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**Cash and Counseling:  
Improving the Lives of  
Medicaid Beneficiaries  
Who Need Personal Care  
or Home- and  
Community-Based  
Services**

*Executive Summary*

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## EXECUTIVE SUMMARY

Medicaid beneficiaries who are elderly or have disabilities and who qualify for home- and community-based assistance with personal care typically have had to rely on Medicaid-certified home care agencies for the paid assistance they need to perform the normal daily activities associated with living in the community. The assistance that beneficiaries receive from agencies, under the Medicaid State Plan optional personal care benefit, Section 1115 demonstration programs, or section 1915 (c) waiver programs, is a huge benefit to recipients and their families. However, for many years, advocates for people with disabilities have raised awareness about some shortcomings of the system from their perspective. Agency services fail to reflect some beneficiaries' needs and preferences for particular types and amounts of care, the timing and methods of delivery of the care, and the individuals or agencies delivering it. This mismatch between preferences and services also can adversely affect the beneficiaries' unpaid caregivers, who may have difficulty working for pay and meeting other family obligations because of the time required to provide caregiving. The inflexibility in and limitations of the paid services might lead to physical or emotional burnout in the unpaid caregivers, which may, in turn, require beneficiaries to move into nursing homes.

To address consumers' desire for greater control over their care, the federal government has encouraged states to offer consumer-directed options for personal care. States have responded by offering a range such options for beneficiaries who are eligible for home- and community-based services (HCBS). These options typically include allowing consumers to hire and direct their own workers, but some states allow consumers to manage an individual budget for their self-directed services and supports. Except in California, where consumer direction is the norm rather than the exception, nearly all of these programs are small.

One of the most innovative and flexible consumer-directed-care models is Cash and Counseling, recently tested in a demonstration program that was co-funded by The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. This report summarizes the findings from five years of research by Mathematica Policy Research, Inc. (MPR) on how each of the three demonstration states implemented its program, and on how the programs have affected the consumers who participated, the consumers' paid and unpaid caregivers, and the costs to Medicaid. The analysis is based on an experimental design to ensure that the estimates of program effects are unbiased, and has sample sizes that are adequate to detect program effects of policy-relevant magnitudes.<sup>1</sup>

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<sup>1</sup> The Centers for Medicare & Medicaid Services approved the demonstration programs under Section 1115 authority of the Social Security Act. The National Program Office for the demonstration, at Boston College and the University of Maryland, coordinated the demonstration, provided technical assistance to the states, and oversaw the evaluation by MPR. This report draws on the many detailed MPR reports and journal articles that have been prepared over the course of the study.

## THE CASH AND COUNSELING MODEL AND DEMONSTRATION

Cash and Counseling gives consumers a monthly allowance that they may use to hire workers, and to purchase care-related services and goods. Consumers can get help managing their care by designating representatives, such as relatives or friends, to help make decisions. It also offers counseling and bookkeeping services to help consumers and representatives to handle their program responsibilities. These tenets of Cash and Counseling—allowing flexible use of an allowance, use of representatives, and availability of counseling and fiscal services—are meant to make the model a viable option for consumers of all ages and abilities. Allowing consumers to hire family members, even legally responsible ones (in some states), without requiring these workers to contract with the state or work for an agency, further increases consumers’ freedom of choice relative to other consumer-directed options.

Arkansas, Florida, and New Jersey participated in a three-state demonstration to test the Cash and Counseling model in their respective Medicaid programs. The three states adhered to the basic principles in establishing their cash and counseling programs but implemented their programs in different ways.

- Arkansas and New Jersey “cashed out” (that is provided cash allowances in lieu of) personal care services (PCS) provided under their respective Medicaid State Plans. Florida cashed out services covered under three Medicaid HCBS waiver programs.
- Florida offered its program to children and adults with developmental disabilities, as well as to frail elderly beneficiaries (age 60 and over) and nonelderly adults with physical disabilities, whereas the two other states both restricted their programs to adults (age 18 and older) with physical (and perhaps cognitive) disabilities.
- Arkansas sought to expand access to paid care for consumers in rural or other hard-to-serve areas, whereas Florida and New Jersey restricted their programs to consumers already receiving (or assessed for) covered services.
- The programs differed widely in the size of the monthly allowance, and in the methods used to determine the allowance amounts. Although all three based the allowance amounts on the consumers’ care plans, only Arkansas and Florida scaled down the amounts (by 10 to 20 percent) to account for historic differences between the hours of care recommended and approved in the care plans and the hours that consumers actually received under the agency-delivered service model.
- The states also differed in the types of people who conducted the counseling, the mechanisms used to pay for the counseling, and the methods used to train the counselors.
- The states differed on many nonprogrammatic dimensions as well, including labor market conditions and relationships with agencies and unions.

