

2012 Statewide Minnesota Participant Experience Survey (MN PES)

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Giving VOICE to CHOICE



Minnesota Department of Human Services
Disability Services Division

2012 Statewide Minnesota Participant Experience Survey (MN PES)

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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 Services¹. [The first survey was completed in 2010.](#)

Legislation enacted in 2007², 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) Waiver³
- 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 18⁴

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.

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- 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:

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- 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)⁵. 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.

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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 designed the interview guide layout including color-coding, symbols, skip pattern instructions, and page references to allow interviewers to efficiently administer the interview. For this survey, the number of symbols, colors, and lines were reduced to focus interviewers on the most critical information. 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.

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- 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.

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- 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 sample⁷ 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).

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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.

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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 1: Status of potential respondents

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

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Passive Refusal*	211	63	75	158	507
Scheduled	413	107	99	219	838
Interviewed	401	104	93	209	807
Not Interviewed	12	3	6	10	31
Total Contacted	1,264	349	429	1,048	3,090
Not Contacted - Scheduling Completed	592	185	423	244	1,444

*Passive refusals included hang ups, not responding to three calls, inability to understand scheduling call and cancellations.

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

Medical Assistance Program Type	Number of Conducted Interviews
DD Waiver	403
BI	102
PCA-T	210
PCA-C	92
Total Conducted	807

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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

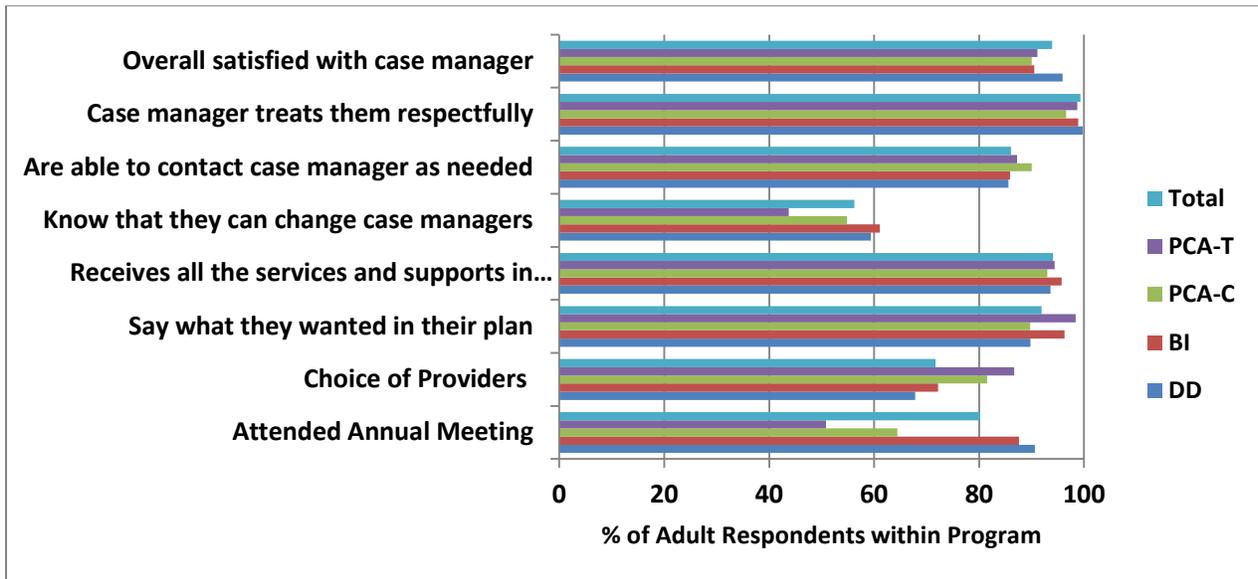
The first set of questions gathered feedback on the person's experience with their case manager (sometimes called a social worker or public health nurse) and service plan development. The adult responses are summarized in Figure 1 below and the minor responses are summarized in Figure 2.

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:

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Figure 1: Experience with case management and service plan development - Adults % within program



* 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.

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).

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Table 3: Have you ever asked your case manager for changes to your services or supports?

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

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

Adults	Program				
	DD	BI	PCA- C	PCA-T	Total
No	15	7	2	6	30
Count					
% within Program	10.7%	21.9%	15.4%	18.8%	13.8%
Yes	119	24	11	23	177
Count					
% within Program	85.0%	75.0%	84.6%	71.9%	81.6%

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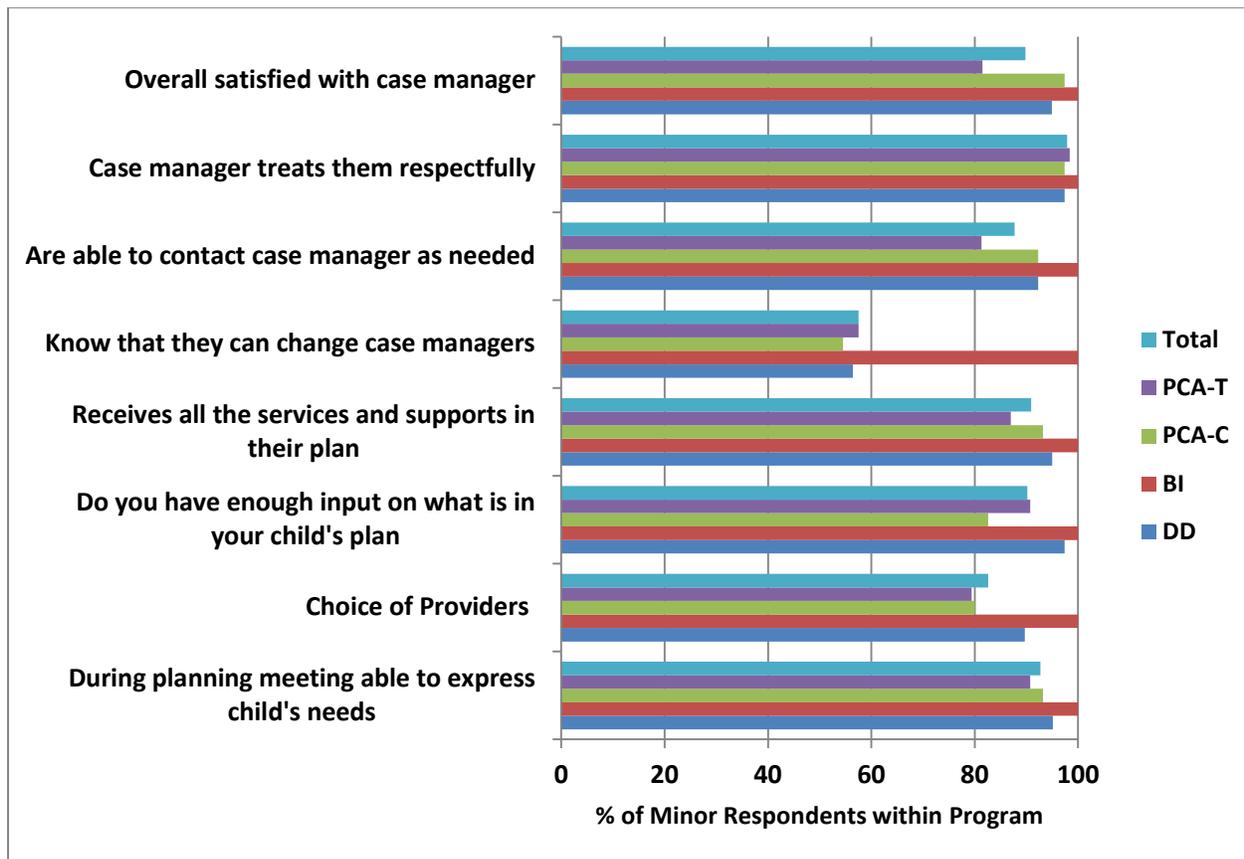
In process	5	0	0	3	8
Count	3.6%	.0%	.0%	9.4%	3.7%
% within Program					
I don't know/not sure	1	1	0	0	2
Count	.7%	3.1%	.0%	.0%	.9%
% within Program					
Total Count	140	32	13	32	217
% within Program	100.0%	100.0%	100.0%	100.0%	100.0%

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 meeting⁸. 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.

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Figure 2: Experience with case management and service plan development - *Minors % within program



*Proxy respondents (predominantly parents) provided responses on behalf of all participants under 18.

*There were a total of four BI Waiver respondents who were minors

* 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.

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.

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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?

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

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

Minor	Program				
	DD	BI	PCA- C	PCA-T	Total
No	30	2	14	17	63
Count					
% within Program	96.8%	100.0%	82.4%	68.0%	84.0%
Yes	1	0	1	4	6
Count					
% within Program	3.2%	.0%	5.9%	16.0%	8.0%

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% within Program					
In process	0	0	2	4	6
Count	.0%	.0%	11.8%	16.0%	8.0%
% within Program					
Total Count	31	2	17	25	75
% within Program	100.0%	100.0%	100.0%	100.0%	100.0%

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.

