

Women and Long-Term Care:
*Where Will I Live,
and Who Will Take Care of Me?*



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A Message from OWL's President

Happy Mother's Day!

EVERY YEAR, OWL WELCOMES Mother's Day as an opportunity to direct attention to issues of great concern to midlife and older women. Few issues fit this description better than long-term care, which shapes the lives of women in so many ways.

The U.S. long-term care system brings together three of OWL's core constituencies: long-term care recipients; their family members and friends, who provide informal caregiving services; and direct-care workers, who provide paid services in communities and long-term care facilities. A majority of each of these groups is women. Clearly, despite increasing participation by men in the work of providing care, long-term care remains a women's issue.

Recent research on the state of long-term care in the United States tells a startling story about a crisis that must not be allowed to worsen over the coming decades. According to a report on frail older adults by the Urban Institute's Retirement Project:

- "Only 53.1 percent of frail older people living alone received regular care in 2002. On average, older women with serious disabilities received 63 hours less care per month than their male counterparts...."
- "About 7 out of every 10 adult children who help their frail older parents are female. Daughters represent an even larger share of children serving as primary [activities of daily living] caregivers. Only about one in six primary caregivers are sons. Even among primary helpers with household chores and errands, daughters outnumber sons by nearly two-to-one."

- "[F]rail older women are less likely than frail older men to receive care from spouses because women are much more likely to be widowed."

The plight of direct-care workers in the long-term care system is equally serious. According to the National Clearinghouse on the Direct Care Workforce, direct-care workers are far more likely than the average American worker to live in poverty.

For this year's report, OWL brings together a panel of friends and allies—national organizations that, like OWL, represent key stakeholders in the panorama of long-term care. The report serves as a written plenary session on the barriers to successful, high-quality care for recipients and their care providers. OWL, in the role of moderator, will respond to these issue briefs with an overview of how each area affects the lives of midlife and older women. Policy recommendations are included as a path to enhancing the long-term care experience for all women involved.

As always, we also present the stories of real women and their experiences with long-term care. These women represent the millions of midlife and older women across the country who deserve our utmost respect this Mother's Day. OWL is honored to dedicate this report to them.



Marilyn Z. Robinson
President, OWL
May 2006

Executive Summary

LONG-TERM CARE IS A WOMEN'S issue. The long-term care system—encompassing a range of services, settings, and programs—could not function without the contributions of millions of women who serve as primary formal and informal caregivers. It is also a family issue, with many families paying a high price—in money, time, and sometimes careers—to ensure their loved one's needs are met.

Research reveals that the need for long-term care is reaching crisis proportions. By 2030, one out of five people in the United States will be 65 or older. Those 85 or older are the fastest-growing segment of the population. As more and more elderly people become disabled and need long-term care, consumers, providers, and policymakers must confront the challenge of financing such care and ensuring its quality.

This report brings together five organizations that represent key stakeholders in the realm of long-term care. Through their voices, we learn about the dimensions of long-term care and about forward-looking policy recommendations that address the needs of our aging population. The report examines these issues across the landscape of service settings—home and community-based care, assisted living, and nursing homes—and through the personal stories of women whose lives have been shaped by the experience of long-term care.

Informal Caregiving—Tradition Is the Norm

- Informal caregiving by family and friends is the primary source of long-term care, providing 80 percent of the help needed. An estimated 44.4 million family caregivers over the age of 18 are providing care.
- While the older adult and society at large benefit from informal care, the caregiver is more than twice as likely to live in poverty and five times more likely to rely on Supplemental Security Income (SSI).

- Data on family caregiving between 1984 and 1999 indicates a drop in the use of formal services and an increased reliance on informal care. During that same time period, the proportion of elders with a disability who received only informal care increased from 57 percent to 66 percent.
- Older caregivers are most likely to be providing care for a spouse. Most are women, and most are over 75. Research shows that these older spousal caregivers are at increased risk of developing health problems themselves.
- Younger informal caregivers often face significant challenges related to their employment. Most report having to make work accommodations to manage their caregiving responsibilities, and as many as nine percent report having to leave their jobs completely.

Aging in Place—At Home and in the Community

The overwhelming preference of older and disabled adults is to remain in their homes and communities, maintaining independence, and aging with dignity without having to enter a long-term care institution.

- Thanks to the Aging Network, funded under the Older Americans Act, a well-established, cost-effective, and responsive system of home and community-based services is in place to provide supports for independent living.
- The Aging Network assists more than 8 million older adults and more than 660,000 caregivers every year in the U.S.; eighty percent of adults 65 and older with long-term care needs receive care and assistance at home and in the community.
- Despite these achievements, funding for institutional care far outweighs resources available for home and community-based services. Funding levels have generally failed to keep pace with inflation and the growing elder population.

- Medicaid offers nursing home care as a basic service, but states face a burdensome waiver process to fund home and community-based care.
- Housing security and safe, reliable, and convenient transportation are critical factors in ensuring that the home and community-based services system can guarantee readily available services.

Assisted Living—Meeting Individual Needs

- Assisted living has emerged over the last 20 years as an important and popular residential care option, allowing individuals to receive care in a manner that—ideally—promotes dignity, autonomy, independence, and quality of life.
- About two-thirds of the 80,000 people living in assisted care residences nationwide are women.
- However, rising costs and lack of public subsidies make this alternative unaffordable for most people with low or moderate incomes. Costs have increased 15 percent in the past year; the average base price of an assisted living unit is now \$2,905 monthly.
- Unlike nursing homes, assisted living facilities are not subject to federal regulation or uniform standards. States vary in regulatory requirements, enforcement, oversight, and inspections. As a result, quality-of-care issues have arisen relating to inadequately trained or insufficient staff, medication errors, and resident abuse.
- High turnover—resulting in unmanageable workload demands on existing staff—is associated with poor resident outcomes. Compounding this problem is the concern that many assisted living workers are midlife and older women who will be hard to replace in the future.
- Care management is another critical component of quality care in assisted living. Coordination among health professionals, consumer understanding of services, and effective

management of medication are major concerns.

Nursing Homes—When Institutional Care Is Unavoidable

- A 65-year-old woman alive today can expect to live another 19.5 years, with the increasing chance that she develop a chronic condition and a physical or cognitive disability.
- The reality is that 40 percent of women will need facility-provided care at least once in their lifetime. Often that care can be provided only in a facility with appropriate medical and social services.
- Nursing home care costs at least \$192 a day (in 2006 dollars) with an average length of stay of two and a half years.
- Nursing homes account for three-fourths of all long-term care spending—more than \$111 billion a year—with Medicaid funding 45 percent and Medicare 12 percent. Twenty-eight percent comes out of the pockets of individual residents and care takers.
- Lack of quality care is a major barrier. Nursing home care is inconsistent and, in some cases, unsafe. More than 90 percent of nursing home facilities lack nursing staff necessary to provide 4.1 hours of basic nursing care per resident each day.
- Workers are paid an average of \$9.96 an hour, contributing to turnover rates ranging from 40 to 300 percent. As a result, residents often do not know from day to day who will be providing their care.
- Public policies are needed to protect nursing home residents from harm and ensure that their rights are upheld, including access to an adequately-funded ombudsman program and reliable information to help them make important decisions about long-term care.
- Also needed is a long-term care financing system that honors the caregiving roles of women and benefits to unqualified providers.

- National policies should be developed to compensate informal caregivers financially—through paid family and medical leave, tax credits, and Social Security credits, for example—and identify and provide support services for both the caregiver and the recipient.
- Who Are the Long-Term Care Workers?*
- Women make up the overwhelming majority of long-term care workers. About half of long-term care workers are people of color and most are in their early forties.
 - Individuals often receive a mix of paid and unpaid care over time. The direct-care worker is generally the lowest paid of all health service support workers. A personal care worker employed by a home health agency earns an average of \$8.18 per hour (though few can find full-time work) and a certified nurse assistant earns about \$10 per hour.
 - Direct-care workers leave their positions in droves and the ones who stay often live in poverty. More than one-quarter live below the federal poverty line and are more likely than other workers to lack health insurance and rely on public benefits to supplement their wages.
 - The direct-care workforce is characterized by chronic shortages and high turnover rates. Serious shortages have been reported in 35 states.
 - At the same time, demand is soaring for personal care providers. An estimated 5 million direct-care workers will be needed by the year 2030. However, the shrinking number of women between the ages of 25 and 40, their higher levels of educational achievement, and economic opportunities available elsewhere are creating a serious “care gap.”

Informal Caregiving

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IN THE UNITED STATES TODAY, informal caregivers—family and friends—are the primary source of long-term care, providing 80 percent of the help needed. According to the NAC/AARP report “Caregiving in the US: Findings of the National Caregiver Survey” (2005)¹, there are an estimated 44.4 million family caregivers over the age of 18. The majority of these caregivers are helping someone over the age of 50, and many are older women.

Women have traditionally made up the majority of the caregiving population; however, an increasing number of men are also providing informal care to a family member. In the 2005 survey, 39 percent of the caregivers were men. Although caregiving has been thought of as a “women’s issue” in the past, it is more accurate to describe it as a “family issue.” Women and men of all ages are care providers or care recipients, or provide support for caregivers and care recipients. This ubiquitous “family issue” is the foundation of our nation’s long-term care system, and many families are paying a high price to make sure that their family member’s needs are met.

In this issue brief, we describe the importance of the informal caregiver to the long-term care “system” in the United States—the issues and obstacles they face in their caregiving activities, their own needs, and recommendations for policy changes.

Family caregiving involves providing and arranging such services as transportation, meal preparation, and, often, personal care. The value of the informal care provided by family caregivers has been estimated at \$257 billion a year.² In addition to the direct contribution of time, almost half the family caregivers surveyed in the 2005 NAC/AARP study reported that they were helping the care

recipient financially, with an average of \$200 per month. This investment of time and money benefits the older adult; however, it is also an investment that benefits society in long-term care cost savings.

🌿 Caregiving for an older parent increases the risk of living in poverty and relying on Supplemental Security Income (SSI) for income.

For women, the cost of caregiving over time can be a serious issue. For example, Wakabayashi & Donato (2004)³ found that caregiving for an older parent increases the risk of living in poverty and relying on Supplemental Security Income (SSI) for income; their data showed that women who were caregivers were more than twice as likely to live in poverty and five times more likely to receive SSI than were non-caregivers.


In a recent analysis of National Long-Term Care Survey data, Spillman & Black (2005)⁴ identified some troubling family caregiving trends. In looking at the data on family caregiving between 1984 and 1999, the researchers found a drop in the use of formal service, compensated for by an increased reliance on informal care and the use of assistive devices. Between 1994 and 1999, the proportion of community-residing elders with a disability who used any formal services fell from 43 percent to 34 percent. During this same time period, the proportion of elders who were receiving *only*

informal care increased from 57 percent to 66 percent. Family caregivers were also more likely to be caring for someone over the age of 85, and more than half of spousal caregivers were age 75 or older.

