Minnesota Department of Human Services Disability Services Division

2010 Statewide Minnesota Participant Experience Survey (MN PES)

Giving VOICE to CHOICE

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EXECUTIVE SUMMARY

Background

In 2010, the Disability Services Division (DSD) of the Minnesota Department of Human Services (DHS) implemented a statewide Participant Experience Survey (MN PES) for individuals receiving home and community-based services (HCBS). The total cost to complete this survey was approximately $404,000. Of this cost $150,000 was for the development of the survey tool; $20,000 was for the translation and back translation of the survey tool and $234,000 was for the implementation of the survey. One-time funding was provided for this activity by the State of Minnesota and Pathways to Employment. 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 first 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[1].

Legislation enacted in 2007[2], required DHS to develop a survey for individuals who receive home and community-based services that meet the following criteria:

- Could be completed annually
- Is independent and random
- Covers 5-10% of recipients
- Can determine the effectiveness and quality of disability services
- Is consistent with system performance expectations of Centers for Medicaid and Medicare Services (CMS) quality management requirements for evidence-based reporting
- Assesses achievement of desired outcomes for those with varying demographic, diagnostic, health, and functional needs receiving different types of services, in different settings, with different costs

There are two versions of the survey – one for adults and one for minor children[3]. Both versions share four common domains:

- Case Management and Service Plan Development;
- Health, Welfare and Safety
- Important Long-term Relationships and
- Quality of Life

[1] Additionally, Medical Assistance for Employed Persons with Disabilities (MA-EPD) as well as individuals receiving personal care assistance (PCA) experiences was explored.
[2] Minn. Stat. § 256B.096 Subd.3.
[3] Proxy respondents (predominantly parents) provided responses on behalf of all participants under 18.

The adult survey has four additional domains:

- Own Home
- Community Membership
- Daily Activities/Employment and
- Experience with Congregate Housing

Survey Results

Of the 977 interview appointments, 825 resulted in conducted interviews, for a completion rate of 84%. Of the 825 conducted interviews:

- 51% (422) were with participants of the Community Alternatives for Disabled Individuals (CADI) Waiver[4].
- 49% (403) were with non-CADI Waiver recipients.
- 3% (26) were conducted in Hmong, Somali or Spanish.
- 10% (87) were with minors under the age of 18.

The average age of survey respondents was 43 years, ranging from two to 78 years.

Of all conducted interviews, approximately:

- 90% of all respondents report that being supported has made their life better than before they were on the program.
- 94% of respondents stated that they are able to vote when they want to.
    - However, almost a third (28%) 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. Over 90% of respondents, report that they are overall satisfied with case management, that their case manager treats them with respect and that they are able to contact their case manger as needed. However, approximately one-third of respondents (34%) did not know that they could change case managers. Additionally, 47% (316 of 673) of respondents wanted to change services or supports in their service plan (see Table 4). Of the requests made,15% (45 of 309) did not occur (see Table 5).

Minor respondents' experience with case management and service plan development is generally positive as well. Over 90% of minor respondents report that they are overall satisfied with case management services, that their case manager treats them with respect and that they are able to contact their case manager as needed. Yet, over half of respondents (53%, n=43) did not know or were not sure that they could change case managers if they wanted to. In addition, 63% (50 of 80) of minor respondents wanted to change services or

[4] This number constitutes a significant sample size. 95% confidence level; +/- 5.25% confidence interval

supports in their service plan (see Table 6). Of the requests made, 74% (37 of 50) did not occur (see Table 7).

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 14% 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:

- 96% of adult respondents feel safe in their homes.
- 93% of adults feel safe when they leave their home and go into the community.

However, 42 (6%) 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.
- 77% of respondents on the Developmental Disability (DD) Waiver are employed and

91% of respondents on Medical Assistance Employed Persons with Disabilities (MA-EPD) 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:

- Over 50% (n=137)of all Community Alternatives for Disabled Individual (CADI) Waiver respondents
- 69% (n=11) of MA-EPD respondents and
- 55% (n=18) of home care respondents.

When interviewers asked respondents if something was holding them back from working, 20% of CADI Waiver respondents and 33% of home care respondents reported that concerns about managing one's health condition, or restatement of one's diagnosis were the main reason holding them back from working.

Conclusions and Recommendations

The MN PES 2010 project provided information that will serve to enhance community-based services for persons with disabilities. Data obtained from MN PES finds that over 90% 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. **Consider alternative PES survey options such as phone, mail or online survey in addition to bi-annual PES face to face interviewing of persons receiving community-based services.**

   Face-to-face onsite interviews are recognized as a vital tool used to obtain rich information (Final Report Development and Testing of the Participant Experience Survey, Minnesota Version as well as from the 2007 Quality Assurance Panel members). Recommendations for obtaining individual information also include using in addition to face-to-face interviews a combination of alternative sampling strategies (i.e. phone, mail and/or online) to provide additional numbers of persons providing feedback. Face-to-face interviews are generally preferred; however, the cost of implementation limits the number of persons that can be surveyed. The MNCHOICES assessment also may be used to supplement questions as well as provide an opportunity to compare responses to the PES in the future when implemented.

2. **Conduct a larger sampling of TBI Waiver recipients, individuals receiving services under the self-directed service option and non-English speaking recipients**.

   Targeted sampling of TBI Waiver recipients, persons using self-directed service options and non-English speaking recipients can 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.

3. **Prior to community-based relocation of persons in institutions as part of Money Follows the Person (MFP), offer a pre and post MN PES to persons relocating from Nursing Facilities (NF's), Institution for Persons with Mental Diseases (IMD's) and Intermediate Care Facilities for the Developmentally Disabled (ICF/DD).**

   The use of pre and post MN PES information from persons who are relocating from institutions will provide important data that will be helpful in planning for future relocations.

4. **Immediately seek to enhance educational information directed at recipients as well as online training curriculum for providers that addresses choice options as well as enhanced discovery efforts leading to targeted remediation efforts as follows:**
    a. Inform individuals on the ability to change case managers, choose provider(s) and to modify individualized coordinated community support plans.
    b. Ensure individualized coordinated community service plans contain strategies designed to ensure access to preferred community activities,
    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.
    d. Create and distribute information that clearly addresses voting rights for persons with developmental disabilities,
    e. Use data and information from current data bases to enhance discovery activities leading to remediation to include:
        - Licensing agency corrective action plans
        - Vulnerable adult and maltreatment of children reports
        - Medical Assistance enrollment information
        - Information obtained from provider desk and field audits

    Enhanced educational information as well as training curriculum that match federal and state expectations will result in improved outcomes. In addition, the review of information collected from additional sources such as vulnerable adult and maltreatment reports, provider enrollment data, licensing activities, and provider desk audits will provide enhanced discovery information leading to targeted remediation efforts.

INTRODUCTION

The state of Minnesota has a long history of consumer and stakeholder involvement in the design and ongoing assessment of publicly funded long-term care services. In developing its recommendations to the state, the Minnesota Quality Assurance Panel[5], recognized the importance of consumer feedback in guiding quality improvement for home and community-based services (HCBS) programs. Over the past few decades, the focus of these services has shifted increasingly toward provision of services and supports in non-institutionalized settings, namely people's homes and communities. Providing supports in the community can help avoid costly institutionalization and enhance quality of life, but it also raises unique challenges to quality oversight. To address these challenges, in 2005 the Minnesota Legislature requested a study of local and regional quality assurance models that might be adopted statewide.

In response, the Department of Human Services (DHS) convened a Quality Assurance (QA) Panel of citizen stakeholders in 2006 that represented a range of perspectives on quality and disability. In its 2007 report to the Legislature, the QA Panel recommended five key components of a revised quality assurance strategy for the state. Two of these components were ultimately incorporated into statute, including the development of an annual survey of waiver service recipients operated by DHS Disability Services Division (DSD).

Legislation enacted in 2007 (Minn. Stat. §256B.096, Subd. 3) required DHS to develop a survey for individuals who receive home and community-based services that meet the following criteria:

- Could be completed annually
- Is independent and random
- Covers 5-10% of recipients
- Can determine the effectiveness and quality of disability services
- Is consistent with system performance expectations of Centers for Medicaid and Medicare Services (CMS) quality management requirements for evidence-based reporting
- Assesses achievement of desired outcomes for those with varying demographic, diagnostic, health, and functional needs receiving different types of services, in different settings, with different costs

[5] Quality Assurance 2007: Findings and Recommendations Final Report 2007

To fulfill its legislative mandate for survey implementation[6], DHS contracted with the healthcare and scientific business of Thomson Reuters to develop and test a consumer survey appropriate for the four home and community-based waivers operated by the Disability Services Division[7] including:

- Community Alternative Care (CAC) Waiver
- Community Alternatives for Disabled Individuals (CADI) Waiver
- Developmental Disabilities (DD) Waiver and
- Traumatic Brain Injury (TBI) Waiver

Thomson Reuters delivered the final report on the development and testing of the Participant Experience Survey, Minnesota version (MN PES) to DHS on June 30, 2009.
The total cost to complete this survey was approximately $404,000. Of this cost $150,000 was for the development of the survey tool; $20,000 was for the translation and back translation of the survey tool and $234,000 was for the implementation of the survey.
One-time funding was provided for this activity by the State of Minnesota and Pathways to Employment. At the time that this report was prepared, there are no ongoing appropriations to implement the PES annually.

MN PES Survey Instrument Development

Thomson Reuters and the University of Minnesota, drafted a survey based on the Participant Experience Survey (PES) released by CMS in 2003[8].

