In 2016, the Home Care Association of America and the Global Coalition on Aging authored *The Value of Home Care Report* to showcase the positive impacts of home care (most often referred to as personal care provided in a private home) on individual care recipients, their families, health care systems and overall economic growth. In that report, we highlighted home care’s increasing value to the healthcare system and the unique role it plays in keeping older Americans and those living with disabilities safe in their homes. Five years and one global pandemic later, the words in that report ring true more than ever. Since the early days of the pandemic, home care workers were deemed essential in all 50 states, going to great lengths and taking on great personal risks to do the jobs they committed to do and keeping people safe and healthy at home.

Yet the pandemic also revealed that our healthcare and long-term care systems were overwhelmed and under-prepared. Healthcare systems had only a limited supply of ventilators, pulse oximeters and intensive care units. Personal protective equipment (PPE) for healthcare and other essential workers was hard to come by.

**Worst of all, the loss of life among older Americans has been harrowing.**

According to AARP, 95 percent of all American COVID-19 deaths were among people 50 and older, and approximately 40 percent of all deaths were in long-term care (nursing home, skilled nursing and assisted living) facilities. Throughout the pandemic, the importance and value of care in the home, especially for older Americans at risk of worsening physical health and social isolation, have come into clear focus.

I am proud that Home Care Association of America members and so many in the home care sector stepped up during these dark and frightening times – taking the actions necessary to keep their clients safe, while balancing the need to keep their families healthy and safe as well. The pandemic shined a light on how older and vulnerable populations are too often left behind. The home care industry is at a crossroads. It is our hope that this rising awareness emerging from the global crisis will create momentum for policymakers across the country to address these faults in our healthcare system. For the home care industry, it has only strengthened our focus on redoubling efforts to provide quality care and keep older Americans in their homes and safe. With greater awareness and smarter policies, home care can and will be a powerful solution to support and alleviate these issues for decades to come.

**THROUGHOUT THE PANDEMIC, THE IMPORTANCE AND VALUE OF CARE IN THE HOME, ESPECIALLY FOR OLDER AMERICANS AT RISK OF WORSENING PHYSICAL HEALTH AND SOCIAL ISOLATION, HAVE COME INTO CLEAR FOCUS.**

Vicki Hoak, CEO
Home Care Association of America
In 2016, the Home Care Association of America and the Global Coalition on Aging authored a report on the role it plays in keeping older Americans and those living with disabilities safe in their homes. Five years and one global pandemic later, the words in that report are even more relevant.

Supply of ventilators, pulse oximeters and other essential workers was hard to come by. Healthcare systems had only a limited supply of personal protective equipment. They were overwhelmed and under-prepared. Healthcare workers – who work for agencies receive professional training to enable them to assist with medical and other activities. Home care workers – also known as professional caregivers, personal care aides or direct care providers for this type of personal care. Home care services are provided by large, multi-state organizations, franchises and independently owned agencies. Medicaid, the Veteran’s Administration and Medicare Advantage plans may also reimburse home care for the elderly.

In this report, we refer to this vital and growing segment of the workforce as “home care professionals” or “professional caregivers.”

In this report, we showcase the positive impacts of home care on individual care recipients, their families, health care systems and overall economic growth. In that report, we also referred to the importance and value of home care.

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Home Care: A Sector Meeting the Needs of America’s Aging Society

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HOME CARE
A SECTOR MEETING THE NEEDS OF AMERICA’S AGING SOCIETY

SECTION 1

Home care, often referred to as personal care, helps older adults maintain healthy, active lifestyles for as long as possible.

State organizations, franchises and independently owned agencies.

Medicaid, the Veteran’s Administration and Medicare Advantage plans may also reimburse services to keep people at home for as long as possible.

In this report, we refer to this vital and growing segment of the workforce as “home care professionals” or “professional caregivers.”

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While not typically medically certified, home care workers serve as an additional set of “eyes and ears” for families, helping to ensure older adults’ safety by recognizing and alerting family members and health care professionals to potential signs of declining health.

Home care workers – also known as professional caregivers, personal care aides or direct care workers – who work for agencies receive professional training to enable them to assist with activities of daily living (ADLs) such as bathing, dressing, meal preparation, eating, and other activities.

Home care services do not require referrals from health care professionals; they are sometimes referred by hospitals and more often sought by families when taking care of an ill or aging loved one.

Home care services are provided by large, multi-state organizations, franchises and independently owned agencies.

While home care in the U.S. is regulated differently from state to state or not at all, the Home Care Association of America (HCAOA) supports state oversight to provide consumer protections and help ensure quality care.

In some states, HCAOA has developed its Code of Conduct, a framework that serves as a basis for delivering high-quality care. The Code includes such standards as supervision, criminal background checks, appropriate insurances and adherence to a care plan. This is an important step in ensuring more care and better care is being delivered to keep people at home for as long as possible.

Quality care. The Code includes such standards as

Absence of national standards and the lack of regulation in some states are important reasons why the Home Care Association of America (HCAOA) has developed its Code of Conduct, a framework that serves as a basis for delivering high-quality care. The Code includes such standards as supervision, criminal background checks, appropriate insurances and adherence to a care plan. This is an important step in ensuring more care and better care is being delivered to keep people at home for as long as possible.
Differentiating Home Care

In America, there are three types of care consumers can receive in their homes: home care, home health and hospice. Even among doctors and discharge planners, home care is often confused with home health or hospice care, but it is typically provided before these services are needed or after an acute care incident, injury or a chronic disease diagnosis to monitor conditions so older adults and individuals with disabilities can remain at home as they age. Home care services do not require referrals from health care professionals; they are sometimes referred by hospitals and more often sought by families when taking care of an ill or aging loved one who requires additional assistance from a trained caregiver.

