

The Invisible Care Gap:

Ten Key Facts



Caregivers without
Health Coverage



PHI (www.PHInational.org) works to improve the lives of people who need home and residential care—and the lives of the workers who provide that care. Using our workplace and policy expertise, we help consumers, workers, and employers improve long-term care by creating quality direct-care jobs. Our

goal is to ensure caring, stable relationships between consumers and workers, so that both may live with dignity, respect, and independence.



Health Care for Health Care Workers (www.coverageiscritical.org), an initiative of PHI, seeks to expand health coverage for workers who provide support and assistance

to elders and people living with chronic conditions and/or disabilities. These consumers need a skilled, reliable, and stable direct-care workforce to provide quality services. We believe that one way to ensure a quality direct-care workforce is to provide quality direct-care jobs—jobs that offer health coverage and pay a living wage.

This document offers interested stakeholders and policymakers facts to draw from as they seek to expand health coverage for direct-care workers. This, and related publications, are available online at the Health Care for Health Care Workers website (www.coverageiscritical.org), or by calling the national campaign office at 718.928.2066.

Many other PHI publications are available through the PHI National Clearinghouse on the Direct Care Workforce, a resource center that provides reliable, up-to-date information related to the direct-care workforce nationwide. To order additional copies of this document please contact the PHI National Clearinghouse on the Direct Care Workforce at:

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Carol Regan, MPH, Director of PHI's Health Care for Health Care Workers, authored this report. Dorie Seavey, Ph.D., Director of Policy Research at PHI, assisted in planning the study and, along with Steve Edelstein, PHI National Policy Director, and Karen Kahn, PHI Communications Director, provided critical editorial support.



Introduction

Most direct-care workers are motivated to become caregivers by a heartfelt desire to make a difference in the lives of those they serve. More often than not, they remain on the job because of their close relationships with those they assist—in spite of, not because of, their wages or benefits. Millions of older Americans and people living with disabilities rely on these workers for the personal care and support they need to maintain their independence and a high quality of life. Ironically, many of those who provide care to others do not have access to health care themselves. Without affordable health coverage, our caregivers are just one major illness or accident away from financial ruin and physical harm.

This report, based on the most recent data available from the U.S. Census Bureau and Bureau of Labor Statistics, provides a snapshot of the health insurance status of our nation's caregivers. The grim picture that emerges illustrates the economic and health insecurity of this workforce, a workforce that Americans are increasingly dependent upon for services and support.

In fact, by 2016, an aging America will require 4 million direct-care workers, more than the number of teachers needed to educate our youth.

Most direct-care workers are women, and caregiving as an occupation ranks sixth in the sheer number of women employed. But building a quality workforce cannot be accomplished on the backs of workers who are underpaid and underinsured. With the demand for these jobs outpacing the supply of available workers, policymakers and employers must work together to create quality jobs that will attract and keep workers in this field.

Health coverage is an essential part of that solution.

Building a quality workforce cannot be accomplished on the backs of workers who are underpaid and underinsured.



Ten Key Facts

- 1:** Nurse aides have the highest incidence rate of workplace injuries and illnesses in the country, making this work America's most dangerous.
- 2:** Nearly 30 percent of all direct-care workers in the United States lack health coverage.
- 3:** Direct-care workers are *less likely* than other American workers to have employer-sponsored coverage.
- 4:** Direct-care workers in institutional settings are *more likely* than those in home and community-based settings to have employer-sponsored coverage.
- 5:** The caregiving jobs that are growing the fastest—those providing personal care services in people's homes—are least likely to have health coverage.
- 6:** Health coverage for direct-care workers varies significantly across the country.
- 7:** With 30 percent of direct-care workers living in or near poverty, very few can afford to purchase their own health insurance.
- 8:** Four out of ten direct-care workers live in households that rely on public benefits to make ends meet.
- 9:** Health insurance is critical to job retention and may be more important than wages in reducing turnover.
- 10:** The growing "care gap" requires immediate action to attract new workers into caregiving jobs.

1. Nurse aides have the highest incidence rate of workplace injuries and illnesses in the country, making this work America's most dangerous.

