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# Long-Term Care Financing Project

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## **Long-Term Care Policy Option Proposal: Consumer Controlled Chronic, Home, and Community Care for the Elderly and Disabled**

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## Preface

At the same time we invest over \$200 billion in public and private resources in long-term care, dissatisfaction with our current public-private financing partnership is widespread. To promote a better partnership for the future, the Georgetown University Long-Term Care Financing Project examined options to move us from a partnership that consists primarily of out-of-pocket financing and last-resort public financing toward a partnership that spreads risk, supports access to quality care, and shares financial responsibility fairly among taxpayers and affected individuals and families.

To identify options, we invited experts to develop their own proposals for new ways to finance long-term care. We sought innovative ideas that varied in the nature of the partnership between the public and private sectors. This working paper is one of a set of eight proposals written for the project. These eight, plus an additional four proposals from other sources, are summarized and assessed in an overview paper, *Long-Term Care Financing: Options for the Future*, written by Judith Feder, Harriet L. Komisar, and Robert B. Friedland. The working papers and the overview can be found at: [ltc.georgetown.edu](http://ltc.georgetown.edu). The Georgetown University Long-Term Care Financing Project is funded by a grant from the Robert Wood Johnson Foundation.

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Project Directors

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# Long Term Care Policy Option Proposal: Consumer Controlled Chronic, Home, and Community Care for the Elderly and Disabled

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## Introduction

The authors propose a long-term care policy reform that would provide a consumer empowerment approach linked with care coordination for both chronic disease education and home and community-based services (HCBS). The coverage would provide care coordination to all high risk Medicare beneficiaries and dually eligible Medicare/Medicaid beneficiaries with Instrumental Activity of Daily Living (IADL) or Activity of Daily Living (ADL) limitations. The proposed reform would integrate advances in medical model chronic disease management with a disability (i.e., self managed) approach (Stone, 2001) to long-term care coverage with both approaches aimed at maximizing consumer choice and involvement. The proposal would integrate partial financing from Medicare (a new care-coordination benefit), Medicaid (HCBS for disabled recipients up to 300% of poverty); and consumer buy-in (HCBS for those over 300% of poverty).

This approach draws from several traditions: a) promising developments in the area of chronic disease management; b) positive outcomes reported by the disabled and elderly in controlling their own care, as well as both U.S. (e.g., Cash and Counseling) and international experiences (e.g., Germany) in providing a set amount of resources to disabled users; c) the need for beneficiaries at all

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levels of disability to have access to a flexible array of medical and HCBS. The approach is targeted to the stated preference of consumers to be able to remain in their homes for as long as possible and receive services without having to transfer to an institutional setting (Bayer & Harper, 2000; Gibson et al., 2003). For those who prefer or require a setting that combines services with housing, we also propose a range of residential options for receiving Medicaid HCBS including supportive housing and assisted living. The Medicare-funded disease management and care-coordination benefit would also be available for beneficiaries living in skilled nursing facilities (SNFs).

## **Benefits**

Benefits would include:

- A) *A flexible package of home and community based care services for Medicaid eligible and dually Medicare-Medicaid eligible disabled and elders with ADL or IADL needs, including personal assistance services, equipment, minor home repairs, adult day health, paratransit, respite, home-delivered meals, a contribution toward assisted living services, or other services as required by consumers.* Medicaid eligibility would be expanded to 300% of federal poverty level for those qualifying under any functional disability category as described further below. More liberal asset tests currently available for nursing home residents, such as splitting of assets for spouses, would also be available to those who qualify for the program. A capped service budget would be established based on level of disability. Consumers would be expected to manage covered services within this budget but would have great flexibility on which services they would choose. The benefit would essentially be a budget authorization to spend funds on services up to the capped level. Consumers would not be paid cash but would authorize payment for services they use. This is the model followed by a number of consumer directed personal care service programs as well as one option offered by Cash and Counseling programs

(Foster, Brown, Carlson, Phillips, & Schore, 2000), which provide payment for a certain amount of services controlled by a disabled consumer. The consumer chooses and supervises the person providing services while an agency or government entity pays the bills and handles tax contributions, etc. Three benefit levels would be authorized including: 1) one or more IADLs but no ADLs; 2) one or two ADLs; 3) three or more ADLs. Cognitive disability would also be included at the same levels in so far as it triggers inability to perform any IADLs or ADLs independently.

- B) *Medicare-funded care coordination, disease management education, and chronic self-care management training.* Care-coordination services would be available for beneficiaries (and their caregivers) who meet either disability criteria or chronic disease thresholds as identified by brief risk assessment or referral by physician. Care coordinators would be expected to provide both disease management education, links to self care management classes, and advise beneficiaries on available home and community services and best use of services within their budgeted allocation of services. Medicare beneficiaries would qualify for care-coordination assistance by either meeting high risk medical standards including suffering from identified chronic diseases, meeting functional disability criteria identified above, or both. Medicare-funded care coordination would allow states to drop Medicaid funded case management services for this population except for their Medicaid only clients.
- C) *A link to existing HCBS for those who are Medicare- but not Medicaid-eligible and arrangements for purchase of HCBS.* Care coordinators would assist Medicare beneficiaries who cannot qualify for the Medicaid HCBS benefit to find available services to purchase in order to meet their disability needs. Care coordinators could also project potential personal

budget targets for buy-in consumers to assist with financial planning needs.