### Home-Based Care

<table>
<thead>
<tr>
<th>Home Care</th>
<th>Home Health</th>
<th>Hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>WHAT TYPE OF CARE?</strong></td>
<td><strong>WHO DECIDES?</strong></td>
<td><strong>WHO PROVIDES?</strong></td>
</tr>
<tr>
<td>• Long-term, continuous care</td>
<td>• Individuals and families</td>
<td>• Individuals and</td>
</tr>
<tr>
<td>• Assistance with activities of daily living</td>
<td>• Health care professionals</td>
<td>families (primarily)</td>
</tr>
<tr>
<td>(such as bathing, dressing, medication</td>
<td>• Must be homebound</td>
<td>• Hospice nurses,</td>
</tr>
<tr>
<td>reminders, etc.);</td>
<td>• Physician order and plan of care required</td>
<td>social workers and</td>
</tr>
<tr>
<td>• Care for people with chronic conditions</td>
<td></td>
<td>hospice aides</td>
</tr>
<tr>
<td><strong>WHO PAYS?</strong></td>
<td><strong>WHO PROVIDES?</strong></td>
<td><strong>WHO PAYS?</strong></td>
</tr>
<tr>
<td>• Individuals and families</td>
<td>• In states where home care is licensed,</td>
<td>• Medicare</td>
</tr>
<tr>
<td>• No homebound requirement or physician order</td>
<td>professional caregivers are vetted, trained,</td>
<td>• Medicare</td>
</tr>
<tr>
<td>requirement</td>
<td>and insured by home care agencies</td>
<td>• Medicaid</td>
</tr>
<tr>
<td><strong>WHO PROVIDES?</strong></td>
<td><strong>WHO PAYS?</strong></td>
<td>• VA</td>
</tr>
<tr>
<td>• Health care professionals</td>
<td>• Medicare</td>
<td>• Medicare</td>
</tr>
<tr>
<td>• Must be homebound</td>
<td>• Medicaid</td>
<td>• Medicaid</td>
</tr>
<tr>
<td>• Physician order and plan of care required</td>
<td>• Hospice nurses, social workers and hospice</td>
<td>• VA</td>
</tr>
<tr>
<td><strong>HOME-BASED CARE</strong></td>
<td>aides</td>
<td></td>
</tr>
</tbody>
</table>
Defining Home Care

Home care, often referred to as personal care, helps older adults maintain healthy, active lifestyles for as long as possible in the comfort of their own homes. Home care has emerged as a valuable solution to fill gaps created by traditional care models, including hospitals, nursing homes, and home health.

Home care workers – also known as professional caregivers, personal care aides or direct care workers, or in some cases, certified nursing assistants (CNAs) – who work for agencies receive professional training to enable them to assist with activities of daily living (ADLs) such as bathing, dressing, meal preparation, eating, transportation, running errands, and light housework. Most importantly, these caregivers provide vital companionship and mental stimulation by engaging their clients in conversation and other activities.

While not typically medically certified, home care workers serve as an additional set of “eyes and ears” for families, helping to ensure older adults’ safety by recognizing and alerting family members and health care professionals to potential signs of declining health.

In this report, we refer to this vital and growing segment of the workforce as “home care professionals” or “professional caregivers.”

Services to Keep People at Home as They Age

Home care is primarily paid for privately – by care recipients and families. However, today Medicaid, the Veteran’s Administration and Medicare Advantage plans may also reimburse providers for this type of personal care. Home care services are provided by large, multi-state organizations, franchises and independently owned agencies.

While home care in the U.S. is regulated differently from state to state or not at all, the Home Care Association of America (HCAOA) supports state oversight to provide consumer protections and help ensure quality care. In the absence of national standards and the lack of regulation in some states, HCAOA has developed its Code of Conduct, a framework that serves as a basis for delivering high-quality care. The Code includes such standards as supervision, criminal background checks, appropriate insurances and adherence to a care plan. This is an important step in ensuring more care and better care is being delivered to keep people at home for as long as possible.
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The Ever-Increasing Need for Care at Home

**An Aging America.**

By 2040, nearly 81 million people in the U.S. will be 65 years older, compared with 77 million under the age of 18. This means that America will soon consist of more old than young. Through modern medicine and healthier lifestyles, average U.S. life expectancy has increased from 68 years in 1950 to 78.6 years in 2017. While life expectancy has declined by more than a year due to the COVID pandemic, the miracle of longevity remains an event to be celebrated. But it also raises new challenges that our healthcare system must be aligned, or realigned to address.

Someone turning 65 today has nearly a 70 percent chance of needing long-term care and support, according to the U.S. Department of Health and Human Services. One out of five will need care for more than five years. The need for care increases with age. In 2018, the percentage of older adults aged 85 and older who needed help with personal care (21%) was more than twice the percentage for adults ages 75–84 (8%) and five times the percentage for adults ages 65–74 (4%). America’s new age dynamics show a surging need among older adults for the highest-quality care. And if most get their preference, that care will happen primarily in their own homes.

**Chronic Conditions Drive Care Needs.**

With aging comes an increase in chronic conditions, but with proper treatment, prevention and care, these conditions need not be inevitable as one grows old. Right now, roughly six in 10 Americans aged 65 and up have at least one chronic condition, such as obesity, diabetes, or hypertension. About 40 percent have two or more. Then there’s the growing wave of people with Alzheimer’s disease and other forms of dementia.

Already, more than 5 million Americans are living with Alzheimer’s. Absent a medical breakthrough, that could hit 14 million by 2050. And three-quarters of people living with Alzheimer’s require assistance to handle the tasks of daily living.

**A Desire to “Stay Put.”**

The vast majority of older Americans want to age at home for as long as possible. However, just 59 percent believe they will actually be able to stay local either at home (46 percent) or elsewhere in their community (13 percent).

**Adult Children Are Less Able to Support Aging Parents.**

Traditionally, older adults have relied on family members for help in dealing with the challenges of aging. This requires a safety net of a family caregiver living nearby. Most seniors don’t have that safety net.

