A WORKFORCE TO CARE FOR OUR AGING

Challenges we face as a nation as the cost and demand for long term care rise without a growing caregiver workforce
While America continues to grapple with ever-increasing health care costs, one aspect of this debate needs heightened focus: the looming gap between the number of people who are projected to need long term care services and the number of workers available to provide care and services. As it pertains to paid caregiving, this gap is the direct result of significant challenges to recruit and retain a sufficient and sustainable long term care workforce. In addition, unpaid family caregivers – on the other end of the spectrum and who account for the largest portion of long term care providers in the nation – are also under severe and growing stress. As the nation’s 78 million Baby Boomers age and their need for care rises, many more families will face difficult choices as they must find a way to balance careers, family and other priorities while providing care for loved ones.

The cost of long term care is increasing because the cost of caregiving is rising. There is a gap between those who need and will need care and those who are and will be available to provide it. This gap has the potential to negatively impact Americans and the American health care system in two ways: the costs of health care may rise significantly as the workforce supply diminishes, and the quality and availability of care may decrease, placing added pressures on family members and friends to care for loved ones who may require long term care.

Care Gap: United States

Between 2000 and 2030, the number of U.S. elders will increase by 104 percent. During the same period, the number of women aged 25 to 44 — the group from which most direct-care workers have traditionally come — will increase by only 7 percent.

Source: www.coverageiscritical.org
Genworth’s 2008 Cost of Care Survey, which provides a comprehensive look at the cost of long term care across the nation, found that the average annual cost of a private room in a nursing home is $76,460. This cost, which has increased more than 15 percent since 2004, is significantly more than the U.S. median household income of $48,201\(^1\) and well above the $54,356 price tag of a four-year public college degree.\(^2\) According to the survey, the costs of residing in assisted living facilities and receiving care at home by skilled home health aides have also increased by double-digit percentages over the last several years.

There is a shortage of long term caregivers; we need to recruit 200,000 new direct-care workers each year to meet future demand

These costs result in large part from a workforce crisis, and no area of the long term care industry is immune to the workforce shortage. Medical professionals (e.g. registered nurses) and direct-care workers (e.g. home health aids, certified nurse aids) providing care in nursing homes, assisted living facilities and in the home through a home health agency or on a freelance basis are all facing significant worker shortages. These shortages are arising just as the nation’s Baby Boomers enter their retirement years.

By 2030, the 65 and older population will double as a result of these aging Boomers. A 2003 survey conducted by the Paraprofessional Health Care Institute found that 80 percent of states surveyed – 33 out of 44 – indicated that direct-care worker shortages were a “serious problem.”\(^3\) In fact, a number of studies have concluded that up to 200,000 workers must be recruited into the long term care workforce each year to keep up with the demand of the Boomer population.\(^4\)

Retaining caregivers in this field of work is a big part of the problem for many reasons

Recruitment and retention challenges are the main contributors to the paid long term care workforce shortage. The turnover rate for paraprofessional long term care workers in the U.S. is disproportionately high – 13 to 18 percent higher than the overall labor force and 20 percent higher than other service workers\(^5\) – due to a wide range of issues including low wages, lack of access to quality training and continuing education opportunities, lack of benefits such as health insurance and generally low worker satisfaction.

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\(^1\) U.S. Census Bureau, Income. Poverty and Health Insurance Coverage in the United States, 2006.

\(^2\) Average published tuition, fees, room and board for in-state students at public four-year colleges and universities are $13,589 per year. College Board, Trends in College Pricing, 2007.

\(^3\) Paraprofessional Health Care Institute, quoted in The Long Term Care Workforce: Can the Crisis be Fixed? Problems, Causes and Options, prepared for National Commission for Quality Long Term Care by the Institute for the Future of Aging Services, January 2007.

\(^4\) Ibid.

Most Americans prefer care in their homes, which will put a greater need on expanding home-based options

Another trend that contributes to the direct-care workforce shortage is the shift from institutional care to home and community-based care. The direct-care workforce providing care outside of a facility environment (nursing homes or assisted living facilities) increased threefold between 1989 and 2004,\(^{6}\) and the Bureau of Labor Statistics estimates that personal home care aids and home health aides will be the second- and third-largest growing occupations between now and 2016. This may not come as a surprise, since facility-based care can be more costly, and the general desire among Americans is to stay at home to receive long term care.

A national public opinion poll conducted for Genworth Financial in 2007 found that if given the choice, three out of four Americans would prefer to receive care in their own home versus a facility.

An ancillary consequence of the long term care workforce gap is an increased number of unpaid family caregivers. Unpaid caregivers – usually a family member or friend providing care within the home – are an integral part of the long term care workforce, providing care valued at an estimated $350 billion per year.\(^{7}\) Yet they often lack professional training and must work jobs outside of the home in order to make ends meet. Family caregivers are often unprepared to deal with the physical, emotional and economic strains of caregiving.

Viable solutions to address the long term care workforce shortage and close the care gap must address the needs of both paid and unpaid long term care providers.

These are serious problems that require results-oriented debate and decisions by policymakers and stakeholders alike

As the nation’s most experienced provider of long term care insurance and the industry’s largest payer for long term care services, Genworth Financial recognizes that the imbalance between long term care workforce supply and demand is contributing to increased costs and demands on family caregivers. Our research shows that most Americans remain unprepared for the challenges associated with providing for their own or a loved one’s long term care needs.

To that end, and in light of the rising cost of care outlined in the 2008 Cost of Care Survey, Genworth Financial has examined the nation’s caregiving workforce – both paid and unpaid – and reviewed the challenges Americans face in building and maintaining an appropriately-sized and qualified workforce to meet future demand. This paper examines several strategies and solutions put forth by independent health care experts, associations, academics and government agencies to meet these challenges, and outlines some of the more prominent policy options present in today’s long term care debate.

