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**MASSACHUSETTS PERSONAL CARE ATTENDANT  
WORKFORCE COUNCIL**

**Consumers' Experience in the Massachusetts  
Personal Care Attendant Program:  
Findings from 2018**

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**PREPARED BY**

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# **Consumers' Experience in the Massachusetts Personal Care Attendant Program: Findings from 2018**



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# Introduction

For over four decades, MassHealth's Personal Care Attendant (PCA) Program has enabled many Massachusetts residents over the age of sixty-five or with disabilities to live independently in the community and avoid costly and unnecessary institutionalizations. 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 (the Council), which is charged with the task of making it easier for PCA consumers to find and hire PCAs who can provide services in their homes. The legislative statute authorizing the inception of the Council also mandated that the Council regularly 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 a first contract to conduct such an evaluation to JSI Research & Training Institute, Inc. (JSI) in June 2008 and a second in January 2018.

The initial study in 2008 consisted of a survey of PCA consumers, focus groups with PCA consumers and semi-structured interviews with key stakeholders. This was the first systematic attempt to characterize the consumer experience with the PCA program and resulted in a number of key findings, including:

- PCA consumers were highly appreciative of the services delivered through the program, which they viewed as increasing their quality of life and ability to live independently;
- The benefits of the PCA program extended beyond simply helping consumers with a specific list of tasks related to their activities of daily living, as many consumers reported receiving valuable social support and other services from their PCAs;
- There were, however, many consumers who reported that the PCA program failed to adequately meet their needs. Some consumers expressed particular frustration with the program's protocol regarding PCA assistance both during the night and during periods of hospitalization. The PCA program had 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.
- The rate of PCA turnover was not as critical a problem as anticipated at the time and was less of an issue than it has been in other long-term care settings. However, for certain sub-populations of consumers, PCA turnover remained an important issue.
- Because PCA consumers often had complex health and functional needs, they received large amounts of informal caregiving from family members, as well as formal assistance from state agencies.

The purpose of the 2018 study is to provide an updated evaluation of the PCA program that compares and contrasts the PCA consumer experience and the perspectives of key stakeholders with the findings from our 2008 study. A number of key changes have occurred in the program and state's economy since this earlier study. The state's collective bargaining agreement with

SEIU 1199, which significantly increased wages to \$15 per hour, had just been negotiated at the time of our 2008 study and had not yet been implemented at that time. At nearly the same time, the state and nation underwent the most serious economic recession since the Great Depression, which had serious implications for the low wage workers who participated in the PCA program, as it made work as PCA more financially attractive than it would have been otherwise. The last decade has also witnessed a large expansion in the number of elderly residents and residents with disabilities in the state. Thus, our 2018 study sought to examine how these dramatic changes in the program, the state's demographic characteristics, and the overall economic situation have impacted the PCA experience. Specifically, the study explores changes in the numbers and composition of the PCA population, the recruitment and retention of PCA workers, and overall consumer satisfaction with the program.

This report summarizes and compares the key findings from the 2018 study with those from our earlier study. This report is organized into several sections. The first describes the methodology employed in the 2018 study, which relied on a more representative sampling design than was possible in 2008. This design enabled us to calculate statewide weighted estimates of the PCA consumer population and various program characteristics. The subsequent sections describe the characteristics of survey respondents, 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, consumer recommendations for improving the program, and specific segments of the PCA consumer population. A final section summarizes the findings and offers some implications for future program directions. The 2018 study was conducted in the context of increasing state and national efforts to integrate long-term services like those offered through the PCA program with acute health care services. JSI hopes that findings from this evaluation will help pave the way for improved care and assistance, including more integrated services, for older consumers and consumers with disabilities in the Massachusetts PCA program.

## Methods

A mixed method design was used to capture both quantitative and qualitative data to obtain a comprehensive understanding of perspectives and issues for PCA consumers in Massachusetts. 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 as well from state and national experts.

### Survey Design

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The PCA consumer survey was initially developed by JSI in 2008 in collaboration with the PCA Workforce Council, MassHealth, and Personal Care Management (PCM) agencies to determine the pertinent topic areas and appropriateness of questions for the project. The topics areas were informed by a literature review and key informant interviews with researchers who have conducted evaluations of other state PCA programs or have collected data on similar issues from similar populations. For topics without previously validated questions, JSI's research team developed questions to target these areas. The initial survey was designed so that it could be easily understood by an individual with an 8<sup>th</sup> grade reading level, and was pilot tested with 16 PCA consumers.

The 2018 version of the survey maintained the vast majority of the questions from the initial survey, but new questions were added based upon key informant interviews and the input from the PCA Workforce Council and its staff. The new questions largely addressed emerging issues that were not present when the survey was initially conducted, including changing characteristics and needs of PCA consumers, the involvement of surrogates in the program, and PCA training provided by the 1199 Service Employees International Union Training and Upgrading Fund. The survey was translated into Spanish using professional translation services.

As in 2008, in 2018 JSI used a telephone survey as the most appropriate mode for data collection given functional limitations of this population. The telephone survey was administered using CASES, a computer assisted telephone interviewing system.

### Sampling and Data Collection

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The 2018 consumer survey was based on a sample frame of “active consumers” as of the last quarter of the previous year, and represented 12,892 unique individuals. MassHealth, the State's Medicaid agency, supplied the consumer sample information, which included the consumer's gender, age, first name, telephone number, PCA service hours received, as well as region of the state of the consumer's residence.

After analysis of characteristics of the frame, it was determined that gender, age (18-49, 50-64 and 65+) and average allotted hours per day (0-3, 4-6, 7+) provided the best opportunity for stratification. Accordingly, randomly selected samples were drawn for 30 replicates, each with an equal count (5) of consumers from the 18 strata. We released a total sample of 2,610 into CASES.

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

Telephone interviews were conducted from February to May 2018. During the call, interviewers confirmed that the respondent was currently receiving PCA services and was at least 18 years old. Consumers were encouraged to participate in the survey themselves, but if unable or unwilling, could have their surrogate, an unpaid person that assists the consumer in the management of their PCA program, participate on their behalf. Interviews were conducted in both English and Spanish.

From the sample of 2,610 consumers, a total of 532 interviews were completed with English- and Spanish-speaking PCA consumers and their surrogates (see Tables 1 and 2). About one-third of eligible respondents with valid contact information completed the interview (31% response rate). About two-thirds of respondents who were successfully reached by telephone completed the interview (69% cooperation rate).

**Table 1 | PCA Consumer Sample Response**

	<b>N</b>
Total sample released	2,610
Incorrect contact information	739
Unable to contact	924
Ineligible	181
Refusals	234
<b>Total Interviews</b>	<b>532</b>

**Table 2 | PCA Consumer Completed Interviews**

	<b>English version</b>	<b>Spanish version</b>	<b>Total N</b>
Consumer interviews	327	67	394
Surrogate interviews	129	9	138
<b>Total Interviews</b>	<b>456</b>	<b>76</b>	<b>532</b>

## Analysis of Survey Data

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Data management, cleaning, coding and analysis were conducted using SAS version 9.4 (SAS Institute, Inc., Cary NC). Results to questions are only reported in the aggregate keeping individual responses confidential. During the data collection stage, response rates were monitored for each of the 18 sample strata (gender, age, service hours), and targeted outreach was used to ensure good representations for each. In the initial stages of the analysis weights were developed to adjust for response rate differences across strata and to bring survey data from equal distribution in the sample frame to the actual proportions of the population. Results on demographics, household and program characteristics are shown in both weighted and unweighted formats to allow for the description of survey respondents (unweighted) and to provide statewide population estimates (weighted). Continuous variables were either categorized based on their distribution or reported as mean values. Results also highlight differences identified in the analysis by age groups, level of service hours or relationship of service provider to the consumer.

## Focus Groups

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The purpose of the focus groups was to collect qualitative, open-ended, in-depth information from PCA consumers about their opinions and experiences in the program. In particular, the focus group questions were designed to elicit participants' perspectives regarding needs and experiences with the program, challenges and concerns with employing PCAs, and recommendations for improving the program. A moderator's guide was used to facilitate discussion and ensure some degree of uniformity in data collection across groups. JSI conducted three focus groups with adult PCA consumers hosted at three different PCMs, each tailored to specific PCA consumer groups: a Spanish-speaking group at Elder Services of Merrimack Valley (N=10), a 60 years and older group at Old Colony Elder Services (N=9), and PCA consumers who use at least 50 hours of PCA services per week at Ethos (N=8). Recruitment of participants was accomplished with help from the PCMs. Participants were given refreshments and a \$50 stipend. Each group was led by an experienced focus group moderator, and an assistant transcribed the notes with the aid of an audio recording. Notes from the groups were reviewed for consistent and distinct themes.

## Key Informant Interviews

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JSI conducted interviews with 11 key informants to 1) inform understanding of important issues and trends at the state and national level to 2) guide updates to the focus group and survey instruments, and 3) obtain input and buy-in from key stakeholders. We developed a semi-structured interview guide to assist the data collection process across interviews. The interviews were conducted over the phone and in-person with individuals representing MassHealth, SEIU, personal care management agencies, disability advocates, and experts on long-term care workforce issues.



# Characteristics of PCA Consumers

## Consumer Demographic Characteristics

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The demographic characteristics of PCA consumers, both in the sample and for the overall population, are summarized in Table 3.

Among the respondents, 9% were ages 18 to 29, 19% were ages 30 to 49, 42% were ages 50 to 64, and 30% were 65 years old or older. The mean age was 56.3 years. A little over half (55%) of the survey respondents were female. About two out of five respondents had never been married (39%), 22% were married or living as married with a partner, 27% were divorced or separated, and 10% were widowed. A majority of respondents self-identified as White (62%), 16% as Black or African-American, 3% as bi/multi-racial, and 2% as Asian. About a quarter of the sample (27%) identified as Latino/a. The majority of respondents were unemployed (59%), about a third were retired (32%), 3% were employed, 3% were in school, and 2% volunteered. About a quarter (24%) of respondents had less than a high school education, 36% graduated high school or received a GED, 22% completed 1 to 3 years of college or technical school, and 17% graduated college or had received an advanced degree.

The demographic characteristics of the sample changed little when weighted to the current PCA consumer population (see Table 3). With the exception of gender (55% female in the sample versus 60% when weighted), the weights only altered demographic characteristics for a difference ranging from 0 to 2%.

**Table 3 | Consumer Demographic Characteristics**

<b>Sample characteristics (N=523)</b>	<b>Unweighted Percent</b>	<b>Weighted Percent</b>
<b>Age</b>		
18 to <30	9	9
30 to <50	19	20
50 to <65	42	41
65 or older	30	30
<b>Gender</b>		
Male	45	40
Female	55	60
<b>Marital Status</b>		
Never married	39	39
Divorced or separated	27	28
Married or living as married with a partner	22	21
Widowed	10	12
<b>Race</b>		
White	62	62
Black or African-American	16	15
Asian	2	2
Native Hawaiian or Pacific Islander	0	0
American Indian or Alaska Native	1	0
Bi/Multi-racial	3	3
Other/Chose to not answer	14	26
<b>Ethnicity</b>		
Non-Latino	73	73
Latino	27	27
<b>Employment Status</b>		
Unemployed	59	60
Retired	32	31
Employed	3	4
In school	3	3
Volunteers	2	2
<b>Highest level of education</b>		
Less than high school	25	24
Graduated high school or received GED	36	36
1 to 3 years of college or technical school	23	22
Graduated college or received advanced degree	16	17

## Consumer Household Characteristics

The respondents in the survey represented PCA consumers across all regions of Massachusetts, as categorized by the State's Executive Office of Health & Human Services: a quarter were from Western Massachusetts (25%), 14% from Central Massachusetts, 13% from Northeast Massachusetts, 20% from Metro West, 17% from Southeast Massachusetts, and 10% from Boston. About third of PCA consumers lived alone (33%), about a third lived with one other person (30%), 18% lived with two other people, and 12% lived with three or more other people.

As with the demographic characteristics, the consumer household characteristics of the sample changed little when weighted to the current PCA consumer population (see Table 4). The weights only altered consumer household characteristics from 0 to 1%.

**Table 4 | Consumer Household Characteristics**

<b>Sample characteristics (N=523)</b>	<b>Unweighted Percent</b>	<b>Weighted Percent</b>
<b>Region</b>		
Western	25	26
Central	14	13
Northeast	13	13
Metro West	20	21
Southeast	17	16
Boston	10	11
<b>Number of people in household</b>		
Living alone	33	33
Living with one other person	30	29
Living with two other people	18	18
Living with three or more other people	12	12

## Consumer PCA Program Characteristics

Half of the PCA consumers in the sample had a surrogate. In terms of hours of PCA services received each day, 32% of respondents used less than 4 hours each day, 34% used 4 to <7 hours each day, and 35% used at least 7 hours of services each day.

