ORIGINAL ARTICLE

Do relative and non-relative personal assistance providers differ regarding their risk of occupational injury and musculoskeletal disorders?

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Abstract

Personal Assistance Services (PAS) employs nearly 900,000 providers of long-term care; many are relatives hired by PAS recipients. Risk of occupational injury and musculoskeletal disorders among PAS providers is a concern and it is unknown if relatives are more vulnerable compared to non-relative providers. This paper explores whether paid relative and non-relative providers differ regarding this vulnerability, using data from a survey of PAS providers (n=855). No differences were found regarding risk of injury or musculoskeletal disorders, which suggests that PAS programs could continue offering options for recipients to hire relatives as providers, with no additional risks placed on relatives.

Key words

Personal assistance services, Relatives, Home health care, Musculoskeletal disorders, Consumer direction

1 Introduction

Personal Assistance Services (PAS) is a primary mode of long-term care, employing nearly 900,000 workers in the United States. These workers provide essential support to people with disabilities living at home. This support includes assistance with activities of daily living (ADLs) (e.g., bathing, transferring, eating) and instrumental activities of daily living (IADLs) (e.g., grocery shopping, meal preparation, housekeeping). About 13 percent of the 10.9 million community residents in the United States receive paid assistance with ADLs and IADLs. Approximately, half of these individuals are nonelderly ^[1].

Publicly-funded PAS programs historically have provided services using workers employed by PAS agencies, but an increasing number of workers are employed through consumer-directed models in which workers are "independent providers" ^[2]. Such workers are hired and supervised directly by the PAS recipients or "consumers" ^[3]. This model gives recipients more control over their supportive services, including the ability, in many states, to hire relatives. Recent policy changes, such as the Community Living Assistance Services and Support Act, are fostering an expansion of consumer-directed care. As of 2009, consumer-direction is an option in 38 states' Medicaid programs ^[4].

Consumer-directed services has been found to be highly satisfactory among PAS recipients, who also prefer having relatives as their paid providers, as permitted by an increasing number of programs ^[5, 6]. However, the use of relatives as paid providers may bring up unintended complications regarding the actual delivery of care, because of the well-documented risk of occupational injury and musculoskeletal disorders (MSDs) among PAS providers ^[7, 8]. Musculoskeletal disorders (MSDs) are defined as "injuries or disorders of the muscles, nerves, tendons, joints, cartilage, and disorders of the nerves, tendons, muscles and supporting structures of the upper and lower limbs, neck, and lower back that are caused, precipitated or exacerbated by sudden exertion or prolonged exposure to physical factors such as repetition, force, vibration, or awkward posture" ^[9].

Briefly, beginning in the 1990s, population-based studies from Scandinavia ^[10-13] have documented PAS-related occupational injury and disability. In the United States, the rate of MSDs among PAS workers exceeded that among construction, mining and manufacturing workers ^[14]. Recently, Kim et al. ^[7] investigated this MSD risk prospectively, using a random sample of over 1600 paid providers. Study results indicated that providers' physical demands providing care are a significant risk factor for MSDs. This risk is of concern to both providers and recipients, as injuries and MSDs can have adverse consequences for both parties' health and can disrupt service delivery.

The literature to date, and the expansion of consumer-directed models, suggest questions for further research, as few studies have explored whether paid relative providers are more vulnerable to injuries or MSDs compared to non-relative paid providers. Reasons for this could include, for example, working more hours, conducting more strenuous tasks, or providing care without ergonomic training or modifications to the home ^[8]. One study ^[15] compared agency and consumer-directed workers (including family and non-family providers), and found that relatives paid as providers compared to non-relative providers were more likely to have another job, live with the recipient, work unpaid hours as a PAS provider in addition to their paid hours, have less choice about how to carry out the work, and provide care to recipients with behavioral problems. While this study's results were mixed regarding positive outcomes of satisfaction or stress among relative and non-relative providers, the differences found between paid relative and non-relative providers regarding how the PAS is conducted pose questions whether there might also be differences about how risk of injury or MSD is recognized or addressed (or not). For example, would relative providers be more likely to accede to recipients' insistence to be lifted or transferred in ways that put the provider at greater risk for MSD? On the other hand, are recipients likely to be more tolerant of poor worker performance if the worker is a relative, perhaps putting themselves and the provider at risk for injury? Other questions might concern whether relative or non-relatives differ regarding age, or whether holding another job besides the PAS job, would lead to greater physical strain or fatigue, and increased risk of injury or MSD.

