



University of California  
San Francisco

*UCSF Health Workforce Research Center  
on Long-Term Care*

## Research Report

---

# California's Medicaid Personal Care Assistants: Characteristics and Turnover among Family and Non-Family Caregivers

Michelle Ko, MD, PhD

Robert Newcomer, PhD

Andrew B. Bindman, MD

Taewoon Kang, PhD

Denis Hulett, MS

Joanne Spetz, PhD

July 15, 2015

---

This project is/was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U81HP26494, Cooperative Agreement for a Regional Center for Health Workforce Studies. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Please cite as: Ko M, Newcomer R, Bindman AB, Kang T, Hulett D, Spetz J. (2015). California's Medicaid Personal Care Assistants: Characteristics of Family and Non-Family Caregivers. San Francisco, CA: UCSF Health Workforce Research Center on Long-Term Care.

UCSF Health Workforce Research Center on Long-Term Care, 3333 California Street, Suite 265, San Francisco, CA, 94118

Copyright © 2015 The Regents of the University of California

Contact: Michelle Ko, MD PhD, [Michelle.Ko@ucsf.edu](mailto:Michelle.Ko@ucsf.edu), (415) 476-9750

## **California’s Medicaid Personal Care Assistants: Characteristics and Turnover among Family and Non-Family Caregivers**

---

### **Table of Contents**

Table of Contents.....	2
Table of Tables .....	4
Table of Figures .....	5
Executive Summary .....	6
Methods .....	6
Results .....	6
Conclusions.....	7
Background .....	8
Methods .....	10
Sample.....	10
Data Sources.....	10
Defining Family versus Non-family PCAs .....	10
Defining PCA Turnover .....	11
Measures .....	11
Recipient characteristics .....	11
Personal care assistant characteristics .....	12
Local market characteristics .....	12
Analyses.....	12
Results.....	13
Characteristics of first-time IHSS recipients .....	13
Majority of personal care assistants are family members .....	15
Characteristics of personal care assistants for first-time IHSS recipients..	16
Characteristics of local market conditions for personal care assistants.....	17
Changes in personal care assistants .....	17



University of California  
San Francisco

Effect of rates of pay and local market characteristics on PCA turnover ...	18
Differences across racial and ethnic groups .....	19
Conclusions.....	21
Limitations .....	22
Implications and Recommendations .....	23
Future Directions .....	23
Acronyms Used in this Report .....	25
Terminology Used in this Report .....	25
References.....	28

**Table of Tables**

Table 1. Characteristics of first-time recipients of In-Home Supportive Services by type of personal care assistant (PCA) 2006-2007 ..... 14

Table 2. Relationships of personal care assistants to first-time recipients of California In-Home Supportive Services, 2006-2007 ..... 15

Table 3. Characteristics of In-Home Supportive Services personal care assistants, 2006-2007 ..... 17

## **Table of Figures**

Figure 1. Family and non-family member personal care assistants for recipients of In-Home Supportive Services. ....	16
Figure 2. Relationship between payment rate and probability of turnover among non-family personal care assistants .....	19
Figure 3. Family member and non-family personal care assistants, by race and ethnicity of the recipient .....	20
Figure 4. Probability of turnover in family and non-family personal care assistants, by race and ethnicity of the recipient .....	21

## **California's Medicaid Personal Care Assistants: Characteristics and Turnover among Family and Non-Family Caregivers**

---

### **Executive Summary**

Personal care assistants (PCAs) provide supports and services that enable older adults and individuals with disabilities to remain in their homes and community settings. State Medicaid Home and Community-Based Services programs facilitate use of alternatives to institutional care by paying for personal care assistance. This study characterizes the personal care assistance role played by both family members and non-family in California, one of the nation's largest consumer-directed Medicaid personal care assistance program. We describe factors that affect turnover among PCAs, as turnover is associated with lower quality of care and adverse outcomes for recipients.

### **Methods**

Using state and federal data sources (2006 to 2008) covering first-time recipients of In-Home Supportive Services, the California Medicaid personal care assistance program, we describe demographic and other characteristics of both care recipients and PCAs. Lastly, we characterize differences in PCA utilization and turnover across racial and ethnic subgroups.

### **Results**

Family members comprise the majority (63.5%) of the PCA workforce under California's Medicaid program. The overall rate of PCA turnover in the first 12 months of service was 13.6%; however the probability of turnover among family member PCAs was less than half that of non-family PCAs. Among recipients with non-family PCAs, higher payment rates and higher local unemployment rates were associated with a lower likelihood of turnover, but these factors were not salient for family member PCA turnover. Black recipients were more likely to experience PCA turnover. Hispanic and Asian recipients were more likely to have family member PCAs, but those with non-family PCAs experienced higher rates of turnover relative to non-Hispanic Whites.

## **Conclusions**

The rate of turnover among personal care assistants in California's Medicaid program is relatively low, and this may be partly due to high rates of family member participation. For those with non-family personal care assistants, raising pay may be an important key to stabilizing the workforce and improving continuity of care. Racial and ethnic minorities who do not have family members to provide personal care assistance may particularly need additional supportive policies to reduce worker turnover.

## **California's Medicaid Personal Care Assistants: Characteristics and Turnover among Family and Non-Family Caregivers**

---

Personal care assistants provide supports and services that enable older adults and individuals with disabilities to remain in their homes and community settings. State Medicaid Home and Community-Based Services programs fund a number of services that facilitate alternative options to institutional care, including personal care assistance. This study characterizes the role that family members play in the nation's largest<sup>1</sup> consumer-directed Medicaid personal care assistance program and describes factors that affect turnover among family versus non-family workers.

