2012 Statewide Minnesota Participant Experience Survey (MN PES)

Giving VOICE to CHOICE
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EXECUTIVE SUMMARY

Background
In 2012, the Disability Services Division (DSD) of the Minnesota Department of Human Services (DHS) implemented the second round of the statewide Participant Experience Survey (MN PES) for persons receiving home and community-based services (HCBS). The total cost to implement the 2012 survey was $240,000. One-time funding was provided for this activity by the State of Minnesota. At the time that this report was prepared, there are no ongoing appropriations to implement the PES annually.

Over the past few decades, the focus of services has shifted toward provision of services and supports in non-institutionalized settings, namely people’s homes and communities. DHS with input from various stakeholders and with direction from the 2007 Legislature contracted with Vital Research (VR) to conduct the second round of the Participant Experience Survey (PES) in Minnesota. The purpose of the MN PES is to provide feedback to state officials about program participants’ experiences with these services and supports they receive from four Medicaid 1915(c) waiver programs operated by DSD within the Department of Human Services. The first survey was completed in 2010.

Legislation enacted in 2007, required DHS to develop a survey for persons who receive home and community-based services.

Survey Results
Of the 838 interview appointments, 807 resulted in conducted interviews, for a completion rate of 96%. Of the 807 conducted interviews:

- 50% (n=403) were with participants of the Developmental Disability (DD) Waiver
- 50% (n=404) were with non-DD waiver recipients
- 6% (n=51) were conducted in Hmong, Somali or Spanish
- 21% (n=171) were with minors under the age of 18

Of all conducted interviews, the average age of survey respondents was 35 years, ranging from one to 96. Of all conducted interviews, approximately:

1 Additionally, persons receiving personal care assistance (PCA) experiences were explored.
2 MN Stat. § 256B.096 Subd.3.
3 This number constitutes a significant sample size, 95% confidence level; +/- 5% margin of error.
4 Proxy respondents (predominantly parents) provided responses on behalf of all participants under 18.
2012 Statewide Minnesota Participant Experience Survey (MN PES)

- 85% of all respondents report that being supported has made their life better than before they were on the program.
- 82% of respondents stated that they are able to vote when they want to.
  - However, 26% of respondents with developmental disabilities stated that no, they are not allowed to vote, were unsure, or did not remember.

Adult respondents’ experience with case management and service plan development is generally positive.

Approximately, 90% of respondents report that:

- They are overall satisfied with case management
- Their case manager treats them with respect
- They are able to contact their case manager as needed

Minor respondents experience with case management and service plan development is generally positive as well. Approximately, 90% of respondents report that:

- They are overall satisfied with case management services
- The case manager treats them with respect
- They are able to contact their case manager as needed

Over 90% of all respondents report that during the planning meeting, they are able to express their needs; have enough input in service plan development and that they receive all the services and supports stated in their plan. However, about 26% of respondents report that they were not given or do not remember having a choice of providers.

Overall, adult respondents feel safe both in their home and in the community:

- 98% of respondents feel safe in their homes and
- 96% of respondents feel safe when they leave their home and go into the community

However, 36 (7%) adult respondents feel unsafe because the people who are paid to help them are not with them when they are supposed to be.

Interviewers asked adult respondents questions about what activities that they engaged in during the day and questions about employment.

- 50% of adult respondents report having a job where they earn money.
- 74% of respondents on the Developmental Disability (DD) Waiver are employed.

Adult respondents that reported that they were not currently working at a paid job were asked if they would like to work. The following respondents reported that they would like to work:
• 68% (n=30) of Brain Injury (BI) Waiver respondents
• 57% (n=17) of Personal Care Assistance Choice (PCA-C) respondents and
• 64% (n=56) of Personal Care Assistance Traditional (PCA-T) respondents

CONCLUSIONS AND RECOMMENDATIONS

The MN PES 2012 project provided information that will serve to enhance community-based services for persons with disabilities. Data obtained from MN PES finds that 85% of the respondents reported that their community-based services have improved their quality of life. Additionally, data obtained from the MN PES project, as well as observations obtained during all phases of the project suggest areas for immediate attention as well as opportunities for improvement.

The following are recommendations to be considered in future surveying projects as well as remediation and quality improvement efforts:

1. Conduct a sampling of CAC Waiver recipients and non-English speaking waiver recipients.

Targeted sampling of CAC Waiver recipients and non-English speaking waiver recipients, which will provide important information that can be used to enhance services that proportional random sampling, did not achieve. Additional attention regarding scheduling interviews for non-English speaking recipients is also recommended to ensure that contacts are culturally sensitive.

2. To consult with the Case Management Reform Group regarding choice of case management.

3. To consult with the recently convened State Quality Council to obtain their recommendations to address remediation activities as follows:
   a) Inform persons on voting rights, choice of provider(s) and to modify individualized coordinated community support plans.
   b) Ensure individualized coordinated community service plans contain strategies designed to ensure paid caregivers are on time and do not leave before other caregivers are available.
   c) Continue to maintain and enhance current local, regional and state projects that focus on employment and jobs for those who want to work and those who have been unsuccessful in either maintaining or finding a new job.
INTRODUCTION

The Participant Experience Survey (PES) is an outcome of legislation contained in Minn. Stat. §256B.096, subd. 3 supported by a broad group of stakeholders in 2008. The statutory goal for the DSD recipient/participant survey is to provide data for the state’s quality improvement system focusing on community-based services, (i.e., waiver as well as Personal Care Assistance (PCA) services). The statute specifies that the survey should include a random sample of 5-10% of service recipients. The face-to-face interviews with participants which include health and safety, provider capability, service access and choice domains provides important information regarding consumer experiences to counties, providers, and DHS. Another important function of the PES is to generate evidence to the federal Centers for Medicare and Medicaid Services (CMS) that the state is meeting the statutory and State Plan assurances required for all 1915c Medicaid HCBS waivers. The 2010 PES final report (PDF) is available on the DHS web site.

Throughout the duration of the contract period, DHS conducted conference calls, e-mail correspondence and received progress reports on the implementation of the project from Vital Research.

