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In-home supportive services for individuals with cerebral palsy in California

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Abstract

Introduction—Individuals with cerebral palsy (CP) may require personal assistance services for optimal functioning. The primary goal of this project is to determine if differences in health services exist between individuals with CP with family versus non-family member paid personal assistance providers. The secondary goal is to describe the population of children and non-elderly adults with CP receiving In-Home Supportive Services (IHSS) and determine their health care costs compared to other IHSS recipients.

Methods—Administrative data from the California Departments of Health and Human Services, Social Services and Developmental Services were linked and de-identified to provide information about individuals receiving IHSS in California in 2005. Recipients with CP were characterized and compared by age. Then to determine the factors associated with hospital use and emergency room (ER) use for IHSS recipients with CP adjusted odds were calculated. Monthly expenditures were calculated from claims data.

Results—2.3% of all IHSS recipients in 2005 had CP of which 46% were children. 59% of recipients with CP have a parent as their paid provider. The presence of other medical diagnoses was the only factor associated with increased adjusted odds of hospital and ER use for both child-aged and non-elderly adult recipients with CP. Functional limitations and provider type were not associated with increased odds of health care utilization. Monthly health care expenditures for recipients with CP were ~\$1000 higher than for other IHSS recipients.

Conclusions—Having a parent as the IHSS provider was not associated with difference in health service utilization. This finding supports the policy of allowing parents to be paid providers.

Keywords

Cerebral palsy; personal assistance services; Medicaid; health care utilization; expenditures

1. Introduction

Cerebral palsy (CP) is an umbrella term for a group of non-progressive disorders occurring in early development that affect movement and posture, and result in activity limitations

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Conflict of interest

The authors report no conflicts of interest.

[31]. Individuals with cerebral palsy often experience additional disturbances in sensation, cognition, communication and/or behavior [4, 6]. While the incidence of CP is relatively stable [25], with reports from various studies ranging between 1.5–2.5 per 1000 live births [26], the estimated prevalence is on the rise with a prevalence of 3.6 cases per 1000 in school-aged children, making it one of the most common disabling condition in childhood [40], and accounting for 67% of severe motor disabilities in children [9]. Overall, there has been a trend toward increased life expectancy [36].

Individuals with cerebral palsy have increased health care utilization rates and often have extensive community service needs especially when they are more severely affected [20,21]. Cerebral palsy has been reported as the third leading cause for the need for assistance with basic life activities for adults in the United States [10], and although there is a shift towards serving the growing aged population, CP continues to be a major cause of activity limitations and the need for personal assistance services [5]. Most children live at home with their parents/caregivers and receive community based supports. Adults with CP commonly live independently with or without in home assistance, but are nonetheless more likely than other individuals with disabilities to live in specialized residential settings or institutions [3,22].

There is an expressed goal to promote accommodations for living in the least restrictive environment aided by the 1999 *Olmstead* Decision which dictated expansions of home and community based services (HCBS) [38]. Medicaid supported HCBS have been important sources of funded personal assistance services across the country [17,19]. Because of the increased survivability of those most severely affected by CP [36] and extensive personal health and social impacts of CP [22,30,32,35], public programs are likely to shoulder increasing costs related to paid personal assistance services for individuals with CP.

For individuals with CP (especially children), families have routinely provided informal or unpaid caregiving and personal assistance services [23,30,41]. In past decades, paying a family member for personal assistant services was discouraged or expressly prohibited [2]. In 2004, Centers for Medicare and Medicaid Services (CMS) officials determined it was within their authority to authorize states' requests to pay legally responsible family members in the Medicaid HCBS waiver programs. The Medicaid financing and service delivery mechanisms for HCBS (enacted in the 2005 Deficit Reduction Act and the 2010 Affordable Care Act) explicitly authorize payments to family caregivers. This includes legally responsible relatives (authorized under the section 1915 (j) "cash and counseling" service delivery option and the section 1915 (k) Community First Choice attendant care benefit).