### **Background**

In-Home Supportive Services (IHSS) is the mainstay of California's Medicaid Home and Community-Based Services programs. In 2008, over 80% of the state's 478,000 participants received IHSS. IHSS is a consumer-directed program, permitting recipients to choose any individual, such as a family member, friend, or an employee of a home health agency, to provide personal care assistance and receive payment from Medicaid. As of 2013, 43 states offered consumer direction in at least 1 waiver program (i.e., a program for a specific group of Medicaid beneficiaries) and 21 states offered it under personal care state plan services (i.e., available to all eligible Medicaid beneficiaries). (For a detailed description on state plan and waiver programs, please refer to Terminology Used in This Report).<sup>1</sup>

Paying family members to provide personal care assistance for elders and disabled persons can help offset the significant costs and burdens of uncompensated family caregiving. California Medicaid beneficiaries who receive personal care from family members have reported higher levels of satisfaction.<sup>2</sup> Early research on IHSS suggests that those who receive care from family members have similar outcomes to those with non-family PCAs.<sup>3,4</sup> If family members can be adequately compensated, this may bolster the number of available PCAs and the options to receive long-term care services outside of institutional settings.

Further, paying family members may increase the stability of the personal care workforce. Turnover in the long-term care (LTC) workforce is high. In

national surveys of LTC workers, 21% reported exiting the industry in the past or current year, and among those employed in private households, exit rates exceed 25%.<sup>5</sup> Jobs in personal care services typically offer low wages, long hours with limited flexibility, and high rates of disability, leading to worker dissatisfaction.<sup>6</sup> In a survey of IHSS PCAs, those who provided care for family members reported lower levels of stress but higher emotional strain.<sup>7</sup> However, studies on informal family caregiving describe poor mental health and strained family relationships,<sup>8</sup> stress related to lost income,<sup>9</sup> and high rates of injury and disability.<sup>10</sup> It is not known whether factors that affect turnover differ for family member versus non-family PCAs.

One study on Medicaid personal care assistants in home and community settings found that recipients who had changed personal care assistants in the previous year were more likely to experience injuries, bed sores or contractures, and hospital admissions.<sup>3</sup> In nursing facilities, high staff turnover is associated with lower quality of care, including outcomes such as increased use of physical restraints and urinary catheters, poor pain management, and higher risk of pressure ulcers.<sup>11,12</sup>

There is a projected shortage of personal assistance caregivers as the nation ages.<sup>13</sup> If family members can be adequately compensated, this may increase the number of available personal caregivers and the options for the frail elderly to receive long-term care services outside of institutional settings. Further, although it is posited that family members would be unable to provide these services absent payment to support themselves, it is unknown whether paying family members to be personal caregivers actually stabilizes PCA continuity, and the level of payment that makes a difference.

In this report, we examine a sample of California recipients of Medicaid personal care assistance and their providers. We describe the role that family members and non-family PCAs play in the nation's largest Medicaid consumer-directed care program. We measured the extent to which recipients change PCAs, and analyzed whether or not those who receive care from family members experience lower rates of caregiver turnover, and whether factors related to turnover differ for family versus non-family PCAs. Lastly, we assessed differences across racial and ethnic groups in rates of receipt of care from family and turnover in personal care assistants. The experience in California, with its diversity of racial and ethnic groups, provides a snapshot of the anticipated demographic shifts in the long-term

care population across the nation, which may inform other states' policy directions regarding consumer-directed care services.

## **Methods**

### ***Sample***

The study sample consisted of first-time recipients of IHSS, the California Medicaid program that covers personal care assistance in home and community settings. We defined "first-time" recipients as those who initiated IHSS in 2006 or 2007, with no receipt of IHSS in the preceding 12 months. The initial sample size was 82,946 recipients. Of those, 74,986 had complete information on personal care assistant and recipient characteristics.

To focus our study on long-term recipients of IHSS, we additionally restricted our sample to those who received IHSS for at least 9 consecutive months or, if they discontinued services, reinstated IHSS within the same year. We found that 6,641, or 8.9% of first-time IHSS recipients, discontinued services in the first 9 months, resulting in a final sample size of 68,345 recipients.

### ***Data Sources***

We used several linked datasets on IHSS recipients and PCAs. We obtained information on recipient demographics, health, and IHSS receipt from California Medicaid and Medicare claims and California state hospital discharge data. We incorporated data on functional status and cognitive limitations from IHSS assessments and from the following Medicare assessment datasets: OASIS (Medicare home health), IRF-PAI (Medicare rehabilitation facilities) and MDS (Medicare nursing facilities). We also linked data from the California Case Management, Information, and Payrolling System (CMIPS) for information on personal care assistants, including demographic characteristics and relationships to IHSS recipients. Lastly, we obtained information on local labor market conditions from the Bureau of Labor Statistics for all California counties in 2008.

### ***Defining Family versus Non-family PCAs***

We defined family member PCAs as those who reported having a relationship to the recipient that included the following categories: Spouse, Adult Child,

Minor Child, Other Relative. We categorized all other PCAs as non-family (Table 2). Examples of non-family PCAs include those employed by home health agencies, neighbors, friends, and unrelated housemates.

Data on PCA characteristics were complete for only 34% of recipients in the month when IHSS was initiated. Completion rates of PCA data increased with duration of services. After 9 months of service, 93% of recipients had complete PCA data.

### ***Defining PCA Turnover***

The CMIPS dataset does not contain unique identifiers for personal care assistants, and thus we were unable to directly assess changes in the identity of PCAs for a particular recipient. As noted below (Table 2), the CMIPS data provide detailed information about the relationship of the recipient to the PCA. We thus defined PCA turnover as a change in the reported relationship between the PCA and the recipient.