All of these differences contributed to differences in the effects of the program across the three states.

## **HYPOTHESES, DATA, AND METHODOLOGY**

The evaluation was designed to investigate questions about how the Cash and Counseling program operated, and questions about the program's effects on participating beneficiaries, on the beneficiaries' paid and unpaid caregivers, and on costs to Medicaid and Medicare. Both the implementation analysis and the impact analysis conducted to answer those questions required multiple data sources.

The impact analysis used an experimental design to assess the effects of Cash and Counseling on the well-being of consumers, and on the consumers' unpaid caregivers. After completing a baseline interview, half of the demonstration enrollees were randomly assigned to the treatment group, whose members were eligible to receive a monthly allowance that they could use to hire workers and to purchase care-related goods and services. The other half were assigned to the control group, whose members had to obtain their personal care services through the traditional agency-based model. In addition, the experiences of the workers hired by consumers were examined and compared with those of agency workers. Separate analyses were conducted for each state, using the same regression models and methodology for each one to ensure comparability.

To test the concern expressed by agencies and some policymakers that consumer direction is not appropriate for elderly people, MPR evaluated program effects separately for elderly consumers (aged 65 or older in Arkansas and New Jersey, aged 60 or older in Florida) and for nonelderly adult consumers, in each state. Effects on children also were evaluated separately. The three age groups were expected to have different needs, and (perhaps) to hire different types of workers. These differences were especially noteworthy in Florida, due to the fact the great majority of nonelderly adults there had developmental disabilities.

Program effects on consumers were measured by comparing the postenrollment outcomes for the full treatment and control groups, regardless of whether a particular treatment group member actually received the monthly allowance. The estimated treatment-control differences therefore reflect the effects on interested beneficiaries of being offered the opportunity to manage an allowance. Some consumers never received their allowances, so this "intent-to-treat" approach understates the impacts of actual participation in the program. Regression models and logit models were used to estimate these treatment-control differences. Only differences that were statistically significant at the .05 level were considered to be evidence of program effects. Patterns of results across measures and subgroups also were used to assess whether statistically significant differences were likely to reflect true program effects or chance differences.

Data on measures of consumer well-being were collected during 30-minute telephone surveys conducted nine months after the consumers had enrolled in the program. Data on Medicaid and Medicare costs and service use were drawn from claims data for the two years after enrollment. MPR also surveyed the individuals who had been the consumers' primary informal (unpaid) caregivers at the time of enrollment, to estimate program impacts on these

caregivers' well-being 10 months after enrollment. Finally, MPR interviewed the individuals who were the consumers' primary paid workers at the time of the consumers' nine-month interviews.

## **CONSUMERS' DEMAND FOR AND EXPERIENCES WITH THE PROGRAM**

Enrollment periods differed among the three states according to each state's readiness to conduct outreach and enrollment activities, and to implement its consumer-directed program. Arkansas started in December 1998 and enrolled 2,008 adult consumers; New Jersey began intake in November 1999 and enrolled 1,755 adult consumers in the demonstration; and Florida enrolled 1,818 adult and 1,002 child consumers beginning in June 2000. Half the enrollees in each state were randomly assigned to the treatment group. Programs stopped enrolling into the demonstration either when they reached their enrollment targets or in July 2002, whichever came first, to allow the evaluation to proceed.

A modest proportion (6 to 10 percent) of eligible adults enrolled, but the program attracted 16 percent of Florida's Medicaid children with developmental disabilities before enrollment was terminated. Across all three states, enrollees generally were eligible individuals qualifying for somewhat larger allowances, those who already were receiving the personal care or waiver services before program enrollment began, and those who survived the entire enrollment period.

