

Minnesota's 2003 PCA Consumer Survey

*Prepared for the
Minnesota Department of Human Services*

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May 2004

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Summary

The Minnesota Personal Care Assistance (PCA) program, managed by the Minnesota Department of Human Services, provides assistance to individuals with disabilities on Medical Assistance (Minnesota's Medicaid program). The program is designed to support individual with daily activities needed to live in their homes, jobs, and communities. Minnesota has provided this service through its State Plan since 1977.

In 2003, Wilder Research Center surveyed 455 PCA consumers randomly chosen from the 6,000 participants statewide. This first survey gives new insight into PCA consumer experiences and views and lays the groundwork for future studies to detect trends and emerging issues.

In general, PCA consumers express strong satisfaction with the quality of care they receive through the PCA program, PCA workers, and their provider agencies. The survey also provides insight about how PCA services affect quality of life and ability to work; as well as strengths and weaknesses of the program from the consumer's viewpoint.

Program background

The PCA program provides supports to approximately 6,000 Minnesotans with disabilities to live more independently in their homes, jobs, and communities. A personal care assistant (PCA) is a person who assists individuals with daily routines. Consumers of PCA services may have physical, emotional, or mental disabilities, chronic illnesses, or injuries or conditions that require assistance with activities of daily living. PCA services must be medically necessary and ordered by a physician. Consumers must be able to direct their own care or have a "responsible party"¹ who can direct it on their behalf. Public health nurses assess consumers annually to determine the number of service hours needed.

¹ A responsible party is a person who can make decisions about a consumer's care and actively participates in the planning and directing of PCA services for a consumer.

PCA services include the following types of assistance:

- Activities of daily living, including eating, toileting, grooming, dressing, bathing, transferring, mobility, and positioning.
- Health-related functions that have been delegated or assigned (as defined by State law) by a licensed health care professional.
- Instrumental activities of daily living, including meal planning and preparation, managing finances, shopping for essential items, performing essential household chores, communicating by telephone and other media, assisting with transportation, and participating in the community, including a place of employment.
- Redirection and intervention for behavior, including observation and monitoring.

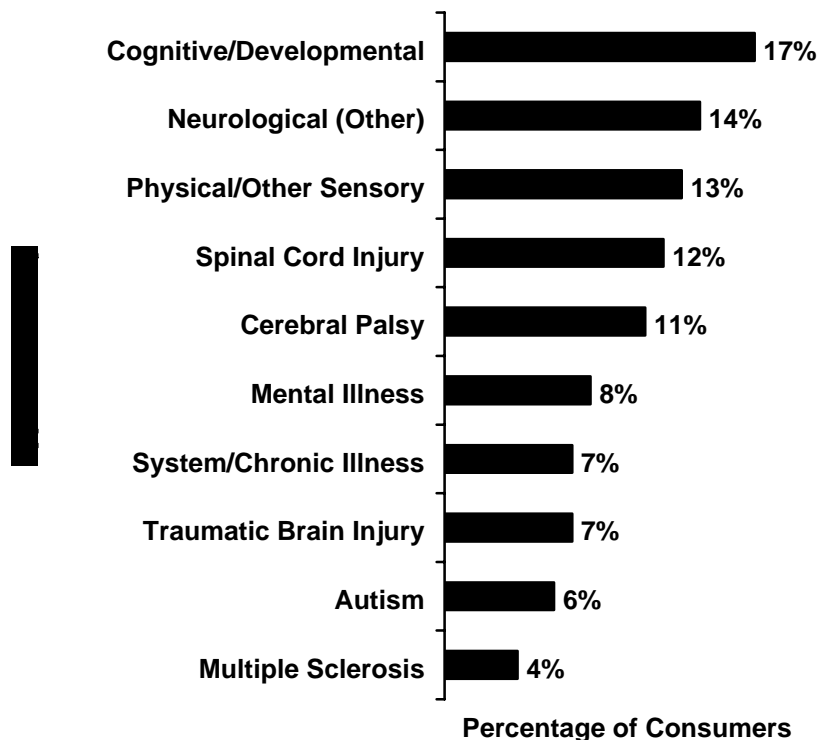
PCA Provider options

All consumers must have a provider agency to obtain PCA services. Consumers have the option to use a traditional PCA agency or to enroll in PCA Choice. Under the traditional model, consumers select an agency that is responsible for hiring, scheduling and managing the PCA workers. This agency determines the consumer's role in these activities. Alternatively, consumers enrolled in PCA Choice are responsible for hiring and scheduling PCA workers and managing their PCA services. PCA Choice agencies serve as fiscal agents that pay Medical Assistance funds to the consumers' PCA workers and are responsible for taxes, Worker's Compensation, etc.

Who participated in the survey?

- Of the 455 people who completed survey interviews, about half were PCA consumers and half were "proxies" – persons speaking for a consumer unable to complete the interview personally. Most (85%) of these proxies were the consumer's parent.
- 64% of the consumers were of working age, 18 to 64 years.
- 82% were White, 9 percent were Asian, and 7 percent were Black.
- A wide variety of disability conditions were represented.

Self-Reported Primary Disability Type of PCA Consumers (N=455)



Details on the survey method

The Disability Services Division supplied Wilder Research Center with a list of 1,200 randomly selected PCA consumers. To participate in the survey, consumers had to be able to direct their own care or have a “responsible party.” Wilder Research Center translated the survey instrument into Hmong, Somali, and Russian; and native speakers conducted 32 interviews in Hmong, nine in Somali, and four in Russian. A total of 455 interviews were completed with a response rate of 78%.

Consumers and their families describe many ways the PCA program improves their quality of life.

Key findings:

- Asked to name the single most valuable aspect of the PCA program, most consumers described how it helps them and their families to lead a more active, less stressful life. “More normal” is a phrase they often used.

“Raising kids, going to school concerts, going shopping... The PCA is like a lean-to shelter that enables me to do the things I do.”

“They [PCA workers] enable me to get my life back.”

--Consumers, 2004 PCA Survey

- Another frequent comment was that PCA services allow the consumer to live on their own or with their family instead of in a nursing home. They also talked about the relief it provided for family members:

“I am stressed out working two jobs. I know that the PCAs are getting [my wife] up, that she is cared for ... I know I don’t have to worry about these things.”

“Whenever a PCA worker comes ... is the only time we can do things. She needs 24-hour assistance ... Without [PCA service] we wouldn’t get a break.”

--Consumers, 2004 PCA Survey

- A concern expressed by a number of consumers is their ability to fully participate in community life appears limited by their available PCA hours and finding PCAs to work when they need them.

“I wish I had more time (proxy) but if she had someone who could help her more with stretches, therapy and could take her places, she would have a better quality of life.”

---Consumer, 2004 PCA Survey

Issues for further consideration:

- Because consumers reported positive impacts of PCA services on their quality of life, continued support of the program would further enhance the quality of life and the community contributions of people with disabilities.

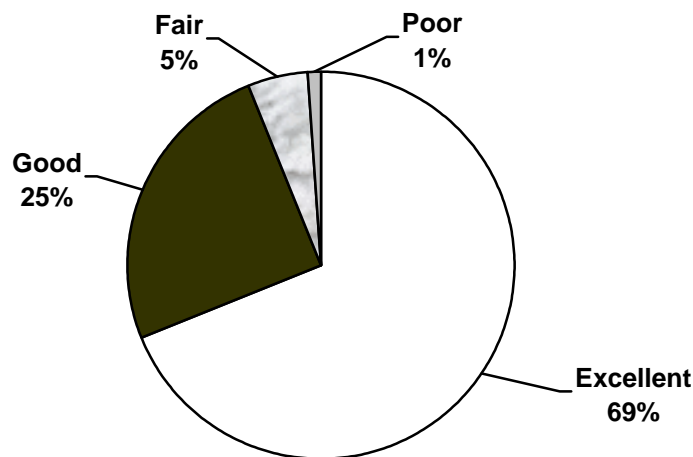
- Although most consumers expressed satisfaction with the assessment process, some said that lack of PCA service hours limits their community involvement. This bears further investigation into the adequacy of the assessment itself and into consumers' awareness of their flexibility in using hours.

Consumers highly rate the quality of the care they receive, but turnover and wages are a problem.

Key findings related to the quality of care include:

- Consumers highly rated the quality of care provided by their PCA workers.

Consumer Rating of the Quality of Care Provided by PCA Worker (N=455)



- Staff turnover was a major problem for about one-quarter of PCA consumers; the problem was worse outside the Twin Cities metro area.
- Most consumers perceived that turnover is related to low PCA wages. Sixty-two percent specifically stated that the PCA wage is too low. Most suggestions on how to improve the PCA program centered on increasing the wages of PCA workers.

“Getting and retaining qualified people, you need to pay them a decent wage. In some cases they need a great deal of medical knowledge and also need people skills.”

“The wages should be higher for incentive and get better quality people. The PCAs seem to be entry level workers. With better wages they could put more qualifications to the PCAs.”

--Consumers, 2004 PCA Survey

- Most consumers were satisfied with the training of their PCA workers, but when additional training was desired, it was most often in the area of specific knowledge about their disabilities and needing better communication with PCAs.
- Consumers gave mixed reports about their preference for training their own PCA workers with 38% preferring to train their own PCAs and were comfortable doing so on their own, 26% preferring to have their PCA workers come to them already trained, 18% preferring to have their current PCAs train a new PCA and 12% training their own PCA workers but with some assistance.
- At least half of PCA consumers received unpaid personal care in addition to their PCA services.
- About 1 in 8 consumers were paying for PCA hours with their own money, mainly because they used workers not employed by their agency or because they did not receive enough PCA service hours to meet their needs.
- Although consumers reported a high level of satisfaction with the assessment process that determines their service hours, many open-ended responses suggested consumers were not obtaining the service hours they needed.

Issues for further consideration:

- Because worker turnover appears closely related to low PCA wages, it is important to consider increasing the overall funding level for PCA services.
- Provider agencies should consider ways to reduce agency administrative costs, in order to increase PCA wages.
- Increase efforts to raise consumers’ awareness about the extent of their ability to set PCA workers’ wages in the PCA Choice program.

- Survey results also suggest some need for enhanced training for PCA workers, particularly around specific disabilities and communication with consumers.

PCA services are an important part of the mix that makes it possible for consumers to work.

Key findings include:

- About one-quarter of survey participants over age 18 were employed
- Only a small proportion of employed consumers used PCA services at work (22%).
- While three-quarters of working PCA consumers reported they don't need PCA services at work, other reasons for not using PCAs at work included 1) not enough service hours; 2) not knowing how to set up the service; 3) having coworkers or staff who help them at work; 4) and their PCA worker is unable to get to their workplace.
- For those who were not currently working, the top barrier to working was their disability. Other barriers to employment reported included: 1) inability to find a job; 2) fear of losing benefits; 3) lack of transportation; and 4) not knowing how to set up PCA services at work

Issues for further consideration:

- PCA services appear to be a necessary component to employment for some consumers. More education on PCA services at work could be beneficial.
- It is unclear from this survey whether low employment rates are related to disabilities or a perception that people with disabilities cannot/should not work.
- The State should consider modifying the PCA assessment to address employment related needs.
- The employment needs of persons with disabilities likely include services that are beyond the scope of the PCA program, such as job placement and transportation assistance.
- Relatively few consumers were familiar with the Medical Assistance for Employed Persons with Disabilities (MA-EPD) program, which allows people with disabilities to maintain their Medical Assistance benefits while working. Providing information about this work incentive may increase the number of PCA consumers who are employed.

Many consumers like to play an active role in choosing, scheduling, and training their PCA workers.

Key findings related to the design and implementation of the PCA program includes:

- Consumers expressed high levels of interest in choosing, training and scheduling their own PCA workers. Many are already doing this regardless of whether they are in PCA Choice or traditional PCA.

“I would like to feel that I have more control over [hiring], since I am capable of doing it.”

--Consumer, 2004 PCA Survey

- PCA Choice participants were three times more likely to be from the Twin Cities metro area than in Greater Minnesota.
- Consumers expressed high satisfaction with their current PCA providers, both traditional and PCA Choice.

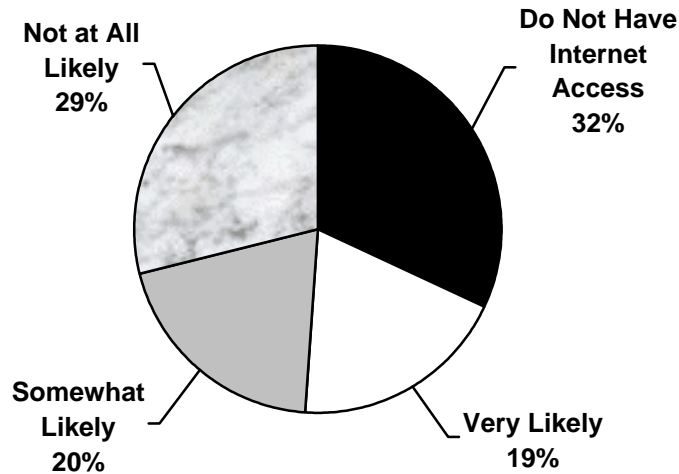
“They do a real good job informing me of how to deal with my PCA, what my PCAs are responsible for and when I call them they get back to me very quickly”

“Because they are very professional yet personal. They take time with you and I have received many referrals from them regarding my son's case.”

