Health Care, Personal Assistance and Assistive Technology: Are In-Kind Benefits Key to Independence or Dependence for People with Disabilities?

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Health Care, Personal Assistance and Assistive Technology

Are In-Kind Benefits Key to Independence or Dependence for People with Disabilities?

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In-Kind Benefits

In addition to cash benefits, the Social Security system in our country provides a variety of benefits in kind to eligible individuals with disabilities. Eligibility for the in-kind benefits, such as health insurance, is typically contingent upon eligibility for cash benefits under the Social Security Disability Insurance (DI) and Supplemental Security Income (SSI) programs, which, in turn, depends upon inability to work due to a medical impairment. This paper considers whether the system’s in-kind benefits, and the way in which they are designed and made available, optimally assist disability beneficiaries to achieve the goals that our nation sets for these programs, and whether there is a better way to fulfill these goals.

The Goal of Independence

There is now a consensus that the goal of U.S. disability policy is to enhance the capacity of people with disabilities to live independently in their communities. This has been the key objective of the independent living movement from its outset in the early 1970s (DeJong 1979, 1981) and was most clearly recognized as a national goal with the enactment of the Americans with Disabilities Act of 1990 (ADA). Disability advocates and researchers have concluded that we must bring the goals and policies of other disability laws and programs, including
the Social Security disability programs, in line with the independent living goals of the ADA (National Council on Disability 1986, 1988; DeJong and Batavia 1990).

While there is general agreement that independence is the goal, this consensus may be somewhat illusory because different people mean different things by "independence." The term is often used loosely and ambiguously to refer to two distinct, and often conflicting, objectives. These are:

1. the ability to live in the community and out of institutions, even if this ability is a direct result of government or philanthropic subsidization (which I will refer to as the support goal), and

2. the ability to live self-sufficiently in the community through one's own employment and resources (which I will call the employment goal).

The ADA, with its Title I employment provisions, clearly emphasizes the employment goal. However, both goals address valid objectives of the Social Security disability programs, which cover some individuals who are incapable of work. Each reflects a different objective of the system, and the contrast between them represents the basic tension between the aims of subsidizing those who need assistance and rewarding those who can make the effort to be productive. Ideally, policy decisions concerning eligibility and benefits should be based upon a careful balancing of likely effects on each of these two independent living goals.

Independence and In-Kind Benefits

Most analysts agree that obtaining in-kind Social Security benefits is extremely important to the ability of people with disabilities to live independently, from both the support and employment perspectives. If, for example, individuals who require full-time personal assistance (e.g., attendant care) cannot obtain such services, they will not be able to live in their communities. If beneficiaries will eventually lose their health coverage as a result of accepting employment, it is not in their interest to take a job that does not provide long-term assurance of at least comparable benefits or their cash equivalent.
Advocates often argue that it makes little policy sense to tie eligibility for disability benefits to the ability or decision to work. Individuals with disabilities will need these benefits to live in their communities whether or not they have a job; linking them through employment-based eligibility criteria will only decrease the incentive to work. The disincentive is likely to be particularly strong to the extent that the benefit is not available through employment, as is the case with some in-kind benefits. Despite recent legislative efforts to eliminate work disincentives, people with disabilities remain concerned about eventually losing their in-kind benefits. This concern will persist as long as the eligibility-employment link remains.

In-Kind versus Cash Benefits

Recognizing the importance of in-kind benefits to the ability to live independently also does not inexorably lead to the conclusion that such assistance must be or should be provided in kind. Presumably, if all other factors were equal, the individual with a disability would prefer an added cash benefit to an in-kind benefit of equal value. The cash benefit would offer far greater flexibility for the individual to pursue his or her independent living goals. However, for a variety of reasons, many people with disabilities currently prefer the benefits they receive in kind rather than in cash, and many policy makers prefer to offer them in kind.

