

# Informal Caregiving: Measuring the Cost and Reducing the Burden

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Aging and Retirement



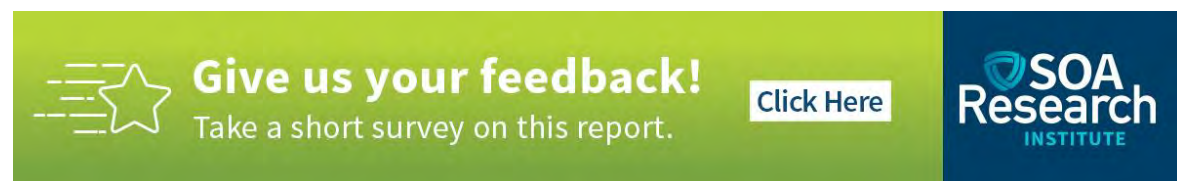
# Informal Caregiving: Measuring the Cost and Reducing the Burden

**Author** Matthew Smith, FSA, MAAA  
Consulting Actuary  
Milliman


Christin Kuretich, BS  
Strategy Consultant  
Milliman

**Sponsors** Aging and Retirement Strategic  
Research Program Steering  
Committee

Long Term Care Insurance Section

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# Informal Caregiving: Measuring the Cost and Reducing the Burden

## Section 1: Introduction

The Society of Actuaries (SOA) Research Institute engaged Milliman, Inc. (Milliman) to conduct an analysis of the need for informal caregiving and its impacts on employees, employers, and other stakeholders. The purpose of this research is to educate stakeholders, policymakers, and other interested parties in the nature of informal caregiving, as well as how the challenges associated with informal caregiving might be addressed.

The review encompassed existing SOA Research Institute research as well as many other sources, both from the public domain as well as surveys and interviews conducted by members of the project team. These sources provided data, personal experiences, analysis, and other information around topics including:

- Total number of informal caregivers in the United States
- Demographic breakouts of informal caregivers
- Longer-term demographic trends
- Financial and other impacts of informal caregiving
- The lived experience of informal caregiving, for both caregiver and recipient
- National data exclusive of informal caregiving
- COVID-related data
- Solutions in existence or under development around caregiving, formal or informal

## Section 2: Executive Summary

### 2.1 BACKGROUND

Informal caregiving is far more costly than many people imagine. And not just in the immediate future; the current demographic trends suggest that caregiving will become even more necessary and costly as the Baby Boomers continue to age and require more support and services.

In 2016, the National Academies of Sciences, Engineering, and Medicine (NASEM) published a report, “Families Caring for an Aging America” in which they estimated that 17.7 million Americans were “family caregivers of someone age 65 and older”<sup>1</sup>. This cohort of aged Americans receiving care received 143.8 unpaid caregiving hours per month<sup>2</sup>, for a combined total of 30.5 billion hours of unpaid caregiving time for the aged population annually<sup>i</sup>. This assistance ranged from household activity support such as laundry, hot meals, and handling medications to more direct self-care help such as assistance with bathing, dressing, eating, and toileting.

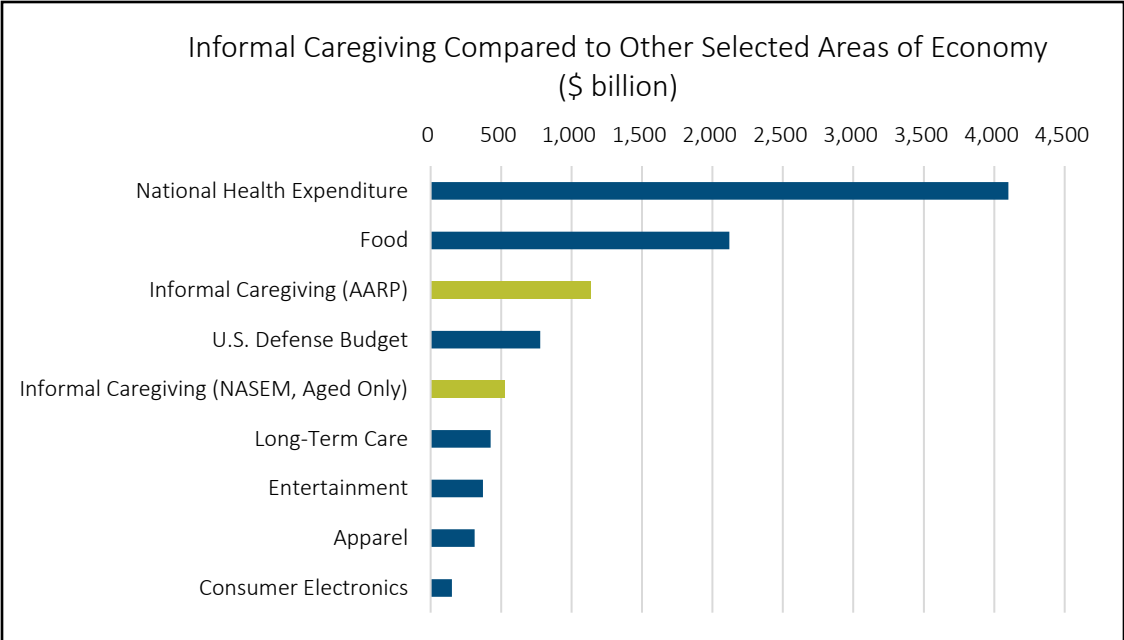
Meanwhile, according to the “Caregiving in the United States 2020” survey on caregiving released by the AARP and National Alliance for Caregiving (NAC), the total number of hours of informal caregiving time (inclusive of both aged and non-aged recipients) had increased to about 65 billion per year<sup>3</sup>. If we assume an hourly cost of \$17.50<sup>ii</sup>, this would put the total annual cost of informal caregiving somewhere between \$530 billion (NASEM) and \$1.14 trillion (AARP). This is a wide range, but even at the lower end of the range, the values are substantial. Moreover, additional costs beyond the values of informal caregivers’ time may be incurred for meals, transportation, medical supplies, educational tools, home modifications, and more<sup>4</sup>.

For comparison, the Center for Medicare and Medicaid Services (CMS) estimated that the National Health Expenditure in 2020 was \$4.1 trillion, meaning that the estimated cost of informal caregiving (using AARP values) is equal to just over a quarter of the total cost of healthcare in the United States<sup>5</sup>. The cost of informal caregiving is also larger than the Congressional Research Service’s estimate of \$475.1 billion of 2020 long-term care costs<sup>6</sup>.

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<sup>i</sup> 30.5 billion hours annually is imputed from 143.8 monthly hours per care recipient and 17.7 million caregivers. We note that this is not a precise estimate, as the relationship between caregivers and care recipients is not always 1:1.

<sup>ii</sup> We discuss this hourly estimate in more detail in section 6.3.4.



Sources: Multiple <sup>7</sup>

We can also consider the cost of informal caregiving as compared to many other aspects of the economy as shown in the figure to the right.

Even using the lower estimate based on the National Academies research, which only addresses aged care recipients and is not trended to today’s environment, more (primarily in terms of time rather than money) is spent on informal caregiving than on aircraft carriers, on iPhones, on clothing, and on entertainment.

Informal caregiving is a part of life that deeply touches many around the country, and indeed around the world, cutting across age, gender, race, financial status, and many other demographic factors. What is known about informal caregiving, and how can the experience be improved?

**2.2 KEY HIGHLIGHTS AND CONCLUSIONS**


The following are key observations from the sources discussed in this report:

- Informal caregiving is a major and growing aspect of current American life, affecting millions regardless of region, wealth, and ethnicity. Per the AARP and NAC’s 2020 study, there are an estimated 53 million adult informal caregivers, approximately 21% of the U.S. adult population<sup>3, iii</sup>
- The demographic breakdown of informal caregivers largely resembles the overall U.S. population in terms of income and race. However, women make up over 60% of all informal caregivers, and over 75% of informal caregivers who are also employed<sup>3, 11</sup>.

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<sup>iii</sup> We note material variation among sources as to the number of informal (or “family”, see section 3.1 below) caregivers. The AARP study estimated that in 2020 there were 53 million total caregivers in 2020 and 41.8 million caregivers of adults 50 and older, up from 43.5 total caregivers and 34.2 million caregivers of adults 50 and older in 2015. Based on the population splits in Figure 23 of the AARP study, this results in an imputed estimate of 26.9 million caregivers of adults 65 or older in 2015. This estimate is materially higher than NASEM’s 2016 estimate of 17 million caregivers of adults 65 and older.