The purpose of the Participant Experience Survey, Minnesota Disability Services Division version (MN PES), is to provide feedback to state officials about program participants' experiences with the services and supports they receive from four Medicaid 1915(c) waiver programs operated by the Disability Services Division within the Department of Human Services.

There are two versions of the survey – one for adults and one for minor children, under the age of 18. The adult version of the survey included 112 items across nine domains. The minor survey included 61 items across five domains, most of which were similar to items on the adult survey. Proxy respondents (predominantly parents) provided responses on behalf of all participants under 18.

Both versions of the survey share four common domains:

1. **Case Management and Service Plan Development**: Includes questions about participant's relationship with his or her case manager, including responsiveness and respect, and involvement in the development of their care plans

[6] Ibid.
[7] Thomson Reuters, June 2009. Development and Testing of the Participant Experience Survey, Minnesota Version (MN PES) Final Report
[8] CMS PES Survey 2003 (http://www.innovations.ahrq.gov/content.aspx?id=1051)

2. **Health, Welfare and Safety**: Includes questions about access to care and unmet need for assistance, relationships with paid staff, safety and maltreatment, including theft and abuse.
3. **Important Long-term Relationships**: Includes questions about reciprocal relationships with individuals not paid to provide services.
4. **Quality of Life:** Includes questions about the impact of services on participants and their families.

Depending on whether the respondent participates in the consumer-directed community supports (CDCS) waiver service option, both adult and children surveys include modules for *Self-Direction* (for respondents using CDCS) or *Experience with Direct Care Staff* (for respondents using agency-provided staff).

The adult survey has four additional domains:

1. **Own Home**: Includes questions about participant's current living situation.
2. **Community Membership**: Includes questions about community membership and participation, including transportation.
3. **Daily Activities/Employment**: Includes questions about organized activities during the day, such as work, school, and training, and items specific to supported employment services and day/habilitation services.
4. **Experience with Congregate Housing:** Optional module for participants who live in group homes that includes questions about participants' ability to make choices and have privacy, and about their rights.

PES Survey Testing

Thomson Reuters conducted cognitive testing of the draft survey using concurrent probes to measure comprehension and interpretation. This process resulted in a need for both an adult and minor version of the survey. Field testing, with a sample of ten participants from each waiver followed and provided baseline data as well as guidance for future implementation.

The testing of the two versions of the instrument established content validity and inter-rater reliability for the PES Minnesota version. Additionally, the testing demonstrated that program participants and/or their proxies could answer the survey questions with an average length of administration under 35 minutes.

MN PES SURVEY IMPLEMENTATION METHODOLOGY

In 2010, DHS issued a Request for Proposal (RFP) to conduct a participant experience survey for individuals receiving home and community-based services via face-to-face interviews. DHS issued contract #B42164 between the state of Minnesota and Vital Research (VR) to conduct the first round of the Participant Experience Survey in Minnesota. The contract went into effect on May 7, 2010 and included the following requirements:

1. Organize materials and personnel to ensure the efficient and effective implementation of the project.
2. Develop a program to ensure the scientific reliability and validity of the interview data collected.
3. Implement an organized, well-planned deployment of interview staff to collect participant satisfaction data.
4. Provide survey results to DHS in electronic format.

Throughout the duration of the contract period, DHS conducted weekly conference calls and received monthly 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.

MN PES Work Plan

The PES work plan was developed based on the expectation of completing 400 face-to-face interviews with randomly-selected individuals receiving CADI Waiver services and 400 face-to-face interviews with individuals receiving CAC , DD, and TBI waiver services, as well as persons receiving home care services. Individuals receiving Medical Assistance for Employed People with Disabilities (MA-EPD) services would be included in the CAC/DD/TBI/Home Care group.

Vital Research implemented the statewide MN PES between August and November 2010.

Project Staffing and Training

Vital Research managed all aspects of the PES staffing and training from their office in Los Angeles, California. Vital Research worked with Express Employment Professionals[9] to recruit ten survey interviewers and one field supervisor across Minnesota.

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. Vital Research designed the interview guide layout to include color-coding, symbols, skip pattern instructions, and page references to allow interviewers to administer the interview efficiently.

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
- Completion of two practice interviews

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

Data Submission and Data Confidentiality

In accordance with HIPAA regulations about confidentiality, a number of measures were in place to ensure the privacy of data. Interviewers signed a confidentiality pledge during training. Vital Research assigned identification numbers to each respondent in order to help keep individual survey responses confidential. The staffing agency, Express Employment Professionals had no access to any of the obtained data.

Vital Research kept any private information about respondents (such as contact information) through the following precautions:

- All electronic data was stored on password-protected computers/servers accessible only to project staff.
- Computers and servers were protected by firewalls and security protocols that encrypt and block unauthorized access.
- Any documents or files that were shipped were tracked via FedEx.
- All survey forms were held in a locked, limited-access office. In addition, the Vital Research office is located in a limited access, secured building with 24-hour on-site patrol.
- Electronic data elements were deleted and hard copies of data were shredded on a DHS-authorized date.

[9] Express Employment Professional is a temp employment agency

SURVEY PARTICIPANT DATA SAMPLE

Sample List

DHS provided Vital Research with a random sample[10]of individuals enrolled in CADI Waiver and five other Medical Assistance programs (CAC Waiver, DD Waiver, TBI Waiver, Home Care[11] and MA-EPD) on three sample lists:

1. 1,000 CADI Waiver and 800 non-CADI Waiver participants (CAC, DD, TBI, HC, and MAEPD) on July 20, 2010
2. 800 CADI Waiver and 900 non-CADI participants (CAC, DD, TBI, and HC) on September 24, 2010
3. 340 non-CADI Waiver participants (MA-EPD) on October 18, 2010

DHS also provided Vital Research with the second and third random sample lists to compensate for the following situations:

- High number of invalid phone numbers
- Unreturned calls and
- Outdated information on the initial sample list

After removal of duplicates, the sample list included 3,799 participants. Of this sample:

- 802 (21%) participants needed guardianship status identified from the county case manager.
- 686 (18%) participants required additional information from DHS prior to Vital Research contacting, mostly because of missing phone numbers.
- 40 (1%) participants spoke a language other than English, Spanish, Hmong or Somali and could not be interviewed.

During the scheduling of interview appointments, Vital Research identified an additional 592 (16%) phone numbers that were out of service or incorrect.

Vital Research forwarded identified missing information to DHS. DHS was able to provide missing phone information for 30 participants by asking participants with an invalid phone number to send in their updated information. It is important to note that the majority of those persons who provided updated information also requested to be interviewed. DHS also provided missing age and language information for 99 participants.

[10] DHS conducted proportional stratified random sampling based on medical assistance program enrollment contained in the Medicaid Management Information System (MMIS).

[11] Home care recipients were only those individuals receiving Personal Care Assistance (PCA) services.

Survey Participation

Vital Research mailed selected 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 County E-list 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.

Survey Participation for Persons with Private Guardians

Vital Research obtained guardianship status and contact information, if applicable, for each participant with a private guardian from the case manager. DHS provided Vital Research with case manager contact information for Hennepin County; however, all other counties required Vital Research to contact the county supervisor to obtain case manager contact information.

Vital Research obtained private guardianship information for 568 out of 802 participants (71%) by calling county supervisors and case managers. For persons under private guardianship, Vital Research established contact with the guardian providing them with the option to withhold consent for participation in the survey. Vital Research scheduled interviews for 245 (43%) participants with private guardians.

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

Between August 25 and November 10, 2010, VR Research Assistants contacted 2,338 potential respondents. From these contacts, 977 (42%) interview appointments were scheduled. Of the 977 interview appointments:

- 825 (84%) resulted in completed interviews (422 CADI Waiver interview and 403 non-CADI Waiver interviews).
- 26 (3%) interviews were conducted in Hmong, Somali or Spanish.
- 87 (10%) of the interviews completed were with minors and their parent and/or guardian present.

Vital Research staff processed and cleaned all data. On December 15, 2010, the final datasets and supporting documents were delivered to DHS.

Interview Data Results

Table 1 shows the final status of the 2,338 potential respondents contacted[12] for participation in the MN PES survey.

Table 1: Status of potential respondents

	CADI	Non-CADI	Total
Scheduled	508	469	977 (42%)
Invalid Phone Number	327	265	592 (25%)
No Return Call	240	211	451 (19%)
Participant Refusal	90	84	174 (7%)
Language Barrier	23	27	50 (2%)
Guardian Refusal	21	31	52 (2%)
Participant Not on Waiver	10	20	30 (1%)
Congregate Housing Difficulty*	5	7	12 (<1%)
Total	**1224**	**1114**	**2338**

*Congregate Housing staff did not provide access to participant

Survey Sample Demographics

Of the 977 scheduled interview appointments, 825 resulted in conducted interviews for a completion rate of 84%.

Of all conducted interviews, the average age of respondents was 43 years, ranging from two to 78. Table 2 shows the number of interviews conducted in each of the six Medical Assistance programs.

[12] 592 (25%) of potential respondents had invalid phone numbers.

Table 2: Number of conducted interview by program type

Medical Assistance Program Type	Number of Conducted Interviews
CADI Waiver	422
MA-EPD	196
DD Waiver	120
HC (PCA)	83
TBI Waiver	4
CAC* Waiver	0
Total Conducted	**825**

*Six CAC participants were on the random sample lists provided by DHS

Vital Research conducted interviews at the respondent's location of choice. 379 (46%) 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. Vital Research conducted interviews at an alternative location 125 (15%) times during data collection.

The average (mean) time to complete an interview was 30 minutes, ranging from 10 to 150 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.

152 (16%) of all participants who made an interview appointment were not interviewed. Table 3 shows the reasons for interviews not conducted.