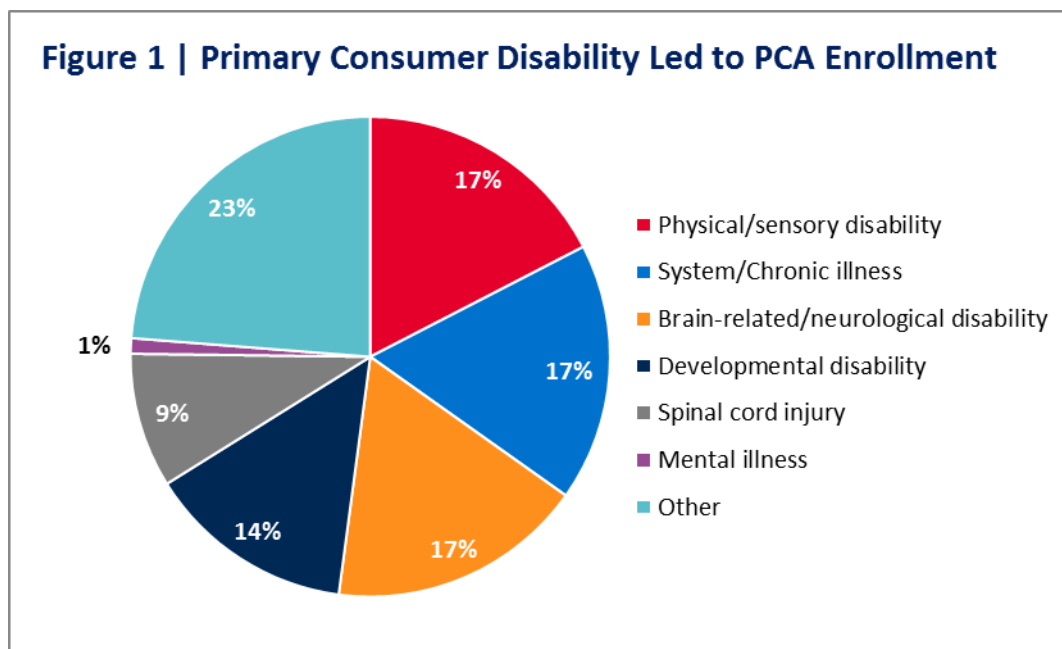
The proportion of consumers with surrogates remained the same after weighting. The weights altered the distribution of consumers' hours of PCA services slightly. Weighted to the current PCA consumer population, 28% used less than 4 hours each day, 37% used 4 to <7 hours each day, and 35% used at least 7 hours of services each day.

**Table 5 | Consumer PCA Program Characteristics**

<b>Sample characteristics (N=523)</b>	<b>Unweighted Percent</b>	<b>Weighted Percent</b>
<b>Surrogate</b>		
Yes	50	50
No	50	50
<b>Hours of PCA Services Each Day</b>		
0 to <4 hrs	32	28
4 to <7 hrs	34	37
7+ hrs	35	35

## Disability and Health Status

PCA consumers reported a variety of primary disabilities that led to their enrollment in the PCA program. The most frequent conditions reported by consumers as a primary disability were a physical/sensory disability (17%), followed by system/chronic illness (16%), and developmental disability (14%), brain-related/neurological disability (13%), and spinal cord injury (9%). About a quarter of consumers (23%) reported other reasons including, but not limited to, respiratory problems and naming multiple primary disabilities.

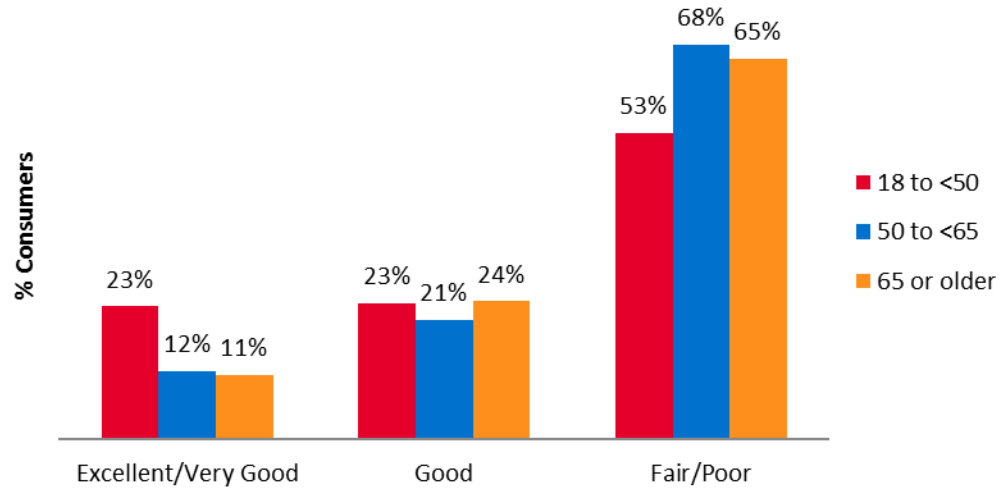


In terms of health status, overall, thirty-seven percent of respondents reported that their health was fair, 25% poor, 22% good, 10% very good, and 5% excellent. PCA consumers face greater health problems than the average Bay Stater; overall, only 14% of Massachusetts adults reported fair or poor health status, compared to 62% of PCA consumers.<sup>1</sup> Generally, PCA consumers reported their health status as staying the same as a year ago (41%) or worse (41%), though some reported their health improving (18%).

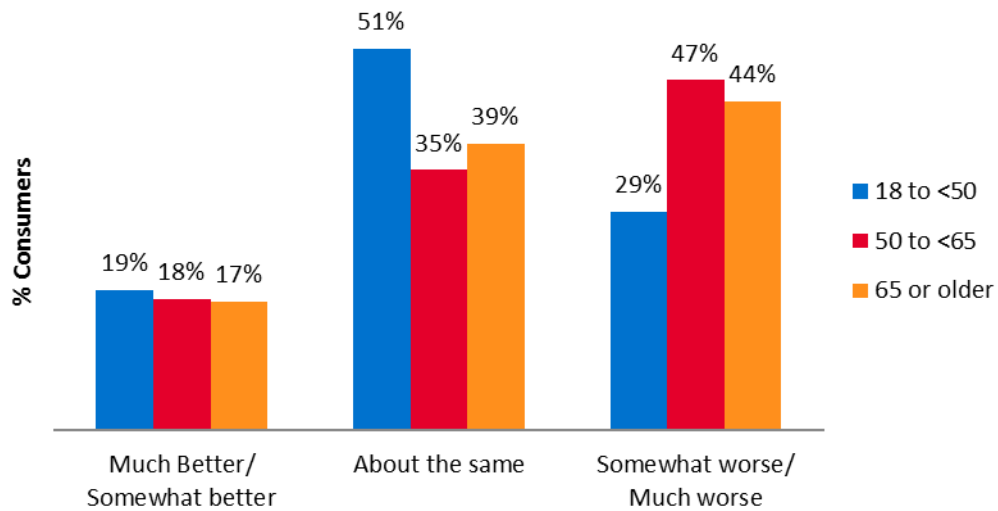
As can be seen in Figures 2 and 3, compared to consumers age 49 and younger, consumers who were at least 50 years old were more likely to report fair/poor health status and worsening health status.

<sup>1</sup> Massachusetts Department of Public Health. *A Profile of Health Among Massachusetts Adults, 2016: Results from the Behavioral Risk Factor Surveillance System*. <https://www.mass.gov/files/documents/2017/09/zt/report-2016.pdf>

**Figure 2 | Self-Reported Consumer Health Status by Age**



**Figure 3 | Change in Consumer Health Status by Age**



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

The PCA program pays PCAs to assist consumers with activities of daily living (ADLs), such as bathing and dressing, and instrumental activities of daily living (IADLs), such as shopping and preparing meals. Nurses under contract with personal care management agencies assess consumer personal care needs and recommend hours of PCA services needed each week as part of the initial enrollment process and as part of a reevaluation process. As shown in Table 6, for each ADL and IADL, the majority of respondents reported having difficulty with that activity, with the exception of eating.

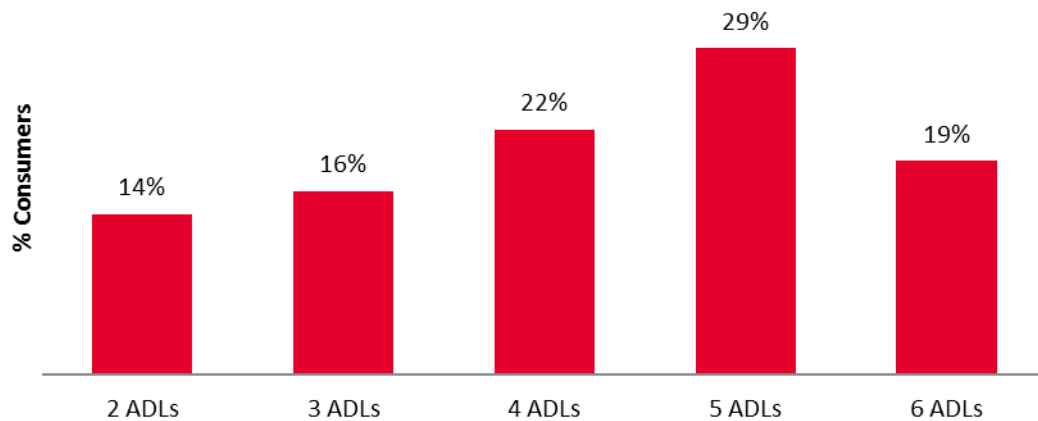
**Table 6 | Consumer Difficulty Performing ADLs and IADLs**

	Weighted Percent
<b>ADLs</b>	
Bathing or showering	92
Dressing	84
Eating	24
Moving in and out of bed and chairs	70
Using the toilet	60
Moving around indoors	70
<b>IADLs</b>	
Preparing meals	90
Shopping	94
Light housekeeping tasks	92
Driving or taking a bus or taxi	83

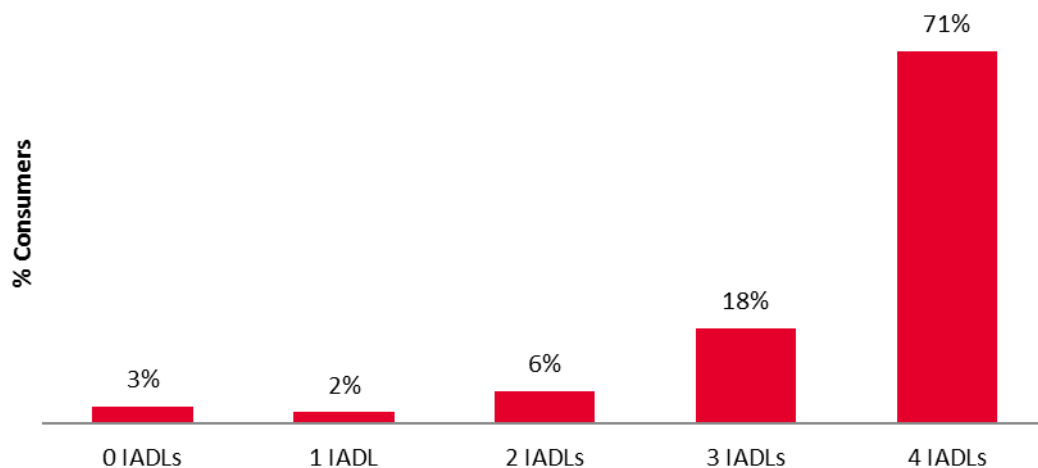
***"It completely changed my life. Before, it was tough doing everything alone. I was dealing with chronic pain and wasn't able to do anything. Through the program I was able to hire people to help me cook and get ready. Those types of things make me complete and have changed my life."***

As shown in Figures 4 and 5, PCA consumers have at least some difficulty with multiple ADLs and IADLs. This is expected, given that requiring assistance with two or more ADLs is a criterion for eligibility in the PCA program.

