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HEALTH CARE REFORM AND PEOPLE WITH DISABILITIES

by Andrew I. Batavia

Prologue: Discussions about reforming America’s health care system focus largely on health care for the vast majority of Americans with average levels of need. Yet those persons with the most at stake in a changing health care system are the estimated 37.3 million people age fifteen and older who have disabilities. As Andrew Batavia argues here, the above-average costs of care for many people with disabilities, and their below-average access to care, often leave them financially vulnerable and unable to live the full, productive lives to which they are entitled. The Americans with Disabilities Act of 1990 (ADA) made significant strides in eliminating discrimination on the basis of disability. However, it “does not fully resolve the issue of access to affordable health insurance for people with disabilities,” Batavia writes, “nor was it intended to do so,” since it is a civil rights law, not a law specifically designed to reform the health care system. However, the ADA is a clear sign that “the clout of disability organizations has increased in recent years,” he continues. The challenge is to channel that political energy into shaping the future U.S. health care system so that the needs of people with disabilities are fully addressed.

Batavia, a prolific author and researcher, has held a variety of positions in both the private and public sectors, with specific emphasis on disability policy. He received a master’s degree in health services research from Stanford Medical School and a juris doctorate from Harvard Law School. When he wrote this paper, he was research director for disability and rehabilitation policy at Abt Associates. Currently he is executive director of the federal National Council on Disability. He served as an associate director of the White House Domestic Policy Council under President Bush. While at the Justice Department as special assistant to Attorney General Dick Thornburgh, Batavia helped to develop regulations for the ADA.
Abstract: As a group, people with disabilities or chronic conditions experience higher-than-average health care costs and have difficulty gaining access to affordable private health insurance coverage. While the Americans with Disabilities Act will enhance access by prohibiting differential treatment without sound actuarial justification, it will not guarantee equal access for people in impairment groups with high utilization rates. Health care reform is needed to subsidize the coverage of such individuals. Such subsidization can be achieved under either a casualty insurance model, in which premiums based on expected costs are subsidized directly, or a social insurance model, in which low-cost enrollees cross-subsidize high-cost enrollees. Cost containment provisions that focus on the provider, such as global budgeting and managed competition, will adversely affect disabled people if providers do not have adequate incentives to meet these people’s needs. Provisions focusing on the consumer, such as cost sharing, case management, and benefit reductions, will adversely affect disabled people if they unduly limit needed services or impose a disproportionate financial burden on disabled people.

The national debate on health care reform and universal health insurance has addressed a wide range of issues concerning access to, cost of, and quality of health care services for the general population. It has not yet focused significantly on how such reform or national health insurance will affect various vulnerable populations. Among those most affected will be people with disabilities. How can the needs of such persons be met equitably and at the lowest efficiency cost to the economy? This paper considers the casualty and social insurance models for subsidizing health care, several approaches to containing costs, and three mechanisms for designing national health insurance (Canadian-style, “play-or-pay,” and managed competition) and how they would affect people with disabilities. Here I use the term disability broadly to include chronic conditions.1

The number of people with disabilities is growing rapidly as the population ages and as modern medicine expands its ability to save and extend the lives of people who have experienced disabling disease or trauma.2 On average, individuals with such conditions have higher rates of health care use, account for a higher percentage of national health care expenditures, and have poorer access to private health insurance than do other members of the population.3 However, the disabled population is also diverse, with great variation in patterns of use, costs, and ability to pay; thus, the amount of needed subsidization for these persons under a national health insurance scheme would have to be highly individualized.

People with certain conditions such as diabetes, spinal cord injury, and acquired immunodeficiency 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 here to include managed care plans and self-insured organizations as well as Blue Cross/Blue Shield and commercial plans) 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.
Where Disability Policy Meets Health Policy

Some 37.3 million people age fifteen and older have at least one physical functional limitation (for example, walking, seeing, or talking) due to a chronic condition. Of these individuals, about twenty-three million people are limited or unable to conduct their major life activity (that is, working or attending school). Over 2.5 million people require assistance with the activities of daily living (ADLs) such as bathing, dressing, grooming, eating, transferring, and using the toilet; and 7.3 million require assistance in ADLs and/or the instrumental activities of daily living (IADLs) such as meal preparation and housework. It is difficult to cull from current national surveys the number of people with chronic conditions that do not result in functional limitations.