### ***Measures***

#### ***Recipient characteristics***

We examined recipient age, gender, and race and ethnicity, with aggregated U.S. Census race/ethnicity categories of non-Hispanic White, Hispanic, (non-Hispanic) Black, Asian, and Other. To characterize recipient health status, we calculated the Chronic Illness and Disability Payment Score (CDPS) from Medicaid and Medicare claims diagnoses. The CDPS aggregates ICD-9 diagnosis codes into 58 categories, with higher numbers reflecting greater chronic disease comorbidity.<sup>14</sup> We measured functional status with the number of limitations in Activities of Daily Living (ADLs) obtained from recipient assessments, dichotomizing the data into those with 3 or more limitations versus those with fewer than 3. We measured the presence of cognitive limitations as those who required supervision for impairment in memory, judgment, or orientation. Because the study period occurs prior to implementation of the Affordable Care Act, individuals were not categorically eligible for Medicaid by income alone. We thus also examined source of Medicaid eligibility (for a detailed description of eligibility categories, please refer to Terminology Used in this Report).

### Personal care assistant characteristics

We examined PCA age, gender, and race and ethnicity. We measured payment rate as the hourly wage reported by the PCA. In California, baseline payment rates for PCAs are determined by each county. County agencies then negotiate the formal payment rate from the baseline for each personal care assistant, with small increases allowed for considerations such as the level of PCA experience. Thus, there is variation in hourly payment rates across the state's 58 counties. This provides an opportunity to examine whether higher payment rates are associated with lower turnover among Medicaid personal care assistants.

We also noted whether the PCA reported English as a primary language, the number of hours authorized to provide services, and whether the recipient had more than 1 PCA. If there was more than 1 PCA on record for the same time period, we defined the primary PCA as the one with the highest number of authorized service hours. Approximately 2% of recipients received services from more than 1 PCA at a time.

### Local market characteristics

We measured local market characteristics with 2 county-level statistics: the unemployment rate and the average weekly wages for the county. Both measures were obtained for the year 2008 from the Bureau of Labor Statistics. We included unemployment rate to account for relative health of the local job market, assuming that in areas of high unemployment, PCAs might be less inclined to leave a current job. We included average wages to account for income differences between counties, and as a control for underlying factors that may influence the base for the PCA payment rate.

### **Analyses**

We examined the characteristics of first-time recipients of IHSS and their primary personal care assistant by whether the PCA was a family member or non-family. We used multivariate logistic regression models to examine the associations between PCA turnover and characteristics of recipients, PCAs, and local market conditions. For the multivariate analyses, we excluded PCA race/ethnicity and language because these variables were strongly correlated

with recipient characteristics. We then repeated our analyses of turnover separately for family PCAs and non-family PCAs.

## **Results**

### ***Characteristics of first-time IHSS recipients***

Table 1 presents the characteristics of first-time IHSS recipients for those who received care from family members as compared with those who had non-family PCAs. A higher percentage of recipients with non-family PCAs were age < 65 years. A higher proportion of recipients with family PCAs were female, Hispanic, Asian, and had 3 or more limitations in ADLs. Those with non-family PCAs were more often non-Hispanic White, Black, and had at least 1 cognitive limitation. Those who were eligible for Medicaid as a family member with dependent children or due to disability were more likely to have family PCAs. Those who qualified for Medicaid due to substantial medical needs relative to income were more likely to have non-family PCAs.

**Table 1. Characteristics of first-time recipients of In-Home Supportive Services by type of personal care assistant (PCA) 2006-2007**

Recipient Characteristic	Family PCA N=43,356	Non-family PCA N=24,989
<b>Age*</b>		
18-<45y	7.5%	11.1%
45-<65y	25.9%	36.1%
65-<80y	44.3%	35.6%
80+y	22.3%	17.2%
Female*	63.5%	59.0%
<b>Race/Ethnicity*</b>		
non-Hispanic White	26.5%	37.3%
Hispanic	27.7%	20.9%
Black	12.1%	19.2%
Asian	27.3%	17.0%
Other	6.4%	5.6%
CDPS*	1.86	1.92
3+ ADL limitations*	13.7%	9.6%
Impaired cognitive function*	12.3%	14.8%
<b>Medicaid Eligibility Category*</b>		
Family with Dependent Children	37.2%	28.3%
Medically Needy	37.9%	49.3%
Aged	0.2%	0.2%
Disabled	23.3%	20.4%
Other	1.4%	1.7%

Source: California Medicaid claims, Medicaid enrollment, and Case Management Information and Payrolling System (CMIPS). CDPS= Chronic Illness and Disability Payment Score, higher numbers indicate greater chronic disease comorbidity.