According to the U.S. Department of Labor's Bureau of Labor Statistics, nursing aides, orderlies and attendants—41 percent of whom work in nursing homes—suffer a higher incidence of injuries and illnesses requiring days away from work than any other job in the country.¹

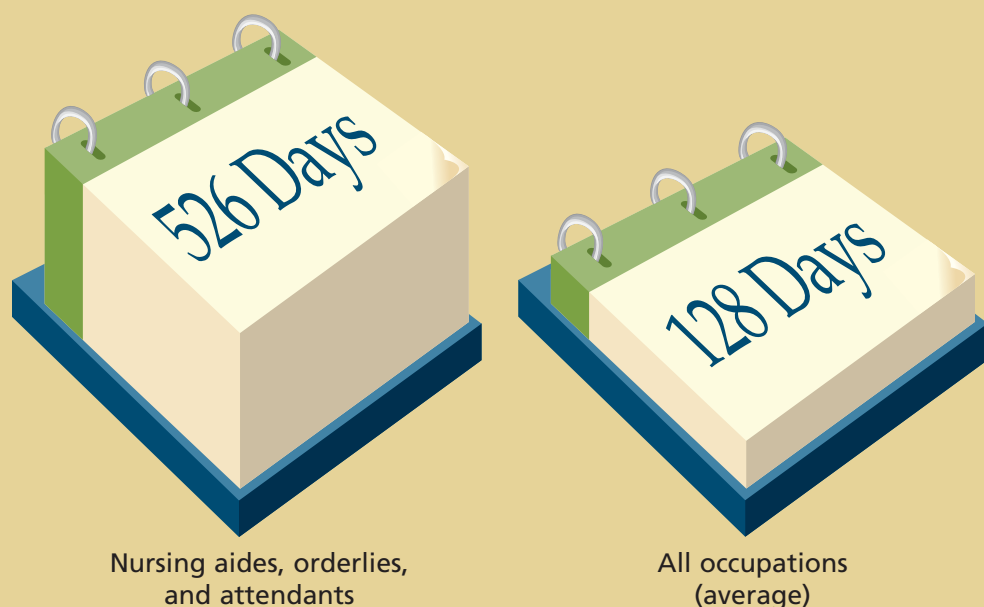
Why? The work is physically demanding and stressful. Workers lift and transfer clients; bend and twist to assist them to dress and carry out other activities of daily living; and manage the sometimes difficult behaviors of those with developmental disabilities, dementia, and mental illness. In the course of this work, direct-care workers experience astonishingly high rates of back injuries, muscle strains, and tears.

Thousands of caregivers suffer chronic, painful injuries that affect their quality of life and sometimes force them to give up jobs they love. Injuries contribute to high turnover rates, undermine quality of care for consumers, and increase the cost of doing business for employers.



Direct-care workers experience astonishingly high rates of back injuries, muscle strains, and tears.

More days away from work per year due to injury or illness (per 10,000 workers)



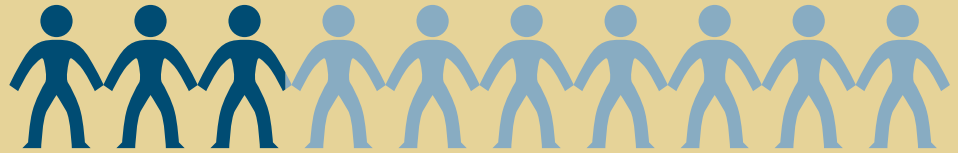
2: Nearly 30 percent of all direct-care workers in the United States lack health coverage.



In light of the high rate of back and other injuries suffered by direct-care workers on the job, their lack of health insurance is alarming. They are almost twice as likely as the general public to lack health coverage (29.2 percent vs. 15.8 percent). In other words, of the over 3 million workers providing services and supports to our nation's elders and persons with disabilities, an estimated 885,000 lack health insurance. That is more than the populations of Delaware, South Dakota, North Dakota, Alaska, Vermont, Washington, D.C., or Wyoming.

Direct-care workers are almost twice as likely as the general public to lack health coverage.

An uncovered workforce



Nearly 3 in 10 direct-care workers lack coverage.

3: Direct-care workers are *less likely* than other American workers to have employer-sponsored coverage.

Health insurance is a highly-valued benefit of employment for most working Americans. Despite the decline in employer-sponsored health insurance, most Americans still get their health insurance coverage from their jobs (62 percent). Yet only about half of direct-care workers (52.4 percent) have coverage from their employer.

