

**Health Insurance Access Survey
of Direct Care Workers
in Nursing Homes
and Home-Based Care Agencies
in Boston, New Bedford/Fall River**
Including surveys of employees and of employers

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EXECUTIVE SUMMARY

Key Findings

This study surveyed one hundred ninety-six direct care workers and thirty-two long-term care employers to determine the health insurance status and needs of direct care workers.¹ It found that direct care workers face more barriers to accessible health care than the general population. Direct care workers interviewed expressed a deep commitment to the people they care for, but many respondents indicated that they may be forced to leave their jobs because of the lack of health benefits. Key findings include:

- 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 all 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 direct care agency clients 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.

These factors combined result in workers missing work or even leaving their jobs to contend with their own or their family's health needs. Off the job pressures - health problems in particular - inevitably contribute to an employee's stress level and ability to function on the job. While other low-wage workers may experience similar problems, it is especially ironic that the people we count on to take care of our family members cannot

¹ This report uses the following terms:

Long-term care includes care provided in nursing homes and home-based care agencies.

Home-based care includes Medicare and Medicaid funded medically related services provided by certified home health agencies and state (Elder Affairs) funded supportive home care services provided by home care agencies.

Direct care workers in this study include certified nursing assistants working in nursing homes and home health aides and homemakers working in home health and home care agencies.

count on receiving the health care they need to care for their own families. Since the wages for long-term care workers are primarily publicly funded, the state has a special responsibility to ensure that the long-term care workforce has access to affordable health insurance.

Background

Long-term care providers (nursing homes and home-based care agencies) are major employers of low-wage direct care workers, including certified nursing assistants, home health aides, personal care attendants and homemakers. These direct care workers provide 90% of the hands-on care to elders and people with disabilities receiving care at home or in facility-settings.

The latest labor force projections suggest that the long-term care sector will continue to grow, with the population of elders, most in need of long-term care, projected to double over the next twenty-five years. During this same period, the overall population of workers will decrease, creating a tighter labor market. Direct care jobs have not proven competitive in a tight labor market. Low wages and benefits for direct care work has resulted in high vacancy and turnover rates. Public payment rates for nursing home and home-based services have a significant impact on these wages and benefits since direct care services are primarily publicly-funded.

Policy leaders have initiated efforts to improve wages and benefits for direct care workers. Senator Moore introduced S. 523, An Act to Survey the Health Insurance Status of Health Care Workers, which would authorize a study and report to the Legislature on the health insurance status and needs of direct care workers across long-term care settings. This study was included in the Nursing Home Quality Initiative developed by Senator Montigny, Chair of the Senate Ways and Means. When the study was not included in the final FY 01 or 02 budgets, the Direct Care Workers Initiative (DCWI),² with private foundation funding, commissioned this study by Health Care for All.

The DCWI is 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. DCWI is facilitated by the Paraprofessional Healthcare Institute (PHI). Funds for the study were provided by the Georgiana Goddard Eaton Memorial Fund, The Boston Foundation, and the Charles H.

² Members of the Direct Care Workers Initiative include Alzheimer's Association, Boston Workforce Development Coalition, Cape Organization for Rights of the Disabled, Greater Boston Elderly Legal Services, Health Care for All, Home and Health Care Association of Massachusetts, Massachusetts Association of Older Americans, Massachusetts Aging Services Association, Massachusetts Council of Home Care Aide Services, Massachusetts Extended Care Federation, Massachusetts Senior Action Council, Medicare Advocacy Project, National Association of Social Workers, Paraprofessional Healthcare Institute, Service Employees' International Union, Locals 285 and 767, Statewide Personal Assistance Coalition, and Women's Educational and Industrial Union.

Farnsworth Charitable Trust. The DCWI participants in the planning process for the study were the Home and Health Care Association of Massachusetts, the Massachusetts Aging Services Association, the Massachusetts Council For Home Care Aide Services, and the Massachusetts Extended Care Federation. DCWI contracted with Health Care for All (HCFA) to design and conduct two surveys, one for employees and one for employers, to collect data to determine the health insurance status and needs of the low-wage, direct care workers within the study margins.

Study Goals and Methods

The employer and employee surveys were undertaken to learn about the health insurance status and needs of direct care workers. The employee survey was designed to collect data on the income, work history, health insurance status and health care needs of direct care workers. The employer survey was designed to collect data on health insurance options offered to their employees, employee participation, the cost of health insurance plans to the employer and the employee, and sources of payment (e.g. MassHealth, Medicare) for clients served by these agencies. Surveys were conducted with long-term care employees and employers in Boston, Fall River and New Bedford.

Interviewers completed 196 employee interviews, 136 home-based care employees and 60 nursing home employees. Most interviews were conducted in face-to-face meetings, often during in-house trainings or shift changes, and a small group was interviewed by telephone. Respondents included union and non-union employees representing various types of direct care work in two geographic areas -- Boston and greater New Bedford, with the majority done in Boston. HCFA mailed surveys to 52 nursing home and home-based care agency employers identified by the DCWI sub-committee. Thirty-two were returned -- nineteen from home-based care agencies, twelve from nursing homes, and one from an undesignated long-term care employer.

The direct care worker population to which these findings apply is a convenience sample. Employees were interviewed with the permission of their employers at the express request of the planning committee. We believe that employers with adequate or generous health benefits are more likely to participate in the study, and thus that the sample over-represents the prevalence of employer-sponsored health insurance.

We note the relative dominance of home-based care employers and employees in the study, and the limited geographic regions represented. There were significant differences between nursing home and home-based care employment reported in several areas - including average number of hours worked, income, eligibility for employer-based health insurance and out-of-pocket health costs -- that could have major implications for potential policy recommendations. Similarly, there are also substantial differences in the public funding sources between nursing homes and home-based care agencies that could also impact the efficacy of any potential solution. The relatively small sample size and these significant differences do not preclude the report's assertion that long term care workers across provider types experience serious health insurance access

problems.

Overview of Findings

- ***One in four direct care workers is uninsured. Direct care workers were three times more likely to be uninsured than the average for adults in Massachusetts.*** Twenty-five percent of direct care workers surveyed were uninsured, compared to the statewide averages of 5.9% overall and 8% for adults (DHCFP, December, 2000). Uninsurance rates of respondents to this survey were similar between nursing home and home-based care workers, with rates of uninsurance higher in Boston than in New Bedford.
- ***More than half of direct care workers earn less than 200% of the federal poverty level (FPL). Uninsured workers report lower income levels.*** The average family income level was \$24,740, with fifty-four percent below 200% of the poverty level (\$29,260 for a family of three). Over 80% of direct care workers are under 300% of the federal poverty level (\$25,770 for an individual and \$43,890 for a family of three). Uninsured workers reported average income one third less than for those who were insured.
- ***Direct care workers hold multiple jobs and have full workweeks.*** Direct care workers hold an average of 1.3 jobs, worked an average of 30 hours in the week they were surveyed, and had worked more than 11 years in the long term care field. Nursing home workers worked more hours, averaging 39 hours/week, compared to home-based care workers, who averaged 26.7 hours per week. Uninsured workers have worked an average of 9.7 years in direct care. Most uninsured direct care workers have worked for the same employer for more than one year.
- ***Less than one half of direct care workers married (45%).*** The remainder is single, either never or no longer married. Statewide, the rate of uninsurance is highest (16%) for those who have never married and lowest for those who are married (3%) (DHCFP, December 2000, p.6). Direct care workers have an average family size of 2.08. Home-based care workers have slightly smaller families (1.89) than nursing home workers (2.52).
- ***Uninsured workers report worse health than their insured co-workers, are half as likely to have a regular provider, and six times more likely to avoid seeing a health provider, usually because of lack of funds.*** 26% of direct care workers report their health as “fair” or “poor,” while 74% reported being in “excellent” or “good” health. Uninsured workers reported poorer health than those with insurance; 40.8% were in “fair” or “poor” health compared to only 21.3% of those with insurance. 40%-50% of all respondents reported having a chronic illness. Over 80% of all direct care workers had a regular health care provider for themselves and their children. Uninsured workers were only half as likely as insured workers to have a regular health care provider. About 12% of respondents avoid seeing a health care provider and for 72% of those, the reason is money. Uninsured workers were over six times more likely to avoid seeing a

health care provider (33.3% vs. 4.9%) and were more likely to cite money as the reason. Uninsured respondents used the emergency room more often and used free or reduced cost care six times as often (61.7% vs. 9%).