D) *Link to supportive housing or assisted living communities for those who prefer or need a residential setting with staff available to provide scheduled and unscheduled assistance.* Care-coordination services would include advice on available settings. HCBS benefit would follow beneficiaries into supportive housing and assisted living settings. Care coordinators would also provide advice on SNFs including review of data provided by the Centers for Medicare and Medicaid Services (CMS). Care coordinators would continue disease management services to beneficiaries in these settings and assist beneficiaries who wished to return to another type of setting. Nursing home coverage would continue to be financed as under the current system with Medicare paying for limited coverage and Medicaid providing custodial care for those who are eligible. Consumers who do not meet Medicaid requirements would pay out of pocket until they had exhausted their resources. The addition of a home and community based service benefit as outlined above would be intended to allow many potential nursing home residents to avoid the need for SNF care by having easier access to HCBS. There would be no change in existing eligibility requirements for SNF services under Medicaid except a requirement that States offer the home and community based service program prior to entry into a nursing home.

## **Consumer Empowerment**

This proposal would offer a consumer-managed set dollar benefit for HCBS under Medicaid or, for those not eligible for Medicaid, a consumer buy-in option. Under the Medicaid option, consumers would have access to a set benefit amount linked to their level of disability with relatively low levels of assistance for those with IADL difficulties only and gradually increasing levels of assistance as ADL needs increase. The service package would be designed

and controlled by the consumer with assistance, if desired, from a Care Coordinator. Consumers could also choose to allow the Care Manager to choose or arrange for services if they prefer not to manage services or do not have the cognitive ability to do so. The Care Coordinator would be paid for by Medicare and linked to chronic disease management needs of the beneficiary. In addition to the home and community service package, the consumer would choose the type of chronic disease approach s/he wishes to be involved in, e.g., group visits, peer support, self care management, in-home monitoring, etc.

## **Financing**

A) Home and Community Based Services would become a mandatory Medicaid benefit for all states with some similarities to 1915c or 1915 b/c combination waivers for Medicaid eligible consumers. Mandatory Medicaid coverage would be provided up to 300% of the poverty level and broad definition of “at risk” for nursing home admission used to encompass the defined eligibility categories. States could choose to include their developmentally disabled adult population in the new program at their discretion. The coverage would provide a defined dollar benefit controlled by the consumer with advice from the care coordinator similar to consumer-controlled personal assistance service models now in place in some areas, but with the added assistance, if desired, from a care coordinator.

The new home and community based service package would be a mandatory program for states but with a requirement that states design a program that can meet the cost effectiveness requirements of current waiver programs and with a federally-supported risk corridor for actual expenditures above the budgeted projections. The cost effectiveness requirement would enable states to design a benefit which would be expected to save nursing home or other Medicaid costs in the long run. Costs associated with the IADL-only category of benefits would be

relatively low but would be expected to delay or avoid future institutional or other Medicaid expenditures. We acknowledge that although Medicaid services provided to the IADL-only group would be minimal, they might make the cost effectiveness rationale difficult to attain over a short time period. Requiring states to design a program with this requirement would both provide a rationale for political support in lean times (when states may be concerned about a woodwork effect) and give both state and federal agencies cost targets to allow for planning and encourage efficient operation. Cost effectiveness targets will also benefit from the federal assumption of care-coordination services through Medicare. States are familiar with making these arguments for current 1915(c) waiver programs and we believe would be able to successfully create a similar rationale for a more comprehensive mandatory program.

The federal government would pay 75% of any portion of total expenditures for this program between 105% and 125% of the projected cost effectiveness budget. Federal payments would return to 50% of any expenditures above 125% and gradually be reduced at higher expenditure levels. The increased federal share for expenditures between 105% and 125% of the projected budget is designed to give states some protection against additional costs associated with expanded benefits. Returning the federal share (the federal medical assistance percentage or FMAP) to 50% or lower once expenditures go above 125% of budget is intended to protect the federal government from larger cost over-runs. All 1915(c) waiver programs and optional home and community based service state plan benefits would fold into the new program with required maintenance of effort levels for existing services. A maintenance of effort clause is intended to discourage states from dropping non-care-coordination HCBS benefits that they currently offer. This requirement would be enforced through CMS's review of a state's plan for implementation of the new benefit. A state could argue successfully to

substitute new HCBS as substitutes for benefits previously offered and of course could change their package of HCBS over time. The maintenance of effort requirement is meant to discourage states from reducing rather than increasing HCBS benefits. States currently funding care-coordination services through their Medicaid programs would no longer fund this service for their dual-eligible recipients. They would continue to fund Medicaid-only users of care-coordination services if they so choose.

