

**Chapter 11**

**Medicaid and Medicare  
as Sources of Funding  
for Long-Term Care of  
Persons With Dementia**

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# Medicaid and Medicare as Sources of Funding for Long-Term Care of Persons With Dementia \*

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When the legislation that created the Medicare and Medicaid programs was being considered by Congress in 1965, it was the object of wildly differing predictions. Some legislators predicted that the bill, if enacted, would “destroy private initiative for our aged to protect themselves with insurance against the costs of illness,”\* and characterized the proposed health insurance coverage as “the ‘smack of socialism’ implicit in a coverage-for-all program without avail.” Others described the bill as the ‘(greatest advance in social legislation ever presented to the Congress of the United States,’<sup>2</sup> and predicted that through the Medicare provisions “public assistance would be relieved of much of its present burden.”

The truth has fallen somewhere between. The Medicare and Medicaid programs today represent an important health insurance resource for millions of the aged and disabled, including persons with dementia.

Those who qualify for Medicare have at least some assurance that a significant portion of their hospital and physician bills will be reimbursed. At the same time, however, many services are not covered under Medicare and even covered services are subject to coinsurance, deductibles, and fee limits that increase the financial burden on program beneficiaries.

The Medicaid program has different benefits and disadvantages. Millions of low-income persons eligible under Medicaid, including many with dementia, can qualify for reimbursement for medi-

cal bills incurred for covered services. Nursing home care for persons with dementia, for example, is largely dependent on the availability of Medicaid reimbursement. But categorical and financial eligibility requirements exclude millions of other indigent persons, and those who do qualify often discover that needed services are not covered or that health care providers will not accept Medicaid reimbursement.

Thus, while the two programs are critically important for many persons with dementia, numerous constraints limit their impact. Some of these constraints are inherent in the legislative structure of the programs. Others are products of interpretations by the Federal and State agencies charged with their administration. Additional factors, especially regarding Medicaid, represent conscious political choices by legislators and administrative officials between various populations seeking government assistance from limited budgets.

Although Medicaid expenditures constitute a relatively small portion of total State budgets, they are perceived as consuming a significant portion of State discretionary funds (10). That perception was heightened during the 1970s as nearly every State experienced at least one period during which Medicaid expenditures rose far beyond budget allocations. These increases led to cutbacks in eligibility, scope of services, and reimbursement, and they resulted in greater legislative watchfulness of Medicaid administration.

That increased scrutiny has resulted, in many cases, in a “status quo” approach to administration. So long as no significant changes are proposed, State officials run little risk of being called to account before legislative budget and appropriations committees. Short-term fiscal planning becomes the rule, rather than the exception. As a result, only a few States have been willing to in-

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<sup>2</sup>Individual views of Senators Harry F. Byrd, John J. Williams, Wallace F. Bennett, Carl T. Curtis, and Thruston B. Morton opposing enactment of the Medicare provisions of H.R. 6675 as amended by the Senate Finance Committee, 1 *U.S. Code Cong. & Admin. News* 2214-2215 (89th Cong., 1st sess., 1965).

<sup>3</sup>Supplemental views of Senators Abe Ribicoff and Vance Hartke to H.R. 6675 as reported by the Senate Finance Committee, 1 *U.S. Code Cong. & Admin. News* 2215-2216 (89th Cong., 1st sess., 1965).

novate in their Medicaid programs over the past few years.

The reluctance to experiment is often reinforced by the competition between various groups for limited funding. The two most significant of these groups are advocates for maternal and child health programs and those for programs for the elderly. Growing concern over infant mortality and morbidity rates has led many States to consider efforts to improve access to prenatal care, labor and delivery services, and neonatal care. At the same time, the increased numbers of elderly persons, especially those over the age of 80, have resulted in pressures for increased funding for long-term care services in the community and in nursing homes. Most States have struggled in attempting to balance these two significant but competing priorities.

Even within the specialized delivery system that serves primarily elderly persons, there is often competition for limited funds. For example, persons with dementia are not the only elderly who need long-term care, although they are perhaps the largest group. The mentally alert frail elderly have equally valid needs for services. Thus, specialized residential care units for persons with de-

mentia must often vie for funds with adult day care programs for mentally alert frail elderly persons.

No attempt is made here to resolve these competing priorities. Rather, this chapter reviews the impact of Federal programs on funding for care and services for persons with dementia. It is based on a review of the existing Federal and State laws, regulations, and policies. In addition, during the fall of 1985 and winter of 1986, interviews were conducted with State administrators, health care providers, program beneficiaries, advocates, and family caregivers in 15 States. These interviews helped highlight the special problems created for persons with dementia due to differences between the theory of Federal and State policies and their actual implementation.

The review also highlighted some of the aspects of these programs that adversely affect persons with dementia. These aspects suggest changes in the programs that could be implemented to improve services for this population. The chapter then concludes by identifying major issues that should be resolved before reform is undertaken. These changes may then be implemented within an overall resolution of program priorities.

## EVALUATING THE PROGRAMS

The Medicare and Medicaid programs are largely "disease-neutral" (see figures 11-1 and 11-2). Applicants need not suffer from a particular debilitating illness in order to qualify for assistance. (The major exception to this rule is the special eligibility program under Medicare for persons suffering from end-stage renal disease (42 U.S.C. 1395c(3)). Services provided under the programs are also generic in nature and are not directed at particular diseases or conditions. (The Medicaid regulations go even further by prohibiting limitations on the "amount, duration, or scope of a required service . . . solely because of the diagnosis, type of illness, or condition" (42 CFR 440.230(c)).

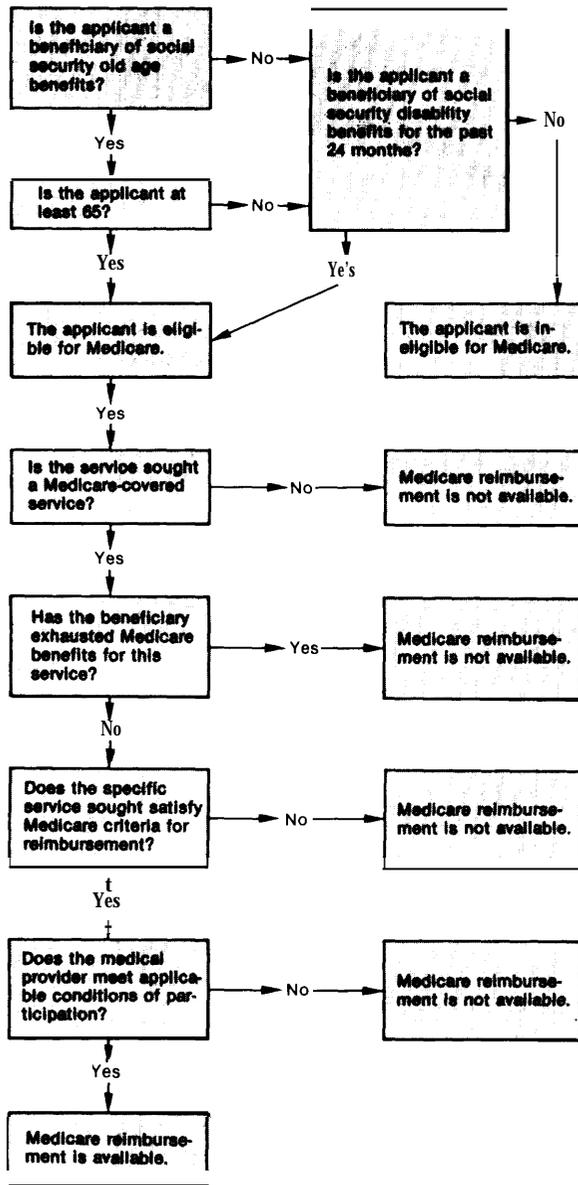
Despite that underlying philosophy, apparently neutral provisions may have a special impact on persons suffering from particular illnesses or conditions. For example, a 14-day limit on inpatient

hospital services may be more than adequate for a pregnant woman who will experience a low-risk delivery. It is far less adequate for a multihandicapped elderly recipient suffering from cancer.

Although the Medicare program now reimburses hospitals on the basis of diagnosis-related groups, the basic scope of services is still disease-neutral. Moreover, under Medicaid, States impose limits on the amount, duration, and scope of services that do not vary based on the diagnosis, type of illness, or condition. As a result, even if a State reimburses hospitals on the basis of diagnosis-related groups, a restrictive limit on the scope of inpatient hospital service may discourage access.

In identifying the factors that affect the role Medicare and Medicaid play in financing long-term care for persons with dementia, it is therefore

Figure 11-1.—Medicare in a Nutshell



important to look beyond the words of a requirement and examine the actual impact on program beneficiaries. Although the term dementia generally refers to Alzheimer’s disease and to various related disorders, certain problems are more

applicable to a single disorder. For example, the current inability to positively diagnose Alzheimer’s disease creates special eligibility difficulties that do not arise for persons with brain tumors. In reviewing program impact, four factors that can influence the availability of financing must be considered—eligibility, scope of services, reimbursement practices, and administrative procedures.

For example, a restrictive eligibility policy may prevent an individual from ever qualifying for benefits. Similarly, even if eligible, an individual may be denied needed care because of the restrictive scope of services covered. Moreover, even if someone is eligible for reimbursement for a covered service, restrictive reimbursement practices may discourage providers from rendering the needed service. Finally, restrictive administrative procedures may inhibit the ability of eligible beneficiaries to receive covered services from participating providers.

By contrast, a State with liberal income and resource standards will permit more individuals to qualify for assistance. A broad scope of services that includes both institutional and noninstitutional care will encourage the delivery of needed care and services in the least restrictive environment appropriate to each patient’s needs. Similarly, reimbursement practices may be modified to encourage the growth of specific classes of providers and thereby improve access to appropriate, high-quality, cost-effective services. Finally, smooth and timely processing of providers’ requests for prior authorization of services can help encourage provider participation and thereby also improve access to services. All these incremental changes will also increase costs of the programs, however.

The factors that affect the current availability of financing for long-term care under Medicare and Medicaid are reviewed in turn in this chapter. Some will have a unique impact on beneficiaries with dementia. Others may adversely affect those with dementia along with other elderly and disabled persons.



## ELIGIBILITY

**Medicare**

Individuals can establish eligibility for Medicare in several ways. The vast majority of beneficiaries qualify at age 65 based on their eligibility for social security retirement benefits. (Several special eligibility provisions for those age 65 or over extend the definition of “covered employment” to include, for example, those who would be eligible if certain Federal employment were considered to be covered employment (42 U.S.C. 1395c(1)). The process of establishing eligibility for applicants age 65 or over generally presents no major difficulties.

By contrast, the major basis of Medicare eligibility for persons with dementia under the age of 65 is fraught with complexities. Those under 65 can establish eligibility if they have been entitled to social security benefits or to railroad retirement benefits because of disability for at least 24 months (42 U.S.C. 1395c(2)), Special problems arise for persons with dementia in establishing eligibility for these disability benefits.

## Definition of Disability

Problems arise with the very definition of disability under the social security and railroad retirement programs: Disability is specified as an “inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment that can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months” (42 U.S.C. 416(i)(1)).

