Providing Long-Term Care Benefits In Cash: Moving To A Disability Model

The cause of patient autonomy is well served by cash benefit programs, although challenges remain.

by Robyn I. Stone

ABSTRACT: This paper examines the role of a disability approach to the allocation of long-term care benefits. It first highlights the important elements of long-term care that support a disability model. It then reviews the advantages and disadvantages of this approach relative to the traditional indemnity model and summarizes key features of selected domestic and international programs that offer a disability-type benefit. The paper identifies and elaborates on the major implementation challenges and concludes with a recommendation for further examination of the costs and benefits of this approach to the public coffers, the private market, and long-term care consumers.

MUCH OF THE POLICY LITERATURE and public debate about the future of U.S. long-term care policy have examined the issues of who should bear the financial burden and how that burden should be distributed. Analysts have weighed the advantages and disadvantages of various options in an effort to strike a balance between public- and private-sector solutions.[1]

In this paper I raise an important issue that has not been adequately addressed in these debates: whether public programs and private market efforts should offer a defined set of services (the indemnity approach) or provide a cash benefit (the disability approach) that allows the consumer to decide how to use available resources to meet his or her long-term care needs. I begin with a discussion of the definition of *long-term care*, establishing the context for why policymakers need to pay attention to how benefits are defined and distributed to public and private program beneficiaries. In the second section I review the advantages and disadvantages of the disability approach relative to the traditional indemnity ap-

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proach and summarize key features of selected public programs and private products that offer a disability-type benefit. I then discuss major issues that must be addressed in the implementation of a disability approach to providing long-term care benefits. I conclude with a recommendation that decisionmakers in the public and private sectors explore opportunities for expanding this approach to long-term care consumers who prefer more choice and autonomy.

Defining Long-Term Care

■ **Services and supports.** Long-term care encompasses a broad range of assistance that persons with chronic disabilities need for a prolonged period of time. These services and supports are designed to minimize, rehabilitate, or compensate for loss of independent physical and mental functioning. Although needs emerge from chronic medical conditions that occur at birth, during developmental stages, or as the result of accidents or injuries, long-term care should not be viewed as just an extension of acute care. Rather, it refers to a constellation of services, assistive technologies, and other supports that allow persons with functional impairments to experience the best quality of life possible for the longest time possible.

Long-term care typically includes assistance with basic activities of daily living (ADLs) such as bathing, dressing, using the toilet, or other personal care and help with instrumental activities of daily living (IADLs) such as household chores, life management, medication management, and transportation. The services tend to be relatively low-tech, although a subset of long-term care beneficiaries, typically recovering from an acute episode, may require more skilled, medically oriented services such as intravenous therapy, wound care, and even ventilator assistance. Long-term care also encompasses a wide range of assistive technologies ranging from canes, walkers, and wheelchairs to computerized medication reminders and alarm systems designed to minimize falls.

■ **Residential environment.** Because of the duration of long-term care needs, one's residential environment is as important as the services and supports one receives. While a person may not be satisfied with the room-and-board accommodations during a hospital stay, its quality is not critical to the person's quality of care or long-term quality of life. In contrast, the nature of one's home—be it one's private home, an assisted living facility or other congregate setting, or a nursing home—can greatly enhance or impede a long-term care recipient's functional ability, independence, and quality of life. Home modifications such as ramps, grab bars, and easy-to-use door handles or the installation of a bedroom and bath on the first floor of a multistory house may be the crucial factor in helping a

person to "age in place" (in his or her own home). Access to a private room with a bath and microwave may improve the quality of life and minimize depression for assisted-living residents who can no longer remain in their own homes. Nursing home wings set up in pods with environmental features that create a "neighborhood feel," offer meals that are culturally appropriate, and minimize visual and auditory distortions may help to limit deterioration or even improve physical and mental functioning.

In short, the goal of long-term care is to achieve a good quality of life for persons with disabilities as well as addressing their clinical and functional needs. Consequently, as we explore mechanisms for financing long-term care, policymakers must begin to examine the best way to allocate resources. Persons who rely on their savings and other private resources to meet their long-term care needs have total discretion in how they use their dollars to purchase services, supports, and housing. For those who rely on some type of public program or private insurance policy, however, choices are more limited. In the next section I describe and assess these two major approaches to defining benefits.