Table 3: Reasons for interviews not conducted

	CADI	Non-CADI	Total
Respondent Canceled	60	46	106
Respondent No Show	13	13	26
Respondent Refusal	4	2	6
Other	9	5	14
Total Not Conducted	86	66	152

SURVEY RESULTS

The survey results for the 825 respondents who participated in the 2010 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

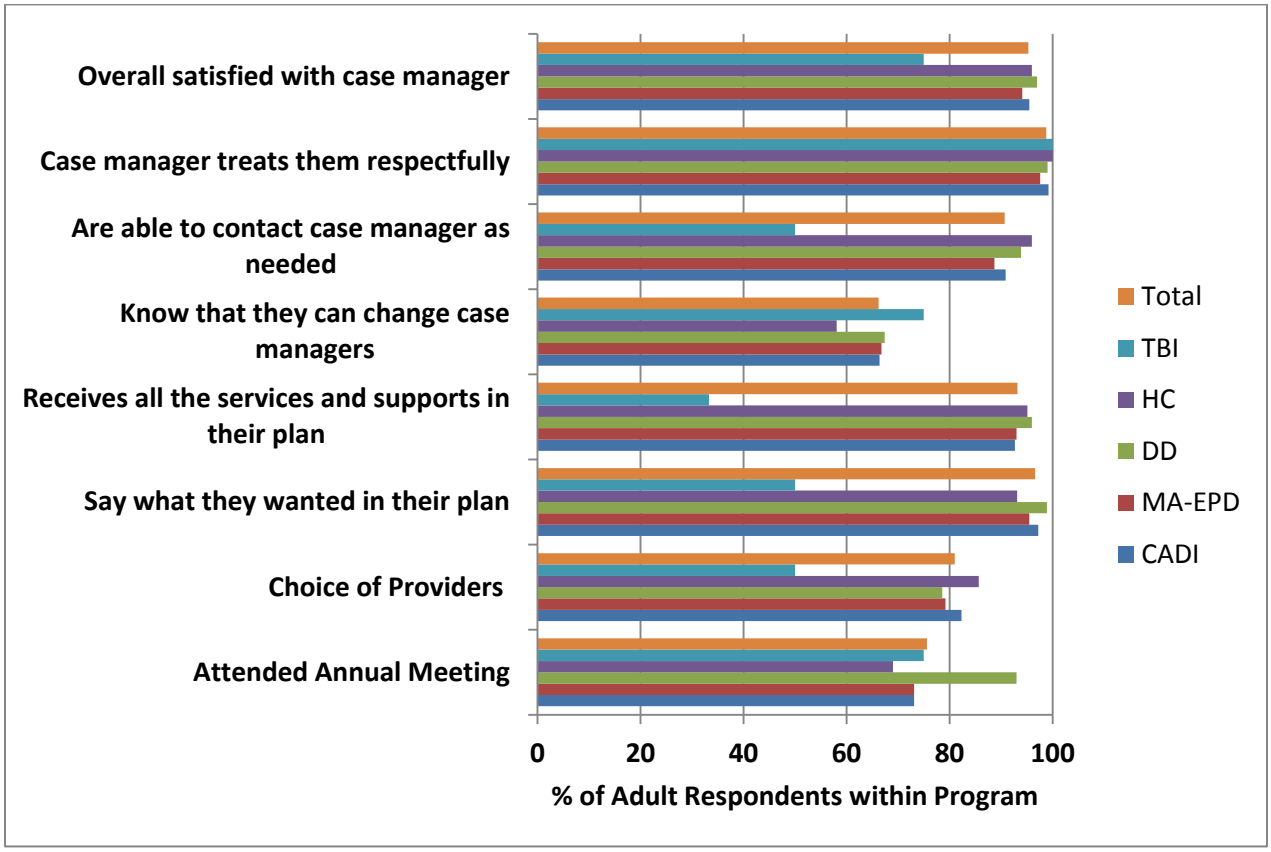
Case Management and Service Plan Development

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

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



*There were a total of four TBI participants in the survey

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, that their case manager treats them with respect and that they are able to contact their case manger as needed. However, 34% (243 of 719) of respondents did not know or were not sure that they could change case managers.

Additionally, 47% (316 of 673) of respondents wanted to change services or supports in their service plan (see Table 4). Of the requests made,15% (45 of 309) did not occur (see Table 5).

Table 4: Have you ever asked your case manager for changes to your services or supports?

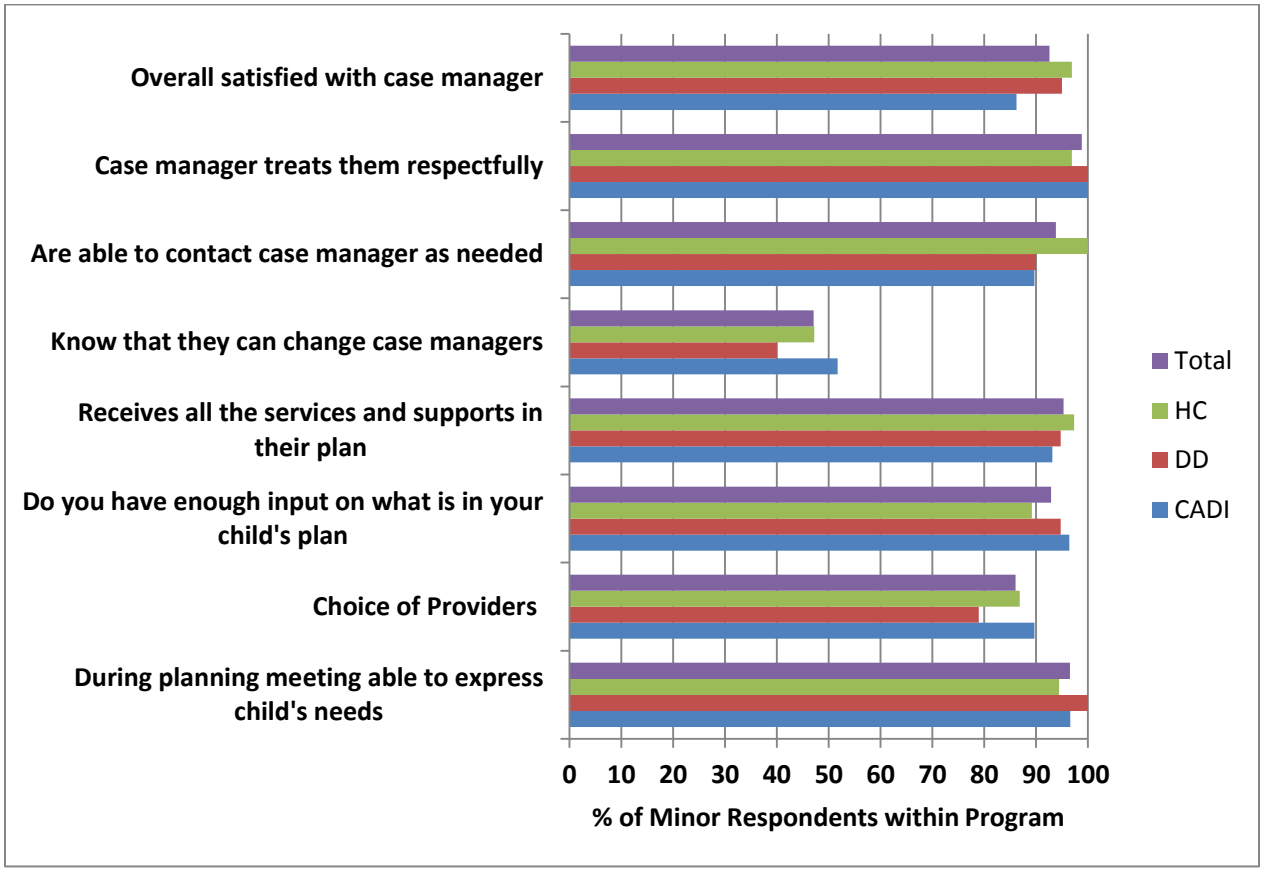
Adults		Program					
		CADI	DD	TBI	HC	MA-EPD	Total
Yes	Count	185	42	3	8	78	316
	% within Program	49.6%	42.0%	75.0%	32.0%	45.6%	47.0%
No	Count	180	56	1	17	89	343
	% within Program	48.3%	56.0%	25.0%	68.0%	52.0%	51.0%
I don't remember	Count	8	2	0	0	4	14
	% within Program	2.1%	2.0%	.0%	.0%	2.3%	2.1%
Total	Count	373	100	4	25	171	673
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Table 5: Did your case manager make the changes in services or supports you asked for?

Adults		Program					
		CADI	DD	TBI	HC	MA-EPD	Total
No	Count	27	5	1	1	11	45
	% within Program	15.1%	11.9%	50.0%	12.5%	14.1%	14.6%
Yes	Count	145	37	0	7	66	255
	% within Program	81.0%	88.1%	.0%	87.5%	84.6%	82.5%
In process	Count	5	0	0	0	0	5
	% within Program	2.8%	.0%	.0%	.0%	.0%	1.6%
I don't know/not sure	Count	2	0	1	0	1	4
	% within Program	1.1%	.0%	50.0%	.0%	1.3%	1.3%
Total	Count	179	42	2	8	78	309
	% within Program	100.0%	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 one-quarter of CADI Waiver, Home Care, MA-EPD, HC and TBI Waiver respondents didn't attend or don't remember attending their annual meeting. Conversely, DD Waiver participants reported annual meeting attendance at 93%. About 20% of respondents reported that they were not given or do not remember having a choice of providers.

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.

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. Over 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, over half of respondents (53%, n=43) did not know or were not sure that they could change case managers if they wanted to.

