

America's Neglected Health Minority: Working-age Persons with Disabilities

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THE ONGOING NATIONAL DEBATE ON HEALTH POLICY has largely overlooked the needs and concerns of 19 million working-age persons with disabilities. Persons with disabilities are a diverse lot whose health care needs are not well understood. They are not ordinarily listed among the various high-risk or vulnerable groups such as elderly persons, children, teenage mothers, black persons, and other racial/ethnic minorities. Yet, working-age, as opposed to elderly, disabled persons present their own constellation of health care issues that are not readily appreciated when health policy focuses on the needs and concerns of other groups. This article seeks to redress this oversight. In so doing, it offers important insight in assessing the United States health care system generally, since persons with disabilities serve as a bellwether group by which the access and adequacy of the system can be tested.

This article has seven objectives. They are:

1. To define and identify the various target populations of working-age persons with disabilities;
2. To explain how the health care needs of working-age disabled persons differ from the health care needs of their nondisabled counterparts;

3. To describe the health care utilization experience of the working-age disabled population;
4. To evaluate the working-age disabled population's access to health care services;
5. To evaluate the extent and adequacy of health insurance coverage for working-age disabled persons from both public and private sector sources;
6. To identify several choices for federal and state policy to meet the needs of working-age persons with disabilities; and,
7. To consider the implications of this discussion for the future of health services research.

Target Populations

How we identify the target population of working-age disabled persons depends in large part upon how we define disability. Each definition of disability will tend to exclude some subset of the disabled population for whom health care delivery and coverage are problems. In this article, we will consider three different definitions of disability, resulting in three different target groups of working-age persons with disabilities.

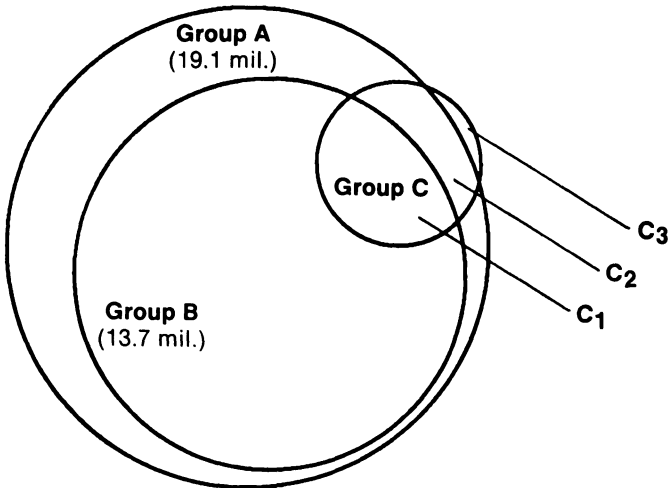
Moreover, our analysis will be limited to working-age persons who live in the community, mainly because the principal data sources used in this article survey only the noninstitutionalized population. We estimate that only approximately 400,000 working-age persons who live in institutions are excluded from the analysis for this reason, based on data assembled by the National Center for Health Statistics (1987, 1988) and the National Institute of Mental Health (1986).

As outlined in Figure 1, the three target groups for purposes of this article include:

Group A: All working-age persons living in the community who are limited in either work or nonwork-related activities because of a health condition.

Group B: All working-age persons with limitations in their *major activity*, which for working-age persons means limitations in their ability to work. Group B is entirely a subset of group A.

Group C: Working-age persons with selected major *physical im-*



- Group A:** All working-age persons with activity limitations living in the community.
- Group B:** All working-age persons with limitations in *major* activity (i.e., work limitations).
- Group C:** Working-age persons with major *physical* impairments.
- C₁** = Working-age persons with major *physical* impairments who are limited in major activity.
- C₂** = Working-age persons with major *physical* impairments who have activity limitations but who are not limited in major activity.
- C₃** = Working-age persons with major *physical* impairments who are not limited in any activity.

FIG. 1 Target Populations: A, B, and C.

pairments. Persons in group C may also be in group A or group B or neither. This group will be described in greater detail later.

We have resorted to this three-group approach mainly because of (1) severe limitations in national survey data and (2) our understanding of the health needs of specific subgroups. In addition, the partitioning of the target population in this manner provides insights into particular health policy issues that might be obscured when we address the target population as a whole. For example, the target population's work status is important when considering the problem of health insurance coverage.

Groups A and B use a functional definition of disability. A func-

tional approach is limited, however, since a functional assessment of disability is influenced as much by the person's environment as by the underlying impairment. Thus, we have introduced group C, which is defined in terms of the presence or absence of specific physical conditions or impairments. These impairments include:

- major amputations
- cerebral palsy
- major head injury
- Friedreich's ataxia
- muscular dystrophy
- spina bifida
- amyotrophic lateral sclerosis
- cystic fibrosis
- spinal cord injury
- multiple sclerosis
- post-polio
- stroke

Group C focuses on chronic impairment primarily, and only secondarily on functional limitations. In terms of functional limitations (see figure 1), we may distinguish between three subgroups within group C:

C_1 = Working-age persons with major physical impairments who are limited in their major activity (i.e., work).

C_2 = Working-age persons with major physical impairments who have activity limitations but who are not limited in their major activity.

C_3 = Working-age persons with major physical impairments who are not limited in any activity.

Because of the high levels of unemployment in most of these impairment groups, most persons in group C are in subgroup C_1 . This segmentation of group C serves to underscore the fact that a major physical impairment does not automatically mean that a person will be unable to work. Thus, a strict functional approach to defining our target population may obscure important health care needs.

Much of the research literature on disabilities is organized around specific conditions or impairments. This follows the pattern of medical specialization in the United States health care system that is organized around specific organs or body systems. The in-depth knowledge that has been obtained on the specific impairments represented in group C often provides a microcosm of the issues facing larger groups, such as groups A and B.

Our focus on these *physical* impairments is only meant to be illustrative. Disability is such a diverse phenomenon that an exhaustive treatment of all conditions would distract from the article's central arguments. We chose physical as opposed to mental impairments only for convenience. Moreover, the impairment groups listed in group C share common needs to be illustrated later.

In many instances, it is difficult simply to generalize from the experiences of one of our three disability groups (groups A, B, and C) to one or both of the other groups. However, in some instances, our knowledge about one of the three groups enables us to make reasonable inferences about the needs of the other groups. For example, inferences can often be made about the likelihood that a certain problem in one group will be experienced to a greater or lesser extent in one or both of the other groups, given our knowledge about each group's characteristics.

Ideally, it would be valuable if the conditions or impairments in group C could be specifically identified in the surveys used to define groups A and B. Conditions represented in group C occur infrequently in larger surveys, however, and result in large standard errors in survey data. This is one of the principal limitations of national survey data.

In discussing the needs of working-age persons with disabilities, we are referring to all working-age persons with disabilities regardless of their present or past employment status. Working age simply means those persons 18 to 65 years of age.