Structure of the MN PES Survey

In addition to the responses to the satisfaction items included in the survey developed by Thomson Reuters, Vital Research was also to collect the following data on all survey forms:

- Interview status - not interviewed or interviewed
- For scheduled but not interviewed respondents, reason why person not interviewed
- Start and end time of each interview started
- Participant ID and age of the respondent
- Language in which the interview was conducted
- Who, if anyone, assisted the participant in completing the questions

DHS provided Vital Research with the MN PES-adult and MN PES-minor versions of the survey in English, Spanish, Hmong and Somali.

5 Previously both PCA-Traditional and PCA-Choice recipients reported high levels of satisfaction with PCA workers’ respect, completion of tasks and overall quality. Similarly, high-levels of satisfaction were also reported with the PCA agencies. See Minnesota’s 2003 PCA Consumer Survey Report.
MN PES Work Plan
The PES work plan was developed based on the expectation of completing 400 face-to-face interviews with randomly-selected persons receiving Developmental Disabilities Waiver services and 400 face-to-face interviews with persons receiving Brain Injury Waiver services, Personal Care Assistance traditional services and PCA Choice Services Option where the consumer is responsible for hiring, training, scheduling and terminating their personal care assistants.

Vital Research implemented the statewide MN PES between May and June 2012.

Project Staffing and Training
Vital Research managed all aspects of the PES staffing and training from their office in Los Angeles, California. Vital Research contracted with twelve local interviewers to complete 800 face-to-face interviews within ten weeks. Six interviewers were recruited in the Twin Cities, including three bilingual interviewers (English/Spanish, English/Hmong, and English/Somali). An additional six interviewers were recruited in areas close to Rochester, St. Cloud, Brainerd and Duluth Minnesota to conduct interviews outside of the Twin City area and minimize drive time. All interviewers were recruited and screened prior to training6.

Field staff training included a combination of classroom instruction and practice interviews with participants over three days. Vital Research enhanced and modified the training content from the Thomson Reuters Self-Study Manual training. In 2010, Vital Research developed a proxy survey for adult participants. Based on interviewer feedback from 2010, a few additional probes were added to the 2012 versions of the survey, along with one follow-up question.

Vital Research used several methods to evaluate the acquired knowledge and skills of trainees including the following:

- Completion of the interview skills checklist
- Ability of trainees to categorize participant responses and interpret information according to the requirements of a structured interview

6 Vital Research processed criminal background checks for each Interviewer through the Internet (NetStudy). All interviewers passed their background check before attending the Interviewer training.
Completion of two practice interviews

Trainees who did not meet the 90% or higher standard were not hired.

Interviewer Behavior Expectations
Interviews were conducted at the respondent’s location of choice. Interviewers were expected to dress professionally and look approachable and comfortable at the same time. Interviewers were required to wear a name badge at all times while they were working and to be professional and courteous with the participant, proxies, guardians, or other caretakers. Interviewers were not allowed to provide physical care. Interviewers had laminated sheets with the announcement letter and a letter addressing data confidentiality from DHS to show to participants and/or guardians.

Interviewers read the introductory script and provided instructions on the response categories. For non-proxy interviews, interviewers were instructed to conduct the interviews in a private place where no staff members or family members could overhear the interview, unless someone was invited by the participant to be present.

Vital Research provided interviewers with Thank You cards to give each respondent at the end of each interview.

Potential for Abuse, Neglect, or Exploitation Report
Interviewers were required to report suspected abuse, neglect or exploitation under the Minnesota Vulnerable Adults Act and Maltreatment of Minors Act. Specifically, if the interviewer observed, or suspected, based on verbal report, that a person was a victim of maltreatment, s/he called the local Common Entry Point (CEP) within 24 hours.

Data Confidentiality and Data Submission

Data Confidentiality
In compliance with federal law, policies were in place to guide the transmission of data, the physical security of data, and the confidentiality of respondents.

Transmission of Data
All participant information was transmitted through a secure HTTPS website using Secure Socket Layer Virtual Private Network (SSL/VPN) technology. Interviewers and VR staff were not permitted to send any participant information via e-mail.

Physical Security
All participant information was kept secure through the following precautions:

- All electronic data were stored on password-protected computers/servers accessible only to project staff. Interviewers were instructed on how to secure their personal computers and set up a separate password-protected account for work-purposes only.
- Vital Research computers and servers were protected by firewalls and security protocols that encrypt and block unauthorized access.
- All documents or files shipped were tracked via FedEx.
- Interviewers were provided with a lock box to store all raw data forms and participant call sheets when not in use.
- All raw data forms and call sheets that were returned to Vital Research were stored in a locked, limited-access office. The Vital Research office is located in a limited access, secured building with 24-hour security.
- Electronic data elements were deleted and hard copies of data were shredded on a DHS-authorized date.

Confidentiality
Vital Research assigned identification numbers to each participant in order to help keep individual survey responses confidential. DHS provided Vital Research with two letters—one for participants and one for guardians—describing Vital Research’s requirement to safeguard private health information. This letter was given to interviewers to distribute during scheduling and it was sent to anyone with questions or concerns about HIPAA or participant’s privacy. Interviewers signed both an independent contractor agreement and a business associate agreement.
SURVEY PARTICIPANT DATA SAMPLE

Sample List
DHS provided Vital Research with a random sample\(^7\) of persons enrolled in the Developmental Disability Waiver and three other Medical Assistance programs (BI Waiver, Personal Care Assistance services and Personal Care Assistance Choice services) on two sample lists:

1. 1,856 DD Waiver and 1,976 non-DD Waiver participants (BI Waiver, Personal Care Assistance services and Personal Care Assistance Choice services) on March 12, 2012
2. 702 non-DD participants (Personal Care Assistance services and Personal Care Assistance Choice services) on June 12, 2012

DHS provided Vital Research with a second random sample list of persons only enrolled in PCA to compensate for the following situations:

- High number of invalid phone numbers
- Unreturned calls and Refusals and outdated information on the initial sample list. Each of the 4,534 people included in the first sample list was placed in one of three categories:

1. Unable to contact
2. Attempt to contact
3. Need Additional Information

\(^7\) DHS conducted proportional stratified random sampling based on medical assistance program enrollment contained in the Medicaid Management Information System (MMIS).
Participants Excluded
The following people were unable to be contacted and were excluded from the list of eligible persons to be interviewed.

