COMMUNITY INTEGRATED PERSONAL ASSISTANCE SUPPORT SERVICES (CPASS)

Information Relating to the Personal Care Assistance (PCA) Waiver and Department of Mental Retardation (DMR) Portions of the Research Study

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Introduction

The overall purpose of the CPASS Study is to evaluate the effectiveness training has on the ability for an employer to hire and manage their personal assistants.

The multi-step nature of this project required a series of small, but focused evaluation strategies that directly addressed each step. The proposed methodology followed each phase of the study. They include the following:

Curriculum Development

At the initial phase of the Community Integrated Personal Assistance Support Services (CPASS) grant, a training subcommittee was formed to review and analyze existing training methods and/or curriculums throughout the country that were researched by CPASS staff. The training subcommittee consisted of a variety of employers with various disabilities who had significant experience in hiring and managing personal assistants.

Based on the review of materials, the training subcommittee stated that there was a need to develop a new curriculum based on information that was thought to be important to someone new or struggling with the process of hiring and managing personal assistants. As a result the following curriculum was developed:

Title: YOU Are the Employer - A Guide to Hiring and Managing Personal Assistance Services

- **Chapter 1:** Knowing What You Need and Want
  This chapter focuses on helping employers identify their needs and wants in order to be able to develop a plan for hiring personal assistants to meet these needs.
- **Chapter 2:** The Hiring Process

This chapter focuses on the various steps needed to hiring a personal assistant. This includes: development of a job description based on the needs expressed in Chapter 1 and other documentation important in the hiring process, recruiting a personal assistant, screening and interviewing for a personal assistant, how to make a decision about who to hire, and orientation of a new personal assistant.

- **Chapter 3:** Tax Considerations

  This chapter focuses on what an employer should know about tax requirements and guidelines as it pertains to hiring a personal assistant, and who is responsible for reporting and maintenance of these requirements.

- **Chapter 4:** Employer Responsibilities

  This chapter focuses on what an employer's responsibilities are in managing personal assistants on an ongoing basis. Areas covered include: ongoing documentation (e.g. personnel file), periodic reviews, issues to be familiar with around safety, abuse and neglect, and termination and unemployment issues.

- **Chapter 5:** Managing Stress

  This chapter focuses on the importance of stress management for both the employer and personal assistant. Areas covered include: identifying stress, communicating needs, preventing burnout and ways to reduce stress.

- **Chapter 6:** Communication Skills

  This chapter focuses on the importance of developing communication skills that are needed to successfully communicate as an employer with a personal assistant. Areas covered include: understanding personalities, communication and learning styles, expectations and clarity, and developing a positive relationship.

- **Chapter 7:** Additional Resources

  This chapter identifies additional resources available around hiring and managing personal assistants.

The topics reflected in the curriculum were discussed by experienced employers who felt these topics were critical to the success of hiring and managing personal assistants as experienced in their own lives and the work they do to assist others with disabilities in the process.

Pilot Phase of Study

One novice employer / intervention pilot participant was chosen from each of four state waiver programs to evaluate the effectiveness of the initial training curriculum that was developed: the Personal Care Assistance (PCA) Waiver, Elder Waiver, Acquired Brain Injury (ABI) Waiver, and Department of Mental Retardation (DMR) Waiver. Pilot participants were trained by CPASS staff using the curriculum as the basis for training. Upon completion of the training, the curriculum was adjusted to meet the needs that were highlighted in the pilot phase of the study. The most relevant of the adjustments included the need to develop several curriculums to meet the individual needs of a particular waiver and the participants they serve. As a result, it was determined that there would be two separate phases of training with curriculums that will meet these needs. The first phase of training would involve training participants in the PCA and Elder Waivers, and the second phase would involve training participants in the DMR Waiver. Due to the scope of the project, a curriculum was not developed for the ABI Waiver.

PCA and Elder Waivers Study Methodology

All evaluation activities were conducted by researchers at the University of Connecticut Health Center, Center on Aging. Once participants were randomly assigned to either the intervention or control group, every participant was required to complete a baseline telephone interview. For the novice employer/intervention group, the interview occurred one week before they began their training sessions. Interviews with the control participants occurred during the same time period, but the controls would not receive the training at that time. The baseline interview first ascertained participants' current personal assistance status, recruitment, and retention for the previous 3 months. A series of standardized scales to use as dependent variables assessed personal assistant (PA) quality of care (Staff Provision to Resident Care), conflicts (Frequency of Interpersonal Conflict Scale, modified for PA employers), employer hassles (Nursing Home Hassles Scale, modified for PA employers), general self-efficacy (General Perceived Self-Efficacy), PA employer self-efficacy (RIS Eldercare Self-Efficacy scale, modified for PA Employers), and depression (CES-D, 7

item version). Additional questions addressed health, social support, and personal demographics. After the completion of their baseline interview, the intervention group then received their training. One week after their training was complete, the intervention group completed a post-training interview to provide feedback on the training and its impact on their ability to hire and manage their PAs.

Follow-up telephone calls were placed at 3 months and 6 months post-training for the intervention group and at parallel times for the control participants. The three month follow-up interview specifically assessed participants' PA recruitment and retention experiences since baseline. In addition to these questions, the 6 month interview repeated all the baseline measures, including the standardized scales measuring quality of care, PA conflicts, employer hassles, general and specific self-efficacy, and depression. A section on skills learned from the training curriculum was also included for the intervention group.

After the 6 month follow-up interviews were completed, control participants had the option to receive the training and would no longer be tracked.

The study methodology called for 3 additional surveys to be completed by the training teams or CPASS staff. After the train the trainer sessions were complete, CPASS staff filled out an evaluation of the training, including a description of the time spent, number of sessions, material covered, and a brief assessment of the ability and preparedness of each team to teach the CPASS curriculum. The training teams themselves filled out a similar assessment form after the completion of a novice employer's training, which included a brief assessment of the novice employer's abilities and preparedness to manage their own PAs. Evaluation forms were also given to each member of the training team after their training with the CPASS staff in order for them to rate the training they received.

PCA and Elder Waivers Train-the-Trainer Recruitment and Overview

In February 2006, four teams of trainers attended three Train-the-Trainer sessions. Each team consisted of a person with a disability who is an experienced employer of

personal assistants, and their personal assistant. Initially, recruitment of trainers was challenging, particularly due to the difficulty applicants had with transportation and the commitment of time involved, even though the grant reimburses transportation as an accommodation. A description of the training teams follows:

- **Training Team #1** - Consisted of a very experienced employer who has been hiring personal assistants for many years. He has a significant disability and has used a wheelchair his entire life. He needs assistance with most tasks of daily living. The personal assistant also has a great deal of experience in working as a personal assistant with people with a variety of disabilities, particularly people with more significant disabilities that require a great deal of support. The employer and the personal assistant have known each other for several years.