Prevalence of Groups A and B

Two sources are used to estimate the size of groups A and B and to characterize the needs of these two groups. First is the National Health Interview Survey (HIS) conducted annually by the National Center for Health Statistics. The HIS is based on a sample of 40,000 house-

TABLE 1
 Disability Status (Activity Limitation) of Working-age (18-64 years)
 Persons in the United States, 1986

Activity limitation	Number (thousands)	Percentage
No activity limitation	126,571	86.9
Some activity limitation	19,107	13.1
Limited but not in major activity	5,377	3.7
Limited in major activity	13,730	9.4
Limited in amount or kind of major activity	7,644	5.2
Unable to carry on major activity	6,086	4.2
Total	145,678	100.0

Source: National Center for Health Statistics 1987b.

holds that include approximately 110,000 persons. Second is the Survey of Income and Program Participation (SIPP) conducted by the U.S. Bureau of the Census (1986). The SIPP is based on a sample of 20,000 households that include approximately 46,000 persons. We will use SIPP data from a supplement administered during the third wave of the 1984-1985 panel. This supplement included extensive questions on disability status. These data sources were chosen because of (1) their functionally-oriented definition of disability which is consistent with our definition of groups A and B, (2) their size, (3) their responsiveness to the issues addressed in this article, and (4) their widespread use in the health services research community. Both surveys are limited to persons living in the community.

Based on the results of the 1986 HIS, group A consists of the 19.1 million working-age persons who have some activity limitation due to a health condition (see table 1). Approximately 5.4 million have an activity limitation but not in their major activity, i.e., work. Group B consists of the 13.7 million persons within group A who are either unable to work or are limited in the amount or kind of work they do.

Results from the 1984 SIPP present a somewhat different approach to the number of working-age persons with disabilities (see table 2). The SIPP presents data on the employment status of the working-age disabled population. Of the almost 18 million working-age persons

TABLE 2
 Employment Status of Working-age Persons (18–64 years) with a
 Disability, United States, 1984

Employment status	Number (thousands)	Percentage
Employed full-time	5,633	31.4
Employed part-time	1,978	11.0
Not employed	10,338	57.6
Total	17,949	100.0

Source: Griss 1988, based on secondary analysis of data from the 1984/85 Survey of Income and Program Participation, conducted by the Bureau of Economic Research, Rutgers University.

who report a disability, 5.6 million are working full-time; 2.0 million are working part-time; and the majority, 10.3 million (57.6 percent), are not working at all. Although the employment status of the working-age disabled population does not provide direct categorization of the target population into groups A and B, the 12.3 million who report that they are employed part-time or not at all, are roughly equivalent to the 13.7 million persons in Group B as reported in the HIS, i.e., those who are limited in their major activity. The 5.6 million in the SIPP who reported that they were working full-time are roughly equivalent to the 5.4 million in the HIS who have an activity limitation but not in their major activity.

While the approaches taken by the HIS and SIPP to working-age disability are somewhat different, both approaches have individual strengths that are useful in evaluating the health care issues facing working-age persons. The HIS indicates how a health condition limits a person's ability to participate in activities such as work. This approach offers an indicator of severity and how it may affect health care utilization. The SIPP reports on the employment status of persons with a work disability. This approach is more useful, for example, in evaluating how health insurance alternatives based on employment status may affect working-age persons with disabilities.

Prevalence of Group C

Most national surveys of the disabled population examine relatively small numbers of persons from each of the impairment groups listed

in group C. As a result, it is difficult to obtain reliable estimates from national survey data in any one year as to the number of persons in group C. Based on an assortment of sources, we estimate that group C is comprised of 1.5 to 3.0 million persons. The exact figure, however, is not important. More important is how the experiences of these different impairment groups illustrate (1) the health care needs of persons with disabilities, and (2) the problems of access to health care.

To obtain in-depth data on group C, it is helpful to draw upon smaller regional and local studies. For purposes of this article, we will be drawing on experiences gleaned from an in-depth regional survey conducted in 1988 by the National Rehabilitation Hospital (NRH) on the health care needs of working-age persons with severe physical disabilities residing in the metropolitan Washington, D.C., area (Batavia et al. 1989). The NRH survey included more than 600 respondents representing ten major groups of persons with major physical impairments. Approximately one-half of these persons use wheelchairs. The data obtained from the NRH survey should be construed as illustrative of, not necessarily representative of, the kinds of problems faced by working-age persons with disabilities.

Comparison with the Elderly Disabled Population

Much of United States health policy focuses on the elderly disabled population. While this population has substantial needs, it is useful to consider the relative proportions of working-age and elderly disabled persons in American society (see table 3). One reason for the current emphasis on the elderly population is that a disproportionate share of the elderly population have disabilities: 22.7 percent of elderly persons have a major activity limitation while only 9.4 percent of the working-age population have a major activity limitation. A different perception emerges, however, when we consider the age distribution of the disabled population: Of those with a major activity limitation, 61.6 percent are working-age persons while only 28.1 percent are elderly persons (Griss 1988a).

Growth of the Working-age Disabled Population

According to conventional wisdom much of the increase in the disabled population is a by-product of an aging population. While this is true,

TABLE 3
Age Distribution of Persons with a Major Activity Limitation,
United States, 1986

Age group	Total population* (thousands)	Persons with limitations in major activity		
		Number (thousands)	Percentage	Percentage in each age group
Under 18 years	63,132	2,292	10.3	3.6
18-64 years	145,678	13,730	61.6	9.4
65 + years	27,538	6,258	28.1	22.7
Total	236,348	22,281	100.0	9.4

* Noninstitutionalized population.

Source: National Center for Health Statistics 1987b.

such observations overlook the tremendous growth in disability among working-age persons over the last 25 years or so. From 1959 to 1984, the HIS reported a 38 percent growth in the working-age population but a 158 percent growth in the number of working-age persons who might be defined as having a severe disability by virtue of their inability to carry on their major activity (DeJong 1987). (These data take into account some of the more important definitional adjustments made by HIS in the early 1980s.) The growth rates were even higher among younger working-age adults (aged 18 to 44).

Many reasons have been posited for this growth in disability within the working-age population. The most important reason is that as mortality rates for certain health conditions decline, the prevalence rates for these conditions increase. In an analysis of HIS data, Verbrugge (1984) examined the mortality and disability statistics for numerous conditions, including such common conditions as heart disease, hypertension, and cardiovascular diseases. Verbrugge observes that while mortality for such conditions has decreased by as much as 50 percent over a period of 10 to 20 years, the number of persons reporting limitations in their major activity because of such conditions has increased, sometimes by more than 100 percent.

This same inverse relation between mortality and disability is known to exist among persons in group C with major physical impairments such as head and spinal cord injury. Over the last 15 years or so, there has been a tremendous growth in the number of persons with high-level spinal cord injuries, largely because of improvements in

trauma care and emergency medicine (Stover et al. 1986). Many persons with high-level injuries now survive with a dependence on ventilators and/or need for substantial personal assistance. As a general rule, for those with central nervous system injuries, the closer a person has come to death (based on probability of survival for various levels of injury severity) and yet survived, the greater the likelihood of a severe disability.

Health Care Needs

Due to the great variability among disability groups, it is difficult to generalize about the health care needs of working-age disabled persons as a population. For example, the health care needs of a person in group A or B with a chronic lower back problem may be very different than those of a person in group C with cerebral palsy or spinal cord injury. Further, the needs of persons in group C with different major physical impairments often differ significantly from each other. Still, to the extent that different types of impairments similarly reduce mobility, physical sensation, and voluntary control over bodily functions, some general characterizations can be made about the needs of group C. As indicated above, the response of the system to persons in group C with their substantial needs may have implications for persons with disabilities not represented in group C.

First, persons with disabilities in group C are more vulnerable to medical problems than persons in the general population. Persons with mobility impairments, for example, have increased risk of pneumonia, bone fractures, urinary tract infections, and pressure sores. They are prone to have a thinner margin of health than nondisabled persons. This narrow margin of health must be carefully guarded if medical problems are to be averted. One test of an adequate health care system is its ability to help maintain the disabled individuals' vital margin of health (Batavia et al. 1988).

