

## Access to Medicaid and Medicare by the low-income disabled

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*The most pervasive eligibility-related problems encountered by low-income disabled persons in gaining access to Medicaid and Medicare are reviewed in this article. A series of options for restructuring program eligibility requirements are presented, with particular attention to improving the plight of the low-income disabled worker during the 24-month waiting period for*

*Medicare. Options for Medicaid involve nationwide income eligibility levels at 100 percent of poverty and mandatory buy-in provisions to Medicaid in all States. For Medicare, the reforms range from altering the waiting period for Medicare by the disabled who are expected to die within 24 months after benefit award to eliminating the waiting period altogether.*

### Introduction

The horror of the acquired immunodeficiency syndrome (AIDS) epidemic has brought to public attention one of the most troubling shortcomings in our public health care system. Access to health care coverage is severely limited for many low-income persons with disabilities. Although the Medicare and Medicaid programs have made enormous progress in extending health care coverage to persons with disabilities, their eligibility requirements restrict coverage for many disabled persons living in poverty. For the Medicare program, these eligibility requirements are uniform nationwide and are federally determined. Eligibility for Medicaid, which is a Federal-State program, can vary enormously from State to State.

The most pervasive eligibility-related problems encountered by low-income disabled persons in gaining access to Medicaid and Medicare are described in this article. Solutions to alleviate these problems, ranging from incremental changes to a major restructuring are proposed. Although impetus for this article came from concerns about the financing issues facing persons with AIDS, the issues that are addressed are generally common to all low-income persons with disabilities.

Definitions of disability can vary widely and must be age-related. Definitions of disabled children, disabled workers, and disabled elderly differ in accordance with expectations for "normal" capacities of individuals within various age groups. However, in determining eligibility for disability-related benefits, the Federal Government has adopted a relatively narrow definition which focuses on the ability of the applicant for benefits to perform productive work, because the inability to perform productive work creates a need for government financial assistance. The definition of disability employed in Medicare and Medicaid and in the cash assistance programs with which they are related, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), is the same: the inability to engage in substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months.

Three important components of this definition are that: the disability must be total, not partial; the disability must be expected to be long-term; and the disability must prevent the individual from working at any substantial level. Short-term, temporary disabilities, no matter how severe, do not render an individual eligible for Medicaid or Medicare benefits.

The focus in this article is on Medicaid and Medicare coverage issues for persons who meet this definition of disability, and, therefore, pass the disability determination process as administered by the Social Security Administration and State Disability Determination Units (DDUs). Although there are a number of legitimate policy issues concerning the reliability, equity, and uniformity of the disability determination process, we do not include a discussion of these issues. Rather, the focus is on the barriers faced by disabled persons who pass the disability screen (or who would pass if they applied) in gaining access to Medicaid and Medicare coverage, because of other program eligibility requirements.

Further, we focus on the subset of persons with disabilities who are low income. The high cost of medical care makes the problem of access to health care financing of special concern for disabled persons living in poverty. In defining low income, the Federal poverty standard is used. In 1989, the Federal poverty level for a single adult (under age 65) was \$538 per month.

It should also be noted that we do not address problems related to the service benefit packages offered under Medicaid and Medicare. Instead, the focus is on eligibility rules and policy. Often, the term access is used to refer to problems with the range of available services covered by health insurance packages. For example, several State Medicaid programs have been criticized for not covering the drug azidothymidine for persons with AIDS, or offering them hospice services. Similarly, the lack of long-term care benefits under the Medicare program is often cited as an access problem. Although these are legitimate access issues, we use a more narrow definition and focus only on eligibility concerns.

Finally, we acknowledge that many of the access problems addressed in this article are not unique to the disabled. To the contrary, they are equally applicable to other Medicaid-covered groups, such as the elderly and families with children.

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## Background

In fiscal year 1988, slightly more than 3.1 million disabled workers under age 65 were covered by Medicare, and more than 3.3 million disabled persons received medical assistance under Medicaid (Social Security Administration, 1988). Approximately 1 million disabled persons received coverage under both programs. Overall, about 5.4 million disabled persons were covered by Medicare or Medicaid in 1988.<sup>1</sup>

A key difference in eligibility requirements for the two programs is that eligibility for Medicare is not means-tested, but eligibility for Medicaid is.<sup>2</sup> A disabled person of any income level can potentially be eligible for Medicare, but only the low-income disabled qualify for Medicaid. Eligibility for Medicare and Medicaid is closely tied to receipt of cash benefits under the SSDI and SSI programs. To be eligible for SSDI, a person generally must have worked and paid into the social security trust fund for a specified period of time in addition to satisfying disability requirements.<sup>3</sup> Disabled workers who receive cash benefits under the SSDI program do not become eligible for Medicare coverage until they have received SSDI benefits for 24 months. Also, dependents of disabled workers who receive cash benefits under the SSDI program (unless they themselves are disabled) are not eligible for Medicare coverage. The only group of disabled persons under age 65 who can receive Medicare benefits without receiving SSDI cash benefits are persons with end stage renal disease.

As eligibility for Medicare is linked to receipt of SSDI benefits, eligibility for Medicaid is closely linked to eligibility for cash benefits under the SSI program. Because many people who become disabled are not covered by SSDI or the amount of social security benefits they receive is small, the SSI program was designed to fill the gaps. Unlike SSDI, the SSI program does not have a work history requirement. Instead, eligibility is based on an applicant's financial status in addition to the disability requirements. The financial requirements for SSI eligibility vary across States, depending on whether or not a State has elected to supplement the Federal benefit level with State supplementation payments (SSP). In most States, persons eligible for SSI/SSP (including those eligible for only a State supplement) are

<sup>1</sup>All disabled Medicare enrollees are under the age of 65, because Medicare switches their eligibility status from "disabled" to "aged" on their 65th birthday. However, the Social Security Administration and State Medicaid programs continue to classify disabled SSI recipients as disabled even after their 65th birthday, and approximately 550,000 disabled Medicaid recipients are 65 years of age or over.

<sup>2</sup>It could be argued, however, that Medicare is a means-tested program for earned income, because earned income above the substantial gainful activity level of \$500 per month is considered evidence that the disabled person is capable of work, regardless of other evidence of physical or mental disability.

<sup>3</sup>The primary exception to this rule is that persons who were disabled in childhood (and, therefore, did not have the opportunity to contribute to the social security trust fund) and who are the dependents or survivors of social security beneficiaries are eligible for SSDI benefits at age 18. Similar to disabled workers, these "adult disabled children" are eligible for Medicare after a 24-month waiting period. In 1987, 561,273 adult disabled children were receiving SSDI benefits (Social Security Administration, 1988).

automatically eligible for Medicaid. Of 3.3 million disabled Medicaid recipients in 1988, about 2.7 million (80 percent) received cash assistance under SSI/SSP (Health Care Financing Administration, 1988).

Unlike Medicare, however, persons with disabilities who do not receive cash benefits can still qualify for Medicaid coverage. States have several options for extending Medicaid coverage to persons not receiving cash assistance. Most commonly, such coverage is extended through a medically needy program or through the use of special financial criteria for the institutionalized. In 1988, about 20 percent of disabled Medicaid recipients qualified through optional coverage provisions for persons not receiving SSI/SSP (Health Care Financing Administration, 1988).

Another important distinction between Medicare and Medicaid is that the programs offer significantly different benefit packages. Medicare primarily covers acute health care needs, mostly hospital and physician services. Medicare also has significant cost-sharing requirements: monthly premiums for Part B coverage for supplementary medical insurance (SMI), deductibles, and copayments. Medicaid generally provides coverage for a broader array of services, including both prescription drugs and long-term care services, although benefit packages vary considerably from State to State. Many low-income disabled Medicare beneficiaries seek Medicaid coverage to cover their Medicare cost-sharing requirements and to obtain coverage for certain services (such as long-term care) not covered by Medicare.