--Consumers, 2004 PCA Survey

- Consumers expressed a preference for in-person response to complaints.
- There appears to be limited potential for Internet communication, based on preferences and limited access.

*Likelihood that Consumer would Use the Internet to Get Information
About the PCA Program (N=455)*



Issues for further consideration:

- Survey findings suggest considering ways to provide consumers with support to do more of their own hiring, scheduling, and training; encourage agencies to allow consumers more control; and expand the pool of qualified PCA workers as well as consumers' ability to tap into that pool (such as a listing service).
- Since a smaller portion of consumers enroll in PCA-Choice outside the Twin Cities metro area, providing education and outreach about this option in greater Minnesota may help enhance consumers' active role in their PCA services.
- Since Internet communication appears to be a limited option for PCA consumers and also a less-preferred way of resolving problems, further reliance on Internet-based communication does not seem to be an effective approach at this time.

Introduction

The Minnesota Department of Human Services' Personal Care Assistance (PCA) program, managed by the Minnesota Department of Human Services, provides services to individuals on Medical Assistance (or Medicaid) who need assistance with daily activities to allow them to live in their own homes and communities. The Disability Services Division contracted with Wilder Research Center to conduct a telephone survey of 450 PCA consumers that began in late 2003 and was completed in early 2004.

Goals of the survey

The telephone survey is one component of the PCA program quality assurance plan established in 2001 by the state legislature. The Disability Services Division had other goals for the survey as well:

- To gather information about consumer satisfaction and preferences related to PCA services from a random sample of consumers using the program
- To explore the extent to which PCA services contribute to consumers' employment
- To learn consumers' priorities for PCA program improvements
- To inform the Minnesota Department of Human Services about possible needs for changes in public policy

Program description

The PCA program provides services to approximately 6,000 Minnesotans with disabilities, supporting them to live more independently in their homes, jobs, and communities. A personal care assistant is a person who assists individuals with disabilities with their daily routines. Consumers of PCA services may have physical, emotional, or mental disabilities, chronic illnesses, or injuries or conditions that require assistance with activities of daily living. PCA services must be medically necessary and ordered by a physician. Consumers must be able to direct their own care or have a "responsible party"² who can direct it on their behalf. Public health nurses assess consumers of PCA services annually to determine the number of service hours needed.

² A responsible party is a person who can make decisions about a consumer's care and actively participates in the planning and directing of PCA services for a consumer.

PCA services include the following types of assistance:

- Activities of daily living, including eating, toileting, grooming, dressing, bathing, transferring, mobility, and positioning.
- Health-related functions that can be delegated or assigned, as defined by state law, by a licensed health care professional to be performed by a personal care assistant.
- Instrumental activities of daily living, including meal planning and preparation, managing finances, shopping for essential items, performing essential household chores, communicating by telephone and other media, assisting with transportation, and participating in the community, including at a place of employment.
- Redirection and intervention for behavior, including observation and monitoring.

PCA Choice option

Consumers have the option to use a traditional PCA agency or to enroll in PCA Choice. Under the traditional model, consumers select an agency that is responsible for hiring and managing the PCA workers, and this agency determines the consumer's role in interviewing and performance evaluation of the PCA. Alternatively, consumers enrolled in PCA Choice are responsible for hiring workers and scheduling PCA services. PCA Choice agencies act as fiscal agents that pay Medical Assistance funds to the consumers' PCA workers and are responsible for taxes, Worker's Compensation, etc.

Methodology

Sampling and survey method

The Disability Services Division supplied Wilder Research Center with a list of 1,200 randomly selected PCA consumers with contact and other information. From this list, Wilder Research Center identified the languages spoken by consumers. The survey was translated into all languages spoken by one percent or more of the sample, or at least 12 of the 1,200 names. These interviews were conducted by native speakers employed by Wilder as survey interviewers. Of the translated interviews, 32 were completed in Hmong, 9 in Somali, and 4 in Russian.

The Disability Services Division sent all PCA consumers a letter notifying them that they might be contacted to participate in the survey. As shown in Figure 1, a total of 780

names were drawn from the list of 1,200 names, including those consumers requiring translation. The sample was released in waves to maintain a high response rate. The telephone interviews were conducted by trained, professional, on-site interviewers employed by Wilder Research Center, using computer-assisted telephone interviewing software (CATI). A total of 455 interviews were completed and a 78 percent response rate was achieved.

1. Sample selection and response rate

| | Number |
|---|---------------------|
| Consumers of Minnesota Personal Care Assistance Program | Approximately 6,000 |
| Random sample of total PCA consumer population | 1,200 |
| Total sample released for the survey | 780 |
| Consumers determined to be ineligible* | 198 |
| Consumers determined to be eligible | 582 |
| Completed interviews | 455 |
| Response rate | 78% |

***Note:** *Ineligibility includes deceased, unable to locate, and no responsible party located.*

Proxy interviews

Proxies are persons who answer survey questions on behalf of individuals. Proxies were interviewed if: the PCA consumer was under 18 years of age; if a “responsible party” other than the PCA consumer was identified at the beginning of the interview, or; if the consumer preferred to have assistance responding to the telephone interview. Of the 455 completed interviews, 211 were proxies. Figure 2 presents proxy relationship by the age of the consumer. As the table shows, 85 percent of the proxies were parents, regardless of age of the consumer. For consumers 18 years and older, proxies were also likely to be adult children, spouses, or siblings.

2. Proxy relationship by age of PCA consumer

| Proxy is... | Less than 18 years (n=152) | | 18 years and older (n=59) | | Overall (N=211) | |
|---------------------------|-------------------------------|---------|------------------------------|---------|--------------------|---------|
| | Number | Percent | Number | Percent | Number | Percent |
| Parent | 146 | 96% | 33 | 56% | 179 | 85% |
| Adult child | 0 | 0% | 8 | 14% | 8 | 4% |
| Spouse | 0 | 0% | 8 | 14% | 8 | 4% |
| Sibling | 1 | 1% | 5 | 8% | 6 | 3% |
| Grandparent, aunt, cousin | 3 | 2% | 3 | 5% | 6 | 3% |
| Guardian | 2 | 1% | 0 | 0% | 2 | 1% |
| Non-relative | 0 | 0% | 1 | 2% | 1 | <1% |
| Unknown | 0 | 0% | 1 | 2% | 1 | <1% |
| Total | 152 | 100% | 59 | 100% | 211 | 100% |

Note: Percentage may exceed 100 percent due to rounding.

Within this report, both consumers and proxies who participated in the survey are referred to as “consumers.”

Analysis

Survey data was analyzed by examining responses to each survey question and comparing specific variables by cross tabulation (for example, comparing type of disability and employment status within a given age group), in order to identify patterns. When a cross tabulation was found to be statistically significant, it is noted in this report. Two findings of statistical significance are discussed in the report: 1) turnover of PCA workers in the seven-county Twin Cities metropolitan area compared with the non-metro area (discussed in the *Quality of care* section) and 2) enrollment in PCA Choice in the seven-county Twin Cities metropolitan area compared with greater Minnesota (discussed in the *PCA program design and implementation* section).

About the survey participants

Age, race, disability, and length of time in the PCA program

Age

Two-thirds of consumers interviewed were of working age, 18 to 64 years. As shown in Figure 3, 34 percent of PCA consumers were less than 18 years old and 3 percent were 65

years or older. This age distribution closely reflects the age distribution of the PCA consumer population.

3. Ages of PCA consumers in this survey

| | Number | Percent |
|--------------------|--------|---------|
| Less than 18 years | 154 | 34% |
| 18 to 64 years | 289 | 64% |
| 65 years and older | 12 | 3% |
| Total | 455 | 100% |

Note: Percentage may exceed 100 percent due to rounding.

Race

Eighty-two percent of the PCA consumers participating in this survey were White, 9 percent were Asian, and 7 percent were Black.

Disability

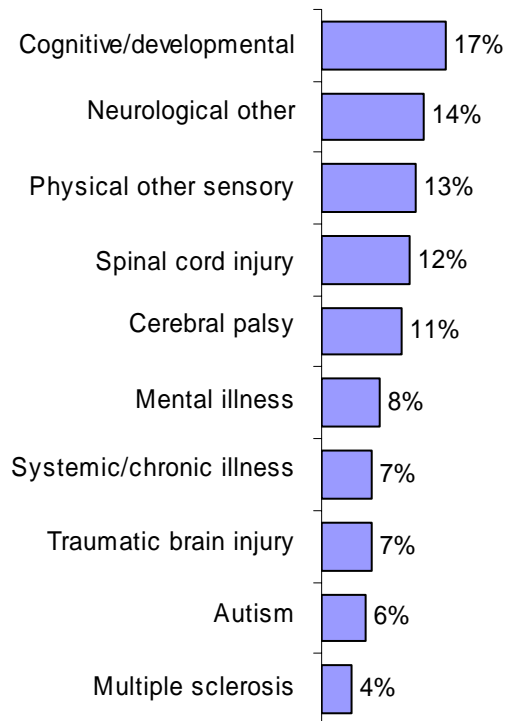
Consumers were asked to identify their primary disability. Responses were grouped into the following categories, listed here in order of decreasing frequency:

- Cognitive/developmental (for example, attention deficit hyperactivity disorder/ADHD, developmental delay, learning disability, retardation, Down's Syndrome, rare chromosome disability, fetal alcohol syndrome, hydrocephalus)
- Neurological other (for example, seizures, muscular dystrophy, spina bifida, amyotrophic lateral sclerosis/ALS/Lou Gehrig's disease, epilepsy, dystonia, hypomelanoses of Ito, Lennox Gaustaut syndrome, neuropathy)
- Physical other/sensory (for example, osteoarthritis, vision, hearing, heart, back pain, amputee, degenerative joint disease, vision, hearing)
- Spinal cord injury
- Cerebral palsy
- Mental illness (for example, oppositional-defiant disorder/ODD, obsessive-compulsive disorder/OCD, reactive attachment disorder, bipolar disorder, depression, behavioral or emotional disorders, conduct disorder, post-traumatic stress disorder/PTSD)
- Traumatic brain injury (TBI)

- Systemic/chronic illness (for example, asthma, emphysema, diabetes, hypertension, stomach distress, autoimmune deficiency, phenylketonuria/PKU, rheumatoid arthritis, fibromyalgia)
- Autism
- Multiple sclerosis

4. Self-reported primary disability type of PCA consumers

Asked of all PCA consumers surveyed, N=455

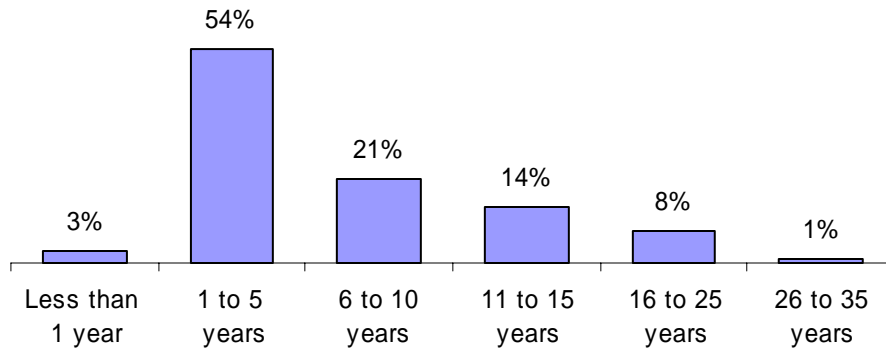


Average length of use of PCA services

On average, consumers had used PCA services for about seven years, ranging from less than one year up to 35 years. As shown in Figure 5, over half of the consumers had been using PCA services for one to five years.

5. Length of time consumers have used PCA services

Asked of all PCA consumers surveyed, N=455



Findings

Survey results are presented in the sections below, grouped to facilitate examination of key issues for PCA consumers related to:

- Quality of life
- Quality of care
- Employment
- PCA program design and implementation

Each section is introduced with a summary of key findings, and concludes with a discussion of issues that the findings suggest may merit further consideration. Unless otherwise stated, response categories shown here are the same as the response options offered to consumers in the survey.

Quality of life

The effect of the PCA program on the quality of life of consumers was measured by the extent to which the program: 1)enables consumers to lead the life they wish to lead; 2)has a positive effect on health and safety of consumers; 3)contributes to a reduction in the stress level of consumers and their families; and 4)increases their ability to remain in their home and participate in community life. The key findings related the PCA program's effect on consumers' quality of life can be summarized as follows:

- Asked to name the single most valuable aspect of the PCA program, most consumers described how it helps them and their families to lead a more active, less stressful life. "More normal" is a phrase they often used. Another frequent comment was that PCA services allow the consumer to live on their own or with their family instead of in a nursing home.

