

Improving Medicare for Beneficiaries with Disabilities



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A few lines caught my eye near the end of a lengthy *New York Times* article on June 11, 2003. The article recounted the growing likelihood that Congress would add prescription drug benefits to Medicare and itemized the trade-offs required to trim projected expenses (Pear 2003a, A21). After describing various components of proposed Senate legislation, the article concluded, “To help offset the costs, Medicare would freeze payments for home medical equipment, like wheelchairs and oxygen, for seven years.”

Of course, the legislation signed by George W. Bush in December 2003 bore little resemblance to this June proposal. In particular, Congress did not overturn Medicare’s central tenet: coverage of only those services that are “reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member” (42 C.F.R. Sec. 402.3), services that fit snugly within the standard medical armamentarium. Although policymakers have strayed occasionally, such as adding coverage for selected screening tests and palliative care, Medicare’s guiding mandate remains inviolate.

Given this context, the acceptability of freezing Medicare payments for wheelchairs and home-based oxygen comes as little surprise—although limiting oxygen payments carries a mischievous symbolism (certainly, oxygen should meet Medicare’s reasonable and necessary standard). This proposal exemplifies a more basic and vexing reality that extends well beyond Medicare: The American health care system fails to meet the daily health and function-related needs of many people with chronic, disabling medical conditions. Although technologies and therapies exist to maintain, restore, or maximize function, they often fall outside health insurance coverage boundaries. Such gaps in coverage prevent people from obtaining services and equipment that are costly to purchase out-of-pocket, needlessly compromising lives.

This observation draws upon long historical roots. Achieving passage of the Medicare program required years of political maneuvering, compromises, and reduced expectations. The Medicare program did cover more non-acute care, including limited stays in skilled nursing homes and home-based rehabilitation, than any

other governmental, nonprofit, or commercial insurer at the time (Fox 1993). Nonetheless, in the end, “Left out were provisions that addressed the particular problems of the chronically sick elderly: medical conditions that would not dramatically improve and the need to maintain independent function rather than triumph over discrete illness and injury” (Marmor 2000, 153). Forty years later, little has changed.

Although these problems wend throughout the health care delivery system, I concentrate on Medicare policies for several reasons. Medicare is huge. In 2002, Medicare insured roughly 40.6 million persons, including 6.0 million individuals under age 65 with disabilities (Centers for Medicare and Medicaid Services [CMS] 2003b). Of an estimated \$236.5 billion expenditures in 2001, Medicare spent \$31.9 billion on beneficiaries with disabilities (CMS 2002). Furthermore, unlike Medicaid programs and private health plans, Medicare’s rules extend nationwide, although specific implementation decisions can vary across regions. Over the years, Medicare policies have frequently infiltrated the rest of the health care system. Therefore, Medicare offers an excellent starting point to examine health care policies for persons with disabilities.

Demographic Trends Breed Urgency

Countless persons with disabilities daily slip through the fault lines crisscrossing the health care delivery system. Why is this issue so pressing now? Numbers offer a clear answer.

Almost one-fifth of U.S. residents—19.3 percent of people age 5 years and older, or 49.7 million—report disabilities (U.S. Census Bureau 2003b). As table

TABLE 13.1 *Estimates of Disability from the 2000 U.S. Census (population in millions)*

Disability ^a	Age 16 to 64 years					Age 65 years and older						
	Total	(%)	Males	(%)	Females	(%)	Total	(%)	Males	(%)	Females	(%)
Population	178.9	(100.0)	87.6	(100.0)	91.1	(100.0)	33.3	(100.0)	13.9	(100.0)	19.4	(100.0)
With any disability	33.1	(18.6)	17.1	(19.6)	16.0	(17.6)	14.0	(41.9)	5.6	(40.4)	8.3	(43.0)
Sensory	4.1	(2.3)	2.4	(2.7)	1.7	(1.9)	4.7	(14.2)	2.2	(15.6)	2.6	(13.2)
Physical	11.2	(6.2)	5.3	(6.0)	5.9	(6.4)	9.5	(28.6)	3.6	(25.8)	6.0	(30.7)
Mental	6.8	(3.8)	3.4	(3.9)	3.3	(3.7)	3.6	(10.8)	1.4	(9.9)	2.2	(11.4)
Self-care	3.1	(1.8)	1.5	(1.7)	1.7	(1.9)	3.2	(9.5)	1.0	(7.5)	2.1	(11.0)
Ability to leave the home	11.4	(6.4)	5.7	(6.4)	5.8	(6.4)	6.8	(20.4)	2.3	(16.8)	4.5	(23.0)
Employment	21.3	(11.9)	11.4	(13.0)	9.9	(10.9)	—	—	—	—	—	—

Source: adapted from the U.S. Census Bureau 2003b.