- B) Medicare Hospital/Acute Care Savings from Chronic Disease Management Education to pay for care-coordination services. We estimate there would be approximately \$1 billion per year in care-coordination costs for Medicare assuming approximately 10% of community dwelling elders, 100% of disabled beneficiaries, and 100% of nursing home residents are eligible for services—although perhaps only 50% to 75% would use the benefit, reducing required expenditures. We expect some level of acute care savings to accrue to the Medicare program both as a result of the disease management activities as well as the possible substitution of HCBS for Medicare benefits (e.g., home health care).
- C) Consumer buy-in would be available for home and community based care if the beneficiary is not Medicaid eligible as defined above and service is not available through the Aging Network. The Aging Network includes services funded through the Older Americans Act, Community Services Block Grants, and a number of state and local sources. These services currently are targeted to a subset of the elderly population and are limited in both type and availability in any given geographic area. Assistance would be available from the care coordinator for all beneficiaries who meet high-risk criteria. The consumer would pay the HCBS provider directly for services at a private market rate although the consumer would benefit from the HCBS infrastructure created by the new Medicaid benefit as well as from the expertise of the care coordinator.

D) We propose a slight increase in Medicare payroll tax contribution (probably less than ½%) for employers and for those individuals with income over 300% of the poverty level, if system-level acute care savings (as measured by CMS) do not cover care-coordination costs and to cover the additional federal share of Medicaid costs if costs are higher than budgeted for cost effectiveness.

## **Regulatory Changes**

- A) Laws governing Medicaid would need to be changed to add additional required state benefits for HCBS including a requirement for states to make a cost effectiveness argument for the new services. Medicaid regulations would also be amended to allow for risk sharing as discussed above.
- B) Medicare regulations would need to be changed to put in place the Disease Management Education/Care-coordination benefit as well as procedures for the first level risk assessment and procurement processes, and the designation of applicable providers for both of these services.

## **Advantages of the Proposed Program**

- Provides care coordinators who would assist in designing home and community-based care package for every disabled beneficiary (the current system is fragmented and unmanageable for most consumers and family members);
- Creates a benefit for all adults and elders with disabilities, not only the low income covered by Medicaid;
- Builds on Medicaid to assure that low income elders and disabled are able to afford chronic care services;

- Builds on chronic disease management findings to improve the quality of care and achieve potential savings;
- Uses the social insurance financing model already in place under Medicare;
- Allows consumers to choose providers and types of services they wish to use for both home and community based care and chronic disease self-care; and
- Provides a needed benefit for a growing group of more knowledgeable and assertive consumers who want to have more control over their own care but also want appropriate assistance in navigating the system.

### **Gaps in the Proposal**

- Does not change nursing home coverage except in attempting to prevent growth of nursing home population by allowing elder and disabled beneficiaries to live at home;
- Assumes that meaningful home and community services can be provided within framework of fixed dollar benefit;
- Assumes that for those above 300% of the poverty level an effective and affordable service package can be structured from existing aging services plus services purchased by the consumer with assistance from a care manager;
- Assumes that Medicare can agree on a workable approach to reimbursing care coordinators in traditional fee-for-service Medicare;
- Financing is based on preventing use of other costly acute services and relies on building links to traditional fee-for-service Medicare system (chronic disease management programs and high-risk beneficiary

management have more typically been used in managed care settings); and

- May generate resistance from states if they are not protected from rising Medicaid costs by the federal government. A new mandated Medicaid benefit and a risk-corridor approach does not fit current attempts to block-grant Medicaid, cap federal expenditures, and allow more flexibility to states—although the specific design of an HCBS benefit could be quite flexible.

## **Implementation and Administrative Issues**

Medicare will be required to establish an appropriate methodology for risk assessment, education about chronic disease and self care management, and appropriate expectations for a care-coordination model that will be flexible and not unduly expensive. Existing work in each of these areas already exists to guide the development of methodologies and expectations, but there is also not clear consensus on the best approaches to use.

We would propose a simple risk assessment tool such as the ACOVE (Assessing Care of Vulnerable Elders) 13-question self-administered questionnaire (Saliba et al., 2001) to be mailed to all beneficiaries by CMS upon enrollment into the Medicare program, at ages 70 and 75 and every two years thereafter. In addition physicians could refer patients to CMS to receive the assessment or beneficiaries could request the assessment from CMS at any time. Beneficiaries meeting either functional or disease criteria would be passed on to a second-level care coordinator phone assessment to verify need and assess level of need. The care coordinator would verify results of the phone assessment by mailing a brief report to a physician or other certified Medicare provider currently serving the beneficiary, who would be asked to confirm the assessment. Assessment information would be provided to the ongoing care coordinator and forwarded to the state Medicaid agency or other

providers at the request of the beneficiary. Qualified beneficiaries would be grouped into four benefit levels: a) targeted chronic disease only; b) chronic disease plus IADL problems; c) assistance needed in 1 or 2 ADLs; d) assistance needed in 3 or more ADLs. Those qualified would be eligible for care coordination and disease management education services. Those beneficiaries certified as having IADL or ADL needs and meeting Medicaid eligibility requirements as defined above would also qualify for Medicaid HCBS. Area Agencies on Aging, other aging and disability providers, and home and community based service providers could bid to serve as delivery agencies to provide phone risk assessment and disease management/care-coordination services to beneficiaries but only under provisions that ensure against potential or real conflict of interest so that there is no self-dealing in assessment and service provision. This would serve the added purpose of having Medicare beneficiaries make contact with these programs which can act as gateways to other aging and disability services not funded under this program.