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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?

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

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)?

Adults	Program					
	DD	BI	PCA-C	PCA-T	Total	
Yes	Count	52	23	18	45	138
	% within Program	14.9%	24.2%	40.9%	35.4%	22.4%
No	Count	297	72	26	82	477
	% within Program	84.9%	75.8%	59.1%	64.6%	77.4%
I don't remember	Count	1	0	0	0	1
	% within Program	.3%	.0%	.0%	.0%	.2%
Total	Count	350	95	44	127	616
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%

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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

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

Approximately 67% (n=396) of adult respondents need assistance with IADLs (Table 10).

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Table 10: Do you need help or reminders from another person to do things like cooking, laundry, using the telephone, shopping or doing housework?

Adults	Program					
	DD	BI	PCA-C	PCA-T	Total	
Yes	Count	241	44	35	76	396
	% within Program	72.4%	48.4%	79.5%	63.3%	67.3%
No	Count	92	47	9	44	192
	% within Program	27.6%	51.6%	20.5%	36.7%	32.7%
Total	Count	333	91	44	120	588
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%

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)?

Adults	Program					
	DD	BI	PCA-C	PCA-T	Total	
Yes	Count	72	19	24	44	159
	% within Program	21.7%	20.9%	57.1%	35.8%	27.0%
No	Count	259	72	17	79	427
	% within Program	78.0%	79.1%	40.5%	64.2%	72.6%
I don't remember	Count	1	0	1	0	2
	% within Program	.3%	.0%	2.4%	.0%	.3%
Total	Count	332	91	42	123	588
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%

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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)?

Adults	Program					
	DD	BI	PCA-C	PCA-T	Total	
Yes	Count	13	0	9	21	43
	% within Program	20.6%	.0%	37.5%	53.8%	30.1%
No	Count	50	17	15	18	100
	% within Program	79.4%	100.0%	62.5%	46.2%	69.9%
Total	Count	63	17	24	39	143
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%

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?

Minor	Program					
	DD	BI	PCA-C	PCA-T	Total	
Yes	Count	37	3	47	72	159
	% within Program	90.2%	75.0%	100.0%	91.1%	93.0%
No	Count	4	1	0	7	12
	% within Program	9.8%	25.0%	.0%	8.9%	7.0%
Total	Count	41	4	47	79	171
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%

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

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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?

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

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

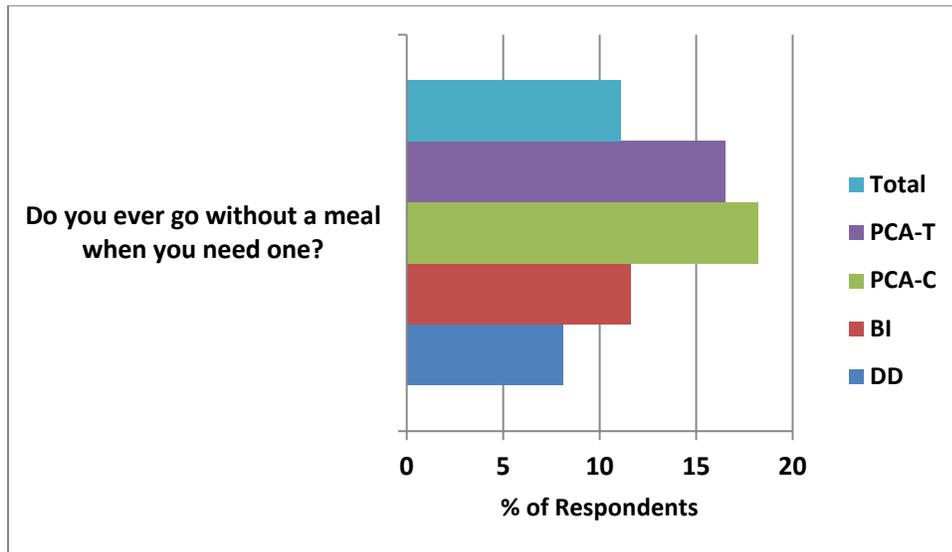
Treatment by Others - Potential for Abuse, Neglect or Exploitation Report

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.

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Figure 3: Respondents that have gone without a meal when they needed one - Adult % within program



Twenty (3%) adult respondents reported that they had someone physically hit or hurt them⁹. 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 them¹⁰. 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.

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- 13 were reported as other

Forty (7%) adult respondents also reported that someone has taken (or stolen) money or things without asking¹¹. 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.

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: Treatment by others - Adult all programs

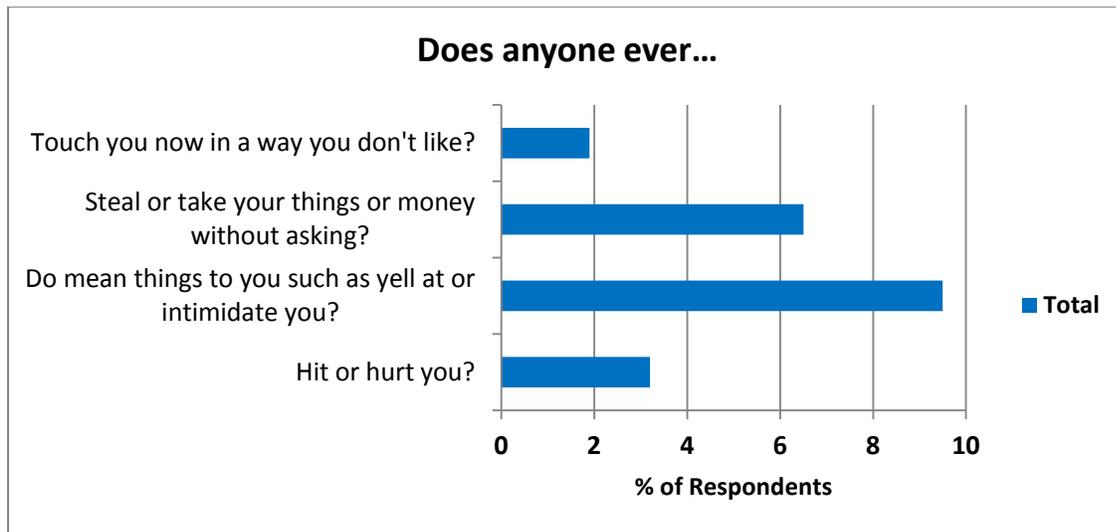
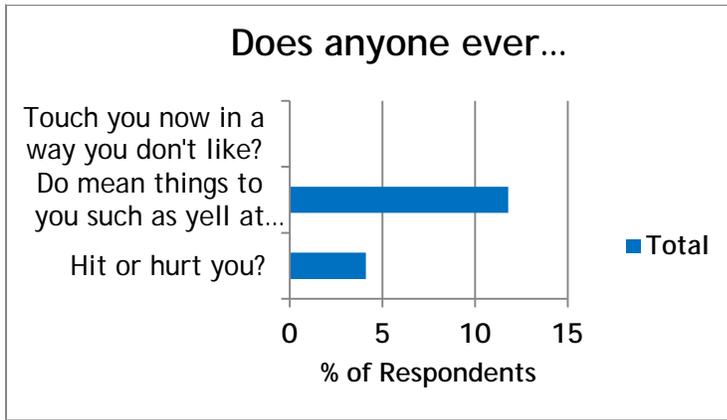


Figure 5 illustrates the treatment of minors by others. Seven of the respondents reported that someone had physically hit or hurt them; four were identified as family members and three were reported as other. Twenty (12%) respondents reported that someone has done mean things to them, such as yell at or intimidate them. Three of these were listed as family members and eighteen were reported as other¹². None of the 171 respondents reported being touched in a way they do not like.

¹² 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.