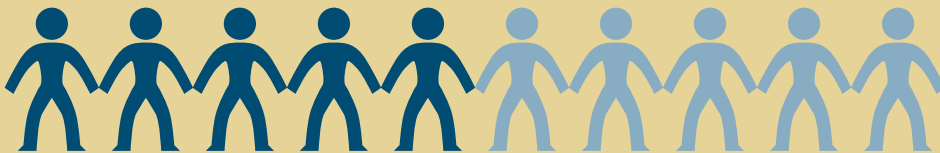
Many direct-care workers work part-time, a fact that clearly affects their coverage: 56 percent of those working full time (35 hours or more per week) have employer-provided coverage, compared to 44 percent working less than full time. But even among full-time workers, coverage rates are low compared to the population in general.



Fewer direct-care workers get health coverage from their jobs



More than 6 in 10 Americans have employer-sponsored coverage.



Only 5 in 10 direct-care workers have employer-sponsored coverage.

Nearly half of all direct-care workers have jobs without employer-sponsored health coverage.

4: Direct-care workers in institutional settings are *more likely* than those in home and community-based settings to have employer-sponsored coverage.



Health insurance status for direct-care workers varies according to the type of work they do and the setting in which they do it. The new CPS data illustrates distinct coverage patterns according to setting (institutions, community, or in-home settings) and the type of work performed within settings (nursing/medical vs. personal assistance only).

Caregivers working in three institutional settings—hospitals, nursing facilities, and residential care facilities²—are more likely to have employer-sponsored health coverage than those who work in home and community-based settings. These workers do a similar job but don't have similar benefits.

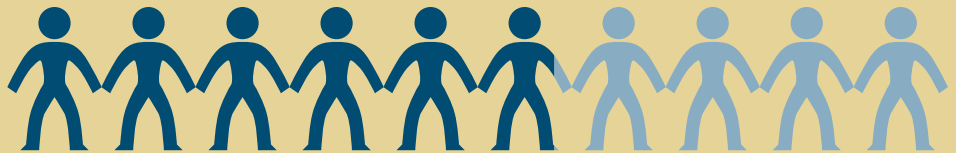
Hospital aides are significantly more likely than other direct-care workers, including those working in nursing or residential care facilities, to have employer-provided health insurance. Over three-fourths of hospital aides (78 percent) have employer-provided coverage, compared to 57.7 percent of nursing care facility aides. Among those working in home and community-based settings, less than half of direct-care workers (42 percent) have employer-provided health insurance.

Caregivers working in institutional settings are more likely than those who work in home and community-based settings to have health coverage from their employer.

Disparity Across Job Settings



Nearly 8 in 10 hospital aides are covered by their employer.



Nearly 6 in 10 nursing care facility aides are covered by their employer.



Only 4 in 10 home care aides are covered by their employer.

5: The caregiving jobs that are growing the fastest—those providing personal care services in people’s homes—are least likely to have health coverage.

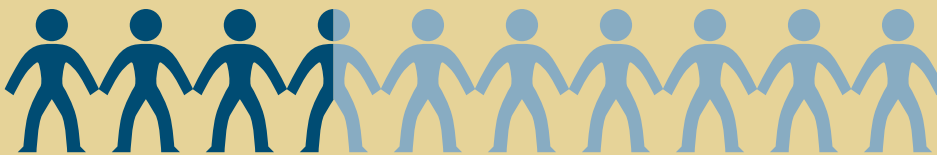
Home care workers are less likely than their counterparts working in institutional settings to have health coverage. While 27 percent of nursing, psychiatric and home health aides lack health coverage, 35 percent—more than one in three—of personal and home care aides are uninsured.

Based on current coverage patterns, trends in the demand for direct-care services are likely to increase the number of direct-care workers without coverage. Home care jobs are growing more rapidly than hospital or nursing aide jobs, not only because of the demand for home and community-based long-term care services but also because cost pressures are driving hospitals and nursing homes to discharge patients as quickly as possible.

This trend is clear in the data: In 2002, 54 percent of workers provided home and community-based services and 46 percent worked in facilities; by 2006 that percentage changed to 59 percent and 41 percent, respectively. By 2016, nearly two of every three direct-care workers (64 percent) will be providing home and community-based services. Thus, caregivers are increasingly finding jobs in the settings least likely to provide health coverage.