Although every treatment group member had the opportunity to receive an allowance, the proportion that actually received one during the first year after enrollment ranged from only 42 percent of the elderly sample members in Florida to 89 percent of the nonelderly in Arkansas. The great majority of those who received allowances began receiving them by the sixth month after enrollment. In Arkansas, however, most cash recipients received their allowances by Month 3, as the state required counselors to have their consumers develop the required spending plans within 45 days after enrolling. In Florida, on the other hand, counselors were uncertain how much help they should give consumers who were trying to develop spending plans because of the program's emphasis on consumer control and empowerment. Because they felt that consumers needing extensive help to develop a care plan were not likely to be able to manage their own care, they did not attempt to provide all of the help such consumers needed.

The allowance amounts varied widely among and within states. The median allowance offered in Arkansas was \$313, compared with \$829 for adults in Florida (\$831 for children), and \$1,097 in New Jersey. Consumers used their allowances mainly to hire workers; few used them to modify homes or cars. Consumers used the counseling and fiscal intermediary services widely and were very satisfied with them.

Program counselors reported very few cases of abuse or neglect of the consumer, or fraudulent use of the allowance. The requirement that only expenditures consistent with the approved spending plan would be allowed by the fiscal agent writing the checks, unless authorized by the counselor, helped ensure that the allowance would not be misused. Most consumers were very pleased with the program, --more than 85 percent of consumers in any age group in any state would recommend the program to others who needed personal care or waiver services. However, more than 30 percent of adults in all three states had disenrolled by the 12th

month after enrollment. Voluntary disenrollment tended to occur within a few months after enrollment, due to difficulties finding or replacing a worker, rather than to dissatisfaction with the program.

## **EFFECTS ON CONSUMERS' USE OF PERSONAL CARE AND WELL-BEING**

For six of the seven state-age groups we examined, the treatment group was significantly more likely than the control group to be receiving paid personal assistance during a two-week reference period preceding the nine-month interview. The difference was largest in Arkansas, where many beneficiaries faced limited access to services due to worker shortages, but it also was sizable in New Jersey and in Florida (except in the case of elderly consumers). However, although treatment group members generally received more paid hours of care, they received less unpaid care than control group members on average, resulting in slightly to moderately lower total hours of care for elderly and nonelderly adults in all states and for children in Florida.

Treatment group members were much more likely than control group members to have their needs met, and to be very satisfied with their care. With one exception, treatment group members in every age group in every state were much more satisfied with virtually every aspect of their care. On the 18 measures examined, which included such indicators as satisfaction with caregivers' reliability, attentiveness, and behavior and consumers' satisfaction with the quality of care, treatment group members consistently gave much higher ratings than control group members to the care they received. Elderly consumers in Florida were the sole subgroup for which there were no favorable effects on satisfaction, as only 42 percent of the treatment group members received their allowances (continuing to rely instead on agency-supplied services).

Despite concerns about consumers' safety under Cash and Counseling, for every age group in every state, treatment group members were no more likely than control group members to suffer care-related health problems on any of the 11 measures examined. Furthermore, for about one-third of the 77 estimates obtained, the treatment group had a significantly *lower* rate of adverse events. Thus, care appears to be at least as good, if not better, under Cash and Counseling than under agency care.

Most important, treatment group members were far more satisfied than control group members with how they were spending their lives. More than one-half of the participants in each of the seven state-age groups reported that the program had improved their lives a great deal.

## **EFFECTS ON USE AND COST OF MEDICAID- AND MEDICARE-COVERED SERVICES**

The Cash and Counseling program was not designed to save money, but rather, to give consumers much greater control and flexibility over their care without costing Medicaid any more per month of benefits received than that care would have cost under the traditional agency-based model. In addition, states are likely to want to understand how the introduction of Cash

and Counseling will affect their *total* Medicaid costs for cashed out services, and whether the program leads to higher or lower costs for other Medicaid services.<sup>2</sup>