- Speaking a language other than English, Spanish, Hmong or Somali
- People identified as deceased
- People appearing twice in the sample list

Attempt to Contact
After consulting with DHS, Vital Research assumed that people receiving PCA services without a case manager listed would likely not have a legal guardian and could be attempted to contact. In addition, all PCA participants on the second sample list could be contacted directly. After cleaning of the lists, approximately one third of participants could be contacted without further information.

Need Additional Information
All remaining people needed either an updated phone number or guardianship information. To obtain guardianship and updated contact information, county supervisors and case managers were contacted. In addition, DHS provided some missing phone information by asking participants with an invalid phone number to send in contact information.

DHS provided case manager contact information for Hennepin County. However, all other counties required calls to the County Supervisor to obtain case manager contact information. Throughout the project, a toll free number was available to participants, guardians, case managers, interviewers and any other stakeholders to speak to Vital Research staff from 9:00 AM CDT until 8:30 PM CDT.

Survey Participation
Vital Research mailed selected survey participants a letter prepared by DHS that described the purpose of the survey and informed them that an interviewer would contact them to participate in the survey. DHS provided Vital Research with the contact information, including phone numbers and addresses. Vital Research scheduled interviews based on region, the number of available interviewers in that region, and any particular language requirement (English, Hmong, Somali or Spanish).

Additionally, DHS staff sent out an announcement using the DSD Stakeholder and County E-lists to inform lead agencies of the MN PES progress and provided contact information for questions/concerns. DHS provided further communication to respondents and stakeholder through the MN Disability Linkage Line® and the DHS Member Help Desk.
Translation and Interpretation Assistance
Three bilingual interviewers (English/Spanish, English/Hmong and English/Somali) were recruited to provide translation and interpreter assistance.

Survey Interview Scheduling
Interviewers started scheduling interview appointments on April 18, 2012. For any survey participants under the age of 15 years and for those who may not be able to respond to all the survey questions, interviewers scheduled a proxy interview (i.e., a proxy provided responses on behalf of the participant). Scheduling was completed on June 21, 2012.

VR Research staff contacted 2,221 potential respondents. From these contacts, 838 (38%) interview appointments were scheduled. Of the 838 interview appointments:

- 807 (96%) resulted in completed interviews (403 DD, 102 BI, 210 PCA-Traditional, 92 PCA-Choice).
- 51 (6%) interviews were conducted in Hmong, Somali or Spanish.
- 171 (21%) of the interviews completed were with minors and their parent and/or guardian present.

Vital Research staff processed and cleaned all data. On June 28, 2012, the final datasets and supporting documents were delivered to DHS.

Interview Data Results
Table 1 shows the final status of the 2,221 potential respondents contacted for participation in the MN PES survey.

<table>
<thead>
<tr>
<th>Status</th>
<th>DD</th>
<th>BI</th>
<th>PCA-C</th>
<th>PCA-T</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not on Waiver</td>
<td>3</td>
<td>1</td>
<td>24</td>
<td>56</td>
<td>84</td>
</tr>
<tr>
<td>Bad Phone Number</td>
<td>109</td>
<td>40</td>
<td>89</td>
<td>317</td>
<td>555</td>
</tr>
<tr>
<td>Language Barrier</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>15</td>
<td>21</td>
</tr>
<tr>
<td>Guardian Refusal</td>
<td>42</td>
<td>4</td>
<td>12</td>
<td>11</td>
<td>69</td>
</tr>
<tr>
<td>Participant Refusal</td>
<td>67</td>
<td>27</td>
<td>31</td>
<td>53</td>
<td>178</td>
</tr>
</tbody>
</table>

Table 1: Status of potential respondents
Survey Sample Demographics

Of the 838 interview appointments, 807 resulted in conducted interviews for a completion rate of 96%. Of all conducted interviews, the average age of participants was 35, ranging from one to 96. Table 2 shows the number of interviews conducted in each of the six Medical Assistance programs.

Table 2: Number of conducted interview by program type

<table>
<thead>
<tr>
<th>Medical Assistance Program Type</th>
<th>Number of Conducted Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>DD Waiver</td>
<td>403</td>
</tr>
<tr>
<td>BI</td>
<td>102</td>
</tr>
<tr>
<td>PCA-T</td>
<td>210</td>
</tr>
<tr>
<td>PCA-C</td>
<td>92</td>
</tr>
<tr>
<td>Total Conducted</td>
<td>807</td>
</tr>
</tbody>
</table>
Vital Research conducted interviews at the respondent’s location of choice. Forty-one percent (n=332) of the total number of interviews were conducted in the Twin Cities. In addition to the person’s residence, alternative locations for survey interviews ranged from public libraries to fast food restaurants.

The average (mean) time to complete an interview was 25 minutes, ranging from nine to 89 minutes.

Changes in the Interview Appointment
Changes in the appointment schedule did occur. Reasons for rescheduling included:

- Interviewer illness
- Respondent cancellations
- Refusals or
- No-shows

If the respondent provided enough notice (at least one day before the interview), Vital Research rescheduled the interview for another time. Ultimately, only three interviews were unable to be rescheduled.
SURVEY RESULTS

The survey results for the 807 respondents who participated in the 2012 statewide MN PES are organized by common domain areas for both adult and minors:

- Case Management and Service Plan Development
- Health, Welfare and Safety
- Important Long-term relationships
- Quality of Life
- CDCS - Self Direction and
- Experience with Direct Care Staff

The adult survey includes four additional domains:

- Own Home
- Community Membership
- Daily Activities/Employment
- Experience with Congregate Housing-Ability to make choices; Privacy; Rights

Case Management and Service Plan Development
The first set of questions gathered feedback on the person’s experience with their case manager (sometimes called a social worker or public health nurse) and service plan development. The adult responses are summarized in Figure 1 below and the minor responses are summarized in Figure 2.

All calculations were computed using SPSS (Statistical Package for the Social Sciences) output with frequencies for each variable separated by individual program. Complete copies of the surveys are available upon request by contacting:

Tom Skarohlid
DHS - Disability Services Division
PO Box 64967
St. Paul, MN 55164-0967
Email: thomas.a.skarohlid@state.mn.us
Adult respondents experience with case management and service plan development is generally positive. Over 90% of respondents report that:

- They are overall satisfied with case management
- Their case manager treats them with respect,
- They receive all services and supports in their service plan and
- They are able to say what they wanted in their service plan

Additionally, 42% (225 of 538) of respondents wanted to change services or supports in their service plan (see Table 3). Of the requests made, 14% (30 of 217) did not occur (see Table 4).