- Informal caregiving can lead to a sense of fulfilment, accomplishment, and meaning. However, it can also take a severe emotional, mental, physical, and financial toll on caregivers. Negative impacts can also spill over to employers, in both direct costs of providing care and indirect costs of employees seeing their performance and overall availability for work deteriorate due to the demands of informal caregiving<sup>4, 18</sup>.
- Informal caregiving support may become an important benefit for employers, both to address potential performance impacts and as a workplace differentiator.
- The COVID-19 pandemic has likely had, and will continue to have, a substantial impact on caregiving, both formal and informal. COVID has increased mortality, especially in nursing homes, and has also had indirect impacts in terms of remote work and overall societal shifts in behavior<sup>21, 22</sup>.
- There are multiple medium- to long-term demographic trends that are likely to increase the need for informal caregiving and decrease the availability of informal caregivers<sup>24, 25, 26</sup>.
- There are limited options available for those who need care and lack the means, through independent wealth or access to relevant insurance, to afford care. Options are especially limited for those who do not have access to informal caregivers among their friends and family, with Medicaid often serving as a provider of last resort<sup>29</sup>.
- There are multiple potential solutions being developed or investigated to address peoples' need for care as well as the impact of informal caregiving on caregivers. Examples of addressing care needs include public programs such as Washington Cares (WA Cares), Hawaii's Kupuna Caregivers Program, and California's changes to state Medicaid benefits. Examples of addressing the individual needs of caregivers themselves include Hawaii's program as well as the burgeoning market of caregiver support companies. Additional alternatives may evolve to help bridge the gap between the current environment and a more sustainable future<sup>4, 31, 32, 33, 34</sup>.
- The challenges associated with informal caregiving are complex and will require complex solutions with the participation of many different stakeholders, and it will be important to assess the success or failure of potential solutions as they are implemented.



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## Section 3: Current State of Caregiving

We start our discussion with what is known about caregiving today. In this section, we discuss aspects of caregiving in today's environment, covering both technical data including a statistical overview as well as more personal discussions around the physical, psychological, and emotional impact of caregiving.

### 3.1 DEFINING INFORMAL CAREGIVING

Before examining in detail what is going on with informal caregiving today, we start by reviewing definitions of what informal caregiving actually is.

One definition of an informal caregiver is:

*... a family member or a natural {as legally defined} person who aids and supervises the daily cares of a disabled person. Informal caregiver contributes and involves in caretaking responsibilities of the weak or disabled person. They provide services on a daily basis like listening to the care recipient, giving companionship and phone contact, assisting with meals, medicines and helping with worries, anxiety and emotional needs.*

- *Informal Caregiver Law and Legal Definition, US Legal.com*<sup>8</sup>

The 2022 National Strategy to Support Family Caregivers, developed jointly by the advisory councils created by the RAISE Family, also discusses both caregiving and caregivers<sup>4</sup>. They define caregiving to include:

*... a wide variety of tasks to meet the individual needs of the person receiving support. Level of effort can vary significantly—from assistance with one (or a few) specific tasks, to live-in assistance that includes medical tasks. It most often describes the support provided to help people live in their own homes and communities, rather than in nursing homes and other institutions. However, it also can include support provided to older people and people with disabilities who live in institutional settings.*

- *2022 National Strategy to Support Family Caregivers*<sup>4</sup>

They define family caregivers interchangeably with informal caregivers:

*... in the broadest possible sense to include spouses, partners, siblings, friends, neighbors, kin, cousins, nieces and nephews, grandparents, parents, godparents, and others.*

*... "Family caregivers" include people of all ages, from youth to grandparents; people with and without disabilities; people providing care from a distance; and people meeting a wide variety of needs, such as supporting people with intellectual and developmental disabilities (ID/DD) across the lifespan, caring for people with serious and/or progressive illnesses like dementia and cancer, and assisting with daily tasks that can be challenging for older people and people with disabilities. The term also recognizes that a single person may receive care from multiple family caregivers.*

- *2022 National Strategy to Support Family Caregivers*<sup>4</sup>

Additionally, the National Strategy notes that care recipients can include:

- Older adults and people of all ages with all types of disabilities
- People with chronic health conditions
- Adults and children with an intellectual or development disability (ID/DD)



- Children in the full-time care of relatives
- Medically-fragile children and adults
- Older adults who are affected by Alzheimer’s Disease and related dementias (ADRD)
- Veterans with injuries and/or chronic conditions
- People who live in nursing homes, board-and-care, and assisted living facilities

The National Strategy also provided a relatively compact definition as **an unpaid individual of any age who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability or functional limitation**<sup>4E</sup>.

We consider this to be a reasonable definition to use for informal caregiving. With this definition in mind, we next look at the current state of informal caregiving.

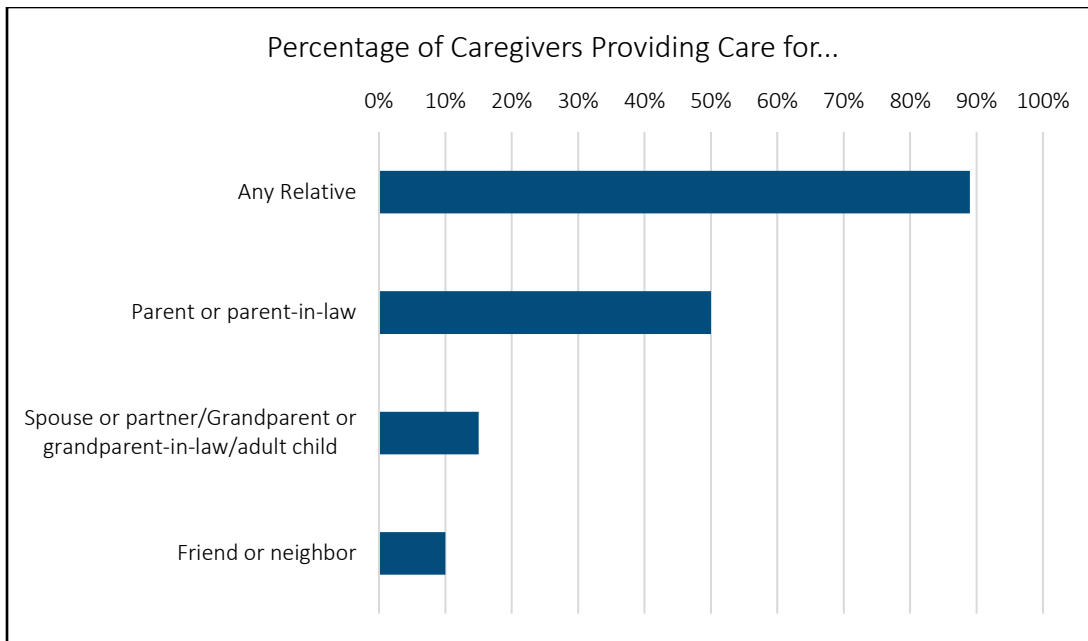
### 3.2 STATISTICAL OVERVIEW

We start our statistical discussion with sources estimating the current prevalence of caregiving.

According to the AARP and National Alliance on Caregiving (NAC), 21.3% of American adults, or 53 million, are caregivers, having provided care to an adult or child with special needs at some time in the past 12 months, at an average of 23.7 hours per week or 1,230 hours per year<sup>3</sup>.

Of those 53 million, 47.9 million are caregivers of adults ages 18+, and 41.8 million are caregivers of adults ages 50+. These prevalence rates were substantially higher than in their 2015 study, where only 43.5 million were caregivers for any age, and 34.2 million were caregivers for adults ages 50+. There is little doubt this segment of our society is growing, but what we will delve into in this paper is why. What is contributing to this growth?

The pandemic has brought to light just how burdensome informal caregiving can be on the working population. Many workers found themselves facing an unexpected shift in the dynamics of care over the past two years due to the pandemic, perhaps taking in a loved one who could no longer live on their own or becoming the guardian or sole caretaker for someone living nearby with deteriorating health. This often meant caring for someone while performing the everyday duties of a parent – often referred to as the “sandwich generation.”



Source: 2020 AARP/NAC study<sup>3</sup>

The common perception of caregiving is focused on the elderly. Typical caregiving needs of the elderly include a parent or grandparent struggling through the stages of dementia or recovering from a stroke and managing the lingering side effects.

However, caregiving is not exclusive to the elderly. As shown in the Figure to the right, caregiving needs also include spouses, children, or adult dependents, and even friends or neighbors, many who are not among the elderly population. Caregiving needs can be as diverse as today’s family structures, and it is useful to be aware of the many different paths caregiving can take when examining the topic as a whole.

The average duration of caregiving for an adult is 4.5 years, though an increasing proportion has been providing care for 5 years or longer (29%, up from 24% in 2015)<sup>3</sup>. Although increases in life expectancy are generally viewed as a positive development, for many a longer lifespan means living longer with a chronic illness or pain, or a cognitive impairment. This in turn puts additional long-term burdens on the informal caregiver as well as the formal institutions providing care.

