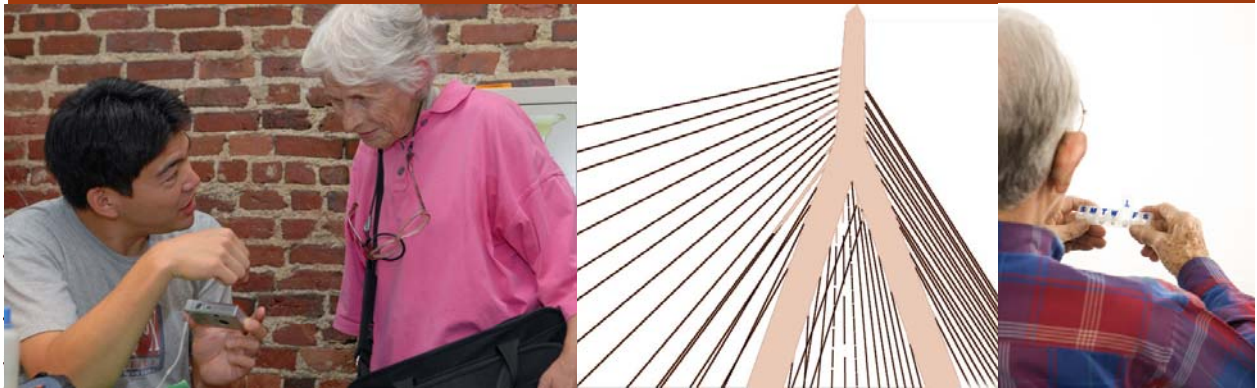


Consumers' Experience in the Massachusetts Personal Care Attendant Program



JSI Research & Training Institute

Report to
The Personal Care Attendant
Quality Home Care Workforce Council

May 2009



JSI Research & Training Institute, Inc.



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Introduction

For over three decades, MassHealth’s Personal Care Attendant (PCA) Program has enabled elderly and disabled Massachusetts residents to avoid institutionalization and remain in their homes. The State reinforced its commitment to providing personal care assistance to these residents in 2006 with the creation of the Massachusetts Personal Care Attendant Quality Home Care Workforce Council, which is charged with the task of making it easier for PCA consumers (those receiving services) to find and hire PCAs (those providing services). The legislative statute authorizing the inception of the Council also mandated that every two years the Council conduct an “evaluation of the health, welfare and satisfaction with services provided of the consumers receiving long-term in-home personal care services by personal care attendants.” The Council awarded the first contract to conduct such an evaluation to JSI Research & Training Institute, Inc. (JSI) in June 2008.

This evaluation occurs in the context of a renewed dedication to improving long-term care to the elderly and disabled in Massachusetts. Governor Patrick has demonstrated the importance of providing assistance for this population and changing long-term care in the state through the Community First Initiative, which seeks to promote flexible service options in the community and treats institutionalization as a last resort. This investment will allow the Commonwealth to offer elderly and disabled MassHealth recipients proper community support, such as increased access to: MassHealth Home and Community Based Services (HCBS), case management services, support for family caregivers, and community-based long term care information and counseling. The PCA program helps support this broader effort of the Governor to create more and better options for those in need of community-based long-term care services.

This report summarizes the results of the research conducted by JSI, which included a survey of PCA consumers, focus groups with PCA consumers and semi-structured interviews with key stakeholders, as well as recommendations on possible ways to improve the program. More specifically, this report discusses the characteristics of survey respondents, the

activities with which program consumers receive both paid and unpaid assistance, the unmet and variable needs of program consumers, the administrative issues that survey respondents have encountered with the program, PCA recruitment and retention, consumer satisfaction, and consumer recommendations for improving the program. The Council has also contracted with JSI for a separate survey of current PCA workers. The results of this survey, available in spring 2009, will provide important information on training and other programs and efforts that will assist with the recruitment and retention of PCAs. JSI hopes that these two evaluations, in conjunction with other State long-term care initiatives, will pave the way for improved care and assistance for PCA program consumers and other elderly and disabled residents in Massachusetts.



Methodology

Because no single research method would capture all of the different perspectives and issues for PCA consumers in Massachusetts, a mixed method design was used for this evaluation study. Quantitative data were collected using a telephone survey of PCA consumers, and qualitative data were gathered from focus groups and key informant interviews. The qualitative data provided the context in which the quantitative data were interpreted and allowed a better understanding of the various challenges, benefits and nuances of the PCA program from the perspective of the PCA consumers themselves.

Survey

The PCA consumer survey was developed in-house at JSI. JSI worked closely with the PCA Workforce Council, MassHealth and Personal Care Management (PCM) agencies in elucidating the pertinent topic areas and appropriateness of questions for the project. A literature review, as well as key informant interviews with researchers who have conducted evaluations of other state PCA programs or have collected data on similar issues from similar populations, informed the topic areas to be included in the survey.^{1,2,3,4,5,6} For topics with no previously validated questions, JSI's research team developed questions to target these areas. Before finalizing the survey, readability statistics helped determine the Flesch reading ease and Flesch-Kinkaid Grade Level. The goal was to produce a survey that could easily be read and understood by an individual with an 8th grade reading level. Additionally, the survey was pilot tested with 16 PCA consumers.

Given the functional limitations of this population, it was decided that telephone surveying would be the most appropriate mode to collect data. The telephone survey was completed using CASES, a computer assisted telephone interviewing system. Consumer names and contact information (phone number and residential address) were obtained with help from MassHealth from the three Fiscal Intermediaries (FIs). For those consumers with identified surrogates to assist with PCA program activities, surrogate names and contact information were also provided by the FIs.

Pre-notification letters were sent out to the randomly sampled subset of consumers one week before interviewers began calling. The purpose of the letter was to alert the sampled PCA consumers about the evaluation study, that they were randomly selected to participate, that participation would not in any way affect the services provided to them by the PCA program, and that they would be contacted shortly by a research team at JSI on behalf of the PCA Workforce Council. This pre-notification letter was signed by the Executive Director of the PCA Workforce Council to legitimize the survey in the eyes of PCA consumers.

In the first wave of interviews, consumers 18 years and older were contacted. A description of the study was read and informed consent was obtained. If during the call it was determined that the consumer was younger than 18 years, spoke Spanish, or was too disabled to complete the survey but had a surrogate who could complete the survey for him/her, then the consumer's interview was postponed to the second wave of interviews.

In the second wave, the Spanish version of the consumer survey was used to interview those consumers who were unable to complete the English version of the consumer survey due to language competencies. Additionally, PCA program-appointed surrogates served as proxies in this wave for consumers younger than 18 years of age and consumers too disabled to complete the survey. Surrogates answered all questions with respect to consumers' experiences and satisfaction with the program.

Given the budget for this project, we originally planned to draw a random sample of 1,000 consumers, proportional to the actual representation of consumers in each of the three FIs. Assuming a 50% response rate, that would result in a final analytic sample of 500 consumers. Unfortunately, almost 60% of the sample was comprised of consumers that were unable to be reached or consumers with bad phone numbers (see Table 1). In the end, we released 2,147 sample into CASES in order to obtain ~500 interviews. A final response rate was not calculated for this project, given the poor quality of the sample.

TABLE 1: PCA CONSUMER SAMPLE CONTACTED FOR INTERVIEW

	Consumer version	Surrogate version	Total
Total sample released	1,650	497	2,147
Total refusals	143	30	173
Total bad phone numbers	433	94	527
Total unable to reach ¹	475	252	727
Total consumer requested surrogate answer	220	n/a	220
Total Interviews	381	121	502

Analysis of Survey Data

After the target sample size was attained, data were managed, cleaned, coded and analyzed by a statistician at JSI using SAS version 9 (SAS Institute, Inc., Cary NC). PCA responses to questions were kept completely confidential and only aggregated data were presented. For categorical variables, proportions were reported and Chi Square tests were used to determine statistical significance ($p < 0.05$). Continuous variables were either categorized based on their distribution or reported as mean values. T-tests were used to determine if statistically significant differences ($p < 0.05$) existed between mean values. Data were presented overall (statewide estimates) and then stratified by: interviewee (consumer vs. surrogate as proxy); gender (male vs. female); age (<50 years vs. 50 to <65 years vs. ≥ 65 years); relationship between consumer and PCA worker (family member vs. friend/neighbor vs. acquaintance/stranger); region² (Southeastern MA/Cape/Islands vs. Suffolk/Northeastern MA vs. West of Worcester); and Hispanic/completed survey in Spanish vs. non-Hispanic/completed survey in English.

¹Call backs, No answer, Answering Machine, Consumer unable to communicate, etc.

²Southeastern MA/Cape/Islands includes Norfolk, Plymouth, Bristol, Barnstable, Dukes, and Nantucket counties. Suffolk/Northeastern MA includes Suffolk, Essex, and Middlesex counties. West of Worcester includes Worcester, Hampden, Hampshire, Franklin, and Berkshire counties.

Focus Groups

The goal of the focus groups was to explore selected topics in greater depth and better understand the experiences of various subgroups of PCA consumers. A moderator's guide was developed a priori to facilitate discussion and ensure uniformity in data collection across groups. A total of three focus groups with 3-12 PCA consumers each were conducted in geographically diverse regions of the State and for specific subgroups of consumers. The exact groups included: consumers from Springfield MA (both English and Spanish speaking); consumers from a support group at the Multi-Cultural Independent Living Center in Dorchester MA; and surrogates for consumers from Fall River MA. Recruitment of participants was accomplished with help from the PCM agencies and snowball sampling (consumers who agreed to participate would help recruit their acquaintances who were also consumers to participate). Participants were given a \$25 stipend and refreshments. Each group was led by an experienced focus group moderator from JSI, as well as a note-taker/assistant moderator. Notes from the groups were reviewed for consistent themes. Major themes for discussion included: the importance of consumer control; improved consumer quality of life due to the program; PCA scope of services regarding doctors' appointments and hospital stays; the process of getting evaluated/approved for more hours of PCA time; process of obtaining and satisfaction with nighttime hours; PCA worker background checks before hiring; and improved compensation/benefits for PCA workers.

Key Informant Interviews

The goal of key informant interviews was to better understand the needs and experiences of PCA consumers and their satisfaction with the PCA program, as well as possible strategies for enhancing the PCA consumer experience. We developed a semi-structured interview guide to standardize the data collection process across interviews. Approximately 25 key informant interviews were conducted over the phone and in person with the following individuals: Workforce Council members who are also PCA consumers; other PCA consumers; Agency surrogates; non-Agency surrogates and researchers that have surveyed similar populations or have conducted evaluations of similar state programs.