Medicaid personal care/waiver costs were significantly and substantially higher for the treatment group than for the control group, both per sample member and per month of benefits received, for most of the state-age group subgroups examined. The treatment group's costs for cashed out services during the first year after enrollment ranged from essentially the same as the control group's (for Florida's elderly consumers) to double the control group's costs (for elderly and nonelderly adults in Arkansas). The costs were higher for the treatment group in Arkansas and in New Jersey in part because many control group consumers in those *states did not receive any paid services for which they were authorized*. However, the treatment group's personal care costs per month of benefits received also was higher than those of the control group in the two states. This unexpected result arose solely because control group care recipients received substantially less care than was authorized in their care plans (even in Arkansas, after the state's pre-demonstration ratio of actual to expected costs was applied to the care plan amount). The treatment group members in both states received, on average, roughly the allowance amounts that their (discounted) baseline care plan called for. In Florida, conversely, costs per recipient month among children and nonelderly adults (nearly all of whom had developmental disabilities) were higher for the treatment group because the group's members received 20 to 30 percent more than was authorized in their baseline care support plans on average. At the time consumers spending plans were developed, counselors revised upward the care/support plans of many consumers, adding additional resources. No analogous opportunity existed for the control group.

Other Medicaid costs were lower for the treatment group in each age group in all three states, but by modest (and statistically insignificant) amounts in most cases (four to seven percent). However, Arkansas's nonelderly treatment group had other Medicaid costs that were 17 percent lower than those of the nonelderly control group, mainly due to lower use of long-term care services, including nursing homes and home health care. Similarly, among Florida children, treatment group members had significantly lower costs than control group members (by 15 percent) for other Medicaid costs.

As a result of these lower costs for other Medicaid services partially offsetting the higher personal care costs, total Medicaid costs were higher for the treatment group than for the control

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<sup>2</sup> The analyses of program effects on costs presented here differ substantially from the budget neutrality calculations performed by the states for CMS. Under the terms of the Medicaid Section 1115 waiver authority for the demonstration, each of the three program states was required to demonstrate that federal Medicaid expenditures with the program are no higher than expenditures without the program, over the life of the program. This test was implemented by comparing the treatment group's average Medicaid cost for a set of "core" services *per month the allowance was received* to the control group's analogous average cost per month that agency-based PCS/waiver services were received. These core services included the allowance and PCS/waiver services plus related services that might be affected by the program, such as home health, targeted case management, hospice, durable medical equipment, and transportation (although the exact definition varies by state). Our calculations in this report differ in that they are limited to the first two years after demonstration enrollment for all consumers, do not examine the "core" services as a group, and are not typically restricted to only months when consumers are receiving the allowance or agency services. CMS has determined that all three states have satisfied the budget neutrality requirements over the life of the demonstration.

group for every state and age group during the first year, but not significantly so in most cases. Only for younger adults in Florida and older adults in Arkansas were the treatment group's total Medicaid costs significantly higher than the control group's.

During the second year after enrollment, the patterns shifted, but in different ways across the three states. In Arkansas, the treatment-control difference in personal care expenditures fell and the savings in other Medicaid costs grew such that the total Medicaid cost differential decreased to a statistically insignificant five percent of the control's average cost. By contrast, in Florida and in New Jersey, the gap in total Medicaid costs for all adults grew to about 12 percent of the control group mean, a statistically significant difference in both states.

## **EFFECTS ON PAID AND UNPAID CAREGIVERS**

Consumers' well-being depends largely on the individuals who are their primary caregivers, regardless of whether the caregivers are paid for any or all of that care. The evaluation therefore examined differences between the experiences of the primary unpaid (at enrollment) caregivers of the treatment and control groups, and the differences between the two groups' primary paid workers. These two groups of caregivers overlapped considerably for the treatment group, because many who were the consumers' primary unpaid caregivers at enrollment (29 percent for adults in Florida, 42 percent in New Jersey, and 56 percent in Arkansas) began receiving pay from consumers.