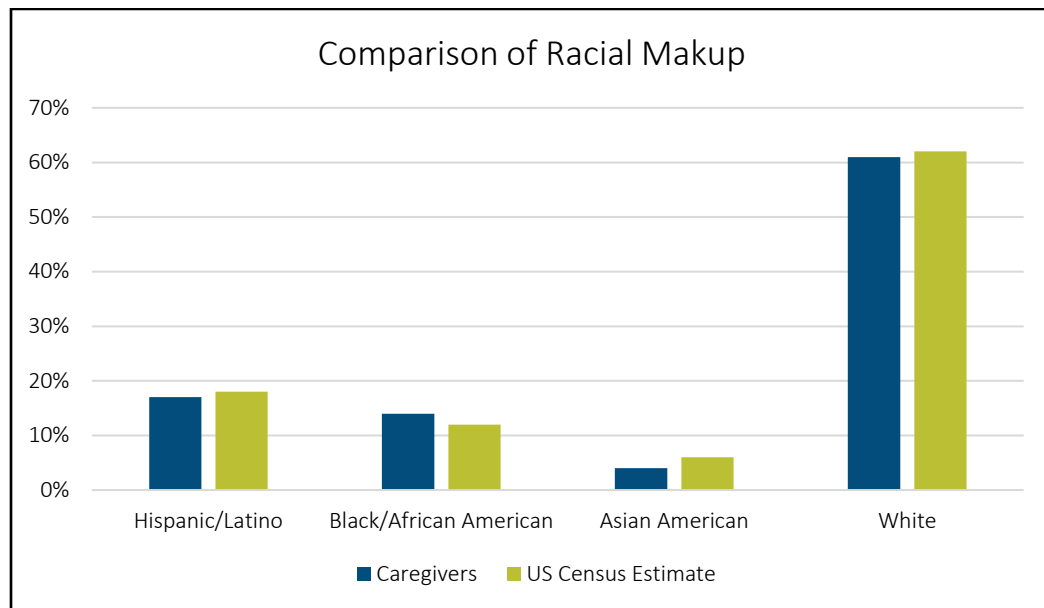
On average, caregivers of adults are 49.4 years old, though 24% are 18-34 years old and 19% are 65 years or older. Meanwhile, 46% of caregiving recipients are 75 years or older, and only 33% are Baby Boomers, up from 29% in 2015<sup>iv</sup>.

Financially, 36% of caregivers had household incomes under \$50,000, while 33% had household incomes of over \$100,000. The overall median household income of caregivers was \$67,500, consistent with the U.S. Census measurement of the 2020 median U.S. household income<sup>9</sup>.

The racial makeup of caregivers also closely matched the overall U.S. adult population. As shown in the Figure to the right, the percentages of Hispanic/Latino, Black/African American, Asian American, and White caregivers closely

<sup>iv</sup> Baby Boomers are those born from 1946 to 1964, who would be between 58 and 76 years old as of 2022.

match the race/ethnic distribution of the total U.S. Census estimate of the adult population<sup>10</sup>. The largest proportional difference was Asian Americans, who were 4% of caregivers vs. 6% of the adult population.



However, the gender distribution of caregivers was much different than the overall population. Compared to a roughly 50-50 split among all adults, over 60% of all caregivers (working and non-working) are women; additionally, a survey from the National Business Group on Health (NBGH) noted that 75% of working caregivers were female<sup>11</sup>.

Informal caregiving (for those over and under 65) continues to grow as additional stressors increase the number of Americans needing care. Contributors to the growing costs and needs of caregiving in the U.S. are impacted by increases in the following areas:

### 3.2.1 PREVALENCE OF CHRONIC DISEASES

Chronic conditions are the leading cause of death and disability in the United States today; more than two thirds of all deaths are caused by one or more of heart disease, cancer, stroke, COPD, and diabetes. One in four U.S. adults currently have two or more chronic conditions, and over half of older Americans have three or more. And trends show that these numbers are continuing to rise, driven in part by the continued aging of the U.S. population<sup>12</sup>.

### 3.2.2 RETIREMENT AGE IN THE U.S.

Over the past three decades, the average age of retirement has risen from 62 to nearly 65<sup>13</sup>. This pattern has held true for both men (increase from 62.6 to 65.6) and women (59.5 to 63).

One of the drivers of this increase in retirement age is that the Social Security full retirement age for those born in 1960 or after is 67 years of age, a year greater than the full retirement age for those born between the years 1943 and 1954, with increasing benefits for those that delay retirement.

While this increase has had some positive economic effects, it can also create caregiving stresses. Many people nearing or at retirement age could otherwise provide care for their parents as their employment ends or reduces freeing up their time. But, as the average retirement age increases, many become less able to do so.

### 3.2.3 DIVORCE RATES AMONG BABY BOOMERS

Divorce rates among adults in the Baby Boomer generation have increased substantially, a phenomenon attributed to “gray divorce,” or divorcees nearing retirement<sup>14</sup>.

As an example, a couple that might otherwise have been able to provide care for each other (one spouse caring for the other, or mutual caring for each other) may now create caregiving needs for their children; alternatively, they may now have more difficulties caring for a parent or child. There are other examples of such situations illustrating how divorce among the Baby Boomer generation may become a stressor for caregivers.

### 3.2.4 LONG-DISTANCE CAREGIVING

One area of substantial growth in caregiving has been long-distance caregiving, as defined by whether caregivers experience complications due to distance (note that this does not necessarily mean very long distances). There were between 5 million and 7 million long-distance caregivers as of 2012. Notably, this growth has occurred despite a decline in rates of geographic mobility<sup>15</sup>.

Long-distance caregiving can put additional strain on caregivers, especially if the care recipient is a family member. When the only connection is virtual, when one cannot be there to provide physical support, and especially when there is an emergency, a long-distance caregiving relationship can provide its own unique challenges.

We will discuss the implications of these trends later in our report.

## 3.3 THE CAREGIVER PERSPECTIVE

Many people do not identify themselves as a caregiver. They are simply performing the duties that a spouse would do or caring for a parent or child. Often, they do not realize they fit into this category until much further into the caregiving experience.

One possible disconnect for those caregivers not identifying as such is that they equate caregiving with medical-related activities. While this is certainly a large part of the experience, informal caregiving usually begins with non-medical activities such as cleaning, organizing the house, or helping to pay bills.

Moreover, as discussed earlier in this paper, there is no single definition of a “caregiver”; in addition to the sources discussed above, there are many resources that have laid out various tasks and situations classified as “caregiving”. For instance, the National Business Group on Health noted that common tasks performed by caregivers include transportation, bathing, feeding, dressing, and help getting around the house<sup>11</sup>. But caregiving can also involve going to appointments, spending time on the phone, or coordinating and scheduling appointments online. These tasks can almost feel like a part-time job.

As part of our research, we interviewed multiple caregivers and caregiving recipients. One of our interviewees shared the journey her family experienced with her father, who handled logistics for various activities, paid bills, and was the lead for other family needs. Her mother began noticing that they were receiving notices of missed payments on various accounts and overdraft fees charged by their bank. As the caregiver – the eldest daughter, in this case – began to investigate, she discovered that her father’s usual system of bill paying, tracking, and general finance management had become a foreign language to him. He could no longer comprehend what was due, what wasn’t, or how to get funds and payments where they needed to go. He had also begun spending a lot of time on the computer, accidentally clicking on bad links, which resulted in a virus-laden home computer. The family realized there had been a serious cognitive decline that impaired his abilities. Now what?

Other caregiver journeys might look different. As an example, a mother of a child with special needs, who has always viewed her child as “one of the kids” may be so accustomed to supporting the child that it doesn’t feel like caregiving.

Another example might be a best friend, who attends every doctor’s appointment with a friend who has breast cancer, and advocates for her because her friend has no family to do so.

The stress of caregiving may not always be apparent to caregivers. For some, the cumulative impact of these responsibilities can sneak up on them. Without clear resources or help, the effects can be more detrimental than they and their support networks may realize. Caregiving often means neglecting one’s own needs, health, or pain to care for someone else. But who cares for the caregiver?

### 3.4 PHYSICAL AND MENTAL IMPACT OF CAREGIVING

Caregiving can take a severe emotional, mental and physical toll on caregivers. We present one example of this with Karen Henderson’s personal story, published in the May 2010 edition of the SOA’s Long-Term Care News<sup>16</sup>:

#### Karen Henderson’s Story

Caregiving is a task-oriented and emotional minefield. Most of us can do the physical job. We even take pride in learning how to assist another with dressing, eating or transferring. On a good day we feel useful, even capable, and positive to the point of believing our expert care may in fact influence the course of the illness. We revel in our accomplishments.

But then a fall happens in the home that we so carefully modified to prevent just such a catastrophe. Our euphoria turns in an instant to despair. We admit the unthinkable: Who am I trying to kid? I can’t change things at all; in fact, I barely cope from day to day.

Our fatigue permits us to surrender to the emotional turmoil that is always just beneath the surface. We are torn between knowing we can do the job better than anyone else and admitting that we lack the tools—knowledge about the diseases we face, treatment options, appropriate medications and, more importantly, the experience to make the right decisions when the times inevitably come to make them. We feel helpless; we become hopeless.

...

Caregivers spend their days walking a fine line between success and failure, joy and grief—between life and death. There is no tougher task in life. We must encourage caregivers to feel and express the dizzying range of emotions that influence their mental health from day to day. By helping caregivers to openly accept their strengths and weaknesses, their own needs and biases, health care professionals can then normalize these feelings and reactions and allow caregivers to better bear the incredible demands made upon their bodies and souls.