- ***Insured respondents rely on employers for insurance.*** About 56% of insured employees received insurance from their own employer (68.4% of nursing home employees vs. 50% of home-based care workers), while 29.5% received insurance through another employer (primarily a partner's employer). About ten percent of insured respondents were enrolled in public health insurance programs; according to reported income data, many more respondents may be eligible for public programs for low-income parents and children.
- ***Almost all employers offer benefits, but one third of nursing home and home-based care workers are ineligible for participation in their employer plans.*** 94% of the employers offered health benefits to employees, with 100% of the nursing homes and 90% of home-based care agencies offering insurance. However, only 68% of employees in both types of agencies are eligible. Both nursing homes and home-based care agencies reported requiring 27 hours (the mean) of work per week for health insurance eligibility.
- ***Most employers provide limited choice of plan.*** A majority of these employers (55%) offered just a single HMO to their employees, while 3% offered just one indemnity plan as an option. Twenty-eight percent of the agencies offered additional pay in lieu of health benefits (50% of nursing homes and 16% of home based care agencies).
- ***Direct care workers employee contribution higher than statewide average:*** Nursing home workers paid an average of \$1104/year for individual coverage and \$3,922 for family coverage. Home-based care agency workers paid an average of \$827/year for individual coverage and \$2,281 for family coverage. The combined average cost was \$960/year for individual coverage and \$3,311 for family coverage. Workers pay from 10% to 50% of the total cost of the premium, with about twenty percent paying 50% of the cost. These costs were higher than statewide averages as reported in a recent state survey. Most nursing home employees reported average out of pocket medical costs of less than \$500/year, while a majority of home-based care employees reported expenses of from \$500-\$1000/year.
- ***Publicly-funded employment:*** Nursing homes had an average of 126 residents, while home-based care agencies had an average of 836 clients. On average, 53 % of the clients of these agencies were funded by MassHealth, 23 % by Medicare and 17 % by other sources, including EOEA. The percentage funded by MassHealth was higher for nursing homes (72 % vs. 38 %), while Medicare funded a higher percentage of home-based care clients (33 % vs. 12 %).

Conclusion

The results of the Direct Care Workers Health Insurance Access Surveys of employees and employers demonstrate that workers have a significant need for assistance in obtaining health insurance for themselves and their families. Direct care workers face more barriers to accessible health care than the general population.

Although direct care workers have spent many years in caregiving work, they frequently work less than full time, particularly in home-based care agencies, and are often ineligible for benefits offered by their employers. Home-based care workers may not know from one week to the next whether their hours will be diminished by the hospitalization or loss of a client. In addition, the income levels of direct care workers is low, leaving many unable to afford to pay their share of the insurance premium, even if insurance is offered. ***For these reasons, the rate of uninsurance among these workers is three times the state average for adults.*** Of those employees who are insured, only 56% receive insurance through their primary employers, with another 30% receiving coverage through their spouses. Even insured direct care workers lack important benefits, such as prescription drugs, and are burdened by high co-pays and deductibles.

Over half of direct care workers have family income of less than 200% of the federal poverty level and one quarter are under 133% of poverty. These income levels would make many workers and/or their children eligible for MassHealth. However, only about 10% of insured respondents reported that they received coverage through government sources, which suggests that more direct care workers and their children may be eligible for existing programs than currently participate. In addition, participation in the Insurance Partnership Program, a state program that reimburses employers and low-income employees for the cost of health insurance, is low, given the income levels of many employees, including long-term care workers. However, the structure of the program may limit participation since it is only open to employers of less than 50 employees who pay at least 50% of the cost of the health insurance.

Lack of insurance is not only a financial burden, but also leads to lower utilization of primary and preventive health care, more use of the emergency room and lower overall health status. These patterns not only diminish the quality of life of these workers, but may also contribute to productivity and turnover.

Direct care services are primarily publicly-funded. Thus public payment rates for nursing home and home-based services have a significant impact on workers' compensation rates, including employment-based health insurance benefits.

Recommendations: In order to increase the health insurance coverage of direct care workers, the state could take a number of approaches, including a combination of public and private initiatives designed to stabilize employment by expanding access to affordable, quality health insurance coverage. **Options include** initiatives within long-term care to lower premiums for employers or make pass-thru payments to cover 100%

of premium costs, redesign of the Insurance Partnership Program or other public-private programs to work within long-term care, and expansion of public coverage either for direct care workers or for all workers in their income levels.

Long-term care is one of the fastest growing employment sectors today, yet the turnover rate for these occupations is extremely high. With a rapidly aging population in Massachusetts and nationally, the demand for direct care workers will only increase. As long as poverty level wages prevail and health and other benefits are not provided, caring individuals who love their work may be forced out of the caregiving field. The case for increasing access to health benefits to these workers is compelling, not only to improve their quality of work life and health, but also to address the growing labor crisis that will profoundly affect the community at large.

Health Insurance Access Survey of Direct Care Workers in Nursing Homes and Home-Based Care Agencies in Boston, New Bedford/Fall River *Including surveys of employees and of employers*

Overview and Background

Long-term care providers (nursing homes and home-based care agencies) are major employers of low-wage direct care workers, including certified nursing assistants, home health aides, personal care attendants and homemakers.³ These direct care workers provide 90% of the hands-on care to elders and people with disabilities receiving care at home or in facility-settings.

The latest labor force projections suggest that the long-term care sector will continue to grow, with the population of elders, most in need of long-term care, projected to double over the next twenty-five years. During this same period, the overall population of workers will decrease, creating a tighter labor market. Direct care jobs have not proven competitive in a tight labor market. Low wages and benefits for direct care work has resulted in high vacancy and turnover rates. Public payment rates for nursing home and home-based services have a significant impact on these wages and benefits since direct care services are primarily publicly-funded.

Policy leaders have initiated efforts to improve wages and benefits for direct care workers. Senator Moore introduced S. 523, An Act to Survey the Health Insurance Status of Health Care Workers, which would authorize a study and report to the Legislature on the health insurance status and needs of direct care workers across long-term care settings. This study was included in the Nursing Home Quality Initiative developed by Senator Montigny, Chair of the Senate Ways and Means. When the study was not included in the final FY 01 or 02 budgets, the Direct Care Workers Initiative (DCWI)⁴ commissioned this study by Health Care for All. Funds for the study were

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This study surveyed one hundred ninety-six direct care workers and thirty-two long-term care employers to determine the health insurance status and needs of direct care workers. It found that direct care workers face more barriers to accessible health care than the general population. Direct care workers interviewed expressed a deep commitment to the people they care for, but many respondents indicated that they may be forced to leave their jobs because of the lack of health benefits.