Disability policy is the branch of public policy that broadly addresses the needs of such individuals, including the need for employment, education, access to public accommodations, personal assistance, telecommunications, income maintenance, housing, assistive technology, transportation, and health care. Thus, contrary to popular belief, health care is only one, albeit important, of several areas of concern to disability policy. Conversely, people with disabilities are one of several vulnerable populations that should be of substantial interest to health policymakers.

Influenced by the independent living movement of the 1970s, a primary goal of disability policy in this country is to empower disabled people to live independently and productively in their communities. As it relates to health care, the objective of disability policy is to ensure that people with disabilities have access to the specific high-quality services they need without compromising their ability to live independently and productively. The inability of many people with disabilities to obtain affordable health coverage interferes with this goal by deterring them from obtaining gainful employment and by making them vulnerable to financial catastrophe.

For example, disabled recipients of Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI), who thereby receive Medicare or Medicaid, respectively, are often concerned that they will lose their insurance coverage by working and that they will not be able to obtain comparable coverage through their employer. While two relatively new laws allow SSDI and SSI beneficiaries to purchase extended Medicare or Medicaid coverage for a reasonable premium after losing their cash entitlements, few are aware of these opportunities, and those who know about them tend to be wary of them.

The majority of people with disabilities are not beneficiaries of government entitlement programs. Lack of access to adequate health insurance also has a negative effect on these individuals. Disabled people who are
employed are often deterred from changing jobs, concerned that their new insurance will not cover their condition for a period of time, if at all. Some live in fear of losing their jobs and thereby losing their access to health care coverage. Many disabled people who would like to start their own businesses are discouraged from doing so because they would not have access to group coverage and cannot obtain or afford individual coverage.

People with disabilities who lack adequate health coverage are financially vulnerable in the event of a major health problem. In such instances society ultimately pays, indirectly through uncompensated care and directly through public income maintenance and in-kind assistance programs. Thus, there is a large cost to society for failing to make affordable health insurance available broadly and adequately to the disabled population.

Background On Insurance And Disability

Of the approximately thirty-five million people in this country who have no health care coverage, about 2.4 million have disabilities.12 Disabled individuals under age sixty-five are about as likely to be uninsured (15.2 percent) as are people without disabilities (14.4 percent).13 This is because many people with disabilities are eligible for Medicaid, Medicare, veterans’ health benefits, and other public-sector health care programs.14 The primary insurance problem confronted by the disabled population is not access to health care coverage per se, but rather access to adequate coverage that meets their specific needs. Consequently, disabled people are well represented in the large underinsured population.15

Underinsurance for people with disabilities is primarily a private-sector phenomenon.16 Public coverage presents other problems for disabled people, such as complex eligibility requirements that impose potential work disincentives and difficulty in finding physicians and other providers because of inadequate payment rates. Private insurers have traditionally addressed the issue of covering people with disabilities through a set of underwriting criteria and coverage rules. The most important of these is the use of “preexisting condition” clauses in insurance contracts, which exclude from coverage, either permanently or for a stated period of time, care for illnesses or disabilities that exist when the insurance contract begins.

Some insurers deny coverage for people with specified conditions or set their premiums, deductibles, and copayments so high that coverage is virtually unaffordable. Even group policies often have preexisting condition limitations and annual or lifetime caps for certain conditions or treatments. Finally, many policies do not cover the full scope of services needed by people with disabilities. For example, health maintenance organizations (HMOs) typically cover only short-term inpatient rehabilitation and often
do not cover wheelchairs and other assistive devices.\textsuperscript{17}

Insurers claim that they must protect themselves from adverse selection, the tendency for high-cost individuals to seek out health care plans that offer the most generous benefits that meet their needs. Adverse selection leads to higher costs for all subscribers to a health plan and thus makes the plan's premiums less competitively priced than premiums of plans that are not subject to adverse selection. The response of many insurers to improve their competitive positions is preferred risk selection, seeking out subscribers who are likely to incur lower costs.

