



Recommendations for Minnesota's Personal Care Assistance Program From Focus Groups of PCA Consumers and PCAs

Interim Report #2

Prepared for: Minnesota Department of Human Services, Disability Services Division

Submitted by: The Lewin Group and the University of Minnesota's Institute on Community Integration

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Table of Contents

I. OVERVIEW OF THE PROJECT/INTRODUCTION.....	1
II. METHODS	2
A. Focus Group Participant Sampling Strategies.....	2
B. Approval for Study from Institutional Review Boards at the University of Minnesota and the Minnesota Department of Human Services	3
C. Participant Recruitment.....	3
D. Focus Group Facilitator Guides and Questions	4
E. Conducting Focus Groups of PCA Recipients and PCAs	6
III. DATA ANALYSIS	7
IV. RESULTS	8
A. Focus Group Participants.....	8
B. Key Findings	10
V. PRELIMINARY RECOMMENDATIONS AND OPPORTUNITIES FOR ACTION	23

APPENDICES

- Appendix A: Focus Groups
- Appendix B: Sample Focus Group Flyers
- Appendix C: Moderator Guides

I. Overview of the Project/Introduction

The Minnesota Department of Human Services (DHS), Disability Services Division contracted with The Lewin Group (Lewin) to conduct a study of the infrastructure of the State's Medicaid State Plan Personal Care Assistance (PCA) program. This study analyzes the drivers of Medical Assistance expenditures in the State's PCA program and provides recommendations to inform legislation to strengthen the PCA program. While the study focuses primarily on PCA State Plan services, important considerations include how other Medical Assistance Programs (e.g., home and community-based waiver programs) provide PCA services, and the interaction between those program requirements and the PCA State Plan program.

This report is the second of several interim reports that Lewin will submit to DHS, in addition to a comprehensive final report. This second report includes findings from a series of 14 focus groups, conducted by the University of Minnesota's Institute on Community Integration (U of M), with recipients of PCA services and PCA workers in a variety of Minnesota Medical Assistance programs offering PCA services. The purpose of conducting these focus groups was to hear from workers about their experiences providing PCA services, and from service recipients about their experiences receiving PCA services. This report provides:

- a description of the methodology used to obtain this data (through the focus groups);
- findings from several topical areas such as services delivered/received, quality of services, wages/benefits, education/training, and family members as PCA workers;
- a summary of focus group participants' recommended key changes to improve the Minnesota PCA program; and
- interim recommendations to improve and strengthen Minnesota's PCA program.

The first interim report focused on a national scan of PCA programs, analysis of Minnesota PCA program enrollment and expenditure data, findings from interviews with state officials in Minnesota and other states with PCA programs, stakeholder interviews, and preliminary recommendations for the State. The remaining interim report will focus on:

- information on provider agency perspectives and related recommendations to strengthen and improve provider-related components of the program, and
- analyses of the types of living arrangements in which individuals receive PCA services and recommendations surrounding the provision of PCA services in those arrangements.

The final report will synthesize the analyses of the several interim reports and make additional recommendations to strengthen and improve Minnesota's PCA program.

II. Methods

A. Focus Group Participant Sampling Strategies

The initial sampling methodology, developed in collaboration with the Disability Services Division, included conducting a total of 10 focus groups (six Personal Care Attendant (PCA) consumer focus groups and four PCA worker groups) with a projected total of approximately 80 participants. When completed, however, a total of 14 focus groups (eight PCA recipient and six worker focus groups) were held. This increase in the number of focus groups from what was originally planned was designed to enable us to reach our target of 80 participants, despite the low attendance at the initial two focus groups¹. Appendix A provides a list of focus groups held, their location, and attendance.

To be reflective of the diversity of the PCA program, the focus groups were held in rural, urban, and suburban areas throughout Minnesota. In designing the focus groups, emphasis was also given to ensuring that individuals selected for participation would represent a diverse population (e.g., race/ethnicity, gender, age, working status, urban/rural, and disability sector) and the wide variety of living arrangements experienced by recipients of PCA services (e.g., shared housing, congregate housing, provider-owned housing, corporate foster care).

It was also important to include individuals who access PCA services through the various program options offered in the Medical Assistance Program (e.g., managed care, fee for service, waiver, and PCA Choice) so that experiences shared by participants reflected the wide range of PCA service options in Minnesota.

Additionally, the PCA program serves people with varied types of health and human service needs. Thus, it was important to ensure that focus group participants included people with intellectual/developmental disabilities, mental health issues, physical disabilities and people who had needs due to aging.

Consumer focus groups included both individuals with disabilities who receive services and parents/family members who are the legal representatives of children and adults who receive PCA services. Including parents and family members was particularly important to ensure that our analysis also reflected the perspectives and experiences surrounding the delivery of PCA services in Minnesota to children with special health care needs, and children with intellectual and developmental disabilities. While the children are the service recipients, their legal representatives (which may include parents, guardians, and other family members) are those who guide and direct the work of the PCA.

The focus group participants represented various service type, demographic and rural/urban perspectives. However, it is important that the reader understand that the sampling methods used enables us to report general findings about the entire focus group population and not specific findings about specific groups/types of PCA users and workers. Findings presented in this report represent that various perspectives of all participants; comparisons between specific

¹ The low attendance is likely explained by reduced recruitment time resulting from delayed Institutional Review Board approvals as well as winter weather conditions.

types of participants are not made due to the methods used in gathering information and the small sample size.

B. Approval for Study from Institutional Review Boards at the University of Minnesota and the Minnesota Department of Human Services

The purpose of Institutional Review Boards (IRBs) is to ensure that research is conducted in an ethical manner, that the proper consent is provided by research subjects, and that the confidentiality and privacy of information pertaining to research subjects is maintained. As a result, collecting data from focus group participants required that we receive IRB approval. Due to the fact that two entities were involved in this project, approval from both the University of Minnesota and the Minnesota Department of Human Services (DHS) Institutional Review Boards was needed.

Consent forms, moderator guides for the focus groups, and the U of M and DHS IRB applications were reviewed by project staff and DHS, and then submitted for approval by both the U of M and MN DHS IRBs. The University of Minnesota IRB requested several changes to the consent forms and other documents as well as to the process for recruiting potential focus group participants. However, the key change requested by the U of M IRB was that the initial contact with or information about the PCA Project needed to come from the University of Minnesota (instead of from a provider organization as proposed). This modification necessitated that an employer or service provider make initial contact with potential focus group participants and encourage them to contact the organizers of the focus groups at the U of MN to obtain information about the focus groups. This made recruitment of participants more challenging as the organizers had to wait until an interested potential participant contacted them for information about the focus groups. The primary change requested by the DHS IRB was that the amount of compensation for a participant be reduced from \$30 per 90-minute focus group to \$25. The U of M response was to use \$25 gift cards instead of \$30 gift cards. Final approval for both IRBs was obtained in late December 2008.

The methods approved by both IRBs required that data transcripts remain confidential and only be available to the researchers at U of M. In addition, they required that data collected be stripped of any identifying information. As a result, demographic data was collected prior to the focus groups and transcript recordings did not occur until after participants identified themselves during the introductory session of the focus group. This data privacy promise makes it impossible to connect demographic and service type information to specific statements made by participants when analyzing the data. Thus, it is impossible to compare participants' perspectives based on demographic information and service type.

C. Participant Recruitment

A variety of strategies were used to recruit participants including: calls to providers and consumers based on lists provided by DHS, networking through the Consortium of Citizens with Disabilities (CCD) members to identify potential consumer and worker participants, and direct contact with county service coordinators/case managers to identify potential participants.

Recruitment success was due in part to the creativity, patience, and persistence of many PCA provider organizations. These provider organizations used a variety of approaches to assist U of M staff in identifying potential focus group participants, including:

- Inserting PCA project flyers in newsletters for recipients and in paychecks for PCAs;
- Distributing the flyer in a post card format to encourage participation;
- Sending a letter or an e-mail with an attached PCA project flyer;
- Posting the study flyer on the agency bulletin board; and
- Asking PCAs to distribute the flyer to the persons they support.

Samples of the flyers used are included in Appendix B.

Study participants were given a \$25.00 gift card for participating in the study. Information about this incentive was included in the recruitment materials. In addition, participants were reimbursed for mileage and any accommodations they needed to ensure their participation.

D. Focus Group Facilitator Guides and Questions

The University of Minnesota staff conducting the focus groups used Moderator Guides designed specifically for each type of focus group (e.g., PCA worker and PCA recipient). These guides, which included an overview, purpose of the focus group, and instructions for facilitating each type of focus group, were developed to ensure consistency in approach and design. The Moderator Guides are included in Appendix C.

Project staff and DHS identified several topics for the focus group discussions (*Exhibit 1*). The questions, prompts, and follow up questions were designed to yield important information about participants' experiences, thoughts, feelings, and ideas about the strengths, challenges, and areas for improving the PCA program in Minnesota.

Exhibit 1. Focus Group Topics/Questions

PCA Recipient Focus Groups

TOPIC Area 1: Quality of Services

1. What do you use your PCA for? How does she or he assist and support you in your life? **Prompts:** Think about: In what areas of your life does your PCA provide you with support? Where are you when they provide you with support? How do they assist you in living your life to the fullest? What works? What are the challenges? **Follow Up:** *What suggestions do you have for improving PCA services available through Minnesota's PCA programs so that they are the most useful to you?*
 2. What are your thoughts or ideas about what and how much choice and control you have about the PCA services you receive? **Prompts:** Think about: What does choice mean to you? What does control mean to you? What is really important to you about the type and amount of control you want in your life related to the PCA services you need? **Follow Up:** *What suggestions do you have for improving the type and level of choice and control persons have for the PCA services available through Minnesota's PCA programs?*
 3. Tell us about how the PCA services you receive help to keep you safe and healthy? **Prompts:** Think about: What does being healthy and safe mean to you? In what ways do your PCAs support you in
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PCA Recipient Focus Groups

being healthy and safe? *Follow Up: What suggestions do you have for improving the PCA services available through Minnesota's PCA programs so that they better support you in being healthy and safe?*

4. What are your thoughts, experiences, and stories about the quality of service you receive through Minnesota's PCA programs? *Prompts:* Think about: What does quality mean to you? How do you feel quality is measured? Who can or must be held accountable for the quality of support you receive—the legislature, state agencies, county personnel, your PCAs? To whom do you go to discuss concerns you may have about your quality of support? *Follow Up: What suggestions do you have for improving the quality of care in Minnesota's PCA program?*