- **Training Team #2** - Consisted of an employer who is somewhat experienced with hiring and managing staff. She has an acquired disability and has been hiring staff for several years. She needs some assistance with personal care, but is still somewhat independent in doing various tasks of daily living. The personal assistant has been working with various people as an assistant for a couple of years. She has worked with people with a variety of needs and is familiar with the roles and responsibilities of being a personal assistant.

- **Training Team #3 -** Consisted of an employer who has a few years experience hiring and managing personal assistants while in college. Her needs have varied over the years from requiring assistance with most tasks of daily living to less support as her disability has changed. The personal assistant also has experience providing a variety of support from the work she has accomplished as a personal assistant and college student.

- **Training Team #4 -** Consisted of an employer who has been hiring personal assistants for several years, and has hired people for more significant support as her disability increased. The personal assistant is new to her experience as a personal assistant, but is familiar with the needs of people with significant disabilities.

The training was conducted over a period of three days, on February 21, 23, and 28, 2006 by two CPASS staff members. Participants were tested on their knowledge following each chapter. Topic areas included a needs self-assessment, the hiring process, tax considerations, maintaining documentation, stress management, communication skills, and additional resources. The training was highly interactive and gave trainers the opportunity to learn information and ask questions about areas that they were not as familiar with. In addition role-playing was included in much of the training as a way for trainers to "teach-back" the content to staff.

Upon completion of the training, recruitment of novice employers occurred. Due to the time commitment, recruitment was difficult. In addition, there were some health and transportation challenges with two of the four training teams. As a result of the challenges encountered, only two training teams conducted trainings with novice employers. The training sessions consisted of the trainers going through the curriculum with each of the novice employers, role-playing, answering questions, sharing helpful information from the trainers' own experiences, and asking for feedback from novice employers to ensure they understood the information presented in each chapter. Trainers were required to provide updates on training sessions to CPASS staff and discuss any difficulties that were arising in the training sessions.

Trainers generally met with novice employers at their homes or living environment (e.g. nursing home) on a weekly basis or a schedule that was convenient for everyone involved in training. CPASS staff attended meetings on an occasional basis to evaluate how the training was going and to address any issues that might arise.

PCA and Elder Waivers Trainer Challenges

A number of challenges arose with the trainings. These challenges included:

- While funds for accommodations were available, transportation was an issue for some of the trainers. CPASS staff were not able to find trainers interested in various areas of the state. As a result, the majority of trainers were from the Hartford area. Only one training team was able to travel throughout the entire state, another training team was able to travel somewhat. The other two training

teams had significant issues with transportation and were not able to participate as trainers. These issues were not expressed until after they went through the train-the-trainer sessions. In addition, with the significant increase in gas prices, transportation overall became an increased issue.

- Scheduling was also an issue with some of the trainers and the novice employers they were assigned to train. This required that some of the trainers be assigned to another participant.

- Some trainers had more experience than others in hiring and managing personal assistants. The curriculum was taught to address very specific topics, however since some trainers did not have experience in these areas, they did not address them in the same way with the people they were training.

- Some trainers had more training skills than other trainers. While trainers were evaluated and received feedback, this created some difficulties.

- There were some personal conflicts between the trainer and the person they were training. This required some changes to be made after training began, impacting the motivation of some participants to continue the training.

- Some trainers were less familiar with some participants' abilities, which was reflected in their training process.

- While trainers had their own individual experiences to share with the people they were training, individual and family dynamics occurred at many of the training sessions that affected the ability of training to be completed as outlined in the train-the-trainer sessions. This required the need for CPASS staff to meet with participants and trainers at times, or provide ways for trainers to work through the issues presented (i.e., issues with family involvement, lack of motivation, or fear of living independently).

- Health issues were a major concern for at least one trainer's ability to adequately complete the training. This created significant gaps in the training sessions, which negatively impacted the participant's ability to retain information. This meant that

often a review of information was needed, and resulted in the training taking much longer than anticipated - sometimes 10 sessions or more.

Challenges were addressed by CPASS staff as they arose, but many of the challenges remained constant throughout the entire training period, which impacted the overall success of the training.

PCA and Elder Waivers Final Outcomes of Training Teams

As noted in the previous section, a number of challenges occurred with the trainer portion of the study. The outcomes of the training teams are as follows:

- **Training Team #1** - Was the most successful of the training teams for a variety of reasons including: 1) they both had significant experience with personal assistance services; 2) their schedules were flexible enough to meet the scheduling needs of the participants; 3) they were able to travel throughout the state for meetings; and 4) they assisted with development of the curriculum so they were very knowledgeable in the content. It should also be noted that the training team stayed together throughout the entire study process.

- **Training Team #2** - Provided significant training to participants in the study. This team had several challenges which affected their ability to provide adequate training. These challenges included: 1) The personal assistant in the training team moved out of state part way through the training, so the employer had to complete training on her own; 2) the employer had significant health and scheduling issues which made it difficult to be consistent with the training overall, and most likely had an impact on the novice employers' ability to learn and retain the content of the curriculum; 3) while the employer has hired personal assistants, she does not have a whole lot of experience in doing so; 4) while the employer stated she had experience with training, previous experience appeared to be different than the training needed for this study and in her experience with people with a variety of disabilities; and 5) traveling was difficult for the trainer so training opportunities were limited overall.

- **Training Team #3 -** Numerous issues occurred with this training team that made it not possible to participate as trainers in the study after the initial train-the-trainer sessions. These issues included: 1) the personal assistant dropped out of the program early on due to work / school scheduling; 2) the employer had significant health issues and was in and out of the hospital; and 3) traveling was difficult since transportation was not available.

- **Training Team #4 -** A number of issues occurred with this training team that also made it so that they could not participate as trainers past the initial train-the-trainer sessions. These issues included: 1) transportation was a significant barrier limiting where the team could train; 2) scheduling was also a barrier and as a result a participant needed to be re-assigned to another team prior to training starting; and 3) retention and knowledge of the curriculum was a challenge throughout the train-the-trainer making it a challenge for the team to train novice employers independently.

PCA and Elder Waivers Participant Recruitment and Overview

Participant recruitment occurred through a variety of ways:
- Allied Community Resources
- The Five Independent Living Centers
- The Nursing Facilities Transition Grant
- Word of Mouth by Oversight Committee Members and CPASS staff

As a result of the above recruitment methods, 26 PCA waiver participants contacted CPASS staff for more information on how to participate in the training. There were no Elder Waiver participants. CPASS staff explained the study in greater detail. CPASS staff then met with anyone who wanted to participate or mailed them the study consent forms. Once the consent forms were signed and returned to the CPASS staff, the participant was randomly assigned to either the intervention or the control group. CPASS staff then gave the research team the participant's name, contact information, and study status. Whenever an intervention participant completed their baseline

interview, the researchers informed the CPASS staff in order that the person's training could begin.