^aItems 16 and 17 on the 2000 long-form census questionnaire addressed disability. The questions and the definition of disability are described elsewhere (U.S. Census Bureau 2003a).

13.1 shows, persons age 65 and older report any disability at higher rates than younger people—41.9 percent compared with 18.6. At younger ages, males generally have higher rates of disability than females, while the reverse occurs over age 64 years. Physical disabilities are more common than sensory or mental health disabilities. Racial and ethnic minority populations have higher disability rates than do whites (see table 13.2).

Even more compelling numbers come from looking ahead. By 2030, the number of people age 65 years and older will rise to 69.4 million (20 percent of the population) from 34.7 million (12.6 percent) in 2000 (Day 1996). Persons age 85 years and older will become the most rapidly growing segment of the population, rising from 4.3 million (1.6 percent) in 2000 to 18.2 million (4.6 percent) in 2050.

This growth reflects lengthening life expectancies, even in recent decades. The average male born in the United States in 1970 could anticipate living to roughly 67 years of age compared with over 74 years for those born 30 years later (Arias 2002). Life expectancy for females rose from 75 years in 1970 to almost 80 years in 2000. Declining death rates from heart disease substantially prolonged longevity, expanding the numbers living with chronic, nonfatal, but disabling conditions. Persons with significant physical disabilities are also living longer, largely because of fundamental medical breakthroughs like advances in antibiotics. According to the National Spinal Cord Injury Statistical Center (2001), persons who become paraplegic at age 40 and survive 1 year following injury can expect to live another 29 years, compared with 38 years for persons without spinal cord injury.

Aging does not invariably produce disability, at least not until near death. Centenarians often remain reasonably healthy until shortly before dying. Recent reports suggest that rates of serious functional deficits are declining among older

TABLE 13.2 *Disability by Race and Ethnicity Groups, 2000 U.S. Census*

Racial/ethnic groups ^a	Age	
	16 to 64 years (%)	65+ years (%)
Total	18.6	41.9
White alone	16.8	40.6
Black or African American alone	26.4	52.8
Asian alone	16.9	40.8
American Indian or Alaskan Native alone	27.0	57.6
Native Hawaiian, other Pacific Islander alone	21.0	48.5
Some other race alone	23.5	50.4
Two or more races	25.1	51.8
Hispanic or Latino (of any race)	24.0	48.5

Source: adapted from the U.S. Census Bureau 2003c.

^aFor the first time, during the 2000 census respondents could indicate membership in more than one race or ethnicity group.

individuals, although evidence about the most severe disabilities is contradictory (Freedman, Martin, and Schoeni 2002). Multiple factors likely underlie improvements in functional abilities among older persons, including new medical therapies and healthier lifestyle. Nevertheless, “disability is not something that happens only to a minority of humanity, it is a common (indeed natural) feature of the human condition. . . . Over the lifespan, [disability is] a universal phenomena” (Üstün et al. 2003, 82).

With the aging population, the absolute number of Americans with functional limitations will rise by over 300 percent by 2049 if the age-specific prevalence of major chronic conditions remains unchanged (Boult et al. 1996). Arthritis, the leading cause of disability among adults, affected 70 million adults in 2001, including 60 percent of people age 65 and older (Centers for Disease Control and Prevention 2003). If current rates remain unchanged, the number of persons over age 65 with arthritis will double by 2030, causing more physical impairments than ischemic heart disease, cancer, and dementia combined. Obesity among adult Americans is also rising, growing from 12 percent in 1991 to 20.9 percent—or 44.3 million persons—in 2001 (Mokdad et al. 2003). Apart from causing disability itself, obesity contributes to other debilitating conditions, including diabetes, arthritis, high blood pressure, and asthma. Many more persons will therefore have multiple coexisting, chronic, disabling conditions in coming years.

Medicare covers more than just people age 65 and older. Rising numbers of disabled workers receive Medicare through qualifying for Social Security disability insurance (SSDI). The average annual rate of growth in Medicare enrollment between 1973, when SSDI recipients could first get Medicare, and 1999 was 4.3 percent for disabled beneficiaries compared with 1.7 percent for aged enrollees (CMS 2003a). In 2002, 5.5 million disabled workers received benefits from the Social Security Administration (SSA). Today’s SSDI recipients look different than those of prior years (IOM 2002b). In 1960, when persons younger than 50 years of age could first receive SSDI benefits, the average disabled worker was 57.2 years old; by 2002, the average age fell to 51.0 years. In 1957, when SSDI benefits first became available, only 20 percent of disabled workers were women, compared with 45 percent in 2002. Disabled women workers receive lower monthly payments than men: \$709 compared with \$936 in December 2002 (SSA 2003). Thus, on average, those receiving SSDI today will likely stay on the rolls longer and have less disposable income than former beneficiaries.