* In many cases, PCA-C and PCA-T respondents have a case manager (e.g. VA/DD Targeted Case Management). Other times they may have perceived their case manager as being a financial worker, Qualified Professional, or Public Health Nurse Assessor.
### Table 3: Have you ever asked your case manager for changes to your services or supports?

<table>
<thead>
<tr>
<th>Adults</th>
<th>Program</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>DD</td>
<td>BI</td>
<td>PCA- C</td>
<td>PCA-T</td>
<td>Total</td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
<td>142</td>
<td>35</td>
<td>15</td>
<td>33</td>
<td>225</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
<td>42.1%</td>
<td>38.0%</td>
<td>51.7%</td>
<td>41.3%</td>
<td>41.8%</td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
<td>192</td>
<td>53</td>
<td>13</td>
<td>46</td>
<td>304</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
<td>57.0%</td>
<td>57.6%</td>
<td>44.8%</td>
<td>57.5%</td>
<td>56.5%</td>
</tr>
<tr>
<td>I don’t remember</td>
<td>Count</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
<td>.9%</td>
<td>4.3%</td>
<td>3.4%</td>
<td>1.3%</td>
<td>1.7%</td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
<td>337</td>
<td>92</td>
<td>29</td>
<td>80</td>
<td>538</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

### Table 4: Did your case manager make the changes in services or supports you asked for?

<table>
<thead>
<tr>
<th>Adults</th>
<th>Program</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>DD</td>
<td>BI</td>
<td>PCA- C</td>
<td>PCA-T</td>
<td>Total</td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
<td>15</td>
<td>7</td>
<td>2</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
<td>10.7%</td>
<td>21.9%</td>
<td>15.4%</td>
<td>18.8%</td>
<td>13.8%</td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
<td>119</td>
<td>24</td>
<td>11</td>
<td>23</td>
<td>177</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
<td>85.0%</td>
<td>75.0%</td>
<td>84.6%</td>
<td>71.9%</td>
<td>81.6%</td>
</tr>
</tbody>
</table>
Although responses were generally positive across the area of service plan development, some respondents did not attend their annual meetings or have a choice of providers. Approximately half of PCA-T and a third of PCA-C respondents didn’t attend or don’t remember attending their annual meeting. Conversely, DD Waiver participants and BI Waiver participants reported annual meeting attendance at 91% and 88% respectively. About a third (28%, n=134) of respondents reported that they were not given or do not remember having a choice of providers.

---

8 For PCA-T recipients that have not had a change in condition nor an increase of units, the assessor has the option of a telephone update assessment for two consecutive years. Additionally, PCA non-waiver recipients may have interpreted that the annual PCA assessment is the same as an annual planning team meeting convened by the county case manager.
Figure 2 illustrates the minor respondent’s experience with case management and service plan development.

Minor respondents experience with case management and service plan development is generally positive as well. Approximately, 90% of respondents report that:

- They are overall satisfied with case management services
- The case manager treats them with respect and
- They are able to contact their case manager as needed

Yet, 43% (68 of 160) of respondents did not know or were not sure that they could change case managers if they wanted to.
Additionally, 53% (78 of 147) of respondents wanted to change services or supports in their service plan (see Table 5). Of the requests made, 84% (63 of 75) did not occur (see Table 6).

Table 5: Have you ever asked your case manager for changes to your services or supports?

<table>
<thead>
<tr>
<th>Minor</th>
<th>Program</th>
<th>DD</th>
<th>BI</th>
<th>PCA-C</th>
<th>PCA-T</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Count</td>
<td>31</td>
<td>2</td>
<td>18</td>
<td>27</td>
<td>78</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>79.5%</td>
<td>50.0%</td>
<td>46.2%</td>
<td>41.5%</td>
<td>53.1%</td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
<td>8</td>
<td>2</td>
<td>20</td>
<td>37</td>
<td>67</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>20.5%</td>
<td>50.0%</td>
<td>51.3%</td>
<td>56.9%</td>
<td>45.6%</td>
</tr>
<tr>
<td>I don’t remember</td>
<td>Count</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>.0%</td>
<td>.0%</td>
<td>2.6%</td>
<td>1.5%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
<td>39</td>
<td>4</td>
<td>39</td>
<td>65</td>
<td>147</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Table 6: Did your case manager make the changes in services or supports you asked for?

<table>
<thead>
<tr>
<th>Minor</th>
<th>Program</th>
<th>DD</th>
<th>BI</th>
<th>PCA-C</th>
<th>PCA-T</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Count</td>
<td>30</td>
<td>2</td>
<td>14</td>
<td>17</td>
<td>63</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>96.8%</td>
<td>100.0%</td>
<td>82.4%</td>
<td>68.0%</td>
<td>84.0%</td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>3.2%</td>
<td>.0%</td>
<td>5.9%</td>
<td>16.0%</td>
<td>8.0%</td>
</tr>
</tbody>
</table>
Over 90% of respondents report that during the planning meeting, they are able to express their needs; have enough input in service plan development; and that they receive all the services and supports stated in their plan. However, about 17% of respondents reported that they were not given or do not remember having a choice of providers.

Health, Support and Safety
Respondents were asked questions that had to do with the quality and adequacy of their supports, including safety. Respondents were asked about the extent to which they do a variety of daily activities for themselves or get assistance from others. They were also asked if there had been times when they could not get assistance with these activities when they needed it. Activities of Daily Living (ADLs) adult responses are summaries in Tables 7, 8 and 9 below. Instrumental Activities of Daily Living (IADLs) responses are summaries in Tables 10, 11 and 12 below. The minor ADL responses are summaries in Tables 13 and 14 below.

Adults who receive PCA-C and PCA-T are most likely to need assistance from others with ADLs at 66% (n=29) and 53% (n=69) respectively. See table 7 below.
Table 7: Activities of Daily Living (ADLs) Do you need help or reminders from another person to do things like get dressed, take a bath, eat or use the bathroom?

