Medicaid and Disability: The Unlikely Entitlement

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means-tested medical care, pays significant benefits to people with disabilities. Yet, the scale of the Medicaid disability entitlement and the unique suitability to persons with impairments of the program's broad and plastic benefit categories have gone virtually unremarked. The history of the Medicaid disability entitlement suggests reasons for its obscurity. It is the product not so much of design as of accretion—the gradual and state-specific accumulation of functions or clienteles—and of default—the failure of social insurance to obviate the need for welfare.

Almost 3.2 million people meeting the program's definition of disability were Medicaid recipients nationally in fiscal year 1986 (U.S. Social Security Administration 1987). In the same year, the National Center for Health Statistics (NCHS) (1987) identified approximately six million working-age Americans with disabilities that rendered them "unable to carry on a major work activity." The two figures are not entirely comparable, because the first includes a small number of disabled children and perhaps half a million people now over the age of 65 but originally eligible for Medicaid on account of disability rather than age (Rymer and Burwell 1987). Still, both NCHS and Medicaid use work as the standard for disability, so the Medicaid program would appear to serve nearly one-half of all Americans too disabled to work. The cost of Medicaid services to these people with

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disabilities was almost \$15 billion or 36 percent of all program expenditures in 1986 (U.S. Health Care Financing Administration 1986).

The Medicaid disability entitlement is also significant by two relative measures. First, the Medicaid program serves as many and spends about as much on disabled as elderly recipients (in about one-half the states, disabled recipients are more numerous or account for more spending)—this despite the fact that poor people with disabilities must prove severe functional limitations while poor elderly people need only be 65 or older to enroll. These two groups, in turn, constitute 28 percent of Medicaid recipients but occasion 75 percent of all program expenditures (U.S. Health Care Financing Administration 1986). Second, as many disabled people are Medicaid recipients as Medicare beneficiaries. This means that individuals meeting virtually the same definition of disability are as likely to become clients of the welfare system as to accrue benefits through the nation's largest public insurance mechanism. Here, people with disabilities stand in stark contrast to older people. The number of elderly Medicare beneficiaries is almost ten times the number of elderly Medicaid recipients (U.S. Social Security Administration 1987).

The significance of the Medicaid disability entitlement is the topic of this article, but it has received surprisingly scant attention elsewhere. Although it was beyond the scope of this effort to exhaust primary sources, secondary accounts of the origin of the Medicaid program describe minimal consideration of disability benefits per se, much less a recognition that the Medicaid disability entitlement would be utilized as widely or as heavily as it has been. Nor is this apparent inattention distinctive to the early Medicaid program. People with disabilities as a category of Medicaid recipient are still rarely the focus of program analysis or of proposals for Medicaid reform.

This article establishes Medicaid's unlikely significance for people with disabilities and their unlikely significance for the program. It first describes the scope of the Medicaid disability entitlement. The second section documents the default of social insurance by comparing Medicaid's disability-related eligibility requirements and service coverage with the same features of the Medicare program. The third section takes up the theme of accretion and Medicaid's incremental, even inadvertent, provision of disability-sensitive services to an expanding disabled clientele. The final section considers, in the light

of earlier discussion, proposals for the reform of health care benefits for people with disabilities. The article focuses special attention on one state, Ohio, in order to clarify the ambiguities of aggregate data across 53 distinct Medicaid programs and to inform speculation about the meaning of national indicators.

The Scope of the Medicaid Disability Entitlement

All disabled Medicaid recipients meet two eligibility criteria—one functional, the other financial. The first is the Social Security Administration (SSA) definition of disability, which is used by both the Social Security Disability Insurance (SSDI) program and Supplemental Security Income (SSI), its welfare counterpart, and which combines physiological and work function. According to this definition, disability is that inability to earn a living which results from a medically verifiable, severe, physical or mental impairment expected to last at least twelve months or to result in death. An individual's inability to engage in what the SSA definition terms "substantial gainful activity" (SGA) is evidenced by earnings of less than \$300 per month, and although impairment must be the primary obstacle to SGA, disability determination takes certain other employment-relevant factors, such as work experience, into consideration.

Persons eligible for Medicaid are generally the poorest of those who meet this definition of disability. In most states, an individual is automatically eligible for Medicaid if he or she is eligible for SSI, for which the means test is currently set at \$354 a month in "countable" income and qualifying assets of no more than \$1,900. In 23 states, Medicaid benefits are also paid to disabled individuals who receive a state-funded welfare payment (U.S. Health Care Financing Administration 1987b). Fourteen states have chosen to exercise the more restrictive, so-called 209(b), option which allows Medicaid eligibility requirements to be more stringent than the means or disability tests for SSI (U.S. Health Care Financing Administration 1987b). Ohio is a 209(b) state: a disabled individual may have only \$300 a month in countable income and hold only \$1,500 in assets to be eligible for the program. SSI benefits are not countable in Ohio, however, and even in states where they are, a federal "spend-down" requirement softens the 209(b) option. Essentially, a program applicant who incurs ã,

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specific medically related expenses is considered to have diminished his or her income by that amount. The 209(b) option, therefore, may close the program to SSI recipients who are more affluent or less impaired, but it extends Medicaid eligibility to SSI ineligibles with costly disabilities. A variation on the 209(b) spend-down provision is the medically needy option available to the states. A disabled person whose income exceeds the SSI limit but who incurs relatively large medical bills may be deemed Medicaid-eligible or eligible for a subset of Medicaid benefits. Medically needy eligibles must spend down to 133 1/3 percent of the AFDC limit within and for an eligibility period of between one and six months, depending on the state. Thirty-five states have medically needy programs (U.S. Health Care Financing Administration 1987b). Nationally, medically needy recipients are approximately 16 percent of all Medicaid recipients (U.S. Health Care Financing Administration 1986).