**Figure 4 | Number of ADLs With Which Consumers Have at Least Some Difficulty**



**Figure 5 | Number of IADLs With Which Consumers Have at Least Some Difficulty**



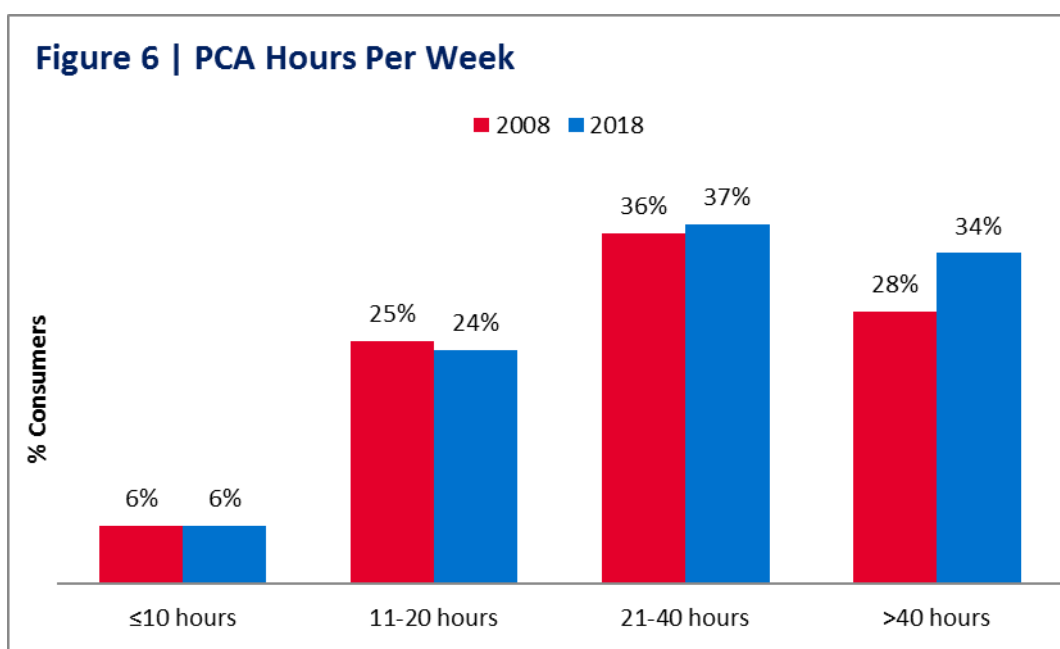


# PCA Program Use

## PCA Program Length of Enrollment and Hours Per Week

More than one-third of consumers have been enrolled in the PCA program for more than five years (36%), just under one-third for three to five years (32%), and the remainder for less than 3 years (31%).

The distribution of hours of PCA services used per week was generally similar between 2008 and 2018. In 2018, 6% of consumers used fewer than 10 hours per week, about a quarter used 11 to 20 hours (24%), over a third used 21-40 hours (37%), and most notably, about a third of consumers used at least 40 hours per week of PCA services (34%).



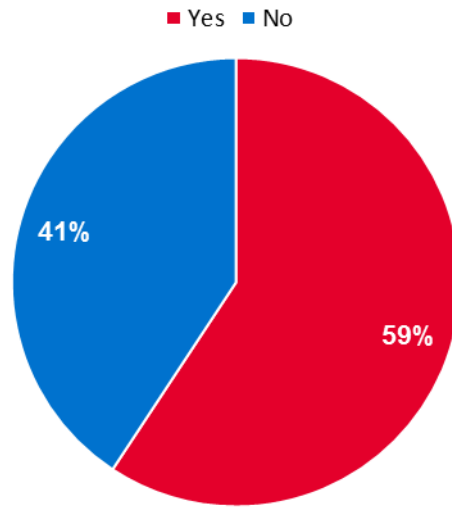
Since they first enrolled in the PCA program, about half of respondents reported that their number of service hours had increased (51%), a third reported that they stayed the same (33%), and 15% reported that they had decreased.

Fifteen percent of respondents reported that they had an individual PCA who worked more than 40 hours per week. When asked about the reason why their PCA worked more than 40 hours per week, the three most frequent reasons reported were: employing only friends or family members (30%), preferring to work with as few PCAs as possible (27%), and not being able to find enough PCAs to work their schedule (17%).

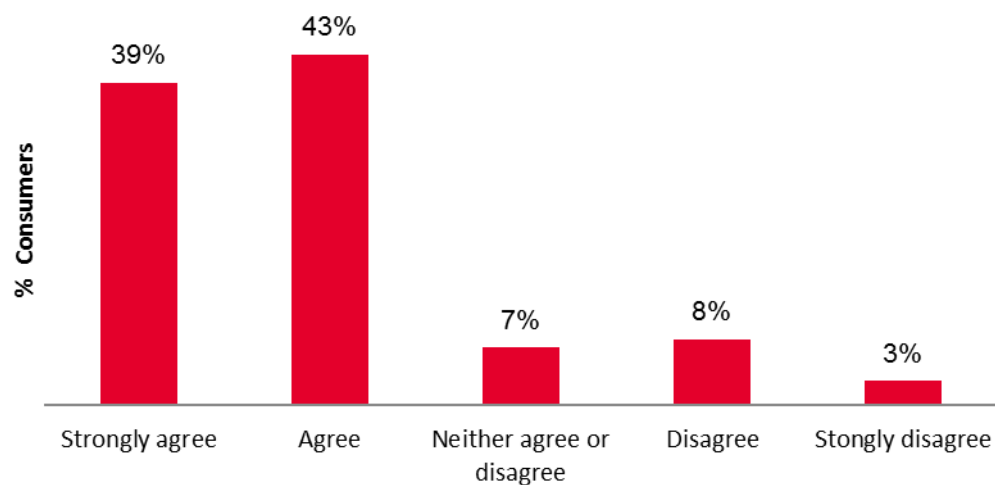
## Varying Needs

Fifty-nine percent of respondents reported that their need for PCA services varied on a day-to-day basis and, of those respondents, 82% strongly agreed or agreed that the PCA program accommodated the variation in their needs.

**Figure 7 | Consumer's PCA Service Needs Vary From Day-to-Day**



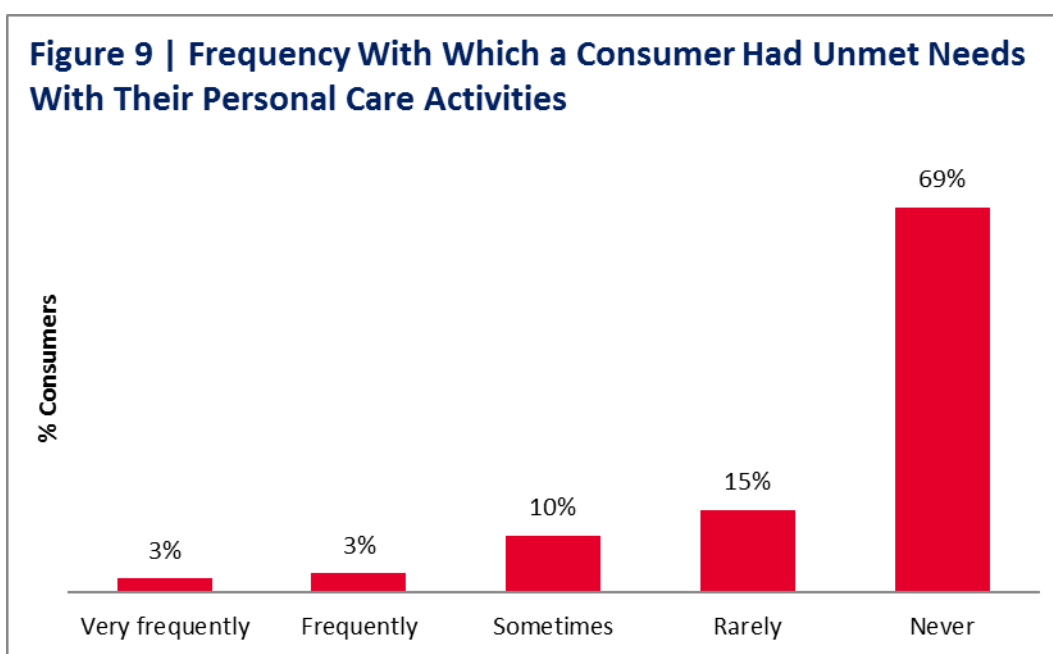
**Figure 8 | PCA Program Accommodates Varying Consumer Needs**



## Unmet Needs

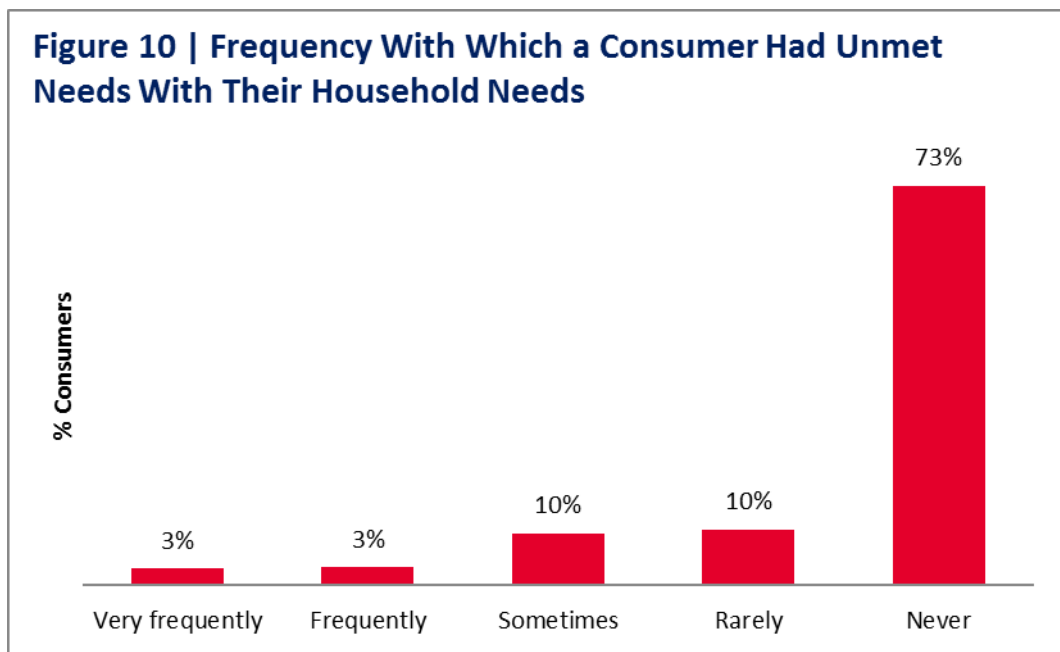
Generally, PCA consumers are able to receive the assistance they need for their personal care activities and household needs. Findings about unmet needs related to personal care activities and household needs are described separately.

Respondents were asked about the frequency with which they needed assistance with personal care activities, but did not receive it, in the past 12 months. For most PCA consumers (69%), they never experienced this unmet need for assistance with personal care activities. However, for the other respondents, 15% rarely did not receive help, 10% sometimes did not receive help, 3% frequently did not receive help, and 3% very frequently did not receive help.



The respondents who reported needing assistance with personal care activities and not receiving it in the past 12 months (31%) were then asked about why they did not receive this assistance. The three most frequently reported reasons that led to respondent's not receiving help managing their personal care activities were needing more PCA hours than currently authorized (52%), not having enough PCA availability to cover hours needed (14%), and a temporary situation such as getting sick or a PCA leaving unexpectedly (12%).

Respondents were also asked about the frequency with which they needed assistance with household needs, but did not receive it, in the past 12 months. Again, for most PCA consumers (73%), they never experienced this unmet need for assistance with household needs. However, in the past 12 months, 10% of respondents rarely did not receive help, 10% sometimes did not receive help, 3% frequently did not receive help, and 3% very frequently did not receive help.



The respondents who reported needing assistance with household needs and not receiving it in the past 12 months (31%) were then asked about why they did not receive this assistance. The three most frequently reported reasons that led to respondent's not receiving help managing their household needs were needing more PCA hours than currently authorized (58%), not having enough PCA availability to cover hours needed (15%), and people who usually provided unpaid help were unavailable (8%).

## Hours of PCA Services Authorized

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Personal care management agencies assess consumers' personal care needs and recommend how many hours of PCA services should receive each week; after approval by the consumer's physician or nurse practitioner, MassHealth authorizes the number of hours of PCA services that will be paid for by the program each week. MassHealth may also approve PCA services during nighttime hours, which are from 12:00 midnight to 6:00am.

Overall, not having enough hours to meet their needs was a key finding both in the survey and focus group data. In the survey, about half of respondents (49%) reported that they did not receive enough daytime hours to meet their needs, and 41% did not have enough nighttime hours to meet their needs. The program not covering enough hours was the most common complaint discussed in the focus groups, who described various limitations to the hours allotted, such as needing extra time to account for delays in travel and medical visits.

Asking for re-evaluation of hours was common among PCA consumers, with 39% of consumers having asked for a personal care management agency to re-evaluate their need for PCA services. Among the 39% of respondents who requested a re-evaluation of PCA service need by a PCM, about half 53% were approved for additional hours. Among these respondents who were approved for additional hours (21% among all PCA consumers), 63% of them reported that the additional approved hours were enough to meet their needs and 37% of them reported that they were not enough to meet their needs.