From the perspective of people with disabilities, and to a large extent of broader society, the restrictions insurers impose are neither rational nor equitable. Disabled people who do not have access to group health insurance are effectively precluded from obtaining affordable private health care coverage and are left with three options: (1) to pay a disproportionate share of their incomes for individual coverage that is typically inadequate; (2) to go uninsured, thereby incurring great financial risk; or (3) to join a public-sector program, often requiring financial destitution to be eligible.

The Consortium for Citizens with Disabilities (CCD), a working coalition of consumer, provider, and professional organizations that advocate on behalf of disabled people, has established five general principles for health care reform from a disability perspective.\textsuperscript{18} (1) Nondiscrimination-People with disabilities of all ages and their families must be able to fully participate in the nation's health care system. (2) Comprehensiveness-People with disabilities and their families must have access to a health care system that ensures a comprehensive array of health, rehabilitation, personal assistance, and support services across all service categories and sites. (3) Appropriateness-People with disabilities and their families must be assured that comprehensive health, rehabilitation, personal assistance, and support services are provided on the basis of individual need, preference, and choice. (4) Equity-People with disabilities and their families must be ensured equitable participation in the nation's health care system and not be burdened with disproportionate costs. (5) Efficiency-People with disabilities and their families must have access to a health care system that provides a maximum of appropriate, effective, high-quality services with a minimum of administrative waste.

These principles represent a broad consensus within the disability community as to what disabled people need from the health care system. Although they do not offer great insight on trade-offs between enhancing access and reducing costs necessary to enact a fiscally responsible health care reform law, they indicate the broad objectives of such reform from the perspective of the disabled population. They also can serve as criteria to determine if specific reform proposals address the needs of this population.
The Americans With Disabilities Act

One law that could potentially enhance access to adequate health care coverage for people with disabilities is the recently enacted Americans with Disabilities Act of 1990 (ADA). The ADA applies to health insurance through its provisions prohibiting employment discrimination (Title I) in employee benefit plans and through its provisions requiring access to places of public accommodation (Title III) such as insurance companies and HMOs. However, for reasons discussed below, the ADA does not fully resolve the issue of access to health care coverage for many people with disabilities.

As a result of a general insurance provision in Title V, the ADA offers conflicting messages on the legality of insurance practices affecting people with disabilities. On the one hand, sections 501 (c) (1) and (2) state that the ADA “shall not be construed to prohibit or restrict [insurers, HMOs, and other entities that administer benefit plans] from underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law.” On the other hand, section 501(c) states that these sections “shall not be used as a subterfuge to evade the purposes of title I and III.” Thus, the ADA appears to say that insurers may continue to treat disabled people differently than nondisabled people but may not do so in a manner that discriminates against disabled people.

The preamble to the Department of Justice regulations for the ADA attempts to clarify this apparent inconsistency. It cites language from congressional reports stating that “[u]nder the ADA, a person with a disability cannot be denied insurance or be subject to different terms or conditions of insurance based on disability alone, if the disability does not pose increased risks” (emphasis added). The Judiciary Committee report indicates that section 501(c) of the ADA was intended to emphasize that “insurers may continue to sell to and underwrite individuals applying for life, health or other insurance on an individually underwritten basis, or to service such insurance products, so long as the standards used are based on sound actuarial data and not on speculation” (emphasis added).

Finally, the Senate report states that “while a plan which limits certain kinds of coverage based on classification of risk would be allowed . . . , the plan may not refuse to insure, or refuse to continue to insure, or limit the amount, extent, or kind of coverage available to an individual, or charge a different rate for the same coverage solely because of a physical or mental impairment, except where the refusal, limitation, or rate differential is based on sound actuarial principles or is related to actual or reasonably anticipated experience” (emphasis added). As an example, a person with a preexisting condition may be denied coverage for that condition for the period stated...
in the policy but may not be denied coverage for illnesses not related to the preexisting condition. Similarly, an insurer may limit coverage for certain procedures or treatments but may not deny coverage entirely for a person with a disability.