Two recent adjustments to Medicaid financial eligibility policy allow for the enrollment of less impoverished people with disabilities. States may now choose to cover disabled people whose incomes fall between previous eligibility levels and 100 percent of the federal poverty level (\$6,320 for an individual in 1987) as long as people over the age of 65, pregnant women, and children under the age of 5 are permitted to meet the same requirement. Seven states were covering disabled people with incomes close to the federal poverty level in 1987 (Lipson, Fisher, and Thomas 1987). A second liberalization of Medicaid eligibility policy occurs under the "1619" workincentive program for SSI recipients. Section 1619 of the 1980 Social Security Act Amendments allows SSI recipients to continue to receive cash benefits after they secure employment at wages in excess of the SGA amount. They may also retain their Medicaid benefits if they need Medicaid-covered services in order to work and cannot afford to purchase them.

The services offered to Medicaid eligibles with disabilities are extensive and usually free. Although federal policy allows for considerable variation among the states in the services they cover, states are required to provide: physician, inpatient and outpatient hospital, rural health clinic, other laboratory and x-ray, home health, and nurse-midwife services; skilled nursing facility (SNF) services for individuals 21 years of age and older; family planning services and supplies; and early and periodic screening, diagnosis, and treatment (EPSDT). States

may also provide any or all of 32 optional services, including several that may be especially important to people with disabilities: prescription drugs; physical, occupational, and speech therapy; prosthetic devices; eyeglasses; rehabilitation; intermediate care facility (ICF) and intermediate care facility for the mentally retarded (ICF-MR) services; and personal care.

Medicaid policy simultaneously ensures access to, and controls utilization of, medical benefits. If a service is part of the Medicaid entitlement, those eligible must be able to find, use, and benefit from it. Only nominal copayments may be required. On the other hand, both federal and state governments impose limitations on mandatory and optional services. Federal limitations tend to emphasize the professional status of the provider or prescriber of a service. Some providers. such as nursing homes, must meet extensive qualifications beyond licensure. Frequently, states reserve the right to authorize services on a case-by-case basis or set the amount to which users are entitled during some period of time. And states exercise considerable discretion in choosing payment methodologies and setting fee schedules and so may depress the supply of any or all services. Still, the Medicaid disability entitlement allows virtually all eligibles to see a doctor and be admitted to a hospital whenever necessary and, in some states, a Medicaid card buys prescription medications, prosthetic devices, physical therapy, and a personal care attendant as well.

Disabled people eligible for Medicaid in the state of Ohio receive all mandatory services and all but one of the optional services named above. Personal care is not yet available, although a proposal for its addition became law with the Medicaid agency's budget for the next biennium. State utilization data for fiscal year 1987 show a total of 124,399 Medicaid recipients eligible on account of disability, constituting 11 percent of all Medicaid recipients in that year. (Unless otherwise noted, all Ohio utilization data are taken from Ohio Department of Human Services 1987). Vendor payments of more than \$795 million were made on their behalf, and these were almost 35 percent of all payments made. Disabled people utilized general medical services most heavily. In addition, just over 8,000 disabled eligibles also resided in ICFs-MR and almost 13,000 in other nursing homes (ICFs and SNFs); almost 4,900 received home health services. The ICF-MR benefit alone cost the Ohio Medicaid program more than \$250 million and other nursing home care for disabled recipients more

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than \$150 million. A little over \$4 million was spent on home health care for Medicaid recipients with disabilities.

In Ohio, 38,093 or about 30 percent of all recipients eligible for Medicaid by virtue of their disabilities receive no cash assistance. Too affluent for SSI, they have spent down their "excess" income and assets on items of medical necessity. Not surprisingly, recipients who have spent down utilize some services more heavily than their SSI-eligible counterparts. Whereas SSI-ineligible recipients are represented among the users of general medical services approximately in proportion to their number, they are disproportionately likely to reside in long-term care facilities, where high unit costs and extended stays create Medicaid eligibility. Spend-down, and similarly the medically needy option, then, allow disabled individuals financially ineligible for income maintenance benefits to acquire through Medicaid the kinds of services that have exhausted their resources.

Medicaid and Medicare: Entitlement by Default

Although Medicare, like Medicaid, serves people who meet the SSA definition of disabled, the programs' eligibility requirements and service coverage diverge markedly. The history of this divergence reveals that Medicare defaulted on a universal disability entitlement, leaving unmet a set of disability-related needs that Medicaid was willing, if not widely observed, to meet. (The so-called repeal of the Medicare Catastrophic Coverage Act of 1988, which repeals expanded Medicare benefits but not the extension of Medicaid coverage, occurred too recently to be incorporated into this article. It does, however, lend support to the argument that follows.)

