out and ride. She really likes to sit on the porch. She also likes to watch TV, especially *Matlock*."
- She had deep brain stimulation and has been unable to work but she has been steadily improving. She has recently taken a few steps and her speech is improving.

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

- Volunteers at Meals on Wheels and works in [the agency workshop].
- Volunteers at the nursing home.
- Volunteers for Meals on Wheels.
- Volunteers with Salvation Army, and has received job training.
- Works at Free Will Christian College but would like more hours. Also volunteers at Meals on Wheels.

B. Respect and Dignity for Main waiver, comments

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

Positive:

- [He] said he gets good treatment from his foster parents and from his day staff. He added that the staff needs more training dealing with individuals with disabilities.
- “I think so.”
- “It's like this: some kids need to be pushed to do good, and that's like me. I need to be pushed for me to get out. I'm kind of spoiled.”
- “My staff treats me like family. They'd do anything for me.”
- “One of the staff, I text with. She's my good friend.”
- Sister comments regarding [her sister's] staff: "Some of [her] staff members have been with her over 20 years. The [Agency] staff is great, and they are welcome in my home any time.”
- [Staff] has been with [her] for five years.
- “The staff I have is really nice to me.”

Negative:

- But family does; but he can show sign language.
- Doesn't know how to report complaint.
- Family does, however.
- Foster mom does.
- He kept shaking his head no and running his fingers across his mouth in a zipping motion.
- Mother and staff do.
- Staff does.

Does anyone ever hit or hurt you?

Positive:

- Housemate.

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

- Housemate does and [she] would like for her to move.
- Individual said a staff member hit her with a curtain rod in her previous home.
- Individual said housemate has "hit me in the stomach."
- [She] said another [person] at [the same agency] pulls on her. She does tell the staff and [they] make her leave her alone. [The other person] does this to everyone, according to [her].
- Other [people].
- [Person] hit him on his arm.
- Says staff hits her.
- She said she did not want to talk about that.
- Someone hits her at home.
- [She] said a member of staff was mean to her.
- When [the individual] was a child, she indicated that her uncle hit her with an iron pipe and raped her.

Negative:

- He has had issues in the past which were reported.
- No; he was hit in his left eye in the recent past but the incident was reported.
- "No way."
- Old roommate.
- Other [people] take stuff sometimes but no staff.
- [She] has hit staff members but no one was injured. Although [she] has a long history of "acting out," her sister said in the last two months [she] has had no behavior problems.

Do you know how to report a complaint?

Positive:

- Call 911! Staff said she'd tear 'em up if anyone tried to hurt her. "She's a tiny thing, but she's got a temper on her!" Staff knows how to file a complaint.
- Call the [development center] office.
- Call police, tell staff.
- Call The Arc Tennessee.
- Caretaker knows.
- Family does.
- Family-based providers do.
- Goes to get staff and leads them to problem or communicates through DynaVox.
- He indicated he would tell [staff person].
- "I could file a complaint with the authorities."
- "I know how to call 911 if I had to. First I'd call the police. I've got a cord at my apartment to pull that goes directly to the police if I had an emergency."

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

- “I would go to the staff and tell them. I'd call my mom. I can call 911, too.”
- I'd call the police. I'd talk to [my Doctor]—she's a sweetheart. She'd get mad.
- “I'd tell staff. I'd call a number” [Staff said it's posted on the wall.]
- “I'd tell the office, my staff. I'd call 911.”
- “I'd try to call the police, I guess. I'd talk to my sister and staff, too. I can call the emergency number, 911.”
- “If someone hurts her, she'll tell you for sure! And we'd file a complaint on her behalf in a minute.”
- Individual clearly didn't comprehend this question, but staff said there's always staff on duty and they know what to do.
- Individual gets angry and upset if he feels he's being taken advantage of.
- “I've had to do that a long time ago, but not now.”
- “Oh, I know what to do to get help if I needed it. I'd call 911 and I'd tell staff.”
- Parents and [care providers] know how to report a complaint
- Sister and ISC do.
- [She] was able to show her sign for yes as an answer to this question. She is also able to show through her emotions if she is unhappy with someone or a situation.
- "Tell. [Call] 911." Her family knows how, and they're very involved with her care.
- Tell a friend.
- Tell companion or other staff.
- Tell Dad.
- Tell house manager.
- “Tell my supervisor.”
- Tell neighbors and [agency] staff.
- Tell program coordinator.
- Tell staff and sister (conservator).
- Tell state and occupational therapist.
- “The police are right across the street. I'd talk to staff.”
- “We know how to file a complaint. It's never happened so we don't know what she'd do, but I think she'd scream or yell.”
- With assistance.
- With help, by sign language.
- “You gotta speak on it, and I wouldn't let nobody hit me. I'd tell somebody. I'd call 911 and there's the abuse number in the kitchen.”

Negative:

- But family does; but he can show sign language.
- Doesn't know how to report complaint.
- Family does, however.
- Foster mom does.

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

- He kept shaking his head no and running his fingers across his mouth in a zipping motion.
- Mother and staff do.
- Staff does.

C. Access to care for Main waiver, comments

Can you always get to the places you want?