The first problem arises from the language “medically determinable.” Although Alzheimer’s disease is an organic brain disorder, it cannot be positively diagnosed during a person’s lifetime using current techniques. Until the individual’s death, when an autopsy can verify the existence of Alzheimer’s disease, diagnosis depends on the exclusion of all other “diagnosable” causes for the symptoms. These problems of diagnosis exist even though recent studies indicate that approximately 90 percent of all diagnoses of Alzheimer’s disease are corroborated through autopsy (see ch. 3).

Apparently the inability to point to a single dispositive medical test is part of the reason for the problem.

The present disability definition therefore makes it quite difficult for someone with Alzheimer’s disease to establish eligibility. The burden of proof is on the applicant to demonstrate the existence of a disability by a preponderance of evidence. Since the diagnosis of this disease, especially in its early stages, is a matter of educated conjecture, many applicants will be initially denied assistance since they cannot meet this burden (14).

## Listing of Impairments

The simplest way of establishing disability is to demonstrate that an applicant’s condition is described in the “Listing of Impairments” (20 CFR 404P App 1). The listing describes impairments that are severe enough to preclude someone from engaging in any substantial gainful activity (the “severity” requirement) and that are expected to result in death or to last for a continuous period of not less than 12 months (the “duration” requirement).

Unfortunately, Alzheimer’s disease and other forms of dementia are not explicitly reflected in the listing as either neurological or mental disorders. In 1985, the Department of Health and Human Services (DHHS) issued a revised listing of impairments to address, at least in part, the criticism by Congress and others of the treatment of mentally disabled applicants. But DHHS again explicitly rejected the inclusion of specific criteria for the evaluation of Alzheimer’s disease and related disorders (50 FR 35038).

Since dementia is not expressly listed as an impairment, the simplest route for establishing eligibility is therefore barred for an applicant with dementia. The person must then demonstrate that all of the elements of the definition of disability are satisfied. The difficulty of doing that is compounded by the varying levels of functional disability demonstrated by persons with dementia at different times. A single brief interview with a consultative medical examiner may not elicit

even the deficits in affect and behavior that are all too apparent to family members and co-workers. That failure contributes to the high likelihood that someone with a dementing disorder will be denied benefits on initial application (14).

### Mental Impairment

The problems encountered by mentally disabled beneficiaries during the Social Security Administration's continuing eligibility reviews have received extensive national exposure. Congress responded (Public Law 98-460) by establishing a moratorium on periodic reviews until new standards could be developed that would treat mentally disabled beneficiaries more fairly. Now that the revised Listing of Impairments has been issued, the continuing disability investigation process has started again.

Although the moratorium provided significant relief for many current beneficiaries by maintaining their eligibility during an interim period, it provided no help for new applicants suffering from dementia. They continue to have their eligibility determined on the basis of policies that have been found by the courts to discriminate against mentally impaired persons (5). As a result, denials of eligibility are still a common response to such applications.

The treatment of dementia as a mental disorder in the Listing of Impairments also creates special problems. Although individuals suffering from the various dementing disorders sometimes display behaviors similar to someone with mental illness, dementia remains an organic brain disorder. The effect of including dementia as a mental disorder may be to discourage applications and to unfairly limit eligibility for needed benefits, care, and services.

### Waiting Period

When an applicant is found to be eligible, disability benefits generally do not begin immediately. The Social Security Act imposes a "waiting period" of five consecutive calendar months before benefits can be initiated (42 U.S.C. 416(i)(2)(A)).

Although the waiting period is designed to ensure that temporarily disabled applicants will not be certified for social security disability benefits,

it works a special hardship on applicants with dementia. As described earlier, it is usually impossible to establish eligibility until many months after the onset of symptoms. The 5-month waiting period is then applied in establishing the beginning date of eligibility for social security disability benefits. Once the waiting period has elapsed, an additional 24 months must pass before Medicare benefits will be initiated (42 U.S.C. 426(b)(2)(A)).

The cumulative effect of these provisions is therefore to delay the onset of Medicare eligibility until long after the benefits are most needed. By the time Medicare eligibility does begin, the applicant's condition may have deteriorated sufficiently so that only custodial long-term care may be needed. As the discussion of services later in this chapter indicates, the value of Medicare eligibility will at that point be greatly diminished.

### **Medicaid**

Whereas eligibility under Medicare is largely determined by the governing legislation, eligibility under Medicaid is largely a matter of political choices by State governments. Although the Medicaid statute requires States to provide coverage for certain categories of persons, most coverage decisions are left to the States, within the categories of persons eligible for Federal matching funds.

As noted earlier, although Medicaid expenditures make up a relatively small portion of total State budgets, they are seen as consuming a significant portion of State discretionary funds (10). As a result, especially in relatively tight fiscal times, State proposals to expand coverage often pit one population of potential recipients against another. The result is frequently a political impasse that prevents any changes in the scope of State programs.

### Confusing Eligibility Criteria

As confusing as the Medicare eligibility process sometimes seems, it is relatively straightforward compared with the complexities of establishing eligibility for Medicaid. Eligibility in this case builds on the complexities of the federally assisted welfare programs and then adds some special wrinkles of its own. The result is a complicated system of rules and regulations that leaves applicants, recipients, providers, advocates, State

agency officials, and, frequently, Health Care Financing Administration staff uncertain over the appropriate interpretation of Federal statutes, regulations, and interpretive rules.

The confusion created by these regulations was noted in the decision in *Friedman v. Berger*. In that decision, while attempting to interpret the legal requirements, the judge noted:

As program after program has evolved, there has developed a degree of complexity in the Social Security Act and particularly the regulations which makes them almost unintelligible to the uninitiated. There should be no such form of reference as “45CFR [see] 248.3 (c)(1)(ii)(B)(2)” discussed below; a draftsman who has gotten himself into a position requiring anything like this should make a fresh start. Such unintelligibility is doubly unfortunate in the case of a statute dealing with the rights of poor people (13).

Since that decision, Medicaid regulations have been further complicated by the enactment of the Omnibus Budget Reconciliation Act of 1981, the Tax Equity and Fiscal Responsibility Act of 1982, and the Deficit Reduction Act of 1984 (Public Laws 97-35, 97-248, and 98-369). Each piece of legislation altered aspects of the Medicaid statute, frequently in a quest for simplification. Their cumulative effect in many areas of the law, however, has been to further confuse and complicate interpretation.

### Welfare Piggybacking

One overriding issue that must be confronted by applicants with dementia is the fact that the Medicaid program “piggybacks” its eligibility requirements on the criteria for the Supplemental Security Income (SSI) and Aid to Families with Dependent Children (AFDC) programs. Unlike Medicare, which is a social insurance program, Medicaid is a welfare program with strict means tests. The overall effect of that linkage is to require most applicants to be impoverished before eligibility can be established. That approach is one of the major criticisms of the Medicaid program by families caring for a relative with dementia.

The problem is magnified because of the unique effects of dementia on middle-class families. The availability of health insurance for most such fam-

ilies means that the majority of medical problems will be paid for in whole or in part by third-party coverage. Few private insurance plans cover the services required by a person with dementia, however. Thus, many middle-class families turn to a welfare program—Medicaid—for partial assistance in financing the costs of care and treatment for a family member with dementia.

**Medicaid/AFDC Linkage.**—The AFDC program provides financial support for children under the age of 18 deprived of parental support or care by reason of the death, continued absence from the home, unemployment, or physical or mental incapacity of a parent (42 U.S.C. 606(a)), Financial support to the child includes payments to meet the needs of the caretaker relative(s) with whom the child is living (42 U.S.C. 606(b)).

Although the onset of dementia usually occurs late in life, it may happen to someone who still has children under the age of 18. In such a situation, the family may be able to establish AFDC eligibility based on the mental incapacity of the parent suffering from dementia. Demonstrating that a parent is incapacitated by dementia is not usually difficult, for the AFDC program’s standards for incapacity are far more lenient than the social security disability standards. Establishing eligibility, however, may still be quite difficult.

AFDC is intended for use by indigent families. Financial requirements under the program are set by the States and are generally far more restrictive than under the adult welfare programs. For example, the AFDC eligibility income standard for a family of three in many States is lower than the SSI eligibility standard for an individual (see table 11-1). Similarly, the resource standard permits a family of six to own less than half as much liquid assets as a couple under SSI. AFDC eligibility is thus available only to very poor families.

Once eligibility is established, all family members included in the AFDC grant will also be certified for Medicaid eligibility (42 U.S.C. 1396a(10)(A)(i)(I)). That certification will be provided without a separate application for each family member as long as the family remains eligible for AFDC (42 CFR 435.909(a)).

**Table 11.1.—Aid to Famines with Dependent Children  
FDC Maximum Benefit and Need Standard for  
a Family of Three**

State	Maximum benefit Standard of need			Percent
	1984 <sup>c</sup>	1985 <sup>d</sup>	1985 <sup>d</sup>	
Alabama	118	118	384	31
Alaska	696	719	719	100
Arizona	233	233	233	100
Arkansas	164	164	234	70
California	526	555	555	100
Colorado	336	346	421	82
Connecticut	529	546	546	100
Delaware	287	287	287	100
District of Columbia	299	327	654	50
Florida	231	240	400	60
Georgia	202	208	366	57
Hawaii	468	468	468	100
Idaho	305	304	554	55
Illinois	302	302	632	48
Indiana	258	256	307	83
Iowa	360	360	497	72
Kansas	364	373	373	100
Kentucky	188	197	197	100
Louisiana	190	190	538	35
Maine	341	370	510	73
Maryland	295	313	433	72
Massachusetts	379	396	627	63
Michigan (Washington Co.)	445	447	592	76
Michigan (Detroit)	418	417	557	75
Minnesota	500	524	524	100
Mississippi	96	96	286	34
Missouri	261	263	312	84
Montana	332	332	401	83
Nebraska	350	350	350	100
Nevada	228	233	285	82
New Hampshire	341	378	378	100
New Jersey	360	385	385	100
New Mexico	258	258	258	100
New York (Suffolk Co.)	579	579	579	100
New York (N.Y.C.)	474	474	474	100
North Carolina	202	223	446	50
North Dakota	357	371	371	100
Ohio	276	290	627	46
Oklahoma	282	282	282	100
Oregon	368	386	386	100
Pennsylvania	350	364	614	59
Rhode Island	462	479	479	100
South Carolina	142	187	187	100
South Dakota	321	329	329	100
Tennessee	127	138	246	56
Texas	148	167	555	30
Utah	362	363	685	53
Vermont	530	558	852	65
Virginia	310	327	363	90
Washington	462	476	768	62
West Virginia	206	206	275	
Wisconsin	513	533	628	85
Wyoming	325	265	265	100

<sup>a</sup>Maximum benefit is the amount paid for a family of three with no countable income. Family members include one adult caretaker. In States with area differentials in benefits, figure shown is for area with the highest benefit. Maximum benefits are identical copayment standards mall States except Colorado, Indiana, Mississippi, and Utah, where the payment standards are higher.  
<sup>b</sup>Standard of need is the amount of money the State determined a family of three needs per month to achieve a minimum standard of living in that State. The standard of need is used to determine initial eligibility for AFDC. Benefits levels do not have to equal a State's need standard.

