Advancing Home and Community-Based Services: Transforming Policies, Programs, and Service Delivery in Long-Term Care
More Change than Continuity?  
The Evolution of Long-Term Care Policy

Robert B. Hudson, Editor

After years of only modest movement, the ground under long-term care policy is shifting to a very significant degree. Eligibility is expanding, benefits are becoming more flexible and innovative, the delivery system is undergoing a paradigmatic shift in the direction of consumer choice, and new financing mechanisms are gaining a foothold in the system.

This issue of Public Policy & Aging Report brings both attention and perspective to these notable changes. Pamela Doty’s introductory essay provides a 30-year review of the evolutionary process, where movement has gone from glacial to visible. Of the themes she touches on, the rise of insurance mechanisms is of particular interest. Private long-term care insurance is carving out a market for itself, and it is now to be joined by the remarkable CLASS Act passed in February as part of health care reform. Making long-term care a social insurance as well as a public assistance benefit represents a policy change of truly momentous proportions. Coupled with private (and public/private) insurance options, enactment of the CLASS Act means that there is coming into place a wide (if not deep) range of insurance options available for those in need of long-term care services.

As outlined by Lori Simon-Rusinowitz and colleagues, consumer-directed initiatives represent a truly innovative development in service delivery. Maturation of the service delivery system is also seen in the new capacities of aging network agencies to manage community-based services as demand and financing for them increases, as noted by Suzanne Kunkel and Abbe Lackmeyer. Workforce issues, of course, continue to be a major concern in the field, and the work of the national panel reported here by Benjamin Rose Institute researchers sets forth concrete if difficult steps that can be taken. That family caregivers may over time join the formal as well as the informal long-term care workforce represents a major possibility, albeit a controversial one.

Whether or not developments along so many fronts can be controlled and coordinated will continue to be a major question. Miriam Rose and colleagues review recent state-level initiatives in home and community care. For example, Ohio represents one testing ground for finding answers to this question, and the state’s long-term care system is put under the microscope here by researchers at Miami University of Ohio. We believe that this issue of PP&AR serves as an excellent “one-stop shop” for seeing where long-term care has evolved and how it may be positioned for the future.

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**The Benefits of Consumer-Directed Services for Elders and Their Caregivers in the Cash and Counseling Demonstration and Evaluation**

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Significant challenges to the current long-term care system (e.g., rising health care costs, the growing number of aging baby boomers, shortages in the direct-care workforce) have policymakers searching for solutions to meet the long-term care needs of elders with disabilities. Consumer-directed (CD) models of home care (also called participant-directed and self-directed) such as Cash and Counseling offer elders who desire this option more flexibility and satisfaction than agency services, and the opportunity to delay or avoid institutionalization and remain in their homes and communities. Yet, some policymakers and others question the appropriateness of CD services for older consumers, often citing fear for their safety as well as beliefs that they would not be interested in CD services or willing/able to perform required tasks. This paper draws on extensive evaluation findings to address their concerns, move beyond ageist assumptions, and inform new health care reform policy decisions.

**The Cash and Counseling Demonstration and Evaluation**

The Cash and Counseling Demonstration and Evaluation (CCDE) tested an innovative approach to providing personal care services; it offered Medicaid consumers of all ages in Arkansas, Florida, and New Jersey a cash allowance (of comparable worth) in lieu of agency-delivered services. The evaluation compared cost, quality, and satisfaction for consumers who received traditional personal care services versus those who received a flexible budget and were able to decide who would provide these personal and essential services, as well as when and how they would be provided. Counseling and bookkeeping services were offered to help consumers manage their monthly budgets and program responsibilities as they took on the role of employer. CCDE consumers were highly satisfied and between 85 and 98 percent said they would recommend the program to others (Schore, Foster, & Phillips, 2007). Compared with traditional agency services, CCDE consumers reported more flexibility and control, greater satisfaction with overall quality of life, and no greater adverse events on 11 health measures. These measures included whether the consumer: fell; saw a doctor because of a cut, burn, or scald; was injured while receiving paid help; had contractures develop or worsen; had bedsores develop or worsen; had shortness of breath develop or worsen; had a urinary tract infection; had a respiratory infection; was in poor health; and was hospitalized or in a nursing home during the previous two months (Carlson, Foster, Dale, & Brown, 2007). Reports suggest that CD care is successful not only for individuals with physical disabilities, but also for those with dementia (Tilly, 2007) and other mental health diagnoses (Shen, Smyer, Mahoney, Loughlin, Simon-Rusinowitz, & Mahoney, 2008). Although the CCDE demonstrated positive outcomes for consumers of all ages, some policymakers and stakeholders remain skeptical about the appropriateness of CD programs for elders. This service delivery option for older persons continues to have important policy implications for consumers, their family members, policymakers, and others.