## Coverage of disabled persons

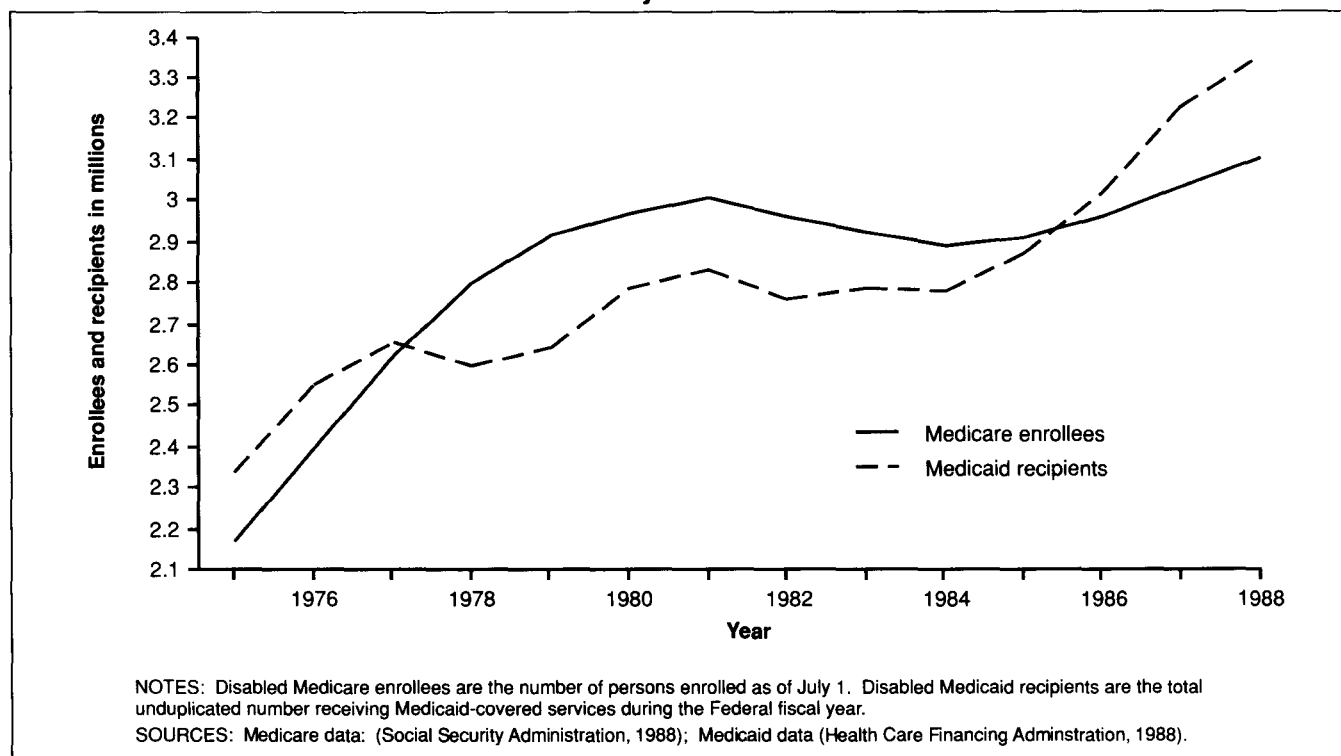
There has been substantial growth in the number of disabled persons under both the Medicare and Medicaid programs. Enrollment of the disabled for both programs from 1975 through 1988 are shown in Figure 1 and Table 1. Disabled Medicare enrollees grew significantly from 1975 to 1980, increasing from 2.2 million enrollees to almost 3.0 million, an increase of 36 percent (derived from Table 1). From 1980 to 1988, the number of disabled Medicare enrollees remained relatively stable. The disabled population in the Medicaid program has exhibited a somewhat different pattern. The number of recipients grew at a moderate pace during the period 1975-80, increasing 19 percent (derived from Table 1) from 2.3 million to 2.8 million. As under Medicare, the number of disabled Medicaid recipients remained stable during the early eighties, but from 1984 to 1988, the number of recipients grew from 2.8 million to 3.3 million, an increase of 20 percent.

In examining trends in Medicaid enrollment, it is useful to divide the Medicaid disabled population into three distinct groups:

- Noninstitutionalized recipients receiving SSI/SSP cash assistance.
- Noninstitutionalized recipients not receiving cash assistance (non-cash recipients).
- Institutionalized recipients (both cash and non-cash).<sup>4</sup>

<sup>4</sup>Institutionalized recipients are defined as persons who received Medicaid-financed care in skilled nursing facilities (SNFs), intermediate care facilities (ICFs), or intermediate care facilities for the mentally retarded (ICFs/MR).

**Figure 1**  
**Number of disabled Medicare enrollees under age 65 for 1975-88 and disabled Medicaid recipients for fiscal years 1975-88**



**Table 1**  
**Number of disabled Medicare enrollees under age 65 for 1975-88, disabled Medicaid recipients for fiscal years, 1975-88, and percent change**

Year	Medicare enrollees		Medicaid recipients	
	Number	Percent change	Number	Percent change
1975	2,168,000	—	2,333,681	—
1976	2,392,000	10.3	2,546,664	9.1
1977	2,619,000	9.5	2,652,740	4.2
1978	2,793,000	6.6	2,595,938	-2.1
1979	2,911,000	4.2	2,642,217	1.8
1980	2,963,000	1.8	2,783,048	5.3
1981	2,999,000	1.2	2,828,533	1.6
1982	2,954,000	-1.5	2,754,378	-2.6
1983	2,918,000	-1.2	2,779,692	0.9
1984	2,884,000	-1.2	2,776,640	-0.1
1985	2,907,000	0.8	2,867,539	3.3
1986	2,959,000	1.8	3,013,521	5.1
1987	3,031,000	2.4	3,225,726	7.0
1988	3,101,000	2.3	3,345,345	3.7

NOTES: Disabled Medicare enrollees are the number of persons enrolled as of July 1. Disabled Medicaid recipients are the total unduplicated number receiving Medicaid-covered services during the Federal fiscal year.

SOURCES: Medicare data: (Social Security Administration 1988); Medicaid data: (Health Care Financing Administration, 1988).

The distribution of the Medicaid disabled population across these three groups in fiscal year 1988 is shown in Figure 2 and Table 2. Approximately 75 percent of the Medicaid disabled were noninstitutionalized cash recipients, 11 percent were institutionalized, and 14 percent were noninstitutionalized non-cash recipients.

This latter group of noninstitutionalized non-cash recipients is of particular policy interest because it is a population that is the focus of contemplated policy changes to expand Medicaid coverage for persons with

disabilities (i.e., persons with disabilities who have income and/or resources that render them ineligible for SSI/SSP cash assistance, but who are still uninsured or underinsured for health care expenses). The number of noninstitutionalized non-cash disabled recipients covered by Medicaid has risen substantially in recent years, increasing by 32 percent during the period 1982-88 (Figure 3). This trend suggests that many disabled persons who do not qualify for SSI/SSP are nonetheless seeking Medicaid coverage for health care expenses that

are not covered by other sources. No doubt this group will continue to grow because State Medicaid programs have been mandated to cover Medicare cost sharing for disabled Medicare beneficiaries with incomes up to 100 percent of the poverty level, enacted with the Medicare Catastrophic Coverage Act (MCCA) of 1988 (Public Law 100-360).

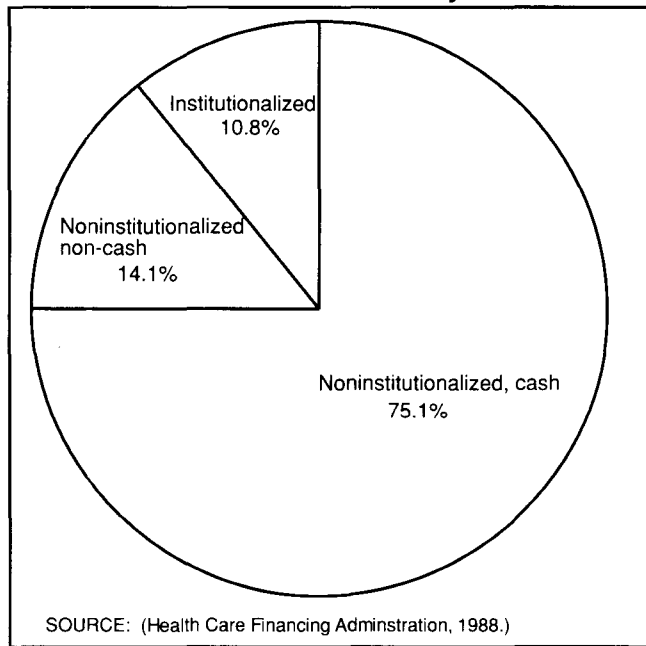
Combined Medicaid and Medicare expenditures for the disabled totaled about \$28 billion in 1988 (Health Care Financing Administration, 1988; Social Security Administration, 1990b). Although the number of disabled persons receiving Medicaid is only slightly more than the

number receiving Medicare, Medicaid expenditures for the disabled are almost twice that of Medicare. In fiscal year 1988, Medicaid spent \$18.2 billion for disabled recipients, compared with about \$10 billion for Medicare in calendar year 1988. This is primarily so because Medicaid provides a much broader benefit package for disabled enrollees, including long-term care benefits. In 1988, Medicaid expenditures for SNFs, ICFs, and ICFs/MR accounted for almost one-half of the total expenditures for disabled recipients. Since 1980, expenditures in both programs for disabled persons have been increasing at an annual compound rate of growth of approximately 10 percent per year.

These program statistics do not yet reflect the impact of the AIDS epidemic on disabled enrollment and expenditures, especially for the Medicaid program. As of April 1990, 128,319 Americans were reported to the Centers for Disease Control (CDC) as having AIDS (Centers for Disease Control, 1990). In 1988, it was estimated that as many as 1 to 1.5 million Americans were infected with the human immunodeficiency virus which causes AIDS (*Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic*, 1988). The costs of treating AIDS will rise dramatically as the number of cases increases. The President's Commission estimated that the direct costs of medical care for AIDS was \$1.1 billion in 1985, but will rise to \$8.5 billion in 1991. Medicaid is a major payer for this care; Medicaid expenditures for AIDS were estimated to be \$600 million in 1988, with a projected increase of \$2.4 billion by 1992. Medicare costs for AIDS have been negligible. Until recently, few persons with AIDS lived long enough to satisfy the 24-month waiting period following SSDI award to qualify for Medicare coverage.