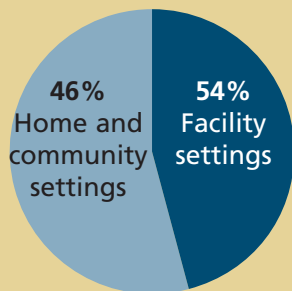


The workers most likely to lack coverage...

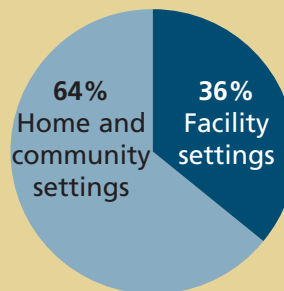


More than 3 in 10 personal and home care aides are uninsured.

...are in the highest demand



Where direct-care workers worked, 2002



Where direct-care workers will work, 2016

Home care jobs are growing more rapidly than hospital or nursing aide jobs.

6 ■ Health coverage for direct-care workers varies significantly across the country.



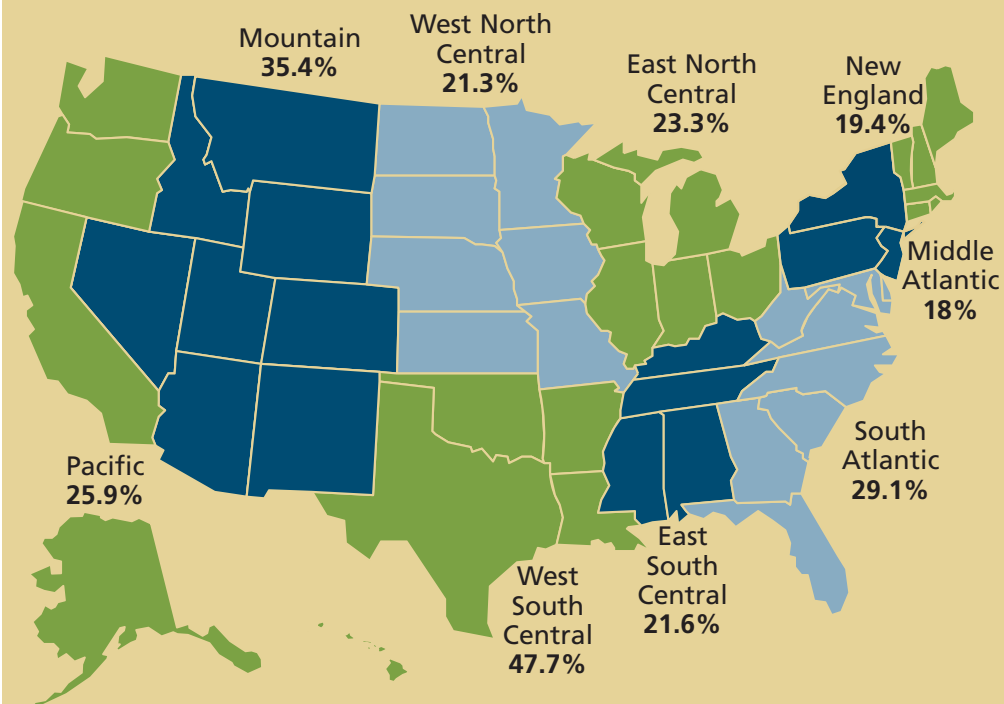
Health insurance coverage in the U.S. varies by where people work and where they live. The same is true for direct-care workers.

In Texas, Arkansas, Louisiana, and Oklahoma nearly half of direct-care workers (47.7 percent) lack health coverage—the highest rate of uninsured in the country. By contrast, in New York, New Jersey and Pennsylvania, 18 percent of these workers are without coverage.

The difference in these rates of coverage is largely due to geographical differences in eligibility for public coverage and the prevalence of collective bargaining agreements that secure health insurance for workers.³

In Texas, Arkansas, Louisiana, and Oklahoma nearly half of direct-care workers lack health coverage—the highest rate of uninsured in the country.

Lack of coverage varies across the country



7: With 30 percent of direct-care workers living in or near poverty, very few can afford to purchase their own health insurance.

