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# Medicare, Medicaid, and People With Disability

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## INTRODUCTION

When Medicare was amended in 1973, expanding entitlement to people with disability, it played a key role in promoting independence and autonomy and enhancing health care for this population, which traditionally had been underserved. Medicare recipients with disability have been the fastest growing Medicare-entitled population, and Medicare, along with Medicaid, has had to adjust to meet the needs of this ever-changing group. Both programs must continue to evolve to develop services designed specifically for people with disability.

Today, more than 6 million Americans under 65 years of age with severe disabilities receive a vast array of medical, hospital, support, rehabilitative, residential, and long-term care (LTC) services through Medicare and Medicaid. These programs have contributed to the sea change in the national attitude toward people with disabilities and promoted the independence and autonomy of millions through the funding of services that were non-existent and perhaps even inconceivable 30 years ago.

In this article, we describe the historic imperative for publicly financed insurance programs for people with disabilities, the characteristics of Medicare- and Medicaid-eligible recipients with disability, the array of services now available to them through these two programs, and lastly, obstacles to and opportunities for continued reform as they present themselves today.

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## WHY MEDICARE AND MEDICAID?

Thirty years ago, people with severe disability were for the most part nameless, faceless, and dependent on segregated institutions or a myriad of distinct State government or charity programs. Care was not an entitlement but a byproduct of whatever public generosity or charitable instincts that existed. Accordingly, services were highly variable with respect to availability, quality, geography, and the disability being treated (Scotch, 1984).

Traditions dating well back into the 19th century defined the institution as the hub of the care system for people with mental retardation or mental illness and people with physical disability who were dependent. Thirty years ago, the values of equal rights, independence, and autonomy, which are so prevalent today, had not yet coalesced into a cohesive disability-rights movement because of the pervasive culture of dependency and paternalism, as well as the fragmentation of the various constituencies with disabilities, which lacked a unified political voice (Willis, 1989).

With this state of affairs, Social Security Administration (SSA) surveys in 1960, 1966, and 1972 comparing people with disability to those without disability could be succinctly summarized as follows: People with disability were poorer and had greater burdens of illness, less private insurance, higher out-of-pocket expenses, and more unmet needs (Krute and Burdette, 1981; Brehm and Cormier, 1970; Advisory Council of Health Insurance for the Disabled, 1969). A new financing mechanism was called for and clearly needed.

## CHARACTERISTICS OF RECIPIENTS WITH DISABILITY

It is estimated that there are more than 14 million people with severe disability in the United States under 65 years of age (U.S. Bureau of the Census, 1991). Of these, approximately 3 million are covered by Medicare through Social Security Disability Insurance (SSDI, which covers persons with a permanent disability that prevents employment) and adults over 22 years of age disabled as children. An additional 2.8 million are receiving Medicaid benefits by virtue of eligibility for Supplemental Security Income (SSI). Finally, about 900,000 individuals receive Medicaid benefits because of a persistent disability that prohibits employment. However, the latter are not eligible for SSI income payments because of income that exceeds the SSI eligibility limits (Center for Vulnerable Populations, 1992; Lubitz and Pine, 1986).

The estimated number of people under 65 years of age with severe disability and the penetration of Medicare and Medicaid as health service coverage for this population are summarized in Table 1. Fifty-six percent of Medicare- and Medicaid-covered disabled recipients are male (U.S. Bureau of the Census, 1989), and nearly 50 percent have total income at or below the poverty level (National Center for Health Statistics, 1990). Conversely, looking at the entire U.S. population, almost one-half of persons with incomes below \$10,000 in 1990 reported a significant disability (National Center for Health Statistics, 1990).

Since the inception of Medicare and Medicaid eligibility for people with disability in 1973, caseloads have grown on average by 7 percent per year. However, this growth has been uneven, with periods of rapid growth before 1981 and after 1987 (Center for Vulnerable Populations, 1992). The expanding caseloads and high health

**Table 1**  
**Estimated Insurance Status of People With Severe Disability: United States**

Population Group	Estimated Number (in Millions)	Percent
Persons Under Age 65 With Severe Disability <sup>1</sup>	14.0	100.0
Persons Eligible for Medicare or Medicaid	6.7	47.9
Persons Eligible for Medicare <sup>2</sup>	3.0	21.5
Persons Eligible for Medicaid <sup>3</sup>	3.7	26.4

<sup>1</sup> A broader and perhaps less severe range of disability than that required for Social Security Disability Insurance (SSDI), Supplemental Security Income, or those adults disabled as children eligible for SSDI.

<sup>2</sup> A large percentage are also eligible for Medicaid, not counted under "Persons Eligible for Medicaid."

<sup>3</sup> Some Medicare- and/or Medicaid-eligible persons may also be receiving Veterans Administration services as well.