Caregiving can cause feelings of guilt, hopelessness, confusion, and anger. Grief can also be a large part of the emotional experience, and it can strike long before a loved one has actually died. It can be grief over the loss of “normal life”, grief because of missed milestones or plans thwarted by illness or injury. The grief can be suppressed, not entirely showing up as grief. Perhaps, it manifests as intense fatigue, confusion, tunnel-vision and inability to ask for help, and eventually anxiety and depression.

While caregiving can also lead to a sense of fulfilment, accomplishment, and meaning, the substantial negative impact on caregivers is prevalent. According to a recent NBGH survey, 88% of caregivers reported that their responsibilities had a negative impact on their personal health and well-being<sup>11</sup>.

In the NBGH study:

- Caregivers were twice as likely to develop chronic illness
- They were twice as likely to develop depression
- 92% reported that caregiving impacted their stress levels, with 48% saying “a lot”
- 49% reported exhaustion
- 27% reported stress on their marriage or relationships
- 25% reported missing their own doctor’s appointments
- 16% reported that not covering what was wanted or needed caused additional stress
- They spent on average \$7,000 of their own money annually on caregiving expenses

Reviewing the above statistics, it is clear that the task of caregiving can cause a reverberating impact for which there is no easy solution. Caring for others is extremely taxing, and when those who provide care become so debilitated that they can no longer provide caregiving, how can the caregiving needs be addressed?

### **3.5 FINANCIAL, EMPLOYMENT, AND CAREER IMPACT OF CAREGIVING**

Beyond the physical and mental detriments of caregiving discussed above, there can be substantial additional costs on caregivers’ careers and earning potential.

The NBGH study also found<sup>11</sup>:

- 75% reported calling in sick or taking paid time off
- 52% reported missing or being late to work due to caregiving responsibilities
- 33% reported higher leave incidence and duration
- 20% reported a decrease in productivity due to caregiving duties

These costs can increase significantly for informal caregivers providing more intense levels of care, as measured by the weekly hours of care as well as the Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) assisted with<sup>3</sup>.

Work accommodations for caregiving can lead to lower earnings, lower benefits, lower retirement income, and lower social security income. Needed employment accommodations can also impose costs on employers<sup>17</sup>.

### **3.6 CURRENT COST IMPACT OF CAREGIVING TO EMPLOYERS IN THE UNITED STATES**

Much of the substantial cost of informal caregiving is currently borne by individual caregivers. However, there are also material costs borne by employers. These costs come both in the form of support for caregiving and indirect costs created by caregiving.

As employers manage their workforce, there are certain employee benefits that are generally recognized as needed for employee retention in the current business climate. Depending on the size and financial position of the employer, these can include: healthcare coverage for both employees and families; dental, vision, and supplemental health products; life insurance, typically employer-paid as a set multiplier of the employee’s salary; buy-up options for term life insurance or even permanent whole life insurance; short- and long-term disability coverage and Family Medical Leave (and in some states, Paid Family Medical Leave).

For many employers, the employee menu of benefits and perks has now expanded beyond just insurance to include offerings such as gym memberships, onsite fitness and wellness programs, Employee Assistance Programs (EAP) and mental health support, and even fertility, adoption, and family planning assistance. These are all options that address a variety of employee needs. However, one area that is just beginning to draw employers' attention from a benefits perspective is the needs of an employee who is also an informal caregiver and the impact of caregiving on that employee's productivity, well-being, and even retention in some cases.

As outlined above, there are extensive physical, mental, emotional, and financial impacts to the individual providing informal caregiving. But from the perspective of the employer, where does its responsibility begin and end as far as aiding and accommodating each unique situation? And are there potential benefits for addressing employees' needs in this area?

According to the Gallup-Healthways Survey in 2011, caregiving-related absenteeism resulted in 126 million missed workdays each year, costing the U.S. economy an annual loss of \$25.2 billion<sup>18</sup>.

Missing work entirely or in pockets of time can begin to degrade the quality or quantity of an employee's work and have a downstream or cross-stream impact across the organization. If too much time is missed, employers will need to make arrangements to cover the employee's role or adjust expectations and deliverables. And even without large amounts of time being missed, unpredictable work schedules can make it difficult for coworkers to count on that working caregiver.

Presenteeism, where employees are physically present but not fully functional, can also be a concern. Presenteeism can result in lost productivity and can also lead to absenteeism which can eventually lead to the loss of employee.

Addressing absenteeism and presenteeism is a priority for employers; caregiving is therefore a topic beginning to interest employers. When an employee becomes a caregiver for somebody, employers face the same problems as though the employee was sick. In addition to the NBGH survey results listed above, according to the "Caregiving in the U.S. 2020" AARP study, 61% of caregivers say that caregiving had an impact on their work, ranging from reduced hours, coming in late or leaving early, and even quitting their job altogether.

In early 2022, Milliman performed a firm-wide Ground-Up Think Tank for Social Impact (GUTSI) informal survey on informal caregiving. Collectively, the 196 respondents told a similar story as the NBGH survey; nearly 50% of participants identified as actively providing care for or previously providing care for a loved one, and of those, 76% reported needing to take time away from work at least one to two times a month, with many indicating a higher frequency. Also, 67% said that neither they nor their loved one had any financial assistance or insurance for their needed care<sup>19</sup>.

Another study, by the Harvard Business School (HBS), found that while just about half of the employers they researched actually tracked data on their employees who are caregivers, 26% gathered information on their employees' needs related to care responsibilities, and 24% recognized that caregiving had a direct impact on their employees' performance<sup>20</sup>.

However, more recognition of the need to accommodate these situations can have a real impact on productivity and retention. In fact, in that same HBS study, employees said the most popular benefit for retention was "referral services for caregivers" when compared with other services related to caregiving respite, including onsite or near-site elder care, paid time off, flexible work arrangements and counseling. Seventy-eight percent of employees said that benefit was "very important" to their decision to stay with their company. However, only 38% of employers considered caregiver referral services as an effective benefit for retaining employees, and only 29% of employers offered that benefit.



Many employers already provide certain benefits to employees to support their health and well-being, both to reduce negative work impacts and to differentiate themselves from competitors. More employers than seen today may come to view caregiving as another area where they can achieve similar aims, especially in more competitive industries.

### 3.7 IMPACT OF THE PANDEMIC

The COVID-19 pandemic has likely had, and will continue to have, a substantial impact on caregiving, both formal and informal.

#### 3.7.1 MORTALITY, MORBIDITY, AND THE BREAKDOWN OF FORMAL CAREGIVING SYSTEM

*When formal systems of caregiving break down (as we saw during the COVID-19 pandemic) or are not available in the first place, family caregivers step in—often on short notice—and cover whatever is needed.*

*- 2022 National Strategy to Support Family Caregivers<sup>4</sup>*

There have been many issues impacting formal caregiving during the height of the pandemic. According to one source, since the onset of the pandemic, more than 200,000 COVID-19 deaths have occurred among long-term care residents and staff, with most of these deaths (150,000) occurring among residents and staff in nursing facilities<sup>21</sup>.

According to another source, as of October 2021, nursing home residents accounted for approximately 19% of all COVID-19 deaths despite making up less than half a percent of the U.S. population<sup>v,22</sup>.

And it has been more than just deaths among formal caregivers. There has been burnout, competition with other care employers (and even other industries entirely, as discussed in 6.3.3), impacts of vaccination refusals, and the need to stay home and support their own families, especially during the shelter in place period. All of these factors have contributed to staffing shortages among formal care outlets, which in turn has resulted in increased demand for and pressure on informal caregivers, exacerbating the difficulties already created from the pandemic.

Beyond the impacts already seen, though, we can also consider the potential impact of Long COVID<sup>vi,23</sup>. While the data on Long COVID is evolving (as of June 2022, the CDC estimated that 7.5% of American adults had Long COVID symptoms<sup>24</sup>), the CDC has noted that Long COVID has materially increased the prevalence of health conditions such as diabetes, heart conditions, or neurological conditions among those who have had COVID-19.

Moreover, additional effects may be found among those experiencing multiple or repeated exposures to COVID-19, which could be an additional risk factor, especially among the elderly population. It may therefore be plausible to see a marked increase in morbidity, which could lead to a substantial increase in the number of people who will require caregiving and/or long-term care.

On the other hand, while the impacts of shortages in formal caregiving settings and increased morbidity among the elderly have increased and will likely continue to increase the demand for caregiving, we must also note that the

<sup>v</sup> The National Academies research also largely agreed with KFF research on total nursing facility deaths, noting that as of February 2022, more than 149,000 nursing home residents and more than 2,200 staff members had died of COVID-19.

<sup>vi</sup> As noted by the CDC, Long COVID, or Post-COVID conditions can include a wide range of ongoing health problems and can last weeks, months, or longer.

increased mortality rates among the elderly have the opposite effect. The full net impact of the pandemic on informal caregiving demand is not yet known and may not be known for some time.