Disease self-management education would feature standard disease specific materials and protocols to be provided to and reviewed with the beneficiary. Some health plans are already using such standardized disease education handouts in their care management programs (Graves, 2003). These materials would be taken from existing self-management education programs (Connelly, 1993; Leveille et al., 1998; Lorig, Mazonson, & Holman, 1993; Lorig et al., 1999). For example, study results for the Chronic Disease Self-Management Program (CDSMP) reported savings of up to \$520 per patient for the 2-year study period related to lower use of hospital and physician services (Lorig, Ritter et al., 2001; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). CMS would not mandate use of any one set of materials but rather general guidelines for disease self management education programs taken from a review of existing programs. Care coordinators would also be expected to discuss personal health plans with beneficiaries which might include changes in diet or exercise relative

to their chronic disease. Care coordinators would also refer beneficiaries to disease self-management classes in their area.

CMS would need to develop care-coordination guidelines and billing codes for care coordination which would allow a range of professionals including registered nurses (RNs), social workers with a Master of Social Work (MSW) or Bachelor of Social Work (BSW) degree, or other related professionals to bill for phone and face-to-face services under the auspices of home health agencies, physician offices, community health centers, public clinics, or other licensed entities. Given the reliance on phone assessment, except in special cases requiring a home assessment, and the range of benefit level, case loads would be much higher than in traditional social service case management models. Codes would allow for disease self-management education services, assessments, care planning with the beneficiary, arrangement of chronic care services, monitoring, crisis assistance, and reassessment. Alternately care coordinators could be paid on a per member per month basis for risk-assessed beneficiaries who choose them as their care coordinator. The per member per month (PMPM) care management rate would be geared to the benefit level for which the beneficiary qualified.

The Medicaid benefit will be implemented more easily by states that already have a significant range of HCBS in place. Infrastructure development for those states without existing services and benefits will be more difficult. All states will be required to make a cost neutrality argument justifying additional home and community based expenditures. This argument will be a different one for states with well-developed HCBS systems than for those who have relied heavily on nursing home care. States with heavy SNF emphasis may be able to claim greater potential savings while states with well-developed home and community based care may have both less need for additional expenditures and fewer potential savings.

*Capitation vs. fee-for-service:* It appears that many of the successful disease management programs have accomplished results including cost savings in capitated health plan settings (Fireman, Carpenter, & Bartlett, 2000; McCulloch, Price, Hindmarsh, & Wagner, 1998; Wagner et al., 2001). It also appears that capitated health and long term care service programs such as PACE (Program of All-Inclusive Care for the Elderly) are able to substitute certain home and community care services for more costly hospital care (Wieland et al., 2000). None-the-less given the reduction in Medicare + Choice health plans (Achman & Gold, 2002; Berenson, 2002), public disenchantment with managed care, and lack of appropriate networks in rural areas, a meaningful long term care reform including a chronic disease approach must be available in the fee-for-service sector to reach the majority of high risk beneficiaries. Home and community based service providers are also not generally familiar with managed care arrangements. Any new benefit should fit into available business frameworks. The benefit should also be available to Medicare + Choice plans with some increase in their rates based on estimated expenditures in the fee-for-service sector. This lack of a capitated, at-risk structure for most beneficiaries may make cost savings more difficult to achieve.

For those who do not qualify for the Medicaid benefit there are two important issues to consider. The experience of slow enrollment in PACE, SHMO (Social Health Maintenance Organization), and other community-based long term care programs suggests that the public in general is not well educated about alternatives to nursing home care for those who need long-term care services. Consumers may also be reluctant to spend necessary dollars to remain at home as shown by the relatively slow growth of PACE buy-in users among those who are not eligible for Medicaid (P. Szutu, personal communication, 2003). The program will need to work with consumer organizations like AARP and the Center for Medicare Education on a social marketing campaign to educate the public about home and community based

long-term care services. In addition, the buy-in side of the program will suffer from a lack of available services and service providers, which may also plague the Medicaid benefit implementation. This shortage may cause prices to rise and thus out-of-pocket expenditures for this population to rise. Together the expanding market for home and community based care will lead to the further development of providers and other suppliers in this area but the supply will lag behind the initial demand as workforce training programs take time to catch up.

The program will require an increase in home and community based service providers as well as care coordinators. Given the shortage in MSWs trained in gerontology (Scharlach, Simon, & Dal Santo, 2002) as well as the well documented national nursing shortage (GAO, 2001), it is probable that care coordinators may include people with BSW degrees, Master in Public Health (MPH) degrees, and those in other comparable disciplines often not currently tapped for this role. It is quite possible that the new benefits will drive up the cost of both care-coordination services as well as that of home and community based care. The potential effect on price and the appropriate requirements for both types of services will need to be studied further during implementation planning.

*Impact on the long-term care insurance market:* Since the new HCBS benefit is targeted at those with limited incomes and assets, we do not expect a significant impact on the sale of long term care insurance products. There might be slight downward pressure based on a more acceptable Medicaid benefit being available. Care coordinators could help those who do have long term care insurance understand and more appropriately access their benefits.

*Tax collection issues:* Payroll tax financing is expected to be progressive in excluding workers with incomes at or below 300% of poverty. A refundable tax credit strategy could be used for workers with incomes below 300% of

poverty although this approach may penalize very low income workers who are less likely to file tax returns and understand tax law.