From the perspective of the policy maker, who is accountable to the taxpayers financing these programs, a cash benefit does not provide the assurance that the money will be spent in a manner that would satisfy taxpayer concerns. This security is critical to ongoing political support for the program. For example, a cash benefit in lieu of Medicare might be used by a beneficiary for better nutrition or housing. While this may be a rational decision on the part of the recipient, taxpayers may resent this use of program funds, recognizing that they will ultimately still have to pay the bill if the individual becomes ill. Some policy makers do not trust beneficiaries to make accountable decisions.2

From the perspective of beneficiaries, an equivalent cash benefit has two significant drawbacks. First, individuals are concerned that a cash payment does not guarantee the ability to purchase the service previously obtained through the in-kind benefit. For example, if private
health insurers will not offer coverage at any price to people with disabilities, the cash benefit in lieu of in-kind insurance will be of little use. This problem could be remedied through certain insurance market reforms, such as guaranteed issue (assuring coverage) and community rating (assuring affordability). Second, beneficiaries are concerned that, even with such reforms, there will be a political tendency for the cash amount to be set below the level necessary to obtain adequate services.

For these reasons, cash in lieu of an in-kind benefit is probably not politically feasible in this country and will not be considered further in this paper. However, a system based on vouchers, Medical Savings Accounts (MSAs), or tax credits providing a "cash equivalent" limited to the purchase of specified services would satisfy the accountability needs of many policy makers. With respect to a tax credit, making it "refundable" and therefore available to individuals with no tax liability could equitably provide support for all individuals who require services.

The feasibility of this cash equivalent approach depends largely on whether it can be structured to satisfy the significant concerns of beneficiaries and their advocates. There would have to be some assurance that the voucher, MSA, or tax credit would be sufficient to obtain the needed service over the long term.

In-Kind Benefits and Public Policy

Eligibility and benefits ideally should be based on empirical evidence of how to achieve the independent living goals of support and employment in the most cost-effective way. While several researchers have identified a Social Security disability work disincentive generally (Leonard 1986, Muller 1989, Burkhauser and Haveman 1982), none has specifically considered whether there is a greater disincentive associated with in-kind benefits. Similarly, there has been little study of other implications of providing benefits in kind rather than through cash equivalents. In the absence of such empirical research, we must rely upon economic theory in conjunction with our knowledge of the behavior of beneficiaries.

According to conventional economic theory, receiving disability benefits in kind or through cash equivalents should not fundamentally
affect the individual's decision to seek gainful employment, *all other factors equal*. Based on a strict rational choice model, the individual would compare the aggregate value of disability benefits, both cash and in kind, with the aggregate value of a job package, including salary, vacation, and all fringe benefits. If the job's benefits exceed the social program's benefits by a sufficient amount to compensate for the value of the person's labor, the individual will seek and accept employment.

However, it is clear that all other factors are not equal in comparing in-kind benefits and cash equivalents. Many of the benefits in kind currently available to people with disabilities would not be available or affordable to them in the market. The most obvious, again, is health insurance. Health insurers in the individual, nongroup market typically either exclude people with disabilities from coverage altogether or make such coverage extremely unattractive due to specific exclusions and limitations for preexisting conditions (Griss 1988; DeJong, Batavia, and Griss 1989). Whether it is feasible to implement significant alternatives to the current in-kind benefit structure will depend partly on whether such other factors can be made equal through public policy (Batavia 1993).

This paper focuses on three in-kind benefits that are considered very important to people with disabilities: health insurance, personal assistance services, and assistive technology. It examines what disability benefits are currently provided, how individuals are eligible for such benefits, whether these benefits are adequate to allow people to live in their communities, whether this approach is helping individuals to seek work, and how we can restructure eligibility and benefits to encourage independence. The paper's basic premise is that both the support and employment goals are more likely to be achieved to the extent that people with disabilities are able to control their lives. Due to the inherent flexibility of cash equivalents, this form of assistance potentially offers greater control than do benefits provided in kind.

**Health Insurance**

Access to health care is key to independent living for many people with disabilities. *On average*, such individuals have greater health
problems and higher rates of health care utilization than nondisabled individuals (Lubitz and Pine 1986; DeJong, Batavia, and Griss 1989; LaPlante and Miller 1992; Rice and LaPlante 1992). Ironically, people with disabilities also have much poorer access to private health insurance than do other members of the population (Griss 1988; Burns, Batavia and DeJong 1991; Agency for Health Care Policy and Research (AHCPR) 1992; National Council on Disability 1993a; LaPlante, Rice and Cyril 1994).

People with disabilities who are without health insurance, or without adequate coverage, are likely to delay treatment of minor health concerns until they have escalated to major problems. For example, an individual with a spinal cord injury can develop a life-threatening decubitus ulcer (bedsore) in a matter of days without detection and appropriate treatment. If an urgent problem occurs, such individuals potentially compromise their financial ability to live independently. Ultimately, our society often pays both indirectly through uncovered care and directly through the public assistance programs (DeJong, Batavia, and Griss 1989).