<sup>c</sup>As of Jan 1, 1984  
<sup>d</sup>As of Jan 1, 1985

SOURCE: US Congress, House Committee on Ways and Means, "Background Material and Data on Major Programs Within the Jurisdiction of the Committee on Ways and Means," Washington, DC, February 1984 and February 1985

Medicaid/SSI Linkage.—Until 1974, Federal law authorized grants-in-aid for States wishing to provide assistance to aged, blind, or disabled persons. Within Federal requirements, States were permitted a wide range of discretion in defining financial and nonfinancial eligibility requirements for these programs. All recipients of aid to the aged, blind, or disabled also received Medicaid coverage (42 U.S.C. 1396a(a)(10)) prior to the changes enacted through Public Law 93-233.

Effective January 1, 1974, Congress "federalized" these adult grant-in-aid programs through the enactment of the Supplemental Security Income program as Title XVI of the Social Security Act. (A few jurisdictions still utilize a grant-in-aid program of Aid to the Aged, Blind, and Disabled (AABD).) The SSI program established a minimum national benefit level and uniform national eligibility criteria. Administration of the adult welfare programs was also shifted from the State welfare agencies to the Social Security Administration.

Because SSI eligibility criteria were generally more liberal than the State welfare criteria they replaced) it was anticipated that thousands of people would suddenly become eligible for SSI benefits. That was not, in itself, of concern to the various States because the grants and administrative costs of the basic SSI program were to be paid by the Federal Government. Thus, States that used to share in the costs of adult welfare programs would now realize some savings.

However, a related aspect of this federalization did cause concern. Because many States used relatively restrictive adult welfare eligibility criteria prior to 1974, the number of persons who automatically received Medicaid benefits was also relatively small. The expected huge increase in eligible persons in 1974 therefore also portended a considerable rise in the number of Medicaid recipients once the new Federal SSI program was fully implemented.

States share the costs of the Medicaid program with the Federal Government. Federal financial participation varies from 50 percent in the wealthier States to a maximum of 83 percent in the poorer States (42 U.S.C. 1396d(b)), so States must fund between 17 and 50 percent of the costs. Fears of huge increases in Medicaid costs in some States resulted in requests for legislative changes in this linkage requirement between SSI and Medicaid.

Congress responded by altering the linkage through legislation now known as the 209(b) option (as it was added as Section 209(b) of the Social Security Amendments of 1972). That option permits States to no longer grant Medicaid automatically to all SSI recipients. Instead, they can apply more restrictive eligibility criteria than those used by the SSI program (42 U.S.C. 1396a(f)).

One other provision has lessened the traditional linkage between adult welfare eligibility and Medicaid eligibility. That provision is known as the 1634 option after Section 1634 of the Social Security Act (42 U.S.C. 1383c; 20CFR 416.2101-416.21 19). Once the SSI program was enacted, Congress authorized the Social Security Administration to contract with States to have the Social Security Administration make eligibility determinations for Medicaid. States electing that option receive a computer tape from the Social Security Administration of SSI/Medicaid eligibles. These individuals are then automatically certified for Medicaid without having to apply separately.

States using SSI criteria that elect to execute 1634 agreements provide Medicaid automatically to all eligible persons. Other States require Medicaid-eligible SSI recipients to request medical benefits separately. Such a requirement for a separate request must be approved under Federal law. The experience in States without 1634 agreements is that some eligible persons will never seek benefits and that some monies can thereby be saved. These savings are supposed to balance out the additional administrative costs of processing separate requests for medical assistance. However, studies commissioned by the Health Care Financing Administration cast significant doubt on the existence of any savings (29).

Applicants suffering from dementia must therefore deal with one of three possible administrative schemes (see table 11-2). In the majority of States participating in the Medicaid program, Medicaid is granted automatically to anyone receiving SSI benefits. In a second group, applicants must separately request Medicaid benefits even if they are receiving SSI benefits. However, they must be found eligible based on that request. Finally, in the third group of States, SSI recipients must separately apply and will be determined eligible only if they meet a State's potentially more restrictive categorical and financial eligibility criteria.

**Table 11-2.—Medicaid Benefits for Aged, Blind, and Disabled Persons**

Medicaid jurisdiction	SSI <sup>a</sup> criteria 1634 Agreement <sup>c</sup>	SSI criteria state determination	209 <sup>b</sup> Criteria
Alabama	X		
Alaska		X	
Arizona	b		
Arkansas	X		
California	X		
Colorado		X	
Connecticut			X
Delaware	X		
District of Columbia	X		
Florida	X		
Georgia	X		
Guam	d		
Hawaii			X
Idaho		X	
Illinois			X
Indiana			X
Iowa	X		
Kansas		X	
Kentucky	X		
Louisiana	X		
Maine	X		
Maryland	X		
Massachusetts	X		
Michigan	X		
Minnesota			X
Mississippi	X		
Missouri			X
Montana	X		
Nebraska			X
Nevada		X	
New Hampshire			X
New Jersey	X		
New Mexico	X		
New York	X		
North Carolina			X
North Dakota			X
North Marianas	X		
Ohio			X
Oklahoma			X
Oregon		X	
Pennsylvania	X		
Puerto Rico	d		
Rhode Island	X		
South Carolina	X		
South Dakota	X		
Tennessee	X		
Texas	X		
Utah			X
Vermont	X		
Virgin Islands	d		
Virginia			X
Washington	X		
West Virginia	X		
Wisconsin	X		
Wyoming	X		
Total—55	35	6	14

<sup>a</sup>SSI = Supplemental Security Income  
<sup>b</sup>Arizona's program is based on a Section 1115 demonstration project waiver  
<sup>c</sup>Based on data from 1982  
<sup>d</sup>In these jurisdictions, Medicaid is provided to recipients of Old Age Assistance (OAA), Aid to the Blind (AB), Aid to the Permanently and Totally Disabled (APTD), and Aid to the Aged, Blind and Disabled (AABD). The SSI program does not operate in these jurisdictions  
 SOURCES: Supplemental Security Income 1634 agreements from Urban Systems Research and Engineering; "Short-Term Evaluation of Medicaid Selected Issues," contract report prepared for Health Care Financing Administration, U.S. Department of Health and Human Services Baltimore, MO, 1984

The confusion created by that variability does not disproportionately affect applicants with dementia compared with others applying for services covered by Medicaid. However, the severity and duration of dementing conditions and the limitations of private health insurance coverage mean families coping with such an illness are much more likely than families dealing with other diseases to seek Medicaid coverage.

### SSI Eligibility

The SSI program began in January 1974 with a monthly benefit level of \$140 for an eligible individual (42 U.S.C. 1382(b)(1)), which had been adjusted for cost-of-living increases even prior to the implementation of the program. Today, the national benefit level for an individual is \$336, with allowances for regular cost-of-living increases (42 U.S.C. 1382). In addition, some States, at their option, provide State-funded cash supplements for some recipients (42 U.S.C. 1382(e)). These optional State supplementary payments are generally limited to those States with higher living costs. These are also generally the States that had relatively more liberal adult welfare programs prior to 1974.

Certain grandfathered recipients also receive mandatory supplements under the SSI program. Section 212 of Public Law 93-66, for example, was designed to ensure that no recipient of aid to the aged, blind, or disabled prior to 1974 would receive a smaller grant under the new SSI program. In addition, certain individuals who were eligible under the State welfare plans in effect prior to January 1, 1974, but who are ineligible under current definitions of disability, are considered to meet current standards (42 U.S.C. 1382c(a)(3)(E)).

To establish SSI eligibility, an applicant with dementia must satisfy both “nonfinancial” and “financial” eligibility requirements. The former are those special characteristics that an applicant must possess in order to establish “linkage” to the SSI program (such as being 65 or older, blind, or disabled). Most applicants with dementia will attempt to establish “linkage” on the basis of either disability or old age. “Financial” eligibility requirements include strict income and resource requirements.

**Listing of Impairments.**—The SSI program relies on the same disability criteria as the social security disability program (42 U.S.C. 1382c(a)(3)(A); 20 CFR 416.925). The criteria under both programs are supposed to be uniform nationally; significant interstate differences in criteria have arisen, however, because of DHHS’s policy of “nonacquiescence.” Under that policy, DHHS decides which decisions of the U.S. district courts and courts of appeal it will apply in cases other than those involving the specific applicant or class of applicants of the case. That policy has been the subject of numerous congressional hearings. The variations in the criteria to be applied also necessarily affect the evidence that can be submitted by an applicant for benefits in attempting to demonstrate disability.

The same problems facing applicants with dementia under the social security disability program therefore must also be confronted when applying for SSI. However, someone found not to meet social security disability standards as applied by the Social Security Administration may still qualify under those same standards as applied by the State Medicaid agency. The Health Care Financing Administration has traditionally argued that such findings of nondisability are binding on the States. A Federal district court recently found that the Medicaid statute granted States the right to make independent Medicaid disability determinations for medically needy and optionally categorically needy persons (24).

A major difference between the two programs is that SSI applicants do not have to meet the earnings requirements of the social security disability insurance program. To be eligible for social security disability benefits, an applicant must have worked 20 of the 40 calendar quarters before becoming disabled (42 U.S.C. 416(i)(3)(B)). That requirement of recent “connection to the labor force” creates additional problems for persons with dementia. **If it takes too long for the applicant to demonstrate disability, the applicant may no longer meet the 20/40 requirements. Once that eligibility period has been exhausted, the applicant cannot again qualify for Social Security disability benefits without reestablishing a connection to the labor force.**

**Financial Eligibility Criteria .—**Applicants for SSI must meet strict income and resources criteria. Individuals with net income or net assets in excess of those standards (after allowable exclusions) are ineligible for SSI.

From 1974 until 1985, the Federal resource standards for SSI permitted an applicant or recipient to own \$1,500 in nonexcludable resources (42 U.S.C. 1382(a) (1)(B)(ii)). (That level was increased to \$1,600 on Jan. 1, 1985; to \$1,700 on Jan. 1, 1986; to \$1,800 effective Jan. 1, 1987; to \$1,900 effective Jan. 1, 1988; and to \$2,000 effective Jan. 1, 1989 (Public Law 98-369 ).) An applicant or recipient with an eligible spouse could own \$2,250 in nonexcludable resources (42 U.S.C. 1382(a)(1)(B)(i); 42 U.S.C. 1382(a)(2)(B)). Although such assets as a home are excluded from consideration, these limited resource standards deny eligibility for individuals and families with savings until those funds have been practically exhausted.

The rules determining which resources are not counted for eligibility may cause some anomalous and potentially inequitable results. For example, although a recipient may own a home worth \$500,000, an applicant with a savings account of \$1,701 is completely ineligible for benefits in 1986. The same result would occur if the applicant owned life insurance with a face value of more than \$1,500 and a cash surrender value of \$1,701.

An applicant living in the community must have a net monthly income under \$336. Since that income places a recipient below the national poverty level, most applicants will by definition be impoverished both before SSI eligibility can be established and after it is certified.