In all three states, among primary caregivers who were unpaid at enrollment, those caring for the treatment group were much more satisfied than those caring for the control group with the overall care that consumers received (and they worried less), and they were less likely to report emotional, physical, or financial strain. Although high proportions of caregivers for both treatment and control group members reported that caregiving had serious adverse effects on their social lives, work lives, and physical and emotional health, the rates were significantly lower for the treatment group's caregivers. As a consequence, the treatment group's caregivers reported much greater satisfaction with life. The only exception to this pattern across states and across age groups within states was for the caregivers for nonelderly adults in New Jersey, where the level of emotional, physical, and financial strain reported by caregivers for the treatment group was not significantly different than that reported by caregivers for the control group. This difference appeared to be due to differences across states in the program's effect on overall care burden. Whereas the treatment group's primary unpaid caregivers provided about seven to nine percent fewer total hours of care than control group caregivers for adults in Arkansas and Florida, the treatment group's caregivers for the non-elderly in New Jersey provided *more* total hours of care than the control group's. (Among the elderly in New Jersey, the total hours of care provided by caregivers for the treatment group was similar to the total hours of care provided by caregivers for the control group.) The favorable effects on caregivers were not due solely to the fact that some caregivers began receiving pay for some of the care provided—those who did not become paid workers also had significantly better outcomes than control group caregivers.

More than two-thirds of workers hired directly by treatment group consumers were previously unpaid caregivers—mostly family members-- and these workers continued to provide many hours of unpaid care. Directly hired workers received wages roughly similar to agency

workers in each of the three states, but the directly hired group was much more satisfied with the pay. Directly hired workers and agency workers experienced similar levels of physical strain and job-related injuries. In each state, however, the directly hired workers had *higher* levels of emotional strain and of feelings of being unappreciated by the care recipients' families and friends. These differences were due to the fact that many directly hired workers were related to their care recipients. Directly hired workers who were not related to the care recipient reported rates of emotional strain and feelings of being unappreciated that were very similar to those of agency workers. The difference between agency workers and directly hired relatives reflects family dynamics and the hired relatives' feeling of being constantly "on-call."

## CONCLUSIONS AND POLICY IMPLICATIONS

Cash and Counseling was implemented successfully in three different states, with three different benefit levels, types of services covered, target populations, program rules, and structures for providing counseling and bookkeeping services. Consumers, often with the help of self-appointed representatives, successfully managed their allowances, hired workers they liked, and terminated the employment of relatives and friends when they had to. The flexibility of the allowance enabled consumers not only to hire whomever they wanted, define the tasks they wanted performed, and specify how and when the tasks would be accomplished, but to meet their needs through the purchase of goods and services not available in the traditional system. These goods and services included special communication devices, transportation, personal care supplies, kitchen appliances, security systems, home and vehicle modifications, and many other items. The counselors'/consultants' reviews of spending plans and monitoring of check requests and time sheets limited incidences of fraud, abuse of the funds, and abuse of consumers to a handful of cases.

The program had overwhelming positive effects on consumers of all ages, and their caregivers. Consumers who managed their own care were far happier with their care and their lives in general, and experienced no more—and in some cases significantly fewer—adverse events than those receiving agency care. Caregivers experienced much less physical, emotional, and financial stress.

The treatment group's higher satisfaction and lower unmet needs occurred in spite of the fact that its total hours of care was lower. Furthermore, the treatment group had more favorable outcomes even when the ratio of actual to expected benefit amounts was controlled for. Thus, the greater amount of benefits received was not the sole source of the treatment group's greater satisfaction. Interviews with consumers suggested that the difference was due to the assistance received being of higher quality and greater efficiency than agency care.

Despite its overwhelmingly positive effects, some potential cost-related and operational drawbacks to the program remain. Among the potential cost-related problems are the following:

- Total costs to Medicaid were consistently higher with Cash and Counseling than without it, a worrisome concern in times of tightening Medicaid budgets, even if the higher costs were due mostly to correction of failings of the traditional system.

