

## Health Insurance Coverage of Direct Support Workers in the Developmental Disabilities Field

William Ebenstein

---

### Abstract

There is mounting evidence that employer-provided health insurance is an important factor in recruiting and retaining a competent and motivated direct support workforce within health and human services occupations. A review of the literature in this area, including new information related to the developmental disabilities field, is presented to assist nonprofit employers and government officials in designing initiatives to address increasing health care costs. Approaches to financing health coverage for frontline staff and a new program in New York that will provide subsidies to agencies to enhance existing coverage are discussed.

Health insurance is re-emerging as one of the most important issues facing our society. The Census Bureau reported that the nation's total number of uninsured people had risen by 1.4 million in 2003, to a record 45 million (DeNavas-Walt, Proctor, & Mills, 2004). A 2004 survey conducted by the Kaiser Family Foundation revealed that health insurance premiums were continuing to increase at double-digit rates (Claxton et al., 2004). In a 2004 national survey of nonprofit organizations conducted by the Johns Hopkins Institute for Policy Studies, Salamon and O'Sullivan reported 11% increases in annual health benefit costs. Over the last several years, there has been a growing interest in the health insurance coverage of direct support staff employed in health and human services occupations as an important factor in recruiting and retaining a competent, caring, experienced, and motivated frontline workforce. In 2002, the American Network of Community Options and Resources (ANCOR), a national provider association in the developmental disabilities field, issued a report that documented this growing crisis (BDO Seidman, 2002). In 2003–2004, the Centers for Medicare and Medicaid Services (CMS) funded several demonstration projects that are offering new or improved health insurance products to direct service workers to determine whether these incentives are effective in improving their recruitment and retention.

In the developmental disabilities field, direct support workers provide hands-on assistance with activities of daily living and community integration and offer a wide range of other supports, including advocacy, personal care, health care, housekeeping, transportation, and recreation. In New York, reimbursements to nonprofit agencies are publicly funded through a combination of state funds and Medicaid program payments. The funding levels are the primary factor in how much these nonprofit employers can afford to pay for wages and benefits. The funding mechanism is the Home and Community Based Services (HCBS) Waiver, administered by the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD). The rising cost of health insurance has been worrying OMRDD and its network of nonprofit providers, including the hundreds of agencies represented by the New York State Association of Community and Residential Agencies (NYSACRA). In 2004, a Health Insurance Task Force consisting of representatives from NYSACRA, OMRDD, and the John F. Kennedy, Jr. (JFK) Institute collaborated on a foundation-funded study to provide relevant data about the developmental disabilities workforce in New York to inform public policies related to the health insurance crisis (Duffy, 2004). In its 2005–2006 budget, OMRDD allocated funding for a new health insurance initiative for direct support staff employed in its network of nonprofits.

The implications of increases in health costs are particularly ominous among nonprofit organizations. Some researchers have speculated that access to affordable health insurance is a critical aspect of nonprofit employment “perhaps offsetting in part the generally lower wages that nonprofits are able to offer” (Salaman & O’Sullivan, 2004). Many surveys indicate that a large majority of companies think it is “very important” that they provide health coverage to their employees and contribute to its cost. At the same time, workers say that employer-sponsored health insurance is a “very important” factor in their decision to take or keep a job. In addition to improving recruitment and retention of staff, most employers also believe that insurance coverage improves employee health, morale, and productivity. These views acknowledge that the value of offering health coverage exceeds its direct cost to employers (Collins, Schoen, Doty, & Holmgren, 2004; O’Brien, 2003).

---

### Stagnant Wages and Shifting of Health Costs to Low-Wage Workers

Employers have responded to escalating health costs by increasing the share of premiums that their employees pay, increasing cost-sharing at the point of service, giving smaller raises, and offering less generous health plans. In general, they have preserved at least minimal benefits but have increased costs to their workers (Collins et al., 2004; Edwards et al., 2004). In the Johns Hopkins survey, almost two thirds of the nonprofits that responded shifted at least part of their health costs to their employees. One third reported reducing or eliminating raises, bonuses, and/or nonhealth benefits as a direct consequence of health cost increases (Salaman & O’Sullivan, 2004).