Older caregivers are most likely to be providing care to a spouse, and most of the spousal caregivers are women. Research has consistently shown that older spousal caregivers are at risk of health problems themselves. Although many adult children who care for parents report high stress levels and increased incidence of illness as a result of their caregiving responsibilities, the older spouse who is caring for a husband or wife is at the greatest risk of adverse outcomes. Caring for a spouse is related to increased risk of depression, illness, and even death, as illustrated by a recent study that found the hospitalization of a spouse increased the risk of death for the older caregiver (Christakis & Allison, 2006)⁵.

Younger caregivers often face a significant challenge related to their employment. The 2005 NAC/AARP survey found that 59 percent of caregivers were employed. Most of these reported having to make job accommodations to manage their caregiving responsibilities, including modifying work schedules, taking unplanned days off, and coming to work late or leaving early. As many as nine percent of employed caregivers said they have left work completely as a result of caregiving. Another 17 reported having to take a leave of absence to manage care. For women, caregiving can have a profound effect on lifelong earnings. Lost wages lead to lower levels of savings and Social Security benefits, creating a cost for caregivers that can extend for decades beyond the caregiving event.

The average age of an employed caregiver is 47; however, it is just as common to find young employees with care responsibilities for an older family member as it is to find older employees. Employees in their thirties may be caring for a grandparent or other older family member and, in some cases, putting their own career and family plans on hold while doing so.

 *Research has consistently shown that older spousal caregivers are at risk of health problems themselves.*

Despite the personal, professional, and financial adjustments required of caregivers, many report that the experience was emotionally rewarding.

There are many changes, however, that would make caregivers' lives better. One is more help and recognition from formal health care providers. Family caregivers are not trained health care professionals, yet they are often called upon to provide tasks that, according to Susan Reinhart of Rutgers Center for State Health Policy, would make a student nurse tremble."

Caregivers tell us that they need more information about diseases, the aging process, and sources of help and support. They need a supportive boss who doesn't begrudge their caregiving role. They need a respite from caregiving. (This is especially true for the older caregiver who is caring for a spouse or sibling and managing their care 24 hours a day.) And they need a responsive long-term care system that doesn't impoverish the users or their families.

POLICY RECOMMENDATIONS

Provide paid family and medical leave benefits on a national level.

To date, only the State of California offers a paid family and medical leave benefit, though several other states are considering adopting one. Leave provided under the federal Family and Medical Leave Act (FMLA) is unpaid and does not cover all workers.

Offer a caregiver tax credit.

Family caregivers are important to the "health" of our long-term care system and should receive at least a tax credit to cover some caregiving expenses.

Institute a national assessment program for informal caregivers.

Supporting the family and informal caregiver is important to the well-being of American families and the long-term care system generally. Such a program would identify those caregivers who need support and help locate services needed by both the caregiver and the care recipient.

Expand respite care services and increase funding for the National Family Caregivers Support Program (NFCSP).

Grant credit for years missed from work as a result of family caregiving.

Women should not have to choose between retirement security and their family responsibilities. We recommend, as has been suggested in the past, that a specified amount be credited to a worker's Social Security record for each year that worker was unable to work due to caregiving responsibilities.

NOTES

- ¹ National Alliance for Caregiving & AARP, *Caregiving in the U.S.: Findings of the National Caregiver Survey* (2005), Bethesda, MD.
- ² Arno, P., "The informal value of informal caregivers," presented at the American Association for Geriatric Psychiatry (2002), Orlando, FL.
- ³ Wakabayashi, C. & Donato, K., "The consequences of caregiving for economic well-being in women's later life," (2004), Department of Sociology, Rice University, Houston, TX.
- ⁴ Spillman, B. & Black, K., *Staying the Course: Trends in Family Caregiving* (2005), Washington, DC: AARP.
- ⁵ Christakis, N. & Allison, P., "Mortality after the hospitalization of a spouse," *New England Journal of Medicine*, 354:7 (2006), pages 719-730.

Informal Caregiving

Personal Story: Bev

CALL IT TRADITION OR EVEN FAMILY values—it has always been an expectation in Bev’s family that you do what it takes to take care of your parents as they get older. Bev fit into that role very easily. After her step-father died, she moved back to the town where she grew up to help her mother, Kate.

Kate was in her seventies and could no longer take care of the family home alone, physically or financially. Bev and her husband built on an apartment where Kate was able to be independent and enjoy daily visits from her family and friends. Bev’s husband, an RN with long-term care experience, was able to attend to Kate’s health issues. She managed her own finances, did her own laundry, cooked her meals and drove her own car. Each week she would prepare one meal for the entire family.

Then, after more than ten years, everything changed. Kate, at age 89, had a stroke while visiting her sister out of town. As Bev and her family rushed 50 miles to the hospital, she knew their lives would change forever. The doctor came out and told Bev that the stroke was severe. Kate’s mind would not realize that her entire left side was paralyzed. While intensive rehabilitation and physical and occupational therapy would help, the prognosis was not good. It was unlikely that Kate would be able to come home to live independently again. As the only surviving child, the entire responsibility for her mother’s well-being fell on Bev. She quickly became Kate’s advocate as well as her caregiver.

For six months, Kate was a skilled nursing/rehab patient at the top-ranked nursing home in Vermont, but her left side did not progress. She could no longer read or do crossword puzzles, and couldn’t see the food on the left side of her meal tray. The care

Kate received at the nursing home’s skilled nursing ward was, to say the least, dismal. She tried to be continent, but time after time she would ring the bell for help only to be told by an aide, “I will be right back.” Repeatedly she was “parked” in hallways with nothing to do but stare. Eyeglasses were left on the nightstand and not put on. Staff called her Katie rather than Kate.

Bev’s patience ran thin. With rehab costing \$30,000 a month and skilled nursing requiring \$11,000 a month, she thought the level of care would be much better. Said Bev, “If this was the best nursing home in the state, what was the worst like?”

Kate was moved from skilled nursing to the regular part of the nursing home where she remains at 92. Despite Bev’s vigilance, severe problems with her care continue. She has suffered a broken leg twice, and Bev routinely finds her with bruises and skin blisters. Bev constantly advocates for better treatment from the staff, but frequent staffing changes force her to start from the beginning to

🔥 Bev explained that she wanted to be able to enjoy the time she has with her mother, and she doesn’t know how much longer that will be.

inform new employees of her expectations for her mother’s care.

It has now been two years since the stroke. Bev feels that her mother’s dignity has been stripped. Kate, who was always neat, clean, and organized

before her stroke, now avoids the dining room because she cannot rely on nursing home staff to tend to help her with soiled pads. Her room, at times, is a mess, with powder in her drinking water, dirty pads exposed in the trash, wipes next to her food tray, and dust on the floors. “My mother wouldn’t live like that!” said Bev.

Every day, Bev works ten hours at her job as a vice president of human resources. She visits her mother at least three days a week. At first, she went every day, but soon became totally exhausted. She started a notebook in which she filled in all care plans, her questions and concerns. She attends care plan meetings every six weeks, taking vacation time to go. The nursing home claims they will follow up with Bev’s concerns, but, with the exception of one wonderful social worker, little has been done.

Then there was Medicare Part D. One week Bev spent over 30 hours on the phone trying to get Kate’s prescription drug coverage arranged.

This past winter, Bev hit bottom. She realized that she had lost balance in her life, that she simply could not be at her mother’s nursing home every day, every hour, and that she needed to take time for herself. At the last care plan meeting, Bev was blunt, telling the nursing home staff that she didn’t like coming in and finding things wrong with each visit. She explained that she wants to be able to enjoy the time she has with her mother, and she doesn’t know how much longer that will be.

Bev continues to wonder—what happens to those who don’t have an advocate for their care? Unfortunately, Bev said, “I think I know by looking up and down the halls and seeing their faces,” Bev said. In her heart, Bev knows “that there is one woman who deserves dignity, respect and the very best advocate—and that is my Mom. She was always there for me when I needed her and now it is my turn to be there for her.”

Home and Community-Based Services

Sandy Markwood, CEO
National Association of Area Agencies on Aging

LONG-TERM CARE IS OFTEN mistakenly thought of as end-of-life care. For many older women, it evokes images of nursing homes or persistent medical conditions that prevent them from caring for themselves or living on their own.

But our vision of long-term care should not be that bleak. The reality for older women is that they will attempt to “age in place”—remaining in their homes and communities for as long as they are able. This is, in fact, what most Americans want.

As older women age, their ability to take care of themselves can decrease. Some need a little bit of help to manage day to day; others need a great deal of help to continue to live independently. Such assistance may consist of a daily or weekly “visit” from a volunteer just to check in and ensure that everything is all right. Or it could be a regularly scheduled ride to medical appointments, a daily home-delivered meal, or assistance with finances, insurance, or legal services. It may also take the form of in-home personal care or home repairs.

Many older women turn to informal or family caregivers to provide assistance with one task or another. While those who are financially able may rely on private providers for support, those who do not have family or friends nearby, or who are without financial means, face major challenges.

The risks of lacking needed support are serious. If an older woman doesn't have the assistance or services she needs, her health and independence are endangered. If she stops cooking, for example, or can no longer get to the doctor's office regularly, her health may decline. If she cannot navigate the stairs in her home, she may be one step closer to institutional care.

THE PHILOSOPHY

Luckily, help isn't far away. In communities across America, there is a system of home and community-based services that can offer older women who need a range of supports to continue living independently and avoid entering a long-term care institution.

🌿 Home and community-based care, which allows individuals to maintain their independence and to age with dignity in the comfort of their own homes, in familiar neighborhoods and communities, is overwhelmingly the preferred choice of older adults, as well as individuals with disabilities.

For the past 40 years, the Aging Network (see below) has provided a broad range of support services to older Americans. Funded through the Older Americans Act, these services (1) promote the health, well-being, and independence of older citizens, and (2) support and complement the work of caregivers through the provision of home health, personal care, homemaker chore services, adult day care, respite care, senior center programs, telephone reassurance, friendly visiting, home repair, and such alternative community living arrangements as adult foster care and assisted living.

However, funding for institutional care in the United States far outweighs the resources directed to home and community-based services, even though studies have shown that older adults prefer to receive care in their homes and that home and community-based services can be provided at about one-fourth the cost of institutional care.

