

The Need for National Training Standards/Guidelines for Privately Paid Geriatric Home Caregivers

Introduction

Margaret, a 78-year-old widow who lives alone, is normally up and ready for breakfast by 7 A.M. Today, however, she was still asleep when the in-home private duty caregiver arrived at the house. When the caregiver checked on her, Margaret said she wanted to sleep. The caregiver, who has cared for older adults for many years, but who has had no formal caregiver training, assumed Margaret must be more tired than usual this morning and left her alone. She cleaned the house and the kitchen as usual and left without taking further action. The next day, Margaret's daughter came by to find her mother still in bed. Margaret was admitted to the hospital with a urinary tract infection.

What if Margaret's caregiver had been professionally trained? A trained caregiver would be alert to such changes in behavior. The caregiver would recognize that increased sleepiness was an indication that something might be wrong with her client. She would have immediately notified Margaret's daughter. Later, she would have learned that Margaret had a urinary tract infection, and that she could remain at home after being placed on antibiotics.

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Fred, an 83-year-old retired businessman, relies on in-home private duty home care several hours each day. Today, however, when his caregiver arrived he was uncharacteristically disheveled, acted as if she were a stranger, and gruffly told her he didn't want her there. The untrained caregiver documented that services were refused and went on to her next client, while Fred was left alone until the next morning. Fred was later hospitalized, with dehydration and delirium.

What if Fred’s caregiver had been professionally trained? When told that she wasn’t needed, a trained caregiver would be alert to the fact that Fred had never refused services before. She would have realized that this change in behavior could be indicative of a change in his medical condition and immediately informed Fred’s daughter-in-law. Later, she would have learned that Fred was taken to his doctor quickly, diagnosed with dehydration and delirium, and sent home with the treatment he needed.

* * *

These examples are typical of events occurring every day in homes across America that compromise the health, safety, and quality of life of older adults in their own homes. In many cases the results are even more extreme—death or permanent loss of functional independence due to caregiver ignorance and/or poor caregiver training. The fact is that in-home caregivers are often untrained and yet they are helping family caregivers provide care for the vast majority of older Americans who are currently “on their own” when they need long-term care—the private (self-pay) sector.

Over the next 40 years there will be at least *4 times* as many older Americans as there are today. America’s 85+ population—the group most likely to need caregiving—will soar from 4.3 millions to 20.9 millions by 2050.¹ Along with increased longevity, this rapidly increasing number of frail adults will have more chronic diseases than any previous generation in history, and will present with progressively complex caregiving issues that require a higher level of care to enable them to stay at home safely, and to maintain functional independence.

Contrary to public opinion, America’s institution-centered long-term care (LTC) system does not serve the majority of older adults. Currently, nursing homes serve less than 20% of older adults needing care,² and thus do not provide a viable solution for future caregiving needs. While these LTC institutions will continue to play an important role in providing care for our most frail older adults who need skilled nursing and/or medical care, they will not be necessary for the vast majority of older adults who simply need nonmedical caregiving, that is, help with activities of daily living. There is, and will continue to be, an urgent need for a large cadre of trained caregivers for older adults who live at home.

Unfortunately, the large majority of today’s in-home caregivers are not trained to provide this advanced level of care. Regulations that govern caregiver training for the aged vary from state to state and apply almost exclusively to long-term care facilities and home health companies that accept Medicare/Medicaid reimbursement. Some states have now extended these training regulations to include caregivers who are employed by private home care agencies.³ *But no consistent national standards/guidelines exist for the training of caregivers who are privately hired and privately paid to care for older adults in a home environment.* There is a critical need for minimal national standards/guidelines for the training of privately hired, privately paid in-home caregivers for older adults.

2 *Preparing for an Aging Nation: The Need for National Training Standards/Guidelines for Privately Paid Geriatric Home Caregivers*

The Need for National Training Standards/Guidelines for Privately Paid Geriatric Home Caregivers

By Larry D. Wright, M.D.

How do trained in-home caregivers for older adults differ from untrained caregivers?

Trained in-home caregivers for older adults are equipped to accomplish caregiving responsibilities based on best practices and quality standards. They are trained to detect and report changes in the condition or physical/emotional status of an older adult, and to take appropriate action when care issues arise. These caregivers are professionals who deliver care with respect, compassion, integrity, empathy, advocacy, and responsibility, and, because of their training, can communicate and interact with the care recipient's family and any other members of the caregiving team involved in the coordination of care. Trained caregivers have passed both a written exam and practical skills competency evaluations at the level for which they have been trained.