<table>
<thead>
<tr>
<th>Adults</th>
<th>Program</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>DD</td>
<td>BI</td>
<td>PCA-C</td>
<td>PCA-T</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
<td>188</td>
<td>37</td>
<td>29</td>
<td>69</td>
<td>323</td>
</tr>
<tr>
<td>% within Program</td>
<td>52.4%</td>
<td>38.9%</td>
<td>65.9%</td>
<td>53.1%</td>
<td>51.4%</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
<td>171</td>
<td>58</td>
<td>15</td>
<td>61</td>
<td>305</td>
</tr>
<tr>
<td>% within Program</td>
<td>47.6%</td>
<td>61.1%</td>
<td>34.1%</td>
<td>46.9%</td>
<td>48.6%</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
<td>359</td>
<td>95</td>
<td>44</td>
<td>130</td>
<td>628</td>
</tr>
<tr>
<td>% within Program</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td></td>
</tr>
</tbody>
</table>

Approximately one-fifth (n=138) of all adults report that they are unable to complete ADLs when they need to (Table 8).

Table 8: Are you ever unable to do any of these things when you need to (dress/bathe/eat)?

<table>
<thead>
<tr>
<th>Adults</th>
<th>Program</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>DD</td>
<td>BI</td>
<td>PCA-C</td>
<td>PCA-T</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
<td>52</td>
<td>23</td>
<td>18</td>
<td>45</td>
<td>138</td>
</tr>
<tr>
<td>% within Program</td>
<td>14.9%</td>
<td>24.2%</td>
<td>40.9%</td>
<td>35.4%</td>
<td>22.4%</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
<td>297</td>
<td>72</td>
<td>26</td>
<td>82</td>
<td>477</td>
</tr>
<tr>
<td>% within Program</td>
<td>84.9%</td>
<td>75.8%</td>
<td>59.1%</td>
<td>64.6%</td>
<td>77.4%</td>
<td></td>
</tr>
<tr>
<td>I don’t remember</td>
<td>Count</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>% within Program</td>
<td>.3%</td>
<td>.0%</td>
<td>.0%</td>
<td>.0%</td>
<td>.2%</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
<td>350</td>
<td>95</td>
<td>44</td>
<td>127</td>
<td>616</td>
</tr>
<tr>
<td>% within Program</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td></td>
</tr>
</tbody>
</table>
Of these respondents about one-third (n=40) state that it is because there is nobody to assist them (Table 9).

Table 9: Unable to complete ADLs and the reason being that there is nobody to assist them

<table>
<thead>
<tr>
<th>Adults</th>
<th>Program</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DD</td>
<td>BI</td>
<td>PCA-C</td>
<td>PCA-T</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes Count</td>
<td>9</td>
<td>2</td>
<td>8</td>
<td>21</td>
<td>40</td>
<td>30.8%</td>
</tr>
<tr>
<td>% within Program</td>
<td>18.4%</td>
<td>9.5%</td>
<td>44.4%</td>
<td>50.0%</td>
<td>30.8%</td>
<td></td>
</tr>
<tr>
<td>No Count</td>
<td>40</td>
<td>19</td>
<td>10</td>
<td>20</td>
<td>89</td>
<td>68.5%</td>
</tr>
<tr>
<td>% within Program</td>
<td>81.6%</td>
<td>90.5%</td>
<td>55.6%</td>
<td>47.6%</td>
<td>68.5%</td>
<td></td>
</tr>
<tr>
<td>I don’t remember Count</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>.8%</td>
</tr>
<tr>
<td>% within Program</td>
<td>.0%</td>
<td>.0%</td>
<td>.0%</td>
<td>2.4%</td>
<td>1</td>
<td>.8%</td>
</tr>
<tr>
<td>Total Count</td>
<td>49</td>
<td>21</td>
<td>18</td>
<td>42</td>
<td>130</td>
<td></td>
</tr>
<tr>
<td>% within Program</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td></td>
</tr>
</tbody>
</table>

Approximately 67% (n=396) of adult respondents need assistance with IADLs (Table 10).
Table 10: Do you need help or reminders from another person to do things like cooking, laundry, using the telephone, shopping or doing housework?

<table>
<thead>
<tr>
<th>Adults</th>
<th>Program</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DD</td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
</tbody>
</table>

27% (n=159) of respondents were unable to complete IADLs when they needed to (Table 11).

Table 11: Are you ever unable to do any of these things when you need to (cooking/laundry/telephone/shopping)?

<table>
<thead>
<tr>
<th>Adults</th>
<th>Program</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DD</td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
<tr>
<td>I don’t remember</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
</tbody>
</table>
2012 Statewide Minnesota Participant Experience Survey (MN PES)

Of these respondents, about 30% (n=43) stated the reason being is that there was nobody there to assist them (Table 12).

Table 12: Is this because you did not have anyone to help you (cooking/laundry/telephone/shopping)?

<table>
<thead>
<tr>
<th>Adults</th>
<th>Program</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DD</td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
</tr>
<tr>
<td>% within Program</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
</tr>
<tr>
<td>% within Program</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
</tr>
<tr>
<td>% within Program</td>
<td>63</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Almost all respondents who were children need assistance with ADLs (93%, n=159).

Table 13: Do you need help or reminders from another person to do things like get dressed, take a bath, eat or use the bathroom?

<table>
<thead>
<tr>
<th>Minor</th>
<th>Program</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DD</td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
</tr>
<tr>
<td>% within Program</td>
<td>37</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
</tr>
<tr>
<td>% within Program</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
</tr>
<tr>
<td>% within Program</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Proxy respondents provided responses on behalf of all participants under 18.*
A small percentage of these respondents reported that they were unable to complete ADLs because there was not anyone available to assist them (11%, n=18).

Table 14: Is your child ever unable to do any of these everyday things because he or she does not have anyone to help?

<table>
<thead>
<tr>
<th>Minor</th>
<th>Program</th>
<th>DD</th>
<th>BI</th>
<th>PCA-C</th>
<th>PCA-T</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Count</td>
<td>2</td>
<td>0</td>
<td>5</td>
<td>11</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
<td>5.1%</td>
<td>.0%</td>
<td>11.6%</td>
<td>15.1%</td>
<td>11.3%</td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
<td>37</td>
<td>4</td>
<td>38</td>
<td>62</td>
<td>141</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
<td>94.9%</td>
<td>100.0%</td>
<td>88.4%</td>
<td>84.9%</td>
<td>88.7%</td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
<td>39</td>
<td>4</td>
<td>43</td>
<td>73</td>
<td>159</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

*Proxy respondents provided responses on behalf of all participants under 18.