Additionally, 63% (50 of 80) of respondents wanted to change services or supports in their service plan (see Table 6). Of the requests made, 74% (37 of 50) did not occur (see Table 7).

Table 6: Have you ever asked your case manager for changes to your services or supports?

Minor		Program			
		CADI	DD	HC	Total
Yes	Count	19	17	14	50
	% within Program	65.5%	89.5%	43.8%	62.5%
No	Count	10	1	18	29
	% within Program	34.5%	5.3%	56.3%	36.3%
I don't remember	Count	0	1	0	1
	% within Program	.0%	5.3%	.0%	1.3%
Total	Count	29	19	32	80
	% within Program	100.0%	100.0%	100.0%	100.0%

Table 7: Did your case manager make the changes in services or supports you asked for?

Minor		Program			
		CADI	DD	HC	Total
No	Count	16	13	8	37
	% within Program	84.2%	76.5%	57.1%	74.0%
Yes	Count	2	3	4	9
	% within Program	10.5%	17.6%	28.6%	18.0%
In process	Count	1	0	2	3
	% within Program	5.3%	.0%	14.3%	6.0%
I don't know/not sure	Count	0	1	0	1
	% within Program	.0%	5.9%	.0%	2.0%
Total	Count	19	17	14	50
	% within Program	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 14% 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 8, 9 and 10 below. Instrumental Activities of Daily Living (IADLs) responses are summaries in Tables 11, 12 and 13 below. The minor ADL responses are summaries in Tables 14 and 15 below.

Adults on the DD Waiver and home care recipients are most likely to need assistance from others with ADLs at 64% (n=63) and 61% (n=27) respectively. See table 8 below.

Table 8: 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					
		CADI	DD	TBI	HC	MA-EPD	Total
Yes	Count	90	63	1	27	38	219
	% within Program	23.1%	63.6%	25.0%	61.4%	19.4%	29.9%
No	Count	299	36	3	17	158	513
	% within Program	76.9%	36.4%	75.0%	38.6%	80.6%	70.1%
Total	Count	389	99	4	44	196	732
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Approximately one-fifth (n=128) of all adults report that they are unable to complete ADLs when they need to (Table 9).

Table 9: Are you ever unable to do any of these things when you need to (dress/bathe/eat)?

Adults		Program					
		CADI	DD	TBI	HC	MA-EPD	Total
Yes	Count	76	12	1	14	25	128
	% within Program	19.7%	12.2%	33.3%	31.1%	12.8%	17.6%
No	Count	309	86	2	31	170	598
	% within Program	80.3%	87.8%	66.7%	68.9%	87.2%	82.4%
Total	Count	385	98	3	45	195	726
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Of these respondents about one-third (n=42) state that it is because there is nobody to assist them (Table 10).

Table 10: Unable to complete ADLs and the reason being that there is nobody to assist them

Adults		Program					
		CADI	DD	TBI	HC	MA-EPD	Total
Yes	Count	26	1	0	6	9	42
	% within Program	35.1%	9.1%	.0%	42.9%	39.1%	34.1%
No	Count	47	10	1	8	14	80
	% within Program	63.5%	90.9%	100.0%	57.1%	60.9%	65.0%
I don't remember	Count	1	0	0	0	0	1
	% within Program	1.4%	.0%	.0%	.0%	.0%	.8%
Total	Count	74	11	1	14	23	123
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Approximately 40% (n=286) of adult respondents need assistance with IADLs (Table 11).

Table 11: Do you need help or reminders from another person to do things like cooking, laundry, using the telephone, shopping or doing housework?

Adults		Program					
		CADI	DD	TBI	HC	MA-EPD	Total
Yes	Count	123	71	2	30	60	286
	% within Program	32.5%	79.8%	50.0%	68.2%	31.6%	40.5%
No	Count	256	18	2	14	130	420
	% within Program	67.5%	20.2%	50.0%	31.8%	68.4%	59.5%
Total	Count	379	89	4	44	190	706
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

About 30% (n=199) of respondents were unable to complete IADLs when they needed to (Table 12).

Table 12: Are you ever unable to do any of these things when you need to (cooking/laundry/telephone/shopping)?

Adults		Program					
		CADI	DD	TBI	HC	MA-EPD	Total
Yes	Count	121	18	2	20	38	199
	% within Program	32.4%	21.2%	50.0%	46.5%	20.1%	28.6%
No	Count	252	67	2	23	150	494
	% within Program	67.4%	78.8%	50.0%	53.5%	79.4%	71.1%
I don't remember	Count	1	0	0	0	1	2
	% within Program	.3%	.0%	.0%	.0%	.5%	.3%
Total	Count	374	85	4	43	189	695
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Of these respondents, about 40% (n=76) stated the reason being is that there was nobody there to assist them (Table 13).

Table 13: Is this because you did not have anyone to help you (cooking/laundry/telephone/shopping)?

Adults		Program					
		CADI	DD	TBI	HC	MA-EPD	Total
Yes	Count	45	2	1	9	19	76
	% within Program	40.5%	12.5%	50.0%	45.0%	51.4%	40.9%
No	Count	66	14	1	11	16	108
	% within Program	59.5%	87.5%	50.0%	55.0%	43.2%	58.1%
I don't remember	Count	0	0	0	0	2	2
	% within Program	.0%	.0%	.0%	.0%	5.4%	1.1%
Total	Count	111	16	2	20	37	186
	% within Program	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Almost all respondents who were children need assistance with ADLs (95%, n=82).

Table 14: 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			
		CADI	DD	HC	Total
Yes	Count	25	20	37	82
	% within Program	89.3%	100.0%	97.4%	95.3%
No	Count	3	0	1	4
	% within Program	10.7%	.0%	2.6%	4.7%
Total	Count	28	20	38	86
	% within Program	100.0%	100.0%	100.0%	100.0%

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

A very small percentage of these respondents reported that they were unable to complete ADLs because there was not anyone available to assist them (6%, n=4).

Table 15: Is your child ever unable to do any of these everyday things because he or she does not have anyone to help?

Minor		Program			
		CADI	DD	HC	Total
Yes	Count	1	1	2	4
	% within Program	4.2%	7.1%	5.9%	5.6%
No	Count	23	13	32	68
	% within Program	95.8%	92.9%	94.1%	94.4%
Total	Count	24	14	34	72
	% within Program	100.0%	100.0%	100.0%	100.0%

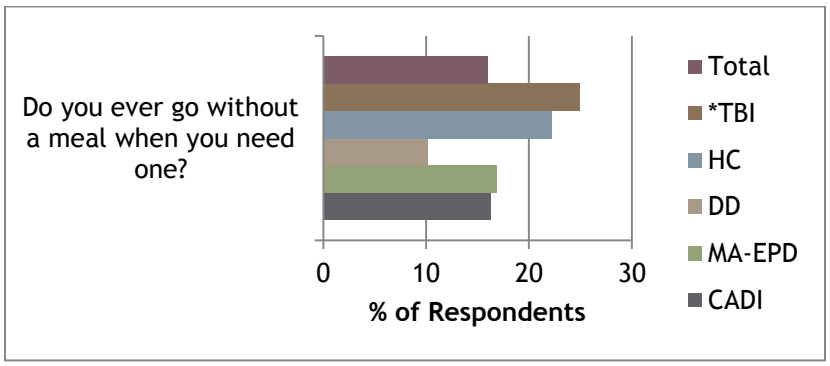
*Proxy respondents provided responses on behalf of all participants under 18.

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. MN PES interviewers communicated over 20 potential maltreatment reports to local CEPs.

Figure 3 depicts that 16% (117 of 729) of adult respondents have gone without a meal when they needed one.

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



*There were four TBI Waiver recipients in the survey

Nine adult respondents (1%) reported that they had someone physically hit or hurt them. Of these:

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

Seventy-nine (11%) respondents reported that someone has done mean things to them such as, yell at or intimidate them[13]. Of these:

- 25% were reported as staff members
- 22% were reported as family members
- 14% were reported as people they live with
- 46% were reported as other

Forty-eight (7%) respondents also reported that someone has taken (or stolen) money or things without asking. Of these:

- 11 were reported as staff members
- 10 were reported as people they live with
- 6 were reported as family members and
- 21 were reported as other

[13] 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.