Figure 5: Treatment by others - Minors all programs



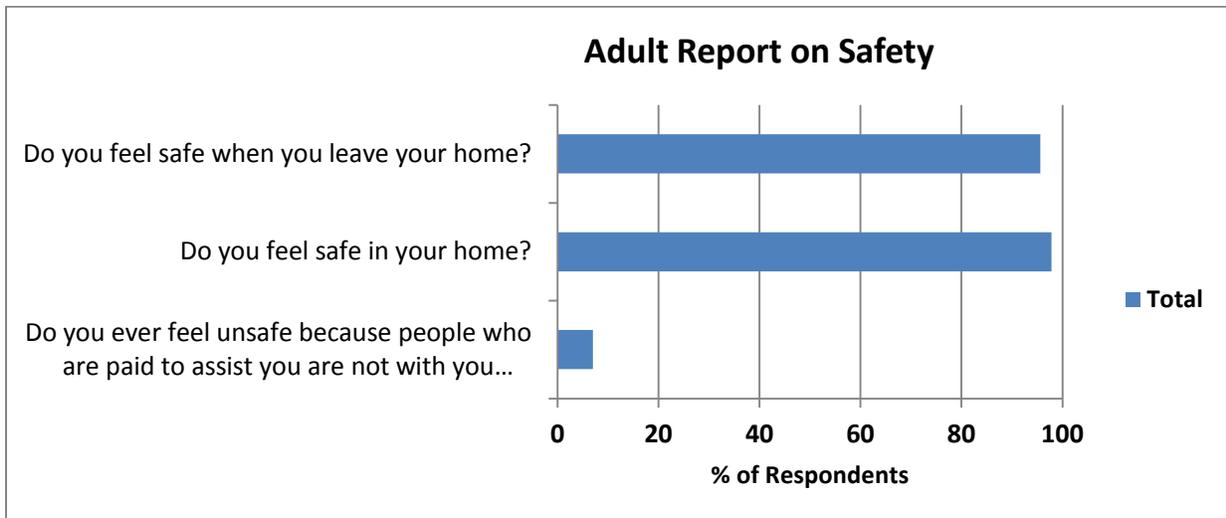
It is important to note that although these questions are intended to assess the prevalence of maltreatment amongst DD Waiver and non-DD respondents, the situations that a respondent responded “yes” may or may not be considered maltreatment of a vulnerable adult/minor.

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.

Figure 6: Respondent reports on safety - Adult all programs



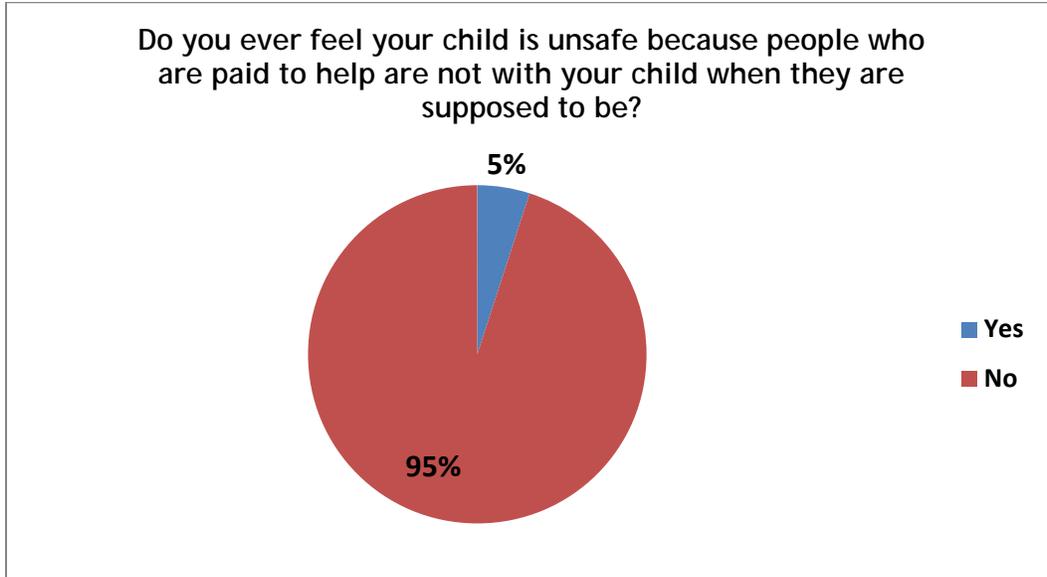
Overall, adult respondents feel safe both in their home and in the community:

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

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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

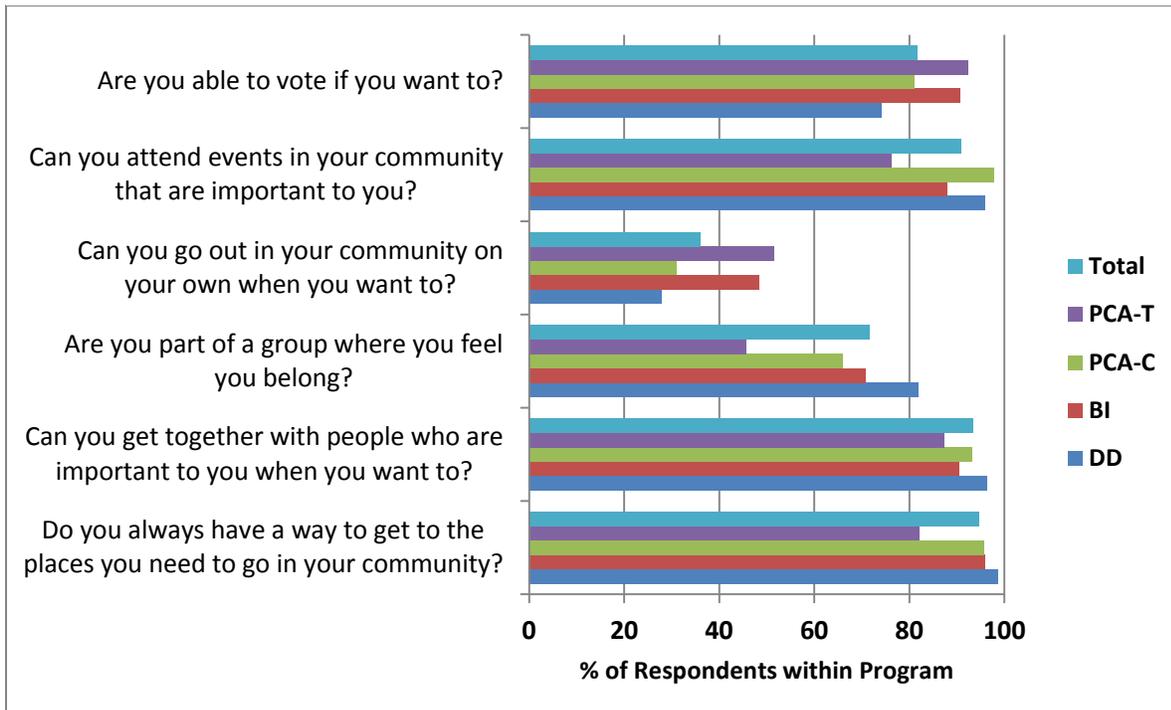


Seven proxy respondents (5%) report that they feel that their child is unsafe because people who are paid to help are not with the child when they are supposed to be.

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



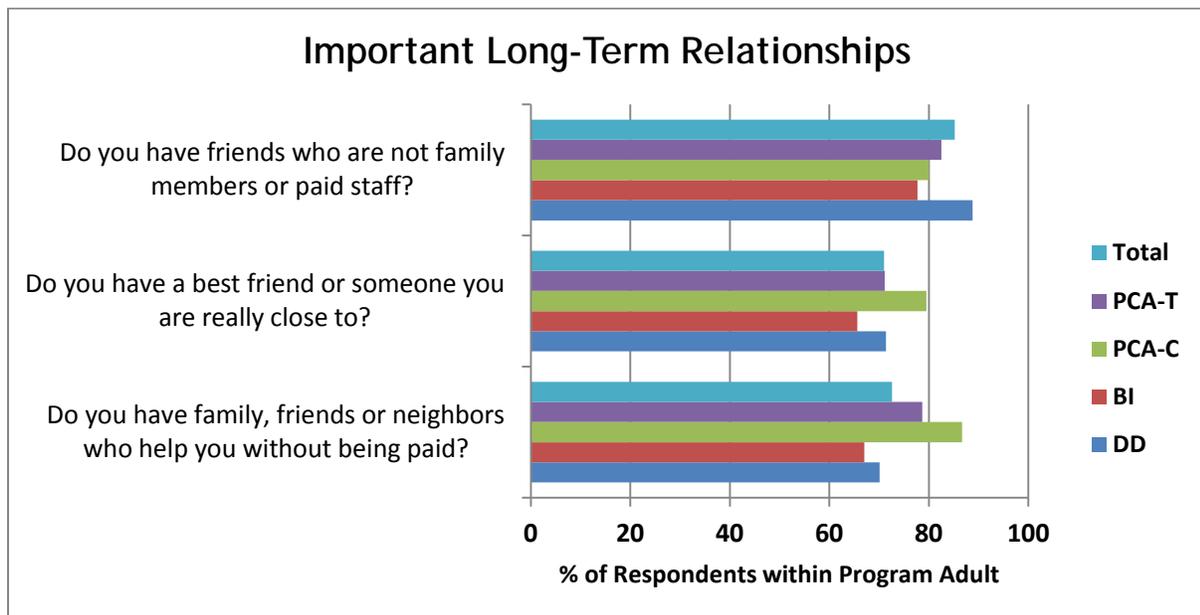
Overall, 82% of respondents stated that they are able to vote when they want to. However, 26% of participants with developmental disabilities stated that no, they are not allowed to vote, were unsure, or did not remember.

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.