SOURCE: (U.S. Bureau of the Census, 1991).

care needs are reflected in high health care costs. In 1993, Medicare expenditures for people under 65 years of age with disability were \$15.9 billion (Health Care Financing Administration, 1995). Earlier studies demonstrated that the average annual per capita health care costs for the Medicare-eligible population under 65 years of age with disability were nearly 30 percent higher than the costs of all elderly Medicare beneficiaries (Lubitz and Pine, 1986). In addition to Medicare and Medicaid spending for physician and hospital services, total Federal and State spending on a subset of these total eligibles—through Medicaid, State Departments of Mental Health, and residential, home care, and LTC services for mental retardation—totaled nearly \$92 billion in 1991 (Center for Vulnerable Populations, 1992).

Because neither Medicare nor State Medicaid programs have historically kept data on the reason for disability, an exact ongoing census of eligible populations with disability by distinct clinical groupings has remained elusive. A household survey of a random sample of SSDI recipients who became eligible for Medicaid in 1973 identified the prevalence of disabling

conditions as follows: cardiovascular and respiratory illness, 40 percent; musculoskeletal illness, 31 percent; mental illness, 10 percent; and neurologic illness or impairment, 6 percent (Hardwick et al., 1994). Because the sample was limited to those living independently, the MR/DD (mental retardation/developmental disability) population was likely undercounted. Brandeis University's Center for Vulnerable Populations (1992) cites population-based surveys of disability in the United States that identify 1.2 million with MR/DD, 1.5 million with severe and persistent mental illness, and 8.6 million with severe functional impairments that could meet SSDI/SSI eligibility criteria. However, it is unknown if the same proportions are reflected in the subset of people with disability who have become eligible for Medicare and Medicaid. In 1993, a far higher percentage of SSI recipients eligible for Medicaid had mental illness or mental retardation as the primary disabling condition than SSDI recipients eligible for Medicare. Twenty-nine percent received SSI/Medicaid because of severe mental illness, 28 percent because of mental retardation, and 43 percent because of physical disability (Drainoni, Tobias, and Dreyfus, 1995). There are no available data describing the reason for disability for Medicare-eligible adults disabled as children, but it is likely that mental retardation and developmental disabilities are highly prevalent.

Despite the diversity of the Medicare- and Medicaid-eligible populations with disability, clinicians, advocates, and policymakers find common elements. People with severe disability generally have ongoing predictable baseline needs for support, residential, or LTC services. They have lower thresholds than the general population for an array of acute medical complications for which considerable medical contact and recurrent hospitalizations are required; and

any diminution or loss of support, housing, or LTC services often translates into increased medical or hospital costs.

## EMERGENCE OF NEW BENEFITS

Perhaps the most significant consequence of Medicare and Medicaid entitlement for people with disability has been the rapid development of an entirely new and unique array of benefits and services designed to promote independence and autonomy. Medicaid became the primary engine for this development. Today, despite limitations, variability, and cost pressures, the State Medicaid programs function as the Nation's only formed disability and LTC insurance program. Over the past 25 years, through the flexibility that States have had in the design and elaboration of optional benefits and the 2176 home and community-based waivers, a de facto benefits policy for people with disability has evolved where none existed before. Examples of these new benefits include: expanded home health aide services for people with chronic disability and/or personal care attendant services in 29 States, licensed residential care facilities in lieu of intermediate care facilities for the mentally retarded and nursing homes for the mentally retarded in 41 States, an array of 2176 case-management, residential, and home care services in lieu of institutional care in 50 States and Washington, DC, and adult day health services in 30 States (Hardwick et al., 1994). The availability of these services by State and their expenditures are summarized in Table 2.

As a consequence, these entitlement programs have been one factor contributing to the substantial de-institutionalization that has occurred over this period and have given a voice to previously voiceless disabled constituencies in the advocacy for and design of services better able to meet their needs.

**Table 2**  
**Expenditures for Home and Community-Based Services**  
**and Services Available, by State: United States**

State	Home and Community-Based Care Expenditures <sup>1</sup>	PCA Services	Adult Day Care Services	Residential Care Services
Totals	\$6,716,404	29	30	51
Alabama	61,399	—	—	x
Alaska	3,093	x	—	x
Arizona	603	—	x	x
Arkansas	70,696	x	x	x
California	60,565	—	x	x
Colorado	92,175	—	—	x
Connecticut	219,852	—	—	x
Delaware	23,036	—	—	x
District of Columbia	16,396	x	—	x
Florida	158,870	x	x	x
Georgia	82,853	—	—	x
Hawaii	14,979	—	x	x
Idaho	19,102	x	—	x
Illinois	139,031	—	—	x
Indiana	41,958	—	—	x
Iowa	20,252	x	—	x
Kansas	46,815	x	—	x
Kentucky	100,206	—	x	x
Louisiana	36,449	—	x	x
Maine	43,274	x	x	x
Maryland	131,616	x	x	x
Massachusetts	253,699	x	—	x
Michigan	255,030	x	—	x
Minnesota	240,725	x	x	x
Mississippi	9,238	—	—	x
Missouri	114,123	x	x	x
Montana	31,023	x	x	x
Nebraska	37,045	x	—	x
Nevada	11,950	x	x	x
New Hampshire	66,109	x	x	x
New Jersey	302,361	x	x	x
New Mexico	25,096	—	x	x
New York	2,239,245	x	—	x
North Carolina	156,405	x	x	x
North Dakota	25,216	—	x	x
Ohio	113,240	—	—	x
Oklahoma	73,788	x	x	x
Oregon	174,138	x	—	x
Pennsylvania	215,628	—	x	x
Rhode Island	87,195	—	x	x
South Carolina	50,761	x	x	x
South Dakota	24,077	x	x	x
Tennessee	33,886	—	—	x
Texas	213,411	x	x	x
Utah	32,911	x	x	x
Vermont	34,757	—	x	x
Virginia	79,836	—	x	x
Washington	153,284	x	—	x
West Virginia	91,830	x	—	x
Wisconsin	172,656	x	x	x
Wyoming	14,521	—	—	x