THE INFRASTRUCTURE FOR HOME AND COMMUNITY-BASED SERVICES

Older Americans Act (OAA)

Since its inception in 1965, the Older Americans Act has been the foundation of services for older adults in the United States. The OAA forms the nucleus of our national system of home and community-based services for older Americans. It provides funding to states for a range of community planning and service programs for older Americans at risk of losing their independence. Since its enactment, the OAA has been amended 14 times to expand the scope of services, increase local control and responsibility, and add more protections for the elderly.²

Aging Network

To develop and implement a wide array of home and community-based services, a system of federal, state, and local agencies—known as the Aging Network—was established under the OAA. The core of the Aging Network is the U.S. Administration on Aging (AoA), 56 state and territorial agencies on aging, 650 Area Agencies on Aging (AAAs), 240 Title VI (of the OAA) Native American aging programs, and more than 30,000 service provider organizations. This critical aging infrastructure is the backbone of the U.S. home and community-based long-term care system, offering support to older persons and persons with disabilities.

Each year through the Aging Network, more than 8 million older Americans receive support services and 500,000 families receive assistance vital to their role as caregivers. While most home and community-based services are available to anyone over age 60, service providers try to target those who are most vulnerable, whether because of isolation, poverty, frailty, or cultural barriers.

Community Access Point: AAAs

Area Agencies on Aging serve as a single point of entry for the complex and fragmented range of home and community-based services for older adults and their caregivers. These include congregate and home-delivered meals, other in-home services for the vulnerable seniors (such as personal care and chore services), elder abuse prevention and protection, the nursing home ombudsman program, senior centers, transportation, consumer information, education and counseling, and senior employment. The local AAA either directly manages or coordinates with service providers to offer this wide range of services.

Many AAAs manage or receive funding from a variety of sources in addition to the OAA, including Medicaid waivers for home and community-based care, social service block grants, transportation funds, and state-funded, in-home service programs. AAAs have an extraordinary record of achievement in stretching limited federal resources to help hundreds of thousands of older people avoid costly nursing home placement and remain independent. OAA funds make it possible for AAAs to leverage millions of non-federal dollars from local governments, foundations, the private sector, and participant and volunteer contributions.

The Results

The home and community-based services system is well-established, flexible, responsive, and cost-effective, and meets the needs of more than eight million older adults and more than 660,000 caregivers every year in the United States.³

Take, for example, a 75-year-old widow who can no longer drive because of physical limitations. Public transportation in her community is scarce or inaccessible. If she can no longer get to the grocery store or her doctor's office, her independence and health are at risk. A senior transportation van to get her to the grocery store or to doctor's appointments could make a significant difference in her quality of life.

Another older woman may find it impossible to cook the nutritious meals for herself that she used to provide for her family, and her health may

deteriorate as a result. Connecting her to a senior center where lunch is served daily, or, if she is homebound, arranging for her to receive Meals-on-Wheels, could make a difference in her health and quality of life.

Recent AoA data show how successful Older Americans Act programs and services are in assisting older adults and their caregivers. AoA reports that 86 percent of family caregivers of OAA clients said the services “allowed them to care longer for the elderly than they could have without the services.”⁴ In addition, OAA-provided meals and services have allowed the nearly one-third of elderly clients who have health conditions that make them nursing home-eligible to remain in the community.

The Challenges

Much more needs to be done to meet the home and community-based service needs of all older adults. The Aging Network provides a proven infrastructure and workforce, OAA programs and services offer a tested and true policy foundation, and consumers and government agree that successful aging in place is the ideal.

Yet we face several major challenges that currently prevent the home and community-based long-term care model from serving all older adults who need it now or in the future: inadequate funding, misdirected federal policies, and a lack of attention to other systems (such as housing and transportation) that affect the provision of home and community-based care.

Until the following policy changes are put in place, older adults’ ability to access the home and community-based care they need is in jeopardy.

POLICY RECOMMENDATIONS

Funding Levels for Home and Community-Based Services Must Be Increased Significantly.

Federal funding for OAA programs and services has not kept pace with inflation or the growing population of eligible elders. Add increasing costs for wages, fuel, and food to the equation, and providers are struggling to offer services to all in need. Waiting lists for transportation services or meals delivery or

caregiver respite are common in some areas of the country.

Every seven seconds, another baby boomer turns 60, the age of eligibility for most OAA programs and services. As a new generation of older adults seeks to age in place, communities and the Aging Network must have adequate resources to be able to respond.

Help communities prepare to meet demographic challenges.

The challenge in 2006 and beyond is largely one of demographics. By 2030, one out of every five people in the United States will be 65 or older. Those 85 and older are currently the fastest growing segment of the population, with their numbers increasing at a rate four times faster than that of any other age group.⁵

The OAA should be amended to authorize State Units on Aging, AAAs, and Title VI Native American aging programs to help communities prepare for aging baby boomers. Professional planners might offer the Aging Network’s expertise to help state agencies, city and county elected officials, local government agencies, tribal councils, and private and nonprofit organizations develop policies, programs, and services to foster livable communities for all ages.

Eliminate the institutional bias in Medicaid long-term care policy.

Many federal policies do not recognize that the most cost-effective form of long-term care is provided through home and community-based services. These services are currently available through a fragmented and inconsistent array of federal, state, local, and private support services paid for through public and private financing.

Medicaid, the largest public program financing long-term care, has an inherent bias toward institutionalization. Congress established the home and community-based service waiver in 1981 to attempt to reduce this bias. The Medicaid waiver program gives states the option to apply for waivers to fund home and community-based services for people who meet Medicaid eligibility requirements for nursing home care. A 2000

study by the Assistant Secretary for Planning and Evaluation with the U.S. Department of Health and Human Services found that average spending on the aged and disabled under the Medicaid home and community-based waiver saved money—providing for an individual under the waiver program costs \$485 a month compared to \$2,426 for nursing home care.⁶ Even so, nursing home care remains a basic service under Medicaid, while states still face a burdensome waiver process to offer home and community-based services.

Link affordable housing with needed support services.

Housing security is critical to the health and well-being of older adults. The home and community-based system will not succeed without the provision of affordable and accessible housing for older adults. Greater coordination needs to occur between housing and service providers to guarantee that such support services as meals, personal assistance, and housekeeping, as well as health services, are readily available and easily obtainable. While policy initiatives are underway to increase assisted living facilities stock, convert existing public housing into accessible housing, and provide increased coordination of support and housing services, progress has been slow and more commitment to these efforts by policy-makers is needed.

Develop systems to help older adults retain mobility.

Mobility is essential for an individual to live at home and in the community. Transportation provides necessary access to medical care, shopping for daily essentials, and the ability to participate in cultural, recreational, and religious activities. Feelings of isolation and loss have been reported among older adults who can no longer use personal automobiles. Public policy must focus on the provision of safe, reliable, and convenient alternative means of transportation for those for whom driving is no longer an option, as well as on efforts to help older adults retain their licenses and cars for as long as it is safe for them to do so.

NOTES

¹ U.S. General Accounting Office, “Long-Term Care Insurance: Better Information Critical to Prospective Purchasers.” Statement of William Scanlon, Director, Health Financing and Public Health Issues, Health, Education, and Human Services Division. Testimony Before the U.S. Senate Special Committee on Aging (September 13, 2000), page 4.

² For more information on the history and current implementation of the Older Americans Act, see the U.S. Administration on Aging’s web site: http://www.aoa.gov/about/legbudg/oa/legbudg_oaa.asp.

³ U.S. Administration on Aging. *2004 Annual Report*, page 7. http://www.aoa.gov/about/annual_report/2004_ar.pdf.

⁴ U.S. Administration on Aging, *Final Annual GPRA Performance Plan for Fiscal Year 2005* (February 2004), page 1. http://www.aoa.gov/about/legbudg/performance/legbudg_performance.asp.

⁵ U.S. Census Bureau. <http://www.census.gov>.

⁶ Doty, Pamela, “Cost-Effectiveness of Home and Community-Based Long-Term Care Services.” U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy (June 2000). <http://aspe.hhs.gov/daltcp/reports/costeff.htm>.

Assisted Living

Kathy Cameron, RPh MPH, Chair
Consumer Consortium on Assisted Living

ASSISTED LIVING HAS EMERGED over the past 20 years as an important and popular segment of the long-term care continuum for older adults. As an alternative to nursing home care, assisted living is a residential care option for people who typically can no longer live independently in their own homes. It provides or coordinates services to meet residents' individualized needs in ways that are intended to promote their independence and reflect their personal choices. This long-term care option is significant for midlife and older women because more than two-thirds of assisted living residents are women and are cared for by women.

As a result of an April 2001 hearing held by the U.S. Senate Special Committee on Aging on quality of care in assisted living, committee staff members asked assisted living stakeholders to develop recommendations designed to ensure more consistent quality in assisted living services nationwide. Shortly thereafter, a core group of assisted living stakeholders extended invitations to numerous national organizations, and the Assisted Living Workgroup (ALW) was formed with nearly 50 organizations representing providers, consumers, long-term care and health care professionals, regulators, and accrediting bodies. One of the first tasks of the ALW was to develop a uniform definition of assisted living that would provide consumers with a clear understanding of what kinds of assisted living services they should expect.

Developing a definition is particularly important because states use more than 26 designations to refer to what is commonly known as "assisted living."

The ALW agreed on the following definition:

Assisted living is a state regulated and monitored residential long-term care option. Assisted living provides or coordinates oversight and services to meet the residents' individualized scheduled needs, based on the residents' assessment and service plans and their unscheduled needs as they arise.

The philosophy underlying most assisted living communities is that a resident has the right to make choices and receive services in a manner that promotes dignity, autonomy, independence, and quality of life. These services are disclosed and should be agreed to in the contract between the provider and resident.

Assisted living is designed to respond to the needs of individuals who require assistance with such daily activities as bathing, dressing, and grooming, but who do not need 24-hour skilled nursing care. Some state regulations require a nurse in an assisted living facility, some require round-the-clock nurse availability and some require no nursing staff at all. Service provisions, as agreed to by the majority of ALW participants, must include but are not limited to:

- 24-hour awake staff
- Provision and oversight of personal and supportive services
- Health-related services (e.g., medication management services)
- Social services
- Recreational activities
- Meals
- Housekeeping and laundry
- Transportation

There is no one type of assisted living model or design. The setting could be a high-rise building housing several hundred individuals, or it could be a small group home for just a few. Living accommodations can include a full-size apartment or a single room. In some facilities, services are limited to meal preparation, housekeeping, medication reminders, and minimal assistance. In others, more intensive services, including help with administering medications, on-site nurses, and regular assistance with such daily activities as bathing and dressing are available. This variability makes it difficult for consumers and/or their caregivers to compare facilities and choose the one that best meets their current and future needs.

Several issues of concern related to assisted living have arisen in recent years. This issue brief will address four key issues that are of utmost importance to two groups of women: residents of assisted living services and/or their caregivers, and the direct care workers in assisted living facilities. These issues are:

- Affordability
- Quality, Accountability, and Oversight
- Staffing Retention and Training
- Resident Care and Care Management

Affordability

A recent MetLife Mature Market survey found that assisted living costs increased 15 percent in the past year. Now, the average base price of an assisted living unit is \$2,905 monthly, or \$34,860 annually. Boston, Massachusetts, had the highest average monthly cost, at \$4,629. The lowest cost was \$1,642, in Jackson, Mississippi. Researchers attributed the rising costs to the increasing popularity of assisted living among older adults.¹ Monthly rates vary significantly depending on the location of the residence, the type of accommodations (such as a private or shared room), and the services a resident needs, including medication management, assistance with activities of daily living, and specialized dementia care. In addition to these monthly costs, some assisted living residences also charge an admission fee.