In contrast, untrained or minimally trained caregivers may not fully understand the health and safety issues involved in caring for older adults, including such risks as falls, pressure ulcers, and changes in behavior that provide a warning signal to a trained caregiver. The dangers of untrained caregivers are exacerbated by the fact that many in-home geriatric caregivers work alone and without professional supervision.

What are the differences between the two current systems of non-medical caregiving in America—public-pay caregiving and private-pay caregiving?

Many older Americans erroneously believe that the government will help pay for their long-term care, either at home or in an institutional setting. This is true only if they qualify for Medicaid. (Medicare covers short-term post-acute caregiving, but not long-term care.) The vast

majority of older Americans are on their own when it comes to finding, managing, and paying for long-term care, including their in-home caregivers. Over eighty percent of all older Americans pay for their own long-term care,² usually at home, where family caregivers provide most care, with support from volunteer and/or paid caregivers.

Currently, a large majority of caregivers who work in the home and care for the majority of all older adults are untrained and inadequately prepared to deliver caregiving that enhances the safety, functional independence, and their quality of life.

By contrast, the highly visible and highly regulated long-term care public-pay sector serves less than 20%² of all older Americans—those older adults who qualify for Medicaid financial assistance for long-term care in any setting, including the home. As a result of government programs and public funding, public-pay caregiving is much more structured and regulated than private-pay care. A mandated minimum amount of caregiver training is required whenever Medicare/Medicaid is involved. All 50 states base their caregiving training on Medicare/Medicaid standards and regulations and then customize their own state regulations, which vary greatly. Further, these required training minimums are generally designed to prepare caregivers to work under professional supervision in a nursing home or for a home health agency⁴ and do not apply to private-paid in-home care. Any changes that would bring about uniform national training standards to address in-home geriatric caregiving are years, if not decades, in the future, since they will require public policy discussions and national and/or state-by-state legislative and regulatory action.

Why will the caregiving crisis be one of our nation's most critical challenges during the early decades of the 21st Century?

The caregiving crisis is occurring because there are too few caregivers, both paid and unpaid, and too many older people needing care. Demographic and social trends are reducing the available pool of family caregivers at the same time that the number of older adults needing care is rising. The caregiving industry, meanwhile, is experiencing a growing shortage of paid paraprofessionals. Affordable, quality in-home private-pay caregiving is increasingly difficult—if not altogether impossible—to find.

America is aging rapidly—the first wave of the 77 million Baby Boomers turned 60 in 2007. The fastest-growing segment of our population over the next three decades will be those over 65, more than doubling the number of older adults. How we provide caregiving for the largest, longest-living group of older adults in human history is, and will continue to be, one of our nation's most critical problems during the first half of the 21st century. Over the coming decades, we will need between 5.7 and 6.6 million caregivers.⁵

Institutional long-term care

In the 20th century America applied the tenets of industrialization to the problem of aging by creating a long-term care system that was institutionally based. The outcomes of this social experiment have been witnessed by today's older adults and Baby Boomers; consequently, most of them prefer to age at home rather than being moved to a nursing home or assisted living facility. They share the conviction of Lawrence Schmieding, CEO of the Schmieding Center for Senior Health and Education, who states, "At home there's always hope." Since our long-term care institutions will be overwhelmed by the sheer number of older adults who will need care now and in the future, the vast majority of older adults will age at home, both by choice and by necessity.

In-home long-term care

Currently, about 40 percent of people over 60 and 1.9 million paid caregivers share the burden of providing in-home care for old and frail Americans.² These statistics do not reflect the significant number of people who go completely without the help they need.

To make matters worse, over the next 40 years there will be at least *4 times* as many persons age 60 and older as there are today. America's 85+ population—the group most likely to need caregiving—will increase from 4.3 millions to 20.9 millions by 2050.¹

Most of these vulnerable older persons will remain at home for their long-term care where most will require competent assistance. Our country already suffers from a critical shortage of knowledgeable, trained in-home caregivers. Where will the necessary caregivers come from? Will they be prepared to deliver the levels of competent care older Americans deserve?