TOPIC Area 2: Staffing

5. What are your thoughts and experiences about being able to be involved in finding, choosing, keeping and training PCAs to provide services that meet your needs? *Prompts:* Think about: What are things you do now to find, choose, keep and train quality PCAs? What training would you like PCAs to receive so that your life is better? How do you recognize and reward your PCAs for doing quality work? *Follow Up: What suggestions do you have for developing or improving the recruitment, hiring, orientation and training activities in Minnesota's current PCA program?*
6. Describe a situation that involves how PCA services have or have not been provided to you? Tell me about a time when back up plans to provide PCA services to you were done well? Poorly? *Prompts:* Think about: The type, level, and quality of services you receive. Do you get the amount of PCA services that are authorized to you? Why or why not? Who is/are the responsible party(ies) for "back-up"? What strategies do your back-up plans include? Who helps out when back-up plans don't work? *Follow Up: What suggestions do you have for improving Service Provision and Back-Up Plans in Minnesota's PCA program?*
7. What are your thoughts and feelings about your family members being able to be your PCA and able to provide PCA services to you? *Prompts:* Think about: The benefits and challenges of family members being able to be a PCA. What it might be like for you as a service recipient to tell a PCA family member that she or he does not do a "good job" as a PCA with certain tasks. How to ensure the PCA family member maintains confidentiality with the family member who is a service recipient. *Follow Up: What suggestions do you have for improving the process for using family members as PCAs in Minnesota's current PCA program?*

PCA Worker Focus Groups

TOPIC Area 1: Your Work as a PCA

1. Tell us about your work as a PCA; what, where, how and why do you do this work? *Prompts:* Why did you choose to do this type of work? Where to you go to do your work, in what types of environments? How many hours do you work in what settings and for how many people with support needs? Describe for us a typical day at your work; what are your job duties and responsibilities? *Follow Up: What are the hardest things about your work? Best things?*

TOPIC Area 2: Compensation and Benefits

2. What are your thoughts, feelings, and experiences about wages and benefits for PCAs in Minnesota's system? *Prompts:* Think about: How does your wage and access to benefits affect your life? How do they compare to the wages and benefits of others in your family, community and other jobs? *Follow Up: What suggestions do you have for improving the wages and benefits that PCAs currently receive in Minnesota's PCA programs?*
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TOPIC Area 3: Provider Organization/Employer

3. In what ways does your employer (the organization in which you work) support you? What are your experiences and stories about receiving orientation as a new PCA and training to meet the needs of service recipients? *Prompts:* Think about: What support do you want but do not receive? How does your organization/employer provide you with orientation? What type of on-going training do you get? *Follow Up:* *What suggestions do you have for improving the support you get from the organization(s) in which you work as a PCA? What suggestions do you have for developing or improving orientation and training activities in Minnesota's current PCA program?*

TOPIC Area 4: Family members as PCAs

4. What are your thoughts and feelings about family members being able to be PCAs? *Prompts:* Think about: The benefits and challenges of family members being able to be a PCA. What it might be like for a service recipient to tell a family member she or he does not do a "good job" as a PCA with certain tasks. How to ensure the PCA maintains confidentiality with the family member as a service recipient. *Follow Up:* *What suggestions do you have for improving the process for using family members as PCAs in Minnesota's current PCA program?*
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E. Conducting Focus Groups of PCA Recipients and PCAs

University of Minnesota staff conducted a total of 14 focus groups (eight PCA recipient and six worker focus groups) across the state in Bemidji, Bloomington, Brainerd, Duluth, Mankato, Minneapolis, Roseville and St. Paul counties. Two U of M staff facilitated the majority of the 14 focus groups (on two occasions focus groups were conducted simultaneously and therefore only had one trained facilitator). A PCA service recipient co-facilitated the recipient focus groups. Each focus group lasted 90 minutes. Refreshments were served and participants were encouraged to network and interact with one another. Ground rules for participation were reviewed with all participants and the facilitators ensured that all participants had a chance to talk and voice their opinions and share their experiences. Participants were active and responsive in all of the focus groups.

III. Data Analysis

The data collected during the focus groups was digitally recorded using two separate digital recorders to ensure that all participants' words were heard and recorded. Each tape was transcribed. Two U of M project staff reviewed the data and identified preliminary codes based on participant answers to each question. Codes are labels given to topics that emerged from the focus group data and were used to identify each time a topic was identified in the data (e.g. low wages, expensive health care benefits, co-worker conflict, health and safety, work hours). The coding completed by each researcher was compared to ensure consistency in the use of the codes (inter rater agreement). Both facilitators reviewed the data with the final codes to identify themes across focus groups. These themes are the key findings of the focus group study.

IV. Results

A. Focus Group Participants

There were a total of 80 focus group participants. These included 55 PCA service recipients, or legal representatives of service recipients who were unable to participate on their own behalf, and 25 PCA workers. Exhibit 2 presents the demographic and other characteristics of the PCA workers and PCA service recipient/personal representatives who participated in the focus groups.

Characteristics of PCA Recipient/Representative Focus Group Participants

- Of the 55 PCA service recipient focus group members, 31 were adults with disabilities who received PCA services and 24 were family members/legal representatives. PCA recipient focus group participants, who were not represented by their parents/legal representatives.
- Of the 55 PCA service recipients who participated, 10 identified themselves as Native Americans, two as Hispanic, one Asian/Pacific Islander, two African American, and the remaining participants (40) were Caucasian.
- Also, of the 55 service recipients who participated (or were represented), 17 were individuals with physical disabilities, 19 had intellectual/developmental disabilities, three had a traumatic brain injury and 16 identified as having mental health diagnoses.
- Of the 31 actual adult service recipients (i.e., those who were not family members/personal representatives), 17 were female and 14 were male.
- Of the 24 participants who were legal representatives, the overwhelming majority were female (21 of them) and three were male. Also, most of the children they represented were female (21 were female and 10 were male). It is important to note that some of these legal representatives had more than one child who received PCA services.
- The overwhelming majority (44) of the 55 participants lived in an apartment or house, 2 lived in corporate foster care and 9 indicated that they lived in shared housing.
- Funding streams identified for these participants included Home and Community Based Services, Fee for Service, Managed Care and PCA Choice. However, it is important to note that, while we asked participants to identify their PCA service type on the demographic form they completed prior to the focus groups, it became apparent during the focus groups that many participants did not have a very clear understanding about the program through which they received PCA services (e.g., FFS versus managed care) or the PCA option (Choice vs. Traditional).

Characteristics of PCA Worker Focus Group Participants

- PCA worker participants ranged in age from 20 to 66, and the majority were female (19 were female and 6 were male).

- Of the 25 PCA workers who participated in the focus groups, the overwhelming majority (22) worked for a provider organization, and the remaining identified that they worked independently.
- There were 18 Caucasian, 4 Native American, 2 Asian/Pacific Islanders and 2 African Americans.²
- Workers who participated in the focus groups delivered PCA services in PCA Choice, Home and Community-Based Services, Managed Care programs, and Medical Assistance State Plan Fee-for-Service. However, it is important to note that while we asked participants to identify their PCA service type on the demographic form they completed prior to the focus groups, it became apparent during the focus groups that many participants did not have a very clear understanding about the program through which they received PCA services (e.g., FFS versus managed care) or the PCA option (Choice vs. Traditional).

Exhibit 2. Demographics of Focus Group Participants

Characteristic	PCA Service Recipient Participants	PCA Worker Participants
Total participants	55	25
Participants with disabilities	31	n/a
Family members/legal representatives of PCA recipients	24	n/a
Age (range)	19 - 76	20 - 66
Gender ^{a/}		
<i>Male</i>		6
Family members/legal representatives	3	
Child	10	
Adult independent	14	
<i>Female</i>		19
Family members/legal representatives	21	
Child	21	
Adult independent	17	
Race/Ethnicity ^{b/}		
Native American	10	4
Hispanic	2	
African American	2	2
Asian/Pacific Islander	1	2
Caucasian	40	18

² The sum of race/ethnicity participant count for PCA worker focus group participants is greater than the total number of PCA workers who participated (25 total participants compared to 26 by race/ethnicity) because some workers identified themselves as more than one race/ethnicity

Characteristic	PCA Service Recipient Participants	PCA Worker Participants
Disability Type		
Physical disability	17	na
Developmental disability	19	na
Mental Health	16	na
Traumatic/Acquired Brain Injury (TBI/ABI)	3	na
Living Arrangement		
Home/Apartment	44	na
Corporate Foster Care	2	na
Shared Housing	9	na
Employer Type		
Provider Organization	na	22
Independent PCA	na	3

- a/ Family members/legal representatives who participated in the PCA recipient focus groups provided their gender and the gender of the child or children they represented. Note that the total number of male and female focus group participants is greater than 55 due to the fact that some legal representatives had more than one child in the program.
- b/ The sum of race/ethnicity participant count for PCA worker focus group participants is greater than the total number of PCA workers who participated (25 total participants compared to 26 by race/ethnicity) because some workers identified themselves as more than one race/ethnicity.

B. Key Findings

We collected a wide range of experiences, perspectives, challenges and recommendations for improving Minnesota’s PCA program, which we summarize below.

PCA Worker Voice

The topics that emerged from PCA workers included wage/benefit levels, PCA services provided to support families and individuals, work life challenges, training/supervision/career development, and issues surrounding family members serving as PCAs. These topics are described in more detail below:

PCA workers expressed lack of benefits and “low” or inconsistent wages across PCA organizations and programs as major employment issues

PCA worker participants strongly voiced concerns about hours worked, wages, and benefits. The range of hours worked by the PCA participants varied widely, from eight hours a week to 16 hour days worked seven days a week. Many worked 80 – 100 hours a week. Some of the workers who worked long hours did so to earn enough money to make ends meet and a few expressed that they worked these long hours out of commitment to the person with a disability they were serving because that person wanted only them as an employee. Many PCA workers complained of having to work split shifts, and spending one-third of their day traveling from one recipient’s home to the next (more often than not without pay). In order to get enough hours to make ends meet, workers noted that they usually have to provide PCA services to

more than one recipient. Many others expressed that they had other paid jobs not involving PCA service delivery.

PCA Story #1:

I am a single Mom with a young boy who has a developmental disability. He can walk with a walker and independently uses the toilet. My PCAs help mostly with following the plans developed by professional therapists—physical, occupational and speech. I also train the PCAs in many of the specific tasks related to stretching, walking, sitting, all of which are very important safety and health situations. The PCAs also help my son with personal hygiene such as showering, using the bathroom, brushing teeth and so forth. They are pretty good with encouraging my son and being there to provide support when he needs it. The PCAs also help me with ideas for making math fun, doing a variety of homework activities, and just having fun with him outside playing games and doing other recreational activities.