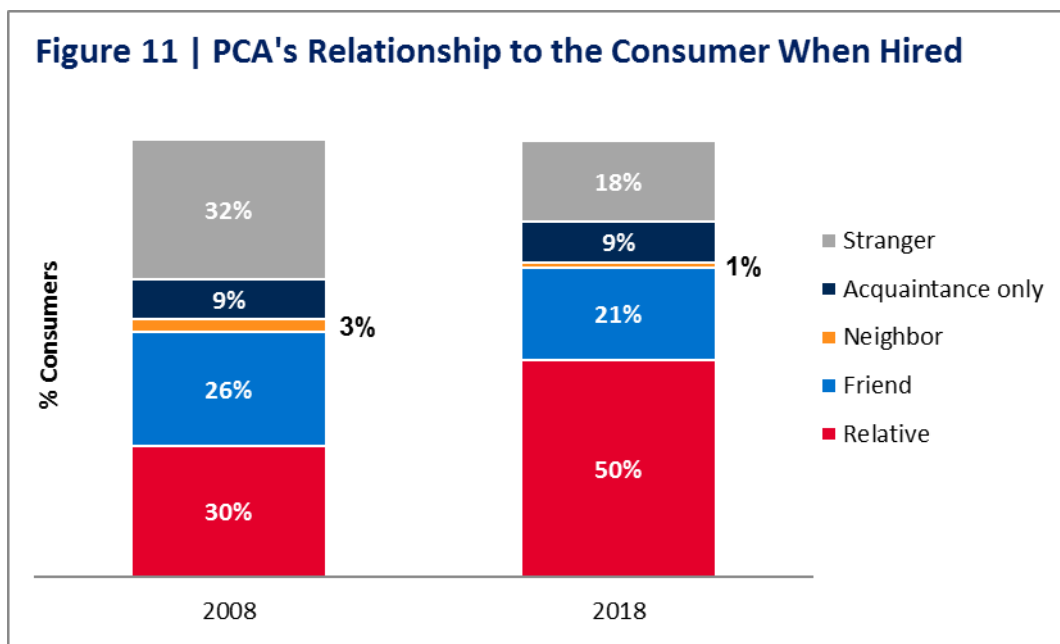
# PCA Recruitment and Retention

## Relationship to PCAs

Just over half of the PCA consumers have had only one PCA in the past 12 months (52%). About a quarter had two PCAs in the past 12 months (24%), 11% had three, 5% had four, 3% had five, and 2% had six.

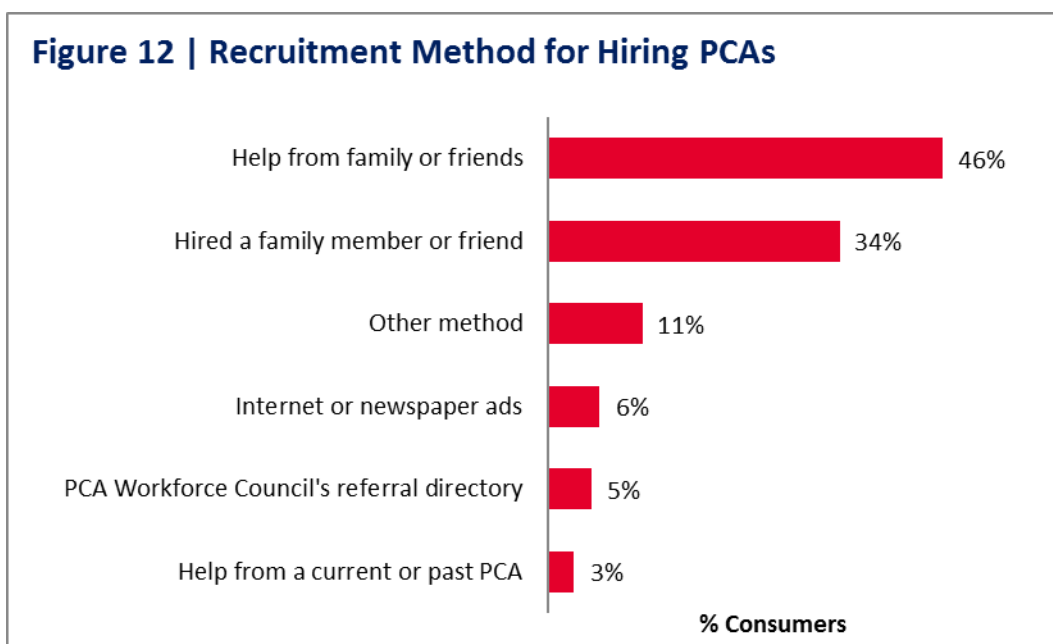
A major theme from the focus groups was that PCA consumers had very close relationships with their PCAs. The foundation for these close relationships may lie in the preexisting connections between consumers and who they hire as PCAs, with nearly three-quarters (71%) of consumers reporting that their main PCA was a family member or friend at the date of hire (50% and 21%, respectively). This contrasts with the 2008 survey data, in which a little over half (56%) reported hiring a family member or friend (30% and 26%, respectively). This represents a very significant change in the PCA program, with consumers increasingly relying on family members and friends to provide PCA services.

*"My PCA is my grandson. His grandpa and my husband died in February, so we have been through a lot. We've grieved together. He knows everything. He does everything for me and lives with me."*



## Recruitment

Consumers were asked about how they hired their most recent PCA, and could select multiple methods in their response. Four out of five consumers recruited PCAs either by receiving help from family or friends (46%) or simply hiring them (34%). In comparison, in 2008, 54% of respondents said they hired with help from family or friends, and only 19% said they hired a family member or friend as a PCA. In 2018, other less common methods were also used to recruit their most recent PCA: 6% posted advertisements online or in the newspaper, 5% used the PCA Workforce Council's referral directory (Rewarding Work), 3% were helped from a current or past PCA, 1% took out advertisements in the newspaper, and 11% used some other method.



Most consumers were able to find and hire PCAs fairly quickly. The last time respondents hired a PCA, 50% took less than one week to find and hire someone, 13% took one week, 17% took between 1 and 4 weeks, 11% took 1-3, and 6% took greater than 3 months.

Almost three-quarters of respondents did not have any difficulty hiring a PCA (73%). Of the respondents who had difficulty hiring a PCA (25%), 26% reported that this was due to the fact that not many people want to work as PCAs.

## Retention

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Retention was somewhat better in 2018 than in 2008, which may be related to the higher proportion of relatives serving as PCAs. In 2008, 39% had a PCA leave in the past 12 months, compared to 28% in 2018. In terms of how many PCAs left, in 2018, 17% of consumers had one PCA leave in the past 12 months, and 7% had two PCAs leave in the past 12 months, and 4% had three or more PCAs leave in the past 12 months.

Since they first enrolled in the PCA program, nearly a third of consumers have had a PCA who decided to leave (32%). A change in jobs or career (34%), other (26%), and a PCA moving away (14%) were the three most frequent reasons that led their PCA to decide to leave.

Twenty-eight percent of respondents have fired a PCA or have told a PCA that they no longer wanted their assistance. When asked about the reason for dismissal, the two main reasons were a lack of PCA reliability (38%) and issues with their PCA, such as stealing, neglect, and disrespect (21%).

## Family and Friends as PCAs

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PCAs who were family or friends of the consumer at the time of hire likely have a closer relationship with the consumer, than do PCAs who were neighbors, acquaintances, or strangers at the time of hire.

Consumers who are older are more likely to hire family or friends as PCAs. Among consumers who hired family or friends as PCAs, 25% of consumers were ages 18 to 49, 42% were ages 50 to 64, and 32% were at least 65 years of age. Among consumers whose main PCAs were neighbors, acquaintances, or strangers, 37% were ages 18 to 49, 37% were ages 50 to 64, and 26% were at least 65 years of age.

Consumers who hired family or friends as PCAs had an easier time recruiting and retaining PCAs. When asked about how difficult it was to hire their last PCA, 81% of consumers who hired family or friends said “not at all difficult,” compared to 54% of consumers who hired neighbors, acquaintances, or strangers. Over half of consumers who hired family or friends as PCAs (61%) were able to hire their last PCA in less than a week, compared to only a quarter (25%) of consumers who hired neighbors, acquaintances, or strangers.

It was also much less common for consumers who hired family or friends as PCAs to have a PCA leave in the past 12 months (20%) or have ever fired a PCA (25%), compared to consumers who hired neighbors, acquaintances, or strangers (46% had a PCA leave in the past 12 months, 50% have ever fired a PCA).



## New Hire Orientation and Training

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The union representing PCAs (1199SEIU) manages the New Hire Orientation and offers skills workshops for PCAs, a new development since the original survey in 2008.

Two-thirds of respondents reported that their PCAs had completed the New Hire Orientation (NHO). Of that 66%, respondents reported that 61% of PCAs completed the NHO during a group session, 19% through the online portal, and 14% using the paper option. Over three-fourths of respondents believed that the NHO increased their PCAs understanding of the PCA program and the respondent's role as the employer (83%).

Nearly two-thirds of PCA consumers were aware that their PCA was at risk for payroll sanctions if he/she did not complete the NHO within six months of initial notification (63%).

Among other benefits, such as eligibility for college tuition vouchers and eligibility to complete the Certified Nursing Aide programs, PCAs are also able to use free training opportunities through the Home Care Training Benefit (1199 SEIU). Nearly two-thirds of respondents were aware that PCAs were eligible for free trainings in skills topic to enhance the care they deliver (62%), and 30% of respondents reported that they were aware that their PCA had attended at least one of the free trainings.

Among the 30% of consumers who said they had a PCA attend trainings, 33% said their PCA attended the CPR/first aid/AED training, 33% attended the CNA certification training, 13% attended the medication safety training, 13% attended the Alzheimer's/dementia training, 11% attended the body mechanics and transferring training, 10% attended the blood borne pathogens training, 9% attended the communication and boundary setting training, and 7% attended the diabetes and nutrition training.

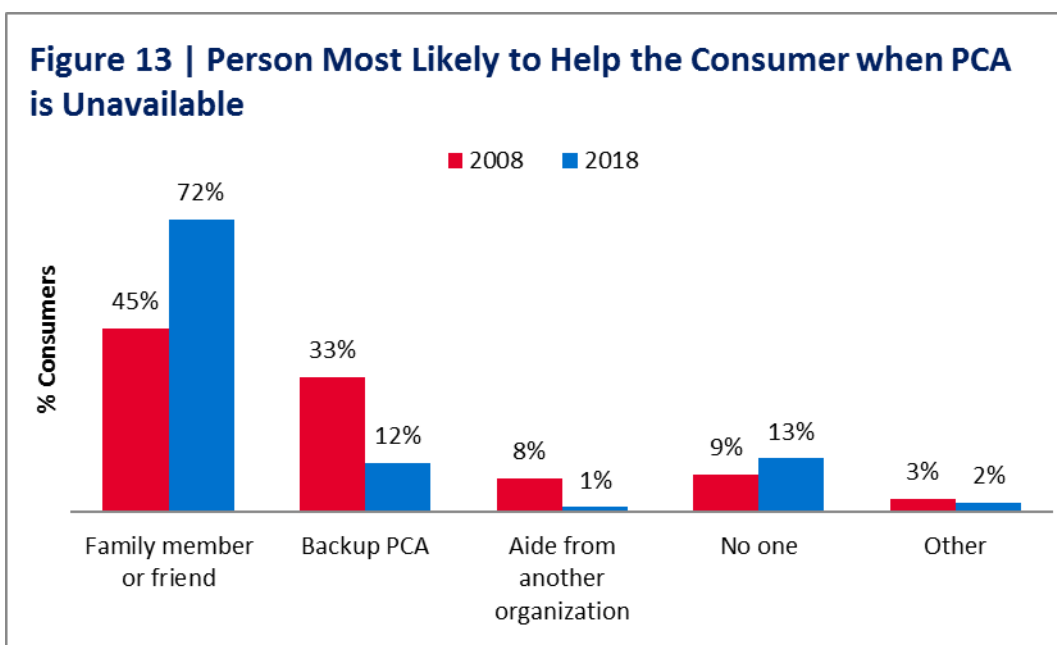
Almost all respondents felt that the trainings their PCAs attended improved the quality of services that they received (95%).

## Backup and Emergency PCAs

A third of PCA consumers reported that there was time in the past year that a PCA could not come as scheduled (33%). When this occurred, 60% of consumers were able to find a back-up PCA.

When their PCA was unavailable, 72% of consumers reported that a family member or friend was most likely to help them with their needs and 12% reported that a backup PCA would most likely help. Nine percent of respondents did not have anyone to help them if their PCA was unavailable and 5% did not need someone to help them in this circumstance. Two percent of consumers reported receiving aid from an “Other” person when their PCA was unavailable.