Care/Indemnity Versus Disability Model

■ **Care/indemnity approach.** The care/indemnity model is the dominant approach to providing long-term care benefits. The major public programs supporting long-term care, Medicaid and Medicare, use this approach, covering only eligible expenses for specified services. Most private long-term care insurers emulate publicly financed health care programs. They typically offer indemnity policies in which the insured person purchases a discrete amount of service per diem in either a nursing home, their own home, or another residential care setting.[2] Some of the "latest-generation" policies also offer care management to assist the insured person in making service decisions and to help control claims costs.

This approach has a number of advantages. First, Americans are comfortable with this model because they understand what it means to have access to a defined set of services. Second, this model specifies which benefits are covered and which are not and provides a record of what has been purchased. The indemnity approach, therefore, gives the public payer or private insurer the opportunity to establish mechanisms for monitoring utilization and for potentially assessing outcomes. Third, public payers and private insurers have some ability to control costs and utilization by imposing cost-sharing requirements on beneficiaries.

The care/indemnity model assumes that consumers do not have the capacity or cannot be trusted to make decisions about the serv-

ices and supports they need; it fails to provide much choice or flexibility in making purchasing decisions. This model also assumes that the long-term care population is homogeneous and that all persons with disabilities need care. Leaders of the disability movement, including younger persons with physical disabilities and those with mental retardation/developmental disabilities, have argued that they are not sick and simply need the flexibility to purchase the services and supports that will help them to live and work independently.[3]

The claims procedure associated with the indemnity approach is complicated for public and private insurers. The insured person's expenses must be carefully defined, and reimbursement claims must be scrutinized. Furthermore, the insurer must establish processes for resolving disputes and for tracking benefit limits and maximums. The administrative costs associated with these processes are costly to the payers, and these costs get passed on to the consumer.

One of the major drawbacks of the use of the care/indemnity model in private long-term care insurance is that policies can become outdated. A sixty-year-old woman, for example, who purchases a policy with specified service coverage (for example, $120 per day in a nursing home or $60 per day for assisted living or home care services) only becomes at high risk for claiming benefits at age eighty. During those twenty years the services available in the marketplace could change dramatically, leaving her coverage inadequate to meet her needs when she is ready to file a claim.

■ **Disability model.** The disability model starts with the premise that long-term care and supports are primarily designed to enhance a person's quality of life, to help ensure as much independence as possible, and to provide flexibility and choice to individuals and their families. Rather than financing a prescribed set of services, this model provides resources directly to individuals through a cash benefit or some type of voucher system. Receipt of benefits is triggered by demonstration of some level of disability or other measure of need for long-term care. This model has strong support from the community of persons with disabilities under age sixty-five but appeals to many older persons as well.[4]

The primary advantage of this model is the flexibility it affords consumers to address their individual needs. In the private market, cash benefits are superior to indemnity products because they do not become obsolete as the nature and scope of services change over time. In a recent study of private long-term care insurance claimants, consumers who had purchased a disability-type policy reported higher satisfaction with their plans than did those who had purchased an indemnity policy.[5]

The disability approach also provides resources that family

caregivers may use to purchase complementary services or supports. They may decide, for example, to pay for evening and weekend respite care, services that are generally not available through care packages defined by public programs or private insurers.

The disability model has the potential to expand the pool of long-term care workers, since individuals can use the funds to pay for services provided by friends, neighbors, and even family members. A recent study of the In-Home Supportive Services Program in California, which allows participants to hire relatives, friends, and neighbors as caregivers, underscores the potential of this model for developing untapped sources of labor. The researchers found that approximately one-fifth of the family and friends hired as paid caregivers had not previously been providing long-term care assistance, either paid or unpaid.[6] This model could be viewed as a mechanism for helping to ameliorate the current and projected shortage of front-line workers.

The major disadvantage of this approach is the difficulty in monitoring how the dollars are spent and in ensuring quality of care and supports. U.S. policymakers are particularly concerned about the potential for fraud and abuse by consumers or their families.[7]

Given the appeal of dollars, this approach may provide an increased incentive for individuals to claim a disability in order to get benefits. Consequently, the initial determination and reassessment of disability level are critical to minimizing this type of woodworking effect and to protect against overuse. While the cash benefit aspect of this approach is relatively simply to administer, the disability determination process increases the costs of this model. Although administrative costs have never been compared, it is likely that the administrative overhead associated with the care/indemnity model is higher, since that approach also requires an eligibility determination process as well as the other tracking and monitoring procedures described above.

