Paying Family Caregivers: An Effective Policy Option in the Arkansas Cash and Counseling Demonstration and Evaluation

Lori Simon-Rusinowitz
Kevin J. Mahoney
Dawn M. Loughlin
Michele DeBarthe Sadler

Lori Simon-Rusinowitz is Research Director, Cash and Counseling Demonstration and Evaluation, University of Maryland Center on Aging, 2360 HHP Bldg., College Park, MD 20742. Kevin J. Mahoney is National Project Director, Cash and Counseling Demonstration and Evaluation, Boston College Graduate School of Social Work, McGuinn Hall, Room 306, 140 Commonwealth Avenue, Chestnut Hill, MA 02467-3807 (E-mail: kevin.mahoney@bc.edu). Dawn M. Loughlin is Senior Researcher, University of Maryland Center on Aging 2360 HHP Bldg., College Park, MD 20742 (E-mail: d.shoop@verizon.net). Michele DeBarthe Sadler, MPH, is Faculty Research Assistant, University of Maryland Center on Aging, 1240E HHP Bldg., College Park, MD 20742 (E-mail: cheleds@comcast.net).

Address correspondence to: Lori Simon-Rusinowitz, Research Director, Cash and Counseling Demonstration and Evaluation, 2360 HHP Bldg., College Park, MD 20742 (E-mail: Ls119@umail.umd.edu).

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SUMMARY. Informal family assistance is often a key factor in determining whether a person with a disability can live in a community setting. However, the practice of paying relatives as caregivers remains controversial. This article reports findings from the Cash and Counseling Demonstration and Evaluation (CCDE) in Arkansas, in which consumers receive a cash allowance to purchase personal assistance services. In this comparison of consumers who hired family vs. non-family workers, consumers who hired relatives received more service and had equal or superior satisfaction and health outcomes, as compared to those who hired non-relatives. Findings are further clarified by drawing from worker focus group reports and program experience, and policy issues are specifically addressed. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com> © 2005 by The Haworth Press, Inc. All rights reserved.]

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INTRODUCTION

The critical role of families in providing care to elders and younger persons with disabilities is well established. Nearly one in four U.S. households are involved in this type of informal (unpaid) care (National Alliance for Caregiving, 1997). Family members comprise more than 70% of caregivers of older persons with activity limitations, and the vast majority (76%) of caregivers are unpaid (Super, 2002). Informal caregivers, usually female family members, provide assistance with activities of daily living, including eating, bathing, dressing, using the toilet, and transferring from bed to chair. Informal caregivers also provide assistance with varied household tasks such as laundry and meal preparation. These types of assistance are often key factors in determining whether a person with disabilities can live in a community setting (Stone, 1995). In addition, the national economic value of informal caregiving labor is great—estimated in 1997 to be $196 billion (Arno, Levine, & Memmott, 1999).

Findings from the 1997 National Caregiver Survey indicate that family caregivers who provide these critical services tend to have multiple responsibilities. About two-thirds of family caregivers in this country are working and 41% have one or more children under 18 years old liv-
The average family caregiver provides care 18 hours per week, while about 1 in 5 provide care at least 40 hours per week (National Alliance for Caregiving, 1997). Despite the important role, economic value and multiple responsibilities of family caregivers, the practice of paying relatives who provide this critical care is considered controversial in this country. Opponents of paying family caregivers raise the issues of appropriate public-private responsibility, quality of care, fraud and abuse, and fears of exploding public costs for services primarily provided for free (Blaser, 1998; Linsk, Keigher, Simon-Rusinowitz, & England, 1992). Proponents of paying family caregivers speak to benefits of the approach, such as increasing consumer choice, improving the quality of care, and expanding the limited worker supply (Linsk et al., 1992; Simon-Rusinowitz, Mahoney, & Benjamin, 1998).

This debate about the advantages and disadvantages of paying family caregivers has also become more important with research showing the effects of caring for a disabled relative on family employment and on retirement income. Findings from a 1995 survey conducted by The Arc show that 52% of families indicated that someone in their family had turned down or quit a job to provide care for their disabled family member (cited in Agosta & Melda, 1995). In addition to losing income, these family caregivers also lose out on earning important Social Security benefits. Because Social Security benefits are determined by an individual’s employment income, unpaid caregivers may receive severely limited benefits. Without Social Security, family caregivers are more vulnerable to becoming impoverished as they themselves age (Kijakazi, 2002). As the majority of family caregivers are female, women bear the brunt of the negative consequences of unpaid family caregiving.

