Recalibrating for Caregivers: Recognizing the Public Health Challenge

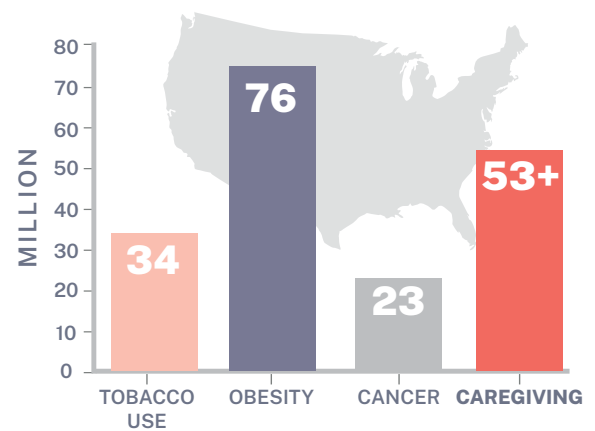## Rosalynn Carter Institute for Caregivers

EXECUTIVE SUMMARY

Roughly 34 million adults in the United States smoke cigarettes; approximately 76 million adults are obese; and 23 million adults have been diagnosed with cancer in their lives. Copious research and dollars are rightfully dedicated to searching for solutions to these commonly accepted public health challenges, while comparatively scant investment is made in the health and well-being of family caregivers, who number **53 million**. Like tobacco use, obesity, and cancer, caregiver health and well-being is an issue of great public health relevance—yet it is not widely recognized as such. With the lives of so many at risk, the health and well-being of caregivers must be considered a public health concern of equal measure.

In November 2019, the Rosalynn Carter Institute for Caregivers (RCI) held *Caregiving in the 21st Century: A National Conversation*—a dynamic, forward-thinking daylong exploration of caregiving. The former first lady galvanized thought leaders from across all sectors, including leaders from corporate America, philanthropies, nonprofit organizations, and government. The audience spent the day unpacking the lived experience of the growing population of caregivers. Feedback on the conversation was overwhelmingly positive; this is an issue that many admit they are not thinking about broadly enough, and they were inspired to be bold and solutions-oriented. And then we all went back to our day jobs, knowing a little more about the startling number of caregivers in the United States and the staggering challenges they face in today's world, eager to do something about it. The underlying questions persist: what can be done? What should be done? And what will help enact positive change to move the needle for caregivers?

By comparison...

...caregivers must be a public health concern

Then, as RCI considered these questions and prepared an action plan to address them, the world changed, unfurling a new reality, for everyone, including caregivers. During 2020, uncertainty borne of a novel virus has wreaked havoc on the nation's social fabric; protests across the country have surfaced deeply rooted systemic racism; and latent yet persistent divisions over privilege and self-determination have been brought to the fore. It would be possible for RCI to ignore these changes in a paper about caregivers, but we feel strongly that would be a lost opportunity. Like all Americans grappling with uncertainty during this time, it feels like an appropriate moment to take stock: to reflect on our legacy and that of our founder; to consider the decisions we have made at the expense of others and the actions we have taken and not taken; and to acknowledge we have not done enough.

The time has come to reexamine how we define and support caregivers in a new and rapidly evolving world:

- To shift the focus from "caregiving" to "caregivers," a clearly articulated acknowledgment of the impact on individuals

- To acknowledge that caregivers are, as a group, a more vulnerable population than non-caregivers

- To understand the shifting demographics of the nation and therefore of caregivers, including growing minority populations, an aging population, rising chronic disease prevalence, and increasing numbers of veterans since the beginning of the Global War on Terrorism

- To see caregiving as a public health issue that should be addressed through a public health pyramid with universal preventive and protective measures followed by targeted programs for those needing additional support

- To provide a support infrastructure that will help ensure caregivers are as healthy as possible and allow families to make the best decisions about how and where care is provided

- To approach solutions with a systems-oriented mindset, considering the many interdependent factors that play a role, taking into account the health care system and health disparities, racism and discrimination, and complex family dynamics

Shifting focus *from* caregiving *to* caregivers as a vulnerable population.