How Do People with Disabilities Currently Receive Health Benefits?

The primary public health insurance programs for people with disabilities are Medicare (Title XVIII of the Social Security Act, hereafter, "the Act"), and Medicaid (Title XIX of the Act). Eligibility for Medicare for people with disabilities is based on eligibility for DI. Eligibility for Medicaid is based on eligibility for SSI. Both cash benefits programs, DI and SSI, use the same definition of disability: the inability to engage in any gainful activity due to a medically determinable impairment that is expected to last for a period of 12 consecutive months or to result in death. When Medicare was established in 1965, it primarily had an acute care orientation and did not focus on the chronic care needs of people with disabilities. In 1972, DI beneficiaries on the disability rolls for at least 24 months were made eligible for full Medicare coverage. This waiting period has been severely criticized, because some beneficiaries have a life expectancy of less than two years and the conditions of others with longer life expectancies may deteriorate if they do not receive the treatment they need in the first two years. In 1992, there were 3.57

Medicaid also was established in 1965. However, unlike Medicare, it had a long-term, chronic care orientation from the outset. Section 1901 of the Act, the introduction to Medicaid, states explicitly that the purpose of the program is to enable states to furnish medical assistance “and rehabilitation and other services ... to help attain or retain capability for independence or self-care.” Consequently, from the beginning, Medicaid has been more closely attuned than Medicare to disability issues. In 1993, there were 4.9 million individuals with “permanent and total disabilities” receiving Medicaid, at a cost of $38 billion (HHS 1994, table 8.E2).

Does the Current Eligibility and Benefit Structure Provide Adequate Support?

Medicare now covers a broad set of acute care and rehabilitation services, including inpatient hospitalization and physician services. Also covered are inpatient and outpatient rehabilitation services at a rehabilitation hospital or unit, an acute care hospital, a skilled nursing facility, a Comprehensive Outpatient Rehabilitation Facility (CORF), a therapist’s office, or the patient’s home. While the Medicare beneficiary’s cost-sharing requirements have increased substantially over time (HHS 1994, table 2.C1), most beneficiaries are satisfied with respect to these covered services.

However, Medicare coverage is weak in the areas of preventive or wellness care, long-term and maintenance care, and prescription drugs. It has been criticized for its primarily acute care orientation and its lack of catastrophic stop-loss protection, particularly in light of the increasing chronic and long-term care needs of an aging population (Griss 1988). Several legislative proposals, such as the Medicare Catastrophic Coverage Act of 1988, have been launched to address these shortcomings. Thus far all have been unsuccessful, largely due to the difficulty in financing these expensive benefits in a manner that is politically feasible.

Medicaid coverage for people with disabilities is fairly comprehensive, partly because the federal government requires, as a condition of
program participation, that mandatory benefits be provided to those who are eligible as categorically needy (such as SSI recipients). These benefits include inpatient and outpatient hospital services, lab and x-ray services, services in a skilled nursing facility, early and periodic screening, diagnosis and treatment, and family planning, physician, and home health services (Batavia 1989).

Medicaid appears to provide adequate coverage generally, although much depends upon how each state implements its own Medicaid program. While state plans must be consistent with federal requirements, states vary in their rules interpreting these standards and in the extent to which they cover optional services. Some states, such as California, are relatively generous in their coverage. Others cover the bare minimum. Overall, payment rates for Medicaid services tend to be substantially below market rates, and many beneficiaries have difficulty finding providers who will accept Medicaid payment (Griss 1988).

Does the Current Eligibility and Benefit Structure Encourage Employment?