### 3.7.2 SOCIETAL IMPACTS INCLUDING REMOTE WORK

Beyond the relatively direct impacts of COVID-19 discussed above, there have also been substantial indirect and societal impacts. Perhaps the largest such impact is the shift towards remote work for many white-collar employees, a trend that very much appears to be here to stay. We do not intend to opine here about the overall pros and cons of remote work, particularly from an employer perspective; however, from a caregiving perspective, this increase in remote work is likely to impact the caregiver population.

To start with, when employees no longer spend an hour or more a day commuting, and when their work hours are more flexible, it becomes far less disruptive to take time off during the day to provide caregiving services, even when the caregiving needs are sporadic or unpredictable in nature. For instance, an unforeseen time commitment (for a caregiving commitment or otherwise) for a couple of hours in the early afternoon becomes much less disruptive to the workplace environment than it used to be. Workplace responsibilities can in turn be offset with increased work time in evenings or weekends, a choice which can appeal to many people with domestic responsibilities, not just caregivers.

Should the trend in increased remote work persist, the resulting reduced disruption may in turn create substantial increases in the supply of informal caregiving, particularly among the white-collar professional population.

The potentially lowered burden of caregiving may also impact average retirement ages; a person who in 2019 might have chosen to retire because the burden of caring for their parents was too difficult to juggle with career responsibilities might well make a different decision in 2023.

These developing near-term shifts in caregiving, with more people requiring care due to COVID impacts, and remote work potentially both increasing the number of people able to provide care, and decreasing the individual burden of care, may further push caregiving further into the spotlight for employers.

## Section 4: Future Caregiving Needs

Having discussed the current state of caregiving, the next question is: what might caregiving look like going forward?

### 4.1 CAREGIVING IN 2040

We start our longer-term outlook by considering 2040 from a caregiving perspective. How might things change in the next 20 or so years?

#### 4.1.1 IMPACT OF THE BABY BOOMER GENERATION

Other than the still-developing shifts due to the pandemic, the most substantial change we foresee affecting 2040 is the aging of the Baby Boomers.

Based on the AARP study, the largest segment of the population of caregiving recipients, 40%, was from the Silent Generation. In 2040, it will be Baby Boomers who are the generation who most need care. Baby Boomers make up a greater portion of the population than every prior generation, including the Silent Generation.

If we define the Silent Generation as those born from 1928 through 1945, that generation represented approximately 47 million Americans, approximately 23 million of whom remain alive today, and approximately 38 million of whom were alive 20 years ago, per a high-level analysis of the 2000 census data<sup>25</sup>.

Conversely, there were approximately 76 million Baby Boomers in 2000, 71.2 million of whom are alive today. If Baby Boomers experience similar 20-year mortality rates as the Silent Generation, the same demographic group could be nearly twice as large, leading to a substantial increase in caregiving demand.

The impact of the Boomers as they age beyond 2040 is also worth considering:

*By 2050 about 8.4 percent of the U.S. will be over age 80. That's an age structure that we only see today in some of the very oldest counties in Florida. And that will be the average in the U.S.*

*- Tara Watson, Brookings Institute Webinar<sup>26</sup>*

Clearly, as Boomers continue to age, their larger population band will in turn require more services than prior generations, both in informal and more formal caregiving settings.

#### 4.1.2 PROJECTED CAREGIVING AMONG EMPLOYED POPULATION

This coming “boom” of caregiving demand leads to the critical question of who will provide care for the Baby Boomers. Currently, a substantial majority of the caregivers providing care for adults 75 years and older (which all Boomers will be as of 2040) is made up of adults 50 years and older, in particular adults 50-64 years of age<sup>3</sup>.

If this proportion holds, the largest expansion of caregivers would be adults 50-64 (older Millennials and younger Generation X); there will still be many more caregivers among younger cohorts, but the increase would be less pronounced than among adults 50-64 or 65 and older.

In general, the average retirement age has been ticking upwards over the previous decades; however, during the pandemic, there has been an increase in the retirement rates among each of the 55-64, 65-74, and 75+ cohorts, although this may change as the pandemic impact lessens<sup>25</sup>.

Given the much larger band of projected caregiving recipients among the Baby Boomer population, the employment situation of the 50–64-year-old band could prove an important issue. While it is unclear what the longer-term trends in retirement ages will be, if this band will be called upon to provide an increasingly large amount of informal

caregiving support, it will be important to consider the overall burden that they must face. As noted in section 3.7.2, remote work has enabled an easing of the caregiving burden; if this easement continues it is possible that a reduction in the caregiving burdens on the 50-64 cohort (especially if the trends in remote work ease burdens as described earlier in the paper) could materially impact the career path of this cohort.

#### **4.2 CAREGIVING IN 2060 AND BEYOND**

Beyond the trends likely to impact the caregiving environment in 2040, we can also consider the more distant future. By 2060, the caregiving market may see the longer-term impacts of the changes in fertility rates over the past few decades. Between 1990 and 2019, the annual birth rate per thousand women ages 15-44 dropped from 70.77 to 58.21<sup>27</sup>.

In other words, despite an overall growing population, the total number of annual births per 1,000 women dropped from 4.1 million to 3.7 million. Additionally, the median age of maternity has increased from 27 to 30<sup>27</sup>.

While these changes in birth rate may not have a major impact on caregiving in 2040, 2060 may be a different story. Without changes to the demographic environment, such as more immigration or a reversal of the birthrate decline, fewer babies today could mean fewer 40-year-old caregivers in 2060, who must take care of older individuals who were born before the decline in fertility rates took hold.

## Section 5: Today's Options for Those who Need Care

We turn our attention to potential improvements in caregiving for both formal and informal caregiving approaches. Although this report primarily addresses informal care, there is an important connection between formal and informal caregiving in serving those with care needs. As a starting point, we discuss options for formal care that exist today.

### 5.1 THOSE WITH THE MEANS TO AFFORD FORMAL CAREGIVING

The simplest discussion about formal caregiving centers around those with the means to afford the care they need, either directly or via insurance coverage.

About 5-7 million people in the United States are currently covered under traditional standalone Long Term Care Insurance (LTCI) policies<sup>vii</sup>. The growth in traditional LTCI policies has declined significantly over time as the market for LTCI has evolved toward newer designs.

These new designs include “hybrid” policies that combine some level of LTC and life insurance coverage. One example is a rider to a permanent life insurance policy that allows policyholders to accelerate a portion of the death benefit to pay for LTC services. In this context, “accelerate” refers to enabling certain benefits in life insurance policies to become available prior to a policyholder’s death. There are also richer options available that provide LTC coverage even after the entire face amount has been accelerated and depleted.

However, despite the growth of hybrid policies, the total number of carriers offering benefits in this market has declined as compared to the 1990-2010 time period.

Another issue for consumers who are considering purchasing an LTCI policy is that depending on when they evaluate a purchase, they may be unable to afford the policy premiums or may not qualify for coverage due to medical underwriting. Readers interested in a more in-depth discussion of the current LTCI market and products may wish to refer to a guide prepared by the National Association of Insurance Commissioners (NAIC) : [A Shopper's Guide to Long-Term Care Insurance](#).

An optimum approach for those who want to ensure they have the caregiving support that they may need later in life could be to buy an LTCI policy when young and healthy, lock in lower issue-age premiums (that are set at the age when the policy is issued) and keep the policy for when LTC needs may arise. However, LTC insurance may not be appealing to younger workers who may have early career financial burdens and are more focused on the short term. Even more problematic is the misperception that health insurance covers sufficient long-term care needs, or that Medicare will necessarily cover a long-term care situation or a home health aide<sup>28</sup>, though we do note that a number of MAPD and DSNP plans do provide limited long-term care benefits.

Medicaid generally covers most costs of LTC services, including both facility and Home and Community Based Services (HCBS). But it is generally not well understood that there is often a “spend down” requirement, wherein an individual who needs long-term care must first drain their own assets to pay for the care until they qualify for Medicaid. Even beyond the issues associated with spending down one’s asset base (discussed in section 5.3 below), having Medicaid as primary coverage can further limit care options. If an individual needs to move into assisted living, supported living or a nursing home, these facilities may only have a certain number of “Medicaid beds” available. This could mean being put on a waiting list and looking for an alternate solution in the meantime, which often falls upon an informal caregiver. However, Managed Long-Term Services and Supports (MLTSS) programs are

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<sup>vii</sup> Statistics aggregated from NAIC statutory filings.

emerging in some states to enable a greater range of care coordination and management within Medicaid and Medicare programs.

Other than purchasing LTC insurance, some will choose to self-fund their LTC needs. However, many who choose to do so may find the rate at which their savings are used each month may be too costly. Although self-funding LTC works for many, there can be a trade-off of having less or even no money for family expenses or other non-LTC needs.

Moreover, even those who have the means to fully fund their care needs in today's environment (whether directly or through a policy) are still subject to long-term risks, most notably cost inflation of long-term care services, as well as the potential lack of availability of formal caregivers. Not all of those who can afford and access the care they need at today's costs and staffing levels will necessarily be able to do the same in the future.