Twenty percent of adult children live more than two hours away by car from their parents. Only about one-third of American families with adult children have all family members within 30 miles, leaving the other two-thirds without family support.

**The Family Caregiving “Balancing Act.”**

Many family caregivers are under severe stress – especially those in the “sandwich generation” who must balance the demands of raising children and caring for aging loved ones. The COVID-19 pandemic has only deepened that stress.

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On September 22, 2021, the Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council submitted its initial report to Congress outlining 26 recommendations to address how the federal government, state governments, and communities - in partnership with the private sector - can recognize and support family caregivers. This roadmap serves as a call to policymakers that America’s caregivers must be supported through a strategy including greater adoption of person- and family-centered care in all healthcare and long-term care settings.
“If you’re at home with someone, you’ve got challenges related to family dynamics. You might have kids coming home from college and trying to engage in remote learning, you might be trying to work remotely, or you might be an essential worker so that you’re coming in and out of the home and there’s that risk of contagion, and you may not have access to respite. So here you are trying to do all this care work, and you’re not really able to get a break, you’re not able to get some time to yourself. It’s that much more intense if you’re caring for someone with a healthcare need or disability.”

- Grace Whiting
Former Chief Executive Officer
National Alliance for Caregiving

Who Uses Home Care?

While home care serves people with illnesses and disabilities of all ages, the majority of home care recipients are older people with an average age of 69.14

Among care recipients aged 65+, more than two-thirds (69 percent) have long-term physical conditions, 39 percent have memory problems, and 21 percent have emotional or mental health issues.15

<table>
<thead>
<tr>
<th>Problem/Illness</th>
<th>Age 18-49 (N=188)</th>
<th>Age 50-64 (N=256)</th>
<th>Age 65+ (N=944)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s, dementia</td>
<td>2%</td>
<td>2%</td>
<td>15%</td>
</tr>
<tr>
<td>Back problems</td>
<td>8%</td>
<td>10%</td>
<td>3%</td>
</tr>
<tr>
<td>Cancer</td>
<td>6%</td>
<td>7%</td>
<td>6%</td>
</tr>
<tr>
<td>Developmental or intellectual disorder/disability</td>
<td>13%</td>
<td>1%</td>
<td>-</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2%</td>
<td>8%</td>
<td>3%</td>
</tr>
<tr>
<td>Heart disease or attack</td>
<td>1%</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>Mental/emotional illness</td>
<td>15%</td>
<td>7%</td>
<td>2%</td>
</tr>
<tr>
<td>Mobility issues</td>
<td>7%</td>
<td>10%</td>
<td>13%</td>
</tr>
<tr>
<td>&quot;Old age,&quot; frailty</td>
<td>-</td>
<td>4%</td>
<td>23%</td>
</tr>
<tr>
<td>Stroke</td>
<td>1%</td>
<td>6%</td>
<td>5%</td>
</tr>
<tr>
<td>Substance abuse</td>
<td>5%</td>
<td>3%</td>
<td>-</td>
</tr>
<tr>
<td>Surgery, wounds</td>
<td>4%</td>
<td>12%</td>
<td>5%</td>
</tr>
</tbody>
</table>
Value of Home Care

In *Caring for America’s Seniors: The Value of Home Care*, we clarified the important benefits of home care as an emerging contributor to healthcare, the nation’s economy, individuals and families.

Home Care Improves the Lives of Older Adults

Professional caregivers help seniors lead more vibrant, independent lives. They provide a range of services that serve as a lifeline for seniors while keeping them safe, healthy, engaged, and active. Important benefits of home care include:

- *Preventing falls and other common injuries* (the leading cause of non-fatal injuries, hospital admissions, and death for Americans over 65);
- *Promoting medication adherence* (a problem for roughly 50 percent of seniors);
- *Reducing loneliness and social isolation and promoting stimulation and companionship* (which can contribute to depression & dementia);
- *Facilitating social engagement and community connections* (keeping seniors more active and engaged).

Length of Time as Family Caregiver

<table>
<thead>
<tr>
<th>Length of Time</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>1-3 years</td>
<td>33%</td>
</tr>
<tr>
<td>3-5 years</td>
<td>44%</td>
</tr>
<tr>
<td>5+ years</td>
<td>24%</td>
</tr>
</tbody>
</table>

Home Care Relieves Stress and Burden on Families

Caregiving can exhaust family members and loved ones who often work full-time in addition to providing care. Today, close to 42 million Americans already serve as family caregivers for someone age 50 and up. Sixty percent of family caregivers work full-time, creating challenging work/life balance issues.

On average, family caregivers spend 23.7 hours per week providing care. And caring for a loved one is often a long-term proposition.

One-third of family caregivers have been providing care for one to three years, 44 percent, for more than three years, and 24 percent for five or more years. This imposes a high toll on family caregivers’ physical and emotional health.

By reducing the time, stress, and workload, professional caregivers can help build stronger relationships among care recipients and their families – allowing caregiving children time to be a son or daughter, and not only a caregiver.
Home Care Benefits America’s Health System Through Lower Costs

Home care has shown to be cost-effective when compared to nursing home care and when compared to not having professional care interventions at all. In 2020, the typical annual cost of in-home care for seniors was about $55,000 for an average of 44 hours of care per week – about half the annual cost of a private room in a nursing home.23

One study revealed that healthcare savings were realized when older adults with certain chronic conditions utilized home care services compared to those not receiving home care. Older adults (averaging 80 years old) with functional limitations who received home care resulted in $500 per member per month lower healthcare costs than those not receiving home care.24 These savings in health plan costs were similar across patients with chronic conditions from diabetes to congestive heart failure (CHF) to chronic obstructive pulmonary disease (COPD).

A recent study published in the Annals of Internal Medicine found that more than $4 billion in Medicare costs are due to lack of non-medical support for older adults with disabilities who have trouble with self-care and household activities.25 These are exactly the kind of services home care is ideally positioned to provide.