Key findings include:

- 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).
- While all 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 direct care agency clients are covered by public programs; therefore, public payment rates for nursing home and home-based services significantly affect workers' wages and access to employment-based health insurance benefits.

These factors combined result in workers missing work or even leaving their jobs to contend with their own or their family's health needs. Off the job pressures - health problems in particular - inevitably contribute to an employee's stress level and ability to function on the job. While other low-wage workers may experience similar problems, it is especially ironic that the people we count on to take care of our family members cannot count on receiving the health care they need to care for their own families. Since the wages for long-term care workers are primarily publicly funded, the state has a special responsibility to ensure that the long-term care workforce has access to affordable health insurance.

Introduction to Study:

The Direct Care Workers Initiative (DCWI) sponsored this study. The DCWI is 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. The DCWI participants in the planning process for the study

were the Home and Health Care Association of Massachusetts, the Massachusetts Aging Services Association, the Massachusetts Council For Home Care Aide Services, the Massachusetts Extended Care Federation, and the Paraprofessional Healthcare Institute. DCWI contracted with Health Care for All (HCFA) to design and conduct two surveys, one for employees and one for employers, to collect data to determine the health insurance status and needs of the low-wage, direct care workers within the study margins.

Between March and July 2001, 196 paraprofessional workers in 14 different long term care settings (nursing homes and home-based care agencies) in Boston, New Bedford and Fall River were interviewed regarding their employment, personal status, and health utilization and insurance characteristics. Four nursing homes and ten home-based care agencies arranged for their employees to participate in the employee interviews

Additionally, thirty-two long-term care employers in Boston and the New Bedford area responded to an employer survey designed to collect data on insurance offered to employees.

Goals

The employer and employee surveys were undertaken to learn about the health insurance status and needs of direct care workers, to assist in policy discussion about how to stabilize the long-term care workforce. Interviews were held in Boston, Fall River and New Bedford, with the majority done in Boston.

The employee survey was designed to collect data on the income, work history, health insurance status and health care needs of direct care workers, including:

- Employment and household characteristics
- Health insurance status
- Cost of coverage for the insured
- Health status
- Use of health services, including hospitals, physicians, and ER services
- Satisfaction with current care and suggestions for future innovations
- Relationship of health insurance status with employment characteristics, health status and health care utilization

The employer survey was designed to collect data on:

- Health insurance options offered to their employees
- Employee participation in employer health insurance plans and in certain public programs available to eligible employees/employers
- Cost of health insurance plans to the employer and the employee
- Sources of payment (e.g. MassHealth, Medicare) for clients served by these agencies

Study Methodology

Paraprofessional Healthcare Institute (PHI), in conjunction with the Direct Care Workers Initiative (DCWI), contracted with Health Care For All (HCFA) to conduct a survey to determine the health insurance status and needs of Boston's low wage, long-term care workers. Working with the Direct Care Workers Initiative (DCWI)'s health insurance subcommittee, HCFA developed two surveys, one for employers and the other for the employees.

The surveys incorporated questions modeled on standard and state surveys, which have been tested for validity and reliability. However, the survey tools used for this project were new ones. The employee survey was designed to elicit certain demographic information, as well as allow for comments and suggestions by the interviewees themselves. HCFA representatives met with the DCWI health insurance subcommittee, and all worked together to ascertain that every option was explored in the design of the surveys and the distribution strategies. On February 23, 2001, the first pilot interviews for the employee questionnaire were done, followed shortly afterward by a pilot of the employer questionnaire. The surveys were subsequently revised and produced in volume.

The employer surveys were distributed by mail to 52 nursing home and home-based care agency employers who were identified by the committee. Thirty-two were returned.

The employee surveys were generally completed by HCFA interviewers in face-to-face meetings. (There was one small group (less than 10) from Fall River for whom this method was not feasible, and their surveys were done via telephone.) One hundred and ninety-six respondents completed the employee survey. The pilot surveys were not included in the results.

The agencies that participated in setting up interviews with employees did so at the request of the organizations working within the DCWI. The long-term care trade associations on the DCWI subcommittee sent letters of support encouraging the providers to participate in the study. The names of agencies and nursing homes were forwarded, along with contact personnel, to Health Care For All who set up the interviews. Employers were asked to support their employees' participation, and no one was interviewed without employer authorization. Most employers posted a flyer and a sign up sheet inviting employees to participate. The employers then alerted Health Care For All as to the expected number of potential interviewees and dates were set. In the case of the home-based care workers, the majority of the surveys were done during or after an in-house training. With the nursing home employees, interviews were conducted as people were coming on or off of their shifts. Each interview took between twenty to thirty minutes, and the interviewees were paid a stipend of \$15.00 each. The majority of direct care workers surveyed were from Boston and New Bedford. The geographic

representation was conceived to portray a fair depiction of both large and smaller urban sites.

The direct care worker population to which these findings apply is a convenience sample. Employees were interviewed with the permission of their employers at the express request of the planning committee. We believe that employers with adequate or generous health benefits are more likely to participate in the study, and thus that the sample over-represents the prevalence of employer-sponsored health insurance.

We note the relative dominance of home-based care employers and employees in the study, and the limited geographic regions represented. There were significant differences between nursing home and home-based care employment reported in several areas - including average number of hours worked, income, eligibility for employer-based health insurance and out-of-pocket health costs -- that could have major implications for potential policy recommendations. Similarly, there are also substantial differences in the public funding sources between nursing homes and home-based care agencies that could also impact the efficacy of any potential solution. The relatively small sample size and these significant differences do not preclude the report's assertion that long term care workers across provider types experience serious health insurance access problems.

Employee Survey Findings

Interviews and respondents

Agencies and location of interviewees (Table 1a and 1b)

The total number of interviews completed was 196. There were more than double the number of interviews done through home-based care agencies (136) as through nursing homes (60). Geographically the interviews were more evenly distributed, with 105 interviews conducted overall in the Boston area and 91 completed in the New Bedford/Fall River area.

Differences between workers in home care agencies and nursing homes.

There are some differences between the two populations. On average, home-based care workers are older (51.89 years) than their nursing home counterparts (43.05 years). Workers in nursing homes reported working an average 44.64 hours per week in the past month, while home-based care workers reported 30.84. Finally, home-based care workers reported an average family size of 1.89 people, while nursing home respondents reported an average of 2.52 people.

Employee Personal Characteristics

Direct care workers are overwhelmingly female (Gender -- Tables 2a and 2b)

Although the respondents were overwhelmingly female (90%), nursing homes had a greater number of male employees (10%) than home-based care agencies, which

are 97.8% female and 2.2% male. In Boston, the ratio of female to male was higher, with 93.3% of the respondents female and 3.6% male. In the New Bedford/Fall river area, respondents were 97.8 female and only 1% male.

Direct care workers are generally middle-aged (Age -- Tables 3a and 3b)

Home- based care workers reported an average age of 51.97, while nursing home workers reported an average age of 43.76. In Greater Boston the average age of workers is 45.77, while in the New Bedford/Fall River area it is 53.67.

Half of direct care workers are single. (Marital Status -- Tables 4a and 4b)

Fifty percent of nursing home respondents reported they are married, 10% are separated, 26.7% are single, never married, 8.3% are divorced, 3.3% are widowed, and 1.7% are not married, living with a mate. Forty-seven percent of home-based care workers reported they are married, 5.2% are separated, 21.5% are single, never married, 20.7 are divorced, 8.1% are widowed, and 1.5 are not married, living with a mate.