Medicare is the medical entitlement that accompanies the contributory SSDI program, but in order to be eligible for Medicare benefits, most SSDI beneficiaries must have received cash payments for twenty-four months. At the end of 1986, 2.7 million disabled workers were being paid SSDI benefits, and about 500,000 adults were receiving a Social Security benefit as disabled children of retired, deceased, or disabled workers. One-hundred-thousand disabled widows and widowers over the age of 50 were also cash beneficiaries (U.S. Social Security Administration 1987). In 1983, the last year for which full

Medicare figures are available, 2.9 million people with disabilities were enrolled in Medicare Part A (U.S. Health Care Financing Administration 1987a). The number of disabled Medicare beneficiaries, then, was likely between 2.9 and 3.3 million in December 1986, because some cash beneficiaries had necessarily received benefits for fewer than 24 months. Whereas disabled adult children, widows, and widowers may be of any age, disabled workers pass out of that category at age 65, so their number is not entirely comparable to the number of disabled Medicaid recipients. But even adjusted upward to include over-age SSDI beneficiaries, the Medicare count is approximately equal to the 3.2 million Medicaid figure. The overlap of disabled Medicare and Medicaid beneficiaries was estimated at 20 percent in 1984 (Gornick et al. 1985; U.S. Health Care Financing Administration 1984). Disabled people are thus either equally likely to be welfare recipients as social insurance beneficiaries or, at the other extreme, they are welfare recipients despite their social insurance benefits.

Medicaid serves several distinct groups of disabled people for whom Medicare is unavailable or insufficient. Medicare eligibility for people with disabilities requires that they meet the SSA definition of disability, that they have paid into the Social Security system for a sufficient period of time, and that they have, in turn, been paid SSDI benefits for 24 months. The Medicaid program also demands that disabled recipients meet the first of these criteria, but a means test replaces both the second and the third criteria. As a result, some Medicare beneficiaries are also eligible for Medicaid because, despite their other benefits, they are impoverished. Some individuals meeting the SSA definition of disability are ineligible for Medicare because they have worked too little to qualify for SSDI. Some are temporarily ineligible for Medicare because, although they qualify for SSDI, they have not yet received benefits for 24 months. If they are poor enough if without other medical benefits, they have spent down into poverty these individuals who are ineligible for Medicare are eligible for Medicaid. People over the age of 65 are less likely to feel the effects of Medicare's default. They are more likely to have contributed to Social Security over time, and, more to the point, they are not required to wait two years between the initiation of cash benefits and the availability of medical benefits. Unlike people with disabilities, moreover, older people who do not receive Social Security benefits may buy health care coverage under Medicare, and recent legislation requires

the Medicaid program to effect a Medicare buy-in for low-income elderly not otherwise enrolled.

Both the Medicare and Medicaid programs furnish health care benefits to eligible populations, but Medicaid benefits are available at a greater remove from acute illness or an acute episode of chronic illness. Because disability is, by definition, residual to or entirely separate from acute illness, the Medicaid policy of finding "medical necessity" in the functional aftermath of medical acuity makes its disability coverage more complete than that provided under Medicare.

That Medicaid takes a broader view of medical care is evident in the range of services for which Medicaid reimbursement is made. Among the mandatory services, both EPSDT and family planning are explicitly oriented toward functioning rather than illness. EPSDT is also one of the few public programs charged specifically with identifying and compensating for sensory impairment in children. Medicaid programs may cover prescription drugs on an outpatient basis. For some people with disabilities, including many mentally ill people, the availability of pharmaceuticals is critical to the containment of dysfunction. Community mental health centers may also receive Medicaid funding through the clinic services option—a very general category more descriptive of setting than service and expressly including preventive and palliative care. Transportation to and from other Medicaid-covered services is also reimbursable under the program.

Medicaid's nursing home benefit, which includes long-term residence in an ICF or ICF-MR, is substantially more generous than Medicare's coverage of time-limited stays in skilled nursing facilities only. Medicare nursing home payments totaled less than \$500 million in 1984. About 300,000 beneficiaries were served; of these, 9,000 were people with disabilities (U.S. Social Security Administration 1987). Medicaid, which covers the cost both of SNF patients whose care is deemed insufficiently "skilled" for Medicare reimbursement (or who are not eligible for Medicare) and of ICF and ICF-MR residents, spent more than \$12 billion on ICF and SNF care, and another \$5 billion on services delivered in ICFs-MR in fiscal year 1986 (U.S. Health Care Financing Administration 1986). Using Ohio as a guide, approximately 17 percent of Medicaid ICF and SNF residents are disabled. ICF-MR recipients raise the figure for all Medicaid nursing homes to almost 25 percent.

Home health benefits also offer a useful comparison between Med-

icare and Medicaid. Medicare provides for intermittent visits to a homebound beneficiary, who may receive home health aide services (including personal care) only if he or she also requires skilled care. As in the case of skilled nursing facility care, this Medicare benefit is intended as a short-term buffer against the disabling aspects of acute episodes but provides little in the way of a strategy for living with disability. The Medicaid home health care beneficiary, in contrast, need not be homebound nor require skilled care, although services must be prescribed and reviewed by a physician and provided by a home health agency. Virtually every state sets limits on the utilization of home health care. Prior authorization is required for nursing services in some states. Others set limits on the number of visits recipients may have or the cost of equipment (U.S. Health Care Financing Administration 1987b). Still, in Ohio for example, any Medicaid recipient whose physician will prescribe it is entitled to up to eight hours a day or forty hours a week each of nursing, physical therapy, and home health aide services.