While the policy debate about the advantages and disadvantages of paying family caregivers has continued for many years, it has become especially relevant in the context of the growing concern about the limited direct care labor force. A recent nationwide survey found that recruiting and retaining direct care workers was a major workforce issue for 42 states (Yamada, 2002). Projections of increased demand for services needed by aging baby boomers, combined with decreasing numbers of traditional workers (i.e., women aged 25-54) indicate the need for expansion of the direct care workforce (Wilner, 2000). Increased interest in consumer-directed services that allow consumers to hire their own workers are likely to increase demand for workers. In addition, implementation of the Olmstead decision (Olmstead: 527 U.S. 581, 1999),
which encourages states to provide community-based long-term services for persons with a disability, are likely to do the same.

**RESEARCH ON PAID FAMILY CAREGIVING**

In 1985, Linsk and colleagues studied payments to family caregivers in the Illinois Community Care Program as an effort to guide Illinois policy makers and leaders in determining whether this caregiving arrangement should be expanded, modified, or discontinued (Linsk et al., 1992). This research found varying levels of policy support, with the majority of the respondents speaking of the advantages of the policy for consumers and their families, including better quality care, improved consumer satisfaction and economic benefits for consumers and families. Other research on payments to family caregivers has also primarily addressed policy and program issues, including the extent of such payment programs and their features (Gerald, 1993; Linsk, Osterbusch, Keigher, & Simon-Rusinowitz, 1986; England, Linsk, Simon-Rusinowitz, & Keigher, 1989; Burwell, 1986), attitudes of administrators and policy makers about family payments (Linsk et al., 1986), consumer-directed homecare approaches, including family providers (Sabatino, 1990), family payments as an incentive to caregivers (Biegel, 1986), and evaluation of specific programs (Whitfield & Krompholz, 1981).

While much research addresses policy and program issues, there is also a body of research that discusses the views of consumers and family care providers. A 1997 evaluation of the California In-Home Supportive Services program reported that about half of the consumers in the consumer-directed model hired relatives and a quarter hired friends. Those consumers who hired relatives tended to be older, less educated and more likely to come from ethnic and racial minorities than other consumer-directed model clients. They also on average felt less risk and felt more secure than those cared for by others. They indicated having more choice about how their services were delivered as well as having more satisfaction about the choice they had, in comparison to clients who did not hire family members. Consumers hiring relatives and friends rated them as more reliable than workers who were strangers. They also felt interpersonally closer to their workers than clients who hired non-family providers (Benjamin, Matthias, & Franke, 1998). Similarly, a 1996 study of elderly Medicaid personal care recipients in Michigan, Texas, and Maryland found that client satisfaction was re-
lated to consumers having the choice of who provides their personal care, and to having the ability to hire family, friends, and neighbors as their caregivers (Doty, Kasper, & Litvak, 1996).

Background research for the Cash and Counseling Demonstration and Evaluation, which permits hiring relatives as workers, has offered similar support for paying family caregivers (Mahoney, Simon-Rusinowitz, Loughlin, Desmond, & Squillace, 2002). Between 90% and 92% of the respondents to a four state telephone survey indicated that they would be interested in a consumer-directed cash option because of the ability to “hire whomever you wanted to provide services, even a friend or relative.” Participants in follow-up focus groups in four states agreed that the option of hiring relatives or friends as their personal care worker was a positive program feature, although reactions were mixed about doing so. A few of the focus group participants were concerned with the possibility of a lower level of professionalism from family members and an ability to deal comfortably with provider-client conflicts. However, most focus group participants liked the idea of being able to pay a friend or family member who was already helping with personal care needs. In addition, consumers felt that their relatives would know their special needs, likes, and dislikes better. Focus group participants also shared that being able to hire a relative or friend would allow consumers to hire someone of the same ethnicity. This last finding appears to be an especially important factor for African-American and Hispanic consumers.

As research shows, paying family caregivers and the more general idea of consumer-directed services are two concepts that tend to be linked. Consumers interested in consumer-directed services have expressed a preference for the ability to hire family and friends as workers, and when these consumers are able to direct their own services they do, in practice, tend to hire family and friends. Similarly, consumers who hire their own workers, including family and friends, conduct employer responsibilities, such as hiring, firing, and supervising workers. The present study also links these issues in its comparison of paid family and non-family caregivers in a consumer-directed setting.

