

O·W·L**FAX TRANSMISSION****Date: April 9, 1996 TOTAL PAGES (w/cover) 2 transmissions-14pgs. each****TO: Barbara Wooley, White House****AT: 456-6682***If problems, call 202-783-6686.***From: Deb Briceland-Betts, Executive Director****COMMENTS/INSTRUCTIONS:**

Thank you for helping with this. We are releasing our annual Mother's Day report the week of May 6-10. We would prefer the 7-8th, but would be flexible to accommodate the First Lady's schedule.

This year's report is on caregiving. OWL has a history of speaking out on this issue. Each year since 1986 it has focused on an issue important to midlife and older women. In 1989, we released a report that became the baseline of information on women as caregivers. This report goes a step further. Women care for their children, then for their aging parents, frail spouse, and when they are old and alone, they care for each other. This report shows that more than 90% of paid caregivers are women and many are midlife and older. The paid caregiving workforce is overworked and underpaid. This report draws the line between the way we treat caregivers and the quality of care they provide. We have the "vulnerable caring for the vulnerable." And, as the report indicates, current congressional proposals would take us in exactly the opposite direction and cut programs so necessary for women as we age. A draft of the report accompanies this fax. Again, the messages can be adjusted to accommodate the First Lady, if necessary. (The state-by-state data is likely to grab the news and there will be 15-20 state press events in key districts held by our chapters the same day. Individual chapter members are also sending "Mother's Day" cards to their Senators. A copy of the card is included w/fax.

We are proposing that the national press event to release the report be held on capitol hill. (Again, we can change sites, if necessary: to a nursing facility, homecare site, or the national press club.) About 10 a.m. We would have paid caregivers and our Executive Director and National Board President speak in addition to the First Lady.

We have talked with Debra Silamaeo of Sen. Daschle's staff about his participation, perhaps Sen. Kassabaum's and Sen. Mikulski.

Consumer and Caregiver Participation in Quality Decisions

"Nursing home residents can never be more empowered than the staff who care for them."
-- Nursing home medical director William Thomas⁴⁷

Long-term care consumers are engaged in an on-going struggle to maintain their dignity and some limited autonomy -- particularly, nursing home consumers. Long term care consumers have the following issues: loss of independence; loss of choice; loss of family and friends; having to depend on others in a new and substantial way; ... quote from other OWL materials.

Caregivers also are plagued with powerlessness; "the nurse's aide, personal care worker or homemaker often has great responsibilities without commensurate authority."⁴⁸ Family members also struggle to assure their loved ones receive high quality care. Caregivers, consumers, and family members alike often feel powerless in their efforts to provide consumers with the highest quality of care.

"My dad's been in a nursing home for six years; he has Alzheimer's. There's no input when a family has an idea about something. It may be a simple idea like a high toilet seat, or... a little cup, so he can hold a cup in his hand... When I have a problem, I go to the administration and they do not listen." - Audrey Bea, family member/MN Sr. Fedn

Family members often lack a strong voice in quality decisions. They may or may not be involved in care conferences (true?). Many express frustration in trying to work with administrators to solve problems. Family councils offer one mechanism through which family concerns can be heard and addressed.

<My agency sends a letter of services I am to provide to every client; however, I never see a copy of the letter.> (chk exact quote, name) -- California home care worker

"I noticed one day <when instructed to write in patient charts> that what I do for the resident was totally opposite to the care plan." -- Tee Martin, nursing home caregiver

Case managers who develop plans of care for consumers rarely talk with the caregivers who actually provide the care.⁴⁹ Home caregivers note that case managers often visit consumers when the caregiver isn't even there. This devalues their insights and adds to their feeling of isolation on the job. Also, caregivers in nursing homes often are excluded from care planning meetings. Care plans written in such a vacuum may be inappropriate or unworkable.

"I think we should sit in <on the patient care conferences> because we know more about the resident; we know what might get this resident to go to activities, or eat better... They just don't think we know enough; they leave us out all the time... I'll say, well you could do it this way, and it would work, but they still don't do it that way."

-- Mary Webb, nursing home caregiver

"I instructed them that that particular resident should not be moved into the same room because... she becomes combative. But, as usual, they didn't listen; they put her in there, and she came up with bruises. Eventually they did move her, but look at what she had to go through. And all they had to do was just listen."

-- Mildred Worthy, nursing home caregiver

Ideally, care plans are written with case managers, caregivers, consumers, and families working together, with informed consent rights for consumers and/or their families regarding important areas of care. Consumers and their families play an obviously important role; case managers bring their professional knowledge to the process; and caregivers bring their understanding of consumer preferences about schedules, activities, diet, acquaintances; further, they carry out the work. On the other hand, if caregivers, consumers, and families are kept in powerless conditions, that can breed resentment and mutual hostility, rather than solidarity.⁵⁰ Only by valuing the insight of those most intimately involved in care delivery can we expect to achieve high quality care that addresses the needs and concerns of consumers and caregivers alike.

Education, Training, and Career Ladders

"The preponderance <of the evidence> shows that one approach to improving quality is to improve the number and skill mix of the personnel providing care.

-- Charlene Harrington, Ph.D., R.N., F.A.A.N.

Despite the range of duties they are asked to perform, and the increasingly complex medical needs of the clients they provide care for, caregivers receive little training and little respect. Caregivers describe a pattern of demeaning practices, such as being forced to work when sick, or being denied access to phone calls if their child is sick. With few outlets to improve their skills and no real career ladder to climb, caregivers face a limited future. Those wishing to advance their career must switch to another profession.

Caregivers help care consumers achieve the activities of daily living, and, increasingly, provide needed medical care. Duties include helping with bathing, dressing, getting to and from the bathroom, providing assistance with eating, and transferring from one place to another -- as well as treatments to control infection, prevent and treat bedsores, replace dressings, give enemas, change catheters -- and regularly monitor vital signs. Caregivers who work in the home provide varying levels of care: some provide personal care services for people needing modest levels of help; others provide skilled nursing care for people who are homebound; and still others offer complex "high-tech" care for high-risk infants, people with cancer, people with HIV, etc. Additionally, paid caregivers help consumers perform the exercises that can maintain their level of physical function, including range of motion exercises and regular walking. Time spent talking with care consumers provides critically important human contact.

"Eighty hours <of training> is not enough for anybody to take on a job caring for people... We should learn all that we possibly can. We should upgrade this industry."