\*indicates statistically significant differences between family and non-family PCA groups

**Majority of personal care assistants are family members**

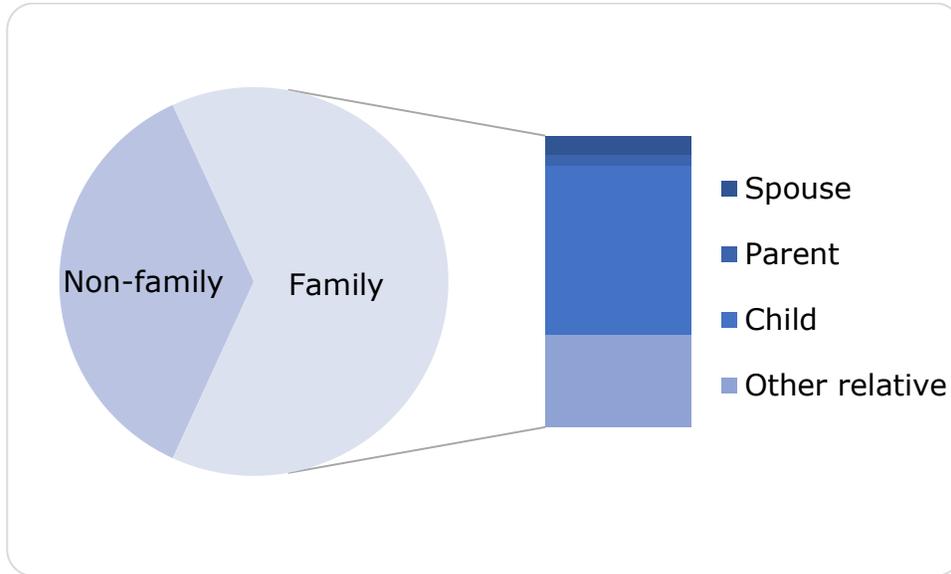
Table 2 displays the relationships between recipients and their primary personal care assistants (PCAs). Family members comprised 63.5% of PCAs among first-time recipients of IHSS. Among family member PCAs, adult children of recipients represented the largest proportion, followed by “Other relatives” (Figure 1). Among non-family PCAs, the most commonly described relationship was “Other,” consisting of 19.6% of all PCAs. A small minority of PCAs (0.3%) were employed by home health agencies. It is notable that the overwhelming majority of PCAs were not individuals placed through a home health agency or private business.

**Table 2. Relationships of personal care assistants to first-time recipients of California In-Home Supportive Services, 2006-2007**

Relationship	Number	%
Spouse	2,839	4.2%
Parent Adult	62	0.1%
Parent Minor Child	1,593	2.4%
Minor Child	76	0.1%
Adult Child	25,040	36.6%
Other Relative	13,746	20.1%
Friend	10,292	15.1%
Neighbor	311	0.5%
Landlord	50	0.1%
Housemate	229	0.4%
Live-In Provider	214	0.3%
Home Health Agency	205	0.3%
Other Business	42	0.1%
Other	13,646	19.6%
Total	68,345	100%

Source: California Medicaid claims, Medicaid enrollment, and Case Management Information and Payrolling System (CMIPS)

**Figure 1. Family and non-family member personal care assistants for recipients of In-Home Supportive Services.**



Source: California Medicaid claims, Medicaid enrollment, and Case Management Information and Payrolling System (CMIPS)

***Characteristics of personal care assistants for first-time IHSS recipients***

Table 3 presents the characteristics of personal care assistants for first-time IHSS recipients, by family and non-family PCAs. For both groups, PCAs were predominantly aged 25-64 years and female. Nearly 5% all PCAs were age 65 and over. Payment rates were similar across both groups, and ranged from \$6 to \$12 per hour, with a mean rate of \$9 per hour. Fewer than half of all PCAs, both family and non-family, reported English as their primary language. Most PCAs were the sole providers of Medicaid personal care services; only 2% of recipients had 2 or more authorized PCAs at the same time, and this finding was similar across groups.

**Table 3. Characteristics of In-Home Supportive Services personal care assistants, 2006-2007**

PCA Characteristic	Family PCA	Non-family PCA
Age (years)*		
14<24	8.9%	5.9%
25-<45	41.7%	33.1%
45-<65	44.6%	55.9%
65+	4.7%	5%
Female*	76.8%	82.4%
Race/Ethnicity*		
non-Hispanic White	42.5%	46.5%
Hispanic	23.5%	21.9%
Black	9.6%	16.0%
Asian	24.0%	15.3%
Other	0.4%	0.3%
English as primary language*	42.4%	49.8%
Mean hourly payment rate	\$9.15	\$9.09
Mean service hours per week	53.8	55.8
Additional PCAs	2%	2%

Source: California Medicaid Case Management Information and Payrolling System (CMIPS). \*indicates statistically significant differences between family and non-family PCA groups.

### ***Characteristics of local market conditions for personal care assistants***

During the time period while PCAs provided services for IHSS recipients, the mean county unemployment rate was 7.8% (range: 4.7%-22.6%). The mean of county average weekly wages was \$957 (range: \$569-\$1,554).

### ***Changes in personal care assistants***

We found that turnover, defined as a change in the reported relationship between the PCA and the recipient, was low in the first year of receiving IHSS, at 13.6%. Among recipients with family member PCAs, 4% switched to another type of family (e.g. from spouse to child) and 5.6% changed to a

non-family PCA. Among recipients with non-family PCAs, 11.4% switched to another non-family type PCA and 9% switched to a family member PCA.

We found that the predicted probability of PCA turnover for recipients with non-family PCAs was more than twice that among recipients with family member PCAs (20.4% of non-family, versus 9.7% of family). PCA payment rates were not associated with the likelihood of turnover.