Despite the greater scope of the Medicaid home health benefit and the fact that it is the fastest growing Medicaid service category (Lipson and Fisher 1986)—utilization rates under that program are similar to home health utilization rates under Medicare. Approximately 4 percent of disabled Ohio Medicaid recipients use home health services (or claim a Medicaid copayment for Medicare home health services); the corresponding Medicare figure was 5 percent in 1983 (U.S. Health Care Financing Administration 1987a). Ohio Medicaid spends about \$900 per user per year on home health services. The Medicare expenditure is closer to \$1,200. Medicaid home health clients are probably not receiving fewer visits than their Medicare counterparts. The lower annual expenditure undoubtedly reflects both the lower rate at which Medicaid reimburses providers for the same service and the Medicare requirement that every home health client be homebound and in need of relatively expensive skilled care. (The inclusion of Medicare copayments for recipients under both programs also reduces Medicaid's per capita figure.) But neither is the Medicaid home health benefit providing substantially more of this service certainly not as much as might be provided given the less restrictive way the benefit is defined.

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underutilization of home health services by disabled Medicaid recipients. Medicaid reimbursement rates are widely considered prohibitively low: in 1986, \$40 per nursing visit from Medicaid compared with a cost-based, agency-specific fee of about \$75 per nursing visit from Medicare. An agency may choose not to participate in Medicaid at all or to provide only those Medicaid visits that can be subsidized through other funding sources. Furthermore, federal Medicaid policy requires that even the least skilled home health services be provided by a home health agency, and because Medicare is, by far, the largest buyer of home health services (Davis and Rowland 1986), home health agencies are oriented toward and staffed for the more skilled—and costlier—Medicare benefit. Whatever the reason, Medicaid characteristically allows recipients to use many of the same services under a less encumbered service category—personal care—which is further discussed below as an instance of accretion.

The history of the two programs shows Medicaid to have evolved largely in Medicare's shadow—and as a brake on the proliferation of universal entitlements that Medicare threatened. These origins and the fact that Medicare's default was only demonstrable over time undoubtedly account for some of the reticence by the policy community to acknowledge the scale of the Medicaid disability entitlement.

In the 30 years following the enactment of the 1935 Social Security Act, access to health care remained problematic. Cash benefits under various programs did not meet rising costs, and many income-maintenance beneficiaries were forced to rely on charity care and bad debt. The extensive, continuous, and heated congressional debate on national health insurance produced two camps—one committed to advancement toward the European model with a universal benefit, at least for the elderly; the other seeking to blunt the desire for national health insurance with a comprehensive but still means-tested medical assistance program. Between 1950 and 1965 the distribution of power in health affairs favored the latter camp. The 1950 Amendments to the Social Security Act authorized vendor payments to health care providers by state agencies on behalf of welfare recipients, and the 1960 legislation known as Kerr-Mills provided a more generous federal/state match and created a new category of recipients—the medically indigent—whose means disqualified them from cash assistance

but whose medical expenses now entitled them to medical relief (Stevens and Stevens 1974). Kerr-Mills, which foreshadowed the Medicaid program, attempted to weaken the case for a universal health care benefit (see, for example, Stevens and Stevens 1974; Marmor 1973). Nevertheless, the limits of the program, especially the requirement that beneficiaries be reduced to indigency, failed to satisfy advocates of national health insurance, especially for the elderly.

Medicaid's inclusion in the 1965 legislation was, in part, a strategic move by Medicare's proponents. Wilbur Cohen reports that he designed the Medicaid program out of the provisions of Kerr-Mills in response to Wilbur Mills's query as to how Cohen would defend Medicare against charges of creeping socialism (Cohen 1985b). Although Stevens and Stevens refer to a group of analysts who viewed Medicaid as a weighty complement to Medicare and some who even saw the former as the forerunner of socialized medicine. Cohen recalls that the "health policy community" occupied itself with Medicare alone, "unaware of the possibilities inherent in Medicaid." Medicare and not Medicaid was, after all, the major departure from previous public provision of health care. It was arguably the first victory in the national health insurance wars, and it benefited a well-organized and watchful elderly constituency. Moreover, Medicare had been terribly hard won. As Cohen puts it, "The fight was so intense that nobody paid much attention to the Medicaid proposal, which accompanied the Medicare proposal" (Cohen 1985a).

Unlike Medicare, Medicaid benefited people with disabilities from the start; as an expansion of Kerr-Mills, it appropriated the entire Kerr-Mills clientele. This inclusion of disability benefits in Medicaid and not Medicare might have made the Medicaid disability entitlement all the more noteworthy. That it did not can probably be attributed to the expectation that public disability benefits would follow incrementally behind benefits for other groups. The Social Security Act of 1935 provided cash assistance to old people and blind people; Aid to the Permanently and Totally Disabled was instituted fifteen years later. Disability insurance was finally appended to old age insurance after 21 years. Four years later coverage was extended to people under 50. Even Kerr-Mills excluded blind and disabled recipients until 1962. In 1965 there was reason, then, to believe that future incremental changes in Medicare would include universal benefits to people with disabilities.

Medicaid and Welfare: Entitlement by Accretion

The current boundaries of the Medicaid disability entitlement were achieved largely by accretion—an accumulation of disabled subpopulations through unrelated policy developments and the addition of optional and waivered services logically or budgetarily linked to prior programmatic commitments.

First, people with disabilities constitute a growing proportion of all Medicaid eligibles as a result of scattered details of income maintenance policy. Because the federally funded SSI benefit is indexed to the cost of living while the federal/state AFDC benefit is neither indexed nor very regularly increased, and because the size of a cash benefit virtually sets its income eligibility level, poor families with children are increasingly denied AFDC and, therefore, Medicaid coverage, while older people and people with disabilities continue to qualify for Medicaid by way of SSI. At the same time, for a variety of reasons including improvements in nonmeans-tested income maintenance programs, proportionally fewer old people depend on the welfare system.