With overall funding in the developmental disabilities field limited by prescribed reimbursement rates, it is inevitable that the need to increase wages for direct care workers will conflict with the effort to limit increases in health costs and other benefits.

In New York State, the average salary for direct support workers in 2001 was \$10.48 per hour. This figure includes over-time, which agencies use to fill gaps in staff coverage due to turnover, and low-wage workers need to earn extra money to make ends meet. From 2000 to 2001, the average salary of direct support workers rose just 2.6%, less than the rate of inflation for the same period. At the same time, health expenditures increased an average of

7.5% across all OMRDD funded agencies. Also, during this time, a growing share of agency operating budgets went toward health care expenditures (Duffy, 2004).

Across all employers in New York State, from 2001 to 2003, workers paid a greater share of the cost of premiums. For individual coverage their share rose from 11% to 18%. For family coverage their share rose from 17% to 23% (Edwards et al., 2004). Increasingly, low-wage workers cannot afford to participate in employer health plans because the cost of coverage amounts to a significant percentage of their income. Nearly 40% of workers who earned less than \$10 per hour spent more than 5% of their income on premiums. The research in this area indicates that when premium costs reach 5% of family income, enrollment among low-wage earners falls off dramatically (Collins, Schoen, Colasanto, & Downey, 2003; Ku & Coughlin, 2000). Low-wage workers who allocated at least 5% of their income for premiums also reported the least comprehensive coverage and the least satisfaction with their health plans. Over 40% of low-wage earners reported having trouble paying medical bills, even when they had coverage. Many went without needed health care because of the high cost of additional out-of-pocket medical expenses (Collins et al., 2003).

---

### Rates of Employer Sponsored Health Coverage

Nationally, due to increases in health costs, about 17% of nonprofits that responded to the Johns Hopkins survey changed some workers from full- to part-time status or moved more work to contract employees. In New York, full-time employment in the developmental disabilities field is declining and increases in health costs may be contributing to this trend. According to Duffy, from 2000 to 2003, rates of full-time employment in OMRDD funded agencies declined from 73% to 68%. Thus, in 2003, about one third of the workforce was part-time. About 62% of OMRDD funded employers offered health coverage to part-time staff. About one quarter of all workers employed by developmental disabilities agencies were not eligible for benefits, mainly because they worked part-time or had not been employed long enough. About three quarters of the workforce was eligible. However, the take-up rate or share of eligible workers that actually enrolled was 70%. Thus, only about

52% actually enrolled in an employer-sponsored plan (Duffy, 2004).

It is likely that management and clinical staff had higher take-up rates than did low-wage direct support workers. The overall rate of enrollment in OMRDD-funded agencies is slightly lower than the 58.5% of all residential care workers in the United States who obtained health coverage through their jobs in 2001 (Fegley, Herzenberger, & Price, 2003). In other studies of only direct support workers in related occupations, 42% of nursing home aides and only 26% of home care aides had employer-provided health coverage (Lipson & Regan, 2004). In New York's developmental disabilities agencies, about 30% of those who were eligible did not accept the offer. Some low-wage workers were enrolled in Medicaid. Other workers had health coverage through a spouse or other person. Most of the others found premiums unaffordable and just went without coverage.

---

### Health Coverage and Job Tenure

Access to health coverage may be a factor in job tenure. A sizeable percentage of core staff has made a long-term commitment to the developmental disabilities field. Nonprofit agencies that responded to a 2004 survey conducted by the JFK Institute for Worker Education reported that 60% of their employees had been working at the agency for over 2 years, 34% over 5 years, and 18% had been employed over 10 years. According to Duffy (2004), in New York the average tenure of agency staff, from executives to direct support workers, was 4.6 years. However, employees at agencies with rates of enrollment in health benefits plans greater than 60% had an average of one additional year of on-the-job tenure compared to those agencies with rates of enrollment below 50%. Also, average tenure was 7 months greater in agencies that spent over \$5,000 per enrollee relative to agencies that spent less than \$4,000 per enrollee.

