PERFORMANCE REVIEW REPORT TO THE GOVERNOR AND THE GENERAL COURT

BY

THE PERSONAL CARE ATTENDANT QUALITY HOME CARE WORKFORCE COUNCIL

December, 2008

PCA QUALITY WORKFORCE COUNCIL

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EXECUTIVE SUMMARY

This initial performance review report is being filed by the Personal Care Attendant Quality Home Care Workforce Council (the Council), pursuant to M.G.L. c.118G § 33. Subsequent reports will be filed every other year as required by statute. The information provided in this report comes from a variety of sources, including: public meetings, outreach workshops and forums conducted by the Council, statistical and financial data provided by staff from MassHealth and the Executive Office of Health and Human Services, a survey of MassHealth members and subsequent analysis, commissioned by the Council and prepared and conducted by the JSI Research & Training Institute, Inc.

The MassHealth Personal Care Attendant program currently serves approximately 16,000 consumers across the Commonwealth. A workforce of more than 25,000 PCAs provides the care that permits consumers to lead independent lives in their own communities. The budget for the PCA program for FY07 is slightly above $299 million dollars, a fraction of the cost of institutionalized care for the program consumers.

On the whole, MassHealth consumers of PCA services are very satisfied with the PCA program and the assistance they receive. The above sources of information strongly support the fact that the PCA program is the critical element that permits consumers to live in their communities and have active, productive lives. Consumers are highly appreciative of the services delivered through the program. Most recognized that their quality of life is enhanced immeasurably by the program and that they would be unable to live independently without these services.

On the issue of recruitment and retention of PCAs, this report shows that, though these remain critical issues requiring policy attention, they may not affect the entire consumer population. For many consumers, family and social relationships frequently shape the process of finding, hiring, and retaining PCAs. Regarding PCA/Consumer relations, the Council is pleased to report that ninety-seven percent of consumers surveyed felt safe with and respected by the PCA that provides the largest number of hours of assistance to

them. Over eighty-seven percent of those surveyed said that the Personal Care Management agencies which provide contracted services to consumers responded promptly to telephone requests for assistance.

Consumers strongly believe in and tie this program's success to the concept of consumer control. One of the strongest benefits reported by the consumers was the consumer-directed nature of the program. Ninety-five percent of consumers surveyed reported that it was very important for them to be able to choose their own PCAs. Among concerns cited by consumers, inadequate pay and benefits for PCAs, regulatory restrictions on the scope of services and issues concerning allocation of hours were the most prominent. Regarding the first of these issues, the Council is pleased to report the completion of the collective bargaining process with the newly elected union; the three year agreement assures long needed pay increases and creates a mechanism for determining future health benefits. Regarding limitations on the scope of services and allocation of hours, the Council is actively engaged in an Administration-led PCA Program Improvement Workgroup which is reviewing these critical concerns.

With respect to the cost of PCA services, the data compiled in this report indicates that, although PCA expenditures have grown steadily over the past several years at an average of 11% per year, PCA expenditures have declined as a percentage of community based long term care expenditures from 35% in FY 03 to 31% in FY 08..

Relative to the function of the Council itself, during 2008, the first year that the Council has had its own staff, considerable progress was made in addressing many of the issues described in this report. Specifically, the Council has:

- Negotiated the initial collective bargaining agreement, referred to above, with 1199SEIU, the union representing MassHealth PCAs.
- Published an RFR and negotiated a contract with Rewarding Work Resources Inc. to develop and operate a web based PCA referral directory that will assist consumers in hiring PCAs.

- Commissioned, in addition to the consumer survey cited in this report, a survey of PCA workers that will be completed early in 2009.
- Provided funding to the Massachusetts Community Colleges Executive Office to provide free training in CPR for any PCAs wishing to take this course at one of the Commonwealth's Community Colleges. In just a few months, approximately 65 PCAs have taken or are enrolled in this program.

The five consumer members of the Council have provided hundreds of hours of volunteer service in support of Council business and projects, making the Council a prime example of civic engagement on behalf of the Commonwealth. [1] In addition to monthly meetings, members of the council have actively participated in collective bargaining, overseeing development of the referral directory, outreach, surveys of consumers and PCAs and the content of the Council newsletter.

This initial performance review report is an important step as the Council charts progress in achieving its goals. Relative to questions posed by its enabling legislation, the

[1] The Personal Care Attendant Quality Home Care Workforce Council (Council) is a governmental body, similar to those in several other states, designed as an instrument for strengthening the Personal Care Attendant program. The Council consists of nine members. Two members, the Secretary of Health and Human Services (or her designee) and the Director of the Office of Workforce Development (or his designee), are members of the administration. The remaining seven members are appointed by one of the Commonwealth's constitutional officers in the following manner:

- The Governor appoints 1 member from a slate of 3 consumers recommended by the governor's special advisory commission on disability policy.
- The auditor shall appoint:
  - 1 member from a slate of 3 consumers recommended by the developmental disabilities council.
  - 1 member from a slate of 3 consumers recommended by the Massachusetts office on disability, and
  - 1 member from a slate of 3 consumers recommended by the statewide independent living council.
- The attorney general shall appoint:
  - 1 member from a slate of 3 consumers or consumer surrogates recommended by the Massachusetts home care association.
  - 1 member from a slate of 3 consumers or consumer surrogates recommended by the Massachusetts council on aging and
  - 1 member chosen at her discretion.

At all times a majority of Council members must be consumers of MassHealth PCA services. The Council is charged with insuring the quality of long-term, in-home, personal care by recruiting, training and stabilizing the work force of personal care attendants.

Council's report recommends no change in current methods for paying PCAs nor in the oversight of their hours.

Sources & Acknowledgements

The information provided in this report comes from a number of sources, including statistical and financial data provided by staff from MassHealth, a survey of 500 MassHealth PCA consumers and subsequent analysis performed for the Council by the JSI Research & Training Institute, Inc. and public meetings, outreach workshops and forums conducted by the Council.

All members of the Council have had experience with issues relating to persons with disabilities. Five members of the Council are consumers of PCA services. Many of these members work at independent living centers or are consultants and advocates on issues affecting persons with disabilities. These Councilors have a wealth of personal and professional experience with the PCA program. Their professional activities have brought them into contact with hundreds of MassHealth consumers.

The Council has been holding monthly public meetings for almost two years. The Council encourages and has received public comment at many of these meetings. Additionally, Council members organized several outreach meetings and workshops during the course of the year. In March, an outreach forum was presented at Springfield Technical Community College. Councilors in attendance presented plans for the upcoming year and took questions and comments from many consumers, PCAs and family members. Workshops were also presented at the Massachusetts Rehabilitation Commission's annual consumer conference at Northeastern University (June, 2008) and the Statewide Independent Living Council's (SILC) annual conference in Marlborough (September, 2008). The SILC workshop included an open forum during which consumers, providers and advocates spoke to Council members concerning many of the areas included in this report.