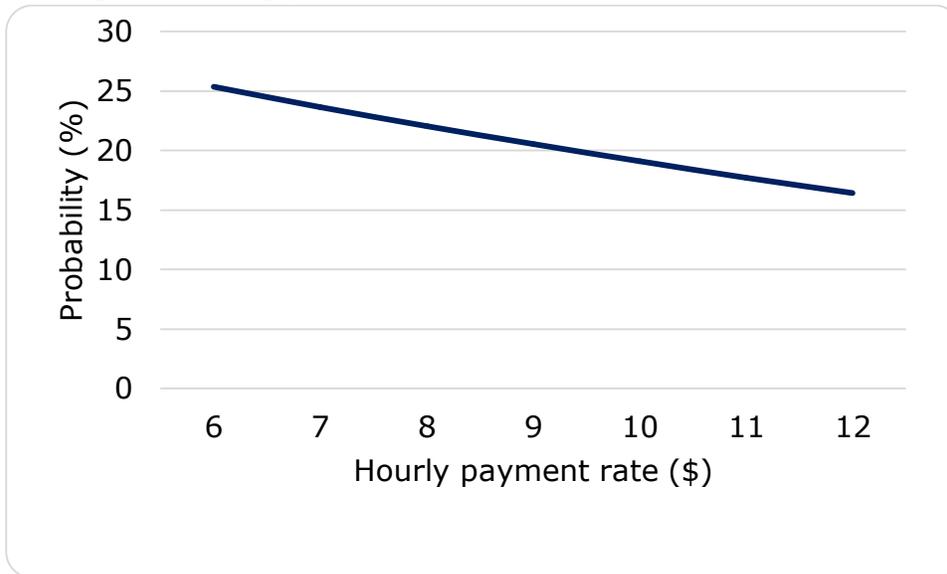
### ***Effect of rates of pay and local market characteristics on PCA turnover***

Analyzing family PCA vs. non-family PCA samples separately for associations with pay rates and local market characteristics revealed stark differences.

Among family member PCAs, a higher payment rate was associated with a higher likelihood of turnover. However, this association was not statistically significant when adjusting for other factors. Local unemployment rates were not associated with turnover probabilities.

Among non-family member PCAs, higher pay was associated with a lower likelihood of turnover, when adjusting for recipient, PCA, and local market characteristics. Figure 2 illustrates the predicted probability of turnover among non-family PCAs across the range of hourly payment rates. The probability of turnover for PCAs at the bottom of the pay scale, \$6 per hour, was 27.4%. Among PCAs at the top of the pay scale, \$12 per hour, the likelihood of turnover was reduced to 15.1%. We found a modest association between county unemployment rate and turnover probability; a 1 percentage-point increase in unemployment rate was associated with a 0.7% decrease in the probability of PCA turnover. A higher number of authorized service hours was also associated with a slightly higher probability of turnover; a 1 percentage-point increase in permitted hours was associated with a 0.03% higher likelihood of turnover.

**Figure 2. Relationship between payment rate and probability of turnover among non-family personal care assistants**

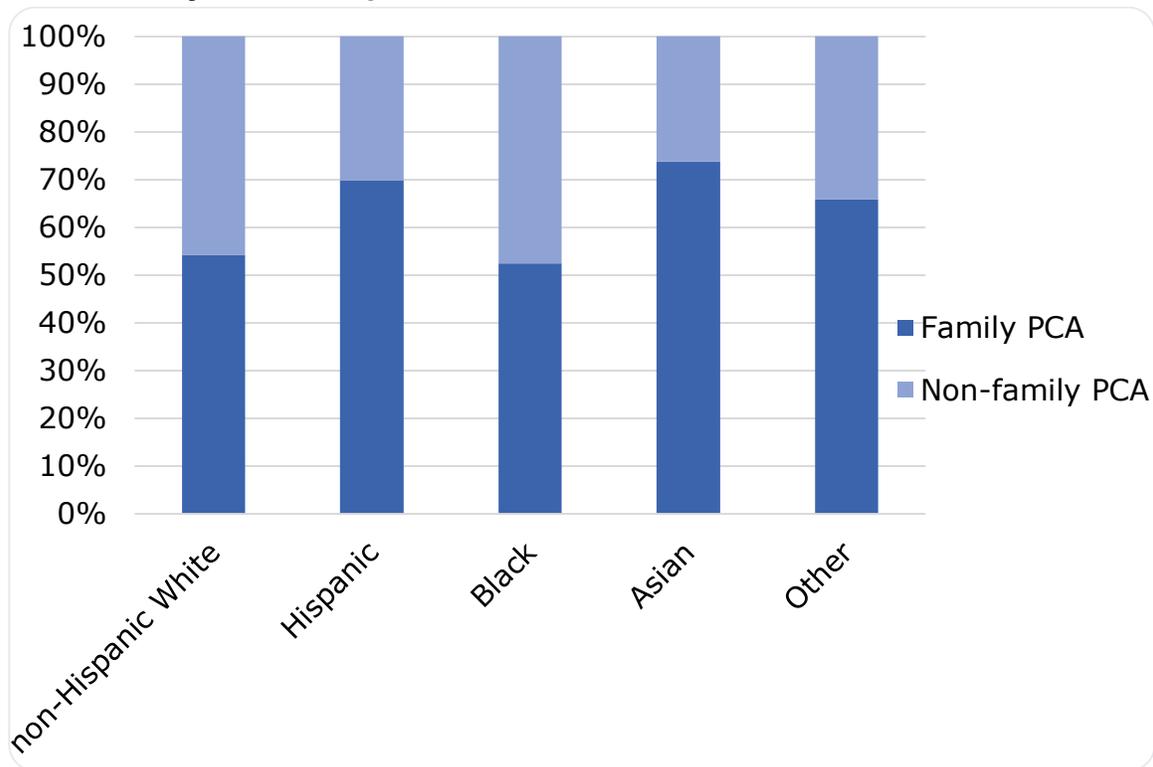


Source: California Medicaid claims, Medicaid enrollment, and Case Management Information and Payrolling System (CMIPS). Probability of turnover adjusted for recipient, PCA, and local market factors.