One final demographic issue involves social, economic, and health disadvantages experienced by many persons with physical, sensory, and psychiatric disabilities. Compared with others, persons with disabilities have less education and higher rates of poverty, unemployment, tobacco use, obesity, and fair or poor health. They are also more likely to live alone and report feeling frequently depressed, anxious, fearful, or under stress. Even with insurance, persons with disabilities could still risk poor health outcomes because of complex underlying medical conditions that need to be treated by diverse clinical specialists, poor coordination of care, inadequate communication or discordant expectations between physicians and patients, physically inaccessible care sites, insufficient health literacy, and finan-

cial barriers. Medicare beneficiaries with disabilities spend \$1,532 out-of-pocket annually for health care services; this amount rises to \$2,175 for persons with two or more limitations of activities of daily living (Foote and Hogan 2001).

Targets for Policy Changes

As the Disability Policy Panel of the National Academy of Social Insurance acknowledged, “Despite its gaps in covered services, Medicare is an essential source of health care coverage for Social Security disability beneficiaries” as well as chronically debilitated older adults (Mashaw and Reno 1996, 144). Indeed, Medicare meets many high-cost service needs of enrollees with disabilities, such as inpatient intensive care, cardiac revascularization, or joint replacement surgery.

Tensions between patients’ needs and coverage limits primarily involve routine non-acute care and services and technologies for maintaining, restoring, or maximizing function. Changes in four areas—medical necessity determinations, homebound requirements, coverage waiting periods, and office visit reimbursement—could considerably improve the lives of Medicare beneficiaries with disabilities. Related issues emerged repeatedly during 119 interviews I conducted with persons with mobility problems and their family members, physicians, physical and occupational therapists, and medical directors of health plans, as the following stories reveal (all proper names are pseudonyms, Iezzoni 2003).

Revising the Definitions of Medical Necessity

“I can’t keep up with this walker,” said Erna Dodd, moving slowly and laboriously, breathing oxygen from a canister dangling from her walker’s handlebars. She had many medical problems: emphysema, diabetes requiring insulin, congestive heart failure, seizures, obesity, and debilitating arthritis. Nonetheless, she refused our proffered wheelchair. Ms. Dodd said, “[I don’t] want people pushing me in a wheelchair. So Max [her nurse] put in to get me a [motorized] scooter. He had my doctor fill out some paper for it. This was a letter they send, telling me they wouldn’t give it to me.” Reaching into her handbag, she retrieved a legal-size envelope containing a single sheet of paper.

“Medicare sent this to you?” I asked, looking at the letterhead, then read aloud, “‘We have received a prior authorization request for the above named beneficiary for a power operated vehicle. This request has been denied because the information did not support the medical necessity of the equipment. If you do not agree with this decision, you may request a review in writing within six months of the date indicated in this letter. Submit any additional documentation to the review department.’ Did Max appeal this for you?”

“I don’t know. I was going to call my doctor and talk to him about it. It would help me a lot.” Dr. Baker, her primary care physician, did contest Medicare’s denial, but Erna Dodd died during the appeals process (Iezzoni 1999, 2003).

Decisions on health insurance reimbursement typically involve two stages: organization-wide decisions about what services will be covered and case-by-case decisions about the medical necessity of covered services for individual persons

(Singer and Bergthold 2001). (As noted below, a third-order decision, critical for some individuals with disabilities, concerns whether persons can receive services at home.) Congress makes Medicare's broad benefit decisions, which are then codified in federal regulations. Local Medicare carriers determine whether individual beneficiaries receive the items or services they request, such as assistive technologies and physical and occupational therapy.