THE PRESENT STUDY

The Cash and Counseling Demonstration and Evaluation (CCDE) is a test of one of the most unfettered forms of consumer-directed services—offering Medicaid consumers in Arkansas, Florida, and New Jer-
sey a cash allowance and information services in lieu of agency-delivered care. CCDE clients can use their cash benefit to purchase personal care services, assistive devices, or home modifications that best meet their individual needs. Information services include assistance with cash management tasks such as hiring, training, and managing workers as well as payment responsibilities. In theory, consumers who shop for the most cost-effective providers may then (through such savings) have funds to purchase additional services (Kapp, 1996).

The CCDE, which will be completed in 2005, compares cost, quality, and satisfaction of consumers receiving traditional personal care services with those receiving the cash option. The evaluation is co-sponsored by the Robert Wood Johnson Foundation (RWJF) and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (DHHS/ASPE). It operates under section 1115 Research and Demonstration waivers granted by the Centers for Medicare and Medicaid Services (CMS). Primary quantitative data collection and analysis is being conducted by Mathematica Policy Research, Inc. For a detailed description of the CCDE design, please refer to Mahoney, Simone, and Simon-Rusinowitz (2000).

This current analysis is based on CCDE data from Arkansas, the first state in which CCDE data has been collected. This analysis is a comparison of related and non-related clients and workers within the consumer-directed cash option group. Specifically, we are comparing the: (1) background characteristics of both consumers who hired a relative vs. a non-relative, and workers who worked for relatives vs. non-relatives, (2) types and amounts of service provided and received by related and non-related clients and workers, and (3) health and satisfaction outcomes for related and non-related clients and workers. The discussion will be augmented with findings from focus groups conducted with paid workers in Arkansas, as well as general CCDE Arkansas experience.

METHODS

Volunteer enrollment for the CCDE Arkansas study, the Arkansas IndependentChoices Program, began in December 1998 and ended in April 2001. At enrollment, clients who felt that they may be unable or unwilling to individually handle the tasks associated with the consumer-directed Independent Choices program, were asked to appoint a program representative—usually a family member or friend, to assist with these responsibilities if necessary.
Clients were randomly assigned to consumer-directed (n = 1004) and traditional service (n = 1004) groups. Traditional service clients were given a list of home health care agencies that they could contact for their personal assistance services, or, if they were currently receiving services, they could continue to rely on their previous agencies. The clients in the consumer-directed group were given a monthly allowance and were responsible for procuring their personal assistance services on their own. Consumer-directed clients could hire whomever they wanted for their personal assistance, with the exception of spouses, or the person acting as their program representative. The amount of the monthly allowance was determined by the number of personal assistance hours in the client’s existing care plan, or, for new clients, the number of hours in the care plan as determined by enrollment nurses. The monthly benefit for consumer-directed clients in Arkansas averaged $320 per month.

Consumer-directed clients had the option to use fiscal intermediaries to handle bookkeeping and payroll services on their behalf, and almost all clients chose to use these free services. Counselors were also available, at no charge to the consumer, to provide advice and support for creating cash management plans and for recruiting and hiring workers. Counselors also approved cash management plans, and monitored the program for fraud and abuse. Consumer-directed clients were free to dis-enroll from the study at any time and return to traditional services. Clients were surveyed at enrollment (prior to randomization), at four months and at nine months, with computer-assisted telephone interviews. Experienced MPR interviewers were trained on the specific surveys. Clients who were unable or unwilling to answer for themselves could provide proxy respondents to answer the surveys for them. In these cases, interviewers asked that the “most knowledgeable person” complete the telephone survey. During the 9-month survey, respondents were asked to provide names and contact information for their primary paid workers. For a detailed description of data collection methods and procedures see Foster, Brown, Phillips, Schore, and Carlson (2003).