Direct-care work is low-wage work. With a median hourly wage of \$9.56 per hour, direct-care workers earn about two-thirds of the median wage for all US workers. This is less than \$20,000 annually, if they work full time. Because these workers also live in households that have limited additional income, tens of thousands live in or near poverty—defined as \$26,400 for a family of three.

Federal Poverty Level Guidelines—2008⁴

Persons in Family or Household	Poverty (100% FPL)	Near Poverty (150% FPL)
1	\$10,400	\$15,600
2	\$14,000	\$21,000
3	\$17,600	\$26,400
4	\$21,200	\$31,800

At these income levels, few can afford to pay even a percentage of the high cost of employer-sponsored health insurance premiums, which average \$4,500 for individual coverage and \$12,106 for family coverage.⁵ When co-pays and deductibles are added in, these workers choose to forego the security of health coverage in order to house and feed their families.

The cost of private insurance coverage in the non-group market—for which age, gender, and health status are used to determine premiums—would be even more prohibitive.



Health care is too expensive for most direct-care workers



Nearly 3 in 10 direct-care workers live in households that have poverty or or near-poverty level incomes.

Few workers can afford to pay even a percentage of the high cost of employer-sponsored health insurance premiums.

8 ■ Four out of ten direct-care workers live in households that rely on public benefits to make ends meet.



Direct-care workers and their families earn such low wages and have so little income that often some members of the household depend on public programs to meet their basic needs. These include Medicaid, food and nutrition programs, cash welfare (i.e., TANF), and housing, energy and transportation benefits. The importance of this support cannot be underestimated, particularly when it comes to health coverage.

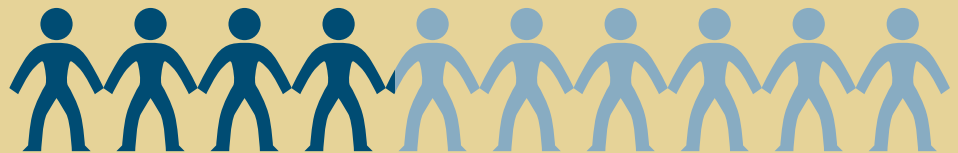
Medicaid, a federal/state insurance program,⁶ is a significant source of coverage for direct-care worker families. Over one in three direct-care workers live in households that receive Medicaid.

Why is the number so high? Not only do workers themselves qualify for Medicaid, but also many are single parents, or grandparents, caring for children who are covered by Medicaid. Others are paid caregivers for family members who are eligible to receive Medicaid-funded long-term care services.

Public programs designed to provide coverage to low-income families fill important gaps for direct-care workers without employer-sponsored insurance. Without Medicaid, the number of uninsured direct-care workers would be even higher.

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Caregivers rely on Medicaid and other public benefits



Over 4 in 10 direct-care worker households receive public benefits.



Over 3 in 10 direct-care workers live in households receiving Medicaid benefits.

9 ■ Health insurance is critical to job retention and may be more important than wages in reducing turnover.

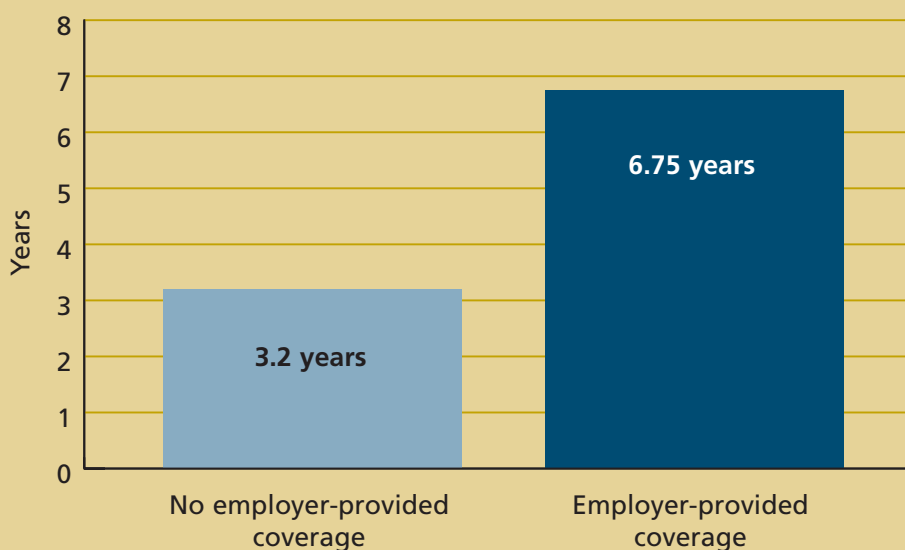
Researchers have found a strong, positive link between health insurance benefits for direct-care workers and worker retention. In fact, frontline health care workers enrolled in employer-sponsored health insurance plans remain in their jobs twice as long as those without employer coverage.⁷