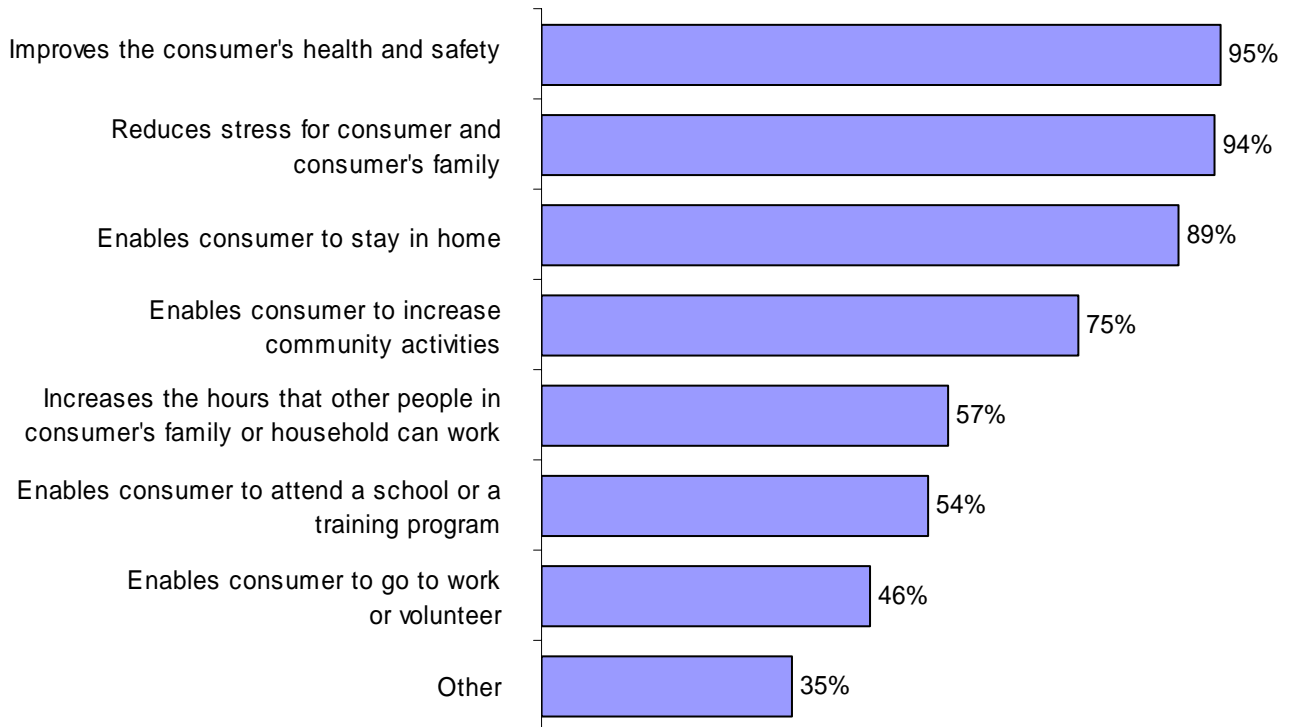
The PCA program has a positive effect on quality of life

In a series of yes-or-no questions, PCA consumers were asked their perceptions of the impact of the PCA program on their lives. Overall, 87 percent of consumers reported that the PCA program supports them in leading the life they want to have. As shown in Figure 6, consumers also reported that the PCA program has a positive effect on their health and safety (95%); reduces stress for consumers and their families (94%); enables consumers to stay in their homes (89%); and enables consumers to participate in community activities (75%).

Among the 13 percent of consumers who said the PCA program does not help them lead the life they wish to lead, the most common reason given was not having enough PCA service hours, mentioned by 53 percent.

6. Overall effect of PCA program on consumers' quality of life

Asked of all PCA consumers surveyed, N=455



What consumers like best about their PCA service

PCA consumers were asked what they liked best about their PCA services, and then asked what they would change if they could change one thing. Responses were coded and then grouped into the following categories for what consumers like best. These categories are illustrated with examples of consumers' own answers.

■ Quality of PCA worker or agency

“Their [PCA workers] reliability and professionalism, an agency that is reliable.”

“Just knowing that they [PCA workers] are going to show up is good. When you have been around them long enough, you don't have to tell them what to do, they just do it. It gives me peace of mind to know they will be here and will be competent at what they do.”

“The agency and the PCAs do a good job. They work with me on my goals.”

■ Improved quality of life

“They (PCA workers) enable me to get my life back.”

“It (the program) enables me to be able to work and make somewhat of a living. Otherwise, I wouldn't be able to do my job.”

“They (PCA workers) are helping him make choices in his life and helping him to move on in his life.”

“It increases her quality of life; makes it easier on her parents. The PCA program helps in our whole family's quality of life as well.”

■ Choice or availability of PCA worker

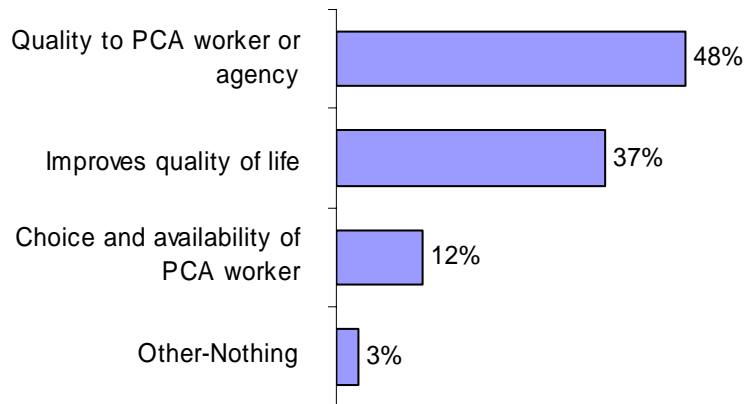
“The flexibility of hiring people you know or interviewing and hiring people you have interviewed yourself and paying them adequate wages.”

“The flexible hours; the flexibility of PCA Choice.”

Figure 7 illustrates the distribution of PCA consumers' responses. A table with illustrative comments is located in the Appendix.

7. The ONE thing that consumers like best about PCA services

Asked of all PCA consumers surveyed, N=455



What consumers feel needs to be changed about their PCA service

Consumers' responses about the one thing they would change about their PCA services were also coded and then categorized as follows:

- The majority of comments received were related to increasing PCA workers' wages,

"I'd give them better wages because it is an important job [Note: 80 of the 164 comments related to PCA workers were about increasing their wages and/or providing health insurance benefits]."

"Wage increases for cost of living for my PCAs. It seems like now it is a set wage that doesn't change until the government chooses to change it, which might be a year or two or more down the road."

"Improve their [PCA workers'] salary, because they are really working hard."

There were also issues related to better training of PCAs and difficulty for either they or their agency in finding PCAs:

"The training! That they could be trained about the specific disability their clients have. Autism and Down's syndrome are two different disabilities and can't be treated the same."

"We would like a greater pool of people who would work for us. If we had a place to call to find more workers [that would be helpful]. We are having a hard time finding people either trained or untrained to be her PCA."

“The interaction with the company [agency], and if a person asks for a person to fill in for time they need, a back up. Giving help if a person, if a PCA, needs a day off. It would be nice to have the same person work for you on a regular basis if you need.”

Availability of workers.

“To have assistance on weekends.”

■ Assessment

“That I had more paid PCA hours. [Note: 48 of the 54 comments on assessment were related to needing more hours]”

“The public nurse assessment process. We’ve been trying to have him re-assessed since September and they haven’t gotten back to us. The agency just put in another request.”

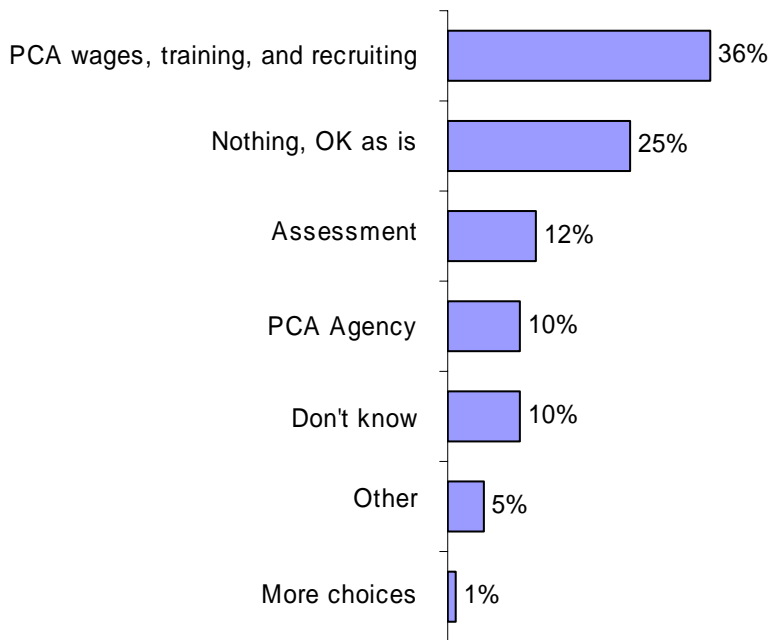
■ Interest in hiring their own PCAs

“I would have to say [the one thing I would change] would be hiring my own PCA instead of the agency doing it for me. Because some of the PCAs that they have put on my doorstep have not been good ones. I would like to feel that I have more control over it, since I am capable of doing it, of hiring my own PCAs.”

Figure 8 illustrates the distribution of PCA consumers' responses. A table with illustrative comments is located in the Appendix.

8. The ONE thing that consumers would change about their PCA services

Asked of all PCA consumers surveyed, N=455

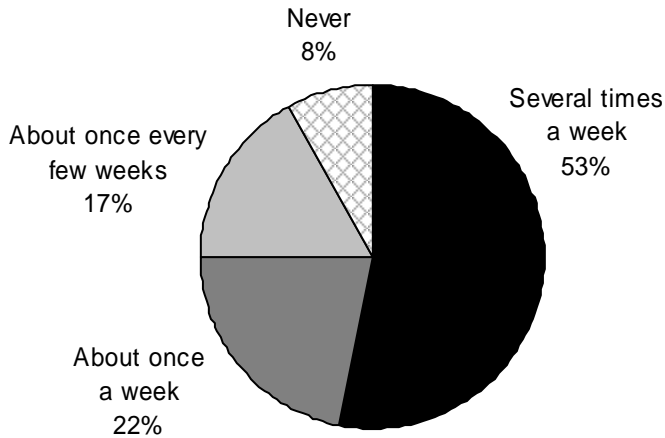


PCA hours enable community engagement

Community engagement is a component of quality of life by most measures. Survey findings indicate that PCA consumers tend to be active in the community, but that for much of the time, many of them are not accompanied by a PCA worker. Just over half of the consumers (54%) said they get out in the community several times a week to engage in activities such as eating out, going to the movies, and visiting family and friends, and 22 percent get out in the community at least once a week, as shown in Figure 9.

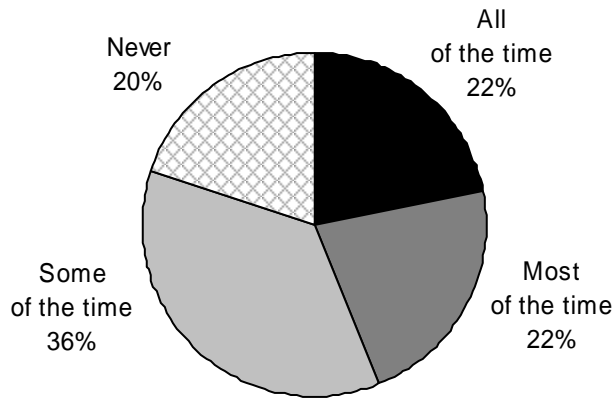
9. Frequency of activities in the community, such as going out to eat, watching movies, visiting friends and family

Asked of all PCA consumers surveyed, N=455



Consumers reported a somewhat mixed response when asked if their PCA workers usually accompany them on community outings, as shown in Figure 10. Twenty-two percent reported that their PCA worker accompanies them “all of the time” when out in the community, 22 percent reported that their PCA accompanies them “most of the time,” 36 percent reported their PCA goes with them “some of the time,” and 20 percent reported their PCA worker “never” accompanies them on community outings. When asked why their PCA worker does not accompany them, 65 percent (of those who said “never” or “some of the time”) reported that they do not receive enough PCA hours to bring a PCA with them.

10. Frequency with which PCA accompanies consumer on community outings
Asked of PCA consumers who ever go out on community outings, N=415



Similarly, of the 15 employed consumers who did not use a PCA worker at work, about 20 percent reported that the reason was that they did not have enough service hours (more fully discussed in *Employment* section).

Issues for further consideration

Consumers give strongly positive reports about the PCA program's benefits for both themselves and their families. These findings suggest that continued support of the program would further enhance the quality of life of persons with disabilities in the state of Minnesota.

Some consumers indicated that limited PCA service hours restricted their community involvement, yet most consumers reported high levels of satisfaction with the assessment process through which service hour needs are determined. This confounding result raises questions about consumers' awareness of how to use PCA hours flexibly. There may also be a need to examine whether or not the assessment process adequately addresses the need for assistance when going out into the community.

Finally the issue of improving PCA wages is a significant one. This is further discussed in the next section on quality of care.

Quality of care

The quality of care provided by PCA workers was measured by consumers' satisfaction with the training of PCA workers, the quality of care and treatment by PCA workers, and the assessment process. Evidence for quality of care was also obtained from consumers' reports of the extent to which they were affected by PCA wage levels and turnover of PCA workers.