Characteristics of PCA Consumers

Demographics of Survey Respondents

In terms of the age distribution, 17% of respondents were younger than 30 years, 26% were 30 to <50 years, 35% were 50 to <65 years, and 21% were 65 years or older (Figure 1). As illustrated in Figure 2, most respondents were unemployed and unable to work (65%), 5% were unemployed but able to work, and 5% were employed. Three-quarters of interviewees were consumers and one-quarter were surrogates to consumers. Almost 40% of survey respondents were from Western Massachusetts (Berkshire, Hampden, Hampshire and Franklin counties) and 24% were from Southeastern Massachusetts (Norfolk, Plymouth, and Bristol counties). A majority of respondents were female (61%). Most respondents were Caucasian (71%), while 9% of respondents were African-American, 7% were bi/multi-racial and 21% were Hispanic. Thirty-seven percent of respondents never married, 28% were divorced/separated, 13% were widowed, and 10% were currently married or living with a partner. Almost one-third of respondents had less than a high school education and 26% were high school graduates (including GED equivalent degree).

FIGURE I: AGE OF CONSUMERS (N=502)

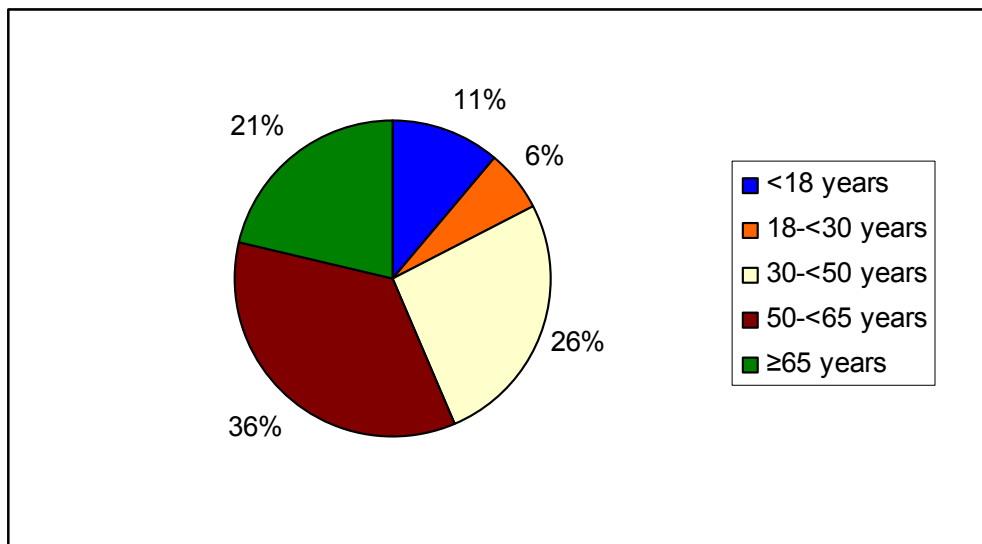
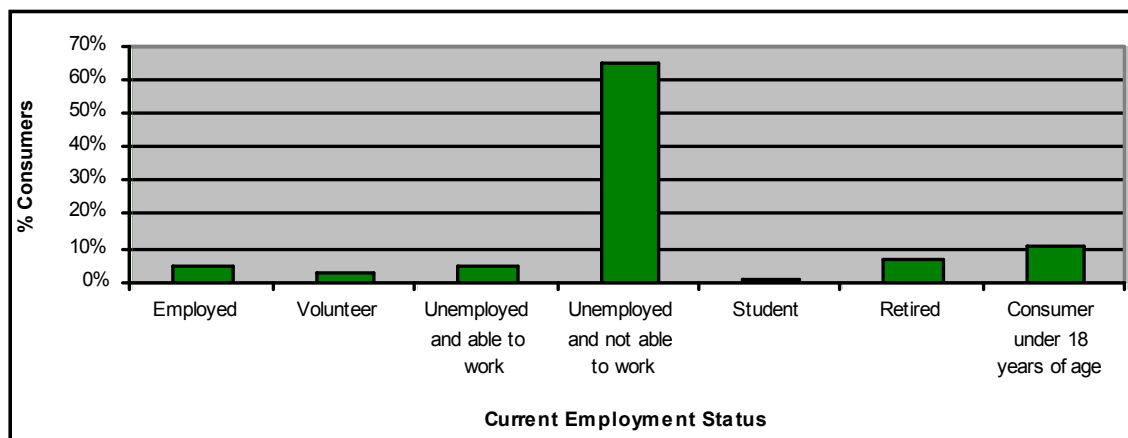


FIGURE 2: EMPLOYMENT STATUS OF CONSUMERS (N=502)

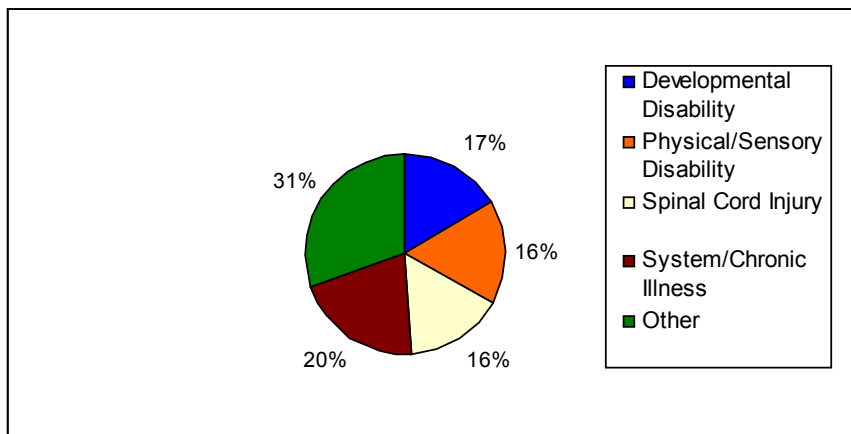


Specific to the surrogates who served as proxies for the consumers, 84% were female and 88% were less than 65 years old (47% were 30 to <50 years). One-quarter of surrogates had a high school education, 22% had some college/technical school, and 26% were college graduates. Most often, surrogates were parents of the consumer (64%). Eight percent were children of consumers, 3% were spouses, 3% were friends, 4% were from an agency, and 14% were other family members. Surrogate respondents helped consumers with a variety of program administrative responsibilities, including finding/hiring PCAs (98%), training PCAs (96%), scheduling PCAs (98%), supervising PCAs (96%), and completing timesheets and other paperwork (97%).

Disability and Health Status

PCA consumers reported severe disabilities and their disabilities were frequently progressive, becoming worse over time. Their disabilities were often the result of health problems or their disabilities themselves had major health consequences. As shown in Figure 3, chronic illness (20%), developmental disabilities (17%), physical/sensory disability (16%), and spinal chord injuries (16%) were the four most frequent conditions reported by consumers that led to their enrolling in the PCA program. A striking 73% of consumers reported that their disabilities had gotten worse over time.

FIGURE 3: CONSUMER PRIMARY DISABILITY THAT LED TO ENROLLMENT IN THE PCA PROGRAM (N=502)



PCA consumers face greater health problems than other people of the same age living in Massachusetts. Fair or poor health was reported by 48% of PCA consumers under age 50, 67% of PCA consumers aged 50-64, and 79% of PCA consumers aged 65 and over (Figure 4a). Nearly two-thirds of respondents reported that their health was fair or poor, and 42% said that their health was somewhat or much worse than it was 12 months ago (Figure 4b). Comparatively, according to the 2005 Massachusetts Behavioral Risk Factor Surveillance System (BRFSS), fair or poor health was reported by 9% of Massachusetts residents aged 18-50, 16% of residents aged 50-64, and 24% of residents aged 65 and over. Figures 4a and 5 indicate that older PCA consumers have worse health and more disabilities. The correlation of poor health to advancing age is vitally important to the future operation of the PCA programs; as the PCA consumer population becomes older, it will require greater PCA resources to have health and functional needs met. In focus groups as well as in the survey's open-ended questions, many PCA consumers reported that they would be forced to live in an institution if they did not receive PCA services.

FIGURE 4A: CONSUMER HEALTH STATUS BY AGE (N=501)

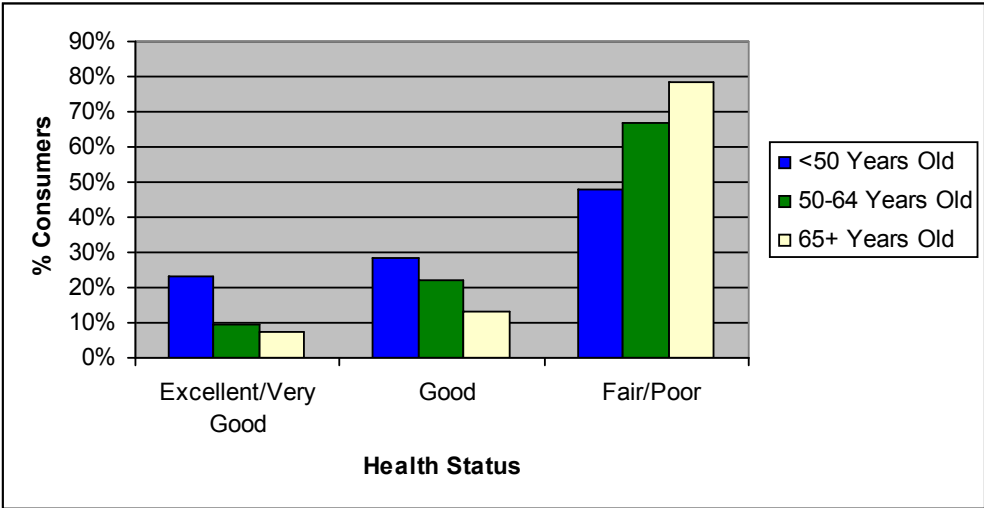


FIGURE 4B: CHANGE IN HEALTH STATUS BY AGE (N=501)