Nine (1%) respondents reported that someone has recently touched them in a way they did not like[14]. Of these:

- 2 were reported as staff members
- 2 were reported as family members
- 1 was reported as a person they lived with and
- 6 were reported as other

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

Figure 4: Treatment by others - Adult all programs

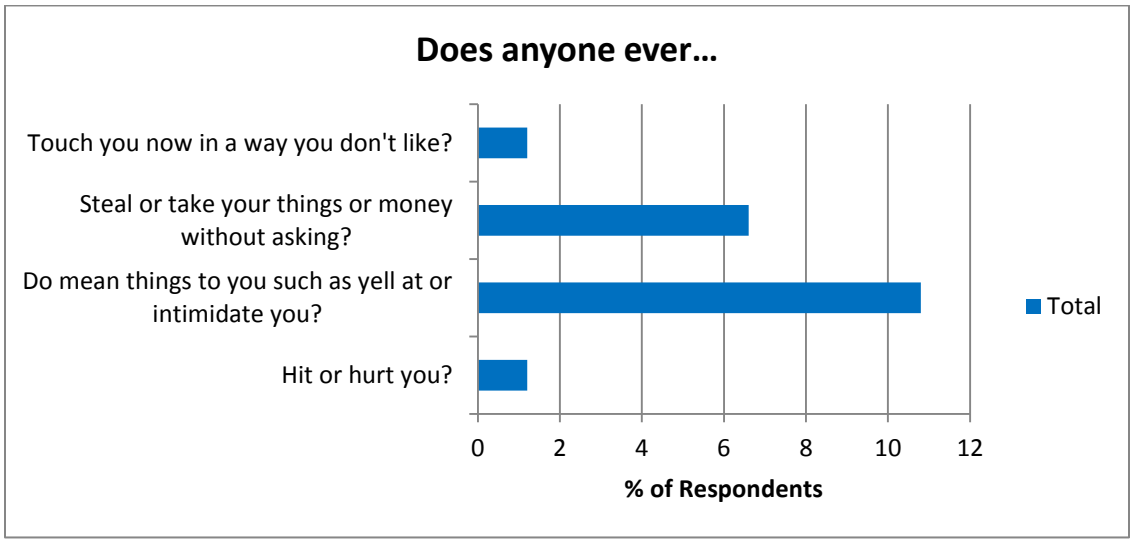
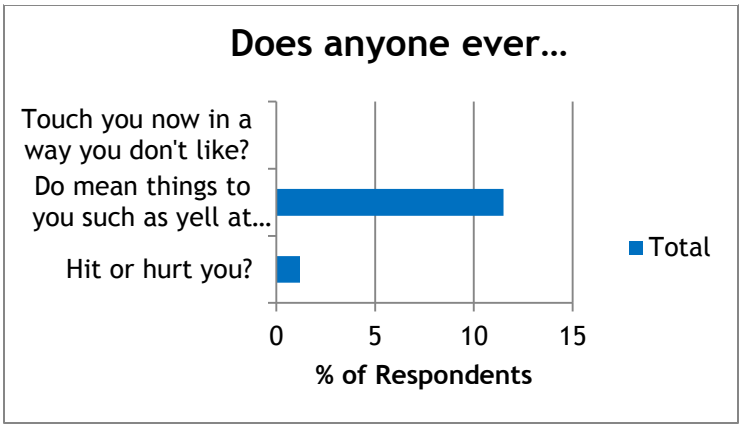


Figure 5 illustrates the treatment of minors by others. One of the respondents reported that someone had physically hit or hurt them; this was identified as a family member. Ten (12%) respondents reported that someone has done mean things to them such as yell at or intimidate them. Eight of these were listed as other. None of the 87 respondents reported being touched in a way they do not like.

[14] In some cases, individual respondents reported more than one person touching them now in a way they do not like such as a staff person, family member or other to the subsequent follow-up questions.

Figure 5: Treatment by others - Minors all programs



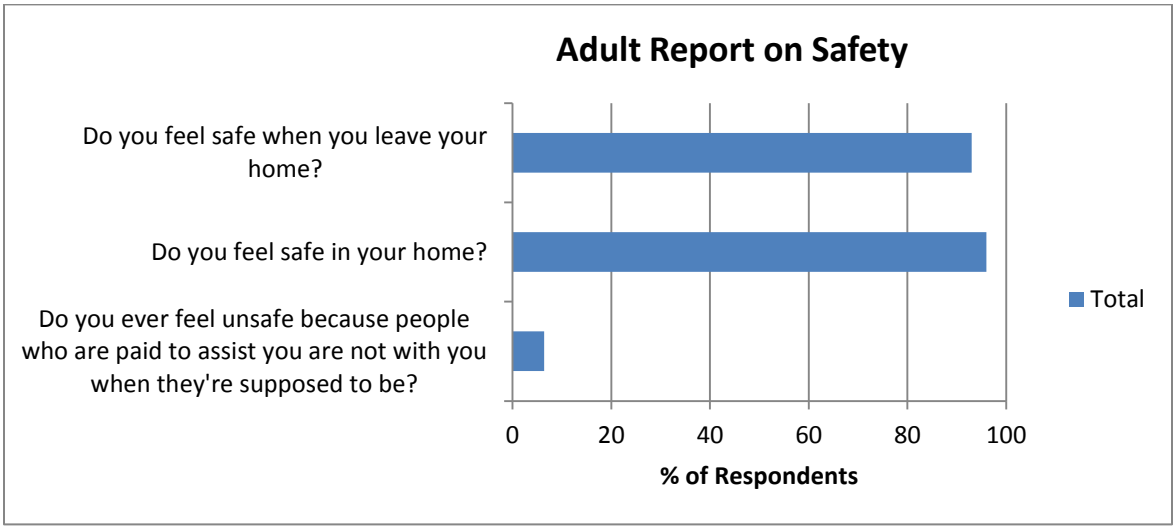
It is important to note that although these questions are intended to assess the prevalence of maltreatment amongst CADI Waiver and non-CADI respondents, the situations that a respondent responded "yes" may or may not be considered maltreatment of a vulnerable adult/minor.

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

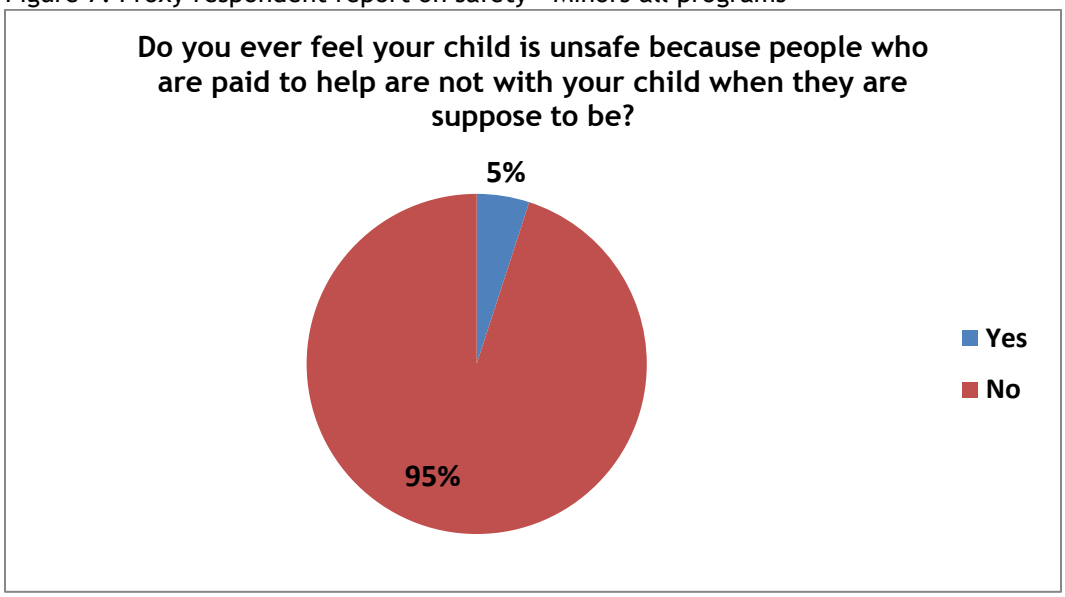


Overall, adult respondents feel safe both in their home and in the community:

- 96% of respondents feel safe in their homes and
- 93% of respondents feel safe when they leave their home and go into the community

However, 42 (6%) 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

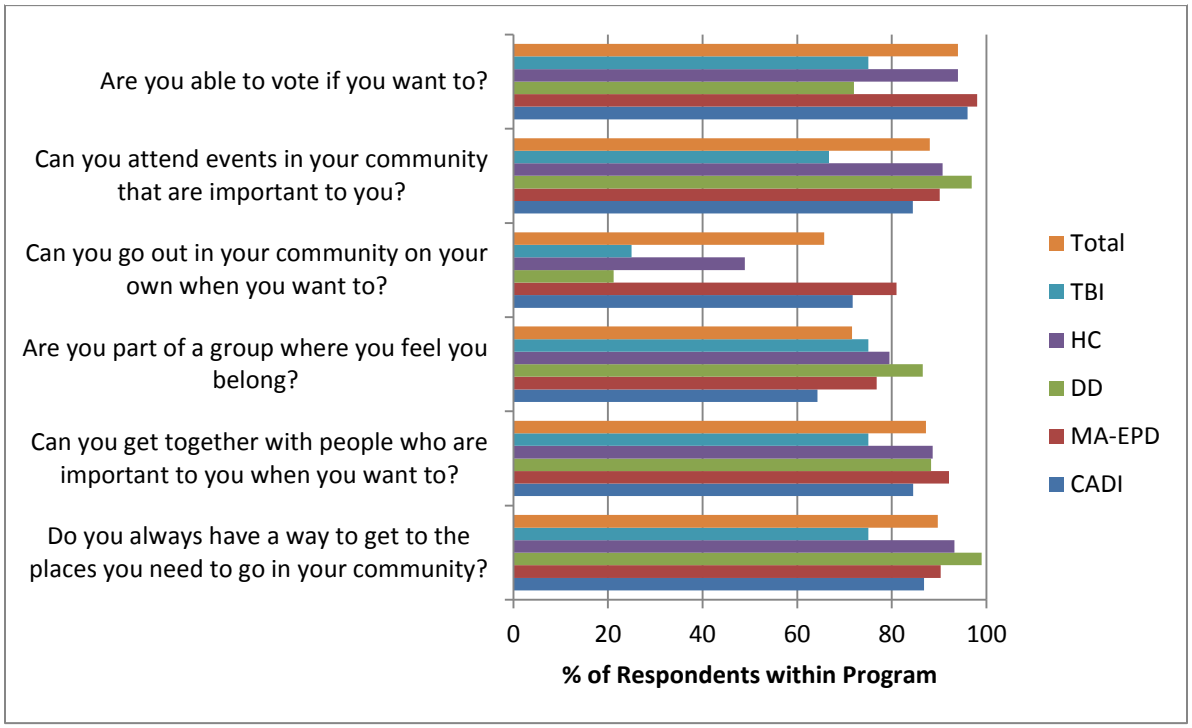


Four proxy respondents (5%) report that they feel that their child is unsafe because people who are paid to help are not with the child when they are supposed to be.