The key findings related to quality of care include:

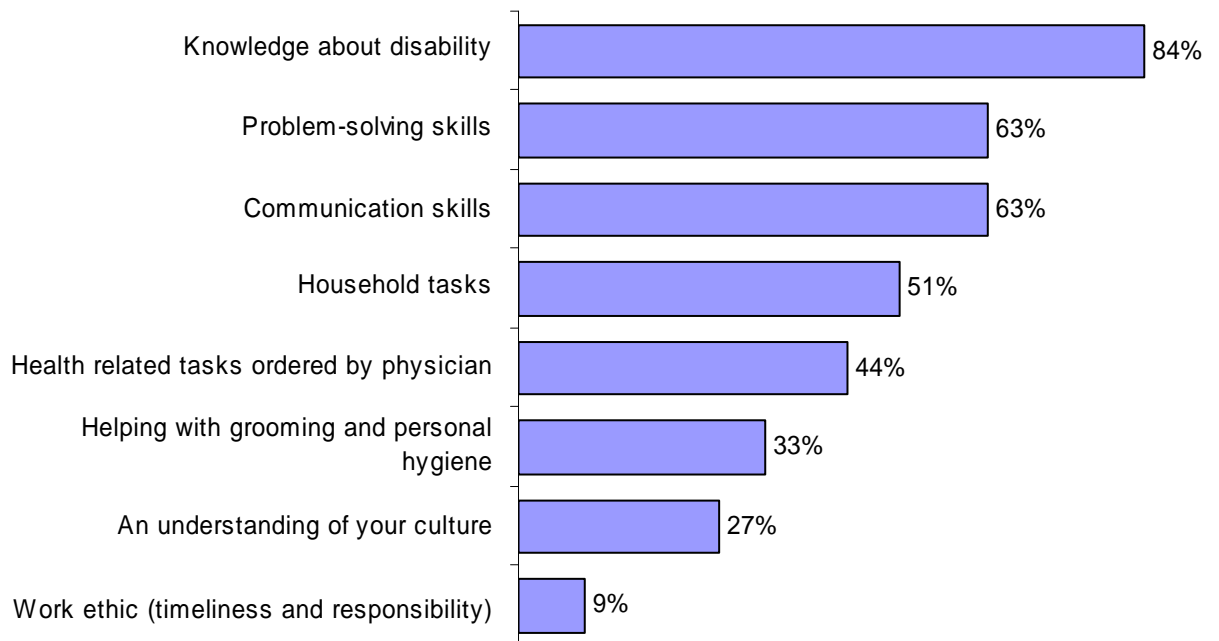
- Most consumers were satisfied with the training of the PCA workers, but when additional training was desired, it was most often in the area of specific knowledge about their disabilities.
- Consumers gave mixed reports about their preference for training their own PCA workers. One out of three preferred training their own workers, and one out of four preferred to have the worker come to them already trained.
- Consumers highly rated the respect shown to them by their PCA workers, their workers' completion of tasks, and the quality of care provided by their PCA workers.
- Staff turnover was a major problem for about one-quarter of PCA consumers. The problem was worse outside the Twin Cities metro area. Most consumers perceived that turnover was related to low PCA wages.
- At least half of PCA consumers received unpaid personal care in addition to their PCA program services.
- About 1 in 8 consumers were paying for additional PCA hours with their own money, because:
 - They used workers who did not work for their agency (in other words, they were hiring and scheduling their own supplementary PCA workers)
 - They reported that they did not receive enough PCA service hours to meet their needs.
- Consumers reported a high level of satisfaction with the assessment process that determines their service hours.

Most consumers were satisfied with the quality of training, but some had suggestions for types of additional training needed

PCA consumers were asked if they thought their PCA workers needed more training. Approximately 80 percent said their PCA workers did not need more training. Conversely, approximately 20 percent (n=93) replied that their workers did need more training. Those 93 consumers were then asked a series of questions about the type of training they felt their workers needed. Figure 17 displays their responses. The greatest perceived needs for additional training were in the areas of knowledge about disability, problem-solving skills, and communications skills.

11. Type of additional training suggested for PCA workers

Asked of PCA consumers who reported their PCA worker needed more training, N=93



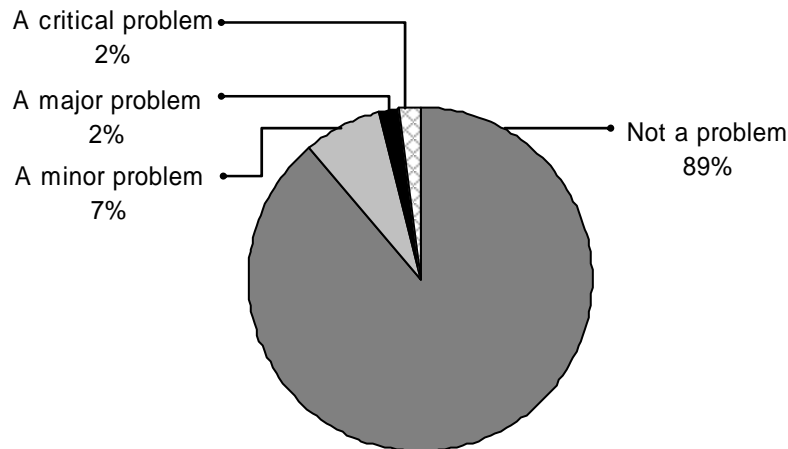
Language differences cause problems for some consumers

As the Minnesota workforce becomes more culturally diverse, there is concern that language differences between the consumers and their PCA workers may lead to communication problems that will adversely affect the quality of care. As Figure 17 above shows, communication skills were one of the more common areas of concern among the minority of consumers who reported a need for more training. As Figure 18 below shows, it appears that communication due to a language difference was not a problem for 89 percent of the PCA consumers surveyed. However, a small minority of 2

percent reported that language differences between themselves and their PCA workers was a critical problem causing a health and safety hazard.

12. Extent to which communication with PCA worker is a problem because of a language difference

Asked of all PCA consumers surveyed, N=455



Consumers expressed mixed preferences for who trains PCA workers

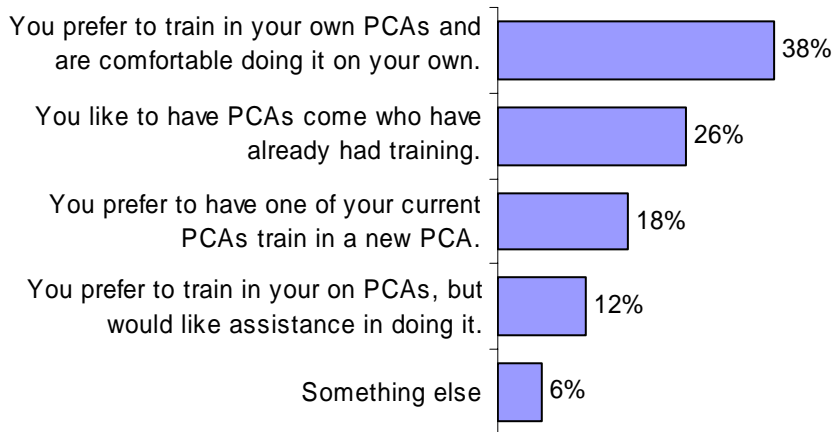
To measure the extent to which consumers prefer to be involved in the training of their PCA workers, they were asked which statement is most true for them:

- You like to have PCAs come who have already had training.
- You prefer to train in your own PCAs and are comfortable doing it on your own.
- You prefer to train in your own PCAs, but would like assistance in doing it.
- You prefer to have one of your current PCAs train in a new PCA.

As shown in Figure 19, only 26 percent of consumers preferred to have their PCA workers come to them already trained. Over one-third (38%) preferred to train their own PCAs and were comfortable doing it on their own. Nearly all the others preferred to have their current PCA train a new PCA (18%), or to train their own PCA workers with some assistance (12%). Open-ended comments about PCA workers suggest that consumers who said they prefer to do their own training may nevertheless expect that PCA workers will already have received training in at least such basic skills as listening to their needs and instructions.

13. Training preference for new PCAs

Asked of all PCA consumers surveyed, N=455

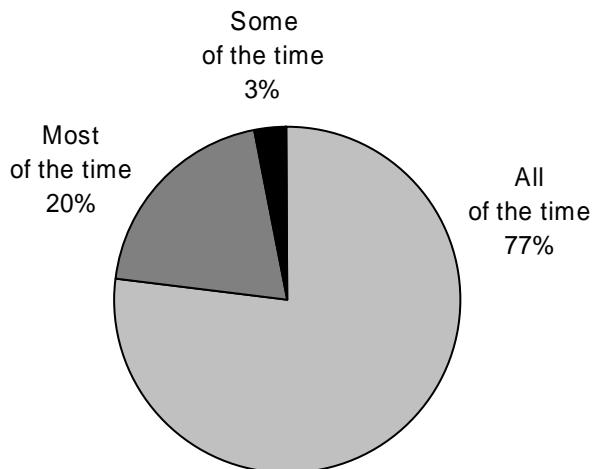


Consumers reported high levels of satisfaction with PCA workers' respect, completion of tasks, and overall quality

When asked if their PCA workers treat them with respect, 78 percent of the surveyed consumers responded that their PCAs treat them with respect “all of the time” and 20 percent said their PCA workers treat them with respect “most of the time.” Figure 20 illustrates the frequency with which consumers said PCA workers treat them with respect.

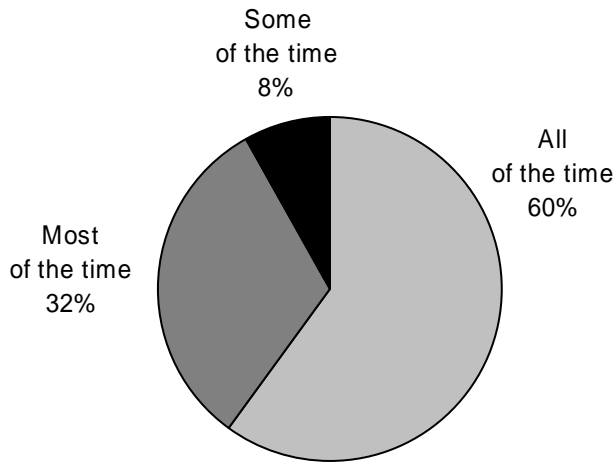
14. The frequency with which PCA workers treat the consumer with respect

Asked of all PCA consumers surveyed, N=455



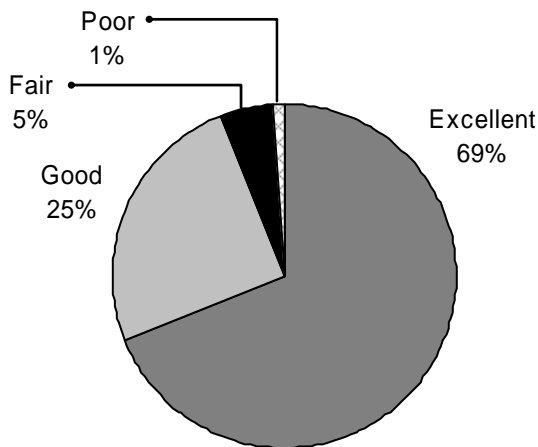
As shown in Figure 21, 60 percent of the consumers interviewed reported that their PCA workers complete the tasks that they want to have done “all of the time” and 32 percent of the consumers interviewed reported that their PCA workers complete assigned tasks “most of the time.”

15. The frequency with which PCA workers complete tasks
Asked of all PCA consumers surveyed, N=455



As shown in Figure 22, nearly all consumers rated the quality of the care provided by their PCA workers as either “excellent” or “good.”

16. Consumer rating of the quality of care provided by PCA worker
Asked of all PCA consumers surveyed, N=455



Over one-third of consumers had family members as PCA workers

Anecdotal evidence in recent years has suggested that there has been an increase in the number of family members providing paid PCA services, and especially in non-parent relatives providing care for minor children. For this reason, the survey asked about the involvement of family members in assisting with the personal care needs of PCA consumers. Survey findings reveal that 39 percent of consumers had family members who are also paid PCA workers, and that among consumers using family members for over half (51%), this family member is their only PCA worker. In addition, it is likely that family members make up a significant share of the individuals who provide personal care that is not paid for by the PCA agency (discussed below in the section on personal care not paid for through the program).

PCA staff turnover was a serious problem for one-quarter of consumers

On average, consumers employed two PCA workers. When we compared the number of PCA workers employed by the consumer with the number of workers who had stopped working for the consumer within the last 12 months, we found that turnover was greater when the consumer employed three or more PCA workers on a regular basis. As shown in Figure 23, 67 percent of the consumers using one PCA worker on a regular basis did not experience any turnover during the past 12 months, whereas 26 percent of the consumers using three or more PCA workers did not experience any turnover. The relationship of “no turnover” with having just one PCA worker on a regular basis may be partly explained by the fact that over half of the consumers with only one PCA worker use a family member for that PCA service.