What is very frustrating for me is the strong bonds that are created by my son and his PCAs and me and then, they leave after six months or a year. It is so hard on him and I have to spend a good deal of time looking for other persons to replace the PCAs. Also, what is a real challenge is the number of people I have to interview to finally find one who will be a quality person for my son, one who is professional in their approach, has good manners, uses grammar that is appropriate, listens carefully to my instructions, and uses their ideas to help improve my son's life. I used to use several different traditional PCA agencies but had so many poor experiences and lack of training with the PCAs they sent me that I switched to PCA Choice. This option allows more freedom in finding and choosing PCAs and does make it easier to pay PCAs a bit more money than traditional agencies but also means more time and energy needs to go into finding and training good DSPs and doing some of the paperwork that the traditional PCA agencies usually do.

I would recommend that a high priority for the future of the PCA program in Minnesota would be to maintain the flexibility of the program because there are so many different needs and circumstances of the persons receiving and providing PCA services. Also, providing competitive wages and benefits is a very strong need if PCAs are going to consider this type of work and stay with their employer for a longer period of time.

PCA wages varied widely, from \$10.00 – \$15.00 hourly. Workers shared that there was inconsistency in the amount of pay they received, which could depend on the type of service delivered, and the organization or recipient for whom they worked. Nearly all PCAs indicated that they also worked hours for which they are not allowed to bill, and therefore for which they were not paid (e.g. working hours beyond the total number authorized for the person they support, running errands for the person they support but without that person in their car). They also indicated that they did not receive overtime pay for hours worked in a given week beyond 40. Several workers suggested that PCAs who support recipients with higher support needs (e.g. severe challenging behavior or physical demands) should be compensated with higher wages. Some PCA workers stated that they were reimbursed for some mileage (e.g. to/from medical appointments or travel in between clients), others were not reimbursed for any mileage though they had similar travel experiences. None of the workers were reimbursed for mileage to take PCA recipients to/from community activities.

"I don't have health insurance, I just go to the emergency room when I get sick."

Workers had varied experiences with benefits offered by their employer. Nearly all workers indicated that they were either not offered health insurance benefits, or that the insurance options they were offered were too expensive, and so they did not utilize them. Many were without insurance, several said they just go to the emergency room when they are sick, some said they have second jobs with health benefits, and others had health insurance through a spouse or the Veterans Affairs.

PCAs expressed that they provide a wide array of services and supports to consumers, thus playing an important role in the lives of the recipients they serve.

PCA workers were asked to identify the types of services and support they provide to people who receive PCA services. They identified a wide variety of tasks representing a vast array of job duties. These tasks also clearly emphasize the important roles that PCAs play in the lives of people who receive these services. These tasks, which we describe in more detail below, include, but are not limited, to:

- Assisting recipients with daily life activities;
- Assisting recipients with health-related tasks and accessing health care;
- Providing physical and behavioral interventions; and
- Supporting recipient's integration in their communities.

PCAs provide a variety of supports in the area of activities of daily living, including: supporting recipients with personal hygiene and grooming; assisting recipients with housekeeping by completing tasks such as sweeping, mopping, dusting, cleaning the bathroom, doing dishes and completing laundry; and assisting recipients with grocery shopping, cooking and eating.

PCAs also provide a wide variety of health-related tasks, including: providing support to people who use G tubes including cleaning, maintenance and monitoring of the G tube; maintaining catheters; assisting with the dispensing of medications, monitoring and implementing medications to treat a variety of health issues such as diabetes; and assisting recipients in going to medical appointments and obtaining their medications.

PCAs carry out interventions and treatments such as range of motion, physical activities and other interventions requested by physical and occupational therapists. These include, for example, performing complete positioning, lifting and transferring support, and working to prevent pressure sores and other problems. Other therapy-related activities include implementing communication programs, and using augmentative and alternative communication strategies to support people to improve and use their communication skills. PCA workers also described their role in supporting recipients who have challenging behavior and communicate their needs and wants through their challenging behavior, including providing re-direction, setting limits, supporting individuals through manic episodes and preventing prevent property destruction, self-injury and harm to others.

PCA Story #2:

I am an older man who is the PCA for my daughter who is a young adult with a developmental disability. Initially, I had a PCA hired through an agency and experienced a lot of things that I didn't like so I decided to give up my job and be her PCA so I could provide her a higher quality of care and a better life. My daughter has many complex medical needs such as feeding her every 3 or 4 hours through a pump and only has a small percentage of her motor skills so I need to transfer her from the bed to a wheel chair or from the wheel chair to the commode. Because she is my daughter I find extra ways to do things for her and don't just follow the manual like combing her hair in a certain way that makes her smile, rubbing her with oils and lotions, and so forth. To be sure, it is very challenging with my wife working with her during the day, and I working with her in the evenings to make sure the feeding pump continues to work smoothly. I also think I advocate more strongly for my daughter than a non-family PCA would do.

I think that PCAs should get paid more and receive benefits like LPNs because the work we do is so difficult and challenging and the people we work with are so vulnerable. Also, just like other professions like nursing and social workers need to be certified, I think PCAs should get certified. Another concern of mine is that agencies need to do a better job of matching a PCA with the needs and wishes of families or adults who hire their own staff. Don't place a PCA who does not have the skills or has problems with younger kids into a home where he is asked to help a family with several children with behavior problems.

A final thought is I think that family members being a PCA should be considered a first choice if they get along well together, listen and follow instructions of their family member, and if they really want to help out their family member. Families can burn out so easily and quickly providing care and comfort both as a caregiver and parent; having another trusting and loving family member do respite care on a weekend is a good way to stay fresh.

Many PCA workers described how they support people to be more integrated into their communities by teaching them to participate in recreation and leisure activities such as going to the movies, swimming, sporting events, church, berry picking, and playing bingo. They also support families by making it possible for families to spend time together and to go to events at school and in the community.

When asked the best thing about being a PCA, nearly always, workers cited the close relationship that develops with the recipient to whom they provide support. The feeling that the PCA worker is wanted, needed, and appreciated by the recipient was identified as a primary reason they chose this profession. Workers indicated that they were also drawn to PCA work for a variety of reasons – some initially wanted to be Certified Nurse Assistants (CNAs) while others got into the work because of the recipient they support. Some workers explained that they had become PCAs because they were looking for a job and had no connection or specific interest in the work. However, over time they developed connections to the people they supported and grew to like the work.

PCA workers expressed challenges in work-life balance and working with clients with challenging behaviors.

When asked about the challenges being a PCA poses, PCAs workers identified balancing work and the need for time with their own families as one of their greatest challenges. Many PCA workers expressed that they had to give up time with their children and family members

because their client needed them to work during times when they otherwise would be with their family members. Loyalty to the person served and the need for full time hours seemed to be the most significant sources of conflicts related to finding work and home life balance.

Several PCA workers also discussed how difficult it was to provide support to recipients who have challenging behavior, who communicate their needs and wants through their challenging behavior, and who can hurt you physically. These workers supported people with various types of disabilities (e.g. intellectual and developmental disabilities, mental health) and felt ill-prepared and experienced a lack of support from employers in knowing how to provide behavioral support. They shared that they sometimes experience stress and burnout due to the demanding nature of the job.

PCA workers described vastly differing experiences with regard to training, career development, recognition and supervision from their employer.

PCA workers described vastly differing experiences with respect to how their employer trained them to be PCAs. Some had absolutely no training or orientation and were just expected to deliver support. Others received a limited amount of orientation/training from their employer, including for example, being asked to read a PCA manual, shadow another PCA, complete answers to questions that were provided to them with their paycheck and turn them in to their employer, or learn specific skills from hospital staff before a client is discharged from the hospital. Some PCAs received three hours of training before working as a PCA on topics such as rotating a person in bed, changing bed covers, washing clothes, assisting with toileting and helping the person get in/out of a wheelchair.

One area in which many PCA workers expressed the desire for more training was in working with recipients who have challenging behavior and mental health issues. Most workers indicated they never received this type of training, but many supported individuals who had challenging behavior or who had mental health conditions for which they were not prepared to support.

Nearly all workers expressed that they would like more opportunities for training and education. They indicated that they felt they could gain more knowledge and acquire more skills that would assist them in providing better support to PCA service recipients through training.

PCA Story #3:

I am an older male who has been a PCA for about thirty years and about half of those years exclusively with a middle-aged gentleman who has a disability and who uses a wheel chair for his mobility. As a PCA, my responsibilities include waking him up in the morning, doing his toileting, brushing his teeth, combing his hair, shave and dress him, cook meals, and feed him. He enjoys doing many activities in the community such as attending sporting events, participating in cultural events, going for a picnic in the park, and doing a workout at a fitness center. He likes to have friends over so I cook the meal and drive him to his friends when they reciprocate the get-togethers. Because of his desire for a strong and active social life, I am his driver and assistant to him with his communication with others.

Before I became a PCA, I worked as the owner of a business but found it unfulfilling. I had a friend who was a PCA and that led me to trying this type of work. I do PCA work because I think I can and do make a difference in people's lives. With my current job as a PCA, I work many hours beyond the hours I am paid because of the strong bonds with him.

I experienced a number of challenges with the earlier PCA agencies that I worked for such as not getting enough money to live on. I know there are PCAs out there who do not do a good job, are not well trained, and think that getting persons up in the morning, helping to shower, clothe, and feed them is all there is to the work. So, pay those who do exemplary work more money and either train or help direct the non-exemplary PCAs to a different type of work. Providing affordable health care insurance is another benefit that should be explored for PCAs. Another area is the lack of regular nursing supervision of my work. They are supposed to provide supervision and guidance about every 6 weeks or so but I only see her a couple of times a year. I do like my current employer because they provide some training, make insurance available (even if not affordable) and do provide at least an adequate wage (but not livable).

Few workers were able to describe ways in which their employer recognized them for a job well done. A few PCA workers were employed in organizations that hosted recognition events or celebrated tenure benchmarks, but most reported no recognition or attempts to show value and appreciation to them as employees.

Additionally, most of the workers said they received little to no supervision and that no one really ever watched them do their work. They relied most heavily on feedback from recipients they served or parents of recipients. Many indicated that they thought someone was supposed to come and observe them once a month but that they rarely if ever had heard from or seen anyone from the organizations in which they employed supervised them.

PCAs voiced mixed views and opinions about family members providing PCA services to their loved one.

PCA workers had mixed experiences and opinions about family members being paid to provide PCA services. Many workers expressed that family members would make the best PCAs because they know the recipient best, and love and trust them. Others expressed concern about family members taking advantage of the recipient, crossing personal/professional boundaries and giving themselves the best hours while leaving the worst hours for the PCAs that work for an organization. Some of these workers had actually observed and

Worker Suggested Key Changes:

- *Affordable health insurance.*
- *Improved wages.*
- *Pay scales to reward expertise.*
- *Increased consistency in pay*
- *More and better training.*
- *Certification of PCAs.*

experienced situations in which family members had provided PCA services and their expressed opinions were based on these experiences. Others seemed to be speculating about what it might be like if a family member provided PCA services.

