

**Health Insurance
Needs and Experiences
of
Massachusetts
Long-Term Care Workers**

November 2002

**Report on
Employer and Employee Focus Groups
Convened from January – October 2002**

*conducted by
Paraprofessional Healthcare Institute
with the
Direct Care Workers Initiative*

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EXECUTIVE SUMMARY

Many workers who provide care to others lack adequate, affordable health insurance for themselves and their families. These workers – the certified nursing assistants, home health aides, homemakers and personal care attendants caring for people living in nursing homes or their own homes – often must go without health care services. Lack of adequate coverage affects workers' health and that of their families, and impedes their ability to stay on the job and care for others. Inability to offer adequate, affordable health insurance to workers impedes long-term care employers' ability to maintain a stable workforce and provide continuity of care. Instability in the workforce creates significant access and quality problems for long-term care consumers.

- **Long-term care workers**, struggling already to live on low wages, are often unable to afford the premiums and co-pays. Most part-time and per diem workers, and some full-time workers go without regular health care services as they are caught in the middle – making too much to qualify for Mass Health, but too little to afford private insurance. They cannot afford family coverage, face high and frequent co-pays for prescriptions for asthma, allergies, diabetes and high blood pressure, and for dental services. Many have chronic health conditions, face recurrent back and other injuries, and exposure to clients' illnesses. Many workers are forced to work hurt when they cannot afford days off without pay. Many have incurred large health care related debt, and many have foregone needed tests or treatments. *“How can you take care of others when you have no health insurance to take care of you?”*
- **Long-term care employers** face steep rate hikes and limits on plan choice from insurance companies who see the caregiving workforce as a high risk, high use pool. With fewer carriers and higher expenses, employers struggle to absorb the increasing insurance costs while facing increasingly tight public payment rates. They try to minimize the impact on their workers, choosing less expensive plans with less coverage but these often require higher co-pays and sometimes a change of doctors. Employers pick up as much of the increase in premium costs as they can but often must require a higher employee contribution to keep overall costs down. As a result, *“We’re losing direct care workers because of low wages and the high cost of health insurance.”*
- **Long-term care consumers** experience the resulting turnover and vacancies within the caregiving workforce as gaps in basic services creating significant access and quality problems. Offering health insurance would increase the pool of workers, and help retain current workers. Without a stable workforce, *“When I have no one coming in, I can’t get to the bathroom, to bed, or be helped to eat.”*

INTRODUCTION

The Direct Care Workers Initiative, a Massachusetts coalition of consumer advocates, providers, labor unions and worker advocates that seeks to improve the quality of long-term care by improving the quality of jobs for direct care workers, is working together to develop recommendations to expand direct care workers' access to adequate, affordable health insurance.

In 2001, the DCWI worked with Health Care For All to survey 196 workers about their health insurance status, needs, and income, and 32 long-term care employers about what they are able to offer to their employees. Key findings of HCFA's report, *Health Insurance Access Survey of Direct Care Workers in Nursing Homes and Home-Based Care Agencies in Boston, New Bedford/Fall River*, issued in 2002, include that:

- One in four direct care workers is uninsured. Direct care workers are three times as likely to be uninsured as the adult population in Massachusetts.
- The majority of direct care workers earn incomes below 200% of the federal poverty level (FPL), or \$23,220 for a family of two in 2001.
- While most long-term care employers offer health insurance to their employees, many direct care workers cannot afford their share of premium costs, which is higher than state averages.
- Uninsured direct care workers are less likely to have a regular provider, more likely to avoid medical care because they cannot afford it, and report lower health status than their insured co-workers.
- Over three-quarters of long-term care consumers are covered by public programs; thus payment rates for nursing home and home-based services significantly affect workers' wages and access to employment-based health insurance benefits.

In 2002, the Paraprofessional Healthcare Institute, which staffs the DCWI, received funding from the Blue Cross Blue Shield of Massachusetts Foundation* to work with direct care workers and their employer to develop a framework and principles for expanding health insurance coverage to direct care workers. To understand more about what workers and employers are experiencing, the DCWI convened focus group discussions with twelve groups of employees working in nursing homes or agencies providing home-based care, three groups of employers, and a group of people with disabilities who directly employ their own workers.