Based on this congressional language, the preamble to the Department of Justice regulations clarifies that under the ADA insurers may no longer treat people differently on the basis of disability unless their differential treatment is justified by sound actuarial principles or reasonably anticipated experience. Unfortunately, this preamble language was not incorporated directly into the language of the regulations. This may prove problematic because, while those regulations reiterate that they may not be used as a subterfuge to evade the purposes of the ADA, they do not state clearly that insurers may not treat disabled people differently without a strong actuarial justification. Without this clarifying language, some will assume erroneously that insurers may continue to conduct business as usual, denying coverage or raising rates without justification.

Health Care Reform: Two Models

Clearly, the ADA does not fully resolve the issue of access to affordable health insurance for people with disabilities, nor was it intended to do so. At most, as a civil rights law intended to eliminate discrimination on the basis of disability, the ADA addresses the fringes of the insurance access issue by prohibiting unjustified differential treatment against disabled people. It does not prohibit disparate treatment based on real differences in health care use and costs among individuals or even based on actuarially sound categories of individuals.

To address these differences, a health care reform law, possibly in the form of a national health insurance program, would be required. Unlike the ADA, such a law would entail some form of subsidization of the higher-than-average health care costs of many people with disabilities. There are two diametrically opposite models to subsidize health care: the casualty insurance model and the social insurance model (Exhibit 1). Along the continuum between these two theoretical endpoints are a wide variety of possibilities on which to base health care reform.

Casualty insurance model. Under the casualty insurance model, premiums are set on the basis of expected losses. This is the model used in automobile insurance and fire insurance. The basic argument in favor of this model is that it encourages responsible risk-reducing behavior. For example, smokers would be charged a higher premium than nonsmokers because of the health risks of smoking. This would theoretically induce them to stop smoking. However, the theory is less applicable as it relates to
individuals who already have a condition, such as a disability, that imposes costs that are beyond the individual’s control. Moreover, the casualty insurance model appears particularly inequitable when the cause of the disability itself was beyond the individual’s control (for instance, a communicable disease or injury caused by another party).

If health insurance were based entirely on a casualty insurance model, without subsidization, many people with disabilities would be largely uninsurable because the loss for which the individual seeks insurance coverage is practically guaranteed. Many people with disabilities either have a condition resulting in high costs (such as AIDS), or have greater vulnerability to health problems (for example, spinal cord injury) than the average nondisabled person. Since the cost of insurance would reflect the expected cost of the individual’s care, many of those disabled people with high costs and moderate to low incomes would not be able to afford coverage.

Using a casualty insurance approach to ensure access for people with disabilities, the government would set a financial subsidy based in large part on the actuarially expected above-average costs of the individual. This, of course, assumes that good actuarial data on the health care costs of people with different impairments and disabilities are available, which is typically not the case. However, assuming that a subsidy could be set fairly, it would theoretically eliminate, or at least greatly reduce, the incentive for insurers to engage in preferred risk selection. Insurers will be encouraged to enroll people with disabilities because the total subsidized premium adequately compensates them for disabled individuals’ cost of care.

**Social insurance model.** Under a social insurance model, expected loss is largely ignored in allocating costs, and extensive cross-subsidization occurs among different risk groups. Advocates of this approach criticize the inequity of charging more to people who have health problems or disabi-
ties, as under the casualty insurance model. They tend to discount the efficiency arguments for casualty insurance, contending that much of health care, particularly for people who are already sick or disabled, is not subject to risk reduction. Moreover, they argue that incentives for risk reduction can be built into the social insurance model (for instance, through cost-sharing mechanisms such as deductibles and copayments).

A health care reform law based on the social insurance model would require the government to impose specific requirements for community rating, mandating cross-subsidies to equalize premiums among different risk groups. This would further require a set of rules prohibiting discrimination that would have to be strictly enforced. For the social insurance model to be efficient, it requires universal coverage. Otherwise, low-cost individuals who subsidize high-cost individuals would opt out of the system. A major advantage of the social insurance model to the government is that its costs are off budget, in that they are imposed on private-sector organizations through mandated cross-subsidization.