THE ASSISTED LIVING RESIDENT

Gender

Over two-thirds of assisted living residents are female.

Age

The average age of residents in assisted living facilities in 2000 was 80. The average age of the oldest residents was 94, and the average age of the youngest resident was 66.

Typical Resident

The typical assisted living resident is an 80-year-old woman who is mobile but needs assistance with two activities of daily living.

Number of Residents Nationwide

Approximately 800,000 people nationwide live in assisted living settings.

Activities of Daily Living

Nineteen percent of assisted living residents need no help taking care of their activities of daily living; others need help to varying degrees.

Moving In

Residents come to assisted living facilities from a variety of settings:

- 46 percent move from their homes.
- 10 percent come from a nursing facility.
- 20 percent come from another assisted living residence.
- 14 percent come from hospitals.

Cognitive Impairment

Approximately half of all residents in assisted living have Alzheimer's disease or other dementia.

Sources

National Center on Assisted Living, 2000 Survey of Assisted Living Facilities, 2001.
Alzheimer's Association. People with Alzheimer's Disease and Dementia in Assisted Living Fact Sheet. 2004.

Home and community-based waivers are the primary Medicaid funding vehicle for low-income persons requiring assisted living services. Medicaid coverage of assisted living services is increasing, albeit gradually. In 2002, Medicaid helped pay for services for approximately 11 percent of assisted living residents in 41 states.² In contrast, Medicaid is the primary source of payment for 58 percent of nursing home residents.³

Assisted living remains primarily private pay. As of 2000, 67 percent of assisted living residents paid with their own funds, and 8 percent received support from family members.⁴ Long-term care insurance paid for assisted living costs for only 2 percent of residents.

Because of their high cost and lack of public subsidies, assisted living residences are often unaffordable for older persons with low or moderate incomes, many of whom are women. For the typical woman over the age of 65 with a current average annual income of \$15,615, paying for assisted living is virtually impossible⁵. Families are frequently called upon to help with the costs of assisted living. However, many families could not begin to take on this level of financial responsibility, no matter how much they love their parents or other family members. For those older adults, assisted living may very well be out of the realm of possibility.

Quality, Accountability, and Oversight

A critical challenge in assisted living is ensuring the quality of assisted living services. Many quality-related issues are of concern to older women, including inadequately trained staff, insufficient staff, medication errors, resident abuse, and the retention of individuals who need more care than the assisted living residence is able to provide.

Unlike nursing homes, assisted living facilities are not subject to federal regulations or uniform quality standards. Each state develops its assisted living regulations. Some states began developing such regulations as facilities began operation in their state. Others lagged in this effort and only began addressing the issue in the past several years. States also vary in the frequency of facility inspections (ranging from once a year to none), licensing

Because of their high cost and lack of public subsidies, assisted living residences are often unaffordable for older persons with low or moderate incomes, many of whom are women.

requirements, quality standards, and monitoring and enforcement activities.⁶ Because of budget cutbacks, some states have reduced oversight of assisted living residences in such areas as inspections and enforcement of state regulations.

Some states use accreditation in lieu of state regulatory inspections. Such accreditation may cover several years, thus eliminating annual inspections of assisted living residences. Many advocates are concerned that a multi-year time span is too long, as potential operational or management changes may also impact the current level of quality in the residence. In 2005, six states already had language in their regulations that allowed for (or will allow for) third-party accreditation for either assisted living or continuing care retirement communities.⁷

To ensure quality assisted living residences, states will need to expand current efforts and make sure that these facilities are adequately funded. Areas where state efforts are often weak include staff training, disclosure of information to consumers, and services to meet the needs of residents with cognitive impairment. The ALW report can be useful to policymakers as they consider ways to improve assisted living quality in their states. Additional research is needed to better understand the effectiveness of various approaches to improving quality.

One very real concern debated by assisted living providers and advocates is the effect of Medicaid, in the form of increased regulatory requirements. While recognizing that one mission of the Centers for Medicare and Medicaid Services includes assuring public accountability and quality long-term care services—especially those subsidized by the

Medicaid program—some assisted living advocates believe that reliance on existing nursing facility regulations will essentially transform assisted living into nursing facilities. Other advocates maintain that regulations are important in assuring quality and that the goal should be to set realistic but flexible standards.

Staff Retention and Training

Issues related to direct-care workers in assisted living are extremely important to women because the vast majority of assisted living workers are midlife and older women caring for older women. A concern among consumer advocates is who will replace these older workers in the future.

Effective recruitment, staff training, and retention practices lead to enhanced quality of life for both residents and staff members of assisted living residences. These practices have direct and significant implications for both residents (with respect to the quality of care and services they receive) and workers (with respect to job effectiveness and job satisfaction). A major concern related to staff training is that every state has different requirements for initial staff training and continuing education, both in the curriculum used and in the number of hours of training.

High turnover and inadequate staffing levels in the long-term care workforce has long been associated with poorer resident outcomes, as it places greater and often unrealistic and unmanageable workload demands on remaining staff. Decreased worker effectiveness, increased levels of stress, and mounting job dissatisfaction have all been cited as negative outcomes of, and potential triggers for, more staff turnover. Absent a resolution of these issues, the question of “who will take care of me” in assisted living will remain unanswered.

Resident Care and Care Management

This issue focuses on the services provided by an assisted living facility before and during a stay there. For example, many states require that assisted living facilities conduct initial assessments and prepare service plans for each resident. Even if the state does not have such requirements, a well-run

facility will use them. A resident service plan is a blueprint for care that describes the resident’s needs and preferences and the specific manner in which such care will be delivered. Prepared thoroughly and thoughtfully, the service plan can help a resident achieve the highest level of function and quality of life. A well-developed plan uses an interdisciplinary approach and includes the resident, the family (if the resident wishes), the facility nurse and resident service coordinator, and possibly the activity and dining directors.

Care management is another critical component of quality care in assisted living. With the increasing age of assisted living residents, it is ever more important for care coordination to be conducted among the health care professionals, such as physicians, pharmacists, and physical and occupational therapists, and in the areas of hospice care and lab work, to manage existing health conditions and prevent new problems from occurring.

Inability to manage medications for chronic and acute conditions is a major reason for the admission of older adults to assisted living facilities. Medication management continues to be a challenge once they enter an assisted living community. Consumer understanding of the services provided and safe and effective management of the resident’s medication regimen are major concerns. Many assisted living residents provide some level of assistance with medications. A resident’s ability to self-administer is determined during the admissions process. If a resident needs support, there are various levels of medication management. Some states have strict guidelines stating that only licensed nurses can administer medications, while others allow unlicensed caregivers to administer medications if they have successfully completed a state-approved course.

Also within the realm of resident care management are dementia care and wellness programs. Some people will be admitted to an assisted living facility with cognitive impairment; others will become cognitively impaired as time passes. Assisted living staff can be trained to recognize the signs and symptoms of cognitive

impairment in residents. All staff should receive this training, even if the assisted living facility has a special dementia care unit, since some residents who are not in that unit may have or develop cognitive impairment over time.

Wellness programs can improve quality of life for residents, and, in some cases, prevent illness from occurring by using a holistic approach to care. Such programs may include health screenings, nutritional counseling, physical exercise programs, and spiritual enrichment.

POLICY RECOMMENDATIONS

ALW developed the following recommendations for the above issue areas for the U.S. Senate Committee on Aging. The complete ALW Report and recommendations can be found at www.aahsa.org/alw.htm.

Affordability

- Create a new consumer-directed federal long-term care program that includes assisted living and expands service eligibility to meet the needs of people who are not nursing home eligible.
- Continue to expand funding for the Medicaid 1915(c) Home and Community-Based waiver program to cover needed services.
- Allocate additional federal and state funding to meet the needs of affordable assisted living.

Quality, Accountability, and Oversight

- Congress and the states should provide adequate funding for the Long-Term Care Ombudsman Program to fulfill its responsibilities under the Older Americans Act, including resolving complaints and representing resident interests in licensed assisted living communities.
- The federal government should exercise its jurisdiction to oversee assisted living and enforce the law in the following areas: protection of

consumers from unfair and deceptive acts and practices under the Federal Trade Commission Act; enforcement of the Medicaid waiver for assisted living; national abuse registries and criminal background checks; civil rights laws such as the Americans with Disabilities Act (ADA); and any other laws and standards that apply.

- State regulatory agencies should make available information that is helpful to consumers and others regarding assisted living residences, including electronic access to statutes and regulations impacting assisted living. States should maintain as public records, for a minimum of three years, all survey and inspection reports and plans for corrections. States should take steps to offer low-cost access to these reports, such as by posting them on state Web pages.

Staff Retention and Training

- State regulatory agencies should develop or adopt a tool for use by surveyors to determine the adequacy of staffing levels to perform tasks specified in the assisted living residents' services plans. This tool should be shared with and used by assisted living residences and by ombudsmen and consumers.
- Direct-care staff in assisted living should be required to complete a state-approved comprehensive training program, including both a classroom and a clinical skills practicum, and to pass a written examination and skills competency test. The training should include components on the philosophy and concepts of assisted living, resident rights, care techniques related to activities of daily living, the aging process, CPR, first aid, responding to falls and other emergencies, environment and safety, and understanding the particular care needs of persons with dementia and challenging behaviors.

Resident Care and Care Management

- Assisted living residences should be required to have or implement policies and procedures for the safe and effective distribution, storage, access, security, and use of medications and related equipment and services by trained and supervised staff.
- Assisted living residences should be required to have in place procedures to: (1) increase staff awareness of signs and symptoms of cognitive impairment/dementia; (2) evaluate or obtain an evaluation of the resident's cognitive status as it relates to the resident's ability to manage his/her own affairs and direct his/her own care; and (3) adapt the resident's service plan to meet his/her needs, given the resident's cognitive status.

NOTES

¹ *The MetLife Market Survey of Assisted Living Costs*, The MetLife Mature Market Institute (October 2005).

² Mollica R., *State Assisted Living Policy* (2002).

³ O'Brien EI, Elias R., *Medicaid and Long-Term Care*, Kaiser Commission on Medicare and the Uninsured (May 2004).

⁴ National Center for Assisted Living (2004).

⁵ State of Older Women in America, OWL Web site www.owl-national.org/owlreports/index.html, accessed March 2004.

⁶ Wright B., *Assisted Living in the United States Fact Sheet*, AARP (2004).