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



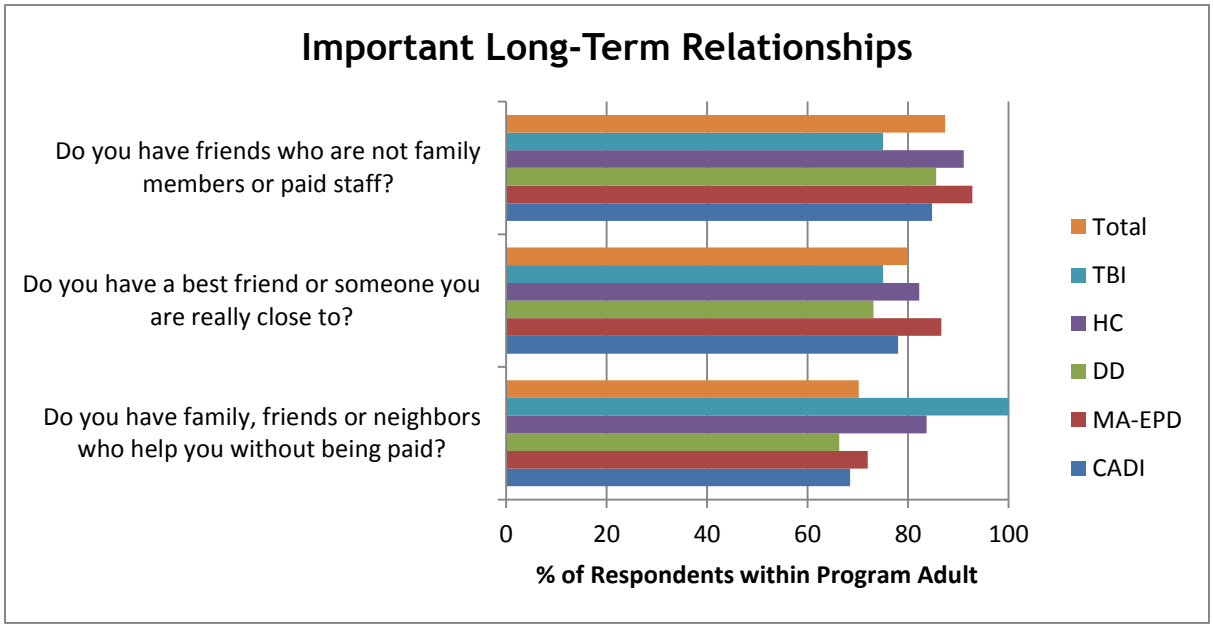
Overall, 94% of respondents stated that they are able to vote when they want to. However, almost a third (28%) of the participants with developmental disabilities stated that no, they are not allowed to vote, were unsure, or did not remember.

Almost 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, about a third of respondents reported that they could not go out in the community on their own when they wanted to and that they did not feel that they were part of a group where they belong.

Important Long-Term Relationships

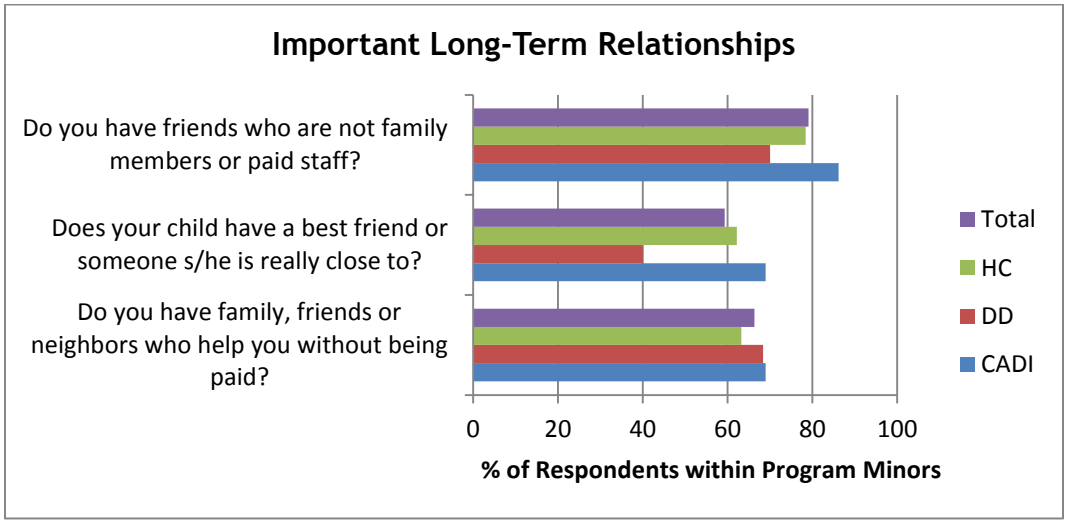
MN PES interviewers asked both adult and minor respondents about important long-term relationships. Questions included having a best friend or someone that they feel close to and if they have family, friends or neighbors who are not paid to help them with everyday activities. Figures 9 and 10 below summarize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

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



Overall, 80%-90% of adult respondents stated that they have friends who are not family members or are paid staff and that they had a best friend or someone with whom they were close. However, about one-third of respondents reported that they did not have family, friends or neighbors to help them with everyday activities without being paid.

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



Almost 80% of proxy respondents report that their child has friends who are not family members or paid staff. Sixty percent of proxy respondents report that their child has a best friend, or someone that they are close to and 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, 86% of adult respondents report that being on their program and receiving services has made their life better than before. The remaining 14% of respondents report that their life is about the same or worse than before they were on their program.

Figure 11: Quality of life - % Adults within program

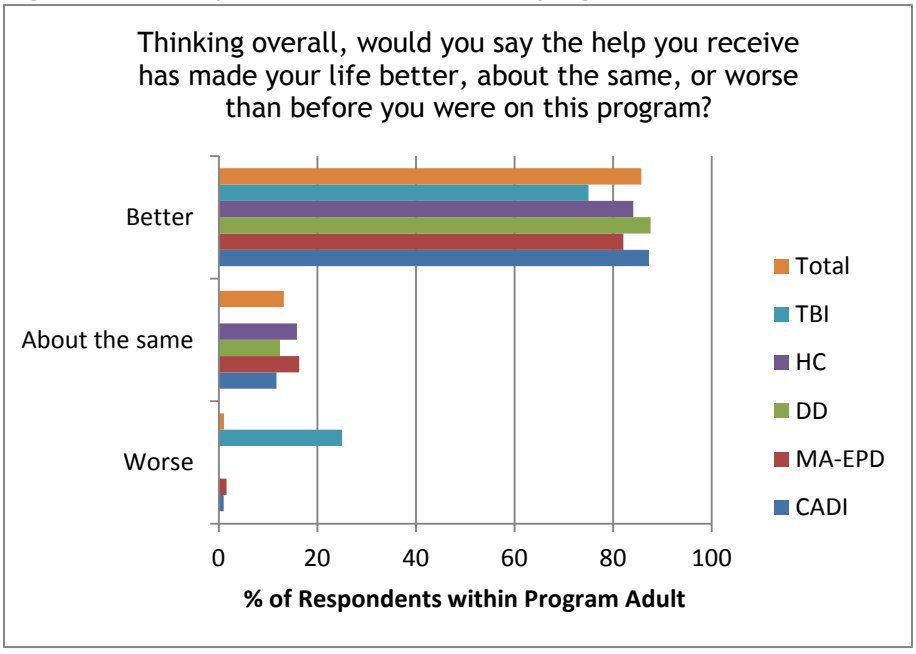
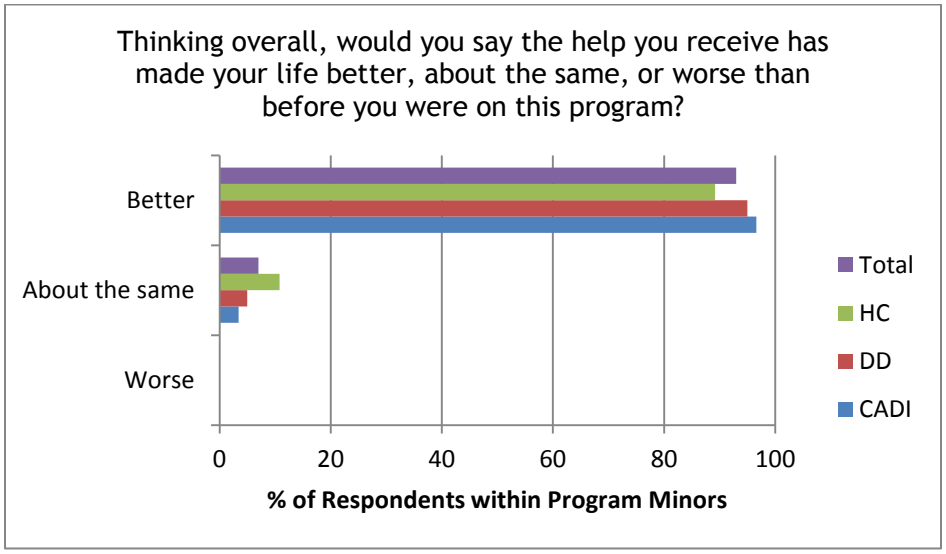