The epidemiology of the disabled Medicaid population also helps explain its gradual, and partially unplanned, expansion. Using the SSI program as a proxy for Medicaid, 27.1 percent of recipients under the age of 65 are mentally retarded and 22.6 percent are mentally ill. The other heavily represented diagnostic groups are diseases of the nervous system and sense organs (12.8 percent), of the circulatory system (8.7 percent), and of the musculoskeletal system (7.6 percent). No other individual diagnostic group accounted for more than 5 percent of the cases (U.S. Social Security Administration 1987). Data from the SSDI (and by proxy the Medicare) program provide a pertinent comparison. Although the definition of disability is the same for SSDI as for SSI, the medical grounds for admission to the former are distributed somewhat differently. Only one-quarter of those receiving SSDI payments are mentally ill or mentally retarded, and mentally retarded beneficiaries constitute only 4.3 percent (U.S. Social Security Administration 1987). The far greater frequency of mental disability among SSI than among SSDI beneficiaries is slightly reduced for the Medicaid program, because mentally disabled SSDI beneficiaries are more likely than their physically disabled counterparts to survive the 24 month waiting period for health care benefits. Still,

Medicaid serves a substantially larger mentally ill and mentally retarded clientele than does Medicare. People with mental disabilities are less likely to have made sufficient payroll contributions to secure SSDI/Medicare benefits. And the service offerings of the Medicaid program—including prescription drugs, personal care, and residence in an ICF-MR—are especially well suited to the large numbers of mentally ill and mentally retarded people released from institutions.

The deinstitutionalization movement of the 1960s and 1970s relocated hundreds of thousands of people with mental disabilities in communities where employment-related health care benefits were generally unavailable to them. Large numbers of people who were expressly ineligible for Medicaid benefits as long as they resided in "institutions for mental disease" or state mental retardation facilities easily met Medicaid eligibility requirements as community residents or, as was frequently the case, once they were "reinstitutionalized" in nursing homes. Analysts disagree about whether or not state governments actually implemented deinstitutionalization in order to replace state-funded institutional care with federally supported benefits to individuals, but, in either case, Medicaid eligibility became a critical underpinning of the deinstitutionalization effort.

Medicaid-covered services to these and other disabled people are unusually responsive to functional impairment. A plasticity of service categories and malleability of benefit limits allow for the easy accretion of, for example, long-term care benefits across settings and levels of medical acuity. The requirement that all Medicaid home health care be provided by agency staff limits access by those eligible to the relatively unskilled services of an aide, but the states' option to make personal care a Medicaid benefit greatly expands the availability of these same services under another name. Federal regulations require that personal care be prescribed by a physician and supervised by a registered nurse, but it may be delivered by anyone, other than a relative, who is merely "qualified to provide the service" (42 Code of Federal Regulations ch. 4 [10-1-87 ed.] sect. 440, no. 170, p. 148). Moreover, federal policy is explicit that the personal care option (which includes bathing and grooming, bladder and bowel care, assistance with medications, and household services related to medical need) is intended to provide "long-term maintenance or supportive care, as opposed to the short-term, skilled care required for some acute illnesses" (U.S. Health Care Financing Administration 1979). 1

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Twenty-three states provided personal care as an optional Medicaid service in 1986. Of these, 20 set limits of some kind, including prior authorization, maximum hour and dollar amounts, or the requirement that recipients exhibit a specified degree of functional impairment (U.S. Health Care Financing Administration 1987b). Still, the Medicaid program nationally spends about as much on personal care as on the home health benefit (interview with a HCFA official), even though the former is offered in fewer than one-half the states.

The Medicaid program accommodates functional impairment even more broadly under Section 2176 of the Omnibus Budget Reconciliation Act of 1981, which allows states to apply for a waiver of federal regulations and so to provide exceptional home- and community-based service packages to specific Medicaid populations. States may use the waivers either to expand the services Medicaid already offers in that state (by, for example, lifting the personal care limits noted above) or to offer completely new services to Medicaid recipients. Forty states hold 2176 waivers (U.S. Health Care Financing Administration 1987b), and approximately \$500 million were spent nationally in fiscal year 1987 for waivered home- and community-based services under the 2176 option (interview with a HCFA official), an increase of 40 percent over 1985 (Burwell 1986).

One scholar of the Medicaid program rightly asserts that the "policy significance of the Section 2176 waiver is often not as appreciated as it should be." He mistakenly claims, however, that "it represents a substantial philosophical shift away from the medical model approach underlying Medicaid service coverage policy since the program's enactment" (Burwell 1986). To the contrary, the 2176 waivers are molded from what is perhaps the signature benefit of the Medicaid program: nursing home vendor payment for services in a SNF, ICF, or ICF-MR. Although the waiver programs vary considerably from state to state, the 2176 provision was designed expressly for aged or disabled recipients who would otherwise require institutional care and who, on average, can be served at home for no more than the cost of that care. A waiver client must at a minimum meet the state's criteria for Medicaid nursing home benefits. States are encouraged to ensure cost effectiveness by using known predictors of nursing home utilization to target admission to the waiver program further. Waiver clients may, depending on state policy, be permitted to meet the less stringent financial eligibility requirements of institutionalized individuals although they remain in the community. Similarly, the number of clients served under the waiver option is limited by a state's ability to prove to federal officials that waiver expenditures are completely offset by savings on nursing home care. In Ohio, the elaborate federal formula used to set waiver capacity yielded a statewide total of 5,708 slots for fiscal year 1988.