Persons with AIDS, as defined by CDC, are automatically assumed to satisfy the disability requirements for both SSDI and SSI/SSP. Whether they will qualify for SSDI (and eventually Medicare) is dependent on their work history, and their eligibility for SSI/SSP (and/or Medicaid) relates to their financial

**Figure 2**  
**Distribution of the disabled Medicaid population, by cash assistance status and institutional status: Fiscal year 1988**



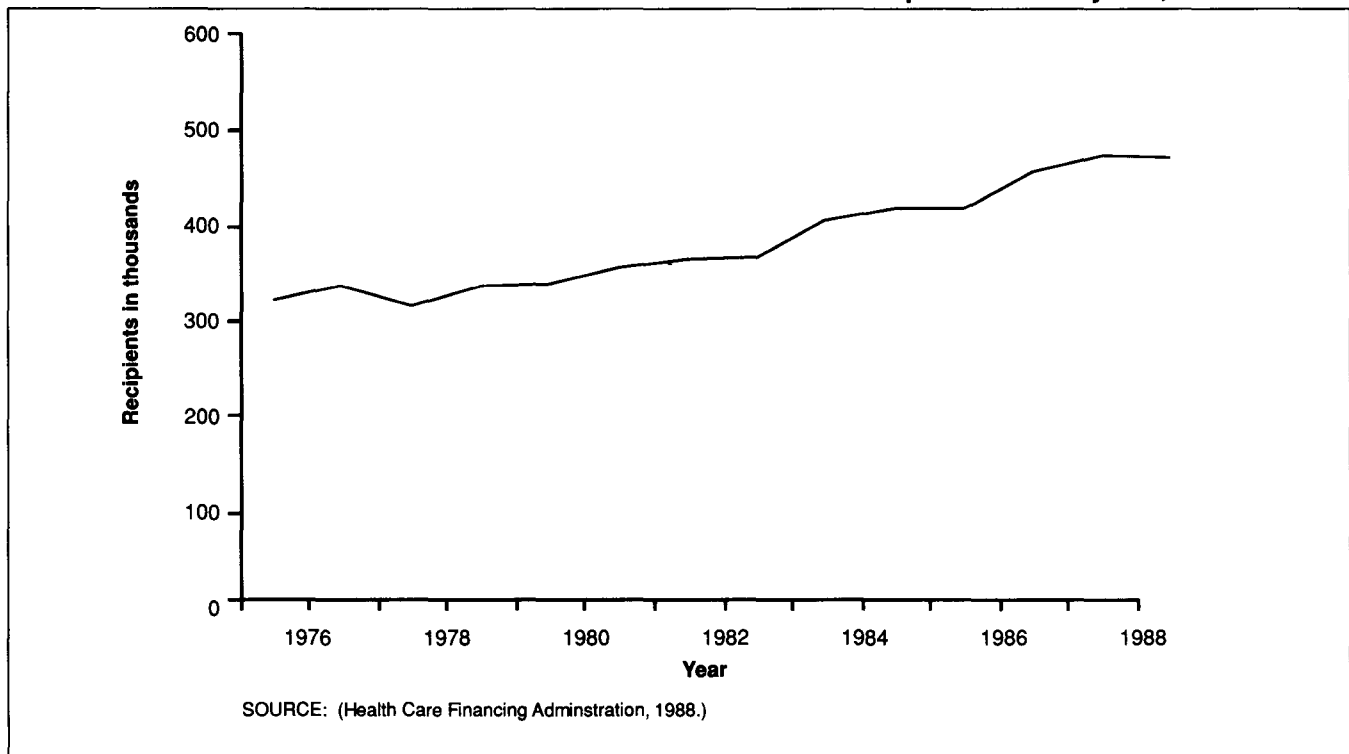
**Table 2**  
**Number of disabled Medicaid recipients by cash assistance status, institutional status, and percent change: Fiscal years 1975-88**

Year	Total	Percent change	Noninstitutionalized cash	Percent change	Noninstitutionalized non-cash	Percent change	Institutionalized	Percent change
1975	2,333,681	—	1,683,212	—	309,442	—	341,027	—
1976	2,546,664	9.1	1,858,645	10.4	324,757	4.9	363,262	6.5
1977	2,652,740	4.2	1,969,408	6.0	301,422	-7.2	381,910	5.1
1978	2,595,938	-2.1	1,891,734	-3.9	325,329	7.9	378,875	-0.8
1979	2,642,217	1.8	1,900,988	0.5	327,472	0.7	413,757	9.2
1980	2,783,048	5.3	2,000,892	5.3	345,567	5.5	436,589	5.5
1981	2,828,533	1.6	2,029,704	1.4	355,160	2.8	443,669	1.6
1982	2,754,378	-2.6	1,974,844	-2.7	357,731	0.7	421,803	-4.9
1983	2,779,692	0.9	1,975,210	0.0	399,659	11.7	404,823	-4.0
1984	2,776,640	-0.1	1,993,917	0.9	414,431	3.7	368,292	-9.0
1985	2,867,539	3.3	2,080,551	4.3	412,665	-0.4	374,323	1.6
1986	3,013,521	5.1	2,194,324	5.5	456,260	10.6	362,937	-3.0
1987	3,225,726	7.0	2,380,731	8.5	474,932	4.1	370,063	2.0
1988	3,345,345	3.7	2,513,084	5.6	470,767	-0.9	361,494	-2.3

SOURCE: (Health Care Financing Administration, 1988.)

**Figure 3**

**Number of noninstitutionalized non-cash disabled Medicaid recipients: Fiscal years, 1975-88**



circumstances and the program structures of the State in which they live.

It is difficult to develop reliable estimates of the number of persons with disabilities who are uninsured or underinsured, partly because survey estimates of the total number of persons with disabilities vary depending upon the definition of disability used in the survey and other design features of the survey itself (U.S. Bureau of the Census, 1986). However, data from the 1984 National Health Interview Survey indicate that of approximately 22.2 million persons with one or more limitations in a major activity resulting from chronic conditions, approximately 2.4 million (10.8 percent) were uninsured (Griss, 1988). Virtually all disabled persons without health insurance were under age 65; 2.2 million were age 18-64, and about 0.2 million were disabled children.

A major target group of the uninsured disabled are SSDI beneficiaries in the 24-month waiting period for Medicare eligibility. For example, in 1986 and 1987, a total of 819,000 new SSDI awards were made to disabled workers. This number can be used to approximate the number of SSDI beneficiaries at any one point in time in the 2-year waiting period. Survey data of new SSDI beneficiaries indicate that approximately 27 percent of disabled workers in months 18-24 of the 2-year waiting period have no health insurance coverage at all (Bye and Riley, 1989). An additional 14 percent reported Medicaid coverage, and 59 percent had some form of private health insurance. Uninsured SSDI beneficiaries are an obvious group of concern. Also of concern are SSDI beneficiaries whose private insurance provides only limited service coverage and those who devote a disproportionate amount of income to obtain health care coverage.

### **Problems with access to Medicaid**

Because States have considerable flexibility in setting their Medicaid eligibility policies, where a low-income disabled person lives makes a big difference. Disabled persons in identical circumstances are not treated the same from State to State. As a result, many of the barriers to Medicaid involve interstate differences which have resulted from State policy options. Although there are understandable reasons for the flexibility States have been given to establish their own criteria for Medicaid eligibility, this flexibility has resulted in inequities with regard to access for the low-income disabled. Access problems also result from inconsistencies in the patchwork of Federal rules that govern eligibility policies. Finally, other barriers to eligibility are a result of implementation issues, not policies per se.

### **Income eligibility levels**

Many low-income disabled cannot become eligible for Medicaid simply because their income is too high to satisfy Federal or State-determined financial requirements. Most disabled persons qualify for Medicaid through the SSI/SSP program. In about one-half the States, the income level for SSI/SSP eligibility (and automatic Medicaid eligibility) is set at the Federal SSI standard (Table 3). In 1989, this level was \$368 a month for a disabled individual living independently, which was only 68 percent of the Federal poverty level of \$538 per month for a single adult under age 65. In only three States (Alaska, California, and Connecticut) did the SSI/SSP