### ***Differences across racial and ethnic groups***

We also examined patterns of family and non-family care and PCA turnover, for different racial and ethnic subgroups (Figure 3). Higher proportions of Hispanic, Asian, and those of Other race/ethnicity had family member PCAs, relative to non-Hispanic Whites and Blacks.

**Figure 3. Family member and non-family personal care assistants, by race and ethnicity of the recipient**

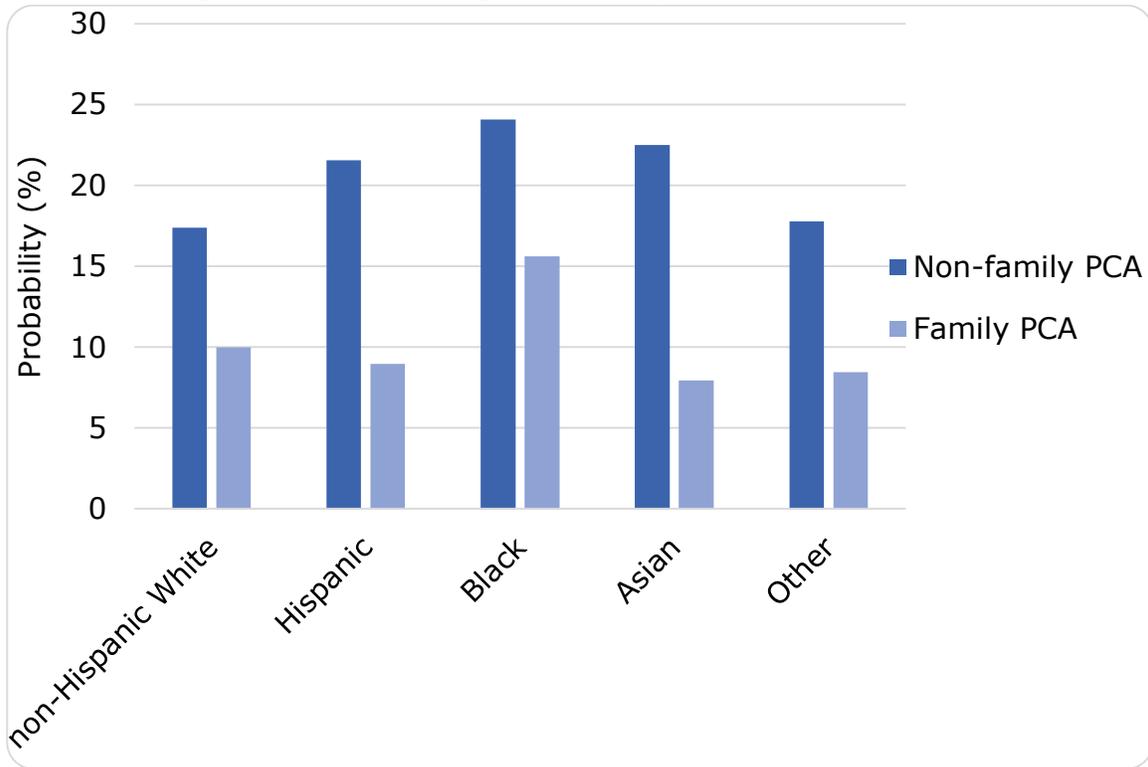


Source: California Medicaid claims, Medicaid enrollment, and Case Management Information and Payrolling System (CMIPS).

We calculated adjusted probabilities of turnover across different racial and ethnic groups, by family and non-family PCAs (Figure 4). Among those with family member PCAs, Black recipients experienced a higher adjusted probability of PCA turnover, relative to non-Hispanic Whites (15.6% vs. 10.0%). Hispanic and Asian recipients experienced lower PCA turnover, but these differences were not significantly different from non-Hispanic Whites.

Among those with non-family PCAs, all minority groups experienced higher probabilities of turnover relative to non-Hispanic Whites (17.4%). Differences were significant for all groups except those of Other race/ethnicity. The highest likelihood of turnover also occurred among Black recipients (24.1%), although rates for Asians (22.5%) and Hispanics were similar (21.6%).

**Figure 4. Probability of turnover in family and non-family personal care assistants, by race and ethnicity of the recipient**



Source: California Medicaid claims, Medicaid enrollment, and Case Management Information and Payrolling System (CMIPS).

### Conclusions

Among first-time recipients of California’s Medicaid In-Home Supportive Services program, turnover among personal care assistants was fairly low in the first year of service. Our observed rates of turnover are lower than for the overall long-term care workforce.<sup>5</sup> Family members comprise a substantial proportion of the Medicaid PCA workforce, which exerts a large influence on overall rates of turnover. Among non-family PCAs, our observed rates were comparable to those reported in national surveys.<sup>5</sup> Few factors, including PCA payment rates and local market conditions, were associated with turnover among family member PCAs. Our findings support prior work that has found an array of factors motivate family members to provide paid personal care assistance, including a deep sense of social obligation,

conformance to gender norms, religious belief, and even a perception of caregiving as a greater public service.<sup>15</sup>

Of concern, hourly PCA payment rates were low, even accounting for the earlier years of the study period. Higher payment rates were associated with lower turnover of non-family PCAs. We also found that a higher local unemployment rate was associated with a lower likelihood of non-family PCA turnover, suggesting that when fewer job alternatives are available, work in personal care assistance may be more attractive.