Positive:

- A van [provides transport].
- Access Ride and his mother [transport him].
- Access Ride and staff transports [her].
- Brother and sister-in-law transport.
- Brother-in-law and his personal assistant provide [individual's] transportation.
- But I can't always go where I'd like to. I'd like to go to Spring Hill or Franklin sometimes, but there's not enough gas.
- Caregiver and her ex-husband transport the individual.
- Companion transports.
- Currently, [he] is living with his sister, who provides his transportation, because [his] mother had knee replacement surgery.
- Family takes her.
- Father and staff take the individual.
- Foster mother takes him to the doctor and the dentist.
- Has his driving license.
- He likes to go to the mall.
- Her staff takes her.
- House Manager transports.
- "I can drive if I get my driver's license. I haven't tried to do that yet."
- "I'd need to check with the people in the house to see if they need to go somewhere, too. But I get where I need to go."
- [She] takes Access Ride to and from the Adult Day Care Center.
- Parents transport.
- Sister transports.
- Staff takes him, and job coach takes him to work.
- Staff transports. At one time [he] had a learner's driving permit, but his license was revoked.
- "[Staff] takes me everywhere, we have a good time."
- "We have a car."

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

Negative:

- Needs his own wheelchair accessible van.
- Person would not answer the question.
- Staff transports. Individual's doctor sometimes visits her at her home.

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

Of the 1098 people receiving services through the Main waiver who responded to this question in 2012, slightly more than 5% (56 affirmative responses) answered yes to needing special equipment that would make their lives easier.

Medical:

- 14 wheelchair requests.
- 4 walker requests
- A bedside commode.
- Needs a knee brace.
- Needs an Easy-stand and a Side-layer for home.
- She needs a hearing aid.

Technology:

- 4 computer requests (including 1 regular computer, 1 with internet service, 1 large screen voice-activated computer, and 1 talking computer.)
- 1 camera to take on trips
- 1 new talking watch
- A download for her communication device.
- His speech therapist wants him to get an I-Pad.

Modifications:

- 5 accessible bath requests (3 shower chairs, 1 walk-in bathtub, 1 bigger bathtub, 1 grab bar, 1 general modification).
- 4 ramps for their homes requests.
- Hand rails for the front door.
- Steps with handrails for hot tub and pool.

Other:

- A treadmill, so he doesn't have to walk in cold.
- Brakes for car.
- Like to get her driver's license.
- Lounge chair.
- Would like an exercise bike.
- Needs a wheelchair accessible van. He is relying on public transportation.

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

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

Positive:

- Bowling and workshop.
- Brother helped her with this.
- Family visits, collecting Eagles and Elvis memorabilia, and watching sports -- particularly the Tennessee Titans.
- Fishing, computer games, and going to the park.
- Going shopping, movies and coloring.
- “Going to church and being with my family are important to me.”
- “Going to church with my girlfriend, going to movies, and playing games are important too.”
- Going to work, bowling and shopping.
- He likes to sing and would like to get some studio time to record music.
- Her cane is very important to her, as well as her music and her mother.
- His family and having money are important to him.
- “I like to watch movies but they got the book.”
- “I'm learning how to knit and crochet and think they put it in my plan because I really like it.”
- In [his] ISP, it states that he can eat hamburgers whenever he wishes, that he can always take his camera with him, that he can listen to music on his stereo and that he can buy clothes and hats.
- “It's good from where I look at it.”
- Magazines and shoes.
- “My computer - that's about it. It's in my plan.”
- “My jobs and vacations.”
- “My video games and basketball.”
- Playing his keyboard and listening to music are very important to [him].
- Playing video games and his sports.
- Plays with his Play Station, Wii, does karaoke, likes movies, going to church, eats at Chuck E. Cheese, Chili's, and O' Charley's, attends church, shops at Rivergate Mall, Target and Wal-Mart, writes short stories.
- Puzzle books.
- See her family whenever she wants to; her job at Belk's. She wants to be as independent as she can be.
- “See my mom and dad, and play ball.”
- “She has a special toy she has to have with her; they put that in her plan. She also goes out a lot because she likes it too much.”

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

- “She likes having her private time and her music. She has purses she loves to carry, and also key chains.”
- “She loves shrimp, and that’s in her plan. Her dolls, getting her hair done, and shopping—all in her plan!”
- “Shopping and going to my church.”
- “They ask me what I like when we have our meetings.”
- “They put down that I like to visit my girlfriend and stuff like that.”
- “Visiting my friends and shopping are important to me.”
- “Visiting my friends is very important to me.”
- Wanted to work, and wanted certain foods, and got those.
- Working at the workshop, and shopping.

Negative:

- He said staff does not take him out enough in the community.
- The meetings are too crowded and they don’t listen to her.
- “They listen only to themselves.”
- [She] says no one listens to her.

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 service sector jobs.

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 mass media to be highly correlated with what is accepted to define community integration (McLeod, et. al, 1996). Computer technology and the Internet also

broadens lives and increases the independence of people with disabilities (Kaye, 2000). Clearly now, with the ubiquity of 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 Main waiver in 2012, only slightly more than one in ten (12.09%) are using the Internet, whereas, according to a 2010 report by the Center for the Digital Future at the USC Annenberg School for Communication, more than eight in ten (82%) of all Americans are going online.

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

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?” 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 over 63% (698 of 1100) of those interviewed who receive services through the Main waiver in 2012 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 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).

Fifty three percent (53% or 584 of 1102) of those interviewed who receive services through the Main waiver responded “Yes,” that they have a boyfriend or girlfriend. The people served by DIDD should be encouraged and 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.

Do you have a boyfriend / girlfriend?