Notably, the likelihood of a family member or friend serving as the backup PCA was much higher in 2018 than reported in 2008 (72% versus 45%). A reason for this, in addition to increased reliance on family members and friends in general, may be changes to the PCA program (e.g. requirement that employee paperwork be completed before an individual can work as back-up). Additionally, another PCA or aide from another organization was much less likely to help in this situation in 2018 compared to 2008 (12% versus 33%, 1% versus 8%).



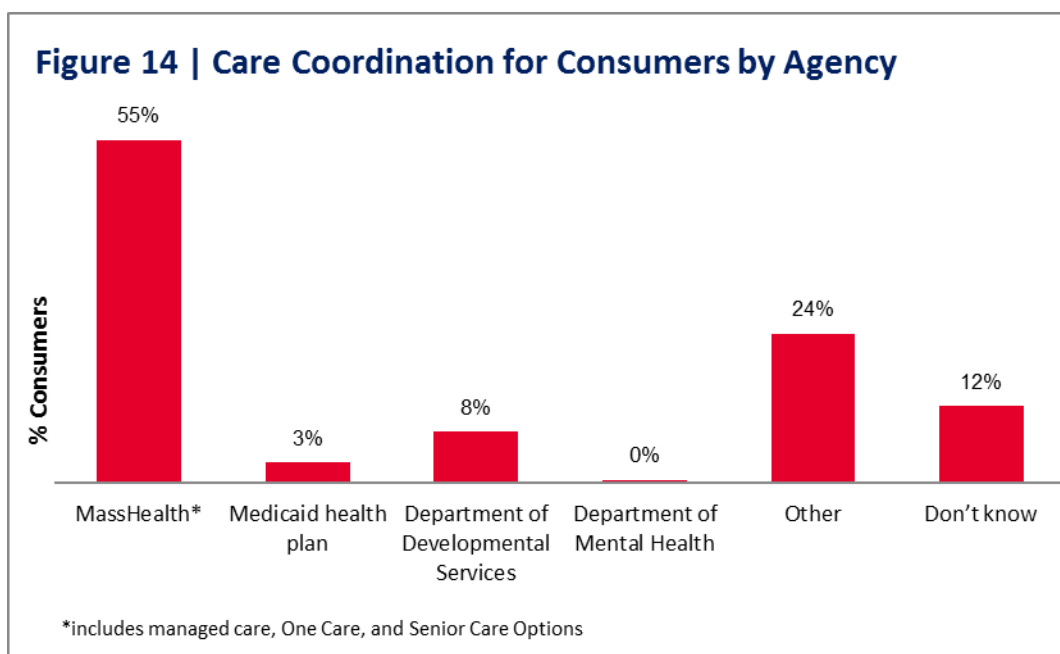
# Other Assistance Provided to PCA Consumers

## Other Formal Services

About one-third of PCA consumers (32%) receive additional formal services outside of the PCA program. Among the respondents who received additional formal services, 13% received services from the Visiting Nurses Association (VNA), 5% from Elder Services, 3% from Adult Day Health/Day Habilitation program, 4% from the Department of Developmental Services (DDS), 2% from the Department of Mental Health (DMH), 2% from the Massachusetts Rehabilitation Commission's Home Care Assistance Program, and 3% received transportation assistance (e.g., the Ride).

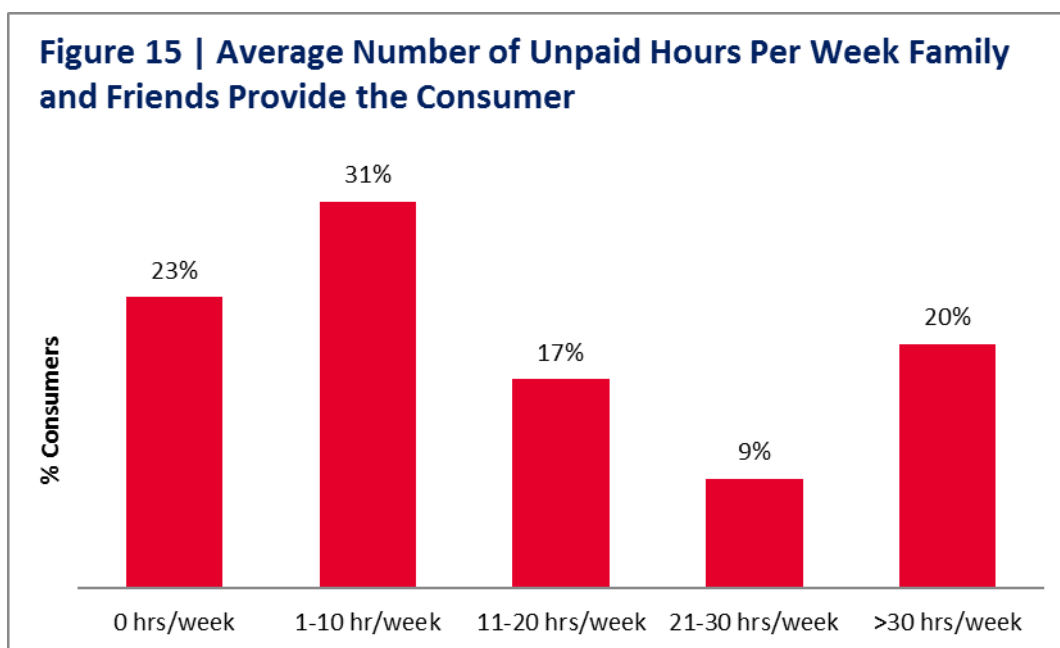
Of those respondents who received additional formal services, 63% received 1-10 hours of these services per week and 16% received 11 hours or more per week.

About one-third of PCA consumers (32%) had a professional help them coordinate and manage their health care services, such as a care coordinator, case manager, or community health worker. These professionals worked for a variety of agencies, with over half from MassHealth (55%; includes managed care, One Care, and Senior Care Options), 3% from a Medicaid health plan, 8% from the Department of Developmental Services, and 24% from another agency (most often, personal care management agencies).



## Unpaid Care and Assistance

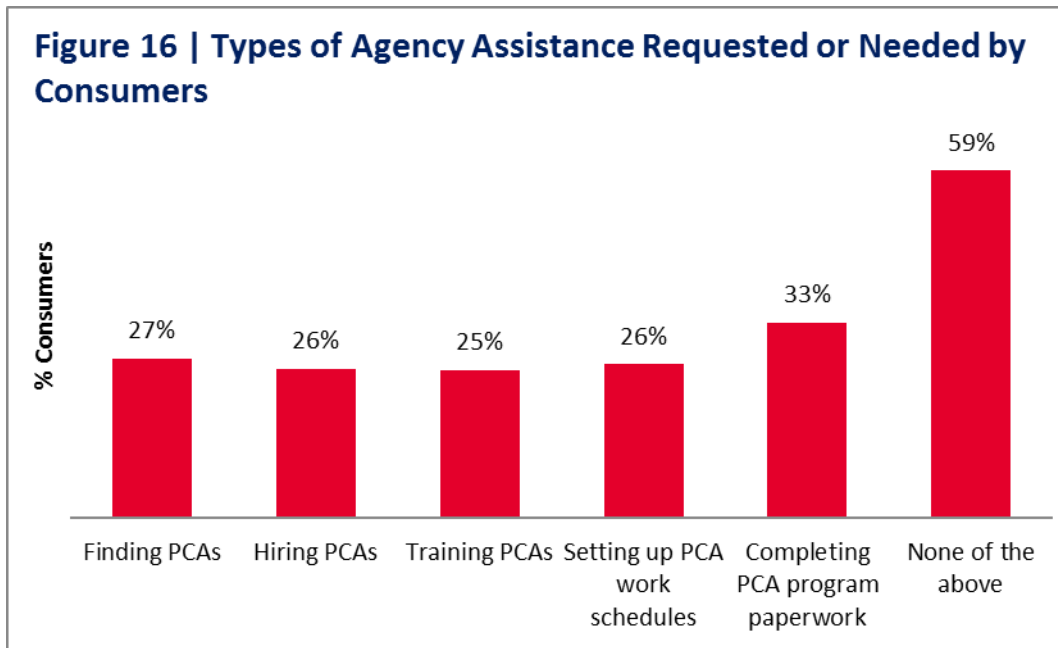
Over three-quarters (77%) of PCA consumers receive some level of help from family and friends on a weekly basis. Each week, about a third of consumers (31%) receive unpaid assistance for 10 hours or fewer, about a quarter of consumers (26%) receive 11 to 30 hours of unpaid assistance, and about a fifth of consumers (20%) receive more than 30 hours a week of unpaid assistance.



Given the high proportion of PCAs who are family and friends, unpaid care and assistance often comes from the PCAs themselves. Focus group participants often described how their PCAs worked above and beyond the hours for which they were paid, and advocated for more hours for PCAs.

## Assistance Employing PCAs

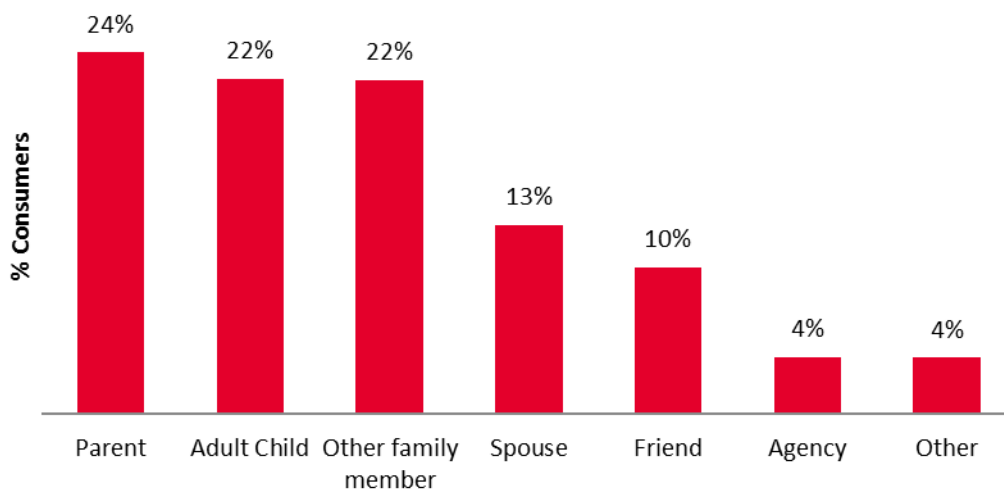
The majority of PCA consumers (59%) did not need or receive help hiring PCAs, training PCAs in the way they wanted to be taken care of, setting up PCA work schedules, or filling out paperwork and timesheets. However, 41% of consumers did need or receive help with these tasks. For any given task, one-fourth to one-third of the PCA consumer population needed or received help with tasks related to PCA employment.



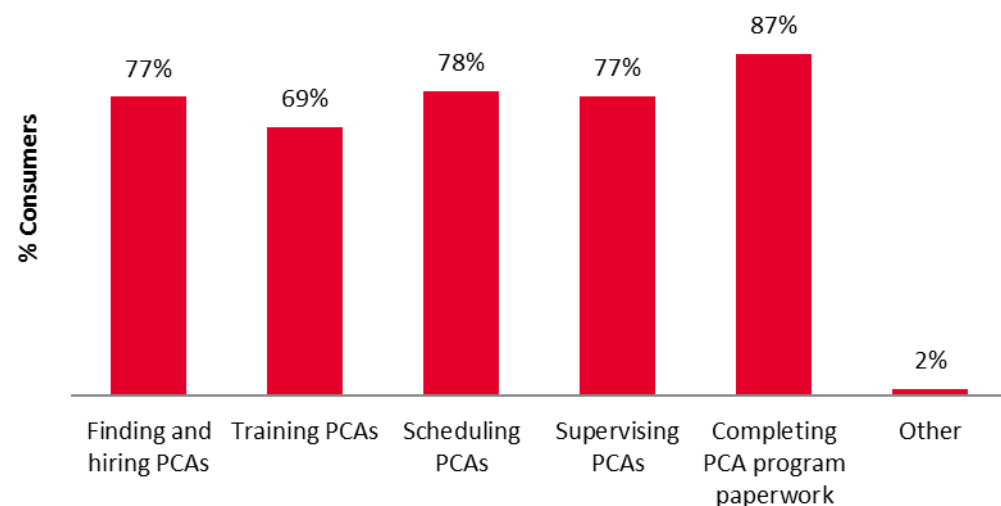
## Surrogate Characteristics and Activities

One half of the PCA consumer population has a surrogate who assists them with the work of employing PCAs. About four out of five surrogates are family members (81%), whether they are parent, child, spouse, or other family member. Two out of three surrogates are female (66%). More often than not, surrogates assist PCA consumers across multiple tasks related to employing PCAs, including finding, hiring, training, scheduling, and supervising PCAs, and completing paperwork.