PCA workers expressed the need for key changes in the areas of affordable health insurance, wages, and training, to improve Minnesota's PCA program

The PCA workers were asked to share their ideas for a key change that would improve PCA services in Minnesota. Nearly unanimously, PCA workers expressed the need to have affordable health insurance. This was their greatest priority.

They also expressed the need for improved wages and felt passionate about how paltry their pay was when considering the enormous responsibilities of their job. Many indicated that the pay was not adequate given that they were providing support to Minnesota's most vulnerable citizens. Several PCA participants suggested the need for pay scales that rewarded working with people who have greater support needs, such as challenging behavior and severe physical and medical needs. PCA workers also expressed the desire to have more consistency in pay across organizations and PCA service types (e.g. fee-for-service, private, PCA choice, managed care). Several participants were surprised by the variation in wages when participants who lived in the same community shared their wages during the focus groups.

PCA workers identified the need for more and better training. Several suggested that Minnesota require certification for PCAs. Several suggested that greater pay be provided for workers who are certified. One PCA worker suggested the building of a worker registry that would match people who need services with workers who can provide the service.

PCA Service Recipient (Consumer) Voice

PCA service recipient focus groups included both recipients directly receiving the services and supports of the PCA, as well as personal representatives of individuals who receive PCA services (e.g., parents, guardians, other family members). For purposes of this discussion, unless otherwise specifically stated, we refer to them collectively as "PCA recipients." Below we discuss their collective experiences and perspectives expressed during the focus groups. Topics that emerged from PCA recipients include PCA wage/benefit levels and PCA hours of work, services PCAs provide to support them and their families, the positive and challenging aspects of PCA Choice versus traditional PCA program options, challenges in recruiting and retaining PCA workers, quality of services, and having family members serve as PCAs.

PCA recipients identified low wages and lack of access to affordable benefits as a barrier to finding and keeping good PCAs.

Nearly all of the PCA recipients identified low wages and lack of benefits such as affordable health care, paid time off and overtime as important factors that contribute to their inability to find and keep good staff. Several shared stories of losing PCAs because they found a job with better pay or access to employer paid benefits. Recipients were passionate about these issues and several expressed that PCA workers needed to be treated as professionals and have the benefits that go with their high levels of responsibility.

PCA recipients described a wide array of services and supports provided by the PCAs, that are very similar to those described by the PCAs themselves.

PCA recipients described job duties of their PCAs that are very similar to those described by the PCA workers themselves, including:

- Assisting them with daily life activities;
- Assisting with health-related tasks and accessing health care;
- Supporting integration in their communities; and
- Providing physical and behavioral interventions, in particular to their children.

In the area of activities of daily living, they described that the job duties performed by their PCA included helping them complete personal hygiene such as getting dressed/undressed, showering, washing/combing/styling hair, bathing, toileting, cutting finger nails, shaving, monitoring skin conditions, putting on lotion/creams, helping people gain access to things they need and brushing teeth. Housekeeping tasks were described as sweeping, mopping, caring for pets, cleaning the bathroom, doing laundry and cooking. While many service recipients indicated that their PCA workers did whatever they needed and wanted them to do, others shared stories of workers refusing to assist with tasks that did not involve traditional daily living skills (e.g. pet care, running errands).

Many PCA recipients described their PCAs as helping them (or their family member) access services in their community and participate in community activities. Activities included shopping for groceries, clothes, or other needed items, and participating in leisure activities such as going to sporting events, recreation and cultural activities.

Recipients expressed that PCAs played significant roles in people's lives by helping them improve their health and stay healthy. Recipients described their PCAs' roles include taking them to/from doctor and specialist appointments (sometimes great distances away if the person lives in a rural area), assisting them with range of motion and other mobility exercises, transferring and lifting them when they need assistance to prevent injuries and sores, and using assistive technology and equipment to help them get around their homes and communities.

"I wouldn't be here and able to live by myself without PCA care. PCAs kind of save us as a family."

Recipients expressed that PCAs provide daily support that assist people in completing everyday tasks; they do so by developing supportive relationships that inspire and motivate the person to do and try new things. Recipients of services talked about the long-term relationships they have had with workers and how the relationships often are a motivating factor for them to do what they need to do to get through their day and their lives.

Parents/family members described the important role PCAs play in helping them with their children that have challenging behavior or severe medical conditions in a way that allows the parent/family member to have a much needed break. Without this assistance and support some parents/family members described their reality as one in which their child/family member would be unable to remain in the community because the parent/family member would burn out. Many parents described situations where they incurred a physical injury from

lifting, transferring, and carrying and moving their family member with a disability. These parents expressed that they had to have assistance from PCAs because they no longer could provide the physical care and, without PCA assistance, they would no longer be able to care for their child at home.

PCA recipients favored the PCA Choice program in terms of level of control and flexibility over the activities the PCA performed, but expressed challenges with their employer responsibilities, and lack of support.

The PCA recipients who participated in these focus groups collectively had a variety of experiences with PCA service options. Many had experiences with both PCA Choice and more traditional models of PCA services. Many consumer participants indicated that PCA Choice allowed more flexibility on how to use their service allocation, and when to use their PCA services because they were not relying on an organization to send staff. Consumers shared a feeling of having more control and being able to ask the PCA to do what they wanted and expecting them to do it. Several shared positive feelings about being able to hire and fire their PCA staff if they were not qualified or made a bad decision.

At the same time, recipients indicated that under PCA Choice, they receive little assistance from an agency with emergency situations (e.g. parent gets sick or a PCA leaves suddenly) and much of the burden of the paperwork, interviewing and hiring falls to the recipient who may not have experience or knowledge with how to do these important tasks. Most expressed a desire to have support and assistance through resources, greater training and individualized support from the state or an entity responsible for providing such support.

PCA recipients expressed mixed experiences regarding the traditional PCA program option.

Several PCA recipients indicated that using more traditional models of PCA services gives them greater support from the organization that can assist with problem solving and talking with PCAs about problems and performance issues. Many reported liking the assistance organizations provided with finding and disciplining PCAs. Recipients who use this model expressed that they felt they had better chances of finding back up staff from their organization when their assigned PCA was absent.

Many of the traditional PCA service recipients expressed that they were also finding their own workers and that the organization hired the people they wanted them to hire and that the organization pretty much allowed them to guide and direct their PCA's work. In some ways, the stories from these recipients sounded identical to those of people talking about their experiences with PCA Choice.

Other recipients had very poor experiences with more traditional PCA services indicating that organizations take no action when a PCA is not performing well, or organizations do not take any care in selecting the type of PCA to support a recipient, so long as one is provided. For example, several recipients expressed displeasure with the quality of PCAs that were sent to them by traditional PCA provider organizations.

No participants expressed any concerns with retaliation or a fear that if they complained about a worker(s) the organization would make it more difficult for them or would not send new

workers. Participants shared that when they had problems, they felt comfortable sharing these problems and in most situations their organizations were responsive.

PCA recipients indicated that it is important for the PCA to have something in common with the recipient, as well as their family members, and that people need to observe and monitor the interactions between the PCA and the recipient to determine if there is a good match. If there is not a good match then recipients need to be able to enforce a change no matter the type of PCA services delivered.

PCA recipients communicated the important and active role that PCAs play in helping them stay healthy and safe.

Recipients expressed that PCAs play important roles in keeping them safe and healthy, including: proactively observing and sharing with the recipient their perceptions about changes in recipients' physical or health condition; monitoring medications and accompanying them to many medical appointments; and taking an active role in helping them exercise and live active lives in their communities (which recipients stated as being a significant contribution to individual health). Several recipients talked about how the tenure of a PCA worker leads to them to being more knowledgeable about the consumer's health conditions and risks.

Similar to the message heard from PCAs themselves, recipients (people with disabilities and family members/legal representatives) described their PCAs as providing support and intervention with challenging behavior to reduce incidents of harm to self and others.

"....he definitely would have been institutionalized at a young age if we had not had PCA services."

Several recipients talked about how calming their PCA was to them and the importance of their relationship.

PCA recipient perspectives reflected similar challenges expressed by workers with respect to the hours worked.

PCA recipients discussed how the schedules that their PCAs have can result in them being overworked, or getting routines mixed up because they work for so many people. Additionally, nearly every PCA recipient was able to share a story about a time when a PCA did not show up to work and how this resulted in the recipient staying in bed all day, becoming dehydrated, not getting food, or missing work or other important social engagements. Others discussed how the lack of flexibility with how their dollars are spent prevents them from accessing other health and safety options such as cell phones or 24 hour emergency support, which can be critical when no PCA is available.

PCA recipients had mixed experiences with the quality of PCA services which they receive.

Recipients experienced a mix of service quality over the years, both positive and negative.

Examples provided by recipients of how PCA services have positive outcomes include: a PCA coming to work at 3:00am to take a person to the hospital; PCAs being able to take direction from the consumer/family member and modify the way they deliver service based on consumer desire or need; PCAs that offer help even when it is not asked for; PCAs that work

extra hours (even without pay) to help someone when they have a need; and PCAs being willing to come in and provide support on short notice, when there is a need for special care or an emergency.

PCA recipients shared the following experiences as examples of poor quality PCA services. Several discussed communication challenges and being unable to communicate their needs and wants to PCAs who do not speak English as a first language. When recipients described services they received from organizations they often shared stories of organizations not sending staff when they were needed and scheduled. Several discussed how the high turnover of PCA workers negatively affects them. They described having to train people over and over and how tiring this is. PCA recipients shared stories of situations in which PCA workers refused to complete certain work tasks that they needed to be accomplished and inconsistencies in what organizations “allow” and “don’t allow” their employees to do. Nearly all of the recipients indicated that the quality of services is directly related to the quality of the PCA and the lack of wages for PCAs.

PCA recipients discussed a wide variety of strategies employed to find, choose, keep and train their PCA workers.

PCA recipients in the focus groups described a wide variety of ways in which they find PCAs. Many used organizations to find their workers, while others used word-of-mouth. Some had “secret strategies” that they were reluctant to share with the group (i.e. recruitment strategies they found to be effective but did not want others to know for fear that they would no longer be effective). Some used Craig’s list, while others used traditional newspaper advertisements. Absolutely all of the recipients reported difficulty in finding good workers.

Every single recipient indicated that the low pay of workers made it difficult for them to find and keep the good workers on the job and that turnover was directly related to low wages.