**Samples**

The current analysis compares outcomes for clients who chose to hire a family worker versus clients who chose to hire a non-family worker, as well as outcomes for those two types of workers—when clients had a choice of workers to hire. We therefore limited our focus to the consumer-directed clients, and their paid family or paid non-family workers.
Client Sample. Attempts were made to survey clients or their proxy respondents at all survey points, even if the client had dis-enrolled (n = 189) from the program or was deceased (n = 32), and 885 clients or proxy respondents from the consumer-directed group (88%) completed the 9-month survey. Of the 885 respondents, 636 respondents were participating in the program and paying a worker at the time of the nine-month survey. For clients with multiple paid workers we could not determine if responses applied to a family or non-family worker, due to the structure of the survey. We therefore further restricted this analysis to clients with only one worker. We included 436 clients in this analysis; 334 clients who were paying one family worker (182 of these had proxy respondents), and 102 clients who were paying one non-family worker (49 of these had proxy respondents). Clients over age 65 were more likely to be dis-enrolled from the study and, if participating, more likely to have had multiple paid workers. Thus, the clients in our analysis sample, which was drawn from 9-month Independent Choices participants with one worker, were slightly younger than the original volunteer sample (64% age 65 or older vs. 72% age 65 or older).

Questions about client satisfaction and quality of care were only asked of clients who responded for themselves, and of proxy respondents who were not also paid workers. For these questions, this analysis sample consists of 215 clients (or their non-worker proxy respondents) who were currently paying one family worker and 88 clients (or their non-worker proxy respondents) who were currently paying one non-family worker.

Worker Sample. Based on client referrals from the 9-month survey, 248 primary paid workers who were not primary informal caregivers at baseline were contacted, and 216 of these workers completed the paid worker survey. During a separate survey of primary informal caregivers who were identified at baseline, an additional 125 respondents were identified as paid (although not necessarily primary paid) workers. Another 175 workers who were identified as primary informal caregivers at baseline were identified again during the 9-month client survey as primary paid workers. Both of these groups also completed survey items that applied to paid workers. We included all three of these groups of consumer-directed paid workers in this analysis, which resulted in a sample of 417 paid family workers and 99 paid non-family workers.

Although the client and the worker analysis samples are drawn from the same treatment group pool, they are not necessarily dyads or matched sets of clients and workers. In some cases a client’s worker could not be contacted, and in eleven cases two paid workers were working for the
same client (only one identified as primary). Since even workers for the same client may have had very different responses, levels of satisfaction, backgrounds or outcomes, in general, all paid worker respondents are included in the paid worker analyses. Questions concerning worker satisfaction and assistance with tasks were restricted to those who were identified as the primary (though not necessarily only) paid worker. For these questions, the sample consists of 306 family workers identified as the primary paid worker and 85 non-family workers identified as the primary paid worker.

**RESULTS**

Sixty-four percent of the clients in our analysis sample were over 65 years of age, and 77% were female. Clients could choose more than one racial category, and thus the racial percentages total more than 100%. Specifically, 60% identified as white, 37% identified as Black, and 5% identified as American Indian or Alaskan Native. Less than 1% each identified as Asian or other. Clients received an average of 25.2 hours of paid care over a two-week period.

The majority of paid workers in our analysis sample were female (88%), but younger than the client sample; the majority of workers were between 35 and 54 years of age. The racial percentages were similar to the client sample—63% identified as white, 35% identified as Black and 5% identified as American Indian/Alaskan Native. Fifty-three percent of the paid workers were married, 37% had children under 18 years of age, and 68% had graduated from high school.

**Client Characteristics**

Table 1 presents characteristics of clients who hired a family worker versus clients who hired a non-family worker. Clients who hired a family worker were more likely to be living with others and to have had previous unpaid help in the week prior to baseline. These clients were less likely to have had previous paid help, and also less likely to have had both paid and unpaid help, in the week prior to baseline. American Indian/Alaskan Native clients made up a smaller percentage than would be expected of those who hired a family member. That is, 11% of clients who hired non-family identified as American Indian/Alaskan Native compared to only 4% of those who hired family.
Paid Worker Characteristics

Paid family workers were more likely to be female, to be married, to have known and helped the client in the past, and to be living with the client (Table 2). Workers who provided routine health care or personal care were asked if they had received training—either in a classroom,
from a health care professional, or formal training from the client or client’s family. Family workers were less likely to report having received training in personal care.

**Services Provided and Received**

The surveys included two sets of measures of the service provided by workers. Clients were asked about services received from their family or non-family worker with a focus on personal care services (Table 3).
Workers were asked a different set of questions about services provided, with these questions reflecting a greater emphasis on routine health care services (Table 4). Clients with a paid family worker reported receiving equal or greater assistance on all measures of assistance. Worker reports show a similar tendency for family workers to provide equal or greater services to clients.

Clients and workers were asked similar sets of questions about the timing of care provided. Both surveys revealed that family workers were more likely to provide care during non-traditional hours such as evenings and weekends (Table 5).