**What the CCDE Tells Us About Elderly Consumers and Their Caregivers**

In the initial evaluation of the experiences of elders in the CCDE, evaluators examined survey
The Benefits of Consumer-Directed Services for Elders and Their Caregivers... results for participants over age 65 in Arkansas and New Jersey, and over age 60 in Florida, to assess unmet needs and satisfaction with life. In almost every state and age group, these older Cash and Counseling participants were much less likely to report unmet needs, and much more likely to report significant increases in satisfaction with paid caregiver help, overall care arrangements, and with the ways they were spending their lives. Participants received more hours of paid care but still received significant hours of informal care. With regard to measures of adverse outcomes, CCDE evaluators summarized results for all age groups, including elders, and reported that “none of the 11 measures of health problems or adverse events examined showed worse outcomes for the treatment group than the control group, for any of the seven state–age groups... Furthermore, for nearly one-third of the 77 comparisons, the treatment group was significantly less likely to experience health problems. The significant differences revealed no consistent pattern across measures, age groups, and states, but they were sizeable, ranging from 20 to 50 percent of control group means” (Carlson et al., 2007, p. 479).

Evaluation of older CCDE consumers’ experiences has continued in secondary analyses, drawing on multiple data sources to provide in-depth understanding of their views about a CD cash option. Our most recent analysis focused on health-related outcomes in relation to specific age groupings. The sample of survey respondents consisted of 4,037 participants divided into three age groups; approximately 21 percent were aged 50 to 64 (10 percent in Cash and Counseling and 11 percent in agency services); 41 percent aged 65 to 79 (21 percent in Cash and Counseling and 20 percent in agency services); 38 percent aged 80 and older (18 percent in Cash and Counseling and 20 percent in agency services). These age categories represent pre-retirees, young-old, and old-old as reflected in the literature. This stratification allows us to look at aging baby boomers as a distinct group. The caseload consists of more young-old and old-old individuals, with fewer pre-retirees in the home and community-based services (HCBS) programs studied. We developed multivariate regression models that controlled for demographics and baseline characteristics.

**Satisfaction with Care**

Results from this analysis of participants over age 50 mirror those found in the overall CCDE evaluation. In all three age groups, older CCDE beneficiaries were more satisfied with their care compared to those receiving agency services. Older CCDE participants reported significantly higher satisfaction with life, paid care arrangements, help around the house, and transportation as compared to those receiving traditional services. Improved satisfaction with transportation is an important finding as home care agency workers often are not allowed to provide this service (along with administering medication) due to liability issues. The ability to match consumer preferences to the desired services is likely to have improved their satisfaction with care. The magnitude of the positive effects tended to decline with age. Yet, we still found a high level of satisfaction with transportation, arrangements of paid care, and paid help around the house for the oldest age group—those age 80 and over.

**Health Outcomes**

Survey results also demonstrated no increase in adverse events in the CCDE program in older populations. We found no effect on self-reported overall health status. The oldest consumers (age 80 and above) in the CCDE program had a lower chance of developing or worsening contractures or developing shortness of breath. The youngest group (age 50-64) had a lower chance of staying overnight in a hospital or nursing home.