Although the SSI standards do exempt some income from consideration—for example, up to \$30 of earned income in a calendar quarter is disregarded if it is received infrequently or irregularly (20 CFR 416.11 12(c) (1))—recipients with pension and similar outside income are not generally eligible because of these low income standards. SSI income standards exempt up to \$60 of unearned income in a calendar quarter (42 U.S.C. 1382a(b) (2)(A); 20 CFR 416. 1124(c)(12)). Unearned income includes social security benefits, public and private pensions, alimony, dividends, and interest. Computed on a monthly basis, that means

that someone with income of \$357 in most States will be ineligible for any SSI benefit and may therefore be ineligible for Medicaid as well.

The SSI income eligibility standard for persons living in nursing homes is even lower. Since 1974, the SSI program has limited such eligibility to those persons who have net income, after applying the income disregards, of less than \$25 per month (42 U.S.C. 1382(e)(1)(B)(i)) on the assumption that Medicaid will pay room and board for a recipient in a nursing home. That amount has not been changed since the SSI program began, in January 1974.

The \$25 grant is supposed to be adequate to pay for personal needs within the facility, such as toiletries, clothing, reading materials, and other items not included within the Medicaid reimbursement rate. In some States, nursing homes charge residents for additional utility costs attributable to a personal television. As in the community, then, a wide gap exists between the allowance and the actual need.

#### Medicaid Eligibility for Non-SSI Recipients

People who cannot establish SSI eligibility because they are not at least 65 or do not meet social security disability criteria generally cannot qualify for Medicaid regardless of the extent of their medical bills (42 U.S.C. 1396a(a) (10)). (A few States provide payments to medically indigent adults out of State funds, however. These medically indigent adult programs vary significantly from State to State in both the financial criteria for eligibility and the scope of services available to the recipient.) That inability to qualify occurs because Federal financial participation under the Medicaid statute is generally limited to those persons who are receiving aid or assistance under the AFDC or SSI programs or who would be eligible to do so but for excess income or resources (42 U.S.C. 1396a(a) (10)(C), 42 U.S.C. 1396d(a)).

Two special eligibility provisions are available for use by applicants with dementia as well as other aged or disabled persons—the nursing home cap program and the medically needy option. These assist persons who are recipients of neither AFDC nor SSI.

**Nursing Home Cap Program.** -Under the nursing home cap program (42 U.S.C. 1396a(a) (10)(A) (ii)(V) and (VI)) a fixed income test is established for residents of nursing homes. The results of that fixed income test cannot exceed 300 percent of the supplemental security income benefit rate (42 U.S.C. 1396b(f)(4)(C)).

Through the nursing home cap program, a nursing home resident with a 1986 income under \$1,009 in a State using the maximum allowable level could be eligible for coverage of the costs of nursing home care and other medical services while residing in the home. This option permits a State to provide some reimbursement for nursing home care without opening up its Medicaid program to all disabled or aged persons with high medical bills.

Since the nursing home cap program uses a fixed income test, an applicant with gross monthly unearned income of \$1,029 would be ineligible for benefits, regardless of medical expenses, since the net monthly income of \$1,009 (\$1,029 minus \$20 per month income disregard) would exceed the eligibility level of \$1,008. Someone with \$1,028 in gross monthly unearned income, however, would be eligible for medical assistance toward the costs of care.

The amount of assistance to be provided is determined through a two-step eligibility process. First, the recipient's net income is compared with the eligibility standard of \$1,008. If the net income after disregards is \$1,008 (\$1,028 minus \$20 income disregard) and the applicant meets resource standards, the person is eligible for Medicaid.

Second, the recipient obligation to pay for care is determined. The recipient is permitted to retain income equal to the personal needs allowance recognized in that State (at least \$25 per month). In a State allowing the minimum, the recipient keeps \$25 of income and pays the remainder (\$1,028 minus \$25, or \$1,003) to the nursing home. The State Medicaid agency reimburses the nursing home for the remainder of its costs up to the maximum Medicaid reimbursement allowed in the State.

**Medically Needy .**-When the Medicaid program was enacted in 1965, one of its major features was a flexible income test, included because of wide-

spread dissatisfaction with the fixed income test used under the Kerr-Mills program, the predecessor to Medicaid. Under a fixed income test, as in the nursing home cap program, applicants with incomes over a certain level cannot be aided even if they have high medical bills that reduce their available income. Under a flexible income test, those with even relatively high incomes can be helped with such medical expenses.

States choosing to establish medically needy programs may provide Medicaid eligibility to applicants who would qualify for AFDC or SSI but for excess income or resources. By incurring medical expenses, such applicants may "spend down" to an income level established by the State. The medical expenses are then deducted from the applicant's net income. Medical expenses incurred after that point may then be covered by the State.

Thirty-nine jurisdictions have elected to take advantage of the medically needy option (see table 11-3). (Some States, however, do not cover disabled or aged adults under this program.) It therefore represents an important program for persons with dementia and currently is an important funding source for care. Several factors affect the scope of the medically needy program, where available.

*(1) Income Levels.*-Federal law prohibits States from using medically needy income standards that exceed 133.33 percent of the AFDC payment standard for an equivalent size family (42 U.S.C. 1396b(f)(1)(B)(i)). Thus, if the AFDC payment standard for a family of four is \$180, the medically needy income level cannot exceed \$240.

AFDC payment standards are generally the lowest welfare payments in a State. In many States, moreover, they equal only a percentage of the standard of need for that size family. As a result, the medically needy income level artificially depresses an applicant's income far below the amount required to live on. Thus, to be eligible under the medically needy program the family of someone with dementia will have to reduce its available income far below the SSI benefit level. Only then will Medicaid pay for the remaining costs of care.

These limitations can lead to some seemingly anomalous results. In a State electing the medically needy option and using an income level of

**Table n-3.-Medicaid Eligibility Coverage in the States**

State	Categorically needy	Medically needy
Alabama	X	....
Alaska	X	....
Arizona	X	X
Arkansas	X	X
California	X	X
Colorado	X	....
Connecticut	X	X
Delaware	X	....
District of Columbia	X	X
Florida	X	•
Georgia	X	•
Hawaii	X	X
Idaho	X	....
Illinois	X	X
Indiana	X	....
Iowa	X	•
Kansas	X	X
Kentucky	X	X
Louisiana	X	X
Maine	X	X
Maryland	X	X
Massachusetts	X	X
Michigan	X	X
Minnesota	X	X
Mississippi	X	....
Missouri	X	....
Montana	X	X
Nebraska	X	X
Nevada	X	....
New Hampshire	X	•
New Jersey	X	•
New Mexico	X	....
New York	X	X
North Carolina	X	X
North Dakota	X	X
Ohio	X	....
Oklahoma	X	X
Oregon	X	X
Pennsylvania	X	X
Puerto Rico	X	X
Rhode Island	X	X
South Carolina	X	a
South Dakota	X	....
Tennessee	X	a
Texas	X	a
Utah	X	X
Vermont	X	X
Virginia	X	X
Washington	X	X
West Virginia	X	X
Wisconsin	X	X
Wyoming	X	....

<sup>a</sup>Medically needy program does not cover all aged and disabled Persons.  
SOURCE: Office of Technology Assessment, 1986.

\$300 for an individual, a disabled applicant with unearned income of \$355 per month would be eligible for SSI and Medicaid benefits. That is true because the applicant’s net income (after applying the \$20 per month income disregard) is \$335, or \$1 less than the SSI benefit level of \$336.

With a gross income of \$357 per month, however, the person would be ineligible for SSI since net income would exceed the SSI benefit level by \$1. The applicant would also be ineligible for Medicaid, since net income under the medically needy program would exceed the medically needy income level by \$37. The \$37 figure is calculated by comparing the applicant’s net income (\$357 gross income minus \$20 income disregard equals \$337) with the medically needy income level in the State of \$300.

In this example, the applicant would have to incur medical expenses of \$37 per month before Medicaid coverage would begin to pay for any remaining bills. A “notch” is thus created in the Medicaid eligibility process whereby an applicant who is ineligible by \$1 for SSI loses \$26 in available income because of the limitations on the medically needy income level.

(2) **Deeming.**—“Deeming” is a concept that affects applicants for both SSI and medically needy coverage. It is also an eligibility factor often encountered by persons with dementia.

One of the principles underlying the administration of most welfare programs is the notion that only income and resources actually available to an applicant or recipient will be considered. Deeming is used to permit the consideration of income and resources that may not actually be available to the applicant or recipient. Instead that income is defined to be available,

For example, pension income received by one spouse may be considered available to the other spouse applying for Medicaid. In determining the spouse’s Medicaid eligibility the “deemed” income will be added to the applicant own income. This is true even if the nonapplicant spouse fails to actually make any income available to the applicant.

In States using SSI criteria, deeming considers the availability of income and resources of a spouse or of the parents of a child under the age of 21. Thus, with some exceptions, the income and resources of one spouse will be considered available to the other spouse regardless of their actual availability.

Two common effects of deeming have been noted. The first is felt when the income and resources belong to the nonapplicant spouse, in which case they are considered available to the

applicant spouse. The “deemed” income or resources may thereby either result in a finding of ineligibility or increase the amount of medical expenses that must be incurred before eligibility is established. At the same time, the nonapplicant spouse will be impoverished since he or she will be forced to live at the SS1 benefit level in most States.

The second effect is felt when the income and resources belong to the applicant. In that case, a portion of that spouse’s income and resources will be considered available to the nonapplicant spouse. If, for example, the nonapplicant spouse has no income in his or her own name, the “deemed” income will be used to support the nonapplicant.

This “backwards deeming” from a spouse in a nursing home to family members outside it is critical if family members are going to have some income to meet their needs for food, clothing, and shelter. However, Federal limits on the amount of income that can be deemed to the nonapplicant spouse ensure that impoverishment will occur.

For example, in the case of an individual in a nursing home with only a spouse at home, the amount that may be set aside for that person’s needs may not exceed the highest of the SS1 benefit standard, the optional State supplement (if any), or the medically needy income standard (42 CFR 435.832). In most States, this means that the spouse in the community must live on \$336 per month. These limited set -asides have been upheld by the courts (21).

The effect is potentially worse in States using more restrictive eligibility criteria. Under the Federal deeming rules, 209(b) States are required to deem income at least to the extent required in States using SS1 criteria. However, these more restrictive States also have the option of deeming to the extent that they did before 1972. The amount of deemed income and resources may therefore be significantly greater in 209(b) States than in those using SS1 criteria.

The deeming requirements in 209(b) States are somewhat unsettled. In 1979, the United States Court of Appeals for the District of Columbia invalidated the Federal deeming rules then in effect for 209(b) States (16). The Court of Appeals

decision was then overturned by the United States Supreme Court (25). During the period between the two decisions, the Secretary of Health and Human Services had rescinded the 1977 deeming rules invalidated by the Court of Appeals and approved by the Supreme Court. The Secretary has since proposed reinstating the 1977 rules.