It must be emphasized that persons with major physical impairments are not necessarily "sick." Their physical impairments typically result in functional limitations, which often increase their vulnerability to certain health problems. Most persons in group C are healthy, however. For this reason, a person's disability status should not be

confused with his or her health status. Too much of the health care system views the individual's disability as the primary pathology and fails to understand the distinctive health problems to which the disabled person may be vulnerable. When the disability is viewed as primary, health care providers are often unable to respond effectively to acute conditions when they do arise (Batavia et al. 1988, 1989).

Second, persons in group C do not have the same opportunities for health maintenance and preventive health as do those in the general population. Those with mobility impairments, for example, usually have few opportunities to participate in aerobic activity needed to maintain good cardiovascular health. Early detection of problems may be difficult because, for example, a person may not be able to experience pain in certain body regions.

Third, persons in group C who acquired their disability early in life may experience the onset of certain chronic health conditions earlier in life than persons in the general population. While we do not know this for certain, prolonged physical immobility and the use of compensatory muscle may aggravate selected body systems and thus precipitate an earlier manifestation of certain health conditions, e.g., arthritis and heart disease. Also, because they are now living much longer, persons with disabilities may be at risk for unknown new health problems resulting from the prolonged use of medications and other interventions (Trieschmann 1987).

Fourth, persons in group C who later acquire a chronic health condition, apart from their disability, are likely to experience secondary functional losses. Thus, the functional consequences of a chronic health condition are usually more severe for a person who already has a disability. For example, the onset of arthritis in one's fingers may compromise what little dexterity remains in limbs that are already partially paralyzed. Many persons with major physical impairments require some form of rehabilitative care near the onset of their disability and/or when they experience secondary functional losses resulting from the onset of new health conditions associated with the aging process (Trieschmann 1987).

Fifth, the treatment of persons in group C is often much more complicated than treatment of nondisabled persons. For example, a person with a major impairment who has diminished physical sensation may not be able to inform the health care practitioner of where pain or discomfort is located in his body. Application of a plaster cast for

a person with a spinal cord injury who breaks his leg may be complicated by the individual's vulnerability to a pressure sore under the cast (Batavia et al. 1988). Furthermore, persons in group C are likely to experience a longer recovery period following an acute episode of illness or injury because of limitations or complications that limit their participation in various therapies.

Sixth, many persons in group C require personal assistance services, as discussed at length below (Litvak, Zukas, and Heumann 1987). Many also require the use of prosthetics, orthotics, mobility aids, respirators, and other durable medical equipment. Many health insurance or health maintenance plans do not provide adequate coverage for these services and devices (Batavia 1989; Griss 1988a, 1988b).

These characteristics set persons in group C apart from the general population. They also apply in varying degrees to persons in groups A and B. The health care needs of working-age persons in all three groups are reflected in their high utilization of health care services. As discussed in the next section, all three groups use considerably more health care services than their nondisabled counterparts. Whether they receive all the health care services they need is considered in the sections that follow on "access to health care" and "health insurance."

Health Care Utilization

Current data on the health care utilization of working-age persons with disabilities will not become available until the results of the 1987 National Medical Expenditure Survey (NMES) are released. In the interim, we must rely on older data going back to (1) the 1977 and 1979 Health Interview Survey (HIS), (2) the 1977 National Medical Care Expenditure Survey (NMCES), and (3) the 1980 National Medical Care Utilization and Expenditure Survey (NMCUES). These data may not be entirely accurate with regard to present health care utilization and costs but they are useful in providing estimates of the utilization and cost experience of working-age disabled persons *relative* to their nondisabled counterparts (see table 4).

The data in table 4 provide an overview of health care utilization and cost experience of groups A and B relative to the nondisabled population in a given year. This table makes no distinction between the health care costs at the onset of a disability and other ongoing

TABLE 4
Health Care Utilization by Degree of Activity Limitation, Aged 18-64, United States, 1977

	Degree of activity limitation				Data source
	No. limitation of activity (not disabled)	Limited, but not in major activity (group A-B)	Limited in amount or kind of major activity (group B)	Unable to carry on major activity (subgroup of B)	
Health care utilization & relative costs (per year)					
Physician visits:					
No. of visits per person	3.6	7.2	8.0	9.6	NMCES (1977)
No. of visits per person	3.9	6.9	10.3	13.6	HIS (1979)
No. of visits per person	4.7	NA	7.6	11.5	NMCUES (1980)
Expenditures relative to those with no limitation of activity	1.0	1.9	2.2	2.7	NMCES (1977)
Hospital care:					
No. of discharges from short-stay hospitals per 100 persons per year	11.3	20.1	35.6	66.5	HIS (1979)
Average length of stay per discharge, in days	5.2	8.1	10.1	14.3	HIS (1979)
Percentage hospitalized at least once	11.8%	19.3%	24.6%	30.1%	NMCES (1977)
Percentage hospitalized 3 or more times	0.4%	1.2%	2.0%	3.9%	NMCES (1977)
Expenditures relative to those with no limitation of activity	1.0	3.8	4.0	6.1	NMCES (1977)
Prescribed medicines:					
No. of prescriptions per person	3.7	9.9	13.1	17.3	NMCES (1977)
No. of prescriptions per person	NA	NA	11.8	21.5	NMCUES (1980)
Expenditures relative to those with no limitation of activity	1.0	2.8	4.0	5.1	NMCES (1977)

HIS = Health Interview Survey.
 NMCES = National Medical Care Expenditure Survey.
 NMCUES = National Medical Care Utilization and Expenditure Survey.

health care costs. While costs at the initial stages of some disabilities are high, they are likely to be low for other disabilities for which there is a very gradual onset.

Physician Visits

Working-age persons with disabilities, on the average, visit a physician two to three times more frequently than their nondisabled counterparts. Persons with greater activity limitations visit a physician more often than those with less activity limitation.

Hospital Care

Working-age persons within group B, who are unable to carry on their major activity, are almost six times more likely than nondisabled persons to have been hospitalized in the previous year. Once hospitalized, these persons are likely to be hospitalized longer than nondisabled persons; the average length of stay for disabled working-age persons is 14.3 days while the average length of stay for nondisabled working-age persons is 5.2 days. The higher incidence and longer length of hospitalization result in a much higher level of hospital charges for working-age disabled persons. As noted in table 4, hospital costs for working-age disabled persons average about 4 to 6 times those of nondisabled persons, depending on the degree of activity limitation.

In a study of Medicare's disabled beneficiaries, Lubitz and Pine (1986) report that working-age disabled beneficiaries are 2.5 times more likely to be hospitalized in a short-stay hospital than their counterparts in the general population. These findings are based on data obtained from a 5 percent sample of Medicare disabled beneficiaries excluding those with end-stage renal disease.

Similarly, persons in group C who have been hospitalized are much more likely to be rehospitalized within any given period of time for the same or for a related health condition (Zook and Moore 1980; Zook, Savickis, and Moore 1980; DeJong et al. 1986). Persons with certain disabilities, such as stroke or cervical level spinal cord injury, have about a 50 percent chance of being rehospitalized in any given 12-month period for the first few years following their initial hospitalization and rehabilitation (Young and Northrup 1980; Zook and

Moore 1980; Zook, Savickis, and Moore 1980; DeJong 1981; Meyers et al. 1985; DeJong et al. 1989; Meyers et al. 1988).