In California, Medicaid's In-Home Supportive Services (IHSS) Program provides paid personal assistance services for individuals with disabilities. This program allows parents, other relatives and non-relatives to be paid as personal assistance providers. Adult IHSS recipients have been allowed to employ their family members as IHSS workers throughout the program's history. But payments to parents of minor children were covered only by state and county funding until 2004 when, with implementation of the IHSS Plus waiver, Medicaid began to share [8]. Whether to authorize payments to family caregivers is now almost entirely up to state policymakers and introduces the question of the relationship between having family members as paid caregivers and health services utilization. Nationally, there has been a shift toward allowing family members to be paid as caregivers [7] to address national provider shortages and to improve consumer satisfaction [12]. But there are limited data regarding how health care costs differ between individuals who employ family members versus non-family members as paid providers [15], and no CP specific data are available.

To address the question of whether or not having a family member as a paid provider is associated with increased hospitalizations or emergency room (ER) use, we evaluated the IHSS data from 2005 for the 3,193 individuals with CP in California under the age of 65 [24]. First, we sought to delineate the demographic, health and provider characteristics of children and non-elderly adults with CP. Then we sought to determine how the odds of all cause hospitalization and ER use vary based on those characteristics. We also sought to compare monthly expenditures for children and adults with CP to the general population of IHSS recipients to determine if having the diagnosis of CP was associated with increased costs.

2. Methods

2.1. Data sources

This project used administrative data from the California Department of Health Care Services, the Department of Social Services, and the Department of Developmental Services. These data were linked using a combination of each data set's identification number, Medicaid eligibility number and a unique assigned identifier for the project. To protect the confidentiality of the recipients' records, only the project's unique identification number was used and all other personal information was removed to de-identify all recipients. The methods to protect confidentiality of the recipients were approved by the Committee on Human Research at the University of California, San Francisco (H945-28245). A detailed description of how the data sources were utilized is available in the Analysis of the California In-Home Supportive Services Plus Waiver Demonstration Program report [24].

2.2. Sample characteristics

The study sample from this project included individuals 3–64 years of age with CP who were IHSS recipients in 2005. Because medical diagnosis data was required for these analyses, only those individuals who participated in Medicaid through fee-for-service were included because Medicaid claims were not submitted for managed care covered services. Thus, this sample represents a subset of all IHSS recipients in 2005 screened for inclusion in the 'Analysis of the California In-Home Supportive Services Plus Waiver Demonstration Program' [24]. Recipients were identified as having CP through the Medicaid claims data which utilized the International Classification of Diseases (ICD-9) on individual claims [11]. Child-aged recipients (3–17 years) were classified separately from non-elderly adults (18–64 years) to identify possible differences between children and adult recipients with CP. The race/ethnicity categories of White, Hispanic, African-American and Asian/Other were used. The IHSS provider relationship type was recorded as parent, spouse, other family member or non-relative. To quantify functional severity, we reported on the recipients' limitations with activities of daily living (ADLs) which included eating, grooming and bathing, dressing, toileting, and transferring. Limitations with ADLs were considered to be present if the recipient needed for assistance from another person to complete the age-appropriate task. The cognitive limitations identified in this analysis were orientation, judgment and memory based whether the individual had difficulties and needed assistance from another person with cognitive tasks. The counts provided in the analysis are based on the number of limitations identified for the recipient in the case files. We also reported on the need for assistance with respiration/ventilation which was recorded as needed or not. Health conditions were identified using ICD-9 codes and the CMS hierarchical condition categories [28]. Additional information about the condition codes is available from the 'Analysis of the California In-Home Supportive Services Plus Waiver Demonstration Program' report [24].

2.3. Health care outcomes

Our outcomes of interest were hospital and emergency room (ER) use as well as the average monthly expenditures for Medicaid claims. Expenditures were adjusted by the number of IHSS eligibility days in the study year and included expenditures from home health care, personal assistance services, hospital based care, nursing, physician and other health care provider services, physical therapy (PT), occupational therapy (OT), speech therapy (ST), durable medical equipment (DME), vision, hearing and mental health service. Notably, pharmacy-related data was not available and therefore not part of the expenditures calculations.

2.4. Analysis

To describe the population of individuals with CP receiving IHSS, we calculated percent distributions. Logistic regression was utilized to evaluate the association between hospital and ER use and demographic, health and provider characteristics. Each unique individual was included only once in the logistic regression. Hospital and ER use were modeled separately using the same predictors which were chosen based on the Aday and Andersen Behavioral Health Model [1]. The models included demographic, health and provider characteristics for adjustment. Missing data was case deleted. All results are reported as adjusted odds ratios. If the 95% confidence interval did not include 1, the adjusted odds ratio was considered significant. Mean monthly expenditures were calculated from all claims data excluding pharmacy services.