**Table 3**  
**Income eligibility levels for disabled Medicaid recipients, by State: 1989**

State	SSI/SSP benefit level		State medically needy level	
	Monthly amount <sup>1</sup>	Percent of Federal poverty level <sup>2</sup>	Monthly amount <sup>3</sup>	Percent of Federal poverty level <sup>2</sup>
Alabama	\$368	69	—	—
Alaska	683	127	—	—
Arkansas	368	68	\$108	20
California	602	112	600	100
Colorado	372	69	—	—
Connecticut	<sup>4</sup> 752	140	452	84
Delaware	368	68	—	—
District of Columbia	383	71	391	73
Florida	368	68	300	56
Georgia	368	68	—	—
Hawaii	373	69	357	66
Idaho	441	82	—	—
Illinois	NA	—	267	50
Indiana	368	68	<sup>5</sup> NA	NA
Iowa	368	68	466	87
Kansas	368	68	368	68
Kentucky	368	68	217	40
Louisiana	368	68	100	19
Maine	378	70	400	74
Maryland	368	68	375	70
Massachusetts	483	90	483	90
Michigan	399	74	391	73
Minnesota	403	75	466	87
Mississippi	368	68	—	—
Missouri	368	68	<sup>5</sup> NA	NA
Montana	368	68	368	68
Nebraska	406	75	392	73
Nevada	478	89	—	—
New Hampshire	395	73	382	71
New Jersey	400	74	350	65
New Mexico	368	68	—	—
New York	454	84	459	84
North Carolina	368	68	242	45
North Dakota	368	68	345	64
Ohio	368	68	<sup>5</sup> NA	NA
Oklahoma	432	80	275	51
Oregon	370	69	385	72
Pennsylvania	401	75	408	76
Rhode Island	430	80	550	102
South Carolina	368	68	—	—
South Dakota	383	71	—	—
Tennessee	368	68	175	33
Texas	368	68	—	—
Utah	377	70	337	63
Vermont	429	80	733	136
Virginia	368	68	250	46
Washington	396	74	396	74
West Virginia	368	88	200	37
Wisconsin	471	90	471	88
Wyoming	388	72	—	—

<sup>1</sup>The SSI/SSP benefit level for each State includes the State supplementation payment, where applicable, for a disabled individual living independently during January 1989. The Federal SSI benefit level in January 1989 was \$368.

<sup>2</sup>The percent of Federal poverty level is calculated using \$538, the 1989 monthly Federal poverty level (nonfarm) for a single adult under age 65.

<sup>3</sup>The medically needy level for each State is the amount of income protected under the State's medically needy program for a 1-person family in September 1989.

<sup>4</sup>Connecticut uses a budget process to establish payment amounts. The amount presented assumes eligibility for the highest rental allowance in the maximum budget amount.

<sup>5</sup>Section 209(b) of the Social Security Amendments of 1972 provided States the option of using more restrictive criteria for Medicaid eligibility than the requirements for SSI. These States use an income spend-down provision in determining Medicaid eligibility for the disabled because of their 209(b) status. However, they do not have medically needy levels per se.

NOTES: SSI/SSP is Supplemental Security Income/State supplementation payments. NA is not available. Dash mark in data columns indicates State did not include this option in its Medicaid program.

SOURCES: SSI/SSP data: (Social Security Administration, 1989); State medically needy data: (Hall, 1990).

level exceed the Federal poverty level (as a result of SSP). Thus, it makes a big difference where low-income disabled persons live as to whether they will satisfy the financial requirements for SSI/SSP and Medicaid.

In 13 States, the low-income disabled who do not satisfy the SSI/SSP eligibility income levels generally cannot qualify for Medicaid unless they are institutionalized. These States are: Alabama, Alaska, Colorado, Delaware, Georgia, Idaho, Mississippi, Nevada, New Mexico, South Carolina, South Dakota, Texas, and Wyoming. This happens because these States do not have medically needy programs or exercise other options which would make Medicaid available to the disabled not eligible for SSI/SSP who live in the community. Thus, a few dollars in income above the qualifying level for SSI/SSP can prevent a disabled person from receiving Medicaid. In these States, there are no options for disabled persons to spend down income to become eligible for the Medicaid program.

Ironically, many of the low-income disabled who cannot qualify for Medicaid in these States are those whose SSDI monthly benefit is greater than the SSI/SSP standard. As a result, disabled persons in these States who have worked enough to satisfy social security requirements can have less health coverage than the disabled who have not worked. Eventually, SSDI beneficiaries are eligible for Medicare, but the 24-month waiting period can leave them without access to health care coverage.

The Omnibus Budget Reconciliation Act (OBRA) of 1986 (Public Law 99-509) created an option that allowed States to set a special Medicaid eligibility income standard for the disabled (and aged) up to 100 percent of the poverty level. To date, however, only seven States (the District of Columbia, Florida, Hawaii, Maine, Michigan, Mississippi, and New Jersey) have exercised this option.

As mentioned earlier, the MCCA of 1988 mandated that State Medicaid programs cover the Medicare cost-sharing for low-income disabled (and aged) Medicare beneficiaries with incomes up to 100 percent of the poverty level. Included in the Medicare cost-sharing expenses are the buy-in premiums for Medicare Part B, copayments, and deductibles. This new coverage will assist SSDI beneficiaries already enrolled in Medicare, but it will not help those in the 24-month waiting period.

### **Medically needy coverage**

One of the most important decisions a State Medicaid program makes with regard to the low-income disabled is whether to extend coverage for the medically needy. By including medically needy coverage, a State makes Medicaid available to disabled persons of any income level, assuming their otherwise uncovered medical bills are high enough and they satisfy applicable resource requirements. This happens because under medically needy programs, applicants' medical expenses must be deducted from income to determine financial eligibility. This process is called spend down. A medically needy program can be viewed as offering protection against

catastrophic health care costs because it does not have any upper income restrictions. In 1989, 34 States covered the disabled in their medically needy programs, as shown in Table 3.

Another three States had similar coverage because of their 209(b) status, which requires that they allow applicants to deduct medical expenses from income in determining Medicaid eligibility.<sup>5</sup> The 209(b) spend-down option makes Medicaid eligibility available to disabled persons of any income level in the same way as does a medically needy program.

The low-income disabled in States without medically needy programs are subject to the so-called "Medicaid notch," whereby \$1 of additional income can mean the complete loss of Medicaid coverage. This notch problem is probably the most fundamental access issue facing Medicaid. Under the spend-down provisions of medically needy programs, a low-income disabled person at least has a way to gain access to Medicaid, even though it may mean incurring substantial medical expenses to attain coverage. This is not an option in States without medically needy coverage. In a State that covers only the SSI/SSP disabled, a person with \$1 income in excess of the SSI/SSP level has no way of attaining Medicaid eligibility, except by institutionalization or waivers.

Even in States with medically needy coverage, income eligibility levels present access problems. By Federal law, medically needy income standards can be no higher than 133 percent of the Aid to Families with Dependent Children (AFDC) benefit level (adjusted by family size). In most States, the SSI/SSP benefit level is considerably higher than 133 percent of the comparable AFDC level. As a result, the medically needy level is often lower than the SSI/SSP level. This means that in many States, a disabled medically needy enrollee who has to spend down to qualify for Medicaid is allowed to retain less income to meet his or her maintenance needs than is an SSI/SSP recipient. As shown in Table 3, 19 of the 34 States with medically needy programs in 1989 had lower income eligibility levels for one person than the State's SSI/SSP level for a disabled individual.

Theoretically, one would expect that the medically needy level would always exceed the cash payment level, so that Medicaid eligibility could be extended gradually to persons whose income was too high to be eligible for SSI/SSP. Then, through the spend-down component of the medically needy program, Medicaid could be extended to disabled persons who could meet their maintenance needs, but could not cover all their medical expenses. Instead, what can happen is that medically needy enrollees can have less money available to meet their needs than can SSI/SSP recipients—the opposite of what seems equitable.

<sup>5</sup> Section 209(b) of the Social Security Amendments of 1972 provided States the option of using more restrictive criteria for Medicaid eligibility than the requirements for SSI. This option was enacted to protect States from massive increases in their Medicaid expenditures due to the implementation of SSI. However, if States elected to use more restrictive criteria for Medicaid, they also had to allow Medicaid applicants to spend down to the income levels used for Medicaid, even if they did not have a medically needy program. For some States then, 209(b) worked to both contract and expand Medicaid eligibility.

Another problem is that medically needy income levels are not indexed. Although the Federal SSI benefit amount and the SSDI benefit amount are indexed annually to allow for increases in the cost of living, States are under no obligation to pass along such increases in their State supplementation programs for SSI, nor are they required to adjust their medically needy income standards. States only infrequently make adjustments to their medically needy income levels because these levels are directly tied to AFDC levels. No States automatically adjust their AFDC levels to allow for cost of living increases. Indeed, the median State AFDC level in 1989 was 37 percent lower in constant dollars than the 1970 level (Committee on Ways and Means, 1989). As a result, medically needy levels have failed to keep pace with inflation. This failure to update medically needy levels is particularly troubling because of the disparity between SSI/SSP income levels and the medically needy income levels in many States.

A final problem is that the OBRA 1986 option allowing States to extend Medicaid coverage to the disabled (and aged) with incomes under the poverty level is not consistent with medically needy provisions. Seven States (the District of Columbia, Florida, Hawaii, Maine, Michigan, Mississippi, and New Jersey) have elected to extend Medicaid coverage to the disabled (and aged) up to 85-100 percent of the poverty level. Some of these States also have medically needy programs under which the disabled could become eligible for Medicaid. This "double" coverage presents an equity problem. For example, in 1989 an applicant with monthly income of \$550 in New Jersey would not qualify for the OBRA 1986 option because his income exceeded the poverty level (\$538 a month) by \$12 a month (data not shown). To qualify for Medicaid, the applicant would have to spend down to the medically needy level (\$350 a month in 1989) because the OBRA 1986 option does not include a spend-down provision. Thus, the disabled person with income slightly above the poverty level is financially worse off than the person with income just under the poverty level.