Because of the cross-subsidy, there is always a tendency for insurers to engage in preferred risk selection under a social insurance model. While regulations may legally prohibit discrimination against people with disabilities, insurers can discourage such individuals from enrolling in their plans in a myriad of subtle ways. These include discriminatory marketing strategies, inaccessible offices, and coverage policies that do not meet the needs of disabled people. The success of the social insurance model depends largely on the quality of the regulations and their enforcement in preventing preferred risk selection.

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**Health Care Reform And Cost Containment**

Any serious health care reform proposal, based on either model, must include a substantial component designed to contain costs. Otherwise, the cost inflation stimulated by the enhanced access under the proposal will ultimately compromise access, thereby defeating an essential purpose of reform. However, cost containment approaches that do not adequately ensure access will ultimately affect the covered population adversely, particularly vulnerable individuals such as many with disabilities. The simplest way to contain costs is to directly reduce access (that is, reduce needed benefits or close facilities), which most would agree is not a socially desirable solution.

The objective of health care reform should not be simply to reduce costs, but rather to increase access and quality while reducing costs through enhanced efficiency. Most cost containment provisions focus on either the provider or the consumer (except for those that address the insurer's admin-
istrative costs). Those that focus on the provider, such as global budgeting, prospective payment, and managed competition, will adversely affect people with disabilities if the provider does not have adequate incentives to meet the needs of disabled individuals. Those that focus on the consumer, such as cost sharing, case management, and benefit reductions, will adversely affect individuals with disabilities if they unduly limit needed services or impose a disproportionate financial burden on disabled people.

**Provider-based cost containment.** Under a global budgeting approach, facilities that are subject to a fixed budget, even if it is adjusted prospectively for case-mix, have an incentive to treat patients who incur low health care costs or who are easy to treat quickly and efficiently. People with disabilities, on average, are more likely to incur high costs and require additional time to treat. Particularly once a facility exceeds its budget, it will be strongly deterred from treating disabled people, unless there are provisions for extra compensation (such as severity of illness, functional deficit, or outlier adjustments) to providers for treating high-cost patients.

Other prospective payment methodologies may have similar incentives, depending on their unit of payment. For example, prospective payment based on payment per case for rehabilitation hospitals is likely to discourage such facilities from admitting patients with the most severe conditions. Physician fee schedules are likely to encourage repeat visits and possible overtreatment of disabled patients. Utilization review may ameliorate these tendencies but is unlikely to alter the basic incentives of a system.

Under a managed competition approach, the provider has an incentive to contain costs to remain competitive. Whether such a system will adversely affect people with disabilities depends largely on how it addresses the issue of risk selection, as discussed above, and how it motivates providers to ration care implicitly. If providers have incentives to discriminate against disabled people, notwithstanding the prohibitions of such discrimination under the ADA, it is likely that they will find ways to do so.

**Consumer-based cost containment.** Cost containment approaches that focus on the consumer fall into two categories: top-down and bottom-up rationing. Top-down rationing refers to the explicit decisions by policymakers, employers, and insurers not to cover certain services and the often implicit decisions by providers or case-managers on what care to provide. The limitations on services covered or provided are imposed from above by someone with authority. From the perspective of people with disabilities, this approach is problematic because it reduces their autonomy. This can be remedied to some extent by ensuring that consumers are adequately represented in the decision-making process.

Bottom-up rationing refers to allocations of benefits that are decided by the consumer, subject to certain economic trade-offs. One way to achieve
this is through “cafeteria-style” plans, in which the consumer chooses among benefits. A problem with this approach generally is that consumers are often not well informed about the specific benefits they need. Disabled people who understand their needs may feel particularly concerned over having to “trade off” some important services, the lack of which will result in greater problems and costs in the future.

Another approach to bottom-up rationing is through imposing high deductibles and copayments and allowing consumers to choose services from among a broader set of covered services than would otherwise be available, recognizing that they will pay for part or most of these services out of pocket subject to a catastrophic stop-loss limit. The advantage of this approach is that it gives consumers substantial autonomy in making decisions concerning services that affect their lives while instilling real cost-consciousness into the system. The disadvantage is that it may impose a great financial burden on some individuals, particularly low-income people with high health care costs. Therefore, this approach would require some form of subsidization to reduce the burden on such individuals.