In Greater Boston, 41% of respondents are married, 7.6% are separated, 33% are single, never married, 11.4% are divorced, 5.7% are widowed, and 1.0% are not married, living with a mate. In the New Bedford/Fall River area, respondents reported that 50% are married, 5.6% are separated, 11.1% are single, never married, 23.3% are divorced, 7.8% are widowed, and 2.2% are not married, living with a mate.

Direct care workers work multiple jobs, many hours (Employment -- Tables 5 - 8)


Workers in the Greater Boston area reported working an average of 1.41 jobs, while their counterparts in the New Bedford/Fall River area reported working an average of 1.16 jobs.

Nursing home employees worked an average of 44.64 hours per week, while home-based care employees worked 30.84 hours per week. In the Greater Boston area workers averaged 39.63 hours per week, while those in the New Bedford/Fall River area averaged 29.74 hours per week. Nursing home workers reported working full-time, or an average of 38.97 hours in the past week, compared to home-based care workers, who worked an average of 26.67 hours in the past week. In the Greater Boston area, respondents reported working an average of 33.51 hours in the past week. In the New Bedford/Fall River area, workers reported working an average of 29.74 hours in the past week.

Virtually all [BF1]direct care workers interviewed reported that this is their main job, with ninety-eight percent of nursing home respondents and 96.2% of home-based care respondents reporting that this is their main job.

Family Characteristics

More than half of direct care workers have family income below 200% of the federal poverty level (Family Income -- Tables 11 through 12)

Family income data in this report is likely to be problematic, because many interviewees did not w the exact amount that their spouses made. With this

limitation, the results showed that respondents had an average income level of \$24,740, with nursing home employees reporting an average family income of \$25,785 and home-based care employees reporting an average of \$24,391. In the Greater Boston area, the average family income reported was \$21,450. In the New Bedford/Fall River area, the average family income reported was \$28,283. The income levels reported for these workers are consistent with their low levels of health insurance coverage; statewide statistics show that workers below 200% of poverty are disproportionately uninsured, with from 12-14% of adults uninsured at this income level, compared to 8% of all adults. (DHCFP, December 2000).

Family income levels in relation to the federal poverty level (FPL) are significant because public insurance program eligibility levels are determined in this manner. For instance in Massachusetts all children through age 18 and below 200% of the poverty level (\$35,300 for a family of four) are eligible for one or another of the MassHealth (Medicaid) programs in the state. Children above this income level or ineligible for MassHealth due to citizenship status are eligible for the Children's Medical Security Program, which provides basic health benefits (hospitalization is provided through the Free Care Pool). Parents under 133% of poverty (\$23,475 for a family of four) are eligible for MassHealth as well.

Twenty-four percent of direct care respondents report family income of less than 133% of the poverty level. (30% of nursing home respondents and 22% of home-based care respondents), which would qualify them for MassHealth if they were parents. Fifty-four percent of direct care workers have a family income of less than 200% of the poverty level, which would qualify their children for MassHealth. (60% of nursing home workers and 52% of home-based care workers). Only 9.8% of insured respondents reported that they received coverage through government source. This figure does not distinguish between the individual worker and their children. However, these results do suggest that more direct care workers and their children may be eligible for current public programs than currently participate.

Dependents (Tables 13 and 14)

Nursing home employees reported an average of 1 dependent under age 19. Home-based care employees reported an average of 1.08 dependent(s) under age 19. In the Greater Boston area, respondents reported an average of 0.75 dependent(s) under age 19. In the New Bedford/Fall River area, respondents reported an average of 0.34 dependents under age 19.

Nursing home employees reported an average of 0.43 dependent aged 19 or 20. Home-based care employees reported an average of 0.19 dependents aged 19 or 20. In the Greater Boston area, respondents reported an average of 0.34 dependents aged 19 or 20. In the New Bedford/Fall River area, respondents reported an average of 0.34 dependents aged 19 or 20.

Family Size (Tables 15a and 15b)

Nursing home employees reported an average of 2.52 family members. Home-based care employees reported an average of 1.89 family members. In the Greater Boston area, respondents reported an average of 2.23 family members. In the New Bedford area, respondents reported an average of 1.91 family members.

Health Insurance Characteristics

One in four direct care workers does not have health insurance – three times the statewide average (Health Insurance Status -- Tables 19a,b, 22a,b, 28a,b)

Twenty-five percent of all direct care workers did not have insurance. Twenty-two percent of nursing home and 26.5% of home-based care workers were uninsured. In the Greater Boston area, 28.8% were uninsured, compared to 20.9% in the New Bedford/Fall River area. These figures are nearly three times the statewide average of 8% for all adults in Massachusetts (0-64 years) reported by the Division of Health Care Finance and Policy in its December 2000 report.

Direct care workers reported that from 8% to 34% of other family members were uninsured. More respondents from New Bedford reported that at least one family member was insured (92.7%) compared to 69.4% of those in Boston. 66 percent of nursing home workers reported that at least one family member had insurance, compared to 87.3% of home-based care workers.

Only half of insured direct care workers receive coverage from their employer – for many, employer coverage is unaffordable. (Sources of Health Insurance -- Tables 20a,b and 21a,b, 26a,b, 27a,b)

For those employees who were insured, 55.7% received insurance from this employer, 29.5% from another employer, 9.8% from the government (non-military) and the rest from other sources. The average number of nursing home employees who received insurance from this employer was 68.4% vs. 50% for home-based care workers. The figures for Boston (54.2%) and New Bedford (57.1%) were essentially the same. Home-based care workers received insurance from another employer (33.3%) more often than nursing home employees (21.1%) did. Again, the figures were not very different across geographic areas for this category.

The primary insurer for the majority of the respondents was themselves (77.3% for nursing home employees and 68.3% for home-based care employees), while the primary insurer was the spouse in 22.7% of the nursing home cases and 30.7% of the home care cases. Respondents in Boston were also more likely to be the primary insured (78.4%) than in New Bedford (63.4%).

Over twice as many home-based care workers received health insurance through the government than nursing home employees. (11.9 % vs. 5.3%). Boston respondents were also over twice as likely to receive insurance from government sources as those in New Bedford (13.6% vs. 6.3%). This is consistent with the fact that in the Boston area

residents can not only enroll in MassHealth and other programs, but can also enroll in programs at Boston Medical Center and Cambridge Health Alliance, which provide comprehensive programs for low income people who do not qualify for some of these other programs.

A majority of direct care workers reported being offered insurance at work, with 100% of nursing home workers reporting this offer, 73.8% of home-based care workers, 77% of Boston workers and 84.1% of New Bedford workers. Forty-three percent of those who declined this coverage said the reason was that they did not need it, 33% said it was too expensive, and 10 percent said they were not eligible.

Direct care workers pay more for their share of insurance coverage costs than other workers statewide. (Cost of Insurance to Employee -- Table 23a,b)

Overall, the direct care workers' average cost for insurance coverage (includes individual or family coverage for workers, whether receiving employer based insurance or insurance from another source), was \$992, with a range from 0 to \$7,200 and a median cost of \$260. Nursing home employees reported paying an average of \$1,929 annually for health insurance, with a range of \$0 to almost \$4000 and a median cost of \$624. Home-based care agency employees reported an average cost of \$578 per year, with a range of 0 to \$7,200 and a median cost was \$0. Because the range is so great in these responses, and the response could refer to many difference insurance arrangements as well as individual or family coverage, it is difficult to interpret the significance of these results.