As suggested, despite substantial legislative efforts, there appears to be a continuing work disincentive associated with the fear of losing health benefits. Throughout the 1980s, Congress enacted laws designed to allow disability program participants to accept employment, under certain conditions, without suffering a precipitous loss of cash or health benefits (National Association of Rehabilitation Facilities (NARF) 1988). The major health insurance work incentive provisions are as follow:

- The Social Security Amendments of 1980 allow DI beneficiaries whose disabling conditions continue after losing DI eligibility to retain Medicare eligibility for up to 36 months and to avoid a second 24-month waiting period before becoming re-eligible for Medicare if they become re-eligible for DI within five years.
- The Employment Opportunities for Disabled Americans Act of 1986 made permanent Section 1619 of the Act, allowing SSI recipients to receive cash benefits while gainfully employed and to retain Medicaid eligibility if their income is insufficient to obtain necessary medical services.
• The Omnibus Budget Reconciliation Act of 1989 allows DI beneficiaries who would otherwise lose Medicare benefits after the 36-month extended Medicare eligibility period to pay premiums to maintain their Medicare coverage (i.e., the Medicare buy-in). It also requires states to pay for the Medicare buy-in for certain low-income individuals.

Despite these provisions, in December 1993, only 35,299 of 5.98 million disabled SSI recipients participated in the Section 1619 work incentive program (HHS 1994, tables 7.F5 and 7.A3). Overall, throughout the history of the disability programs, regardless of significant incremental changes in the laws likely to cause work disincentives, relatively few beneficiaries have become employed and left the disability rolls (Muller 1989). This suggests the need for more fundamental, comprehensive reform of our approach to encouraging people with disabilities to seek gainful employment.

**How Can We Better Satisfy the Goals of Support and Employment?**

As a general rule, the work disincentive associated with health insurance is proportional to both the generosity of the health benefit that could be lost and the likelihood that it will be lost and inversely proportional to the generosity of the health coverage or cash equivalent that would be obtained through employment. Consequently, both sides of the health care equation must be addressed to encourage disability beneficiaries to work. Currently, the program benefit to be lost is substantial, and the employment benefit to be gained varies according to individual job skills and employment opportunities, but would be unavailable for many workers with disabilities.

The best way to deal with both sides of the equation is through policy reform that offers access to coverage whether or not the individual is employed or changes jobs. Developing truly “portable” health insurance was one of the primary objectives of the great health care reform debate of the 103rd Congress. Unfortunately, the focus of the debate was the Health Security Act (i.e., the Clinton plan), which proved to be unduly complex, bureaucratic, unaffordable, and ultimately unacceptable to the American public. Other alternative plans could achieve the objectives of health reform, including the independent living goals of support and employment, without creating a bureaucratic behemoth.
One encouraging approach developed by the Heritage Foundation would offer direct tax credits to all individuals, irrespective of employment status, based upon their health care costs relative to their incomes. Under this proposal, insurers would have to make their plans available to all people including people with disabilities, who would receive the purchasing power to obtain a health plan of their choice (with at least catastrophic coverage). If the individuals accepted employment, the amount of their tax credits would be reduced according to the increase in their incomes. If they experienced high costs in a particular year, the credit would increase, thereby automatically reducing their financial burden.

Another approach, developed by the National Center for Policy Analysis (NCPA), would allow beneficiaries to apply the actuarial value of their Medicare or Medicaid benefits to purchase a catastrophic health insurance plan with a large deductible (e.g., $3,000) and to establish a Medical Savings Account (MSA) with the remaining funds to pay for amounts up to the deductible (NCPA 1995). The MSA could be structured to allow the beneficiaries to accumulate savings from year to year without compromising eligibility. The savings could be used for any of their independent living needs. As with the Heritage proposal, the amount of the government contribution to an MSA could be reduced as income increases. By eliminating or greatly diminishing the link between eligibility and employment, these approaches would significantly reduce the work disincentive.

**Personal Assistance**

About 9.6 million people with disabilities require the help of another person with basic personal maintenance, hygiene, and household tasks to be able to live independently (Kennedy 1993). The term “personal assistance services” includes aid in the following activities:

- personal or bodily care functions, traditionally referred to as activities of daily living (ADL);
• meal preparation, laundry, light housekeeping, handling money, shopping, and transportation activities, traditionally referred to as instrumental activities of daily living (IADL);
• reader services for blind persons; and

Under the “independent living model” of personal assistance, particularly favored by many working-age people with disabilities, the disabled individual actively recruits, selects, manages, and directs his or her own provider of services, known as a “personal assistant.” The assistant typically is neither trained as, nor supervised by, a health care professional. The disabled person is a consumer of services, not a patient, and the assistant is accountable to the consumer, not to a supervising nurse or agency (DeJong 1981; DeJong and Wenker 1983). This model was developed by people with disabilities as a reaction to the perceived paternalism of health care professionals giving care under the “medical model” (Batavia, DeJong, and McKnew 1992).