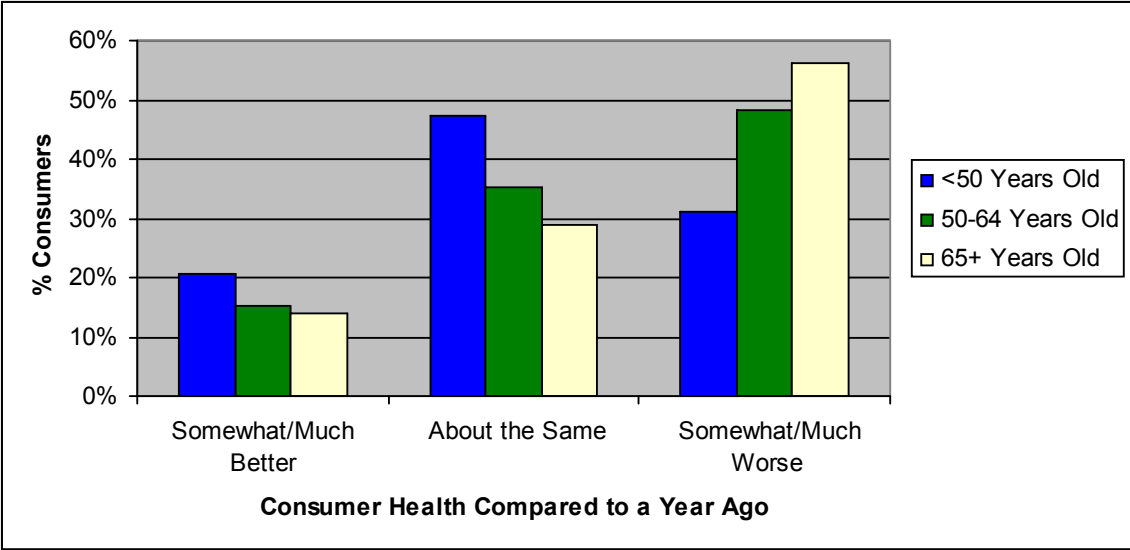
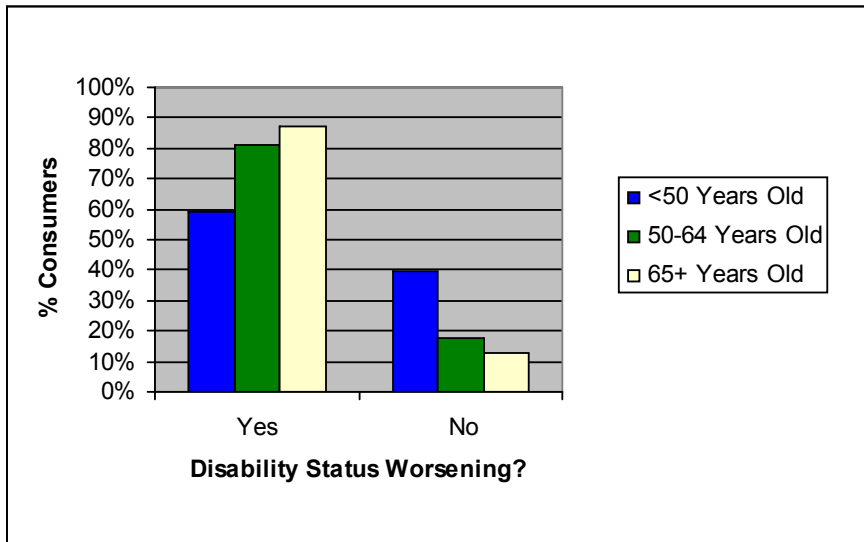


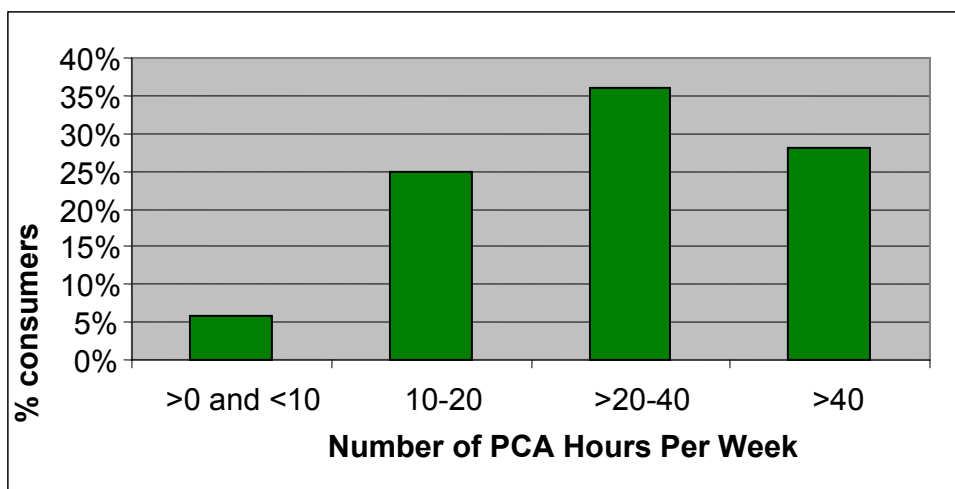
FIGURE 5: CHANGE IN DISABILITY STATUS BY AGE (N=501)



PCA Program Use

Many PCA consumers 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 number 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,

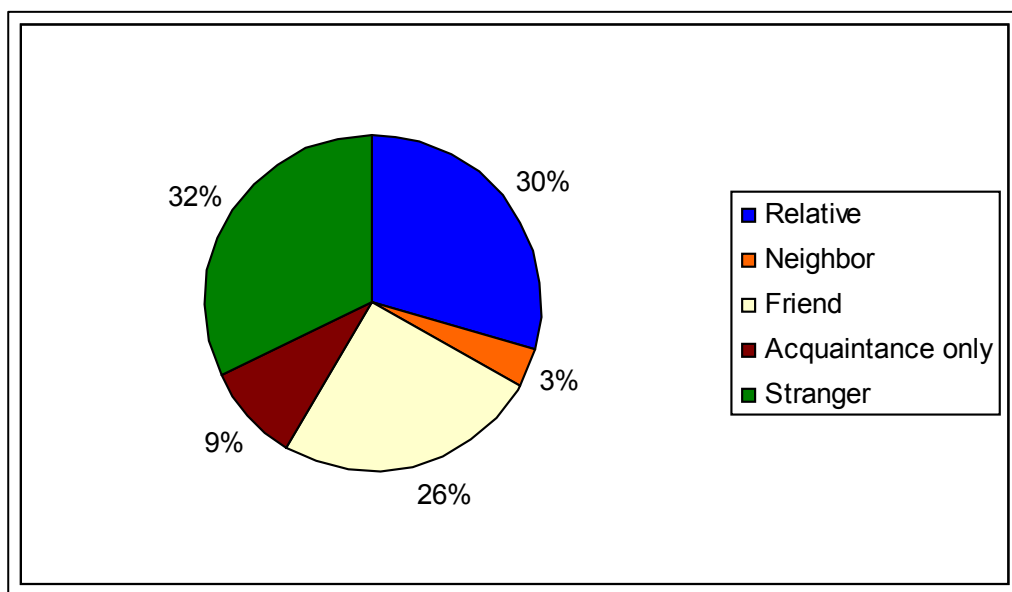
FIGURE 6: CONSUMERS' PCA HOURS PER WEEK (N=502)



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.

Many PCA consumers reported receiving a significant number of PCA hours and services each week, and the majority (54%) of PCA consumers relied on a single personal care attendant. Twenty-four percent received assistance from two PCAs and 22% received assistance from three or more PCAs. The majority of consumers had 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 41% were acquaintances or strangers prior to their employment (Figure 7).

FIGURE 7: PCAs' RELATIONSHIP TO CONSUMERS WHEN HIRED (N=502)



Consumers over age 65 were more likely to have only one PCA and for that PCA to be a relative, as compared to consumers age 64 and under. The relationship of the PCA to the consumer has major implications, such as consumer satisfaction with the program, consumer quality of life, quality of the PCA/consumer relationship, and PCA turnover.



Assistance Provided to PCA Program Consumers

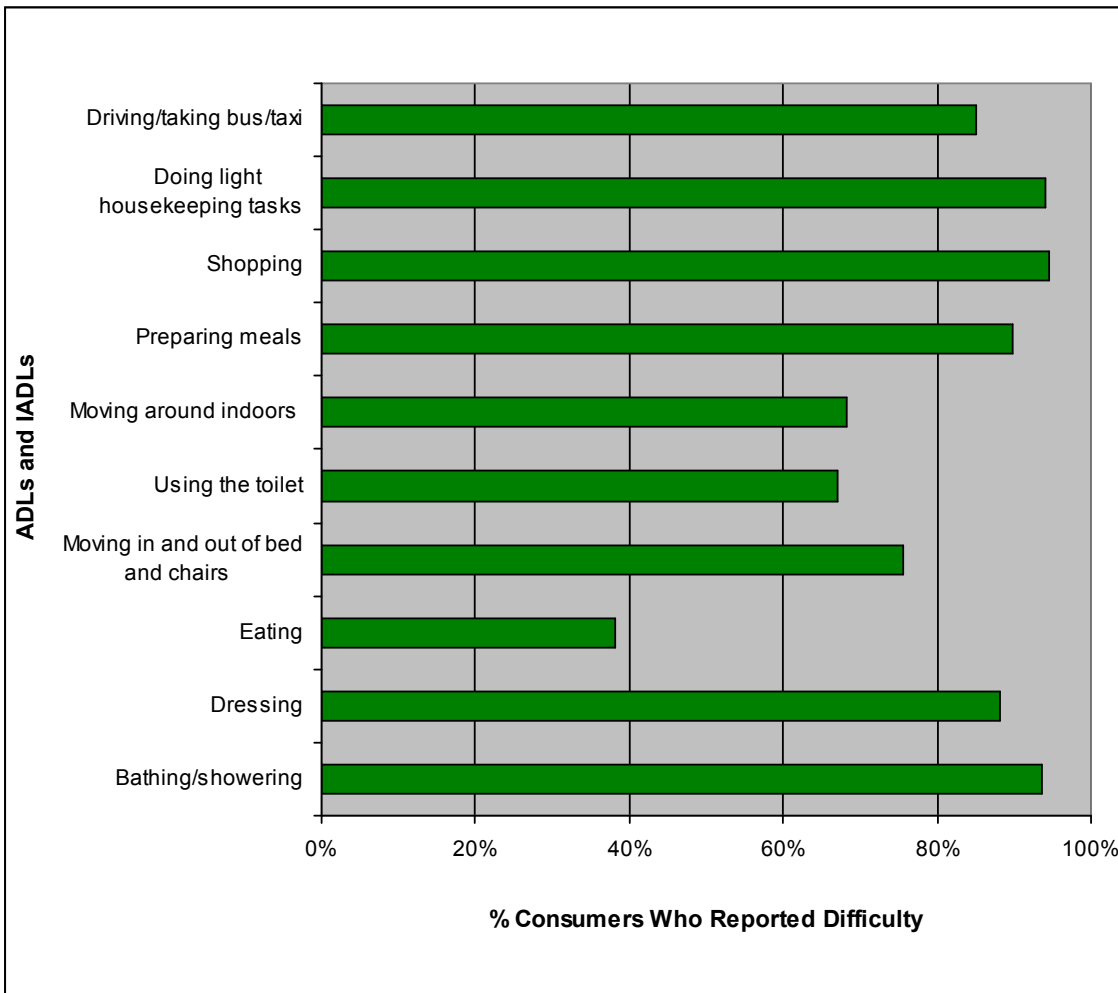
Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)

The PCA program funds PCAs to assist consumers with demonstrated needs in the areas of activities of daily living (ADLs), such as bathing and dressing, and instrumental activities of daily living (IADLs), such as food shopping and preparing meals.³ Nurses under contract with PCM agencies⁴ conduct an assessment of consumer needs regarding ADLs and IADLs as part of the initial enrollment process and as part of a reevaluation process. Enrollment and allocation of hours is based on a person's ability to perform ADLs and IADLs independently. In general, PCA consumers reported high levels of difficulty in performing ADLs and IADLs, ranging from 38% of consumers who reported difficulty eating to over 94% who reported difficulty shopping (Figure 8).