In the employer survey, employers estimated that nursing home employees paid an average of \$1104 for individual coverage and \$3922 annually for family coverage, while home-based care workers paid an average of \$837 for individual coverage and \$2821 for family coverage. The combined average was \$960 for individual coverage and \$3310 for family coverage. These contributions are higher than statewide averages reported in the DHCFP 2001 Employer Health Insurance Survey, based on a survey conducted from April-November, 2001. Statewide the average annual employee contribution for an individual plan was \$669/year (up from \$578 in 2000) and \$2,074 for a family plan (up from \$1,670 in 2000).

Comparing the average cost of \$992 reported by the employees themselves to the average family income of \$24,740 which they report, respondents are spending approximately 4 % of their income on health insurance.

Out of Pocket Health Care Costs (Table 24a,b)

The majority of respondents (72%) reported spending under \$500 on out-of-pocket medical expenses (co-payments, deductibles, eyeglasses, dentures, prescription drugs and medical equipment not covered by insurance.). There were substantial differences in site types as 78.6 % of nursing home respondents spent under \$500, while none of the home-based care respondents reported spending under \$500. 64.9% of home-based care respondents reported spending between \$501-\$1,000, while only 17.9% of nursing home respondents reported spending between \$500-\$1,000.

Compared to their reported income, nearly 80% of nursing home workers paid under 2% of their average family income of \$25,785 in out of pocket medical costs, while 70% of home health workers paid from 2-4% of their average family income of \$24,391 in out of pocket medical costs.

Health Status and Utilization

Health Status (Tables 16a, b, 17 a,b and 18a,b)

About three quarters of direct care workers rate themselves in excellent or good health and a quarter in fair or poor health. Rates were similar across types of agencies; 15% of nursing home respondents reported that their health is excellent, while 55% reported that their health is good. (total then of 70% in excellent or good health.) Thirty percent were in fair health, and 0% reported poor health. Among home-based care respondents, 23.5 reported excellent health, 52.2 reported that their health is good (total 76% excellent or good) while 21.3 reported fair health and 2.9 reported poor health.

New Bedford/Fall River reported being in somewhat better health. Greater Boston area respondents reported that 19% are in excellent health, 47.6 reported good health (total of 67 % excellent or good), 31.4 reported fair health and 1.9 reported poor health. Of New Bedford/Fall River respondents, 23.1% feel their health is excellent, while 59.3% reported their health is good (total 82% excellent or good), 15.4% reported their health is fair, and 2.2% reported their health is poor.

Forty percent of nursing home workers reported that they had a chronic illness and forty percent that there was at least one person in their household with a chronic illness. This compared to 47.7% of home-based care workers with a chronic illness and 45.6% with at least one person in the household with a chronic illness. The figures on chronic illness were similar across geographic areas, with 47.6% of respondents in Boston reporting that they had a chronic illness and 46.7% with at least one person in their household with a chronic illness. In the New Bedford/Fall River area 42.5% of respondents had a chronic illness and 40.7% had a member of the household with a chronic illness.

Health Care Utilization (Tables 29-34)

Eighty-six percent of all direct care respondents reported that they had a regular provider, with 82% of nursing home employees and 88% of home care based workers. The percentage was the same in both Boston and New Bedford. About 80% reported that their children also had a regular provider.

Twelve percent of both nursing home and home based care respondents reported avoiding seeing a provider. However, about twice as many in Boston reported avoiding seeing a provider as in New Bedford/Fall River (16% vs. 8%), which bears further inquiry since there are more hospital and health center resources available in the Boston area. For those that avoided seeing providers, both nursing home and home-based care

respondents reported overwhelmingly (72%) that money issues were the issues. Transportation difficulties were cited by 14% of those nursing home workers who had avoided seeing providers (but not by home based care workers). 6% of those who had avoided seeing providers in Boston cited transportation difficulties and no one in New Bedford/Fall River cited transportation difficulties.

Nearly 30% of nursing home respondents had used the emergency room in the last year, compared to nearly 50% of home-based care respondents. Forty-seven percent of Boston respondents had used the emergency compared to 30% of New Bedford/Fall River respondents. Of those that had used the emergency room, eighty seven percent did so because they had a medical emergency. In the interviews, many described the medical emergency as an exacerbation of a chronic condition. Twelve percent had used the emergency room for other unspecified reasons (but not because of the other choices we inquired about---regular provider closed, no regular provider, money issues or transportation).

Home-based care agency respondents reported spending more days in the hospital (390 days per thousand people) than nursing home respondents (350 day per thousand). The number of days in New Bedford/Fall River (505 days/thousand) was about twice that in Boston (267 days/thousand). Possible reasons for this gap might be that the average age of home care based workers and of respondents in New Bedford/Fall River is higher by about 8 years in both cases, and more home health workers are women. In addition, Boston has more extensive and comprehensive free care available in hospitals as well as an extensive system of neighborhood health centers, which may provide preventive and primary care and free prescription drugs, all of which have an impact on hospitalization rates.

Twenty-five percent of nursing home respondents reported receiving free or reduced cost care in hospitals or community health centers. Twenty-two percent of home-based care respondents received free or reduced cost care. In Boston, the number that received free or reduced cost care (30%) was nearly double the number (15 %) in the New Bedford/Fall River area. Again that would seem to bear out the fact that free or reduced cost care is more readily available in the Boston area.

Impact of Lack of Health Insurance (Appendix E, Tables 1-4)

Health care utilization, costs, health status and hours of work were compared for direct care workers with insurance and those without insurance. For purposes of this analysis, all respondents were aggregated into those with and without insurance. (Table E1-E4).

Utilization -- Uninsured direct care workers are less likely to have a regular provider or go to a health care provider when they have health needs.

Only 55 % of respondents with no insurance had a regular provider, compared to 95.9% of those with insurance. Even more strikingly, 33.3 % of the uninsured workers avoided seeing a provider, vs. only 4.9% of those with insurance. Money issues were

cited for avoiding seeing a provider by 87 % of those without insurance, but only 50% of those with insurance.

Nearly 47% of those without insurance used the emergency room in the last year, while 37% of those with insurance used the emergency room. These overall percentages were higher than adults statewide, although the differential was consistent; 32.2% of uninsured adults visited an ER in the last year compared to 22.5% of insured adults. 4.3% of the uninsured who used an ER cited “no regular provider” as the reason, compared to none of those with insurance. 90.7% of the insured used the ER because of a medical emergency, compared to only 78.3% of those with no insurance. For respondents without insurance, 8.2% had an inpatient hospital stay in the last year, compared to 11.6% of those with insurance.

Costs and income -- Uninsured direct care workers are more likely to use free care and more likely to have significant health care debt.

There was a six fold difference in the use of free or reduced cost care between those without insurance (61.7% used such care) vs. those with insurance (only 9 %). In addition, 19.1% of those without insurance had incurred significant health care debt, compared to 14.5% of those with insurance. There was also a significant difference in family income between the uninsured respondents, with an average family income of \$18,868 per year, and the insured respondents, with an annual average family income of \$26,504 annual average family income. (Note: While there may have been underreporting of family income by respondents because some did not report their spouse' income, this underreporting could be expected to be the same between insured and uninsured respondents, so that this comparison may be more reliable than the overall income figures).

Health Status -- Uninsured direct care workers have significantly lower health status.

