Health Care for Americans with Disabilities

Issue

More than 50 million individuals, or roughly one in five Americans, have a disability. Diverse in health-care needs, levels of functioning, goals, and life circumstances, many count on Medicaid and Medicare to provide coverage for a range of health and long-term services and supports. While people with disabilities are relatively heavy users of healthcare services, they often receive these services much less frequently than is recommended. Health issues that are important to people with disabilities span a wide range, but center on access to health insurance, coverage for essential services including prescription drugs and long-term services, and the financing of Medicaid and Medicare, given the critical role that they play in the lives of people with disabilities of all ages.

Background

People with disabilities have a wide range of conditions including physical impairments such as blindness and spinal cord injury; severe mental or emotional conditions; and other serious and disabling conditions including cancer, cerebral palsy, cystic fibrosis, Down syndrome, mental retardation, Parkinson's disease, multiple sclerosis, autism, and HIV/AIDS. Relative to the general population, those with disabilities have lower incomes and are far less likely to be employed. People with disabilities are also much more likely to have fair or poor health, to be limited in their activities of daily living, and to reside in nursing homes or other institutions. Some people with disabilities can obtain private health insurance, either from an employer or by purchasing it on their own, but significant gaps exist. Many people with disabilities do not work at jobs that provide access to employer-sponsored coverage, while individual insurance policies for persons with less-than-perfect health are too expensive, or not offered at all. Policies may also severely limit or exclude core disability services, such as prescription drugs, mental health services, rehabilitation services and personal care services.

Public programs—Medicare and Medicaid—play a major role in assuring healthcare for people with severe, permanent disabilities. Medicare provides health coverage to over 6 million non-elderly adults with permanent disabilities, in addition to 35 million seniors. Adults are eligible for Medicare if they receive Social Security Disability Insurance (SSDI), but must wait over two years before they can enroll. Medicare covers basic physician and hospital services, but does not currently pay for prescription drugs or long-term services. Beginning in 2006, Medicare will begin to provide prescription drug coverage.

Medicaid is the nation's primary program serving people who cannot obtain or afford private health coverage. The program provides coverage for over 50 million Americans, including 8 million people under age 65 with disabilities, 5 million seniors, and 38 million adults and children in low-income families. Medicaid covers a broad spectrum of services, ranging from physician care and prescription drugs to behavioral health and support services that are often critical to enabling individuals with disabilities to work or remain in the community. Medicaid is often the only source of public financial assistance for long-term services, including institutional care. Long-term services provide assistance with activities of every day life, such as bathing and

dressing, using the toilet, preparing meals, or managing finances. Low-income Medicare beneficiaries rely on Medicaid to fill in many of Medicare's gaps, including prescription drugs and long-term care.

Major Issues of Importance to People with Disabilities

Health Coverage

Medicaid and Medicare both play a pivotal role for people with disabilities, but millions fall outside their reach because coverage is often restricted to the poorest and most severely disabled. Recent policy efforts have focused on targeted improvements. For example, some states now guarantee continued access to Medicaid under "buy-in" programs that enable people with disabilities to become competitively employed without fear of losing health coverage. In addition, a few states have extended Medicaid coverage to people who have certain progressive conditions, such as HIV/AIDS or multiple sclerosis, for whom early treatment could slow the progression of disease. Other targeted proposals being discussed include permitting states to expand Medicaid coverage for children with disabilities in families with slightly higher incomes (up to about $40,000 a year) and eliminating the Medicare two-year waiting period for people with disabilities under age 65.

Broader efforts to expand health coverage to the nation's uninsured could help improve coverage for people with disabilities. Some have proposed subsidizing the purchase of individual health insurance plans. This strategy is likely to be of limited help to people with disabilities unless policies are offered to people with chronic conditions, premiums are affordable, and benefits are sufficiently broad. Broader insurance market reforms may be needed if the individual market is to address the needs of people with disabilities. Others have proposed expanding Medicaid and SCHIP to cover more of the low-income uninsured and shoring up the employer-market by providing federal financing for high-cost cases. Building on Medicaid and SCHIP would capitalize on the prominent role that public programs currently play for people with disabilities, but would work only if sufficient funding were provided by the federal and/or state governments to assure adequate benefits.

Prescription Drugs Under Public Programs

Access to the right medicines enables people with disabilities to participate in the workforce and in their communities, and, in some circumstances, may make the difference between life and death. However, affording prescription drugs can be a daunting challenge. In the absence of drug coverage under Medicare, Medicaid has played an essential role in helping low-income people with disabilities have access to a broad range of medicines.

Beginning in 2006, Medicare will begin offering new prescription drug plans. For Medicare beneficiaries who have multiple health conditions and take numerous prescription medications, critical issues will include whether the drug benefit is adequate in providing all of their needed medications and whether it will do enough to lower their drug costs. Low-income beneficiaries (generally those with incomes less than about $14,000/year) will be able to sign up for help in paying premium and cost-sharing requirements for the new plans, but efforts will be needed to let people know about this assistance and to facilitate enrollment.