## **Data and Experiences Supporting Feasibility of the Reform Approach**

### **A) Consumer Controlled Benefit with Identified Budget**

Theoretical and empirical support for consumer centered and directed care (beneficiary empowerment): Existing studies show that that the benefits of consumer satisfaction and active beneficiary involvement reached health policy via three paths: (1) disability advocates who have promoted the Independent Living Movement and the Americans with Disability Act (ADA), for which consumer direction and empowerment are cornerstone principles (Wiener, Estes, Goldenson, & Goldberg, 2001); (2) research on the effective interventions aimed at health promotion, disease prevention and delays in the onset of chronic conditions through the reduction of behavioral and environmental risk factors , e.g., the case of diet and exercise for congestive heart failure (U.S. Department of Health & Human Services, 1998), and (3) critiques of the inappropriate and costly bio-medicalization of aging (Estes & Binney, 1989) in which aging is treated as a disease under the control of medical personnel and large financial and bureaucratic settings that increase patient dependency and helplessness.

Arguments have been made for an “empowerment imperative” for the disabled, chronically ill, and elderly (Estes, Casper, & Binney, 1993), not only on political and ideological grounds, but also with the knowledge that (a) the acute care model fails to deal with the largely social supportive and personal care needs of the chronically ill and disabled; and (b) positive benefits accompany self-efficacy and a sense of personal control. The medical model of care and financing (e.g., reimbursement limits and omissions for rehabilitation, prevention, and self directed care) encourage patient passivity and risk unnecessary and prolonged dependency.

The recent Institute of Medicine (IOM) study, *Improving the Quality of Long-Term Care*, (Wunderlich & Kohler, 2001) distinguished between “consumer-centered care” and “consumer-directed services.” *Consumer-centered care* is patient-centered health care that is “closely congruent with and responsive to patients’ wants, needs, and preferences (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993)...[It] refer[s] to a shift from a more professional-driven health care system to one ... incorporat[ing] an individual patient’s perspectives (Laine & Davidoff, 1996 in Wunderlich & Kohler, 2001, p. 28). “*Consumer- directed services*” consider the capacity of individuals to “assess their own needs, determine how and by whom these needs should be met and monitor the quality of services they receive” (National Institute on Consumer-Directed Long-Term Services, 1996, in Wunderlich & Kohler, 2001, p 29).

According to Kane, Wiener and other IOM study long-term care experts, there is evidence supporting “the value of and the need for consumer-centered care,” and research is needed on “barriers to access and barriers to consumer-centered care.” They urge states, providers and consumers to provide community based long-term care options in which individual consumers are “afforded the opportunity to specify the degree of control and influence that they are able to or wish to assume over the direction of their care” (Wunderlich & Kohler, 2001, Appendix B, p. 289).

Four types of consumer directed Long Term Care models have been identified-(Wunderlich & Kohler, 2001) those with: “(1) consumer selection, training, and supervision of caregivers and providers of service; (2) individualized supports essential to maintaining the consumer’s health and quality of life in the community (e.g., personal assistance, assistive devices, environmental modifications, consumer education, service coordination, and family and social supports); (3) consumer involvement in the development and approval of support plans and the authorization of payment; and (4) consumer monitoring of the quality of care” (DeJong, Batavia, & McKnew, 1992; Fenton et

al., 1997 in Wunderlich & Kohler, 2001, p. 29). Most existing consumer directed programs have been developed through state level Medicaid waivers and personal assistance programs or the Veterans Administration (Stone, 2000).

Despite the contention that consumer control is primarily an issue for the younger disabled, recent survey data (Coleman, 2001) suggest that a significant and growing number of elderly consumers prefer some level of control over services they receive. Existing consumer control initiatives focus on disabled consumers controlling the hiring, supervising, and perhaps training of their own personal care workers (Mahoney, Simone, & Simon-Rusinowitz, 2000) or initiatives like the Cash and Counseling program where disabled consumers have some control over how either a cash or community service benefit is expended (35 of 50 states have some type of program).

The SHMO I demonstration's also used a set dollar benefit for home and community based care services managed by a care coordinator (Newcomer, Manton, Harrington, Yordi, & Vertrees, 1995), which suggests the possibility that a care coordinator/case manager and a beneficiary can successfully manage a set budget or benefit level for a range of chronic care services. In Canada, the province of Manitoba provides a self-managed care option assigning a set dollar amount which the consumer can spend on home and community care (Martin, 1999).

There is some research on the outcomes of consumer-directed care. Doty and colleagues (1999) compared worker and client outcomes for those participating in a California independent provider program (In-Home Supportive Services or IHSS) with those receiving case-managed services from a California county agency. This U.S. Department of Health and Human Services study shows that the consumer-directed model produced more positive client outcomes in 3 areas than did the model of professionally managed services: satisfaction with services, feelings of empowerment, and perceived quality of life. There were no significant differences in client safety and unmet needs.

Agency-based program workers received better hourly wages than independent providers and were more likely to have health insurance and other benefits, although there were no significant differences in job satisfaction between workers in both models. However, independent providers had better client relationships than agency-based workers (Doty, Benjamin, Matthias, & Franke, 1999; Stone, 2000). The same study also shows “old age is not an inevitable barrier to self-direction” (Benjamin & Matthias, 2001, p. 1). Comparisons of self-directed care for the young-old (65-74) and the old-old (75+) show small age differences in most service outcomes. In an 8 state study, Tilly & Wiener (2001) “suggest better or, at least, no worse quality of life issues for consumer directed service beneficiaries when they direct their services” (p.1). Problematic issues identified concern the cognitively impaired, worker benefits, and regulating quality of care. Meiners and colleagues (2002) examined consumer direction in managed long-term care, finding their experience is limited and underdeveloped and that there are concerns about the profitability and the perceived interest and benefit of clients Meiners, Mahoney, Shoop, & Squillace (2002).