The breadth of Medicaid's nursing home coverage both motivates less restrictive home care options and provides a care setting uniquely organized around functional impairment. Because intermediate care facility services are minimally specified in federal regulations, the ICF benefit funds a variety of congregate living arrangements. ICF care includes room and board and health-related services—a term loose enough to include personal care and social casework and to justify utilization long after the experience of acute medical need or in its complete absence. Although it is an optional service, ICF care is a benefit in every state, and if a beneficiary is deemed to have a "nursing home level of care," i.e., to require a state-specific standard of need beyond room and board, there are no day limits set on her or his stay (U.S. Health Care Financing Administration 1987b).

A further variation on Medicaid long-term care, the ICF-MR benefit, appends "active treatment" to ICF care. Medicaid recipients with mental retardation or related conditions may reside in an ICF-MR as long as they also require and participate in a regimen of programming designed to maximize adaptive behavior. The overwhelming majority of ICF-MR residents are mentally retarded, but related conditions are virtually synonymous with developmental disabilities and include many physically disabled people who were less than 22 years of age at the onset of disability. The budgetary impact of the ICF-MR benefit is considerable: \$4.7 million, or 12.7 percent of the Medicaid budget, in fiscal year 1985; .7 percent of all Medicaid recipients and 5 percent of all disabled Medicaid recipients resided in ICFs-MR that year. Utilization of ICF-MR services rose steeply between 1975 and 1980, when many state mental retardation institutions became certified for Medicaid payment (Rymer and Burwell 1987). Furthermore, some of the smallest ICFs-MR are indistinguishable from other group homes, so states may close their institutions altogether and relocate the residents, with full Medicaid coverage, to community-based facilities.

This highly plastic Medicaid nursing home benefit, source of additional services to people with disabilities, itself had two distinct

historical sources (Vladeck 1980). The first is the almshouse, where the improverished "aged and infirm," "insane," and "defective" resided from the early nineteenth century (Stone 1984). It became a fixture of American aging policy in 1950, when amendments to the Social Security Act both allowed payment of old age pensions to residents of public nursing homes and provided federal matching funds for nursing home vendor payments on behalf of impoverished residents. The second source is the medical-care facility, an increasingly prominent focus for twentieth-century health policy and an identity accorded nursing homes in 1954 when they became eligible for federal construction subsidies (Vladeck 1980).

The Medicaid program which, unlike Medicare, embraced both the almshouse and medical facility traditions, offered extensive nursing home benefits from the start, but originally only in facilities meeting Medicare conditions of participation. So few of the nursing homes being paid through Kerr-Mills were able to meet those conditions, however, that under pressure from the nursing home industry, Congress created the intermediate care facility—a nursing home held to lower standards ostensibly because its residents required less (Vladeck 1980)—and the ICF benefit: a simultaneous accommodation of disparate income maintenance, health care, and regulatory policies.

Medicaid's long-term care entitlement is also a product of generalized, accretive characteristics that predispose the full Medicaid benefit package toward services defined and delivered to mitigate functional impairment. Medicaid was created as a welfare program and as such, made it a program policy to (re)establish functional independence in individuals and families. Medicaid was similarly motivated to blur distinctions between medical and social services, professional and practical care giving, so as to move a recipient toward disenrollment. Unlike Medicare (or the medical benefits associated with workers' or veterans' compensation), Medicaid disability benefits are paid to people who by definition are not yet economically self-sufficient; they have two problems, so to speak, and disability-related services, with their functional orientation, may be viewed as a means for addressing both.

Finally, Medicaid was structured as a state/federal, rather than purely federal, program; federal legislators created broad service categories which would preserve the authority of state governments, meanwhile trusting that the burden of a state match would encourage

states to delineate modest benefits within those categories. Unfortunately for many eligibles with disabilities, the promise of decentralized policy making remains a hostage to its cost. Some states have chosen to provide less rather than more in the way of services, usually as a result of competing demands on state revenues. Still, if long-term care coverage is illustrative of the workings of the program, the lure of partial federal funding for popular benefits such as the 2176 waiver may move states to take further advantage of Medicaid's potential for accretion.

Disability and Health Care Financing Reform

Critics of Medicaid policy consider the pairing of acute care for poor families with children with nursing home care for older people the idiosyncratic weakness of a program whose design was hurried and unthinking. In fact, restrictive Medicare eligibility requirements for people with disabilities and their need for function- rather than illness-related services make Medicaid's inadvertent pairing of acute and long-term care uniquely suitable to the health needs of disabled people. It is for disabled recipients alone that the Medicaid program serves as both primary insurer for general medical care and payment source for needed long-term care services.

Proposals for health care financing reform—and even for Medicaid reform—generally neglect this compatibility of the program with the needs of disabled people. One frequently offered proposal would separate acute care from long-term care benefits, often so as to remove the latter from the Medicaid program altogether. The National Study Group on State Medicaid Strategies (1984) "finds no conceptual, practical, or political justification for maintaining the current combination of primary, acute health care and long-term care services in one program" and proposes that primary health care for poor people and long-term care for people with functional impairments constitute two distinct public enterprises. Charles Atkins, Commissioner of the Massachusetts Department of Public Welfare, testifying before the Senate Finance Committee on behalf of the American Public Welfare Association, argued for removing long-term care expenditures from the Medicaid budget so as to increase health care coverage for poor families with children. According to Atkins, the latter needlessly ē

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compete with the elderly for Medicaid funds when long-term care could be financed through the creation of a Medicare Part C and/or private long-term care insurance (Atkins 1987). Similarly, a recent report by the American Hospital Association (AHA) notes that Medicaid "has become a secondary insurance program for the elderly, blind, and disabled, rather than a primary insurance program for the poor" (Iglehart and White 1987). The AHA also proposes that long-term care benefits be removed from the Medicaid program and relocated in Medicare (Friedman 1987).