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 tube-feeding 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;

FIGURE 8: CONSUMER DIFFICULTY PERFORMING ADLS AND IADLS (FOR ADLS, N=502; FOR IADLS, N=446⁵)

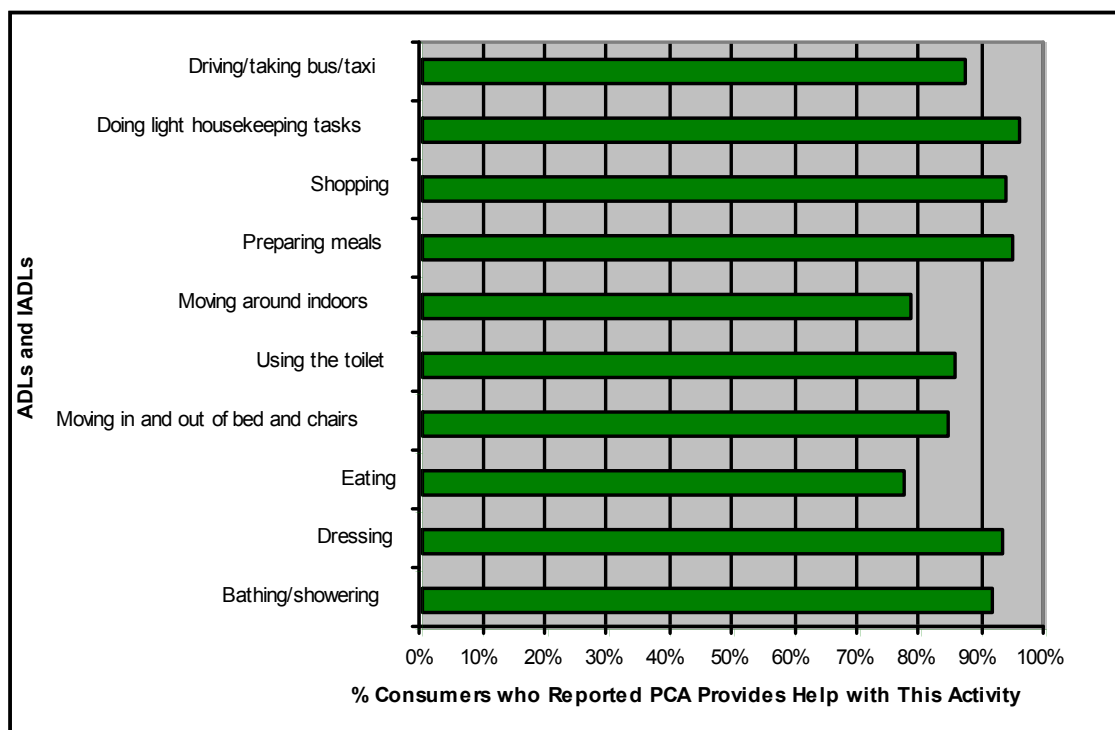


- (3) transportation: accompanying the member to medical providers; and
- (4) special needs: assisting the member with:
 - (a) the care and maintenance of wheelchairs and adaptive devices;
 - (b) completing the paperwork required for receiving personal care services; and
 - (c) other special needs approved by the MassHealth agency as being instrumental to the health care of the member.

⁴The PCM is a public or private agency under contract with EOHHS to provide personal care management (PCM) services in accordance with MassHealth regulations and the PCM services contract.

⁵ The sample size is lower for those responding to questions regarding difficulty performing IADLs because these questions were not asked of surrogates for consumers <18 years old.

FIGURE 9: PCA PROVIDES HELP WITH ADLS AND IADLS (AMONG CONSUMERS WHO REPORTED DIFFICULTY PERFORMING ADLS AND IADLS); (FOR ADLS, N=502; FOR IADLS, N=446⁵)



As expected given the nature of the program, those consumers that reported difficulty and needing assistance with ADLs and IADLs often received help from PCAs in these areas (range: eating, 78% to doing light housekeeping tasks, 96%). See Figure 9. However, the assistance and support provided by PCAs is not restricted to only those tasks associated with ADLs and IADLs. From focus groups and qualitative interviews, 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, consumers and surrogates reported that PCAs often act as advocates for consumers in their interactions with physicians and other health providers. Figures 10 and 11 show the percentage of consumers by the number of ADLs and IADLs with which they have at least some difficulty.

FIGURE 10: NUMBER OF ADLs WITH WHICH CONSUMERS HAVE AT LEAST SOME DIFFICULTY; (N=446)

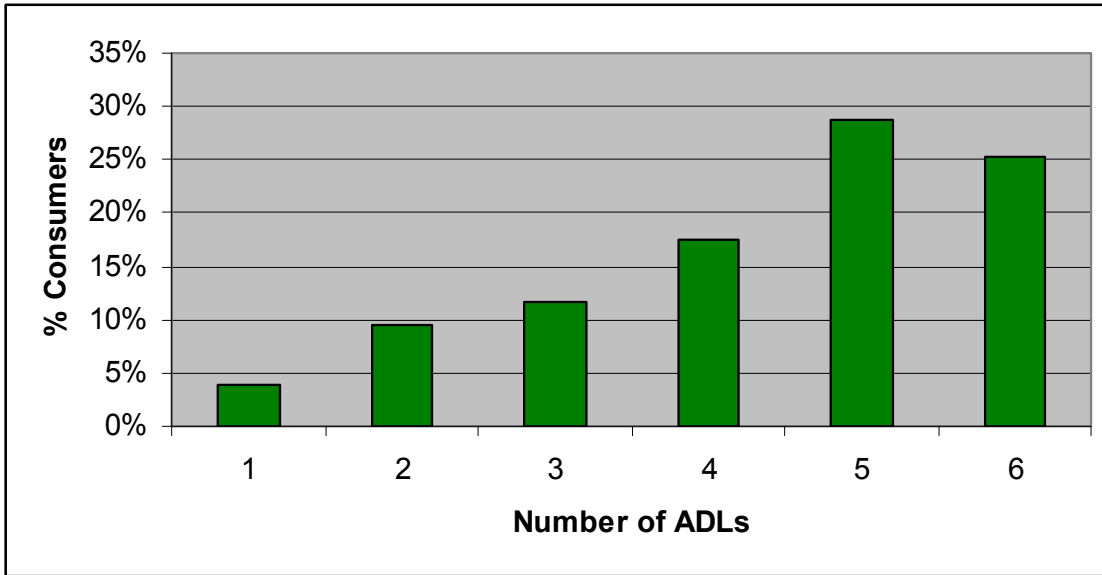
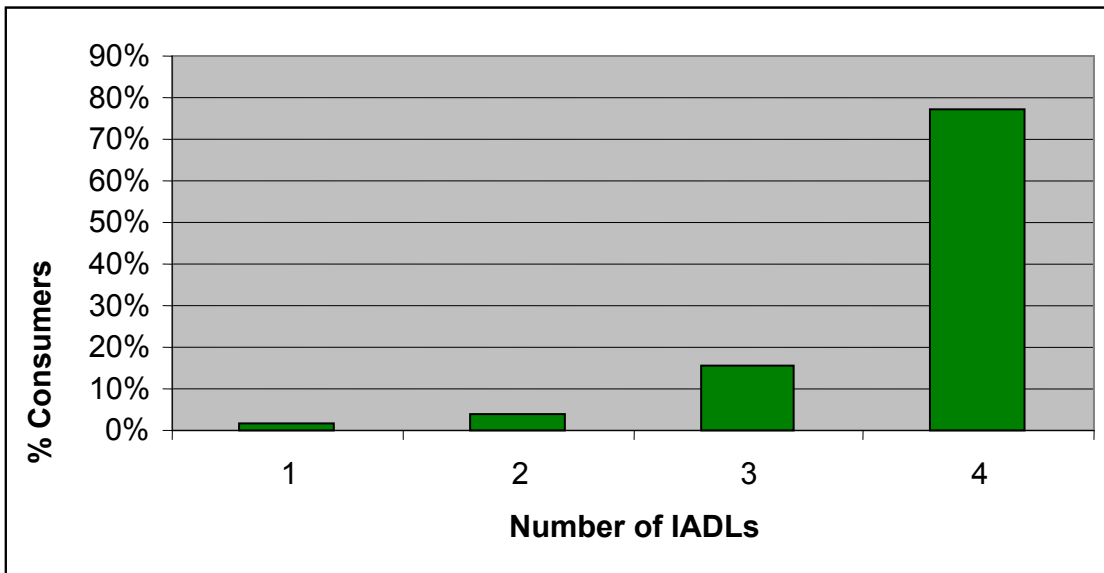


FIGURE 11: NUMBER OF IADLs WITH WHICH CONSUMERS HAVE AT LEAST SOME DIFFICULTY; (N=446)



Unpaid Care and Assistance

Family members and friends provide a vitally important source of caregiving for PCA consumers. Fifty-six percent of consumers reported receiving unpaid services from family members and friends. Of those receiving unpaid care, over 40% received more than ten hours of assistance per week. Consumers who reported having a family member PCA were more likely than consumers who reported having a non-family member PCA to receive unpaid care and assistance from family members and friends. It is possible that this trend occurs because the PCA program allows family members to be paid for some of the care and assistance that they provide to consumers.