⁷ American Association of Homes and Services for the Aged, Assisted Living and Continuing Care Retirement, *Community State Regulatory Handbook* (2005).

Assisted Living

Personal Story: Jackie's Father

JACKIE IS THE DAUGHTER OF AN 88-year-old widower who began living in an assisted living community six years ago. When he entered the community, Jackie's father was cognitively sharp, relatively independent, and mobile, requiring little staff assistance.

Since that time, his chronic heart failure and Parkinson's disease have worsened. For the past three years, he has required a walker and has become progressively unsteady in gait and mobility. Ever since an acute cardiac hospitalization and rehabilitation episode two years ago, he requires medication management and far greater personal assistance from the staff. He is now embarrassed that he has so much trouble getting in and out of his chair in the dining room. Last spring, he developed acute pneumonia, which caused yet another round of hospitalization, rehabilitation, and further weakening of his general health. A year ago, Jackie arranged for a supplemental private duty aide to live in her father's apartment, since he now spends most of his time in his wheelchair.

It is difficult for Jackie to use the term "affordability" when she thinks about her father's assisted living fees. While the average monthly rate for assisted living is less than \$3,000, that rate varies considerably depending on the facility's location. Jackie's family pays \$5,000 a month for her father's assisted living facility in the northeast and an additional monthly fee for medication management. His pension, Social Security, and savings don't begin to cover these costs, so the financial responsibility has fallen upon Jackie and her sisters.

Jackie believes that she and her family are indeed fortunate that their father's assisted living residence

is in a state that has appropriate regulations and oversight. However, these safeguards are still not enough to truly ensure quality of care in assisted living. Jackie believes that one of the best ways to ensure quality care for her father is for her to be involved with the administrators and staff members at his facility. Jackie is an active participant in family council meetings, maintains open communications with the staff, and views herself as part of his "care team." Jackie's family is proactive in bringing up any concerns they may have so that they can all work together to resolve them. She believes that their caring, respectful, appreciative manner toward the other residents, staff, and administrators these past six years have gone a long way toward ensuring that her father will be treated in a similar caring and respectful manner.

It's difficult for Jackie to use the term "affordability" when she thinks about her father's assisted living fees.

The amount of time and energy devoted to finding an appropriate facility for Jackie's father and the continuing challenge of checking on the quality of his services have been enormous, yet worth it. Jackie's involvement has made a significant difference in improving her father's quality of care. Her advice to assisted living residents and their caregivers is to be as proactive as possible in advocating for improved services.

Nursing Home Care

Alice H. Hedt, Executive Director
National Citizens' Coalition for Nursing Home Reform

AS WOMEN EXPLORE COMMUNITY long-term care alternatives to nursing home placement, they must constantly be thinking about the unthinkable—what will happen to me when I am so frail that I can no longer stay in my own home and in the community where I have lived independently?


The stark reality is that 40 percent of all women will need some type of facility-provided care at least once in their lifetimes—for short-term rehabilitation or long-term living—and oftentimes the need for 24-hour care and nursing services can only be met in a nursing home or an assisted living facility with appropriate medical and social services.¹ Most of these women will seek placement due to family factors, rather than critical health needs.² In addition, a 65-year-old woman needs to prepare to live another 19.5 years with the increasing chance that she will have a chronic condition and/or a physical or cognitive disability. Should nursing home care be needed, she can anticipate that this will cost at least \$192 a day, or \$70,080 a year (2006 dollars), and that her length of stay will be nearly two and a half years.³

Individual and Systemic Issues

The cost of nursing home care, both to individuals and to society, is a primary issue in long-term care. Nursing homes account for three-fourths of all long-term care spending, more than \$111 billion a year, with Medicaid funding 46 percent, Medicare 12 percent, and 28 percent coming from the pockets of individual residents.⁴ Nearly 70 percent of all nursing home residents are on Medicaid and use most of their personal income for the cost of care, supplemented by Medicaid to pay the difference.⁵

The 1.26 million women currently in nursing homes (67 percent of all residents),⁶ and those of us who will need nursing homes in the future, face additional barriers—individual and systemic.

As individuals, we must remember to speak up and speak out so that we can give voice to what gives quality to our lives and be a part of decision-making.⁷ The Nursing Home Reform Law (NHRL) of 1987 provides basic protections for residents. It guarantees residents' rights, setting forth the vision that each individual resident should be "cared for in such a manner and in an environment that will promote maintenance or enhancement of the quality of life" in nursing facilities that "must provide services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of *each* resident."

 *As individuals, we must remember to speak up and speak out so that we can give voice to what gives quality to our lives.*

Residents' Rights

Women, however, must *know* their rights and take advantage of the opportunities to exercise them in the nursing home environment. High-quality facilities will support residents' well-being by:

- Encouraging full participation in individualized care planning that spells out essential aspects of the female resident's day-to-day life as well as involvement in resident and family councils.

- Promoting person-directed care and a facility culture that revolves around the preferences and schedule of the resident, rather than forcing the resident to adapt to the routines of the institution.⁸
- Fostering respect for workers and residents and building relationships between caregivers and care receivers based on adequate staffing and dignity.
- Ensuring that the environment is safe—from fire (sprinklers), from abuse (criminal background checks), and from neglect, which, if left unchecked, can result in suffering, pain, and premature death.
- Being part of a surrounding neighborhood that is involved with the residents and provides resident access to community services, legal support, and meaningful activities.

The primary barrier for women in need of nursing home care, however, is *lack of access* to a facility that provides such high-quality care. Despite 30 years of advocacy, congressional hearings, legislation, and regulations, nursing home care in this country is not consistent, or—in some cases—even safe. Over 90 percent of nursing home facilities in the United States do not have the 4.1 hours per resident day of nurse staffing needed to provide basic care, and 50 percent of nursing homes do not have enough staff to prevent harm.⁹ Turnover rates of 40 to 300 percent result in women residents not knowing from day to day who will be providing their most intimate personal care. Too often facilities have only “yo-yo” compliance with the NHRL regulations, resulting in survey deficiencies that occur year after year. Residents report that some facilities step up their performance prior to the annual survey through increased staff, new linens, and better food, with noticeable declines occurring once the inspection has been completed. African American women are four times more likely to be living in a nursing home with the worst staffing levels and inspection records.¹⁰

While it is important to realize that many American women do not have a choice of nursing homes—because there are no good homes in their

community, because of discrimination based on race or Medicaid eligibility, or because they have no family to help them get into a good facility. Those who do have options need information to help them choose wisely. They should use information now available on the Internet¹¹ and seek guidance from a long-term care ombudsman, who can provide facility-specific information. It is very important that women visit facilities and see for themselves the kind of care and quality of life offered there, asking questions about staffing levels, training, and facility priorities.

POLICY RECOMMENDATIONS

Pass NCCNHR’s minimum staffing standard of 4.13 hours per resident day.¹²

Developed by consumers and validated by a consensus panel of stakeholders, the NCCNHR staffing ratio is very close to the government report ratio of 4.1 needed to provide essential care. In addition, public policy should support comprehensive staff training, adequate living wage compensation, and benefits that recognize the important work performed by direct care workers.

Ensure adequate funding and staffing levels for agencies tasked with protecting the rights and well-being of nursing home residents.

These federal and state regulatory agencies must be required to respond to complaints in a timely manner. Further, public policies must protect residents’ ability to exercise political will to levy and collect penalties and other sanctions when facilities do not provide the care for which they are paid.

Require all nursing home facilities to implement fully the components of the NHRL.

Nursing home facilities should be required to fully implement the components of the NHRL, including individual care planning, family and resident empowerment through independent councils, freedom from fear of retaliation for residents and their families, and an environment that allows residents to make and execute meaningful decisions in all aspects of their lives. Federal and state

regulatory agencies must promulgate and enforce regulations that guarantee residents' rights and individualized care and decision making, and that provide incentives for incorporating the philosophy and vision of deep culture change that respects resident autonomy.

Require nursing homes to provide all residents access to a long-term care ombudsman program.

Each program must be adequately funded to meet or exceed the ombudsman-to-resident ratio, as identified in the 1995 Institute of Medicine study *Real People: Real Problems*. Each ombudsman program should operate in an environment that is free of conflict, with full capacity to represent resident interest to public officials and to be effective advocates for residents, as described in 712(a)(4)(B)(i) of the Older Americans Act.

Ensure that the long-term care financing system protects caregivers and nursing home residents.

Congress must establish a long-term care financing system that, first, honors the caregiving roles of women by ensuring that public benefits, including Medicaid, are available when needed and, second, denies Medicare and Medicaid benefits to providers who consistently provide poor care.

Promote nursing home accountability and transparency.

The Centers for Medicare and Medicaid Services should be required to post in every nursing home accurate, audited data on nursing staff levels (including ratios of nursing staff to residents), fire safety information (including inspection findings and whether or not the facility is sprinklered), all state and federal sanctions imposed for poor care, and information about who owns and manages the facility.

Protect residents' right to civil justice remedies.

Congress must ensure that all women retain the right to civil justice when they are neglected or abused in a nursing home. Attempts to cap jury awards for pain and suffering (noneconomic damages) are particularly unjust for unpaid

caregivers and nursing home residents, who have no earned income to replace with economic damages. Medical malpractice reforms that cap noneconomic damages deny the protection of the law to those who are most vulnerable and need it most.

NOTES

- ¹ Centers for Medicare and Medicaid Services website, *What Is Long-Term Care?*, cited in U.S. Department of Health and Human Services Study.
- ² Young, Rosalie, *Women Care for Men with Alzheimer's; Nursing Homes Care for Women*, Wayne State University (2003).
- ³ MetLife, *Market Survey of Nursing Homes and Home Care Costs* (2004).
- ⁴ O'Brien, Ellen, *Medicaid's coverage of nursing home costs: Asset shelter for the wealthy or essential safety net?*, Issue Brief, Georgetown University Long-Term Care Financing Project (May 2005).
- ⁵ Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, U.S. Bureau of the Census (2000).
- ⁶ Centers for Medicare and Medicaid Services, *Nursing Home Data Compendium* (2005).
- ⁷ Burger, Sarah Greene, Fraser, Virginia, Hunt, Sara, & Frank, Barbara, *Nursing Homes: Getting Good Care There*, Second Edition (2002).
- ⁸ See www.pioneernetwork.net.
- ⁹ Centers for Medicare and Medicaid Services, *The Appropriateness of Minimum Nurse Staffing in Nursing Homes* (2001)
- ¹⁰ Mor, Vincent, "Driven to Tiers: Socioeconomic and Racial Disparities in the Quality of Nursing Home Care," *The Milbank Quarterly*, 82:2 (2004).
- ¹¹ See, for example, <http://www.medicare.gov/NHcompare>.
- ¹² National Citizens' Coalition for Nursing Home Reform, *NCCNHR Resolution: Consumer Minimum Staffing Standard for Nursing Homes, Resolution*, <http://www.nccnhr.org/uploads/ResolutionsbyTopic.pdf> (1998).
- ¹³ AARP Public Policy Institute, *Direct Care Workers in Long-Term Care*, DD117 (2005).