One of the perverse effects of deeming is to encourage the separation of families through placement of a family member in a nursing home or through divorce. In States using SSI criteria, for example, when a spouse moves to a nursing home deeming must end with the beginning of the first day of the first full month of residency (20 CFR 416.1167(a)). (Some States had deemed income indefinitely prior to the promulgation of SSI standards. This limitation lessens some of the harshest effects of deeming in States utilizing SSI criteria, but has also been cited as a reason some States elect to use the 209(b) option.) Similarly, if a husband and wife are divorced, only actual contributions will be considered between husband and wife.

Since these incentives run contrary to traditional governmental policies, two approaches have been developed to discourage the results. The first permits waiver of the deeming rules on a case-by-case basis when costly nursing home care could be avoided by the availability of Medicaid funding for home-based care. This waiver is referred to popularly as the “Katie Beckett” waiver after the name of the child whose case led to the waiver authorization (42 CFR 435.734(b)). The second approach permits States to provide home- and community-based services to individuals who, in the absence of such services, would require institutional care and would be eligible for Medicaid if they moved to nursing homes (42 U.S.C. 1396n).

The waiver language includes deeming both from parent to child and from spouse to spouse, but its limited use has been directed almost entirely to the first situation. Nothing would prevent it from being used more extensively to encourage home-based care for persons with dementia, however, especially during the early stages of the disease, when home management is frequently realistic.

Although the deeming process appears to be sex-neutral, it frequently has a disproportionately ad-

verse effect on women. At least for the near future, most husbands will earn more than their wives and therefore will have a greater entitlement to pension benefits. Although both spouses may intend to have these benefits available to support them in retirement, serious problems occur when the man is placed in a nursing home first.

In SSI States, for example, the income of the person in the nursing home will be deemed to the spouse living in the community. From her husband's deemed income, a woman will be allowed as her living standard a maximum amount equal to the SSI benefit level or \$336; she is limited indefinitely by Federal law to an amount far below the poverty standard. By contrast, if the man is the spouse still in the community, his obligation to pay any portion of his income to the wife would end with the beginning of her first full month in the nursing home.

Because of widespread dissatisfaction with these outcomes, some exceptions are being carved out. Some States with community property laws as well as other jurisdictions are attempting to divide income and resources more equitably between spouses in nursing homes and in the community. Those attempts have been met with great resistance from the Health Care Financing Administration. In California, for example, the Health Care Financing Administration disapproved a State plan amendment to use the State's community property rules to determine eligibility (ref. 6, Report Letter 487).

In community property and noncommunity property States, courts have begun carving out additional exceptions. (See, for example, *Purser v. Rahm, 1985*; similar cases have been brought in California, New York, and other States.) Under the judicial approach, a less than truly adversarial support lawsuit may be initiated by the spouse in the community against the spouse in the nursing home to define the former's property rights. Such a suit usually results in an allowance for the spouse in the community far in excess of \$336 per month. Attempts by the State Medicaid agencies to disregard this judicial determination have generally not been successful (23).

(3) Residency.—Another problem that frequently arises for applicants with dementia is the issue

of residency. Under Federal law, States are only obligated to provide medical assistance to eligible persons residing in the State. The problem arises in determining the State of residence under those regulations. For example, assume that an adult had been living in one State for his or her life. Now, after the onset of dementia, adult children decide to move the parent closer to their homes in another State. Under Federal law, the State in which the children live would now have an obligation to provide medical assistance coverage.

Federal regulations indicate that the residence of an adult is ordinarily where the adult is living with the intent to remain indefinitely (42 CFR 435.403(i)(1)(i)). The previous regulations, however, indicated that the residency of an adult no longer capable of stating intent was the State in which the person was living when that capability was lost (49 FR 13526; 47 FR 27078). A disabled parent therefore frequently remained in the State of origin, far from the children, since Medicaid reimbursement was often such a critical factor.

The current regulations constitute a significant change. Instead of linking the disabled parent to the home State, the regulations now provide that an adult incapable of stating intent is a resident of the State in which the person is living (42 CFR 435.403(i)(1)(i)). This change makes a significant difference in encouraging adult children to provide some care and support for disabled parents. In practice, however, interviews with State agency staff and reviews of State policies indicated that many States are still following the previous rules (4).

(4) *Accounting* Periods.—Another issue that affects Medicaid eligibility for applicants with dementia is the length of the accounting period for determining it. Under Federal law, States electing to establish medically needy programs may use accounting periods of up to 6 months (42 CFR 435.831). Thus, instead of determining eligibility on a month-by-month basis, States can determine an applicant's status for a 6-month period.

For example, if it is determined that an applicant exceeds the medically needy income level by \$135 each month in a 6-month accounting period (*because the person's net income equals \$455 in a State using a \$300 eligibility level*), the applicant

would have a total spend-down liability of \$810 in medical expenses (six times \$135 per month). Only after the applicant incurred \$810 in medical bills would Medicaid eligibility be established and additional covered expenses reimbursed.

The longer the accounting period, the more medical expenses must be incurred and the more difficult it is for an applicant to establish eligibility. Few health care providers are willing to extend credit to permit an applicant to incur sufficient expenses. Thus, the applicant must pay out of pocket to the provider a substantial amount even though the applicant's income is already far below the poverty level.

The other effect of a longer accounting period is to make it more difficult for an applicant to establish eligibility in the community. An applicant who became ill in a single month might generate enough medical bills to satisfy the \$135 spend-down obligation and thereby establish Medicaid eligibility for remaining bills in that month. However, it is extremely unlikely that the same applicant would generate \$810 in medical expenses (the spend-down liability if a 6-month accounting period is used) without some institutional care.

Attempts to challenge accounting periods exceeding 1 month have been unsuccessful (1,11)18). In *hogan v. Heckler*, the Court of Appeals for the First Circuit described the impact of the 6-month accounting period on one of the applicants, a veteran with quadriplegic, in the following language:

Receiving Veterans and Social Security benefits that bring his spend-down up to nearly \$2,300, the applicant is assertedly forced to operate on credit, depending on the willingness of his attendant to go unpaid for months at a time, while his medical expenses accumulate to reach the required amount. At some point, the applicant was abandoned by his attendant and was forced to seek emergency care at a hospital for a short spell to increase his medical expenses. Other members of the plaintiff class are in a similar situation (18).

Despite recognizing the hardships longer accounting periods work on applicants, the courts have ruled that the Federal regulation authorizing 6-month accounting periods is not illegal. Any change would therefore require congressional action.

**(5) Responsibility of Relatives.-Medicaid** policy regarding the financial responsibility of relatives is one of the areas of greatest confusion among applicants and recipients. In some cases this confusion leads to unnecessary separation or divorce. In others the result is needless delays in applying for assistance.

The Social Security Act restricts the circumstances in which relative responsibility can be applied to spouse for spouse and to parent for minor child or adult child who is disabled or blind (42 U.S.C. 1396a(a) (17)). Thus, an adult child is not liable under the Medicaid statute for the support of elderly or disabled parents. Even in those circumstances in which relative responsibility is possible, it is seldom pursued. Under Federal law, "deeming" is the only form of relative responsibility mandated on the States (see, for example, 42 CFR 435.723 and 435.724). Few States go beyond that requirement.

A few States do aggressively pursue relative responsibility by enforcing general support laws. In these cases, requests for contributions maybe sought from responsible relatives who are not actually supporting recipients at levels established by the State. Court actions may also be filed to compel support payments from noncontributing relatives.

A closely related approach involves the use of liens. The Medicaid statute had traditionally barred most use of liens by States to recover Medicaid payments that had been properly paid (see Section 121(a) of the Social Security Amendments of 1965 (public Law 89-97), as amended by Section 13(a)(8) of public Law 93-233 and Section 132(a) of the Tax Equity and Fiscal Responsibility Act of 1982)). That restriction has now been changed to permit the use of liens against the real property of certain elderly recipients and certain recipients under 65 who are in a nursing home and not expected to return home (42 U.S.C. 1396p). However, even in these circumstances, liens are prohibited against a home occupied by the recipient's spouse, by a minor child, or by a blind adult or disabled child (42 U.S.C. 1396p(a)(2)).

These statutory changes in the lien provisions are relatively recent and few States have amended their plans to include this requirement. Many,

however, are considering such changes as part of a comprehensive plan to target limited financial resources while permitting more liberal allowances for the needs of spouses and children of applicants.

**(6) Transfer of Assets.**—In part because of the low resource standards under Medicaid, the specter of wealthy individuals transferring assets for less than fair consideration in order to qualify for Medicaid benefits has haunted the program almost since its inception. Anecdotes, whether true or false, have been widely circulated of people transferring hundreds of thousands of dollars in order to be covered by Medicaid in a nursing home.

Few data are available to support these anecdotes. Moreover, several incentives under Medicaid would discourage such transfers. A person who gave up substantial assets in order to qualify for Medicaid would have to live on a personal needs allowance of \$25 per month. At the same time, the recipient would be limited to nursing homes willing to accept Medicaid patients. These two factors would operate to discourage most truly consensual transfers. Nevertheless, the specter still persists.

Initially, the Medicaid program, by incorporating the resource requirements of the SSI program into the adult medically needy program, prohibited States using SSI criteria from penalizing individuals who transferred assets for less than fair consideration. A 209(b) State applying more restrictive criteria could include a transfer of asset prohibition so long as such a requirement was validly part of the State's 1972 Medicaid plan. Most State efforts to impose such requirements prior to 1980 were unsuccessful (see, e.g., 2,12),

That situation was changed in 1980 by the Boren-Long Amendments to the Social Security Act (Public Law 96-611, sections 5(a)-(c)). That legislation amended the SSI program to prohibit transfers of assets for less than fair market value within 24 months of applying for assistance where the purpose of the transfer was to qualify for SSI or to establish continuing eligibility. States were also authorized to impose similar or even more restrictive requirements under their Medicaid programs (see 42 U.S.C. 1396p(c) as added by Section 132(b) of the Tax Equity and Fiscal Responsibility

Act of 1982 (Public Law 97-248), and as amended by the Technical Corrections Act of 1982 (Public Law 97-448)).

Although these provisions attempted to deal with what was perceived to be a significant problem, they opened as many loopholes as they closed. Any applicant with substantial assets to protect could simply transfer those assets with impunity more than 2 years in advance of applying for assistance. Federal law could have used a longer period than 2 years for prohibiting transfers. As the period increases, however, it becomes more and more difficult to demonstrate that the transfer was for the purpose of qualifying for assistance. States that have tried to use longer periods have not achieved great success in discouraging transfers. The 2-year provision is especially relevant for persons with dementia, because the illness is protracted and years may pass between the onset of symptoms and the need for nursing home care.

Most recently, a further attempt was taken to deal with this problem through the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) (Public Law 99-272, Section 9506(a)). Most States do not consider assets placed in a discretionary trust in determining the eligibility of an applicant or recipient. A discretionary trust is one in which the assets are to be spent in the sole discretion of the trustee for the benefit of the beneficiary. The trust assets are therefore not actually available to the beneficiary although trust payments to that person would be considered as income. The act of placing assets in a discretionary trust, within 2 years of applying for assistance or while a recipient, might also trigger a State's transfer of asset provision, however.

The COBRA legislation amended Federal law to declare that discretionary trusts, referred to as Medicaid qualifying trusts, are no longer exempt from consideration as an asset. These amendments are therefore designed to discourage the practice regardless of when the trust was created.