**Figure 17 | Surrogate's Relationship to the Consumer**



**Figure 18 | Types of Surrogate Assistance Provided to Consumers**

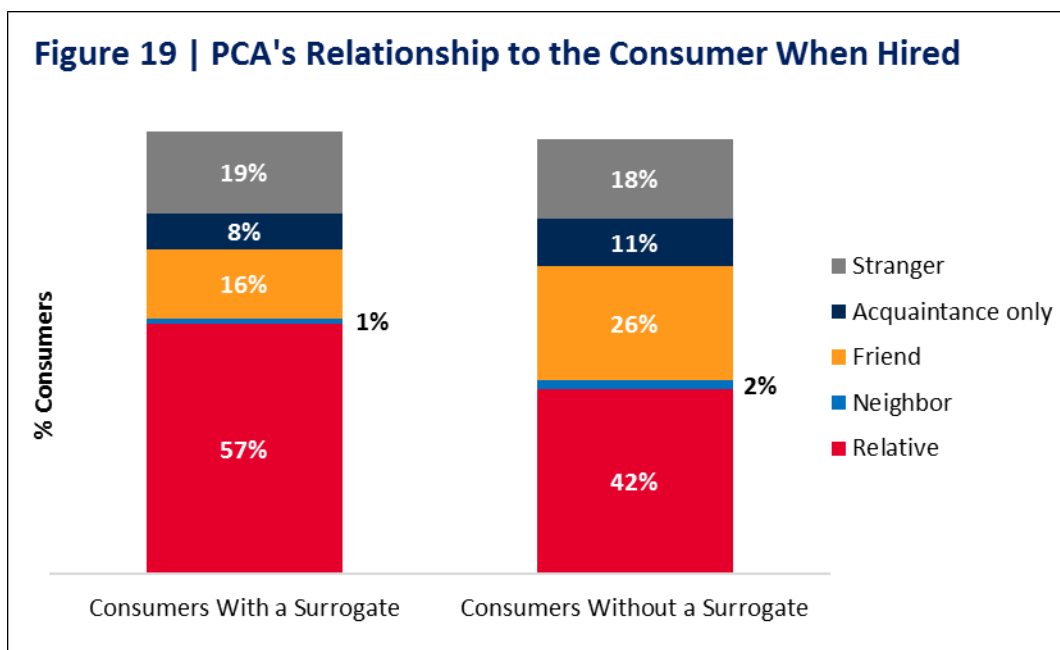


## Consumers with Surrogates

As described on earlier p10, one half of PCA consumers have a surrogate. Overall, consumers with surrogates tend to be authorized for more hours of PCA services than consumers without surrogates. Among consumers with surrogates, 37% were authorized for more than 40 hours per week, whereas 30% of consumers without a surrogate were authorized for over 40 hours per week.

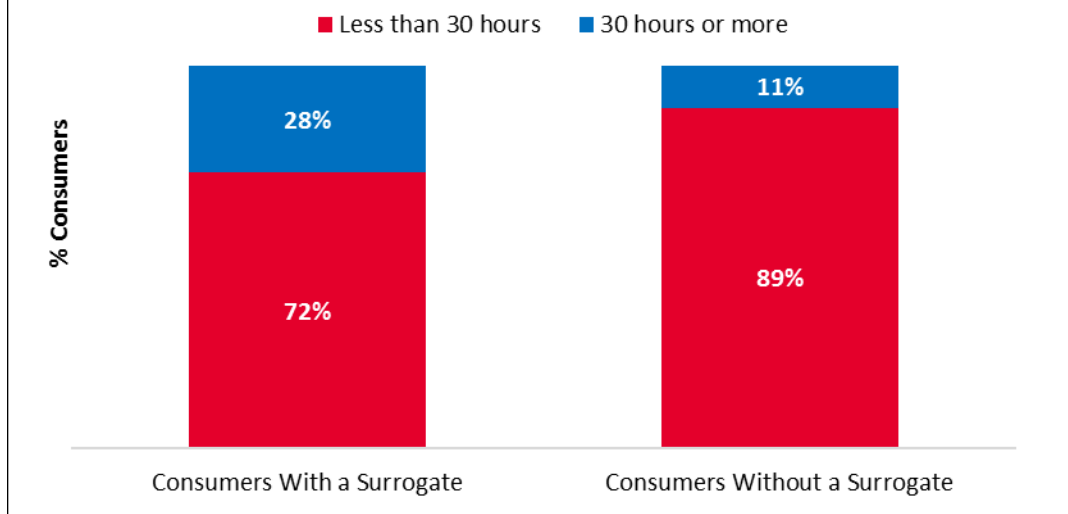
Consumers with surrogates were slightly less likely than those without to report having insufficient daytime hours to meet their needs (45% versus 54%, respectively). In contrast, consumers with surrogates were much more likely than those without to report having insufficient nighttime hours to meet their needs (43% versus 37%, respectively).

Consumers with surrogates not only often rely on family members as surrogates, but they are also more likely to hire relatives as PCAs. Fifty-seven percent of consumers with a surrogate reported hiring a relative as their PCA, compared to 42% of consumers without a surrogate. Consumers with surrogates were also less likely than those without to hire a friend (16% versus 26%, respectively).



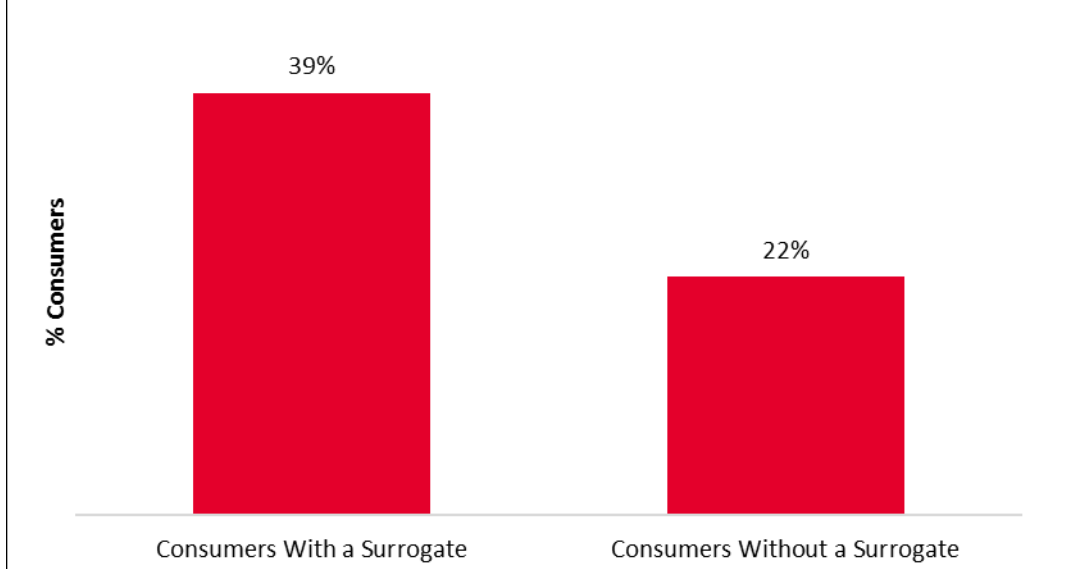
Compared to consumers without surrogates, consumers with surrogates relied much more heavily on unpaid help from family or friends. As shown in Figure 20, over a quarter of consumers with surrogates (28%) received over 30 hours per week of unpaid help, whereas about one in ten (11%) of consumers without surrogates received that level of unpaid help.

**Figure 20 | Average Number of Unpaid Hours Per Week Family and Friends Provide to the Consumer**



In addition to receiving more unpaid help, consumers with surrogates were more likely to report receiving formal services beyond the PCA program. Thirty-nine percent of consumers with a surrogate reported that they received other formal services outside of the PCA program compared to 22% of consumers without a surrogate.

**Figure 21 | Consumer Received Other Formal Agency Assistance**





# Consumer Satisfaction

## Satisfaction with PCA

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The vast majority of PCA consumers reported being very satisfied or satisfied with the quality of services provided by their PCA (84% and 16%, respectively). When asked if they were satisfied with the way in which their needs were being met, 54% of respondents were very satisfied, 35% were satisfied, 8% were somewhat satisfied, 1% were a little satisfied, and 2% were not at all satisfied.

*"I can't say enough good stuff about her. She knows all of my problems, when I have to go to the doctors, what I can do, what I can't do, what I'm not supposed to do, she knows them all."*

*"Not only is she there to do housework and what we need and then leave. She is also there too when we are feeling a little bit down, she helps pick you up or talks to you. You get to be friends."*

Almost all consumers said they got along very well or well with their PCA (89% and 11%, respectively). Ninety-four percent of respondents reported that their PCA always treats him/her with respect, 96% always feel totally safe with their PCAs and the assistance that they provide, and 97% feel very comfortable having their PCA care for them. Nearly all PCA consumers reported never having been mistreated by any of their PCAs (97%).

## Consumer-Directed Model

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The vast majority of PCA consumers (96%) felt that it was important or very important that they were able to choose their own PCAs. Some focus group participants described having negative experiences with PCAs from other agencies, which they did not choose themselves. Because trust was essential to the PCA-consumer relationship, focus group participants described having choice as paramount to them.

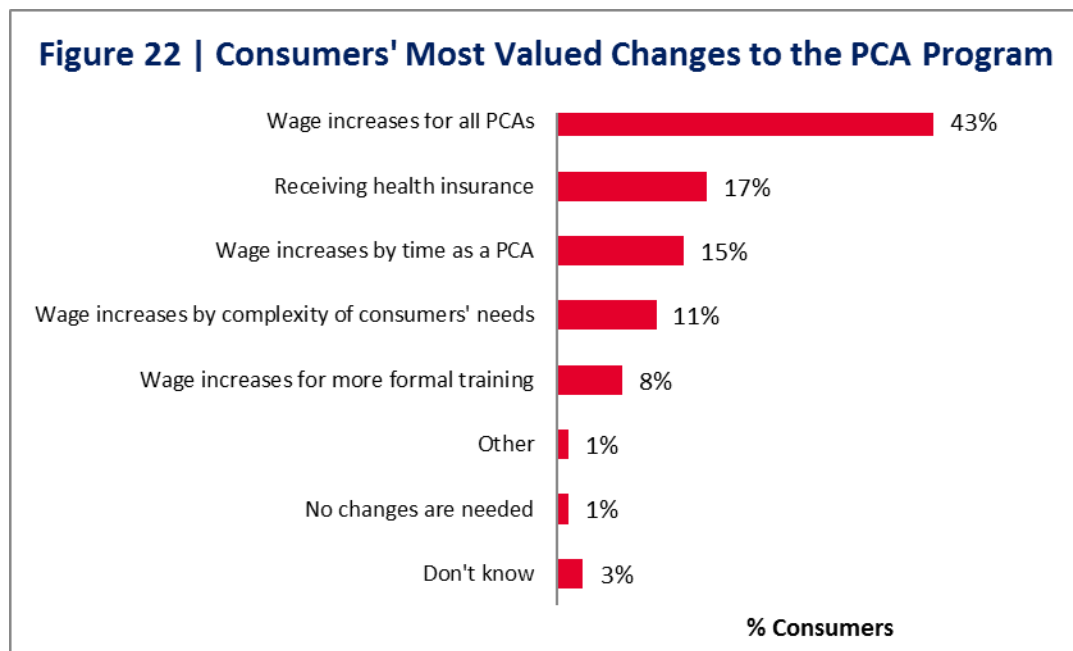
*"I hand pick who I want. I only go with people who I know and have a long history with."*

Respondents were asked whether consumers would be interested in letting an agency manage some or most employment-related tasks (i.e. finding, hiring, training, and scheduling PCAs, and filling out paperwork) for them in the future, if they felt they could not handle them on their own. Forty percent of respondents were not at all interested in letting an agency handle some or most of these tasks for them, 20% were somewhat interested, 15% were a little interested, 14% were interested, and 8% were very interested. The majority of respondents were very satisfied (45%) and satisfied (38%) with how the PCA program handled administrative services.

## Consumer Recommendations for Improving the PCA Program

The number one request from PCA consumers in the focus groups was to have more hours.

When asked about potential changes to the wages and benefits offered by the PCA program, the most frequent answer was wage increases for all PCAs (43%). Seventeen percent said receiving health insurance was the most important potential change, 15% said increasing PCA wages the longer he/she is on the job, 11% said increasing wages for PCAs who care for consumers with the most complex needs, and 8% said wage increases for PCAs who have had more formal training.