PCA recipients shared a wide variety of strategies and experiences with regard to how their staff were oriented and trained. Most PCA recipients indicated that PCA workers came to them with very little experience or training. They also shared that individual PCA recipients or their family members/legal representatives needed to be involved in training. Recipients who were people with disabilities were less likely to indicate that they wanted PCAs to come to them with some basic training. Family members often reported that they wished they did not have to train PCA workers over and over again and wished the workers came with some basic training. Several recipients indicated that specialists such as nurses, physical therapists, occupational therapists or speech therapists needed to be involved in training PCAs who required these specialty interventions and program plans. Several recipients talked about the lack of respect for this profession and how this contributes to high burn out and turn over.

Most participants reported the importance of verbal praise and daily recognition as a powerful means to retain staff. Others did simple things like inviting the worker to join them for a meal or buying small gifts on birthdays. The relationship that evolves between the service recipient and the PCA worker was described as an essential element of retention.

There were some discrepancies between what family members did to retain staff and what people with disabilities were able to do. Some families reported that they sometimes pay

overtime or retention bonuses to their PCAs out-of-pocket because they have found this to be an effective strategy to keep good workers. This was troublesome to many people with disabilities in the focus groups because they did not have the financial means to provide such incentives.

PCA recipients expressed challenges associated with having an appropriate and adequate back-up plan in place to implement when their usual PCA is not available.

Recipients talked about using provider agencies as their back up plans, calling 911 or relying on family members or close friends to assist them when their PCA did not show up or when they had an emergency. Recipients who did not have family members shared how this lack of support resulted in them being more vulnerable because they had to rely on agencies to offer back up plans, and these agencies were often inconsistent and unreliable. Many expressed they could not participate in PCA Choice because they were simply not able to ensure their own back up staff in case of emergencies.

"...don't have good back up plans or services and this is directly related to low wages, no overtime, no benefits and a lack of a career path."

Both service recipients and family members/legal representatives talked about how life stops when their PCAs fail to show up for work or when they quit. Parents shared how they had lost jobs because they had to stay home so much to care for their child as a result of not having a PCA, and recipients talked of having to be hospitalized because they had to have help and they had no PCA. Several recipients talked about how the lack of back up plans and security of service was directly related to low wages, no overtime, no benefits, and lack of a career path. An example from one family member was that when their loved one was sick and in the hospital, their PCA simply was not paid.

Most consumers favored having family members as PCAs.

There were far fewer concerns expressed by PCA recipients about using family members as PCAs than were expressed by PCA workers in their focus groups. Most of the recipients expressed the important role families play in the lives of their loved one and indicated that as long as the service recipient did not object to their family member working for them, then it was fine. Some suggested that professional boundaries would need to be discussed and implemented. Examples were shared about situations in which couples got divorced so they could provide PCA services to their spouse and how in some programs parents are able to provide PCA services for their friend's child but not their own child. Many recipients advocated for the use of family members (including parents) as PCAs as a means to resolve the shortage of staff to hire. A few recipients expressed concern that they had no family in the area and that they would never be able to rely on family to provide their PCA services, so the system has to have other alternatives to help them find and keep PCA workers.

PCA recipients expressed the need for key changes in the areas of benefits, wages, training, supervision and better matching of the PCA to the recipient, to improve Minnesota’s PCA program

As with the PCA worker participants, the PCA consumer participants were asked what one thing they would recommend or change to improve PCA services in Minnesota. While many of the suggestions for improvement were directly related to recipients’ service needs and service delivery, interestingly, the most significant change recipients suggested related to the working conditions of their PCA workers.

Like the workers, recipients of PCA services identified improved wages and access to benefits as the number one improvement needed. They also wanted to see better supervision, support, certification and improved career options for PCAs through training.

Consumer Suggested Key Changes:

- *Improve the professionalism expected of PCAs.*
- *Pay livable wages and good benefits.*
- *Offer career options, retirement, and paid time off.*
- *Provide more oversight for the Department of Human Services.*
- *Provide training based on needs of person served.*
- *Create a pool of PCAs and match to consumer needs.*

Other suggestions, related directly to the service recipient’s needs and service delivery, included: not requiring annual assessments for people who have disabilities that do not change year to year, differentiating mental health needs from physical needs and providing appropriate training and PCA hours based on these needs; consider creating a pool of PCAs so that matches between PCAs and PCA recipients can be made more easily; making it possible to have more than one PCA at a time based on need; and to allow for communication between one PCA and another that work for the same person.

Finally, as solutions to the challenges these consumer participants had with ensuring safety through back up plans, recipients suggested: improving the professionalism expected and given to these workers, paying livable wages and good benefits, offering career options, retirement programs and paid time off and providing more oversight by provider agencies and the State Department of Human Services.

C. Other Interesting Findings

There were several unexpected findings from the focus groups with both PCA service recipients and PCA workers. All focus group participants seemed to enjoy the opportunity to share their stories and to provide one another with ideas and suggestions for how to resolve, address or prevent issues and challenges they were facing. Participants often exchanged contact information and many expressed the desire to have opportunities to connect and network with one another. This type of networking and connecting and information exchanged seemed to be a means of quality monitoring and enhancing the program. Participants were working together to find mechanisms for improvement and accountability.

V. Preliminary Recommendations and Opportunities for Action

The participants in the focus groups were vocal and had much insight into the benefits and significant challenges of the current PCA program in Minnesota. Based on the key findings from the focus groups and the suggestions for changes expressed by participants in both the PCA Worker and PCA Recipient Focus Groups, we have developed preliminary recommendations to help strengthen and improve the PCA program and opportunities for action. These are summarized in the Exhibit below.

Improve the quality and accessibility of the PCA workforce, through a comprehensive evaluation of wage levels and insurance options for workers, and developing options for improvement.

Low wages and lack of affordable benefits were clearly identified by both recipients and PCA worker in the focus groups as critical problems that contributed to health and safety issues and the inability to get and keep good workers. People who worked in and received all types of PCA services in Minnesota (e.g. PCA Choice, traditional PCA services, managed care) identified wages and benefits as key problems. Several focus group participants noted that PCAs were working substantially too many hours in order to earn a livable wage and that working so many hours each day for too many days in a row puts the PCA at greater risk of making errors and harming PCA recipients. Many PCA workers indicated that they worked other jobs. The direct care worker/provider survey which is currently being conducted as part of this study should provide greater insight into wage levels, ranges and variations. As a result, we expect to have more information to address these issues in the future.

Other options to consider for incentivizing PCA workers to continue in their field include:

- Developing wage incentives for PCAs based on demonstrated competence in the service needs of PCA recipients (e.g. completing training in a well-designed certification or credentialing program addressing complex behavioral and health challenges such as the framework offered by the National Alliance for Direct Support Professionals (NADSP) – www.nadsp.org), and
- Reimbursing PCAs for a defined set of activities that are related to, but are not, direct care service delivery (e.g., time spent in training, travel time in certain circumstances).

In addition to addressing reimbursement levels, efforts should be made to improve access to affordable health insurance for PCAs. Many workers are going without health insurance because premiums are too costly and wages are too low to enable them to purchase insurance premiums from their paychecks. Efforts should be made to find more affordable health insurance by, for example, creating access to affordable pools for PCA agencies or workers.

Continue to maintain and strengthen PCA services as a Medical Assistance service option for individuals with a variety of physical, intellectual/developmental disabilities and mental health disabilities.

It is clear that the participants in these focus groups considered PCA services as essential to the safety, health, well-being and enrichment of the lives of the thousands of persons who need this

type of support in Minnesota. This service is delivered to and essential for people who have physical disabilities, mental health disabilities, intellectual and developmental disabilities, people who are elderly and people with traumatic brain injury. Families are often able to stay together and people with disabilities can remain in their communities and homes because they are able to use PCA services. This service is keeping many people out of more restrictive service settings and plays an absolutely critical role in the lives of Minnesotans with disabilities and their families. The State should make every effort to maintain this service option for people who need it.

Develop a comprehensive training program and professional guidelines/ethical practice standards for PCA workers.

The lack of adequate, sufficient and right types of training was a major concern of the majority of focus group participants. In most situations, PCAs felt unprepared and unqualified to provide PCA services to the individuals they supported. Most PCA recipients, especially those using a traditional PCA service approach, expressed strong and consistent opinions about the lack of basic and specific training their PCAs had to provide quality PCA services to meet their needs.

PCAs need to be trained. They need to be afforded a set of professional guidelines and ethical practice standards. There are core competencies that all PCAs need to have in order to be effective at their jobs and other skills that PCAs only need if they are providing services to someone who requires that skill. Efforts should be made to create a statewide infrastructure for a multi-tiered training and career development program for PCAs. This training model should include basic, advanced, and specialized training components that are available to the workers in ways that are easily accessible and timely. Completion of each tier could be accompanied with a wage incentive to support retention and professional development of PCAs in Minnesota.

Develop and provide a specific training curriculum for PCA workers who serve recipients with behavioral needs.

PCAs are providing services and supports to individuals who have significant needs in the area of interpersonal skill development, challenging behavior and counseling. The PCA program is based on a medical model and has traditionally been offered as a means to provide support to people who need help with activities of daily living and instrumental activities of daily living. Over time, the PCA program has been used to support people with greater mental health and cognitive needs, and has prevented many people with these needs from living in more expensive institutional and congregate care settings. However, PCAs are not trained to provide adequate mental health and behavioral support services. They need this advanced level training. The Minnesota Department of Human Services should ensure that PCAs who support people with challenging behavior and mental health needs are adequately trained to do so.

Ensure that adequate supervision is provided to all PCAs working in all types of PCA services in Minnesota.

PCAs are workers. They need training, support and supervision to be effective at their jobs. Both workers and recipients who participated in the focus groups indicated that PCAs receive

little to no supervision. Stories were shared by workers that illustrated that when supervision does occur it most often happens in the office or in a group situation where an organization brings all PCAs together in a group meeting and calls that supervision. PCAs need one-to-one supervision and need to be observed doing their work on the job where the work happens. Efforts need to be made to develop and ensure that adequate supervision is provided to PCAs in ways in which they get individual guidance, mentoring, feedback, direction and support from a supervisor on site.

Strengthen and support family members as caregivers and develop monitoring protocols to address unique challenges posed by this service model in the PCA program.

While PCA workers expressed differing views about allowing family members to be paid caregivers in Minnesota's PCA program, recipients overall favored this care delivery model. However, the concerns raised by workers, such as the potential for family members to take advantage of recipients and the need for professional boundaries expressed by family members, warrant close monitoring of this model.