-- Carrie Bradford, nursing home caregiver

"We take care of people that would've been in the hospital for a couple of months, back then <several years ago>."

-- Lynn (MN LPN)

As a byproduct of health care industry restructuring, caregivers are caring for consumers with more serious medical needs. Due to the growth of managed care, consumers of all ages who used to receive care in the hospital are being shifted to nursing homes; many who used to be in nursing homes may be moving to assisted living facilities; many who used to be in assisted living facilities or other community facilities may soon receive their care in the home.

The Nursing Home Reform Act of 1987 requires nursing home workers to complete a 75-hour course and exam, to become certified nurse assistants. Such training includes ... Home care workers are not subject to federal requirements regarding training (true?). The Home Care Aide Association of America offers a voluntary certification program which includes 75 hours of training and a test. (how many take this training?) The Association is in the process of assessing how well this training program covers the increasing medical needs of consumers.

Training requirements in place today are uneven. Particularly in home care, the lack of

uniformity in job description and training standards creates an uneven system of training and care. Training requirements for home care vary state-by-state and even county-by-county, depending on the type of health care program and the source of funding.⁵¹ In some cases where training is required, home care workers may begin work before training is completed.⁵²

Given the increasing care needs of consumers in nursing homes, community-based care, and home care, it is more important than ever that caregivers receive appropriate training and continuing education. Motivated caregivers also should be offered additional educational opportunities, to allow them to develop their skills further, to equip them to care for people with more extensive medical needs.

"We receive no promotions <in the California home care system>."

-- Mae Moore, home caregiver

Caregivers also should be offered opportunities for promotion reflecting their expertise -- along a career ladder that involves increasing authority and commensurate rates of pay. Today, for the best and most dedicated caregivers, there's no reason to stay on the job, beyond their love for the consumers for whom they care. The caregiving profession must adjust career opportunities in order to reduce turnover rates and retain highly qualified and committed caregivers.

Hazardous Working Conditions

"I have a bad back from years of doing what I do. It's not fixable. The rate of turnover is common among CNAs because of back problems and other related body problems such as knees, feet and shoulders, from lifting. -- Arlene Cooper, nursing home caregiver

Working conditions in nursing homes are among the most hazardous of all industries. Of the 20 fastest-growing industries in the country, nursing homes have the highest rate of occupational illness and injury, and the highest rate of lost workdays. <endnote> In 1992, the injury rate for nursing home staff was the highest of any group of health services workers.⁵³ Occupational illness and injury rates for nursing home workers increased 55 percent between 1983 and 1993, with greater than 200,000 injuries reported each year; the number of lost workdays almost doubled over the same period of time.⁵⁴

Back injuries caused by lifting patients without appropriate help are the most common injury reported.⁵⁵ Injuries to the back and trunk account for over half of all injuries to nurse aides working in nursing homes. Certain inspections by the Occupational Safety and Health Administration (OSHA) revealed that safety training programs for nurse aides are not effective. Many nursing home operators provide back belts, but there is no evidence they reduce the hazards of repetitive lifting, pushing, and bending. More research is needed to find the best ways to minimize injury rates.

Additionally, chronic care workers are exposed to consumers' illnesses. Caregivers complain about being exposed to infectious conditions -- including tuberculosis and scabies -- without even being informed. And, nursing and personal care facilities have a high incidence of workplace violence -- 47 cases of violence for every 10,000 workers, compared with an average of three of every 10,000 workers overall.⁵⁶ Nursing home workers have higher rates of occupational illness and injury than workers in mining and construction.

"We're working with back injuries; we're working hurting all over. We're unable to go to the doctor because we don't make enough money to go. Nobody seems to care. But we still love the job that we do -- we love taking care of people. We've got to love it because there's no money to love." -- Betty Davis, nursing home caregiver

Funding cuts for long term care that result in one caregiver taking care of too many consumers risk unnecessary injuries. If there are enough caregivers on staff such that people can help each other with heavy lifting and transferring tasks, injuries may be reduced. When these same tasks are done by a single caregiver, the risk of injury is far greater, both for caregivers and consumers, who sometimes fall down together.

"You get hit; you get called <racial> names... if a resident has a behavior problem, that takes time."

-- Tee Martin, nursing home caregiver

When caregivers have too little time to focus on each consumer, certain consumers may become resentful. Caregivers often suffer the physical abuse of disgruntled consumers; turning such situations around may require spending time listening -- if time is not available, there may be no chance for the physical abuse to abate.

"I was assigned 13 patients one day. I was lifting the resident and my hand was injured; my tendons were damaged. If I wasn't a conscientious person or a caring person, I would have dropped this patient -- but I couldn't. I had to endure the pain I was going through to easily set this patient down... We've got the hydraulic lifting equipment, but <it's missing the seat>."

-- Helen Smith, chronic caregiver

More studies are needed to determine the most appropriate technology to aid lifting and transferring without injury. Adequate lifting equipment combined with adequate staffing might protect caregivers from some of the most hazardous lifting tasks. OSHA has not yet developed an <ergonomics> standard for caregiving. Such a standard should include an analysis of risks; feasible ways to prevent and reduce identified risks; and treatment programs that can offer prompt care at the first sign of injury. On-going education and training on the safest ways to lift and transfer consumers also could reduce the rates of occupational injury. In March 1996, OSHA released voluntary guidelines for health and social service providers -- to reduce workplace violence; if employers implement it these standards, that could reduce the incidence of violence against caregivers.

Collective action through family councils, independent resident organizations/consumer groups, and employee unions

"We're not supposed to have a relationship with the family. We're not supposed to tell them anything. We're supposed to go along like everything's peachy, but it's not. A lot of us let the family know what's happening, and they'll in turn, go to the Administration... they come back and see nothing has changed."

-- Mary Webb, Chronic Caregiver

Consumers and caregivers have a joint interest in achieving the employment conditions that promote the highest quality of care. Too often, administrators lack sufficient funds, or are unwilling, to implement reforms that would improve deficient conditions.