Further, according to one study on aging in place, providing peer support, occupational therapy, home repairs and conversations about health care goals—all of which home care can deliver—can generate annual cost savings in the hundreds of millions to billions of dollars.26
Home care workers – also known as professional caregivers, personal care aides or direct care providers for this type of personal care. Home care services are provided by large, multi-state organizations, franchises and independently owned agencies. Medicaid, the Veteran’s Administration and Medicare Advantage plans may also reimburse providers for this type of personal care. Home care is primarily paid for privately – by care recipients and families. However, today many families are relying on publicly funded care due to the cost of care. This causes uncertainty to care recipients and their families.

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In this report, we refer to this vital and growing segment of the workforce as “home care professionals” or “professional caregivers.”

While not typically medically certified, home care workers serve as an additional set of “eyes and ears” for families, helping to ensure older adults’ safety by recognizing and alerting family members and health care professionals to potential signs of declining health. Caregiving is typically provided through two frameworks that serve as a basis for delivering high-quality care. The home care industry and raising public perceptions of caregiving, while also helping to alleviate strain on industry, workers & care recipients.

Data Provided by Polsinelli, PC

**SECTION 2**

**SUSTAINABILITY OF THE HOME CARE INDUSTRY**

**CHALLENGES FOR THE FUTURE OF CARE**
Standardization of Services & Employment Models Needed to Alleviate Strain on Industry, Workers & Care Recipients

Absence of national care standards minimizes the importance of the sector.

Strong standards – including both state oversight and national standards – are essential to elevating the home care industry and raising public perceptions of caregiving, while also helping to ensure care recipients get the highest quality of care.

Standards to emphasize caregiver training and employer expectations can also elevate work performed in this field, helping to promote compensation commensurate with the value of the services caregivers provide.

Industry fragmentation highlights need for a home care model that supports care workers.

Caregiving is typically provided through two different models: the employer-based model and the independent worker model. Caregivers that are employed through reputable agencies pay fair wages and offer training, credentialing programs, and other benefits for care workers. But those who work independently, or as contractors, may not have proper training and skills, which offers little certainty to care recipients and their families.

Employer-based home care ensures quality, safety, and accountability. Agencies provide background checks and comprehensive training to ensure care recipients and families have a peace of mind about their caregivers. Training opportunities offer continuous growth for employees as well as professional career pathways, access to new technology, and administrative support.

Lack of licensing across half of U.S. creates inconsistencies and inequality of care.

Licensure across states varies dramatically, with only 30 of 50 states and the District of Columbia requiring agencies to obtain a personal care license. Given rising demand and the value of the care provided, this inconsistent system is not set up to deliver the quality, consistent care that America’s older citizens need and want.

Absent national standards, quality of care can be overseen, monitored, or guided through state licensure and HCAOA’s own Code of Conduct, recently enacted and adopted by HCAOA members.

While the industry is increasingly recognized as an essential sector of the economy, its status among the public and policymakers has not kept pace with its growth and value. Several factors contribute to the misalignment.

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State License Requirement for Home Care Agencies

*Data Provided by Polsinelli, PC*
Caregiver Shortage Prevents Industry Growth

Caregiver supply can’t catch up to demand.

The home care industry is rising to the challenge of America’s surging demand for care. What was once a cottage industry of small operations has become a powerful job creation engine, offering rewarding employment to hundreds of thousands of people who find purpose and satisfaction in caring for others.

Between 2008 and 2018, the number of home care workers increased by 151 percent – from 898,600 to 2.26 million. Yet even this increase can’t keep pace with demand.

While many professions are becoming automated or replaced by artificial intelligence (AI) and technology, caregiving requires a human touch. And, there are simply not enough professional caregivers to meet today’s needs, let alone the future needs of our aging population.

Paul Osterman of MIT’s Sloan School of Management projects a national shortage of 151,000 paid direct care workers and 3.8 million unpaid family caregivers by 2030. By 2040, the shortfall will balloon to 355,000 paid and 11 million unpaid caregivers.

Caregiving recruitment waning.

Caregiver recruitment is the perennial top challenge for home care agencies. One survey found that over 70 percent of home care agencies recently turned down potential clients due to staffing shortages, and more than half of HCAOA member agencies have reported turning away more than 10 clients per month.

To address the shortage, many home care agencies are boosting wages, benefits and incentives, including bonuses up to $1,200. The head of one agency reported she hopes to recruit another 1,000 to 1,500 caregivers, luring them with $100 to $500 bonuses after three months.

Yet, turnover remains high. In a 2018 study, 97 percent of caregivers said they were open to a new job and 65 percent reported they’re always searching for new opportunities. Interestingly, the pandemic has begun to reverse that trend. In 2021, Home Care Pulse reported turnover rate at 65 percent, a steep decrease from previous years.

Even so, the recruitment and retention challenge requires a wholesale change in the way we look at the caregiving profession.
Profile of a professional caregiver is misunderstood.

It takes a special kind of person to be a caregiver. When asked why they joined the profession, more than 88 percent of caregivers cited a desire to help people.35

High-performing caregivers bring a unique mix of skills to the job, including patience, empathy, dependability, flexibility, trustworthiness, compassion, rapport, enthusiasm, and exceptional communications skills.36

Yet society often fails to adequately value these skills, leading to a lack of public recognition and respect for caregiving as a profession.

The demographic makeup of this workforce also lends to stereotypical misperceptions of the skills and value of the workforce. Nearly one-third of home care workers were born outside the United States.37 By comparison, people born outside the U.S. make up less than 15 percent of the total population.38

Reversing misguided perceptions starts with paying caregivers commensurate with the value they provide. Across the U.S., about 40 percent of agencies are now offering sign-on bonuses, and 94 percent have increased pay, some by as much as $10 or more an hour based on experience.39

“Society’s reliance on [the family caregiver] “work force” — largely taken for granted — is unsustainable. While the demand for caregivers is growing because of longer life expectancies and more complex medical care, the supply is shrinking, a result of declining marriage rates, smaller family sizes and greater geographic separation.”