For those who currently rely on Medicaid, Medicare will take over drug coverage and Medicaid coverage of prescription drugs will end. A critical issue for these "dual eligibles" will be how this transition from Medicaid to Medicare is handled, whether there are gaps in coverage, how much

out-of-pocket spending is required, and how readily individuals and physicians will be able to challenge or appeal denials of prescribed drugs.

Coverage of Long-Term Services and Supports

Finding ways to assure adequate access and financing for long-term care services is an important policy issue for people with disabilities, as well as the broader population. The aging of the population and growth in the number of people under 65 with disabilities will increase the demand for long-term care services. Most long-term care is provided informally through family and friends, often at a considerable emotional, physical, and financial toll. When ongoing needs surpass caregiver's capacities, nursing home or community care costs can quickly exceed most people's financial resources. Medicaid is the nation's primary program that pays for long-term services, but is generally available only to those who are poor or have exhausted their resources paying for care. Medicare does not generally cover long-term services, and private insurance for long-term care is not typically available or affordable for people with disabilities.

In the current fiscal environment, there is little discussion of expanding Medicare to cover more long-term services or developing a new national long-term care program, although proponents view a social insurance program, like Medicare, as the best way to share the risk that we all face for needing long-term care. Others support private sector solutions by changing the tax laws to provide greater incentives for individuals to purchase long-term care insurance and employers to offer long-term care insurance as an employee benefit. Proponents believe these actions could lessen future pressure to publicly finance long-term care, but others doubt that private long-term care insurance will be affordable for low or middle income Americans. More modest proposals would provide a tax deduction or credit to caregivers.

Some support strengthening Medicaid's ability to serve low and middle income people with disabilities by increasing the income and asset guidelines that states employ or developing partnerships that are more affordable to the government and to families because they link private coverage with a public safety net. These options build on state long-term care systems, but recognize that given Medicaid's role as the sole program to help with long-term care bills, rules that require impoverishment may be too severe and, in some cases, undermine the ability of people to stay in the community. Despite their appeal, public-private partnerships are limited to a handful of states and enrollment is low.

Reversing Medicaid's "institutional bias" by promoting more home- and community-based alternatives is also an important goal of the disability community. Recognizing that most Americans do not want to be in nursing homes or other institutions, states have increasingly taken steps in their Medicaid programs to provide more community-based services. The 1999 Supreme Court decided, in the case of *Olmstead v L.C.*, that unjustified institutional isolation of people with disabilities is illegal under the Americans with Disabilities Act (ADA). Unfortunately, progress has been slow and waiting lists for community services are often long. While community-based options are often less expensive than institutional care, some policymakers are reluctant to propose new programs or expand existing programs, fearful that overall costs will increase if more people seek assistance. The Administration has supported several "New Freedom" demonstration programs that have focused on supporting community services and providing greater consumer direction over services and individual budgets in the community by approving "Independence Plus" waiver programs. The Administration also supports "Money Follows the Person" legislation to support the transition from the nursing home to the community. In addition, some have called for modification of the Medicare homebound rules to permit individuals to participate more fully in community life.

Financing Medicaid and Medicare

Looking forward, the financing of both Medicaid and Medicare will be an important and challenging issue for policymakers. Medicaid is financed by the federal and state governments, but state resources have been strained in the last several years as economic conditions deteriorated. The future financing of Medicaid is a central issue for people with disabilities as more people at younger ages survive with significant needs and disabilities and the population in the United States continues to age. The recent period of fiscal stress has rekindled interest among states and at the federal level in restructuring federal Medicaid law, particularly with respect to the way the program is financed and the relative role of states and the federal government. The outcome of discussions about restructuring the program will have significant implications for state budgets, Medicaid beneficiaries, and the ability of the Medicaid program to continue to serve as a critical safety-net program.

Medicare will also face significant financing challenges in the coming decades. The number of beneficiaries is projected to grow from 41 million today to 76 million by the year 2030. To assure that financing is adequate to pay for benefits, policymakers are examining alternative options. Proposals to make Medicare financially solvent include: restructuring the Medicare program along the lines of the Federal Employees Health Benefit program, cutting the growth in Medicare payments to doctors, hospitals, and health plans, increasing beneficiary premiums and cost-sharing, and raising the age of Medicare eligibility.

Assessing Candidate Positions

Health coverage provided by public programs is an issue of crucial significance to people with disabilities, often meaning the difference between life and death. Many individuals with disabilities say their ability to lead active and independent lives is inextricably linked to their access to needed services, medications, and social support. These issues will play out as the future of public programs is debated, as the new Medicare drug law is implemented, and as the need for long-term services continues to grow. The following questions could be useful in understanding how the candidates propose to address some of the major areas of health policy affecting people with disabilities.

- How would your plan to expand health coverage affect people with disabilities? Would benefits be comprehensive and coverage affordable?
- How would you ensure that individuals with a disability or those supporting a disabled dependent do not lose their coverage when returning to work?
- What strategies should be implemented to eliminate Medicaid's institutional bias and increase the availability of services in the community?
- Should Medicaid and Medicare financing be restructured? If so, how?

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