Information on the Council's CPR scholarship program was compiled and provided by Michelle Byrd, Senior Executive Assistant to the Council. Councilors Joe Bellil and Eileen Brewster supervised the preparation of this report. Rachel Richards, Director of the MassHealth Office of Long Term Care and Lois Aldrich, Director of Community Services, have provided considerable time, resources and advice in the preparation of this report. From 2006 until the end of 2007, Rachel Richards served as primary staff for the Council, in addition to many other responsibilities. Lois Aldrich directed her staff to provide information needed for the intensive services part of Section I as well as Section II of this report and provided helpful comments and insight on the text of this report.

Janet Gard**,** then Budget Director, MassHealth Long-term Care & Behavioral Health, provided the chart showing the comparative history of PCA and other long term care costs. Susan Engel, who provides information analysis for the IT unit, provided the majority of the data for the section on additional and more intensive services.

The advice and suggestions of Assistant Secretary, Dr. Jean McGuire were especially helpful in drafting this report.

In addition to the careful preparation and execution of the consumer survey that makes a significant contribution to this report, three members from the JSI Institute, Dr. James Maxwell, Dr. Karen Schneider and Jaya Mathur, contributed language, ideas, charts, advice and context to this report. Their assistance was crucial to the quality and completion of this report.

I. HEALTH & WELFARE OF MASSHEALTH CONSUMERS

M.G.L. c. 118 §33 (b) asks for an *evaluation of the health, welfare and satisfaction with services provided of the consumers receiving long-term in-home personal care services from personal care attendants … including the degree to which all required services have been delivered, the degree to which consumers receiving services from personal care attendants have ultimately required additional or more intensive services, such as home health care, or have been placed in other residential settings or nursing homes, the promptness of response to consumer complaints and any other issue considered to be relevant.*

PCA consumers have serious disabilities and/or chronic illnesses, which may become worse over time. Their disabilities are often the result of health problems or their disabilities themselves have major health consequences. Chronic illness, developmental disabilities, physical/sensory disability, and spinal cord injuries are the four most frequent conditions reported by consumers that led to their enrolling in the PCA program. Among survey participants, a striking 72.7% of consumers surveyed reported that their disabilities had progressed over time with 42.5% stating that their health had declined within the past year. [2] A reasonable prediction is that as the consumer population continues to age this trend will become more pronounced.

The correlation of poor health to advancing age is critically linked to the future need for operation of the PCA programs. An expanding aging cohort in the state is likely to result in increased PCA program participation; similarly, as the existing PCA consumer population ages, members are likely to require greater PCA resources to meet their health and functional needs. Future PCA program participants are likely to report, like current PCA consumers, that they would be forced to live in an institutional setting if they did not receive PCA services, usually at a far higher cost to the Commonwealth. All available sources of information described in this report strongly support the fact that the PCA program is the critical element that permits consumers to live in their communities and lead active, productive lives.

[2] A profile of the consumers who were the subject of the survey is included as **Appendix 1A**.

A. Consumer Satisfaction with Services

Assessing consumer satisfaction and service availability were core obligations of the legislative mandate. Survey information provides the primary basis for addressing issues associated with service access and satisfaction. This section details the outcome of those assessments. For purposes of this report, the Council defines satisfaction with services as:

1. The degree to which the consumer's ADL & IADL[3] needs are met;
2. The ability to recruit and retain PCAs;
3. The quality of consumer/PCA relationships
4. Satisfaction with PCM/ FI[4] support including promptness of response to consumer complaints
5. Responsiveness of family and other agency support

1. The degree to which the consumer's ADL & IADL needs are met

As is shown by Figure 1, most consumers reported that they received assistance with a broad range of ADLs and IADLs and that their PCAs do an extraordinary job of providing assistance with these tasks. This belief was confirmed through the Council outreach forums, the focus groups and the telephone survey conducted by JSI Institute.

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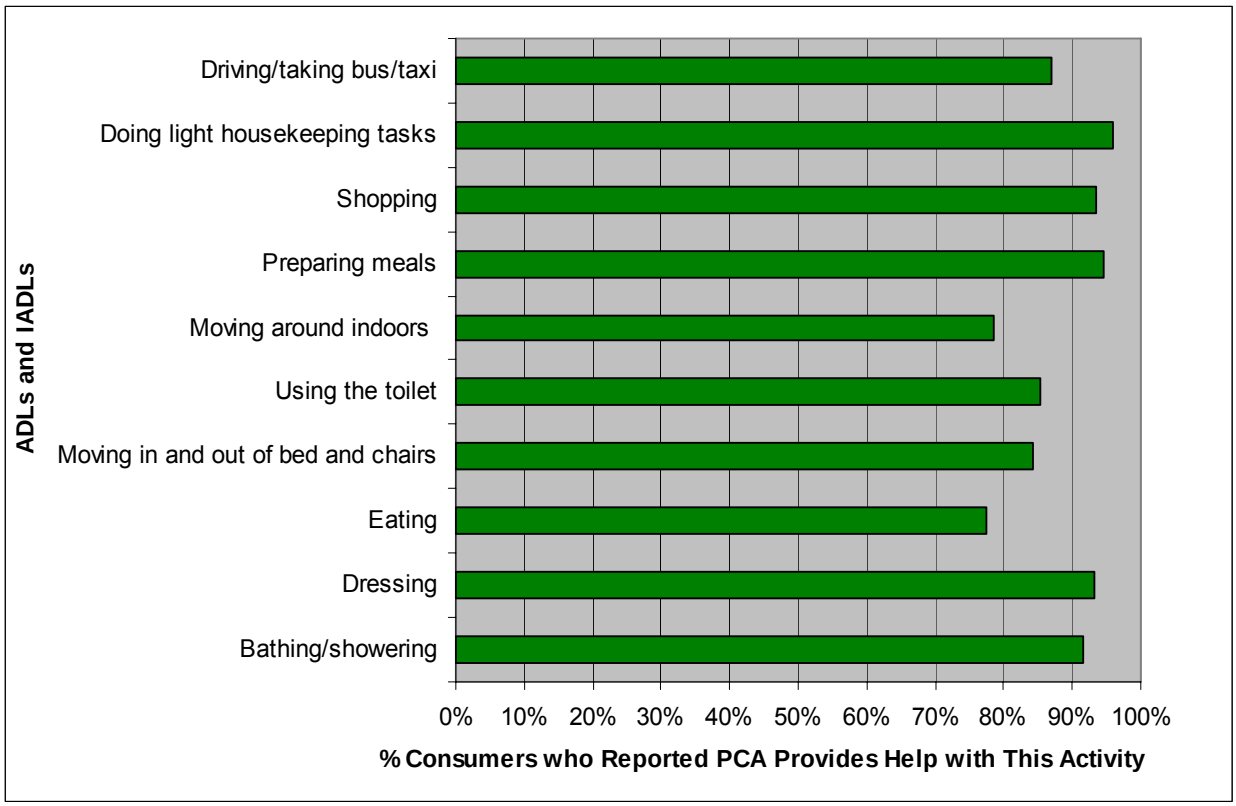
[3] 130CMR 422.410: **Activities of Daily Living and Instrumental Activities of Daily Living**
(A) **Activities of Daily Living (ADLs)**. Activities of daily living include the following:
(1) mobility: physically assisting a member who has a mobility impairment that prevents unassisted transferring, walking, or use of prescribed durable medical equipment;
(2) assistance with medications or other health-related needs: physically assisting a member to take medications prescribed by a physician that otherwise would be self-administered;
(3) bathing/grooming: physically assisting a member with basic care such as bathing, personal hygiene, and grooming skills;
(4) dressing or undressing: physically assisting a member to dress or undress;
(5) passive range-of-motion exercises: physically assisting a member to perform range-of-motion exercises;
(6) eating: physically assisting a member to eat. This can include assistance with tubefeeding and special nutritional and dietary needs; and
(7) toileting: physically assisting a member with bowel and bladder needs.