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\(^{6}\) Institute of Medicine of the National Academies, Retooling for an Aging America: Building the Health Care Workforce, April 2008.

What is Long Term Care?
The U.S. Department of Health and Human Services defines long term care as a range of medical and/or social services designed to help people who have disabilities or chronic care needs. Services may be short- or long-term and may be provided in a person’s home, in the community or in residential facilities (e.g., nursing homes or assisted living facilities).

Individuals who receive long term care often have chronic conditions, trauma, illness or cognitive impairment, such as Alzheimer’s disease, that limit their ability to execute various activities of daily living (ADLs), such as bathing, dressing and feeding themselves, or instrumental activities of daily living (IADLs), such as housekeeping, meal preparation, medication management, shopping or bill paying. In 2007, 12 million of the 34 million elderly Americans required some form of long term care; by 2050, the U.S. is expected to have more than 80 million elderly citizens, 20 million of whom are expected to need long term care.8

Who Provides Long Term Care?
The truth is, the network of individuals who provide care for even a single recipient can be vast, and can range from multiple doctors and geriatric care managers to nurses, homemakers, grocery shoppers, drivers, and family members and neighbors who might help with (bill paying or taking out the trash each week. Care is provided in a range of environments, from nursing homes to assisted living facilities (which have become mainstream in the last decade), adult day care centers, and the home.

The long term care workforce addressed in this paper is comprised of both paraprofessionals (e.g. paid “formal” workers or direct-care workers certified by the state) and unpaid family caregivers.

Note: From a provider perspective, Genworth and other insurers typically pay for services provided by “informal” caregivers in some of their policies with the exception of family members (spouses, children) who reside in the same home as the policyholder. Genworth views “formal caregivers” as credentialed providers and “informal caregivers” as non-credentialed providers and family members who provide care.

Direct-Care Workers
According to the Bureau of Labor Statistics, there are about three million formal (direct-care) caregivers in the United States.9 These workers are categorized into three groups: nursing assistants/certified nursing assistants, orderlies and attendants (1,391,430); home health aides (663,280); and personal and home care aides (566,860).10 Direct-care workers are sometimes referred to as either “skilled” or “unskilled,” indicated by what types of care the worker is qualified to provide.

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8 Center for American Progress, Long Term Care by the Numbers, 2006.
The majority of these direct-care workers—90 percent—are women, with more than 36 percent over the age of 50.11 One-third of direct-care workers are African-American and 15 percent are Hispanic.12

Both “skilled” and “unskilled” formal caregivers, according to a 2001 report by the Urban Institute, are relatively low-income and have low levels of educational training.13 More than a quarter of the U.S. population has completed four years of college, compared to just 4.2 percent of nursing home aides and 6.5 percent of home care aides.14

“Skilled” Formal Long Term Care Workers
The federal government requires professional training and certification only for those nursing assistants and home health aides who work in Medicare- and Medicaid-certified homes and home health agencies.15 These workers, along with those who are trained to provide rehabilitative services, are often referred to as “skilled workers.” Preparation includes 75 hours of training, passing a standardized state exam, and inclusion in the state registry. Training curricula includes communication and interpersonal skills, basic infection control procedures, reviewing patient rights, and basic nursing skills. Sixteen of the 75 total training hours are devoted to hands-on practice of clinical tasks under the instruction of a registered nurse.

Nursing assistants assist patients with ADLs such as bathing, dressing and feeding as well as perform clinical tasks such as range-of-motion exercises. In some states, nursing assistants are also qualified to administer oral medications.

Home health aides provide services similar to those of a nursing assistant but are based out of a home or community setting. Often, home health aides perform light housekeeping duties, such as preparing food or changing linens, in addition to assisting patients with ADLs.

“Unskilled” Formal Long Term Care Workers
Personal and home care aides, often referred to as “homemakers” or “unskilled” workers, do not provide the hands-on care of nursing assistants and Medicare-certified home health aides. Rather, homemakers work in a home or a group setting, providing services such as housekeeping, meal preparation, medication management, shopping, transportation and bill paying. While numbers indicate that there are nearly 570,000 personal and home care aides in the U.S. today, a growing number are employed directly by the care recipient or their family and thus are not included in this estimate.16

There are no federal training requirements for personal assistance workers, although some states have established their own requirements.17

12 Ibid.
13 The Urban Institute, Who Will Care For Us? Addressing the Long Term Care Workforce Crisis, 2001.
14 U.S. Census Bureau 2001, Tables 44 and 45.
15 Ibid.
17 Paraprofessional Health Institute, National Clearinghouse on the Direct-Care Workforce, Job Duties and Training Requirements, 2008.
Informal Caregivers
Informal and family caregivers are individuals who provide unpaid care to loved ones and friends in the home. Family caregivers provide an estimated 80 percent of all long term care services in the U.S. today. In fact, according to the National Family Caregivers Association (NFCA), over three-quarters (78 percent) of adults living at home depend on family and friends as their only source of care; 14 percent receive a combination of unpaid and paid assistance and just eight percent utilize the services of a home or healthcare agency professional exclusively.18

Approximately 45 million informal and family caregivers provide care to individuals over the age of 20 who are ill or disabled,19 and the National Alliance for Caregiving (NAC) estimates that 21 percent of all adults in the United States provide some level of informal care each year. The typical informal caregiver is a 46 year-old woman who provides an average of 20 hours of unpaid care per week. 20

The AARP notes that family caregiving is the backbone of the long term care system, with an economic value of $350 billion in 2006. U.S. employers lose more than $34 billion each year due to absenteeism and workday interruptions from full-time employees who serve as caregivers.21

Informal family caregivers often endure emotional, economic and physical hardships associated with providing long term care to a friend or loved one. More than 92 percent of informal caregivers report a major change in their work pattern: 41 percent are forced to take a leave of absence, while 37 percent go from full- to part-time work in order to care for relatives.22 Aside from the toll this takes on the individual family, a 92 percent shift in work patterns among informal caregivers likely impacts federal and state tax revenue, since the workers’ taxable income may become less as a result of juggling a career with providing care.