Racial and ethnic minorities, particularly Hispanics and Asians, were more likely to receive care from family members. This is consistent with prior studies on both paid and informal personal care assistance.<sup>16</sup> However, minorities with non-family PCAs experienced higher turnover of their PCAs relative to non-Hispanic Whites utilizing non-family PCAs. This finding is particularly concerning, as Black individuals in need of personal care assistance face known barriers to access for home and community-based services,<sup>17</sup> potentially related to racial discrimination and the reluctance of PCAs to work in poor neighborhood environments.<sup>18,19</sup>

### **Limitations**

Because we did not have access to unique identifiers for personal care assistants, our measurement of turnover was limited to changes across relationship categories. Our count of turnover is likely an underestimate of actual turnover. We were unable to measure changes within "Other relatives," such as switching from a cousin to an aunt, or within "Other" non-family.

Second, our data are limited to those who initiated personal care assistance services in 2006 or 2007, in a single state, and thus may not reflect more contemporary trends in caregiving and other state Medicaid programs. However, California's population of recipients is racially and ethnically diverse, and local economic conditions vary widely across the state. Thus, these data provide insights into states with newer programs and increasingly diverse aging populations.

Third, our data are restricted to services covered by Medicaid. We were unable to measure the extent of unreimbursed services received. Given that

our recipients are eligible for Medicaid, we expect that relatively few have the resources to pay for extensive out-of-pocket personal care assistance. Recipients may receive adjunct support and care from volunteers, such as additional family members, neighbors, and friends, which is not measured in these data. A prior survey of IHSS PCAs found that family member PCAs were more likely to provide additional unpaid assistance beyond the authorized service hours.<sup>4</sup>

Fourth, we limited our study to those who stayed in IHSS for at least 9 months or re-instated within the same year. We did not examine those who left the program within 9 months. It is possible that those who experienced higher rates of PCA turnover were more likely to leave the program and enter nursing facilities. Our conclusions are therefore limited to those expected to remain in home and community settings for the long term.

### **Implications and Recommendations**

The findings from this report suggest that as state Medicaid programs expand consumer direction in personal care assistance, a high proportion of the PCA workforce will consist of recipients' family members. Examining the effects of payment rates in aggregate, without accounting for family member participation, would lead to the erroneous conclusion that payment rates do not impact turnover among PCAs. Instead, raising payment rates for PCAs may be an important key to improving stability in the non-family PCA workforce. Because fewer than 1% of all PCAs were home health agency providers or other business employees, our findings suggest that the non-family PCA workforce was likely not "professional." Thus we expect payment rates to remain salient as other options (e.g., employment in nursing homes) and benefits (insurance, job advancement) are less likely to be available to this group. Over half of California Medicaid personal care assistants have poverty or near-poverty incomes.<sup>20</sup> States that aim to shift Medicaid long-term care services to home and community settings should consider the impact of PCA payment rates on access and quality.

### **Future Directions**

Our findings also suggest that minorities with non-family member PCAs may have more trouble keeping the same PCA. This merits additional investigation, because even after accounting for family caregiving, demand

for long-term care is still expected to rise in parallel with the diversity of the aging population.<sup>13</sup>

Furthermore, providing personal care assistance is associated with a number of negative health and personal consequences for family caregivers. Among California IHSS PCAs, working for 2 or more years is associated with higher rates of injury.<sup>21</sup> Additional research is needed on long-term trends beyond the first year of care, and the extent to which non-family personal care assistants can supplement family caregiving.

## **Acronyms Used in this Report**

ADLs: Activities of Daily Living

HCBS: Home and Community-Based Services

IADLs: Instrumental Activities of Daily Living

IHSS: In-Home Supportive Services, the California Medicaid personal care assistance program

PCA: Personal Care Assistant

## **Terminology Used in this Report**

**Activities of Daily Living (ADLs):** The basic personal tasks of everyday life including getting in and out of bed, dressing, bathing, eating, and using the bathroom

**Consumer direction (participant direction):** Consumer direction is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services they received. Consumer direction may exist in differing degrees and may span many types of services. It ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. The unifying force in the range of consumer-directed and consumer choice models is that individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services (National Institute of Consumer-Directed Long-Term Care Services 1996).

**Home and community-based services (HCBS):** Services and other supports to help people with disabilities of all ages to live in the community. Each state has a mix of programs and funding sources. The Medicaid program pays for many of these services in all states. There are also other federal, state and local dollars that fund home and community-based services,

including the Social Services Block Grant (SSBG), Older 44 Americans Act (OAA), Education and Rehabilitation funds and state general funds. Various types of services may be provided in the home or in the community to enable individuals to remain in their own home. Assistance is generally provided with Activities of Daily Living and Instrumental Activities of Daily Living.

**Instrumental Activities of Daily Living (IADLs):** Everyday tasks including housekeeping, cooking, shopping, laundry, medication management, money management, and communication.

**Medicaid Home and Community-Based Services State Plan:** The HCBS programs offer different choices to some people with Medicaid. If you qualify, you will get care in your home and community so you can stay independent and close to your family and friends. A State Plan is a contract between a state and the federal government describing how that state administers its Medicaid program. It gives an assurance that a state abides by federal rules and may claim federal matching funds for its Medicaid program activities. The State Plan sets out groups of individuals to be covered, services to be provided, methodologies for providers to be reimbursed and the administrative requirements that states must meet to participate. Optional benefits for personal care services can be included under the Medicaid State Plan. An HCBS State Plan must meet the following broad federal criteria: (1) Comparability, such that all eligible beneficiaries receive a set of services that is equal in amount, duration and scope; (2) Statewideness, such that benefits must be the same statewide; and (3) Freedom of choice, such that beneficiaries may choose among providers and managed care plans.