---

### The "Job-Lock" Literature and the Aging of the Workforce

The job-lock literature suggests that for certain individuals having employer-provided health insurance reduces turnover, and the possibility of losing health benefits when leaving a job also reduces turnover (O'Brien, 2003). Although the research is sometimes contradictory, it appears that the stron-

gest evidence of job-lock is among women, who tend to use health care services more than men do (Buchmueller & Valletta, 1996). According to job-lock theory, individuals covered by employer-sponsored health insurance plans are less likely to retire before they become eligible for Medicare at 65, if doing so would mean losing their health benefits. Therefore, it is important that employers maintain access to affordable health coverage, not only to recruit new workers, but also to forestall a wave of early retirements, especially among women and older workers.

---

### Labor Unions and Health Coverage

In New York State, a significant percentage of direct support workers employed by nonprofit developmental disabilities agencies is represented by unions. Of agencies that responded to the JFK Institute survey, 21% employed at least some workers who were unionized. Historically, union members are more likely to have employer-provided health insurance and more generous health plans. Also, employers of unionized workers generally pay a larger share of both individual and family coverage (Mishel & Walters, 2003).

The growing health insurance crisis is becoming a contentious issue in labor-management contract talks. Both unions and employers must balance the necessity of modest wage increases with the desire to maintain existing benefits. Organized labor regards the shift in health costs to represented workers as an attack on a traditional perk of union membership. Access to high-quality, low-cost health insurance is an important part of the history of the labor movement, and one of its most important organizing tools. Rising health costs are also causing problems for union-administered health insurance programs. All these factors are putting greater pressure on labor negotiators to increase the employer share of rising health costs.

---

### Approaches to Financing Health Coverage

Meaningful wage increases for low-wage workers are unlikely until health costs are contained. At the same time, increases in health costs are being passed along, at least partially, to those who are least able to afford it. It is clear that these issues are part of a broader national problem. Trends in health coverage for direct support workers in the devel-

opmental disabilities field are similar to those for frontline workers in related health and human services occupations, and for low-wage workers in other sectors of the economy. Nevertheless, it is important that the developmental disabilities field takes the lead in implementing practices that begin to address this mounting crisis.

### *Prorating Premium Payments*

Most employers require the same premium contributions for the same health plan for all workers, irrespective of their salaries or family income. A novel approach discussed by Meyer and Wicks (2003) is a sliding scale for premiums based upon a percentage of a worker's salary. If an agency's priority is covering direct support workers, prorating employee contributions based upon salaries is a relatively fair way of spreading health costs across all personnel categories within an organization. Also, many eligible part-time employee do not enroll in employer-provided insurance because they are required to pay a greater share of the cost of premiums compared to those who work full-time. Agencies could prorate premium contributions based on the number of hours worked per month, from part-time to overtime. However, redistributing the cost of benefits within an organization does not address the system-wide crisis of escalating health costs. An example of sliding-scale employee contributions is the Family and Children's Association on Long Island. Agency policy is that percentage of cost-sharing is tied into salary. The maximum cost sharing is 50% and the lowest paid staff pay 10 to 15% of cost (Scaglione, 2005).

### *Large Insurance Pools*

The Johns Hopkins survey indicated that the health plans of most nonprofits are fairly sophisticated and that 80% use some type of controlled-access plan, such as a Preferred Provider Plan (PPO) or Health Maintenance Organization (HMO) as their major health insurance offering. There are hundreds of nonprofits that are funded through OMRDD, and each one negotiates its own health plans with insurers. Most agencies offer several different plans, with HMOs being the most common type. The cost and quality of the plans is not uniform across companies, between large agencies and smaller ones, or even within the same organization. For stabilization of health costs and creation of a standard of comprehensive coverage to occur within the field, opportunities and incentives

to participate in "group purchasing arrangements" should be expanded.

One possibility that has been explored is the New York State Health Insurance Program (NYSHIP), which is the largest public employer insurance program in the nation outside of the federal government. Its Empire Plan was developed as a result of collective bargaining between the state and its employee unions. If special legislation was passed, OMRDD-funded providers could join NYSHIP under the quasi-public organization rubric. Nationally, the federal government's proposed Association Health Plans, which would allow employers to band together to provide insurance, might be another possibility, provided that all workers were allowed to participate and consumer protections were built-in.