In light of the above questions and within the context of the expansion of consumer-directed services and use of relatives as paid providers, it is timely to explore whether paid relative and non-relative providers differ in terms of their demographics, health, the conditions of their employment and work; and whether any differences affect the risk and occurrence of occupational injury and MSDs. In particular, this paper addresses the following unanswered questions:

- Do relative and non-relative providers differ in terms of demographics or health, including injury or MSD?
- Do relative providers work more hours weekly as PAS providers or experience greater physical strain than non-relative providers?
- Do relative and non-relative providers differ regarding factors that could help prevent injury or MSD an ergonomic home, lift equipment, or safe lift/transfer training?

2 Methods

To investigate these questions, we conducted a statewide telephone survey between April and August 2009 of providers in California's consumer-directed PAS program known as In-Home Supportive Services (IHSS). IHSS serves more than

400,000 PAS recipients per month and employs more than 380,000 PAS providers – including relatives as paid providers. About 90% of IHSS recipients obtain their assistance from independent providers hired under a consumer-directed model.

The research protocol was approved by the state Committee for the Protection of Human Subjects (#06-02-03), University of California, San Francisco Committee for Human Research (#H945-28245), and San Francisco State University's Committee for the Protection of Human Subjects (H8-012R1).

2.1 Sample design

The survey sample frame was compiled from the Case Management Information and Payrolling System (CMIPS). These administrative records are maintained by the California Department of Social Services, the state agency responsible for the IHSS program. CMIPS includes information on IHSS recipient and provider eligibility, demographic information, contact information, and recipient assessments. The assessment data were used to screen recipients for ADL limitations. To be eligible for this survey the IHSS provider had to be working with a recipient who had limitations in two or more ADLs. The potentially eligible provider-recipient dyads were stratified into two recipients age groups: 18-64 and 65 and over. Recipient age stratification was used because of the assumption that younger persons with disabilities may be more directive about the care they receive than are older persons, thus potentially influencing the degree of risk (or risk prevention) of injury or MSD.

Within each age group the recipient and provider dyads were sorted into those having paid relative providers, and those with paid non-relative providers. Recipient-provider dyads involving a spouse or parents as paid provider were excluded from the sample frame. The exclusion of spouses and parents had two primary bases. First, these account for relatively few providers (Non-aged, Parents =15.7%, Spouses =5.3%; Aged 65+ Spouses=2.2%), and the expense of oversampling these cases was not seen as cost effective. Second, we were concerned about possible reporting bias, with parents and spouses possibly being more likely than non-relatives to underreport injuries or MSDs. If more than one eligible provider was associated with a recipient, we selected the provider with the most authorized service hours. Provider participation was limited to those who spoke English, Spanish, Tagalog, Cantonese, or Mandarin.

A stratified probability sample (n=5000) involving the presumptive eligible dyads was drawn. Each age and provider-recipient subgroup was of equal size. Race/ethnicity groups within each strata were selected proportional to their presence in the subgroup, i.e., there was no oversampling on race/ethnicity.

All sample recipients and providers received a letter and information sheet describing the purposes of the survey. An honorarium of \$20 was given to those completing the interviews. Mailing materials and the survey instrument were translated into Spanish, Chinese, and Tagalog. Mailings included both English and translated forms using the provider's and IHSS recipient's preferred language as indicated in the CMIPS records. Interviewers, bilingual in English and one of the eligible languages, were matched to the known language preferences of the sample subject. Provider contact information was obtained from CMIPS at study baseline (March 2009) for the initial sample contact. This information was refreshed in June 2009 to capture address and phone number changes.

An average of 9.5 contact attempts were made to each active telephone number, and two messages were left on answering machines. Potential respondents who indicated willingness to cooperate in the survey or who had completed some portion of the survey were called up to 40 times. Contact was terminated with potential subjects if a hard refusal or a never-call request was received on the "opt out" postcards included in the initial mailing. Once contacted, potential survey participants were screened to confirm eligibility. Those unable to speak English, Spanish, Cantonese, Mandarin, or Tagalog were considered out of scope or ineligible for the survey.