17. Number of PCA workers who have stopped working within the last 12 months, by the number of PCA workers employed on a regular basis

Asked of all PCA consumers surveyed, N=455

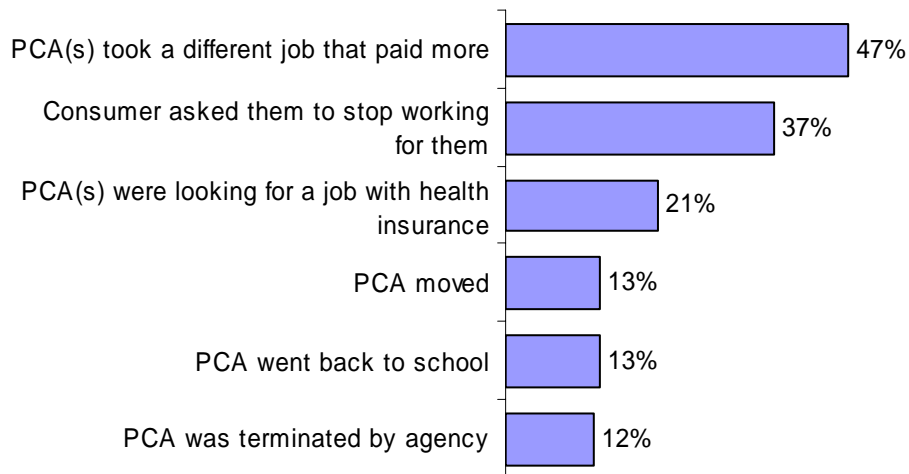
| Number of PCAs who stopped working within the last 12 months | Number of PCAs used on a regular basis | | | Total N=450 |
|--|--|-----------------|----------------------------|----------------|
| | 1 PCA n=223 | 2 PCAs n=115 | 3 or more PCAs n=112 | |
| None (no turnover) | 67% | 43% | 26% | 51% |
| 1 PCA worker stopped working | 15% | 22% | 17% | 17% |
| 2 to 4 PCA workers stopped working | 15% | 24% | 46% | 25% |
| 5+ PCA workers stopped working | 3% | 11% | 11% | 7% |
| Total | 100% | 100% | 100% | 100% |

Note: Total of 450 excludes five consumers who did not know how many PCA workers they used.

Consumers experiencing turnover were asked why their PCA worker or workers stopped working for them. Their responses, as shown in Figure 24, indicate that the majority of the PCA workers quit, to take a higher paying job.

18. Reasons for PCA worker turnover

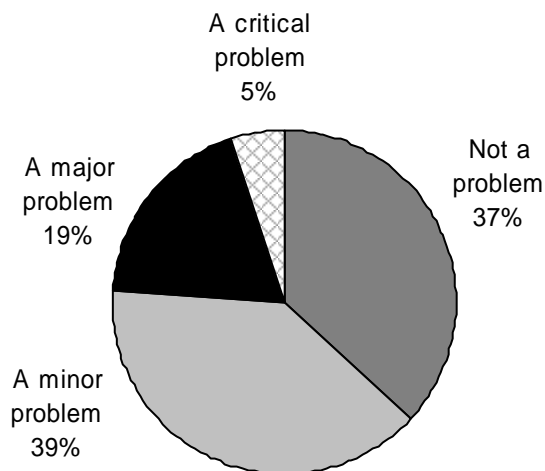
Asked of PCA consumers who experienced PCA turnover during the past 12 months, N=222



Consumers reporting PCA worker turnover within the last 12 months (49%, n=222) were asked to what extent the turnover had been a problem for them. As shown in Figure 25, three-quarters of them reported that turnover had not been a problem for them or had been only a “minor problem, causing some inconvenience.” One-fifth reported turnover as a “major problem, causing major inconvenience.” Of most concern are the 12 consumers, representing 5 percent of those who had experienced PCA worker turnover, who indicated that the turnover had been a “critical problem, causing a health and safety hazard.”

19. Extent to which PCA worker turnover is a problem

Asked of PCA consumers who experienced PCA turnover during the past 12 months, N=222



Turnover was lower in the metro area than in greater Minnesota

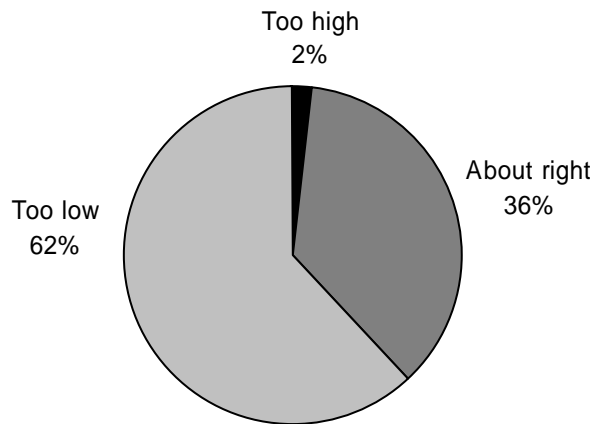
There was a statistically significant difference between PCA turnover rates in the seven-county Twin Cities metropolitan area and in greater Minnesota. Fifty-seven percent of the metro area consumers experienced no turnover during the past 12 months, compared to only 42 percent of the greater Minnesota consumers.

Low PCA wages were a major concern for consumers

PCA wage levels were of concern to consumers, as low wages were reported to be the primary reason PCA workers quit their jobs. Consumers were asked their opinion about PCA workers' wage levels. As shown in Figure 26, a majority of consumers (62%) felt that PCA wages were too low. Another third (36%) reported that they felt the wages were “about right,” and only 2 percent felt that wages were “too high.”

20. PCA consumers' opinions about PCA wage level

Asked of all PCA consumers surveyed, N=455



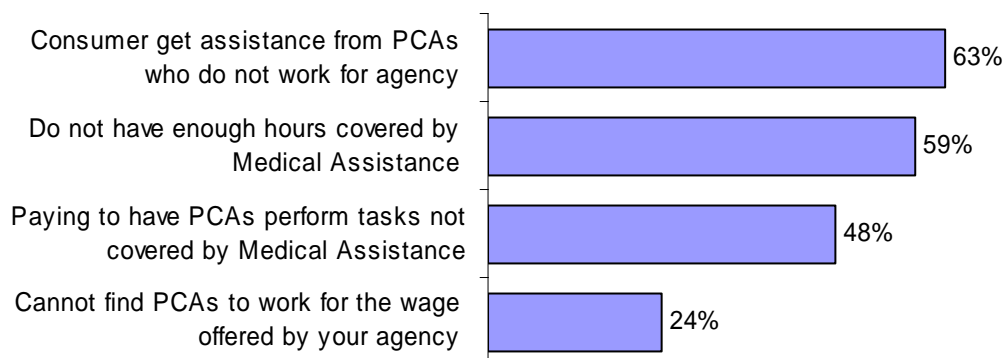
Over half of consumers were receiving personal care not paid for through the PCA program; some were paying for additional care with their own money

Consumers were asked how much of their care was provided by someone who was not paid by the PCA agency. Twenty-nine percent of the consumers reported that “most of their care” was provided by a person, or person(s), who was not paid by the PCA agency; and 35 percent responded that “some of their care” was provided by people not paid by the PCA agency. However, the survey found that 13 percent of consumers reported that they used their own money to pay for additional care. Subtracting these 13 percent from the 64 percent who received some or most of their care from non-program caregivers, we find that at least half of consumers were receiving unpaid personal care.

Reasons given by consumers for paying for additional care with their own money are shown in Figure 27.

21. Reasons why consumers use their own money to pay for additional PCA service

Asked of PCA consumers who use their own money to pay for PCA services, N=59



We considered the hypothesis that consumers with jobs might be more likely to use their own money to pay for additional care. However, the analysis shows no statistically significant association between employment and payment for additional services.

Consumers reported minimal issues with accuracy of time cards

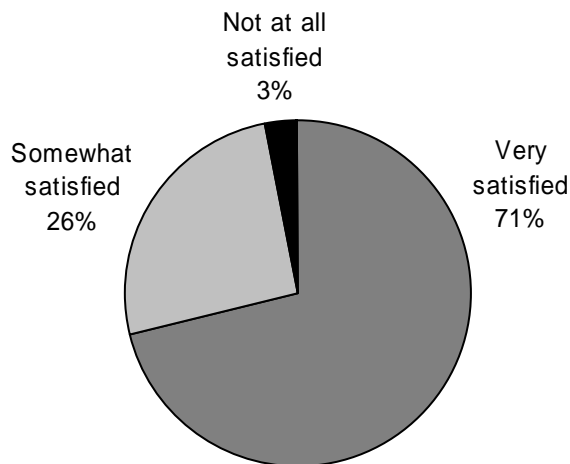
In trying to assess whether accurate reporting on timesheets was an issue warranting further investigation, consumers were asked the following two questions, "Has a PCA ever asked you to sign a blank time card?" and "Has a PCA ever asked you to sign time cards for hours that they did not work?" Only 7% of consumers answered "Yes" to these questions.

Consumers expressed general satisfaction with the PCA assessment

As reported above, some consumers reported that limits in their approved service hours prevented them from using PCA workers at work or when going out. It was also a reason given for why people were paying for additional hours of service. Nevertheless, a large majority (85%) of consumers reported that the "PCA assessment provides a clear picture of their needs". As shown in Figure 28, 71 percent of the PCA consumers are "very satisfied" and 26 percent are "somewhat satisfied" with their last PCA assessment.

22. PCA consumer satisfaction with PCA assessment

Asked of all PCA consumers surveyed, N=455



A majority (69%) of consumers surveyed reported that they received information at their assessment about the choice of having a qualified professional (such as a nurse) supervise their PCA workers. Of those who did not, 41 percent said they would like to receive

information about this option (n=49). This represents 11 percent of all consumers surveyed.

PCA consumers were asked how the assessment process might be improved. Twenty-one percent provided suggestions for improvement. The top suggestions or observations of the consumers offering comments were as follows:

- 17 percent of the consumers offering comments remarked that assessment questions are vague and don't reflect real needs (4% of all consumers surveyed)
- 17 percent said the nurse went too fast and should spend more time with the consumers to do the assessment properly (4% of all consumers surveyed)
- 3 percent suggested not having the assessment done annually, mostly because the situation does not change (3% of all consumers surveyed)
- 8 percent said the assessment is too long, requires too much paperwork every year, and that only differences in consumers' situations need to be noted (2% of all consumers surveyed)

Issues for further consideration

Because worker turnover appears closely related to low PCA wages, it is important to consider increasing the overall funding level for PCA services. Quality of care will be in partly determined by the wages paid to PCA workers. Turnover rates in greater Minnesota are already more than 50% and are causing health and safety concerns for some consumers.

Provider agencies should also consider possible ways to reduce agency administrative costs in order to increase PCA wages. PCA Choice may be a one way to do this.

There needs to be increased efforts to raise consumers' awareness about the extent of their ability to set PCA workers' wages in the PCA Choice program.

Survey results also suggest some need for enhanced training for PCA workers, particularly about specific disabilities of their consumers. Another area expressed by consumers was more effective communication and ability to follow their instructions.

Employment

One topic explored by this survey was the extent to which PCA services are a determining factor in employment. Nationally, 30 percent of persons with disabilities are unemployed. The Center for an Accessible Society has found that persons with disabilities were not included in the economic expansion and increased employment rates of the 1990s, despite policy and program development to promote employment for persons with disabilities.

This section examines the employment rate of PCA consumers of working age, the number of hours worked by employed consumers, the use of and payment for PCA services at work, the relationship between disability type and employment, reasons given by consumers for not working, and enrollment in the Department of Human Services' Medical Assistance for Employed Persons with Disabilities program (MA-EPD) program.

Key findings from this survey related to employment include:

- About one-quarter of the Minnesota PCA consumer population was employed.
- Only a small proportion of employed consumers used PCA services at work (22%).
- While three-quarters of working PCA consumers reported they do not need PCA services at work, other reasons for not using PCA services at work included not enough service hours, not knowing how to set up the service, having coworkers or staff who help them at work, and their PCA worker being unable to get to their workplace.
- Besides the disability itself, the main barriers to employment include:
 - Not being able to find a job
 - Being afraid to lose benefits such as Medical Assistance
 - Not having transportation
 - Not knowing how to receive PCA services at work

The employment rate was low among PCA consumers

In this survey, 331 consumers (or 74 percent of all those surveyed) were age 15 or older and thus potentially of working age. Of these 331 respondents, 24 percent said that they had paid jobs, and 11 percent reported that they had volunteer jobs. Adjusting for the 4 percent who reported having both paid and volunteer jobs, we find that 31 percent of PCA consumers of working age were working, volunteering, or both.

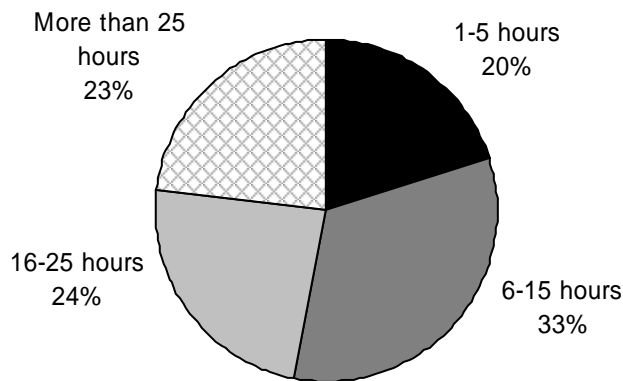
This figure of 24% is below Minnesota's Medical Assistance Disabled population whose unemployment rate is approximately 28%.

Number of hours worked by PCA consumers

PCA consumers who were employed tended to work a variety of schedules, ranging from part-time to full-time. As shown in Figure 11, roughly half (53%) worked 15 hours per week or less, and half (47%) worked 16 hours or more per week. The average number of hours of work among consumers with a paid job was 17 hours per week.