Several European countries have also instituted home and community based service benefits that provide either cash or voucher type of benefits to the disabled. In the German program consumers can choose between a cash benefit and a larger agency provided benefit. Most recipients choose the cash benefit and receive benefits at three different levels depending on the amount of assistance needed (Cuellar & Wiener, 2000; Schunk & Estes, 2001).

Both the National Association of State Units on Aging (NASUA) and the National Association of Area Agencies on Aging are interested in consumer-directed care models and the role that their member agencies may play. In 1999, NASUA produced a report, *Consumer Direction in Home and Community Based Services: An Assessment Guide*, to help states assess their systems of HCBS to identify opportunities for increasing consumer choices and control

over their services (NASUA, 1999). Ten states are currently using this guide to develop a state-specific consumer direction reform agenda. In 1993, NASUA also developed Case Management Standards in State Community Based Long Term Care Programs for programs funded by Older Americans Act and other state funds, Medicaid HCBS Waivers, and Social Services Block Grant (SSBG) funds under Title XX of the Social Security Act. Services for older adults under SSBG include home care, protective services to prevent abuse and neglect, congregate and home-delivered meals, adult day care, case management, legal services and transportation. SSBG funding in fiscal year 2002 was authorized at \$1.7 billion, well below its initial authorization of \$2.8 billion.

Since the Comprehensive Services Amendments of 1973, the Older Americans Act (OAA) has developed an “aging network” of state and area agencies to plan, coordinate and pool resources for support services for older adults. OAA funding overall is slightly above \$1 billion, of which almost one-third is for supportive services (at \$325 million in 2001). These resources are dwarfed by the \$16 billion in Medicaid funding, but this network of agencies is important because it is explicitly designated with broad responsibilities for meeting the needs of the elderly, including long-term care. In 2001, Congress approved \$125 million in funding for the National Family Caregiver Support Program (NFCSP) as part of the reauthorization of the OAA. This program enables local communities to connect families with information on caregiver resources and local services, provides counseling, training and peer support for caregivers, and provides services needed by older adults and their families, such as respite care, in-home services and adult day care. The role of State Units on Aging (SUAs) and Area Agencies on Aging (AAAs) in long-term care and the various models of organizing such care are quite varied across different states and localities. But these entities are one possible resource for the intermediary or other roles in the policy option proposed. A caution is the issue of conflict of interest. Historically, there has been debate about the appropriate role of state and area agencies on aging in long-term care, when

they are funders of service provision and could be found or perceived to be in conflict of interest situations regarding their funder roles and potentially competing with direct service providers themselves.

The promise of increased consumer satisfaction and consumer empowerment as well as the possibility of providing personal care at lower than agency costs has encouraged continued expansion of consumer controlled options. This is occurring as increased experience in setting benefit levels makes implementation of a broader consumer controlled Medicaid HCBS benefit possible. The availability of care-coordination assistance for those who chose not to manage their own care, provides a second level of choice.

#### **B) Care Coordination has potential to improve both medical and functional outcomes**

Mathematica contracted with the Health Care Financing Administration (HCFA) in an effort to study successful chronic illness care-coordination programs and recommend design options for fee-for-service Medicare beneficiaries (Chen, Brown, Aliotta, & Fox, 2000). They identified these programs as “serving chronically ill persons ‘at risk’ for adverse outcomes and expensive care” by... “1) identifying those medical, functional, social and emotional needs that increase their risk of adverse health events; 2) addressing those needs through education in self-care, optimization of medical treatment, and integration of care fragmented by setting or provider; and 3) monitoring patients for progress and early signs of problems” (Chen et al., 2000, p. xiii).

In addition to identifying the process (assess and plan, implement and deliver, and reassess and adjust) followed by these programs they further delineated “*case management programs*” which target high risk patients with costly utilization and complex medical and social problems and “*disease management programs*” which focus on a specific major chronic problem such as diabetes or congestive heart failure even though the recipient services may have additional chronic problems. Disease management programs tended to

have more specific guidelines and procedures and use information technology to help with feedback and management. Emphasis was on building relationships with patients, education of patients, and monitoring care for compliance with protocols. Case management programs were more likely to cover medical, functional, social and emotional issues (Chen et al., 2000, p. xvii-xix).

Financial incentives for both types of programs would seem to favor their implementation in organizations that bear some risk for high cost patients including health plans, medical groups that share risk with health plans, and hospitals which either share risk or bear risk for length and cost of hospital stays under the DRG (diagnosis-related group) reimbursement system.

One local randomized controlled trial measuring the effects of a social-work oriented case management model found no significant reduction in health care costs for older Medicare Plus Choice enrollees (Boult, Rassen, Rassen, Moore, & Robison, 2000). Similar findings were reported for three other HCFA-funded case management demonstrations for high-cost fee-for-service Medicare beneficiaries with no improvements in self-care, health or Medicare spending (Schore, Brown, & Cheh, 1999). However, this study's authors recommend investigating other models with more physician involvement, goal-orientation, and financial incentives tied to cost savings.