(B) **Instrumental Activities of Daily Living (IADLs).** Instrumental activities of daily living include the following:
(1) household services: physically assisting with household management tasks that are incidental to the care of the member, including laundry, shopping, and housekeeping;
(2) meal preparation and clean-up: physically assisting a member to prepare meals;
(3) transportation: accompanying the member to medical providers; and
(4) special needs: assisting the member with:
(a) the care and maintenance of wheelchairs and adaptive devices;
(b) completing the paperwork required for receiving personal care services; and
(c) other special needs approved by the MassHealth agency as being instrumental to the health care of the member.

[4] The PCM is an agency under contract with EOHHS to provide personal care management (PCM) services The FI or Fiscal Intermediary is similarly under contract to provide financial management services.

Figure 1: PCA Provides Help with ADLs and IADLS (among consumers who reported difficulty performing ADLs and IADLs); (For ADLs, N=502; for IADLs, N=446)



Consumers expressed a high level of appreciation of the services delivered through the program. Most recognized that their quality of life is enhanced immeasurably by the program and that they would be unable to live independently without these services. The benefits of the program are reflected in the 96% very satisfied/satisfied rating given to the quality of services provided by the consumer's primary PCA. It is evident that PCAs provide friendship, companionship, and other forms of social support for consumers that are outside their realm of formal responsibilities. Furthermore, in qualitative interviews and focus groups, consumers and surrogates reported that PCAs often act as advocates for consumers in their interactions with physicians and other health providers.

Even with the number of supportive services provided to PCA consumers, a significant portion of consumers still report unmet ADL/IADL needs, as measured by situations in which no one is available to provide needed assistance. The amount of unmet need

varies from 5% (for those who only need help in preparing meals) to more than 60% (for those who need help moving around indoors). The consumers with the most unmet needs were those consumers who also presumably have the greatest needs as indicated by the fact that they were also the individuals who had the greatest number of PCA hours. These individuals' need for support and socialization often exceed the statutorily reimbursable service availability.

2. The ability to recruit and retain PCAs

"Tough to find them, tougher to keep them" is the phrase one Councilor recalled hearing from many consumers that he worked with, summing up the difficulties they face in recruiting and retaining PCAs.

Because of the relative low wages and lack of benefits available to PCAs, as well as the intimate nature of the job, consumers are understandably concerned about their ability to recruit and retain highly qualified PCAs. This concern has been reinforced through many comments made at meetings, outreach forums and calls for assistance to Council staff from social workers and family members. Data from the JSI survey documents that recruitment and retention problems, though still critical issues requiring policy attention, may not affect the entire consumer population. Family and social relationships shape the process of finding, hiring, and retaining PCAs for many program participants.

When the survey asked about how they recruited their most recent PCA, most reported that they found someone through a network of family or friends or that they hired a family member. Fifty-four percent reported receiving help from family and friends in finding a PCA, while 19% said that they had hired a family member or friend. Only a small percentage of consumers relied upon other recruitment methods, such as newspaper advertisements, to find a PCA. The data suggest that recent changes in regulation by MassHealth allowing family members to serve as PCAs has made it easier for many consumers to find and keep PCAs. However, consumers surveyed who do not have family members as PCAs reported difficulty in finding and keeping PCAs. These

challenges are likely to grow in the future with an increasingly older, frail, and diverse consumer population in the PCA program.

Council Action:

In an effort to provide assistance with recruitment, as directed by M.G.L. c 118G § 30, 3, the Council has signed a contract with Rewarding Work Resources (RWR) to have them adapt a web based referral directory for use by MassHealth consumers. As part of the agreement, RWR will undertake extensive outreach and recruitment efforts to enroll new, potential PCAs as well as current PCAs in the directory. MassHealth members will have free access to a searchable database that the consumer can conform to his or her specifications. The directory is expected to be operational by June, 2009. Also, as an initial part of what is planned to be a more extensive workforce development program, the Council provided $10,000 to the Massachusetts Community Colleges Executive Office. This funding will support free tuition for PCAs attending a course in CPR offered at one of the Commonwealth's Community Colleges. Courses have been held at Holyoke, Roxbury and Massasoit Colleges and a course is scheduled at Quinsigamond College for December. To date, approximately 65 PCAs have taken or are enrolled in this program.

3. The quality of consumer/PCA relations

The health and well being of consumers depends on PCA services being delivered effectively and compassionately by PCAs. The intimate nature of these services and the fact that they are delivered in the consumer's home requires that PCAs treat consumers with respect and provide a safe and trusting environment for them to live independently in their homes.

Ninety-seven percent of consumers surveyed expressed feeling safe and respected with the PCA that provides the largest number of hours of assistance to them. This confirms statements made by consumers and PCAs at forums, focus groups, collective bargaining and other settings. During focus groups of PCA program consumers, participants made comments that "the PCA program has allowed me to live my life" and expressed gratitude that "these programs help elderly stay out of nursing homes."

4. Satisfaction with **PCM/ FI[5] support**

MassHealth contracts with 30 Personal Care Management (PCM) Agencies and 3 Fiscal Intermediaries (FIs) and is responsible for monitoring the contracts and conducting performance reviews. A PCM review carried out by MassHealth in late 2007 mapped out needed policy, structural and performance improvements for the program. With regard to PCMs, the need for improvement in the timeliness and quality of evaluations and the quantity and quality of skills training were highlighted. On the issue of agency support, 86.6% of the responding consumers were very satisfied/ satisfied with the agency performance. While more than 93.2% of consumers surveyed responded that the PCM promptly sent out a nurse to perform evaluations, only 80% said that they had received information about the PCA program or been talked to about how to manage and supervise PCAs. This finding is supported by the focus groups where a general lack of awareness about the availability of skills training was evident. This is an area where further study and evaluation is warranted.

a. Promptness of response to consumer complaints

The JSI telephone survey specifically asked consumers: *In general, does the PCM agency promptly respond to questions and phone calls?* 87.6% of consumers responded yes to this question, a very positive response. This response complements those received from focus groups and many individual conversations with consumers.