Such quality of care protections, and employment protections, are most achievable in the context of collective action. Through independent organizations -- including independent family councils, unions for caregivers, and independent resident organizations or consumer groups -- families, caregivers and consumers can work with administrators to promote changes that will improve the quality of care, including:

- * Improved funding for long term care -- to improve access and quality of care;
- * Legislated minimum staffing ratios, to allow caregivers sufficient time to provide each consumer the care they need;
- * Wage levels that reduce turnover by offering caregivers a living wage;
- * Benefit protections that promote a more stable workforce, including health benefits that allow workers to get the medical care they need and sick leave that allow workers to stay home when they are sick;
- * Full participation of workers and consumers in quality decisions, including job security protections that allow caregivers to speak up about quality problems and demand appropriate corrections;
- * Continuing education and training in caregiving, to assure a skill level sufficient to provide care for consumers with complex medical needs;

"If I were to go to the Director and say this is going on and you go as a single entity, they say, 'that's funny, no one else is having that problem.' If you have a family council, use it because as a group, you have power. But, as a single person, like these girls <caregivers>, they don't listen to you."

-- Raelene Nowak, Family member

Empowered family councils and patient care committees can work together to fight for needed improvements, such as patient care committees, ... <Note OBRA language on consumer and family council participation; note some family council victories, if we know of any>

Similarly, caregivers can demand, and enforce collective bargaining agreements that promote high quality care, including adequate staffing levels, and legislated wage pass-throughs. < Note some actual victories, if we know of any >

"Our work together will change the system. We'll make it better for you and for me."

-- Ed Roberts, Consumer, and Founder of <disability group>

"The workers are going to have to not be afraid to relate what is taking place with the residents in the facility."

-- John Floyd, Alzheimers Association

Caregivers and consumers can work effectively together if they have the power to make needed changes to improve the quality of care. The protections noted above would benefit consumers, caregivers and administrators alike -- as consumer protections and caregiver employment protections together promote high quality care.

RECOMMENDATIONS

I. Reimbursement levels adequate to cover improved staffing and better wages/benefits:

- Federal funding for long term care must be sufficient to assure everyone access to care and to promote the level of high-quality long-term care that our society values.
- Reimbursements must be used efficiently, and translate into the working conditions and quality improvements that allow caregivers to provide high-quality care. Specifically, reimbursement rates should be set at levels sufficient to provide a living wage and family health benefits to caregivers who work in home care and in nursing homes.

II. Adequate Staffing:

- Nursing homes should be required to provide staffing that averages at minimum, one caregiver for every eight residents; this standard should be adjusted to ensure additional staffing to meet the higher acuity care needs of consumers. Federal funding must be adequate to cover such staffing levels.
- Each nursing home should assure it has sufficient staff to fully minimize use of restraints.
- Each locality should have a registry of available and qualified home care workers, so that workers, families and agencies could find one another more easily. This is important for substitute and weekend care needs, and for longer-term assignments.
- Home care agencies should assure that care plans and assigned hours are consistent, so that caregivers have time to provide needed care.

III. Consumer quality protections must be maintained and improved:

- The Nursing Home Reform Act of 1987 must be kept in place, with funding levels that make compliance possible.
- The Nursing Home Reform Act should be improved to include enforceable staffing ratios; informed consent for consumers/families for restraints; clearer language precluding discrimination against consumers based on race, payment, income, assets, or level of care; improved enforcement mechanisms and sufficient funding to achieve improved enforcement.
- Federal quality protections for all home health care should be established, including caregiver training requirements, certification and registry of home caregivers; federal oversight of quality through publicly accountable mechanisms.
- Whistle blower protections for all caregivers, consumers and families who report suspected quality violations to facility or agency officials or public regulators.
- Private right of action for consumers of long term care, to enforce existing protections.

IV. Consumer and Caregiver Participation in Quality:

- Consumers deserve informed consent in care planning and other important decisions.
- Caregivers should be encouraged as partners in care planning and day-to-day care decisions -- rather than just functionaries instructed to carry out someone else's orders.

V. Education, training, and career ladders for caregivers:

- Federal requirements for caregiver training must be improved, to meet the increasing care needs of consumers. Employers should be required to provide continuous education and training appropriate to the type of care that caregivers are asked to provide.
- Nursing homes, community care providers, and home care providers should establish career ladders for caregivers, recognizing increasing skills with commensurate pay.

VI. Hazardous Working Conditions

- The Occupational Safety and Health Administration (OSHA) should develop and implement workplace standards that would be effective in reducing or eliminating the incidence of workplace injury.
- In addition to OSHA requirements, employers should act to further minimize or eliminate potential hazards for caregivers and consumers alike.

VII. Collective action through family councils, independent resident organizations, and employee unions:

- Publicly post in each nursing home and home care agency a "bill of rights" which describes mandated protections and encourages caregivers, families, consumers and administrators to work together to promote quality care, and to report any quality problems. Provide additional copies of the "bill of rights" to all home care consumers.
- Assure consumer and family protections through independent resident organizations and family councils that are empowered to work with administrators to effect needed changes.
- Assure caregiver protections by protecting workers rights to bargain collectively.

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6. Op cit 4.
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19. Generations
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24. "Nursing Home Facts, September 1995," National Citizens' Coalition for Nursing Home Reform.

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49. Yee, p. 60, in Generations

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1996 Mother's Day Report***Faces of Care:***

*An Analysis of Paid Caregivers
and Their Impact on
Quality Long Term Care*

Embargoed
until May 7th/8th
1996

Jen —
Looking to do
photo op on
Mon. May 6
w/ Flotus
OK w/ you, the
report.

— Barbara

A Message from Dr. Johnetta Marshall

President of the Older Women's League

Happy Mother's Day!

As you look around this holiday, notice how many older women you care about have spent a life time caring for others. Women have been the traditional caregivers in our society. We care for our children, we care for our aging parents, we care for our ailing spouses, and then when we are old, frail, and alone, we care for each other. As we look at the long term care network: the family, the consumer, and the paid caregiver — we notice that all are predominantly women and most are midlife and older women.

Our daughters and daughters-in-law provide the vast majority of care for family members. The 1989 OWL Mothers Day report indicated that women who are now in their midlives will spend more time caring for their parents than they have for their children.

If our daily needs surpass our family members' ability to care for us, or if we are among the increasing numbers among us who live alone, we rely on paid caregivers — in our homes or in nursing homes — to care for us. Startlingly, more than 90% of paid caregivers are women — a large portion are midlife and older women. The average age of women who work in nursing homes is 37 and those who work as home caregivers average 47 years of age (Crown). Thirty-six percent of home care workers are 55 or older (Crown).

Sadly, we pay the women who care for our mothers — and others who need long term services and supports — lower wages than we pay those who fix our cars. Such low pay makes life hard, compromises caregivers' ability to care, and sends a message that the work is not valued.