### Table 3. Assistance Received by Client During Two-Week Reference Period by Family vs. Non-Family Paid Worker

<table>
<thead>
<tr>
<th>Type of Assistance</th>
<th>Percent of Clients Receiving Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help with light housework/laundry</td>
<td>Family Paid Worker (n = 334) 98%</td>
</tr>
<tr>
<td>Help doing other things</td>
<td>Non-Family Paid Worker (n = 102) 88***</td>
</tr>
<tr>
<td>Help around house/community</td>
<td>93%</td>
</tr>
<tr>
<td>Help with shopping</td>
<td>71***</td>
</tr>
<tr>
<td>Help with bathing or showering</td>
<td>90%</td>
</tr>
<tr>
<td>Help with other personal care</td>
<td>77%</td>
</tr>
<tr>
<td>Help taking medications</td>
<td>77%</td>
</tr>
<tr>
<td>Help with eating</td>
<td>67%</td>
</tr>
<tr>
<td>Help with transportation</td>
<td>67%</td>
</tr>
<tr>
<td>Help w/routine health care</td>
<td>63%</td>
</tr>
<tr>
<td>Help getting in or out of bed</td>
<td>62%</td>
</tr>
<tr>
<td>Help getting to or using toilet</td>
<td>60%</td>
</tr>
</tbody>
</table>

**p < .01    *** p < .001

Note: Based on non-missing client responses from CCDE Arkansas 9 month client survey for participating clients with only one paid worker.

Client Health and Satisfaction Outcomes

The surveys provided several measures of health and satisfaction outcomes for both consumer-directed clients and their workers. At the nine-month survey point, about 15% of clients with a family worker or a
non-family worker, when asked about their overall health, reported good or excellent versus fair or poor. There were no differences in measures of activities of daily living: difficulty taking a full bath without help, difficulty getting out of bed without help, or difficulty using the toilet or commode without help. Clients with a family or a non-family worker were also about equally likely to report taking medicine regularly (95%), and equally likely to report having a chronic health condition (89%). Ninety-seven percent of clients with a family worker and clients with a non-family worker felt that their worker had sufficient knowledge to care for their condition.

Similarly, clients with a non-family or family worker were about equally likely to report having, in the past month: shortness of breath developing or worsening (34%), forgotten medicine at least once (23%), been in a hospital or nursing home (17%), developed contractures (17%), had a urinary tract infection (15%), been injured by a paid helper (1%),

<table>
<thead>
<tr>
<th>Type of Assistance</th>
<th>Family Paid Worker (n = 417)</th>
<th>Non-Family Paid Worker (n = 99)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helped with any routine health care</td>
<td>97</td>
<td>90</td>
</tr>
<tr>
<td>Helped with taking medicine</td>
<td>77</td>
<td>51***</td>
</tr>
<tr>
<td>Range of motion/other exercise</td>
<td>53</td>
<td>53</td>
</tr>
<tr>
<td>Special care of feet</td>
<td>42</td>
<td>33</td>
</tr>
<tr>
<td>Helped by checking vital signs</td>
<td>32</td>
<td>21*</td>
</tr>
<tr>
<td>Caring for pressure sores</td>
<td>28</td>
<td>19</td>
</tr>
<tr>
<td>Care of ventilator/care lung</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Helped by checking blood sugar</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>Care of urinary catheter</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Use/care of feeding tube</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Care of colostomy</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Helped with other routine health care</td>
<td>29</td>
<td>18*</td>
</tr>
</tbody>
</table>

* p < .05  ** p < .01  *** p < .001
Note: Based on non-missing worker responses from CCDE Arkansas paid worker survey.
seen a doctor for a cut, burn, scald or other injury (< 1%). Clients with a family worker were, however, less likely to report a respiratory infection (26% vs. 37%, p < .05), bed sores or pressure sores (4% vs. 12%, p < .01), and having fallen (16% vs. 29%, p < .01).

Over 96% of consumer-directed clients in both groups reported that they were satisfied with how they got along with their paid worker, the time of day they got help, and the routine care, personal care and help around the house provided by their paid worker (when applicable). Clients were equally likely to report unmet need for help around the house, help with medication, and help with transportation. Clients with a family worker were more likely to be satisfied with overall arrangements for care (99% vs. 91%, p < .01), and less likely to report unmet need for personal care (22% vs. 36%, p < .05).