- Using a “discount factor” to scale down care plan amounts by the share that consumers actually receive on average may be needed to keep costs the same under Cash and Counseling, but could leave some consumers with too little money to meet their needs. In practice, none of the three states actually restricted cash allowances to less than the expected cost of the approved care, even though both Arkansas and Florida did use a discount factor. In Florida, consumers actually received substantially more than their care plan amounts due to generous reassessments when spending plans were being developed. In Arkansas, the amount allocated for counseling services was reduced over time, through more aggressive negotiating, and the surplus was used to augment the amount paid per hour of care in the care plan. Thus, the demonstration provides no evidence on what would happen if the allowance were actually discounted. Failure of the traditional program to provide the number of authorized hours because of agencies’ inability to find enough workers (as occurred in Arkansas) should not be compounded by scaling down allowances by a comparable percentage for those who self-direct.
- Costs could increase if the existence of the program were to lead some eligible Medicaid beneficiaries who would not have applied for the PCS or HCBS benefit under the agency model to do so under Cash and Counseling. The fact that only one-third of Arkansas’s control group consumers who were not receiving agency services before enrollment received them after enrolling suggests that at least some of these consumers were not interested in receiving agency-based services; many non-recipients in the control group said they did not seek agency services. Other evidence, however, suggests that an inadequate supply of workers is probably the reason why most of the members of that group of consumers did not receive services. Florida and New Jersey limited their programs to consumers who had been receiving (or, in New Jersey, those who already had been assessed for) the benefit in the traditional program, and they advertised the programs only to those consumers. However, limiting enrollment to current recipients of services prevents people who have access problems under the traditional program from resolving these problems through participation in Cash and Counseling.
- Except in Arkansas, the cost savings in other Medicaid costs for adults, most notably the adults’ long-term care costs, did not persist into the second year. This suggests that substantially increasing the number of eligible beneficiaries receiving services and filling major gaps between actual and authorized levels of services may be the only way to generate savings in other long term care costs.

The demonstration states each learned a number of important lessons about how costs can be controlled. Attention to these lessons by other states adopting Cash and Counseling or similar programs may lead to better lives for consumers at little or no additional costs to the states:

- The assessments and reassessments used to determine consumers’ PCS/waiver benefits on which the allowance is based should be prepared by trained independent state staff, rather than counselors, who may act more as advocates for

the consumer than as objective assessors of need. The assessments and reassessments should be done without regard to whether the consumers will be directing their own care. New Jersey did this successfully, using Medicaid nurses to conduct the assessment and avoided the problem experienced by Florida of consumers receiving far more resources on average than were authorized in their *initial* care plan.

- Contracting for counseling services should be done in a manner that provides incentives for cost efficiency. For example, Arkansas found that the length of time until consumers' required spending plans were completed, and the corresponding cost to the program, decreased substantially when the state shifted from paying counselors a fixed monthly fee per consumer to paying a one-time lump sum for each consumer until the consumer began receiving his/her cash allowance.
- Unused allowance amounts should be recovered by the state at regular scheduled intervals made known to consumers.
- Costs for Cash and Counseling and the traditional PCS/waiver program should be monitored on a regular and frequent basis against authorized care plan amounts. This monitoring will help to ensure that consumers receiving agency care and those who self-direct both receive the care that has been authorized, and that cost disparities between the two systems do not develop.

Other problems experienced by the programs also merit attention:

- Unless counselors aggressively seek to help consumers to establish their spending plans within a short period after enrollment, many consumers who want to direct their own care might not ever do so. The very low proportion of Florida's elderly beneficiaries who participated suggests that states may have to develop incentives for counselors and may have to train counselors to encourage and help consumers to develop their spending plans within a few months of enrollment. Arkansas's method of requiring counselors to get consumers started on the cash allowances within 45 days was particularly effective.
- The program's favorable effects on consumers may not be realized or, if realized, may not be sustained if many consumers are unable to hire workers, or if stress leads hired family workers to quit. States should consider establishing worker registries or offering consumers lists of current or former hired workers who would like to work for additional consumers to help consumers with the critical task of obtaining or replacing hired workers. States should also consider providing resources, such as information brochures and referrals, to help consumers' relatives to cope with the emotional stress of caregiving, and with the lack of respect they perceive from other family members.

The early evidence from the demonstration has convinced many states to implement their own Cash and Counseling programs, or to adopt principles from Cash and Counseling, to

improve the lives of consumers who are receiving PCS or HCBS. The three demonstration states have renewed their 1115 waivers and have ongoing Cash and Counseling programs. Eleven new states have been selected to participate in the next round of Cash and Counseling, and each one has received start-up grants from RWJF. A twelfth state program (in Illinois) is being funded by the Retirement Research Foundation. By taking advantage of the lessons learned from the demonstration, these states may be able to achieve for their beneficiaries the same type of gains in well-being as demonstration participants and caregivers experienced, while controlling their costs and, perhaps, reducing beneficiaries' dependence on other long-term care services.