Positive:

- 15 girlfriends.
- 5 boyfriends.
- At church.
- At school.
- Calls one of the staff his girlfriend.
- “Can’t count how many.”
- “Every girl is his girlfriend.”
- Had a girlfriend, but she passed away. He has many friends. He is very outgoing.
- [He and his girlfriend] are talking about getting married.
- He has 4 girlfriends.
- He has 6 girlfriends and they all know about each other.
- He has lost count of how many.
- He is trying to quit them.

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

- [He] recently had his first date at a prom.
- He said if he could he would marry and move in with his girlfriend.
- “I got some boyfriends in Lewisburg. I got boyfriends in Alabama, in Nashville. But I do believe in marriage.”
- “I like everybody.”
- Individual has a lady friend at Clover Bottom.
- Individual has been dating his girlfriend, who lives in Dickson, for one year.
- Lives with her boyfriend.
- Lots of friends.
- Married.
- “My girlfriend is very sweet and she takes real good care of me. I try to take real good care of her, too. Her family likes me. Hopefully one day her mom will let us get married.”
- “Picked up two on St. Patrick’s Day.”
- “Same one I always got. I don't see her often.”
- “She loves men—she's got boyfriends all over the place!”
- She saw him at the lasagna dinner.
- “Tony Stewart, professional racecar driver.”
- “We've been dating 2 years, sort of. I broke up with her once but I got back with her.”

Negative:

- According to her dad, [she] is a big flirt.
- “But I want one.”
- But she likes [him], and got really excited when we asked about him.
- Has had a previous girlfriend.
- He is outgoing & positive but has no actual friends.
- “He left me.”
- He said his mother does not want him to date or get married.
- He used to have a wife but she passed on about seven years ago.
- He wants one.
- He's looking.
- He's married to someone else.
- “Holding out for Mr. Right.”
- “I found one the other night in a mini skirt! I wish I had one.”
- “I shut the door on them.”
- “I'm married.”
- Just friends.
- Not very sociable.
- "Not yet."
- She doesn't want one they are trouble.
- She had a previous boyfriend.

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

- She just has friends.
- She was married at one time, but they decided it just wasn't working out. But they're still friends.
- “That embarrasses me a little!”
- “They are too much trouble.”

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

Positive:

- And boyfriends sometimes.
- Every other weekend.
- “Every day!”
- Family lives far away, but he sees his girlfriend.
- Goes to see his mom every Friday.
- Her sister is devoted to [her].
- “I see them on Sundays.”
- “My sister lives just down the road from me.”
- She does have family who are active in her life but they live out of state.
- “She’s just on the other side of the road to me.”

Negative:

- Because of transportation.
- Family doesn’t have transportation.
- Family lives out of town.
- “Gas prices are too high.”
- Has to be scheduled.
- “I don't like going out too much.”
- “If someone takes me I can.”
- “I hadn't got a way to get over to house all the time.
- “I have no one to see.”
- “I have to ask to visit - they have their own schedules and such.”
- “I'm supposed to go see them in June when my sister gets married. I can only see them when we go to New York. But I talk to them on the weekends.”
- “It can be hard to find the time.”
- “It's sometimes hard to find the time when we can get together. Mostly around the holidays.”
- “It's up to their schedules.”
- Lives at a distance.
- “No one I care to see.”
- “No one to see.”

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

- “Some people I want to visit live too far away.”
- They live at a distance and can’t come to see her very often.
- They live too far away to see. Only a few times a year
- Won’t let him visit with girls.

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 96% (1096 of 1136) of the interviews collected in 2012. Most responded ‘Yes’ with no comment. Following are the few comments that PTP did collect.

Positive:

- As soon as she gets home she immediately goes to her room and listens to her music.
- [Her] personal space is very important to her.
- “I can go in my room and shut the door.”
- “I have staff three days a week. I’m alone at night and on the weekends. I have a ride to church on Saturday.”
- “I sleep by myself. Staff is only with me until 7:00 or 8:00 at night.”
- “If I want to be alone I go in my room and close the door or go out walking.”
- “It’s all right for now. I’d kind of like to be left alone at the house more but since I don’t really know anybody it’s probably not a good idea. I can stay at the house for up to two hours by myself.”
- Roommate walks in on him all the time.
- She said that when her roommate comes into her room, staff will get her out. She said that she has good staff.

Negative:

- Because someone steals his stuff.
- He said his staff checks on him too often due to seizures.
- [He] says he doesn’t have enough privacy because his girlfriend can’t come in his room.
- [He] wants to put a lock on his bedroom door because housemate keeps coming inside.
- “Housemates go in and out of my room so I can’t be alone when I want to.”
- Housemate comes into his room naked and he doesn’t like it.
- Individual said that due to the layout of his home, he does not have privacy while dressing after showering because his housemates are present.
- Individual said his housemate not only enters his bedroom without permission, “but also listens outside my door to hear what I’m saying on the phone.”
- [She] feels she does not have enough privacy because she must remain in sight of her staff.
- Would like people to quit going into his room.

D. Community Inclusion for Main waiver, comments (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 do not otherwise come up during the interview. Following are both positive and negative comments made by people receiving Main Waiver services interviewed in 2012 across Tennessee.