## **Income spend down**

The income spend-down component of State medically needy programs deserves special discussion. The income spend-down process is repeatedly cited as one of the most difficult and confusing aspects of Medicaid eligibility. A major problem with spend-down policy is that it imposes a 100 percent marginal tax rate for income above the medically needy level. Generally, every dollar of income above the medically needy income standard (except for the disregard applied to earned income) has to be offset by incurred medical expenses, according to current Medicaid policy. Thus, a disabled person in 1989 who had SSDI income of \$538 (the poverty level) living in a State with a medically needy level of \$382 (the median State medically needy level) would have to have had a spend-down amount of \$156 monthly in order to qualify for Medicaid. The spend down would represent 29 percent of the applicant's monthly income. Current spend-down policy provides no incentive or reward then

for having higher income (often SSDI income). In many States, spend-down applicants with incomes at the poverty level would have to devote one-third to one-half of their income for medical care to satisfy Medicaid spend-down requirements. Most analysts would agree that this is an excessive proportion of income to require for access to medical benefits, especially for persons considered to be in poverty. This spend-down policy is particularly devastating to the disabled who (unlike the aged) do not have immediate access to Medicare and who often have chronic health care needs.

A second problem with the spend-down process relates to the accounting periods that States use in calculating the size of the spend-down liability. States can use from 1 to 6 months as the accounting period. Generally, a shorter accounting period favors applicants, whereas a longer period favors States. For example, if a low-income disabled person with income in excess of a State's medically needy income level had an emergency whereby immediate hospitalization was required for a 2-week period, how much that person would have to spend down in order to qualify for Medicaid assistance during the 2 weeks of hospitalization would vary according to the length of the accounting period used by the State. For a person with \$538 in monthly income (the poverty level) living in a State with a medically needy level of \$382 a month (the median level for States with medically needy programs), the spend-down amount would be \$156 if the State used a 1-month accounting period. In a State using a 6-month accounting period, the spend-down liability would be equal to 6 months of income in excess of the medically needy level, or \$936 for this example. Obviously, it would be easier for a disabled person to incur medical expenses of \$156 than \$936. Many providers would be unwilling to extend services without guarantee of payment for the 6-month liability.

The one advantage of a 6-month accounting period is that it allows a person to enroll in Medicaid for the balance of the 6-month period, once the spend-down liability is met (versus only the balance of 1 month). For many people with recurring chronic health care needs, it will not matter which accounting period is used because they will likely satisfy the spend-down liability under any period. For persons with acute short-term problems, a shorter accounting is clearly preferable.

In 1987, 17 States used a 6-month period, 7 a 3-month period, 10 a 1-month period, and 1 State a combination of periods (Neuschler, 1987).

A final problem with spend down relates to the provider community. In order for many applicants to satisfy income spend-down requirements, a provider has to extend credit or provide a service without assurance of payment. This happens because an applicant needs to incur a certain level of medical expenses in order to spend down. Many applicants report difficulty with this step of the spend-down process. Often providers either are unwilling to extend services on credit or they do not understand that the applicant has to incur some costs directly in order for Medicaid to cover the balance of the bill. Provider credit is especially problematic in situations in which a large spend-down liability is involved.



Providers may have legitimate reason to doubt whether they will be paid for services that are part of a spend down.

## Restricted Medicaid eligibility

In 1989, 13 States elected to use more restrictive criteria to determine Medicaid eligibility for SSI/SSP recipients, using the 209(b) option (Social Security Administration, 1989). States can set more restrictive criteria as long as the criteria used were part of the State's Medicaid plan in January 1972 (when the SSI legislation was passed). However, as noted previously, by electing the 209(b) option, States are required to allow disabled Medicaid applicants to spend down to the income levels that are designated for eligibility, regardless of whether the State has a medically needy program. As shown in Table 4, the 209(b) option reduces the proportion of disabled SSI/SSP recipients who become Medicaid recipients. In 209(b) States, only 63 percent of disabled SSI/SSP recipients were reported to be Medicaid recipients in 1988. In States (called 1634 States) that automatically extended Medicaid to disabled SSI recipients, 99 percent were reported to be Medicaid recipients.<sup>6</sup>

The more restrictive criteria used by States under option 209(b) cover a range of eligibility criteria, including the definition of disability (for example, excluding children), disregards, countable resources, treatment of household goods, automobile, income-producing property, life insurance, and burial space and funds (Hall, 1990).

A second option available to States with regard to Medicaid eligibility for SSI/SSP recipients is to require a separate application for Medicaid. In 1989, six States (Alaska, Idaho, Kansas, Nevada, Oregon, and Utah) elected this option. SSI/SSP recipients in these States become enrolled in Medicaid only if they complete a separate application. Because the eligibility criteria in these States are identical to those used for SSI, the SSI recipient's eligibility for Medicaid should be automatic once the application is submitted. However, this duplicative administrative requirement appears to somewhat restrict access to Medicaid for disabled SSI/SSP recipients, as shown in Table 4. In 1988, only 75 percent of disabled SSI/SSP recipients were reported to be Medicaid recipients in States requiring a separate Medicaid application.

Previous research showed that the 209(b) States and the States requiring a separate Medicaid application had significantly higher average Medicaid expenditures per recipient than the States providing automatic eligibility (Rymer and Adler, 1984). These results suggest that restricting coverage does not screen out the high users in the SSI/SSP group. The 209(b) option and the option to

<sup>6</sup>In States with automatic Medicaid eligibility, some States show fewer than 100 percent of disabled SSI/SSP recipients reported to be Medicaid recipients, but others show more than 100 percent. There are two reasons for this. First, not all SSI/SSP recipients who are enrolled in Medicaid actually use Medicaid services. Only service users are reported as Medicaid recipients under Federal reporting requirements. Second, the SSI/SSP recipient numbers are as of July 1988, and the Medicaid SSI/SSP recipient user numbers are for Federal fiscal year 1988. Thus, some States may show more than 100 percent participation.

allow States to require separate Medicaid applications were originally intended to protect States from massive increases in their Medicaid expenditures as a result of implementation of SSI (and the expected increases in the number of recipients). It seems legitimate to question whether after 15 years it continues to be necessary to allow States to use more restrictive criteria or separate applications for Medicaid eligibility for the low-income disabled who satisfy SSI/SSP criteria.

## Medicare buy-in

The Medicare Catastrophic Coverage Act (MCCA) of 1988 significantly increased access to medical care for the low-income disabled (and the low-income aged). It requires State Medicaid programs to phase in coverage of Medicare cost-sharing expenses for Medicare beneficiaries up to the poverty level. By 1992, all States should be covering all Medicare cost-sharing requirements for the low-income disabled who are enrolled in Medicare. However, this expansion does nothing to assist the low-income disabled who are not eligible for Medicare under SSDI. Nor does it provide disabled Medicare beneficiaries access to the full Medicaid benefit package, only the costs of Medicare SMI premiums, copayments, and deductibles.

Thus, SSDI beneficiaries still in their 24-month waiting period for Medicare and the low-income disabled not eligible for Medicare (and not otherwise eligible for Medicaid) are not covered by this expansion. Instead, the group helped by this expansion is the low-income disabled already eligible for Medicare, which already has at least some access to health care benefits.

## Home and community-based waivers

Medicaid home and community-based waiver programs are another option available to States to expand Medicaid eligibility and services for low-income persons with disabilities. Although the primary policy objective of the Medicaid waiver program is to provide cost-effective alternatives to institutional care, there are a few eligibility options that can be used in conjunction with the expanded service coverage provisions of these waivers. These are:

- States may use institutional income and asset limits for waiver recipients living in the community.
- States may use institutional deeming of income requirements for waiver applicants.

The latter option means that States are not required to take the income and assets of a spouse or parents into account when determining the eligibility of a waiver applicant. Under this provision, virtually any disabled child can become eligible for Medicaid waiver services, regardless of the financial status of the child's household. Waivers have become a popular financing mechanism for States to use to develop alternative home care programs for disabled children with severe medical conditions.