How Do People with Disabilities Currently Receive Personal Assistance Benefits?

The majority of individuals who require personal assistance currently do not receive it under either the independent living or the medical model; they receive assistance through informal supports, such as family, friends, and volunteers (Kennedy 1993, Rutgers Bureau of Economic Research and World Institute on Disability 1990). This informal support model has been criticized because it often fosters an unhealthy dependency-based relationship between the disabled individual and the unpaid caregiver (Batavia, DeJong and McKnew 1992).

In response to these criticisms and to the growing need for personal aid in the population, government programs of paid assistance have been established. The main federal initiatives that offer personal assistance and other home-based services to disability beneficiaries are home health, homemaker, and chore services financed under Medicaid and under the Social Services block grant program (Title XX of the Act); services under Medicare when home-based assistance is associ-
ated with a recent hospital stay; and similar services for disabled senior citizens provided under the Older Americans Act.

The independent living model has been adopted by the Department of Veterans Affairs in its Aides and Attendant Allowance Program and by several states in their Medicaid and Social Services programs. For example, Massachusetts, California, and Pennsylvania have incorporated independent living concepts into their interpretation of the federal regulations governing community-based services (DeJong and Wenker 1983; Zukas, Cone, and Leon 1984; Allard and Spence 1986). Other states provide home-based long-term care services under a more medically oriented model using agencies and medical supervision (Litvak, Zukas, and Heumann 1987; Egley 1994).

**Does the Current Eligibility and Benefit Structure Provide Adequate Support?**

Whether individuals who require personal assistance services receive the support they need under the model that they prefer depends in large part on the state in which they live. In its 50-state survey of all publicly funded in-home service programs, the World Institute on Disability (WID) found that 42 percent did not cover both personal and domestic services, 22 percent do not cover services seven days per week, 50 percent did not serve persons with incomes above the poverty level, and 67 percent did not allow aides or personal assistants to help in personal care involving medications, catheters, suppositories, or menstrual needs (Litvak, Zukas, and Heumann 1987). While some states have since improved their coverage, most still do not conform to the independent living model (Nosek and Howland 1993; Kennedy 1993).

Thus, most states have not responded to the preferences of many people with disabilities for personal assistance services. To the extent that states or agencies have attempted to fund personal assistance services, most have done so in an uncoordinated and nonsystematic manner. Few provide such services in a way that offers consumers maximum control over their lives, optimally supporting their ability to exist independently in their communities (Nosek 1992). Many programs retain strong elements of the medical model, including reliance on institutional placement (Kennedy 1993).
In addition, states typically have not provided adequate funding to meet the substantial need for such services and have developed a variety of rationing mechanisms to limit their financial responsibility. These include eligibility criteria that limit enrollment to those "at risk of institutionalization" or to people with physical disabilities; coverage rules that prohibit funding for certain nonmedical services; rules prohibiting funding for assistants who are related to the recipient; limitations in the number of hours of services covered; and restrictions concerning the site of services.

One reason for such approaches is that states are concerned over "the woodwork effect" (people who are receiving assistance from relatives or friends coming "out of the woodwork" to request funding) and adverse selection (i.e., the tendency of disabled persons to move to those programs and insurance plans that offer the most generous benefits that they need) (Batavia, DeJong, and McKnew 1992). For example, it is generally acknowledged that many younger disabled persons decide to reside in California because it has a comprehensive in-home support services program based on the independent living model.

Does the Current Eligibility and Benefit Structure Encourage Employment?

As in the case of health insurance, the extent of the work disincentive is directly related to the generosity of the benefit. In those states with very generous personal assistance services programs, the work disincentive appears particularly strong. Personal assistance services are not covered under any private health insurance plans available through employment or in the individual market. Consequently, if an individual were to eventually lose his or her personal assistance benefit, he or she would require a very substantial income to be able to pay for such services out of pocket. Without having access to such services, the individual would have to rely on the assistance of unpaid friends or relatives, if available.
How Can We Restructure Eligibility and Benefits to Encourage Independence?