3. Results

3.1. Demographic and health characteristics

There were 137,085 IHSS recipients under the age of 65 in 2005, of which 8.4% were under the age of 18. Of these 137,085 IHSS recipients, 2.3% had CP, of which 46% were under the age of 18 (See Fig. 1 for age distributions). Table 1 details the demographic and health characteristics of recipients with CP. Among adults, the men and women were essentially equally represented among IHSS recipients, but boys made up a majority of recipients in the pediatric age group (58%). Similarly, the ethnicity of the recipients with CP differs by age. Hispanics made up 56% of IHSS recipients with CP aged 3–17 years but only 32% of adults. White Non-Hispanics with CP made up 25% of child recipients and 43% of the adult recipients. Approximately one-quarter of child and adult recipients with CP had cognitive limitations. When cognitive limitations were present, a majority of recipients with CP (75%) had limitations in all three domains (orientation, memory and judgment). The number of ADLs where assistance was needed, differed by age; 70% of child recipients needed assistance in all 5 ADLs compared to only half of the adults with CP. Four times as many adult recipients with CP required help with two or fewer ADLs compared to child recipients with CP, (17.5% versus 4.3%, respectively). Similarly, 22% of child recipients with CP needed assistance with ventilation/respiration compared to only 11% of adult recipients with CP. As one would expect, parents were more frequently providing the IHSS care for child recipients with CP compared to adults (76% versus 44%, respectively). Non-relatives providers were over three times more common for adults than children with CP.

3.2. Adjusted odds of health care utilization

The adjusted odds ratios of health care utilization (hospital and ER use) for recipients with CP aged 3–17 and 18–64 years are presented in Table 2. Hispanic children with CP had lower odds of hospitalizations compared with Whites, AOR = 0.67. Asian/Other adults with CP also had lower odds of hospitalization, AOR = 0.52. Children with CP with breathing limitations had increased adjusted odds of hospital use, AOR = 1.58. For both children and adults, the adjusted odds ratios of hospital use were increased when other health conditions

were present, AOR = 1.58 and 1.49, respectively. Gender, the presence of activity limitations, the presence of cognitive limitations and provider type were not associated with increased adjusted odds of hospital use. Similar to hospital use, Asian/Other adults with CP had lower odds of ER use compared to Whites, AOR = 0.48. Also similar to hospital use, the adjusted odds of ER use were higher for children and adults with other health conditions, AOR = 1.86 and 1.76, respectively. Children with breathing limitations had over twice the adjusted odds (AOR = 2.17) of ER use than children without breathing limitations. For adults, the adjusted odds of ER use were lower for those with at least one cognitive limitation (AOR = 0.68), but higher for adults with difficulties with 3 or more ADLs (AOR = 1.53). Gender and the type of IHSS provider were not associated with ER use in the adjusted analysis.

3.3. Health care expenditures

Graphical representation of the mean monthly Medicaid expenditures for children and adults with CP compared to the general population of IHSS recipients is displayed in Fig. 2. The mean monthly Medicaid expenditures for child and adult recipients with CP were \$2,573 (SD = 4,453) and \$2,533 (SD = 5,160), respectively. Monthly expenditures were approximately \$1000 higher for individuals with CP than the general population of IHSS recipients. No substantial differences were noted when comparing the expenditures of children versus adult IHSS recipients.

4. Discussion

This study highlights characteristics of the special population of individuals with cerebral palsy receiving In-Home Supportive Services in California. Recipients with CP make up a small proportion of all IHSS recipients currently. But this proportion is likely to change because nearly half of the IHSS recipients with CP are currently children. It is well documented that children with CP are aging into adulthood in greater numbers with increasingly complex needs [13,33,36,37]. If child-aged recipients with CP continue to need IHSS as they transition to adulthood, the proportion of IHSS recipients with CP will likely increase. This could strain an already constrained system of support.

The racial distribution of IHSS recipients with CP differed by age. There was a high percentage of Hispanic children with CP receiving IHSS compared to adults. Over half of the child IHSS recipients with CP in this study were Hispanic, which corresponds well to the overall racial distribution of children in California (The Child and Adolescent Health Measurement Initiative). The reasons why Hispanics were potentially under-represented and whites over-represented among adult IHSS recipients with CP cannot be determined from this analysis. Some possible explanations include the changing demographic of Californians, especially among children, differences in access to the program between Hispanics and whites in the adult population, and residential care placement choices by families. Further investigation and analysis would be required before drawing conclusions regarding the etiology of these racial differences.