Other Health Care

Working-age persons with disabilities also use and spend more than the nondisabled population for health services such as care from non-physician personnel, prescription drugs, and durable medical equipment.

A Note on Averaging

The data presented here are averages and are potentially misleading. By averaging high and low users of health care, we overestimate the utilization experience of some and underestimate the utilization experience of others. Moreover, by averaging data we also create the impression that an entire class of persons called "disabled persons" are a high-risk group. Such an impression should not be used to justify actuarial discrimination by insurers. Instead, we believe that it should be used to stimulate the identification of interventions that can reduce these higher-than-average rates of health care utilization and costs, preferably through prevention and early detection of disability-related problems. As will be noted in the next section, many of the medical complications experienced by persons in group C are entirely preventable.

Access to Health Care

Although working-age persons with disabilities in all three groups have higher-than-average rates of health care utilization, questions remain as to whether they have adequate access to the kinds of care they need. What is the availability and adequacy of primary care, hospital care, and long-term care (often in the form of personal assistance services) for working-age persons with disabilities? Can more appropriate levels of care help to avert their higher-than-average use of the more intensive and expensive services such as hospital care?

Access to Primary Care

While few statistics are available, many disabled persons in group C report that, after the onset of their disabilities, they are no longer able to use their customary source of primary care for common health problems. A recurring complaint among persons with disabilities is that, if they use a primary care physician, they must constantly educate their physician about the idiosyncracies of their impairment and how it needs to be taken into account when prescribing treatment. Timely access to primary care from a provider who is knowledgeable about the confounding factors that may accompany a disability is essential if major medical problems are to be averted (Batavia et al. 1988).

The family physician, the local internist, or the obstetrician/gynecologist generally is unaccustomed to treating patients with severe disabilities. In the mind of the practitioner, the disability, and not the present complaint, often becomes the more important health issue (DeJong et al. 1989). These perceptions of the patient's health, as correct as they may at times be, often motivate the primary care physician to seek specialty help. As a result, the person in group C is prone to be referred to a specialist, a specialty hospital-based outpatient clinic, or an emergency room. Often, the unfortunate outcome of such a referral pattern is (1) unnecessary hospitalization or (2) delayed attention to an emerging health problem that will ultimately require hospitalization.

These shortcomings in the nation's primary care system are borne out in the NRH survey of working-age disabled persons with major physical impairments (Batavia et al. 1989). The survey found that 27.5 percent of the respondents had difficulty in the past 12 months finding a physician who was knowledgeable about the particular health care needs related to their disabilities. This percentage increases to 45.1 for those with a spinal injury. Some 23.3 percent report that one or more hospitalizations could have been averted in the previous 12 months if they had gained timely access to a physician or other health care provider who was knowledgeable about their disability. This percentage increases to 50.0 percent for those with spinal injury.

These statistics are also reflected in the many open-ended comments about access to primary care from respondents who participated in the NRH survey:

- Rarely do medical personnel understand the complexities of a

[spinal cord injury]. Medical plans rarely address all the care and special medical needs and comprehensive coverage necessary to stay healthy.

- Physician offices in general lack equipment needed for wheelchair patients, e.g., lack of room to maneuver, no sit-in scales, examining tables too high to get onto. [P]hysicians need to be made aware of these things.
- We all need our annual GYN exams and some of us need obstetrical care. Women who are paralyzed or disfigured have a variety of problems with regular GYNs . . . You should consider care in this area. All women need it. They might feel much more comfortable with nurses and doctors who understand and who are comfortable with both our sexuality and our bodies.
- [From a surrogate respondent for a young woman with a head injury]: Most [of her problems with the health care system] can be summed up as a lack of coordination in a very fragmented system. She still has no one physician who can help her find . . . care or supervise her general health (Batavia et al. 1989).

Access to Hospital Care

As compared to access to primary care, there appears to be reasonable access to needed hospital care for persons in group C. This is reflected in the high utilization of hospital services by this population. Whether such access is provided in an optimal and timely manner, however, depends largely on the disabled individual's access to effective primary care and personal assistance, and on the availability and adequacy of health insurance. As a result of problems in access to these important support services and to problems with insurance coverage for this population, admission to a hospital may be delayed until a problem has escalated to an emergency. This may provide part of the reason for the high utilization of hospital emergency room care and the long lengths of hospital stay for this population (Meyers et al. 1987).

Access to Long-term Care/Personal Assistance Services

Results from the 1984 Survey of Income and Program Participation (SIPP) indicate that there are 2.7 million persons in group B, persons with a work disability, who need *some* assistance from another person in activities such as personal care, meal preparation, housework, or

simply getting around. Most of this assistance is provided informally without pay by spouses, other family members, relatives, neighbors, and friends (Litvak, Zukas, and Heumann 1987).

From the standpoint of long-term care policy, one needs to consider the numbers of persons who require such assistance on a regular and ongoing basis as opposed to those who may need such help only intermittently. In an analysis of data drawn from the Home Care Supplement used in the 1979 and 1980 National Health Interview Survey (HIS), LaPlante (1989) reports that there are 574,000 working-age adults in group A whose need for assistance in personal care and mobility requires that there be someone at home all, most, or some of the time (as opposed to "once in a while" or "never"). This number rises to 894,000 working-age adults when activities such as meal preparation, household chores, shopping, and handling money are included.

While there is a substantial number of working-age disabled persons who need assistance with personal care and related activities, they represent a very small proportion of the population. These individuals comprise about 4.7 percent of persons in group A and only 0.7 percent of the entire working-age population. Moreover, it is difficult to determine from HIS data the number of persons who require a level of assistance to warrant a paid source of outside help. In contrast, according to the NRH survey, some 33 percent of persons in group C require regular and ongoing help in their personal care needs (Batavia et al. 1989). As indicated above, however, the population of working-age persons with major physical impairments is relatively small; thus the absolute number of persons in group C who require personal assistance is manageable from the standpoint of public policy.

Despite this manageable level of need, the personal care assistance needs of working-age disabled persons are a much neglected area of American long-term care policy. Most long-term care policy in this country is driven by the needs of older persons. This is because a greater percentage of older persons require some form of personal assistance than do working-age persons. This observation often causes policy analysts to overlook needs in the working-age population. It should also be recognized, however, that approximately 40 percent of the noninstitutionalized population (excluding young children) who need assistance from another person in various activities are persons under the age of 65 (LaPlante 1988).

The erroneous perception that the need for personal assistance is mainly an aging problem is reinforced by provider groups such as the home health industry that are committed to a specific model of care that tends to overlook the needs, tastes, and preferences of younger working-age adults. The home health industry is committed to a model of care that views the older person as a passive recipient of care who requires professional supervision, especially in aspects of care that involve the administration of medications, catheters, suppositories, and any touching of the human body (DeJong 1986). In short, the recipient of services is a patient. Accountability for care flows toward the supervising nurse or home health agency. This system of care is a direct extension of the "medical model" in which the recipient is expected to assume the sick role (DeJong and Wenker 1983).

A very different model has surfaced among a cohort of working-age disabled persons, particularly those in group C who are committed to the values of the independent living movement and disability rights movement (DeJong 1979; DeJong and Wenker 1983). In this "independent living model" the disabled person is an active participant who recruits, selects, manages, and directs his or her own care provider. No professional supervision is used (except in the initial and subsequent assessments of need to determine level of payment, as required in some states). In short, the participant is a consumer of services, not a patient. Accountability for quality of care flows toward the consumer. This model of care is a direct extension of the independent living philosophy, which assumes that the participant is a self-directed consumer of services (DeJong 1986). The model has been modified somewhat to accommodate groups of disabled persons whose mental impairments limit their capacities for self-direction (Litvak, Zukas, and Heumann 1987; DeJong and Wenker 1983).