The disability approach may not be appropriate for all persons who need long-term care, particularly those with cognitive impairment or other limitations in mental functioning. Critics of consumer direction in long-term care (including cash benefits) argue that there is a basic conflict between an approach designed to protect and nurture consumer choice and autonomy and a population whose autonomy has been compromised by dementia or other cognitive impairments. Others point out that even persons with cognitive impairment can express choices and values and that with a surrogate decisionmaker, the disability model could work for them.[8]

Disability Model In The Public And Private Sectors

Federal and state programs and the private market have some experience in applying the disability model to the distribution of long-term care benefits. Several European countries provide cash benefits to some or all of their long-term care beneficiaries. The following examples are provided to illustrate the diversity of approaches within this model.

■ **Public programs.** *Federal.* The U.S. Department of Veterans Affairs' Housebound and Aid and Attendance Allowance Program, marking its fiftieth year in 2001, is the only federal program that uses a disability model to cover long-term care benefits. This program provides cash grants in lieu of formally provided homemaker, personal care, and other supports to veterans and their surviving spouses who are disabled and need long-term care in the community. In 2001 a single veteran qualifying for this benefit was entitled to $518 per month in addition to the regular pension of $775.

State. In 1999 researchers at the National Council on Aging surveyed state officials from departments on aging, Medicaid, vocational rehabilitation, and programs for mental retardation/developmental disabilities to ascertain the range and scope of consumer-directed programs (including those providing cash benefits) supported by their organizations.[9] Approximately 35 percent of the 185 programs identified offered cash benefits to various subgroups of persons with long-term care needs.

The most ambitious state initiative to date is the Cash and Counseling Demonstration and Evaluation, developed and supported jointly by the Office of the Assistant Secretary for Planning and Evaluation (ASPE), the U.S. Department of Health and Human Services, and the Robert Wood Johnson Foundation. This project was initiated in 1997 to test the efficacy of "cashing out" Medicaid-funded home and community-based care services.[10]

The participating states—Arkansas, Florida, and New Jersey—obtained Medicaid waivers under Section 1115 of the Social Security Act to allow the payment of cash allowances in lieu of a service package, to permit spouses and parents of minor children to be paid caregivers, and to permit Medicaid beneficiaries to use cash benefits to purchase disability-related goods and services not covered by Medicaid. Officials from the Social Security Administration and the Departments of Agriculture, Education, and Housing and Urban Development agreed to exempt participants in the treatment group (those randomly assigned to receive cash) from rules related to means testing that might have jeopardized their eligibility for Supplemental Security Income (SSI) payments, food stamps, disability-related education and vocational rehabilitation benefits, and low-

income housing.

Demonstration participants were randomly assigned to a "cash group" and an "agency-delivered service package group," with the cash payment value being roughly equivalent to the cost of a traditional care plan. Benefits to elderly and younger disabled beneficiaries vary widely across the three states depending on the generosity of the public program, with monthly cash payments in 2000 averaging $1,200 in New Jersey, $350 in Arkansas, and $300 in Florida. Persons in the cash group (including "consumer representatives" in situations where the individual is not capable of total self-direction) have access to a wide range of counseling services to help them use the funds appropriately and assistance with fiscal tasks such as paying Social Security and workers' compensation benefits for their home care and personal care workers.

While it is too early to assess the impact of this demonstration, preliminary results from the evaluation in Arkansas indicate that contrary to conventional wisdom, recipients of the cash benefit were more likely to be elderly, in poor health, and severely disabled, suggesting that this benefit does appeal to older as well as younger persons with disabilities.[11] After nine months, two-thirds of the cash beneficiaries were still in the program; 9 percent had died.

More than 90 percent of the participants hired family members, friends, or neighbors to provide personal care services. Approximately 10 percent used the cash to purchase or repair disability-related equipment, 10 percent used it to make home modifications, and 2 percent used it to make vehicle modifications. More than nine out of ten participants (including disenrollees from the cash group) indicated that they would recommend the cash option to others seeking greater control over their personal care decisions.

■ **Private-sector activity.** Two private insurance companies, UNUM and Aetna, offer long-term care insurance policies that use the disability approach. Consumers purchase policies with a daily, weekly, or monthly benefit cap. When the insurance company's assessment specialist or care manager certifies that the insured person is disabled (usually measured by the need for assistance with at least two or three ADLs or cognitive impairment), the person becomes eligible to receive the cash benefit. The insurance company conducts periodic reassessments of the claimant's functional status to ensure that he or she still qualifies for the cash payments.