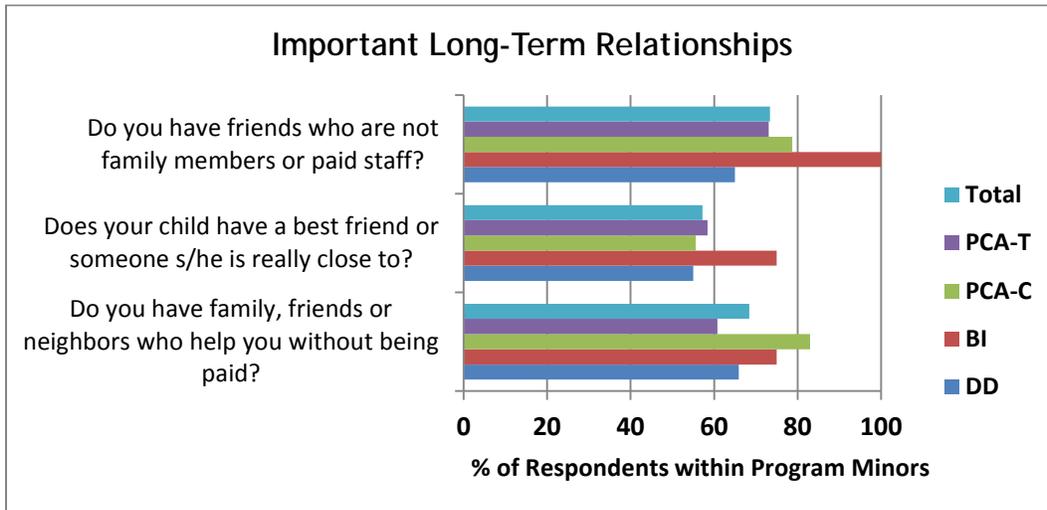
Figure 9: Important long-term relationships - % Adult within program



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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



*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.

Figure 11: Quality of life - % Adults within program

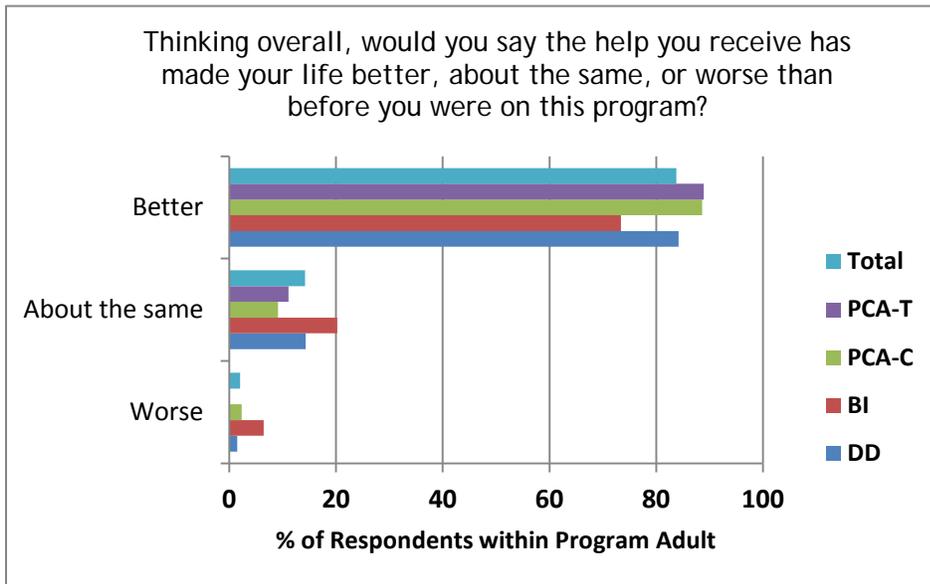
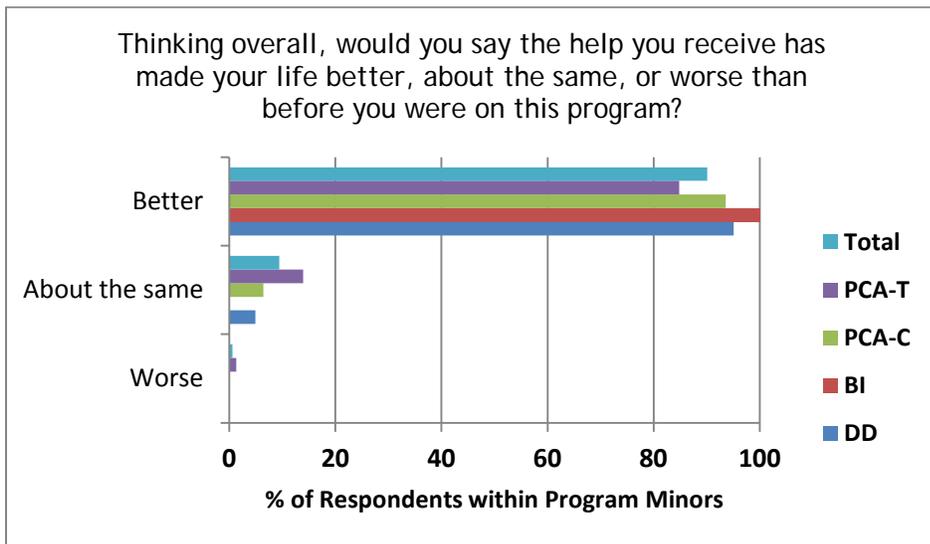


Figure 12: Quality of life - % Minors within program



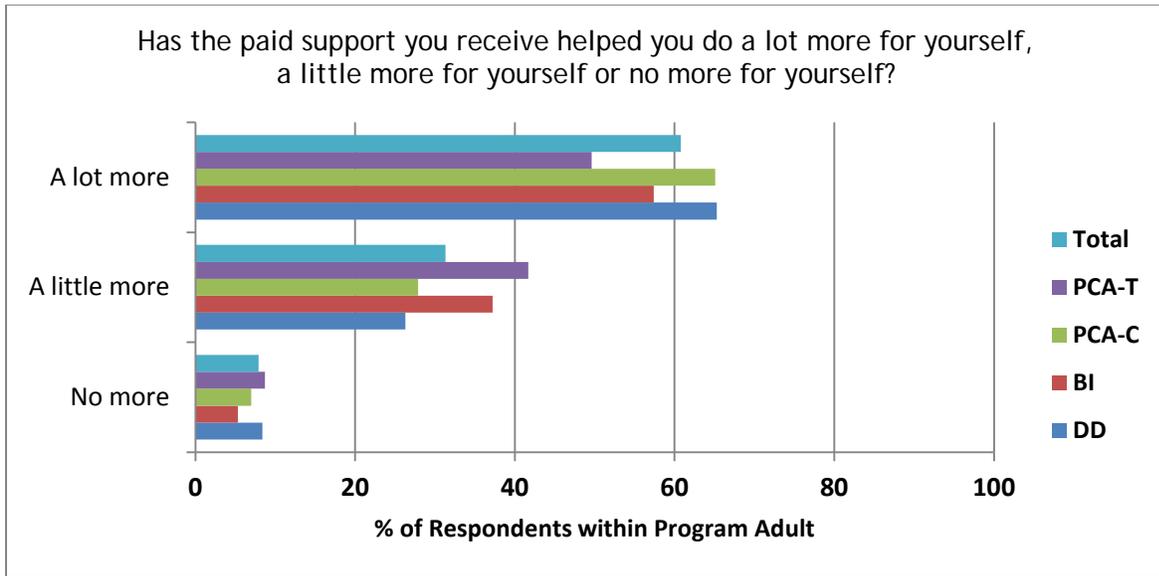
The quality of life improved for 90% of minor respondents because of the services they receive on their program. The remaining 10% of respondents report that the quality of life before and after being on their program is about the same (9%) or worse (<1%).

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.