Child and adult recipients with CP also differed by condition severity. While the number of cognitive limitations did not differ between children and adults, children with CP had more activity limitations and respiratory impairments than adults. A substantial majority of children needed assistance in 5 activities of daily living compared to just over half of adults. This may be in part due to a maturation effect in which children gain more independence as they develop or may indicate improved survivability of those most severely affected. The finding that twice as many children needed assistance with respiration than adults indicates that these children are more severely affected than their adult counterparts in the program. These findings highlight an area of potential concern for service providers and payers

because we can anticipate increased service need as children with CP who are severely impaired age into adulthood.

One of the main goals of this project was to determine which factors were associated with health services utilization. An important finding was that provider type did not impact hospital or ER use, which likely indicates that family members are providing equivalent quality supportive care compared to non-relative providers. This argues for allowing and potentially encouraging family members to be paid providers. This finding may be of particular interest to policy makers because family members frequently provide informal care and are, in increasing numbers, providing paid personal assistance services [14,18]. Thus state Medicaid administrators are interested in having the flexibility within their personal assistance care plans to authorize payment to family members to provide care for Medicaid recipients [24].

As one would expect, recipients with CP who had additional medical diagnoses were at increased risk for using hospital and ER based care. According to the Aday and Andersen framework for medical care access, need characteristics of individuals are associated with use of health services and health care expenditures [1]. This held true for both adults and children with CP –those with additional health conditions had more hospital and ER use. Based on the behavioral health model, one may expect that individuals with more limitations would also have more health care utilization. Interestingly, our findings were mixed. In this study, we found that children with CP, but not adults, with breathing limitations had increased odds of service use. Also, difficulty with three or more ADLs was associated with increased ER use for adults only. These findings indicate that limitations are not necessarily indicative of medical severity requiring emergency services.

The finding that both children and adults with CP had markedly higher monthly health care expenditures compared to other IHSS recipients is not unexpected given the health care utilization rates of recipients with CP. Of note, expenditures for children and adults with CP were similar despite the finding that child-aged recipients were more severely affected than non-elderly adults in this sample. This finding warrants additional research to determine how health care utilization and expenditures change as recipients with CP age into adulthood. This is particularly important as life-expectancy improves and transition services are being designed to maximize the health and function of children with CP as they become adults [34,36].

4.1. Limitations

This study has notable limitations. First, only Medicaid fee-for-service administrative data was used and therefore, recipients in Medicaid managed care plans were not included in the study. This could have led to systematic bias in our analysis if the population of recipients differed by Medicaid payment plan. Second, the diagnosis of CP was made based on ICD-9 codes. This introduces the possibility of misidentifying individuals; a concern that has been reported in the cerebral palsy literature [16,27,42]. Thus some individuals with CP might not have been included in the sample and some individuals with other diagnoses with similar clinical characteristics to CP may be in the sample. Based on a recent registry study that found a 5.2% misclassification rate occurring mostly in young children [42], we believe that the potential for misclassification in our sample was low and would not impact our analyses. Third, we separated child recipients from adult recipient based on the age of adulthood. This cutoff could be seen as arbitrary as we would anticipate that young adults with CP would be more similar to children with CP than older adults. This highlights the need to study the population of transitioning young adults specifically. Fourth, this study evaluated only a portion of all individuals with cerebral palsy in California. Because the individuals with CP who are receiving IHSS services are likely to be more severely affected than individuals

with CP in the general population, no generalizing conclusions can be drawn. And fifth, this study is limited by the complex nature of administrative data. For example, we were unable to capture pharmacy data which may markedly impact health care expenditures. We were also unable to determine which ER visits and hospitalizations were directly related to the diagnosis of CP. Additionally, we could not account for the specifics of each individual's functioning and how that related to their care needs, or hospital or ER use.