- Dhruv Khullar, M.D., M.P.P.
  Resident Physician
  Massachusetts General Hospital
  & Harvard Medical School 34

“With the workforce the way it is, there’s children at home, there’s parents at home, there’s people with disabilities. I see the trend that we’re getting back to being concerned about one another. It’s almost like a new normal now. More people need that help and support. The ones that are caregiving, the first responders, we all need that support. But sometimes we need a break. And our families need a break. There’s a lot of us [caregivers] that step right in and are right there for our families and friends and people are out there for us as well.”

- Zora Bullett
  Professional Caregiver
Rising to the Pandemic Caregiving Challenge

Home care workers were designated as essential employees early in the COVID-19 pandemic, who, along with other front-line workers, put themselves at great personal risk to provide care. As one home caregiver noted, “We are risking our own life, going out to work not knowing if we are going to take the virus home to our family or not.”

Heroic efforts to provide care during the pandemic should erase all doubts about the value of caregiving professionals to those they serve. But the pandemic has provided indisputable evidence about the value of caregiving to America’s overall health care system.

Out of all patients requiring additional hospitalization following a COVID-19 diagnosis, readmissions were much lower among those receiving home care or self-care (7 percent) compared to those needing home health (12 percent) or discharged to a skilled nursing facility (15 percent).

As a direct result of the COVID-19 pandemic and the high incidence of COVID deaths in nursing home residents, CMS provided $165 million in funding across 33 states to accelerate long-term care system transformation toward more care in the home and community. CMS has cited both quality care and cost savings across the care continuum as motivations for this approach.

“The tragic devastation wrought by the Coronavirus on nursing home residents exposes America’s over-reliance on institutional long-term care facilities. Residential care will always be an essential part of the care continuum, but our goal must always be to give residents options that help keep our loved ones in their own homes and communities for as long as possible... Home- and community-based care is not only frequently more cost effective, but is preferred by seniors and adults with disabilities seeking to maintain the dignity of independent living.”

- Seema Verma
Former CMS Administrator
Rising to the Pandemic Caregiving Challenge

CMS has cited both funding across 33 states to accelerate long-term care. As one home caregiver noted, “We are themselves at great personal risk to provide care. But the pandemic has provided knowing if we are going to take the virus home to our family or not.”

Home care workers were designated as essential during the pandemic. Building a larger professional caregiving workforce is only part of the challenge. The other major question: Who will pay for care? Long-term care—which 70 percent of adults 65 and older will require at some point—costs $55,000 annually for 44 hours per week of home care to more than $93,000 per year for nursing home or assisted living care.

**Current long-term care spending mix too much for families.**

Current long-term care spending mix too much for families. A recent Milken Institute analysis found that individuals and families pay 52 percent of all long-term care (LTC) costs out of pocket. Medicaid pays for nearly 34 percent, primarily for low-income people or those who spend down their assets to qualify for coverage. Private LTC insurance covers less than 3 percent. The financial burden of caring for our aging population—on individuals, families, and our society/economy—is simply unsustainable on today’s payment model.

One step in the right direction is the bipartisan Credit for Caring Act, introduced in May 2021 in both the U.S. Senate and House of Representatives. The legislation recognizes the financial strain of caregiving, especially for working family caregivers. The tax credit would help families defray costs of keeping a loved one safe at home, such as home care services or installing smart-home technologies or ramps. While ultimately eliminated from Build Back Better plan in 2021, the legislation continues to gain support in Congress in recognition of the critical role of family caregivers to the nation’s infrastructure.

**Retirement savings can’t fully cover caregiving need.**

Retirement accounts don’t provide much financial cushion. The vast majority of Americans don’t have enough savings to cover the cost of care. Seventeen percent of people 65 and up have less than $5,000 saved for retirement. Among elderly Social Security beneficiaries, 21 percent of married couples and 45 percent of single people rely on Social Security for 90 percent or more of their income. By 2029, 54 percent of the 14.4 million middle-income seniors will have insufficient resources to pay for care.

**Need to supplement Medicaid and Medicare Advantage to address care gaps.**

Governments recognize the value of home care in the overall health ecosystem. Medicaid funding of nursing home care became an entitlement in the 1960s; the program now pays for care for seven out of every 10 nursing home residents.

Yet this payment system effectively incentivizes older adults to choose more expensive nursing home care over the home care most of them prefer because receiving home care through government services requires going through an onerous “waiver” process. The number of people eligible is typically capped, so today there are more than 800,000 Americans waiting to receive Medicaid-funded home care.

For millions of Americans who are not eligible for Medicaid because they are above the income threshold, the only option is to pay for home care themselves, unless they are veterans or have a Medicare Advantage plan that covers home care.

The U.S. is the only industrialized nation without a national public fund for long-term services and supports (LTSS), which leaves huge gaps along the care continuum. However, the state of Washington launched a fund in 2019, which initially was to begin in 2022, but has been delayed, will be supported by contributions from future care recipients, that provides recipients over 65 with a total benefit of $36,500 annually.
Some states stepping in.

To supplement Medicaid and Medicare, some states offer programs to help pay for home care needs. State programs, such as Pennsylvania's lottery-funded program offering home care for those with incomes over the Medicaid limit, Nevada's COPE (Community Options Program for the Elderly), Arizona's Non-Medical, Home and Community Based Services program, and Washington's Tailored Support for Older Adults (TSOA), offer home care to keep “at risk” seniors out of nursing homes.52

While these efforts can help address some financial challenges, today's patchwork approach to long-term care is overly complex, inequitable, and not adequate to meet the urgent nationwide need.

When Medicaid/Medicare and state programs fail to cover costs, many turn to hiring caregivers directly. Those that hire outside professional care agencies are often left vulnerable because this option provides no requirements for criminal background checks, training, supervision, workers compensation and no backup should the caregiver become ill.