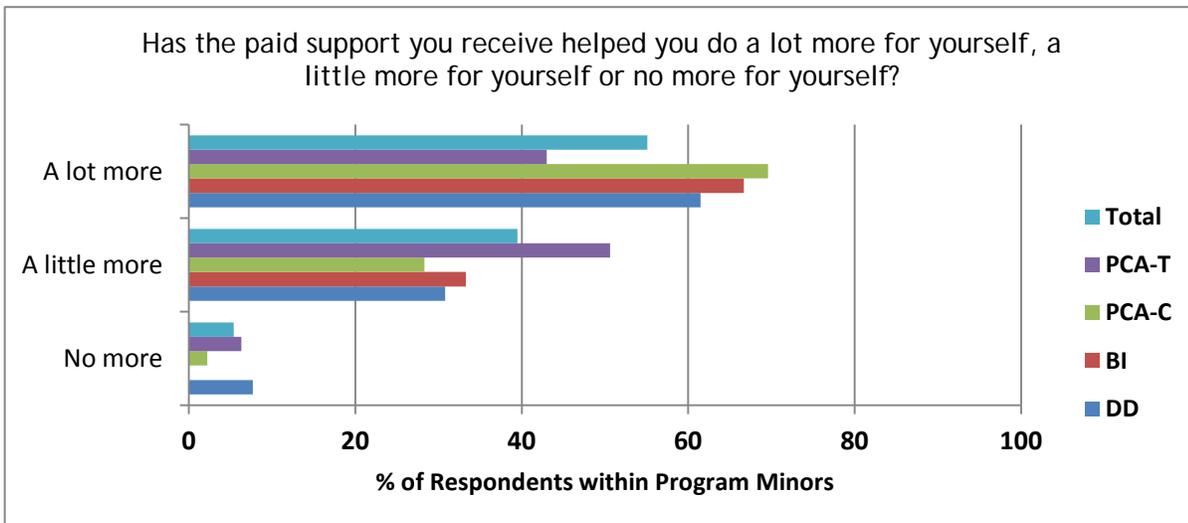
2012 Statewide Minnesota Participant Experience Survey (MN PES)

Figure 13: Quality of life independence - % Adult within program



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.

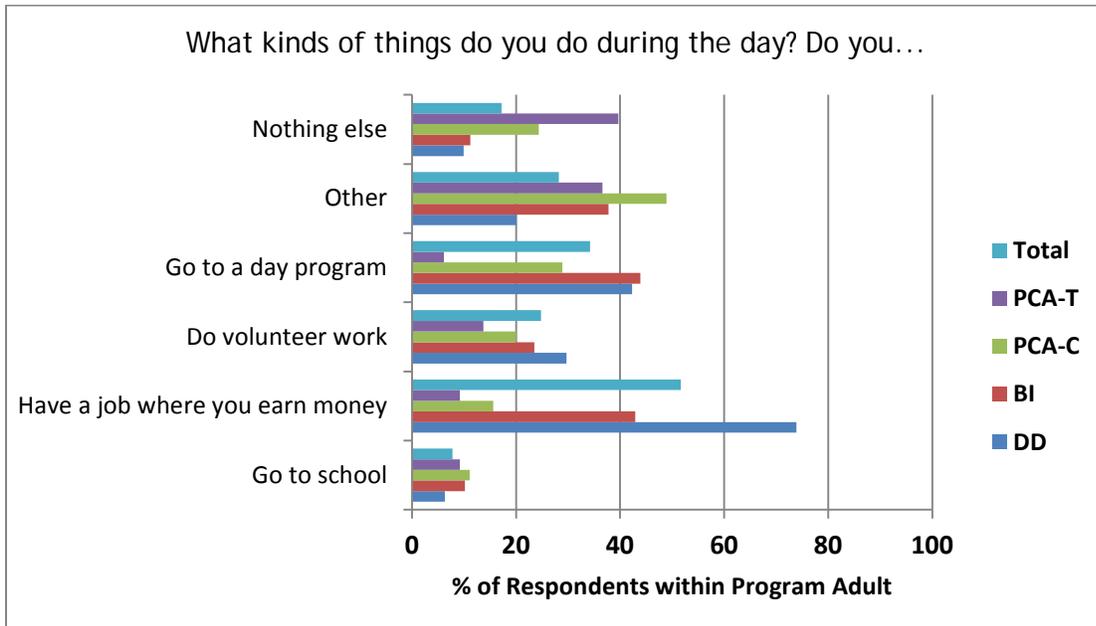
Figure 14: Quality of life independence - % Minors within program



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.

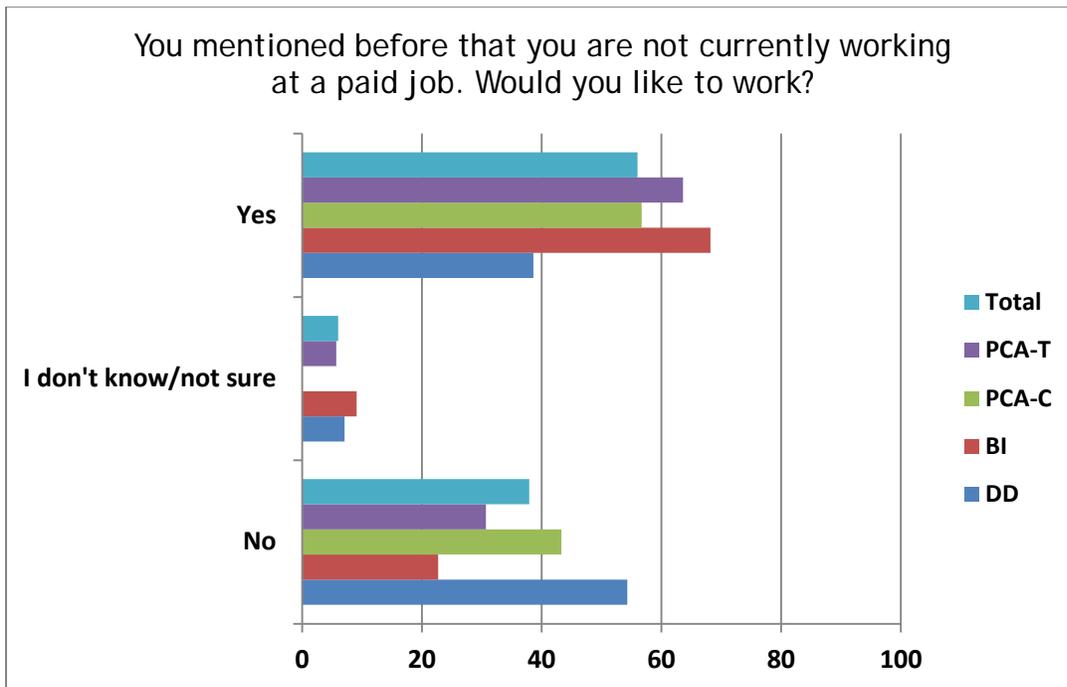
Figure 15: Activities adults are involved in during the day - % Adult within program



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.

Figure 16: Adults not currently working but would like a job - % Adults within program

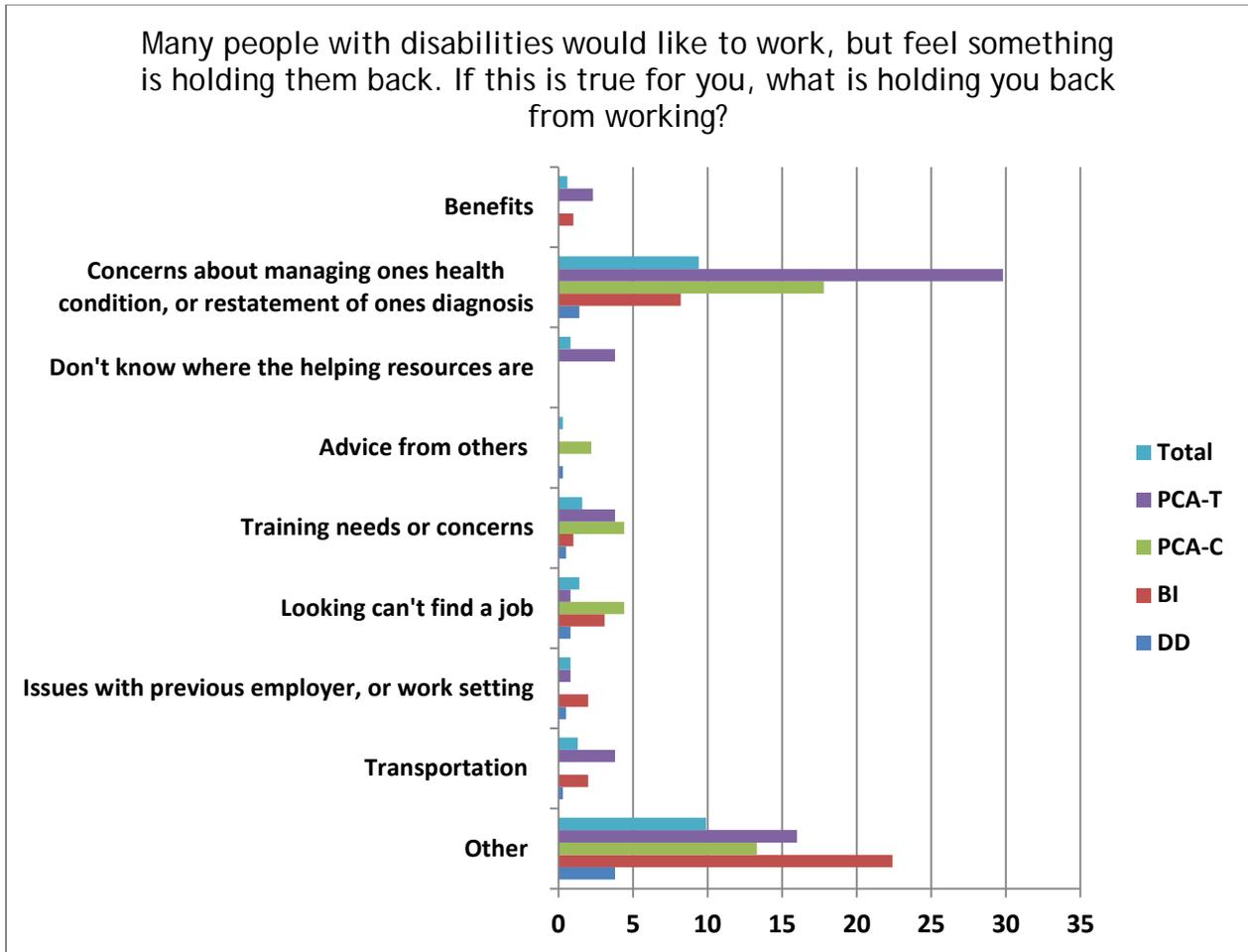


Barriers to Work

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.