**Medicaid Home and Community-Based Waiver Programs (HCBS):** Medicaid HCBS waiver programs relax the restrictions of the State Plans. These programs can be targeted for specific populations, such as the mentally retarded and developmentally disabled, or for specific communities within the state, and are not required to offer a choice of providers. These waivers include: 1915(c), 1915(i), 1929(b), 1115 demonstration waiver.

**Medicaid Eligibility Categories:** These categories were combined from the California Department of Health Care Services. Definitions of Medi-Cal (the name for Medicaid in the state of California) aid codes may be found in the Aid Codes Master Chart in the Medi-Cal Provider's Manual at:

[http://files.medi-cal.ca.gov/pubsdoco/publications/masters-mtp/part1/aidcodes\\_z01c00.doc](http://files.medi-cal.ca.gov/pubsdoco/publications/masters-mtp/part1/aidcodes_z01c00.doc).

Family with Dependent Children: Includes those who are eligible by income and caring for dependent children.

Medically Needy: Includes those with "spend-down" eligibility, based upon income after paying for healthcare expenses.

Aged: Includes those over age 65 and those who meet Supplemental Security Income/State Supplemental Payment (SSI/SSP) financial limits.

Disabled: Includes those who meet the SSI/SSP program financial limits and criteria of Disabled or Blind.

Other: Includes the remainder of eligibility categories that include LTSS benefits for adults.

**Personal care assistants:** These direct-care workers assist the elderly, convalescents, or persons with disabilities with daily living activities at the person's home or in a care facility. Their duties are performed most often at place of residence and may include keeping house (making beds, doing laundry, washing dishes) and preparing meals. PCAs may advise families, the elderly, convalescents, and persons with disabilities regarding such things as nutrition, cleanliness, and household activities.

## References

1. Ng T, Harrington C, Musumeci M, Reaves EL. *Medicaid Home and Community-Based Services Programs: 2011 Data Update*. Kaiser Family Foundation;2014.
2. Benjamin AE, Matthias RE. Age, consumer direction, and outcomes of supportive services at home. *The Gerontologist*. 2001;41(5):632-642.
3. Newcomer RJ, Kang T, Faucett J. Consumer-directed personal care: Comparing aged and non-aged adult recipient health-related outcomes among those with paid family versus non-relative providers. *Home Health Care Services Quarterly*. 2011;30:178-197.
4. Newcomer RJ, Kang T, Doty P. Allowing spouses to be paid personal care providers: Spouse availability and effects on Medicaid-funded service use and expenditures. *The Gerontologist*. 2012;52(4):517-530.
5. Frogner B, Spetz J. *Entry and exit of workers in long-term care*. San Francisco, CA: UCSF Health Workforce Research Center on Long-Term Care;2015.
6. Seavey D, Marquand A. *Caring in America: A Comprehensive Analysis of the Fastest-Growing Jobs: Home Health and Personal Care Aides*. Bronx, NY: PHI International;2011.
7. Benjamin AE, Matthias RE. Work-life differences and outcomes for agency and consumer-directed home-care workers. *The Gerontologist*. 2004;44:479-488.
8. Penning MJ, Wu Z. Caregiver stress and mental health: Impact of caregiving relationship and gender. *The Gerontologist*. 2015.
9. Lilly MB, Laporte A, P.C. C. Labor market work and home care's unpaid caregivers:A systematic review of labor force participation rates, predictors of labor market withdrawal, and hours of work. *The Milbank Quarterly*. 2007;85(4):641-690.
10. Liu Y, Kim K, Zarit SH. Health trajectories of family caregivers: Associations with care transitions and adult day service use. *Journal of Aging and Health*. 2015;27(4):686-710.
11. Bostick JE, Rantz Mj Fau - Flesner MK, Flesner Mk Fau - Riggs CJ, Riggs CJ. Systematic review of studies of staffing and quality in nursing homes. (1525-8610 (Print)).
12. Castle NG, Anderson R. Caregiver staffing in nursing homes and their influence on quality of care: Using dynamic panel estimation methods. *Medical care*. 2011;49(6):545-552.
13. Spetz J, Trupin L, Bates T, Coffman JM. Future demand for long-term care workers will be influenced by demographic and utilization changes. *Health affairs (Project Hope)*. 2014;34(6):936-945.

14. Kronick R, Gilmer T, Dreyfus T, Lee L. Improving health-based payment for Medicaid beneficiaries: CDPS. *Health care financing review*. 2000;21(3):29-64.
15. Stacey CL, Ayers LL. Caught between love and money: The experiences of paid family caregivers. *Qualitative Sociology*. 2012;35:47-64.
16. Bradley E, Curry LA, McGraw SA, Webster TR, Kasl SV, Andersen R. Intended use of informal long-term care: the role of race and ethnicity. *Ethnicity and Health*. 2004;9(1):37-54.
17. Casado BL, van Vulpen KS, Davis SL. Unmet needs for Home and Community-Based Services among frail older Americans and their caregivers. *Journal of Aging and Health*. 2011;23(3):529-553.
18. Ferris RE, Glicksman A, Kleban MH. Environmental predictors of unmet Home-and Community-Based service needs of older adults. *Journal of Applied Gerontology*. 2014.
19. Hernandez M, Newcomer RJ. Assisted living and special populations: What do we know about differences in use and potential access barriers? *The Gerontologist*. 2007;47(SIII):110-117.
20. Hoffman G, Wallace S. *Hidden in plain sight: California's paid Medi-Cal caregivers are vulnerable*. Los Angeles, CA: UCLA Center for Health Policy Research;2012.
21. Faucett J, Kang T, Newcomer RJ. Personal service assistance: Musculoskeletal disorders and injuries in consumer-directed home care. *American Journal of Industrial Medicine*. 2013;56(4):454-468.