How we treat paid caregivers is not just an issue for those who care about a worker's right to be properly valued for her labor, but it is a concern to each and every one of us who care about the quality of care received by those we love who may need to be cared for in a nursing home or who may need a caregiver's assistance at home.

Increasingly, researchers in the field of chronic care are identifying the connection between the way we treat paid

caregivers as employees and the quality of care that we receive as consumers. It means that when we are struggling too hard to do our job, we simply cannot do our best.

And women who work as paid caregivers must frequently struggle too hard to do a hard job!

Women who care are not only paid low wages, but they often lose pay for time away from the job if they are sick or take a vacation. The majority of paid caregivers receive no medical insurance from their employers. Paid caregivers' access to medical care is often Medicaid — the same program that pays the

nursing home and home care bills of the women for whom they care. The long term care system is a network of women on the economic edge caring for women on the edge of life.

The demand for caregiving services is growing tremendously as America's population ages and develops chronic illnesses. Twenty five years from now, there will be twice as many Americans over the age of 65 needing some type of long term care services, increasing from 7 million people today to more than 14 million people in 2020. Over the next decade, home care aides and home health aides will be the two fastest-growing professions; their ranks are expected to more than double.

Changes in health care delivery are altering the nature of caregiving. As managed care continues to move people out of hospitals sooner and into nursing homes or to home and community-based care, more of us are being cared for by paid caregivers in homes and nursing homes. Paid caregivers need more and better training to deal effectively with the increasingly complex medical needs of the people for whom they care.

On Mothers' Day we focus on the women who demonstrate their love by caring for others. The Older Women's League calls on Congress to leave intact our current long term care programs through Medicare and Medicaid and to increase needed resources to insure that paid caregivers work and retire in dignity.

Faces of Care: An Analysis of Paid Caregivers and Their Impact on Quality Long Term Care

Women and Long Term Care

Long term care access and quality are concerns for all Americans, but they are special concerns for women. Women are caregivers throughout life. Women spend an average of 11.5 years out of the work force in a caregiving capacity (AFSCME/OWL).

Women are more likely to need long term care because women outlive their male counterparts by an average of seven years (Butler). As women age, chronic conditions become more prevalent. When their spouse is no longer able to help, or when they have outlived their spouse, older women may need paid long term care services. Seven in ten nursing home residents (72%) are women (NCCNHR, 1995b) and two-thirds of home care consumers are women (IOM).

Paid caregivers — including home health aides, personal care aides, and nursing home aides — provide the bulk of day-to-day care in consumers' homes and in nursing homes. They make up about 70 percent of the home care workforce (SEIU, 1996) and deliver

80 to 90 percent of the direct care in nursing homes (McDonald, citing Harper, 1986). In return for back-breaking work, women who care receive low pay and poor benefits.

High quality care offers consumers the assistance they need to maintain and improve their level of function — physically, mentally, and socially. Poor care can cause consumers to lose critical abilities, such as walking or bladder control. Poor quality care results from insufficient staffing levels, insufficient training, high turnover rates among staff, unsafe conditions, and inadequate consumer power.

Improving Quality of Care

The quality of long term care will improve only when caregivers' employment conditions improve. Improving quality will require a comprehensive strategy to: assure adequate staffing; improve training and safety; maintain and improve consumer quality protections; stabilize the workforce by paying caregivers a living wage with health and pension benefits; and give caregivers, consumers and families more

power in facility and agency decisions affecting quality of care.

Finally, as efforts to reform our nation's public benefits programs and efforts, such as the Massachusetts program, continue to

The Quality of Long Term Care is Inextricably Linked to Caregivers' Employment Conditions.

move more women into training programs in allied health services, the report reveals that these women are relegated to a work life of low wages and no benefits. The majority of these women, now in midlife older, will face their retirement years almost solely dependent on Social Security — a program that is under assault.

As Penny Hollander Feldman of Harvard said, "The consumers are frail and often poor, and the workers are often poor enough to qualify for Medicaid. The situation is precarious. Vulnerable people are providing services for vulnerable people."

This report focuses on quality in long term care, including staffing, health and safety, limited consumer and worker involvement in quality care planning and decisions, inadequate funding levels that lead to high staff turnover, and insufficient caregiver training. Report recommendations are centered on: 1) the need to improve caregivers' employment conditions and include them in quality care planning; 2) the need for adequate financing — as funding levels determine staffing levels, the level of health and safety protections, and staff turnover rates — which are high due to poor wages and benefits; and 3) the need to give consumers and families more power in decisions affecting quality.

Caregiving and Women of Color

Paid caregivers are disproportionately women of color. Thirty percent of nursing home caregivers and 29 percent of home care aides are African-American (BLS). A growing proportion of nursing home caregivers are Hispanic.

These statistics reflect the general clustering of African-American and Hispanics, especially women, in low-paying jobs such as caregiving. In 1992, 27 percent of African-American women workers and 37 percent of Hispanic women workers had wages below the poverty line, while 21 percent of white women workers had low wages (Census Bureau). In 1995, the median weekly earnings for white men were nearly twice that of Hispanic women and more than one and one-half times that of African-American women. (BLS)

Within the caregiving profession, women earn less than men; at only \$275, the median weekly paycheck of women nursing home caregivers was \$56 leaner than that of male nursing home caregivers. (BLS)

Older Women's League

Staffing Problems in Nursing Homes

"Staffing levels in nursing homes have been traditionally low and these are considered to affect quality of care directly."

— Charlene Harrington, Ph.D., R.N., F.A.A.P. (1995)

Consumers and caregivers agree that staffing is a critical element of high quality care — in both institutional and community-based care. Inadequate staffing results in poor care for the consumer and injury and stress for the caregiver.

"I'm responsible for the care of more than fifty frail elderly and disabled people daily. Every year that there have been budget cuts, we've seen staff reductions... it's amounted to a speed-up of our work." — Ellen Helferd, caregiver in adult day care Alzheimers program

On average, nursing homes have one nurse's aide for every twelve consumers (Harrington); there are generally more staff on the day shift and fewer staff working during nights, weekends, and holidays. The National Citizens Coalition for Nursing Home Reform recommends a minimum of one caregiver for every five consumers on the day shift; a 1:10 ratio for the evening shift and a 1:15 ratio for the overnight shift — but recommends higher staffing ratios to reflect the acuity of care needs.