To meet the need for personal assistance services equitably, and to reduce adverse selection, a national personal assistance services policy is needed (Batavia, DeJong, and McKnew 1992; Nosek and Howland 1993). Such a policy should provide a comprehensive approach to financing assistance services and helping disabled persons to recruit competent, dependable personal assistants. One national model is the Department of Veterans Affairs program, which provides funds directly for personal assistance services based on need to qualified disabled veterans, regardless of employment status. This model would have to be adapted to protect against the woodwork effect in serving the much larger civilian disabled population.

A possible approach would be to implement a system based on tax credits, MSAs, or vouchers, similar to that suggested for health insurance. In one regard, this approach would be easier to apply to personal assistance because there are no significant barriers to purchasing such services through the general market. The primary challenge would be to develop an equitable and efficient mechanism that is not easily subject to fraud and abuse for purposes of determining the appropriate amount of the credit, MSA, or voucher.

Assistive Technology and Durable Medical Equipment

Just as personal assistance services can compensate for lost functional capacity, assistive technology can also help people with disabilities to live independently. In certain circumstances, it can even provide a cost-effective means of reducing the need for certain kinds of personal assistance. Examples of assistive devices used by people with disabilities include wheelchairs, augmentative communication devices, page turners, environmental control units, and amplified listening devices (Seelman 1993).

Estimates from the National Health Interview Survey suggest that about 5 percent of the civilian noninstitutionalized population currently uses assistive devices, excluding eyeglasses (LaPlante, Hendershot,
and Moss 1992). About 1 percent of the population indicated that they
did not have at least one assistive device that they needed, primarily
due to financial considerations. For many of these individuals, the abil-
ity to obtain such items would significantly enhance their ability to live
more independently and productively.

How Do Disabled People Currently Receive Assistive
Technology Benefits?

Medicare Part B covers the purchase or rental of certain devices that
qualify as durable medical equipment (DME), such as wheelchairs. In
addition, it covers prosthetic devices, orthotic devices, and certain
medical supplies. Yet, DME suppliers received only 3.5 percent of all
Medicare Part B payments in 1990. Medicare accounted for 17.8 per-
cent of DME, while private insurance paid 10.4 percent, and individu-
als paid 67.3 percent out of pocket. The vast majority of Medicare
DME expenditures are for such medical equipment as oxygen, 34.4
percent; prosthetics and orthotics 18.8 percent; and tube feeding 17.2
percent (Committee on Ways and Means 1991).

States again vary as to the generosity of their Medicaid coverage,
although this is generally limited to fairly basic durable medical equip-
ment. While motorized wheelchairs tend to be covered, most other
devices that would support independent living are not. Those SSI
recipients who are on the Plan to Achieve Self-Sufficiency (PASS) Pro-
gram may set aside funds to purchase assistive devices without com-
promising their program eligibility. Also, some state vocational
rehabilitation programs provide assistive devices to support an educa-
tional and vocational strategy. However, most people with disabilities
who need “nonmedical” assistive devices pay for them out of pocket.

Does the Current Eligibility and Benefit Structure
Provide Adequate Support?

Medicare does not pay for services or devices “which are not rea-
sonable and necessary for the diagnosis or treatment of illness or injury
or to improve the functioning of a malformed body member.” Many
assistive devices are routinely disallowed because they are considered
“convenience items.” Motorized wheelchairs are denied to individuals
who can operate a manual wheelchair in their homes, even if they would need the motorized wheelchair to transport themselves in their communities (Griss 1988, National Council on Disability 1993b).

As with health insurance and personal assistance, whether Medicaid beneficiaries receive the assistive devices they need depends on the state in which they reside (National Council on Disability 1993b). No state covers the full range of needed devices; items such as environmental control units are virtually never included under state Medicaid plans.15 Two significant policy barriers to obtaining assistive devices under Medicaid are the requirements that the recipient demonstrate "Medical Need" and obtain "Prior Approval" for the device. Interpretations of these requirements, and the extent of the barriers, vary from state to state (Seelman 1993).

**Does the Current Eligibility and Benefit Structure Encourage Employment?**

The current system promotes employment to the extent that it provides individuals with the assistive devices they need to seek and maintain jobs. For the most part, individuals do not receive the work-related devices they need under Medicare or Medicaid. Conversely, the eventual loss of eligibility for these programs would consequently not impose a significant work disincentive, except to the extent that needed medical devices, such as oxygen, would be lost. For individuals with requirements for such covered durable medical equipment, the work disincentive is likely to be substantial. Again, the link between eligibility and employment is problematic.