We also note that even many of those with means and access to formal care will still choose to rely on informal caregiving as much as possible. When their needs are relatively light, they may entirely rely on informal care among family or friends, and when their needs grow, they may engage their family and friends as much as they are able, relying on formal care for specific tasks that need to be outsourced to expert care.

But even this approach can at times be fraught, as outlined in the research excerpt shown below<sup>29</sup>.

### Research Excerpts Perspectives From Caregiver and Receiver

All close relationships experience conflict to some degree, but frequent conflict in a strongly interdependent relationship such as the caregiving relationship can dominate the relationship to the exclusion of all else<sup>29A</sup>. Conflict arises when the goals or perspectives of the dyad are incongruent, as in the case of a caregiver who feels both guilty and unappreciated whereas her husband feels overprotected and dependent<sup>29A, 29B, 29C, 29D</sup>. Conflict can also arise from developmental differences<sup>29E</sup>.

As with any relationship, the caregiving relationship is not without its history, and in fact the caregiving situation can reawaken old family conflicts, which may "ripple" to other relationships<sup>29A, 29F, 29G</sup>. Conflict has implications for the well-being of the care recipient and caregiver and influences the likelihood of success in meeting each of their needs<sup>29B, 29H, 29I</sup>.

...

There is little research exploring the effects of formal services on the care recipient's well-being or the caregiving dyad. Evidence suggests that the use of formal services is associated with greater dyadic incongruence<sup>29J, 29K</sup>. Friedman and Kaye (1980) reported that one fifth of service plans were rejected and disrupted when family members, other than the care recipient, were not included in the decision-making process<sup>29L</sup>.

It is possible that the receipt of formal services means different things to the caregiver and care recipient. The care recipient may view such services as unnecessary and may feel overprotected, leading them to resist the help, whereas the caregiver may perceive the extra help as a way to lower strain<sup>29F</sup>. This may, in turn, lead them to perceive the care recipient's impairment quite differently.

## 5.2 THOSE WITHOUT THE MEANS TO AFFORD FORMAL CAREGIVING, BUT WITH THE ABILITY TO ACCESS INFORMAL CAREGIVING

For many others, the only choice available is to rely on informal caregiving. We have discussed the benefits and burdens of informal caregiving from the caregiver perspective earlier in the paper, but the care recipient perspective is just as important to consider.

When it comes to imagining the perspective of the person receiving care, often an elderly grandparent in a nursing home comes to mind. But we should also consider parents in their 60's cared for by a child or spouse for more acute needs such as a shoulder injury, or more prolonged needs such as cancer treatments.

From the perspective of the one receiving care, caregiving can have lasting effects on the relationship between the caregiver and the recipient because of the emotional toll caregiving has on both parties.

We spoke with one care recipient who expressed incredible feelings of guilt watching his wife care for him through many surgeries, chemotherapy, and radiation.

*"I felt like somehow it was my fault that I got sick, and that maybe she would be better off if I wasn't here instead of enduring the upside-down chaos of my cancer treatment."*

*-Anonymous, 46 years old, Wisconsin*

He also shared that while he had overwhelming feelings of gratitude and comfort, it was contrasted with feeling worthless and helpless to be a husband in that compromised state. Having survived cancer but being left with chronic pain and debilitating physical ailments, the husband wondered what the impact would be on his wife in the long term, and if the "caregiver" role would ever end.

We also spoke with a mother and daughter who have been in several acute but lengthy caregiving situations, including breast cancer, two cataract surgeries, and a broken shoulder. Throughout each of these health crises, the mother felt more and more like a burden. This got to the point where she became terrified to call her daughter when something bad happened, because she knew her daughter would respond and even when doing so could interrupt her own life and responsibilities.

*"I didn't raise my children to have them take care of me. I feel like such a burden. Who wants to spend their best adult years caring for a sick parent? I should have taken better care of myself, maybe then my daughter wouldn't have to spend so much time on my care."*

*-Jan, 77 years old, Illinois*

Beyond our direct research, we also were able to review other stories and testimonials. In one case, a subject spoke about her daughter caring for her through a dementia diagnosis. Her daughter struggled mentally and emotionally, and eventually got support from an outside organization, whose primary focus is on supporting the caregiver on all levels. This support and resource direction enabled her to have Bible study at her home, which her mother participated in as well; this experience helped deepen their relationship and provide release from some of the stresses that being an informal caregiver created<sup>30</sup>.

This experience had a positive impact on both the caregiver and the care recipient; however, because the caregiving focus tends to turn primarily to the care recipient instead of the caregiver, this sort of intervention was not originally on their radar and may not be something that others in similar situations would necessarily be aware of the value of or know how to access.



### 5.3 THOSE WITHOUT THE MEANS TO AFFORD FORMAL CAREGIVING OR ACCESS TO INFORMAL CAREGIVING

For many more, even the trying situations described above are outside their reach. Many people find themselves in need of care but lacking LTC insurance and lacking enough (or perhaps any) support from friends and family. For these people, Medicaid may become their only option. However, to be eligible for Medicaid, they need to spend down their financial resources drastically.

Consider the story (excerpted below) of Marcella Wagner, who was left quadriplegic from a car accident while pregnant, her husband Dave, and their young child Logan who was safely delivered<sup>31</sup>. While Marcella and Dave's specific circumstances may be unusual, many with long-term care needs face similar "spend down" requirements.

#### A Family on Medicaid As Told by Their Sister-in-Law

Marcella qualified for Medi-Cal because she is disabled, but because Medi-Cal is for poor people, Dave and Marcella have to be poor to receive it — they have to "meet" the program's "income test." Counterintuitively, meeting the income test doesn't mean having enough income (as in doing well on a test), but rather having low-enough income. The income test is actually an income limit.

Moreover, because Dave is employed, he and Marcella would be in a particular version of the program called "Share of Cost" Medi-Cal. It works this way: As a family of three with one disabled member, they are allowed to keep \$2,100 of Dave's \$3,250 monthly earnings to live on. The rest of Dave's earnings, \$1,150, would go to Medi-Cal as the family's share of cost. That is, any month in which Marcella incurred medical expenses, she and Dave must pay the first \$1,150. To our surprise, if Dave earned more money, the extra amount would also go to Medi-Cal: The cost sharing is a 100% tax on Dave's earnings.

I figured out later that the \$2,100 my brother and sister-in-law are to live on puts them at 133% of the federal poverty level for a family of three.

Essentially, the way they meet the income test is for Medi-Cal to skim off Dave's income until they are in fact poor.

**Brian (their social worker) noted that they are "lucky" that they are allowed to retain that much income; if Marcella weren't disabled, the amount they'd be allowed to retain would be even lower than \$2,100. And this is how things will be indefinitely. In order to get poor people's health insurance, Dave and Marcella must stay poor, forever.**

Another example, more directly related to senior caregiving needs, comes from a discussion between a parent and adult child, noted as part of 2017 research done by the SOA Research Institute to evaluate Americans' awareness of retirement risks:<sup>32</sup>

*Q: Do you have any plans for if you need nursing care or care?*

*A: "I don't expect to go that route."*

*Q: But in the future. Not tomorrow, but I'm saying ...*

*A: "Yeah. When I have to go, I have to go."*

*Q: How would you pay for that?*

*A: "How does that work? You have to pay to go to a nursing home? Doesn't your insurance take care of that?"*

*Q: No, it doesn't. Medicaid might, if you have no assets.*

*A: "I better stay healthy!"*

*- Higher-asset, elderly female (85+ In-depth Interviews)*

Even those of means cannot always afford the level of insurance that can pay for formal caregiving needs. And for those of insufficient means, beyond the emotional components they must deal with, it can be difficult to navigate accessing and even just understanding which resources are available.

In our next section, we will focus on potential solutions to these issues.

## Section 6: Potential Solutions to Address the Demand for Caregiving

There are many different types of solutions, or at least improvements, to today's model of caregiving that can be considered. This section is by no means a comprehensive review, but we offer several current or future solutions in development.

### 6.1 PRINCIPLES FOR SOLUTIONS

Before we discuss particulars of potential solutions, we first consider general principles that can inform these solutions. Here we refer to the work already done by the RAISE Act Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren (SGRG) <sup>4B</sup>.

They note four key issues to address:

- Person- and family-centered approaches
- Trauma and its impact
- Diversity, equity, inclusion, and accessibility
- And the direct care workforce

Beyond these four points, other important concerns for solutions to address include affordability, flexibility, sustainability, and appropriate integration between public and private programs and stakeholders. We also note that using Home and Community Based Services (HCBS) instead of facility care has long been a point of emphasis, particularly in Medicaid, and should be considered here as well <sup>33</sup>.

### 6.2 PUBLIC PROGRAMS ALREADY UNDER DEVELOPMENT

The state of Washington is trying something new to address care needs and is providing an intriguing study in not only what a state-funded plan could look like, but also how consumers might behave when given a requirement. The concept of the Washington Cares Act (or "WA Cares") was relatively simple on the surface; opt out of the program by showing evidence of private long-term care insurance (which needed to have been purchased by Nov 1, 2021) or be subject to mandatory enrollment in the publicly funded plan, which meant a payroll tax of \$.58 per every \$100 of wages<sup>34</sup>. Choices would then be permanent; workers could not subsequently change their minds and enroll in the program after getting an exemption and could not qualify for an exemption after the relevant deadlines passed.