The Trend Toward Home-Based Care and its Impact on Demand
A poll conducted for Genworth in 2007 found that if given the choice, three out of four Americans would prefer to receive care in their home versus a facility. Of course, there will always be circumstances that make this choice unfeasible, such as a medical condition or a family’s ability to make home care a viable option. Nonetheless, the nationwide trend toward home and community-based care will logically place significant future demand on informal family caregivers, skilled and unskilled home health aides, and homemaker service providers.

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19 Ibid.
20 AARP, Caregiving in the United States, April 2005.
21 Center for American Progress, Long Term Care by the Numbers, 2008.
22 Ibid.
Long Term Care Financing: Who Pays?

Long term care is usually financed in one of three ways: through individuals, private insurance or Medicaid. The federal Medicare program does not generally pay for long term care services, particularly for an extended period of time. It pays for some services usually when provided at a certified healthcare facility, and coverage typically does not exceed 100 days. The state Medicaid program provides a large portion of long term care in the U.S., but pays only after a care recipient has exhausted his or her own financial resources and is financially destitute. Considering the costs, paying out-of-pocket for an extended period of time can be challenging – if not prohibitively expensive – for most families.

According to the Congressional Budget Office, the U.S. spends more than $200 billion annually on long term care, not including unpaid services provided by friends and family members. Even excluding donated services, the cost is still a staggering $135 billion per year. Genworth Financial currently pays approximately $1 billion annually for long term care.

In 2005, Medicaid paid more than $101 billion for long term care. Medicaid financing is hampered by an increased number of individuals who rely on its funding for their long term care services. According to a 2007 national public opinion research poll commissioned by Genworth, some 44 percent of Americans incorrectly believe that Medicare or their private health insurance will provide the funding for their long term care needs.

As the long term care needs of Baby Boomers are more clearly realized over the next two decades, the payers outlined above – which essentially make up the current long term care financing model in the U.S. – will naturally feel greater financial pressure. Additionally, the costs associated with long term care will likely continue to follow the upward trend detailed in Genworth’s annual Cost of Care Survey, a reality that has a direct correlation to the workforce shortage discussed in this paper.

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23 Ibid.
The fact that Americans are living longer translates into an increased need for long term care services. Between 2000 and 2030, the elderly population in the U.S. is projected to increase by 104 percent, from 35 million to more than 71 million people.\textsuperscript{25} While the demand for long term care services is projected to increase during this 30 year period, the number of women aged 25 to 44 – the group that typically provides long term care services – will increase by only seven percent.\textsuperscript{26} The result of this increased demand meeting insufficient supply is a looming “care gap” – that is, the projected disparity between demand for long term care and the workforce supply.\textsuperscript{27}

This care gap directly contributes to rising costs for long term care. Long term care spending for all care recipients from both public and private sources was $137 billion in 2000, and long term care spending for the elderly could nearly quadruple to $379 billion by 2050, according to some estimates.\textsuperscript{28}

Over the past five years, Genworth Financial has conducted its “Cost of Care Survey,” which studies thousands of private pay rates for nursing homes, assisted living facilities, home care agencies and adult day health care facilities, which is new to the survey this year. In 2008, Genworth Financial gathered data from over 2,000 nursing home facilities, 4,500 assisted living facilities, 3,000 home care agencies and approximately 1,000 adult day health care facilities in 90 markets across the United States. Year after year, this analysis shows that the cost of receiving long term care is steadily increasing. In most states, the cost of living in a nursing home for one year is more than the median U.S. household income.

The 2008 Cost of Care Survey found that the average annual cost of a private room in a nursing home in the United States is $76,460, up more than two percent from 2007. The research found that the average cost for a private room in an assisted living facility is $36,090, up a staggering 11 percent from last year.

### 2008 Genworth Cost of Care Survey Data

<table>
<thead>
<tr>
<th>Service</th>
<th>Per Day</th>
<th>Per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private Nursing Home</td>
<td>$209/day</td>
<td>$76,460</td>
</tr>
<tr>
<td>Private One Bedroom, Assisted Living Facility</td>
<td>$100/day</td>
<td>$36,090</td>
</tr>
<tr>
<td>Non-certified Home Health Aide</td>
<td>$19/hour</td>
<td>Depends on hours worked</td>
</tr>
<tr>
<td>Adult Day Health Care</td>
<td>$59/day</td>
<td>$15,236*</td>
</tr>
</tbody>
</table>

*Assumes five days a week


\textsuperscript{26} Ibid.

\textsuperscript{27} Ibid.

\textsuperscript{28} United States General Accounting Office, \textit{Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets}, 2002.
However, the most significant cost increase was for Medicare-certified home health aides. The hourly rate for a home health aide, paid to a Medicare-certified home care agency in 2008, is $38 per hour, an 18 percent increase.

The costs associated with home care vary greatly, as outlined in Genworth’s 2008 Cost of Care Survey, and depend on the types of services being provided; the type of caregiver providing the care (e.g. certified nursing assistant versus someone providing homemaker services); CMS certification (to work with Medicare and Medicaid patients on a reimbursable basis); state licensure; and other factors associated with home health agencies such as insurance, overhead, and operating costs. Non-certified home health aides are more common, as CMS reimbursement systems have yet to fully adapt to the home-based care model. The 2008 Cost of Care Survey finds that the average hourly rate for a non-certified home health aide is $19 per hour.