<sup>1</sup> Expenditures include all home health services, home and community-based services of personal care attendants, and home and community service waivers.

NOTE: PCA is personal care attendant.

SOURCE: (Hardwick et al., 1994).

Upon its inception, Medicare was created to cover acute episodes of illness; therefore, strict limitations on home health benefits existed. Over the past 30 years, with the exception of the liberalization of home health benefits, Medicare benefits have not evolved, in contrast with the substantial evolution of Medicaid benefits.

## **FUTURE PROBLEMS AND OPPORTUNITIES**

As we celebrate the 30th anniversary of Medicare and Medicaid, we recall how access to health care for people with disability has developed and realize the importance of continual development and reform. Today, the central issues of the policy debate are the continuation of Medicaid entitlement and the rapid movement toward privatization through managed care contracting. In fact, the two issues are linked. The continuation of Medicaid entitlement is essential to prevent a return to relative dependency and care delivered only as a byproduct of public and/or philanthropic largess. Further, individual entitlement is an essential precondition to effective managed care contracting for people with disability. Enrollment in prepaid plans that deliver an array of benefits to the individual enrollee for a fixed price is in fact the hallmark of individual entitlement. For people with disability, Medicaid contracting with health plans to cover its array of benefits on an individual basis is essential for the development of lower cost, appropriate care for these populations. If the focus of Medicaid were changed from the individual to block grants for States, it is highly likely that in many States such contracting would be impeded or perhaps non-existent.

Managed care, though feared and resisted by many, offers the promise of providing a

comprehensive array of health services to people with disability. Such services promote independence, empowerment, and efficiencies through coordination and lower cost alternatives to institutional care. Prepaid contracting allows flexibility in the design of benefits and provider roles that are simply not possible in the fee-for-service systems. In addition, the effectiveness of prepaid contracting to promote more appropriate care models has been demonstrated in a number of special population-based programs in recent years (Master et al., 1996; Shen and Iversen, 1992). However, a number of important policy changes are essential if the potential of prepaid managed care for people with disability is to be fully realized on a larger scale.

Medicare-eligible recipients with disability as well as their SSI/Medicaid-eligible counterparts vary greatly in the severity of their disability or illness and therefore in their medical service expenditures. The adjusted average per capita cost (AAPCC) formula and simple SSI capitated-payment approaches require substantial modification, if plans are to be rewarded for developing systems of care that are responsive to people with disability. First, capitation payments must be clinically risk-adjusted, because there are many identifiable subgroups whose health service expenditures are well above the average or the rates reflected in the prevailing AAPCC formula. Without such risk adjustment, plans face strong incentives to avoid the very populations for which managed care offers the greatest promise. The adjustment of Medicaid capitation rates to reflect the risks of people with disability has been addressed in detail in a recent article (Kronick, Zhou, and Dreyfus, 1995). Similar works now are needed for the Medicare-eligible population with disability as well.

Second, creative risk-sharing and reinsurance arrangements will be required until such a credible risk-adjusted capitation system is developed and tested. Currently, some State Medicaid programs are offering such risk-sharing and reinsurance arrangements in their managed care contracting for people with disability, but there are no such arrangements for Medicare risk-based capitation contracting.

Third, Medicare capitation needs to flow into plans concurrently with Medicaid capitation for dually entitled recipients with disability. Because a substantial number of dually entitled recipients are likely to be cared for in prepaid plans that are not Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA)-qualified, any large-scale effort to combine Medicare and Medicaid funding streams will require liberalization or elimination of TEFRA reserve requirements, 50/50, 75/25, public payer/Medicaid, and commercial enrollment requirements, respectively.

For people with disabilities, the potential pitfalls of managed care are many, with serious implications for the health of a population that includes some of the most vulnerable members of our societies. Yet the potential benefits of managed care for people with disabilities certainly far surpass the benefits of managed care for the people without disability.

Since their inception, Medicare and Medicaid have been the catalysts to restructuring and providing access to health services for populations with disability. As we move forward into the era of managed care, the experience of the past 30 years has given us a sophisticated knowledge of people with disability and their needs, in ways that were inconceivable at the inception of these programs. If the past is to be our guide, that knowledge will promote the evolution of Medicare and Medicaid to

continually enhance the effectiveness of care to our Nation's people who have the severest disability and are the most vulnerable.

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