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Figure 17: Barriers to work - % Adults within program

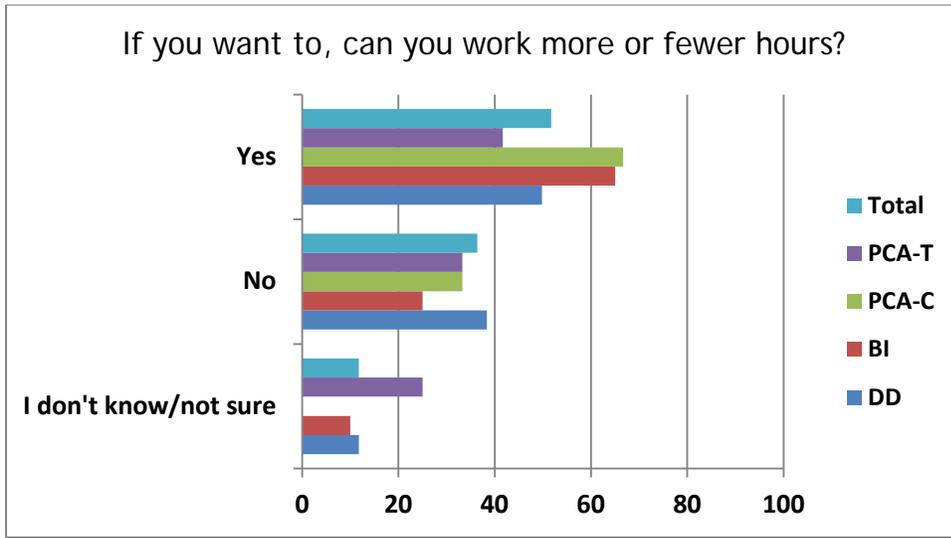


Option to Work Additional or Fewer Hours

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.

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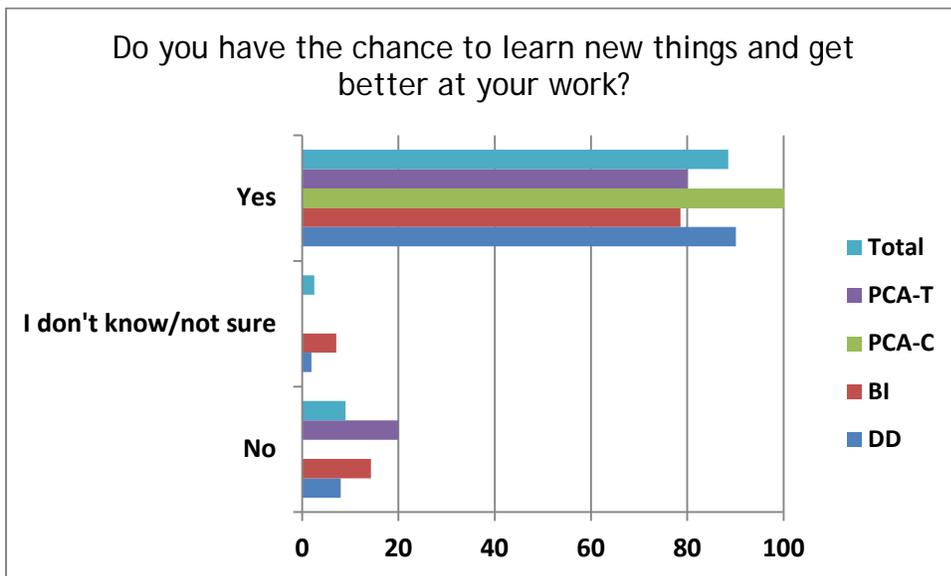
Figure 18: Flexibility of work schedule fewer or additional hours worked - % Adult within program



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.

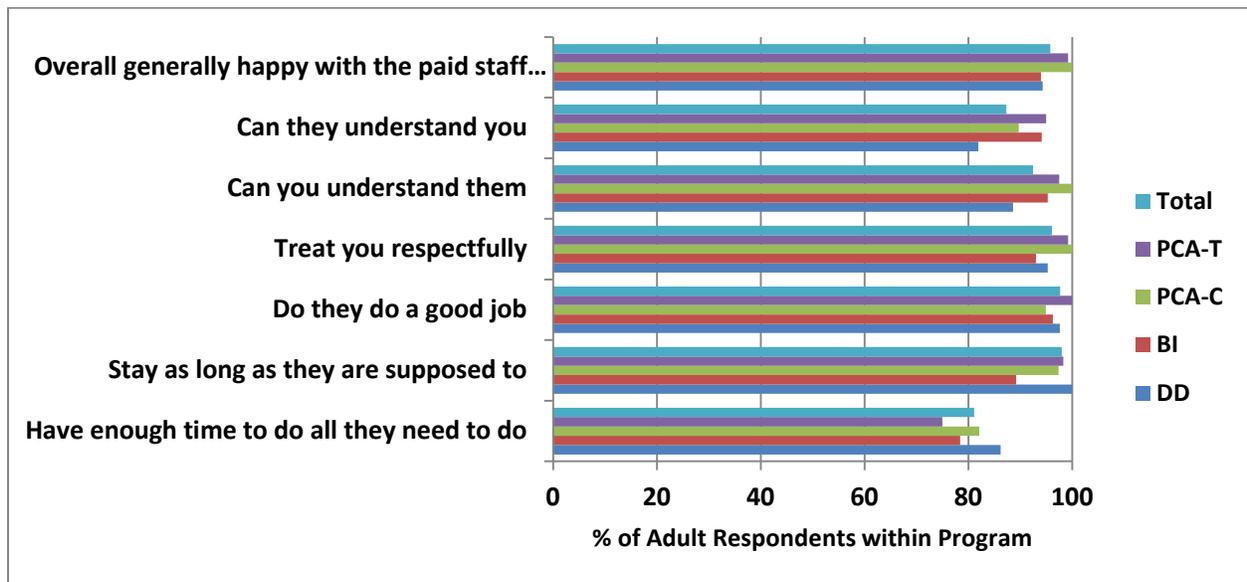
Figure 19: Opportunity to learn new skills and get better at their job



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.

Figure 20: Experience with Direct Care Staff (non-CDCS individuals who use agency-provided staff) - Adults % within program



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

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Table 15: Did you help pick the people who are paid to help you? - Adults % within program

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

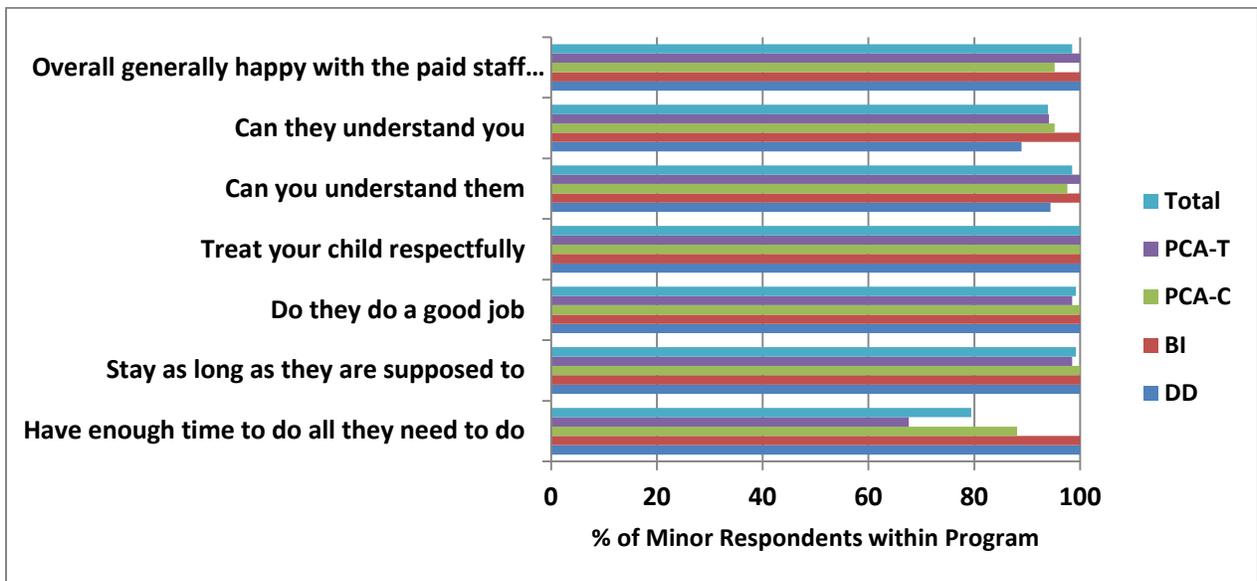
Table 16: Would you like to help pick the people who are paid to help you? - Adults % within program