Uninsured direct care workers responding to this survey showed significantly lower health status. Of those without insurance, 59.2% reported themselves to be in excellent or good health, compared to 78.8% of those with insurance. 40.8% of those with no insurance were in fair or poor health, compared to only 21.3% of those with insurance. These health status results are illuminated by the 2000 Division of Health Care Financing and Policy survey. While most adults reported needing medical care in the past twelve months, insured adults statewide were 26% more likely to seek medical care in the past twelve months. More uninsured adults statewide reported having a medical condition or disability than insured adults (13% vs. 10%). Furthermore, insured adults with chronic illnesses were 1 ½ times more likely to make physician visits and were almost twice as likely to have filled a prescription or taken a medicine prescribed for their condition than uninsured adults with chronic illnesses (DHCFP, June 2001).

Employment -- Uninsured direct care workers average 28.85 hours of work per week and 9.7 years work experience.

Those without insurance worked two hours less per month than those with insurance (28.85 hours vs. 30.85 hours respectively). Those without insurance also had

worked fewer years in long-term care---9.7 years for the uninsured vs. 11.54 years for the insured.

Employer Survey

The employer survey was conducted in order to provide information about the health insurance offered to direct care employees by their employers, as well as to provide a context for the interviews with direct care employees. The results provide an overview, through employer self-reporting, of the types of insurance benefits offered to direct care workers in nursing homes and home-based care agencies as well as the participation of employees in these plans. The insurance status of direct care workers is affected by the private health insurance benefit offerings of their employers, as well as by the eligibility requirements of these employment-based programs and of public programs that might be available to these workers. Another factor, which may have relevance for the state when considering health insurance options for these workers, is the payment source for the clients served by the long-term care providers. Although these providers are private employers, and therefore their workers are not public employees, the majority of the clients served by these providers are funded through state or federal public programs.

The employer survey was distributed to fifty-two long-term care employers, including nursing homes and home-based care agencies suggested by the DCWI health insurance subcommittee. Thirty-three were returned. None of the providers that arranged for their employees to be interviewed returned the employer survey, so there is not a direct relationship between the results gathered from the two groups.

Employer Survey Results

Agency Characteristics (F: Table 1 a-c)

Workforce

In the thirty-two surveys completed by employers, the average number of employees in the agency was 126 employees, 74 part-time and 49 full-time. A larger percentage of nursing home employees were full time than employees of home-based care agencies. Twelve nursing home employers completed surveys, and the average number of employees was 97 (median size 85 employees), with an average of 36 part-time and 57 full-time. Nineteen home-based care agencies completed the survey, with an average number of 144 employees with 98 part-time and 43 full-time.

Public-payment sources for Clients/Residents

The nursing homes had an average of 126 residents, with a range of 53 to 190 and a median of 122. Home-based care agencies had an average of 836 clients, with a range of 20 to 5000 and a median size of 350 clients.

On average 53 % of the clients of these agencies were funded by MassHealth, 23 % were funded through Medicare, and 17 % are other sources. MassHealth funded a higher percentage of residents in nursing homes (72 % MassHealth, 12 % Medicare and 13 % other) than home-based care agencies (38 % MassHealth, 33 % Medicare and 13 % other sources, including EOEA funding).

Health Insurance Benefits or Programs offered by employer

Employers offering benefits (F: Table 2a)

Of the 32 responding employers, 94% offered health benefits to employees, with 100% of the twelve nursing homes reporting that they offered health benefits and 90% of home-based care agencies offering insurance. However we did not collect data from the employers on employee utilization of this benefit.

Benefit Structure -- Limited choices (F: Table 2b)

A bare majority of these employers (55%) offered a single HMO to their employees, while 3% offered just one indemnity plan as an option. The others offered either more than one HMO or indemnity, or a mix. Twenty-eight percent of the employers offered additional pay in lieu of health benefits. Of the nursing homes, 17% offered one HMO and 8% offered one indemnity, while among the nineteen responding home-based care agencies, 18% offered only one HMO and 6% offered one indemnity plan. Fifty percent of the nursing homes offered pay in lieu of health benefits, compared with and 16% of home-based care agencies

Participation in public subsidy programs (F: Table 4 a-c)

Massachusetts provides an option for employers to participate in subsidy programs for employees whose incomes are under 200% of the federal poverty level. The Insurance Partnership provides subsidies to the employee and the employer. Seven percent of the employers that responded reported participating in this program, with 8 percent of the nursing homes and 5 percent of the home-based care agencies reporting participation.

Employee Eligibility and Costs

One-third of direct care workers are not eligible for participation in their employer plans (Eligibility -- F: Tables 3 a-c)

The mean number of hours required to be eligible for health benefits was reported to be 27 hours and was similar between nursing homes and home-based care agencies. The average number of employees eligible for their employer plans was 67% in nursing homes and 68% in home-cared based agencies.

Cost of employer benefits to employees -- F: Tables 5 a-c)

Nursing home workers paid an average of \$1104/year for individual coverage and \$3,922 for family coverage. Home-based care agency workers paid an average of \$827

/year for individual coverage and \$2,281 for family coverage. The combined average was \$960 for individual coverage and \$3,311 for family coverage. The workers' share of the premiums varied from 10 percent to 50 percent of the total cost of the premium, with about twenty percent paying 50% of the cost.

Share of premium (F: Tables 6 a-c, 7 a-c)

Direct care workers' share of the total premiums for individual coverage was reported to vary from 10 percent to 50 percent., with about a third of the workers paying 10-20%, a third paying from 30-40 % of the cost, and 20% paying one half the cost.

Participation in Employer Based Coverage Unknown (F: Tables 8 a-c)

Employers did not consistently report levels of participation by employees in the health plans offered. When asked about the trend of worker participation in these plans, the majority (79%) of employers said that employee participation was staying the same, while only 10% said that it was going up and 10% that it was going down.

Discussion and Recommendations

Discussion

The results of the Direct Care Workers Health Insurance Access Survey reflect significant similarities and differences between direct care workers and the general population. 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. Though direct care workers work multiple jobs and have worked for many years, the majority earn incomes below 200% of the federal poverty level. While all long-term care employers offer health insurance to their employees, offerings are limited. One-third to half of direct care workers do not meet employer eligibility requirements and when employees do participate, many cannot afford their share of premium costs, which are 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.

The results of the Direct Care Workers Health Insurance Access Surveys of employees and employers demonstrate that workers have a significant need for assistance in obtaining health insurance for themselves and their families. Direct care workers face more barriers to accessible health care than the general population. Though survey respondents indicate a high level of commitment to caregiving work, many report that because of lack of health insurance benefits, they may not be able to continue working in long-term care.

Direct care services are primarily publicly-funded. Thus public payment rates for nursing home and home-based services have a significant impact on workers' compensation rates, including employment-based health insurance benefits.

These statistics for direct care workers reflect trends in the general population. Portions of the population, such as low-income and part-time employees, African-Americans and Latinos, and never married individuals have a higher propensity to be uninsured. Paraprofessional direct care workers often fit into one or more of these categories; home-based care workers, for instance, never know from one week to the next whether their hours will be diminished by the hospitalization or loss of a client. In addition to the ever-present threat of lost wages, some workers become ineligible for health insurance benefits if they do not work a certain number of hours, and others can't afford their share of the insurance premium when it is offered. For these reasons the rate of uninsurance among these workers is three times the state average for adults. Of those employees who are insured, only 56% receive insurance through their primary employers, with thirty percent of those that are insured receiving insurance through their spouses.

Noteworthy in the section reserved for interviewee's comments (Appendix G) is the fact that direct care workers are more knowledgeable about their health benefits than they were several years ago. Even with this level of recognition of public programs, the surveys showed that only about 10% of those who were insured identified a public program as the source, whereas the low income levels of these workers indicates that many more may be eligible. However, nearly all New Bedford respondents and about two thirds of Boston respondents did report that at least one family member was insured, which may be an indication that children are participating in the programs now available to all children in the state.