Physician-led and/or nurse-managed models of case management seem to report better outcomes, particularly those that are disease oriented. For post myocardial infarction (MI) patients, such case management efforts have been found to be "considerably more effective than usual medical care for modification of coronary risk factors after myocardial infarction" (DeBusk et al., 1994) and able to significantly reduce psychological distress risk factors, such as anxiety and anger (Taylor, Miller, Smith, & DeBusk, 1997). Similarly, nurse case managed programs in group-model HMOs have reported improved management and control of diabetes (Aubert et al., 1998) (Sikka et al., 1999).

Case management services provided through the Medicare Alzheimer's disease demonstration were shown to be protective against nursing home placement and hospitalization (Newcomer, Arnsberger, & Zhang, 1997), to have a tendency toward reduced health care expenditures (Newcomer, Miller, Clay, & Fox, 1999), and to significantly reduce unmet needs without reducing informal caregiving (Yordi et al., 1997).

One asthma disease management program was shown to reduce emergency visit rates and result in projected Medicaid savings of "\$3 to \$4 for every incremental dollar spent providing disease management support to physicians" (Rossiter et al., 2000). A 1999 review of 16 studies from 1983-1998 reported that heart failure disease management programs "appear to be a cost-effective approach to reducing morbidity and enhancing quality of life in selected patients with heart failure (Rich, 1999). However, the effectiveness and reach of the more innovative chronic disease management programs is reportedly limited "by their reliance on traditional patient education, rather than modern self-management support, poor linkages to primary care, and reliance on referrals rather than population-based approaches (Wagner, Davis, Schaefer, Von Korff, & Austin, 1999).

Several projects are also currently using care coordinators to provide both disease management education and coordination of HCBS to high risk beneficiaries (Coleman, 2002; Program for Elders in Managed Care, 2002). Preliminary findings from Sharp Health Care in San Diego indicate both positive results in terms of patient satisfaction as well as health plan savings from this approach (Graves & Slater, 2002).

Additional studies will be forthcoming on CMS-sponsored demonstration and evaluation projects on disease management and care coordination in the fee-for-service arena (Mathematica Policy Research, 2002).

### **C) Non-Medicaid-eligible consumers could buy in for home and community based services benefit**

The availability of a care coordinator funded through the Medicare program would allow beneficiaries to receive assistance in identifying HCBS available through the aging network or through home and community based service agencies. They would also receive the disease management services offered by the care coordinator. The aging network, although limited, does provide some basis for consumers to locate necessary support services.

### **D) Residential Care Options**

We have proposed that the HCBS part of the reform could be taken into residential settings such as supportive housing and assisted living, and that the care-coordination service could be provided to skilled nursing residents as well. In the case of supportive housing, care coordination and HCBS could be used in a congregate housing setting. This model of coordinating housing and services has been tested for formerly homeless adults as well as elderly through the U.S. Department of Housing and Urban Development's Congregate Housing Services Program. Supportive housing for formerly homeless adults, many with disabilities, has also been shown to reduce emergency room visits, hospital days, 911 calls, and evictions in projects sponsored by the Corporation for Supportive Housing (Houghton, 2001).

Over 40 states have designed assisted living benefits (Mollica, 2002) either through the Medicaid state plan or through 1915(c) or 1115 demonstration waivers. Medicaid services are provided in a range of existing residential care facilities, congregate housing, and in some cases in individual homes. Our proposal would allow consumers to take their HCBS benefits into all levels of housing.

We have proposed to continue Medicare-funded care-coordination services in SNF settings to assist with both chronic disease education as well as assuring that residents continue to be aware of other options to institutional

care. There is some evidence of benefits to patients as well as reduction in costs and utilization of services when additional health care services are provided in skilled nursing facilities (Kane & Huck, 2000).

### **E) Medicaid Home and Community Based Services and Cost Effectiveness**

All states, except Arizona, currently administer at least two 1915(c) waiver programs which expand HCBS to limited numbers of residents with special needs. Arizona provides HCBS under an 1115 managed care waiver (LeBlanc, Tonner, & Harrington, 2000). Although provision of services is limited to set numbers of participants under the 1915(c) waiver program, states clearly have experience in both designing such programs and in making the required (Harrington, LeBlanc, Wood, & Statten, 2000) cost effectiveness arguments to support their applications. Waiver recipients range from under 1,000 in Delaware to over 50,000 in California. States also are familiar with using both aggregate and individual cost caps in their waiver programs with caps set relative to the cost of institutional care (LeBlanc et al., 2000). This experience suggests that states would have some ability to design a mandated HCBS benefit program and set relative individual budget amounts geared to a percent of nursing home cost with lower disability level set at lower cost to indicate less risk of institutionalization and higher level recipients geared much closer to the states nursing home payment rate.

States have consistently expressed concerns about growing Medicaid expenditures and the burden on stressed budgets (Guyer, 2001; National Association of State Budget Officers, 2002) as well as unfunded mandates. The inclusion of cost effectiveness rationales backed by federal risk sharing, which has been used in some waiver and demonstration programs (e.g., Texas Star Plus, PACE, SHMO I) for cost over-runs should help speak to their concerns. This proposed reform while reaching a much larger Medicaid population would also allow for a reduction in administrative complexity for those states, which currently run several waiver programs. Some states such as Oregon are already

working to streamline administration of their varied waiver programs and reduce the number of departments and agencies involved (LeBlanc et al., 2000).