This report synthesizes findings from these discussions as a starting point for identifying what is needed in any policy recommendation to expand health insurance coverage. It will provide the starting point for work by the *Health Insurance Working Group*, which consists of DCWI members and representative workers and employers from each of the workplaces where discussions were held, to participate in deliberations with policy-makers seeking to identify affordable health insurance coverage options for certain health and human service workers, including direct care workers in long-term care.

* This work is also supported by grant funds from The Boston Foundation, the Jessie B. Cox Charitable Trust, The Hyams Foundation, and the Long-Term Care Foundation.

EMPLOYEE FOCUS GROUPS:

From April – October 2002, the Paraprofessional Healthcare Institute staff met with 12 groups of workers, from 5 nursing homes (including 2 groups from 1 home) and 6 home-based care agencies. A total of 160 workers participated in these discussions, describing their experiences related to health insurance coverage and access to health care services. The major themes identified by workers in these discussions include:

Cost-Related Issues:¹

- ***Unaffordable health insurance:*** A number of workers who are eligible for health insurance cannot afford the premiums. Workers participating in these focus groups had individual insurance premium costs ranging from \$10 per month to \$35 per week. One workplace covered 100% of employee premium costs and one workplace didn't offer its employees health insurance. Another workplace used to pay 90% of the premium but had to reduce its share to 70%. Many workers, unable to afford the premiums, go without coverage, pay out of pocket or, if they are eligible, turn to Mass Health or free care. Among those who do purchase health insurance, repeatedly workers spoke to the high cost of these premiums compared with their small hourly wages, saying, ***"I spend all my pay check on health insurance and only get a little left."***
- ***Unaffordable Family Coverage:*** An overwhelming number of workers cannot afford to purchase family coverage. Premium costs for family coverage for workers participating in these focus groups ranges from \$43 per week to \$547 per month. Some workers turn to free care or Mass Health² for coverage for their children, but others are ineligible for coverage for their children, yet unable to pay for family coverage. A number of workers are needed but weren't able to provide coverage for an ailing spouse. One worker described the anguish of not being able to provide for her children's health, ***"As head of family you feel selfish when you can cover yourself but not cover your kids."***
- ***High Share of Cost:*** Even with insurance, workers frequently reported foregoing doctor's visits, tests, or prescriptions because they could not afford the co-pays. Reported co-pays for doctor visits ranged from \$3 to \$25, and co-pays for prescriptions ranged from \$5 to \$56. One worker, describing a week in which she paid \$95 in co-pays, including a \$50 co-pay for an emergency room visit, a \$20 co-pay for a doctor's visit and a \$25 co-pay for a test, said ***"They take all your money that you make in a week."***

Coverage Issues:

- ***Ineligibility for Insurance:*** Many workers are ineligible for insurance because they work part-time or are per diem employees. Part-time work is especially predominant among

¹ See Appendix 1 – Employee Costs for Health Insurance

² Many workers and their employers are unaware of or uncertain about how to access existing free and subsidized health care programs, such as the Children's Health Insurance Plan and free cervical/breast cancer screening programs for low-income women through the Women's Health Network.

workers in home-based care agencies. Among those ineligible for health insurance at their workplace, some are eligible for Mass Health or free care, others pay any medical expenses out of pocket, and many go without medical care. A number of workers said, ***“If there’s anything medical, I pay out of pocket. I’ve gone for years with no insurance – I can’t afford it.”***

➤ ***Underinsured:*** Many workers who have insurance find themselves unable to access services because they cannot afford the co-pays. This was particularly true for ***prescription drugs and for dental coverage:***

◆ ***High Cost of Prescription Drugs:*** Numerous workers reported problems with co-pays on prescriptions. Co-pay amounts vary widely. Often workers do not know how much they will be charged for a prescription until they pick it up. Many workers with chronic conditions (asthma, diabetes, allergies, and high blood pressure) reported they had to pay higher than usual co-pays or needed medications so frequently they could not afford the co-pays. ***“We can’t afford to pick-up prescriptions or we won’t be able to get groceries or pay rent. I’m doing the same thing I see my patients doing – I can’t follow my own advice to get and take the meds.”***