Once enrolled, WA Cares would then provide a long-term care insurance benefit for all eligible workers, which could either be used as the sole LTC benefit or used alongside other benefits.

While WA Cares provided some coverage for this important need, the benefit itself is insufficient to cover all needs. Once an individual has contributed to the state plan for 10 years, they are eligible for a lifetime benefit amount of \$36,500; even when adjusted for inflation, this will not cover many long-term care costs beyond a few months. Moreover, implementation has been delayed by subsequent legislation, with premium collection reset to begin on July 1, 2023<sup>35</sup>.

Regardless of the limitations of the WA Cares benefit, though, it has drawn attention to a need that has often gone unmet or barely met. And Washington is not alone; other states are also beginning to consider what a state-funded plan might look like<sup>36</sup>.

One of these states, California, has created a Long-Term Care Insurance Task Force with the goal of exploring the feasibility of developing and implementing a culturally competent statewide insurance program for long-term care services and supports<sup>37</sup>. The task force is currently working on a feasibility report, with the help of many experts in

the field, that will demonstrate the viability of such a program by January 1, 2023. Following that, they plan to produce an actuarial report of the recommendations made by the Task Force, which – if approved – will then move on to the Legislature.

Prior to creating the LTC Task Force, California announced a focused, long-term plan for the aging population called the Master Plan for Aging, which has 5 goals<sup>38</sup>:

- Housing for all Stages & Ages
- Health Reimagined
- Inclusion & Equity, Not Isolation
- Caregiving That Works
- Affording Aging

Among the changes already made by the state is an increase to the Medicaid asset limit for long-term care from \$2,000 to \$130,000 for individuals and from \$3,000 to \$195,000 for couples. The state also plans to fully remove the limit as soon as 2024<sup>39</sup>.

Another example of state-funded informal care support is Hawaii. In contrast to the Washington and California programs, which are more focused on care recipients directly, Hawaii has provided support, financial and otherwise, for unpaid caregivers via the Kupuna Caregivers Program (KCGP). KCGP has been available since 2018 and provides up to \$350 a week to qualified caregivers. Qualified caregivers must be providing care for an elderly U.S. citizen (or qualified alien) who is at least 60 years of age, must themselves be working at least 30 hours a week outside the home, and must not be self-employed. Additionally, care recipients must require help with at least 2 of 6 Activities of Daily Living (ADL's), must be living at home, and must not be eligible for any other programs or services. At this time, the program does not provide benefits for part-time workers, but may in the future<sup>40</sup>.

Meanwhile, Maine recently launched a two-year pilot program from October 2022 to September 2024. This program, called "Respite for ME", reimburses up to \$2,000 annually for informal caregivers. Recipients can use funds for respite care, counseling and training, legal and financial guidance, assistive technology, or services to maintain their own health such as occupational or physical therapy. This program also has additional eligibility requirements, including the need to demonstrate that recipients were hurt in some way by the COVID-19 pandemic<sup>41</sup>.

These and other efforts may help improve the caregiving experience; they may also serve to continue the trend towards emphasizing HCBS in state Medicaid programs. We also note that the American Rescue Plan Act (ARPA) provided for additional funding for HCBS, and other states have proposed caregiver-related initiatives<sup>42</sup>. Medicaid.gov has posted additional state-specific information, including CMS responses to many of these plans<sup>43</sup>.

State governments are not the only public entities involving themselves in caregiving work. The Lifespan Respite Care Act of 2006 has provided federal support for the Lifetime Respite Care Program, funding approximately \$2 to \$4 million per year for state programs. Additionally, on October 1, 2022, the U.S. Department of Health and Human Services (HHS) released the 2022 National Strategy to Support Family Caregivers for public comment<sup>4</sup>. Among the items included in the strategy was a document highlighting nearly 350 actions the federal government will take to support family caregivers, as well as over 150 actions that can be adopted at other levels of government and across the private sector<sup>4C, 4D</sup>. These actions are grouped into five categories:

- Increasing awareness of and outreach to
- Advancing partnerships and engagement
- Strengthening services and supports
- Ensuring financial and workplace security

- Expanding data, research, and evidence-based practices

### 6.3 ADDRESSING INFORMAL CAREGIVING

Beyond the programs and improvements in place or already under consideration, there is more that can be done to support informal caregiving and caregivers. Broadly speaking, improvements can take two forms: replacing some amount of informal care with formal care; and providing support for informal caregiving that eases the physical, financial, emotional, and time burdens. While we would expect that actual solutions would combine the two to some degree, we consider these two concepts separately below.

#### 6.3.1 SUPPORTING INFORMAL CAREGIVING

In the last five years or so, there has been an emerging market of caregiver support companies, not only connected with Medicare, Medicare Advantage, and Medicaid programs, but also with a focus on the employer space. Some of these companies look and feel similar to other point solutions, like second-opinion referral services, claims navigation, and billing transparency programs. Some even get mistaken for Employee Assistance Programs (EAP), though their services go far beyond the typical EAP.

The primary goal of these firms is to support the caregiver themselves. While different support companies have different approaches and areas of focus, services provided can include:

- Education, including knowledge of the underlying conditions and how to direct care for their loved one
- Finding providers, including free or low-cost options for care
- Assisting with medical claims
- Looking for alternative treatments, and helping with referrals to research hospitals or clinical trials
- Individualized support for caregivers, such as connecting to respite care or finding therapists
- Other more pragmatic, day-to-day tasks that may not be difficult but can be time-consuming, like organizing medical records from various providers or scheduling appointments

In some support companies, caregivers are matched with someone who gets to know their unique situation and becomes an extension of the family to provide a wide variety of support and services. This concierge, “care coordinator”, “care expert”, or “care advocate” can provide many of the services discussed above, helping to create a holistic approach to support and mitigate crises as or before they ensue.

These companies are growing at a rapid rate due to the urgent need for this kind of support. But the landscape is still wide open for not only more players, but also more iterative solutions to expand the platform and services beyond what is possible today.

#### 6.3.2 REPLACING INFORMAL WITH FORMAL CARE

Another point of interest is not simply supporting the caregivers themselves, but rather finding ways to replace some of their responsibilities more directly. Replacement models could be focused around replacing specific responsibilities on a longer-term basis; or they could be based on respite care, which provides short-term breaks for caregivers by providing most or all required care at home, at adult day centers, or at assisted living or respite care facilities<sup>44</sup>.

With that in mind, we consider which services could be provided to replace at least some of the work that informal caregivers perform today, and at what availability and cost.

To start with, as noted earlier in this paper, today’s caregivers primarily perform the following functions<sup>11</sup>:

- Transportation
- Financial assistance
- Help dressing
- Help getting in/out of bed
- Bathing
- Feeding
- Nursing tasks
- Help going to the bathroom

Any replacement model would likely feature three distinct resources: long-term care facilities; formal caregivers; and other support such as financial assistance.

The main relevancy of long-term care facilities in this context would be situations where informal caregiving happens because the patients and/or their families cannot afford (or have access to, regardless of cost) long-term care facilities. We also note that in many cases, patients will eventually move to long-term care facilities as their conditions develop. We therefore do not consider long-term care facilities to be a primary solution to informal caregiving needs. It is already an option used by many, and there would certainly be some cases where better access to long-term care would be ideal as compared to current care. However, we would not envision this as a major component of improving informal caregiving today given its high costs, limited availability, and the current choices that many families and caregivers are already making.

“Other support” could also be relevant here. The RAND Corporation study also estimated that replacing informal caregiving with minimum wage care would reduce costs by nearly 60%, with the reduction in foregone wages by current informal caregivers more than netting out the direct costs of minimum wage care<sup>45</sup>. We certainly do not imagine that all informal caregiving could productively be replaced by minimum wage care; many functions would expect to be performed by licensed and formal caregivers, and there is no guarantee that a substantial supply of minimum wage labor would even be available. Nevertheless, it is reasonable to consider whether some portion of informal care could productively be replaced by relatively low wage work. As one example, transportation to doctor’s offices could realistically be performed by low wage labor (or even be supported by ride-share apps such as Uber or Lyft).

Formal caregiving is another option. We describe some of the challenges associated with availability and cost of adding formal caregivers in sections 6.3.3 and 6.3.4 below.

We must also emphasize the importance of ensuring that any replacement is done appropriately; as noted earlier in the paper, there can easily be situations where introducing outside caregivers can put a strain on the existing caregiving relationship.

Nevertheless, finding ways to offload some of informal caregivers’ responsibilities may be a useful avenue of overall improvement to the caregiver experience by reducing their overall burden.

### 6.3.3 AVAILABILITY OF FORMAL CAREGIVERS

The main issues to address in terms of using formal caregivers to replace some or all of current informal caregiver support would be availability and cost. In terms of availability, any widespread solution that shifts resources to formal caregivers would require a substantial increase in the supply of formal caregivers.