In many ways personal assistance has become the premier long-term care issue for organized groups of working-age persons in group C and their advocates. The personal assistance model has served as a benchmark by which independent living advocates have evaluated existing in-home service programs. In its 50-state survey for all publicly funded in-home service programs, the World Institute on Disability, (1987) found that:

- 44 percent exclude certain disabling conditions;
- 42 percent do not cover both personal and domestic services;

- 22 percent do not cover services seven days per week;
- 50 percent do not serve persons with incomes above the poverty level;
- 67 percent do not allow attendants to assist in personal care involving medications, catheters, suppositories, or menstrual needs (Litvak, Zukas, and Heumann 1987).

These findings illustrate how existing community-based long-term care services have not been able to respond to the needs of working-age disabled persons.

Health Insurance

Among the most important determinants of access to any level of care are the availability and adequacy of health insurance. More than any of the issues delineated above, access to affordable and adequate health insurance unify the three groups of working-age persons with disabilities. Members of groups A, B, and C often are rejected by private insurers through medical underwriting criteria, or are discouraged from enrolling because of benefit packages that limit the health-related services they most need (Griss 1988a, 1988b; Batavia 1989).

In this risk-averse industry, private health insurers have developed insurance practices that facilitate "preferred risk selection" in part to avoid "adverse selection" by persons with disabling conditions (Batavia 1989). As for public-sector health insurance coverage, working-age disabled persons are less likely than older disabled persons to satisfy eligibility requirements. In contrast to older disabled persons who are eligible for Medicare simply on account of age (65 years or older), working-age disabled persons must meet highly restrictive public health insurance eligibility criteria, based not on their health care needs, but on inability to work.

Health Insurance Status

According to the results from the 1984 SIPP presented in table 5, 55.9 percent of persons in group B rely exclusively on private health insurance. Only 20.5 percent rely exclusively on public health in-

TABLE 5
 Percentage of Health Insurance Coverage by Employment Status and Income Assistance Status of Working-age (18-64 years)
 Persons with a Work Disability, United States, 1984

Health insurance coverage	Employment status						Total N = 17.95 million
	Employed			Not Employed			
	Full-time (N = 5.63 million)	Part-time (N = 2.00 million)	Subtotal (N = 7.63 million)	Receiving SSDI or SSI (N = 4.69 million)	Not receiving SSDI or SSI (N = 5.65 million)	Subtotal (N = 10.34 million)	
Private only	82.6%	65.0%	78.0%	25.2%	51.3%	39.5%	55.9%
Private and Medicare	0.9	1.5	1.0	16.8	1.9	8.7	5.5
Private and Medicaid	1.1	1.0	1.0	3.4	1.2	2.2	1.7
Medicare only	0.2	1.5	0.5	14.7	0.4	6.9	4.2
Medicaid only	4.4	8.0	5.4	21.5	17.7	19.4	13.5
Medicare and Medicaid	0.7	0.5	0.7	9.2	0.4	4.4	2.8
Other	1.8	1.5	1.7	0.6	2.5	1.6	1.7
No insurance	11.9	21.0	14.3	12.8	26.9	20.5	17.9
Adjusted totals*	100.0	100.0	100.0	100.0	100.0	100.0	100.0

*Percentages total slightly (1.8 to 4.2 percent) more than 100 percent because all categories were not mutually exclusive.
 Source: Griss 1988, calculated from SIPP (1984) data analyzed by the Bureau of Economic Research, Rutgers University, 1988.

surance such as Medicare or Medicaid. Another 7.2 percent rely on both public and private coverage. Some 17.9 percent have no health insurance coverage at all.

As one might expect, the type of health coverage available to working-age persons is directly related to their employment status. Some 82.6 percent of those employed full-time depend entirely on private health insurance. For those not employed, this figure drops to 39.5 percent, although another 10.9 percent of those not employed have both private and public coverage.

Eligibility for public coverage is related to one's eligibility or potential eligibility for income assistance. Interestingly, less than one-half (45.4 percent) of the persons in group B who are not working receive income assistance through one of the nation's two main income assistance programs for working-age disabled persons, i.e., the Social Security Disability Insurance (SSDI) program and the Supplemental Security Income (SSI) program. Disabled persons who are eligible for SSI generally are eligible for Medicaid; disabled persons who are eligible for SSDI generally are eligible for Medicare (Batavia 1989).

Individuals who are not employed and not receiving SSDI or SSI are the most likely to be uninsured (26.9 percent). They do not have employment-based health insurance (except possibly through a family member) nor do they have Medicare or Medicaid (except possibly through Medicaid's spend-down formula which requires that an individual must first spend down his or her resources on health expenses below a state-determined poverty level before one can qualify for medical assistance). Because of their work and income status, these individuals are generally unable to afford individual private health insurance plans, which tend to be more expensive and less comprehensive than group plans. This group comprises approximately 1.5 million persons exclusive of dependents. They represent a major challenge for health insurance reform, because they are largely unreachable by either private health insurance or by public health care coverage.

Even those who do qualify for income assistance may be uninsured. The findings in table 5 indicate that 12.8 percent or about 600,000 of those receiving income assistance are uninsured. The vast majority of these people are persons who qualify for the SSDI program but are in a mandatory 24-month waiting period to become eligible for Medicare. The health insurance needs of this group can be met by removing the 24-month waiting period (Batavia 1989; Tanenbaum 1989).

Adequacy of Health Insurance

Whether a disabled individual has health insurance provides a very incomplete picture of his financial access to needed health care services. It is also important to consider the adequacy of the health insurance plans in which disabled persons participate. By adequacy, we mean the extent to which health insurance policies will (1) cover and (2) pay adequately for the health care services that a disabled person needs to cope with his or her disability or chronic health condition.

There are at least five ways in which private health insurance carriers can limit coverage or payment for their disabled subscribers:

1. By using "pre-existing condition" exclusions that limit coverage for a condition for a specific period of time;
2. By failing to cover or by limiting the coverage of specific health services or devices needed by disabled persons such as durable medical equipment (e.g., wheelchairs);
3. By limiting coverage to certain types of providers in selected settings such as hospitals;
4. By requiring that certain services be designated by a physician as "medically necessary";
5. By imposing deductibles and copayments that the enrollee must pay (Griss 1988a, 1988b; Batavia 1989).

The extent of these limitations and how they affect persons with disabilities are not fully known. We do know, however, that these kinds of limitations are characteristic of many health plans today. We also know that these limitations have a disproportionate effect on persons with disabilities since disabled persons are more likely to have pre-existing conditions and chronic health care needs that are not well served by a private health insurance system geared to acute care. The official rationale for many of these limitations is (1) to reduce insurer risk in a manner that will enable the insurer to be price competitive in its underwriting markets and (2) to make the individual enrollee a more prudent consumer of health care services. Unofficially, they may also serve to discourage certain groups, such as working-age persons with disabilities, from enrolling in their plans (Batavia 1989).