This paper considers what will be needed to make the kinds of system-level changes to improve the health, strength, and resiliency of informal family caregivers. It outlines the current state of affairs for caregivers and proposes what is needed to move forward, acknowledging that there is not much bold, disruptive thinking currently taking place around how to best support caregivers. In fact, one of the clearest lessons to date from the COVID-19 pandemic is that even the most fundamental information, such as the number of caregivers in the United States, can change at a moment's notice. This work presents a series of questions and pursuits for allies of all sorts—employers, caregiver advocates, policymakers, payers, and health care providers—to join us in the work of exploring solutions. Caregiving is a complex challenge, with countless angles, and it will take all of us, working together, to address it.

Achieving caregiver health, strength, and resilience through system-level change.

> **There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver.**
>
> *Former First Lady Mrs. Rosalynn Carter*

INTRODUCTION

From the time former First Lady Rosalynn Carter's father was diagnosed with cancer to his passing when she was 13, she helped her mother care for him and her younger siblings. Within a year of his death, her grandmother unexpectedly passed away, and her grieving grandfather moved into their home. These experiences shaped Mrs. Carter's understanding of the loneliness and stress caregiving can cause, along with the satisfaction it can bring, and led to her advocacy work on behalf of caregivers.

She wrote in her autobiography: "Now [my grandfather] leaned on Mother for strength, as did we. And my mother…now had the responsibility, not only of managing the meager finances of our family, but also of raising four children and caring for her father."[1] The year was 1940, and Mrs. Carter's mother was 34 years old. Eighty years later, while society has advanced markedly, little has changed for caregivers—particularly for marginalized populations. Some family caregivers reap great joys from caring for a loved one, but others find caregiving responsibilities complicated, stressful, and isolating. In a world that is constantly changing, in many ways, it has not changed in nearly a century for family caregivers.[2,3] Sometimes called informal caregivers, family caregivers are typically relatives or friends who provide unpaid care or support to the care recipient.[2,3] In this paper, we use "caregiver" to refer to family caregivers and specify when the reference is to paid caregivers or the formal caregiving workforce.

There are many types of caregivers and tremendous variation in the level of care they provide, which can make it difficult to track them with precision.

Caregiving spans a wide spectrum, ranging from occasional assistance with housework and shopping or financial support on one end, to daily wound care and administering medication on the other. In addition, caregivers often help coordinate care with providers and act as advocates for care recipients with health or functional needs, and they often provide emotional support at each stage.

Today, family caregivers number 53.0 million in the United States,[3] and the urgency to support them could not be more pressing, especially as we navigate both a global pandemic and a national reckoning with racism. Both affect caregivers in complex and perhaps unforeseen ways. In this paper, we consider caregivers within this new reality. We recognize there will be many new caregivers in the United States by the time the COVID-19 pandemic is through, and many of them will be people of color since racial and ethnic minority populations have been more affected by the pandemic.[4] We reflect more broadly on health disparities among marginalized populations who are also caregivers and argue that since caregiver status affects health outcomes, particularly for high-risk populations, it ought to be recognized widely as a social determinant of health.

Further, we attempt to shed light on how caregiver status intersects with other identifying factors such as religion, race, class, social status, and the like. For example, a caregiver may identify as a millennial, Latinx service member and concurrently as a student living in the South with young children — and each of these experiences shapes them. It is at the intersection of these identities where life happens. The demographics of the country are changing, and to create inclusive interventions and approaches that address the needs of all caregivers equitably, caregiving status must be considered together with other social determinants through a lens of intersectionality.

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We make the case that caregiver health—including mental health—and well-being should be recognized as a public health issue and approached with the same preventive strategies as comparable public health issues. We consider the benefits of approaching caregiver health through a pyramid framework, beginning with broad prevention measures and becoming more interventionist as caregivers "rise" higher in the pyramid. A successful public health approach will better treat the needs of caregivers before those needs become emergencies.

We advocate that thought leaders and policymakers consider the challenges facing caregivers in light of the changes taking place within the United States. None of the issues facing America takes place in a vacuum, and none can be addressed independently. To make real progress for caregivers, a new perspective is needed—a systems perspective that considers all these factors and how they are connected.