### *Shifting Costs to Public Insurance Versus Supporting Employer-Provided Coverage*

In a time of double-digit increases in the cost of health benefits, maintaining coverage for direct support workers is a challenge. The tradeoffs between modest wage increases and health coverage cannot continue to be made at the expense of frontline staff, or, increasingly, they will "opt-out" of the system of employer-provided insurance. There are many reasons to support the employer-based system. It can provide coverage for the whole family and can reach families who would otherwise avoid public coverage because of the stigma that they might associate with it. Job-based enrollment and premium payments through payroll withholding are convenient features.

Over 40% of the agencies that responded to a recent JFK, Jr. Institute survey provide bonuses to employees who can demonstrate that they have coverage through another source, such as a spouse. A possibility for the lowest wage workers is enrollment in Medicaid. In studies of comparable health-care workers, 18% of nursing home aides and 19% of home health aides had family incomes below the poverty level, and over 10% were enrolled in Medicaid (General Accounting Office, 2001). Many agencies facilitate the enrollment of their staff into public programs. The bonuses they offer can amount to a significant increase in income for low-wage workers. At the same time employers save on their share of the health premiums.

The decision to facilitate enrollment in public programs or to develop alternatives that strengthen the employer-based system is a critical public policy

choice point. In the absence of any realistic options, more workers will enroll in public programs, and will be encouraged to do so by their employers. In the long run, this will weaken the bond between the worker and the employer and may have other undesirable consequences. More workers will refuse additional hours to maintain their income eligibility for public insurance. Opportunities for promotions will be turned down. Over 20% of agencies that responded to the JFK, Jr. Institute survey indicated that they were aware of employees who had quit or worked part-time in order to maintain eligibility for Medicaid. Also, there will likely be more turnover by direct support workers if doing so does not result in the loss of their health benefits.

Neuschler and Curtis (2003) have suggested that as an alternative to shore up rather than undermine the employment-based system, states should consider crafting a premium subsidy program via the Health Insurance Premium Payment (HIPP) program and/or the Health Insurance Flexibility and Accountability demonstration (HIFA). Many direct support workers who are eligible for publicly subsidized health insurance do participate in employer-provided health plans. Through HIPP, states could use Medicaid funds to help pay the health insurance premiums for the percentage of the direct support workforce that is eligible for public coverage. Premium contributions paid for private insurance on behalf of Medicaid-eligible employees amounts to a significant subsidy of the publicly funded health insurance system. Through HIPP, states could be compensated for the health care costs of employees and their dependents who could be covered by Medicaid, if they were not participating in an employer-sponsored plan. In addition, with federal approval, through the HIFA demonstration initiative, states can also use Medicaid funds to subsidize the purchase of health insurance for “expansion populations” that do not satisfy existing Medicaid requirements. Instead of facilitating their enrollment in public programs by providing incentives to “opt-out,” these approaches seek to access additional federal dollars and build upon the advantages of a job-based system (Mitchell & Osber, 2002; Neuschler & Curtis, 2003; Sachs, 2003).

### *New York's New Direct Support Worker Health Care Initiative*

In its 2005–2006 budget, OMRDD allocated \$70 million for a health care initiative that will provide subsidies to nonprofit developmental dis-

abilities agencies to enhance existing employer-provided health insurance benefits. The subsidy would be based upon an agency's overall effort in providing a positive environment for its workforce and could be used to reduce existing co-pays, deductibles, or other participation costs; reduce costs of family coverage; pay for additional coverage; make deposits to health savings accounts and flex plans; and gain access to coverage for staff, such as part-time employees, who may not be currently insured. Hundreds of nonprofit agencies in New York State offer a vast array of health plans. About 30 small agencies do not offer health insurance to any direct support staff. Some agencies, especially those with unionized workers, pay all health costs for their employees. The OMRDD has formed a workgroup with provider associations to come up with a process for allocation of this funding.