Despite these eligibility options offered in conjunction with Medicaid home and community-based care waivers, other conditions are attached to using waivers to extend Medicaid eligibility to disabled persons. First, to be eligible for the waiver, a person must meet level-of-care

**Table 4**  
**Impact of option 209(b) and separate Medicaid application requirement on Medicaid enrollment of disabled SSI/SSP recipients, by State: 1988**

State	SSI/SSP recipients <sup>1</sup>	Disabled Medicaid cash recipients <sup>2</sup>	Ratio of SSI/SSP to Medicaid cash
United States	2,925,909	2,669,554	0.91
<b>1634 States<sup>3</sup></b>			
Average ratio 0.99			
Alabama	75,157	72,900	0.97
Arkansas	42,287	44,229	1.05
California	454,878	494,580	1.09
Colorado	24,517	17,988	0.73
Delaware	5,846	5,156	0.88
District of Columbia	12,566	12,829	1.02
Florida	117,941	122,877	1.04
Georgia	97,609	103,637	1.06
Iowa	21,408	23,194	1.08
Kentucky	72,471	75,869	1.05
Louisiana	83,046	65,975	0.79
Maine	15,237	15,239	1.00
Maryland	40,585	36,648	0.90
Massachusetts	61,627	73,468	1.19
Michigan	101,618	110,240	1.08
Mississippi	65,536	64,942	0.99
Montana	6,793	6,438	0.95
New Jersey	67,174	69,574	1.04
New Mexico	18,599	18,518	1.00
New York	262,398	232,799	0.89
Pennsylvania	129,309	126,737	0.98
Rhode Island	11,306	13,819	1.22
South Carolina	55,351	55,813	1.01
South Dakota	6,216	6,338	1.02
Tennessee	86,511	88,248	1.02
Texas	149,268	120,098	0.80
Vermont	6,793	5,312	0.78
Washington	41,944	45,108	1.08
West Virginia	34,132	28,204	0.83
Wisconsin	56,702	70,692	1.25
Wyoming	2,020	1,656	0.82
<b>209(b) States<sup>4</sup></b>			
Average ratio 0.63			
Connecticut	32,803	12,710	0.39
Hawaii	7,238	7,087	0.98
Illinois	147,820	113,307	0.77
Indiana	42,267	21,320	0.50
Minnesota	27,901	18,437	0.66
Missouri	56,412	9,419	0.17
Nebraska	11,392	8,202	0.72
New Hampshire	4,822	3,067	0.64
North Carolina	90,135	40,339	0.45
North Dakota	4,777	3,424	0.72
Ohio	114,823	89,881	0.78
Oklahoma	37,945	24,723	0.65
Virginia	58,148	45,738	0.79
<b>State determination<sup>5</sup></b>			
Average ratio 0.75			
Alaska	2,857	3,011	1.05
Idaho	7,394	1,954	0.26
Kansas	17,044	14,530	0.85
Nevada	5,015	5,344	1.07
Oregon	21,962	11,905	0.54
Utah	8,309	6,031	0.73

<sup>1</sup>SSI/SSP recipient data are as of July 1, 1988.

<sup>2</sup>Disabled Medicaid cash recipient data are for Federal fiscal year 1988.

<sup>3</sup>The 1634 States provide automatic Medicaid eligibility to SSI/SSP recipients without the need for a separate Medicaid application.

<sup>4</sup>Section 209(b) of the Social Security Amendments of 1972 provided States the option of using more restrictive criteria for Medicaid eligibility than the requirements for SSI. These States use an income spend-down provision in determining Medicaid eligibility for the disabled because of their 209(b) status.

<sup>5</sup>The State determination States extend Medicaid eligibility to all SSI/SSP recipients, but require a separate application.

NOTE: SSI/SSP is Supplemental Security Income/State supplementation payments.

SOURCES: SSI/SSP data: Social Security Administration: *Social Security Bulletin*. Vol. 51, No. 10. Pub. No. 13-11700. Washington, U.S. Government Printing Office, Oct. 1988; (Health Care Financing Administration, 1988).

criteria for placement in a Medicaid-certified institution. For persons with AIDS, for example, the episodic nature of opportunistic infections does not fit well with waiver eligibility requirements that require applicants to meet institutional level-of-care criteria.

Second, the number of persons States may serve in their waiver programs each year is limited in their approved waiver applications. Thus, even among disabled persons with severe functional impairments, access to home and community-based services through Medicaid waiver programs is limited by the number of waiver "slots" available.

## Program administration

Another problem area that affects access to Medicaid for the low-income disabled is that the program is often administered by States in such a way that it is completely confusing and discouraging to applicants, particularly those who have to spend down. Application forms are often unnecessarily lengthy and poorly written. Procedures are nebulous. The level of public information, both for applicants and providers, leaves much to be desired. It seems feasible that differences in the proportion of medically needy recipients relative to overall Medicaid enrollment across State Medicaid programs can be explained in part by administrative differences.

When applicants are very sick, negotiating the complicated administrative requirements may be troubling and difficult. Similarly, providers may be uneducated about the inner workings of Medicaid eligibility. As a result, they may refuse to extend "credit" to allow persons to satisfy spend-down liability requirements, thereby denying access to care.

The length of the disability determination process is another problem area. For example, States reported that the most difficult eligibility problem in administering Medicaid waivers for persons with AIDS was getting through the social security disability determination process. Medicaid eligibility cannot begin until a person has been determined disabled. Although presumptive disability can be granted based upon a confirmed diagnosis of AIDS, States still reported that completing the required medical documentation to make such a determination was problematic and often led to delays in the initiation of services. Also, the presumptive eligibility period lasts for only 90 days, and requisite documentation to make a final disability determination must be accumulated and reviewed during that 90-day period. Some States reported that delays in the disability determination process have resulting in the 90-day presumptive eligibility period expiring, with Medicaid eligibility interrupted until the final determination was made.

The overall paperwork burden for the disabled applying for Medicaid waiver programs was cited as a problem area. To apply for Medicaid waiver services, many persons must apply to the local social security office for SSI/SSP cash assistance, to the State welfare office for Medicaid eligibility, and to the Medicaid waiver program itself. These multiple application procedures create an immense amount of paperwork for waiver applicants to

manage, particularly when they are also dealing with the problems of their disease. All State waiver programs use case managers to help waiver applicants negotiate the paper maze associated with program eligibility requirements, but States acknowledged that some applications inevitably fall through the cracks because of problems in paper flow and documentation.

## Disabled children

Prior to enactment of the SSI program in 1974, disabled children generally were not eligible for Medicaid coverage at all, unless they lived in AFDC households. The extension of SSI and Medicaid benefits to disabled children which occurred in 1974 was, therefore, a major leap forward in providing medical assistance to families with a severely disabled child. By 1988, about 280,000 SSI/SSP disabled children were receiving health insurance coverage through Medicaid. Data are not available on the number of disabled children receiving Medicaid benefits through State medically needy programs, although the number is believed to be small.<sup>7</sup>

Recent Medicaid expansions for poor children in general may also have had some impact on improving access for disabled children. For example, by April 1, 1990, States were required to phase in coverage of all children under the age of 6 years who live in families with incomes below 133 percent of the poverty level. Also, at their option, States may now extend coverage to children under age 1 in families with incomes up to 185 percent of the poverty level.

However, all of these eligibility coverage provisions generally require States to take the income and resources of parents into account in determining the eligibility of a disabled child for Medicaid. The process by which this determination is made is called "deeming." Deeming of parental income and resources is a complicated calculation. In general terms, parents are allowed the normal SSI disregards for earned and unearned income and then their remaining income is compared with the SSI/SSP income eligibility level for a couple (or an adjusted level if other minor children are in the family). Any remaining income is then "deemed" to be available to the disabled child. The deemed income for the child is compared with the SSI/SSP level or (where available) the medically needy level to see if the disabled child would qualify for SSI/SSP and/or Medicaid.

The problem is that many families incurring catastrophic health care costs for their disabled child have difficulty satisfying these financial eligibility requirements. For example, about 255,000 families are reported to be spending more than 20 percent of their total annual income on health care costs for their disabled child (McManus, 1988). However, for many middle-income families, this level of expenditure still would not reduce the income deemed to be available to the disabled child to the SSI/SSP or medically needy levels in most

<sup>7</sup>The Supreme Court ruled in March 1990 that the Social Security Administration had been employing a harsher disability test for children than was intended by Congress. As a result, many additional children are expected to qualify for SSI/SSP and/or Medicaid under new standards.

States. Clearly, these families could not qualify in a State without a medically needy program. Even with medically needy coverage, the spend-down provisions are such that a much greater proportion of income would have to be incurred for medical care to achieve Medicaid eligibility.

For many years, the only situation in which deeming of parental income was waived for Medicaid eligibility purposes occurred when a disabled child became institutionalized. Under SSI and Medicaid rules, parental income and resources are not considered to be available to an institutionalized child. This policy was clearly problematic because it forced many parents to institutionalize their disabled children in order to obtain Medicaid coverage. As a result, beginning in 1982, States were given the option to waive the deeming of parental income and resources when a disabled child meets the following criteria:

- The child would be eligible for Medicaid if institutionalized.
- The child meets institutional level-of-care criteria.
- Noninstitutional care is determined appropriate.
- The estimated cost to Medicaid of noninstitutional care is less than the estimated cost of institutional care.

Thus, although disabled children in families of all income levels are potentially eligible for Medicaid under this provision (because parental income and resources are not deemed), the provision is limited to children with extremely severe disabilities. As of March 1988, 22 States had elected this Medicaid coverage option (Congressional Research Service, 1988). Many States have also used Medicaid home and community-based care waiver programs to provide both regular Medicaid coverage and supplemental community-based services to disabled children, regardless of parents' income or resources. However, the waiver restrictions discussed earlier limit the number of children who can be served under waiver programs.

## Problems with access to Medicare

In contrast to Medicaid, the eligibility policies for Medicare are fairly straightforward and they are uniform nationwide. Thus, it is easier to analyze the access problems with current Medicare policies for the disabled.