Nursing Home Care Personal Story: Judith


JUDITH IS A NURSING HOME RESIDENT in Indiana. She is 51 years old and has been in a long-term care facility since she was 21 years old. Judith, who needs around-the-clock nursing care, suffers from lupus and pulmonary fibrosis and is an above-the-knee amputee on her left side.

When Judith began her experience in the long-term care system, there were no long-term care ombudsman programs in place. If she had a problem with her care, she had to stand up for herself. In order to make her voice be heard, she learned to be her own care advocate. When her mother moved into the same nursing home facility where Judith lives ten years ago, she became her mother's advocate, too.

Judith's mother must rely on the nursing home staff to feed her, since she cannot do so herself, but the way she has been treated at mealtimes has been

difficult for her. When she says something to the staff, she feels as though they just want her to be quiet, as if they don't want to be bothered. Judith feels that many other residents also try to advocate for themselves, but they too often have a hard time getting anyone to listen to their concerns.

Judith has often felt she had to speak up about her treatment and her rights, as well as the situations of others. She feels that a lot of residents are treated as though they were children rather than adults. They are told to wait for medication when they are in pain, and some are even told to wait if they need assistance to use the restroom. When Judith reports mistreatment like this, it seems nothing is done about it. Nonetheless, Judith is determined to continue speaking up when something isn't right.

 *She feels that a lot of residents are treated as though they were children rather than adults.*

Long-Term Care Workers

Milly Silva, President

Service Employees International Union (SEIU) 1199NJ

ONE OF THE MAJOR CHALLENGES facing our nation is how to meet the growing need for long-term care services among older Americans. The looming demographic explosion of Americans over age 65 begs the question that forms the title of this report: Who will care for us?

To answer this question satisfactorily, we need to look at who is providing care now, what the current problems are, and what steps must be taken to ensure a trained and qualified workforce of long-term caregivers that older Americans can count on in the coming years.

Who are Long-Term Care Workers?

Women make up the overwhelming majority of long-term care workers regardless of setting.¹ About half of long-term care workers are people of color,

and the median age is 41 years for home health aides and 39 years for nursing home workers.²

Chances are that if you receive long-term care services, you do so from a woman in her early forties—either a member of your family working through a state home care program, or someone who is sent from an agency or works in a nursing home.

Whatever the type of care, it is hard work that is physically and emotionally draining. It involves tending to the intimate and very personal care needs of an individual, providing assistance with bathing, toileting, dressing, and other activities of daily living.

Individuals often have a mix of paid and unpaid care over a period of time. Together, paid and unpaid caregivers create an interdependent but often fragile web of supports that is the infrastructure of the long-term care system.

EMPLOYED PERSONS BY SELECTED OCCUPATIONS, SEX, RACE, AND HISPANIC OR LATIN ETHNICITY, 2005

Occupation	PERCENTAGE OF TOTAL				
	Total Employed	Women	Black/African American	Asian	Hispanic/Latino
Nursing, Psychiatric & Home Health Aides	1,900,000	89%	33%	5%	15%
Personal & Home Care Aides	668,000	86%	24%	5%	16%


Source: U.S. Department of Labor, Bureau of Labor Statistics Household Data Annual Averages

Caregivers Living in Poverty

Unfortunately, the direct-care worker is generally the lowest paid of all health service support workers. A personal care worker employed by a home health agency earns an average of \$8.18 per hour, but that figure is deceptive in terms of annual income since very few workers can find full-time work.³ Wages are just slightly higher for certified nurse assistants, about \$10 per hour.

The result is that direct-care workers leave in droves, and those who stay live in poverty. More than one-quarter live below the federal poverty line, and they are more likely than other workers to lack health insurance and to rely on public benefits to supplement their wages. Among single-parent nursing home and home health aides, 30 to 35 percent receive food stamps.

Access to health insurance is a problem for direct-care workers. About 40 percent of home care workers lack health insurance, and 25 percent of nursing home workers are similarly uninsured.⁴ As a result, many direct-care workers must rely on publicly funded health care.⁵

 *Unfortunately, the direct-care worker is generally the lowest paid of all health service support workers.*

High Turnover Jeopardizes Quality of Care

Given low pay and lack of benefits, it is no great surprise that chronic shortages and high turnover rates characterize this workforce. Serious shortages of direct-care workers have been reported in 35 states.⁶ A 2003 survey of North Carolina direct-care workers found they earned more after leaving the field, an indication of lagging opportunities.⁷

This is not a temporary phenomenon, nor just a function of the business cycle. The shortage of long-term care workers is the rational response of people, mostly women, to lousy wages and working conditions at a time when far better economic opportunities are available.

The Growing Need for Long-Term Caregivers

Demand is soaring for personal care providers. An estimated 5 million direct-care workers will be needed by the year 2030 to match growth in the elderly population, which is expected to increase by 40 percent by 2030.⁸ The shrinking number of women age 25-40, their higher levels of educational attainment, and greater economic opportunities available elsewhere are steadily creating a “care gap” in the U.S. Fewer and fewer women go into long-term care work, and those who do often leave for better paying jobs in other fields.⁹ Smaller families and greater geographic mobility among American families mean even informal care is affected.

POLICY RECOMMENDATIONS

Increase wages and benefits of direct-care workers to improve quality of care.

The shortage of direct-care workers can only be solved by improved wages and benefits. Such a fundamental economic change will, no doubt, require a shift in attitudes toward workers and the work itself. Current working conditions for direct-care workers are marked by lack of respect for the work. The abundance of informal caregiving gives the false impression that direct-care workers in the formal economy can get by on minimum wage and no benefits.

The labor market for long-term care workers is easily influenced by changes in wages and working conditions. A study of California home care workers who organized through SEIU found that raising wages and providing health insurance and other benefits reduced turnover by almost two-thirds. The pay raises had the support and encouragement of consumers, who rightfully believed it would increase their ability to get help and reduce their anxiety over disruptions in service caused by workers getting offers for higher paying jobs elsewhere.¹⁰ This confirmed a study of Los Angeles home care workers that found that providing health insurance to these workers improved retention.¹¹

The *status quo* is not acceptable. The current system impoverishes direct-care workers, and high turnover adds unnecessary costs to the entire

system. According to one recent study, the average direct cost of a long-term care worker's leaving was \$2500—money that would be better spent in wages and benefits, particularly for a society on the precipice of a demographic revolution.¹

²

Improve staffing levels in institutional settings to improve quality of care.

A major research study commissioned by the U.S. Department of Health and Human Services (HHS) recommended nurse staffing levels that would allow at least 4.1 hours of direct nursing care per resident in nursing home settings.¹³ Congress has yet to adopt these minimum recommended standards. Pending legislation introduced by Rep. Henry Waxman (D-CA) would establish minimum staffing standards for nurses and nurses' aides in skilled nursing facilities following the recommendations of the HHS report.¹⁴

Expand consumer-directed programs that address workforce issues.

The advent of consumer-directed services represents one of the most promising developments in long-term care. The theory behind this idea is that individuals living in the community should determine who will care for them and how that care will be provided. In practice, consumer-directed care enables consumers, not home care agencies, to select and direct caregivers in a setting they choose, typically the consumer's own home. Consumers are able to hire friends and family to care for them—one way of meeting the growing need for caregivers.

Consumer-directed care is a humane and compassionate approach to caregiving, but programs built on consumer direction need to be structured to support the direct-care workforce. Consumer-directed care is a breakthrough in the paradigm of care, but without an adequate workforce, it usually does not succeed. Where workers are employed solely by the consumer, it is often impossible for the worker to earn adequate wages or get health benefits. Small employers can rarely afford to provide benefits, and with means-tested programs where the "employer" is poor, such benefits are impossible.

Workforce policies should support consumer-directed services by establishing wage rates and group health benefits that will attract and retain high-quality workers, and by making a public entity a co-employer. This can be done without sacrificing the consumer's control over care or the caregiver. Without policies like those found in California, Oregon, Washington, and Michigan, workers in a consumer-directed program may be further isolated from the real economy and at risk of losing the legal protections they enjoy under federal labor law.

Similarly, proposed federal legislation like the Community Living Assistance Services and Support (CLASS) Act, co-sponsored by Senators Mike DeWine (R-OH) and Edward Kennedy (D-MA), demonstrates the ability to create a program for the disabled centered around notions of consumer-directed care, but structured to ensure a stable and expanding workforce.¹⁵ This legislation shows promise in its efforts to unite consumer direction with fair treatment of workers.

Support direct-care workers having a voice.

Consumers, workers, and providers share common cause in the development of a long-term care system that meets consumer needs for choice of setting and high-quality long-term care. When workers have a voice in the system, they will use it to address the problems they face as an invisible and largely neglected workforce. Their gains in wages and benefits and access to training programs and career ladders, won through collective bargaining and other methods of collective action, directly affect the availability and reliability of direct-care services.

Providers who use public funds to fight their workers' attempts to unite are missing an opportunity to work with other stakeholders to stabilize and expand the workforce and to improve quality of care. Better enforcement of laws requiring public funds to be used for public services in long-term care will allow workers more opportunities to join the movement that has brought gains to a half million workers in the United States.

NOTES

- ¹ U.S. General Accounting Office, *Recruitment and Retention of Nurses and Nurses Aides Is a Growing Problem*, as cited in Bernadette Wright, *Direct Care Workers in Long-Term Care Research Report*, AARP Public Policy Institute (2005).
- ² *Ibid.*, page 1.
- ³ Bureau of Labor Standards (BLS), *Occupational Employment and Wages* (November 2004).
- ⁴ *Health Insurance for Direct Care Workers: Riding Out the Storm*, Better Jobs Better Care Issue Brief No. 3 (March 2004).
- ⁵ U.S. General Accounting Office, *Recruitment and Retention of Nurses and Nurses Aides Is a Growing Problem* (2001), as cited in University of California, San Francisco, Center for California Health Workforce Studies, *An Aging U.S. Population & the Health Care Workforce: Factors Affecting the Need for Geriatric Care Workers* (February 2006).
- ⁶ Harmuth, Susan & Dyson, Susan, *Results of the 2003 National Survey of State Initiatives on the Long-term Care Direct-care Workforce*, Paraprofessional Healthcare Institute (PHI) and the North Carolina Department of Health and Human Services' Office of Long Term Care (March 2004).
- ⁷ Konrad, T., *Where Have All the Nurse Aides Gone? Part III*. Report prepared for the North Carolina Division of Facility Services and the Kate B. Reynolds Charitable Trust. North Carolina Institute on Aging (2003).
- ⁸ Congressional Budget Office, *Projections of Long-Term Care Expenditures for the Elderly* (March 1999).
- ⁹ Dawson, Steven, Paraprofessional Healthcare Institute, *Direct Care Health Workers: The Unnecessary Crisis in Long Term Care* (2001).
- ¹⁰ Candace Howes, *Wages, Benefits and Flexibility Matter: Building a High Quality Home Care Workforce*. http://www.bjbc.org/content/docs/UCLA_ConnCollegePressReleaseFinal31406.doc.
- ¹¹ RTZ Associates, *Impact of Health Benefits on Retention of Homecare Workers: Analysis of the IHSS health benefits program in Los Angeles County*, Los Angeles County Personal Assistance Services Council (September 2005).
- ¹² Dorie Seavey, *The Cost of Frontline Turnover in Long Term Care*, Better Jobs Better Care Policy Report (2004).
- ¹³ U.S. Dept. of Health and Human Services, Center for Medicaid Services, *Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes*, Report to Congress: Phase II (2002).
- ¹⁴ H.R.4293, Nursing Home Staffing Act of 2005.
- ¹⁵ S. 1951, Community Living Assistance Supports and Services (CLASS) Act of 2005.