Positive:

- “Everything is going well.”
- Has television in his room.
- He really likes where he lives.
- “I just love my job and wish I could work every day.”
- Individual said she likes listening to music artists Gary Allen and Brittany Spears.
- Like everyone and very loveable.
- Like scary movies.
- Like to be with her staff. [She] has OCD and likes a routine.
- Like to go to church; likes to work.
- Likes it when people talk and people listen.
- Likes to play games and eat.
- Likes to work hard.
- Loves being [at this agency] because they have helped her a lot.
- Loves T.V. and loves coloring.
- Mother's comments: "When we first met [him], he was very sexually inappropriate, grabbing women's vaginas and breasts. [He] no longer does those things. Also, [he] used to smear feces on the walls, but that doesn't happen now. I think that all of [his] inappropriate behavior changed when he found that we loved him."
- Mr. and Mrs. [name removed] are very happy with services.
- Mr. [name removed] is very pleased with all services.
- Really happy and loves being at [his current agency].
- Says she's happy.
- [She] meets with her behavioral analyst every Monday, who said "I have few behaviors to report. She is a joy to be around."
- [She] has bad eyesight and some trouble walking so she uses Access Ride and staff members to take her places because of her difficulty.
- Staff member said [he] "has made a lot of improvement. He works well with the staff."

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

Negative (by category):

Choice

- He is unhappy with his brother living with him but asked the team to not tell his father because he didn't want his father to be upset.
- [He] told us how he use to live with his brother and his brother wasn't nice to him, but now he is so much happier in his new home.
- [He] wants to go more places and have more one-on-one [interactions].
- "I have new teeth. I want my own phone."
- "I want to go to the store and get some lip gloss."
- "My Roommate cusses at me all the time, I'm tired of living there."
- Roommates are too noisy.
- [She] is in the process of moving to a new house with housemates but she would like to live alone with staff because crowds and noises bother her.
- Sometimes staff wakes her up too early to do her chores.
- The individual said she has a history of self-abuse and she has problems with impulse control. She has feelings of guilt for things she has said in the past to her housemates. She said that she has a desire to "make things better for her housemates and staff."
- Would just like to have one roommate.
- Would like a break from his wife wants some time alone.
- Would like to live alone someday.
- Would like to live by herself.
- Would like to live somewhere else that is not so crowded.
- Would like to move to a new place with new people.

Employment:

- "I would like to go to vocational school, and get a job."
- Wants a job.

Medical

- His problems include diabetes, high cholesterol, hypertension, edema and skin cancers.
- He falls down sometimes because of a bad leg.
- He has a current problem with his ear that is causing him some discomfort.
- [He] has seizures and bladder problems.
- He said he has a history of assaultive behavior. He also said he has another personality.
- "I have arthritis and some days I feel real bad."
- Mother comments: "[He] has a sleep disorder which caused him problems in school. [He] is still affected by the death of a very close friend in middle school."

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

Services

- [He] does not care for his night nurse because she gets hateful sometimes. He said she might be kidding but he doesn't like it. [He] says she has never hurt him.
- [He] feels that his staff person hates him, and wants him out of the house.
- He does not like to ask staff if he can go out onto the porch.
- Mother said that [the current agency] is the only agency she has encountered that deals effectively with his autism. His mother indicated she has tried to enroll him in every agency in the area but none made allowances for his sometimes aggressive behavior. In particular she said that [one center] would not even talk to her about enrolling him there. She indicated that she feels [he] has been discriminated against because of his behaviors. [His] mother said they have received great services from The Arc over many years. She holds The Arc TN in very high standing! She also indicated that she appreciated PTP's time and attention to [her son].
- Mother's comments: "I have not been pleased at all with the residential programs [my son] has been in. She said [two of the agencies] took money from his account one month and therefore he did not receive a check. She said [her son's] staff [at another agency] was very hard to contact. "I could not reach [their] staff once for three or four days because, apparently, they didn't have any cell phones." She said when [her son] was in a residential program, he suffered a black eye. She said she didn't know if staff or an individual hit her son. "I would like to enroll [my son] in a day program, but [two different agencies] said his behavior was not suitable for their programs. "I think [my son] would greatly benefit from a day program because they provide structure like he has at home and I feel with structure his behavioral problems would improve. If I can get [my son] into a day program, and if his in-home staff went with him, they could show agency staff how best to deal with his behaviors." [Her son], who has sensory issues, also has many of destructive behaviors: destroying furniture, putting holes in the wall of his home, head-butting cabinets and damaging their car. "Currently, [my son] takes [medications] to help him to keep calm."
- "[My] brother and sister-in law are my conservators but I signed papers and I don't know what the papers mean." He also said his agency staff "is not as helpful as they should be."
- Nancy expressed a desire to move to another day program. She said she did not like the program [she currently attends].
- New staff member gave [him] the wrong medication.
- [She] said she wants to see her former house manager.
- [She] wants her former house manager back.

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

- Sister's Comments: "I don't like the way [the home] spends its money regarding [her]. They have not bought her anything for some time. I make sure she has enough food to eat because [the home] says that [she] doesn't pay enough rent to cover all her food costs. [She] has run out of food before. I will always advocate for my [sister], and I don't care what others say or think about me. The main reason I have not pulled [my sister] out of [her current] program is that, overall, it's the best agency she's received services from. I feel very strongly that [this] program has excellent staff and that [my sister] is happy there. [She] does not like staff changes, which causes her to act out. [She] is a very clean person and always hangs up her clothes."
- They are concerned because the amount of time that they are allowed a personal assistant has been reduced.
- Wants his staff to stop yelling at him and wants to watch TV by himself.
- Would like a new conservator. Advised individual to ask during an ISP meeting.
- Would like to go more places but not enough staff and need transportation.