Nearly 40% of consumer survey respondents reported having a surrogate, though Mass-Health records indicate that there is an even high percentage of surrogates among the total consumer population. Surrogates interviewed reported helping consumers with the following tasks: finding and hiring PCAs, training PCAs, scheduling PCAs, supervising PCAs, and completing timesheets and other paperwork. Eighty-two percent of surrogates interviewed reported helping consumers with five tasks, while 8% reported helping with four tasks and another 8% reported helping with six tasks. These percentages, however are based on self-reporting by surrogates and do not capture the degree of assistance provided by surrogates whose consumers elected to complete the survey themselves. Of the 121 surrogates interviewed, 89% were family members of the consumers for whom they served as a proxy. Family members are becoming increasingly important in the program, often serving as surrogates and providing informal caregiving as well as paid caregiving. Seventy-one percent of consumer survey respondents had family members playing at least one of these roles.

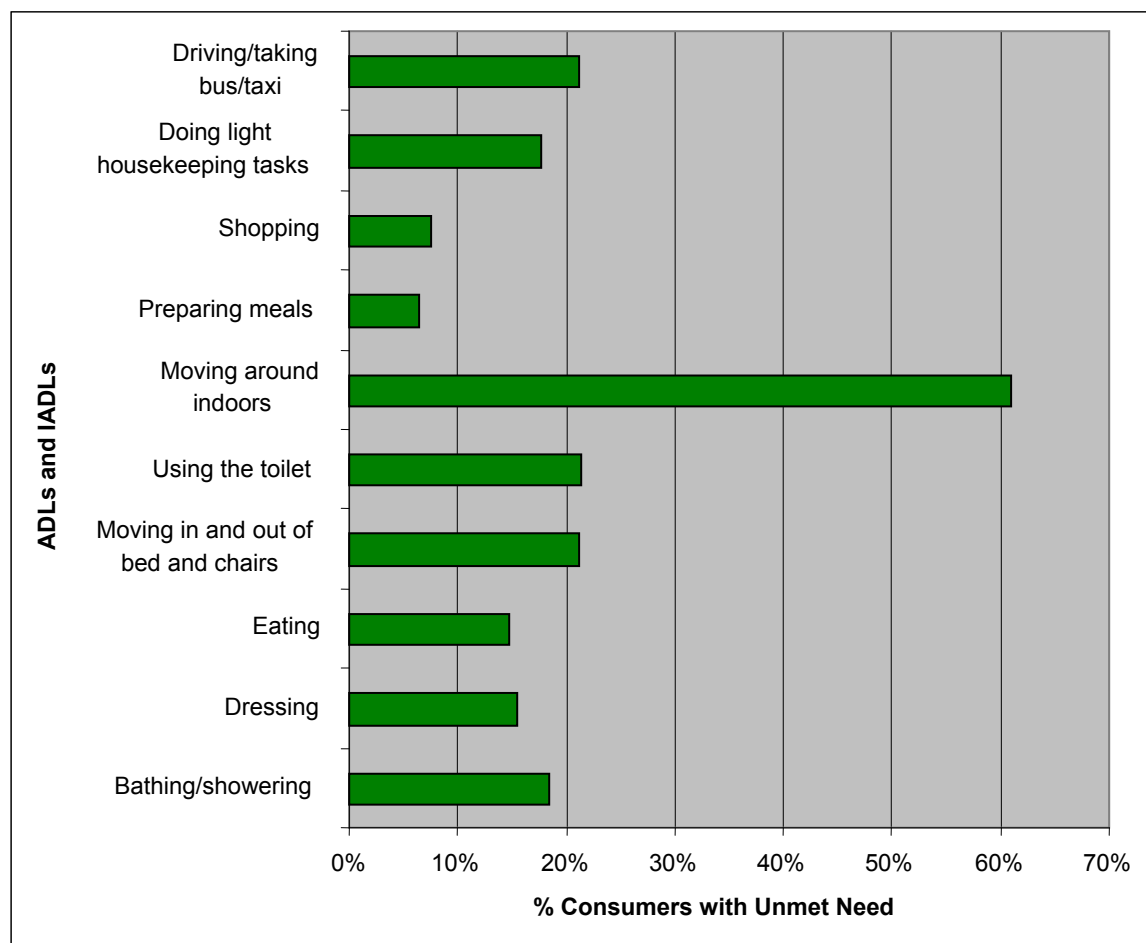
Other formal services

The fragility and complex health and functional needs of many PCA consumers are reflected in the fact that many are receiving other publicly funded services. 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 Association (VNA). The majority of consumers received ten or fewer hours per week of these other formal services (59%). As the consumer population grows older, it will be more likely that they will need and use these other formal services.

Unmet and Variable Need

Even with the number of supportive services provided to PCA consumers, a significant portion of consumers still reported unmet need, as measured by situations in which no one was available to provide needed assistance. As Figure 12 shows below, the amount of unmet need varied from 6% (for those who needed help in preparing meals) to 57% (for those who needed help moving around indoors). The consumers with the greatest unmet need were those consumers who had the greatest number of PCA hours.

FIGURE 12: UNMET NEED (AMONG CONSUMERS WHO REPORTED DIFFICULTY PERFORMING ADLS AND IADLS); (FOR ADLS, N=502; FOR IADLS, N=446⁵)



Another measure of unmet need is the consumer's perception of whether the number of hours allocated for PCA services by MassHealth is sufficient or adequate to meet their needs. Almost two-thirds of consumers indicated that their 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 43% said that their daytime hours were not adequate. Similarly, roughly half of consumers who were allocated nighttime hours reported that the nighttime hours were adequate, while 46% said that they did not have enough nighttime hours.

In focus groups, consumers reported several other types of unmet needs relating to the program's scope of services. 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 were concerned because they felt as though PCAs were more capable of attending to their personal care needs than the medical professionals, who provided only medical care. They were also concerned for their PCAs who, in some cases, continued to provide care during their hospital stay, but who were not compensated by the program. As a result, consumers felt that PCAs may suffer financial hardship or be forced to take other employment in the event that their consumers were in the hospital for more than a few days. Consumers reported that their PCAs take them to doctor's appointments and communicate with providers about consumers' health status, yet are not compensated for this time by the PCA program either. 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.

Re-evaluations

Still another concern raised by consumers in focus groups and the survey is adequacy of the re-evaluation process. As described above, many consumers have conditions that cause their ability to function and perform activities to vary over time, thus causing their need for PCA services to vary as well. When their conditions change, consumers must apply for additional hours and services through their PCM agency. Roughly half (55%) of consumers have ever requested more PCA hours, and of those requests, only 51% were approved. Among those with additional hours allocated, 54% reported that the time allotment was enough to meet their needs.

These survey results are also reflected in the comments made by consumers and surrogates in focus groups. A few participants reported that they would like to see more flexibility in how hours are allocated because consumers' needs vary on a day-to-day basis. Others were unhappy that, upon requesting an increase in hours, they did not receive the increase and, in some cases, even had their hours cut. One consumer reported that the nurse conducting her re-assessment discouraged her from requesting more hours. On the other hand, some participants felt that they did have enough hours and, therefore, did not encounter problems related to re-assessments.

Special Considerations for Hispanic Consumers

Hispanics make up a significant and growing share of the PCA consumer population. More than one-fifth of our sample (n=111) either identified themselves as Hispanic or completed the interview in Spanish. Compared to non-Hispanics, the Hispanic respondents were, as a group, older (> 65 years old: Hispanics, 35% versus non-Hispanics, 17%), and had a higher percentage of women than the non-Hispanic respondent group (75% versus 57%). Hispanic consumers were more likely to be from the Berkshire/Hampden/Hampshire/Franklin region (66% versus 28%) and much less likely to have completed a high school education (59% < high school graduate versus 27% < high school graduate) than non-Hispanic respondents. This group of Hispanic consumers also reported differences in their needs and in their uses of PCA program services compared to non-Hispanic consumers.

Hispanic consumers reported significantly worse health but equivalent functional status to non-Hispanics. As illustrated in Figure 13, 80% of Hispanics reported fair or poor health compared to only 56% for the non-Hispanic group. Hispanics were also more likely to report that their health status had gotten worse over the past year (60% versus 38%), and that their disability status had gotten worse over time (84% versus 70%). Although Hispanics reported significantly worse health than non-Hispanic respondents, their reported numbers of ADLs were similar (72% of Hispanics reporting ≥ 4 ADLs versus 71% of non-Hispanics), as seen in Figure 14.

FIGURE 13: SELF-RATED HEALTH STATUS BY HISPANICS (N=111) AND NON-HISPANICS (N=391)

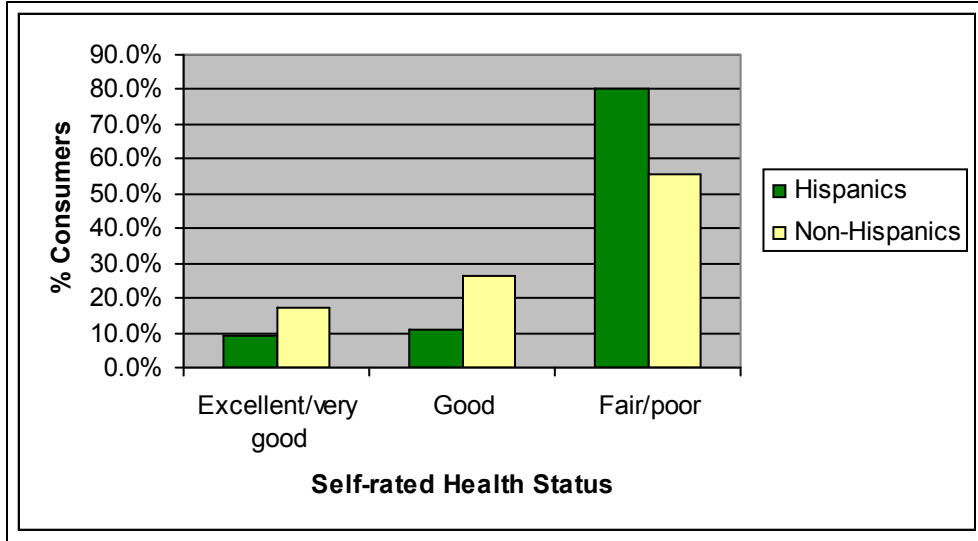
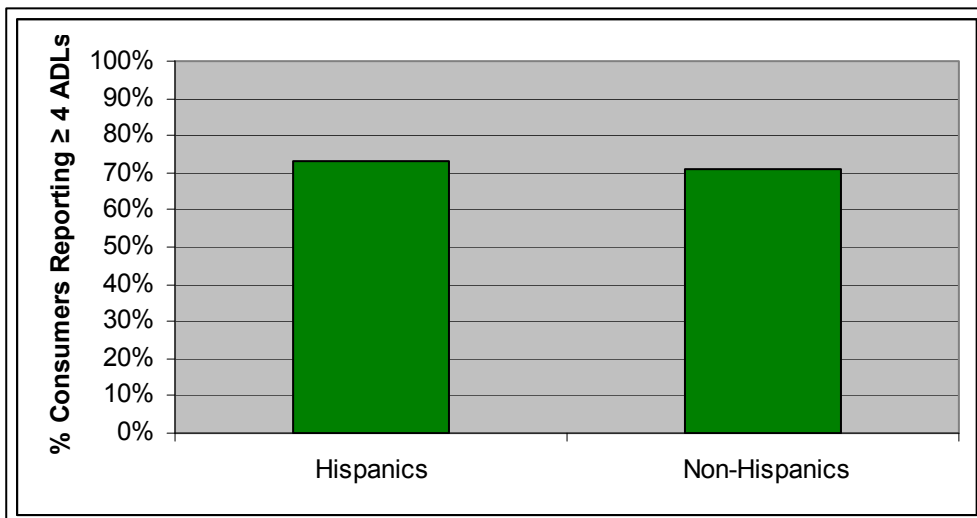