A total of 16 PCA waiver participants were randomly assigned to the intervention study group:

Participant #1 - Initially assigned to work with Training Team #3. Training Team #3 had significant health issues and was not able to do the training. As a result, Participant #1 was assigned to Training Team #1. Participant completed the CPASS training, although several issues arose throughout the training that lengthened the process. Participant #1 had significant health issues and was hospitalized. In addition, the residence of Participant #1 is in a rural area that was difficult for Training Team #1 to get to in the winter time. Other issues that arose during training involved family dynamics. Training Team #1 worked with the mother of the participant to help her understand the training to date, but also encourage Participant #1 (who is a young adult and lives with her mother) to take on more responsibility with the training. Accommodations were made to enable the participant to read the CPASS curriculum from a computer, which helped her to become more independent with the training.

Participant #2 - Was initially assigned to Training Team #4. Schedule conflicts prevented them from working together, and the participant was reassigned to work with Training Team #2. Training Team #2 worked with Participant #2 from August 2006 until November 2006. They completed the training through Chapter 4. Several issues arose during the training that ultimately impacted the ability of Participant #2 to complete the entire training. As the participant was deaf, an interpreter was assigned to attend all training sessions, but scheduling needed to occur at least two weeks prior to the next session. This created gaps in training sessions. In addition, Participant #2 had a great deal of anxiety and difficulty in completing the training on her own. She requested that her personal assistant (who also knew sign language) attend all of the trainings. In November 2006, her assistant left her job to go to school. As a result, Participant #2 did not want to complete the training without her.

Also, additional accommodations were also needed after training occurred. Participant #2 needed to either have the curriculum on her computer or needed someone to assist her with reading and turning pages. Participant #2 had an older Apple computer that could no longer support the computer file of the curriculum (a PDF file). A volunteer was assigned to assist Participant #2 in turning pages but she did not know sign language. Training was also going to be reassigned to Training Team #1 because Training Team #2 had significant health issues and scheduling conflicts that arose. Participant #2 decided not to complete training as a result of the issues mentioned.

Participant #3 - Was assigned to work with Training Team #2. At the beginning of the training in March 2006, Participant #3 was living in a nursing home and preparing to transition into an apartment in the community. He met with Training Team #2 until August of 2006 when he moved to his apartment. Training was completed through the start of Chapter 4. Once Participant #3 moved into the community, he started to have significant health issues and was in and out of the hospital. Training Team #2 also had significant health issues and needed to reschedule several meetings. As a result of the issues, Participant #3 needed to drop out of the training.

Participant #4 - Was assigned to work with Training Team #1. Training occurred between May 2006 and July 2006. Participant #4 is currently living in an apartment in the community but is working through an agency to obtain home health aides / personal assistants. She would like to hire her own assistants again (had some negative experiences in the past). There were no barriers identified based on feedback from Training Team #1. Training Team #1 felt Participant #4 had a very good understanding of the curriculum.

Participant #5 - Was assigned to work with Training Team #1. Training occurred between June 2006 and December 2006. Participant #5 is currently living with his mother. He hires personal assistants, but has great difficulty doing so. His mother primarily assists Participant #5 with the entire hiring and managing process, creating some issues for this participant's independence. As a result, Participant #5 was very

passive throughout the training. CPASS staff worked with the participant and training team to discuss the issues in order for training to be completed. As a result, Participant #5 agreed to complete the training and was less passive; however, he still had difficulties in independent living as it relates to personal assistance hiring and management.

Participant #6 - Was assigned to work with Training Team #1. Training occurred between June and July 2006. Participant #6 was living with his family and preparing to go to college in the fall. He did not have any experience with hiring and managing personal assistants. Training Team #1 completed Chapters 1 and 2 with the participant. The participant at that time would not return phone calls or respond to a letter sent by CPASS staff to find out if he was interested in completing the training. Therefore, he was removed from the study. Feedback from Training Team #1 stated that the participant was extremely passive in completing chapters and in his overall understanding of why it is important to receive training on hiring and managing personal assistants. It was stated that he did not appear to be ready to hire and manage staff.

Participant #7 - Was assigned to work with Training Team #1. Training occurred between May and September 2006. Participant #7 lived in a nursing home and had acquired his disability fairly recently. He wanted to move into the community but did not know anything about hiring and managing personal assistants. There were no barriers that were identified based on feedback from Training Team #1. Training Team #1 felt Participant #7 had a very good understanding of the curriculum. After completion of the training, Participant #7 located housing to move into. However, due to a waiting list, he was not able to obtain services through the PCA Waiver and was unable to move.

Participant #8 - Was assigned to work with Training Team #2. Training occurred between August and December 2006. Participant #8 was living with her family. She had been hiring and managing personal assistants, but had struggled with this. Due to health related issues (mostly of the trainer) and support needed to help the

participant go through the chapters, training took a lot longer than expected. Training Team #2 stated she did well with learning the curriculum and had a very good understanding of how to hire and manage personal assistants.

Participant #9 - Was assigned to work with Training Team #2. Training occurred between June and December 2006. Participant #9 was living in a nursing home. She has lived in the community in the past and has hired personal assistants but really struggled with this, and ultimately had to move into a nursing home due to lack of supports and other health related issues. Again, training took a lot longer than expected due to health related issues for both the participant and the trainer. In addition, Participant #9 had a lot of anxiety issues that often needed to be addressed throughout the trainings, by CPASS staff as well as the training team. Participant #9 also required additional accommodations. A tape recorder and a volunteer to assist with reading the materials were provided to assist in learning and understanding the curriculum. While issues did occur, Training Team #2 felt Participant #9 had a good understanding of the curriculum and how to hire and manage personal assistants. However, it was also recommended that the participant receive ongoing support with "the ups and downs" of hiring personal assistants.

Participant #10 - Was assigned to Training Team #2. Training occurred between September and October 2006, but has not been completed. Training included Chapters 1 and 2. In May 2007 Participant #10 contacted CPASS staff asking if she could complete the training. An additional training session occurred and Chapters 4 and 5 were reviewed. Training still has not been completed. Several barriers occurred including health related and scheduling issues with both the participant and the trainer. In addition, there appeared to be some conflict between the participant and the trainer, but the participant did not want to work with another trainer. The trainer stated that Participant #10 appears to be somewhat prepared to continue to hire and manage personal assistants (she has been doing so for some time, but not very successfully). The trainer states that the participant has a great deal of anxiety and depression issues that may impact her ability to hire and manage assistants. In

addition, her disability may also make it difficult for her to be organized and stay on task.

Participant #11 - Was assigned to work with Training Team #1. Training occurred between October and December 2006. This participant already had a good understanding and experience of hiring and managing personal assistants. Training Team #1 stated she learned and discussed new techniques presented in the curriculum and is very prepared to continue to hire and manage personal assistants.

Participant #12 - Completed the baseline interview. This participant met once with Training Team #1, but decided not to participate in the training. She stated health was an issue.