National Health Insurance

Three general approaches to national health insurance are under serious consideration: Canadian-style systems, “play-or-pay” or employer mandates, and managed competition systems. Any of these approaches could potentially benefit people with disabilities if designed with a benefit package, cost containment structure, and service delivery system that meets their needs and does not penalize them. There is nothing inherent in any approach that guarantees that it will be sensitive to the needs of disabled people. Here I analyze each with respect to its likely effect on such individuals.

Canadian-style systems. Under a Canadian-style system, all citizens would be insured through the government, which serves as the single payer, determines the level of coverage, and pays providers according to a schedule of negotiated fees. The system is financed through general tax revenues. This type of national health insurance system is virtually always based on the social insurance model in which cross-subsidization takes place within the single-payer system. In this sense, it is similar to our Medicare and Medicaid systems, although far more universal in coverage.

A major advantage of a Canadian-style system for people with disabilities is that it eliminates the tie between health insurance and employment. Consequently, a change of employment status does not reduce access to insurance coverage. While this aspect of the single-payer approach would benefit the country generally, it would particularly benefit people with
disabilities who are concerned about limitations on coverage of preexisting conditions. As compared with other approaches that guarantee "portability" of insurance coverage when employment status changes, this approach is simpler in that portability is not even an issue when everyone is covered under the same system.

Like the other approaches to national health insurance, the extent to which a single-payer system would meet the needs of people with disabilities depends primarily on how it is designed to ration care. Single-payer systems tend to ration care based upon a set of top-down rationing rules concerning who is entitled to specific services in different circumstances. Such nonprice rationing can accrue to the substantial benefit of the disabled population if needed services are sufficiently covered and adequately compensated. Whether this would occur depends on the political clout of the disabled population.

It is likely that a single-payer system designed from the outset with the input of people with disabilities and their representatives would include a benefit package and other provisions adequate to meet the basic needs of disabled people. What is less certain is whether these benefits would be maintained over time if the costs of the system escalate and there is a need to cut back. It appears likely that the political clout of the disability lobby would be overwhelmed by that of the general population and its perceived need for more generalized acute care services. The proposed Oregon Medicaid plan amendment offers an interesting case study of how services needed by disabled people could potentially be rationed in a single-payer system that needs to contain costs.29

**Play-or-pay or employer mandate systems.** Two prominent approaches to financing national health insurance are mandating employers to provide insurance coverage for their employees or offering them a play-or-pay option. Under a play-or-pay system, employers are required either to provide a specified amount of health care coverage or to pay an employment tax for each of their employees to be covered by a public health plan. A recent study by the Urban Institute concluded that many employers would find it more economical to pay the tax than to provide the insurance.30 This finding has particular relevance for people with disabilities.

Fewer than 40 percent of people with disabilities are employed; only about 25 percent work full time.31 All of those not employed full time would be relegated to the public program. In addition, those employed disabled persons whose employers choose not to offer health insurance would have to be covered under the public program. The larger the number of high-cost individuals an employer has, the more likely it will choose not to "play." Thus, there would be a tendency under play-or-pay for people with disabilities, in particular, to be insured publicly.
While both employer mandates and play-or-pay are financing mechanisms that could be applied in systems using either the casualty insurance or the social insurance model, they are typically associated with the social insurance model. Under an employer mandate, the higher costs of a disabled employee are cross-subsidized by other employees. Under play-or-pay, whether the employer provides health insurance or pays the tax for the public program, the higher costs of disabled employees are cross-subsidized by other employees (in the case of the employer’s own plan) or by other employers or taxpayers (in the case of the public program).

An advantage of play-or-pay over mandated employer coverage is that it does not induce employers to discriminate against hiring applicants with disabilities on the basis of expected health care costs, because the employer can pass those costs off to the public system. While Title I of the ADA prohibits employment discrimination against disabled people on the basis of health care costs and requires that disabled employees be offered the same health benefits package as nondisabled employees, employers faced with the prospect of very high health insurance costs are likely to find ways to discriminate against disabled applicants.