Neutral:

- [He] wants someone to mail him a voter's registration card.
- [He] would like to have letters from people. He wants to get letters in the mail—just more contact with the outside world.
- "I would like to have a dog. I love dogs."
- Individual said she would like "someone to talk to."
- [Parent] is concerned because her health is getting bad and she worries about what will happen to [individual]. She is checking on some options.
- [She] asked us several times if the interview questions were a test. We reassured her there were no right or wrong answers so our reassurance throughout the interview process gradually made her more comfortable talking with us. (Interviewers' comment.)
- Staff comments: "[He] is a totally different person at home. He does not mingle with housemates socially or at meals. [He] is in the early stages of dementia, which is increasing rapidly. Before [he] developed dementia, he did not want to visit with his parents. [He] came from a sad living situation. He has many medical needs."
- Wants a dog.
- Wants cowboy boots for Christmas.
- Would like to take her G.E.D. test.

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

Do you like where you live?

Positive:

- Lives with family.
- Lives with sister.
- Would like to go back to Knoxville school for the deaf.

Negative:

- “I want to move into a house with a big kitchen. I don't like this apartment.”
- Individual plans to move to another house because where she presently lives "is too crowded."

Did you choose the place you live?

Positive:

- She lives with her family.
- Family.
- Lives with dad.
- With agency assistance.

Negative:

- Agency chose.
- Family chose.
- Her mother chose for her.
- Her sister chose it.
- His conservator chose for him.
- His parents chose for him.
- “I live with my family.”
- “I live with my sister.”
- Lives with mom.
- Lives with her family.
- Mom chose.
- Mom and dad chose.
- Parents did.
- She lives with three housemates.
- [The Agency] did.

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

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

Positive:

- But likes them.
- [He] says he understands how to do this and will tell his mom when he is. Unhappy with someone.
- Likes his staff.
- With dad's help.

Negative:

- "If I was told, I forgot."

Can you talk to your ISC when you need to?

Positive:

- But mom can.
- Dad talks to her.
- "I think I can."
- "I think I can; I've never had to call."
- "If I need to."
- Staff can.

Negative:

- "I've never had to call."

Would you like to work somewhere else?

Positive:

- "Any job is fine as long as I can make some money."
- He is unsure where he would like to work.
- He would like to get a job.
- "I'd like a job working with computers."
- "I'd like to cut grass."
- "I'd like to work as a janitor."
- "I'd like to work as a mechanic."
- "I'd like to work as a security guard."
- "I'd like to work as a teacher."
- "I'd like to work at a store."

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

- “I’d like to work at a day care center.”
- “I’d like to work at a nursing home.”
- “I’d like to work at Domino's pizza.”
- “I’d like to work at KFC.”
- “I’d like to work at McDonald's.”
- “I’d like to work at Wal-Mart.”
- Individual formerly mopped, swept floors, took out trash, and wiped trays at previous job; He said he would like to work at Goodwill and Dollar Tree.
- Recycling job.
- She is unsure where she would like to work.
- She wants to work in a Laundromat.
- Shredding.
- “Someplace simpler.”
- Unsure where he wants to go.
- Would like to be a dishwasher.
- Would like to work.
- Would like working at the fire dep.
- Wants more work.

Negative:

- Has worked at Hardees and Cici's Pizza.
- “If the need arises.”
- “I like my job at the workshop.”
- “I like the job I have now.”
- “I love my job that I have now but I would love to have more hours at McDonald’s.”
- “I work at a church now.”
- “I work at McDonald's now.”
- “I work part-time now.”
- “I'm working now part time at [supermarket].”
- “I'm working now part time at meals on wheels.”
- “I'm working part time now.”
- Individual retired from a Nashville-area workshop after 15 years sealing envelopes.
- “Like her job at the work shop and want is to stay the same.”
- “Like it the way it is.”
- “Like working at the workshop.”
- Previously, [he] volunteered at the Senior Center with Meals on Wheels.
- She worked at the Nashville Airport for 18 years before being laid off. Also worked at the Standard Candy Co.
- Sometimes volunteers at a nursing home.
- Works at a pet store on Wednesday. Likes her job.

B. Respect and Dignity for Self Determination waiver, comments

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

Positive:

- Her Support Staff are her parents.
- Some of the staff doesn't talk to her much.

Negative:

- Not happy with staff at [this agency]—not very nice.

Does anyone ever hit or hurt you?

Positive:

- Individual said someone hit her recently but was not specific.
- A person hit her on Access Ride about 5 yrs. ago

Do you know how to report a complaint?

Positive:

- “Call the crisis center.”
- Individual said if she had a complaint with someone, “I would ask them about it.”
- She would call the Police.
- Sister and brother do.
- Talk to supervisor where she is employed (Goodwill).
- Tell Father.
- Tell her sister.
- Tell parents.
- Tell staff or father.
- Tell staff.
- With Assistant.
- With dad’s help.
- With help from staff or family.

Negative:

- “But mom would though.”

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

Can you always get to the places you want?