### Waiting period for Medicare coverage

The 24-month waiting period for Medicare's eligibility (plus the 5 months after disability onset before eligibility can commence for SSDI) is a major access issue for the low-income disabled.<sup>8</sup> There have been repeated calls for shortening this waiting period. During the 24-month waiting period, many disabled persons do not have access to employer-related insurance or cannot afford the premiums if group insurance is available.

<sup>8</sup>At one time, the 24-month waiting period requirement was 24 consecutive months of SSDI benefits. However, the current requirement is 24 months without any stipulation that the months of SSDI benefits be consecutive.

Although the aged were covered by Medicare from its beginning in 1967, the disabled were not extended coverage until 1973. Unlike the aged, the coverage for the disabled included the 24-month waiting period provision. Committee reports indicate that the 24-month waiting period for the disabled was enacted to control Medicare costs. Congress did not want Medicare to displace private group insurance coverage believed to be available for many of the disabled. Also, there was concern that Medicare be available only to those disabled whose disabilities proved to be severe and long-lasting (Bye and Riley, 1989). To date, this waiting period has been waived for only one group of disabled beneficiaries—those with end stage renal disease.

Much has been written about the inequity of the waiting period provision, particularly since the AIDS epidemic. The short life expectancy for persons with AIDS has meant that almost all public financing of AIDS health care has been through the Medicaid program, not Medicare. Further, in order to become eligible for Medicaid, many SSDI beneficiaries with AIDS have had to impoverish themselves. As a result, when it comes to health coverage, many disabled persons who have participated in the work force long enough to be eligible for SSDI benefits are no better off than disabled persons who have never worked. Although much of the attention has focused on the problem of the Medicare waiting period for AIDS beneficiaries, the waiting period problem can affect persons with all types of disabilities. For example, many persons with cancer die before the 24-month waiting period is completed.

The number of SSDI beneficiaries who go without health insurance coverage is significant. Bye and Riley (1989) report that 27 percent of SSDI beneficiaries in months 18-24 of the 24-month waiting period had no insurance coverage, but 57 percent had some form of private health insurance or Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) or military coverage. An additional 14 percent reported Medicaid coverage.

Bye and Riley estimate that eliminating the 24-month waiting period would increase Medicare costs for disabled beneficiaries by 45 percent. Thus, expenditures for the disabled would rise from \$8.1 billion to \$11.7 billion (in 1987 dollars). About 13 percent of SSDI beneficiaries die within the 2 years before Medicare eligibility commences. Previous research has shown that, on average, persons in the last year of life experience much higher than average medical costs. About one-third of the cost increase would be attributable to persons who died during the 24-month period. Bye and Riley estimate costs increases of 20 percent if the waiting period were reduced to 12 months. However, it should be noted that their estimates for both alternatives (no waiting period at all or a 1-year period) assume Medicare would bear the full costs of care, without any participation by private plans. Thus, the cost could be considerably less if employers were required to continue to offer extended health insurance coverage.

## Employer group rate premiums

The Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985 (Public Law 99-272) required that employers provide employees the option to purchase health insurance coverage for 18 months (after leaving their jobs) if the employees paid the full group rate premium. Employers were allowed to add 2 percent to the premium charge in order to cover administrative costs. Thus, the monthly charge was 102 percent of the full premium. This statute considerably improved the access for disabled workers to private health insurance, but it did not go far enough. The 18 months of coverage fell considerably short of the 29 months until Medicare commences for disabled workers. Accordingly, the Omnibus Budget Reconciliation Act (OBRA) of 1989 (Public Law 101-239) added a disability extension provision which required employers to extend coverage for SSDI beneficiaries during months 19-29 prior to Medicare. Employers were authorized to charge 150 percent of the premium cost for coverage during this 11-month period.

For disabled workers with higher incomes, these provisions are important in assuring continued access to health care coverage. However, many SSDI beneficiaries cannot afford the expense. Group premiums for private health insurance averaged about \$2,600 annually per eligible employee in 1989, or \$217 a month, according to the Foster and Higgins benefit consulting firm (*Medicine and Health*, 1990). If the employer charged 150 percent of the premium cost as allowed, continuing coverage in months 19-29 would be \$325 a month.

In 1989, the average monthly SSDI benefit award for "new" disabled workers was about \$540 a month, just \$2 over the poverty level for that year (Social Security Administration, 1990a). On average, then, a new disabled worker would be paying 41 percent of his or her monthly SSDI award for continued employer health coverage in months 6-18 ( $\$217 \times 1.02 \div \$540 = .409$ ) and 60 percent in months 19-29 ( $\$217 \times 1.5 \div \$540 = .603$ ). It would be an even greater proportion of income for the disabled whose SSDI income was less. Clearly, most low-income disabled will not be able to take advantage of the COBRA 1985 and OBRA 1989 coverage extensions because the premiums are too high.

Recently, some State Medicaid programs have moved to assist the low-income disabled in buying into continued employer coverage. In addition, the cost of health insurance premiums can be used to meet spend-down liabilities for Medicaid. However, these options are not available in all States.

## Alternatives for improving access

To improve the access of low-income disabled persons to Medicaid and Medicare, a series of options for restructuring program eligibility requirements are presented. Low-income disabled workers without access to health care are the focus of many of the proposed reforms. In the current system of public health care financing, arguably the disabled person who is the worst off with regard to health care coverage is the SSDI

beneficiary who is ineligible for Medicaid during the 24-month waiting period for Medicare.

Denying or restricting access to health care financing for disabled workers, while providing it at no cost to the disabled who have not worked, seems to be the greatest inequity in current eligibility provisions for Medicaid and Medicare. Work is one of the major values in our income maintenance and health care financing systems. Accordingly, the reforms have as their objective opening Medicaid and Medicare to all the low-income disabled and restoring some reward for having worked.

The proposed changes were not designed to fit together into one package. Sometimes more than one option is presented to remedy a particular access problem. In addition, Congress and the Administration could enact some of the reform options without electing others.

## Medicaid reforms

### Mandatory medically needy programs

An obvious improvement to Medicaid access for the disabled (and other groups as well) would be to mandate medically needy coverage nationwide. Otherwise, in many States the low-income disabled who do not qualify for SSI/SSP have no means of accessing Medicaid, except by institutionalization. This access problem is particularly troubling for SSDI beneficiaries who are not yet eligible for Medicare. Because their SSDI benefits are too high, they are ineligible for SSI/SSP and thus Medicaid in many States. It seems particularly inequitable to make Medicaid inaccessible to the low-income disabled who have worked and paid into the social security system. The public health care system should not make access to health care more difficult for persons who have worked than persons who have not worked.

### Minimum medically needy income levels

Currently, State medically needy income levels can be no higher than 133 percent of the AFDC payment standard. As a result, 18 States in 1989 had medically needy levels that were lower than their SSI/SSP levels for the disabled. In these States, persons with SSDI income can be worse off than persons eligible for SSI/SSP. This happens because medically needy persons have to spend down to a lower income level. A more equitable approach would be to set the minimum medically needy level for all groups in each State at the SSI/SSP level. For States that supplement the Federal SSI amount, the medically needy minimum would be set at the State supplement level.

In addition, consideration should be given to moving toward a minimum medically needy standard equal to the poverty level nationwide. Currently, the Federal SSI level is about 68 percent of the poverty level. With this as the medically needy minimum as well, States could move to 85 percent of the poverty level in 2 years and 100 percent in 3 years. Because the MCCA 1988 mandated that State Medicaid programs cover the Medicare cost-sharing expenses for the disabled (and aged) up to 100 percent of the poverty level by 1992, there is already a precedent in

this direction. Again, this provision would be especially helpful in bridging the health care access problem for SSDI beneficiaries in their 24-month waiting period for Medicare. Under this reform, States would continue to have the option to set their medically needy levels above the poverty level if they chose.

### **Elimination of restrictions to Medicaid**

The 209(b) option and the provision allowing States to require separate Medicaid application were implemented in 1974 to smooth the transition to the SSI program for States. It no longer seems appropriate to allow States to impose more restrictive eligibility requirements for Medicaid on SSI/SSP recipients. It also seems unnecessary to impose on the low-income disabled the burden of two separate applications if the eligibility requirements for SSI/SSP and Medicaid are identical. As a byproduct, this reform would reduce administrative costs because it would eliminate dual eligibility determination systems in many States.

### **Income-related buy-in**

The 100 percent marginal tax rate imposed by the current spend-down provisions provide no "return" to the low-income disabled for having higher income as a result of having worked in the past. Every dollar of SSDI benefits above a State's medically needy level must be offset by medical expenses in order to obtain Medicaid eligibility. Thus, a disabled worker does not realize any benefit from having a higher SSDI award. For example, in a State with a monthly medically needy level of \$382 for one person (the median State), the disabled worker with SSDI benefits of \$700 a month has to spend down \$318 monthly, and the disabled worker with SSDI benefits of \$400 a month has to spend down \$18 monthly. Because of the 100 percent marginal tax rate, there is no reward to the disabled worker with the higher SSDI award.

Spend-down policies also deter many families with disabled children from satisfying Medicaid financial eligibility requirements. For these families, there is only a limited incentive to increase earnings. One-half of every additional dollar in earnings is deemed to be available to the disabled child and would increase the size of the spend-down liability.