Treatment by Others - Potential for Abuse, Neglect or Exploitation Report
All MN PES interviewers were required to report suspected abuse, neglect or exploitation under the Minnesota Vulnerable Adults Act and Maltreatment of Minors Act. Specifically, if the interviewer observed, or suspected, based on verbal report, that a respondent was a victim of maltreatment, s/he called the local Common Entry Point (CEP) within 24 hours. Interviewers also completed a Potential for Abuse, Mistreatment, of Neglect Report form and called the contractor Vital Research Project Director or Project Manager to receive the phone number for the local CEP.

Figure 3 depicts that 11% (69 of 622) of adult respondents have gone without a meal when they needed one.
Twenty (3%) adult respondents reported that they had someone physically hit or hurt them. Of these:

- 2 were reported as a staff member that resided in their residence
- 1 was reported as a family member
- 9 were reported as people they lived with and
- 9 were reported as other

Fifty-nine (10%) adult respondents reported that someone has done mean things to them such as, yell at or intimidate them. Of these:

- 16 were reported as staff members that resided in their residence
- 4 were reported as staff members residing outside of their residence
- 6 were reported as family members
- 25 were reported as people they live with

---

9 In some cases, individual respondents reported more than one person physically hit or hurt them such as a staff person, family member or other to the subsequent follow-up questions.
10 In some cases, individual respondents reported more than one person yelling at or intimidating them such as a staff person, family member or other to the subsequent follow-up questions.
Forty (7%) adult respondents also reported that someone has taken (or stolen) money or things without asking\textsuperscript{11}. Of these:

- 10 were reported as staff members that resided in their residence
- 3 were reported as staff members residing outside of their residence
- 10 were reported as people they live with
- 3 were reported as family members and
- 17 were reported as other

Twelve (2%) adult respondents reported that someone has recently touched them in a way they did not like. Of these:

- 2 were reported as staff members residing outside of their residence
- 1 was reported as a family member
- 4 were reported as people they lived with and
- 5 were reported as other

Figures 4 and 5 summarize treatment by others for all programs for both Adult and Minors.

\textsuperscript{11} In some cases, individual respondents reported more than one person has taken (or stolen) money or things without asking them such as a staff person, family member or other to the subsequent follow-up questions.
Figure 4 illustrates the treatment of minors by others. Seven of the respondents reported that someone had physically hit or hurt them; four were identified as family members and three were reported as other. Twenty (12%) respondents reported that someone has done mean things to them, such as yell at or intimidate them. Three of these were listed as family members and eighteen were reported as other. None of the 171 respondents reported being touched in a way they do not like.

\[\text{Figure 5 illustrates the treatment of minors by others. Seven of the respondents}\]

\[\text{reported that someone had physically hit or hurt them; four were identified as family}\]

\[\text{members and three were reported as other. Twenty (12\%) respondents reported that}\]

\[\text{someone has done mean things to them, such as yell at or intimidate them. Three of}\]

\[\text{these were listed as family members and eighteen were reported as other.}\]

\[\text{None of}\]

\[\text{the 171 respondents reported being touched in a way they do not like.}\]

\[\text{In some cases, individual respondents reported more than one person yelling at or intimidating them}\]

\[\text{such as a staff person, family member or other to the subsequent follow-up questions.}\]
It is important to note that although these questions are intended to assess the prevalence of maltreatment amongst DD Waiver and non-DD respondents, the situations that a respondent responded “yes” may or may not be considered maltreatment of a vulnerable adult/minor.

Cases where the respondent or their proxy responded affirmatively to any of these questions were referred to the Adult/Child Protection Common Entry Point for the county in which the respondent resides.

**Safety**
Adult respondents were also asked about their personal safety in their own home and in the community. Proxy respondents were asked about the safety of the minor respondents as summarized in Figure 6 and 7 below.

Overall, adult respondents feel safe both in their home and in the community:

- 98% of respondents feel safe in their homes and
- 96% of respondents feel safe when they leave their home and go into the community
However, 36 (7%) adult respondents feel unsafe because the people who are paid to help them are not with them when they are supposed to be.

**Figure 7: Proxy respondent report on safety - Minors all programs**

![Pie chart showing 95% feeling safe and 5% feeling unsafe.]

Seven proxy respondents (5%) report that they feel that their child is unsafe because people who are paid to help are not with the child when they are supposed to be.

**Community Membership**

Interviewers asked adult respondents about community membership including voting, attending events and community inclusion. Figure 8 summarizes the results.

**Figure 8: Community membership - % Adult within program**

- Are you able to vote if you want to?
- Can you attend events in your community that are important to you?
- Can you go out in your community on your own when you want to?
- Are you part of a group where you feel you belong?
- Can you get together with people who are important to you when you want to?
- Do you always have a way to get to the places you need to go in your community?
Overall, 82% of respondents stated that they are able to vote when they want to. However, 26% of participants with developmental disabilities stated that no, they are not allowed to vote, were unsure, or did not remember.

Over 90% of all adult respondents report that they can attend events in the community that are important to them; that they can get together with people that are important to them when they want to; and that they always have a way to get to the places they need to go to in their community. However, almost two-thirds (60%) of respondents reported that they could not go out in the community on their own when they wanted to and about a third (28%) reported that they did not feel that they were part of a group where they belong.

**Important Long-Term Relationships**

MN PES interviewers asked both adult and minor respondents about important long-term relationships. Questions included having a best friend or someone that they feel close to and if they have family, friends or neighbors who are not paid to help them with everyday activities. Figures 9 and 10 below summarize the results.

**Figure 9: Important long-term relationships - % Adult within program**
Over 85% of adult respondents stated that they have friends who are not family members or are paid staff. Approximately two-thirds of adults reported that they had a best friend or someone with whom they were close to; and that they did have family, friends or neighbors to help them with everyday activities without being paid.