**How Can We Better Satisfy the Goals of Support and Employment?**

The major difference to be considered in analyzing personal assistance services and assistive devices is that some assistive devices are currently covered through private employer-based health insurance. However, this varies from plan to plan; very few health maintenance organizations (HMOs) cover DME to the same extent that Blue Cross plans do. If other payors do not improve their coverage, Blue Cross may eventually have to cut back to remain competitive. From a policy perspective, this suggests that the playing field should be leveled
among different health plans through a uniform minimum benefits requirement. If all private health plans covered DME, the work disincentive associated with such equipment would be reduced.

Another alternative would be to remove assistive technology and DME from the health care financing system and to subsidize them in another manner, such as through tax credits, MSAs, or vouchers. As with personal assistance services, this approach would give individuals with disabilities flexibility in choosing and obtaining the devices they need to live independently. Like personal assistance, it also raises concerns as to how to restructure the financing of services. A major issue is how to determine the amount of the credit, MSA, or voucher.

Conclusions

The benefits that are provided in kind under the Social Security disability programs have a profound effect on the capacity of people with disabilities to live in their communities and to seek gainful employment. An analysis of how health insurance, personal assistance services, and assistive technology are currently provided suggests that they satisfy the support goal to a greater extent than the employment goal. From the low numbers of beneficiaries who have left the disability rolls, it now appears clear that further tinkering with the system’s work disincentives is unlikely to achieve independent living objectives.

More fundamental change is necessary. We must reexamine the premises of the current system to determine whether they are consistent with the system’s goals. Services that are currently provided in kind could be offered in a number of different ways. No special significance should be attributed to the fact that they are currently provided in kind except to the degree that they would otherwise not be available or affordable to people with disabilities. To that extent, reforms should be implemented to eliminate barriers to an accessible market for such services. The focus must be on meeting the basic support needs of the individual while encouraging self-sufficiency.

The cash equivalent approach advocated in this paper is particularly compatible with these goals for two reasons. First, it is philosophically consistent because it treats people with disabilities in an integrated
manner with other people while recognizing, through the subsidy, the additional financial burdens of disability. It thereby implicitly acknowledge that disability is a normal aspect of the human experience. In contrast, the current system treats people with disabilities in a segregated manner, as if they were a separate species. Second, the cash equivalent approach would require less bureaucracy because it would be administered largely through existing structures (i.e., the tax system).

Whether we continue to provide services in kind or through vouchers, MSAs, or refundable tax credits, the issue of eligibility will remain critical. This is particularly true if we divorce the benefits now provided in kind from the present cash benefit programs. Current mechanisms for determining eligibility are grossly inadequate and are at odds with the goal of employment. New approaches, including different definitions and review methods, will be necessary to assure that only individuals with significant functional limitations are eligible for benefits and that these individuals receive the benefits they need to live independently (Batavia and Parker 1995).

Linking eligibility to work is not necessary and is counterproductive to the extent that it creates a self-fulfilling prophecy convincing beneficiaries that they are unemployable. There is no compelling policy rationale for providing benefits in kind, and by doing so we send the implicit message that we do not trust beneficiaries to make decisions for themselves. Alternatively, by providing cash equivalents regardless of employment status and phasing them out as income increases, we can offer people with disabilities greater control over their lives, and we are more likely to satisfy both the support and employment goals.

In pursuing this approach, it is essential to recognize that people with similar impairments and functional limitations can vary dramatically in their need for services and that some mechanism would have to be devised to determine the appropriate amount of the credit, MSA, or voucher. Ideally, this determination should be based on a valid and reliable assessment of each individual’s functional capacity and need for services. Unfortunately, we currently have only relatively simple, unsophisticated approaches to assessing functional status, based largely on ADLs that are subject to manipulation (Batavia 1992).

An alternative to basing a cash equivalent on functional assessment would be to use a significant cost-sharing requirement to induce indi-
viduals to be cost conscious in their decisions. For example, we could permit a refundable tax credit for a specified percentage of service or coverage costs based on income (e.g., 90 percent for people with incomes up to 200 percent of the poverty level, 80 percent for incomes between 200 percent and 300 percent of the poverty level, etc.) up to a maximum amount (e.g., $15,000 per year). This approach raises certain equity issues that will have to be seriously considered in structuring the credits, MSAs, or vouchers.