23. Hours per week worked by PCA consumers

Asked of employed PCA consumers with paid jobs, N=80



Most employed consumers did not receive PCA services at work

Of the 103 consumers who had a paid or volunteer job, approximately 22 percent reported that they received PCA service at work. As shown in Figure 12, 41 percent of these consumers reported that their PCA helped for one hour per day at work. Eighteen percent received PCA service for two hours per day, 23 percent received three to four hours of help per day, and the remaining 18 percent received PCA service for five to eight 8 hours per day at work.

24. Hours per day PCA worker helps employed consumer at work (paid or volunteer)

Asked of PCA consumers who use PCA services at work, N=22

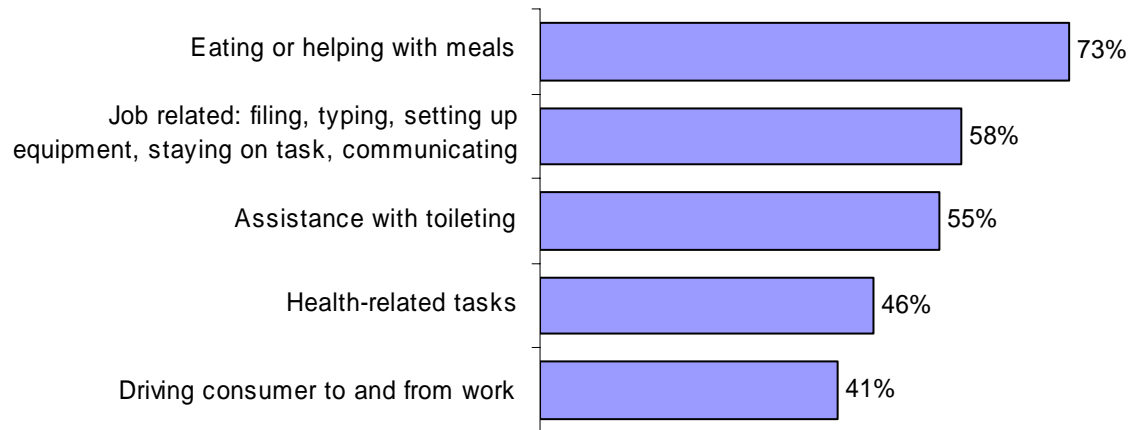
| | Number | Percent |
|--------------|---------------|----------------|
| 1 hour | 9 | 41% |
| 2 hours | 4 | 18% |
| 3 to 4 hours | 5 | 23% |
| 5 to 8 hours | 4 | 18% |
| Total | 22 | 100% |

Note: Percentage may not total 100 percent due to rounding.

The types of assistance provided by PCA workers at consumers' places of employment are shown in Figure 13. The most common type of help was with eating or meals (73%), followed by job-related help (58%) and assistance with toileting (55%). Health-related tasks (46%) and transportation to and from work (41%) were also common.

25. Types of assistance provided by PCA at work (paid or volunteer)

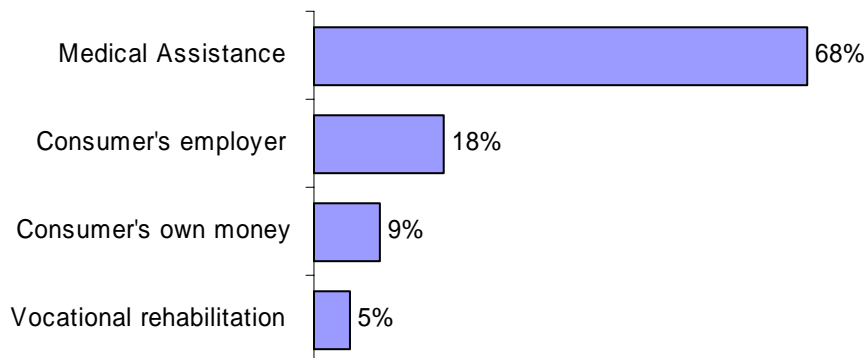
Asked of PCA consumers who use PCA services at work, N=22



Typically, PCA services at work were paid for by Medical Assistance, as shown in Figure 14. The next most common payment source was the consumer's employer.

26. Who pays for PCA services at (paid or volunteer) work?

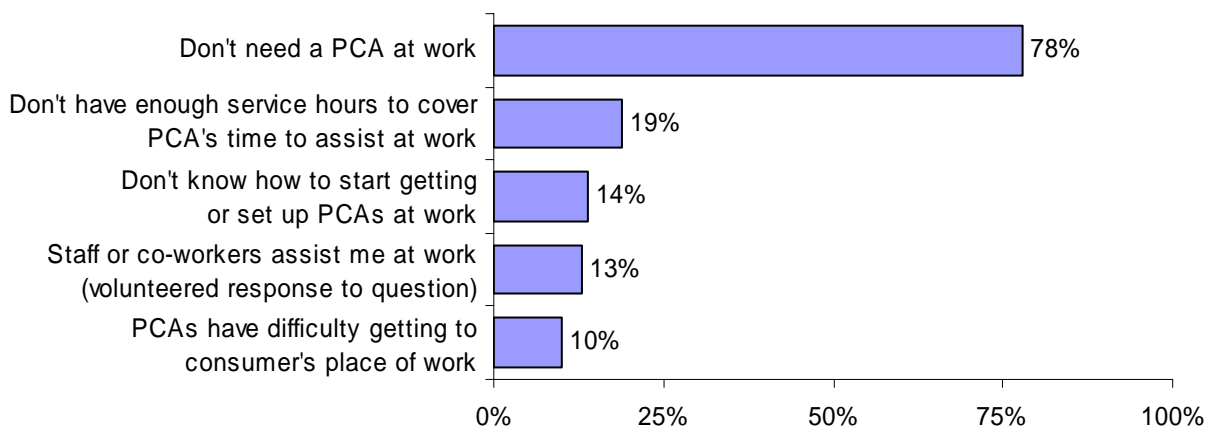
Asked of PCA consumers who use PCA services at (paid or volunteer) work, N=22



Employed consumers who were not using PCA services at work were asked why they did not have PCA service at work. Their responses are displayed in Figure 15. For the most part, PCA consumers (78%) reported that they did not need PCA services at work. However, one out of five employed consumers (n=15) who did not use PCA services at work reported that one reason was that they did not have enough service hours.

27. Reasons consumers do not have PCA service at work

Asked of employed PCA consumers who do not use PCA services at (paid or volunteer) work, N=80



Employment rates varied by type of disability

The type of disability was compared for working and non-working consumers. The top disability categories for employed consumers were:

- Cerebral palsy (24%)
- Spinal cord injury (21%)
- Neurological disability (16%)
- Cognitive or developmental disability (14%)

The top disability categories for unemployed, working age consumers were:

- Physical, visual, or hearing impairments (19%)
- Neurological disability (15%)
- Spinal cord injury (13%)
- Traumatic Brain Injury (10%)
- Mental illness (9%)
- Cerebral Palsy (9%)

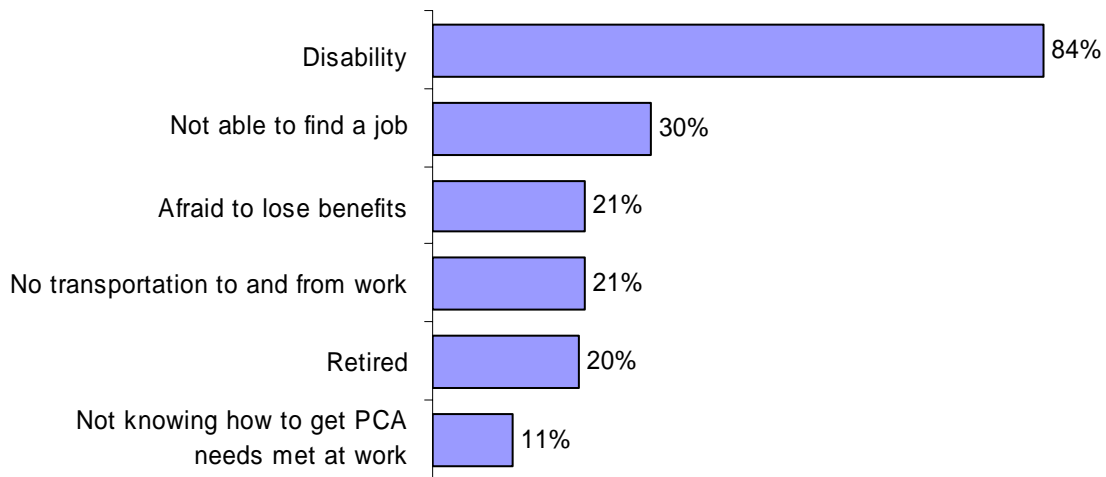
While these results were not tested for statistical significance, the differences show that individuals with cerebral palsy, spinal cord injuries, and cognitive or developmental disabilities were employed in proportions above those in the general population of PCA consumers, while individuals with physical or sensory impairments were less likely to be employed compared to other PCA consumers.

PCA consumers cited a variety of reasons for not working

Approximately 75 percent of the working age consumers in this survey were unemployed. Although disability was cited by the largest number of unemployed consumers as the reason for not working, many consumers also indicated other barriers to becoming employed such as: not being able to find a job, being afraid to lose benefits if they do work, not having transportation to and from work, and not knowing how to have their PCA needs met at work. Consumers' responses are presented in Figure 16.

28. Reasons given by PCA consumers for not working

Asked of unemployed, working-age PCA consumers, N=228



Even though a large majority of consumers cited "their disability" as the main reason they were not working, it is unknown whether they are physically or mentally incapable of working or whether this might be a response based on societal expectations/messages they have internalized about not working.

It is also interesting to note that while nearly half of all consumers surveyed reported that the PCA program enabled (or would enable) them to go to work or volunteer, many (47%) of these consumers nevertheless were not working. Of the unemployed consumers who said the PCA program would enable them to work, 46 percent said that not being able to find a job was a reason they are not working, 31 percent said they were afraid of losing their benefits if they worked, 23 percent said the lack of transportation was a reason they were not working, and 11 percent said not knowing how to set up PCA services at work prevented them from working.

Many consumers were unaware of the Medical Assistance for Employed Persons with Disabilities (MA-EPD) program

The Minnesota Department of Human Services implements a program, Medical Assistance for Employed Persons with Disabilities (MA-EPD), that enables persons with disabilities to work and maintain their Medical Assistance health benefits. Approximately 89 percent (n=294) of the consumers of working age who participated in this survey were not enrolled in MA-EPD. Seventy-four percent of these non-enrolled consumers said they were not familiar with the program.

Issues for further consideration

For many, PCA services are a necessary, but not complete solution to employment barriers. Of those who indicated the PCA program could enable them to work, three of the top reasons for not being employed were: the difficulty of finding a job; fear of losing public benefits, and; difficulty securing reliable transportation.

Employed consumers indicated that limited PCA service hours may restrict their employment, yet most reported high levels of satisfaction with the assessment process through which service hour needs are determined. This confounding result, like that for community involvement, raises questions about consumers' awareness about their role in directing how PCA service hours may be used, and whether or not the assessment process fully captures employed consumers' needs for assistance at work.

Furthermore, relatively few consumers were familiar with the MA-EPD program, which would allow them to maintain their Medical Assistance benefits if they became employed.

Thus, it appears that enhancing job training and job placement assistance for PCA consumers (to help them find jobs), more effectively informing them about the MA-EPD program (to help them keep their benefits), and assisting with transportation arrangements could improve employment prospects for a substantial number of PCA consumers. Some of these issues may go beyond the scope of the PCA program, but they form a holistic picture from the consumer's viewpoint.

PCA program options and implementation

This section examines the PCA provider options (the traditional agency-based model and PCA Choice) and the way in which consumers use and communicate with the program. It compares responses from consumers in the two different programs in four areas: 1) how they learn about program options and PCA agencies; 2) their reasons for choosing their type of provider and individual agency; 3) their ability to find and schedule PCA workers when needed, and 4) their satisfaction with their current agency. It discusses traditional agency consumers' responses about their current participation and interest in hiring, training, and scheduling PCA workers. (This was not asked of PCA Choice consumers since they are required to do these tasks) Finally, it presents findings about consumers' preferences for methods of communication with the PCA program.

Key findings related to the design and implementation of the PCA program include:

- Consumers expressed high levels of interest in choosing and scheduling their own PCA workers.
- Many consumers were taking an active role in hiring, scheduling, and training whether or not they are in PCA Choice, the consumer-directed option.
- Fewer consumers outside of the seven-county Twin Cities metropolitan area were enrolled in PCA Choice compared to those in the metro area.
- Consumers expressed a preference for in-person response to complaints.
- There appears to be limited potential for Internet communication, based on the consumers' preferences and limited access to the Internet.

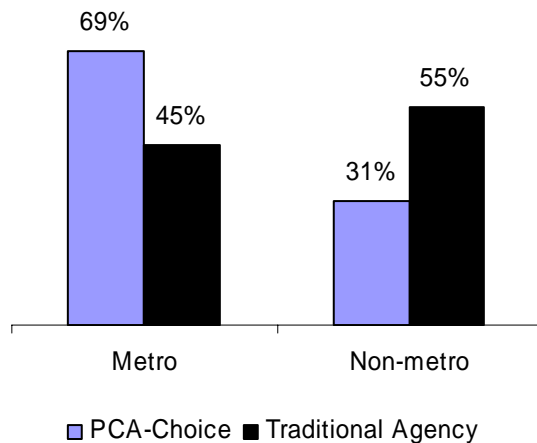
Use of traditional PCA agencies or PCA Choice

The random sample of PCA consumers interviewed for this study included 328 consumers using traditional model agencies and 127 consumers enrolled in PCA Choice, the consumer directed PCA option which began in 2000. This indicates a significant increase in the number of consumers participating in PCA Choice from three years ago when only approximately 2% of consumers were enrolled in PCA Choice.