Health Insurance and Work Incentive

The continued availability of health care coverage is an important consideration for SSDI and SSI recipients who are considering gainful employment. As indicated above, one's eligibility for SSDI also largely determines one's eligibility for Medicare; and one's eligibility for SSI largely determines one's eligibility for Medicaid. A person's eligibility for, and level of benefits under, SSDI or SSI can change materially when he/she engages in gainful employment. Thus, the decision to accept gainful employment may affect a person's continued eligibility for medical benefits under either the Medicare or Medicaid program.

Many SSDI and SSI participants know that they have (1) recurring health care needs, (2) higher than average health care costs, and (3) a greater risk of acquiring a financially catastrophic illness or secondary health problem. They also recognize that, in many cases, public health care coverage under Medicare or Medicaid offers greater protection against unusual health care expenses than does private health insurance, and that many employers do not offer any health insurance. Thus, the decision to accept gainful work sometimes creates an uncertain future about one's most secure source of health care coverage. Hence, the potential work disincentive.

Since 1980 Congress has taken several steps to help mitigate this potential work disincentive. These include the Social Security Disability Amendments of 1980 (P.L. 96-265), the Employment Opportunities for Disabled Americans Act (P.L. 99-643), and the Omnibus Budget Reconciliation Act of 1987 (P.L. 100-203). As a result of this legislation, SSDI beneficiaries can now retain their Medicare benefits up to 48 months once they resume working. Moreover, their Medicare eligibility can be reinstated without another 24-month waiting period should they once again become eligible for SSDI.

SSI recipients can now retain their Medicaid coverage when they resume working even after their cash benefits are phased out, provided that they continue to meet all SSI eligibility criteria (including resource tests) except for earnings. Under Section 1619 of the Social Security Act, which became effective in 1987, working-age disabled persons on SSI can maintain their Medicaid coverage until their earnings are sufficient to replace the value of the cash assistance payments, medical assistance, and their publicly funded attendant care benefits for which they would be eligible by not working. This earnings-based

phase-out of cash and in-kind benefits is not available to SSDI beneficiaries.

The various work-incentive provisions are very complicated and are probably not well understood by those who might potentially benefit from them. Persons with disabilities must invest considerable time and effort in establishing their eligibility for publicly supported income and medical benefits, which are predicated on their inability to work. Thus, persons with disabilities are naturally reluctant to test their work capacity after they have fought so hard to acquire some measure of income and medical security. According to the Social Security Administration's Disability Advisory Council (1988), much of this reluctance could be eliminated if the work-incentive provisions were clarified and better understood.

The need to extend Medicare or Medicaid eligibility for persons with disabilities simply underscores the shortcomings of the private health insurance system. Without better access to adequate private health insurance, persons with disabilities must continually be cognizant of public eligibility criteria and remain resource-poor in order to retain their eligibility for programs such as Medicaid. Present eligibility criteria, even with the new work-incentive provisions, make it difficult for Medicaid recipients to build with their earnings a resource base needed to meet future household or family needs. Policy options to rectify some of these shortcomings are discussed in the next section.

Policy Choices

A disability perspective in health care is long overdue. The provision and financing of health care services in the United States is still driven by a model of acute care medicine with its alluring array of high-technology interventions. This approach has helped us to avert or delay death, but has not been conducive to meeting the ongoing health care needs of persons with disabilities. The policy choices before us will not become clear until we consider the nature of disability and chronicity, and how they alter a disabled person's interaction with the health care system. At the same time, disability and chron-

icity should not blind us to the acute nature of many health problems experienced by persons with disabilities.

The policy choices before us fall into four broad categories: (1) access to health care services, (2) access to adequate health insurance, (3) access to personal care assistance (i.e., long-term care), and (4) insurance-related work disincentives. In addition, it is important to consider an overriding issue: Should disability policy, in the context of health care, focus on "targeted solutions" specifically directed to persons with disabilities or on "mainstream solutions" which focus on integration of the disabled population with the general population?

Access to Health Care Services

This article has underscored the shortcomings of the current health care delivery system in meeting the needs of working-age persons with disabilities. It points to the need to develop alternative health care delivery systems that are more responsive to the needs of working-age persons with disabilities. The 1980s have been a decade of ferment and experimentation in health care delivery as evidenced by the growth of managed-care schemes such as HMOs and PPOs. These developments, however, have not adequately addressed the health needs of working-age persons with disabilities.

In particular, demonstration projects designed to test new ideas in health care for vulnerable groups have focused on other disabled populations, and have generally overlooked the needs of working-age persons with disabilities. Despite this, we believe that there is much to learn from the experiences of these projects in developing alternatives for working-age persons with disabilities. A case in point is the On Lok Community Care Organization for Dependent Adults, which provides comprehensive, managed health care financed on a capitation basis to the frail, elderly population in San Francisco's Chinatown. On Lok's managed-care program has been able to provide effective services and achieve considerable cost savings. These savings result from the provision of early primary medical care and from keeping its enrollees out of institutions and hospitals (Zawadski et al. 1985). In short, On Lok has been successful in part because it has avoided artificial distinctions between acute and long-term care. The On Lok model is now being expanded to ten additional sites throughout the country. Other demonstration projects that have been

directed mainly to the *long-term* care needs of elderly persons have proved less successful in reducing hospital and nursing home utilization despite the increase in client and family care-giver satisfaction (Hughes 1985; Franklin et al. 1987; Kemper et al. 1986; Morris et al. 1987; Spitz 1987).

While demonstration projects generally have not focused on the health care needs of working-age persons with disabilities, there are two notable exceptions that have been concerned with working-age persons in group C. The first exception is the Urban Medical Group in Boston which has been providing managed health care services to working-age disabled persons since the early 1980s (Meyers et al. 1987). The second exception is the National Rehabilitation Hospital in Washington, D.C., which, following a feasibility study, has proposed the development of a managed health care program for the Washington metropolitan area using a preferred provider arrangement (PPA) model (Batavia et al. 1989). Under this model, health care services are provided at a discount negotiated by the provider and the patient's source of health insurance coverage. The goal of both the Urban Medical Group program and the National Rehabilitation Hospital plan is to avert costly and unnecessary hospitalizations and emergency room visits through effective case management and primary care services. This would include home visits by nurse practitioners to mobility-impaired persons who may be unable to make an office visit when ill.

The On Lok program received its initial funding through a variety of public and private sector agencies, including the Health Care Financing Administration, the Administration on Aging, and The Robert Wood Johnson Foundation (RWJF). The Urban Medical Group program and the National Rehabilitation Hospital program share a common sponsor, namely the Robert Wood Johnson Foundation. Their experience points to the need for leadership in both the public and private sectors to foster new health service delivery ideas for the working-age disabled population. Following the lead of the RWJF, other private foundations are also now expressing an interest in addressing the health care needs of the working-age disabled population. Federal and state governments need to expand their efforts by providing the necessary financial support and regulatory waivers that will permit more complete testing of alternative health delivery approaches for working-age persons with disabilities.

Access to Adequate Health Insurance

The health care needs of working-age persons with disabilities place in sharp relief the weaknesses of the current health insurance system. We noted that almost 18 percent of this population have neither public nor private health insurance, and there is strong reason to believe that a much higher percentage are seriously underinsured because of the numerous exclusionary clauses and coverage limitations in traditional health insurance policies. If people with disabilities were the only group adversely affected by existing health care financing policies, then adding another "patch" to the existing system of health care financing might be the most feasible alternative.

