

# POLICY DATA BRIEF

## Access to Health Care for People with Paralysis

84% of people living with paralysis in the U.S. — an estimated 2,630,224 individuals — are unable to obtain necessary medical care, tests or treatment.



### THE ISSUE

People with paralysis often need more health care than others. Despite their need, 84% of people with paralysis say they are going without medical care, tests and treatments that they or their doctors believe are necessary.

The major barriers to health care are typically financial or physical. More than 30% of people with paralysis say they cannot afford the health care they require— even those with health insurance often struggle with high copayments or coverage denials. Others report having trouble finding transportation or locating nearby health providers. One-quarter of respondents cite lack of accessible medical facilities and services as a barrier.

## BARRIERS TO HEALTH CARE

### Financial Barriers

Among people living with paralysis, financial barriers most often stand in the way of receiving necessary health care.

Even when they have insurance, people with disabilities are much more likely than people without disabilities — 16% versus 5.8% — to go without needed care because of cost. <sup>1</sup>

### Physical Access Barriers

The Americans with Disabilities Act (ADA) was passed in 1990, yet many health facilities and services remain inaccessible to people with paralysis. Moreover, people with disabilities generally have no way of knowing which medical facilities can accommodate them before arriving for appointments.

## HEALTH INSURANCE STATUS AMONG PEOPLE UNABLE TO ACCESS CARE

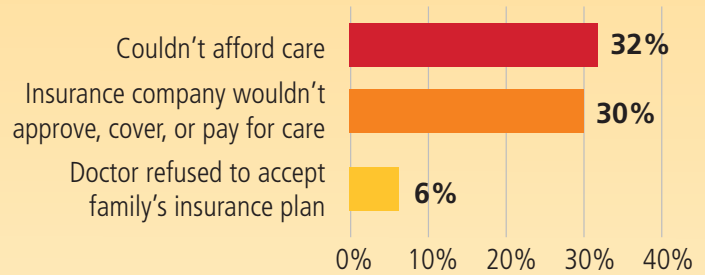
Most people living with paralysis who could not obtain necessary health care had health insurance.

**Only 12% of those who couldn't access health care were uninsured**

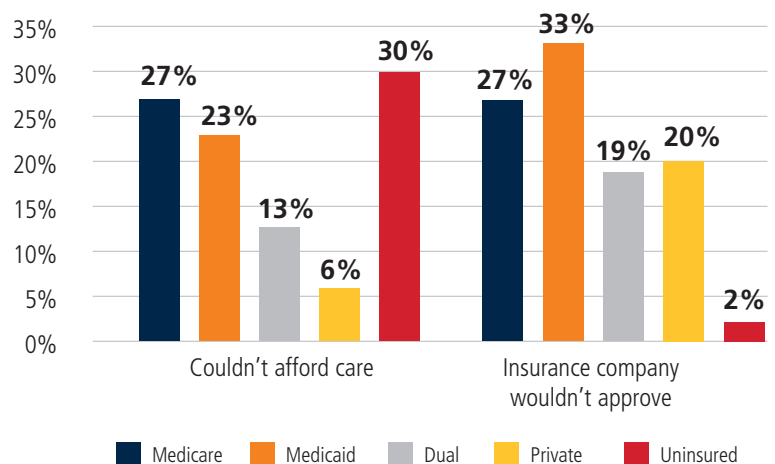
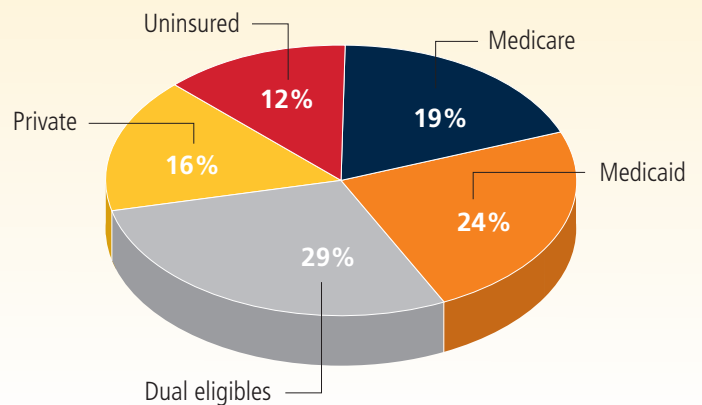
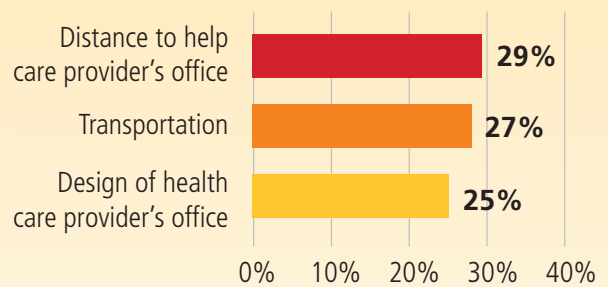
Of people with paralysis who couldn't afford health care, most were uninsured. Of those who were denied coverage by their insurer, most had Medicaid.