**Managed competition.** Several private-sector health reform proposals fit largely under the rubric of “managed competition,” originally conceptualized by Alain Enthoven. These rely primarily on changing tax incentives to induce cost-consciousness among consumers and inducing strong price competition among private-sector health care plans. Many of these proposals, such as the Managed Competition Act of 1992 (H.R. 5936), are based primarily on the social insurance model. Because they rely largely on community rating to cross-subsidize care, they require extensive monitoring to avoid the problems of preferred risk selection against people with high levels of health care use.

The Heritage Foundation has proposed a managed competition approach that is based on the casualty insurance model. It uses experience rating and would replace the current tax exclusion for employer-provided health benefits with a system of refundable tax credits for health care expenses. The size of the credit would depend on a household’s total health care spending relative to its income. Thus, to the extent that disabled people have higher-than-average health care costs, they would be compensated for those higher costs.

From the perspective of people with disabilities, the Heritage approach might be attractive theoretically, for two reasons. First, because it is based on the casualty insurance model, it should not induce insurers to discriminate subtly against disabled people through preferred risk selection. Second, because it recognizes that people with high health care costs relative to income bear an unfair economic burden in our society, it would financially
people with disabilities 53

compensate those disabled people with significant health care costs through the tax system.

However, a practical shortcoming of this general approach with respect to people with disabilities is that, because of their higher costs that would not be cross-subsidized within the system and federal budgetary pressures to contain system costs, there would be a political tendency over time for the amount of the subsidy to be severely reduced. This is particularly likely because the low-income people who would receive the largest subsidy have relatively little influence in the political process. To the extent that the subsidy becomes inadequate, insurers would have an incentive to engage in preferred risk selection, thereby violating the nondiscrimination principle.

Thus, while the Heritage Foundation proposal may in theory be appealing to people with disabilities, it is less attractive in practical terms, because of the realities of government budgetary processes. Other managed competition proposals based on the social insurance model using community rating may ultimately prove more politically attractive to the disabled population. While such proposals also would subject high-cost, low-income individuals to some vulnerability in the event of budgetary cutbacks, the adverse financial effect on such individuals would be reduced by cross-subsidization within the system. However, they would still be adversely affected if the system does not adequately address the problem of preferred risk selection.

In Closing

Any attempt at health care reform will greatly affect the disabled population, with its existing health conditions and statistically above-average health care needs. A health care reform package based on either a casualty or a social insurance model could meet the needs of people with disabilities if it is specifically designed to do so. This, in turn, will depend on the political power of disability organizations to incorporate their constituencies’ needs into the reform package, and whether they will receive the same consideration as those of the much larger and less segmented, acute care-oriented, nondisabled population. The clout of disability organizations has increased in recent years, as evidenced by the enactment of the ADA.

Many disability rights advocates appear to favor a Canadian-style approach to health care reform. They are particularly attracted to the portability of coverage under this approach, and they believe that the benefit package will be broad and the individual’s financial burden will be small. As one researcher with a disability (resulting from spinal cord injury), I am concerned about our government’s capacity to contain costs under such a system, given constant political pressure to satisfy every health care con-
stituency. I believe that a Canadian-style system would almost inevitably result in strong cost escalation and top-down rationing that would affect people with disabilities adversely. A preferable approach, for the general population and the disabled population, would be to maintain consumer autonomy in choosing services, subsidize coverage equitably in a non-employer-based system, and contain costs by rationing from the bottom up.

For example, I would support a managed competition proposal with the following features: (1) an obligation for each household to enroll once a year in a federally qualified health care plan (such as an HMO) with a federally specified standard benefit package; (2) a broad standard benefit package with a comprehensive set of covered services (including supportive, rehabilitative, and long-term care), decided by a national board with adequate representation of disabled people; (3) bottom-up rationing achieved through a deductible per household per year (such as $3,000 per individual and $6,000 per family), a copayment (such as 10 percent up to $20,000 beyond the deductible), and a lifetime deductible for long-term care (for example, $75,000); (4) provision of full catastrophic protection once the deductibles and copayments are satisfied and first-dollar coverage for a limited number of services with proven preventive benefits (such as immunizations and prenatal care) decided by the national board; (5) replacement of Medicaid, Medicare, and the current tax exclusion for employment-based insurance premiums with direct payment of premiums, deductibles, and copayments for indigent people (incomes up to 200 percent of the poverty level) and refundable tax credits to other households based on health care expenses relative to income; (6) treatment of insurers as common carriers that must offer the standard benefit package (and any supplemental insurance package offered) for the same price to all those who request coverage; (7) prohibition of preexisting condition limitations and prohibition of other restrictions not included in the standard benefit package; and (8) substantial provisions to guard against preferred risk selection.