**Qualitative Interview Results**

To continue the focus on older age groups, we also examined data from qualitative in-depth
interviews conducted by University of Maryland, Baltimore County (UMBC) researchers during the CCDE. The interviews were conducted between March 2000 and August 2002 as part of a larger UBMC study of cash option participants in Arkansas, Florida, and New Jersey CCDE programs. The ethnographic study examined 76 care teams in these three states, with each team composed of one consumer, one representative, one paid caregiver, and a consultant. The in-person interviews were conducted in the consumers’ homes and were semi-structured, open-ended, and lasted 60 to 90 minutes. The qualitative study examined how each care team worked together to provide insight into choices made by the consumer and challenges posed by participation in the CCDE (San Antonio, Simon-Rusinowitz, Loughlin, Eckert, & Mahoney, 2007). Of the 76 original ethnographic stories, 45 represented consumers age 50 or older: 10 from Florida, 17 from New Jersey, and 18 from Arkansas. We selected age 50 as the cutoff point to maintain consistency with the quantitative analysis, and examined the interview data regarding health outcomes and satisfaction with care.

The CD approach gave elderly individuals with disabilities feelings of autonomy, well-being, and independence. Consumer teams in all age groups expressed overall satisfaction with the CCDE in terms of being able to direct their finances and choose goods and services that best fit their individual needs. These benefits allowed some older participants to do things they could not do before, and others were able to remain in their own homes longer. Consumer teams reported that trusted family and friends were more dependable and responsible than previous agency workers. Many were more confident that caregiving tasks would be completed. Elderly consumers enjoyed peace of mind and reported that they felt safer and better taken care of by family or known caregivers whom they selected. Some consumer teams described better family relationships because of the program. Many caregivers were able to anticipate consumer needs and take action before problems arose; “Since he is a renal dialysis patient, he receives treatment several times per week early in the morning. To accommodate his needs, Barbara comes each morning between 5:00 to 7:00 to prepare his breakfast” (AR Consumer Team); “I prefer her. It is the trust. To give me a bath and everything” (NJ Consumer Team).

The qualitative analysis indicated no age differences among consumers in their overall satisfaction with the flexibility of the program or with their relationships with their caregivers, although we noted some differences in responses among the age groups. Younger consumers (ages 50 to 64) mentioned satisfaction with the program consultant more often and feeling confident that caregiving tasks would be performed. They also reported feeling more autonomous with the program and expressed enjoyment about controlling their own services. A good relationship or friendship between consumer and caregiver was mentioned more often in the 50 to 64 year and 65 to 79 year age groups versus those in the 80 and older age group. Consumers in the 65 to 79 year and 80 and older age categories mentioned more than younger consumers that they felt safer with their caregiver and less fearful for their personal safety when their caregiver was present. Consumers over age 65 felt that their caregiver was concerned about them and consumers over age 80 spoke more often about caregivers addressing private or intimate needs. Some younger consumers discussed dissatisfaction with their caregiver while no consumers over age 80 mentioned dissatisfaction with a caregiver. Although these data are limited by small numbers of consumer teams, findings suggest that the focus of satisfaction with the CCDE was slightly different for the three age groups and represented a shift from concerns about autonomy and control (for the younger age groups) to concerns focused more on intimacy, privacy, and safety (for the oldest seniors); “Roger explains it, ‘I can look in his eye and know what is going to come.’ Roger feels that the most important thing he does for his father is to protect him” (FL Consumer Team).

Despite high levels of overall satisfaction, consumer teams also noted areas of dissatisfaction with the cash option. Several consumers in each age category mentioned dissatisfaction with the amount of money or number of hours of care they received.
with the program. Some of these same consumers expressed dissatisfaction with other aspects of the program, such as difficulty understanding the program, contacting the program consultant, or finding and scheduling caregivers. Programs were able to use these findings to address areas of dissatisfaction.

**Caregiver Well-Being**

Caregiver burden can have negative consequences for the health of both caregivers and consumers and may result in earlier nursing home placement for consumers. We sought to determine if informal and paid caregivers for older consumers also have been satisfied with and benefited from their roles in the CCDE. Similar to findings from the original evaluation, informal caregivers for CCDE participants in the 50 to 64, 65 to 79 and over 80 age groups were more satisfied with life and arrangements for client care, and experienced less physical, emotional, and financial strain as compared to informal caregivers for participants who received traditional services.\(^1\) In the qualitative interviews, they spoke about the program flexibility and how that helped them manage multiple responsibilities. For example, families could schedule coverage during work hours (even non-traditional work schedules) and during other responsibilities to allow them to manage caregiving with child care and college classes. Informal caregivers in the CCDE program were less worried about the client’s care or safety. They spoke about the peace of mind that came from the ability to hire their own workers (e.g., relatives, friends, others) whom they trusted to provide high quality care.