In an industry with chronically high turnover (50 to 70 percent annually), these findings are significant. For consumers, constant turnover among caregiving staff is disruptive, affecting both the quality and continuity of care. A sustained, caring relationship is crucial to both health and overall comfort and contentment of those who need long-term care services.

For employers, constant recruiting and training of new staff is time consuming and expensive. Employers spend, on average, \$2,500 to replace each worker—roughly \$2.5 billion annually—a cost in large part born by U.S. taxpayers since these services are primarily paid for by Medicaid and Medicare.⁸ Health coverage at \$4,500 per worker would be a far better investment.



Direct-care workers with health coverage stay in their jobs twice as long



NOTE: Data based on unpublished study using National Longitudinal Survey of Youth, 1979 cohort, by Duffy, N. (2004). *Job Tenure of Frontline Healthcare Workers: Do Benefits Reduce Turnover?* JFK Jr. Institute for Worker Education. City University of New York.

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10: The growing “care gap” requires immediate action to attract new workers into caregiving jobs.



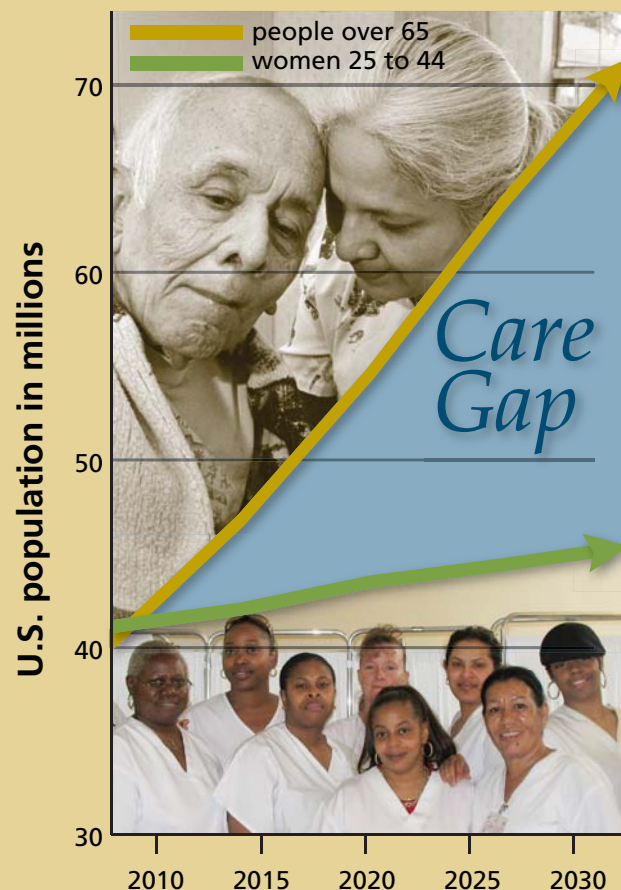
By 2016, an aging America will require 4 million direct-care workers, more than the number of teachers needed to educate our youth.

The population of adults over age 65 is growing at *three times* the rate of the population of family members available to care for them (primarily spouses and adult children aged 45 to 64). These demographic changes are increasing the demand for paid caregivers.

Between 2006 and 2016, for example, the need for personal and home care aides is expected to grow by 51 percent, while the traditional labor pool from which these workers are drawn—women aged 25–44—will barely hold its own, increasing during this period by only 2 percent.

This emerging “care gap” requires improving the quality of caregiving jobs to attract workers and increase the probability of their staying in the profession. Providing a living wage and decent health care coverage is crucial.