As costs continue to rise, the financial burden of paying for long term care services falls primarily on the families and individuals needing the care. A national public opinion poll commissioned by Genworth Financial in 2007 found that more than 55 percent of Americans have a family member or close relative who has needed long term care services, yet roughly three in four people have made no plans for their own or a loved one’s future long term care needs. The poll found that Americans underestimate the cost of long term care, making out-of-pocket costs for long term care especially burdensome. Ultimately, overburdened government programs are forced to cover the gap, further straining our nation’s public assistance programs. For some, long term care insurance is a reasonable solution to the often overwhelming expenses brought on by long term care needs. Yet fewer than 10 percent of Americans most likely to need long term care currently have private coverage.  

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While we cannot change the demographic factors driving demand, we can address the care gap by looking at the challenges facing the long term care workforce. Increasing the supply of long term care professionals requires finding solutions that encourage recruitment and retention of the direct-care workforce. Viable solutions must address a series of issues that contribute to high turnover rates and low recruitment, including:

- Limited professional growth and education
- Lack of sufficient benefits
- Low wages
- Dangerous working conditions
- Low worker satisfaction

**Limited Professional Growth and Education:** Generally, certification requirements for direct-care workers across all long term care settings are sparse or non-existent. Federal law requires nursing assistants or home health aides to have two weeks of training, and no training is required for home care workers. As a result, large numbers of workers are minimally prepared for the demands of providing for an individual with long term care needs, and often workers leave their jobs within the first few months. The lack of preparation and training to address the unique medical and health needs of ill or elderly care recipients contributes to retention woes, as long term care workers are understandably frustrated when they feel unqualified to provide adequate care and powerless to make healthcare decisions for their patients.

In addition, opportunities for advancement within the paraprofessional workforce are also lacking, contributing to high job turnover rates.

**Lack of Sufficient Benefits:** Because nearly 15 percent of nursing home aides and more than 24 percent of home care aids work part-time, most long term care facilities and agencies do not offer employee benefits such as health insurance, pensions or flexible working schedules. Low worker satisfaction in the long term care workforce is compounded by the fact that personal and home care aides are even less likely to receive benefits than other caregiving professionals. One in every four nursing home workers and more than two out of five home care workers lack health insurance coverage. Two-thirds of Americans under the age of 65 receive health coverage through an employer, but fewer than half of nursing aides and one-third of home care aides have employer-based coverage.

**Low Wages:** Inadequate pay is one of the most common factors behind high turnover rates. Professional caregivers are usually hourly on-call workers and are not reimbursed for travel time to and from the home or care facility. Workers are also more likely to be part-time and thus less likely to sustain themselves. According to the 2000 census, 19 percent of home care aids and 16 percent of nursing homes aides did not make enough from their caregiving job to rise above the poverty line.
**Dangerous Working Conditions:** Physical demands and workplace dangers also contribute to high turnover rates. A 2004 study conducted by Health and Human Services found a higher rate of worker injury (13 per 100 employees in 1999) in the long term care workforce than in the construction industry (8 per 100 employees).35

**Low Worker Satisfaction:** Providing long term care for someone in need is a very personal, labor-intensive profession. Duties include everything from food preparation, personal hygiene maintenance and bathing to managing personal finances and maintaining a safe, clean household. Care recipients depend on caregivers to provide them with a comfortable environment and help them maintain an optimal level of functioning.36 Despite the difficulties and wide range of tasks caregivers must provide, many feel that society as a whole does not value or respect a caregiver’s contributions to the care recipient, their family and their community.

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**Am I a Professional?**
by Roberta Record

*I have respect for the people I assist, and I work hard to show this in my work. Struggling to live on low wages, not having my own health needs covered because I don’t have insurance, being treated as less than a 'professional' makes me have to work hard to maintain self-respect. I regain strength through the individual encounters I have with the people who depend on me every day, but sometimes I wonder: how does the public view me and the thousands of other caregivers and personal assistants working to support our elders and people with disabilities in the community?*

*I am a personal care attendant. The people I assist, their families, the public, and my employer need me to be professional. They expect me to be professional. I would appreciate being valued for the work I do, for the difference I can make.*

*Perhaps we need to start by getting others in the caring and support profession to acknowledge us – the front line caregivers, aides, and assistants – as part of the profession. As professionals.*37

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36 Family Caregiver Alliance, National Center for Caregiving, Selected Long Term Care Statistics, 2008.
The Role of Home Care/Health Care Agencies

Finding qualified professionals who can provide the highest quality of care possible is of paramount importance to most individuals seeking long term care services for their loved ones. When faced with the difficult and often emotional task of making long term care decisions for those loved ones, a long term care employment agency can be a tremendous help.

A reputable long term care employment agency will ensure long term care professionals sent into the field will have the proper certification for the task at hand as well as meet the standards set by federal, state and local regulators. A trustworthy agency will also conduct follow-up inspections of the client’s residence to make sure a clean and safe living environment is being maintained. Most importantly, a good long term care employment agency should provide those who employ the workers the peace of mind that their loved ones are receiving the best care possible.

While licensures for agencies that provide long term care vary by state, many entities provide oversight and accreditation. The National Association for Home and Hospice Care provides information on these agencies. Some individuals choose to engage a professional geriatric care manager, a person who is trained to identify the exact long term care needs and create a care plan that suits a care recipient’s unique needs. Additionally, most states have an Office on Aging within their Health Departments. These offices can be a good resource for families looking for local choices. While options abound, finding the right level and quality of care is a personal decision for the individual and his or her family.

Immigration

It is difficult to quantify what percentage of the long term care workforce is occupied by new immigrants, documented and undocumented, but care is being provided by immigrants of both categories. Some nations view immigration as a source to fill a labor shortage need, which is an issue of great controversy in the U.S. It is likely that lawmakers will face this issue again as they address the long term care workforce shortage in the future.

Given the current labor shortage and projections about the future demand for long term care, some groups advocate that immigration may provide an important supplement to the country’s long term care workforce. According to the Institute for the Future of Aging Services, labor growth between 2000 and 2020 will rely heavily on new immigrants and people age 55 and older.38

Meanwhile, opponents in this debate argue more should be done to recruit and retain a qualified workforce from within the U.S., and the lack of proper training and cultural issues, including but not limited to language barriers, would do more harm than good in providing direct care for the elderly.