Table 1 shows the sample disposition. Of the original 5000 provider subjects, almost 2100 cases were determined during the screening interview to be ineligible. This was due to corrections of the provider relationships information obtained in

the CMIPS file, or because providers were found to have an out of scope language. This high rate of ineligibility is attributable to the fact that language preferences among providers were missing in about half of the CMIPS records. The screening interviews attempted with these cases were successful in retaining about a third of the cases with missing language preference values. The cooperation rate among those both eligible and able to be located was 49.5%.

Table 1.	Sample	disposition
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	Number	Remaining
Original sample	5000	
Ineligible provider	350	4650
Ineligible recipient	140	4510
Out-of-scope language	1601	2909
Unable to be located	1183	1726
Refused	871	855
Completed	855	0

2.2 Instrument

Instrument development was informed by Faucett's theoretical framework ^[16] that examines the impacts of the work environment on worker health. The survey included demographic and work environment questions and validated measures to assess provider health, and work injuries and musculoskeletal disorders ^[17].

The temporal work environment was assessed with items on hours of work, ability to take breaks, and predictability of work hours. The physical work environment was evaluated by asking providers to report on the physical space, availability of assistive equipment (e.g., lift equipment), number of times per day they engaged in physically difficult activities (e.g., lifted/transferred the recipient, pushed/pulled/lifted/carried items weighing more than 25 pounds, etc.). Provider health was assessed using the general health perception item from the Short-Form 36 Health Survey ("*In general, would you say your health is...*" [options are: Excellent, very good, good, fair, or poor]) ^[18]. The survey determined provider injury and musculoskeletal disorders in the previous 12 months using items drawn from a modified Nordic Musculoskeletal Questionnaire ^[19]. Injury was defined as a health problem that occurred on a specific day or at a specific time, differentiated from "musculoskeletal aches and pains" that "build up over time rather than happen suddenly on a specific day; for example, a chronic back or shoulder pain that may have just gotten worse over time or comes and goes periodically in the same spot." The questionnaires used have been shown to have strong validity and reliability ^[20-22]. Focus groups and cognitive interviews were conducted during development of the translated survey instruments to assure that the translated items were being appropriately understood by respondents.

2.3 Data analysis

Descriptive statistics were used to provide a demographic, health, and risk factor profile of the sample and to explore differences between relative and non-relative providers on these items. Analysis was conducted using SAS (version 9.2) and SPSS (version 19).

3 Results

3.1 Respondent demographic and health-related characteristics

Table 2 compares the demographic characteristics of respondents in the paid relative and non-relative provider groups. Paid relatives and non-relative providers were remarkably similar in gender and health status. Most (80%) were women

between 41-60 years old (56%) and distributed among several race/ethnicities: Latina (35%), White (27%), African American (20%) or Asian/Asian American (15%). Respondents' primary language was either English (57%), or Spanish (24%). Consistent with the stratified design, about half (55%) were relatives of the PAS recipient. Most (86%) respondents self-rated their general health to be Good, Very Good, or Excellent; and 89% reported no "health problems". However, 31% of respondents reported a musculoskeletal disorder (MSD) and 6% reported an injury during the past 12 months.

	Other Relative (n=474)(55%)		Non Relat	Non Relative (n=381)(45%)		
	n	%	n	%	— Significance	
Sex					ns	
Female	376	79	310	81		
Male	98	21	71	19		
Race/ethnicity					ns	
Hispanic/Latino	166	35	129	34		
White	128	27	101	27		
African American	89	19	81	21		
Pacific Islander	17	4	9	2		
Asian/Asian American	72	15	55	14		
Native American	2	<1	2	<1		
Age (years)	Mean 43.2	s.d ±13.8	Mean 49.4	s.d ±11.0	<i>p</i> < .001	
Years of education	Mean 12.4	s.d ±3.2	Mean 11.7	s.d ±3.3	<i>p</i> < .01	
	n	%	n	%		
Self-rated general health status						
Excellent	121	26	82	22		
Very good	101	21	82	22		
Good	177	37	164	43		
Fair	64	14	49	13		
Poor	10	2	2	<1		
No self-reported health problems	420	89	338	89	ns	
Sustained injury	26	6	22	6	ns	
Sustained MSD	150	32	110	30	ns	

Table 2. Characteristics and health of respondents (N=855)

Statistically significant differences were found for age and years of education. Paid relative providers were on average six years younger than the non-relative providers, and were more likely to have completed 12 years of education (the equivalent of a high school degree).