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Although the contrast in the survey responses for paid-directly hired workers versus agency workers was not as striking as for the informal caregivers, the direction of the effects were similar (i.e., CCDE directly hired workers (most of them family or friends) reported equal or less physical and emotional strain and equal or better relationships with clients as compared to agency workers); “Sylvia...feels that she can do a better job [in a CD setting].... I’m happy. It’s better pay. I’m more relaxed. I don’t have to worry about getting a phone call [from the agency] every 15 minutes to go here and go there....the job is friendlier...It’s like being in my own family. This is what I try to tell the girls [at the agency who burn out]” (FL Consumer Team).

Findings from the ethnographic study clearly demonstrated the importance of paid and unpaid workers functioning as a team to care for a consumer. When these relationships were coordinated everyone benefited—consumers received better care, and both paid and informal caregivers experienced decreased emotional strain and worry.

These analyses should help to address persistent concerns about the interest and ability of elders to manage a CD personal care option. Evidence from the survey and ethnographic study analyses indicates that older CCDE consumers generally were satisfied, experienced enhanced well-being and no increases in adverse effects, and that informal and paid caregivers benefitted as well. While a CD model of personal care services may not be the choice of every consumer, our analyses suggest that it should be one option among others for all consumers, including elders.

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Endnote
1. A substantial number of informal caregivers identified at baseline were subsequently paid for their work. Payment most likely contributed to their increased satisfaction and decreased strain. For example, in their further analysis of similar treatment effects for Arkansas Cash and Counseling informal caregivers for clients of all ages, Foster, Brown, Phillips, & Carlson (2005) concluded that “estimated program effects were not driven solely by a payment effect, but payment may have contributed to the magnitude of the impacts” (p. 481).

References


Meeting the long-term care needs of the growing aging population is a priority policy issue in the United States. Even as public resources become more limited and policymakers seek to target areas of waste, fraud, and abuse to trim program budgets, participants today demand and expect more flexibility and responsiveness in public services. We need imaginative solutions to address the challenges created by the combination of a growing number of elders and people with disabilities and a limited long-term care workforce. The traditional model of home and community-based services emphasizes professional decision making and agency oversight, and imposes rules and restrictions regarding the timing, duration, amount, and scope of services. In contrast, participant-direction (PD; also called consumer-direction [CD] and self-direction [SD]) is a service model that offers elders and persons with disabilities more control over their services. Cash and Counseling, one of the most flexible models of PD, allows participants the authority to manage a personal care budget, hire, supervise, and fire their own personal care workers (including relatives), and purchase other personal assistance goods and services. While some speak about CD and hiring relatives as if they are one and the same, not all CD programs include this option.

Participant-direction has become increasingly appealing to policymakers and others who view it as a way to empower participants, improve care, and stretch scarce resources. Opponents of hiring relatives as caregivers, however, have raised concerns, especially about the option of hiring legally responsible relatives, such as parents and spouses of people with disabilities. They question whether hiring relatives who otherwise might provide service to loved ones for free is an appropriate mix of public-private responsibility. They have raised concerns about the quality of care elders and people with disabilities may receive, and the potential for fraud and abuse. They also fear increased public costs if the unpaid care hours that currently are provided to participants by friends and relatives were substituted with paid care. Proponents of the option to hire family members as caregivers have cited benefits such as expanding the worker supply to compensate for the limited and decreasing pool of workers, increasing participant choice, and improving the quality of care that participants receive.

“This ability to choose and hire workers, including family members, enhanced not only quality of care, but also the participant’s ability to receive paid care at all.”

This article highlights new information that can inform the long-standing policy debate about hiring relatives as caregivers (Linsk, Keigher, Simon-Rusinowitz, & England, 1992; Simon-Rusinowitz et al., 2010; Simon-Rusinowitz, Mahoney, Loughlin, & Sadler, 2005). Rather than relying on long-standing fears and myths, a synthesis of existing research about this key policy option can inform difficult state program and budget decisions as well as national health care reform policy choices. In particular, these findings can guide policymakers as they determine how to implement the Community Living Assistance Services and Supports (CLASS) provisions in the new health care reform legislation.