In actuality, however, the effect of these amendments will likely be to encourage applicants wishing to qualify for Medicaid to make outright gifts of assets that would otherwise be placed in a discretionary trust. Since many States succeeded in

requiring beneficiaries to petition courts to invade such trusts, the short-term effect of these amendments may be counterproductive by reducing the assets that States might otherwise reach.

For persons with dementia, transfer-of-asset provisions may block steps that could be taken to ease the hardship on spouses in the community without outside income. If the spouse in a nursing home has all of the income in his or her name, the amount allocated to the spouse in the community will vary between approximately \$72 and \$336, depending on the State involved. To ease the hardship created by that limitation, a spouse in a nursing home might attempt to transfer income-generating assets to the sole ownership of the spouse outside the nursing home. Such

an approach would be barred by existing law unless the transfer takes place more than 2 years before the spouse in the nursing home needs Medicaid reimbursement for care.

On the other hand, families with a relative with dementia may actually be less disadvantaged by the transfer-of-asset prohibition than other families. The current provision tends to reward families that seek legal and financial advice early. Because of the time that may pass between onset of symptoms and the need for nursing home care for a patient with dementia, a family that transfers assets early will be able to protect those assets for the use of other family members and still maximize Medicaid eligibility.

## SCOPE OF SERVICES

### *Medicare*

The Medicare program covers primarily acute medical care and does not cover protracted long-term care. Moreover, while hospital services, physician services, and skilled nursing care are included, some basic acute medical services, such as prescription drugs, are excluded. The limitations on the scope of services therefore have a direct impact on the importance of the Medicare program for beneficiaries with dementia,

The coverage of a service, however, does not necessarily imply that reimbursement will be available for beneficiaries with dementia. In interviews conducted during the course of this assessment, Medicare beneficiaries uniformly decried what they described as “misleading” Federal brochures—pamphlets, for example, that indicate that Medicare beneficiaries can receive up to 100 days of nursing home care (4). Although that statement is factually correct, few people who receive Medicare ever receive this reimbursement for nursing home care.

Those who were interviewed felt that they had been led into a false sense of security by the brochure explanations of coverage. The two most dramatic examples of this problem occur with regard to two exclusions from coverage under

Medicare—the “not reasonable and necessary” exclusion and the “custodial care” exclusion.

#### “(Not Reasonable and Necessary)” Exclusion

The Social Security Act excludes from reimbursement under Medicare “any expenses incurred for items or services which . . . are not reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member” (42 U.S.C. 1395y(a)(1)(A)). The exclusion thus places the burden on the beneficiary to show that the particular item or service for which reimbursement is sought will “treat” the disease. Since the services required by a patient with dementia, for example, will not cure the disease but only manage its symptoms, reimbursement is uncertain. Yet, most chronic diseases of the elderly are not “cured” by medical care and treatment. For example, a patient with coronary heart disease will frequently require care and treatment designed to manage the symptoms of the disease even though the underlying disease will not be cured. Because there is no similar medical protocol for patients with Alzheimer’s disease, however, and because the services required by patients with dementia are not purely medical, the standard ex-

eludes coverage for many services for many patients with dementia.

This exclusion problem is similar to the drafting difficulties encountered in legislative attempts to cover hospice care under Medicare (42 U.S.C. 1395d(d)). (Section 122(h)-(k) of the Tax Equity and Fiscal Responsibility Act of 1982 added hospice care as a covered service.) It was not sufficient to simply amend the Social Security Act provisions defining scope of services. Since hospice care is not a cure-oriented service, but rather a supportive maintenance one, the “not reasonable and necessary” exclusion’s focus on treatment would have presented coverage problems.

Congress opted to modify the “not reasonable and necessary” exclusion to permit coverage of hospice care that is reasonable and necessary for “the palliation or management of terminal illness” (42 U.S.C. 1395y(a)(1)(C)). This standard differs significantly from the “diagnosis or treatment” standard and thereby authorizes coverage that would not otherwise be available.

#### “Custodial Care” Exclusion

The Medicare program also excludes items or services that “are for custodial care” (42 U.S.C. 1395y(a)(9)). This exclusion is similar to and often overlaps the “not reasonable and necessary” exclusion. Indeed, the 1982 amendments authorizing reimbursement for hospice care also had to modify the “custodial care” exclusion by denying reimbursement for “custodial care (except, in the case of hospice care, as is otherwise permitted under paragraph [1862(a)] (1)(c))” (42 U.S.C. 1395y(a)(9)).

The “custodial care” exclusion is perhaps most often used with regard to nursing home care. Since only skilled nursing and rehabilitation services are covered under Medicare, “custodial care” is defined to include all services that do not qualify as “skilled nursing and skilled rehabilitation services” (42 CFR 405.310(g)).

“(Skilled nursing” services:

1. are ordered by a physician;
2. require the skills of technical or professional personnel such as registered nurses, licensed practical (vocational) nurses, physical therapists,

apists, occupational therapists, and speech pathologists or audiologists; and

3. are furnished directly by, or under the supervision of, such personnel (42 CFR 409.31(a)).

That definition has been applied restrictively to deny reimbursement for many otherwise covered services. (Many of these initial denials have been overturned at the administrative law judge hearing stage or in judicial review; see ref. 6, para. 4115). Such denial of coverage has occurred because insufficient weight has been given to such factors as when a technical or professional person’s skills are required to observe and assess the patient’s changing condition.

Although the regulations expressly recognize the needs of “patients who, in addition to their physical problems, exhibit acute psychological symptoms such as depression, anxiety, or agitation, etc., [and therefore] may also require skilled observation and assessment by technical or professional personnel to assure their safety and/or the safety of others” (42 CFR 409.33), Medicare reimbursement for extended nursing home care is nonetheless unusual. One aggravating factor for persons with dementia is the limited rehabilitation potential. As noted earlier, the Medicare program remains “cure-oriented.” With regard to nursing home care, the Federal regulations acknowledge that “even if full recovery or medical improvement is not possible, a patient may need skilled services to prevent further deterioration or preserve current capabilities” (42 CFR 409.32(c)).

However, even the best skilled services will frequently not prevent, but will only slow, further deterioration under current treatment protocols for persons with dementia. And the best skilled services will generally not preserve current capabilities, but will only slow their loss.

### **Medicaid**

Although the Federal Medicaid statute permits substantial State flexibility in identifying which services will be reimbursed for which populations, it also imposes some uniform requirements. Those persons who are described as “categorically needy” must be reimbursed for the following services: inpatient hospital services, outpatient hos-

pital services, rural health clinic services, other laboratory and x-ray services, skilled nursing facility services, early and periodic screening diagnosis and treatment services, family planning services and supplies, physician services, and nurse-midwife services (42 U.S.C. 1396a(a) (10)(A) and 1396d(a)). Home health services must also be provided for any person entitled to skilled nursing facility services (42 U.S.C. 1396a(a) (10)(D)).

The term “categorically needy” is not used in the Social Security Act. It has become a term of art under the Federal Medicaid regulations (42 CFR 435.500). It refers to those persons receiving SSI and AFDC (the mandatory categorically needy) as well as those special groups (the optional categorically needy) who display special characteristics, such as the nursing home cap population, that entitle them to eligibility. Most of the optional categorically needy groups were added to the Medicaid rolls after 1965 without express statutory authorization. Starting in 1981, many of these groups were expressly added to the Social Security Act.

If a State plan covers the “medically needy,” separate service requirements are imposed. Furthermore, if a State covers the “medically needy” and reimburses for services in institutions for mental diseases or in intermediate care facilities for the mentally retarded (or both), then it must also cover either the services required for the “categorically needy” or an assortment of the services for which Federal reimbursement is available.

#### Uncovered services

The initial problem confronted by a recipient with dementia may be that the services needed are not covered by the State plan, for one of two reasons. First, some services are not eligible for Federal financial participation under the Federal Medicaid statute, which only authorizes reimbursement for “medical care” and “remedial care” (42 U.S.C. 1396d(a)). (These terms have been expanded in recent years to include services authorized pursuant to home- and community-based waivers.) Services such as respite care, which may be important for the maintenance at home of a person with dementia, are not covered. Minor structural changes to a home that would delay

or avoid institutionalization of a person with dementia are also not covered.

Second, the Federal Government has chosen not to make the Medicaid program uniform in the 55 jurisdictions administering the program. States continue to possess the discretion to decide what services are to be covered for which populations.

#### Amount, Duration, and Scope

Inclusion of a service in the State plan for a particular population does not automatically ensure coverage. States are permitted to impose limitations on the amount, duration, and scope of covered services that may greatly reduce availability. For example, a State may cover physician services, but may permit only one visit per month. Similarly, inpatient hospital services may be covered, but only for 12 days of coverage per fiscal year.

Legal challenges to such limitations have been largely unsuccessful. Federal regulations require that services must be sufficient in amount, duration, and scope to reasonably achieve their purpose (42 CFR 440.230(b)), yet most courts have ruled that no violation is present even if many medical procedures reasonably require services in excess of the limitation (3,8)17).

Similarly, although Federal regulations prohibit States from arbitrarily denying or reducing the amount, duration, or scope of a required service to an otherwise eligible recipient solely because of the diagnosis, type of illness, or condition (42 CFR 440.230(c)), most courts have ruled that limitations due to fiscal reasons are not arbitrary and do not discriminate even if certain diagnoses, illness, or conditions generally require services in excess of the limitation (3,8,17). Moreover, although Federal regulations authorize State Medicaid agencies to place limits on a service based only on such criteria as medical necessity or on utilization control procedures (42 CFR 440.230 (d)),” most courts have upheld across-the-board limits that are not based on these considerations (3,8,17).

#### Institutions for Mental Diseases

Another possible influence on the availability of nursing home care for Medicaid recipients with

dementia is the Federal exclusion of services in institutions for mental diseases except for persons at least 65 and for inpatient psychiatric hospital services for persons under age 21 (42 U.S.C. 1396d (a)(B)). The Federal administration of this provision has been the subject of much controversy. The Health Care Financing Administration has defined the term “institution for mental disease” (IMD) in guidelines in the State Medicaid Manual.

These IMD guidelines look to such factors as the licensure status of the facility, the way the facility advertises and “holds itself out” to the public, and the facility’s level of security. The factor that probably has presented the greatest difficulty for States and providers has been the guideline that considers whether “more than 50 percent of the patients have mental diseases which require inpatient treatment according to the patients’ medical records” (ref. 26: Section 4390).

The Federal IMD guidelines have been upheld by the U.S. Supreme Court (7). The clear signal to State agencies and nursing homes from that decision was to carefully monitor the patient mix in order to stay below the 50 percent guideline. Because persons with dementia often have behavioral symptoms, nursing homes have incentives to deny admission to these individuals.

Yet the same Federal guidelines expressly exclude persons with dementia when calculating the 50 percent. The guidelines emphasize that:

... in using the ICD-9-CM [International Classification of Diseases, 9th revision, Clinical Modification], it is important to note that, although the senile and presenile organic psychotic conditions listed [including senile dementia, presenile dementia, senile dementia with delusional or depressive features, and arteriosclerotic dementia] . . . are included as mental disorders, these diagnoses represent the behavioral expression of underlying neurological disorders. For this reason, these conditions are not to be considered mental diseases for purposes of IMD identification (ref. 26: Section 4390).