3.2 Temporal work environment

Table 3 shows that relative and non-relative providers reflect some differences in the hours of home care provided weekly, but these do not obtain a level that is statistically significant. However there is a tendency for more paid relative providers Published by Sciedu Press 31 to work (in all their jobs) more than 48 hours per week. The ability to take breaks on a typical home care work day is similar in both groups, as is the proportion reporting that they have predictable work hours.

	Other Relative (n=474)(55%)		Non Relative (n=381)(45%)		- Significance
	n	%	n	%	- Significance
Total home care hours worked weekly					ns
\leq 20 hours/week	180	38	118	31	
21-35 hours/week	173	37	152	40	
36-48 hours/week	59	12	67	18	
>48 hours/week	62	13	44	12	
Total hours worked weekly (all jobs)					<i>p</i> < .01
\leq 20 hours/week	119	25	94	25	
21-35 hours/week	149	31	144	38	
36-48 hours/week	68	14	68	18	
>48 hours/week	138	29	75	20	
Able to take breaks on typical day	343	72	265	70	ns
Predictable work hours	277	58	216	57	ns

Table 3. Temporal work environment (N=855)

Table 4. Physical work environment (N=855)

	Other Relative (n=474)(55%)		Non Relative (n=381)(45%)		– Significance
	n	%	n	%	- Significance
Number transfers* daily					<i>p</i> < .001
0 times/day	133	28	149	39	
1-4 times/day	106	22	84	22	
5-12 times/day	99	21	81	21	
>12 times/day	136	29	67	18	
Number times push/pull/carry/lift >25 lbs daily					ns
0 times/day	210	44	201	53	
1-2 times/day	126	27	88	23	
3-6 times/day	96	20	65	17	
>6 times/day	42	9	27	7	
Number reaching events [¶] daily					<i>p</i> < .01
0 times/day	161	34	120	32	
1-2 times/day	179	38	107	28	

(Table 4 continued on page 33)

Table 4. (Continued.)

	Other Relative (n=474)(55%)		Non Relative (n=381)(45%)		Significance
	n	%	n	%	0
3-6 times/day	105	22	129	34	
>6 times/day	29	6	25	6	
Number bending events daily					ns
0 times/day	62	13	56	15	
1-2 times/day	186	39	129	34	
3-6 times/day	173	37	163	43	
>6 times/day	53	11	33	9	
Number squatting/kneeling events daily					ns
0 times/day	207	44	180	47	
1-2 times/day	169	36	137	36	
3-6 times/day	84	18	52	14	
>6 times/day	14	3	12	3	
Recipient's home					
Doorways/hallways wide enough for wheelchair or walker	422	89	338	89	ns
Ramps/street level entrances - no stairs	249	53	193	51	ns
Space to maneuver equipment near bed	397	84	305	80	<i>p</i> < .05
Lift device available (all respondents)	52	11	46	12	ns
Needed lift device available (573 respondents who do 1+ transfers daily)	47	14	34	15	ns
Nothing in home makes using lift equipment difficult (all respondents)	44	85	46	100	<i>p</i> < .01
Nothing in home makes using lift equipment difficult (573 respondents who do 1+ transfers daily)	40	49	34	46	<i>p</i> < .05
Any kind of equipment to maneuver recipient available (includes lift device) [†] (all respondents)	91	19	80	21	ns
Any kind of equipment to maneuver recipient available (includes lift device) ^{\dagger} (573 respondents who do 1+ transfers daily)	78	23	59	25	ns

* Transfer = moving recipient from one location to another (e.g., bed to chair)

¶ Reaching event = extending torso and upper body (e.g., recipient's bed is in corner, no side access; cleaning bathtub without long-handled scrubber)

† Besides lift devices, respondents cited other types of such equipment including: belt, slide/transfer board, shower chair, toilet seat raise, wheelchair, hospital bed, pull bar/cord.