The problems of access to adequate and affordable health care for persons with disabilities, however, are occurring in the midst of a larger health care financing crisis that is threatening many other interests. These include (1) the growing number of uninsured persons and older persons who are increasingly in need of long-term support services, (2) the major payers of health care including employers and the government which are concerned about the burden of rising health care costs (which have increased 10-fold over the last 20 years), and (3) health care providers who are concerned about the burden of uncompensated care. Whether these groups can come to view each other as allies in health insurance reform will determine the options that are possible.

The vulnerability of people with disabilities is likely to increase as the major payers of health care implement various strategies for cost containment. These strategies often shift costs to the users of health care through higher premiums, deductibles, and copayments which disproportionately penalize high-risk health care users, and create incentives for health care providers to limit their services, especially when uncompensated. Meanwhile, the capacity of the federal government to respond to the needs of persons with disabilities is severely squeezed between the mounting federal budget deficit on the one hand, and spiraling health care costs on the other hand.

We believe that the best approach to addressing the substantial problems associated with our highly fragmented health insurance system is through the development of a well-designed national health insurance program. Such a program ideally should be centrally co-

ordinated, decentralized in the provision of services, and sensitive to the needs and utilization experience of all high-risk groups.

Short of a well-designed national health insurance program, three strategies or approaches have gained some degree of political currency. Each of these will be considered here in terms of its effectiveness in addressing the health insurance needs of persons with disabilities.

The first strategy is to require all employers, both large and small, to provide health insurance to their employees and their employees' dependents. In the legislation proposed by Senator Edward M. Kennedy and Representative Henry A. Waxman, for example, small employers would be required to purchase group insurance through a regional insurance pool that would ensure that all employers pay the same community-rated premium for each employee and his/her dependents. The main problem associated with an employer mandate is that minimum coverage requirements are likely to be defined in terms of what is affordable and acceptable to the average employer. In the Kennedy-Waxman bill, the minimum essential benefits package does not address all of the health-related needs of persons with disabilities. For example, medical rehabilitation is not included in the minimum benefits package even though it is considered cost effective and important for disabled persons. Moreover, the strategy of employer mandates is prone to continue the acute care bias of traditional health insurance and to further legitimate the continued separation of acute care and long-term care financing.

A second strategy for financing health care is to expand existing government programs like Medicare and Medicaid for persons with higher than average risks, including persons with disabilities. Government programs could be expanded by (1) eliminating the two-year waiting period for Medicare; (2) requiring state Medicaid programs to pay for specific health-related services at certain minimum levels; (3) expanding eligibility for government-sponsored programs; and (4) broadening Medicare benefits to include long-term care. Massachusetts, for example, has recently implemented a Medicaid buy-in plan that allows persons with disabilities to pay a premium to "buy into" the state Medicaid program on a sliding fee scale. The major limitations to expanding public programs are constraints imposed by the federal deficit, particularly in light of the growing number of persons without insurance and concerns over "dumping" from the private

sector. This indicates that insurance regulation in the private sector may be a necessary underpinning for improvements in public-sector financing.

A third strategy, which is often discussed for persons with disabilities, is to create high-risk pools. Promoted by the health insurance industry as a way to avoid access problems for people with disabilities, this financing mechanism guarantees access to health insurance for people who have been rejected by the private sector for pre-existing conditions *if* they can afford the high premium, deductible, and copayments. Bovbjerg and Koller (1986) estimate that 90 percent of the high-risk pool expenses are borne by enrollees with disabilities. Advocates for high-risk pools argue that such pools should not be expected to cover services beyond what is offered in major medical insurance policies for nondisabled persons (Trippler 1987). While this approach has some appeal for disability groups that see no other immediate solution to their access problem, it is not clear how the high-risk pool provides a meaningful "stepping stone" to a broader definition of health care benefits or to a more equitable distribution of health care costs. Moreover, the high-risk pool alternative creates an incentive for private insurers to "dump" into the pool their most difficult cases.

The more fundamental choice to be made is whether to view health care simply as a commodity or service that "should be distributed according to the ability to pay for it" or to view health care as a right that should be seen "as a social good of special moral significance" (Daniels 1986). Like Daniels, we believe that health care's moral significance derives in part from the fact that disease and disability limit normal functioning and deprive people of certain opportunities in a society committed to equal opportunity. Thus, our society's commitment to equal opportunity also obligates us "to provide access, without financial or discriminatory barriers, to services that adequately protect and restore normal functioning" (Daniels 1986). As important, we believe, is the concept of community responsibility in which risks of ill health and disability, especially those that are not self-inflicted, are shared (DeJong and Batavia 1989).

Working-age disabled persons comprise less than 10 percent of the 37 million Americans without health insurance. This percentage may be higher if we consider the number of dependents of disabled persons who may also be uninsured as a result of a work disability. A fun-

damental dilemma for the disability community is whether disabled persons should view themselves as a vanguard in the movement for health insurance reform for everyone, or as a small but deserving minority whose needs should be considered apart from the needs of the general population. This dilemma arises from the fear that the needs of working-age disabled persons are likely to get lost in the larger debate on health care financing reform (Griss 1988a, 1988b).

Personal Assistance

As indicated earlier, personal assistance is the premier long-term care issue for younger working-age persons with disabilities. The policy choices here are broad mainly because the parameters of what is now called personal assistance remain to be defined. In this article, we have used the term narrowly to refer to assistance with personal care activities. Personal assistance, however, also includes, interpreters for hearing-impaired persons and readers for visually impaired persons. The first policy choice, therefore, is which personal assistance services are to be covered. We believe that the full range of such services should be covered by insurance, since they are essential for disabled persons to maintain independent lifestyles.

The second choice concerns the funding mechanism for personal care services. There are a variety of options that may vary with the employment status of the user. For example, there is the possible use of tax credits, tax deductions, and sliding fee scales for persons who are employed. Generally speaking, we would discourage funding mechanisms in which eligibility is defined on the basis of a person's employment status, mainly because such funding mechanisms have an uncanny way of creating inadvertent work disincentives that undermine independent living goals.

A related choice is whether personal care assistance should be funded mainly through means-tested health care funding programs such as Medicaid (Title XIX) or through social service programs such as the social services block grants (Title XX). Both are presently being used in varying degrees in different states. Some advocates are ideologically opposed to the use of Medicaid funding since it includes trappings of the medical model. We believe that this concern is somewhat misplaced because the trappings can be quite minimal and because many trappings of the medical model have also been introduced in

personal assistance programs funded under social service programs. A more important consideration, we believe, is the fact that funding for social service programs tends to be capped whereas health programs tend to be more open-ended.

Regardless of funding source, there is an ever-present tendency in American long-term care policy to segregate the "medical" from the "nonmedical" domains of home care and to segregate the in-home forms of assistance from the out-of-home forms of assistance. Many groups of disabled persons find these distinctions to be extremely artificial and a constant source of frustration in their daily lives. A recent example of these distinctions is a proposed federal Medicaid regulation which would limit household tasks to one-third of a recipient's personal care benefit (Health Care Financing Administration 1988).

The third choice to be made is whether, and the extent to which, the personal assistance needs of working-age disabled persons should be linked with the personal assistance needs of elderly disabled persons. Presumably, there are substantial similarities between the personal assistance needs of these groups. Moreover, older persons have many of the same aspirations to live independently and to manage their own care as advocated by working-age persons within the independent living movement.