Although health insurance coverage is not tantamount to a better quality of health, there is an obvious connection. In fact, state data indicates that uninsured adults are more likely to rate their own quality of health as fair to poor, and are less likely to visit the doctor than are insured adults. In addition, uninsured adults are more likely than insured adults to make one or more visits to the ER. (DHCFP, December 2000). These results are borne out by the responses from these workers as well. Therefore, lack of health insurance is affecting the health and quality of life of direct care workers, which may also negatively affect their work performance, absenteeism and turnover rates.

Interviewers found that when respondents have affordable coverage they are extremely appreciative of the benefit. Unfortunately, most felt that their access to insurance was fraught with problems. A range of these responses can be found in the comments from respondents reported in Appendix G). Many respondents discussed the lack of certain benefits such as prescription drugs or dental coverage. Others mentioned the difficulty in finding providers who accepted the plan, and still others noted the difficulty in getting to the providers. Perhaps the most vocal were those who decried the cost of the premiums and co-pays. One parent told of having to make a co-pay for each of her children, even though the doctor saw them all together. In addition, when it

became obvious that they all needed the same medication, she was given several prescriptions for the same medication, resulting again in several separate co-pays.

Lack of health insurance is associated with delays and avoidance in seeking health care access, which was reflected in the results of the employee survey. Having some insurance but still being unable to afford out-of-pocket expenses may also have adverse health consequences. Many interviewees, who were uninsured, expressed anger and anxiety about their inability to get affordable insurance. Several respondents articulated a desire to remain in the direct care field, but said that because of the lack of benefits they did not know how much longer they would be able to do so. In the case of the interviewees who were eligible for insurance but were uninsured, the majority cited cost as the reason. Not surprisingly, over 58% of uninsured Boston residents and 66.4% of New Bedford/Fall river residents live in low-income households. Among single, never married direct care workers in Boston, 33.3% were without insurance. Among the same population in the New Bedford/Fall River area the percentage was much lower at 11.1%. While it can be theorized that ethnicity and religion are contributing factors to this particular discrepancy, the survey tool was not designed to elicit that information.

The employer survey confirmed the picture that emerged from the employee interviews. Although nearly all employers report that they offer health insurance to their direct care employees, only 67 % of nursing home employees and 68 % of home based care employees were eligible for that benefit, based on hours of work and length of employment. Given that 25% of direct care employees reported being uninsured, it is clear that many cannot take advantage of insurance benefits when they are eligible. The employer survey also showed that when employees do participate, the costs are high on average and higher than state averages. Despite the fact that over half of direct care workers surveyed have incomes below 200% of poverty, few of these employers (7%) participate in the state's Insurance Partnership Program, which subsidizes the employer cost of health insurance for such low-income employees. However, many may not be eligible, since the program is only available to employers with less than 50 employees, and the median size of the agencies that responded to the survey was 85 employees. Employers who responded did report paying at least 50% of the cost of insurance, which is required for participation in the IPP.

Despite the variation in some of the data between nursing home and home-based care agency, or Boston and New Bedford/Fall River, what becomes clear is that overall, the basic characteristics of income, hours worked, marital status (single, never married), as well as those which this survey did not address (race, age, etc.) point to a dismal insurance forecast for those respondents. The data show that direct care workers, though they are essential to Massachusetts' health care system, face more barriers to accessible health care than the general population. We hope that highlighting the differences and similarities will lead to a strategic plan that will better inform policy makers and health care providers.

Recommendations

Direct care work in long-term care is one of the fastest growing employment sectors today, yet more than 13% of families headed by direct care workers live in poverty (under 100% of the Federal Poverty Level) and over half at significantly low-incomes (under 200% of FPL). The turnover rate for these occupations is extremely high. With a doubling of the elder population in Massachusetts over the next 25 years, the growing need for long-term care for elders and people with disabilities will increase the demand for direct care workers. As long as poverty level wages prevail and health and other benefits are not provided, caring individuals who love their work will be forced out of long-term care choosing less physically and emotionally demanding jobs available that provide higher wages and better benefits. High rates of turnover and labor shortages are likely to increase under these circumstances, creating more crises for the long-term care system as it seeks to maintain a qualified and caring workforce.

Health insurance is a significant factor in the overall wage and benefit structure, which must be addressed within long-term care. Many of the predictors of whether or not a person has insurance have been discussed previously. Generally those differences reflect variations in income, occupation, health status, gender, etc. The cost of health insurance and the underlying costs of health services, and the patchwork of public policies regarding insurance coverage all contribute to the economic pressures on employers, insurers, government health insurance programs and employees themselves. Small employers, and particularly employers of middle-aged women, are especially likely to face high premium costs in securing health insurance plans for their employees.

In long-term care, there are many workers who can't afford to accept their employers' health plans because they may be expected to pay $\frac{1}{4}$ to $\frac{1}{3}$ or even more of the total cost of the premium, in addition to deductibles, co-pays and services not covered by the plan. Low-income families are often unable to sustain their part of the health plan, and either become uninsured or are forced to seek work in another field that provides better wages and/or benefits.

Direct care services are primarily publicly-funded. Thus public payment rates for nursing home and home-based services have a significant impact on workers' compensation rates, including employment-based health insurance benefits.

In order to increase the health insurance coverage of direct care workers, the state could approach the problem in a number of ways, including a combination of public and private initiatives designed to stabilize employment by expanding access to affordable, quality health insurance coverage. Options include initiatives within long-term care to lower premiums for employers or make pass-thru payments to cover 100% of premium costs, redesign of the Insurance Partnership Program or other public-private programs to work within long-term care, and expansion of public coverage either for direct care workers or for all workers in their income levels.

APPENDICES A-E. EMPLOYEE SURVEY TABLES

- A. Employment Characteristics
- B. Family Characteristics
- C. Health Insurance Characteristics
- D. Health Access and Utilization
- E. Impact of Access to Health Insurance

APPENDIX F. EMPLOYER SURVEY TABLES

APPENDIX G. COMMENTS FROM INTERVIEWEES

APPENDIX H. INSTRUMENTS

APPENDIX I. BIBLIOGRAPHY AND NOTES

[P1] Facility Code

[P2] Case Number

[P3] Interviewer Initials

[P4] Subject Initials

[P5] Date _____

[P6] Time Interview starts _____

Hello, my name is _____. I work for Health Care For All, a group which has been hired to interview long term care workers such as yourself, to find out how you get your health care. The purpose of these interviews is to figure out the best way to ensure that long term care workers will have access to high quality health care. It is very important for you to know that nothing that you say to me during this interview will be shared with your employer or anyone else in a way that it could possibly be associated with you. In other words, this interview is completely confidential, and no-one will know what you tell me. I hope that with this in mind, you will feel free to be open and honest with me about yourself and your health care needs.

If at any time during the interview you think of anything that could change the way I have marked a previous answer, please let me know. At the end of the interview I will give you an opportunity to make additional comments or raise concerns that haven't been covered in the questions.

Also, at the end of the interview, I will give you a card that will give you a number to call if you have any questions about health access programs in Massachusetts, or if you would like to tell your story to someone else so that we can improve health access for all long term care workers.

Shall we begin?

The first set of questions concerns your work situation.

[W1] How many jobs do you have beside this one?

[W2] About how many hours per week, on average, did you work last month in ALL your jobs?

[W3] About how many hours per week, on average, did you work last month in this job only?

[W4] How many of the jobs were in long term care?

[W5] How many years (or months) have you been in the long term care field?