5. Responsiveness of family and other agency support

The fragility and complex health and functional needs of many PCA consumers are reflected in the fact that many surveyed are receiving other publicly funded services and large amounts of unpaid care giving assistance from family members and surrogates. More than one-quarter of consumers used assistance from other agencies in addition to the PCA program, with the largest number using services from the Visiting Nurses

[5] The Personal Care Management (PCM) agency is under contract with EOHHS to provide personal care management services, including intake, evaluations and skills training. The FI or Fiscal Intermediary is similarly under contract to provide financial management services.

Association (VNA). The majority of consumers received fewer than ten hours per week of these other formal services.

Family members and friends provide a vitally important source of care giving for PCA consumers. More than 60% of consumers received unpaid services from family members and friends. Of those providing unpaid care, roughly half provided more than ten hours of assistance per week. Consumers who reported having a PCA who was a family member were more likely than consumers who reported having a PCA who was a non-family member to receive unpaid care and assistance from family members.

B. Consumers Requiring More Intensive Services

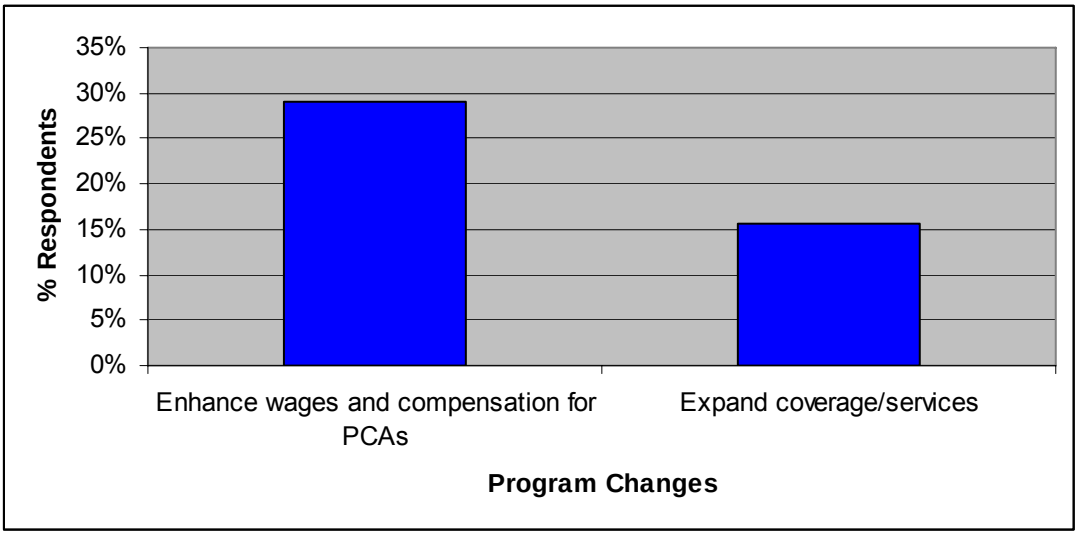
The Council's enabling legislation requires it to report on the extent to which PCA program participants "ultimately" require other intensive community based or nursing facility support services. While the purpose of this directive is not entirely clear, for this report the Council has defined the term "additional or more intensive services" and assembled statistics that give a broad view of consumer utilization of these services. **Appendix 1B a** lists the nine categories that MassHealth staff has identified as comprising "additional or more intensive services" and shows utilization by both former and current PCA consumers. While it is known that many consumers of PCA services require, from time to time, hospitalizations and other forms of intensive treatment, it is difficult to draw firm conclusions from this data. **Appendix 1B b** displays an unduplicated count of members in both groups, along with the number of categories for which there are paid claims. As clearly shown in this chart, a large percentage of consumers do not utilize multiple intensive services.

C. Other Relevant Issues

1. Increased compensation

Through an open ended question, surveyed consumers and surrogates were asked to name what they would most like to change in the program. Higher wages and benefits for PCAs was the most frequent recommendation (29%). The second most frequently cited recommendation was to expand the scope of services covered under the program (16%).

Figure 15: Consumers' Top Priorities for Changing the PCA Program (N=502)



When asked what one change in the program consumers and surrogates felt was most important to PCAs, an increase in wages was the most frequent response. Thirty-one percent of those surveyed said that an overall increase in wages was most important. Twenty-eight percent said that wage increases linked to job tenure was most important. Twenty-three percent cited the provision of health insurance as the most important change. This data echoed comments made at Council outreach forums and in the focus groups.

Council Action:

The Council has positively responded to the need for increased wages through the collective bargaining process. Recognizing that it had been approximately three years since PCAs had received a wage increase, the Council and the union recently negotiated an agreement raising PCA wages from $10.84 to $12.48 per hour over the three year period of the contract. The initial increase is effective July 1, 2008. The contract also provides a limited benefit for paid time off and funds a study to look into options for health coverage. The parties will resume negotiations on health care coverage in 2009.

2. Consumer control

One of the strongest benefits reported by consumers was the consumer-directed nature of the program. Ninety-five percent of consumers surveyed reported that it was very important for them to be able to choose their own PCAs. Strong support for continued consumer control, however, does not mean that consumers reject any agency assistance with the recruiting process. Receiving agency help with pre-screening and recommending potential PCAs was supported by more than 60% of those surveyed. (Q's 450-451).

Council Action:

In negotiating the first ever collective bargaining agreement for PCAs, members of the Council made protecting consumer direction of the program a high priority and negotiated provisions that are quite unique and distinct from traditional labor contracts. The contract entered into with 1199SEIU includes specific language reaffirming consumer control on issues such as hiring and firing PCAs. The contract also exempts consumers from the grievance procedure. Highlights from the collective bargaining agreement concerning compensation and consumer control are attached as **Appendix 1C**.

3. Scope of services and allocation of hours

In outreach forums, focus groups and survey responses, many consumers expressed dissatisfaction with the current rules of the program, which do not allow PCAs to provide care while consumers are being treated in the hospital. Consumers are concerned because they feel as though PCAs are more capable of attending to their personal care needs than the medical professionals, who provide only medical care. They are also concerned about their PCAs who, in some cases continue to provide care anyway during their hospital stay, but who are not compensated by the program. PCAs may suffer financial hardship or be forced to take other employment in the event that the consumers they provide care to are in the hospital for more than a few days. Many PCAs also take their consumers to doctor's appointments and even communicate about consumers' health status with providers, yet are not compensated for all of this time by the PCA program. In addition, some consumers reported that, while the PCA program tends to their needs

inside the home, it does not facilitate their quality of life socially or in other ways outside the home. Studies have linked social contact to improved health[6]. These concerns warrant a closer look at federal regulations to determine whether changes broadening the areas that PCAs can receive compensation for would aid the long term health of consumers in a cost effective manner.