◆ ***Inadequate dental coverage:*** Many workers find that their dental coverage does not pay for the services they need, and that they must incur large debt or go without these services. Workers described needing a range of dental work not covered by their dental insurance, or for which they needed to pay a large share of cost, including dental surgery, frequent cleanings, braces, and extractions. Many are paying over time for bills ranging from several hundred to several thousand dollars. Others are foregoing treatment. ***“I have to go often for teeth cleaning. I had to have two teeth extracted, then I needed x-rays. The insurance only covered 25%. I have to pay 75% - that’s \$400. I’m making the payments every month. I know it doesn’t sound like a lot of money, but when you don’t have it, it’s a lot of money.”***

Access Issues:

➤ ***Access problems with employer-based health insurance plans:*** A number of workers reported long waits for appointments and difficulties finding new doctors when their employer changed plans. With these disruptions in the continuity of their services or delays in finding a new primary physician, workers sometimes had to go to the emergency room for help, incurring large co-pay costs for doing so. ***“They keep changing plans and I have to keep changing doctors and then starting all over again having them get to know me.”***

➤ ***Access problems in free care:*** A significant number of workers rely on free care for themselves or their families. They report a wide range of experience with free care. It is a primary source of medical services, often a lifeline. However, the coverage varies considerably. Many medical services are not covered under free care. Workers are often not able to see the specialists, get the tests, or buy the medications they need. At times, workers must endure long waits for services. ***“If you need a mammogram you have to wait a year, and a year for a pap smear. You shouldn’t wait that long for tests.”***

- **Problems with Mass Health:** Many workers who rely on Mass Health reported problems with inappropriate denials of eligibility and delays in paperwork that impeded their access to services. Workers are told they are not eligible when they are, are told they are eligible when they're not, are promised applications they don't receive. They have little time to challenge the bureaucracy. Additionally, Many workers and their employers are unaware of or uncertain about how to access existing free and subsidized health care programs, such as the Children's Health Insurance Plan and free cervical/breast cancer screening programs for low-income women through the Women's Health Network. *"Mass Health told me yes and then I went to the doctor and he looked it up – the computer said no, I wasn't covered. I found out I wasn't eligible that way, in the doctor's office."*

Impact of Lack of Comprehensive Affordable Coverage on Direct Care Workers:

- **Medical Issues:** Health care workers have a high incidence of back injuries, are exposed to the illnesses of those for whom they care, are required to have a clean bill of health in order to return to work from an illness, and especially among part-time employees, often go without paid time off, so they must work hurt or lose the day's pay. Many workers go without medical care, without regular check-ups, screenings, tests, or medicines. A significant number of workers regularly contend with chronic conditions and chronic pain.
 - ◆ **Back Injuries:** Many direct care workers have back injuries, which are continually exacerbated by the nature of the work. Unable to take time off to heal, and unable to access medical services or afford the medications they need to treat their condition, workers are often at risk of reinjury, *"In this field you'll hurt your back."*
 - ◆ **Working in health care without health insurance:** Workers are providing health care services to others while unable to access health services for themselves. As health care workers, they are exposed to illness without adequate access to services, and they risk exposing clients to their illnesses when they are unable to go for needed treatment. *"How can you take care of others when you have no health insurance to take care of you?"*
 - ◆ **Working Hurt:** Many home care workers who are paid on an hourly basis and other workers who work part-time or per diem, have no paid time off for illness or injury. They describe working hurt, getting sicker in the process, and having no choice because they cannot afford to go without pay. Workers describe living with enormous pain and illness, while continuing to tend to the pains and illnesses of others. *"Sometimes I can hardly move, but I have to go to work, or I won't get paid."*
- **Dangers of going without medical care:** Workers without coverage avoid medical visits, don't fill prescriptions, and hold off on emergency treatment. They work hurt, live in pain, and go without preventive screening, routine tests, and regular treatments, because they cannot afford them. They know they are neglecting their health and worry about it, but they avoid services because they do not want to incur large medical bills. *"You never know what might be wrong. I know I should get a physical, but I can't afford it."*