These proposals reveal a misunderstanding of the history of Medicaid utilization by disabled people. They ignore people with disabilities or consider them equivalent to elderly people. Categories are confounded; a Medicaid program devoted entirely to acute care will certainly not serve AFDC recipients alone, when in Ohio 29 percent of inpatient hospital, 22 percent of outpatient hospital, and 21 percent of physician services are claimed by people with disabilities. Nor will the transfer of responsibility for long-term care to Medicare accommodate all the users of nursing home services. Unofficial data from the Ohio Medicaid program indicate that 44 percent of disabled recipients under the age of 65 residing in long-term care facilities are ineligible for Medicare. A Medicare long-term care program would benefit disabled Medicare beneficiaries, but the poorest of them would still depend on Medicaid for the inevitable premiums, copayments, and deductibles

The source of contemporary reticence about the Medicaid disability entitlement appears to be primarily conceptual. Despite the increasing visibility of people with disabilities generally and the Medicaid-targeted advocacy by and on behalf of people with specific disabilities, the population of disabled recipients simply does not cohere in the minds of most policy makers. A recent memorandum from the State Medicaid Directors Association announces the reorganization of that group's committee structure. Neither are the new committees—Eligibility, Reimbursement, Program Operations, Program Integrity, Medical Coverage and Policy, and Long-term Care—population-specific, nor do the brief agendas included make reference to individual populations (except in the case of an ICF-MR item, where a specific service is available to only one recipient group). Most internal Medicaid reporting reveals the same service-focused rather than population-focused bias. Financial eligibility for the program is often determined

separately from disability status and both determinations are organizationally discrete from the expenditure of service dollars.

The rules of the Medicaid program are themselves partially responsible for the inattention of most administrators to the eligibility categories of the people they serve. Medicaid is an all-or-nothing entitlement. One is eligible or one is not, and once eligible, the grounds for eligibility are irrelevant to access; the basis for all future claims is the very generic "medical necessity." Even at the service delivery level, disabled Medicaid recipients do not immediately present themselves as members of a single group. Middle-aged people with lower-back pain and heart disease, mentally retarded people living in long-term care facilities, ventilator-dependent children, mentally ill people living independently on strict drug regimens, and employed people with quadriplegia and a personal care attendant do not easily cohere in the minds of those running, worrying about, or even attempting to reform welfare medicine in America.

Some recent legislative proposals do, however, address Medicaid benefits for people with disabilities. One seeks to redress the institutional bias of Medicaid services to mentally retarded people by mandating extensive home- and community-based care for, and expanding the population that would qualify as, "developmentally disabled." A second, similarly ambitious, proposal by Senator John Chaffee would create a Medicaid "buy-in" for a population more affluent than current Medicaid eligibles but too poor or too impaired to secure private health insurance. States could opt to provide a set of basic services, including rehabilitation and prosthetic devices, to any individual whose income is less than the federal poverty level, to those with incomes between 100 and 200 percent of that level for a slidingscale premium, and to those whose incomes exceed 200 percent of the poverty level but whose disabilities or previous medical expenses have made them uninsurable, for a premium equal to the average recipient's annual expenditures. Some services would be mandatory for any state choosing to participate in the buy-in; others, such as home- and community-based care, would be optional. Nursing home care, however, including services in an ICF-MR, would be excluded from the program, reportedly because the senator believes that all long-term care needs are better met at home.

The last proposal represents a promising departure from the Med-

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icaid disability entitlement as it currently operates. Access to health care would be considered separately from the Social Security Administration's work-related definition of disability. Income level and the threat of uninsurability to solvency would replace a capacity for substantial gainful activity as the gate to Medicaid benefits. Moreover, people with disabilities would buy into a program whose service coverage is better suited to their needs than are Medicare or private insurance policies. The most useful aspect of Medicaid's welfare legacy—entitlement to services in the space between acute illness and functional independence—would be preserved even as the most punitive one—stringent financial eligibility requirements—was softened. In addition, the introduction of an insurance principle into Medicaid would both broaden its constituency and increase its palatability to recipients and the general public.

Such a change in the design of the Medicaid program would implement the claim that disability is less a personal misfortune than the shared misfortune of living in a disabling environment (Hahn 1987). Not only does insurability modify the terms on which disabled people interact with the environment, but its very addition to the Medicaid program would be a form of environmental modification. Medical insurance is a basic structure of modern society; insurability through Medicaid would adapt that structure for use by people here-tofore excluded because insurance was inadequately designed.

Finally, a Medicaid buy-in would respond to both the significance of the Medicaid disability entitlement and the reasons that significance has been achieved without notice. It would make explicit the historical functions of the Medicaid program: to provide a safety net beneath our (not-quite) universal entitlements, to accommodate the shifting boundaries of the population at risk, and, further, to insure a diverse population broadly and deeply enough to create if not a universal benefit, an intelligently categorical one. Conceptually, the Medicaid buy-in offers to resolve the confusion evident in proposals to separate poor recipients from disabled ones. It finds the convergence of poverty and disability in uninsurability, which plagues both those who can pay too little and those who may cost too much. A Medicaid buy-in could not avoid a set of difficulties that have been described elsewhere (for example, Kosterlitz 1988). Neither would it insure all people with disabilities. It would, however, make fewer arbitrary

distinctions among them as well as assert a logical commonality, if not an identity of needs, with young families and old people similarly at risk.