The Nursing Home Reform Act of 1987 states there should be "sufficient" staffing to promote the highest level of functioning, avoid the misuse of medications and restraints, and assure individual rights of privacy and personal choice — but it does not specify minimum staffing levels. Yet, nursing home caregivers routinely work "short-staffed;" they are directed to care for more consumers than is reasonable. Without minimum enforceable staffing standards, consumers may not always get the care they need, even as caregivers work as fast as they can.

Staffing Problems in Home Care

"When we're at somebody's house for an hour to give them a bath, we have to take the time to chart at the end, because they won't pay us for that."

— Connie Williams, home caregiver

Home caregivers and consumers also feel the brunt of inadequate staffing. Often caregivers are presented with a care plan that takes more time than the amount allotted to be in that consumer's home. In many cases, caregivers "work off the clock" — that is, work beyond the amount of time they are paid for — in order to provide the care consumers need.

"I know women who've gone a whole weekend without any care. They go home from the hospital quicker and sicker... and they're left all weekend because they can't <find> staff."

— Merla Carlson, consumer advocate

"There is no system set up <for caregivers> to take time off. One time... the substitute <I hired> didn't show up for the evening shift... My client didn't get dinner or medication, and her potty chair was not changed. I was out \$25 and my client was lucky she survived." — Barbara Coleman, home caregiver

For consumers and their families, one of the most difficult problems is finding a caregiver. Consumers often go without care because they cannot find an appropriate person. In some instances, home care agencies do not identify substitutes when caregivers are sick, or need a day off — leaving caregivers to find their own substitute. Clearly, quality of care is undermined through such haphazard arrangements.

Short Staffing Leads to Patient Care Problems

"We are robbing the residents of their dignity, we do not have time to give them what they deserve. The people are going unturned; sometimes they're not fed; we can't do for them like we'd want to because we don't have the help we need." — Mattie Beach, nursing home caregiver

"It is really disturbing to me as a nurse to try to feed somebody a bowl of oatmeal that has been sitting there for a long time... I think of my parents and me—when we get there, what will there be for us? Will I have to look forward to that cold oatmeal too?" — Lynn Feierstein, LPN

In short-staffed nursing homes, regular visits to the bathroom, timely help with eating a full meal, range of motion exercises and walks to prevent muscle atrophy, even conversation — are all time-consuming and thus, may fall by the wayside. Forced to "care faster," caregivers can achieve only sub-minimal standards of care, putting at risk consumers' physical capacity and mental well-being.

Such inadequate care can lead to loss of bladder control, from not being toileted often enough; loss of mobility, for lack of assistance in walking and other movement; insufficient nutrition and hydration, due to a lack of timely assistance with eating and drinking; and a deterioration of mental well-being because of a lack of much needed personal interaction.

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The High Cost of Short Staffing

"If we did have adequate staffing... I truly believe we would save them tremendous amounts of money in acute hospitalizations for bedsores, for instance. If you had patients who needed to be turned on a regular basis, if there was the staff to turn them, to feed them, to hydrate them, to keep them healthy, you wouldn't have people going into the hospital for bedsores or dehydration." — Kim Kelly, nursing home caregiver

If caregivers are given sufficient time to care well, that improves the quality of life for consumers and also saves the system money by reducing levels of preventable incontinence, preventable bedsores, and preventable falls (NCCNHR, 1995a). Avoiding even one costly hospital stay per year, per nursing home, can save enough money to cover the cost of one or more additional caregiving staff.

Health and Safety Problems for Caregivers and Consumers

Working conditions in nursing homes are among the most hazardous of all industries. Working in a nursing home is more dangerous than working in a coal mine, a steel mill, a warehouse, or a paper mill (SEIU, 1994). Occupational illness and injury rates for nursing home workers increased 55 percent between 1983 and 1993, with greater than 200,000 injuries reported each year; the number of lost workdays almost doubled over the same period of time (SEIU, 1994).

"I have a bad back from years of doing what I do. It's not fixable. The rate of turnover is common among CNAs because of back problems and other related body problems such as knees, feet and shoulders, from lifting." — Arlene Cooper, nursing home caregiver

Back injuries caused by lifting patients without appropriate help are the most common injury (SEIU, 1994). Nursing home caregivers routinely lift consumers from bed to chair, from chair to toilet, from toilet to bath, and from bath back to chair. Two caregivers are needed in such transfers, but staff shortages often prevent

"You get hit; you get called names... if a resident has a behavior problem, that takes time." — Tee Martin, nursing home caregiver

Workers also are subject to violent behavior. Nursing and personal care facilities have a high incidence of workplace violence — 47 cases of violence for every 10,000 workers, compared with an average of three of every 10,000 workers overall (Reich). Caregivers need enough time to address resentful consumers who may turn to violence. Caregivers may need to spend time listening, in order to address consumers' concerns and stem the violent behavior. If time is not available, there may be no chance for the physical abuse to abate.

Home care workers are exposed to similar, and additional dangers — including physical and verbal assault, sexual assault, traveling alone through dangerous neighborhoods, and working in homes where furnaces, electrical systems and smoke alarms may not always be maintained, or utilities and telephones might be shut off.

Consumers too are sometimes in a vulnerable position with little ability to hold caregivers accountable for unacceptable behavior.

Such inappropriate behavior can be reduced through employer screening at hiring; providing training programs in sensitivity and conflict resolution; reducing rates of turnover; and matching consumers and caregivers appropriately.

Participating In Decision-Making

"How much of their freedom we take away is a real issue. How do we assure some consumer choice for a population that is actually losing a lot of their capacity to choose? ... One of the ways to do that is working with the family... ensuring freedom for our patients, our consumers, is the real issue here." — Carla Hale, nursing home caregiver

this. Caregivers and consumers are at greater risk of injury when a caregiver transfers someone alone. Typically, the caregiver injures their back while the consumer who falls might break a bone. More research is needed to find the best ways to minimize injury rates, but minimum staffing levels may be the most important protection.

Caregivers also are exposed to consumers' illnesses, and vice versa. Many caregivers lack health insurance or sick leave, and so they work while sick, which may put consumers at unnecessary risk of infection. Caregivers complain about being exposed to infectious conditions on the job — including tuberculosis and scabies — without even being informed.