Adults	Program				
	DD	BI	PCA-C	PCA-T	Total
Yes	65	26	2	12	105
Count					
% within Program	32.3%	45.6%	28.6%	46.2%	36.1%
No	112	23	3	12	150
Count					
% within Program	55.7%	40.4%	42.9%	46.2%	51.5%
I don't know/not sure	24	8	2	2	36
Count					

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Count	11.9%	14.0%	28.6%	7.7%	12.4%
% within Program					
Total Count	201	57	7	26	291
% within Program	100.0%	100.0%	100.0%	100.0%	100.0%

Figure 21: Experience with Direct Care Staff (non-CDCS individuals who use agency-provided staff) - Minors % within program



*There were a total of four BI Waiver respondents who were minors

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

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- 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

Minors	Program				
	DD	BI	PCA-C	PCA-T	Total
No	6	3	1	10	20
Count					
% within Program	33.3%	75.0%	2.4%	14.7%	15.2%
Yes	12	1	41	58	112
Count					
% within Program	66.7%	25.0%	97.6%	85.3%	84.8%
Total	18	4	42	68	132
Count					
% within Program	100.0	100.0%	100.0%	100.0%	100.0%

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

Minors	Program				
	DD	BI	PCA-C	PCA-T	Total
Yes	3	1	0	4	8
Count					
% within Program	60.0%	33.3%	.0%	44.4%	44.4%
No	1	1	0	4	6
Count					
% within Program	20.0%	33.3%	.0%	44.4%	33.3%
I don't know/not sure	1	1	1	1	4
Count					
% within Program	20.0%	33.3%	100.0%	11.1%	22.2%

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% within Program					
Total Count	5	3	1	9	18
% within Program	100.0%	100.0%	100.0%	100.0%	100.0%

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.

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

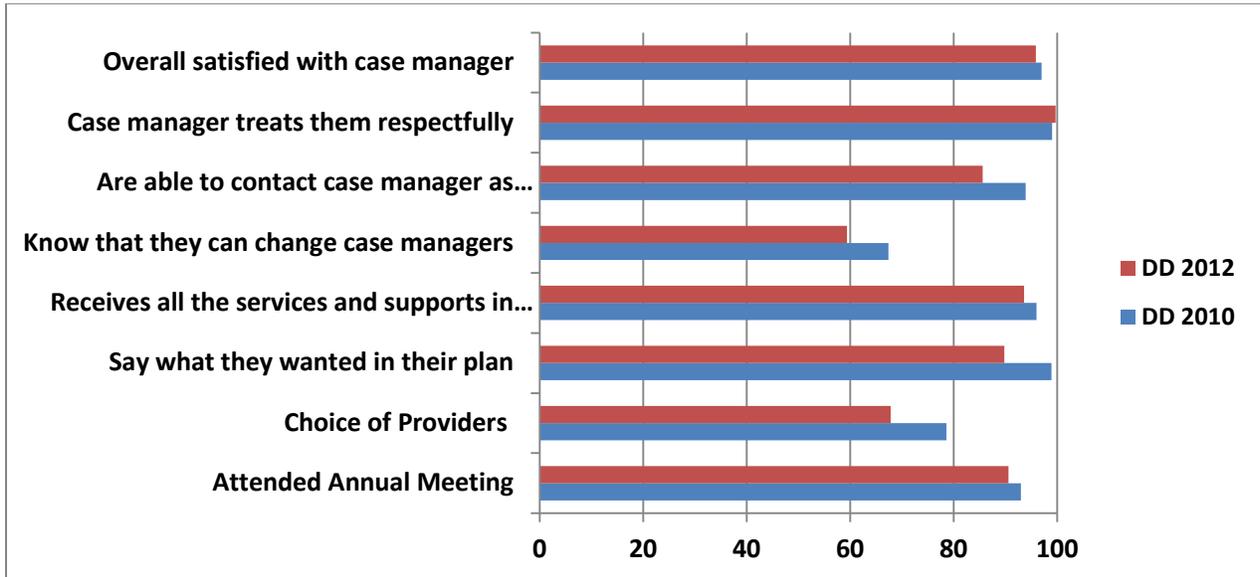
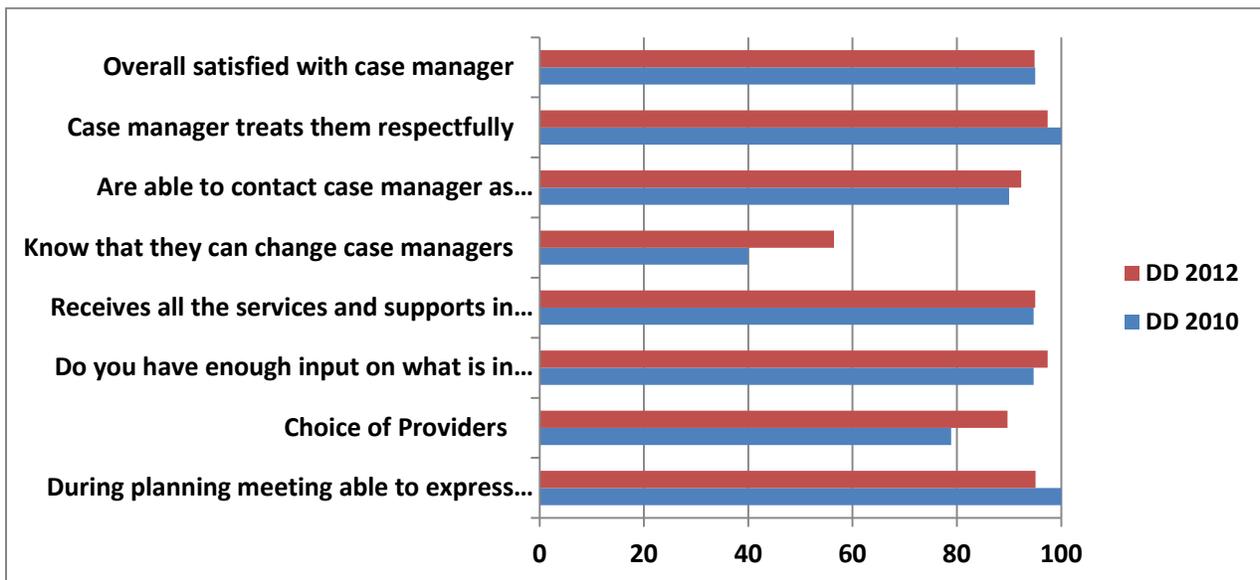


Figure 23: DD Waiver participant experience with case management and service plan development 2010 to 2012 - Minors % within program



Community Membership comparison 2010 to 2012

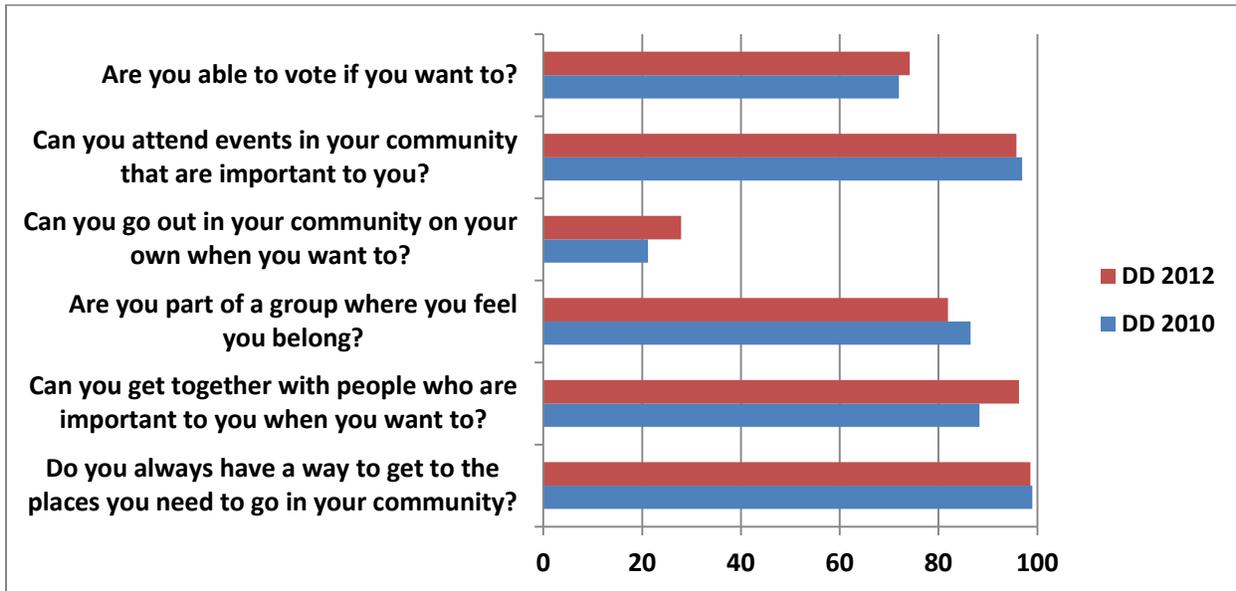
Over 80 to 90 percent of adult DD respondents report that they:

- 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

2012 Statewide Minnesota Participant Experience Survey (MN PES)

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.