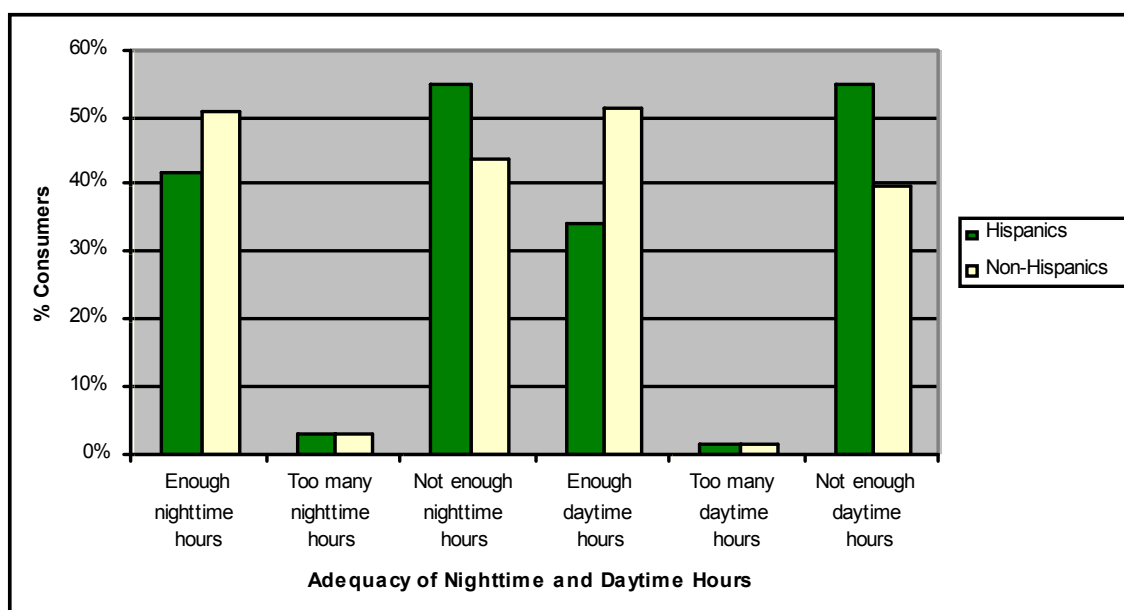
FIGURE 14: NUMBERS OF ADLs BY HISPANICS (N=111) AND NON-HISPANICS (N=391)



Hispanics also exhibited a different pattern of using PCA services than the non-Hispanic group. Hispanics were much more likely to rely on a single PCA, as opposed to multiple PCAs, than non-Hispanics (72% versus 49%). The PCA who worked the most hours for a consumer was more likely to be a family member for Hispanics than non-Hispanics (39% versus 27%). For these reasons, and perhaps others as well, Hispanic consumers had lower turnover rates for their PCAs than non-Hispanics.

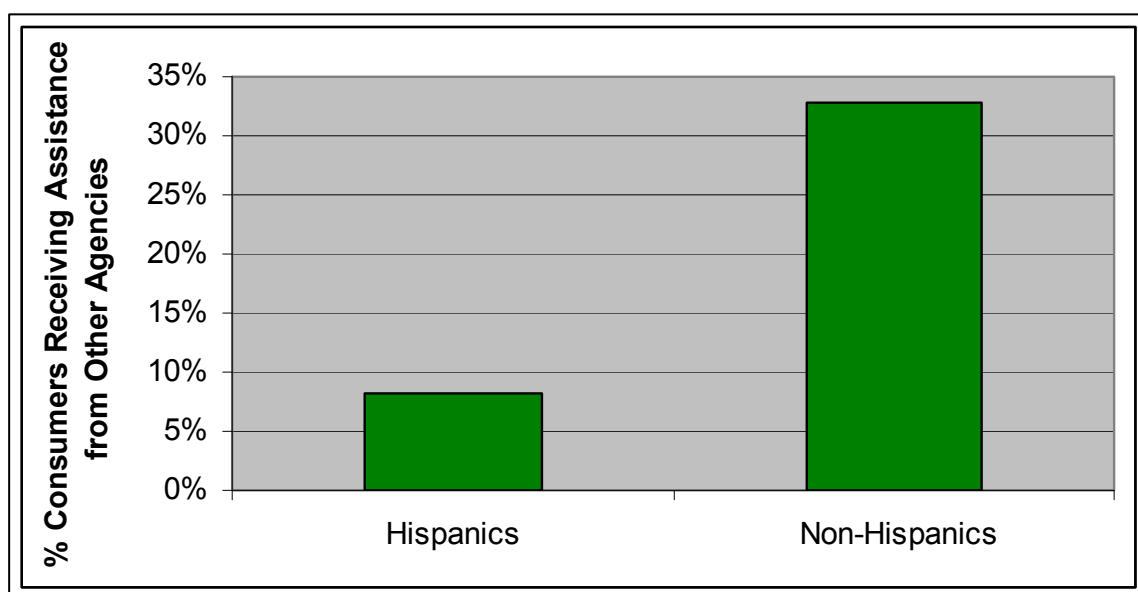
As shown in Figure 15, Hispanics were significantly more likely to report that they did not receive enough hours of PCA services to meet their needs than non-Hispanics. Fifty-five percent of Hispanics said they did not receive enough daytime hours to meet their needs compared to 40% of non-Hispanics. Hispanics also were more likely than non-Hispanics to report that they did not receive enough nighttime hours (55% versus 44%). When Hispanics asked for an increase in PCA hours, they were less likely to receive additional hours than non-Hispanics (45% versus 52%). Furthermore, for those Hispanic consumers who reported receiving additional PCA hours after a re-evaluation, 56% reported that the increase in hours was inadequate compared to 40% of non-Hispanics who reported that the increase in hours was inadequate.

FIGURE 15: ADEQUACY OF NIGHTTIME AND DAYTIME HOURS BY HISPANICS (N=111) AND NON-HISPANICS (N=391)



Hispanics were much less likely to receive informal caregiving support from family members and services from other agencies outside the PCA program. Fifty-six percent of Hispanic consumers did not obtain any informal caregiving support from family members or friends compared to 33% of non-Hispanics. There were even more striking differences in their receipt of other formal services. Ninety-two percent of Hispanics reported not getting any assistance from other agencies, such as the VNA or Adult Day Care, compared to 67% of non-Hispanics.

FIGURE 13: SELF-RATED HEALTH STATUS BY HISPANICS (N=111) AND NON-HISPANICS (N=391)

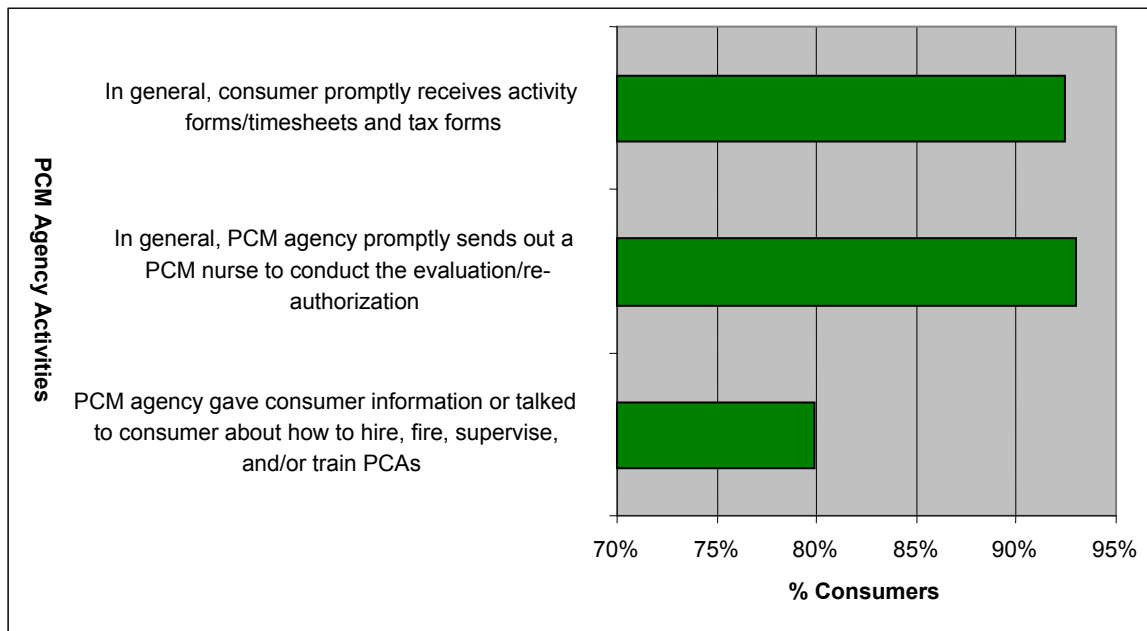


Hispanic consumers differ in important ways from non-Hispanics in the PCA program. All of these factors place them at risk of for not receiving the PCA care they need. This initial analysis of Hispanic PCA consumers suggests the need for continuing monitoring of their participation in the program, especially given the record of continuing health disparities in access to health and long-term care services for this group.

Administrative Issues

The PCM agencies and the FIs share administrative responsibilities for the PCA program. PCM agencies conduct assessments, provide consumers' with functional skills training, and handle other administrative support for consumers. Fiscal intermediaries coordinate billing and payment to PCAs for their services. Consumers were generally satisfied with the administrative performance of the PCMs and FIs.