Another area identified for Council review was the allocation of hours. More than two-thirds of consumers surveyed indicated that their ADL and IADL needs vary on a day-to-day basis. Forty-eight percent of consumers reported that their approved daytime hours were enough hours to meet their needs, while 42% said that their hours were not adequate. Similarly, roughly half of consumers surveyed who were authorized nighttime hours reported that the nighttime hours were adequate, while 46% said that they did not have enough nighttime hours. Allocation of hours may have a bearing on the unmet ADL/IADL needs reported earlier.

II. FULL COST OF PERSONAL CARE SERVICES

M.G.L. c. 118G §33 (c) asks for *an explanation of the full cost of personal care services, including the administrative costs of the council, unemployment compensation, Social Security and Medicare payroll taxes paid and any oversight costs.*

1. Administrative cost of the Council

The FY08 budget for the Council is set out in **Appendix 2A**. The Council budget was not approved until October, 2007 and the first permanent staff began working in December, 2007. For this reason, the funds allocated for various projects, notably the web-based PCA referral directory, were not expended in FY08. $200,000 of FY08

[6] House JS, Landis KR, Umberson D. Social relationships and health. Science 1988; 241: 540–5; Berkman LF. The role of social relations in health promotion. Psychosom Med 1995; 57: 245–54

funding was pushed forward into FY09 to cover one time start up expenses for the directory project.

For FY09 the Patrick administration recommended a Council budget of $725,000. The House of Representatives approved a Council budget of $705,000. The Senate Ways & Means Committee, without explanation, reported a budget in the amount of $300,000. The latter figure was adopted by the full Senate and prevailed in Conference Committee negotiations. At its current level of $300,000, the Council budget comes to approximately one tenth of one percent of the annual expense of the PCA program.

At the current level of funding, the Council projects not having sufficient funding to commission another survey (app. $90,000 needed) for its next performance review report, due December, 2010.

2. Unemployment compensation, Social Security and Medicare payroll taxes paid

The legislation also requires the Council to report as fully as possible the costs of personal care services: **Appendix 2 B** summarizes these costs, including payment to PCM agencies, which evaluate and assist consumers ($9,913,404.42) and payments to the three Fiscal Intermediary organizations that pay PCAs and manage the financial aspects of the program for MassHealth consumers ($8,559,922.28). The specific costs listed in M.G.L. c. 118G §33 (c), along with payroll, are also listed here ($274,805,578.91).

Appendix 2C shows the cost of the PCA program from FY03 through FY07 and also as a percentage of expenditures for community long term care services (CLTC) and overall long term care (LTC) expenditures during that period. As the chart shows, expenditures for the PCA program have maintained a steady 10-11% of the overall LTC budget and have fallen slightly (34 – 30%) as a percentage of CLTC expenditures.

III. RECOMMENDATIONS & FINDINGS

M.G.L. c.118G §33(d) states: *The performance review report will make recommendations to the legislature and the governor for any amendments to sections 28 to 33, inclusive that will further ensure the well-being of consumers, and the most efficient means of delivering required services. In addition, the first performance review report will include findings and recommendations regarding the appropriateness of the council's assumption of responsibility for verification of hours worked by personal care attendants, payment of personal care attendants and other duties.*

A. Findings

1. Should the Council accept responsibility for verification of hours worked by PCAs?

M.G.L. c. 118G § Section 31 (a) states that : *Consumers or the consumer's surrogate retain the right to select, hire, schedule, train, direct, supervise and terminate any personal care attendant providing services to them.* The consumer survey conducted by the JSI Institute shows a high degree of consumer support for the right to choose their PCA. With that right, however, the consumer shoulders the responsibility to verify the hours worked by a PCA. In addition, fiscal intermediaries process each activity form (timesheet), track consumer utilization and notify the consumer and the PCM agency of any overbillings of PCA hours in a given payroll period that exceed the authorized amount. The fiscal intermediaries process over 20,000 activity forms each payroll period, issuing checks for over 25,000 PCAs, who are employed by over 16,000 consumers. Verification of hours worked is therefore an ongoing challenge.

MassHealth, which administers the PCA program, has developed a comprehensive administrative oversight network. This network involves not only MassHealth staff, but the staff at PCM and Fiscal Intermediary agencies under contract with the state. MassHealth regularly reviews and seeks to improve this structure. It is the Council's view that changing the responsibility for overseeing the verification of PCA hours would be disruptive and would not improve the effectiveness of current measures.

2. Should the Council assume responsibility for payment of PCAs?

The network of PCM and Fiscal Intermediary (FI) agencies, supervised by MassHealth, perform a number of tasks of importance to MassHealth members (consumers) receiving services from the PCA program. The FIs manage a complex package of financial records and reporting requirements for individual consumers, including taxes, payroll and workers' compensation. These functions are essential to the consumer's role as employer, but are taxing, time-consuming activities that are better administered by an experienced agency. The FIs have had a contractual relationship with MassHealth for almost a decade. Under MassHealth's guidance and supervision, the FIs payroll and administrative systems have been substantially upgraded in order to accommodate the needs of collective bargaining. A transfer of responsibility for PCA payment would not achieve any gains in efficiency or regulatory compliance and may adversely affect those areas. The consumer survey shows a high level of consumer satisfaction with the current administrative structure. Absent a compelling reason, the current system should not be changed.

3. Should the Council assume other duties?

M.G.L. c.118G §29 (a) states that the mission of the Council is: *recruiting, training and stabilizing the work force of personal care attendants.* In pursuit of that mission the Council has negotiated a labor agreement that increases wages for PCAs and signed a contract for the development of a referral directory of PCAs as called for in §30. Council members and staff will be setting up a labor management committee with 1199SEIU to oversee the new relationship occasioned by the unionization of PCAs. Council staff will also be supervising the contractor for the referral directory. In addition to developing the directory, the contractor has outreach and recruitment responsibilities to discharge as part of their contract.

M.G.L. c.118G §28 *et seq.* also requires the Council to undertake recruitment and training efforts. Some recruitment functions will occur through the new registry. Additionally, modest recruitment and training activities will occur through the ongoing

work of the Council. However, in view of the substantial reduction in the Council's budget (see §II, 1), members and staff of the Council will be challenged to meet the current mandates assigned to the Council and are not in a position to assume additional responsibilities.

B. Recommendations

1. Ensure consumer well being

M.G.L. c.1128G §33 (d) limits the Council to making: *recommendations to the legislature and the governor for any amendments to sections 28 to 33, inclusive that will further ensure the well-being of consumers ….*

As the Council continues to work on recruitment, retention and related issues, the experience gained by Council members could be more broadly used if the Council had a mandate to make consumer related suggestions beyond the scope of this statute.