In order to address the unique challenges that family members as paid caregivers in Minnesota's PCA program present, DHS should develop and implement appropriate monitoring protocols that facilitate consumer choice in using this model, yet reduce potential abuses and inappropriate activities, however limited or rare, that this model may elicit. Support and training specifically for families who work as PCAs should also be provided. This training should include ethical practice guidelines (such as the NADSP standards) and provide training on how to balance the dual roles of PCA provider and family member. National and non-profit organizations could serve as resources to develop a stronger model in Minnesota to support family members serving as PCAs: the Administration on Aging's National Family Caregiver Support Program is one resource.³

Develop a systemic tool that will assist in facilitating recruitment of PCAs by recipients and help link PCAs to recipients.

Many PCA recipients, as well as some PCAs, experienced some significant difficulties with matches made between PCAs and PCA Recipients. Also, service recipients who used the PCA Choice model expressed difficulty finding qualified PCAs using traditional recruiting strategies such as newspaper advertisements, posting on bulletin boards or web sites and referrals from people who did not know them or their needs. Consideration should be given to developing and maintaining a statewide systemic method for matching PCA workers to service recipients that can be used by PCA recipients (or their families), PCAs and organizations.

³ http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx. The Administration on Aging's National Family Caregiver Support Program established in 2000, provides grants to States and Territories, based on their share of the population aged 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible.. Resources and studies about various states' programs may provide insight for Minnesota to strengthen its program.

Exhibit 3. Summary of Preliminary Recommendations and Opportunities for Action

Topic	Findings		Discussion	Recommendations
	PCA Recipient Focus Groups	PCA Worker Focus Groups		
PCA program in general	<ul style="list-style-type: none"> ▪ Service recipients and family members/personal representatives described a wide array of services and supports provided by the PCAs that are very similar to those described by the PCAs themselves. ▪ PCA recipients communicated the important and active role that PCAs play in helping them stay healthy and safe. 	<p>PCAs expressed that they provide a wide array of services and supports to consumers, thus playing an important role in the lives of the recipients they serve.</p>	<ul style="list-style-type: none"> ▪ PCA services are essential to the safety, health, well-being and enrichment of the lives of recipients. ▪ PCA program provides essential services to people with physical, mental health, intellectual, and developmental disabilities, the elderly, people with traumatic brain injury. ▪ PCA program allows families to stay together; persons with disabilities can remain in their communities and homes. ▪ The PCA program keeps many people out of more restrictive service settings. 	<ol style="list-style-type: none"> 1. Continue to maintain and strengthen PCA services as a Medical Assistance service option for individuals with a variety of physical, intellectual, and developmental disabilities.
Family Members as PCAs	<p>Most consumers favored having family members as PCAs</p>	<p>PCAs voiced varied and opinions about family members providing PCA services to their loved one</p>	<ul style="list-style-type: none"> ▪ Family members to work as PCAs for their loved ones helps meets a service gap and provides consumer choice. ▪ Family members as paid caregivers present unique challenges to the program. 	<ol style="list-style-type: none"> 1. Continue to allow family members to serve as PCAs. 2. Develop and implement strategies to address specific challenges posed by family members and paid caregivers. 3. Review national resources for ways to strengthen and support this program (e.g., NADSP Code of Ethics).

Findings

Topic	PCA Recipient Focus Groups	PCA Worker Focus Groups	Discussion	Recommendations
<p>PCA Working Conditions (i.e., wages, benefits, hours worked, etc.) and Service Quality</p>	<ul style="list-style-type: none"> ▪ PCA recipient perspectives reflected similar challenges expressed by workers in with respect to the hours worked. ▪ PCA recipients had mixed experiences with the quality of PCA services which they receive. ▪ PCA recipients expressed challenges associated with having an appropriate and adequate back-up plan in place to implement when their usual PCA is not available 	<ul style="list-style-type: none"> ▪ PCA workers expressed lack of benefits and “low” or inconsistent wages across PCO organizations and programs as major employment issues. ▪ PCA workers expressed the need for key changes in the areas of affordable health insurance, wages, and training, to improve Minnesota’s PCA program. 	<ul style="list-style-type: none"> ▪ Low wages and lack of affordable benefits were clearly identified by both recipients and PCA worker, and in all programs (e.g. PCA Choice, traditional PCA services, managed care) as critical problems that contributed to health and safety issues, retention of good PCAs, and overall service quality. ▪ Long working hours in order to make a “livable” wage puts the PCA at greater risk for making errors and harming PCA recipients. ▪ Poor wages and lack of access to health benefits affect quality and quantity of services delivered. 	<ol style="list-style-type: none"> 1. Conduct a comprehensive evaluation of wage levels and insurance options for workers, and develop options for improvement (e.g., the currently ongoing direct care worker/provider survey). 2. Develop affordable health insurance options (e.g., access to affordable pools for PCA agencies or workers, or buy-in options under existing government programs). 3. Develop wage incentives for PCAs based on completion of a well-designed certification or credentialing program for PCAs (e.g. NADSP credentialing framework) which demonstrates competence in the service needs of PCA recipients (e.g. complex behavioral and health challenges).
<p>PCA Training, Supervision and PCA/Recipient Support</p>	<ul style="list-style-type: none"> ▪ PCA recipients expressed mixed experiences regarding the traditional PCA program option. ▪ PCA recipients favored the PCA Choice program in terms of level of control and flexibility over the activities the PCA performed, but 	<ul style="list-style-type: none"> ▪ PCA workers expressed challenges in work-live balance and working with clients with challenging behaviors. ▪ PCA workers described vastly differing experiences with regard to training, career development, 	<ul style="list-style-type: none"> ▪ The lack of adequate, sufficient and right types of training was a major concern of the majority of focus group participants ▪ PCAs felt unprepared and unqualified to provide PCA services to the individuals they supported. ▪ Most PCA recipients, especially those using a 	<ol style="list-style-type: none"> 1. Develop a comprehensive training curriculum to include: <ul style="list-style-type: none"> - Professional guidelines/ethical practice standards for PCA workers. - Core competencies that all PCAs need to have in order to be effective at their jobs and other skills that PCAs. - A specific curriculum for

Findings

Topic	PCA Recipient Focus Groups	PCA Worker Focus Groups	Discussion	Recommendations
	<p>expressed challenges with their employer responsibilities, and lack of support.</p> <ul style="list-style-type: none"> ▪ PCAs get little on site supervision from organizational supervisors. ▪ Service recipients are not trained on how to hire, train and supervise workers. 	<p>recognition and supervision from their employer.</p> <ul style="list-style-type: none"> ▪ PCAs get little to no supervision. When it does occur it often happens at the organizations office or in a group situation. ▪ PCAs want more direction and guidance on how to do their jobs. 	<p>traditional PCA service option, expressed strong and consistent opinions about the lack of basic and specific training their PCAs had to provide quality PCA services to meet their needs.</p> <ul style="list-style-type: none"> ▪ PCAs are providing services and supports to individuals who have significant needs in the area of interpersonal skill development, challenging behavior and counseling. ▪ Over time, the PCA program in MN has been used to support more people with greater mental health and cognitive needs. However, PCAs are not trained to provide adequate mental health and behavioral support services. ▪ PCAs are workers. Workers need training, guidance, direction and support. This happens from a designated supervisor and it was not occurring for nearly all of the PCA workers in the focus groups. 	<p>PCAs who service recipients with behavioral health needs.</p> <ol style="list-style-type: none"> 2. Create a statewide infrastructure for a multi-tiered training and career development program (basic, advanced, specialized curriculum) for PCAs by working through the Minnesota State Colleges and Universities (MNSCU) and other educational institutions and private sector businesses/providers. Provide a wage incentive by tier to support retention and professional development of PCAs in Minnesota. 3. Ensure that all PCAs who work in all types of PCA services in Minnesota receive adequate supervision on site. 4. Ensure that service recipients who self-direct receive training on how to be an effective supervisor.

Findings

Topic	PCA Recipient Focus Groups	PCA Worker Focus Groups	Discussion	Recommendations
PCA recruitment	PCA recipients discussed a wide variety of strategies employed to find, choose, keep and train their PCA workers		<ul style="list-style-type: none"> ▪ PCA recipients and PCAs, experienced difficulties with finding the right PCA worker-recipient match. ▪ Recipients in the PCA Choice option expressed difficulty finding qualified PCAs using traditional recruiting strategies such as newspaper advertisements, posting on bulletin boards or web sites and referrals from people who did not know them or their needs. 	1. Developing and maintain a statewide method that can be used by PCA recipients (or their families), PCAs and organizations to find effective and appropriate PCAs and match them to people who are trying to find a PCA.

Appendix A

Focus Groups

Appendix A
List of PCA Consumer and Worker Focus Group

Focus Group Type	Location	Date	Participants
Consumer	Bloomington	1-21-09	7
Consumer	Mankato A	1-23-09	4
Consumer	Roseville	1-26-09	9
Consumer	Duluth	1-28-09	10
Consumer	Minneapolis	1-30-09	7
Consumer	Bemidji A - Native American	3-4-09	3
Consumer	Bemidji B - Open	3-4-09	6
Consumer	Mankato B	3-12-09	9
SubTotal			55
Worker	Brainerd A	1-20-09	2
Worker	St. Paul	1-27-09	3
Worker	Minneapolis	2-4-09	12
Worker	Brainerd B	2-24-09	1
Worker	Bemidji - Native American	3-4-09	3
Worker	Mankato	3-12-09	4
SubTotal			25
Total Focus Groups 14		8 Locations	Total 80

Appendix B

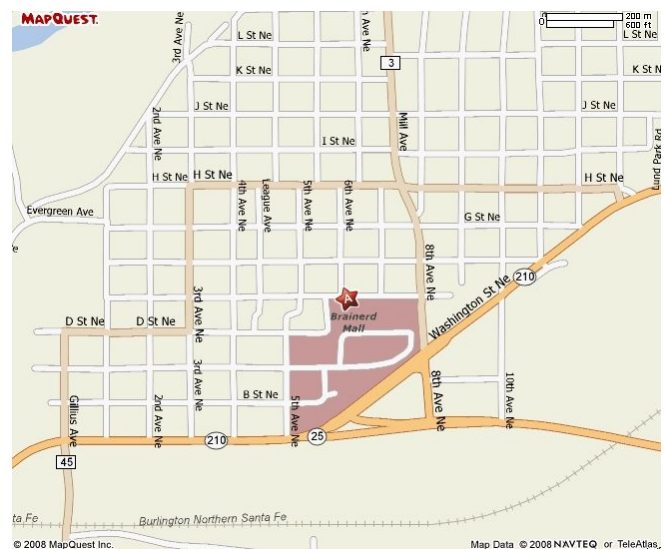
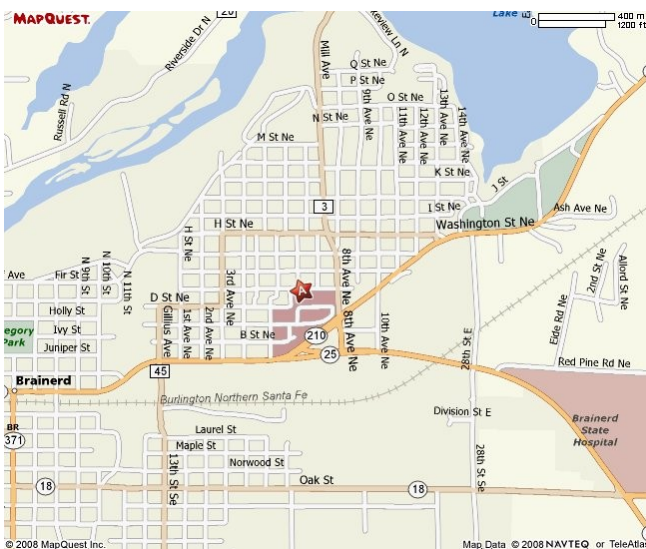
Sample Focus Group Flyers

Minnesota PCA Services Focus Group for Workers

Brainerd
Tuesday February 24, 2009
3:30-5:00PM

The purpose of this study is to learn more about how well personal care assistant services helps (or does not help) people with disabilities (and their families) function in their daily lives and activities. We want to learn how people with disabilities (or their families) use personal care assistant services.