FIGURE 17: PCM AGENCY PERFORMANCE BY ACTIVITY (N=502)



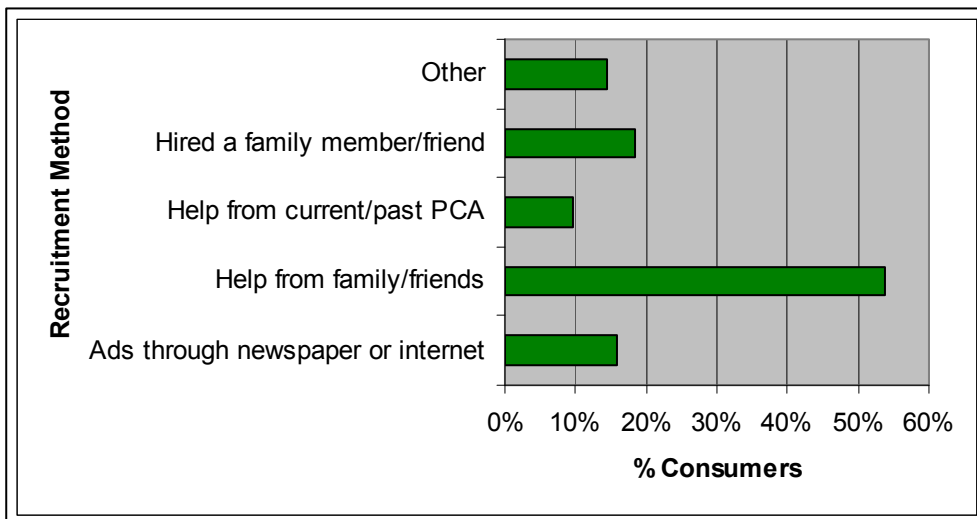
Eighty-eight percent of consumers reported that their PCM agency responded promptly to questions and phone calls and 93% reported that their PCM agency responded promptly to requests to schedule an evaluation or re-authorization for PCA services (Figure 17). More than 90% of consumers also reported that they promptly received activity forms, timesheets, and other forms from the FIs. However, even with these high levels of satisfaction, 31% of consumers reported that they had a situation where the PCA was not paid on time. The reason for why the PCA was paid late (e.g., consumer did not submit timesheet on time, FI did not process check on time) was not specified.

PCA Recruitment and Retention

Because of the low wages and lack of benefits available to PCAs, as well as the intimate nature of the job, consumers were understandably concerned about their ability to recruit and retain highly qualified PCAs. Anecdotal evidence suggests that consumers have difficulty finding PCAs and retaining them over long periods of time. Results from this survey documented that, even though recruitment and retention problems are still critical issues requiring policy attention, they may not be as severe as expected. Family and social relationships were shown to shape the entire process of finding, hiring, and retaining PCAs.

When asked how they recruited their most recent PCA, over half of consumers reported that they found someone through a network of family or friends (54%). Nineteen percent said that they hired a family member or friend, 16% reported using advertisements in the newspaper or on the internet, and 15% reported using other methods to recruit a PCA (Figure 18). Ten percent of respondents said they had help from a current or past PCA to recruit a new PCA.

FIGURE 18: RECRUITMENT METHOD FOR HIRING A PCA (N=494)



With respect to turnover, 61% of consumers reported no turnover of PCAs in the past twelve months, with even lower rates among those who relied on family members as PCAs. Thirty-eight percent of consumers reported having at least one PCA leave in the past year. Turnover rates varied by number of hours of PCA time per week (<40 hours per week, 14% turnover versus \geq 40 hours per week, 20% turnover) and consumer-PCA relationship (family member, 12% turnover versus friend/neighbor, 12% turnover versus stranger/acquaintance, 20% turnover).

Additionally, 44% reported ever having a PCA leave the job and 36% reported ever having to fire a PCA. The main reasons for dismissal were related to lack of reliability (35%) and issues of abuse and neglect (24%). Seventy-two percent reported that it took less than one month to find a new PCA; more specifically, nearly half reported that it took less than one week. One-quarter reported any difficulty the last time they had to hire a PCA.

The recruitment and retention of reliable and qualified PCAs is vitally important to consumers enrolled in the program. 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 felt safe and respected with the PCA that provides the largest number of hours of assistance to them.

The data suggest that recent changes in regulation by MassHealth allowing family members to serve as PCAs are making it easier for many consumers to find and keep PCAs. However, consumers who do not have family members as PCAs still face significant challenges in finding and keeping PCA. These challenges are likely to grow in the future with an increasingly older, frail, and diverse consumer population in the PCA program.

Background checks

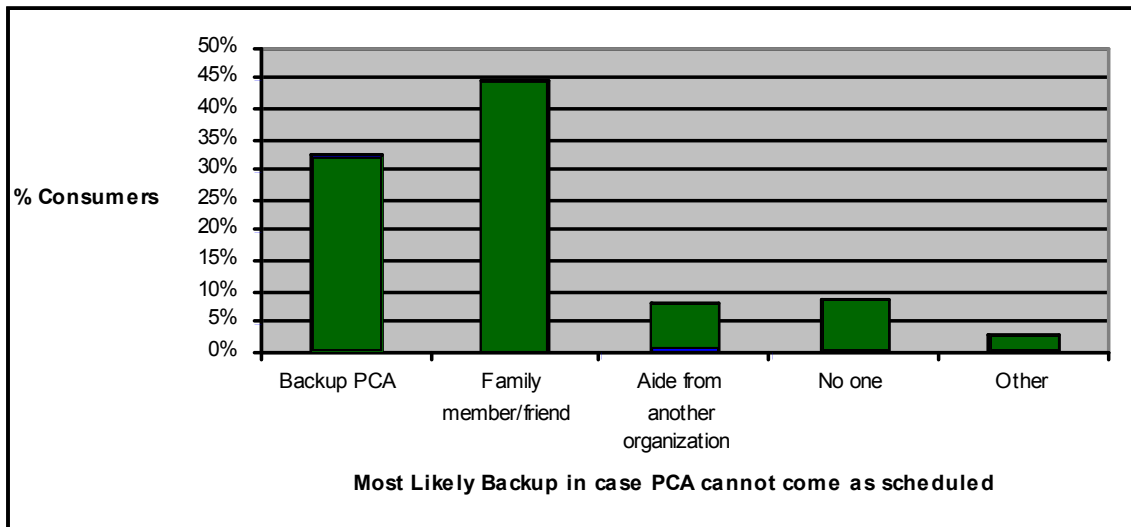
In the focus groups, consumers consistently and regardless of race/ethnicity or age emphasized the importance of being able to trust their PCAs. Many consumers explained that trust was a significant reason for selecting family members to serve as their PCAs. Many focus group participants also shared that they had either personally experienced a breach of trust with a PCA, such as theft, or knew of someone who had. As a result, focus group participants were interested in the PCA Program conducting background checks on potential PCAs for consumers. Participants recommended that the PCA Program collect the following information on potential PCA job candidates: criminal history; whether the person had previ-

ously served as a PCA and, if so, why he/she left the job. The participants who advocated for a systematic background check process re-enforced that they appreciate being able to select and hire their own PCAs, but explained that they also would like Program assistance with filtering out inappropriate applicants.

Backup and Emergency PCAs

A related issue concerns the availability of backup PCAs who can provide services in the event that a regular PCA cannot make a scheduled shift. In addition, some consumers have expressed a desire to have emergency PCAs that could provide PCA services while a consumer is in the process of recruiting and hiring a permanent PCA. Forty-four percent of consumers reported that there was time in the past year that a PCA could not come as scheduled. In these situations, 64% of consumers were able to find a back-up PCA, leaving many without needed assistance. When asked who would fill in were a PCA hypothetically not to come as scheduled, 45% reported that assistance would be provided by a family member or friend, 33% a backup PCA, 8% a home aide from another agency, and 9% reported that no one would fill in (Figure 19).

FIGURE 19: MOST LIKELY BACKUP PCAs FOR CONSUMERS (N=502)





Consumer Satisfaction

Consumers' Perceived Benefits of the PCA Program

Overall, consumers were highly appreciative of the services delivered through the program. Most recognized that their quality of life was 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 high overall satisfaction ratings with the program. At the end of the survey, consumers and surrogates were asked the following open-ended question, “In your opinion, what is the one thing you like best about the PCA program and the services that are provided to you/the consumer?” Five overarching themes arose from consumers’ responses.

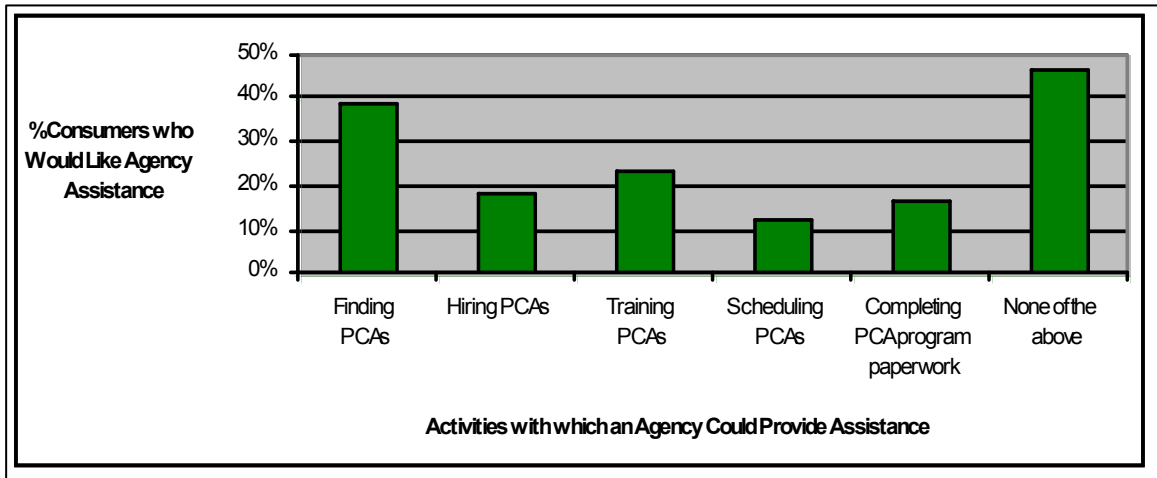
Thirty-four percent of respondents reported increased quality of life, which includes having help available, as the greatest benefit of the program. Twenty-four percent of respondents cited program characteristics, including program convenience, flexibility, and the existence of the program, as the greatest benefit. Fourteen and twelve percent of respondents believed that the best things about the program were relationship with PCAs/characteristics of PCAs and the consumer-directed nature of the program, respectively. Finally, ten percent were most appreciative of their ability to live independently and not in an institution. Surrogates, who tended to be family members of consumers, reported that one of their greatest perceived benefits of the PCA program was being able to have help providing care. 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.”