Medicare Advantage growing to meet home care demand.

In 2020, there were over 24 million Medicare Advantage members in the U.S., more than double the number in 2010 and nearly five times the amount in 2005.53

In 2019, the Centers for Medicare and Medicaid Services (CMS) expanded the supplemental services provided under Medicare Advantage plans to include home care if it is used to “to diagnose, prevent, or treat an illness or injury, compensate for physical impairments, act to ameliorate the functional/psychological impact of injuries or health conditions, or reduce avoidable emergency and healthcare utilization.”54

In 2020, CMS revised the codes again to “address social determinants of health for people with chronic disease.”

This move to cover home care shows policymakers increasingly recognize the growing demand for personal care as well as the benefits – both for an individual's quality of life and on government budgets.55

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The Annual Cost of Long-Term Care (2020)56

<table>
<thead>
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<th>Service</th>
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<td>Nursing home (semi-private room)</td>
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<tr>
<td>Home care (44 hours/week)</td>
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- Takes seniors out of their homes
- Keeps seniors in their homes
Spotlight: Professional Caregivers

**Greg Gorton**  
*Like Caring for Family*

I’m a family man, and I bring this attitude to my work as a caregiver, helping other families in times of need. I enjoy going into homes and establishing a bond with my clients and their families. As a musician, I like to play bluegrass on my ukulele for my clients, to soothe them and brighten their day. **I understand the importance of providing great care for clients, just as I wanted to for my own parents, because my clients are someone else’s parents.** With 15 years of caregiving experience, I like to accept the biggest challenges – patients who have difficult lives, who may be in hospice, or whose families may be overwhelmed. I take pride in providing the best care I can and hopefully making a difference for the people and families I serve.

**Renate Jefferson**  
*Committed to Client First*

I’ve devoted my life to caring for the elderly as a CNA, providing them with all aspects of care and even sometimes taking care of their pets as well. This has been a satisfying career, and I appreciate all of the compliments I have received for my work. **The COVID pandemic changed so much, but it didn’t change the need for caregiving.** Even when our state went into lockdown, I thought “this is my job, and my client needs me.” Even as other caregivers developed COVID symptoms, I kept working, to put my client’s needs first.

**Zora Bullett**  
*Working With My Heart*

For me, being a caregiver is not only about providing excellent care but training others so they can provide great care as well. I’ve been doing this job for over a decade, and I’ve worked with clients facing a variety of serious health challenges, like dementia, MS and Parkinson’s. **Caregiving is working with my heart as well as with my hands.** I have been trained in hospice and was honored recently when the family of a client I had served called me to stand with them at the funeral of their family member. It’s a privilege to care for these precious people at the very end of their lives, giving them dignity and respect as well as the best possible care.

**Paolo Moyani**  
*From Caregiver to Citizen*

My parents emigrated from the Philippines when I was 19. Just after we arrived in the U.S., I was diagnosed with a brain tumor. After surgery and follow-up chemo and radiation, I have now been cancer-free for six years. And I proudly became a U.S. citizen in 2019. **While receiving treatment, I studied to become a CNA and got my certification.** At the end of 2018, I began a long-term assignment with a deaf client. Despite all the challenges, I found effective ways to communicate with him. I taught him to dance and gave him the gift of song despite his deafness. And I showed him how to use an iPad and brought him Filipino foods so he could try a new cuisine.
HOME CARE AT A CROSSROADS

POLICY POSITIONS
Establishing National Standards of Care

An industry-coordinated set of standards, established at the federal and state level, can assist families seeking home care services to understand the quality of care they can expect to receive. That is why HCAOA continues to promote state licensure and looks for ways to establish clearer standards at the federal level, including home care for veterans. Without standards on caregiver training, inconsistencies in types, levels and quality of service may hamper the ability of the industry to define itself as a trusted and sought-after service provider. This has implications for the safety of home care clients as well.

During the COVID pandemic, home care providers have increased starting wages and boosted incentives and bonuses to recruit and retain workers. Providers face the challenge of balancing employee compensation with the overall cost of care to clients. HCAOA members will continue to work creatively to help make caregiving financially rewarding for workers without driving costs so high that services become too expensive for families.

The industry can increase client satisfaction and trust through steps that promote uniform training, standards for caregivers, and certifications that help create strong career path at the state and federal level.

TAKING ACTION

Industry leaders should “set the bar” for national standards that balance high-quality care with the long-term financial sustainability of the industry. By doing so, home care providers will not only improve quality and accountability, but they will also be more fully integrated as a valuable component of the country's healthcare continuum.
Collecting, Evaluating and Utilizing Data to Validate the Value of Home Care

While home care is increasingly showing its value to the healthcare system and to improving the health and well-being of America’s older population, it is mostly proven through anecdotes and small-scale validation studies. A number of recent studies – many referenced in this report – provide a glimpse into how hours of personal care delivered in people’s homes can result in health care savings by reducing hospitalizations. And yet, sparse research on the impact of home care overall has hindered the advancement of home care in securing a place in this country’s health care system.

Real data – rigorously collected and analyzed – that in turn can demonstrate cost savings will be essential if policy change is to take place. Therefore, investments must be made toward collecting, analyzing and utilizing data through large-scale studies.

TAKING ACTION

The home care industry should lead a coordinated effort to conduct studies showing how the presence of a home care aide on a continuous, routine basis can contribute to a person’s health status, from ensuring medication compliance, nutritional oversight, and monitoring changes of conditions. Collecting and analyzing such data will require significant investments in time and finances, and therefore the industry will have to work together to prioritize this goal. Through partnerships with academic institutions, third-party research institutes, and government champions, the industry can ensure such research can be conducted and communicated.

Embedding Home Care in the Healthcare Ecosystem

While federal policy has gradually come to recognize the value of home care, that attention has fallen short of offering home care as an entitlement under Medicaid or fuller coverage under Medicare. Home care must be part of the policy dialogue as health systems adapt to a more value-based approach to healthcare. Policymakers should more fully integrate home care into the healthcare system as a means toward healthier lives and more financially viable budgets.