The individual policy market for disability-type policies has had little growth over the past decade, probably because of the higher premiums associated with this product relative to indemnity plans.[12] There is, however, some evidence that this concept is taking hold in the employer-based market. Although not a random sample, a recent

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study of ninety-three employers offering long-term care insurance found that 43 percent of the plans provided cash benefits.[13]

■ **Tax credits.** The tax credit is another mechanism that could be considered part of a disability approach, since cash is paid to the individual after services are purchased or, in the case of family caregivers, rendered. Legislation was recently introduced in both the House and the Senate to provide up to a $3,000 annual tax credit to persons with long-term care needs or their family caregivers. Another Senate bill would incorporate respite care costs in the dependent care tax credit and make the dependent care credit available to nontaxpaying caregivers.

The major limitation of using the tax code this way is that the need for cash is greatest at the time of service purchase, not the following year after their tax forms have been filed. Furthermore, nontaxpayers (many of whom are elderly) would not be eligible for most of the proposed credits. Finally, the history of tax credits suggests that there would have to be a major education campaign to encourage eligible persons to take advantage of this benefit.

■ **International experience.** A number of European countries, including Austria, France, Germany, and the Netherlands, use the disability approach to provide part or all of their long-term care benefits. The largest program is in Germany, which introduced a new non-means-tested social insurance program for long-term care in 1995. Funding for this mandatory program is 1.7 percent of salaries and pensions, with contributions shared by employers and employees and retirees and pension funds.[14]

The German system recognizes three levels of dependency and offers nursing home and home care options to qualified beneficiaries. Beneficiaries living in the community can select a cash benefit, agency services set at twice the monetary value of cash, or a combination of the two. The program imposes no major restrictions on how the cash is used and encourages hiring relatives and friends. Among this population, 76 percent chose cash rather than services in 1998, although the proportion of beneficiaries choosing services or a combination of services and cash has risen slightly since the program's inception.[15] The proportion of beneficiaries opting for cash varies with disability level; in 1998, 65 percent of the most disabled group chose cash only (not in combination with services), compared with 80 percent of the least disabled.

Implementation Issues

The disability approach to allocating benefits offers flexibility and may be more appropriate for long-term care because the services and supports needed go far beyond care delivery. Public policymakers and private insurers, however, must address the following issues in exploring the extent to which they want to adopt this model for financing long-term care.

■ **Scope of the benefit.** All of the programs described in this paper have used the disability/cash benefit in the context of low-tech home care, personal care services, and supports such as assistive devices and home modifications. For the most part, delivery of these types of services does not require much clinical knowledge or additional high-tech interventions from health professionals. Consequently, consumers should be able to make their own decisions about the services and supports that best meet their needs.

It is highly unlikely that a disability/cash benefit would be appropriate in the context of nursing home care or postacute home health care, because most consumers do not have the knowledge or skills to purchase skilled nursing or rehabilitation services on their own. It may, however, be possible to "cash out" that portion of the service package that relates to the less technical tasks performed by aides (such as assistance with ADLs) and allow the consumer to have more choice in that aspect of care delivery.

The logistics of this approach in the nursing home setting, including the coordination that would be required and the loss of economies of scale that are achieved through nurse aides caring for multiple residents, probably militates against this option. It may be more feasible to adopt a disability approach for the nonskilled part of home health care, and there may even be cost savings to the Medicare program if consumers choose to hire unlicensed workers, including family and friends. This would require a major change in Medicare rules, including the requirement that a licensed nurse supervise the activities of the home health aides. The partial adoption of a disability model also would necessitate drawing a clear distinction between what is a skilled and a nonskilled service. This may be extremely difficult to achieve as the lines between postacute, chronic, and long-term care become increasingly blurred.

■ **Determining eligibility.** Eligibility determination is a challenge in implementing the disability model because the potential for overuse is greater with cash than with an indemnity approach. The first hurdle is to establish the disability threshold for receipt of benefits and minimize the propensity for individuals to claim a higher level of disability than really exists (referred to as "ADL

creep"). Most of the programs identified in this paper use a functional screen to determine eligibility—usually the need for assistance with a certain number of ADLs. Over the past two decades many states have developed and applied such measures to ascertain eligibility for home and community-based services, and most private insurance companies now use this type of functional assessment to trigger benefits. Germany's program requires that applicants demonstrate the need for assistance with at least two ADLs and some IADLs such as meal preparation or medication management.[16] Austria has not adopted a functional screen; instead, its program provides benefits to persons who need more than fifty hours of care per month or who use a wheelchair.[17]