Four participants were chosen randomly to participate in the study as the control group:

Participant #13 - Completed all the phone interviews and was assigned to Training Team #1 to obtain the training that was optional once the phone interviews were completed. This participant already had significant experience in hiring and managing personal assistants. This participant met with Training Team #1 a couple times to review the content of the curriculum, but felt he/she did not need to go through the entire training.

Participant #14 - Completed all the phone interviews and was assigned to Training Team #1 to obtain the optional training. Participant #18 had significant health issues and was not able to complete the training.

Participant #15 – Completed baseline interview. No response to attempts to contact by either telephone or mail for first follow-up interview. Considered withdrawn from study.

Participant #16 – Completed baseline interview. When contacted for first follow-up interview, interviewer informed by family member that the participant could not continue with the program due to a relapse in her health problems. Considered withdrawn from study.

One other participant signed consent forms and was assigned to the control group, but did not complete any phone surveys due to significant health issues and asked to be removed from the study.

Nine additional people contacted CPASS staff to inquire about the training / study. Consent forms were mailed to them but they decided not to participate. Reasons expressed for not participating were that if they could not receive training immediately, they did not want to be a part of the study; no longer interested once the study was described; length of time of the training; and not wanting to sign consent forms / HIPAA forms.

This resulted in 20 participants from the PCA waiver who completed at least a baseline interview: 16 intervention participants (4 pilot and 12 randomly assigned) and 4 control participants (all 4 randomly assigned). The results of their final interview status is as follows:

Intervention (n=16)
- 12 completed the baseline interview, the complete training, the post training interview, and at least 1 follow-up interview (75% completion rate). The completion rate for the 12 non-pilot participants alone is slightly lower (67% completed training and at least 1 follow-up interview).
- 1 completed the baseline interview, the training through Module 4 and the post training interview, but no follow-up interviews.
- 3 completed the baseline interview only: 2 of these completed only the first or second Module of the training, and 1 withdrew after the baseline but before the training began.

Control (n= 4)

- 2 completed all 3 interviews – the baseline, 3 month and 6 month (50% completion rate).
- 2 completed the baseline interview only.

DMR Curriculum Development

The curriculum for waiver participants from the Department of Mental Retardation (DMR) covers the same content, but uses agency terms, such as direct support staff instead of personal care assistant. In addition, the curriculum was rewritten using the Flesh-Kincaid Grade Level Readability Statistic. Individual paragraphs were checked for the entire curriculum to ensure the reading level was at the 6 grade level or lower. The curriculum included specific DMR forms and requirements for hiring and managing direct support staff. Before the curriculum was finalized, a draft version was given to be reviewed by DMR self-advocates and self-determination directors.

DMR Study Methodology

The study methodology used for DMR participants was essentially the same as the one used for the PCA and Elderly waivers. However, due to time constraints, the timing for the follow-up interviews was shortened and the number of follow-up interviews condensed to one. The one follow-up interview for both intervention and control participants consisted of the original 6 month interview, plus 4 questions from the 3 month interview not asked on the 6 month. Intervention participants also completed their post-training interview at this time as well. After this one follow-up interview was complete, control participants again had the option to receive the training and would no longer be tracked.

As requested by DMR, all eight Connecticut DMR self-advocate coordinators were trained as CPASS trainers. To reduce the possibility of transportation difficulties interfering with the novice employer training, the DMR waiver trainers were assigned to novice employers in their region. At least 2 novice employers were then recruited

for each of the eight teams. One was then randomly assigned to the intervention group, and one to the control groups.

As with the PCA trainers, the train the trainer teams for the DMR participants were asked to complete an evaluation of their experience training the novice employer, as well as an evaluation of their own CPASS training.

DMR Train-the-Trainer Recruitment and Overview

In April 2007, eight teams of DMR trainers attended three Train-the-Trainer sessions. Each team consisted of a self-advocate coordinator, who is a DMR consumer, and a self-determination director who is hired DMR staff that assist the self-advocate coordinators. There were no noticeable differences to report among the teams. All self-advocate coordinators were capable trainers, and the self-determination directors were supportive individuals who did their best to provide the necessary supports. Due to resource and time constraints, it was not possible to observe the individual team trainings. However, reports of how the trainings went were provided from the DMR Self-Determination Director, who oversees all self-determination directors and self-advocate coordinators.

The training was conducted over a period of three days, on April 16, 18, and 19, 2007. Participants were tested on their knowledge following each chapter. Topic areas included assessing needs, the hiring process, tax considerations, maintaining documentation, stress management, communication skills and additional resources. The training was highly interactive and gave trainers the opportunity to learn information and ask questions about areas that they were not as familiar with. More time was given to chapters that were challenging for the self-advocate coordinators. For example, completing the Job Activities List was difficult for many people. As a result, extra time was spent on Chapter 1. Role-playing was included in much of the training as a way for trainers to "teach-back" the content to staff, although additional time would have been beneficial for "teach-back" for this group of trainers.

DMR Training Challenges

The novice employer training sessions consisted of the training teams going through and teaching the modified curriculum to the novice employer. The speed at which the training progressed was based on the experience of the employer. Trainers generally met with novice employers at their homes or living environment on a weekly basis or a schedule that was convenient for everyone involved in training. Techniques used in the trainings included role-playing, answering questions, sharing personal experiences, and testing the employer's understanding of a chapter's content.

Trainers were required to provide updates on training sessions to CPASS staff and discuss any difficulties. A few challenges arose with the trainings. These challenges included:

- Participant confusion about the project resulting from the initial contact. Initial participant contact was done by the self-advocate coordinator. In one instance, this led to confusion, causing the individual to withdraw from the project. The goal is to let self-advocates do as much of the work as independently as possible. Nevertheless, it may be helpful to have one of the self-determination directors sit in on at least the initial contact to help address any questions that the self-advocate coordinator may not know how to answer.

- Weak participant commitment to the project. A concerted efforts needed to be made to explain how the training would benefit DMR consumers to become better employers. Direct support staff play an important role in the life of DMR consumers. Hiring direct support staff that respect an individual's rights and that are a good fit for the individual can have a profound impact on the person's quality of life. A better job in communicating this to DMR consumers may have resulted in more participants for the study and a stronger participant commitment.

- Estimated time to complete program tasks took longer than initially anticipated, resulting in less time to complete the trainings. Tasks such as rewriting the curriculum and recruiting took much more time than initially anticipated. In the end, two of the training teams did not have the opportunity to train because no consumers were found for them to train.

DMR Final Outcomes of Training Teams

As noted in the previous section, a number of challenges occurred with the trainer portion of the study. The outcomes of the training teams are as follows:

- **Training Team #1** – Was able to successfully complete the training in only two sessions, which each lasted three hours. The trainee for Team #1 was a more experienced employer. In addition, the individual was a guardian and did not have an intellectual disability.

- **Training Team #2** – Was unable to do their training. The trainee canceled before they were able to begin any training.