Years _{WSA}

(or Months) _{WSB}

[W6] Do you consider this your main job?

Yes ₁ No ₂

The next set of questions concerns your family

[F1] What word or phrase would best describe your marital status?

Married ₁

Separated ₂

Single, never married ₃

Divorced ₄

Widowed ₅

Not married, living with mate ₆

Other ₇

If the answer is Married, ask [F1a] Are you living with your spouse? Yes ₁ No ₂

[F2] How many children that you have responsibility for that are under the age of 19?

[F3] How many children that you have responsibility for that are 19 or 20?

For all of the rest of the questions about your family, answer them only about yourself, your spouse (*if applicable*) and the children you are responsible for that are **under 19** years old (*if applicable*).

[F4] Is there any member of your family who has a chronic illness, such as diabetes or sugar, heart trouble, or asthma? Yes ₁ No ₂ Don't Know ₉

IF YES, then ask [F5] Who is it?

Self ₁

Spouse/Mate/Partner ₂

One child ₃

More than one, but not all children ₄

All children ₅

Don't know ₉

The next set of questions concerns your health insurance situation.

[H1a] Are you covered by health insurance? Yes ₁ No ₂

[H1b] Is anyone else in your family covered by health insurance?

Yes ₁ No ₂ Don't know ₉

IF the answers to H1a and H1b are NO, go to question H10

IF the answer to H1b is YES, go to question H9

[H1c] Do you have insurance that covers prescription drugs or dental services?

(Circle one answer)

Prescription Drugs only ₁

Dental Services only ₂

Both ₃

Neither ₄

Don't know ₉

[H2] Who is your insurance company?

- Private Carrier ₁
- Government (non-military) ₂
- Government (military) ₃
- Other ₄
- Don't know ₉

[H3] Who is the primary insured in your family?

- Self ₁
- Spouse/Mate ₂
- Other ₃
- Don't know ₉

[H4] Who do you get insurance through?

- This employer ₁
- Another employer ₂

IF H4 is “Another employer,” then ask

[H4a] (Is the other workplace also a long term care employer?)

- Yes ₁
- No ₂

- Purchase directly or through a broker ₃
- Government (nonmilitary) program ₄
- Government (military) program ₅
- Other ₆
- Don't know ₉

[H5] Did you have a period of time last year where you lacked health insurance for a month or more? Yes ₁ No ₂ Don't Remember ₉

[H6] About how much are you paying in health insurance premiums?

Per Year _{H6A}

Per Quarter _{H6D}

Per Month _{H6B}

Per Week _{H6C}

If subject doesn't know, circle Don't Know ₉

[H7] Who is covered under this insurance plan? Include only yourself, your spouse (if applicable), and your children under age 19. (Circle all that apply)

- Self ₁
- My spouse/partner/mate ₂
- All of my children ₃
- Some of my children ₄
- Don't know ₉

[H8] Is there anyone in your family who has health insurance in addition to this plan?
 NOTE: Remember to answer this question only for yourself, your spouse (if applicable) and your children under age 19 (if applicable).

Yes ₁ No ₂ Don't Know ₉

IF YES, ask [H9]

[H9] Who is it and where do they get their insurance from? (Circle appropriate entry. If subject does not know answer, leave blank.)

**My spouse/
partner/mate**^{H9a}

**More than one, but not
all of my children**^{H9b}

**All of my
children**^{H9c}

Type of insurance

Type of insurance

Type of insurance

This workplace ₁

This workplace ₁

This workplace ₁

Another workplace ₂

Another workplace ₂

Another workplace ₂

Purchase directly or through a
broker ₃

Purchase directly or through a
broker ₃

Purchase directly or through a
broker ₃

Government (nonmilitary)
program ₄

Government (nonmilitary)
program ₄

Government (nonmilitary)
program ₄

Government (military) program ₅

Government (military) program ₅

Government (military) program ₅

Other ₆

Other ₆

Other ₆

If question H9 was answered, GO On to question H11

[H10] Even though you don't get insurance from this employer, do they offer health insurance benefits? Yes ₁ No ₂ Don't Know ₃

IF H10 Is "Yes," then ask

[H11] Why don't you get health insurance benefits through this employer?

- Don't need ₁
- Too expensive ₂
- Not yet eligible ₃
- Other ₄

Do you have any other kind of health insurance?

Dental *(Circle all that apply)*

- For [H12a] spouse/partner/mate ₁
- [H12b] all children (under age 19) ₁
- [H12c] some children (under age 19) ₁
- [H12d] don't know ₉

Prescription drug coverage *(Circle all that apply)*

- For [H13a] spouse/partner/mate ₁
- [H13b] all children (under age 19) ₁
- [H13c] some children (under age 19) ₁
- [H13d] don't know ₉

[H14] Aside from health insurance premiums, what were your medical expenses last year? Medical expenses include co-payments, deductibles, payments for eyeglasses, dentures, prescription drugs, wheelchairs or any other medical-related equipment or services that your insurance didn't cover.

- Under \$500 ₁
- Between \$501 and \$1,000 ₂
- Between \$1,001 and \$2,000 ₃
- Between \$2,001 and \$3,000 ₄
- Between \$3,001 and \$4,000 ₅
- Between \$4,001 and \$5,000 ₆
- Over \$5,000 ₇
- Don't Know ₈

Here are some more questions about you, your family, and your health.

[P1] How old were you on your last birthday?

[P2] Interviewer identify the subject as (Circle) Female ₁ or Male ₂

[P3] Do you have a regular health care provider? (PROMPT: For example, a doctor nurse practitioner, or a medical practice)

- Yes ₁
- No ₂

[P4] Do your children (under age 19) have a regular health care provider?

Yes, some do ₁

Yes, all do ₂

No, none do ₃

Don't know ₉

[P5] In the past year, did you avoid seeing a health provider for any reason?

Yes ₁

No ₂

Don't Remember ₉

IF YES, ask [P6] What was the reason?

No regular provider ₁

Inconvenient hours ₂

Difficulty in transportation ₃

Money issues ₄

Other ₅

Don't Remember ₉

[P7] Did you use the emergency room for any reason? Yes ₁ No ₂

IF YES, ask [P8] What were the reasons? (Circle all that apply)

Medical emergency _[P8a]

Regular provider closed _[P8b]

No regular provider _[P8c]

Money issues _[P8d]

Transportation difficulty _[P8e]

Other _[P8a]

Don't Remember ₉

[P9] Did you spend any time as an inpatient in the hospital last year?

Yes ₁

No ₂

IF [P9] is YES, ask [P10] How many days?

[P11] Did you receive health care services for free or at a reduced cost in the past year?

Yes ₁ No ₂ Don't Know ₉

IF YES, ask [P12] Where did you receive free or reduced cost services?

At a hospital? ₁ What hospital? _{P12A}

At a community health center ₂ What community health center? _{P12B}

Other ₃ Where? _{P12C}

[P13] Do you have a significant amount of debt from a health care provider?

Yes ₁ No ₂ Don't Know ₉

(Note, if the interviewee asks what "significant debt" is, explain that it is whatever is significant to them.)

[P14] Generally speaking, would you describe your health as

Excellent ₁

Good ₂

Fair, ₃ or

Poor ₄

[P15] What was your total family income last year. Remember, all answers are confidential.

Income for 2000

\$

[C1] If you have any concerns or comments you would like to say about health insurance and your access to care, please share them with me now.

[P6] Time Interview ends _____

Length (for data processing use only)

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[BF1]The stats in this graph say 98 or 96 % yet it starts by saying “all” – should it be virtually all?