As Figure 29 shows, over two-thirds (69%) of PCA Choice consumers were located in the metro area, and only 31 percent were located in greater Minnesota. This regional difference was statistically significant.

29. Enrollment in traditional program and PCA Choice, by region

Asked of all PCA consumers surveyed, N=455



Consumers of traditional PCA agency services were also asked a series of questions related to their interest and satisfaction with being involved in the hiring, training, and scheduling of their PCA workers.

Differences between traditional agency consumers and PCA Choice agency consumers

How consumers learned about program options and agencies

Public health nurses appear to play a major role in referring consumers to the PCA Choice program. Approximately 46 percent of the PCA Choice consumers learned of the PCA Choice option through their public health nurse. However, when locating an agency, PCA Choice consumers most often found their current agency through their county worker (28%). Other main ways of finding agencies were through a friend (23%) and through their public health nurse (20%).

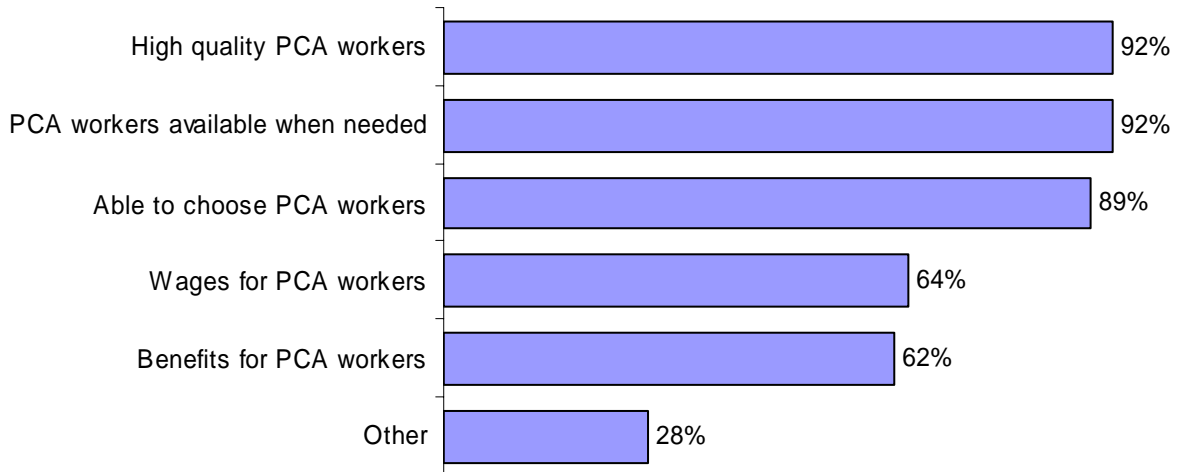
Traditional PCA agency consumers used the same three main sources to locate their current agency, and in the same order of frequency (33% through a county worker, 14% through a friend, and 14% through their public health nurse).

Reasons for choosing a traditional agency or PCA Choice option

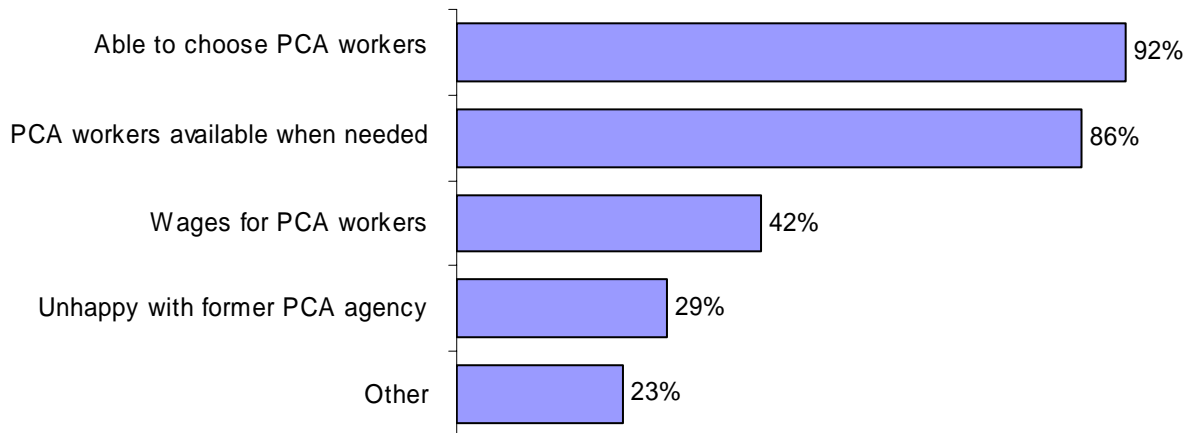
As shown in Figures 30 through 32, the top reasons consumers cited for choosing a traditional agency and for choosing using the PCA Choice option were the same: being able to choose their PCA workers (Traditional: 89%; PCA Choice: 92%) and being able to schedule PCA workers when needed (Traditional: 92%; PCA Choice: 86%). These results seem rather surprising considering that traditional providers are responsible for hiring and scheduling PCA workers. This seems to indicate that they are involving consumers in that process.

Consumers using traditional agencies also cited high quality staff as another reason for choosing their current agency (92%). Surprisingly, paying higher wages for PCA workers was not a significant reason for choosing the PCA Choice option (42%), but wages (64%) and benefits (62%) for PCA workers did appear to be a factor in the decision to select a traditional agency

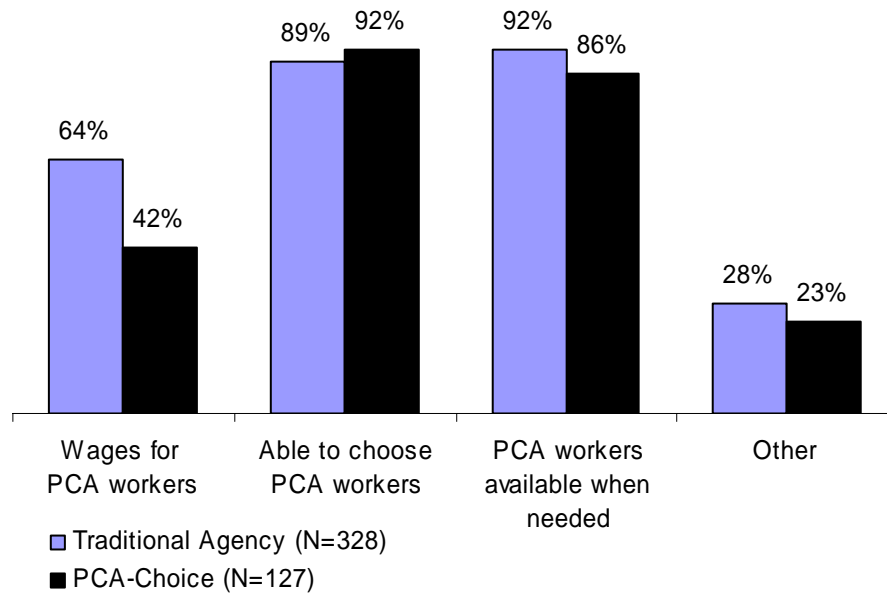
30. Reasons for choosing a traditional PCA agency
Asked of PCA consumers in traditional agencies, N=328



31. Reasons for choosing the PCA Choice option
Asked of PCA consumers enrolled in PCA Choice, N=127

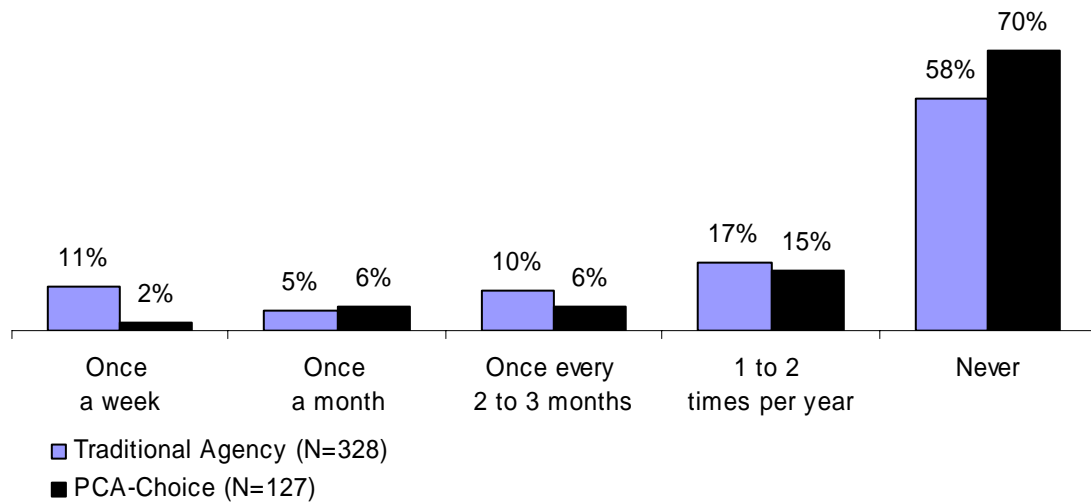


32. Traditional agency and PCA Choice consumers: comparison of reasons for selecting traditional agency or the PCA Choice option



Ability to schedule PCA workers when needed was a primary reason given by many consumers for choosing either a traditional or PCA Choice agency. As shown in Figure 33, 70 percent of the consumers using the PCA Choice option reported that they “never” had trouble finding PCA staff, whereas 58 percent of the consumers using a traditional agency reported that the agency “never” had trouble finding staff. The main reasons cited by consumers using traditional agencies for difficulty in finding staff were “the wages are too low” (30%) and “the agency has too few staff” (22%). The main reasons cited by consumers using PCA Choice for difficulty in finding PCA workers were “the hours you need PCAs to work” (32%) and “The wages for PCAs are too low” (22%).

33. How often traditional agencies or PCA Choice consumers have trouble finding PCA workers



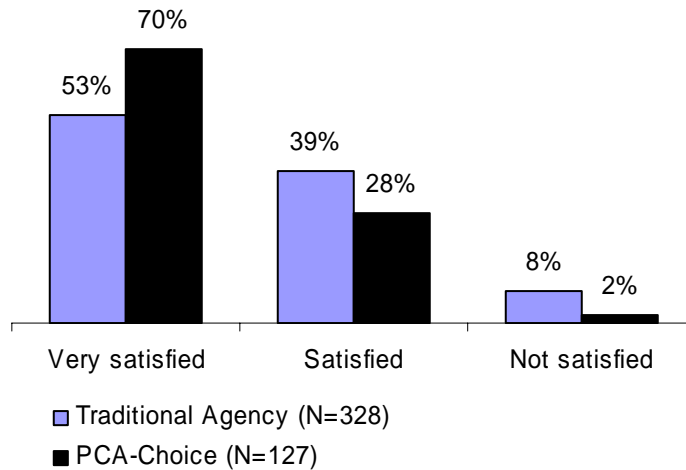
Consumer satisfaction with PCA agency

Consumers using traditional agencies and consumers using PCA Choice similarly report that agencies treat them with respect “all of the time” (Traditional: 75%; Choice: 77%) or “most of the time” (Traditional: 18%; Choice: 21%).

Consumers in the PCA Choice option reported slightly higher levels of satisfaction with their current agency, as shown in Figure 34.³ Ninety-two percent of the consumers using traditional agencies reported being “very satisfied” or “satisfied” with their current agency (very satisfied: 53% satisfied: 39%). Ninety-eight percent of the consumers enrolled in the PCA Choice option reported being “very satisfied” or “satisfied” with their current agency (very satisfied: 70%; satisfied: 28%). When asked if they would recommend their current agency to others, 89 percent of the traditional agencies consumers said “yes” and 90 percent of the PCA Choice consumers said “yes” they would recommend their agency to others. The reasons why consumers would recommend or not recommend their current agency are included in the Appendix.

³ Satisfaction scales differed slightly for traditional agency and PCA Choice agencies. For traditional agencies, satisfaction was measured using a four-point scale: “very satisfied,” “satisfied,” “dissatisfied,” and “very dissatisfied.” For PCA Choice, a three-point scale was used: “very satisfied,” “somewhat satisfied,” and “not at all satisfied.” For comparison, “very satisfied” and “satisfied” are compared with “very satisfied” and “somewhat satisfied,” and “dissatisfied” and “very dissatisfied” are compared with “not at all satisfied.”

34. Consumer satisfaction with agency



Consumers using traditional agencies: interest in and satisfaction with hiring, training, and scheduling PCA workers

Consumers who were using traditional agencies were asked about their interests in recruiting, hiring, training and scheduling PCAs to assess interest in more consumer directed services.

Most were at least somewhat interested in recruiting PCA workers

For consumers using traditional PCA agencies, the interest in finding their own workers was fairly evenly distributed between “very interested,” “somewhat interested,” and “not at all interested”: 40 percent said they were “very interested” in finding their own workers, 30 percent said they were “somewhat interested,” and 30 percent said they were “not at all interested” in finding their own PCA workers.