- **Training Team #3 –** Was able to successfully complete the training in eight sessions. The team had some scheduling conflicts, which is understandable considering they were training a couple and not just one person. In addition, the participants are visual learners and the trainers had to develop appropriate training material to accommodate their learning style. This resulted in the eight training sessions being spread out from May through August.

- **Training Team #4 -** Was unable to do their training. Team #4 had to reschedule a lot of the initial meetings due to the trainer's health problems. As a result, the participants assigned to Team #4 became frustrated and dropped out of the study before beginning any training.

- **Training Team #5** – Started the training, but was unable to complete the training before the study ended. The training team was able to complete the first two chapters. The biggest problem they encountered was scheduling appointments. The trainer stated that the participant was very slow in responding to telephone calls and e-mails.

- **Training Team #6** – Was unable to start the training. The consumers from the training team's region who had given verbal agreement to participate decided in the end not to do so. Recruitment efforts to find a replacement volunteer in the team's region were unsuccessful.

- **Training Team #7** – Was unable to start the training. The consumers from the training team's region who had given verbal agreement to participate decided in the end not to do so. Recruitment efforts to find a replacement volunteer in the team's region were unsuccessful.

- **Training Team #8** – Was unable to begin the training. The self-advocate lost their job and had to focus on this rather than do any trainings. No consumers were assigned to this person to train.

DMR Participant Recruitment and Overview

Recruitment of novice employers occurred after the team trainings. DMR participant recruitment was conducted solely by DMR without assistance from the UCEDD, per DMR's request. The consumer participants were recruited by the Self-Determination Directors. Word of mouth was the primary method of recruitment. Flyers were also created by the UCEDD and provided to the Self-Determination Directors to assist in the recruitment process. From this process, at least two individuals from each of the three DMR regions across the state originally agreed to participate.

Initially, it was thought that recruitment of participants would not be a problem. The Self-Determination Directors received verbal agreements from many DMR consumers to participate in the study. However, these potential participants were not initially aware of the time commitment. When self-determination directors asked these individuals to sign-up and the time commitment was more fully explained, many were no longer interested. As a result, recruiting DMR consumers became a challenging task. In the end, two training teams were not able to participate because DMR was unable to locate DMR consumers to train.

As a result, the following DMR waiver participants were randomly assigned to the intervention group:

Participant #1 – Is a sibling of a person who receives services from DMR. The person does not have an intellectual disability and had experience hiring and managing direct support staff. The person was prepared and highly motivated. The trainers reported that the individual had a very strong understanding of the information covered in the training.

Participant #2 – Is a consumer of DMR services. The person initially signed the form committing to the training and completed the baseline interview. However, when the trainer made the introductory phone call to begin the training, the person decided not to participate in the study. The conversation was either confusing or offensive to the participant. This led to the participant dropping out of the study.

Participants #3 and #4 – Are a couple who both receive services from DMR. They were both very motivated and very prepared to complete the trainings. It took them eight sessions, each lasting approximately 45 minutes, to complete the training. Trainers had to adapt training materials to the participants' visual learning style. After completing the training, the trainers reported that they both had a strong understanding of the information covered in the training.

Participants #5 and #6 – Are a couple who both receive services from DMR. Both initially signed the forms committing to the training, and each completed their own baseline interview. After the trainer rescheduled many of the trainings, they decided to not to participate any further in the study.

Participant #7 – Is a consumer of DMR services. The person was very interested in the study at first and completed the baseline interview. However, after beginning the training and learning of the extensive time commitment, the person's interest faded. The participant did not respond to subsequent e-mails and phone calls to set up further training sessions.

In addition, five participants were randomly assigned to the control group. This resulted in 12 participants from the DMR waiver who completed at least a baseline

interview: 7 intervention participants and 5 control participants. The results of their final interview status are as follows:

Intervention (n=7)

- 3 completed the baseline interview, the complete training, and the comprehensive follow-up interview (43% completion rate).
- 1 completed the baseline interview and part of the training, but no follow-up interviews.
- 3 completed the baseline interview only, but did not receive the training.

Control (n= 5)

- All 5 completed their baseline and comprehensive follow-up interview (100% completion rate)

Evaluation Results

PCA Waiver Participants

Results for the PCA waiver group (n=20) are based on the following information:

Table 1. Number of PCA Waiver Participant Interviews Completed

	Baseline	Post training interview	3 month post test	6 month post test
Intervention	16	13	10	12
Control	4	0	2	2
Total	20	13	12	14

Table 2. PCA Characteristics (n = 20)

	Percent	Number
Gender		
Female	65	13
Male	35	7
Race		
White	70	14
Black	20	4
Other race (did not specify)	10	2
Gross household income (per year)		
< $10,000	55	11
$10,000 to $25,000	20	4
$25,000 to $50,000	5	1
> $50,000	20	4
Health status		
Excellent	10	2
Good	50	10
Fair	35	7
Poor	5	1

Education		
Some high school	10	2
Completed high school but did not receive diploma	5	1
High school diploma or GED	40	8
Some college or 2 year degree	35	7
Completed 4 year college degree	5	1
Post-graduate	5	1

Seventy percent of the PCA group currently have personal assistants working for them, and 80 percent overall have employed personal assistants at one time or another. Nearly half (44%) of the participants indicated that over the past three months they did have a personal assistant stop working for them, and of those about half (43%) said that they had fired or had to let their personal assistant go. Over half (65%) of the participants said that they did try to hire a new personal assistant over the past three months. Of those, only 38 percent were successful in hiring a new personal assistant. The following quotes are illustrative of the difficulties encountered by these employers, taken from their baseline interviews before any training.

> *"[The PA] was unreliable. She just didn't show up."*

> *"We have no problems hiring – we just have problems with some of them afterwards."*

> *"I took one person [before CPASS training] with no experience but I liked her, but she is basically useless."*

Overall, nearly one-third of those participating in the initial interview said that they found it very difficult to talk to their personal assistant about the work responsibilities. Fifty percent of those responding said that it was either very easy or somewhat easy to talk to their personal assistant about work responsibilities. At baseline, the majority of participants (94%) felt that racial or ethnic differences between themselves and their personal assistants were not a problem.

Eighty-one percent (n=13) of the people in the intervention group completed at least through Module 4 of their training. The majority of these indicated that the length of the training was just right. Only one person thought that it was too short. Seventy percent of those who experienced the training felt that the material presented in the training program was either very easy or somewhat easy to understand. Ninety-two percent now feel either very prepared or at least moderately prepared to tackle any difficulties as they hire and manage their own personal assistants. Some positive responses about the training follow.

"Very thorough, nothing was missed."

"[It showed you] the types of people you might run into. Made you aware of what you need to do."

"Seeing someone else do it – sitting in on the interviews so you can really get to see what it is like and how people respond."