The myth of "trained" in-home caregivers

In a recent Harris Interactive survey, conducted for *The Caregiving Project for Older Americans*, 78% of people polled said they believed their caregivers had formal training. This is a misconception. The truth is that privately paid in-home caregivers today are usually unskilled or poorly trained. Unlike many other service occupations (cosmetologist, barber, hairstylist, to name a few), the U.S. has no national training requirements for privately paid caregivers. Neither independent contractors who work as in-home paid caregivers, nor caregivers who receive training through their home care agency or community program must adhere to national standards if they are privately paid. While there are noteworthy exceptions, training for most of these caregivers is often non-existent or haphazard. It is also important to note that currently 23 states require private duty home care agencies to be licensed, but licensure does not ensure that their employees are adequately trained.⁶

National in-home caregiver training standards/guidelines will help insure the delivery of the higher level of in-home care required.

Many geriatric professionals believe that caregiving for older adults is different from caregiving for disabled younger adults or children and that it requires a specialized training and attitudinal approach. Older adults have unique, age-specific physical, mental and social changes and vulnerabilities. Some specific examples of such differences in older adults include skin fragility, balance problems, drug interactions, incontinence, and dementia, as well as a multiplicity of stressors that often result in functional decline.

For optimal care, it follows that national standards and subsequent training should be specifically designed to meet the needs of older adults in a home setting rather than the “universal” caregiver training generally used to train public-pay caregivers working in institutional settings. National caregiver training standards/guidelines that reflect age-specific standards of care are necessary for the delivery of quality long-term care for older adults who pay for their own care in a home environment

Also, caregiving in a home setting is very different from institutional caregiving. The home environment is less equipped, less organized, less structured and unsupervised by healthcare professionals—leaving the frail aged at greater risk.

For these and other reasons, many geriatric experts believe that caregiving for an older adult at home actually requires *more hours* of training and *more specialized* training than caregiving within a structured institutional setting. Home caregivers must make decisions without supervision or support that affect the quality of life and safety of older adults.

In addition, training for in-home geriatric caregivers should be tailored to the different levels of need to be found in older adults. While some older adults need only a companion, others need some personal care and still others require higher levels of non-medical personal care. One size does not fit all! Therefore, having training standards/guidelines matched to the levels of required care will maximize quality of care while minimizing the costs of training.

The private-pay sector is the first and most urgent priority for the establishment of national in-home caregiver training standards/guidelines.

There are compelling reasons for developing national in-home caregiver training standards/guidelines for privately hired, privately paid in-home caregivers. This group serves the majority of older adults needing caregiving assistance and it is presently without uniform standards or training requirements. The setting of national standards/guidelines for private in-home caregiver training, expressed through accredited curricula and caregiver certification, can proceed much more quickly than would be possible in the public arena.

In the public-pay sector both custodial (nonmedical) and skilled (medical) caregivers work under the supervision of nursing professionals and are required to have some training if the organization accepts Medicare/Medicaid reimbursement.

Creating national training standards/guidelines for the private-pay in-home caregiver will not only contribute to the assurance of basic quality of care in the home, it will also help educate families and older adults as to what is required for home care that is minimally supervised and what expectations they should have.

How it can be done

1. Develop and implement national training standards/guidelines for the training of privately hired, privately paid in-home caregivers for older adults.

The national training standards/guidelines will be structured to include both core caregiving competencies and specific content for the care of older adults in the home environment. These minimum standards/guidelines will be foundational in developing training curricula that properly prepare both independent contractors and those who work for home care agencies to provide professional caregiving for older adults in the home. (Please note that home care agencies are not the same as home health agencies⁴ that accept Medicare/Medicaid reimbursement and are subject to public-pay regulations.)

2. Promote voluntary adoption of the national caregiver training standards/guidelines by both independent contractors and by private home care agencies.

Compliance with private sector national caregiver training standards/guidelines will be voluntary because they will not carry the force of law, unlike the public sector Medicare/Medicaid requirements. It is likely that independent contractors and home care agencies will comply with these new national standards, both as a matter of self-interest and to protect their customers and the general public. Home care agencies may well avoid over-regulation by self-policing the quality of in-home caregivers they provide to private-pay customers. Otherwise, these private-sector businesses face the forced imposition of expensive and burdensome state/federal regulations, which were originally intended for the highly regulated public-pay sector. The unintended consequences of such regulations would include increasing the cost of caregiving for families and reducing their access to the

kinds of nonmedical caregiving families need. Similar “voluntary” compliance with training standards has been effective in comparable situations, such as the National Association of Professional Geriatric Care Managers and in the specialty of Palliative Care.