The Cost of Long-Term Care

More than 8.6 million community-living adults over age 65 need assistance with one or more activities of daily living or instrumental activities of daily living. The cost in 2003 for each nursing home patient was estimated to be $66,000 per year (Congressional Budget Office [CBO], 2004). This is about three times...
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higher than individual costs for community residents, and differences in the level of care needs between community-living individuals and nursing home patients do not account for the significant difference (Kaye, Harrington, & LaPlante, 2010).

Over 10 million individuals receive care at home from unpaid caregivers. The estimated 29 million unpaid caregivers are typically female and either spouses or middle-aged daughters of the care recipients (Institute of Medicine [IoM], 2008). The economic value of unpaid help is over $300 billion dollars per year (AARP Public Policy Institute, 2008; Iglehart, 2010). The role of unpaid or informal caregivers will continue to grow with the increasing aging population and the number of individuals with unmet needs also will continue to grow. Individuals with disabilities who live alone without family help are at risk for having unmet healthcare needs. It is difficult to project the future cost of long-term care for elders with disabilities, especially since the location of this care and who provides it are important factors. Kaye et al. (2010) suggest that a redistribution of care, from institutional and agency to non-institutional and individual providers, will result in the greatest decrease in long-term care spending.

The issue of cost in public services also is integrally tied to the question of whether people actually receive services. A program that provides immediate service inevitably will cost more initially than a program in which those entitled to service linger on waiting lists. Since more than half of Cash and Counseling participants opted to hire relatives, this likely explains some increased ability to obtain personal care services. When comparing program costs, we must acknowledge that a key program benefit—increasing timely access to services—may lead to increased initial program costs. Cash and Counseling Demonstration and Evaluation (CCDE) evaluators concluded that “Medicaid costs [for personal care services] were generally higher under Cash and Counseling because those in the traditional system did not get the services they were entitled to.” (Dale & Brown, 2007, p. 488). They noted, however, that it is unlikely that policymakers would seek to contain costs by depriving beneficiaries of necessary services.

Even in early stages of program implementation, CCDE evaluators found evidence of potential long-term cost savings, from reduced use of other Medicaid services, such as nursing home care and/or skilled home health services (Dale & Brown, 2007). By the third year of implementation in Arkansas, their Cash and Counseling Program, “IndependentChoices” had reduced nursing facility use by 18 percent over the three-year period. Follow-up cost evaluations conducted in Arkansas have shown that Cash and Counseling reduced overall Medicaid program costs and produced savings of over five million dollars over the first 10 years of implementation (Arkansas Department of Human Services, 2008).

A recent analysis of California’s In Home Supportive Services (IHSS) Plus waiver program provides additional information about the costs of hiring legally responsible relatives as caregivers. In this analysis, Newcomer and Kang (2008) compared recipients having a waiver-eligible provider (i.e., parents of children, spouses of adults) for any portion of 2005 with recipients in the regular IHSS program who received personal assistance services through other relatives and non-relative providers. The researchers found “no financial disadvantage and some advantages to Medicaid from allowing spouses, parents (and other relatives) to be paid IHSS providers.” Their research “argues in favor of honoring the recipient’s and family’s preference for such providers” (p. 42). They also suggest that the preference for family caregivers in this program may continue to grow, due to the increase in enrollment of Hispanic and Asian populations who are more likely to select the option.

“For the two-week period prior to the 9-month evaluation, the number of volunteer care hours provided for Cash and Counseling participants is quite impressive, with averages ranging from 74 hours of unpaid care received by non-elderly participants in Arkansas to 148 hours received by non-elderly participants in FL.”