Worker Satisfaction

We found that paid family and non-family workers were about equally likely to report the following problems: pay delayed (35%),
need for client to show more respect for the work done by the worker (16%), received less pay than earned (6%), close supervision interfered with work (5%), asked to do tasks not agreed to (2%), and disagreement concerning schedule (1%). Family and non-family primary paid workers were also about equally likely to report that they were satisfied with the feedback they were given on their performance (95%), that they liked the supervision they received (89%), and that they had a say about when to do things (91%). However, among primary paid workers, family workers were more likely to report having to hurry to complete tasks (24% vs. 11%, n = 388, p < .01). Among all paid workers for consumer-directed clients, family workers were more likely to agree that the client's family members "need to be more respectful of the work I do" (40% vs. 21%, n = 502, p < .01). Overall, however, 96% of all paid workers for consumer-directed clients felt prepared to do what was expected of them, and over 99% indicated that they were satisfied with their working conditions.

**DISCUSSION AND POLICY ISSUES**

The practice of paying family members who care for their relatives continues to be a controversial policy issue in this country. The findings from Arkansas clearly address policy concerns including quality of care, amount and types of services provided, as well as consumer health and satisfaction outcomes. This section will draw upon the findings reported in this article to address policymakers’ frequently asked questions. Quotations from focus groups conducted with paid workers in Arkansas will be used to clarify and exemplify the results of the quantitative study. Typical policymaker issues include: reasons consumers choose to hire relatives, who will choose to hire relatives, the impact of this consumer-directed approach on consumers, informal caregivers and paid family caregivers, as well as the quality of care provided by a relative, and concerns about fraud and abuse.

**Why Do Consumers Choose to Hire a Relative?**

An interesting question to consider is why consumers who are given a choice frequently select relatives to provide their care? We found that a majority of our sample hired a relative as their paid worker. Research has shown that many consumers choose to hire a relative because they believe they receive better care from a person who knows and cares
about them rather than a stranger. They also feel more comfortable having a trusted family member enter their home and provide intimate care than allowing a stranger to do so (Mahoney et al., 2002; Benjamin et al., 1998). Our findings support these beliefs, including reports that consumers with a paid family worker had no adverse health outcomes and fared better in some important areas, despite the fact that those relatives had less training in personal care. Consumers with paid family caregivers were also more likely to receive care during non-traditional hours, and they reported less unmet need for personal care. In a recent focus group with IndependentChoices paid workers, that primarily included paid relatives, one individual captured this point saying, “A lot of people on IndependentChoices right now are getting better care from their family members than they could ever get in any other situation” (Zacharias, 2002).

We found that Black consumers were a little more likely to hire a relative, as compared to consumers of other racial/ethnic backgrounds. This finding, although not statistically significant, is consistent with previous research (Benjamin et al., 1998). However, American Indian/Alaskan Native consumers were comparatively less likely to hire a relative. This is a clear reminder that cultures may differ in their norms and expectations, especially in such sensitive areas as family relations, health practices, and disability issues. Future research should be directed toward a more thorough investigation of these issues for minority clients.

We also found that consumers who hired family were more likely than those who hired non-family to have had previous unpaid care, and were more likely to be living with others. On the other hand, consumers who hired non-family were more likely to report previous paid care, and more likely to report both types of care. We can view these results as both a reflection of the family “connectedness” with the consumer, and as simple continuity. That is, consumers who hire family are likely to be those who have relatives ready and available to work for them; they are able to hire those relatives and many may prefer to continue a pre-existing care relationship. Consumers who hire non-family are more likely to have had a paid non-family worker available, and many may have preferred to continue that relationship. Although the data does not address this issue, it is also possible that some consumers were not able to hire their preferred worker, relative or non-relative, as that person was not available. For example, the paid worker shortage may limit the workers available to those who prefer a non-relative. However, some consumers who would prefer a relative may not have an appropriate relative to hire.
Is a consumer-directed option that allows payments to family workers good for caregivers? For family members who struggle to balance demanding caregiving and work responsibilities, the cash option might help balance these conflicts by allowing them to work fewer hours or leave their jobs. While the average Arkansas cash benefit has been about $320 per month, this relatively small amount might provide an informal caregiver enough income to either decrease their work hours or leave an outside job. The benefit also offers the possibility of paying for respite care, another avenue to help informal caregivers juggle demanding responsibilities. A few paid family workers who took part in recent focus groups reported that they were able to quit other full-time jobs to become an IndependentChoices paid worker, but others said they were not able to decrease their regular work hours even after they became an IndependentChoices paid worker.