**Location: Lutheran Social Services
Training Room
716 E. Street
Brainerd, MN 56401**



LSS is located in the East Brainerd Mall

For further information please contact John Sauer at: sauer006@umn.edu, W: 612-626-0535, C:651-231-1262

PCA Services Consumer and Worker Focus Groups to be held in January '09

The Minnesota Consortium for Citizens with Disabilities (MN-CCD) is working with the University of Minnesota, College of Education and Human Development, to identify organizations that can help the University of Minnesota find participants for a series of focus groups on the topic of Minnesota's Personal Care Assistant (PCA) Program. The results of these sessions will be used to make recommendations that will improve the PCA Programs in Minnesota.

The U of MN is requesting your organization's assistance in helping to identify PCA consumers to participate in these focus groups.

Focus Group Participants:

- Should receive personal care assistant (PCA) supports OR should be employed as a personal care assistant either through Minnesota's Medicaid State Plan Services or through Minnesota Home and Community Based Waiver Services.
- Will be in a focus group with about 7 – 10 other people and the focus group will last about 1.5 hours.
- Will answer questions about how they use or provide personal care attendant services.
- Will be given a \$30 gift card for their participation in the focus group, and if requested transportation costs necessary for participation will be reimbursed.
- Will be assured accommodations (translator, ASL interpreter, etc...) if necessary for participation.

Focus Groups:

- Will be held in six locations throughout MN during the month of January. The six sites will be: Roseville, Bemidji, Mankato, Bloomington, Duluth and Minneapolis.
- Will last approximately 90 minutes.
- Detailed information regarding specific dates and locations will be provided to those who express interest in participation.

If you are interested in working with the U of MN staff on this project, please contact John Sauer at: 612.626.0535 or e-mail him at sauer006@umn.edu. You may also leave a message for him to return your call at 1-800-582-5256, ext. 112.

Thank you for your consideration of assisting the U of MN staff in identifying participants for this important study.

Minnesota PCA Services Focus Group for Consumers

Tri-Reservation

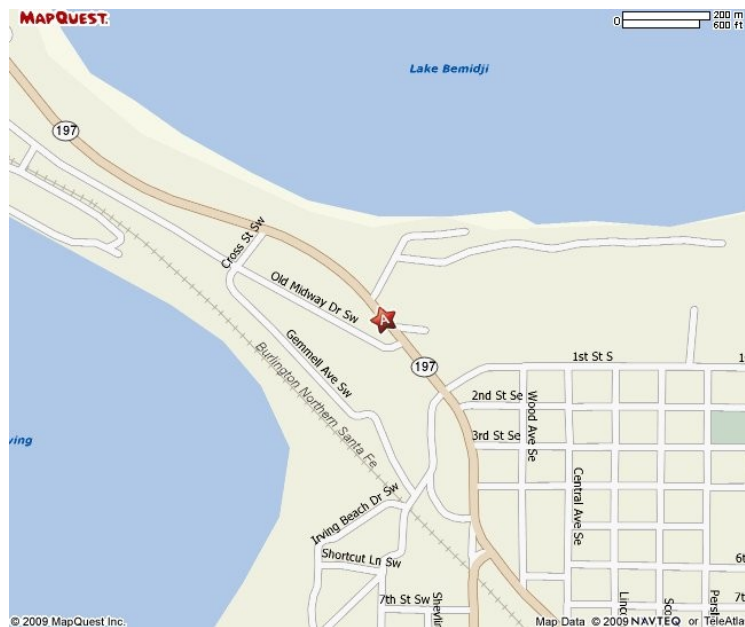
(Red Lake, White Earth, Leech Lake)

Wednesday March 4, 2009

3:30-5:00PM

The purpose of this study is to learn more about how well personal care assistant services helps (or does not help) people with disabilities (and their families) function in their daily lives and activities. We want to learn how people with disabilities (or their families) use personal care assistant services.

Location: Hampton Inn and Suites
1019 Paul Bunyan Drive So.
Bemidji, MN 56601
Room 322



For more information on directions, please contact the Hampton Inn at:
218-751-3600

For further information please contact John Sauer at: sauer006@umn.edu, W: 612-626-0535, C:651-231-1262

Appendix C

Moderator Guides

Focus Group Moderator Guide

For

Focus Groups with Personal Care Assistants (PCAs)

December 11, 2008

Needed resources:

- A comfortable and private room with seating arranged in a circle
- Flipchart and markers
- Name tags or name cards (first names only)
- Refreshments (ensure accessibility)
- Digital Audio Recorder (Useable with groups of 8 - 12 participants)
- Demographic survey copies
- Accessible space and materials

Moderator Instructions:

1. Plan to spend about 2 hours for preparation, facilitation, and follow-up for each session.
2. Plan for groups of 8 to 12 participants for seating, refreshments and any materials.
3. If possible, have a partner to help with the group, so that one can facilitate and one can record
4. Start with informal conversation, invite participants to have refreshments, and make sure that their name cards on the table in front of them.

Welcome/Introductions/Logistics

- Begin the Focus Group session with: *"Hello and welcome to our focus group session today. Thank you for taking the time to join our discussion about your experiences as a Personal Care Assistant and for your willingness to share your thoughts, feelings, and suggestions. I know that in Minnesota we also use titles like Personal attendants, personal assistants, direct care workers. For our focus group today, we will use PCA or Personal Care Assistant throughout our time together."*
- Moderators(s) introduce yourself and indicate your role as the moderator (or co-moderator) and also introduce the recorder and any other U of MN staff present.
- Inform people where they can find the bathrooms and that they can help themselves to refreshments, and take a stretch whenever they need to. Ask them to do this quietly if they do.

Purpose of Focus Group

- We are working on a project funded by the Minnesota Department of Human Services regarding PCA services in Minnesota. We are trying to get a better picture and understanding of Minnesota's Personal Care Assistant services by listening to the thoughts, stories, and experiences of PCAs who work directly with service recipients. Some of the main topics we will talk about include:
 - wages and benefits,
 - your work
 - hours you work and the provider/organization you work for
 - environments and locations in which you provide PCA services,
 - reasons you choose this type of work
 - job responsibilities and duties
 - the type of support you get from the organization in which you work
 - orientation and training for PCAs.
 - using family members as PCAs
- At other times and places, we will also be conducting focus groups with persons who receive PCA services, including adults, adolescents, and family members of children.
- We will use the results of these sessions to make recommendations that will improve the PCA Programs in Minnesota.
- Describe how participants were selected.
 - *Personal Care Assistants:* You were invited to participate in this discussion today because you work as a PCA. We worked with the Department of human Services, Provider Organizations, and Advocacy Agencies to identify participants.
 - Your thoughts, stories, and suggestions are a very important part of future planning for Minnesota's PCA programs by the Disability Services Division and Long Term Care Program within Minnesota's Human Services Department. Your comments and shared suggestions will be confidential and your names will not be shared.

Guidelines for Participating in the Focus Groups

Explain the following items briefly:

- Participants are assured of complete anonymity. Our reports will NOT include any names, and only aggregate information will be shared with the Department of Human Services or the public.
- It is important that you remember the need to keep the names and personal information about the people you support confidential. You should be able to do this by simply not sharing the names or any identifying information about them. Just refer to "the person I support....." when talking about a specific person.

- Participants must give their consent to participate in these focus groups. This is a requirement of conducting research at the U of MN and the Department of Human Services. Please make sure that you have given this consent.
- We will be asking you, as a participant in this group, to give their thoughts, experiences, and suggestions in response to the specific questions we ask.
- We expect to spend about an hour to 1 ½ hours with each session. We will not be taking a formal break. Please feel free to leave the table to use the restroom, get some refreshments, or stretch, but please do so quietly.
- We will be tape-recording the session because we don't want to miss any one's comments. Having an audio tape will help us capture your thoughts completely and accurately. Only the researchers at the U of MN responsible for summarizing people's comments will have access to the tapes.
- Only one person should talk at a time. If several people are talking at once, the tape will get garbled and we'll miss your comments. Please speak loudly and clearly.
- We want to hear from everyone in the group. Please monitor yourself and make sure that you are giving everyone a chance to talk. From time to time, as a moderator, I might remind the group that we need to give everyone a chance to talk.
- We will be discussing your ideas and experiences about Minnesota's PCA services. Your opinions are important. There are no right or wrong answers, but rather differing points of view. Please feel free to share your point of view, even if it differs from what others have said.
- Please keep the conversation on track – as the moderator, I may steer you back if the conversation gets off-topic.
- If you find that there is something you would like to say, but you feel uncomfortable saying it out loud, you can write it down or approach one of the moderators at the end of the group session and we will make sure that we gather your input and response to the question.

Questions: Personal Care Assistants focus groups

Introduction: *“Let's begin. We've placed name cards on the table in front of you to help us remember each other's names. Let's find out some more about each other by going around the room one at a time. Please introduce yourself and share anything else you feel comfortable sharing with other participants (For example: How many years you have been providing PCA Services)”*.

TOPIC Area 1: Your Work as a PCA

1. Tell us about your work as a PCA; what, where, how and why do you do this work?

Prompts: Why did you choose to do this type of work? Where to you go to do your work, in what types of environments? How many hours do you work in what settings and for how many people with support needs? Describe for us a typical day at your work; what are your job duties and responsibilities?

Follow Up: What are the hardest things about your work? Best things?