TAKING ACTION

Americans need choice in how, where and what type of care services they receive. By making home care available under Medicare and Medicaid, the federal government will give care recipients that options they want and deserve.
To ensure there are enough caregivers for the rising tide of aging Americans, recruitment and retention practices need to be improved – particularly given high turnover rates and the projected shortage of needed caregivers.

Home care requires people who bring a unique mix of “hard” and “soft” skills. This makes the profession a bright spot amid concerns about automation (machines replacing humans) and a future of work dominated by AI rather than human intelligence. Technology can play a role in improving home care whether by verifying the hours of care electronically or facilitating timely consultation with a health care professional.

Raising retention in the industry is not merely a matter of dollars and cents. A recent US study found many factors contribute to turnover – including job satisfaction, consistency of assignments, availability of health insurance, satisfactory work hours, training to reduce on-the-job injuries and appealing to the needs of all demographic groups.

A recent report from the Global Coalition on Aging and Home Instead calls for multi-stakeholder action to build the caregiving workforce of the future. The report details four recommendations to help achieve that goal: (1) changing the perception of the caregiving profession so it is appreciated for its value to society; (2) bolstering training and education standards to ensure consistent quality and accountability; (3) supporting and rewarding caregivers commensurate with the demands of the job and the value they provide; and (4) fully integrating the home care workforce into the 21st-century health care ecosystem.

By addressing these issues, home care agencies can help ensure they not only attract more workers, but also support workers in developing long-term, satisfying careers in the home care profession. By doing so, they can also help alleviate strains on overburdened family caregivers and provide peace of mind that their loves ones are getting the quality care they need.

**TAKING ACTION**

Improving perceptions of the caregiving workforce can help ensure the growth of this essential group of American workers. Providers – regardless of payment source – must work together to provide the best possible working conditions, benefits, flexibility, training and career path opportunities to ensure there will enough quality workers to meet America’s exploding care needs.
Financing Care in an Era of Rising Longevity

America’s healthcare systems and reimbursement mechanisms were not designed for a world of rising longevity and a nation that will soon have more older people (65+) than young (18 and under). Created in large part nearly half a century ago, they are inadequate and unsustainable financially.

Government leaders are starting to recognize the added value of in-home care providers – both for individuals and our health care system as a whole.

The Senate Special Committee on Aging, for example, has proposed greater investment in home and community-based services as a means to spur economic recovery and improve the quality of life for older adults.

The Biden Administration Infrastructure Plan initially earmarked $400 billion for home and community services, later reduced to $150 billion.

The new law, if passed, would expand access to quality, affordable home care and support training for care workers. It will also expand access to Medicaid home and community-based services (HCBS) to support innovations in the industry.

To help people prepare for their future health and care needs, both the public and private sectors should continue to promote savings mechanisms that include financing for professional home care.

Planning and saving for future long-term care needs will require multiple options, based on one’s ability to save and projected care needs. Saving for care in old age should be as top-of-mind as saving for education when a child is born. Government and private-sector stakeholders must make financing for care a priority and develop a suite of options to fit the diverse financial and care needs of older Americans.

“Vous can’t finance these 100-year lives purely by public purse or purely by private purse. You need the two to come together.”

- Surya Kolluri
Managing Director, Bank of America

TAKING ACTION
Addressing Immigration to Ensure the Caregivers We Need

Immigrants make up a large and valued segment of the caregiving workforce. Nearly one-third of home care workers were born outside the U.S., compared to less than 15 percent of the total population. Uncertainty about America’s immigration policy and the immigration status of many of these workers exacerbates the already critical shortage of home care professionals; threatens the livelihoods of immigrants who are providing care; and undermines potential opportunities for new immigrants to help supplement the caregiving workforce.

"The reliance on immigrant workers in the home health care sector would present a continuation of current labor practices since 2.1 million immigrants are already working in the field...the U.S. immigration system lacks temporary non-immigrant and immigrant visa categories designated for low-skilled home health care workers. Consequently, passing immigration reforms that consider the needs of the home health care sector is essential."

- National Immigration Forum

TAKING ACTION

A stable, predictable, bi-partisan immigration policy that recognizes the value of home care professionals is critical to supporting America’s current immigrant caregivers and ensuring the availability of future immigrant workers who can address the growing shortfall of the caregiving workforce while building futures for their families.
Looking Toward the Future

In recent years, home care as an industry has become more visible, more relevant and more vital to meeting the care needs of an increasingly older America. Home care is the preferred choice of most older Americans; a lifeline for millions of families with elderly loved ones; a set of eyes and ears for doctors to monitor patients; and an enormous potential source of savings to government and private health insurance programs.

Despite significant advances, many reforms will be needed to realize the full value of home care as a significant solution to America’s long-term care crisis. HCAOA and GCOA look forward to working with partners across all stakeholder groups to deliver a future where every American gets the care they want, need and deserve.

The Policy Imperatives in this report above serve as a reminder that while government must step up and take a leading role, the home care industry itself must continue to evolve and innovate. By working together, policymakers and industry leaders can create a vibrant home care industry that can meet the massive demand for care services from America’s aging population, create a stronger social safety net, and enable all Americans to age with satisfaction, comfort, safety and dignity.
Looking Toward the Future

satisfaction, comfort, safety and dignity.

population, create a stronger social safety net, and enable all Americans to age with innovate.  By working together, policymakers and industry leaders can create a vibrant home forward to working with partners across all stakeholder groups to deliver a future where

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In recent years, home care as an industry has become more visible, more relevant and more

END NOTES

1. 95 Percent of Americans Killed by COVID-19 Were 50 or Older. AARP. April 2021. Available at: https://www.aarp.org/health/conditions-treatments/info-2020/coronavirus-deaths-older-adults.html


Home care, often referred to as personal care, helps older adults maintain healthy, active lifestyles for as long as possible in the comfort of their own homes. Home care has emerged as a valuable solution to fill gaps created by traditional care models, including hospitals, nursing homes, and home health. Home care workers – also known as professional caregivers, personal care aides or direct care workers – who work for agencies receive professional training to enable them to assist with activities of daily living (ADLs) such as bathing, dressing, meal preparation, eating, and other activities.