An added benefit for paid family workers is the opportunity to contribute to the Social Security program. Their status as a paid worker allows them to earn credits toward both disability and retirement benefits. In addition, they may be able to save some wages for retirement, an important opportunity for this primarily low-wage, female workforce. Finally, their wages provide recognition that their labor is important to their relative and to the larger community.

Policymakers worry about a “substitution effect” from this policy option, resulting in families who previously cared for a relative without pay (informally) now doing the same caregiving for pay. However, it is important to note that our findings indicate that consumers who hired a relative still received the same amount of unpaid care as those who hired non-family. In addition, in focus groups, most paid relatives reported that they had provided care prior to IndependentChoices, and that they were providing care for more hours than those for which they were paid. This would seem to negate the concern that when family members become paid workers, they will only provide care when paid. To the contrary, this finding raises a concern about family caregivers becoming overburdened by working too many hours. Twenty-four percent of the paid family workers in our sample reported having “to hurry to get things done” (vs. 11% of non-family workers). Thirty-eight percent of the paid family workers in this sample had children under 18 years of age. Future research will need to explore this “addition” effect, as much as any substitution effect. It is also important to note the many positive client outcomes associated with paying family caregivers, including in-
creased consumer satisfaction and decreased unmet need. These outcomes may also balance policymakers’ substitution effect concerns.

The current analyses show high levels of worker satisfaction among all cash option workers, family and non-family alike. Paid workers from both groups were highly satisfied with the supervision and feedback they received. Paid family workers in our sample were no more likely than non-family workers to indicate any lack of respect for their work from their clients. Clients expressed equal satisfaction with how they got along with family and non-family workers. However, paid family workers were more likely to indicate a perceived lack of respect for their work from clients’ families (and presumably their own). Interestingly, IndependentChoices paid family worker focus group participants did not confirm a lack of respect from family members. Further research should explore this issue of family respect to determine what meaning it has to the family worker and to develop appropriate program supports.

In light of a concern that some family members might feel coerced into being a paid worker, especially with a labor shortage, the recent focus groups explored paid family workers’ views about their positions. Of the 18 participants in the IndependentChoices paid worker focus groups, all but one had been a caregiver for the IndependentChoices client prior to the client’s enrollment in the program; some for a few months or several years, others for the client’s entire life. For all of them, there was no question that they would become the paid worker when the client enrolled in IndependentChoices. For some, this choice was influenced by the belief that it would be difficult finding a personal care worker willing to work for relatively low wages. For others, there were no other family members available or willing to be a caregiver. But all of these participants wanted to be the personal caregiver, and they did not report feeling obligated to accept this role. Many caregivers reported feeling “blessed” to provide care to a loved one, as indicated by the following statements from caregivers: “I think that God has put me in this position to take care of my mother at this time; my mother helped me with my children, we would’ve starved years ago if I didn’t have my mother and it’s my turn.” “None of us sitting here could be doing this if God hadn’t put it on our heart, . . . we’re just living out what we’ve been called to do.” “I just feel good that I’m able to be there for her right now.” When asked about the challenges of being a paid caregiver, these participants acknowledged the time demands of this difficult role and the ways in which it limited their family and social lives. However, overall they appeared to accept these challenges and were happy to care for their loved ones.
Do Consumers Get Good Quality Care from a Relative?

Policymakers often express concern about the quality of care provided by family members who do not receive the same training required for agency workers. Although none of the workers in this analysis were agency workers, the non-family workers were significantly more likely to have received training in personal care. However, family worker focus group participants explained that they learned various tasks and procedures from observing home health and hospital nurses, although some noted that additional training would be helpful.

Despite differences in training, the current analysis indicates positive health and satisfaction outcomes for consumers with paid family workers, as compared with consumers with non-family workers. They reported fewer respiratory infections, bed sores or pressure sores, and falls. There were no statistically significant differences in other health or disability outcomes between clients who hired family vs. non-family. Clients with paid family caregivers reported less unmet need for personal care.