While the most prudent approach regarding immigration and the long term care workforce shortage is not clear, the topic deserves to be discussed and more thoroughly examined when lawmakers ultimately craft public policies to resolve this issue.

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Public Programs to Support Unpaid Family Caregivers

Support for unpaid family caregivers is a critical issue, as providing unpaid services to a friend or family member carries significant financial costs. The typical working family caregiver loses approximately $110 per day in wages and health benefits due to caregiving responsibilities. In addition to the financial burdens, family caregivers are often unprepared to deal with the physical and emotional effects of caring for a loved one with long term care needs.

In recognition of these challenges, the majority of states provide some sort of compensation to unpaid family caregivers, either through a state-sponsored program or through a Medicaid home and community-based waiver program. These state programs are generally tied to federal funding.

The National Family Caregiver Support Program, a 2000 reauthorization of the Older Americans Act, is a federal program that calls for collaboration between states and their local care providers and facilities. The program provides a public forum for state agencies on aging and local community service providers to offer basic services for family caregivers, including access to information on available services within the community; assistance in utilizing these services; counseling, support groups and caregiver training programs; respite care; and supplemental care services such as emergency response systems and home modifications.

The Medicaid Home and Community-Based Services (HCBS) waiver program provides support for informal caregivers by offering services not traditionally covered under the Medicaid entitlement program. Services are generally administered through the state unit on aging, and include respite care to allow for time away from caregiving duties, education and training programs.

HCBS waivers are paid for by the state and are not bound by federal Medicaid or Older Americans Act regulations, thus providing a flexible array of benefits that family caregivers might not otherwise receive.

A survey conducted by the Rutgers Center for State Health Policy/National Academy for State Health Policy on behalf of the Center for Medicare and Medicaid Services in 2005 found that HCBS waiver programs varied greatly amongst states and that guidelines for defining services – especially respite care – are far from uniform. Costs vary greatly from state to state as well, further complicating the impact of waiver programs. Nonetheless, the study concludes that the wide range of services offered under state waiver programs provide substantial benefits to both the care recipient and the care provider.

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The National Alliance for Caregiving (NAC) provides numerous resources for caregivers, including forums and support services, links to local providers, and answers to caregiving questions. The NAC also commissions research that quantifies economic value, productivity losses and demographics of the caregiving workforce and identifies the needs of the caregiver. A recent NAC survey found that a majority of caregivers identified two valuable resources they’d like to see: “an expert you can call 24 hours a day toll-free to talk about stress and other caregiving issues, so you do not feel alone,” and “a mobile health service that comes to your neighborhood, with services such as blood tests, blood pressure monitoring, flu shots or eye exams.”

The Family Caregiver Alliance (FCA) is a not-for-profit organization that addresses the needs of families and friends providing long term care at home. As part of the FCA, the National Center on Caregiving provides personalized help to caregivers in identifying local resources.

The National Family Caregiver Association (NFCA) is an additional resource for caregivers looking for support. In addition to providing links to useful guides, organizations and workshops, the NFCA also creates a caregiver community through its Caregiver Community Action Network. Through this subset of the NFCA, caregivers can connect for support and advice.

In addition, some private insurance policies offer reimbursement for care-related expenses to non-family members providing informal care. For example, Genworth offers a caregiver benefit to reimburse caregiving-related expenses for non-family members providing care in the home.

Additionally, Genworth puts a strong emphasis on helping families navigate through their options when a long term care need arises. When Genworth’s claim center receives a call, it is usually from the adult daughter of a policyholder, with the heaviest volume of calls following the holidays when families gather. These calls are taken by trained professionals who explain the policyholder’s choices and how the process works, and sends someone to their home to assess the situation and help begin developing the plan of care. Genworth has learned that having a trained professional involved every step of the way to answer questions comes as a great relief to families who are understandably stressed with their loved one’s long term care needs.

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Federal Tax Credits and Tax Deductions for Unpaid Family Caregivers

Tax credits aimed at assisting the 34 million Americans who serve as informal, unpaid family caregivers have been proposed. The Long Term Care and Retirement Security Act of 2003, for example, set forth a tax credit for eligible caregivers who care for those with long term care needs. An amendment to The Family Caregiver Relief Act of 2003, which was not included in the final legislation, proposed creating a $5,000 tax credit to help pay for expenses of families who care for loved ones with chronic needs.

Tax credits for family caregivers would provide much-needed relief to individuals who are straining under the economic pressures of providing long term care to a loved one.

Betty’s Story

My name is Betty. I am 58 years old. I am the sole caregiver to my husband, John, 64 years old, who was diagnosed with primary-progressive multiple sclerosis in 1985, three months following his retirement. He is paralyzed from the upper chest downwards, and is losing ground every day.

By necessity I have learned to use power tools, do plumbing chores, get urine out of the carpet, recognize possible pressure sores and dress a 6’5”, 240 pound dead weight. All the errands, car servicing and driving are my responsibility. I do all the cooking, shopping, cleaning and laundry and have learned to give haircuts because the outside world really isn’t wheelchair accessible.

Our only socializing is with other disabled couples because wheelchairs, trembling, infirmities and system failures make former friends and even family uncomfortable and eventually distant. I miss the hugs, the snuggling, the hand holding, the dancing, and the strong shoulder to lean on. Depression, loneliness, hopelessness, and fear (including fear of getting sick myself and not being able to care for him and the fear of what will happen to me) – and guilt because I feel those things – are my constant companions.


Solutions for addressing the long term care workforce shortage require a fourfold approach:

• Targeted recruitment efforts at the federal and state level
• Training programs aimed at making long term care a more attractive career choice
• Proposals to increase wages and benefits for long term care workers
• Support systems for long term care workers and their families

Below are just some of the many current programs and proposals that are aimed at bridging the care gap.