A clear majority (92%) of those who did take part in the training say that they would recommend the CPASS training to another person interested in hiring a personal assistant. Fifty-eight percent of the people who took part in the training rated the CPASS training program as excellent and another third (33%) rated it as very good. Only one person gave fair as an overall evaluation.

At the end of the interview process, of the nine people who had tried to hire a personal assistant over the past three months, five of them (56%) were successful. All of them attributed their success to the CPASS training program.

"[The CPASS training] helped me to evaluate what skills the person had, and to make my decision based on how good they did their job, and how compatible, honest and reliable they are."

"I was able to ask better questions to get more info about person."

PCA Train the Trainer Evaluation

All 8 members of the PCA training teams completed an evaluation of their train the trainer (TtT) training by the CPASS staff. Overall, the participants rated the training highly; in each category, a majority strongly agreed or agreed with each statement (see Table 3 below). A majority of participants strongly agreed that the material was useful and well organized and that the CPASS staff were knowledgeable and presented the material in a helpful manner. In addition, most participants (75%) strongly agreed that they would recommend the training to others.

Two areas were not rated quite as highly: preparedness to train others and length of the training. Comments made on the forms indicated that the trainers would have liked the TtT training to be taught over several days so less material would be covered each time, as voiced by one participant, "Trying to learn the amount of subject matter in the time allotted. It was a lot to digest all at once." Some participants did not like using the multiple module evaluation forms, finding them to be lengthy and too much like a test.

When asked what part of the TtT training they liked the most, participants mentioned the role playing most frequently, as it gave participants a way to practice their new skills as well as experience the roles of both the employer and the PCA. Comments from different participants emphasize the helpfulness of this teaching tool:

>*"Role playing [because you] experienced roles from different perspective."*

>*"I liked the role playing because it helps you understand how another person feels."*

Several participants also liked learning information about the topic area which they were most unfamiliar with, including hiring, tax information, and record keeping. Given the unfamiliarity of these topics, spending more time on these areas in particular would be valuable in future trainings.

Table 3. PCA Train the Trainer Evaluation (percentages)

Content	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The content was useful.	75	25			
The ideas were well organized.	63	37			
The handouts enhanced my learning.	50	50			
Implementation					
I feel prepared to train future employers in the CPASS program.	37	50	13		
Trainer					
The trainers were knowledgeable.	88	12			
The trainers' presentation styles helped me learn.	75	25			
Location					
The lighting was good.	37	50	13		
The temperature was comfortable.	37	37	13		13
Overall Impressions					
The length of the training was just right.	25	50		25	
I would recommend this training to others.	75	13	13		

PCA Novice Employer Evaluation

Each training team was asked to complete a Training Evaluation Form upon completion of the training, describing the training and rating the novice employer's PCA management abilities. A majority of the PCA trainers sent in a completed form (82%). Only one of the four DMR forms was returned. This was at least partly due to confusion on the part of the self-determination directors as to when and how to complete the form. All training evaluation forms for the train the trainer sessions were completed by the CPASS staff.

The number of sessions and total time to complete the PCA novice employer training varied widely. This is most likely due to the prior experience, abilities, and circumstances for both the training teams and participants. Completion of the PCA training took from three to seventeen sessions (average of 11 sessions), with an average total time of 15 hours (range 5 to 27 total hours). Overall, trainers spent the most time on Module 2, and the least time on Module 3. The modified DMR waiver training is not included in these numbers; the one Appendix B sent in for this waiver indicated that this person's training was completed in two sessions totaling six and a half hours.

The majority of PCA waiver participants (both trainers and novice employers) were rated highly by their trainers on all three ability measures: 92% of PCA participants understand the material moderately or very well; 69% are moderately/very prepared to tackle PA management difficulties; and 85% are moderately/very motivated to do so. Further training suggested by trainers include self advocacy and in depth tax issue training, as well as a review of the materials in the future.

DMR Waiver Participants

Results for the DMR waiver group (n=12) are based on the following information:

Table 4. Number of DMR Waiver Participant Interviews Completed

	Baseline	Post training interview	3 month post test
Intervention	7	3	3
Control	5	0	5
Total	12	3	8

Table 5. DMR Characteristics (n = 12)

	Percent	Number
Gender		
Female	50	6
Male	50	6
Race		
White	92	11
Black	8	1
Gross household income (per year)		
< $10,000	42	5
$10,000 to $25,000	17	2
$25,000 to $50,000	25	3
> $50,000	17	2
Health status		
Excellent	33	4
Good	17	2
Fair	42	5
Poor	8	1
Education		
Eighth grade or less	17	2
Some high school	17	2
High school diploma or GED	50	6
Some college or 2 year degree	17	2

The majority of DMR participants (92%) do have support staff currently. All of the participants have had support staff at least at some point in their lives. Only two of the participants indicated that they had support staff leave or stop working for them over the past three months. Two of the DMR participants had tried to hire new support staff over the past three months but only one was successful. The following quotes are illustrative of the difficulties encountered by these employers, taken from their baseline interviews.

"I had to fire him because he wasn't showing up when he was supposed to. He wouldn't answer his cell phone."

"It is very difficult to find appropriate support staff. It's complicated because my [family member] is also there; there is a little overlap."

Three DMR intervention participants completed the training and its evaluation. All three felt that the length of the CPASS training program was just right, not too long or too short. Two participants indicated that the material presented was very easy to understand; the third rated it as somewhat easy to understand. All would recommend the CPASS training to other individuals interested in hiring additional support staff.

DMR Train the Trainer Evaluation

The train the trainer classes for the DMR self-advocates (n=8) and their support staff (n=8) were held over three days. All 16 participants completed an evaluation of this training which was taught by the CPASS staff. As with the training manual, the CPASS training was modified for the DMR self-advocate trainers. Following the revised manual, the DMR training used more role playing and "teach-back" methods, where the self-advocates would describe in their own words what was discussed.

Overall, the participants rated the training favorably; in each category, a majority agreed or strongly agreed with each statement (see Table 6 below). However, except for physical environment, these participants rated the other items not quite as highly as their PCA counterparts. For example, only half strongly agreed that the content was useful, and a smaller proportion (38%) strongly agreed that the handouts enhanced their learning. The CPASS staff trainers were given lower ratings as well. These findings may indicate that the training modules need other modifications to increase its usefulness for future self-advocate trainers.

As with the PCA training, preparedness to train others and length of training were also the most problematic areas for the DMR trainers. Comments made on the forms indicated that the trainers would have liked to have had more time to learn and

practice the materials, as voiced by one participant, "The time – I feel [there were] too short sessions for so much information to take in and remember." Difficulty understanding the material was a challenge for some. Other participants found the start of the training difficult, especially as it was all new to the participants.

The role playing was once again reported most frequently as the part of the training participants liked the most. Participants found it gave them an opportunity to practice new skills and learn by doing, in addition to having fun and breaking up the "book" learning.