Clients were highly satisfied with both family and non-family paid caregivers; however, those with family caregivers were more satisfied with their overall care arrangements. Clients’ increased satisfaction may be related to findings that paid family caregivers were more likely to work non-traditional hours, twice as likely to provide care on weekends, and they were significantly more likely to assist with numerous tasks. A statement drawn from recent focus groups with paid family caregivers indicates their experience and confidence in caring for their relatives: “we’ve had these family members all these years and we know what has to be done on a daily and hourly basis.” Our analysis supports this view as 97% of clients (with both family and non-family workers) thought their worker had the necessary knowledge to care for them.

Cash Option Consumers

Will cash option consumers, especially those with paid family caregivers, take the cash and use it inappropriately? Will they make bad choices? Will they suffer abuse and neglect? Policymakers often worry that cash option consumers will use their cash benefit for purposes other than personal care and forego needed services. They are especially concerned about a consumer from a dysfunctional family who, for example, hires a relative with substance abuse problems and the worker squanders the cash benefit on drugs or alcohol. Our comparisons of client
health and satisfaction outcomes, as well as CCDE experience to date, offer no support for this concern. While it is possible that a dysfunctional family could participate in the cash option, the CCDE States have incorporated a system of “checks and balances” (i.e., consumer representatives, bookkeeping services, as well as monitoring by counselors and fiscal intermediaries) to prevent and monitor such abuses. Contrary to policymakers’ concerns about consumers with a paid family caregiver going without needed care, we find that paid family caregivers tend to provide care beyond the hours for which they are paid.

**Do Paid Family Caregivers Increase the Labor Supply?**

Policymakers are concerned about finding approaches to address the long-term care worker shortage. Would a policy that allows payment to family caregivers expand the limited labor supply?

Findings from this analysis, as well as CCDE experience thus far, indicate that the ability to hire family members expands the limited labor supply. At the nine-month follow-up survey, half of new recipients in the CCDE control group (i.e., those assigned to receive agency services) lacked any paid care, while the majority of cash option clients had hired at least one relative (Dale, Brown, Phillips, Schore, & Carlson, 2003). Thus, it is clear that the ability to draw upon a non-traditional labor source seems to expand the labor supply. Another important issue is that paid family caregivers have provided more flexible times during which consumers receive care. Rather than serving consumers only during traditional work hours, paid family caregivers were more likely to provide care during early morning, evening, and weekend hours.

Policymakers also want to know if this non-traditional labor source will expand the labor supply on a long-term basis (i.e., will family members only enter the labor pool to care for their relatives, or will they care for others as well). While the current analysis does not address this question, the recent focus groups explored this issue. When asked if they would consider being a personal care worker for someone other than a family member, focus group participants gave mixed reactions. Many stated that while they were comfortable providing services to a family member, they were less certain about caring for a stranger. Others might consider this possibility.
Study Limitations

Due to the survey design, this analysis was limited to clients who had only one paid worker. Clients with multiple workers may have had some differences in outcomes. Their workers may have had more respite and fewer care burdens, which could have a positive effect on the care received. However, clients with multiple workers may also experience greater inconsistencies in care. Further research should be directed toward outcomes for clients with multiple family and non-family workers.

The Arkansas IndependentChoices program does not allow clients to hire spouses as paid workers. In addition, the benefit amount in Arkansas is relatively small. These program features may impact some program outcomes, including the amounts of unpaid care that would continue when a relative is hired. In CCDE programs in New Jersey and Florida, clients may hire spouses and the benefit amounts are larger. We will learn more about these issues, as results for these states become available.

In addition, the effects of the existing shortage of personal care workers are difficult to assess. Some clients who hired a family member may have preferred to hire non-family if a worker was available. It is likely that some clients who were excluded from this comparison analysis because they had no worker at the nine-month survey point would have acquired a worker if they could. However, the shortage of personal care workers is a real life factor for clients, and this analysis sought to compare the outcomes for clients hiring family or non-family, within those real circumstances.

CONCLUSION

Overall, the experience of clients and their family workers in the consumer-directed CCDE in Arkansas appears to be quite positive in every area that has been of concern to policymakers. The majority of consumer-directed clients hired family workers, and those clients received equal or greater services, and experienced less unmet need, as compared to clients who hired non-family workers. Although two issues for family caregivers were identified, caregiver burden and respect from family members, these paid family workers reported overall high levels of satisfaction with the care arrangement. Clients who hired a family member also report superior health and satisfaction outcomes. To date in the CCDE experience, cases of fraud or abuse have been rare. We hope that these findings will inform the long-standing debate about payment to family caregivers and make this option more widely available for those who choose it.
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