Fewer workers, growing demand



Conclusion

Though they work in one of America's most dangerous occupations, direct-care workers are *less* likely to have employer-sponsored health coverage and are *more* likely to be uninsured than other workers in the United States. Issues such as chronic back pain force workers to leave the field, particularly when they cannot access regular medical care. Moreover, without coverage, chronic illnesses such as diabetes are not well-managed, causing caregivers to miss work and, sometimes, to become disabled themselves. This undermines the quality of care for consumers and, if unaddressed, places our nation's long-term care system in jeopardy.

As direct-care work shifts from institutional to home-based care, current coverage patterns suggest that fewer workers will have jobs with health coverage, further compromising our ability to care for America's aging population—unless policymakers take action. With nearly \$207 billion spent annually on long-term care—69 percent paid for with public funds—federal and state policymakers have the responsibility *and* the ability to respond. They must make the economic and health security of America's direct-care workers—who provide an invaluable service to our families—a top priority.

Without a comprehensive strategy to ensure health care for caregivers, America cannot meet the caregiving needs of elders and people with disabilities now and in the future.



This report uses the U.S. Census Bureau's Current Population 2007 March Supplement, the only national survey source large enough to examine the insurance status of occupational groups. Regional rates are based on 2005–2007 pooled data. In order to provide a more complete picture of the insurance status of this workforce compared to previous studies, we included data on the full spectrum of direct-care workers working in both institutional and non-institutional settings, including aides working in vocational rehabilitation services (not included in previous studies) and male workers (11 percent of the direct-care workforce).

Following conventions used in other major surveys, direct-care workers' health insurance status was established using an algorithm that sorts through responses to the multiple items on the survey related to health coverage. Using this method, individuals were categorized as follows:

- **Uninsured:** Individuals reporting no form of coverage during the year
- **Employer-provided insurance:** Individuals reporting that they had insurance coverage provided by their employer at any time
- **Other private coverage:** Individuals reporting any other form of private coverage (including coverage under a spouse or partner's group plan)
- **Public insurance:** Individuals with no private coverage who report receiving coverage under any public program⁹

Endnotes

¹ Bureau of Labor Statistics, U.S. Department of Labor, Survey of Occupational Injuries and Illnesses. Available at <http://www.bls.gov/iif/oshwc/osh/case/osch0034.pdf>

² The Census Code definition of residential care includes some providers of home and community-based services.

³ Schmitt, J., Waller, M., Fremstad, S., Zipperer, B., *Unions and Upward Mobility for Low-Wage Workers*. Center for Economic and Policy Research, August 2007. See also Kaiser Family Foundation, www.statehealthfacts.org

⁴ These FPL guidelines are for the 48 Contiguous States and Washington D.C. See <http://aspe.os.dhhs.gov/poverty/08poverty.shtml>

⁵ Kaiser Family Foundation (2007). Employer Health Benefits: 2007 Summary of Findings. Available on-line at <http://www.kff.org/insurance/7672/upload/Summary-of-Findings-EHBS-2007.pdf>

⁶ Medicaid eligibility varies by state with certain minimum eligibility requirements set by the federal government. See www.kff.org/medicaid/upload/7235-02.pdf

⁷ Duffy, N. (2004) *Keeping Workers Covered: Employer Provided Health Insurance Benefits in the Developmental Disabilities Field*. JFK Jr. Institute for Worker Education. City University of New York.

⁸ Seavey, D., *The Cost of Frontline Turnover in Long-Term Care*, Better Jobs, Better Care, October 2004.

⁹ Because the algorithm for assigning insurance coverage assigns people with any form of private coverage to the private categories, individuals who had multiple forms of coverage, such as Medicare beneficiaries who purchased individual supplemental coverage, or workers who may have received Medicaid benefits at some point during the year and employer coverage at some other point, are counted as having employer-sponsored or other private coverage.



As Americans, we believe that everyone—young, old, able-bodied, or living with disabilities—deserves to live with dignity, with as much independence as possible. As we

age or become disabled, we want to remain at home or in communities where we can maintain our routines and our relationships. We want to have a choice, and for Americans, being able to choose requires the assistance of a direct-care worker. To ensure health care choices for ourselves and for our loved ones in the future, we need to begin caring about our caregivers today. One of the first steps is ensuring that these workers have affordable health insurance coverage.





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