In its pamphlet *Your Medicare Benefits*, CMS informs beneficiaries that original Medicare covers services or supplies that are medically necessary or that:

- Are proper and needed for the diagnosis or treatment of your medical condition;
- Are provided for the diagnosis, direct care, and treatment of your medical condition;
- Meet the standards of good medical practice in the local area; and
- Are not mainly for the convenience of you or your doctor. (CMS 2003d)

Two major questions generally drive decisions regarding requests from individual Medicare beneficiaries: (1) How long will the person need the service? Chronic needs raise more questions than short-term demands; and (2) Will the service result in measurable improvement of physical deficits caused by medical illness or injury? Neither question is especially propitious for persons with disabilities. By definition, these individuals generally need services long-term, and their impairments are unlikely to improve. Medicare also explicitly denies items judged only for personal comfort or not primarily medical in nature, such as hearing aids, grab bars, and routine foot or dental care (42 C.F.R. Sec. 411.15). This prohibition against convenience items likely doomed Erna Dodd's request for a motorized scooter. Long-term physical, occupational, or speech-language therapy to maintain function or prevent further declines would likely also fail these tests as the term treatment assumes recovery or improvement. In addition, decisions regarding individual medical necessity often appear idiosyncratic and subjective and deficient communication compounds the problem (Rosenbaum et al. 1999). "Denial letters rarely explain who made the decision, the reason for the decision, what sources of evidence were considered, what coverage policies were applied" (Singer and Bergthold 2001, 204).

These problems are well recognized. The IOM's Committee on a National Agenda for the Prevention of Disabilities lauded the potential for rehabilitation services, assistive technologies, and even modest items like grab bars to improve safety and quality of life for persons with disabilities. The committee noted that coverage and payment policies impede people from getting these devices, which could potentially save health care dollars downstream: "Denial of reimbursement for technology that assists in the performance of daily activities and reduces risk of secondary conditions is likely to result in long-term costs that exceed initial savings. For example, Medicare regards grab bars for bathrooms as convenience items, even though falls in the bathroom are a leading cause of hip fractures and other injuries among the elderly. The health care costs associated with hip fractures alone are large and growing. This shortsightedness is also reflected in the

inadequate coverage that most insurers provide for long-term maintenance and replacement of the few assistive technologies they do fund” (Pope and Tarlov 1991, 227).

Like this committee, a panel of the National Academy of Social Insurance put this topic among its short- to mid-range recommendations for making Medicare more responsive to chronic care.

Strive to include services related to function and health-related quality of life:

- Cover durable medical equipment with the specific intent of maintaining or restoring function.
- Provide for assistive devices that compensate for sensory or neurological deficits.
- Support rehabilitation as a tool to improve, maintain, or slow the decline of function. (Eichner and Blumenthal 2003, v)

Medical necessity judgments, while ostensibly ensuring that Medicare covers only “health-related needs,” also serve as a form of rationing available resources. Yet Medicare’s current provisions deny the realities of a large fraction if not the majority of its beneficiaries—people with chronic debilitating conditions that will not improve. With appropriate technological or rehabilitative support, many of these individuals could continue living independently in the community, postponing the overwhelming expense of long-term institutionalization. Revisiting Medicare’s medical necessity limits on items and services that help people with disabilities function is long overdue.

Enabling People with Disabilities to Go Outside Their Homes

A colleague who lives in a small mountain town described his neighbor. “Mary Jo is her name. She lives three blocks from us. She’s thirty-nine or forty, and she has diabetes. She’s had one leg amputated, and the other leg is constantly in danger. She lives in a low-income apartment, one of those little places like a motel room. Some friends raised the money and gave her an electric wheelchair—a real cheap one, but it allowed her to get out the door and up to a small park. On a nice spring day, she can go out and sit under a tree and come back in. That’s all she ever did with it.”

A home health nurse treats Mary Jo’s ulcerated leg, among other medical problems. “One day, the home health nurse saw the electric wheelchair sitting in the apartment, and she said, ‘You know what? I can’t come anymore.’ Mary Jo is disabled under Medicare, and Medicare won’t pay for home health unless the person is homebound. So the wheelchair has now been folded up and is gathering dust in the corner. It’s been retired from use, and every time a home health aide comes, she tries not to see it.”

Mary Jo’s friends rightly assumed that Medicare would refuse to purchase her power wheelchair since she does not need it within her tiny apartment—as for Erna Dodd, it would not have been deemed medically necessary. So they bought it themselves. The independence conveyed by the power wheelchair, however, could

risk Mary Jo's eligibility for home-based nursing care for her remaining leg ulcerated by diabetes: If Mary Jo sits under a tree in her power wheelchair, she risks losing home health care, so she stashed away her power wheelchair. Staying indoors when she could venture out not only diminishes Mary Jo's quality of life but also could compromise her overall health.

Two paradoxical Medicare policies entrap Mary Jo. The first policy relates to eligibility for Medicare home care. To qualify for home-based services, Medicare regulations stipulate that individuals be homebound, defined as "a normal inability to leave home, that leaving the home requires a considerable and taxing effort by the individual." While absences for medical care, adult day-care, and attending religious services are allowed, other absences must be "infrequent or of relatively short duration" (42 C.F.R. Sec. 1814[a] and Sec. 1835[a]).