Finally, as mentioned earlier, the spend-down amount is often one-third to one-half of income, even for the disabled with incomes below the poverty level. Access to Medicaid should not require this proportion of income.

A much more reasonable system would replace the spend-down requirements with an income-related buy-in premium. Other reports have suggested from 2 percent to 10 percent of income as a reasonable limit. Regardless of the percent chosen, there would be better incentives to increase income and some return for having the higher SSDI benefits.

Another criticism of current spend-down policies has been the administrative complexity involved in implementation. Using a buy-in premium paid directly to the State Medicaid programs would eliminate many of the

administrative problems. First, applicants would no longer have to track their medical expenses and report them to local Medicaid offices in order to successfully spend down. Second, State Medicaid programs would no longer have to worry about the definition of allowable medical expenses to count as part of the spend-down liability. Third, the disabled would no longer be dependent on the willingness of providers to extend credit before they could spend down to achieve Medicaid eligibility. Finally, this approach would eliminate the controversy over the accounting period to be used because the buy-in could be set at a monthly amount.

### **Public information program**

If the reforms outlined above were implemented, State administration of Medicaid should improve considerably because of program simplification and uniformity. However, this would make a significant difference in the health care coverage of persons with disabilities only if they learn about it. Historically, the general public and health care providers have been very poorly informed about Medicaid eligibility requirements. This problem has been exacerbated because these requirements vary among States and are so complicated.

Recent demonstration projects to improve SSI/SSP participation rates have shown that outreach and improved public information can make a significant difference. At three demonstration sites where multiple outreach approaches were implemented, SSI/SSP applications increased by 97 percent, and 58 percent more awards were made during a year's period, compared with the previous 3 years (National Health Policy Forum, 1989). It seems reasonable that such outreach activities could be extended to the Medicaid program. The health care provider community should be included in any outreach efforts because they can be instrumental in assisting persons with disabilities to apply for coverage.

It is not obvious who the principal players should be in any new outreach effort. Because the Social Security Administration has direct contact with SSDI beneficiaries, there is some logic to using its local office network and experience with outreach for SSI/SSP. Congress may also want to consider mandating that State Medicaid programs begin outreach efforts.

## **Medicare reforms**

### **Buy-in to employer coverage**

As mentioned earlier, the average monthly SSDI benefit in 1989 was about \$540 for new beneficiaries. On average, a disabled worker with this award would have to spend 41 percent of the SSDI benefit in months 6-18 to buy into employer coverage and 60 percent in months 19-29. Workers are also responsible for coinsurance and deductibles in most group plans. This results in an exorbitant proportion of the SSDI award to spend for health care coverage.

Two options are available to address this problem. First, State Medicaid programs could be mandated to assist disabled workers with income below the Federal

poverty level in paying the premiums for continued employer coverage. This program could be parallel to the Medicaid cost-sharing of Medicare expenses for the low-income disabled already eligible for Medicare. It could be limited to only the premiums and cost-sharing for services covered by the employer insurance plan, or participation could entitle applicants to the full range of Medicaid benefits.

A second option would be to establish a supplementary program under Medicare to assist the low-income disabled in purchasing continued employer coverage. Thus, as opposed to shortening the Medicare waiting period, Medicare could instead assume a limited role in financing health care for the low-income disabled during the 2-year waiting period. The appeal of either option is the reliance on continued private sector involvement.

With either option, this reform would help only the disabled worker who has access to continued employer coverage. No doubt many new SSDI beneficiaries worked for employers who did not provide health care coverage. These disabled workers have no access to employer group plans.

### Reduced waiting period requirements

Many groups have called for shortening the 24-month waiting period for Medicare eligibility for the disabled under SSDI. The problem of access to health care coverage during this period is particularly acute for disabled workers without access to continued employer coverage. As mentioned earlier, however, the expense of such a move is staggering. Bye and Riley (1989) have estimated that Medicare expenditures for the disabled would increase by 45 percent if the 24-month waiting period were eliminated. However, this estimate does not take into account any continued employer coverage as mandated by COBRA 1985 and OBRA 1989. Whatever changes are taken to redefine the waiting period requirements, it seems unwise to displace the responsibility of employers to provide access to private group coverage.

One option would be to amend the waiting period requirements for only a subgroup of the SSDI disabled. In particular, the waiting period requirements could be waived for SSDI beneficiaries whose health care problems are likely to result in death within 2 years. Again, this expansion should not displace the current responsibility of employers under COBRA 1985 and OBRA 1989. Instead, Medicare could assist any low-income SSDI beneficiary falling into this group in buying into employer coverage that is available. SSDI beneficiaries with sufficient income to purchase the extended employer coverage would be expected to do so. For SSDI beneficiaries without access to employer coverage, Medicare coverage could commence immediately upon SSDI award. Some steps would be required to ensure that the service packages and cost sharing were equivalent, whether coverage was provided under the employer plan or Medicare.

This option would seem to address the reasons originally cited for having a 2-year waiting period for the disabled. As mentioned earlier, Committee reports indicate that Congress did not want Medicare to displace private group insurance coverage. It also did not want to provide Medicare to the disabled whose disabilities did not prove to be severe and long-lasting. No doubt it would be a challenge to develop screening criteria for determining which disabilities would meet the "likely to result in death within 2 years" definition. However, there are some disabling conditions, such as AIDS, which obviously fall into this category.

Additional options would be to reduce the Medicare waiting period for all disabled workers to 12 or 18 months, or eliminate it altogether. Medicare could opt to buy into continued employer coverage for disabled workers who qualify under any of these options. However, it would be important to make sure the coverage is equitable, whether it is provided by private employer insurance or Medicare. Equity considerations would involve both the service package and the cost-sharing requirements (including the premium costs for extended employer coverage). This would obviously be the most expensive alternative.

### References

- Bye, B., and Riley, G.: Eliminating the Medicare waiting period for social security disabled-worker beneficiaries. *Social Security Bulletin*. Vol. 52, No. 5. Pub. No. 13-11700. Office of Research and Statistics, Social Security Administration. Washington. U.S. Government Printing Office, May 1989.
- Centers for Disease Control, Center for Infectious Diseases, Division of HIV/Aids. *HIV/Aids Surveillance Report*, Atlanta, Ga., Apr. 1990:1-18.
- Committee on Ways and Means: *Background Material and Data on Programs within the Jurisdiction of the Committee on Ways and Means*, 1989 Edition. U.S. House of Representatives. Washington, Mar. 1989.
- Congressional Research Service: *Medicaid Source Book: Background Data and Analysis*. Washington. U.S. Government Printing Office, Nov. 1988.
- Griss, B.: Measuring the health insurance needs of persons with disabilities and persons with chronic illness. *Access to Health Care* 1 (1 and 2). Washington. World Institute on Disability, Sept. 1988.
- Hall, L.: *Medicaid Eligibility: Selected Program Characteristics*. National Governors' Association. Washington, D.C. Feb. 5, 1990.
- Health Care Financing Administration, Bureau of Data Management and Strategy: *Data from HCFA Form 2082*, 1988. *Medicine and Health*. Vol. 44, No. 5. Washington. Feb. 5, 1990.
- McManus, M.: *Workshop on Children's Catastrophic Health Care: National Forum on the Future of Children and Their Families*. Summary of workshop sponsored by the Institutes of Medicine. Washington. McManus Health Policy, Inc. Aug. 5, 1988.
- National Health Policy Forum: *Supplemental Security Income: Expanding the Reach of a Program*. Issue Brief No. 518. George Washington University, Washington, D.C. Apr. 1989.

Neuschler, E.: *Medicaid Eligibility for the Elderly in Need of Long-Term Care*. Report for Congress. Contract No. 86-26. Prepared for Congressional Research Service. Washington, D.C. Sept. 1987.

*Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic*. Submitted to the President of the United States. Washington. June 24, 1988.

Rymer, M., and Adler, G.: Short-term Evaluation of Medicaid: Selected Issues, HCFA Working Paper 84-9. Health Care Financing Administration. Baltimore, Md. July 1984.

Social Security Administration: *Social Security Bulletin, Annual Statistical Supplement, 1988*. Pub. No. 13-11700. Office of Research and Statistics, Social Security Administration. Washington. U.S. Government Printing Office, Dec. 1988.

Social Security Administration: *Characteristics of State Assistance Programs for SSI Recipients: January 1989*. SSA Pub. No. 17-002. Office of Supplemental Security Income, Social Security Administration. Baltimore. U.S. Government Printing Office, Apr. 1989.

Social Security Administration: *Social Security Bulletin*. Vol. 53, No. 1. Pub. No. 13-11700. Office of Research and Statistics, Social Security Administration. Washington. U.S. Government Printing Office, Jan. 1990a.

Social Security Administration: *Social Security Bulletin*. Vol. 53, No. 6. Pub. No. 13-11700. Office of Research and Statistics, Social Security Administration. Washington. U.S. Government Printing Office, June 1990b.

U.S. Bureau of the Census, Current Population Reports, Series P-70, No. 8, *Disability, Functional Limitations, and Health Insurance Coverage: 1984/85*, U.S. Government Printing Office, Washington, D.C. Dec. 1986.