

**Access to health care for people with disability in the U.S.**

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There are about 56.7 million people living with disability in the U.S., a dramatic increase over the past 10 years. The U.S. uses a number of national surveys to determine health status and health care usage, with disability defined variously by functional limitation, health condition, or employment status. Using the 6 questions recommended by the U.S. Department of Health and Human Services' national standard for population-based health surveys (related to hearing, vision, cognition, mobility, self-care, and independent living), about 12% of working-age adults (18-64 years) report disability, and the vast majority (60%) report only one disability type. Low socioeconomic status correlates with higher number of disability types reported by individuals, and a lower percentage of adults with disability are employed compared to those without disability (1). Over a third of adults 65 years or older and 8.4% of children under age 15 years report disability (2). Thus we have a sizable population of people with disability, which is anticipated to increase with the influx of medical advances and the increasing prevalence of chronic conditions associated with disabilities.

The U.S. is in the midst of health care changes and reforms. However, there has always been a safety net for people with disability within the system: 1) a national social security program (Social Security Administration) has provided assistance to older and unemployed Americans who have worked, later including people with disability with or without a work history, since the 1950s; 2) Medicare has provided medical insurance for Americans over age 65 years and those with certain permanent disability since the 1960s; 3) Medicaid, a federal-state matching grant program, has supported medical care for children, pregnant women, parents, seniors, people with disability since its inception in 1965. Amendments and legislation have expanded and adjusted the coverage these programs provide including rehabilitation services (inpatient and outpatient), durable medical equipment, prescription drug benefits, skilled nursing facility support, hospice care, and home care to a larger population, including coverage for those with select chronic diseases and disability that prevent them from full time employment, at any age. The Veterans Health Administration provides lifelong care for Americans who have served in the active military, and offers significant support for people with disability. Private health insurance has been the basis of health care coverage for over a century, although participation had decreased since 2000. Because of this, the Patient Protection and Affordability Care Act (ACA) was enacted in 2010, with the intent to increase access to health care for all Americans, achieve a quality standard, promote a wellness agenda through prevention, and control costs. The impact of the ACA on access for people with disability is not yet known, but there are some benefits: pre-existing disability and health conditions are no longer barriers to coverage, young adults can be maintained on parents' plans through age 25 years, out-of-

pocket expenditures are capped, total lifetime coverage is not limited, and health care access is not tied to employment. Over the past year, ACA managed insurance programs available to Americans have dramatically decreased but plans have been continually limited since inception because of costs. Unfortunately, many managed care plans limit high level rehabilitation services as cost containment. However, in 2015, Medicare and Medicaid provided health insurance coverage for 1 in 3 Americans, with or without disability and chronic conditions. 46 million older adults and 9 million younger adults with permanent disability comprised the Medicare population (3). Therefore it appears that people with disability likely have reasonable health care insurance coverage opportunities in the U.S.

Despite reasonable coverage opportunities, there have been reports of differences and disparities in health care access for people with disability for some time, and these differences continue to be reported. In general, people with disability are found to have less documented preventive services compared to those without disability, other than immunizations. A recent study compared mammography over a 10-year period (1998-2010), and noted women with disability had lower rates of mammography consistently over that time (4). The ACA has as its centerpiece enhanced preventive services, although development of accessible diagnostic equipment standards has not yet come to fruition. A priority for wellness programs has not been realized, and modifications for people with disability have not been addressed. Disparities in overall health, primary care visits, and insurance coverage appear to be present for people with less severe disabilities, especially Hispanics. These disparities were not noted for people with more severe disabilities affecting self-care and independent living (5). People with disabilities tend to receive health care through Emergency Departments because of the complexity of their health profiles, reporting poor access to care (6). Most ACA managed Medicare and Medicaid plans do not cover comprehensive inpatient rehabilitation, despite patients being eligible for services.

People with disability continue to report environmental access issues and limited knowledge and experience of clinicians. Barriers from exam table height, need for accessible scales, and poorly designed patient bathrooms are the most common reported (7,8), despite the Americans with Disability Act (ADA) legislation (enacted 1990). Women with disability are usually not offered pre-conception planning or counseling (9); in general, U.S. women commonly receive birth control counseling, but usually only limited pre-conception care (10). Families and patients report limitations in clinician knowledge and skills related to disability (9,11).

The utilization of services and actual cost of care for people with disability in order to maintain their health and ability to function have not been well understood or publicized. The Medical Expenditure Panel Survey (MEPS) provides the best detail of these issues (2006-2008 survey data). In general, among working age adults (18-64 years), there is both high cost and high utilization of services for people with chronic conditions plus disability; the presence of disability is a significant predictor of high utilization. Annual health care expenditures were noted to be \$14K for those with high utilization of services and \$25K for those with high cost services (12). This is a sizable expenditure needed to maintain the health and function of people with disability, especially those with significant disability, a vulnerable population. Therefore targeting cost reductions, especially in the care for people with disability, may not be a wise goal for U.S. health care.

While there appears to be reasonable health care insurance coverage opportunities for people with disability, survey data show there continue to be differences in utilization and possibly access to all services, compared to people without disability. The health needs of people with disability are complex and cost to maintain health and function can be high. To put these challenges in perspective, a study using data from a 2002-2003 joint health survey between the U.S. (private and public insurance, prior to ACA) and Canada (national health care system) noted parity between insured Americans with disability and Canadians with disability related to access, and in both countries, people with disability had a greater rate of unmet needs (13). Therefore, it is important for the field of disability and health to clearly articulate the health, health care needs, and cost of that care for people with disability. The increasing use of managed care organizations and other private insurance plans in the U.S., with a goal of reducing costs, poses a risk to those with disability. While the ACA will continue to evolve, it is not yet clear how the needs of people with disability will be affected by this overhaul of the health care system (14).

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