Figure 12: Quality of life - % Minors within program

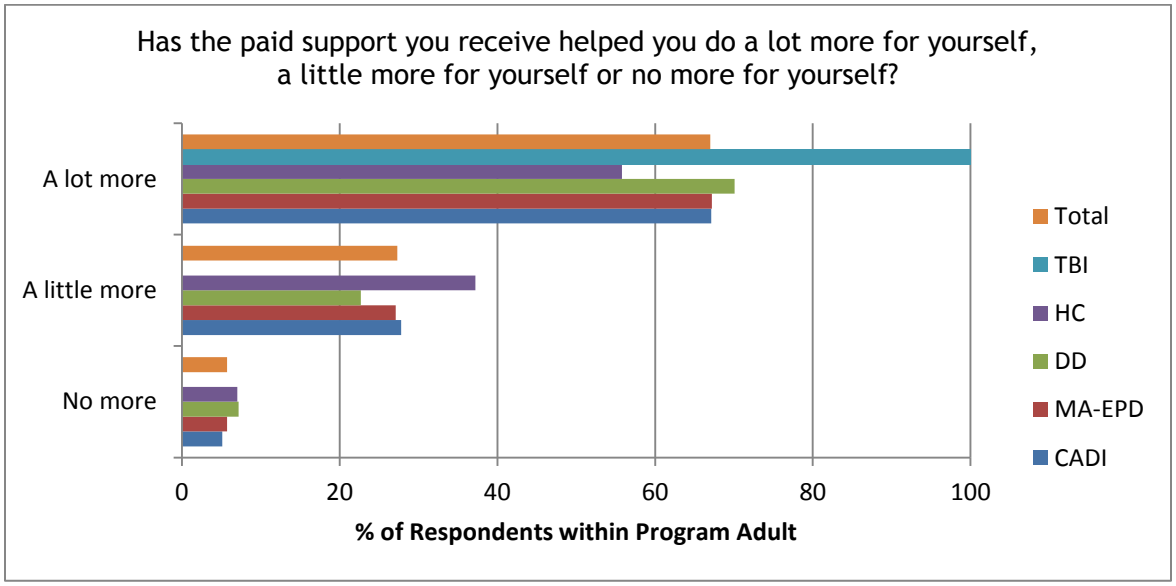


The quality of life improved for 93% of minor respondents because of the services they receive on their program. The remaining 7% of respondents report that the quality of life before and after being on their program is about the same.

Increased Independence

Adult and minor respondents were asked about the paid support that they receive and how it has affected their independence. Figures13 and 14 below summarize results.

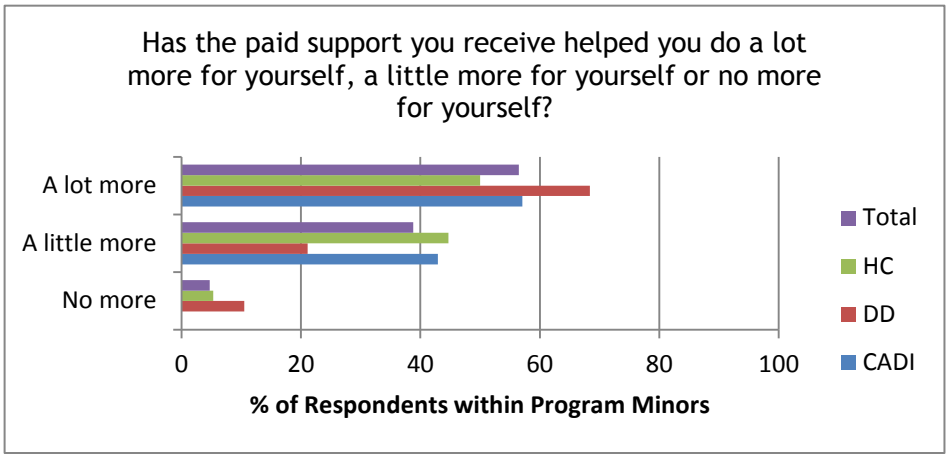
Figure 13: Quality of life independence - % Adult within program



Two-thirds 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.

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

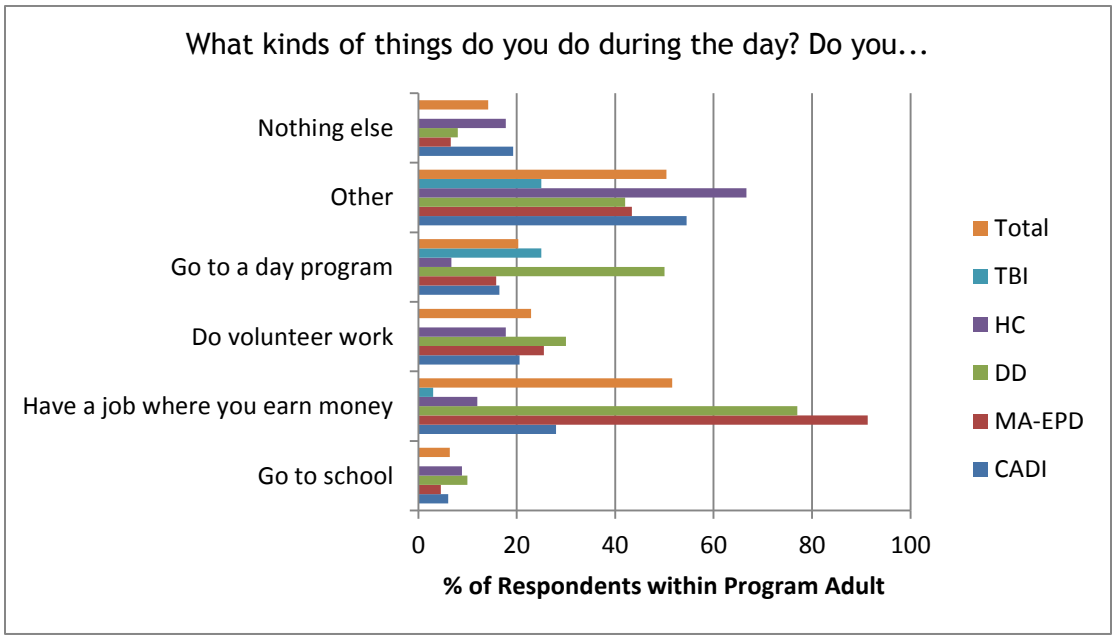
Overall, minors report that their independence has increased because of the paid support that they receive.



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

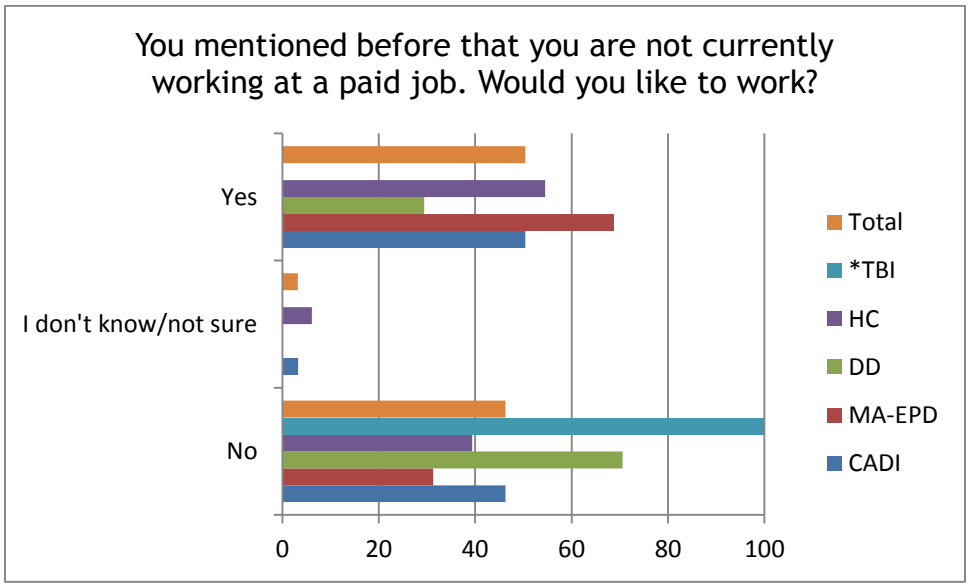


Over 50% of adults have a job where they earn money. DD Waiver and MA-EPD respondents report employment at 77% and 91% respectively. During the day, about one-fifth of respondents either volunteer or go to a day program. About half of respondents report that

they do other things during the day. Six percent of respondents report that they go to school and 14% 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 CADI Waiver (50%, n=137), MA-EPD (69%, n=11) and home care respondents (55%, n=18) 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