TOPIC Area 2: **Compensation and Benefits**

2. What are your thoughts, feelings, and experiences about wages and benefits for PCAs in Minnesota's system?

Prompts: Think about: How does your wage and access to benefits affect your life? How do they compare to the wages and benefits of others in your family, community and other jobs?

Follow Up: What suggestions do you have for improving the wages and benefits that PCAs currently receive in Minnesota's PCA programs?

TOPIC Area 3: **Provider Organization/Employer**

3. In what ways does your employer (the organization in which you work) support you? What are your experiences and stories about receiving orientation as a new PCA and training to meet the needs of service recipients?

Prompts: Think about: What support do you want but do not receive? How does your organization/employer provide you with orientation? On-going training?

Follow Up: What suggestions do you have for improving the support you get from the organization(s) in which you work as a PCA? What suggestions do you have for developing or improving orientation and training activities in Minnesota's current PCA program?

TOPIC Area 4: Family members as PCAs

4. What are your thoughts and feelings about family members being able to be PCAs?

Prompts: Think about: The benefits and challenges of family members being able to be a PCA. What it might be like for a service recipient to tell a family member she or he does not do a "good job" as a PCA with certain tasks. How to ensure the PCA maintains anonymity with the family member as a service recipient.

Follow Up: What suggestions do you have for improving the process for using family members as PCAs in Minnesota's current PCA program?

IV. Concluding the focus group

Turn off the tape recorder. Our discussion is now officially completed. Thank you for your time and assistance. Do you think we've missed anything in the discussion? If so, tell me about it.

After the focus group

At the end of each focus group recording, please dictate: the Date and Location of the focus group, the type of group you led (PCAs or Recipients of Services), the number of people in your group, and the name(s) of the moderator(s).

Bring the digital recorder to Amanda Webster at ICI and ask her to transcribe and clearly label each focus group discussion and to send an e-mail to John Sauer at sauer006@umn.edu and to Amy Hewitt at hewit005@umn.edu with the attached transcriptions

Focus Group Moderator Guide

For
Focus Groups with Recipients of PCA Services

Dec 11, 2008

Needed resources:

- A comfortable and private room with seating arranged in a circle
- Flipchart and markers
- Name tags or name cards (first names only)
- Refreshments (ensure accessibility)
- Digital Audio Recorder (Useable with groups of 8 - 12 participants)
- Demographic survey copies
- U of MN staff to who are not facilitating the focus groups to assist with filling out demographic surveys and back up for any personal needs
- Accessible space and materials

Moderator Instructions for all groups:

1. Plan to spend about 2 hours for preparation, facilitation, and follow-up for each session.
2. Plan for groups of 8 to 12 participants for seating, refreshments and any materials.
3. Ensure that there are two U of MN staff moderators to help with the group, so that one can facilitate and one can record
4. Ensure that there is at least one additional U of MN staff person to assist the participants as needed. This person(s) should not have any facilitation or recording responsibilities.
5. Start with informal conversation, invite participants to have refreshments, and make sure that their name cards on the table in front of them.

Welcome/Introductions/Logistics

- Begin the Focus Group session with: *“Hello and welcome to our focus group session today. Thank you for taking the time to join our discussion about your experiences as a Recipient of Personal Care Assistant Services and for your willingness to share your thoughts, feelings, and suggestions. I know that in Minnesota we also use titles like Personal Attendants or Personal Assistants. For our focus group today, we will use PCA or Personal Care Assistant throughout our time together.”*
- Moderators(s) introduce yourself and indicate your role as the moderator (or co-moderator) and also introduce the recorder and any other U of MN staff present.

- Inform people where they can find the bathrooms and that they can help themselves to refreshments, and take a stretch whenever they need to. Ask them to do this quietly if they do.
- Let the group know that we have U of MN staff there to support them in whatever way they need.

Purpose of Focus Group

- We are working on a project funded by the Minnesota Department of Human Services regarding PCA services in Minnesota. We are trying to get a better picture and understanding of Minnesota's Personal Care Assistant programs by listening to the thoughts, stories, and experiences of persons who receive PCA services, including adults, adolescents, and family members of children who have various types of disabilities and support needs. Some of the main topics we will talk about include:
 - How you use PCA services
 - Areas of life assistance
 - Locations/where they work
 - quality of services,
 - consumer choice and control,
 - health and safety
 - changes you would recommend
 - staffing
 - availability of providers and PCAs,
 - service provision and back-up plans,
 - family members as PCAs,
 - opportunities to be involved in recruitment, selection, training and retention of PCAs
- At other times and places, we will also be conducting focus groups with PCAs who support children, adults, elderly and people with various types of disabilities throughout Minnesota.
- We will use the results of these sessions to make recommendations that will improve the PCA Programs in Minnesota.
- *Describe how participants were selected.*
 - *Persons who are using PCA Services:* You were invited to participate in this discussion today because you use PCA services. We were able to invite you because the Department of human Services, your provider or an advocacy organization recommended that we invite you.
 - Your thoughts, stories, and suggestions about Minnesota's PCA services are a very important part of future planning for the Disability Services Division and Long Term Care Program within Minnesota's Human Services Department.

Guidelines for Participating in the Focus Groups

Explain the following items briefly:

- Participants are assured of complete anonymity. Our reports will NOT include any names, and only aggregate information will be shared with the Department of Human Services or the public.
- It is important that you remember the need to keep the names and personal information about your specific PCAs confidential. You should be able to do this by simply not sharing the names or any identifying information about them. Just refer to “my PCA, or a PCA I know....” when talking about a specific person.
- Participants (or as applicable their legal representatives) must give their consent to participate in these focus groups. This is a requirement of conducting research at the U of MN and the Department of Human Services. Please make sure that you have given this consent.
- We will be asking you, as a participant in this group, to give their thoughts, experiences, and suggestions in response to the specific questions we ask.
- We expect to spend about an hour to 1 ½ hours with each session. We will not be taking a formal break. Please feel free to leave the table to use the restroom, get some refreshments, or stretch, but please do so quietly.
- We will be tape-recording the session because we don’t want to miss any one’s comments. Having an audio tape will help us capture your thoughts completely and accurately. Only the researchers at the U of MN responsible for summarizing people’s comments will have access to the tapes.
- Only one person should talk at a time. If several people are talking at once, the tape will get garbled and we’ll miss your comments. Please speak loudly and clearly.
- We want to hear from everyone in the group. Please monitor yourself and make sure that you are giving everyone a chance to talk. From time to time, as a moderator, I might remind the group that we need to give everyone a chance to talk.
- We will be discussing your ideas and experiences about Minnesota’s PCA Programs. Your opinions are important. There are no right or wrong answers, but rather differing points of view. Please feel free to share your point of view, even if it differs from what others have said.
- Please keep the conversation on track – as the moderator, I may steer you back if the conversation gets off-topic.
- If you find that there is something you would like to say, but you feel uncomfortable saying it out loud, you can write it down or approach one of the moderators at the end of the group session and we will make sure that we gather your input and response to the question.

Questions: Recipients of PCA Services focus groups

Introduction: “Let’s begin. We’ve placed name cards on the table in front of you to help us remember each other’s names. Let’s find out some more about each other by going around the room one at a time. Please introduce yourself and share anything else you feel comfortable sharing with other participants (For example: how long you have been using PCA services).

TOPIC Area 1: Quality of Services

1. What do you use your PCA for? How does she or he assist and support you in your life?

Prompts: Think about: In what areas of your life does your PCA provide you with support? Where are you when they provide you with support? How do they assist you in living your life to the fullest? What works? What are the challenges?

Follow Up: What suggestions do you have for improving PCA services available through Minnesota's PCA programs so that they are the most useful to you?

2. What are your thoughts or ideas about what and how much choice and control you have about the PCA services you receive?

Prompts: Think about: What does choice mean to you? What does control mean to you? What is really important to you about the type and amount of control you want in your life related to the PCA services you need?

Follow Up: What suggestions do you have for improving the type and level of choice and control persons have for the PCA services available through Minnesota's PCA programs?

3. Tell us about how the PCA services you receive help to keep you safe and healthy?

Prompts: Think about: What does being healthy and safe mean to you? In what ways do your PCAs support you in being healthy and safe?

Follow Up: What suggestions do you have for improving the PCA services available through Minnesota's PCA programs so that they better support you in being healthy and safe?

4. What are your thoughts, experiences, and stories about the quality of service you receive through Minnesota's PCA programs?

Prompts: Think about: What does quality mean to you? How do you feel quality is measured? Who can or must be held accountable for the quality of support you receive – the legislature, state agencies, county personnel, your PCAs? To whom do you go to discuss concerns you may have about your quality of support?

Follow Up: What suggestions do you have for improving the quality of care in Minnesota's PCA program?

TOPIC Area 2: Staffing

5. What are your thoughts and experiences about being able to be involved in finding, choosing, keeping and training PCAs to provide services that meet your needs?

Prompts: Think about: What are things you do now to find, choose, keep and train quality PCAs? What training would you like PCAs to receive so that your life is better? How do you recognize and reward your PCAs for doing quality work?

Follow Up: What suggestions do you have for developing or improving the recruitment, hiring, orientation and training activities in Minnesota's current PCA program?

6. Describe a situation that involves how PCA services have or have not been provided to you? Tell me about a time when back up plans to provide PCA services to you were done well? Poorly?

Prompts: Think about: The type, level, and quality of services you receive. Do you get the amount of PCA services that are authorized to you? Why or why not? Who is/are the responsible party(ies) for "back-up"? What strategies do your back-up plans include? Who helps out when back-up plans don't work?

Follow Up: What suggestions do you have for improving Service Provision and Back-Up Plans in Minnesota's PCA program?

7. What are your thoughts and feelings about your family members being able to be your PCA and able to provide PCA services to you?

Prompts: Think about: The benefits and challenges of family members being able to be a PCA. What it might be like for you as a service recipient to tell a PCA family member that she or he does not do a "good job" as a PCA with certain tasks. How to ensure the PCA family member maintains anonymity with the family member who is a service recipient.

Follow Up: What suggestions do you have for improving the process for using family members as PCAs in Minnesota's current PCA program?

IV. Concluding the focus group

Turn off the tape recorder. Our discussion is now officially completed. Thank you for your time and assistance. Do you think we've missed anything in the discussion? If so, tell me about it.

After the focus group

At the end of each focus group recording, please dictate: the Date and Location of the focus group, the type of group you led (PCAs or Recipients of Services), the number of people in your group, and the name(s) of the moderator(s).

Bring the digital recorder to Amanda Webster at ICI and ask her to transcribe and clearly label each focus group discussion and send an e-mail to John Sauer at sauer006@umn.edu and to Amy Hewitt at hewit005@umn.edu with the attached transcriptions