- **Economic Issues:** Many workers find themselves caught in the middle because they earn too much to be eligible for Mass Health but they earn too little to afford health insurance for themselves or their families. Many incur large debt to pay for health care services. Almost every worker described painful trade-offs between life necessities and medical necessities – groceries vs. medicines – that they must make on a regular basis.
 - ◆ **Caught in the middle:** Many direct care workers earn just too much to qualify for Mass Health and much too little to afford health insurance through their workplaces. Workers struggle not just with the premiums but also with the co-pays and other shares of cost. For some, cutting back on their hours will allow them to qualify for Mass Health, but many cannot afford reductions in their pay, and so they go without. *“I earn too much for help but too little to buy health insurance through the company.”*
 - ◆ **Giving up the necessities:** With coverage, workers struggle to pay their share of costs. Without coverage, they struggle to cover out-of-pocket medical expenses. They describe daily struggles between competing necessities – food, rent, medications and health insurance premiums. *“You either have insurance or you have groceries.”*
 - ◆ **Medical debt:** Many uninsured and underinsured workers carry long-term medical debt, and pay off their debt like a monthly bill. They hesitate then to seek medical services, often putting themselves at potential risk. *“I had trouble breathing and I wasn’t able to talk. The police called an ambulance and that cost me \$469 from the hospital. I try to pay a little at a time until I’m finished with the bill.”*

EMPLOYER FOCUS GROUPS:

Between January and April, 2002, the Paraprofessional Healthcare Institute held three focus group discussions with nursing home and home-based care agency employers about their experiences related to health insurance. Twenty-nine employers participated in these discussion groups. The major themes identified by employers include:

Lack of Leverage with Insurers:

- **Premium increases:** Premiums have risen significantly in the last year – increases ranged from 8% to 58%. Employers tried to negotiate for cheaper plans to keep costs down, but this led to fewer choices and higher co-pays and premiums for workers. *“It’s always a struggle to provide health benefits, but now the health insurance companies are charging so much that we can’t cover the costs. When our rate went up this time, we cried.”*
- **Caregiving workers represent a high risk pool:** Premiums go up because long-term care workers are seen as a poor risk pool. They are middle age women considered to be high risk and high users due to age, sex, and occupation factors. Health care workers are knowledgeable health care consumers and at risk of injuries due to occupation. *“We begged the broker to look at our company’s track record, but they go by the risk, not the history.”*

- ***Lack of Leverage to Negotiate Rates or Offer Choices:*** Nursing homes and home-based care agencies are small employers, unable on their own to negotiate lower rates with insurance companies. Insurers narrow the range of coverage bids they offer long-term care employers. Some long-term care providers affiliated with larger companies, such as hospitals, health care systems, or multi-facility corporations, have been able to benefit from being part of a larger risk pool which allows them lower rates and more plan choices. However, most long-term care employers, regardless of the size of their employee pool, have found that insurers see their employee pool as too high risk. These employers describe putting out their business for bid, but receiving no or very little response from insurers, effectively limiting, if not eliminating, their choice of insurance providers. A number of employers described negotiating to keep premiums down by purchasing plans that had higher co-pays and required employees to change doctors. ***“We wanted to offer more choices, but the insurer demanded all our business or they’d pull out.”***

Inability to Cover Larger Share of Costs:

- ***Employee Share:*** Employers reported a wide range in the employee share of costs based on number of hours worked and on plan choice (if employees chose cheaper plans, employers covered a higher percentage of premium costs). A number of employers offered workers higher pay in lieu of benefits. Employers reported covering anywhere from 40% to 100% of premium costs for individual coverage and anywhere from 0% to 80% of premium costs for family coverage. As employers faced rate increases from insurers, they’ve had to pass some part of increase along to workers because they couldn’t absorb the entire increase. In many cases this has meant that workers must carry a higher share of the cost. ***“Our employees are working two jobs, one for their health insurance and the other to live on.”***
- ***Per diem and Part-time staff often do not qualify:*** Most workplaces offered coverage to their full-time employees and paid a higher percentage of the premium for their full-time employees. Most workplaces either didn’t offer insurance to part-time employees or covered a smaller percentage of the cost. Many workplaces had per diem employees and a number of workplaces offered their employees higher hourly wages in lieu of benefits. Very few part-time workers take the benefits, because they cannot afford the premiums. Particularly in home-based care agencies, workers hours fluctuate from week to week, making it difficult to establish a set number of hours for eligibility for benefits. ***“For part-time employees, their whole check would go to health insurance. They don’t have any take-home after their premium costs.”***
- ***Workers need family coverage:*** Employers report that a number of workers have spouses who lost jobs after Sept. 11th and now need family coverage for their spouses. Many potential workers with children stay away from jobs without family coverage. Employers report trying to negotiate options for family coverage and couple coverage with their insurers, but finding family rates unaffordable. ***“People with families can’t afford to work here.”***