Despite the clear language of that provision, nursing home administrators interviewed during the course of this assessment frequently referred to the IMD exclusion as the reason they are reluctant to admit patients suffering from dementia (4). The incentive to refuse admission therefore

persists because administrators prefer not to risk their certification or to jeopardize their substantial Federal funding for intermediate and skilled nursing facility care. Their cautiousness apparently stems from a fear that the IMD guidelines will be applied to include facilities that are not institutions for mental disease (27).

#### Home- and Community-Based Services

The home- and community-based services waiver, added to the Medicaid statute in 1981 as part of the Omnibus Budget Reconciliation Act, was designed to permit Medicaid funding of services in the community for individuals who would otherwise require placement in a nursing home. Although costs associated with room and board in the community were still excluded, Federal funding became available for the costs of case management, homemaker, home health aide, personal care, adult day health, habilitation, respite care, and other services requested by the State and approved by the Secretary (46 FR 48532). Combining this “services” waiver with the “eligibility” waiver of deeming requirements for persons who would otherwise be at risk of nursing home placement significantly expands the options for families with someone with dementia.

The potential expansion has been largely unrealized, however. The major obstacle appears to be the restrictive interpretation of cost-effectiveness employed by the Health Care Financing Administration and by the Office of Management and Budget in reviewing waiver applications. The Federal statute requires States seeking home- and community-based services waivers to provide satisfactory assurances that “average per capita expenditures . . . with respect to such individuals” will not exceed “the average per capita expenditure . . . for such individuals if the waiver had not been granted” (42 U.S.C. 1396n(c)(2)(D)). The emphasis in that congressional language on “such” individuals indicates that a waiver application should be granted if a State can show that the waiver will be cost-effective for individuals served under the waiver.

By contrast, the regulatory formula for evaluating cost-effectiveness does not simply consider the costs associated with individuals who would be served under the waiver (42 CFR 441.303). In-

stead, it also considers costs attributable to other recipients under the State plan. The effect has been to limit the scope of the waiver process. If, for example, a State proposed to add home- and community-based services to its plan, some persons could be moved from a nursing home and served in the community. Unless the beds occupied by those persons remained vacant, however, average per capita costs under the regulatory formula might actually increase due to the community costs associated with the recipients now in the community and the nursing home expenditures associated with “substituted” recipients.

Some of these “substituted” recipients are current Medicaid enrollees who could not gain access to nursing home beds and therefore could not generate expenditures. Other “substituted” recipients are not current enrollees because they could not gain access to nursing homes and thereby generate sufficient expenses to meet medically needy spend-down requirements. Costs associated with both classes of “substituted” recipients make it difficult for a State to meet regulatory cost-effectiveness criteria.

The Federal regulatory approach to measuring cost-effectiveness appears to run contrary to the express language of the statute and its legislative history. It effectively “caps” the number of nursing home beds in the State and thereby limits the entitlement aspect of the Medicaid program. It remains, however, the standard applied in evaluating waiver applications. The net effect has been to permit only limited use of the waiver authority, largely in cases when an institution is being closed and therefore no “substitution” can occur.

### Community Services

One persistent criticism of the Medicaid program is that it is oriented too much toward institutional care and services. Part of this “bias” is an inevitable result of the low eligibility levels used under the program. Few nonwelfare applicants will be eligible without having incurred substantial medical expenses, which are most likely to be incurred in an institutional setting.

In addition, many State plans do not include the range of community services needed to avoid or delay nursing home placement. Medical day care

and personal care services, for example, can qualify for Federal reimbursement without a waiver when provided through a medical model. Few States include such services in their plans and even fewer have been able to attract enough providers to permit recipients broad access to services.

The orientation toward institutional care and services is not illegal under the Medicaid statute. The effect, however, has been to make it more likely that a recipient with dementia will be served in an institutional setting, if at all, since that is often the only service site for which reimbursement will be available.

### Intermediate Care Facilities

Unlike the Medicare program, the Federal Medicaid statute authorizes reimbursement for intermediate care facility services (42 U.S.C. 1396d(a)(15)). That provision is an important funding source for long-term nursing home care of dementia patients. Federal regulations define intermediate care to mean services in a facility that:

(1) Fully meets the requirements for a State license to provide, on a regular basis, health-related services to individuals who do not require hospital or skilled nursing facility care, but whose mental or physical condition requires services that—

- (i) Are **above the level of room and board;**  
and
- (ii) **Can be made available only through institutional facilities (42 CFR 440.150(a)(1)).**

**Although this definition is less stringent than that of skilled nursing care under either Medicare or Medicaid (42 CFR 440.40), it may still restrict access for persons with dementia.**

The restrictions usually stem from implementation of the words “can be made available only through institutional facilities.” Although most individuals with dementia will require more than room and board (such as skilled observation and behavior management) due to their mental condition, few require nursing home placement for this level of care. In fact, many families can and do manage home care of spouses and relatives suffering from dementia through services both in and outside the home (such as respite care, personal care, attendant care, and adult day care).

Despite the potential problems that the intermediate care requirement poses, most States interpret the standard in a lenient manner. Instead of considering the theoretical availability of noninstitutional care, many utilization reviewers look

to the practical availability of that care. Nevertheless, different interpretations of this criterion for coverage have spawned large variations from State to State and even within States.

## REIMBURSEMENT PRACTICES

Reimbursement practices are often thought of as a matter between the bill-paying agency and the provider of services that does not really affect program beneficiaries. But these practices directly influence provider participation and, therefore, access to services. Moreover, the level of reimbursement will influence the amounts that program beneficiaries have to pay for covered services.

### **Medicare**

#### Diagnosis-Related Groups

The adequacy of Medicare reimbursement for hospital services has received considerable public scrutiny recently. The introduction of reimbursement for hospital services based on diagnosis-related groups (42 U.S.C. 1395ww) resulted in complaints of dumping of “heavy-care” patients—those likely to generate costs during a stay above the average for that class of diagnosis. Such dumping has special implications for patients with dementia.

Medicare reimbursement for inpatient hospital services related to a diagnosis of Alzheimer’s disease or another form of dementia tends to be adequate to cover services needed. However, adequacy of reimbursement does not guarantee access to care.

Once a person has been diagnosed as suffering from dementia, he or she must ultimately be discharged to an appropriate family, community, or institutional care setting. To the extent that these service settings are not available, patients may become “backed-up” in hospitals, which can push costs above the available reimbursement. Such difficulties in placement may then dissuade hospitals from admitting persons likely to be difficult to discharge—including those with dementia (although there is no quantitative evidence of this).

A related problem arises when a person with dementia is admitted for a condition unrelated to the underlying illness. Patients with dementia are commonly perceived as being more difficult to manage. More intensive staff services for supervision and patient management may be required. Hospitals may therefore have a financial incentive to discourage admission of such patients.

Hospitals are also prevented from simply shifting costs to a patient:

A hospital may not charge a beneficiary for any services for which payment is made by Medicare [under the prospective payment system], even if the hospital’s costs of furnishing services to that beneficiary are greater than the amount the hospital is paid under the prospective payment system (42 CFR 412.42).

#### physician Reimbursement

Medicare reimbursement for physician services has also been the subject of congressional action. Most Medicare beneficiaries have difficulty finding physicians willing to accept Medicare assignment for the costs of care. Under Part B of the Medicare program, a physician is not generally required to accept Medicare reimbursement as reimbursement in full. Instead, reimbursement is limited to 80 percent of a fee established for that provider. When a physician accepts assignment, the Medicare program makes reimbursement directly to the physician, and the Medicare beneficiary is responsible for paying the remaining 20 percent. In nonassignment cases, the Medicare program still pays only 80 percent of the established fee. However, the beneficiary is liable for paying the difference between the Medicare-established fee and the actual fee. Since actual fees generally exceed the Medicare-established fees significantly, the beneficiary is usually liable for far more than the 20 percent of the established nonassignment cases.

Congress attempted to remedy this situation in the Deficit Reduction Act of 1984 by establishing a voluntary participation system for physicians and suppliers willing to accept assignment for all services provided to Medicare patients during a fiscal year (42 U.S.C. 1395u(h)).

The incentive to encourage participation included listings in directories and toll-free telephone lines, electronic transmission of claims, and certificates of participation. Probably the most significant factor, however, was an expected exemption from freezes on fees to Medicare beneficiaries.

Under the Medicare and Medicaid Budget Reconciliation Amendments of 1984 (enacted as part of the Deficit Reduction Act of 1984), beginning July 1984, all customary and prevailing charge levels for physicians' services were "frozen" at the levels in effect from July 1983 to June 1984. That freeze prohibits both participating and nonparticipating physicians from passing on increases in charges during that period. However, participating physicians would receive a retroactive "catchup" in their fee profiles (42 U.S.C. 1395u(b)(4)).

Although this approach held out some promise of increasing the number of physicians willing to accept assignment, the physician fee freeze may have undercut most of the benefits anticipated. That problem, which adversely affects all Medicare beneficiaries, may have special consequences for persons with dementia.

If a physician believes the costs of treating a patient outweigh the financial benefits, access to care may be reduced. Because the fee for providing a specific service is the same for light-care and heavy-care patients, a physician is more likely to see the light-care patient unless too few patients are scheduled to fill the workday.

The management problems frequently associated with patients with dementia, along with the high frequency of related problems and the limited rehabilitation potential, lead many providers to view patients with dementia as needing heavy care. Although the Medicare regulations permit an adjustment in fee levels for special factors (42 U.S.C. 1395u(b)(3); 42 CFR 405.506), the cumbersome administrative machinery for invoking this

adjustment is generally not worth the effort. The effect, therefore, is to discourage equal access to care for the population of persons with dementia.

### Nursing Home Reimbursement

Although hospitals are now reimbursed on the basis of diagnosis-related groups, the Medicare program continues to use a retrospective reasonable-cost reimbursement system (42 U.S.C. 1395f(b); 42 U.S.C. 1395x(v)). The theory behind that system is that a provider's actual and reasonable costs related to patient care will be reimbursed by the program.

The effect of that system on recipients requiring heavy care is to discourage access to nursing homes. Since most homes are for-profit facilities, they have a financial incentive to maximize revenues in relation to costs. This incentive will be advanced most by admitting light-care patients. The nursing home will receive its actual costs related to providing services and will receive the same return on equity capital.

A nursing home that admits a heavy-care patient will still receive only its actual costs of providing care for that individual. As it will receive no increase in profits, and as heavy-care patients are more trouble for the facility, the nursing home has an incentive to admit the "cream"—light-care patients—and to discourage those perceived as needing more care.

Data on whether persons with dementia actually require more care are still preliminary. Some studies indicate that residents with dementia need more care and attention from nursing staff, with one study reporting that nursing staff spent approximately 36 percent more time on patients with "senile dementia" than the minimum time required for nursing care in general (19). However, as indicated in chapter 7, that additional requirement may be largely due to inhospitable physical environments and inappropriate care approaches.