Clearly, this policy makes little sense for Mary Jo. To qualify for nursing care in her home, Mary Jo first needed to demonstrate that skilled services were medically necessary. With diabetic ulcerations on her remaining leg needing constant clinical attention, Mary Jo easily met the medical necessity criterion. Traveling daily to a clinic or hospital for this care would pose an enormous, perhaps impossible, burden. Since Mary Jo obviously had compelling medical needs, as well as substantial physical impairments, why couldn't she take short jaunts out in her power wheelchair without risking home care coverage?

For years, concerns about increasing home care costs have stalled efforts to broaden the homebound definition. From 1989 to 1996, Medicare Part A home health spending soared from \$2.8 to \$11.3 billion (U.S. General Accounting Office 1997). To reverse this trend, the Balanced Budget Act of 1997 significantly changed Medicare home health care payment policies. Total home care expenditures plummeted by 50 percent between 1996 and 2001, and the average number of days on home care fell 28 percent, from sixty to forty-three days (Medicare Payment Advisory Commission [MedPAC] 2003b). Some worry that these cuts have gone too far, especially for home care recipients who are frail, disabled, or medically vulnerable. MedPAC (2003b) found evidence "that for beneficiaries with certain clinical conditions, SNF [skilled nursing facility] use may be partly replacing home health use." Furthermore, "A number of home health agencies reported changing the way they operated, being more careful about accepting long-term, chronic, or higher-cost beneficiaries" (MedPAC 2003b, 77). Someone like Mary Jo might now find it difficult to get Medicare home care.

One highly public case underscores the consequences of Medicare's homebound definition. Georgia resident David Jayne had developed amyotrophic lateral sclerosis (ALS) in 1988 at age twenty-seven, and over the years he had become totally physically incapacitated. In 1997 Medicare started paying for skilled nursing care in his home. In 2000, Mr. Jayne traveled out of town with a college friend to watch a Georgia Bulldog football game. The trip and Mr. Jayne's story appeared in an Atlanta newspaper, and shortly thereafter his home health agency discharged him for violating the homebound definition. His congressman arranged for Medicare to reinstate the services, and Mr. Jayne began campaigning to reform the homebound definition. He founded the National Coalition to Amend the

Medicare Homebound Restriction and proved an exceptional lobbyist, although now he speaks only with aid of a computer.

Prompted by Mr. Jayne's story and to commemorate the twelfth anniversary of his father's signing of the Americans with Disabilities Act, on July 26, 2002, President George W. Bush addressed concerns about Medicare's homebound requirement. Urging people with disabilities to meet friends, join family reunions, and even attend baseball games, President Bush announced, "We're clarifying Medicare policy, so people who are considered homebound can occasionally take part in their communities, without fear of losing their benefits" (White House 2002). However, Bush did not alter the language requiring considerable and taxing effort to leave home. Anecdotal reports suggest that little has changed since Bush's pronouncement and that Medicare carriers still interpret the homebound definition strictly.

The second paradoxical home-related Medicare policy entangling Mary Jo involves the purchase of her wheelchair. Since most mobility aids will not improve baseline physical function, medical necessity judgments cannot in this case rely on the usual standard of restoring function. Instead Medicare seeks to determine whether the equipment allows someone to perform minimal activity—moving around within one's home. Medicare "pays for the rental or purchase of durable medical equipment . . . [only] if the equipment is used in the patient's home or in an institution that is used as a home" (42 C.F.R. Sec. 410.38[a]). Getting around outside the home is a convenience and not medically necessary, as Erna Dodd found.

According to this stringent standard, many people with progressive chronic conditions who still get around inside their homes, such as by furniture surfing, cannot qualify for mobility aids through Medicare. Requirements are even stricter for power wheelchairs. To obtain a power-operated vehicle (POV) for their patients, physicians must complete the "certificate of medical necessity" (form DMERC 07.02B and OMB No. 0938-0679). Section B of the form asks:

- Does the patient require a POV to move around in their residence?
- Have all types of manual wheelchairs (including lightweights) been considered and ruled out?
- Does the patient require a POV *only* for movement outside their residence?