## **Potential Costs of the Benefit**

We supply very rough estimates of the cost of the new Medicaid benefit in Table I. We assume a relatively small benefit for those with IADL problems only, the equivalent of four hours per week to get help with tasks like shopping, heavy cleaning, bill paying, and other household tasks. Potential benefit levels go up in the second two benefit tiers as increased help with ADL tasks is required. We estimate the number of disabled eligibles in each category (Tilly, Goldenson, & Kasten, 2001), suggest that 60% is a rough estimate for those who may fall below 300% of poverty level, and estimate the costs if 90%, 75%, and 50% of the potential number of users actually make use of the benefit. We also assume that although the benefits are estimated in hours, the consumer could use the budgeted allocations to buy other goods or services such as supplies or respite care (as in current Cash and Counseling benefits). The potential Medicaid cost of the benefit would fall in the range of \$19.2 billion (at 50% use level) to \$34.5 billion (at 90% use). This would be offset by the approximately \$15 billion now being spent in the Medicaid program on Personal Care, HCBS waiver programs, and at least some portion of Medicaid Home Health expenditures (Fox-Grage, Folkemer, Burwell, & Horahan, 2001). It is also likely that the \$10.4 billion spent on Medicare Home Health Services (Health Care Financing Administration, 2000) would be reduced somewhat by the availability of the new benefit as some of these costs would be transferred to Medicaid. If \$2 billion (approximately 20%) were saved in Medicare home health expenditures, total current expenditures, which could help offset costs of the new program would be \$17 billion. At the upper estimate of potential users this would leave approximately \$17 billion to be made up in potential reduction of future nursing home use or in other savings.

We also supply rough estimates of the Medicare care coordination and disease management benefit in Table 2. These estimates are based on the assumption that approximately 1.5 million beneficiaries are in nursing home settings and would require disease self-management education and occasional care coordination. We assume that a care coordinator could supply such minimal service to approximately 500 members per year. We assume that all disabled beneficiaries and 10% of community dwelling elders would qualify as high risk and be eligible for the disease self-management/care-coordination benefit for a total of approximately 8.8 million (5.5 million disabled and 3.3 million elderly) beneficiaries. We assume that care coordinators would cover approximately 250 community dwelling beneficiaries per year. At an overall cost of \$50,000 per case manager per year, estimated costs for disease management care coordination would be approximately \$2 billion.

Additional Medicare costs would include costs for administration and scoring of the screening instrument and assigning of eligible beneficiaries to care coordinators. There would be some additional costs for reimbursement of group chronic disease management education classes (Lorig, Sobel et al., 2001), which would become a Medicare benefit under the program. We have not attempted to estimate these costs but assume that they would be substantially less than individual disease management education/care-coordination services discussed above.

## Tables

**Table 1. Rough Estimates of Eligible Medicaid Beneficiaries in the Community at Various Benefit Levels and Cost of Benefit.**

	<b>Total</b>	<b>Medicaid</b>		<b>Cost/ yr/</b>	
	<b>Number</b>	<b>Eligible</b>	<b>Benefit</b>	<b>Beneficiary</b>	<b>Total Cost</b>
<b>IADLs Only</b>	3.4	2.04	8 hrs / wk		
	million	million	416 hrs / yr	\$4,160	\$8.486 billion
<b>1-2 ADLs</b>	2.118	1.271	16 hrs / wk		\$10.575
	million	million	832 hrs / yr	\$8,320	billion
<b>3 or More ADLs</b>	1.578	.947	32 hrs / wk		15.758 billion
	million	million	1,664 / yr	\$16,640	
<b>Total</b>	7.3	4.38			\$34.819
	million	million			billion
				<b>Plus 10% Admin</b>	\$38.301
					billion
				<b>@ 90% Use</b>	\$34.471
					billion
				<b>@ 75% Use</b>	\$28.726
					billion
				<b>@ 50% Use</b>	\$19.155
					billion

**Table 2. Rough Estimate of Medicare Costs for Individual Disease Management Education and Care-coordination Benefit.**

(Assume \$50,000 cost per care coordinator per year.)

	<b>Number of Beneficiaries</b>	<b>Beneficiaries/care coordinator/yr</b>	<b>Total Cost</b>
<b>SNF Residents @ 100%</b>	1.5 million	500 / year	\$150 million
<b>Community Dwelling Disabled @ 100%</b>	5.5 million	250 / yr	\$1.1 billion
<b>Community Dwelling Elders @ 10%</b>	3.3 million	250 / yr	\$660 million
<b>Totals</b>	10.3 million		\$1.91 billion
		<b>Total Plus 10% Admin</b>	<b>\$1.051 billion</b>

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**About the Project**

The *Georgetown University Long-Term Care Financing Project* pursues analysis designed to stimulate public policy discussion about current long-term care financing and ways to improve it. The project is funded by a grant from The Robert Wood Johnson Foundation. More information about the project and other publications can be found at <http://ltc.georgetown.edu>.