Older Women's League

"I instructed them that that particular resident should not be moved into the same room because ... she becomes combative. But, as usual, they didn't listen; they put her in there, and she came up with bruises. Eventually they did move her, but look at what she had to go through. And all they had to do was just listen." — Mildred Worthy, nursing home caregiver

Caregivers are plagued with powerlessness in their efforts to provide consumers with the highest quality of care; "the nurse's aide, personal care worker or homemaker often has great responsibilities without commensurate authority" (Kane). Consumers and family members also often feel powerless in their efforts to win changes that will improve the quality of care.

"My dad's been in a nursing home for six years; he has Alzheimer's. There's no input when a family has an idea about something. It may be a simple idea like a high toilet seat, or ... a little cup, so he can hold a cup in his hand When I have a problem, I go to the

administration and they do not listen."

— Audrey Bea, family member, Minnesota Senior Federation

"I don't like to hear that the county will somehow send to the worker what I'm supposed to be doing in my life. I need to make some decisions." — Ed Roberts, home care consumer, and President of the World Institute on Disability (deceased, 1995).

Caregivers and consumers alike express frustration that care plans and other day-to-day care decisions are made without their input. Case managers in home care agencies and nursing homes often write care plans that are more responsive to controlling costs than to the consumer's needs. Case managers who develop plans of care for consumers rarely talk with the

caregivers who actually provide the care; consumers also feel excluded from the process (Yee). Home caregivers note that case managers often visit consumers when the caregiver isn't even there. Ignoring the input of caregivers devalues home care aides and adds to their feeling of isolation on the job.

"We're not supposed to have a relationship with the family. We're not supposed to tell them anything." — Mary Webb, nursing home caregiver

"If I were to go to the Director and say this is going on and you go as a single entity, they say, 'that's funny, no one else is having that problem.' If you have a family council, use it because as a group, you have power. But, as a single person, like these girls <caregivers>, they don't listen to you." — Raelene Nowak, Consumer Advocate

Consumers, caregivers and families have a joint interest in achieving the employment conditions that promote the highest quality of care. Too often, administrators lack sufficient funds or are unwilling to implement reforms that would improve deficient conditions.

"There's a need for the worker and the person with a disability, or their family, to work together — never take the power away from that relationship." — Ed Roberts, home care consumer, and President of the World Institute on Disability (deceased, 1995).

"The workers are going to have to not be afraid to relate what is taking place with the residents in the facility." — John Floyd, Alzheimers Association

Caregivers and consumers can work effectively together if they have the power to make needed changes to improve the quality of care. Winning consumer protections and caregiver employment protections together promote high quality care.

Workers, Consumers, and Families Organizing Together for High Quality

Family members and caregivers working together can achieve quality victories which neither could achieve alone. For example, in one Pennsylvania nursing home, family members and caregivers organized together to overturn administrative limits on family visiting hours; those limits had applied only to certain families. In an Alabama nursing home, the former head of the family council, who had been unsuccessful for years in winning corrections of serious quality problems, organized with caregivers to issue a report documenting quality problems. And, in another nursing home, family members and caregivers, unsuccessful for over a year in convincing the administration to fix the problem of no hot water, won hot water after they circulated a petition among family members and caregivers, and presented it to the press.

Families, consumers and caregivers also have had success fighting for improvements through the state legislature, including minimum staffing levels and increased reimbursements targeted to caregiver wages. Caregivers have won collective bargaining agreements that promote high quality care through mechanisms such as: the establishment of a joint labor/management patient care committee and a patient care representative to work on patient care issues; infection control measures; staffing levels that promote quality patient care and minimize worker injuries; and protection against retaliation for caregivers who report quality problems.

"We should sit in on care conferences because we know more about the resident. They leave us out all the time. I'll say, well you could do it this way, and it would work, but they still don't do it that way."

**Mary Webb,
nursing home caregiver**

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Education and Training

"The preponderance <of the evidence> shows that one approach to improving quality is to improve the number and skill mix of the personnel providing care."

— Charlene Harrington, Ph.D., R.N., F.A.A.N.

"Eighty hours <of training> is not enough for anybody to take a job caring for people We should learn all that we possibly can. We should upgrade this industry. . . . It might be you and I that needs this service."

— Carrie Bradford, nursing home caregiver

Despite the range of duties they are asked to perform, and the increasingly complex medical needs of the clients they provide care for, caregivers in homes, communities and nursing homes do not receive substantial training.

The Nursing Home Reform Act of 1987 requires nursing home workers to complete a 75-hour course and exam to become certified nurse assistants. Some states have greater training requirements.

Many home care workers receive no training whatsoever. Training requirements vary state-by-state and even county-by-county, and also by the type of health care program and source of funding (Yee, citing Cupitman, et al). Where training is required, home care workers often begin work before training is completed. (Yee, citing Sadowsky).

There is great range in the types of home care provided. Some home caregivers provide personal care services for people needing modest levels of help; others provide skilled nursing care services for people who are homebound; and still others offer complex "high-tech" care for high-risk infants, people with cancer, people with HIV, etc.

A 1995 survey of home care agencies found that more than half of the aides in their area were being assigned to non-traditional tasks. To meet the more medically complex needs of managed care consumers who are receiving care at home or in a nursing home, and of the growing ranks of the oldest-old, appropriate training is of paramount importance.

1987 Nursing Home Reform Act: Consumer Protections

The OBRA 1987 Nursing Home Reform law put in place a range of important quality requirements. Among other reforms, the Nursing Home Reform Act provides:

- Patient rights, including: immediate access to a long-term care ombudsman, family members and physicians; the freedom to express grievances and a right to timely response; the ability to participate in resident/family councils; notice regarding transfer and discharge; restrictions against the use of chemical or physical restraints; free choice of providers; privacy, confidentiality, accommodation of needs, and access to information about Medicare and Medicaid eligibility and benefits.
- Limited staffing protections, including the presence of a licensed nurse 24 hours/day, this must be an R.N. for at least 8 hours a day, with some exceptions; and round-the-clock staffing "sufficient" to allow residents to maintain their functional capacity;
- Minimum training requirements: 75 hours of training for nurse aides plus additional in-service education; employee training history and competency evaluations must be documented, and incidents of abuse or neglect must be included in a state registry;
- Initial and annual assessments of consumers to determine their individual needs and capabilities, to develop a plan of care to "attain or maintain the highest practicable physical, mental and psycho social well-being of each resident," and prevent deterioration of a consumer's condition, unless it is clinically "unavoidable."