Long-Term Care Workers Personal Story: Virginia

VIRGINIA, 57, HAS BEEN A HOME-care worker for most of her adult life. She provides care for a 56-year-old man with developmental disabilities and an 83-year-old woman who is deaf and has mental impairments. This is in addition to caring for her own mother, who is elderly and has several health impairments.

Each day starts around 6 a.m., with Virginia passing out medication, cooking meals, helping her clients take baths, cleaning up after them, and taking them to doctors' appointments. "It's God's work. I like to work with those who need help," says Virginia.

The state gives Virginia a total of \$475.75 a month to care for her

two clients—about \$1.16 an hour for her constant 12-hour days. "That's what I get, it's as simple as that. It's not easy. You have no safety net at all."

One of Virginia's biggest challenges, aside from finances, is finding health care coverage for herself.

She has lived without health insurance for much of her life, getting by with over-the-counter remedies and a weak safety net of free clinics.

Within the past five years, she has had surgery for carpal tunnel syndrome and was hospitalized for injuries suffered in a car wreck. The health care bills totaled \$8,000, which she was unable to pay. The accounts were turned over to a collection agency, and her credit is ruined.

 *The state pays Virginia a total of \$475.75 a month to care for her two clients—about \$1.16 an hour for her constant 12-hour days.*

Long-Term Care Advocacy—A Call to Action

Laurie M. Young, Ph.D., Executive Director
OWL, the voice of midlife and older women

THIS REPORT PRESENTS THE VOICES of the nation’s key stakeholders in the increasingly loud discussion about the current and future landscape of the American long-term care system. Collectively, these voices are women’s voices, as we learn through this report that long-term care remains in the hands of women. This is true throughout the continuum of service settings: home and community-based care, assisted living, and nursing homes. By bringing together the national organizations represented in this report, we focus on the critical issues we must address to deliver the quality long-term care services our seniors and disabled Americans require.

Last December, delegates from across the country convened at the 2005 White House Conference on Aging. The focus of this mandated conference—held only once a decade—was on preparing for the impact of America’s aging baby boomers. We know all the statistics about how many boomers will soon turn 65 and start using the safety support network for seniors. For decades to come, the number of Americans over the age of 65—and over 85—will continue to increase dramatically. Delegates at the conference rightly identified long-term-care as a priority requiring a comprehensive national public policy overhaul.

I came to OWL following my own life experience as a member of the “sandwich generation.” While raising a young daughter, I became my mother’s caregiver during her end-of-life journey. In spite of my profession as a mental health advocate, I was unprepared for the daily experience of confronting the unnecessary barriers to quality care during my mother’s last months. I learned quickly that decisions must often be made and actions taken in

moments of crisis, and that there is a long learning curve when it comes to maneuvering the long-term care system, particularly in nursing homes. A hastily made decision when faced with hospital discharge can lead down a path that, while expedient at the time, ends in a maze of confusion regarding who is in charge of care and how effective caregivers can be in monitoring quality of services. The outcome of that confusion can be deadly.

It is clear that services must be delivered in a manner that ensures a higher quality of life for all—the care recipients and the paid and informal caregivers. To achieve a positive outcome and a healthy, responsive service system, all these stakeholders—all these women, who are predominantly in midlife and older—must be

I learned quickly that decisions must often be made and actions taken in moments of crisis, and that there is a long learning curve when it comes to maneuvering the long-term care system.

considered. Long-term care *is* a women’s issue. In the brief on family caregivers, we learn that these individuals are “more likely to be caring for someone over the age of 85, and more than half of the spousal caregivers were 75 years of age or older.” In addition, “[o]lder caregivers are most likely to be providing care to a spouse, and most of the spousal caregivers

are women.” In fact, the existing system of long-term care in this country could not function without the contributions of millions of women as formal and informal caregivers of the nation’s aging and disabled populations.

To move forward with a more progressive system of care, a cycle must be broken. It is imperative to understand how the contributions of midlife and older women as caregivers directly impact their own long-term care needs as they age, and their ability to find and secure affordable and appropriate long-term care. Too often, as the report notes, due to the demands of caregiving, women lose time out of the workforce, receive little or no pension income, and therefore become more reliant on Social Security for much of their retirement income. Caregiving, in turn, results in a loss of Social Security credits due to years out of the workforce, or part-time employment. We know that caregivers are at increased risk of mental and physical impairments, adding to the experience of many older women of managing multiple chronic diseases—often without the necessary financial or health insurance coverage.

In the brief on informal caregivers, we learn that “caregiving for an older parent increases the risk of living in poverty and relying on Supplemental Security Insurance (SSI) for income” and that “women who were caregivers were more than twice as likely to live in poverty and five times more likely to receive SSI than were non-caregivers.” And so the cycle continues; today’s caregivers are like to be tomorrow’s care-recipients. According to the brief from the National Citizens’ Coalition on Nursing Home Reform, “[the] stark reality is that 40 percent of all women will need some type of facility-provided care at least once in their lifetimes—for short-term rehabilitation or long-term living—and oftentimes the need for 24-hour care and nursing services can only be met in a nursing home, or an assisted living facility with appropriate medical and social services.”

What can women and men then expect when faced with institutionally based care? We learn from the Service Employees International Union (SEIU) brief that the paid workforce faces formidable challenges in providing quality care:

A personal care worker employed by a home health agency earns an average of \$8.18 per hour, but that figure is deceptive in terms of annual income since very few workers can find full-time work. Wages are just slightly higher for certified nurse assistants, about \$10 per hour. The result is that direct care workers leave in droves, and the ones who stay live in poverty. More than one-quarter live below the federal poverty line, and they are more likely than other workers to lack health insurance and to rely on public benefits to supplement their wages. Among single-parent nursing home and home health aides, 30 to 35 percent receive food stamps. Access to health insurance is a problem for direct care workers. About 40 percent of home care workers lack health insurance, and 25 percent of nursing home workers are similarly uninsured. As a result, many direct care workers must rely on publicly funded health care.

Thus, we learn from this brief that the unintended consequences for our frail elderly can be devastating when we devalue the work of the paid caregivers, predominantly midlife women, and often women of color.

Despite all the problems and barriers to a quality long-term care continuum of services, we know there is good news as well. The National Association on Area Agencies on Agency tells us that, given the choice, most older women want to “age in place.” The desire to stay in their homes and communities is powerful, and through the successes of the Aging Network and the Older Americans Act, a range of services are available. This brief describes in detail the comprehensive services and outreach that exist within home communities.

Through the Older Americans Act and the Aging Network, we know how to meet the needs of our aging population. The technology of service


delivery is known and the needs of “over eight million older adults and 660,000 caregivers are met each year.” It is often the case that public policy lags behind best practices, hindering their widespread implementation on the ground. Despite the fact that we know what to do, we still have an unnecessarily complicated process for funding the best in home and community-based care for aging seniors.

IT'S TIME FOR CHANGE

Neglect of these situations and of the mechanisms by which they perpetuate hardship and inequality for women will only magnify the problem for current and future generations of midlife and older women. OWL, as always, is committed to working with our membership, allied organizations, and policy-makers to ensure that the necessary changes, many of which are outlined in this report, are made. Our history of outspoken advocacy and activism on the issue of long-term care, our mission, and our sense of both outrage and optimism demand no less.

The policy recommendations of each of our authors are presented in three ways:

1. *We must provide adequate and appropriate levels of funding for Older Americans Act programs and the Aging Network.* The reauthorization of the Older Americans Act was the top priority resolution of the 2005 White House Conference on Aging. Along with proper funding levels, such barriers as the continued institutional bias in Medicaid funding impede the translation from best practices into best services. Services must include affordable housing and accessible transportation to make the system work. Policy-makers need to think of cost-shifting as well as cost-saving in making home and community-based services more readily and

 OWL, as always, is committed to working with our membership, allied organizations, and policy-makers to ensure that the necessary changes, many of which are outlined in this report, are made.

easily available. While additional funding will be needed during the decades to come with the aging of the baby boomer generation, it is not just how much money we spend, but how we spend it that makes for better public policy.

2. *We need a national policy to address the needs of informal caregivers in this country, who bear the greatest burden of service provision to the aging and disabled community.* Through legislation, we can begin to ameliorate the unfair financial burden carried by informal caregivers, which adds to the probability of financial distress or crisis as the caregiver herself ages. Legislation to provide paid family and medical leave benefits will be a critical step. Caregivers can no longer afford to be punished for the caring and loving choices they must make. Tax credits for caregivers and the ability to “earn” Social Security credits during work absences for caregiving responsibilities represent the beginning of compensation for caregivers and can help break the cycle in the transformation for caregivers to care recipients.
3. *We must increase the wages and benefits of the paid workforce in long-term care.* Providing care to the aging and infirm must be seen as the important, difficult, and challenging work it is. Raising wages and benefits will impact the quality of care across the board, from home and community-based care to assisted living and nursing homes. With a well-compensated, well-trained, and highly valued workforce, the rights of the residents of assisted-living and nursing homes will be ensured. Along with appropriate compensation, the institutions must be required to provide adequate staff to meet the needs of the residents. Too often, poor quality care and dangerous treatment is experienced because work shifts carry too few employees

to meet residents' needs. With adequate compensation, more people will be willing to work in this industry. Workers must be able to organize to ensure that workplace protections, wages, benefits, and training will be addressed appropriately.