Recruitment Efforts

At the federal level, The Caring for an Aging America Act (S. 2708), introduced in March of 2008, proposes to address the projected healthcare workforce shortages through loan forgiveness and career advancement opportunities aimed at providing an incentive for students to enter the health care workforce. The bill would establish loan repayment programs for students who become physicians, physician assistants, advance practice nurses, psychologists and social workers trained in geriatrics or gerontology. In addition, the bill would expand eligibility for the Nursing Education Loan Repayment Program to include registered nurses who provide long term care.

Other recruitment possibilities include:

• Targeted High-Growth Job Training Initiative. The Department of Labor (DOL) partnered with several long term care employers to increase job growth potential. One example is DOL’s partnership with managers of health care facilities to offer scholarships and worker certifications to those interested in the health care field.

• Apprenticeship Programs. This DOL-administered program includes structured on-the-job training and educational instruction tailored to industry requirements. In the health care field, the focus is on careers that require a two-year degree or less.

• Electronic Information Systems. DOL, working with the American Health Care Association (AHCA) and the American Association of Homes and Services for the Aging (AAHSA), has helped establish an online job bank, which advertises openings for long term care nurses. Another resource is O*NET, which includes career exploration tools to help individuals better understand long term care occupations.

• One-Stop Career Center System. These centers integrate and coordinate employment and training services from numerous federal and state programs. The system provides local career information and job training and is often cited as a resource to address long term care workforce shortages.47

Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long Term Care Policy, U.S. Dept. of Health and Human Services, The Future Supply of Long Term Care Workers in Relation to The Aging Baby Boom Generation, May 2003.
Several states have worked to broaden the pool of potential long term care workers utilizing funds allocated through the Workforce Investment Act (WIA). Developed in 1998 by the U.S. Department of Labor, the WIA establishes federal grants for states that establish state Workforce Investment Boards. These boards collaborate with the state’s governor in developing local workforce investment areas, training programs and grants to help alleviate, among other goals, the long term care workforce shortage.

A handful of states, including New Jersey, New Mexico, Florida and Arkansas, have initiated job training for former welfare recipients. These programs work with state agencies and local care facilities to transition individuals moving from welfare to work, helping to alleviate the current long term care workforce deficit while decreasing the number of people on welfare.

**Training Programs and Advancement Opportunities**

While specialty training to care for the unique needs of long term care recipients exists, direct care workers do not often have access to this training.

The Carl D. Perkins Career and Technical Education Act (Perkins), reauthorized in August of 2006, allocates federal monies to qualified career and technical programs that provide training for careers in the long term care workforce, among others. Perkins grants are provided to states that, in turn, allocate funds to both secondary and post-secondary institutions. Eighty-five percent of the monies are needs-based, targeting disadvantaged students and poorer economic regions.

Like the Perkins program, Job Corps and National Registered Apprenticeships – programs administered by the U.S. Department of Labor – aim to integrate technical education and skills with career paths. Job Corps provides free education and vocational training programs to young Americans aged 16 to 24 who commit to job training for careers such as direct care. Participants receive a monthly stipend along with career counseling and transition support. National Registered Apprenticeships provide post-secondary education, employment and training opportunities for participants of any age. Available in most states, these apprenticeships are a joint effort between the federal and state government as well as local businesses, employer organizations, labor groups and educational institutions. The training predominantly occurs in high-growth industries or those like the long term care workforce which face critical skilled worker shortages.

Efforts to create more stringent training standards are another way states are working to recruit and retain their pool of long term care workers. While the federal government requires 75 hours of training for workers to become Certified Nursing Assistants (CNAs), about one-third of U.S. states are mandating additional hours in order for a worker to be considered a CNA within their state.48 This education often involves specialization training to care for patients with Alzheimer’s disease.

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48 Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long Term Care Policy, U.S. Dept. of Health and Human Services, *Recruiting and Retaining a Quality Paraprofessional Long Term Care Workforce: Building Collaboratives with the Nation’s Workforce Investment System*, May 2004.
Some states have experimented with creating “career ladders” to encourage workers to enter the long term care workforce and view caregiving as a lifelong career opportunity. Massachusetts, for example, developed the Extended Care Career Ladder Initiative in response to high turnover rates and lack of caregivers in long term care facilities. The program partnered organizations such as community colleges, workforce investment agencies, unions, and community-based organizations with long term care facilities to raise awareness amongst the long term care workforce and provide opportunities for advancement of an individual’s workforce training.

Creating a career ladder and possibilities for advancement and training makes the caregiving field more appealing to current and future workers. The Institute for the Future of Aging Services (IFAS) has developed a workforce improvement plan that includes recommendations for employers to develop, implement and evaluate career advancement opportunities. IFAS suggests industry-wide partnerships to streamline training and identify best practices. In addition, they propose financial assistance for long term care workers who aspire to become licensed practical nurses (LPNs) or registered nurses (RNs), creating flexible training opportunities that combine work and study, and developing lateral career pathways so workers can move throughout the health care sector or onto more specialized positions.

IFAS also calls for classes through satellite broadcasts or on-the-job training that would make it easier for workers to attend.\textsuperscript{49}

The Assistant Secretary for Planning and Evaluation (ASPE), under the U.S. Department of Health and Human Services (HHS), is a principal advisor to the Secretary of HHS on policy development. ASPE supports increasing the growth potential of the long term care workforce through the creation of career ladders and increased training opportunities.\textsuperscript{50}

**Wages and Benefits**

Because much of the long term care workforce providing services in facilities or through health care agencies is paid for by public funds, the potential for salary increases is limited. As the Paraprofessional Healthcare Institute (PHI) notes in a 2007 report, “[government financing policies] limit the number of new employees that providers are willing to add to the labor pool... assumptions that the private market will take care of workforce shortages without additional public dollars are probably far-fetched.”\textsuperscript{51}

One option for addressing this challenge is increasing Medicaid reimbursement for health care workers. More than a dozen states have instituted a wage pass-through (WPT) policy in an effort to increase worker wages. Under a WPT, reimbursement from a public source of funding – generally Medicaid – is earmarked for supplementing wages and benefits for direct care workers.