This paper relies on the important contributions from our peers and partners in the caregiving community—particularly, findings from the recent ***Caregiving in the U.S.*** report by AARP and the National Alliance for Caregiving. Our intent is not to duplicate their efforts, but rather, to stand on the shoulders of this thoughtful work and paint a vision of a society in which caregivers reap the rewards of their roles, and also feel seen, heard, and supported through the stress and strains of caregiving. As Mrs. Carter reminds us, there is a person behind every program and number that deserves to be recognized and felt understood.

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CAREGIVER HEALTH AND WELL-BEING: A PUBLIC HEALTH ISSUE

Over the past several decades, experts have come to understand that health is influenced not only by genetics, behaviors, and medical care, but also by a myriad of other factors—commonly known as social determinants of health.[5] Social determinants include conditions and characteristics such as income and social status, racism and discrimination, education and literacy, and physical environment. These factors can dramatically affect an individual's health outcomes. As an example, having a college degree statistically reduces the likelihood of death due to drug overdose, suicide, or alcohol-related liver disease.[6] Likewise, the negative effects of caregiving disproportionately affect those who already are likely to have poorer health outcomes. On the other hand, caregiver support programs—such as RCI REACH (Resources Enhancing Alzheimer's Caregiver Health) and Operation Family Caregiver, RCI's one-on-one coaching program for anyone caring for someone with an injury due to military service—have shown demonstrable improvements on the health and well-being of participating caregivers.[7–10] A systematic review of caregiver support interventions, including respite care, group and individual interventions, and technological support, found inconsistent results but were generally beneficial to caregivers.[11]

Caregiving status is not typically considered a social determinant of health, but it should be. Like those who do not have college degrees or who have been diagnosed with a chronic disease, caregivers face considerable vulnerabilities and greater health risks. Overall, America's 53 million family caregivers are more likely than their non-caregiving peers to suffer from adversity as a result of their caregiving, including poorer health, reduced financial security, and greater levels of stress. These disparities are magnified among racial, ethnic, gender, and sexual minorities.[3]

Because caregivers live within a diversity of contexts, some are more at risk than others. Caregivers who live in rural areas, for example, are more likely to have lower household incomes, lower education levels, and to report being in fair or poor health than caregivers living in urban environments.[12] Likewise, for African American caregivers, researchers have found that a complex interaction of sociocultural and environmental stressors—including experiences with racism and discrimination, cultural norms, financial concerns, and environmental safety—influence caregiving and self-care.[13] In addition, caregivers who come from marginalized populations are less likely to have access to the supports that benefit caregivers in more privileged positions, such as better leave and health care benefits. It is incumbent upon our nation—including policymakers, employers, and organizations such as RCI—to advance solutions that address these disparities and create more equity through public health interventions.

Only recently has caregiving been mentioned as—or suggested to be—a public health issue.[14] Frequently, the concept of "supporting caregivers" is associated with policy solutions such as paid leave in the workplace and respite care at home—safety net benefits rather than a public health approach. Yet caregiver health and well-being should be recognized as a public health issue much like

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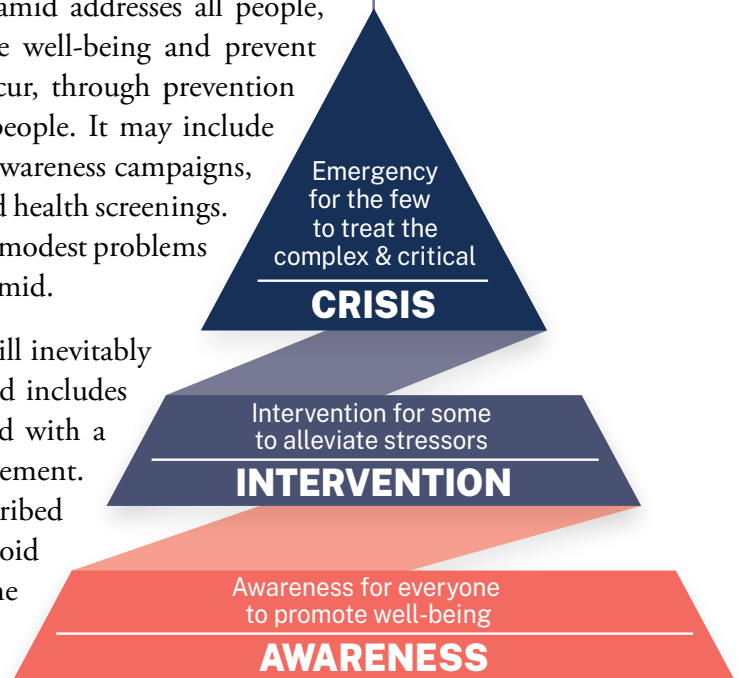
smoking cessation, obesity prevention, and cancer surveillance. More than twice as many adults in the United States will serve as caregivers by the end of 2020 as there are adults who have ever been diagnosed with cancer. To be more precise: within the past 12 months, 53.0 million American adults have provided care to an adult or a child with special needs,[3] while 23.3 million adults have received a cancer diagnosis at any time in their lives.[15]