Figure 10: Important Long-Term Relationships - % Minors within Program

<table>
<thead>
<tr>
<th>Important Long-Term Relationships</th>
<th>Total</th>
<th>PCA-T</th>
<th>PCA-C</th>
<th>BI</th>
<th>DD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have friends who are not family members or paid staff?</td>
<td>80</td>
<td>92</td>
<td>75</td>
<td>76</td>
<td>92</td>
</tr>
<tr>
<td>Does your child have a best friend or someone s/he is really close to?</td>
<td>60</td>
<td>70</td>
<td>50</td>
<td>50</td>
<td>70</td>
</tr>
<tr>
<td>Do you have family, friends or neighbors who help you without being paid?</td>
<td>70</td>
<td>80</td>
<td>60</td>
<td>62</td>
<td>80</td>
</tr>
</tbody>
</table>

*There were four minor respondents receiving BI Waiver services

Over 70% of proxy respondents report that their child has friends who are not family members or paid staff. Almost 60% of proxy respondents report that their child has a best friend or someone that they are close to and over two-thirds report that they have family, friends or neighbors who help them with everyday activities without being paid.

Quality of Life
Respondents were asked about the quality of their life based on program participation and services received. Figures 11 and 12 below illustrate the results.

Overall, 84% of adult respondents report that being on their program and receiving services has made their life better than before. The remaining 16% of respondents report that their life is about the same (14%) or worse (2%) than before they were on their program.
The quality of life improved for 90% of minor respondents because of the services they receive on their program. The remaining 10% of respondents report that the quality of life before and after being on their program is about the same (9%) or worse (<1%).

**Increased Independence**

Adult and minor respondents were asked about the paid support that they receive and how it has affected their independence. Figures 13 and 14 below summarize results.
Over 60% of adults report that because of the paid support that they receive they do a lot more for themselves than before. Additionally, 30% of adult respondents report that they do a little more because of the paid support that they receive. Overall, minors report that their independence has increased because of the paid support that they receive.
Employment and Daily Activities
Adult respondents were asked questions about what activities that they engaged in during the day. Figure 15 summarizes the results below.

Figure 15: Activities adults are involved in during the day - % Adult within program

What kinds of things do you do during the day? Do you...

- Nothing else
- Other
- Go to a day program
- Do volunteer work
- Have a job where you earn money
- Go to school

% of Respondents within Program Adult

Over 50% of adults have a job where they earn money. DD Waiver respondents report employment at 74%. During the day, about one-third goes to a day program and a quarter of respondents do volunteer work. About one-third of respondents report that they do other things during the day. Eight percent of respondents report that they go to school and 17% state that they do nothing else during the day.

Adults that mentioned before that they were not currently working at a paid job were asked if they wanted to work. Over half of all BI Waiver (68%, n=30), PCA-C (57%, n=17) and PCA-T (64%, n=56) respondents that are not currently working would like a job. Figure 16 illustrates this below.
Barriers to Work
Respondents were asked if something was holding them back from working. Approximately, one fifth of PCA-C and one-third of PCA-T reported that concerns about managing one’s health condition, or restatement of one’s diagnosis were the main reason holding them back from working. Figure 17 is illustrated below.
Many people with disabilities would like to work, but feel something is holding them back. If this is true for you, what is holding you back from working?

Option to Work Additional or Fewer Hours
Interviewers asked adult respondents if they had the option to work more or fewer hours. Over half had this flexibility with their work schedule. Twelve percent said that they did not know or were not sure. However, Almost 40% said they did not have the option to work more or fewer hours. See Figure 18 below.


Employment - Opportunities for Improvement
Interviewers asked respondents if they had a chance to learn new things and get better at their work. Overall, 89% of respondents report that they have opportunities to learn new skills and get better at their job. Figure 19 summarizes responses.

Figure 19: Opportunity to learn new skills and get better at their job

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2012 Statewide Minnesota Participant Experience Survey (MN PES)
Experience with Direct Care Staff
Interviewers asked adult and minor respondents about their experience with direct care staff (for those non-CDCS individuals who use agency-provided staff). The adult responses are summarized in Figure 20 below and the minor responses are summarized in Figure 21.

Overall generally happy with the paid staff...
- Can they understand you
- Can you understand them
- Treat you respectfully
- Do they do a good job
- Stay as long as they are supposed to
- Have enough time to do all they need to do

Adult respondents experience with direct care staff is generally positive. Over 95% of adults report that they are generally happy with the people paid to help them in their homes, treat them respectfully, that they do a good job and stay as long as they are supposed to. However, about 20% of adult respondents report that direct care staff does not have enough time to do all they need to do.

Additionally, adults were asked if they helped pick the people who are paid to help them; 40% (216 of 539) of respondents helped pick the people who are paid to help them (see Table 15). Subsequently, those persons that did not help pick the people who are paid to help them were asked if they would like to (see Table 16). Of these:

- 36% (105 of 291) responded that they would
- 52% (150 of 291) responded that they would not and
- the remaining 12% (36 of 291) did not know or were not sure
### Table 15: Did you help pick the people who are paid to help you? - Adults % within program

<table>
<thead>
<tr>
<th>Adults</th>
<th>Program</th>
<th>DD</th>
<th>BI</th>
<th>PCA-C</th>
<th>PCA-T</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Count</td>
<td>218</td>
<td>61</td>
<td>8</td>
<td>32</td>
<td>319</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>72.9%</td>
<td>75.3%</td>
<td>20.5%</td>
<td>26.7%</td>
<td>59.2%</td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
<td>79</td>
<td>20</td>
<td>31</td>
<td>86</td>
<td>216</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>26.4%</td>
<td>24.7%</td>
<td>79.5%</td>
<td>71.7%</td>
<td>40.1%</td>
</tr>
<tr>
<td>I don’t remember</td>
<td>Count</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>.7%</td>
<td>.0%</td>
<td>.0%</td>
<td>1.7%</td>
<td>.7%</td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
<td>299</td>
<td>81</td>
<td>39</td>
<td>120</td>
<td>539</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

### Table 16: Would you like to help pick the people who are paid to help you? - Adults % within program

<table>
<thead>
<tr>
<th>Adults</th>
<th>Program</th>
<th>DD</th>
<th>BI</th>
<th>PCA-C</th>
<th>PCA-T</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Count</td>
<td>65</td>
<td>26</td>
<td>2</td>
<td>12</td>
<td>105</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>32.3%</td>
<td>45.6%</td>
<td>28.6%</td>
<td>46.2%</td>
<td>36.1%</td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
<td>112</td>
<td>23</td>
<td>3</td>
<td>12</td>
<td>150</td>
</tr>
<tr>
<td>% within Program</td>
<td></td>
<td>55.7%</td>
<td>40.4%</td>
<td>42.9%</td>
<td>46.2%</td>
<td>51.5%</td>
</tr>
<tr>
<td>I don’t know/not sure</td>
<td>Count</td>
<td>24</td>
<td>8</td>
<td>2</td>
<td>2</td>
<td>36</td>
</tr>
</tbody>
</table>
Minor respondents experience with direct care staff is generally positive as well. Over 95% of minors report that they are generally happy with the people paid to help them in their homes, treats them respectfully, that they do a good job and stay as long as they are supposed to. However, about 20% of minor respondents report that direct care staff does not have enough time to do all they need to do.