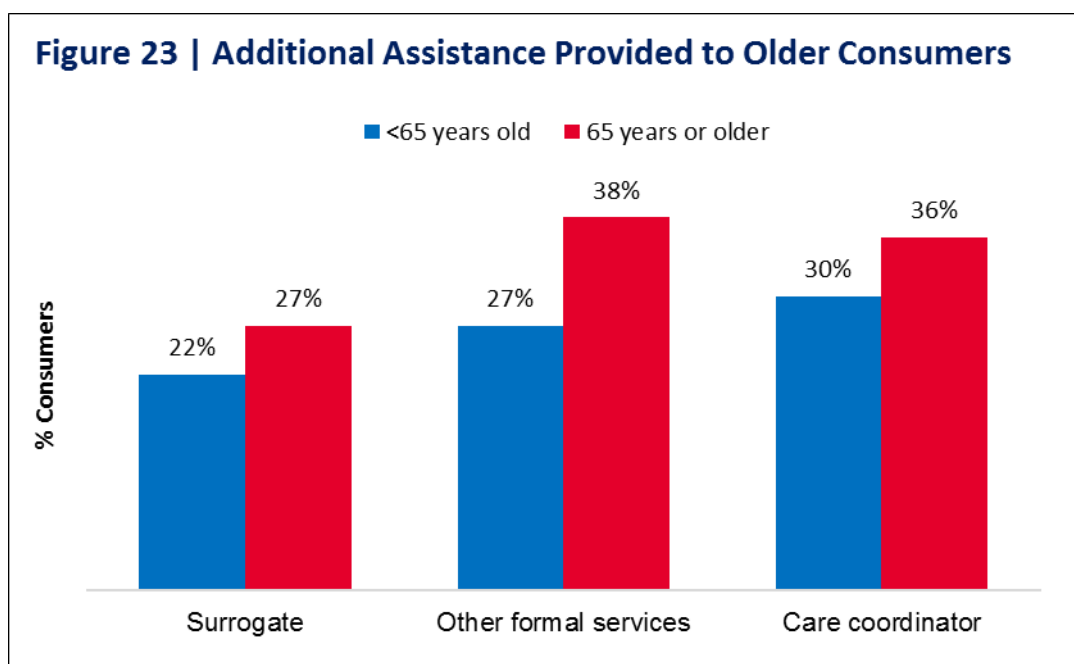
# Specific PCA Consumer Segments

## Consumers 65 Years Old or Older

Consumers who were 65 years of age or older represented nearly a third (30%) of the PCA consumer population in 2018. As described earlier, older consumers were more likely to report poor health than younger consumers.

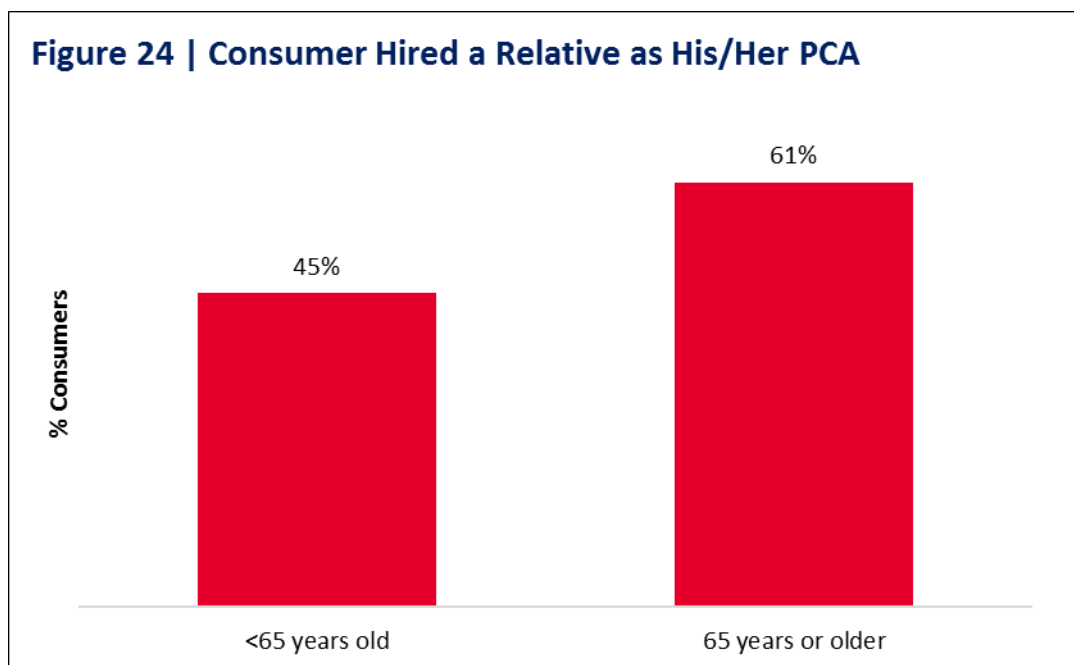
Older consumers tended to be authorized for more hours of PCA services than their younger counterparts. Thirty-eight percent of consumers who were at least 65 years old were authorized for more than 40 hours per week, compared to 32% of consumers less than 65 years old. This greater number of authorized hours is related to the fact that older consumers had difficulty with a greater number of IADLs, with 77% of consumers at least 65 years old having difficulty with 4 IADLs, compared to 69% of their younger counterparts.

Older consumers also tended to have more assistance beyond the PCA program. Older consumers were more likely to have a surrogate (27% versus 22%), receive formal services outside of the PCA program (38% versus 27%), and have a care coordinator (36% versus 30%).



Compared to their younger counterparts, the primary disabilities that led older consumers to need PCA help were more likely to be cognitive impairments, such as Alzheimer's and dementia, and chronic illness, perhaps related to their age. Consumers under 65 years of age were more likely to have primary disabilities such as developmental disabilities and spinal cord injury.

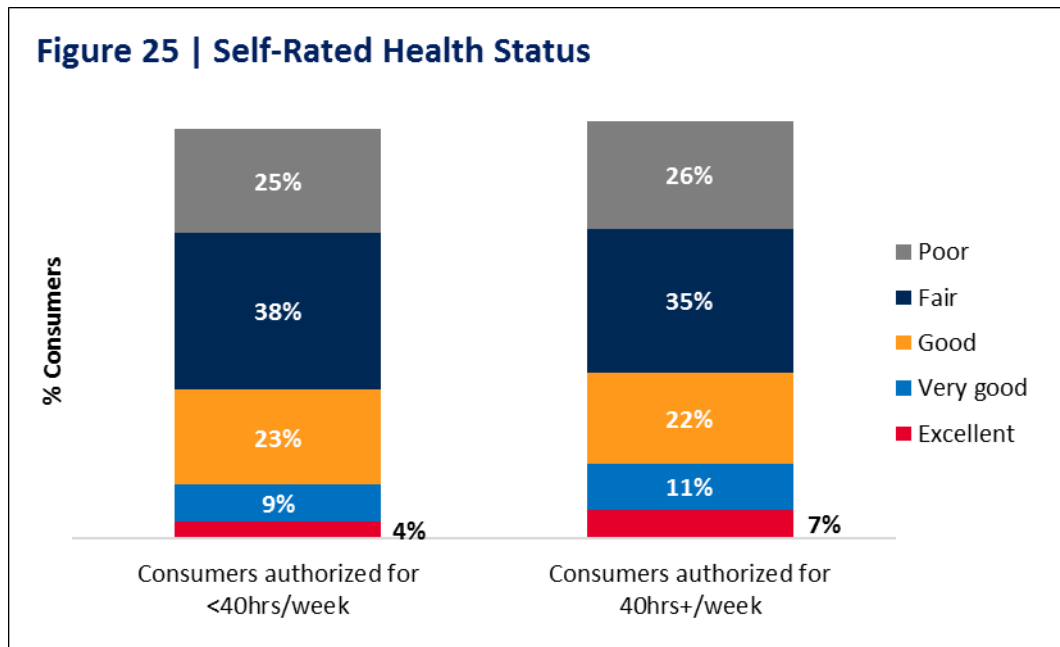
Consumers who were at least 65 years old were more likely than their younger counterparts to hire a relative as their main PCA (61% versus 45%). The greater reliance on family members as PCAs likely reduces recruitment and retention issues. Older consumers were less likely to have had a PCA leave in the past 12 months (18% versus 32%), have a PCA ever leave (23% versus 37%), or to have ever fired a PCA (19% versus 31%).



When asked about whether they would be interested in letting an agency handle employment-related tasks, older consumers were less interested in this possibility than were consumers under 65 years of age. Over half (54%) of older consumers were not at all interested, compared to about a third (34%) of younger consumers indicating no interest.

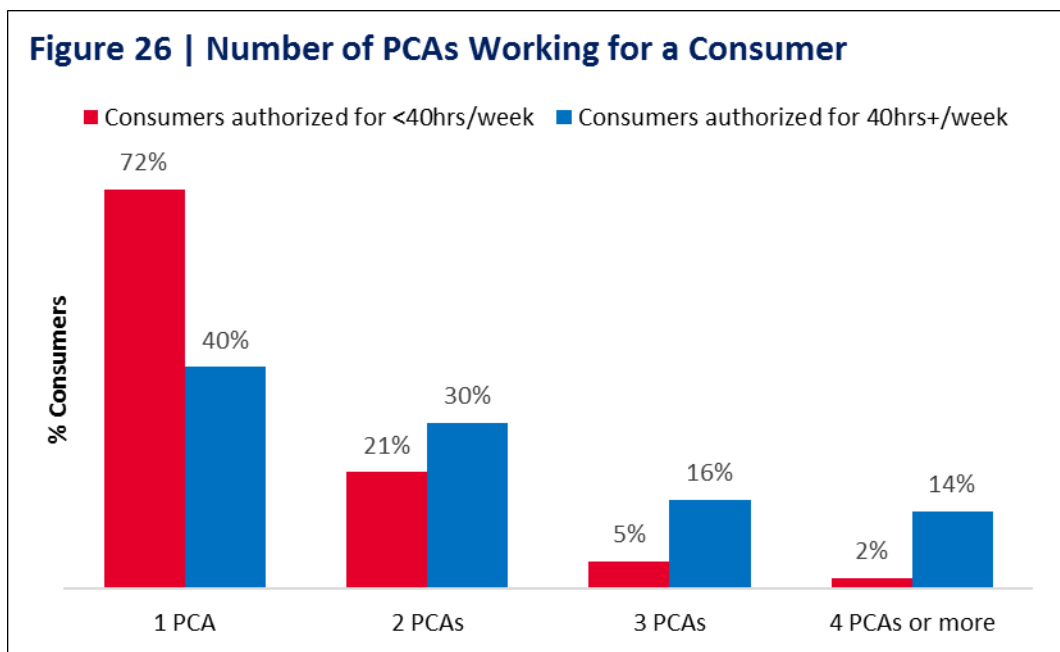
## Consumers Authorized for Over 40 Hours Per Week

Although consumers authorized for over 40 hours per week had difficulty with a greater number of ADLs and IADLs than consumers who were authorized for fewer hours, the self-reported health status was generally similar between these two groups.



Though consumers authorized for over 40 hours per week and their counterparts reported similar levels of unmet need for daytime hours (50% versus 49%, respectively), consumers authorized for over 40 hours per week were much more likely to report unmet needs for nighttime hours (48% versus 33% among consumers authorized for 40 hours or fewer).

Consumers authorized for over 40 hours per week employ a greater number of PCAs than consumers authorized for 40 hours or fewer. Among consumers authorized for over 40 hours per week: 40% employed one PCA, 30% employed two PCAs, 16% employed three PCAs, and 14% employed four or more PCAs. In contrast, among consumers authorized for 40 or fewer hours per week: 72% employed 1 PCA, 21% employed two PCAs, 5% employed three PCAs, and only 2% employed four or more PCAs.