2. Assure the most efficient means of delivering required services

American Heritage Dictionary defines efficient as: *Acting directly to produce an effect*: The Council acted directly this year by agreeing to a labor contract providing for wage increases for three consecutive years and making initial steps to craft a benefits package for PCAs. The effect of this action is an important first step in meeting the Council's mandate to *insure the quality of long-term, in-home, personal care by recruiting, training and stabilizing the work force of personal care attendants.*

All Council members have volunteered for numerous hours of service and understood from the beginning that their service was not going to be compensated. Collectively, the members of the bargaining team contributed hundreds of volunteer hours to a difficult but ultimately successful undertaking. The bargaining committee will reconvene in 2009 to discuss the contract reopener on health care benefits. Committee members are also likely to serve on the labor management committee and have to confront a second reopener in the contract in eighteen months.

The decades of experience that the Council members brought to the bargaining table were invaluable in negotiating a fair and workable agreement that protected the concept of consumer control. The process would have been much more difficult without their participation; however, it is neither realistic nor fair to expect this level of activity to continue at their own expense.

APPENDICES

PERSONAL CARE ATTENDANT QUALITY HOME CARE WORKFORCE COUNCIL PERFORMANCE REVIEW REPORT

APPENDIX 1A

PROFILE OF CONSUMERS WHO WERE PART OF THE SURVEY SAMPLE

Information on the manner in which the consumer survey was conducted is contained in the Methodology for PCA Workforce Council Survey, submitted as part of this report. PCA consumers who participated in the JSI survey are diverse in gender, age; race/ethnicity and educational background. A majority of PCA consumers were women (67% versus 38% for men). More than half of PCA consumers who responded to the survey were fifty or older. Seventy-one percent of consumers identified themselves as white, 9% as African-American, and 20% as Hispanic. Only 5% reported that they were employed, with more than two-thirds reporting that they were unable to work because of their disabilities.

Figure 1: Age of Consumers (N=502)

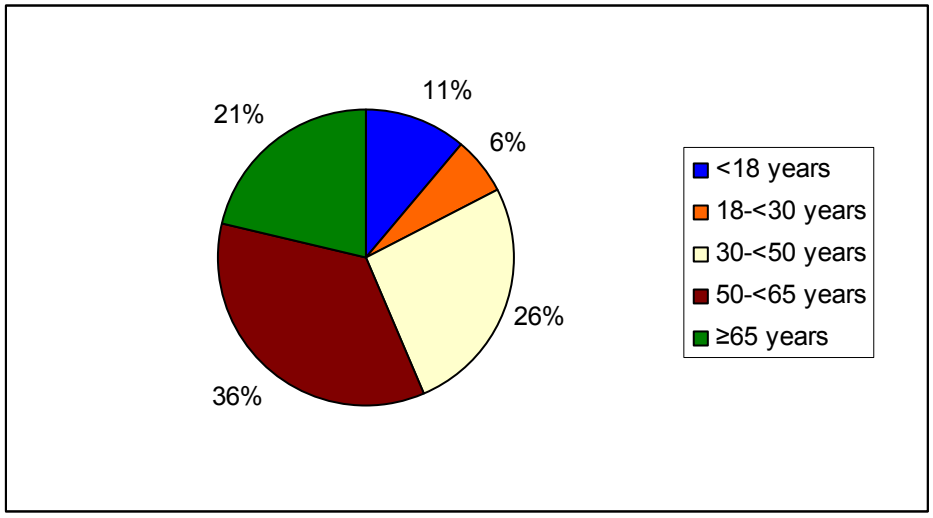
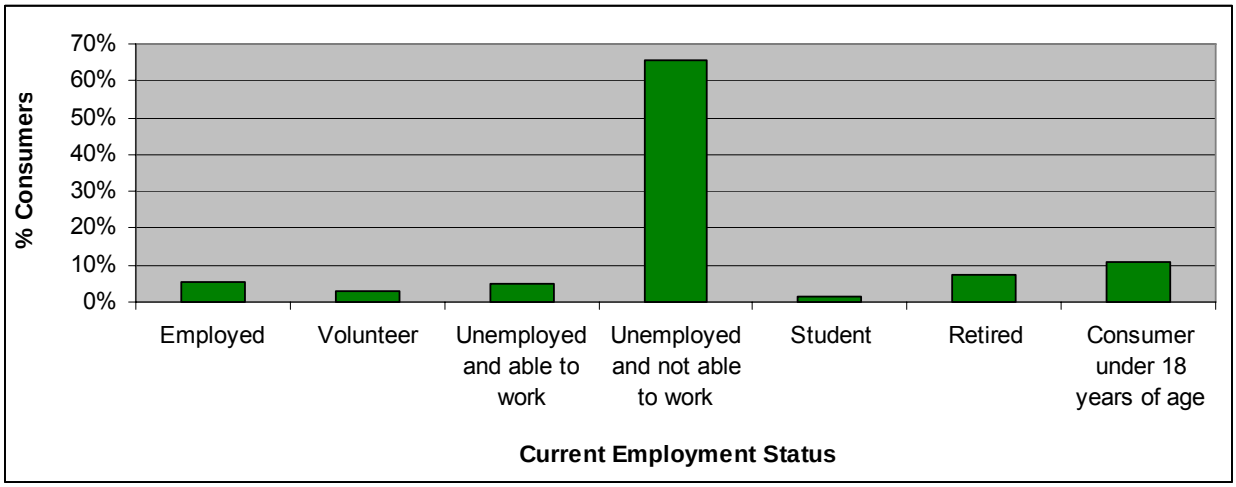
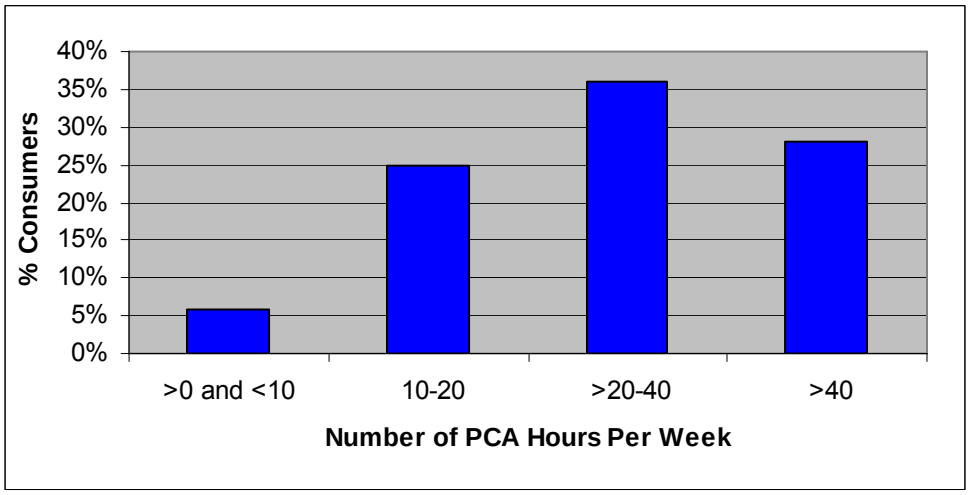