Figure 24: DD Waiver participant experience with community membership 2010 to 2012 - Adults % within program

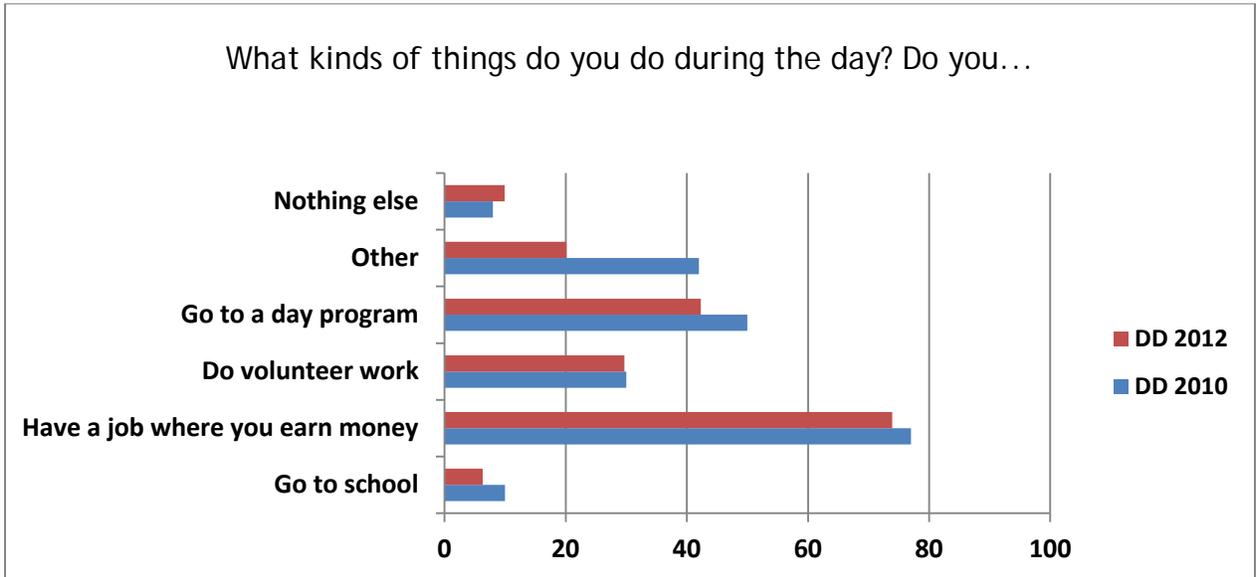


Employment and Daily Activities comparison 2010 to 2012

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.

2012 Statewide Minnesota Participant Experience Survey (MN PES)

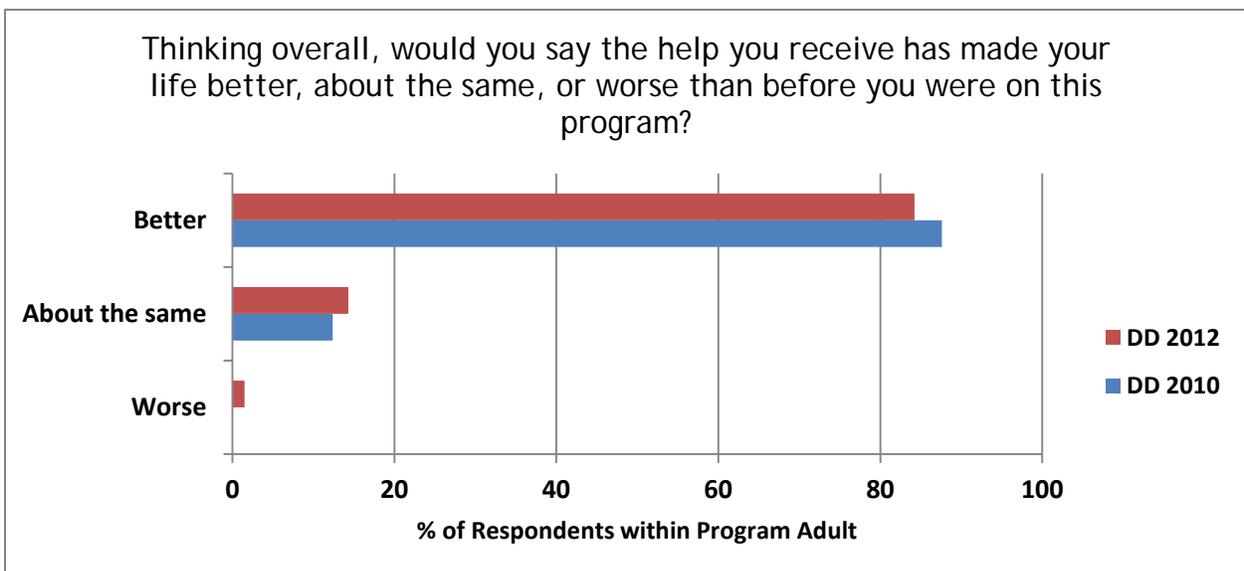
Figure 25: Activities DD adults are involved in during the day 2010 to 2012 - % Adult within program



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.

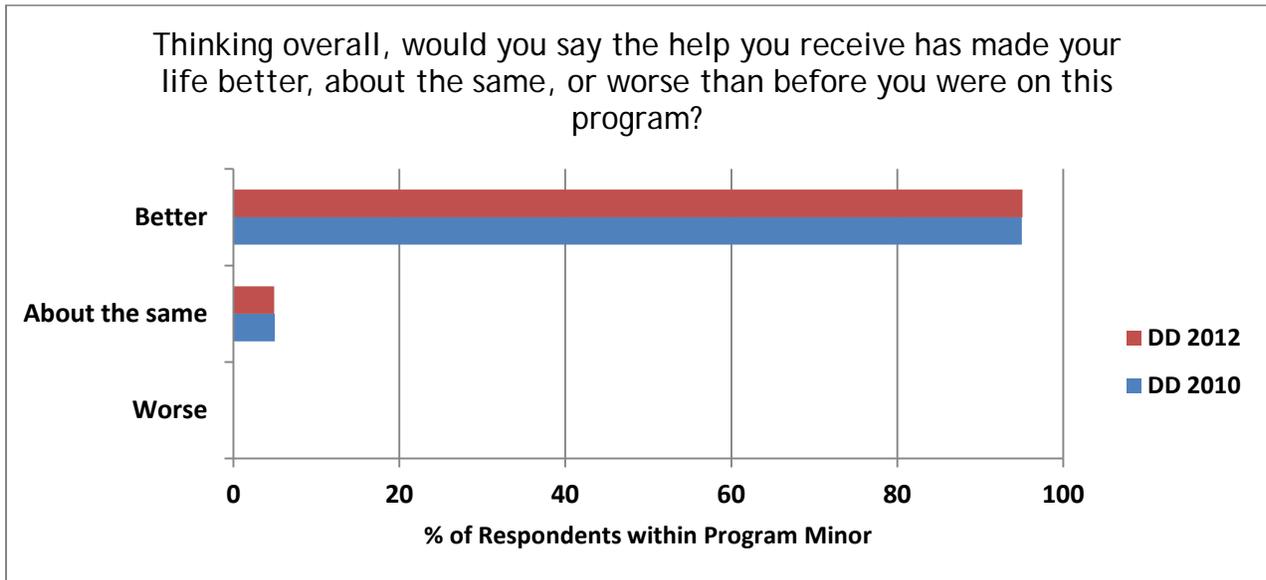
Figure 26: Quality of Life comparison 2010 to 2012- % Adult within program



2012 Statewide Minnesota Participant Experience Survey (MN PES)

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

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