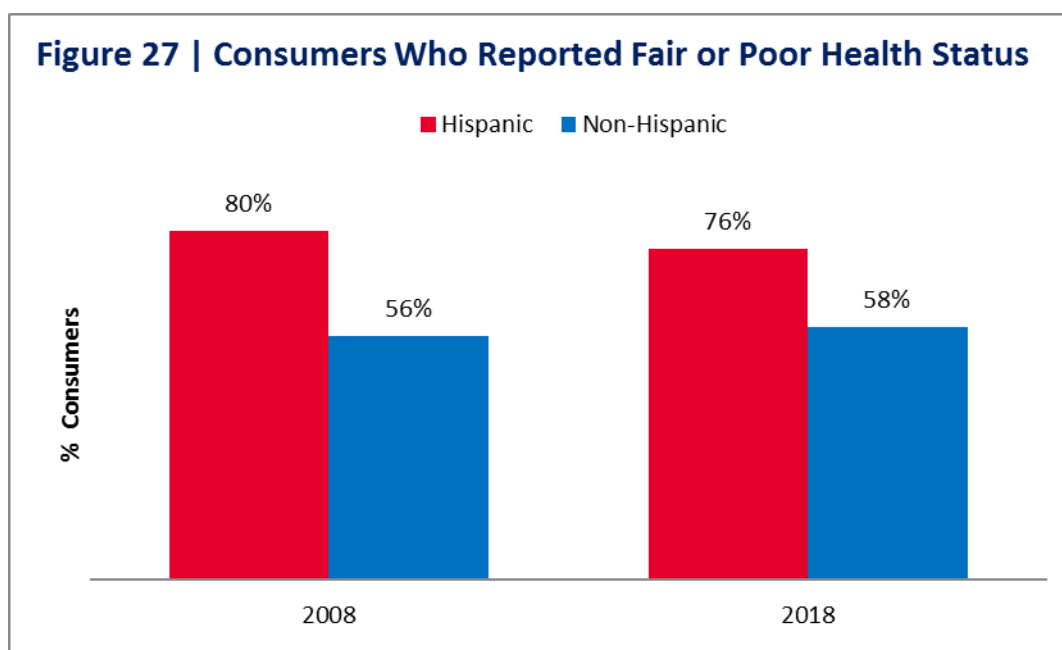
Though consumers authorized for over 40 hours per week and their counterparts hired relatives as their main PCA at similar rates (49% versus 50%, respectively), the former were more likely to hire strangers as their main PCA compared to their counterparts (24% versus 16%).

The combination of needing more PCAs and having to recruit beyond their immediate social network can make it harder for these consumers to recruit. Consumers authorized for over 40 hours per week were more likely to say it was very difficult to recruit their last PCA (12% versus 5%), and less likely to say it was not at all difficult (62% versus 79%).

## Hispanic or Latino/a Consumers

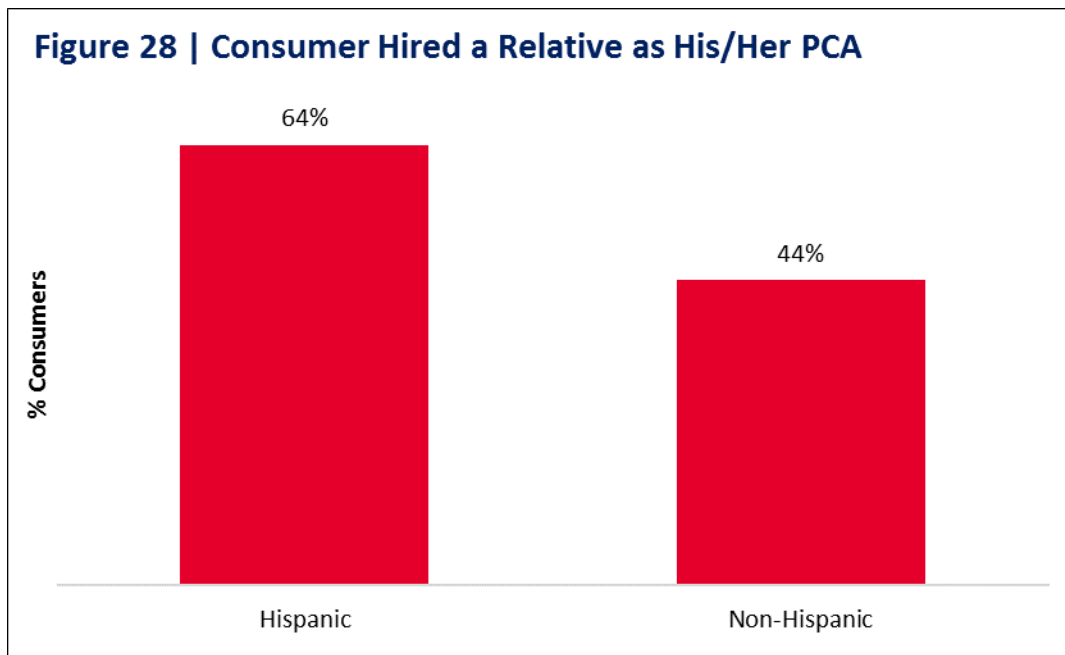
As described in the 2008 report, Hispanic consumers make up a significant and growing share of the PCA consumer population. In 2008, 20% of respondents identified as Hispanic or Latino/a, and in 2018, this proportion rose to 27%. Demographically, Hispanic consumers were similar in age, but were less likely to be White (34% versus 72%) and less likely to have obtained at least a 4-year college degree (10% versus 19%). They were also more likely to live in Central and Northeast Massachusetts, and less likely to live in MetroWest.

In 2008, Hispanic consumers were more likely report fair or poor health compared to non-Hispanic consumers (80% versus 56%), and this disparity has reduced slightly in 2018 (76% versus 58%). Additionally, in 2008 Hispanic and non-Hispanic consumers reported difficulty with a similar number of ADLs, but in 2018, Hispanic consumers were more likely to report difficulty with at least 4 ADLs (74% versus 62%), which can be related to their poorer health status.

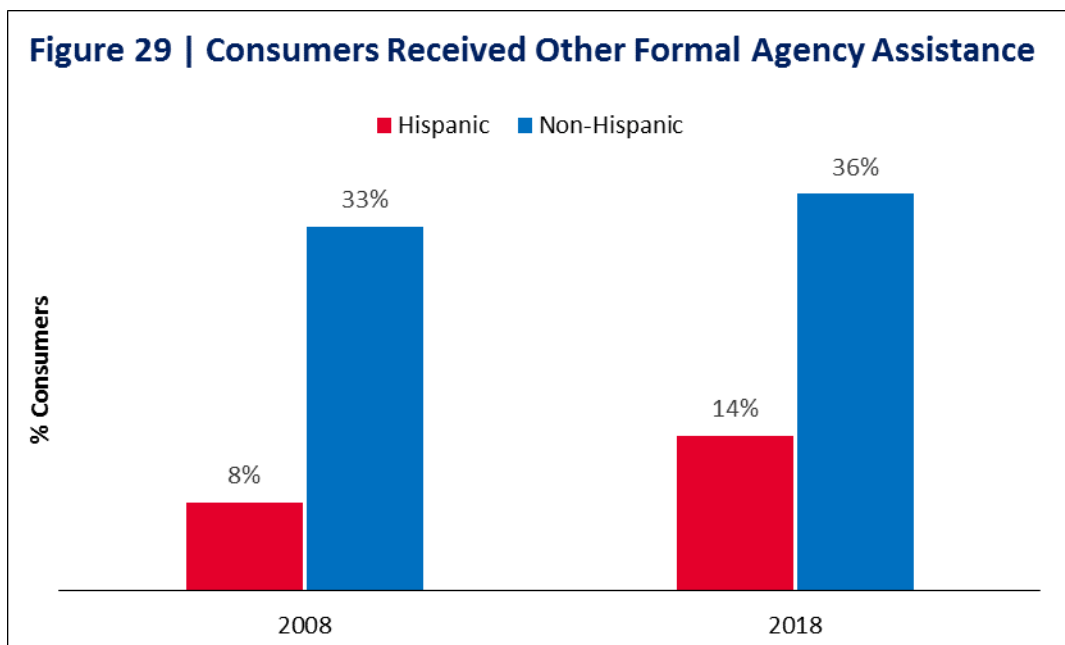


In 2008, there was a large gap between the proportion of Hispanic and non-Hispanic consumers who reported having insufficient daytime hours and nighttime hours (55% versus 40% for daytime hours and 55% versus 44% for nighttime hours). In 2018, this gap largely disappeared (52% versus 50% for daytime hours and 42% versus 39% for nighttime hours) through a combination of greater unmet need for daytime hours among non-Hispanic consumers and less unmet need for nighttime hours.

In 2018 there has been an increased reliance on family members as PCAs, and this is especially true for Hispanic consumers (64% versus 44%). The greater reliance on family members likely makes recruitment easier: 81% of Hispanic consumers said it was not at all difficult to recruit their last PCA, compared to 71% of non-Hispanic consumers.



In 2008 and 2018, Hispanic consumers reported receiving less other formal agency assistance than non-Hispanics. In 2008, 8% of Hispanic consumers reported receiving other formal agency assistance compared to 33% of non-Hispanic consumers. Although Hispanic consumers in 2018 received more formal agency assistance than ten years ago, a gap still remains between Hispanic and non-Hispanic consumers (14% versus 36%).





## Summary and Implications

The PCA program was designed to provide people with disabilities and older Massachusetts residents with assistance in conducting activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Overall, consumers are highly satisfied with the PCA services they receive and the nature of their relations with their PCA(s), similar to the findings from the 2008 study. In both studies, consumers described the program as essential to their ability to live independently in the community and their quality of life. As in 2008, many consumers expressed that the utility of the PCA program extends far beyond simply helping consumers with a specific list of tasks. Consumers often cited strong relationships with their PCAs, which often provided valuable social support to consumers, especially the most socially isolated consumers. Additionally, consumers surveyed in 2018 reported high satisfaction with New Hire Orientation and free skills trainings for PCAs, program features that were not available to PCAs in 2008.

Despite high levels of satisfaction with their PCAs employed through the program, consumers continue to report high rates of unmet needs in the 2018 survey. Among survey respondents and focus group participants, chief complaints include the insufficient allotment of hours, difficulties in obtaining approval for additional hours of care, and program limitations in how hours can be allotted that do not take into account extra time needed for typical delays in travel or at medical visits.

Though many findings appeared in both the 2008 and 2018 studies, there were also some emerging themes that have important implications for the future of the program. First, both the number and percentage of older consumers in the PCA program have increased, as older consumers now represent nearly one third of PCA consumers. Older consumers are distinct in a number of ways. Older consumers tend to rely more on family members as PCAs, which is linked to reduced recruitment and retention issues. Survey findings, focus group discussions, and key informant interviews all suggest that this older age group experiences poorer self-reported health and a greater burden of aging-related chronic diseases, including dementia. As a result, some of these older consumers have more complex needs than the typical PCA consumer and require greater coordination of their PCA and health care services. Older consumers are also more likely to use formal services outside of the PCA program, and more than one in three have a care coordinator. Although there is already some coordination of PCA services with One Care and Senior Care Options programs, extensive coordination is not common. However, the increasing number of older PCA consumers reflects a growing opportunity—and, perhaps, need—for greater integration of the PCA program with other MassHealth programs.

The greatest shift in the PCA program over the last decade is the far greater reliance on family members as PCAs, which has multiple implications for the nature of PCA employment. In 2018, when hiring PCAs, 50% of consumers hired a family member and another 21% hired a friend.

This reliance on family and friends as PCAs means that—for a large majority of PCA consumers—the program does not operate as do most typical labor markets. For consumers that rely on family and friends as PCAs, it is easier to recruit and retain PCA workers; this ease of recruitment and retention contrasts the greater difficulties faced by consumers who employ strangers as PCAs. Consumers who employ family members and friends as PCAs are also far more likely to receive significant amounts of unpaid assistance from their PCAs. State and union efforts to support the recruitment and training of PCAs will need to consider the impact of this increasing trend of employing friends and family members as PCAs.

Another key theme to emerge from the 2018 study is that consumers who are authorized for more than 40 hours of care per week experience more difficulties in recruiting and retaining PCAs. These high users of PCA services are similar in health status and age, though they have more ADLs/IADLs than lower users of services. Consumers authorized for more than 40 hours hire more PCAs and experience far higher rates of PCA turnover than other consumers; additionally, this group hires more PCAs who are strangers, as opposed to the friends and family member PCAs that are more common amongst other consumers. For these consumers who rely on strangers as PCAs, various state and national factors—particularly the strength of the job market and efforts to increase the minimum wage—can create uncertainty for consumers about future impediments to recruiting and retaining non-family member PCAs. To address these challenges and uncertainties, the State and the union can focus additional efforts to improve recruitment and retention strategies for these consumers who use a high number of hours or require more intense care.

A final key theme from our 2018 study is the continuing strong endorsement of the consumer-directed model across multiple groups participating in the PCA program. The vast majority of consumers greatly value the ability to choose their own PCAs, but they are open to agencies managing other employment-related tasks. Two out of five consumers already need or receive assistance with employment related tasks from surrogates or agencies. When asked if they had interest in letting an agency manage employment-related tasks if they felt they could not handle them on their own, the majority reported at least some level of interest in agency support. Our findings suggest that consumers overwhelmingly endorse the consumer-directed model and would likely resist any attempt to move to pure agency model, but they would be willing to accept and even endorse greater support from surrogates and agencies in carrying out employment related tasks.

## Authors and Acknowledgments

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