3. Establish a national organization to provide support for privately hired, privately paid geriatric in-home caregivers.

An organization, whether newly created or in partnership with existing entities, will oversee accreditation of training curricula that meet national caregiver training standards/guidelines, certification of graduates, official nomenclature, continuing education, and education pathways, while providing support and benefits for privately paid in-home caregivers.

4. Educate the general public about the benefits of trained in-home caregivers.

A key factor in improving the quality of in-home caregiving is educating and building awareness among families regarding the benefits of trained caregivers for their loved ones, the minimum level of training they should expect, where to find trained caregivers, and how to evaluate whether or not a prospective caregiver is qualified. As families learn more about the benefits of competent caregiving, their appreciation for trained paid caregivers will be enhanced. Families will continue to be free to hire any independent contractor they choose to provide care for older adults in the home; as they have better information, more options, and improved access, many families will insist upon trained caregivers.

Obstacles

How will America fund the creation and implementation of national training standards/guidelines for private pay in-home caregiver training? Who will pay for the training itself? Who will oversee the quality of private in-home caregiving without the mandatory carrot/stick of reimbursement/regulation implicit in public funding? There are major barriers to be overcome in the process of providing national caregiver training standards/guidelines for private-pay in-home caregivers:

1. Over-regulation

A growing threat to private-pay caregiving is the imposition of restrictive government regulations upon private businesses and non-profit agencies who deliver nonmedical in-home caregiving services direct to the

consumer. Such regulations were originally intended for the public-pay, institutional long-term care environment, not for the private-pay home environment. But in a growing number of states, private home care agencies that provide in-home caregivers directly to the consumer are not only being licensed (23 states) and are also being burdened with regulations designed for the institutional environment.

This regulatory approach effectively expands the public-pay, institutionally-based caregiving system, including its concomitant regulations and restrictions, into the home environment. A highly regulated approach to in-home caregiving may be appropriate when applied to low-income older adults whose in-home caregiving is provided by the public sector and paid for with public funds. However, such regulation is inappropriate when it affects the private-pay majority of America’s older adults who are responsible for their own long-term care and who receive no financial or other government support. The negative impacts of such regulation almost certainly include higher nonmedical caregiving costs, layers of institutional bureaucracy, and reduced access to competent in-home caregivers for the private-pay majority of older adults.

An alternative is the government *deregulation* of the private, nonmedical in-home caregiving sector, along with the creation of a private-sector/non-profit partnership to provide more appropriate national training standards/guidelines for privately paid geriatric home caregivers. A private non-profit organization will oversee accreditation of training curricula that meet the national in-home caregiver training standards/guidelines and certification of graduates. Older adults and their families will continue to have the right to hire anyone they choose to provide nonmedical caregiving in their own homes—whether they hire those caregivers directly or through a home care agency (either privately-owned or non-profit).

2. Funding

Public funding for geriatric caregiving, whether institutional or home-based, is primarily focused on low-income older adults who qualify for Medicare/Medicaid financial assistance. It will require a private/public partnership to create and provide national training standards/guidelines for privately paid geriatric home caregivers. Funding leadership must come from foundations, major corporations, communities, social entrepreneurs, and from federal/state government programs such as workforce development and consumer-directed care.

There are compelling incentives for private/public partnerships that combine for-profit companies, non-profit organizations, and government programs to fund the infrastructure for the private caregiving sector. Many of America's largest and most influential for-profit and non-profit organizations are already deeply involved in finding solutions to the problems of aging and caregiving. They will rally around a realistic proposal for improving in-home caregiving for the majority of older Americans who are definitely on their own when it comes to long-term care.

3. Oversight and compliance

The successful creation and implementation of national training standards/guidelines for privately paid geriatric home caregivers depends on a national accrediting and caregiver certifying organization that provides oversight/compliance standards for the private geriatric caregiving arena.

Both independent contractors and home care agencies will rally around the training standards/guidelines and the oversight organization as a matter of self-interest. Self-policing the performance of trained in-home caregivers is absolutely necessary for the private home care industry to grow successfully and to avoid over-regulation by federal/state governments.