3.3 Physical work environment

As seen in Table 4, relatives and non-relatives tended to report similar proportions regarding exposure to risk factors for injury or MSD. However, there were statistically significant differences in the number of daily transfers and reaching events. Paid relative providers reported more transfers than non-relatives, while non-relative providers appear to have had more reaching events than paid relatives. Few differences were found regarding characteristics of the recipient home, including presence of equipment used to lift, transfer, or maneuver recipients. There is a striking lack of access to such equipment, as 67% of respondents (573) reported doing one or more transfers daily, but only 14% of these individuals had Published by Sciedu Press

an available lift device, and only 24% had access to any kind of equipment to help maneuver recipients (lift device, sliding board, belt, etc.). A higher percentage of relatives compared to non-relatives reported adequate space to maneuver equipment near the bed, but a lower percentage of non-relative providers reported barriers to using a lift device. Lastly, among the 199 respondents (23%) who reported receiving any kind of formal training, the two groups did not differ regarding whether they had received training on safe ways to lift or turn recipients (data not shown).

4 Discussion

This study explored differences between relative and non-relative providers regarding provider demographics, health, and their temporal and physical work environments, including access to equipment to help lift or maneuver recipients. Exploring these differences is timely because of the expansion of consumer-directed services and use of relatives as paid providers. Understanding these issues may help to inform long-term care policy regarding use of family providers in publicly-funded Personal Assistance Services programs.

Bivariate analysis showed that the two groups were very similar demographically, although paid relative providers were generally younger and had more education compared to non-relative providers. For both groups, self-reported general health was good to excellent, although nearly one-third (31%) self-reported a MSD. Regarding temporal and physical work factors, relatives reported working more than 48 total hours weekly and did more transfers, but had fewer reaching events compared to non-relatives. Regarding factors that could help prevent injury or MSD – an ergonomic home, lift equipment, or safe lift/transfer training – no differences were found between the two provider groups. However, among respondents who reported having an available lift device, 100% of non-relatives compared to 85% of relatives reported no barriers to using it. This finding should be understood within the larger context of overall poor access to lift/transfer equipment. As noted earlier, while 67% of respondents reported doing one or more transfers daily, only 14% of these individuals actually had access to lift devices, and only 24% had access to any kind of equipment to help maneuver recipients.

The commonalities between paid relative and non-relative providers found in this study may be a result of the study design, which was stratified to select only recipients with two or more ADL limitations to assure that providers had relatively similar levels of risk in their caregiving. While no differences were found regarding provider ethnicity between groups, differences based on recipient ethnicity and provider choice were found in a study of IHSS recipients ^[23]. Investigators found that Hispanic and Asian recipients were more likely than their White counterparts to be choose relatives as their paid providers.

5 Limitations

Several limitations in the study should be noted. First, this was a cross-sectional study and causal relationships cannot be determined. In addition, all data are self-reported. Most importantly, however, is the limitation regarding sample bias. Although we constructed a stratified probability sample, the respondents are not necessarily randomly drawn from the sample. Over one-third of the stratified probability sample of 5000 IHSS providers had to be excluded because of ineligibility or out of scope language. This limits the generalizability of the results. More problematic is that 41% of the remaining individuals could not be contacted despite more than nine attempts to reach them. However, among the 1726 providers who were both eligible and contacted, nearly half (49.5%) completed the survey. This completion rate, while not ideal, is comparable to those reported in other surveys of IHSS recipients and providers ^[5, 24].

Results of all analyses use unweighted data, and should not be interpreted as population estimates. For example, findings such as the majority of respondents self-reporting good to excellent health may be due to respondent self-selection into the survey rather than characteristic of all PAS workers. Regarding the participation of paid relative providers, the sample may be skewed in favor of those less likely to have had injuries, as an injured paid relative provider may result in the

institutionalization of the care recipient. Almost half of the refusals (43.3%) were individuals whose language preference was not English, nor one of the other target languages. Of these, the largest language groups were undetermined (228 cases), Armenian (74 cases), and Russian (27 cases). The non-respondents included both hard refusals (either by phone or postcard), and those who did not respond to answering machine messages.

Completion rates were within 1% point for those providing care to recipients aged 65 or over vs. those who were younger, and within 2% comparing male vs. female providers. Importantly too, the completion rates were within 1% among providers serving those with two ADL limitations up to those serving persons with four limitations. This difference widened to 3% among those with five ADL limitations. Such patterns suggest minimal systematic participation bias associated with care burden or relationship. Language may have contributed to the high rates of not being able to locate or refusals, but there was no consistent evidence for this.