As with other public health issues, not addressing the additional stress borne by caregivers affects not only those individuals and their families, but the health of our nation—the economy, national security, and health care. In addition, negative outcomes experienced by caregivers have a multiplier effect, as the caregivers become less able to provide care, resulting in an additional need for their care recipient and perhaps themselves. Considering caregiving status as a public health concern does not disregard the needs of individual caregivers, just as focusing on lead paint in houses does not obviate the need for doctors to treat children suffering from lead poisoning, or addressing loneliness among older people does not mean they should not be treated for depression. By taking a broader and more holistic view, policymakers and practitioners can develop policies and bolster systems that focus on protecting the health of caregivers in the United States.

Applying the public health prevention paradigm

One paradigm often used by public health professionals to support health improvement and disease prevention is a pyramid framework with three distinct layers of prevention: primary at the base, with secondary and tertiary prevention layered on top.[16] The base of this pyramid addresses all people, healthy or sick. Here the objective is to promote well-being and prevent disease or negative health impacts before they occur, through prevention on a large scale to reach the greatest number of people. It may include such protective measures as public education and awareness campaigns, promotion of healthy lifestyles and vaccinations, and health screenings. The aim is to minimize the number of people whose modest problems result in an advance to the middle layer of the pyramid.

Despite broad preventive measures, some people will inevitably develop disease, and the midsection of the pyramid includes those people who develop disease or are diagnosed with a disorder and require treatment or disease management. They may be treated with medication or prescribed special diets to begin managing their health to avoid complications. For many people, this will solve the problem; however, some small number of people at the crown of the pyramid may suffer acutely.

Emergency
for the few
to treat the
complex & critical
CRISIS

Intervention for some
to alleviate stressors
INTERVENTION

Awareness for everyone
to promote well-being
AWARENESS

They may end up in the emergency room, perhaps needing surgery or some other complex treatment. At this level, the goal is to prevent life-threatening outcomes and help manage long-term health issues that are often complex.

Caregiver well-being can be considered in the same way. Prevention and awareness should begin with the entire population, many of whom may be cared for or be caregivers themselves—or both—at some point in their lives. Caregivers in the middle of the pyramid, as suggested by recent evidence, may suffer from burdens, disrupted social engagement, isolation, and tension in their relationships or with finances, among other stressors. Many will endure the hardship, but a small number of caregivers may succumb to the stress, leaving them in peak crisis, perhaps suffering from depression and despondency. At this point, they might cease self-care, consider suicide, abuse substances, and neglect or harm their care recipient.

In the case of caregiver well-being, the public health paradigm is unique in that the affected population includes not only the caregiver but also a care recipient. Because the caregiver's well-being is directly related, in many cases, to the well-being of their care recipient,[17] protective and prevention efforts around caregiver health arguably have even greater value for the nation than many other public health prevention efforts. A study in Washington state, for example, offered tailored caregiver support plans unique to the person's needs.[18] Results demonstrated a significant reduction in stress and depression while reducing the risk of burnout, while at the same time cutting the use of the state's Medicaid Long-Term Care/Long-Term Support Services by 20 percent and reducing the state's annual cost burden by $20 million.[19]

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The challenges plaguing the U.S. health care system are exacerbated among caregivers. The earlier caregivers are supported in their journey—the lower on the pyramid—the fewer interventions they may need, reducing the burden on society at large. Building resiliency and creating a more supportive infrastructure will serve caregivers as their caregiving experience grows more intense, by better equipping them to respond to increasing needs.