This potential linkage between the working-age and older populations is also politically attractive because it brings the political weight of another major constituency behind the concept of consumer-directed personal care services (Mahoney, Estes, and Huemann 1986). As attractive as this may appear, we are not certain that the personal assistance policy goals of the independent living movement would survive such a political marriage. Provider interests in the area of elderly health policy are so dominant that any political momentum behind the concept of user-directed personal care services could end up being redirected to establishing an even stronger provider-controlled system of in-home services. Two possible ways by which this pitfall can be averted are (1) by ensuring that elderly persons themselves are involved in the political debate and (2) by providing some residual role for the home health services industry in the delivery of personal care services, such as making in-home assessments of need and determining eligibility.

The fourth main choice is to determine the respective roles of federal

and state governments in providing access to personal care services. Should the federal government be the main source of funding or should the federal leadership come mainly in the form of developing national standards for the delivery of personal assistance services among the states? Or both? The National Council on Disability (1988), an independent federal board appointed by the president, has recommended that the federal role be mainly a standard-setting one. We believe, however, that a more aggressive federal policy is needed to address this major unmet need among working-age persons with disabilities.

Health Insurance-related Work Disincentive

Other than implementing a national health insurance system, there are two solutions to the problem of work disincentives associated with access to health insurance. The first is to use the private sector by mandating that private health insurance plans cover the kinds of services that disabled persons are likely to need. This is because, as noted earlier, much of the problem relating to health insurance-related work disincentives results from inadequacies in the private health insurance system.

The second is to modify the public-sector programs by extending a person's eligibility for certain public health insurance benefits when becoming gainfully employed without requiring the individual to impoverish him or herself to retain eligibility. While many modifications have already been made in both the SSDI and SSI programs that will allow persons with disabilities to retain their eligibility for Medicare and Medicaid when they accept or return to gainful work, more needs to be done to inform SSDI and SSI participants of the options now available to them. Furthermore, additional modifications are in order. SSI recipients who return to work can retain their Medicaid coverage but must still meet Medicaid's stringent resource tests that effectively preclude the accumulation of any assets necessary for long-term income security. Also, the SSDI program should be modified to allow SSDI beneficiaries the same cash assistance phase-out available to SSI recipients when they return to work.

These adjustments to the SSDI and SSI programs may create major new inequities between (1) current SSDI or SSI recipients and (2)

persons who may be similarly situated but never qualified for income assistance in the first place and are therefore ineligible for extended health care coverage. This kind of inequity can be averted by giving persons in the second group, or their employers, an opportunity to buy into a publicly-sponsored health care program such as Medicaid.

Targeted versus Mainstream Solutions

The most fundamental choice to be made is whether health policy should view working-age persons with disabilities as (1) a group whose distinct needs warrant targeted (i.e., separate) solutions or (2) a group whose needs should be resolved in the context of larger health care reform. This issue goes to the heart of a larger and long-standing debate about the merits of separate services versus mainstreaming. The ideology of the independent living movement strongly favors mainstream solutions. The movement, however, also strongly supports solutions that emphasize self-determination and self-direction that are notably absent in many programs directed to larger populations. When the element of self-direction is absent as in the case of home health services, the independent living movement has not hesitated to support, at least as an interim measure, more specialized programs emphasizing consumer management even when such programs have been limited to a very narrow segment of the population.

In the context of health policy, we believe that this dichotomy between mainstreaming and targeting can be useful if we focus on the distinction between health care delivery and health care financing. In the case of health care delivery, a good case can be made for some degree of targeting where important needs have been left unmet. In the case of health care financing, it is essential that the health care financing needs of disabled persons not be viewed separately from the health care financing needs of the larger community of which disabled persons are a part.

In health care delivery, some degree of targeting and specialization is inevitable, if not desirable, given (1) the highly diverse nature of the disabled population and the specialized needs of persons with different disabling conditions and (2) the highly specialized and segmented character of American medicine. One reason the ongoing post-rehabilitative health care needs of persons with disabilities are often overlooked is because no single medical discipline has made such

needs of disabled persons a major focus or area of specialization. Most medical knowledge is organized around specific organs or body systems while most severe disabling conditions and their health effects are not isolated to one organ or body system. Many disabilities are "orphaned conditions" that are not the province of any one medical discipline. Thus, persons with disabilities have lacked advocates for their health care needs within organized medicine and as a result have never been viewed as a specialized segment of the American health care market.

The failure of American medicine to specialize around the needs of persons with disabilities can also be attributed to the fact that, while the number of working-age persons with disabilities is large enough to warrant special attention, the number of persons with any one disabling condition is usually small in any given market area. Yet, if the health needs of persons with disabilities are to be met, American medicine needs to recognize and organize around these needs.

In health care financing, including health insurance, the concept of mainstreaming is essential. Any further segmentation of access to health insurance protection, based on individual or group risk, will only serve to exclude even more persons with disabilities from mainstream sources of private health insurance. And the more that persons with disabilities must rely on public sources of health care coverage, the greater the potential for work disincentives as persons with disabilities try to make the leap from public assistance to gainful employment. Thus, although persons with disabilities serve to underscore the weaknesses of the present health care financing system, we favor health insurance reform that is not targeted exclusively to persons with disabilities. We, therefore, favor such broad approaches as development of a national health insurance program or a Medicaid buy-in program.

We believe that the characterization of working-age persons with disabilities as a "health minority" has considerable utility in understanding this group's unmet needs with respect to health care delivery and financing and in devising new strategies for health service delivery to this group. However useful this characterization may be, it is fraught with potential problems if it leads to segregated solutions directed to the financing of health insurance for persons with disabilities. The health insurance needs of persons with disabilities cannot be divorced from the health insurance needs of other groups.

In Closing: The Need for a Disability Health Services Research Capacity

The issues presented in this article point to a major deficit in both health and disability policy, namely the lack of a health services research capacity that considers working-age disabled persons as consumers of health care services. The only major exception to this observation is perhaps the research done on health service utilization among persons with psychiatric disabilities. The disability research community has seldom looked to health care issues beyond medical rehabilitation (DeJong and Batavia 1987). The health services research community has almost totally ignored working-age disabled persons as a vulnerable health minority. What accounts for this mutual neglect?

The answer to this question starts with the fact that people with disabilities have always been a devalued group in our society and as such have not been deemed, until recently, as worthy of serious scholarly work and research. As a result, disabled persons have not experienced the social legitimacy that comes with academic validation. This devaluation, we fear, finds its way into the health services research community.

The neglect in the disability and rehabilitation research communities can be attributed to the academic and research isolation these communities have experienced until recent years. Disability issues were considered the exclusive province of rehabilitation counselor programs that were tucked away in schools of education. To this day, apart from the needs of older disabled persons, disability health issues are seldom a major topic of mainstream fields such as public health, the social sciences, and medicine. This fortunately is changing but not fast enough. At present, apart from some isolated research efforts, there are only two or three disability health services research programs anywhere in the nation. Such a capacity is sorely needed.

We believe that the time is right for a more complete hearing on the health care needs of working-age disabled persons. During the late 1980s, the dormant issues of catastrophic health care coverage, long-term care, and health insurance have resurfaced as major domestic policy issues. Moreover, we believe that the twin problems of (1) the uninsured and (2) uncompensated care will bring the issue of a national health insurance plan back onto the national health policy agenda. It

is uncertain whether working-age persons will be able to project their own needs onto the emerging national health policy debate on health insurance and long-term care. Their ability to do so will depend in part on whether they, as a health care constituency, will be able to marshal the necessary analytic muscle needed to support their claims. Although there is considerable data to support the claims for a more responsive health care system, working-age persons with disabilities have been disadvantaged by the lack of a health services research capacity to assess and legitimize their needs.

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