> *"Role playing so that everyone had a good understanding of what was being taught.*

> *"A chance for participants to speak up and participate."*

> *"Practicing the interviewing. I did a good job and made a deal with her."*

Learning how to manage stress and hearing other people's opinions and experiences were also mentioned as topic areas participants liked the best. In addition, overall satisfaction was high. All but one of these participants were satisfied or highly satisfied with the training, as evidenced by this participant's comment:

> *"The materials are very complete. The role modeling/playing was very useful as hands-on experience. Presenters were easy going and relaxed."*

Overall, the DMR trainers were not quite as satisfied with the train the trainer training. Further modifications to the training content and/or training methods may be needed to increase the usefulness of the CPASS training for these participants. This could include increasing the time spent on unfamiliar content areas, holding the training over more than three days, increasing the use of role-playing as a "teach back" method, and including more review of previous material. These changes would likely increase these trainers' confidence in their preparedness to train novice employers.

Table 6. DMR Train the Trainer Evaluation (percentages)

Content	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The content was useful.	50	50			
The ideas were well organized.	56	44			
The handouts enhanced my learning.	38	44	19		
Implementation					
I feel prepared to train future employers in the CPASS program.		63	31		6
Trainer					
The trainers were knowledgeable.	56	38	6		
The trainers' presentation styles helped me learn.	38	50	13		
Location					
The lighting was good.	63	31	6		
The temperature was comfortable.	63	25	13		
Overall Impressions					
The length of the training was just right.	31	31	25	6	6
I would recommend this training to others.	50	44	6		

Comparison of Intervention and Control Groups

Individually, DMR and PCA Waiver samples were not large enough to statistically analyze. To maximize the sample sizes for control and intervention comparisons, DMR and PCA subjects were combined. The interventions were considered similar across the different waivers. Summary scores for each of the six standardized measures were calculated from their Likert scales. Mean summary scores were compared between groups using independent t-tests at the final post test. Most of the comparisons of the intervention and control groups were not statistically significant. Specifically, PA quality of care, employer hassles, and PA employer self-efficacy were not significantly different. The intervention group showed higher levels of general self-efficacy than the control (p = .04) (Figure 1). Interpersonal conflict

appeared to decrease in the intervention group, but was not statistically significant (Figure 2). The control group reported lower levels of depression than the intervention group (p=.02) (Figure 3).

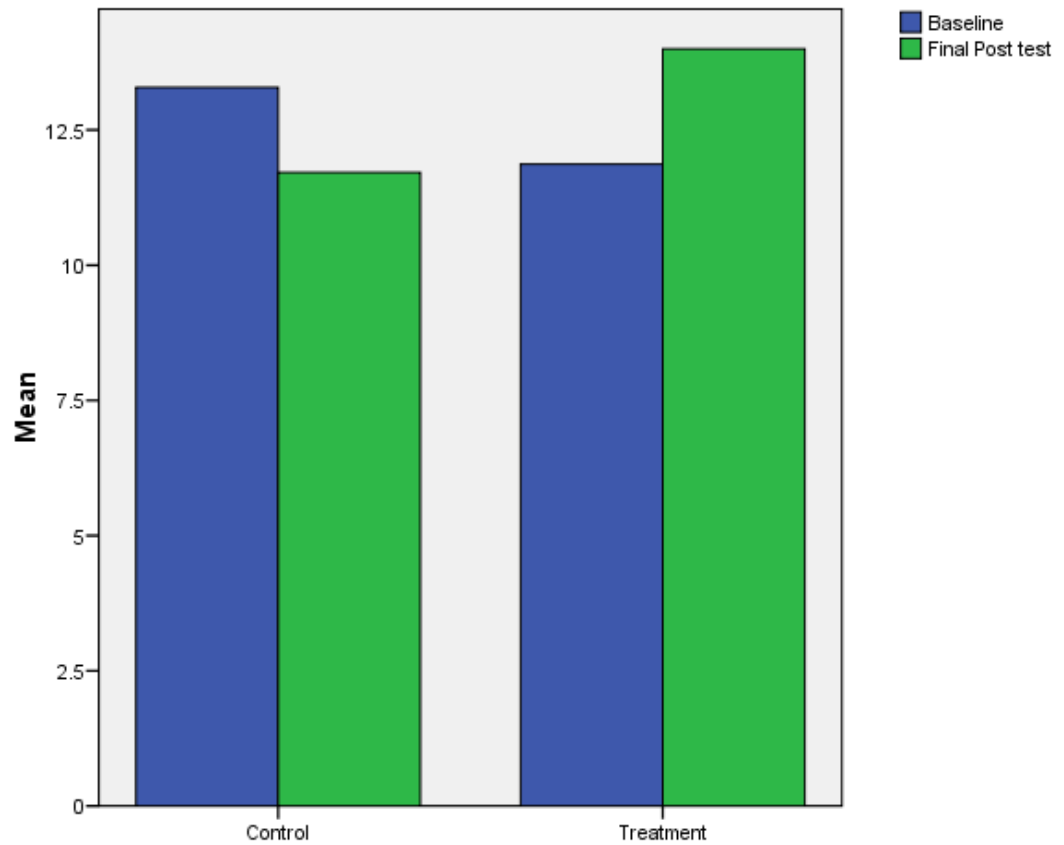Figure 1. Mean Summary Scores for General Self-Efficacy