\textsuperscript{49} Institute for the Future of Aging Services, National Commission for Quality Long Term Care, *The Long Term Care Workforce: Can the Crisis be Fixed*, January 2007.

\textsuperscript{50} Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long Term Care Policy, U.S. Dept. of Health and Human Services, *Recruiting and Retaining a Quality Paraprofessional Long Term Care Workforce: Building Collaboratives with the Nation’s Workforce Investment System*, May 2004.

\textsuperscript{51} Ibid.
While most agree that improving wages and benefits will require fundamental reforms in the way care is distributed, organizations such as the Institute for the Future of Aging Services (IFAS) have put forth numerous short-term possibilities, such as achieving equality of wages between long-term and acute care; creating a working group of leading health care organizations to provide benefit strategies; and reinvesting savings through reducing temporary personnel.\textsuperscript{52}

The American Association of Homes and Services for the Aging (AAHSA) maintains that retention greatly increases when flexible benefit packages are offered to direct-care workers. These packages may include provisions to subsidize health insurance and allow individuals with incomes up to 300 percent of the poverty line to “buy-in” to Medicaid.

AAHSA also calls for benefits that assist workers with transportation, meals, housing and child care.\textsuperscript{53} The National Commission for Quality Long Term Care (NCQLTC) suggests forming an industry work group to put forth possible benefits solutions, ranging from “pay for performance” proposals to Medicaid wage pass-throughs, discussed in the previous section of this paper.\textsuperscript{54}

Increased benefits will make entering the long term care workforce more appealing to future workers and provide incentives for current workers to remain in the field.

Health Insurance Coverage

Of the more than three million direct-care workers nationwide, one in four lack any health insurance coverage for themselves or their dependents.\textsuperscript{55} Health insurance benefits directly affect retention rates, and researchers have found that health insurance may be even more important than wages in terms of its effect on retention.\textsuperscript{56}

Some states are providing solutions to make employer-based insurance more affordable. In North Carolina, for example, eligible workers receive a monthly subsidy to apply toward their insurance premiums. Maine developed a state-supported health insurance plan in 2005 aimed at small businesses and low-income workers. In seven counties throughout Michigan, a “third share program” called Access Health Plan splits insurance costs between the employer, the employee and the county.

States such as Montana, New York and California have worked to build insurance costs into Medicaid reimbursement. Montana’s Healthcare for Montanans Who Provide Healthcare (HCM) creates an incentive for home care agencies to provide insurance to their workers. Those agencies that provide health insurance receive an enhanced Medicaid reimbursement rate. The program will begin in January of 2009 and is estimated to expand coverage to 1,000 home care workers.\textsuperscript{57}

\textsuperscript{52} Institute for the Future of Aging Services, National Commission for Quality Long Term Care, \textit{The Long Term Care Workforce: Can the Crisis be Fixed}, January 2007.
\textsuperscript{53} American Association of Homes and Services for the Aging, \textit{Issue Brief, Long Term Care Workforce}, March 2007.
\textsuperscript{54} National Commission for Quality Long Term Care, \textit{From Isolation to Integration: Recommendations to Improve Quality in Long Term Care}, December 2007.
\textsuperscript{55} Paraprofessional Health Institute, \textit{The Invisible Care Gap: Caregivers without Health Coverage}, 2008.
\textsuperscript{56} Ibid.
Many states also use Medicaid wage-pass-through policies to provide funding for health care coverage. New York state pays up to $2,500 annually per employee to providers for health insurance coverage, and California’s Medicaid rates include a partial reimbursement for the cost of health insurance to those in its In-Home Supportive Services Program.58

Some states are also experimenting with flexible reimbursement programs. New Mexico’s Health Care Reimbursement Arrangement, for example, is a grant program aimed at assisting direct-care workers with health care expenses. Reimbursements can be used toward health care insurance, prescriptions, and tax-free monthly cash allowances for eligible expenses.

Support Systems
Support groups and organizations for long term care providers come in many forms and are spread across the country.

The Paraprofessional Healthcare Institute (PHI), to name just one, focuses on providing services to the paid long term care workforce. PHI recommends the use of mentors, support groups and recognition days to create a stronger workforce community. PHI also recommends that employers recognize the personal barriers that their low-income workers face. This type of support overlaps with increased benefits and includes assisting the workers with applying for public benefits, providing emergency assistance, and creating child care services.59

The Alzheimer’s Association supports both paid and unpaid caregivers dealing with dementia patients. Alzheimer’s disease presents additional challenges and the Association provides much-needed expert advice.60 There are also many state and local support groups for family caregivers organized through hospitals and non-profit organizations such as the National Alliance for Caregiving and the National Family Caregivers Association. These caregiver support programs are invaluable resources for sharing information and advice, and, for many, provide an environment where unpaid family caregivers can find empathy for their hard work and sacrifices.

Technology is a useful tool for improving efficiency and safety, and many organizations address technology’s role in assisting the long term care workforce as a means to offset some of the need for additional workers. If, for instance, a family currently pays someone to sit with their elderly parent during the workday to essentially make sure he or she doesn’t leave the house, new passive monitoring systems might replace the need to employ the “sitter.” In fact, some such systems are advanced enough to monitor the use of the kitchen stove, alert the family in the event of a slip and fall, and assist in the administering of medicines.