An alternative to Medicaid reform is to liberalize Medicare eligibility requirements to include a buy-in for disabled people who have not contributed payroll taxes or who have received SSDI benefits for fewer than 24 months. Medicare Part B, after all, is already funded entirely from premiums and general revenues and Medicaid already pays the premiums, deductibles, and copayments for low-income Medicare beneficiaries. Moreover, just such a buy-in option is currently available to anyone over the age of 65 whether or not they receive Social Security benefits. Expanded Medicare eligibility for people with disabilities could be paired with the widely proposed expansion of Medicare long-term care benefits to approximate the kind of Medicaid reform described above; and Medicare reform would, of course, be uniform across states.

Medicaid is surely not the only programmatic locus for improving the health care entitlements of people with disabilities. For now, however, Medicaid benefits make a significant contribution to their well-being. We should fully exploit and closely guard them, and carefully consider their reasoned extension—by accretion in the face of default.

References

- Atkins, C. 1987. Testimony before the Subcommittee on Health, Committee on Finance, U.S. Senate, Hearing on Financing Long-Term Care, June 12. (Unpublished.)
- Burwell, B. 1986. Home and Community-Based Care Options under Medicaid. In Affording Access to Quality Care: Strategies for State Medicaid Cost Management. ed. R. Curtis and I. Hill, 65-94. Washington: National Governors Association.
- Cohen, W.J. 1985a. The Long, Difficult Road to Enactment. Health Progress 66(6):22-23.
- 1985b. Reflections on the Enactment of Medicare and Medicaid. Health Care Financing Review. 1985 Annual Supplement. 3–11. Washington: U.S. Department of Health and Human Services.
- Davis, K., and D. Rowland. 1986. Medicare Policy: New Directions for

- Health and Long-term Care. Baltimore: Johns Hopkins University Press.
- Friedman, E. 1987. Medicaid's Overload Sparks a Crisis. *Hospitals* 61(2):50-54.
- Gornick, M., J.N. Greenberg, P.W. Eggers, and A. Dobson. 1985. Twenty Years of Medicare and Medicaid: Covered Populations, Use of Benefits, and Program Expenditures. *Health Care Financing Review*, 1985 Annual Supplement, 13–59. Washington: U.S. Department of Health and Human Services.
- Hahn, H. 1987. Public Policy and Disabled Infants: A Sociopolitical Perspective. Issues in Law and Medicine 3(1):3-28.
- Iglehart, J.K., and J.K. White. 1987. Push to Close Medicaid Eligibility Gap Grows. *Health Progress* 68(8):14-15, 22, 25.
- Kosterlitz, J. 1988. Buying Into Trouble. *National Journal* 20 (December 31):3245-49.
- Lipson, D.J., and R. Fisher. 1986. Major Changes in State Medicaid and Indigent Care Programs, January-December 1986. Washington: Intergovernmental Health Policy Project.
- Lipson, D.J., R.S. Fisher, and C. Thomas. 1987. Major Changes in State Medicaid and Indigent Care Programs, January-August 1987. Washington: Intergovernmental Health Policy Project.
- Marmor, T.R. 1973. The Politics of Medicare. London: Routledge and Kegan Paul Ltd.
- National Center for Health Statistics. 1987. Current Estimates from the National Health Interview Study, United States, 1986, ed. D.A. Dawson and P.F. Adams. Vital and Health Statistics, series 10, no. 164. Washington.
- National Study Group on State Medicaid Strategies. 1984. Restructuring Medicaid: An Agenda for Change, Summary Report. Washington: Center for the Study of Social Policy.
- Ohio Department of Human Services. 1987. Statistical Report on Medical Care: Eligibles, Recipients, Payments, and Services for Fiscal Year 1987 (form HCFA-2082). Columbus.
- Rymer, M.P., and B.O. Burwell. 1987. Medicaid Eligibility: Analysis of Trends and Special Population Groups. MPE Working Paper 5.6. Lexington, Mass.: SysteMetrics/McGraw-Hill.
- Stevens, R., and R. Stevens. 1974. Welfare Medicine in America: A Case Study of Medicaid. New York: Free Press.
- Stone, D.A. 1984. *The Disabled State*. Philadelphia: Temple University Press.
- U.S. Health Care Financing Administration. 1979. Guidelines for State Use in Defining, Categorizing, and Standardizing the Provisions of

- Personal Care Services Rendered to a Recipient in His Own Home. Action Transmittal, January 17. Washington.
- ——. 1984. Short-Term Evaluation of Medicaid: Selected Issues. Washington.
- ------. 1986. Statistical Report on Medical Care: Eligibles, Recipients, Payments, and Services for Fiscal Year 1986 (form HCFA-2082). Washington.
- -------. 1987a. Annual Medicare Program Statistics: Medicare Enrollment, Reimbursement, and Utilization, 1983. Washington.
- U.S. Social Security Administration 1987. Annual Statistical Supplement, 1987. Washington.
- Vladeck, B. 1980. Unloving Care: The Nursing Home Tragedy. New York: Basic Books.

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