Consumer Recommendations for Improving the PCA program

Although PCAs were highly appreciative of the services funded through the PCA program, they had a number of suggestions for improving the compensation and benefits for PCA workers and the scope and types of services offered through the program. One of the strongest benefits reported by consumers was the consumer-directed nature of the program. Ninety-four percent of consumers reported that it was very important for them to be able to choose their own PCAs.

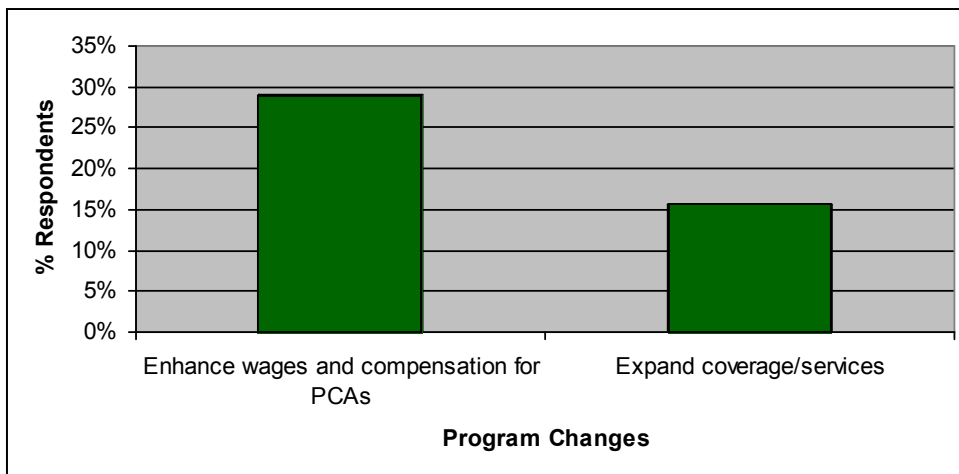
When asked whether they would like support from an agency for specific activities such as finding and hiring PCAs, 46% consumers said that they did not need any help. Thirty-nine percent of consumers reported that would like assistance from an agency in finding PCAs, 24% in training, 19% in hiring, and 17% in completing paperwork (see Figure 20).

FIGURE 20: TYPES OF AGENCY ASSISTANCE REQUESTED BY CONSUMERS (N=502)



Through an open-ended question, consumers and surrogates were asked to name what they would most like to change about the program. Higher wages and better benefits for PCAs was the most frequent recommendation (29%). The second most frequently cited recommendation was to expand the number of PCA hours available and the scope of services covered under the program (16%). See Figure 21.

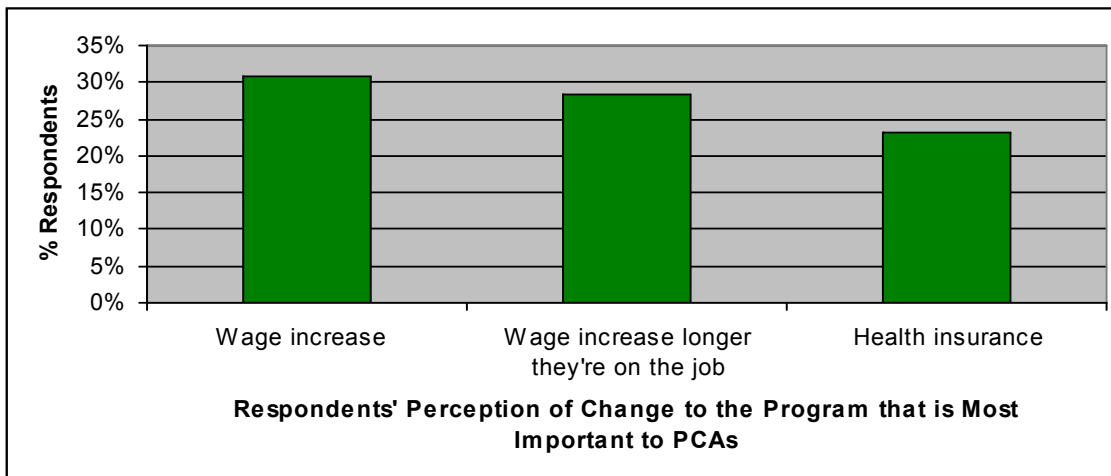
FIGURE 21: CONSUMERS' TOP PRIORITIES FOR CHANGING THE PCA PROGRAM (N=502)



Consumer interest in helping the PCA workers is logical because consumers value the services and companionship provided by PCAs.

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 (Figure 22). Thirty-one percent said that an overall increase in wages was most important, and 28% that wage increases linked to job tenure was most important. Twenty-three percent cited the provision of health insurance as the most important change. Many focus group participants also expressed a desire for their PCAs to receive better compensation and benefits, including: a wage increase; health benefits; and paid holiday and vacation time. A few consumers believed that the PCAs would provide better care and assistance and would be more likely to remain as PCAs if the program were to improve PCA compensation and benefits.

FIGURE 22: FROM CONSUMER AND SURROGATE PERSPECTIVE, MOST IMPORTANT CHANGE TO THE PROGRAM FOR PCAs (N=502)





Summary & Implications

The PCA program was designed to provide elderly and disabled Massachusetts residents with assistance in conducting activities of daily living (ADLs), such as bathing and dressing, and instrumental activities of daily living (IADLs), such as shopping and attending appointments. For many, the program represents the ability to continue to live independently and avoid institutionalization. Historically, the program has served children with disabilities, adults with disabilities and chronic illness, and the elderly. Our data confirm that the consumer population has limited function, as well as poor health, and that both tend to get worse over time. Given the age distribution of the current population, as well as the expansion of enrollment among the elderly, the population is likely to become even frailer in the future. As this trend continues, greater PCA resources will be necessary to meet consumers' health and functional needs.

As mentioned above, PCA services are provided to eligible individuals who require assistance with personal and home care tasks. However, it is evident that PCAs also often provide support in areas beyond their formal responsibilities, by acting as companions and advocates in medical settings. For some consumers, PCAs are their only form of social interaction. In addition, because PCAs often become very familiar with the health and disabilities of the consumers for whom they work, they may be in a position to relay information to consumers' health care providers. Therefore, in many cases, the utility of the PCA program extends beyond the intention to simply help consumers with a specific list of tasks.

There are, nevertheless, many consumers who report that the PCA program does not adequately meet their needs. The PCA program has a difficult balance to strike between attempting to fulfill the health and functional needs of consumers and not expending resources to accommodate consumers' needs beyond the scope of the program. Some consumers expressed particular frustration with the program's protocol regarding PCA assistance during the night and when they are in the hospital. Additionally, more than two-thirds of consumers indicated that their needs vary on a day-to-day basis and that they therefore find the rigidity of PCA hours restrictive. The PCA program may actually be more flexible in the use of allo-

cated hours than most consumers think. As employers within the program, consumers are responsible for scheduling PCAs and have flexibility with regard to when they schedule PCAs within a pay period. In addition, consumers can request an adjustment in hours both for the long-term (in the case of a permanent change in condition) or for the short-term (in the case of a medical emergency).

Hispanic consumers are a vulnerable sub-population for many reasons. Hispanics make up a significant and growing share of the PCA consumer population and were significantly more likely to report that they did not receive enough hours of PCA services to meet their needs. They were also more likely to report that they were not allocated enough hours of PCA services when they asked for an increase during a re-evaluation, as compared to non-Hispanics. Hispanics were also much less likely to receive informal caregiving support from family members and services from other agencies outside the PCA program. The access issue affecting Hispanics may warrant further investigation, and/or outreach to the Hispanic consumer population should be explored.

The data confirm that the change in regulation by MassHealth that allows family members to work as PCAs was beneficial in many respects. The data indicate that consumers with family members as PCAs have an overall more positive experience with the program than consumers with strangers/acquaintances as PCAs, reporting less mistreatment in the past year and less unmet need for ADLs. Allowing family members to serve as PCAs also makes it easier for many consumers to find and keep PCAs. Consumers with family members as PCAs were more likely than consumers with strangers/acquaintances as PCAs to take less than one week to find a new PCA, as well as to report that it was not at all difficult to find a PCA.

The rate of turnover was not as critical a problem as originally anticipated and was less of an issue than in other long-term care settings. For certain sub-populations of consumers, however, PCA turnover was more of an issue. In addition, more than 60% of survey respondents wanted a referral directory of PCAs, an agency to pre-screen PCA candidates, and an agency to recommend people to hire as PCAs. The data indicate that consumers who do not have family members as PCAs still face challenges in finding and keeping PCAs, as do consumers who have greater than forty PCA hours per week. In focus groups, many consumers expressed that they would like to see the PCA program conduct background checks on potential PCAs, which they feel might increase trust in the PCA-consumer relationship and decrease turnover.

Overall, consumers were highly appreciative of the services delivered through the program. Survey respondents reported the following as the greatest benefits of the program: increased quality of life, program characteristics, relationship with/characteristics of PCA(s), the nature of the consumer-directed program, and ability to live independently. Consumers and surrogates named higher wages and benefits for PCAs as the most frequent recommendation for improving the program, suggesting that consumers value their PCAs and the services that they provide and that consumers believed that their PCAs were not being adequately compensated. To a degree, this issue is starting to be addressed through collective bargaining between the Council and 1199SEIU, which has led to the approval of a PCA wage increase and limited benefits. This data reinforces the importance of PCAs in the lives of consumers.

The second most frequently cited recommendation was to expand the number of PCA hours available and the scope of services covered under the program. Expanding the scope of services could include allocating PCA hours for accompanying consumers to doctors' appointments or allowing PCAs to assist consumers in the hospital. Altering the program's scope of services, however, would require regulation changes at the federal and state level.

Because PCA consumers have such complex health and functional needs, they are receiving large amounts of informal care giving from family members, as well as formal assistance from state agencies. The program needs to do a better job of educating consumers and/or others responsible for managing the health and well-being of consumers, such as surrogates, family members and PCAs, about the PCA program and the other state services available. The program could enhance the health and well-being of consumers by facilitating their receipt of other State services or, for those consumers already receiving additional formal assistance, coordinating the way in which PCA and other services are provided.

Authors and Acknowledgements

This report was written by staff from JSI Research & Training Institute, Inc. (JSI), including James Maxwell, PhD; Karen Schneider, PhD; Jaya Mathur, BA; and Craig Stevens, MPH. JSI is a leading public health research and consulting organization with offices in Colorado, Massachusetts, New Hampshire, Vermont, Rhode Island, Georgia, Washington, D.C., and California.

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Endnotes

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