**30% of those who couldn't afford care lacked insurance, and 33% of those who received insurance denials had Medicaid**

**Most commonly reported financial barriers are unaffordability of care and denials from insurers**



**Most commonly reported physical barriers include distance, transportation and inaccessibility of provider's office**



## RECOMMENDATIONS

High-quality, affordable health care should be within everyone's reach. For people living with paralysis who are at higher risk of developing preventable secondary and other conditions, eliminating financial, environmental, physical, cultural and attitudinal barriers to health care is even more critical. The Affordable Care Act greatly increased access to care for people with paralysis, but many barriers remain.

- Since the Affordable Care Act (ACA) became law in 2010, insurers may not deny coverage on the basis of preexisting conditions. However, many individual plans sold in the ACA marketplaces have prohibitive out-of-pocket costs, such as high deductibles and copayments. **Federal and state governments should fully enforce—and Congress should strengthen—the cost-sharing protections of the ACA.**
- Section 5307 of the Act authorized federal grants for training health care professionals in working with people with disabilities. Unfortunately, funds for this program have never been appropriated by Congress. People with disabilities continue to face attitudinal and programmatic barriers in accessing health care. **Congress should fully fund Section 5307 training programs to enhance the ability of physicians to appropriately serve people with paralysis.**
- Section 1557 of the Act prohibits discrimination on the basis of disability in health insurance. Enforcement of this provision will improve accessibility and coverage of care needed by people with disabilities. In 2013 the Office of Civil Rights at the US Department of Health and Human Services issued a Request for Information from stakeholders about the implementation of this section. As of this document's publication, disability advocates still await proposed regulations to implement this policy and give further enforcement power to the ACA's prohibition on disability discrimination. **The HHS Office of Civil Rights should create strong regulations to enforce section 1557 nondiscrimination protections that incorporate input from disability advocates.**
- Section 4203 of the Act requires the Architectural and Transportation Barriers Compliance Board to issue standards for physical accessibility of medical diagnostic equipment. In 2013 the Board's advisory committee on this effort issued recommendations, but at the time of this document's publication the Board had not issued final regulations. The regulations will provide minimum standards for equipment, but not accessibility standards for physician offices. **The Access Board should issue the final standards for accessible medical diagnostic equipment, and the Food and Drug Administration and Department of Justice should enforce the guidelines.**
- Many states have tried to implement cost-sharing in their Medicaid program, including as a part of the Affordable Care Act's Medicaid Expansion and through 1115 demonstration waivers. Cost-sharing in Medicaid will increase financial barriers to health care among an already low-income population, including people living with paralysis. **The Department of Health and Human Services should reject Medicaid waiver proposals that include new cost-sharing, work requirements, or other new financial mechanisms that limit Medicaid beneficiaries' access to care.**

## ABOUT THE SURVEY

A national, population-based, random-digit-dial survey of over 70,000 households was conducted in 2012 to better understand the health and quality of life of people living with paralysis. The survey used a functional definition of paralysis based on the International Classification of Functioning: *“Paralysis is a central nervous system disorder resulting in difficulty or inability to move the upper or lower extremities.”* Paralyzing conditions include stroke, spinal cord injury, multiple sclerosis, spina bifida, cerebral palsy and others. Items used on the population survey were taken from normed, validated surveys including the American Community Survey, Behavioral Risk Factor Surveillance System and others, for the purpose of comparing people who are paralyzed with people with other physical disabilities as well as with those without disabilities. The survey focused on health status, severity, use of and barriers to receiving health care, secondary conditions and comorbidity, affordability of health care, preventive care and health risk behaviors.

## ACKNOWLEDGMENTS

This brief was supported in part by cooperative agreement number 90PR3001-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Intellectual and Developmental Disabilities policy. This work was previously funded under Cooperative Agreement # CDC-RFA-DD11-1102 with the Centers for Disease Control and Prevention.

This brief was produced by faculty and staff of the Center for Development and Disability at the University of New Mexico School of Medicine under a cooperative agreement with Christopher & Dana Reeve Foundation Paralysis Resource Center. For more information about the Foundation’s public policy efforts, contact Rachel Patterson at [rpatterson@christopherreeve.org](mailto:rpatterson@christopherreeve.org). For additional information about the collection of data, contact Dr. Anthony Cahill at [acahill@salud.unm.edu](mailto:acahill@salud.unm.edu).



636 Morris Turnpike, Suite 3A  
Short Hills, NJ 07078  
(973) 379-2690  
(800) 225-0292

[ChristopherReeve.org](http://ChristopherReeve.org)