Positive:

- Boyfriend or neighbor takes [individual].
- His personal assistant, who also works at McDonald's, takes him where he needs to go.
- Mom takes her.
- “Momma takes me.”
- “Mother takes [me] or I ride a bus.”
- Parents transport.
- She takes the MTA and her brother takes her places.
- Sister and staff transports.
- Sister transports.
- Staff and family transport.
- Staff transports.
- Uses Access Ride to travel to and from work; parents also take her shopping and to the doctor.

What special equipment would make your life easier?

More than 7% (12 of 165) of the people receiving services through the Self-Determination waiver interviewed in 2012 answered “yes” to needing special equipment that would make their lives easier. Six (6) were for accessibility accommodations to their homes including hand-rails, ramps, and grab-bars for the bathroom, three (3) for walkers or wheelchairs, two (2) for a new TV, one (1) for a car, and one (1) for an adult tricycle.

Medical:

- 2 walker requests.
- 1 wheelchair request.

Modifications:

- 2 ramp requests.
- She needs handrails for front steps and a chairlift to go downstairs.
- Tub rails.
- Walk in tub.

Other:

- New bed, a sink in her room, like to have a TV, a big closet, and a washing machine.
- “New TV someday for my room.”
- She could use an adult tricycle.
- Wants a car.

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

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

Positive:

- I think so.

Negative:

- No safe way for her to enter/exit residence has been provided.

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 broadens lives and increases the independence of people with disabilities (Kaye, 2000). Clearly now, with the ubiquity of 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 2012, fewer than two in ten (18.90%) are using the Internet! Yet, again recall that according to a 2010 report by the Center for the Digital Future at the USC Annenberg School for Communication, more than eight in ten (82%) of all Americans are going online!

This measure, although increasing, remains at least 60% 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 nearly 58% (95 of 164) of those interviewed who receive services through the Self-Determination waiver in 2012 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).

Fifty four percent (54% or 88 of 163) 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:

- A girlfriend at workshop.
- All friends at church & workshop.
- At church.
- Boyfriend is [name removed], and best friend and neighbor is [name removed],
- Girlfriend is [name removed].
- He has two.
- He says that he has two and that they know about each other.
- "I have lots of friends."
- "I write letters to my girlfriends."
- Lots of friends at church.
- Many friends.
- Many friends, boys and girls.
- Married.
- "She is about to get under his skin."

Negative:

- He doesn't want one.
- Previously had a boyfriend.

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

Positive:

- "All my friends are at the workshop. I see them every day."
- "Most of my friends come to the center, I see them there".

Negative:

- "It's sometimes hard to find the time when we can get together."
- "It's sometimes hard to find the time when we can get together. Mostly around the holidays."

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

Positive:

- "If I want to be alone I go in my room and close the door."

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 both positive and negative comments made by people receiving Self-Determination waiver services interviewed in 2012 all across Tennessee.

Positive:

- He loves his daddy.
- “I am going to graduate this year.”
- “I have everything I need and I am very happy.”
- “I played softball in Special Olympics and threw the ball a really long way. My dad and mom are very good to me. I love my apartment.”
- “Not really, we are very happy with all services.”
- She's fine would like to live in Cookeville in a year or so.
- “We are very happy and satisfied with everything.”

Negative (by category):

Choice:

- “I would love to go see Alan Jackson concert, but the center says I can't go to Nashville.”

Medical:

- Her teeth hurt.
- “I have asthma but not too bad. I am trying to get my car fixed for my boyfriend. I grow great tomatoes.”
- Individual has several health problems, especially with her immune system which is very fragile so she needs constant monitoring. Also, she has kidney problems, heart problems and uses oxygen to sleep.

Services:

- “I need help getting handrails!”
- She was told that she would get new furniture when she moved into her apartment a year ago but hasn't seen it yet.
- Would like a new conservator.

Neutral:

- “My daddy is in hospital [nursing home]. I miss him.”
- Would like a new dog.

A. Choice and Control for Arlington waiver, comments

From 2011 to 2012, there were 58% fewer interviews conducted with people receiving services through the Arlington waiver, while the number of people receiving services through the Arlington waiver has increased 56% (from 330 in 2011 to 587 in 2012). This decline decreases the measure of confidence level (accuracy or relevancy of the statistic) from +/- 10.2% in 2011's report to +/- 13.9% in this 2012 report.

Do you like where you live?

Positive:

- "I like it here, but I am going to move to another apartment complex in Millington sometime soon."

Did you choose the place you live?

Positive:

- "I live with my family."

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

There were no comments following one hundred seven (107) positive responses and forty-eight (48) negative responses.

Can you talk to your ISC when you need to?

Positive:

- "I think I can; I've never had to call."

Negative:

- "I've never had to call."

Would you like to work somewhere else?

Positive:

- "Any job is fine."
- "Any job is fine as long as I can make some money."

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

- “I’d like to work as a bus driver.”
- “I’d like to work at a hospital.”
- “I’d like to work at Pizza Hut.”
- “I’d like to work at Wal-Mart.”
- Individual would like to wash cars.
- He said he would like to work at Kroger moving carts, and that he used to shred paper.

B. Respect and Dignity for Arlington waiver, comments

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

Each respondent replied positively with no comments to this question.

Does anyone ever hit or hurt you?

Each respondent replied negatively with no comments to this question.

Do you know how to report a complaint?

Positive:

- Tell staff, Tell ISC, Call 911
- Tell staff.

C. Access to care for Arlington waiver, comments

Can you always get to the places you want?

Positive:

- Parents transport.
- Staff transports.