Notes

1. Richard W. Johnson and Joshua M. Wiener, "A Profile of Frail Older Americans and Their Caregivers," Urban Institute, Occasional Paper Number 8, February 2006.
2. Of 10.1 million adults age 65+ needing long-term care in 2002, 1.4 million resided in nursing homes and 8.7 million (86%) lived at home. Only 15.5% of older adults needing long-term care receive public assistance through Medicaid. Source: "A Profile of Frail Older Americans and Their Caregivers." The Retirement Project, Urban Institute, February 2006. According to the study: "In 2002, about 8.7 million at-home people age 65 and older, or 26.5 percent of the population, had at least one ADL or IADL limitation. About 6.1 percent of these, or 2.0 million people, were severely disabled, with three or more ADL limitations. By comparison, about 1.4 million older adults resided in nursing homes." Further, "In 2002, only 15.5 percent of frail older adults and 27.3 percent of those with severe disabilities had Medicaid coverage."
3. **Home care agency** This term is commonly used to refer to any agency that provides services to people in their own homes. As such, it is too broad to be helpful. In this paper it is used as a synonym for *home caregiving agency*, which is defined as any organization providing nonmedical, in-home caregiving services. It is distinct from a *home health agency*. Home caregiving agencies do not accept Medicare/Medicaid reimbursement, and so provide *self-pay* nonmedical caregiving. Most home caregiving agencies (sometimes called Homemaker or Home Care Aide Agencies) recruit, train, and supervise their personnel and thus are responsible for the care rendered. Some states require these agencies to be licensed and meet minimum standards established by the state.
4. **Home health agency** An agency that is certified to receive reimbursement as a home health agency under Medicare has met federal minimum requirements for patient care and management and therefore can provide Medicare and Medicaid home health services. Individuals requiring skilled home care services usually receive their care from a home health agency. Certified home health agencies must offer at least two of six specific services: nursing, physical therapy, occupational therapy, speech therapy, medical social work, and home health aides. Home health agencies recruit and supervise their personnel; as a result they assume liability for all care. Due to regulatory requirements, services provided by these agencies are highly supervised and controlled.
5. "In-home Caregiving for Older Adults: A Reality Check," Robert N. Butler, M.D., EONS, <http://www.eons.com/love/feature/parentcare/inhome-caregiving-for-older-adults/15206>.
6. "Private Duty Today" Magazine Website, Non-Medical Home Care Company Licensing Requirements: State-by-State Guidelines for Private Duty Home Care, <http://www.privatedutytoday.com/licensing.htm>.

This issue brief is adapted from an online report available at www.schmiedingcenter.com.

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The Caregiving Project for Older Americans is an action-oriented collaboration that aims to improve the nation's caregiving workforce through training, the establishment of standards, and the creation of a career ladder. Bolstering support for family caregivers is another major goal of the project. A joint venture of the International Longevity Center-USA (ILC-USA) and the Schmieding Center for Senior Health & Education (SCSHE), the effort combines the talents of a policy research center with a clinical outpatient and health education program.

The Schmieding Center for Senior Health and Education of Northwest Arkansas, located in Springdale, Arkansas, provides older adults and their families with education, health care, information resources and other services for more positive aging. Education services include unique in-home caregiver training programs, public programs on positive aging, and professional programs to improve the geriatric expertise of health care professionals and students. Health care services include comprehensive clinical care and rehabilitation by an interdisciplinary team of geriatric professionals. The Schmieding Center is a partnership of the University of Arkansas for Medical Sciences Donald W. Reynolds Institute on Aging, the Area Health Education Center-Northwest, and Northwest Health System.

The International Longevity Center-USA is a non-profit, non-partisan research, education, and policy organization whose mission is to help individuals and societies address longevity and population aging in positive and productive ways, and to highlight older peoples' productivity and contributions to their families and society as a whole. The organization is a part of a multinational research and education consortium, which includes centers in the United States, Japan, Great Britain, France, the Dominican Republic, India, South America, Argentina, the Netherlands and Israel. These centers work both autonomously and collaboratively to study how greater life expectancy and increased proportions of older people impact nations around the world.



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This issue brief was developed under the auspices of the Caregiving Project for Older Americans and made possible by the generous support of MetLife Foundation