---

### **Conclusion**

As the ranks of the uninsured continue to grow, and the costs of health care spiral out of control, especially for low-income workers and their families, there is increased evidence that the provision of affordable employer-sponsored health insurance may be an important factor in recruiting and retaining a competent, caring, experienced, and motivated frontline workforce. However, agency responses to increases in health costs, although expedient, may be counterproductive. Wages are stagnant, while increases in costs are passed along as higher premiums. Inferior plans are offered, with less coverage and more out-of-pocket expenses. There are longer waiting periods and more ineligible part-timers. Fewer direct care workers are able to afford health coverage even if they are eligible. Labor–management negotiations are becoming more contentious.

Agencies are trying to respond to a difficult situation. A few are experimenting with prorating health premium payments based on a worker's salary. Professional associations are discussing the possibility of their member agencies entering larger insurance pools. Also, many agencies will continue to shift the health insurance burden to public insurance programs by expanding “opt-out” incentives, such as wage bonuses to Medicaid-eligible workers. This will result in further erosion of the employer-sponsored system. Another approach is to apply subsidies, funded through Medicaid and/or state funding, or another source, to help direct support

workers get health insurance through their jobs. This option builds upon the many strengths of the employer-based system. From the point of view of increasing job tenure, enhancing productivity, improving morale, and fostering organizational commitment, this latter approach is preferable.

Over the last 20 years, much of the debate around the direct support workforce has focused on wages. The growing health care crisis requires that this debate be broadened to include the cost of benefits, for both employers and workers. With funding limited by reimbursement rates, the field needs to develop a more comprehensive approach to the workforce that encompasses wages, health benefits, and educational benefits. All these elements must be in place to have a stable, competent, and motivated workforce.

The health insurance crisis also raises questions related to quality care and ethics. Can we continue to advocate for adequate health care services for people with developmental disabilities without advocating for comprehensive coverage for frontline staff? Is it fair to expect a worker to administer medication to a consumer if she cannot afford medicine for her own family? Can an uninsured worker with a chronic back problem safely lift a frail consumer? Will morale suffer if a worker advocates for a consumer in a doctor's office, while he or she must seek health care in a hospital emergency room (Case, Himmelstein, & Woolhandler, 2002)?

Leaders in the developmental disabilities field will need to forge new partnerships with other key stakeholders. Frontline workers in the long-term care field have similar problems with low wages and inadequate health coverage. Unions push for higher wages and health benefits for their low-wage workers. The growing health care crisis provides an opportunity to build a broader alliance around this common concern. If a state achieves broad health care and health insurance reform, this will benefit direct support workers as well as other low-wage workers in other sectors of the economy; therefore, it is important that disability advocates, direct care workers and their representatives, and employers become more active in coalitions in their state to bring about needed health insurance reform.

## References

BDO Seidman. (2002, December). *On the growing crisis in recruiting and retaining the direct support workforce*. American Network of Community

- Options and Resources. Retrieved December 27, 2005, from: <http://www.ancor.org>
- Buchmueller, T. C., & Valetta, R. G. (1996, April). The effects of employer-provided health insurance on worker mobility. *Industrial and Labor Relations Review*, 49, 439-455.
- Case, B. G. S., Himmelstein, D. U., & Woolhandler, S. (2002, March). No care for the caregivers: Declining health insurance coverage for health care personnel and their children, 1988-1998. *American Journal of Public Health*, 92, 404-408.
- Claxton, G., Gil, I., Finder, B., Holve, E., Gabel, J., Pickreign, J., Whitmore, H., Hawkins, S., & Fahlman, C. (2004). *Employer Health Benefits, 2004 annual survey*. Kaiser Family Foundation and Health Research and Educational Trust. Retrieved December 27, 2005, from <http://www.kff.org/insurance/7148>
- Collins, S. R., Schoen, C., Colasanto, D., & Downey, D. A. (2003, April). *On the edge: Low-wage workers and their health coverage*. New York: Commonwealth Fund.
- Collins, S. R., Schoen, C., Doty, M. M., & Holmgren, A. L. (2004, March). *Job-based health insurance in the balance: Employer views of coverage*. New York: Commonwealth Fund.
- DeNavas-Walt, C., Proctor, B. D., & Mills, R. (2004, August). *Income, poverty and health insurance coverage in the United States: 2003*. United States Census Bureau. Retrieved December, 27, 2005, from <http://www.census.gov/hhes/www/income.html>
- Duffy, N. (2004, October). *Keeping workers covered: Employer provided health insurance benefits in the developmental disabilities field*. New York: The City University of New York, John F. Kennedy, Jr. Institute for Worker Education. Retrieved December 27, 2005, from <http://www.nysacra.org>.
- Edwards, J. N., How, S., Whitmore, H., Gabel, J. R., Hawkins, S., & Pickreign, J. D. (2004, May). *Employer-sponsored health insurance in New York*. New York: Commonwealth Fund.
- Fegley, C., Herzenberger, C., & Price, M. (2003, October). *Threatening the promise: Workforce crisis and funding shortfalls jeopardize community-based mental health and mental retardation services*. Keystone Research Center. Retrieved December 27, 2005, from <http://www.keystoneresearch.org/publications>
- Ku, L., & Coughlin, T. (2000). Sliding scale premi-