IT'S TIME TO ACT

These policy recommendations require the following actions:

- *Key decision makers must move forward the legislation called for in the policy recommendations in each brief and summarized in this call to action.* This must occur on all three levels of government: local, state, and national. National policy must ensure that all Americans will have access to the quality of long-term care they deserve.
- *As constituents of policy makers, we all must be unrelenting in our efforts to educate decision makers about our needs and priorities.* We must continue to raise our voices and express frustration about the failure to value the aging and the infirm and those who care for them. We must educate ourselves about the devastating consequences of failing to develop a humane and comprehensive system of long-term care. And we must insist that there is an appropriate governmental role in ensuring that quality care is available, affordable, and accessible to all who need it.
- *We must demand a national program to help informal caregivers understand—long before a crisis occurs—how to use the long-term care system.* This program must educate those who are aging to plan for themselves and with their caregivers, so that informed decisions can be made both before and during a crisis.

OWL's 2006 Mother's Day Report is a call to action for all of us.

Contributing Organizations

The organizations listed below generously submitted briefs for this report. OWL is pleased to share their insights and analyses, and we urge interested readers to visit their Web sites to learn more about their efforts to improve the U.S. long-term care system.

The **Consumer Consortium on Assisted Living** (CCAL) is the only national consumer education and advocacy organization focused on the needs, rights, and protection of assisted living consumers and their caregivers and loved ones. CCAL educates consumers, trains professionals, and advocates for assisted living issues. CCAL works collaboratively with a broad spectrum of people and organizations to support quality assisted living and to provide options for individuals with low incomes. www.ccal.org

The **National Alliance for Caregiving** is a nonprofit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations. The Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients. www.caregiving.org

The **National Association of Area Agencies on Aging** (n4a) is the leading voice on aging issues for Area Agencies on Aging (AAAs) across the country and a champion of Title VI (of the Older Americans Act) Native American aging programs in our nation's Capital. n4a also provides training, technical assistance, and support to the national network of 650 AAAs and 240 Title VI agencies to assist them in achieving the collective mission of building a society that values and supports people as they age. www.n4a.org

The **National Citizens' Coalition for Nursing Home Reform** (NCCNHR) is a nonprofit membership organization founded in 1975 by Elma L. Holder to protect the rights, safety, and dignity of America's long-term care residents. www.nursinghomeaction.org

The **Service Employees International Union** (SEIU) is an organization of more than 1.8 million members united by a belief in the dignity and worth of workers and the services they provide and dedicated to improving the lives of workers and their families and creating a more just and humane society.
www.seiu.org

Additional Resources

Listed below are organizations and programs cited in this report. Please visit their Web sites for more information.

AARP

<http://www.aarp.org>

Aging Network

<http://www.ianet.org>

Alzheimer's Association

<http://www.alz.org>

Assisted Living Workgroup

<http://www.aahsa.org/alw.htm>

Center for Excellence in Assisted Living

<http://www.theceal.org>

Centers for Medicare and Medicaid Services

<http://www.cms.hhs.gov>

National Center on Assisted Living

<http://www.ncal.org>

National Family Caregivers Support Program

<http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp>

National Long-Term Care Ombudsman Program

<http://www.ltombudsman.org>

Pioneer Network

<http://www.pioneernetwork.net>

Urban Institute, The Retirement Project

<http://www.urban.org/toolkit/issues/retirementproject/index.cfm>

Glossary

Activities of Daily Living (ADL) - Simple tasks performed on a day-to-day basis, such as getting dressed, eating, or brushing your teeth.

Americans with Disabilities Act (ADA) - The Americans with Disabilities Act gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications.

Assisted Living Facility - A residential care setting that combines housing, support services and health care used by people who are not able to live on their own, but do not need the level of care that a nursing home offers.

Cognitive Impairment - Deterioration of conscious intellectual activity. Symptoms may include short- or long-term memory impairment, impaired judgment, difficulty managing routine tasks, disorientation to time and place, fearfulness or paranoia, wandering, and repetitive actions.

Community-Based Care - Assistance with daily activities that generally helps people with disabilities to remain in their homes. Community-based services include personal care, chore assistance, transportation, and group meals. People who use these services live in a range of settings: their own homes or apartments, assisted living facilities, adult foster homes, or other supportive housing.

Consumer-Directed Services (CDS) - This allows consumers or their guardians or designated representatives to be legal employers of record for the service providers. Under CDS, consumers have greater control and responsibility for their care.

Continuing Care Retirement Communities - Residential communities set up to provide residents with easy access to health care.

Direct Care Workers - Direct care workers are people who care for individuals of all ages who have disabilities or impairments and need their assistance. They can work in someone's home or in a nursing home.

Family and Medical Leave Act (FMLA) - Passed in 1993, the U.S. Family and Medical Leave Act mandates up to 12 weeks of unpaid medical leave in a 12-month period of time, for employees of companies with more than 50 employees. Under this act, people can also take leave to care for a sick child, parent, or spouse.

Informal Caregiving - Caregiving provided by families and friends, who offer unpaid assistance for the physical and emotional needs of a loved one, ranging from partial assistance to 24-hour care.

Long-Term Care Insurance - Coverage that, under specified conditions, provides skilled nursing, intermediate care, or custodial care for a patient (generally over age 65) in a nursing facility or his or her residence following an injury.

Medicaid - A program sponsored by the federal government and administered by states that is

intended to provide health care and health-related services to low-income individuals.

Medicaid Home and Community-Based Waiver Programs – Programs which can be used to fund services not otherwise authorized by the federal Medicaid statute, such as respite care, home modifications, and non-medical transportation. Waivers can also be used to provide optional Medicaid services for waiver participants not offered to other adult Medicaid beneficiaries, such as case management and personal assistance services.

Medicare - A federal health insurance program for people age 65 and older and for individuals with disabilities.

Nursing Home Reform Law (NHRL) – The objective of this law is to ensure that residents of nursing homes receive quality care that results in their ability to achieve or maintain their “highest practicable” physical, mental, and psychosocial well-being. To secure quality care in nursing homes, the NHRL requires the provision of certain services to each resident and establishes a Residents’ Bill of Rights. Nursing homes receive Medicaid and Medicare payments for long-term care of residents only if they are certified by the state to be in substantial compliance with the requirements of the NHRL.

Older Americans Act - Federal legislation created to form a network of state and area agencies on aging. These agencies help plan and fund programs and services for persons over the age of sixty.

Social Security - A federal program that provides retirement income, health care for the aged, and disability coverage for eligible workers and their dependents.

Supplemental Security Insurance (SSI) - A federal income supplement program funded by general tax

revenues (not Social Security taxes). It is designed to help aged, blind, and disabled people who have little or no income; and it provides cash to meet basic needs for food, clothing, and shelter.

U.S. Senate Special Committee on Aging - The United States Senate Special Committee on Aging was initially established in 1961 as a temporary committee, and became a permanent committee in 1977. As a special committee, it has no legislative authority, but it studies issues related to older Americans, particularly Medicare and Social Security.

Wellness Programs – Programs provided by employers to employees that are designed to improve awareness of the factors that can affect health and longevity and to enable employees to take increased responsibility for their health behaviors.

White House Conference on Aging - A national event held once a decade to develop recommendations for the President and Congress on aging-related issues, policy, and research.

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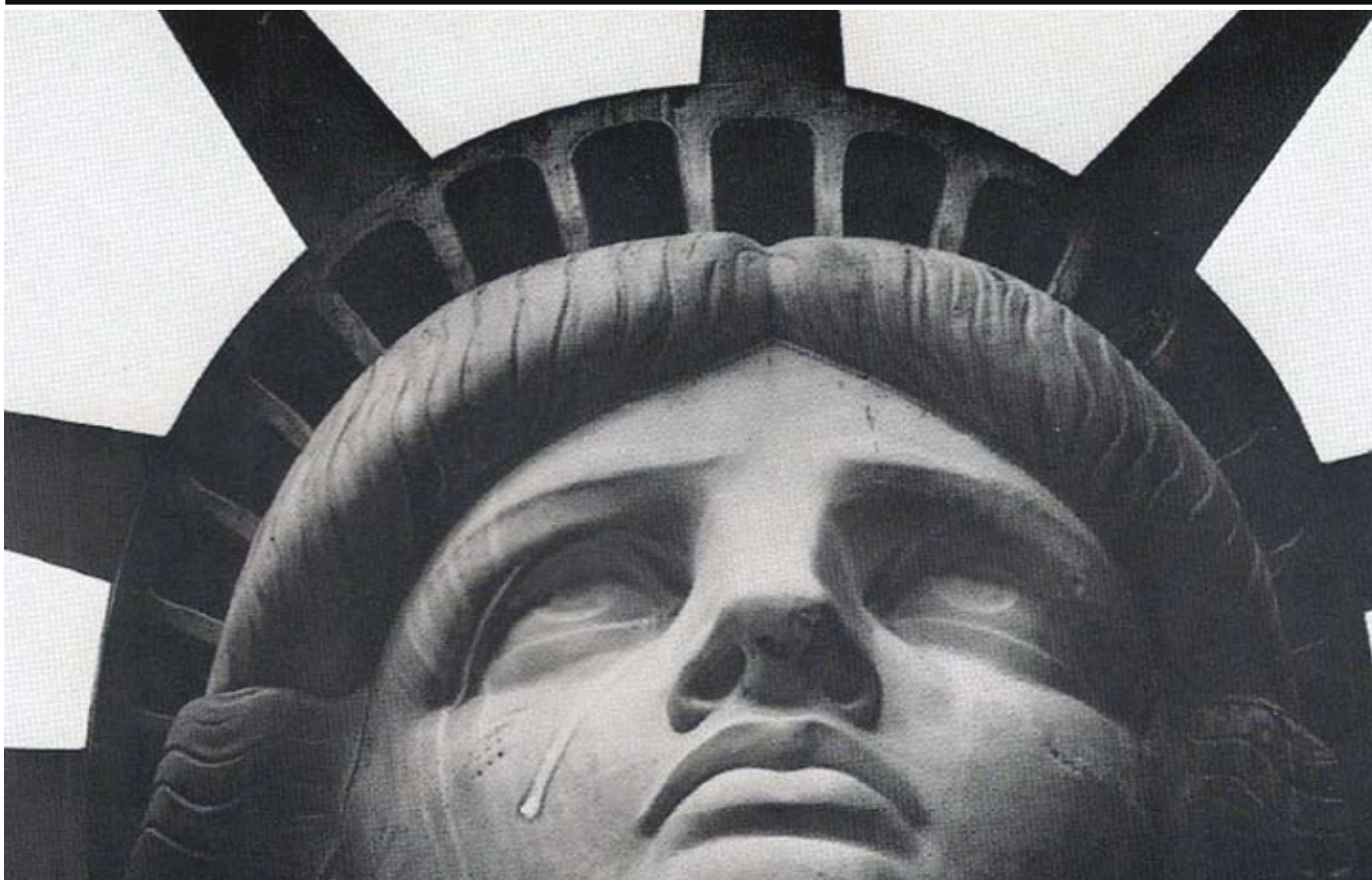
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Please send this form and membership dues/contribution to:

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