The use of cognitive impairment as an eligibility criterion is more problematic, although the programs that offer agency-based services suffer from the same lack of precision. Some programs have developed instruments that take into account need for hours of supervision, a proxy for cognitive impairment. The German program does not include the need for supervision in its eligibility determination, because many policymakers were concerned that counting supervision hours in the assessment process would place virtually all cognitively impaired persons in the most costly, most impaired category.[18]

The disability model also requires that a system be in place for assessment and eligibility determination. The state programs that offer a cash option already have an infrastructure for conducting these assessments and have developed instruments and protocols for determining and reassessing eligibility. Private insurers who use disability triggers typically contract with independent organizations to determine eligibility as well as to conduct periodic reassessments. In Germany, physicians and nurses employed by the local sickness funds—quasi-public, quasi-private insurers that were established to administer acute care benefits—perform the functional assessments and eligibility determination.

■ **Administering the cash benefit.** Public and private programs that adopt the disability approach must establish an appropriate benefit amount. In New Jersey's Cash and Counseling Demonstration and Evaluation, officials use the hours of service a participant is allotted during the initial assessment or reassessment, with the number of hours converted into a dollar amount using the existing New Jersey rates for Medicaid personal care assistance reimbursement. A small portion of the payment is subtracted for the counseling component, the cost of distributing the cash grant, and other administrative expenses. Participants can opt to receive a monthly check for the entire amount via direct deposit after they have demonstrated competency in managing the fiscal responsibilities inher-

ent in becoming an employer, or they can have the monthly cash grant deposited in an account managed by a fiscal intermediary, who handles all payroll responsibilities, tax deductions, and withholding obligations.[19]

The German cash benefit is approximately half the value of the service package; in 1999 the monthly payments for levels 1, 2, and 3 were $200, $400, and $650, respectively.[20] The benefit structure has been stable for five years, with no adjustments for inflation. There are no fiscal intermediaries, and the payments are sent directly to beneficiaries.

■ **Controlling fraud and abuse.** One of the major fears expressed by many U.S. policymakers about a disability approach to long-term care is that fraud and abuse will become rampant. Most are concerned that the cash payments will not be spent appropriately on long-term care–related services. Where family members are involved, either as caregivers or as surrogate decisionmakers, the fear is that they will use the cash for their own purposes rather than to provide assistance to the beneficiary.

There does not seem to be the same level of concern about fraud and abuse in several of the other countries that use a disability approach.[21] In Austria and Germany, for example, there are no major restrictions on use of the cash benefit, and the governments do not monitor how beneficiaries spend the money. Dutch beneficiaries receive a voucher to purchase services from workers or agencies.

The programs described in this paper conduct some type of periodic reassessment to determine whether the level of disability has changed. The state programs that provide cash payments rely on local agencies to conduct the reassessments; private insurers contract with independent care management agencies to reassess claimants (usually every three to six months, depending on the policy).

■ **Monitoring quality.** In the private sector there is no explicit concern about the quality of the services and supports purchased by individuals; beneficiaries are responsible for their bad as well as their good choices. The focus on quality monitoring and assurance is greater among programs where public dollars are involved, although there is variation in the degree of concern and the oversight mechanisms in place to address this. Some have argued that by empowering consumers (or surrogates) to hire and pay providers and to purchase needed supports, individuals are free to set and enforce their own notions of quality by establishing the process parameters of their care and determining the credentials of their workers.[22]

Counseling programs, periodic reassessments, and consumer satisfaction surveys are the major tools used in the United States to monitor quality. Several states have developed worker registries

from which consumers can hire persons who have passed criminal background checks.[23] Most of the European countries are not as concerned about quality, although all do some reassessments and random audits.

As policymakers, researchers, and consumers continue to struggle with how to finance long-term care in the United States, they need to examine the best mechanism for getting resources to those who need them. This paper has highlighted the limitations of the indemnity approach to benefit design and suggested that providing cash payments to individual consumers and their families may be an appropriate option, at least for nonmedical services and supports. The review of selected domestic and international programs in both the public and private sectors demonstrates the potential of this approach for social insurance and mean-tested programs as well as individual and group long-term care insurance policies. Several demonstration programs in the United States and experience from other countries suggest that many persons prefer cash to a defined set of services, even when the payments are greatly reduced relative to the service package. The implementation issues identified in this paper are challenging but not insurmountable and in most respects are no more complex than those raised by the care/indemnity model. Policymakers and private insurers need to recognize the value of the disability model to many consumers and should further examine the costs and benefits of this approach to the public coffers, the private market, and persons who want more flexibility and responsibility.

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NOTES

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