The Institute for the Future of Aging Services (IFAS) recommends government and private investment in information technology to reduce the paperwork burden for long term care providers. Administrators and nurses are often hampered by the amount of paperwork necessary to comply with federal standards. This paperwork severely limits the time they are able to spend leading, motivating and mentoring staff, along with the time necessary for overseeing and providing care.61

The National Commission for Quality Long Term Care (NCQLTC) is also in favor of creating a workgroup between private and public organizations involved in long term care policy to provide a platform for devising technology solutions as well as support to establish these new technologies.62

Passive monitoring systems and other technologies that are the focus of the Center of Aging Services Technologies (CAST) and others essentially allow the elderly to stay in their homes and live more independently, reducing the need for around-the-clock direct care. Such technologies may help contain some of the growing demand for direct-care workers, though it will not alleviate this need altogether. Additionally, CAST notes that misconceptions, inadequate infrastructures and financial incentives to invest in technologies, and a lack of consensus on value hinder the ability for technology to truly take off as a critical component in the future model for the way long term care is provided and perceived in the U.S.

There may be an economic benefit yet to be fully explored that would come with a greater emphasis on the role of technology and how it might offset the workforce shortage. It is reasonable to assume that public programs such as Medicare and Medicaid will save when their beneficiaries require fewer direct-care services due to new or more broadly utilized technologies.


62 National Commission for Quality Long Term Care, From Isolation to Integration: Recommendations to Improve Quality in Long Term Care, December 2007.
OPPORTUNITIES FOR COLLABORATION
AMONG STAKEHOLDERS

Partnerships between public and private entities with a stake in the long term care workforce are critical to addressing the workforce crisis.

One such example is Own Your Future, a joint federal-state initiative led by the U.S. Department of Health and Human Services to increase awareness about the importance of planning for future long term care needs. As of January 2008, 18 states have participated in the Own Your Future campaign, which has provided millions of Americans with important information about long term care planning, services, and financing options.

The States’ Partnership Expansion program is another initiative that helps consumers protect their assets while reducing the burden of increasing long term costs on public assistance programs such as Medicaid.

The Institute for the Future of Aging Services (IFAS) promotes efforts through its proposal to create a new investment fund between private and public organizations that would develop, evaluate and disseminate new ideas for long term care services’ organization and delivery.  

In addition, the U.S. Department of Health and Human Services’ Assistant Secretary for Planning and Education (ASPE), in cooperation with the U.S. Department of Labor, has established opportunities for collaboration between the long term care sector and workforce organizations. These ideas include advertising job openings through America’s Job Bank, participating on state and local Workforce Investment Boards, encouraging local Boards to make long term care training a priority, and including training programs on the eligible provider list. Collaboration would promote on-the-job training and customized training, identify and work with employers to recruit, train, and support staff, and explore avenues for making jobs more attractive.

Certainly there are many more opportunities for stakeholders in the long term care space to collaborate and work together in addressing the caregiving workforce shortage.

Given the experience with Own Your Future and the State Partnerships programs, consumers benefit when private entities partner with government programs. As lawmakers tackle this issue, the role of the private sector and how this role might aid the government from a budgetary and practical standpoint should be closely considered.

64 Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, The Future Supply of Long Term Care Workers in Relation to The Aging Baby Boom Generation, Report to Congress, May 2003.
CONCLUSION

As America faces an imminent workforce shortage in the long term care industry, the cost of care will continue to rise across the board. This will negatively impact millions of Americans and their families who will need these services over the next few decades.

Unless policymakers at the federal, state and local levels work together to provide financial incentives along with some basic job training and support services, the number of qualified long term care workers will continue to decline in relation to the growing need for their services. This is true for both the paid caregiving workforce as well as the millions of unpaid family caregivers who make great personal and financial sacrifices in order to care for their loved ones. Caregivers at both ends of the spectrum need help.

With a rising need for long term care services, the lack of long term care workers will cause demand to reach a tipping point that will mean service shortages and drive costs for the remaining services to ever-higher levels. This, in turn, will result in a rise in the number of unpaid family caregivers, people who are often unprepared to deal with the physical, emotional and financial hardships of caring for a loved one.

Comparatively low wages, lack of benefits, and stressful working environments make attracting and retaining highly skilled and qualified workers to the long term care industry extremely difficult. At the same time, unpaid family caregivers are often lacking adequate support systems and financial assistance. While many programs have had a positive impact at the local level, more remains to be done if we are to successfully meet the projected demand for long term care services.

Successful solutions revolve around addressing the recruitment and retention of workers while providing adequate support systems for both paid and unpaid caregivers. For instance, government-supported education incentives that produce a greater supply of direct-care workers will result in a win-win situation for everyone, whereby more people will enter and remain satisfied in this workforce, making more options available to families as they make their decisions.

The challenges and potential solutions identified in this paper are only the beginning of the long term care workforce shortage dialogue. This discussion requires buy-in from all stakeholders so that our nation can realize meaningful and permanent solutions to the long term care workforce crisis.
**Adult day care** refers to care, health support, or rehabilitative services provided at a center or facility during the day.

**Assisted living care** or **residential care** facilities provide nursing or custodial care in an environment that helps maintain independence and an active lifestyle.

**Direct-care workers**, also referred to as paraprofessionals or formal workers, provide the majority of paid, hands-on care to older adults and Americans with long term care needs.

**Home health care workers** provide home services such as occupational, physical, respiratory, speech therapy, or nursing care. These workers typically include medical, social worker, home health aide, and homemaker services.

**Homemakers** provide household support such as light housekeeping, laundry, shopping, cooking, home management, and similar services.

**Hospice care** is usually provided at home and provides care to alleviate physical, emotional, or spiritual discomforts near the end of life.

**Informal care workers**, also referred to as family caregivers, provide the bulk of long term caregiving in the U.S. They assist with activities of daily living (ADLs), such as bathing, eating, dressing, and other routine activities in addition to providing homemaker services and emotional support.

**Nursing homes** are generally a state licensed facility that provides room and board and a planned, continuous medical treatment program, including 24-hour-per-day skilled nursing care, personal care, and custodial care.