What special equipment would make your life easier?

Each respondent replied negatively with no comments to this question.

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

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

Each respondent replied positively with no comments to this question.

D. Community Inclusion for Arlington waiver, comments

For 2012, nearly half of people served by the Arlington waiver who were interviewed by PTP (35 of 72) were working in workshops or identified as participating in day programs. Thirty-three (33) people interviewed responded that they participated in their communities, including a person who reported working at Pizza Hut. Also, only one person 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:

- Likes all the ladies.
- Lots of friends.
- Many friends at the center.
- Michelle.
- “My best girlfriend is at [the day program].”

Negative:

- Kind of a loner.
- Likes all the ladies.

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

Thirty-seven (37) respondents replied positively with no comments to this question.

Negative:

- “It’s sometimes hard to find the time when we can get together.”

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

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:

- “Dora is my favorite DVD.”
- “I just got out of hospital because I couldn't breathe good. I am better now. I have a birthday soon. Come back for my birthday.”
- “I would like to have a job in an office or go to art school. I can draw good.”
- [He] has family in New Jersey and says he would like to move to New Jersey.
- He can read some words and demonstrated for us. [His] mother told us in a separate discussion that he had some behavioral issues. We had no problems with [his] behavior other than he couldn't sit still and was constantly moving.

Negative:

- “I am going to the doctor tomorrow. My knee is hurting.”

A. Choice and Control for Developmental Centers, comments

Do you like where you live?

There are no comments following this question for the thirty-two (32) interviews completed with individuals residing at the Greene Valley Developmental Center or at intermediate care facilities in Tennessee in 2012.

Did you choose the place you live?

There were no comments following this question.

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

Twenty-one of thirty-two (21/32 or 66%) respondents replied positively with no comments to this question.

Negative:

- Will show displeasure if he doesn't like someone.
- He likes the staff.

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

There are no interview respondents to this question who commented. For all but one person interviewed in 2012 residing at an intermediate care facility, it was communicated that they could talk with their Case Managers when they needed to. Most people interviewed (22/32 or 69%) for this population resides at East Tennessee's Greene Valley Developmental Center. In Shelby County, PTP interviewed two and half times as many people (10) at Intermediate Care Facilities when compared with 2011's four (4) interviews at intermediate care facilities.

A. Choice and Control for Developmental Centers (continued)

Would you like to work somewhere else?

Positive:

- [He] wants to work at Goodwill. Previously, he worked at Second Harvest Food Bank.
- [She] wants to work with cats and dogs at a veterinary clinic.

Negative:

- Twenty-nine “No” responses without comments.

B. Respect and Dignity for Developmental Centers, comments

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

Positive:

- There were sixteen (16) positive responses from thirty-two (32) interviews without comment.

Negative:

- Sixteen (16) individuals were unable to clearly respond to this question because of limited communication abilities.

Does anyone ever hit or hurt you?

In 2012, this question received no affirmative responses from people residing at the Greene Valley Developmental Center or at private intermediate care facilities. In 2011, PTP also received no affirmative responses. 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?

This question elicited 50% (16 of 32) positive responses with no comments from the interviews with people at the Greene Valley Developmental Center or at intermediate care facilities.

C. Access to care for Developmental Centers, comments

Can you always get to the places you want?

Positive:

- Staff transports.

What special equipment would make your life easier?

One person at a private intermediate care facility answered “a wheelchair.”

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

Positive:

- Without comments, sixteen (16) “Yes” responses

No negative responses or comments to this question were obtained from the 32 interviews

D. Community Inclusion for Developmental Centers, comments

Mirroring 2009 and 2010 results, in 2012 only one person at the Greene Valley Developmental Center reported using the internet.

Do you have a boyfriend / girlfriend?

Negative:

- Without comments, thirty (30) “No” responses.

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

Positive:

- Without comments, twenty-two (22) “Yes” responses.

Negative:

- Without comments, eight (8) “Sometimes” responses.

D. Community Inclusion for Developmental Centers (continued)

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

This final qualitative question creates an opportunity for expression of additional comments or concerns that would not have otherwise appeared through the interview process. The single comment came from an interview at an intermediate care facility.

Positive:

- Staff says [he] smiles all the time; everything is going well for him.

6. GOALS

In the year 2012, PTP was again asked to conduct interviews with a minimum of 1,200 people receiving services through the various waiver programs. In 2012, PTP successfully conducted and recorded 1379 interviews with individuals in 62 of Tennessee's 95 counties.

The following table lists all Tennessee's counties and the number of interviews conducted in 2012 by PTP teams.

Anderson	26	Fentress	0	Lauderdale	5	Roane	2
Bedford	3	Franklin	4	Lawrence	0	Robertson	13
Benton	24	Gibson	59	Lewis	0	Rutherford	8
Bledsoe	3	Giles	0	Lincoln	0	Scott	11
Blount	3	Grainger	0	Loudon	8	Sequatchie	2
Bradley	98	Greene	59	Macon	0	Sevier	1
Campbell	0	Grundy	21	Madison	4	Shelby	118
Cannon	0	Hamblen	15	Marion	1	Smith	11
Carroll	32	Hamilton	194	Marshall	0	Stewart	25
Carter	0	Hancock	0	Mauzy	8	Sullivan	2
Cheatham	1	Hardeman	15	McMinn	14	Sumner	0
Chester	0	Hardin	6	McNairy	0	Tipton	9
Claiborne	0	Hawkins	0	Meigs	1	Trousdale	0
Clay	0	Haywood	2	Monroe	0	Unicoi	0
Cocke	0	Henderson	14	Montgomery	25	Union	0
Coffee	8	Henry	17	Moore	0	Van Buren	0
Crockett	13	Hickman	4	Morgan	1	Warren	0
Cumberland	21	Houston	5	Obion	36	Washington	16
Davidson	118	Humphreys	28	Overton	7	Wayne	9
Decatur	4	Jackson	0	Perry	0	Weakley	33
DeKalb	0	Jefferson	2	Pickett	0	White	21
Dickson	27	Johnson	0	Polk	0	Williamson	9
Dyer	33	Knox	59	Putnam	10	Wilson	22
Fayette	5	Lake	0	Rhea	22	TOTAL	1379