Nursing Home Quality Requirements

The OBRA 1987 Nursing Home Reform law put in place a range of important quality requirements. Studies show quality improvements brought about by the law. One study of 4,000 nursing home residents found that high-cost hospitalizations dropped by 25 percent (amounting to \$2 billion in savings to Medicare); a 50% drop in dehydration; a decline in the use of restraints and urinary catheters; and a two percent drop in people with bedsores (NCCNHR, 1995a).

Other studies have shown that curtailing chemical restraints, which was required by the Nursing Home Reform law, resulted in increased independence, 80 percent fewer falls, increased activities, increased weight gain, and decreased problems with bowel

or bladder incontinence (NCCNHR, 1995).

Despite the vast improvements won as a result of passage of the Nursing Home Reform Act of 1987, serious quality problems remain. An investigation by *Consumer Reports* found 40 percent of nursing homes certified by the Health Care Financing Administration have had repeated vio-

"In reality, you go to the nursing home that has the space, whether it's the best one in town or the worst one in town. The discharge planner places you in the very first bed she can locate."

Theresa Johnson, Older Women's League

lations over a recent four year period; demonstrating a need for better enforcement.

Older Women's League

Reimbursement Levels and Caregiver Wages and Benefits

Wage and benefit levels are a function of Medicare and Medicaid payment levels, as these two programs pay for the majority of long term care. Decent pay rates and other employment benefits can improve the stability of the workforce. Nursing home payments average more than \$30,000 per year, per consumer (NCCNHR, 1995b). Approximately half of these expenses go toward nurse assistant wages and benefits. Home care visits cost about \$50 each in 1995 (NAHC); wages and benefits account for about 70 to 90 percent of home care costs. (NAHC and Doty, et al)

According to the Health Care Financing Administration, approximately 65% of long term care costs are paid by Medicare, Medicaid, or other public programs; the rest is paid either out of pocket by individuals or by private insurers (HCIA). For two-thirds of nursing home residents, Medicaid is the primary payer (HCIA).

"Low reimbursement rates make it impossible to properly compensate home care paraprofessionals." — Halamandaris and Arrindell

"Many of the ladies <caregivers> are working two jobs in order to get the minimum things they need for their family." — John Floyd, Alzheimers Association of Southeast Michigan

For all they give, our nation's paid caregivers get very little in return. "Overworked and underpaid" is an apt description of the caregiving profession in America. On average, nursing home workers earned about \$6.50 per hour in 1995 — certified nurse assistants earned \$6.50; uncertified workers earned \$6.36 (Hospital and Health Care Compensation Service). Average pay for home

Home Care Quality Requirements

Generally, home care services are unregulated or poorly regulated. Agencies certified to provide services through Medicare must meet certain training requirements, but quality and content of training vary widely. The quality of home care paid for by Medicaid may be monitored by varying state or county rules. The lack of a home caregiver registry, like the nursing home registry, may set up consumers for potential abuse and/or neglect.

health aides in 1995 was \$7.25 per hour; average pay for home care aides providing personal care services was \$5.70 per hour (Hospital and Health Care Compensation Service). Considering that home care workers generally are not paid for their transportation time from one home to the next, and that many spend more time with their clients than they are paid for, the actual hourly pay for home caregivers is meager. Seventy percent of home care workers are not even given full time schedules (NAHC) adding to the insecurity of their paycheck amount.

"Nursing home workers — I believe we receive the lowest wages I know janitors receive more. I've even seen people at McDonald's get more for flipping burgers. We're working with people's mothers and fathers, sisters and brothers, and we're getting less pay. It seems like every other job in this nation is paid better than people who take care of people...Good workers are walking away to work with automotive parts and machines; and what is this leaving for human beings? The love in our hearts for people is one of the greatest things on earth, but you also need benefits; you need money to keep yourself going on." — Betty Davis, nursing home caregiver

CHARTS

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9A

Poor wages and benefits make it difficult for paid caregivers to care for themselves properly, which limits their ability to care for others. Low pay forces many to work two jobs, and even then, many scrape by. Home caregivers often lack sick pay — so they either work sick, or lose pay. According to the 1996 Institute on Medicine report, "Clearly, the combination of low average wages and benefits contributes to high turnover and poor quality care."

"I have a four-year-old that is a sickle cell patient. I am concerned about just having the medical <insurance> for him The health benefits . . . <cost> way

more than I can afford to put my other two children on and my husband on, because of the low wages. The companies are making more money, but they're giving us less." — Carla Hale, caregiver

"You're a very important part of my life and I want you to get the kind of money

you deserve, and you should get benefits as well. The fact that you have no health care benefits and if you get sick what happens to me? I'm up the creek." — Ed Roberts, home care consumer and President, World Institute on Disability (deceased, 1995)

A recent survey of 5,000 Illinois home care workers revealed that only one in ten received health insurance through their job; two-thirds reported going without needed medical care. Eight in ten had never had a paid vacation or holiday; two-thirds lose pay for time off, and more than two-thirds reported not having enough to eat by the end of their paycheck.

hours. Only about 15% of home care workers and 20% of nursing home workers have pension coverage. (Crown) Many home care workers do not receive sick pay or vacation pay.

"We have what's called the rotating door syndrome; come in and go out,

come in and go out." — Marsha Valtakis, caregiver

"I don't want another attendant in six months. I've just been through six months of getting to know you and to learn about what your needs are so you can learn about what my needs are. And that relationship for many of us, is the key relationship in our lives." — Ed Roberts, home care consumer and President, World Institute on Disability (deceased, 1995).

Given the poor employment conditions, it is difficult to attract and retain caregivers; turnover rates are inordinately high. On average, the turnover rate among caregivers in nursing homes is more than 100% per year. (IOM) Turnover among home caregivers who work for private agencies is estimated at 12% (Feldman, citing Marion Merrill Dow) but turnover among home caregivers working for public agencies is much higher (SEIU, 1996); wages are significantly lower for home caregivers in public agencies (SEIU, 1996).

High turnover undermines the continuity of care so important in assuring high quality. Caregivers are less familiar with consumers' needs and desires, and less able to recognize medically important changes in behavior or routine.

9B

Recommendations

Adequate Staffing:

- Nursing homes should be required to provide staffing that averages at minimum, one caregiver for every eight residents; this standard should be adjusted to ensure additional staffing to meet the higher acuity care needs of consumers.
- Each locality should have a centralized registry of available and qualified home care workers, so that workers, families and agencies can find one another more easily.
- Home care agencies should assure that care plans and assigned hours are consistent, so that caregivers have time to provide needed care.