Medicare's intent is clear: It will pay for the more expensive POV only if cheaper options are ruled out. But standards for ruling out manual chairs remain unspecified, leaving considerable leeway for subjective judgments and denials. A social worker told me about a man paralyzed by a stroke whose POV request was refused. Medicare asserted that his elderly wife could push him in a manual wheelchair within their home although she is also frail and weak. In the past, compared with other types of durable medical equipment, POVs were relatively rarely requested, and no evidence suggested that they were over-prescribed (Wickizer 1995). However, since 1999, power wheelchair purchases through Medicare have soared, and fraudulent practices by unscrupulous vendors cost Medicare \$84 million in 2002 (Janofsky 2004). Medicare has recently cracked down on abusive practices,

causing consternation among advocates for persons with disabilities. POVs are now even harder to obtain than before. As one woman whose husband is severely debilitated by multiple sclerosis said, “I don’t believe there’s massive abuse, that people are buying things that they don’t need. There’s a 20 percent copay. My husband’s wheelchair is \$20,000. That’s a \$4,000 copay. Do you think I’m going to spend \$4,000 just for the fun of it?”

Policymakers must recognize that requiring persons to remain in their homes and denying them mobility aids ignores a critical reality. Today’s assistive technologies allow people with substantial physical impairments, such as Mary Jo and David Jayne, to leave their homes and participate within their communities. People with disabilities no longer accept being shut away in their homes.

Medicare Coverage from Day One of Disability

Jimmy Howard is in his late forties with arthritis and diabetes. He has a high school education and lifted heavy boxes in ManuCo’s warehouse for years before being fired because he had difficulty walking. Mr. Howard moves firmly with an aluminum cane, although sometimes he falls unexpectedly. After ManuCo fired him, he applied to SSA for disability benefits. He has incapacitating stiffness each morning and other “objective medical evidence” of “arthritis of a major weight-bearing joint,” as specified in *Disability Evaluation under Social Security* (SSA 1998).

Five months following his disability determination, Jimmy Howard started receiving cash SSDI benefits. According to federal regulations, he must wait another two years to obtain Medicare coverage—a total of twenty-nine months beyond the date of SSA’s disability determination. Mr. Howard, however, can’t wait for health insurance to keep his diabetes under control, as well as treat his arthritis. So he pays \$400 per month for private health insurance under COBRA provisions. Sometimes he and his wife, who also doesn’t work, can barely make this payment.

P.L. 92-603, signed by President Richard Nixon on July 1, 1972, granted Medicare coverage to individuals who have received SSDI cash benefits for twenty-four months (42 U.S.C. Sec. 226[b][2][A]). The law also reduced to five months the waiting period between qualifying for SSDI and actually receiving cash payments. On July 1, 2001, Congress passed a special waiver rescinding the twenty-four-month wait for Medicare coverage, but only for persons who qualify for SSDI because of ALS. This exemption, won through active lobbying by ALS advocates, reflects the reality of rapid debilitation that generally accompanies that disease. But what about other SSDI beneficiaries who also need care, including Jimmy Howard with his diabetes and arthritis?

Separating Medicare coverage from disability determination makes little sense. The 1972 law aimed both to limit Medicare costs and avoid dislodging private employer-sponsored health insurance that SSDI applicants presumably had. To receive SSDI, applicants must prove disability by meeting explicit medical criteria determined by the SSA: “The inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s)

which 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” (SSA 1998, 2). Surely applicants who might face imminent death and can’t work ought to receive health insurance coverage immediately! Persons who qualify for Supplemental Security Income, another financial support program that uses identical application procedures as SSDI, obtain immediate Medicaid coverage.

The reasons for this baffling incongruity remain murky. Vladeck and colleagues explain the roots and tenacity of the Medicare gap as reflecting “ambivalence about the meaning of disability itself: The truly disabled—those who have a clear right to protection—cannot be easily identified in the modern social context in which disability is a matter of degree. . . . Disability consists of a hard physical core with an expanding penumbra of mental and psychological nuance not generally as visible (or acceptable) to society. As a result, gaps in services betray a deeply rooted ambivalence toward certain classes of the disabled. Most especially, a fundamental skepticism of those who are disabled because of a mental illness, alcoholism, or drug addiction seems ingrained in the culture” (1997, 87).

In earlier years, most new SSDI recipients qualified because of conditions that obviously warranted close medical attention. In 1981, circulatory conditions accounted for 25 percent of disability determinations, followed by other systemic diseases at 19 percent; musculoskeletal conditions contributed 17 percent, and mental disorders 11 percent (IOM 2002b). Two decades later, the situation has changed considerably. In 2001, mental disorders contributed the largest percentage (26.8 percent) of new SSDI beneficiaries (1.5 million persons), with musculoskeletal conditions in second place (21.7 percent, 1.2 million persons) (SSA 2002). Circulatory disorders fell to 9.6 percent.