Whatever the ultimate findings, access patterns are now sculpted by the perception that individuals with dementia need extra care. Nursing home administrators interviewed for this assessment reported almost unanimously that it is more difficult for persons with dementia to gain access be-

cause of heavy-care requirements (4). So long as these perceptions control admissions practices, access for persons with dementia will continue to be more difficult.

### ***Medicaid***

For many years the Federal Medicaid regulations have recognized the direct link between provider participation and fee levels. (Several studies have noted this link but also that fee levels are not the only factor affecting access and they may not even be the most significant factor in some cases (e.g., 9,22).) Thus, Federal regulations require fees to “be sufficient to enlist enough providers so that services under the plan are available to recipients at least to the extent that those services are available to the general population” (42 CFR 447.204).

In practice, that goal has not been realized. Medicaid recipients do not have the same access to services as the general population. Thus not only do persons with dementia in general have difficulty obtaining appropriate care, the problems are compounded if they are dependent on Medicaid.

Nursing home reimbursement under Medicaid must be “reasonable and adequate to meet the costs that must be incurred by efficiently and economically operated providers to provide services in conformity with applicable State and Federal laws, regulations, and quality and safety standards” (42 U.S.C. 1396a(13); 42 CFR 447.253(b)(1)). In practice, most States have established a per diem rate for each facility based on some statewide limits on allowable costs.

Under a per diem system, facilities have a strong financial incentive to deny admission to persons

they perceive will need heavy care. Since the facility in such a State receives the same amount regardless of the needs of the individual, a light-care patient will be more profitable for the facility. The present reimbursement model in many States therefore discourages access for persons with dementia.

Other States use weighted systems, following a “case mix” or “patient mix” reimbursement methodology, that reimburse facilities based on the service needs of individual residents. These systems have the potential to eliminate any bias in admissions against patients regarded as needing heavy care, such as those with dementia. They could also improve patient care.

To the extent that the assessment tool used in these systems accurately reflects the functional disability of the individual and the associated service needs, higher reimbursement will be available for persons with greater service needs. Nursing homes would then have no incentive to limit admissions to light+ care patients. In addition, to the extent that greater reimbursement is available to fund care for an individual, more services can be provided to meet that person’s needs.

These potential benefits may not automatically be realized, however, simply because a State uses a case mix system. Some of these systems focus primarily on the medical needs of the individual and do not give sufficient weight to the person’s supervision and behavior management needs (see chs. 6 and 8). Unless these other needs are accounted for, the service needs determined for the patient and the associated reimbursement will not be adequate. The bias against admitting persons with dementia will persist, and promises of appropriate care may not be realized.

## **ADMINISTRATIVE PROCEDURES**

### ***Barriers Under Medicare***

The administrative procedures that raise barriers to beneficiaries with dementia are the same as those for others using Medicare. Obtaining information about services from fiscal intermediaries or carriers or about eligibility from Social

Security district offices is frequently difficult. It may take years to overturn an initial erroneous denial of eligibility for benefits and, thus, to obtain coverage.

Appeals of denial of eligibility are often delayed, especially at the reconsideration and administra -

tive law judge levels. Appeals about coverage of services are subject to the same limitations applicable generally: Hearings will not be granted under Part A unless the amount in question is \$100 or more, and judicial review will only be available if at least \$1,000 is in dispute (42 U.S.C. 1395ff (b)(2)). Appeal rights under Part B are more restrictive—a hearing will not be granted unless \$100 or more is in question, and no judicial review is available for dissatisfied beneficiaries (42 U.S.C. 1395u(b)(3)(C); see also, 15).

### ***Barriers Under Medicaid***

Similar administrative barriers exist in the Medicaid program. Eligibility determinations are often subject to substantial delays, above and beyond those associated with the underlying social security or welfare determinations. But there are some additional barriers unique to Medicaid.

#### **Civil Rights Enforcement**

The Medicaid eligibility rolls tend to include more people belonging to racial and ethnic minorities than do the Medicare rolls. The traditional access problems experienced by minority persons may therefore be present to a greater degree under Medicaid. Discrimination in violation of Title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d) may take many forms.

People in minority groups tend to have poorer health and may need more services. Yet in many States black Medicaid recipients 65 and older use only half the amount of services used by white Medicaid recipients of similar age. (See, e.g., 20.)

Recipients with dementia may also experience discrimination on the basis of national origin. Someone who learned English as a second language may revert to his or her original language after the onset of dementia. That person will face substantial difficulties obtaining services if providers do not communicate in the same language.

Discrimination on the basis of handicap (in violation of Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794)) may also be a problem. Bias against individuals perceived by nursing homes as needing heavy care persists despite the issu-

ance of letters of findings by the Office for Civil Rights of the Department of Health and Human Services. For example, the Office for Civil Rights has found a violation where a nursing home excluded persons with colostomies and ileostomies (28). Persons with dementia may experience such discrimination in attempting to gain access to day care and other providers as well.

Without civil rights enforcement by States (which are primarily responsible for limiting participation in the Medicaid program to providers who comply with Title VI and Section 504) and by the Federal Government (which through the Office for Civil Rights of the Department of Health and Human Services is ultimately responsible for enforcing compliance with the civil rights laws under both Medicare and Medicaid), these patterns and practices may persist.

Independent legal challenges by dissatisfied beneficiaries and recipients have been successful in some cases. However, the scope of the potential problem and the magnitude of the resources that may be needed suggest that private civil rights actions cannot substitute for government enforcement.

#### **Fair Hearings**

Medicaid recipients have a broad legal right to administrative hearings under the program. This hearing right could be used to check erroneous actions by agencies or providers. Its use, however, is limited.

Although statistics are no longer being collected, quality control data collected by DHHS prior to 1981 show that fewer than 5 percent of all recipients challenged actions taken in violation of Federal law to withhold, terminate, or deny benefits. Thus, at least 95 percent of the recipients subjected to negative case actions allow themselves to be deprived of their entitlements.

The problem is compounded by incentives created by the quality control process. States can have Federal financial participation disallowed only for erroneous State payments (see 42 CFR 431.804 for Federal policy after Jan. 1, 1984). A State can be penalized for overpayments or for inappropri-

ate coverage. Yet, if a State erroneously fails to make a payment or makes too small a payment, no meaningful Federal check exists. States thus

have a Federal incentive to reduce payments or services, but not to ensure full payments for all eligible persons,

## **OTHER FEDERAL PROGRAMS**

Before reviewing the issues that should be considered in reforming Medicare or Medicaid to better assist persons with dementia and their families, it is important to recognize that other Federal programs also provide services to this population. Although their funding levels are not as great, these programs often fill important gaps for Medicare and Medicaid beneficiaries and provide significant funding for those ineligible for either program.

Among these other Federal programs are the Legal Services Corporation Act (providing civil legal assistance for indigent persons) (42 U.S.C. 2996 et seq.) and the Food Stamp Act (providing funding for purchases of food by indigent persons) (i' U.S.C. 2011 et seq.). But probably the two most important programs affecting persons with dementia are the Older Americans Act (42 U.S.C. 3001 et seq.) and the Social Services Block Grant (42 U.S.C. 1397 et seq.).

The Older Americans Act is a Federal formula grant program that provides grants to States that submit approved plans for the provision of services to persons 60 years of age or older. Funding is available under the act for such services as legal assistance, meal programs at designated congregate sites, and home-delivered meals. In addition, funding can be provided for supportive services designed to prevent unnecessary institutionalization.

The Social Services Block Grant operates in a similar manner with a target population of low-income children and adults. Again, States must submit an approved State plan. Many use this funding to provide support for adult day care, respite care, home modifications, and similar community services that can improve the quality of life for persons with dementia and their families.

Because these two programs have limited funding, many States try to use these funds only for persons or services that cannot be reimbursed through programs such as Medicare and Medicaid. A State survey conducted in conjunction with this assessment revealed, however, that communication and coordination between the agencies administering these different programs is not always ideal (4). As a result, services are not always maximized.

In some instances, for example, formula grants fund services that could be reimbursed under Medicaid. In others, the failure to provide funding under a formula grant for a service (such as in-home respite care) that cannot be reimbursed under Medicaid without a waiver means that unnecessary placement of a person with dementia in a nursing home may occur as families become exhausted.

## **CONSIDERATIONS FOR REFORM OF THE MEDICARE AND MEDICAID PROGRAMS**

Three different types of options are available if it is decided to expand Federal support for persons with dementia and their families. Within each, decisions would have to be made about eligibility, scope of services, the method of reimbursement, and the nature of the administering agency or agencies.

Under the first option, Congress could decide to overhaul the existing Medicare and Medicaid programs. Apparent inequities and inefficiencies could be eliminated, eligibility requirements could be simplified, and services could be expanded to all groups in need of financial assistance. Various proposed national health insurance and cata-

strophic health insurance plans fall under this option. As a group that would be affected by any such changes, persons with dementia would be aided as others are.

Under the second option, Congress could decide to make incremental changes to the existing programs in order to improve Federal funding for persons with dementia. These changes could focus on the disease-neutral and other criteria that are inconsistent with public policy.

For example, the Listing of Impairments could be amended to specifically include dementia as a qualifying diagnosis. Similarly, a fairer division of marital income and assets could be mandated to bring many spouses living in the community above the poverty level. Case mix reimbursement systems could be mandated to eliminate any disincentives that may exist for the treatment of persons with dementia. Education of beneficiaries could be improved to foster a clearer understanding of the scope and limitations of the programs and to improve families' planning and decision-making. These incremental approaches and others would substantially improve the quality of life for persons with dementia and for their families.

Under the third option, if Congress concludes that insufficient support exists for significant reform of Medicare and Medicaid, it could still recognize the need for some additional Federal role to lessen the hardship of people with dementia and their families. Reform could consist of a specialized program to assist these groups. To the extent that such an approach is based on a closed appropriation, costs could be controlled while testing various financing and service delivery models. These models could then be expanded when additional funding became available.

Each approach has advantages and disadvantages. Before deciding on the most appropriate model, several questions should be answered.

**First, should the approach be categorical? Many of the problems identified for long-term care of persons with dementia are shared by elderly persons and other groups. Should the solution to these problems be limited only to a single category of disabled persons?**

**Second, should the approach be limited to those most in need? A social insurance program like Medicare provides benefits to the wealthy as well as to the poor. Should a solution be limited to only those who require governmental assistance based on some means test?**

**Third, should the approach be built around existing medical reimbursement programs? Medicare and Medicaid generally fund medical services. The long-term care services required by persons with dementia include medical, social, and other services. Should these nonmedical services qualify for support?**

**Fourth, what role should relative responsibility play? How should any changes be made so that they encourage the continued provision of voluntary care by relatives or others and do not simply substitute government-funded services for private care?**

These are among the major questions that must be asked and answered before reform is undertaken. Incremental or broad reform can then be initiated to address the critical unmet needs of persons with dementia and their families. Whatever approach is undertaken, because the size of this population is potentially so large and the unmet needs so great, any significant improvement in the current situation will necessitate a significant commitment of governmental financial resources. Thus, the current suffering can be significantly ameliorated, but only at a significant fiscal cost.

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