5. Conclusions

Cerebral palsy has multi-dimensional impacts on individuals, families, communities and health systems. The findings detailed above highlight the high costs and health service use for this population and also support the use of paid family members as personal assistance services providers because no differences in hospitalization, ER visits, or health service utilization costs were associated with family member IHSS providers compared to non-family member IHSS providers. With goals of community inclusion and maximizing health in function for individuals with CP, it is important to consider care delivery models that meet the needs of the population. In the face of a national shortage in personal assistance services workers and the trends within the population of individuals with CP, adopting flexible policies to promote care within the home environment will likely become increasingly important for people with cerebral palsy.

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Abbreviations

IHSS	In-Home Supportive Services
CP	cerebral palsy
HCBS	home and community based services
AOR	adjusted odds ratio
ADLs	activities of daily living
ER	emergency room
SD	standard deviation

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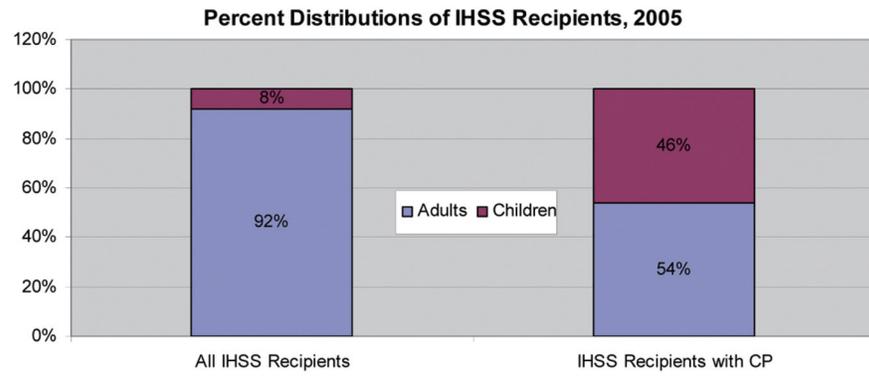


Fig. 1. Age categorization (child versus adult status) of all non-elderly 2005 IHSS recipients (N = 386,447) categorized by the diagnosis of CP (N = 3190).

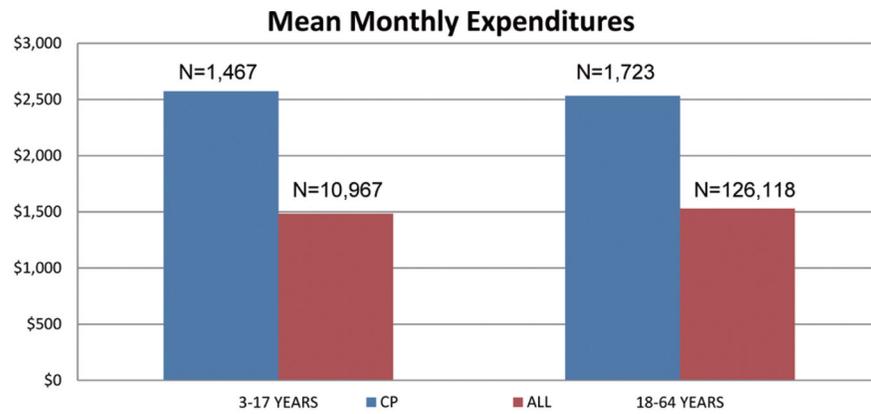


Fig. 2. Average Medicaid Expenditures per Month for IHSS Recipients (N = 137,085) by Age and CP Status (N = 3190). Expenditures include home health, personal assistance services, hospital care, nursing, physician and other health care provider services, PT/OT/ST, DME, vision, hearing, and mental health services (excludes pharmacy services).

Table 1

Characteristics of individuals with CP who received IHSS in 2005 (Percent distributions)