It must be emphasized that whether or not a cash equivalent approach will benefit people with disabilities will depend entirely on how it is structured. A poorly designed program using MSAs, for example, could lead to substantial adverse selection that could destroy the Medicare or Medicaid system. Careful attention must be paid to ensuring that a plan does not simply provide a windfall for those who are healthy, depleting the low risks from the general insurance pool and imposing higher costs on those who are less healthy (American Academy of Actuaries 1995).

While systematic reform is necessary, it need not occur all at once. Given the incremental nature of our political system, it would be preferable to achieve these changes in several stages. A first stage might remove barriers to the establishment of a competitive market, in which people with disabilities would have access to services currently provided in kind. Subsequent stages might entail the creation of tax credits, MSAs, or vouchers to offer greater access to these markets and might involve the implementation of demonstration projects to test these approaches.

Whichever specific approach is adopted, and however it is implemented, we must boldly reform our disability programs. A system that does not service the long-term interest of its intended beneficiaries cannot and should not be sustained.

NOTES

1 It is the author's belief that the vast majority of people with disabilities are capable of gainful employment. Individuals with very substantial functional limitations, including respirator dependency, high-level quadriplegia, and mental retardation, have been able to remain productive in the public or private sector. However, it is clear that some individuals, such as those with very severe brain damage, have disabilities that preclude employment.

2 In the worst-case scenario, policy makers are concerned that some beneficiaries may use the cash for entirely unjustifiable purposes, e.g., for the purchase of alcohol or illegal drugs. Such rare
situations, which are occasionally revealed through the press, can jeopardize support for an entire program.

3. An MSA is a tax-advantaged savings account, similar to an Individual Retirement Account (IRA), which could be used for certain specified purposes (e.g., medical costs, long-term care, personal assistance services) and could accumulate from year to year (Goodman and Musgrave 1992)

4. People with certain conditions, such as diabetes, spinal cord injury, and acquired immune deficiency syndrome (AIDS), statistically have higher than average health care costs. People with other disabilities, such as blindness, deafness, and mental retardation, have close to average costs, but are often perceived and treated by health insurers (defined broadly in this paper to include commercial insurers, Blue Cross/Blue Shield, managed care plans, and self-insured organizations) as costing more than average. Individuals in both groups find it difficult or impossible to obtain affordable health insurance unless they have access to a group policy.


7. However, at the time of this writing, Congress is considering legislation that would give states far greater discretion in setting their Medicaid policies unencumbered by federal requirements.

8. While there are numerous possible explanations for the small number of beneficiaries who leave the rolls, I believe that it is a result of a combination of three factors: (1) the substantial psychological investment that beneficiaries must make in initially demonstrating their inability to work in order to establish eligibility, (2) a basic distrust that the government will fulfill its end of the bargain to provide continuing benefits once they become employed or to reestablish their eligibility if they lose their jobs, and (3) an inability to obtain equivalent benefits through employment.

9. One study has found that disabled persons employed part-time are significantly less likely to have any insurance coverage than those employed full-time or not at all, suggesting that disabled individuals who cannot make the transition directly to full-time employment and those who are only capable of part-time employment are likely to have a substantial work disincentive (Burns, Batavia, and DeJong 1994).

10 The Health Security Act of 1993, H.R. 3600 and S. 1757 (103rd Congress).

11 A bill based on this approach, the Consumer Choice Health Security Act of 1993, S. 1743, was introduced by Senator Don Nickles (Republican-Oklahoma) in the 103rd Congress, 1993.

12 Among the advantages of this approach are that it could be designed to offer universal coverage, shift the system from employment-based to household-based, thereby offering full portability of coverage when one changes employment status, provide the type of protection that is most needed, catastrophic and long-term care coverage; stimulate competition among health plans, thereby containing costs while maintaining access and quality; enhance consumers' cost consciousness while maintaining their autonomy and control; and subsidize people who have undue financial burdens (Batavia 1993).

13 Under this model, personal assistance has been defined as “Assistance, under maximum feasible control, with tasks aimed at maintaining well-being, personal appearance, comfort, safety, and interactions with the community and society as a whole” (Litvak, Zukas, and Heumann 1987).

14 It is reported that some long-term care policies are beginning to offer personal assistance services as an option.

15. To the limited extent that they are available to people with disabilities using state funds, it is typically through the vocational rehabilitation system on a discretionary basis.
References


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