- um health insurance programs: Four states' experience. *Inquiry*, 36, 471–480.
- Lipson, D., & Regan, C. (2004, March). *Health insurance coverage for direct care workers: Riding out the storm. Better jobs better care* (Issue Brief, No. 3).
- Meyer, J. A., & Wicks, E. K. (2003, April). *Issues in coverage expansion design: Options for financing health coverage expansion*. Economic and Social Research Institute. Retrieved December 27, 2005, from <http://www.esresearch.org/newsletter/aprilos/financing.pdf>
- Mishel, L., & Walters, M. (2003). *How unions help all workers*. Economic Policy Institute Briefing Paper. Retrieved December 27, 2005, from [http://www.epinet.org/briefingpapers/14\\_3/bp143.pdf](http://www.epinet.org/briefingpapers/14_3/bp143.pdf).
- Mitchell, J. B., & Osber, S. (2002, Spring). Using Medicaid/SCHIP to insure working families: The Massachusetts experience. *Health Care Financing Review*, 23(3), 35–45.
- Neuschler, E., & Curtis, R. (2003, May). Use of subsidies to low-income people for coverage through small employers. *Health Affairs, MarketWatch*. Retrieved December 27, 2005, from <http://content.healthaffairs.org/cgi/reprint/hlthaff.w3.227v1.pdf>
- O'Brien, E. (2003). Employers' benefits from workers' health insurance. *Milbank Quarterly*, 81(1). Retrieved December 27, 2005, from <http://www.milbank.org/quarterly/8101feat.html>
- Sachs, T. (2003, November). HIFA at age two: Opportunities and limitations for states. *State Coverage Initiatives*, IV(6). Washington, DC: Academy Health. Washington, DC. Retrieved December 27, 2005, from <http://www.statecoverage.net/pdf/issuebrief1103hifa.pdf>
- Salamon, L. M., & O'Sullivan, R. (2004). *The health benefits squeeze: Implications for nonprofit organizations and those they serve*. Baltimore: Johns Hopkins University, Institute for Policy Studies.
- Scaglione, F. (2005). How's your health? Insurance costs sicken sector. *New York: Nonprofit Press*, 4(1).
- U.S. General Accounting Office. (2001, May). *Nursing workforce: Recruitment and retention of nurses and nurse aides is a growing concern* (Testimony before the U.S. Senate Committee on Health, Education, Labor and Pensions, on May 17, 2001, by William J. Scanlon, Director of Health Care Issues, U.S. General Accounting Office. Retrieved from <http://www.gao.gov/new.items/d01750t.pdf>
- Yamada, Y. (2002). Profile of home care aides, nursing home aides and hospital aides. *Gerontologist*, 42, 199–206.

Received 2/21/05, first decision 7/18/05, accepted 9/5/05.

Editor-in-Charge: Steven J. Taylor

---

**Author:**

**William Ebenstein, PhD**, Executive Director, John F. Kennedy, Jr. Institute for Worker Education, The City University of New York, 101 W. 31st St., 14th Floor, New York, NY 10001. E-mail: William.Ebenstein@mail.cuny.edu