7. RECOMMENDATIONS

Careful evaluation and monitoring of a program and the system within which it operates is important to maintain the quality and effectiveness of the services it provides. Program evaluation seeks to gather information to 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 2012 PTP report, representative data and statistics about the people receiving services will continue to contribute to improving the system and the services delivered by that system.

What does this analysis say about Tennessee's service delivery system? Based upon the PTP interview findings for 2012, the following recommendations are made within these categories:

Abuse/Neglect

- ❖ [Address the needs of people who have been abused in the past.](#) Be aware that individuals continue to bring up past abuses, and that they would benefit from counseling or other services to help with these issues.

Employment

- ❖ [Increase the number of gainful employment opportunities in the community.](#) DIDD continues to promote employment through its *Employment First!* Initiative and has shown substantial improvement moving from 16.3% of persons supported by DIDD in September 2011 to nearly 22% in December 2012 (<http://www.tn.gov/didd/EmploymentFirst/documents/Employment%20Statistics%20-%2020130201.xlsx>). This is very encouraging and raises hopes that DIDD will soon surpass the high near-25% employment rate reported in December 2004!

7. RECOMMENDATIONS (continued)

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*. True choice of employment is not “this job or no job.” Choice in living arrangement should not be “the bed on the left or the bed on the right.” 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). How can DIDD assure that there is choice in an individual’s life if that person does not know what *choice* is or what it means? 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 are complaints 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 many individuals needing special equipment to make their lives better. Some items listed may not be easily funded or found. Supplementary training in options available to purchase adaptive equipment may benefit ISCs and the people who need the equipment.

7. RECOMMENDATIONS (continued)

Program Recommendations

Adjusting the instrument

In 2012, 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. Discussion is ongoing with representatives at DIDD to revisit the wording of the PTP interview questions. A revised PTP interview instrument will remove ambiguous questions, and should increase the rigor and applicability of statistical findings. For example, ambiguous questions in the current interview include: *Does anyone ever get angry and yell at you?* This is ambiguous because the ‘and’ suggests that someone must be yelling for the answer to be ‘yes,’ yet someone could express anger without also yelling. Another ambiguous question is, *Who do you talk to when you have problems?* This question does not specify which type of problem and requires subjective interpretation.

Subjective interpretation of such 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 now hopes to put a revised interview tool into use soon.

7. RECOMMENDATIONS (continued)

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>) DIDD should consider linking Project Titan with PTP and SurveyMonkey, through which changes in a person's residential and contact information may be securely shared.

- 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.

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

2012 PTP interviews	1336 Main waiver respondents	165 Self-Determination waiver respondents	46 Arlington waiver respondents	32 Greene Valley Developmental Center or private intermediate care facility respondents
People who needed special equipment to make their lives easier.	5.1%	7.5%	0.0%	3.1%

8. UNANTICIPATED OUTCOMES

PTP has encountered both positive and negative outcomes:

- 1) In the 2011 Annual Report, PTP set a goal to complete at least 1,200 interviews. In 2012, PTP teams met with 1,379 individuals and recorded the results of their interviews, exceeding the 2012 goal by 15%.
- 2) Automatic submission of Survey Notification forms for individuals unable to communicate responses to the interview questions resulted in an increase of SNFs issued to the state in 2012 by more than five-fold as compared with 2011.

2012 Survey Notification Forms



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.
- ✓ Anticipated effects of this new procedure include more comprehensive interview data, which has not previously included information relating to individuals unable or unwilling to participate in interviews. Such incomplete interviews totaled 368 in 2012, or 21% of the total interviews attempted. Going forward, the Survey Monkey should contain more interview responses, and the state should receive fewer SNFs not citing any specific issues or complaints. 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.
- ✓ Discussion continues with representatives at DIDD to revise the PTP interview. The survey instrument generally aligns with the Personal Outcomes Measures evaluation system used by the Council on Quality Leadership (CQL), a national non-profit supporting organizations and systems that serve people with disabilities.

9. FUTURE PLANS (continued)

As DIDD makes its way through the accreditation process, the Project Director expects to effect some revisions to the interview instrument and procedures—aligning more with CQL efforts. A revised interview instrument will enhance the person-centeredness of the project and clarify the questions, thereby increasing accuracy of statistical findings for future comparison.

- ✓ 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 2012

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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--Quality Assurance Frequently Asked Questions

www.tn.gov/didd/quality_management/faq.shtml

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www.tn.gov/didd/newsroom/OpenLine/resources/Project%20Titan%20-%20Regional%20Kickoff%20Meeting.pptx

--Project TITAN 2013

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