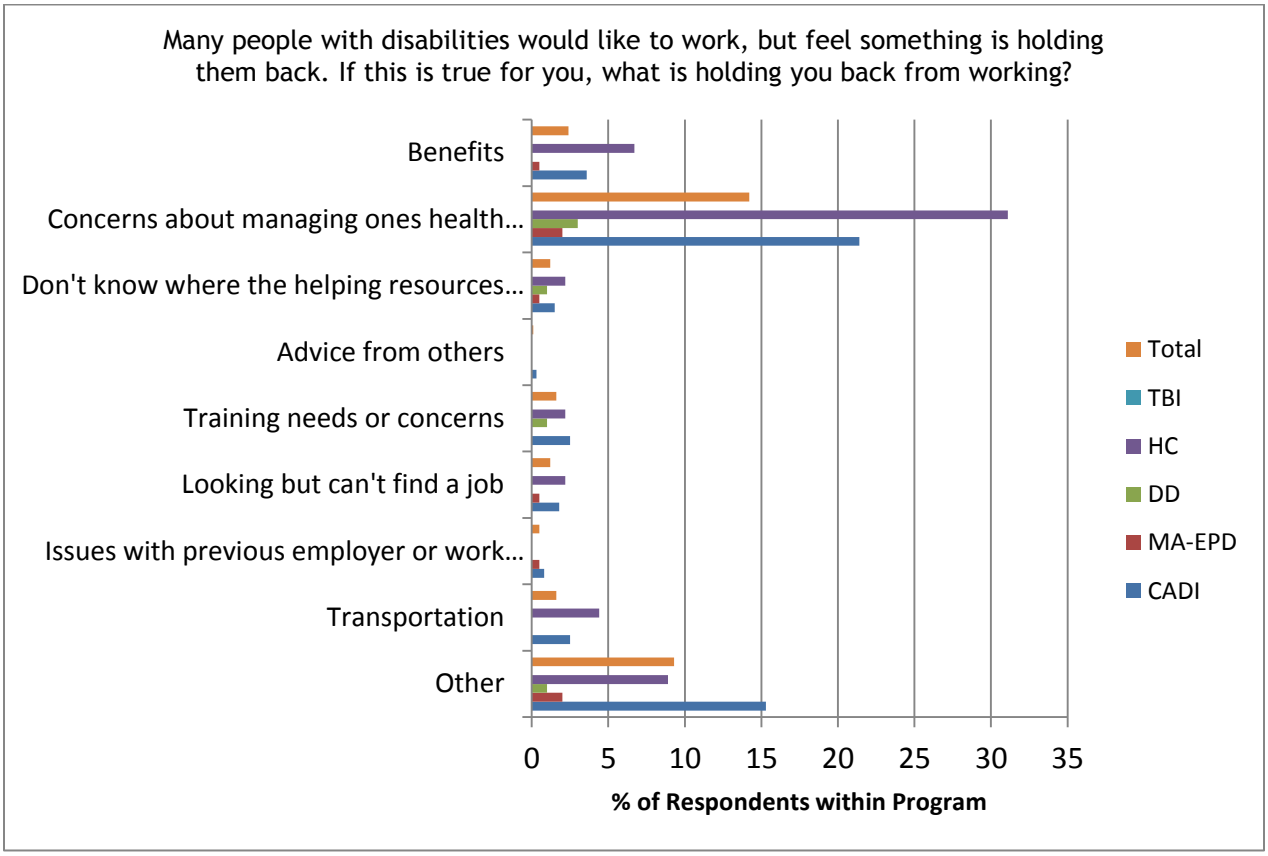


*There was one TBI respondent that answered this question

Barriers to Work

Respondents were asked if something was holding them back from working. One fifth of CADI Waiver and one-third of home care respondents 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.

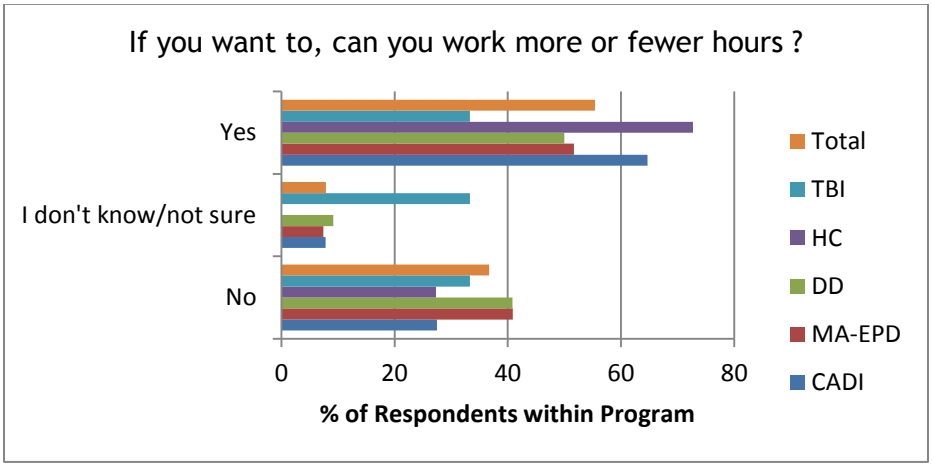
Figure 17: Barriers to work - % Adults within program



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. Eight 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.

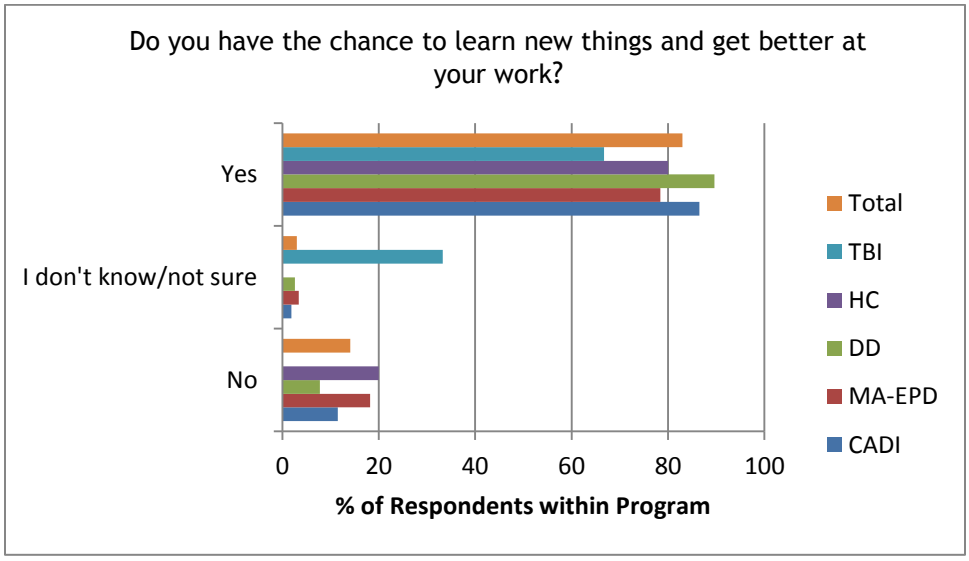
Figure 18: Flexibility of work schedule fewer or additional hours worked - % Adult within program



Employment – Opportunities for Improvement

Interviewers asked respondents if they had a chance to learn new things and get better at their work. Overall, 83% 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



CONCLUSIONS AND RECOMMENDATIONS

The MN PES 2010 project provided information that will serve to enhance community based services for persons with disabilities. Data obtained from MN PES finds that over 90% 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 made 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. **Consider alternative MN PES survey options such as phone, mail or online survey in addition to bi-annual MN PES face to face interviewing of persons receiving community-based services.**

   Face-to-face onsite interviews are recognized as a vital tool used to obtain rich information (Final Report Development and Testing of the Participant Experience Survey, Minnesota Version as well as from the 2007 Quality Assurance Panel members). Recommendations for obtaining individual information also include using in addition to face-to-face interviews, a combination of alternative sampling strategies (i.e. phone, mail and/or online) to provide additional numbers of persons providing feedback. Face-to-face interviews are generally preferred; however, the cost of implementation limits the number of persons that can be surveyed. MNCHOICES assessment also may be used to supplement questions as well as provide an opportunity to compare responses to the PES in the future when implemented.

2. **Conduct a larger sampling of TBI Waiver recipients, individuals receiving services under the self-directed service option, and non-English speaking recipients**.

   Targeted sampling of TBI Waiver recipients, persons using self-directed service options, and non-English speaking recipients can 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.

3. **Prior to community-based relocation of persons in institutions as part of Money Follows the Person (MFP), offer a pre and post MN PES to persons relocating from Nursing Facilities (NF's), Institution for Persons with Mental Diseases (IMD's) and Intermediate Care Facilities for the Developmentally Disabled (ICF/DD).**

   The use of pre and post MN PES information from persons who are relocating from institutions will provide important data that will be helpful in planning for future relocations.

4. **Immediately seek to enhance educational information directed at recipients as well as online training curriculum for providers that addresses choice options as well as enhanced discovery efforts leading to targeted remediation efforts as follows:**

   a. Inform individuals on the ability to change case managers, choose provider(s) and to modify individualized coordinated community support plans.
   b. Ensure individualized coordinated community service plans contain strategies designed to ensure access to preferred community activities
   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.
   d. Create and distribute information that clearly addresses voting rights for persons with developmental disabilities,
   e. Use data and information from current databases to enhance discovery activities leading to remediation to include:
      - Licensing agency corrective action plans
      - Vulnerable adult and maltreatment of children reports
      - Medical Assistance enrollment information
      - Information obtained from provider desk and field audits

   Enhanced educational information as well as training curriculum that match federal and state expectations will result in improved outcomes. In addition, the review of information collected from additional sources such as vulnerable adult and maltreatment reports, provider enrollment data, licensing activities, and provider desk audits will provide enhanced discovery information leading to targeted remediation efforts.

ACKNOWLEDGEMENTS

The Disability Services Division (DSD) of the Minnesota Department of Human Services would like to thank the Minnesota Quality Assurance (QA) Panel of citizen stakeholders representing a range of perspectives on quality and disability. The QA Panel originally recommended five key components of a revised quality assurance strategy for the state, including the development of an annual survey of service recipients from waivers operated by DHS' Disability Services Division.

We would also like to thank the 2007-2009 QA Stakeholder Advisory Group for its role in the development and implementation of the statewide survey that is consistent with the system performance expectations of the Centers for Medicare and Medicaid Services quality management requirements and framework. Subsequently the survey analyzed whether desired outcomes have been achieved for persons with different demographic, diagnostic, health and functional needs receiving different types of services, in different settings and with different costs. DSD would like to thank Pathways to Employment for their financial support and interest in this project.

Finally, DSD would like to thank the participants and their family and friends who took the time to participate in this survey along with the many staff members that were involved in the development of the survey tool, securing and coordinating the contract and with the implementation and writing of the report.

Their commitment and collaboration was essential in the initial 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.