Among the advantages of this approach are that it would offer universal health care coverage without fundamentally altering the health care and insurance industries; shift the system from being employment-based to being household-based, thereby offering the benefits of full portability of coverage; provide the type of coverage that is most needed—catastrophic and long-term care coverage (and coverage of proven preventive services); stimulate competition among managed care plans, thereby containing costs while maintaining access and quality; enhance the cost-consciousness of consumers while maintaining their autonomy through bottom-up rationing; and subsidize people with undue financial burdens. Disabled people would not be adversely affected if preferred risk selection is prevented and if the tax credit remains adequate to compensate for higher-than-average
costs relative to incomes. The bottom-up rationing aspect of this approach could also be used in a Canadian-style or employer-based system.

Whatever approach to health care reform is ultimately adopted, it is essential that the needs and concerns of people with disabilities are considered in its design from the outset. Policy changes have been difficult to incorporate into programs not designed initially to meet the needs of disabled people, such as Medicaid. In part because of the lack of a disability perspective from the outset, such programs have often failed to meet the disabled population’s needs in an acceptable manner, sometimes leading to situations of undesired dependency such as institutionalization. As a result, it has been necessary to modify Medicaid policy over time to meet this population’s independent living objectives.

A well-designed national health insurance system should be developed from the outset to offer access to comprehensive, affordable health care coverage in an appropriate, equitable, efficient, and nondiscriminatory manner, particularly for vulnerable populations. It should meet the health care needs of disabled people while offering them options to live as independently as possible in their communities. It should not deter them from contributing as productive members of our society. If the health-related needs of people with disabilities are not met adequately, our nation will continue to pay in the long run.

The views in this paper are solely those of the author and do not necessarily represent the positions of any federal agency.

NOTES

1. Disability refers to a limitation in function or activity resulting from an impairment. Chronic condition refers to the presence of a specific diagnosed impairment that may or may not result in a functional or activity limitation. Both people with disabilities and people with chronic conditions, as groups, have difficulty gaining access to private health insurance for similar reasons, and therefore it is appropriate to treat both groups together for purposes of this paper.


8. The total direct cost of disability to our nation in 1986, including income transfers, medical expenditures, and direct service expenditures (and not including lost productivity), was estimated to be $169.4 billion. M. Berkowitz and C. Green, “Disability Expenditures,” American Rehabilitation 15, no. 1 (1989): 7-15, 29.


11. The Medicare extension was enacted in section 6012 of P.L. 101-239 (the Omnibus Budget Reconciliation Act of 1989). The Medicaid extension is in section 1619(b) of the Social Security Act, made permanent in 1987 by the Employment Opportunities for Disabled Americans Act, P.L. 99-643. As of 1991, of the more than six million people on SSI and/or SSDI, only 414 have been approved for the Medicare extension provision and 29,792 for the Medicaid extension provision.

12. R. Griss, Access to Health care 1, nos. 1 and 2 (Berkeley, Calif.: World Institute on Disability, 1990), 25, analyzing data from the National Health Interview Survey.
15. Griss and Hanson, *Accessibility, Adequacy, and Affordability of Health Insurance*.
16. Ibid.
20. Similarly, section 501 (c)(3) states that the ADA does not prohibit or restrict “a person or organization covered by this Act from establishing, sponsoring, observing, or administering the terms of a bona fide plan that is not subject to State laws that regulate insurance.”
25. 28 C.F.R. Section 36.212.
28. Several health care reform plans under discussion do not constitute national health insurance proposals. Some of these fit under the rubric of small-group market reform. These modifications would benefit people with disabilities to the extent that they prevent or reduce the use of preexisting condition clauses, nonsubsidized experience rating, nonextension of coverage, and other politics that have a disproportionately negative effect on people with disabilities.