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Shortages in the Direct Care Workforce

A 2008 Institute of Medicine (IoM) report outlined policy issues related to long-term care workforce shortages and deficiencies (including health care professionals, paid, and unpaid direct care workers). The report suggests that the direct care workforce is not sufficient to meet the demand, and this problem will grow as more elders with disabilities shift to using home and community-based services. Low salaries, minimal benefits (i.e., health insurance and sick leave), and lack of flexibility are some of the factors associated with the high turnover rate (80 to 90 percent turnover within the first two years) of direct care workers. Low employee retention and inadequate training often lead to poor quality care. Suggestions to reform long-term care and ensure an adequate and skilled workforce include: increasing recruitment and retention efforts, providing workforce education and training, increasing financial incentives to make jobs more competitive, and redesigning services to be more effective and efficient.

The IoM identified three key principles for redesigning long-term care services:

- The health needs of the older population need to be addressed comprehensively;
- Services need to be provided efficiently; and
- Older persons need to be active partners in their own care.

The report also explored several care delivery models, including Medicaid Demonstration Projects, considered as innovative in their efforts to reduce workforce shortages. Cash and Counseling is a CD model that addresses these key principles. The program evaluation has shown positive results in improving care coordination while allowing individuals to participate in selecting services.

The critical shortage of direct care workers in the U.S., combined with our aging population, highlights the crucial need for expansion of the direct care workforce. Proponents of hiring relatives as caregivers have suggested that the option may provide entry into the field of home health care for people who may not have otherwise considered this career option. Thus, the option to hire relatives as caregivers offers exciting possibilities not just for the care of one participant, but for expanding the pool of personal assistance workers for all participants. The critical question, however, has been: will workers who gain experience caring for a family member remain in the home health care field?

A recent study addressed this by surveying caregivers who previously had been employed through IHSS caring for a friend or relative (Benjamin, Matthias, Kietzman, & Furman, 2008). The study compared 180 caregivers who had remained in the home health care field after their IHSS experience (“stayers”) with 203 who had not stayed in the field (“leavers”). The authors estimate that about 5 percent to 10 percent of IHSS family caregivers remain in the field to care for others after their initial caregiving experience. In addition, even in the absence of targeted retention efforts, the proportions of leavers who said they were willing to care again for family (59 percent) and for strangers (43 percent) was encouraging for states looking to expand their direct care workforces. These findings suggest that former family caregivers could be targeted for recruitment as professional caregivers, and that family caregiving has the potential to increase significantly the direct care workforce. The researchers concluded that “the growing number of programs that pay family members to provide home-based services are attracting relatives and friends who had not considered home care as a career option. With more outreach … about home care employment options, these related workers may help solve the long-term care workforce shortage problem” (p. 104).

Participant Preferences, Quality of Care, and Substitution of Care

More than 6,500 Medicaid consumers in Arkansas, Florida, and New Jersey participated...
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in the Cash and Counseling Demonstration and Evaluation (CCDE)—a real world test of this model in which volunteers were randomized to receive either traditional agency services or PD services. More than half of participants that were given the option to hire their own worker opted to hire relatives to address unmet personal care needs (including legally responsible relatives such as parents of children with disabilities in Florida and spouses in Florida and New Jersey). CCDE evaluators addressed the issue of quality of care and concluded that “the control and flexibility offered by the program greatly increased consumers’ satisfaction with the help they received and with their overall quality of life. Consumers under Cash and Counseling appeared to receive care at least as good as that provided by agencies, in that they had the same or an even lower incidence of care-related health problems” (Carlson, Foster, Dale, & Brown, 2007, p. 480-81).

In a further analysis that compared satisfaction with directly hired related versus non-related workers in Arkansas, researchers found that participants who hired relatives reported that they were more satisfied with their care, reported fewer adverse health effects, were more likely to receive care during non-traditional hours and reported less unmet need for personal care as compared to those who hired a non-relative personal attendant (Simon-Rusinowitz et al., 2005).