Additionally, minors were asked if they helped pick the people who are paid to help them; 85% (112 of 132) of respondents helped pick the people who are paid to help them (see Table 17). Subsequently, those individuals that did not help pick the people who are paid to help them were asked if they would like to (see Table 18). Of these:

- 44% (8 of 18) responded that they would
• 33% (6 of 18) responded that they would not and
• the remaining 22% (4 of 18) did not know or were not sure

Table 17: Did you help pick the people who are paid to help you? - Minors % within program

<table>
<thead>
<tr>
<th>Minors</th>
<th>Program</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DD</td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
</tr>
<tr>
<td>% within Program</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
</tr>
<tr>
<td>% within Program</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
</tr>
<tr>
<td>% within Program</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Table 18: Would you like to help pick the people who are paid to help you? - Minors % within program

<table>
<thead>
<tr>
<th>Minors</th>
<th>Program</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DD</td>
</tr>
<tr>
<td>Yes</td>
<td>Count</td>
</tr>
<tr>
<td>% within Program</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
<tr>
<td>No</td>
<td>Count</td>
</tr>
<tr>
<td>% within Program</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
<tr>
<td>I don’t know/not sure</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>% within Program</td>
</tr>
</tbody>
</table>
2012 Statewide Minnesota Participant Experience Survey (MN PES)

<table>
<thead>
<tr>
<th>% within Program</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Count</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

DD participant comparison to 2010 and 2012 surveys

Case Management and Service Plan Development comparison 2010 to 2012
Overall, both adult and minor DD Waiver participants responded similarly on the Case Management and Service Plan Development questions across both years¹³ (Figure 22 and 23).

¹³ A 95% confidence level +/-9% margin of error for the 2010 sample and +/-5% margin of error for the 2012 sample were used to determine statistical significance.
2012 Statewide Minnesota Participant Experience Survey (MN PES)

Figure 22: DD Waiver participant experience with case management and service plan development 2010 to 2012 - Adults % within program

Figure 23: DD Waiver participant experience with case management and service plan development 2010 to 2012 - Minors % within program

Community Membership comparison 2010 to 2012
Over 80 to 90 percent of adult DD respondents report that they:

- Can attend events in the community that are important to them
- Are part of a group where they feel they belong
- Can get together with people who are important to them when they want to and
- Always have a way to get to the places they need to go to in their community
However, DD Waiver participants continue to respond less frequently that they are able to vote when they want to (72% - 2010 and 74% - 2012) and go out in the community independently (21% - 2010 and 28% - 2012). Figure 24 illustrates the results below.

Employment and Daily Activities comparison 2010 to 2012
Approximately three-quarters of DD participants continue to report that they have a job where they earn money (77% - 2010 and 74% - 2012). Additionally, about half of DD participants report that they go to a day program (50% - 2010 and 42% - 2012). See Figure 25 below.
Quality of Life comparison 2010 to 2012
Overall, adult respondents continue to report that being on their program and receiving services has made their life better than before they were on their program (88% - 2010 and 84% - 2012). The remaining respondents report that their life is about the same (12% - 2010 14% - 2012) or worse (2% - 2012) than before they were on their program. Figure 26 illustrates this below.
Overall, 95% of minor respondents continue to report that being on their program and receiving services has made their life better than before they were on their program across both years. The remaining respondents report that their life is about the same at 5% (Figure 27).

Figure 27: Quality of Life comparison 2010 to 2012- % Minor within program
CONCLUSIONS AND RECOMMENDATIONS

The MN PES 2012 project provided information that will serve to enhance community-based services for persons with disabilities. Data obtained from MN PES finds that 85% of the respondents reported that their community-based services have improved their quality of life. Additionally, data obtained from the MN PES project, as well as observations obtained during all phases of the project suggest areas for immediate attention as well as opportunities for improvement.

The following are recommendations to be considered in future surveying projects as well as remediation and quality improvement efforts:

1. Conduct a sampling of CAC Waiver recipients and non-English speaking waiver recipients.

Targeted sampling of CAC Waiver recipients and non-English speaking waiver recipients, which will provide important information that can be used to enhance services that proportional random sampling, did not achieve. Additional attention regarding scheduling interviews for non-English speaking recipients is also recommended to ensure that contacts are culturally sensitive.

2. To consult with the Case Management Reform Group regarding choice of case management.

3. To consult with the recently convened State Quality Council to obtain their recommendations to address remediation activities as follows:
   a) Inform persons on voting rights, choice of provider(s) and to modify individualized coordinated community support plans.
   b) Ensure individualized coordinated community service plans contain strategies designed to ensure paid caregivers are on time and do not leave before other caregivers are available.
   c) Continue to maintain and enhance current local, regional and state projects that focus on employment and jobs for those who want to work and those who have been unsuccessful in either maintaining or finding a new job.
ACKNOWLEDGEMENTS

The Disability Services Division (DSD) of the Minnesota Department of Human Services would like to thank the State Quality Council Panel of stakeholders representing a range of perspectives on quality and disability. In addition, DSD would like to thank the participants and their family and friends who took the time to participate in this survey. Their commitment and collaboration was essential in the initial 2010 and subsequent 2012 implementation of the statewide Minnesota Participant Experience adult and minor surveys (MN PES). These surveys allow DSD to gather information directly from the people that receive services about their experience in order to measure, plan and improve quality assurance efforts and inform future policy decisions.