No publicly available data describe SSDI beneficiaries during the waiting period. Dale and Verdier pieced together information from various sources to sketch this population, which they estimated at 1.26 million individuals in 2002. Approximately one-third, or 400,000 persons, lack health insurance during their waiting period, while roughly 40 percent, or 504,000 adults, enroll in Medicaid programs, costing the federal and state governments \$7.6 billion in 2002. Eliminating the waiting period would add about \$8.7 billion (3.4 percent) to Medicare costs at 2002 spending levels. However, lower state and federal Medicaid expenses would offset roughly 30 percent of the Medicare rise (Dale and Verdier 2003).

Questions remain about what health care services SSDI recipients obtain during the wait. Being uninsured, even for one to four years, may worsen general health status (IOM 2002a). Having financial access to health care services is essential to “fostering early interventions to prevent diseases or impairments from becoming permanent work disabilities” (Mashaw and Reno 1996, 135). While awaiting Medicare coverage, uninsured SSDI beneficiaries might skimp on care that could prevent or slow progression of their diseases, thus decreasing longevity, hastening functional declines, and increasing health care costs. One study of persons who had been continuously uninsured from ages sixty through sixty-four years found that, upon joining Medicare, they considerably increased their use of basic covered services. For instance, upon getting Medicare, “continuously

uninsured adults with arthritis reported greater increases in arthritis-related medical visits and limitations of activity than continuously insured adults with arthritis” (McWilliams et al. 2003, 762).

Adding new SSDI beneficiaries to the Medicare rolls would undoubtedly fractionally increase costs, at least in the short term. However, longer-term savings could outweigh these costs. Jimmy Howard’s primary care doctor told me a year or two later that his diabetes had been poorly controlled and he risked losing toes to gangrene. Might Medicare coverage have prevented or slowed that progression?

Paying the Right Amount for Office Visits

Joe Alto, a former backhoe operator in his late thirties, has had multiple sclerosis for twelve years and has used a wheelchair for three. Mr. Alto’s primary care physician does not have an adjustable examining table—a table that automatically lowers to wheelchair height with the touch of a pedal. Instead, the physician uses a fixed-height table, conveniently positioned for standing physicians. “There’s no way for me to get onto their examining tables—they’re too high,” Mr. Alto reported. He worries that his primary care physician gives him short shrift. “Most of the time, he wants to do my physical exam in my wheelchair. I’m not even undressed. All he does is listen to my heart and ask what’s wrong. He can’t diagnose me in my wheelchair. I want to get on the table. Get me undressed like the rest of the people—treat me like the others!”

Joe Alto believes that the problem is money and time. Examining tables with pedal-operated lifts cost at least twice as much as standard, fixed-height tables. He also worries that some physicians want to avoid patients who use wheelchairs. “When they see you coming in the wheelchair, they say, ‘That’s going to be a lot of work,’” said Mr. Alto. “Insurers don’t pay extra for someone like me, so the doctor isn’t going to want me there.” Minute by minute, “The doctor’s not getting as much money for a disabled person as he’s getting for someone else.”

Roughly 85 percent of Medicare beneficiaries belong to the traditional fee-for-service program, up several percentage points from 1998, the peak of managed care enrollments (MedPAC 2003a). In 2004, Medicare expects to pay about \$48.7 billion to nine hundred thousand fee-for-service physicians and other providers, rising from an estimated \$47.9 billion in 2003 (CMS 2003c). To be paid for the office visit, Joe Alto’s primary care physician must submit a claim to Medicare listing an evaluation and management (E&M) code indicating the level (from one to five) of the visit. His physician will choose the E&M code that matches the extent of the clinical history, the physical examination, review of body systems, clinical issues discussed with Mr. Alto, and the time spent. Medicare’s resource-based relative value scale, the basis for physician payment for the last decade, sets payments for each code physicians list on their claims. This scale attempts to narrow the reimbursement gap between primary care and specialist physicians. However, “reimbursement for routine primary care visits is insufficient for the care of many with chronic conditions, as care for this population usually takes a considerable amount of time, particularly when self-management and mul-

multiple conditions are addressed. . . . [Furthermore, the E&M classification] is a barrier to chronic care. E&M codes account for almost half of Medicare-paid physician services. These codes fail to adequately reflect the additional complexity and time requirements associated with care for many beneficiaries with chronic conditions” (Eichner and Blumenthal 2003, 30).