While not typically medically certified, home care workers serve as an additional set of “eyes and ears” for families, helping to ensure older adults’ safety by recognizing and alerting family members and health care professionals to potential signs of declining health. Home care providers for this type of personal care. Home care services are provided by large, multi-state organizations, franchises and independently owned agencies. Home care is primarily paid for privately – by care recipients and families. However, today some states, HCAOA has developed its Code of Conduct, a framework that serves as a basis for delivering high-quality care. The Code includes such standards as consumer protections and help ensure quality care. In the


36. HCAOA Focus Group, February 2020.


42. CMS Announces New Federal Funding for 33 States to Support Transitioning Individuals from Nursing Homes to the Community. CMS. gov. September 2020. Available at: https://www.cms.gov/newsroom/pressreleases/cms-announces-new-federalfunding-33-states-support-transitioningindividuals-nursing-homes


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50. Kaiser Family Foundation. Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers. 2018. Available at: https://www.kff.org/healthreform/state-indicator/waiting-lists-for-hcbswaivers/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D


Home care, often referred to as personal care, helps older adults maintain healthy, active lifestyles for as long as possible. Home care has emerged as a valuable solution to fill gaps created by traditional care models, including hospitals, nursing homes, and other facilities. By keeping people at home, quality care is often delivered to ensure better care and patient outcomes. Home care is paid for primarily by care recipients and families, but today it is also reimbursed by Medicaid, the Veteran’s Administration, and Medicare Advantage plans. Home care services are provided by large multi-state organizations, franchises, and independently owned agencies.

While not typically medically certified, home care workers serve as an additional set of “eyes and ears” for families, helping to ensure older adults’ safety by recognizing and alerting family members and health care professionals to potential signs of declining health. Home care workers provide vital companionship and mental stimulation by engaging their clients in conversation and other activities. Workers may transport older adults to doctors and appointments, run errands, and light housework. Also, they provide assistance with activities of daily living (ADLs), such as bathing, dressing, meal preparation, eating, and other activities for patients in need of assistance. Home care workers – also known as professional caregivers, personal care aides, or direct care providers – who work for agencies receive professional training to enable them to assist with ADLs. Home care workers who work for independent agencies or individually receive no professional training and are not required to be certified or to receive any check on their background or qualifications.

In this report, we refer to this vital and growing segment of the workforce as “home care providers” or “professional caregivers.”

As the emphasis on home care has grown, so has the focus on quality assurance and accountability. As the number of home care providers has grown, so have the number of inconsistencies in the delivery of care. This lack of consistency is a problem for patients, caregivers, and providers alike. In the absence of national standards and the lack of regulation in some states, the Home Care Association of America (HCAOA) supports state oversight to provide consumer protections and help ensure quality care. In the absence of federal oversight, a framework that serves as a basis for delivering high-quality care is needed.

Some states, HCAOA has developed its Code of Conduct, a framework that serves as a basis for delivering high-quality care. The Code includes such standards as supervision, criminal background checks, appropriate experience, and education. This is an important step in ensuring more care and better care is being delivered to keep people at home for as long as possible.

The Code of Conduct is a framework that serves as a basis for delivering high-quality care. The Code includes such standards as supervision, criminal background checks, appropriate experience, and education. This is an important step in ensuring more care and better care is being delivered to keep people at home for as long as possible.
Home care, often referred to as personal care, helps older adults maintain healthy, active lifestyles for as long as possible in the comfort of their own homes. Home care has emerged as a valuable solution to fill gaps created by traditional care models, including hospitals, nursing homes, and home health. While home care in the U.S. is regulated differently from other sectors of the health care market, the absence of national standards and the lack of regulation in some states, HCAOA has developed its Code of Conduct, a framework that serves as a basis for delivering high-quality home care; serves as a unified industry voice on key issues in Washington, D.C. and state capitals; and connects its members through education and awareness efforts. From standing up to dangerous misinterpretations of long-standing laws to ensuring that caregivers and clients are protected from abuse, HCAOA is a champion and advocate for its members, for caregivers and for seniors across America.

Founded in 2002, the Home Care Association of America is the industry’s leading trade association for providers of home care – representing nearly 4,000 companies that employ nearly one million caregivers across the United States. HCAOA supports seniors’ wellbeing and enables them to age in place by setting standards for high-quality home care; serves as a unified industry voice on key issues in Washington, D.C. and state capitals; and connects its members through education and awareness efforts. From standing up to dangerous misinterpretations of long-standing laws to ensuring that caregivers and clients are protected from abuse, HCAOA is a champion and advocate for its members, for caregivers and for seniors across America.

The Global Coalition on Aging is the world’s leading business voice on aging policy and strategy, aiming to reshape how global leaders approach and prepare for the 21st century’s profound aging demographic shift. GCOA uniquely brings together a cross-section of influential global companies with common strategic interests in aging and an optimistic view of its impact. Working together with business, governments, global institutions, NGOs and academia, and recognizing the once extravagant prospect of growing old has now become the norm, GCOA shapes the dialogue and advances solutions to ensure aging is a path for economic growth, winning business strategies, and social wellbeing.

Special thanks to Axxess for supporting this report through a generous financial contribution.

Axxess is the leading technology innovator for healthcare at home, providing solutions that help improve care for more than 3 million patients worldwide. Trusted by more than 9,000 organizations, Axxess offers a complete suite of easy-to-use, enterprise software solutions that empower home health, home care and hospice providers to grow their business while making lives better.