Public Programs:

- ***Help workers with eligibility information for Mass Health and Free Care:*** Employers reported that they try to help address staff health care needs by letting them know about Mass Health and free care coverage for themselves or their children. Other employers expressed a need for assistance with information about such programs and an eagerness to share such information with their employees. Workers in home-based care agencies who are eligible for Mass Health or free care must constantly balance their hours worked in order to keep their eligibility. ***“They’re juggling all their hours to keep their benefits. That boxes them into a corner. A change in case load can change their eligibility.”***
- ***Insurance Partnership:*** Many long-term care employers reported that the Insurance Partnership program has not been an option for them because of the limit on number of employees, the required employer contribution, and the limits on employee income levels. ***“The program doesn’t fit for us and our workforce.”***

Impact on Labor Pool:

- ***Inadequate health insurance benefits pose a barrier to recruitment and retention:*** One home-based care agency surveyed 250 people interviewed who didn’t take the job to ask why not and got a 35% response rate. The predominant answer was: “The pay is too low and the cost of health insurance is too high.” These respondents choose to work in a hospital or nursing home. Many workplaces reported that potential workers tell them, “We can’t come to work for you because premium is too high on family plan.” Employers see their employees squeezed – the pay is so low and the health insurance costs are so high, that their workers take home nothing at the end of the week. Employers reported that the lack of adequate insurance coverage leads to high turnover and a smaller labor employee pool. ***“They leave us for someplace with benefits.”***
- ***Impact of having staff who have chronic injuries and untreated medical conditions:*** Providing hands-on care puts workers at higher risk of injury and illness, yet many workers have little ability to afford adequate health care coverage, so their conditions go under-treated and they often don’t have time to recover before they must return to work. Many career caregivers have chronic health problems that can be aggravated by work. Supervisors must be cognizant of workers’ physical condition in making assignments. ***“When thinking about who to send out on a case, I have to think, ‘who is the least broken’.”***

CONSUMER-EMPLOYER FOCUS GROUP

We also met with a group of people with disabilities who directly employ their own workers. They echoed the problems employers described above but live the impact of recruitment and retention barriers more directly. In the disability community, those who directly employ workers report that they are finding it increasingly difficult to replace workers. For many there has been a recent shift in their ability to employ workers. Many had depended on workers who had been long-term employees who have recently left. Filling these low-wage, no benefit vacancies, has been very difficult. A worker who must have health care benefits cannot afford to work in this

arena. For this community, the inability to attract workers can have serious consequences—it can mean a loss of independence. When a consumer-employer does not have a worker coming it may mean that they can't get to the bathroom, to bed, or prepare food. Although many in the group reported a shrinking pool of potential employees, there was also consensus that to be able to offer healthcare benefits would increase the number of people that would be able to consider working in this field. Without a stable workforce, people who have vigilantly tried to preserve their independence may be forced to consider options that would limit their independence and quality of life. *“When I have no one coming in, I can't get to the bathroom, to bed, or be helped to eat.”*

CONCLUSION:

High health insurance costs have a serious impact throughout the long-term care system, among employers, workers, and consumers.

Many direct care workers cannot afford employer-offered health insurance because the premiums and co-pays are too high. Many other direct care workers make daily trade-offs between necessities like groceries and medicines, incur large debt, or forego treatment, working hurt and living in pain, in jobs that put them regularly at risk of injury or exposure to illness.

Their employers face premium increases that are higher than other employment sectors because their workforce is considered a high risk, high use pool. They are unable to absorb those costs because of increasingly tight public payment rates, and are forced either to negotiate for lesser coverage or pass along some of the increased cost to their employees.

Consumers live with the consequences of high turnover and high vacancy rates, whether they are direct employers or rely on nursing homes or home-based care agencies for services. Many consumers have problems accessing services, experience deterioration in the quality of services, and suffer from lack of continuity of caregivers.

One of the indirect benefits of the focus group discussions was that each group gained valuable information. Employers learned how changes impacted their workers, and workers learned that the employers were doing what they could to offer coverage. This growing awareness of the magnitude of this problem has the potential for uniting workers and employers in their struggles to deal with the complex issues of health insurance. By putting a human face on this problem we can start the process of understanding what it is that will be needed to adequately address this problem.