Most had been involved in interviewing PCA workers, and more were interested in doing so

A majority of the traditional PCA consumers (66%) said they had interviewed their PCA workers before they began working. Nearly all (95%) of those who had interviewed PCA workers said they did so because they wanted to.

Overall, there was 16% of traditional agency consumers surveyed that were either “very interested” or “somewhat interested” in interviewing their workers, that had never been involved with interviewing.

Most had been involved in scheduling PCA workers

Most traditional PCA consumers (73%) had been involved in scheduling their PCA workers. Of these, most (85%) said it was because they wanted to be. Similar to their interest in interviewing PCA workers, some (9%) of those consumers who were “very interested” in scheduling their PCA workers had never been involved with scheduling.

Most had provided information for the PCA worker’s job evaluation

A majority (65%) of these traditional PCA consumers said they had provided PCA worker job performance information to their PCA agency. However, 18 percent of these consumers surveyed are either “very interested” or “somewhat interested” in providing their PCA agency with information for their PCA workers’ job evaluations, but had not ever done so.

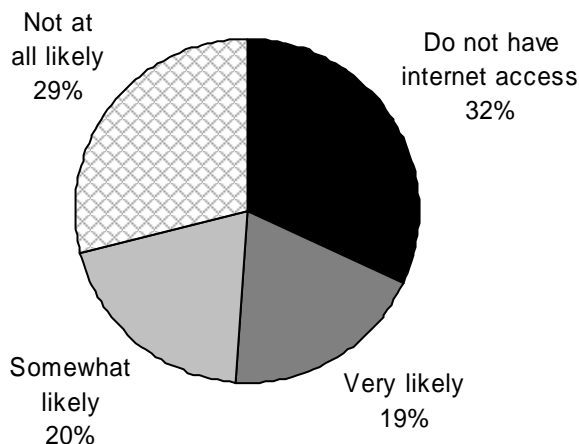
Communicating with the PCA program

Most PCA consumers are unlikely or unable to use the Internet to obtain information about the PCA program

Consumers were asked about the likelihood that they would use the Internet to obtain information about the PCA program. As shown in Figure 35 below, 39 percent were either “very likely” or “somewhat likely” to use the Internet. However, 32 percent reported that they did not have Internet access. Combining those consumers lacking Internet access with those who said they were not likely to use the Internet to obtain program information, a total of 61 percent of consumers did not see the Internet as an option for obtaining program information.

35. Likelihood that consumer would use the Internet to get information about the PCA program

Asked of all PCA consumers surveyed, N=455



Consumers preferred to communicate complaints in person

Only 8 percent of consumers reported that they had ever filed a complaint about their PCA services. Consumers who had filed a complaint had most often done so with their PCA agency. Sixty-one percent of the consumers who had filed complaints reported that they were either “very satisfied” or “somewhat satisfied” with the outcome of the complaint. The preferred method of communicating a complaint (60%) was to speak to someone in person. When asked for suggestions for improving the system for filing a complaint, 6 percent of consumers replied that they would like to have more information on how to file, and 4 percent said that quick follow-up would improve the system.

Issues for further consideration

More consumers are taking control over hiring, scheduling, and training. There remain a number of consumers who have not had the opportunity to take control, but expressed an interest in doing so. Findings suggest that providing consumers with support in these activities, encouraging agencies to allow consumers to have more control if they desire, and expanding access to a pool of qualified PCA workers that consumers can call upon may warrant further consideration.

Despite consumers’ high interest in having more control over hiring, scheduling, and training, only about one-third of consumers are enrolled in PCA Choice. Moreover, a significant portion of PCA Choice consumers reside in the Twin Cities metropolitan area. These findings suggest that targeting education and outreach about the PCA Choice option to consumers in greater Minnesota may further expand the number of PCA Choice consumers in greater Minnesota. This could, in turn, help to address worker shortage issues in greater Minnesota..

Also related to program design and implementation are preferred methods of communication. Internet communication appears to be a limited option for PCA consumers to learn about the program. Consumers’ responses suggest that reliance on Internet-based communication with PCA consumers would not be effective for many consumers. Consumers also expressed preference for in-person responses to complaints, suggesting the need for a PCA ombudsman who could provide one-on-one assistance to consumers experiencing problems with their PCA services.

This report and a printable PDF Executive Summary are available on DHS’s website under "Publications and Reports" at:

http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/DHS_id_003516.hcsp

Appendix

Open Ended Responses

A-1. The ONE thing consumers like best about their PCA services

A-2. The ONE thing consumers would change about their PCA services

A-1. The ONE thing consumers like best about their PCA services

| Themes | Examples of typical responses | Number of responses | Percentage (Base=444) |
|----------------------|--|---------------------|------------------------|
| PCA worker or agency | <p>That everything I want done gets done and it's done in such a way that it doesn't interrupt anything else I want to do.</p> <p>There are a couple of PCAs that really are great. There are different ones with different backgrounds and I learn a lot from them. I think I teach them some things, too.</p> <p>The agency and the PCAs do a good job. They work with me on my goals.</p> <p>I know she [the consumer] is going to get individual care and I think [the care] is good and reliable.</p> <p>I am a mother of several children. [The consumer] is a disabled child. With the PCA coming to the house to take care of him, it really helps me a lot. He likes the PCA coming to help him with things like taking a bath and to read to him. He really likes spending time with him.</p> <p>I wouldn't trade the nurse that comes to visit us once a month. She takes the time to stay with me to talk with me so I have someone to talk to for me. She cares to hear about how I am feeling, how I can't get sleep, and a grown up to talk to. I have another son who uses PCA services so it' really a resource for me.</p> <p>Their reliability and professionalism, an agency that is reliable.</p> <p>I have been able to trust them and rely on them to come when they are scheduled, and to know that [the consumer] is being taken care of while [I am] at work.</p> <p>Just knowing that they are going to show up is good. When you have been around them long enough, you don't have to tell them what to do, they just do it. It gives me peace of mind to know they will be here and will be competent at what they do.</p> <p>The PCA workers have always been respectful to him and they are kind and compassionate.</p> <p>PCA worker listens and communicates very well with me.</p> | 213 | 48% |

| Themes | Examples of typical responses | Number of responses | Percentage (Base=444) |
|-----------------|--|---------------------|------------------------|
| Quality of life | <p>They [PCA workers] enable me to get my life back.</p> <p>It [the program] enables me to be able to work and make somewhat of a living. Otherwise, I wouldn't be able to do my job.</p> <p>The [PCA workers] are helping him make choices in his life and helping him to move on in his life.</p> <p>It increases her quality of life; makes it easier on her parents. The PCA program helps in our whole family's quality of life as well.</p> <p>It is a service that has allowed him to be in control of his own care, to get out into the community, educate others, be in control of personal hygiene, allowed him to be independent, allowed mom and dad to work, and reduced stress. It has allowed mom and dad to be a family.</p> <p>I am stressed out working two jobs. I know that they are getting her [wife] up, that she is fed, that she is cared for, that her clothes are cared for. I know I don't have to worry about these things.</p> <p>Independence-it's all about living on your own.</p> <p>What I like...it [the PCA program] gives him a chance to get out in the community a little more. It gives him the opportunity to get out and do things that I may not have time to do because I don't have time or am tired. His PCA takes him out and does a lot of different things. They visit a lot of different places and she teaches him a many different skills.</p> <p>It allows me time to relax a little bit. If I had to do all the things my PCA helps me with, I would be greatly stressed, to say the least - raising kids, going to school concerts, going shopping, etc. The PCA is like a lean-to shelter that enables me to do the things I do on a very modest income level. It enables me to survive. They are an essential part of the make-up that enables me to care for myself and to care for my children. They are a support system for low income survival.</p> <p>It allows me to live a better live and allows me to live an enjoyable life, and to do things that I want to do.</p> <p>The exposure she has with other people, the fact that she can feel like a "normal" student in school. They are very good about helping her feel normal.</p> <p>Whenever a PCA worker comes to watch her is the only time we can do things. She needs 24 hour assistance and supervision. Without [PCA service] we wouldn't get a break.</p> | 166 | 37% |
| Choice and | The flexibility of hiring people you know or interviewing | 53 | 12% |

| Themes | Examples of typical responses | Number of responses | Percentage (Base=444) |
|----------------------------|---|----------------------------|-------------------------------|
| availability of PCA worker | <p>and hiring people you have interviewed yourself and paying them adequate wages.</p> <p>The flexible hours; the flexibility of PCA Choice.</p> <p>The flexibility. The options that you get now, that I can hire who I want to hire. And, basically, I am just thankful that they have the PCA services, so she can stay home. (she likes) From her it is just the contact with people. She signs things like "me happy friend". And the ones that she has had the longest love her to death, and she loves them to death. She waits and watches for them to come, and she wants to know who is coming.</p> <p>That I'm in charge.</p> <p>That I can hire my own people.</p> <p>That I can choose the person who is going to provide the service.</p> | | |
| Other-Nothing | <p>That I don't have to pay for them [PCA workers].</p> <p>I like everything equally.</p> <p>Nothing.</p> | 12 | 3% |

A-2. The ONE thing consumers would change about their PCA services

| Themes | Examples of typical responses | Number of responses | Percentage (Base=454) |
|--|--|----------------------------|------------------------------|
| <p>PCA wages, training, and recruiting</p> | <p>I'd give them better wages because it is an important job (80 of the 164 comments related to PCA workers were about increasing their wages and/or providing health insurance benefits).</p> <p>Wage increases for cost of living for my PCAs. It seems like now it is a set wage that doesn't change until the government chooses to change it, which might be a year or two or more down the road.</p> <p>The pay rate. Getting and retaining qualified people, you need to pay them a decent wage. In some cases they need a great deal of medical knowledge and also need people skills.</p> <p>Improve their [PCA workers'] salary, because they are really working hard.</p> <p>In the last couple of years there has a movement toward self-directed care options, and the amount of money that was going to administrative costs was too high and taking away from what the PCA could be paid and wasn't helping the families get the care they need. The choice option is the way to go, [but] change the agencies. It is hard to find potential workers though, if something could be done to help parents find workers that are experienced/qualified/certified, and are all on a list or something we could get a hold of, without going through an agency, another method to find people easier, and we could pay a lot more [than the agencies] and make those people [PCA workers] much happier.</p> <p>To be able to eliminate the control of the agency over the PCAs in terms of pay. The agencies make more money than the PCAs who do all the work.</p> <p>If they paid PCAs more, it would be easy to find PCAs.</p> <p>We would like a greater pool of people who would work for us. If we had a place to call to find more workers. We are having a hard time finding people either trained or untrained to be her PCA.</p> <p>I would like better training for the PCA and better understanding about the disability.</p> <p>The training! That they could be trained about the specific disability their clients have. Autism and down syndrome are two different disabilities and can't be treated the same.</p> <p>There is a place where I'd love to hire PCAs, they</p> | <p>164</p> | <p>36%</p> |

| Themes | Examples of typical responses | Number of responses | Percentage (Base=454) |
|---------------------|---|---------------------|-----------------------|
| | <p>work with gentle teaching methods, that they'd train them in for six months, if I had the money I pay for that for him but it is \$16.00 and hour and I am very low income. The PCA service is a glorified babysitting service. Part of the problem is my inability to supervise, and my PCAs don't do the things I think they should do for client. There is no training ground, no training money; training should be taken care of with much more emphasis.</p> <p>That they [PCA workers] could provide transportation for swimming lessons, therapies outside the home, community involvement.</p> | | |
| Nothing, okay as is | <p>I wouldn't really want to change anything.</p> <p>I can't think of anything, no complaints.</p> <p>Nothing that I can think of.</p> | 115 | 25% |
| Assessment | <p>The public nurse assessment process. We've been trying to have him re-assessed since September and they haven't gotten back to us. The agency just put in another request.</p> <p>That I had more PCA paid hours (48 of the 54 comments on assessment were related to needing more hours).</p> <p>The way that they assess. The needs for the amount of time given in order to have a PCA in. Maybe come up with additional ways other than just filling out a standard questionnaire, like if there are people they can interview other than the PCA as the main caregiver. Add that into their input, along with what they [Public Health Nurse] see themselves.</p> | 54 | 12% |
| PCA agency | <p>Better communication with the agency regarding staffing.</p> <p>Always have someone as a backup. If one person can't come then another can come to care for [the consumer].</p> <p>That there would be more people willing to work in pediatric care so we would have back-ups for our PCA.</p> <p>The burden of the weekly time sheets and paper when things never change. It is so repetitious.</p> <p>The paperwork could be more user-friendly.</p> <p>Continuity of workers.</p> <p>To have assistance on weekends.</p> | 47 | 10% |

| Themes | Examples of typical responses | Number of responses | Percentage (Base=454) |
|---------------|--|----------------------------|------------------------------|
| More choices | I would have to say [the one thing I would change] would be hiring my own PCA instead of the agency doing it for me. Because some of the PCAs that they have put on my doorstep have not been good ones. I would like to feel that I have more control over it, since I am capable of doing it, of hiring my own PCAs. | 5 | 1% |
| Other | The funding source! There are so many co-pays right now. Awareness [in] society as to what a PCA should be. I think a lot of people don't know what a PCA is. That I wouldn't have to change companies because of insurance. I would make it a family service.... It would be good to look at families as a whole. I would like to have a home rather than an apartment. | 22 | 5% |
| Don't know | I don't know. I have nothing to say. | 47 | 10% |