Figure 2: Employment Status of Consumers (N=502)



Many of the PCA consumers surveyed are long-term users of the program and rely on receiving many hours of PCA services per week. More than one-third of consumers have been enrolled in the program for more than five years, roughly one-third for three to five years, and the remainder for less than 3 years. As shown in figure 6, the severity of consumers' conditions is reflected in the numbers of hours of PCA services they have been assigned. Twenty-eight percent reported receiving more than 40 hours per week, 36% reported 20-40 hours per week, 25% reported 10-20 hours per week, and less than 6% used fewer than 10 hours per week. Nearly half (49%) of consumers reported their hours had increased since they first enrolled in the program.

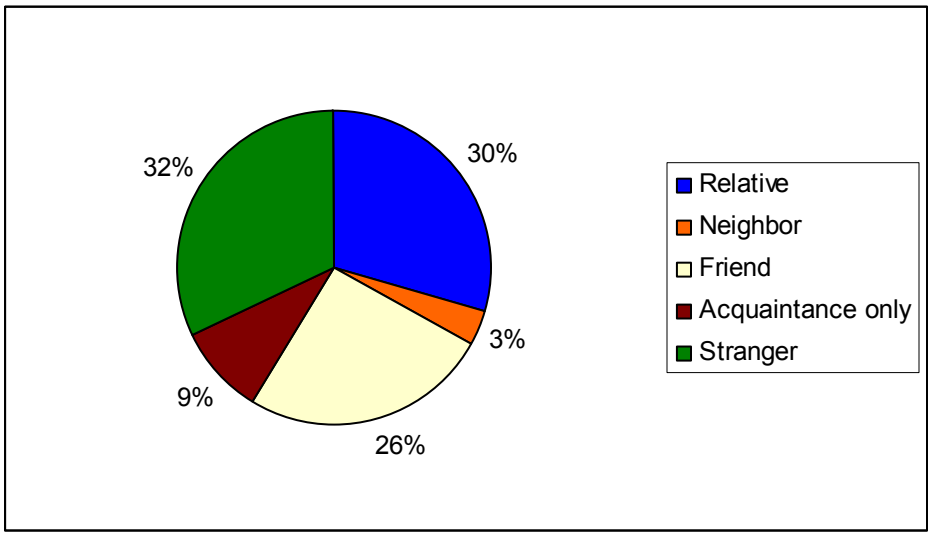
Figure 6: Consumers' PCA Hours per Week



(N=502)

Although many of the PCA consumers surveyed receive a significant number of PCA hours and services each week, the majority (54%) of PCA consumers rely on a single personal care attendant. Twenty-four percent receive assistance from two PCAs and 22% receive assistance from three or more PCAs. The majority of consumers had some relationship, either a friendship or familial relationship, with their PCA prior to developing an employment relationship. Twenty-nine percent were relatives, 29% were friends or neighbors, and acquaintances, and 42% were acquaintances or strangers prior to their employment.

Figure 7: PCAs' Relationship to Consumers When Hired



(N=502)

APPENDIX 1B a

MassHealth Consumers receiving more intensive services

Types of Services & # of members

Consumers no longer on PCA svcs	FY07	FY08
NURSING HOME	322	236
STATE AGENCY (DMH/DMR)	198	162
HOME HEALTH	143	50
ADULT FOSTER CARE	27	38
HOSPICE	47	28
ACUTE INPATIENT	494	181
CHRONIC INPATIENT	83	45
INPATIENT PSYCHIATRIC < AGE 21	1	1
SEMI ACUTE INPATIENT HOSPITAL	0	2
TOTAL	1315	743

Consumers receiving PCA svcs		
NURSING HOME	992	1149
STATE AGENCY (DMH/DMR)	3345	3200
HOME HEALTH	1978	1849
ADULT FOSTER CARE	90	141
HOSPICE	62	130
ACUTE INPATIENT	3846	4037
CHRONIC INPATIENT	341	389
INPATIENT PSYCHIATRIC < AGE 21	25	29
SEMI ACUTE INPATIENT HOSPITAL	10	9
TOTAL	10689	10933

APPENDIX 1B b

Unduplicated count of members

	Consumers no longer on PCA svcs		
year	No. of services claimed		number of members
FY2007		1	533
FY2007		2	271
FY2007		3	65
FY2007		4	10
FY2007		5	1
	unduplicated member count		880
FY2008		1	287
FY2008		2	148
FY2008		3	44
FY2008		4	7
	unduplicated member count =		486
	Consumers receiving PCA svcs		
FY2007		1	5573
FY2007		2	1816
FY2007		3	429
FY2007		4	48
FY2007		5	1
	unduplicated member count		7867
FY2008		1	5767
FY2008		2	1839
FY2008		3	426
FY2008		4	50
FY2008		5	2
	unduplicated member count		8084

APPENDIX 1C

Highlights from the PCA Workforce Council – 1199SEIU Labor Agreement

WAGE INCREASES PROVIDED FOR IN THE LABOR AGREMENT

Effective July 1, 2008, the PCA wage rate shall be $11.60 per hour.

Effective July 1, 2009, the PCA wage rate shall be $12.00 per hour.

Effective July 1, 2010, the PCA wage rate shall be $12.48 per hour.

Article 11 : Health Insurance

A committee shall be established to study health insurance options for PCA's
The committee will have representation from the 1199SEIU, the Council, the Commonwealth Connector, the Secretaries of Health and Human Services and Administration and Finance. The study will be conducted during the first year of this agreement. The findings from the study will be used to inform negotiations over eligibility for health benefits, benefit levels and contribution levels.

- The Commonwealth is committed to initiating contributions in fiscal year 2010 for the provision of health insurance for PCA's determined to be eligible, subject to the Council reaching agreement with the union
- The union acknowledges that the Commonwealth has fiscal constraints that may limit its capacity to meet all of the health insurance funding needs for PCA's that may be identified pursuant to the study.
- … The parties to this agreement will … begin negotiations regarding health benefits with the intention of reaching agreement before July 1, 2009 to commence implementation in FY2010.

CONSUMER RIGHTS UNDER THE LABOR CONTRACT

Now that PCAs have a union, a number of questions have arisen among consumers: Can I still fire a PCA that I am dissatisfied with? Can a PCA file a grievance against me? To clarify matters, below is language directly from the contract signed by the Council.