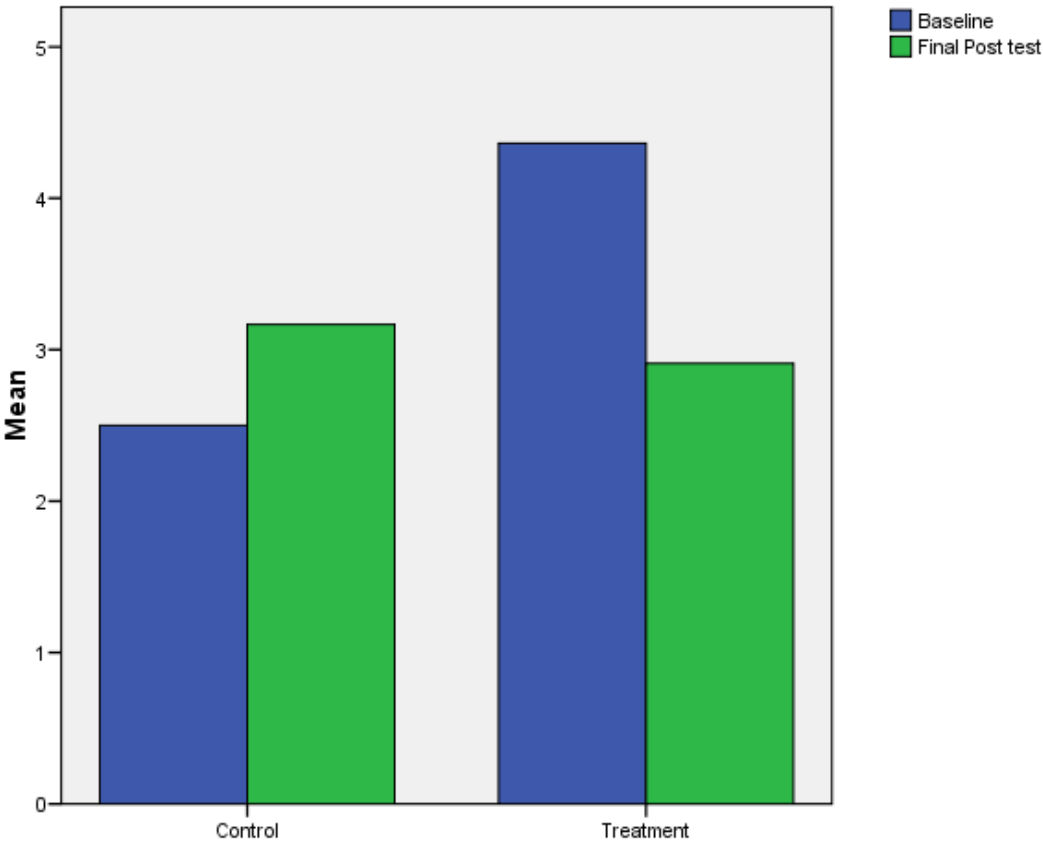Figure 2. Mean Summary Scores for Interpersonal Conflict Scale
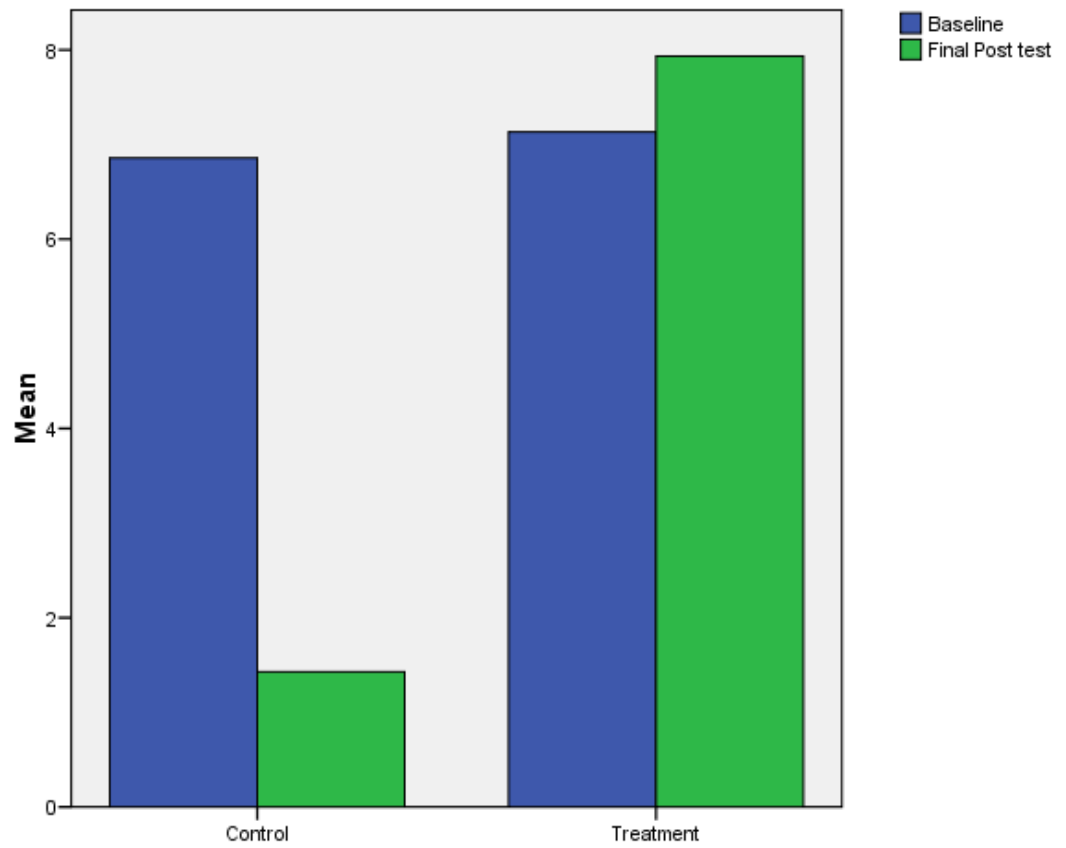
Figure 3. Mean Summary Scores for Depression (CES-D)

These comparisons must be considered preliminary due to the very small sample sizes.

Preliminary Recommendations for Overall Training

Based on some of the observations and feedback received from trainers, some preliminary recommendations to address the challenges identified include:

- The need to have specific trainers identified in various areas of the state so there is less need for traveling long distances.

- While individual training in homes was initially seen as the most effective way to train, there may also be a benefit for some people to receive training in small groups so they can share experiences and provide support to each other. What appears to be effective with the individual training model is the time spent in working through individual needs and choices when arranging for hiring a personal assistant (development of a needs assessment in chapter 1). In addition, individual training in homes is positive in identifying barriers or challenges in the home, including observation of family dynamics. Therefore preliminary recommendations are that a combination of training (individual and small group) occurs. Group training would be especially important for young adults, people in institutional settings looking to move into the community, and people struggling with the process. Training should be available not just initially, but on an ongoing basis if needed.

- Peer support and training is critical. However, based on the various challenges that occurred and the need for CPASS staff to be available to trainers on a regular basis, it is recommended that the overall training be facilitated by an experienced trainer for training to be most effective. This would include a trainer with personal and professional experience. In addition, it would also be important to have additional peer support throughout the process (such as what the trainers provided in the CPASS training). This peer support would be helpful as participants work through the hiring and managing process once initial training occurs. What appears to be most helpful would be to have an experienced trainer with a

disability conduct small group trainings and provide support to peer mentors as they continue to assist novice employers throughout the process. For some employers, this may be initial support, but for others it may be ongoing as staff changes and/or issues occur.

- It should be noted that health plays an important role in length of training and understanding. Due to some significant health issues, there is a need for some individuals with disabilities who hire and manage staff to have support at times when health or other issues may interfere with the process of hiring and managing staff (e.g. a personal manager chosen by the person with the disability to assist with the process a little or a significant amount depending upon what the person needs and chooses).

- State Waiver programs should consider the impact training and peer support may have on whether or not someone is successful in hiring and managing staff. While the PCA and Elder Waivers require someone be able to self-direct their supports, there may still be a need for some employers for additional training and peer support if challenges arise. This is especially true for novice employers, people who have limited experience in living independently and young adults who are beginning the process. Funding to enable additional supports should be considered (i.e. funding for a personal manager).

- The program appears to have some preliminary evidence of positive outcomes for people who went through the CPASS training. The program should be modified according to the preceding recommendations and then evaluated on a larger scale to determine the impact.