Health and Safety:

- The Occupational Safety and Health Administration (OSHA) should develop and implement workplace standards that would be effective in reducing or eliminating the incidence of workplace injury. In addition to OSHA requirements, employers should further minimize or eliminate potential hazards for caregivers and consumers alike.

Consumer Protections:

- The Nursing Home Reform Act of 1987 must be kept in place, with funding levels that make compliance possible
- Assure that consumers, families and workers are empowered to participate in care planning and to work with administrators to improve quality.

Education and Training for Caregivers:

- Federal requirements for caregiver training must be improved, to meet the increasing care needs of consumers, including people with disabilities, older people, and managed care consumers. Employers should be required to pay for continuous education and training appropriate to the type of care that caregivers are asked to provide.

Reimbursement Levels Adequate to Cover Improved Staffing and Better Wages and Benefits:

- Federal funding for long term care must be sufficient to assure everyone access to care and to promote the level of high-quality long-term care that our society values.
- Reimbursements must be used efficiently, and translate into the working conditions and quality improvements that allow caregivers to provide high-quality care.

FUTURE — IMPACT OF PROPOSED CUTS IN MEDICAID AND MEDICARE

Substantial cuts in Medicaid and Medicare would have a dramatic impact on care for the elderly and chronically ill. Medicaid cuts would threaten eligibility and quality in nursing home care and home care. Cuts in Medicare long term care spending would affect beneficiaries who are homebound; imposing prospective payment for Medicare home care could undermine quality and access to care. Studies have linked prospective payment systems to staffing reductions (Harrington, citing Dubay). And, past cost containment measures have already taken a toll on the quality of care in some nursing homes providing care for Medicaid patients.

The state-by-state data in this report offers a graphic depiction of the kind of impact that sharp cuts in public long term care funding can have on the quality care. As presented here, if the Medicaid

cuts passed by Congress in 1995 had been signed into law, that could have reduced staffing ratios in nursing homes from the current ratio of 1:12 to an overwhelming 1:15 ratio by the year 2002. This analysis was based on an assumption that spending cuts would be targeted to provider payment rates.

If we are to assure the level of quality of care that our society values, we cannot cut funding for long term care. Adequate long term care financing is critical to assuring Americans access to the high quality long term care everyone deserves. Further, consumers, families and caregivers must be empowered to work together to assure that long term care funding levels are used efficiently to provide the highest quality care possible.

"Our work together will change the system. We'll make it better for you and for me." — Ed Roberts, home care consumer and President, World Institute on Disability (deceased, 1995)

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Potential Impact of Medigrant Funding Cuts on Staffing Ratios in Nursing Homes

<u>State:</u>	<u>Current Policy:</u> Nurse Aide to Consumer Staffing Ratios 1995	<u>Had Medigrant Been Enacted:</u> Nurse Aide to Consumer Staffing Ratios 2002
Alabama	1:10	1:13
Alaska	1:8	1:10
Arizona	1:10	1:12
Arkansas	1:13	1:18
California	1:11	1:14
Colorado	1:12	1:15
Connecticut	1:13	1:14
Delaware	1:10	1:12
Dis't of Col.	1:10	1:11
Florida	1:12	1:16
Georgia	1:12	1:16
Hawaii	1:11	1:13
Idaho	1:10	1:13
Illinois	1:13	1:17
Indiana	1:13	1:17
Iowa	1:13	1:20
Kansas	1:13	1:14
Kentucky	1:10	1:14
Louisiana	insufficient data	Insufficient data
Maine	1:9	1:12
Maryland	1:11	1:14
Massachusetts	1:11	1:13
Michigan	1:10	1:13
Minnesota	1:13	1:15
Mississippi	1:10	1:14
Missouri	1:11	1:12
Montana	1:10	1:14
Nebraska	1:13	1:16
Nevada	1:13	1:15
New Hampshire	1:11	1:11
New Jersey	1:11	1:13
New Mexico	1:11	1:16
New York	1:12	1:14
North Carolina	1:11	1:14
North Dakota	1:11	1:13
Ohio	1:11	1:14
Oklahoma	1:13	1:16
Oregon	1:10	1:12
Pennsylvania	1:12	1:14
Rhode Island	1:11	1:16
South Carolina	1:11	1:13
South Dakota	1:13	1:16
Tennessee	1:13	1:18
Texas	1:12	1:15
Utah	1:11	1:14
Vermont	1:13	1:18
Virginia	1:12	1:14
Washington	1:11	1:14
West Virginia	1:11	1:16
Wisconsin	1:11	1:14
Wyoming	1:11	1:14
United States	1:12	1:15

Methodology

If Medicaid cuts were implemented to reflect 1995 Medigrant, those cuts would have reduced quality of care, prevented some people from getting needed care at all, or both. This methodology assumes that Medigrant funding cuts in the area of nursing-home spending would affect provider pay rates, but not access. Thus, this analysis presents the potential impact of spending cuts on staffing ratios.

To generate the potential staffing ratios that could result from such provider pay cuts, the following steps produced our baseline. We started with state-by-state nurse aide hours per resident (Harrington) and, using state data for median number of beds and occupancy rates, calculated for each state the number of nurse assistant full-time equivalent caregiver staff in a median nursing home. We converted this to an average nurse aide staff ratio (baseline). We assumed this current staffing ratio would remain the same by 2002, absent change in policy.

To calculate the change in staffing ratio, we started with the number of full-time equivalent caregivers who would no longer be working if Medigrant cuts were enacted. We began with each state's percentage cuts to the Medicaid program in each year 1996-2002. Assuming that all Medicaid sectors would be reduced by the same percentage amount, and that cuts in the nursing home sector would be entirely rate cuts, no eligibility cuts, a new per diem pay rate was calculated. This was converted to average loss per facility, adjusted to reflect 66% of beds as Medicaid beds. Taking 46% of this amount, to reflect the proportion of facility budgets spent on caregiver staffing, we divide the losses by the average salary for caregivers in each state, to get the number of full-time equivalent nurse aides who would be lost. Those FTEs were converted into losses in terms of nurse aide staff ratios.

Note: For DC, HI, ME, RI, UT and WY, we lacked data for average CNA salary. In these states, we used the national average reduction in caregiver staffing to calculate the new ratio of nurse aides per resident.