Article 2: Consumer Rights

Section 1: General Rights
As provided by M.G.L. c.118G, section 31 (a), Consumers and/or their Surrogates shall retain the right to:

1. *Hire PCAs of their choice;*
2. *Supervise, manage and train PCAs in their employ;*
3. *Determine the work schedules of PCAs in their employ:*
4. *Terminate PCAs from their service at will; and*
5. *Determine under any circumstances who may and may not enter their home or place of residence.*

Such authority and control on the part of the Consumers is not, and shall not be, diminished in any way whatsoever by this Agreement.

Article 14: Dispute Resolution

1) *No matter arising from, or dispute pertaining to, the exercise by a Consumer and/or his or her Surrogate of any rights … including, but not limited to, the right to select, hire, schedule, train, direct, supervise and/or terminate any PCA providing services to him or her, shall in any way be subject to the provisions of … this Article.*

From time to time, consumers may receive union materials in the mail they receive from the Fiscal Intermediaries. Consumers should give these materials to their PCA. Remember, consumers have a stake in a strong union as the union promotes better wages and benefits for PCAs, thus increasing the number of people wanting to do PCA work and making it easier for consumers to recruit PCAs.

APPENDIX 2A

PCA Workforce Council Budget

Expense Categories	FY 08 Obligation Ceiling Amount	FY08 Total Spending
AA - REGULAR EMPLOYEE COMPENSATION	192,424	191,386
BB - REGULAR EMPLOYEE RELATED EXPEN	21,350	1,242
CC - SPECIAL EMPLOYEES	29,465	-
DD - PENSION & INSURANCE RELATED EX	2,559	2,545
EE - ADMINISTRATIVE EXPENSES	71,650	66,155
GG - ENERGY COSTS AND SPACE RENTAL	40,000	-
HH - CONSULTANT SVCS (TO DEPTS)	160,000	159,221
JJ - OPERATIONAL SERVICES	55,000	53,607
KK - EQUIPMENT PURCHASE	3,000	1,050
UU - IT Non-Payroll Expenses	276,665	1,000
All Object Classes	**852,113**	**476,206**
NOTES:		
AA - Total Compensation includes salary for Council Office staff including the Director, Executive Assistant and Lead Labor Negotiator. Additional EOHHS staffing costs provided to the Council prior to the full staffing of the Council's office totaled $68,689.00.		
BB - Employee travel expenses to related meetings and conferences.		
EE - Administrative Expenses includes Office Supplies, Printing, Postage and Travel related expenses for Council members.		
GG - Space Rental costs were deferred due to space being secured in a state owned property.		
HH - Consultant Services includes $100,000 for the PCA and Consumer Surveys, $10,000 for Scholarships to provide CPR training to PCAs, and $15,000 for the Council Retreat.		
JJ - Operational Services includes $48,717.00 for 50% share of the Labor Election conducted by the American Arbitration Assn.		
UU - IT Expenses. Delays in the hiring of staff and the the RFR process for the referral directory delayed payment of funds in FY08. PAC funding of $200,000 was approved for initial start-up costs for the Directory to be spent in FY09.		

APPENDIX 2 B

Cost of PCA Program

PCM Agency Annual Expenditures	**FY 07**	
Skills Training	$	7,610,364.20
Intake and Orientation	$	532,759.51
Initial Evaluations	$	595,552.47
Re-Evaluations	$	1,174,728.24
Total PCM Expenditures FY 07	**$**	**9,913,404.42**
# consumers billed by PCM Agencies		15,903
Fiscal Intermediary Annual Expenditures		
Payroll Costs (CY07)		
Payroll	$	242,277,600.00
SUTA	$	8,191,963.28
FUTA	$	1,200,117.09
FICA/Medicare	$	19,155,242.74
Workers' Compensation	$	3,980,655.80
Total Payroll Costs	$	274,805,578.91
FI Administrative Fee (CY 07)	**$**	**8,559,922.28**
Total FI Expenditures for CY 07	**$**	**283,365,501.19**
# consumers billed by FIs		15,755
Total Annual MH Expenditures for PCA program*	**$**	**293,278,905.61**

* expenditures are based on PCM Agency and FI paid claims

In addition, the total admin/overhead/operations cost of operating the PCA program is $5.74M.

APPENDIX 2 C
PCA/Long Term Care Expenditures

Dollars in Millions

Provider Category	FY2003	Trend	FY2004	Trend	FY2005	Trend	FY2006	Trend	FY2007
Institutional LTC	-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-	-
Inpatient Rehab/Chronic	$111.0	-2%	$108.3	-1%	$107.2	18%	$126.1	11%	$139.8
Outpatient Rehab/Chronic	$13.4	-14%	$11.5	-12%	$10.1	1%	$10.2	17%	$11.9
Nursing Homes	$1,448.5	7%	$1,548.0	2%	$1,586.5	2%	$1,613.7	-4%	$1,554.6
Total Institutional LTC	$1,462.0	7%	$1,559.5	2%	$1,596.6	2%	$1,623.9	-4%	$1,566.5
Community LTC									
PACE	$43.2	-2%	$42.4	15%	$47.7	18%	$56.1	7%	$60.2
PCA (total program including wages)	**$194.2**	**15%**	**$222.8**	**10%**	**$244.9**	**10%**	**$268.9**	**9%**	**$293.3**
Home Health Agency	$98.8	1%	$99.8	5%	$104.5	4%	$108.2	9%	$117.7
PDN	$1.2	16%	$1.3	59%	$2.1	85%	$3.9	63%	$6.4
Adult Foster Care	$53.9	11%	$59.6	10%	$65.5	8%	$70.5	7%	$75.6
Adult Day Health	$36.5	10%	$40.3	6%	$42.8	7%	$45.8	15%	$52.8
Day Habilitation	$83.0	7%	$89.1	6%	$94.2	7%	$101.0	6%	$106.6
Hospice Care	$24.5	50%	$36.7	21%	$44.3	34%	$59.4	48%	$87.7
Therapies	$2.4	-23%	$1.8	-2%	$1.8	14%	$2.0	6%	$2.2
Prosthetics/Orthotics	$3.5	4%	$3.7	-3%	$3.6	4%	$3.7	18%	$4.4
DME/Oxygen	$37.4	-6%	$35.1	-6%	$33.0	7%	$35.2	9%	$38.3
SCO Capitation	$0.0	n/a	$0.3	5746%	$12.8	242%	$43.9	####	$98.5
Total Community LTC	$578.6	9%	$632.9	10%	$697.2	15%	$798.7	17%	$934.9
Total LTC MH Spending	$2,040.5	7%	$2,192.4	5%	$2,293.8	6%	$2,422.6	3%	$2,501.4
Total LTC MH Spending w/o PCA	$1,846.4	7%	$1,969.6	4%	$2,048.9	5%	$2,153.6	3%	$2,216.7
PCA spending as a % of total LTC Spending	10%		10%		11%		11%		11%
PCA as a% of Community LTC Spending	34%		35%		35%		34%		30%