As noted above, there is the potential for a healthy respondent bias in our data, as IHSS recipients can be expected to retain providers only if they are able and willing to render the assistance needed. Given the survey's modest response rate it is possible that providers transitioning into or out of their positions may have been less inclined to participate in the survey than those who were in established provider-recipient relationships. Therefore, the incidence of injury or MSD among older paid caregivers may likely be higher than for those reported in our study.

Lastly, this study focused solely on publicly-funded personal care recipients and their paid providers, and reflects a very different population than the broader population that includes recipients of informal or unpaid care, as described in a recent study ^[25]. Contributing to the differences are the income and asset thresholds that an IHSS recipient must be meet in order to be eligible for Medicaid. One consequence of these income/asset eligibility rules is that fewer IHSS recipients are living with spouses than would be found in the general population. A second consequence is that proportionately more of the spouses present may be in need of assistance themselves ^[25]. Remarkably, in the IHSS recipient population three-quarters of the present spouses among aged IHSS recipients, and 37% among non-aged recipients, were themselves IHSS recipients. Of the remaining spouses, the next consideration in the IHSS program is whether the spouse is "able and available" to be a care provider as determined by the program social worker. Among the aged (65+ years) IHSS recipients, 4.1% had an able and available spouse, compared to 8.8% among non-aged recipients. More than half of these able and available spouses were paid as IHSS providers ^[25]. Further, the differences between the general population and the IHSS recipient population suggest that the injury/MSD rates derived from our recipient sample would not be representative of the broader population of informal caregivers. While we believe that our findings have potential implications for injury/MSD rates among informal caregivers, we would prefer to limit our conclusions to the comparisons directly studied, namely the injury/MSD incidence among paid relatives (e.g., children or other non-legally responsible relatives like siblings) and non-relative providers. This emphasis is a limitation of the study's external validity, but not a limitation on its internal validity.

6 Directions for future research: Healthy physical and temporal work environments in home care

While no differences were found in this study between relative and non-relative providers' risk of injury or MSD, occupational safety remains an important concern, as nearly one-third of respondents reported sustaining an MSD during the past 12 months. This may be an underestimate, since it likely that there is a healthy worker bias in those responding to the survey. Even if the MSD was not directly caused by home care work, it could easily become a work-related injury if physical strain from performing the home care work prevented healing and led to the condition becoming chronic. An ergonomic work environment in home care has been shown to be an important factor in preventing occupational injury and MSD ^[7, 12]. This study documents that most respondents reported hallways or doorways wide enough for wheelchair or

walker, but about half indicated recipients' homes did not have ramps or street level entrances. Furthermore, there is a substantial gap between need for lift/transfer equipment and access to such equipment.

Further research could support or coordinate with intervention studies to assess the ergonomics of the physical home care work environment, and identify and remediate barriers to working safely. If effective, the programs could be expanded or replicated in other regions. In a qualitative study of injured PAS providers ^[26], relative and non-relative providers described home environments in which ergonomic lifting or transfers was difficult to impossible, or lift equipment was not utilized because of recipient fears, provider difficulty, or lack of space in which to maneuver the equipment. What may be even more relevant than research or intervention regarding the physical home care work environment, however, is increased resources for assistance for obtaining and correctly utilizing lift equipment or other safety devices, or modifying the recipient's home so that PAS may be provided in a more ergonomic environment.

Regarding the temporal work environment and its impact on providers, this study found that relatives were more likely to work more total hours weekly. These data suggest that relatives are more likely to work a double-shift, holding outside jobs as well as the paid PAS job. This finding is in line with Benjamin & Matthias^[15] who found that 31% of relative providers vs. 23% of non-relative providers reported having another job. Short- or long-term fatigue may be important to address in future research. Furthermore, future research should inquire into the changing hours and activities providers may experience over time, and whether this is associated with injury or MSD, such as when providers who previously shared the work with others then become the sole provider.

Finally, there appear to be substantial commonalities between paid relative and non-relative providers regarding demographics, health status, work environment, and ultimately in the incidence of self-reported MSD and injury. These commonalities suggest that PAS programs can continue to offer options for recipients to hire relatives as their paid providers, with no additional risks placed on paid relative providers compared to non-relative providers.

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