The ability to choose and hire workers, including family members, enhanced not only quality of care but also the participant’s ability to receive paid care at all. For example, in New Jersey, for the two weeks prior to the nine-month follow-up survey, 92 percent of cash option participants ages 18 to 64, and 94 percent of cash option participants age 65 and older were receiving paid care. For those participants who were randomized to receive agency services, the corresponding percentages representing those who received any paid care were 79 percent and 82 percent respectively. The magnitude of this effect depended on the availability of directly hired workers versus agency workers, and was most pronounced in Arkansas, due to worker shortages. On average, participants who relied on paid agency services received fewer hours of paid care and slightly more hours of unpaid care. However, for both Cash and Counseling participants and those randomized to receive agency services, family members and friends continued to provide for their loved ones; 90 percent or more of consumers in both groups in every state and age group continued to receive some unpaid care at nine months. For the two-week period prior to the nine-month evaluation, the number of volunteer care hours provided for Cash and Counseling participants was quite impressive, with averages ranging from 74 hours of unpaid care received by non-elderly participants in Arkansas to 148 hours received by non-elderly participants in Florida (Carlson et al., 2007).

Lack of Research Support for Concerns about Fraud and Abuse

Cash and Counseling does not screen participants for inclusion or exclusion, but has several built-in mechanisms to track service quality and to help prevent fraud and abuse, that is, to protect the participant as well as program integrity. (Not surprisingly, approval of Medicaid waiver applications requires a strong program design emphasis on preventing fraud and/or abuse.) These checks and balances apply to all participants, not just those hiring relatives. A bookkeeping service writes checks to workers and pays taxes, allowing participants to direct the use of their allowances without managing large cash amounts. A participant-designated representative helps those consumers who need and/or prefer assistance with employer tasks such as hiring and supervising workers. Consultants help develop and approve cash plans, and monitor participant well-being. Consultants also are responsible for reporting suspicious cases, which includes notifying the program office and/or an adult protective services agency. If a consultant is concerned about a difficult family relationship with a paid family worker, the consultant can increase monitoring, help the participant change workers, or ask the participant to return to agency-delivered services.

The CCDE evaluation found that these built-in mechanisms were effective, and fraud and abuse were

“The CCDE evaluation found that these built-in (quality monitoring) mechanisms were effective, and fraud and abuse were not major concerns.”
not major concerns. Phillips et al. (2003) reported that “instances of exploitation of consumers who were already receiving the allowance were rare in the three Cash and Counseling programs. Those that did occur were resolved” (p. 32). In addition, CCDE survey data indicated that Cash and Counseling participants were less likely than those randomized to agency services to report problems with their caregivers, such as neglecting them, being disrespectful, and taking things without asking (Carlson et al., 2007).

Participants and caregivers provided additional information in focus groups and in-home interviews. Consistent with the CCDE survey data, the interview data revealed no evidence of family caregivers who abused or neglected participants. To the contrary, participants described closeness, loving care, and trust as a part of the care they received. For example Mrs. Williams is an 85 year-old African American woman who lives with and is cared for by the youngest of her four daughters. Three of her four daughters live nearby and help in her care. They care for Mrs. Williams because “it’s basically a family thing… I can remember the time she used to walk to work, she did housekeeping. … she provided for us and let herself go, and now is our time to try to help her as much as we can. Because I can remember times she made sure we had shoes and she was putting cardboard in the bottom of her shoes to make sure we had them. It’s our time to see that she gets what she needs” (p. 154). Family caregivers were very dedicated, often worked more hours than were paid for, and used their pay to buy items for the participant. Participants and caregivers often spoke of the friendship or affection they shared (Eckert, San Antonio, & Siegel, 2001).

Many caregivers reported feeling blessed or lucky to be able to provide care to a loved one. For example, one Arkansas caregiver stated: “I just feel good that I’m able to be there for her right now” (Simon-Rusinowitz et al., 2005, p. 100). When asked about the challenges of being a paid caregiver, participants acknowledged the time demands of this difficult role, and the ways in which it limited their family and social lives. Overall, however, they appeared to accept these challenges and were happy to care for their loved ones. A statement drawn from focus groups with paid family caregivers summarizes their experiences 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” (p. 101).

**Conclusion**

Creating public policy to provide high quality and accessible home care services is a critical responsibility. Policymakers and other stakeholders are wise to proceed cautiously when creating policy for our most vulnerable citizens. Recent research results about the desirability, quality, and cost-savings of hiring relatives as caregivers, however, support the view that this option is an important component of long-term care policy. These substantial research findings can replace long-standing fears about this option and guide policymakers and other stakeholders when making tough state budget decisions and deciding how to implement new national health care reform legislation.

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