	Recipients with CP		CP 3-17 yrs		CP 18-64 yrs	
	N = 3190	%	N = 1467	%	N = 1723	%
Gender						
Male	1734	54.4%	851	58.0%	883	51.2%
Female	1456	45.6%	616	42.0%	840	48.8%
Ethnicity						
White	1111	34.8%	370	25.2%	741	43.0%
Hispanic	1370	43.0%	815	55.6%	555	32.2%
Black	453	14.2%	186	12.7%	267	15.5%
Other	256	8.0%	96	6.5%	160	9.3%
IHSS Provider						
Spouse	38	1.2%	0	0%	38	2.2%
Parent	1876	58.8%	1121	76.4%	755	43.8%
Other relative	440	13.8%	177	12.1%	263	15.3%
Non relative	836	26.2%	169	11.5%	667	38.7%
Number of Cognitive Limitations*						
0	2491	78.1%	1129	77.0%	1362	79.1%
1	107	3.4%	55	3.7%	52	3.0%
2	68	2.0%	30	2.1%	38	2.2%
3	524	16.4%	253	17.2%	271	15.7%
Number of ADLs** requiring assistance						
0	85	2.7%	6	0.4%	79	4.6%
1	98	3.1%	17	1.2%	81	4.7%
2	179	5.6%	38	2.7%	141	8.2%
3	250	7.8%	106	7.2%	144	8.4%
4	689	21.6%	285	19.4%	404	23.4%
5	1889	59.2%	1015	69.2%	874	50.7%
Needs assistance for respiration***						
NO	2683	84.1%	1144	78.0%	1539	89.3%

	<u>Recipients with CP</u>		<u>CP 3–17 yrs</u>		<u>CP 18–64 yrs</u>	
	N = 3190	%	N = 1467	%	N = 1723	%
YES	507	15.9%	323	22.0%	184	10.7%

Source: Derived from California Department of Health Care Services, Medicaid claims.

* Requires human assistance with memory, orientation and/or judgment.

** ADLs = Activities of Daily Living (eating, bathing and grooming, dressing, toileting, and transferring).

*** Considered limited if required human or paramedical services are required.

Table 2

Adjusted odds ratios of hospital use and emergency department use in 2005 for individuals with CP by age (N = 3190)

	Hospital use		Emergency room use	
	CP 3–17 yrs AOR (95% CI)	CP 18–64 yrs AOR (95% CI)	CP 3–17 yrs AOR (95% CI)	CP 18–64 yrs AOR (95% CI)
Gender				
Male	REF	REF	REF	REF
Female	0.83 (0.63–1.09)	0.82 (0.63–1.08)	0.72 (0.52–1.01)	0.82 (0.64–1.04)
Race/Ethnicity				
White	REF	REF	REF	REF
Hispanic	<i>0.67 (0.48–0.95)</i>	0.93 (0.67–1.29)	1.30 (0.86–1.95)	0.93 (0.69–1.26)
Black	0.83 (0.52–1.32)	1.28 (0.87–1.89)	1.78 (1.00–3.16)	0.91 (0.63–1.31)
Asian/Other	0.57 (0.31–1.05)	<i>0.52 (0.30–0.92)</i>	0.70 (0.36–1.37)	<i>0.48 (0.30–0.76)</i>
1 Cognitive Limitation *				
No	REF	REF	REF	REF
Yes	1.12 (0.80–1.56)	0.94 (0.64–1.38)	0.95 (0.62–1.45)	<i>0.68 (0.48–0.97)</i>
Difficulty with 3 ADLs **				
No	REF	REF	REF	REF
Yes	1.10 (0.55–2.19)	1.04 (0.67–1.63)	2.01 (0.88–4.61)	<i>1.53 (1.03–2.27)</i>
Breathing Limitations ***				
No	REF	REF	REF	REF
Yes	<i>1.59 (1.16–2.18)</i>	1.39 (0.94–2.06)	<i>2.17 (1.26–3.74)</i>	1.42 (0.89–2.27)
Other Health Conditions ****				
None	REF	REF	REF	REF
Present	<i>1.58 (1.49–1.68)</i>	<i>1.49 (1.42–1.56)</i>	<i>1.86 (1.70–2.03)</i>	<i>1.76 (1.66–1.88)</i>
IHSS Provider				
Non relative	REF	REF	REF	REF
Spouse	n/a	1.96 (0.87–4.41)	n/a	0.92 (0.39–2.20)
Parent	1.12 (0.71–1.76)	0.99 (0.71–1.48)	0.87 (0.53–1.44)	0.96 (0.71–1.30)
Other relative	1.24 (0.70–2.19)	1.01 (0.67–1.53)	0.66 (0.35–1.24)	0.97 (0.66–1.43)

Source: Derived from California Department of Health Care Services, Medicaid claims.

Bolded odds ratios are significant with a 95% confidence interval.

* Requires human assistance with memory, orientation and/or judgment.

** ADLs = Activities of Daily Living (eating, bathing and grooming, dressing, toileting, and transferring).

*** Considered limited if required human or paramedical services are required.

**** Based on ICD-9 classification.