This requirement would be particularly important given today’s shortages of formal caregivers. A 2022 article in the Washington Post discussed the current shortage, where some low-wage caregivers are finding easier jobs with equal or better pay in other industries, such as retail or restaurants<sup>46</sup>. Representative quotes from this article include:

*“We have that increased need, yet we are having to turn away people because we don’t have staff.”*

*-Vicki Hoak, Chief Executive Officer of Home Care Association of America*

*“This is a very thankless job and people don’t really need to do it. There are other options to make money.”*

*-Osagie Edison, Assistant Living Director, Anchor House*

The National Strategy document draws a similar conclusion:

*Developing a ready and well-qualified direct care workforce through better pay and working conditions, training, and improved career pathways, on the other hand, has the potential to reduce burnout among informal or family caregivers by increasing access to a range of support options. That in turn could allow caregivers to provide high-quality support for longer.*

*- 2022 National Strategy to Support Family Caregivers <sup>4B</sup>*

Turning around the shortage of formal caregivers, both lower-wage and higher-wage caregivers, will likely require a substantial increase in the labor pool, especially as Baby Boomers continue to age. One potential solution that has been discussed would be increased levels of immigration, though the particulars around that option are beyond the scope of this paper.

But addressing the need for formal caregivers will require more than just a larger labor pool; it will also require recruiting, extensive and specialized training, licensing, and potentially more lucrative compensation options. To the extent that a meaningful portion of current caregivers can find higher wage opportunities in many different industries including retail and restaurants, it will likely take a substantial shift in compensation levels to attract enough workers to meaningfully address today’s and tomorrow’s shortages.

#### **6.3.4 COST OF FORMAL CAREGIVERS**

While estimating the costs of improving pay and working conditions for formal caregivers is outside the scope of this analysis, we can still consider what the costs of formal caregiving look like today as well as how these costs may compare to the already existing value of the time of informal caregivers.

One estimate of current formal caregiving costs comes from a 2014 study of the cost of informal caregiving in the U.S. performed by the RAND Corporation<sup>45</sup>. In this study they estimated the cost at \$522 billion a year, from about 30 billion hours a year of caregiving time; this also corresponds to a roughly \$17.50 per hour cost, which we used in our calculations in the Introduction section. Using an average full-time annual workload of 1,801 hours per year would then equal \$31,518 per year in cost of a full-time caregiver<sup>47</sup>.

This annual cost can be compared to both the median U.S. salary of \$41,353 in 2020 for all workers 15 and over, and to the median U.S. salary of \$56,287 for full-time, year-round employees<sup>9</sup>. Please note that these values exclude any potential increases in compensation levels for caregivers above and beyond today’s levels that might be required to ensure adequate supply.

Given administrative overhead and support, the cost of employing caregivers would be higher than the salary values cited in the surveys. However, given the relativity of caregiving salaries to the median U.S. salary, it is realistic to



presume that the costs of replacing informal caregiving with formal caregiving should be comparable for many employees of companies in many industries on an hourly basis<sup>viii</sup>.

We next consider how this could be paid for.

## 6.4 PAYING FOR MORE CAREGIVING SUPPORT

There are multiple ways that the cost of caregiving support can be addressed. We discuss two of these potential sources below: public (government) and private (employers). Additionally, we consider what an insurance model around caregiving support might look like.

### 6.4.1 PUBLIC/GOVERNMENT SUPPORT FOR CAREGIVING

In section 6.2 above, we discussed public programs already in development from a number of states as well as the federal government. As the need for caregiving grows, and as these and potentially other public programs engage with the market, we would expect to see additional attempts by these and other governments to address caregiving needs.

While public policy in this area is still developing, and there are not yet any generally accepted “best practices”, we would nevertheless expect that any solution to today’s caregiving problems would involve substantial public support.

### 6.4.2 EMPLOYER SUPPORT FOR CAREGIVING

In addition to public support, however, we would also expect private sources to be relevant here, particularly employers. As noted above, for many roles, companies, and industries, the cost of replacing certain services currently provided by informal care with more formal support would likely be comparable or potentially even less expensive than the value of employees’ time. And while it is true that much of the cost of informal caregiving is directly borne by employees rather than employers, it is also true that employers still bear some of those costs given issues around absenteeism and presenteeism.

Additionally, as noted earlier in the paper, employee benefits is a competitive and expanding area of focus for many employers. An effective program for caregiving support may be a useful differentiator when it comes to attracting the best employees to a company.

There is also the growing segment of workers identified as the gig economy; those workers who either work for themselves or outside of the traditional employer/employee relationship. This group of workers typically does not obtain benefits from an employer directly. Sometimes benefits are offered through an organization or association of some sort, but most often a gig worker is purchasing medical benefits on the ACA Health Insurance Marketplace (Exchange), as well as life insurance and short-term disability, dental, and vision benefits online or through an app. While there is little to no gig worker regulation, they remain part of the same population who will be providing care while trying to work part-time or full-time.

The benefits world is shifting with the new generations entering the workforce. Expectations are changing, with reduced loyalty to individual employers and reduced appetite for and understanding of insurance, but increased

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<sup>viii</sup> We also note additional complicating factors such as PTO and benefits. For the sake of this analysis, we consider situations where the hourly value of PTO and benefits for employees who are informal caregivers would be comparable or greater than the hourly cost of PTO and benefits for formal caregivers.

comfort with online purchasing and subscription services<sup>48, 49</sup>. We therefore consider it possible that some form of app-based subscription service will become an important part of caregiver support.

### 6.4.3 INSURANCE MODEL SUPPORTING CAREGIVING

We can also ask if there is the potential for an insurance model that could potentially support caregiving from a caregiver perspective, instead of just from a care recipient perspective.

When determining what such an insurance model would cost, we must consider two things: who it would cover, and what services it would cover.

Currently, most health insurance coverage for working age adults is provided through employers. It is reasonable to think that a functional offering for caregiving support insurance would also come through employers. This would potentially reduce anti-selection, as well as possibly provide tax advantages similar to those found in other “cafeteria”-type benefit products.

The question of what services would be covered is an important one. Full “replacement” coverage of informal caregiving would presumably cover some combination of long-term care facilities, formal caregivers, and lower wage work support. Given the high costs of long-term care, as well as a likely lack of ability to manage utilization of long-term care facilities, or manage anti-selection, such coverage would likely be very expensive.

A leaner form of coverage might instead only cover selected services, such as formal caregivers and lower wage work support, or have specific limitations on the amount of coverage (in dollars, hours, or both) for support. However, such coverage may run into regulatory issues should it not cover long-term care facilities.

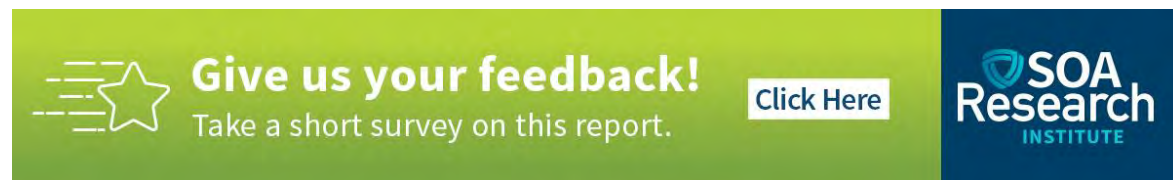
Given these considerations, the potential costs of an insurance model to cover caregiving could vary substantially, with lean coverage costing relatively little and generous plans costing much more.


## Section 7: Conclusions


As we have discussed, informal caregiving is a major and growing aspect of current American life, affecting millions regardless of region, age, wealth, and ethnicity.

Informal caregiving is an important part of many peoples' lives and can lead to a sense of fulfilment, accomplishment, and meaning. However, there are substantial challenges to be addressed to improve the lives of both care recipients and caregivers, and these challenges will likely become greater if today's demographic trends continue into the future.

Fortunately, we are seeing attempts to address these problems in both the public and private spheres. We further expect to see additional efforts as the difficulties inherent in caregiving are experienced by greater portions of the population. It will be important to assess the success or failure of potential solutions as they are implemented. This is a complex situation and will require complex solutions with the participation of many different stakeholders.



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Robert Eaton, FSA, MAAA

Jill Bruckert, FSA, MAAA

Nicole Gaspar, FSA, MAAA

Stephanie Scholz

Mindy Hsu

Greyson Britt

### **Project Oversight Group:**

Christine Bishop

Steve Cooperstein, FSA

Jack Cumming, FSA, MAAA

John Cutler, Esq.

Sam Gutterman, FSA, MAAA, FCAS, FCA, HONFIA, CERA

Cindy Levering, ASA, MAAA

Jeffery Rykhus, FSA, MAAA

Steve Schoonveld, FSA, MAAA

Stephen Weber

### **SOA Research Institute:**

Steve Siegel, Sr. Practice Research Actuary, ASA, MAAA

Barbara Scott, Sr. Research Administrator

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Society of Actuaries Research Institute  
475 N. Martingale Road, Suite 600  
Schaumburg, Illinois 60173  
[www.SOA.org](http://www.SOA.org)