Other aspects of Medicare’s physician reimbursement policies are also problematic. The Medicare statute requires adjusting up or down the physician fee schedule based on how actual expenditures compare to a target rate, the sustainable growth rate or SGR. CMS (2003c) calculates the SGR “based on medical inflation, the projected growth in the domestic economy, projected growth in the number of beneficiaries in fee-for-service Medicare, and changes in law or regulation.” Substantial growth in Medicare physician outlays, combined with the slow economy, led to cuts in Medicare physician payments in the early 2000s. In fiscal year 2003, Medicare cut physician payments by 5.4 percent, and CMS proposed a 4.2 percent cut for 2004 (CMS 2003c).

Continued cuts in physician payments could make it harder for people like Joe Alto to find routine care. In 2002, 70.1 percent of physicians accepted new Medicare fee-for-service beneficiaries, down from 76.4 percent in 1999 (MedPAC 2003a). Even some generalist physicians avoid new Medicare beneficiaries. A spokesperson for the American Academy of Family Physicians reported that more than one-fifth of family physicians no longer accept new Medicare patients (Pear 2003b). In March 2003, MedPAC warned, “If the Congress does not change current laws, . . . then payments may not be adequate in 2003 and a compensating adjustment in payments would be necessary in 2004” (2003a, 72).

Physicians clearly need more time to fully examine persons using wheelchairs and persons with other disabling and complex conditions and to discuss their medical concerns. Paying more per visit for persons with disabling conditions than for healthier, able-bodied persons (i.e., “risk adjusting” office visit fees for patients’ health-related risks) therefore makes sense. Risk-adjusting E&M codes could substantially improve quality of care (Eichner and Blumenthal 2003).

Ensuring Health Care Quality

Current Medicare coverage policies do not match basic needs of persons with disabilities for interventions to maintain, restore, or maximize their functioning. These policies pose barriers to “patient-centered” care—care that is “respectful of and responsive to individual patient preferences, needs, and values” (IOM 2001, 42). Many strategies now exist to allow persons even with significant disabilities to live independently in the community, minimizing their risks of developing debilitating and costly secondary conditions. But coverage gaps prevent people from obtaining this care.

Addressing the four targets described in the previous section could substantially ameliorate this situation. However, skyrocketing costs pose formidable obstacles. Total Medicare expenditures are expected to reach \$450.1 billion by 2011, compared with \$245.6 billion one decade earlier (Heffler et al. 2002). Expanding

coverage to include more function-related services has always proved politically unpalatable: “The cost implications of disability-related services . . . frighten policymakers away from contemplating all but the narrowest of expansions. What looks like a half-empty glass when benefits are being designed may be a bottomless pit once the payments begin to flow” (Vladeck et al. 1997, 88).

Although I concentrate here on Medicare, deep cuts in state budgets are fraying Medicaid’s safety net. In designing Medicaid, Congress recognized that low-income persons have little to spend on care, so it adopted broader benefits than for Medicare. All states must cover core services (e.g., inpatient hospitalizations, skilled nursing facility stays, home health care), but they can also offer various optional services including prescription drugs, physical and occupational therapy, prosthetic devices, eyeglasses, and durable medical equipment. In 2002, Medicaid insured about 42.8 million persons, including 7.7 million low-income individuals, eligible because of disability or blindness, who consumed 37.8 percent of Medicaid’s resources (CMS 2002).

When facing substantial budgetary shortfalls, states frequently cut benefits, eliminating or reducing payments for optional items and services. In 2003, forty-five states implemented cost controls on prescription drugs, and twenty-five reduced Medicaid coverage for vision care; dental services; physical, occupational, and speech therapy; and home oxygen (Smith et al. 2003). With continuing budget deficits, state legislatures will likely continue chipping away at Medicaid benefits.

With these cuts, failures to expand Medicare coverage, and other related policy decisions, our nation consciously chooses to limit the quality of life, independence, and even health of many persons with disabilities. Politicians could credibly argue that coverage costs are too high, competing with other pressing societal needs. To counter such arguments, we need better evidence about potential cost trade-offs. For example, does providing a power wheelchair to improve independent mobility save money in the long run by reducing secondary disabilities, such as falls and depression, and lowering costs of home-based and institutional care?

As countless others have said, how we care for our most vulnerable citizens speaks volumes about our values as a nation. With mounting federal and state budget deficits, little will likely change in the next few years. But rethinking fundamental Medicare coverage policies may gain political momentum as millions of baby boomers care for aging parents and then retire themselves. Sally Ann Jones, a wheelchair user and SSDI recipient, feels that politicians have missed the obvious. “It amazes me that nobody’s gotten this notion yet: the baby boomers are coming. Despite MS and other diseases, they’re going to live longer. We’re not going to warehouse them in nursing homes. These boomers simply won’t do that. They’re not going to go quietly into the night.”

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