Base: Awareness

In this scenario, as the caregiving experience becomes more widely recognized as a public health issue, interventions should begin at the base of the pyramid with the entire populace, and they may take many forms. For example, health care providers should screen for caregiving status and raise awareness about the risks and stress that can accompany taking care of a loved one or relative. Government surveys such as the Current Population Survey, the decennial census, the National Health Interview Survey, and others should move to include questions about caregiving status and track the prevalence across the country. Corporate and philanthropic entities should create national campaigns to increase awareness of caregivers among the general public and help caregivers see themselves as such. Subgroups and subpopulations that are more likely to need a caregiver, such as those medically discharged from the military or suffering from

chronic diseases, should be specifically targeted with appropriate messaging and additional strategies. Overall, the goal is to move from awareness about "caregiving" as a field to recognizing and supporting "caregivers"—the very real people who are affected.

Middle: Intervention

For those identified as caregivers through screening—in the middle of the pyramid—health care providers and practitioners should be able to recommend interventions aimed at treating and alleviating concerns. Nonprofit organizations such as the Rosalynn Carter Institute for Caregivers and the Family Caregiver Alliance offer programs to support caregivers through their journey, as do many local and federal government agencies and academic institutions. Private and public payers should align incentives to ensure caregivers recognize the risks borne by this role and can take advantage of programs or other interventions. Employers should facilitate uptake of such programs by ensuring employees have access to resources, encouraging the creation of informal networking groups or Employee Resource Groups, and reducing stigma. Policy solutions could help as well, including state and federal policies such as tax incentives and benefits for caregivers, expansion of family and medical leave, increased funding for long-term care, and support for respite care. The intent is to support caregivers in the places they live, work, and play, approaching and engaging them through multiple channels. A supportive environment and more flexible policies will help foster resilience and ensure support for caregivers' physical, mental, and financial needs.

Top: Crisis

As with disease, the goal is to curtail the need for "emergency rooms" in a caregiver's journey by better treating their needs before they rise to an urgent level. By the time caregivers have reached the top of the prevention pyramid, their challenges are much more difficult to treat. Many have reached the proverbial end of their rope and may be struggling with depression, drug abuse, and suicidal thoughts. In addition, their physical health by that time has likely suffered, whether as a result of taking worse care of themselves, the physical manifestation of mental health concerns, or cardiovascular and other diseases resulting from persistent stress.[20] At that point, restoring a caregiver to optimal health is even more difficult.

Understanding cost savings

Researchers and public health advocates frequently point to cost savings as a major reason for investing in public health.[21] Little is known about the money saved as a result of early interventions for caregivers, but we do know that $187.8 billion was spent on mental health and substance abuse disorders in

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2013, with $71 billion spent on depressive disorders.[22] With research showing that nearly one-third of people caring for terminally ill loved ones suffer from depression,[23] building resiliency in caregivers likely would result in some cost savings. Similarly, research has shown that avoiding preventive care has cost implications. According to a report from the Trust for America's Health, investing just $10 per person per year in proven community-based programs that increase physical activity, improve nutrition, and prevent tobacco use could result in a health care savings of more than $16 billion annually within five years.[24] And the Centers for Disease Control and Prevention (CDC) has estimated that avoidable chronic diseases reduce economic output in the United States by $260 billion per year.[25] It is likely that ensuring caregivers take care of their own health needs—through preventive health screenings and regular primary care—will keep costs down.

The unknown impact of the COVID-19 pandemic

The percentage of people acting as caregivers is likely to increase after the COVID-19 pandemic subsides for four potential reasons: 1) protracted recovery time and/or long-term health consequences for recovering from COVID-19; 2) potential long-term impacts of postponed or deferred medical treatment and emergency room visits; 3) an expected mental health "aftershock" that could result in waves of depression, substance abuse, suicide, and post-traumatic stress; and 4) rising nursing home placement deferments to avoid the risk of infection and isolation.

As of fall 2020, still little is known about the long-term effects of COVID-19, but many experts expect that those who recover from a severe bout with the disease may incur lasting detrimental effects on the lungs, heart, and central nervous system. With nearly 50,000 laboratory-confirmed hospitalizations related to the disease as of August 2020, and the figure continuing to climb, the number of caregivers is likely to rise for the foreseeable future.[26] While the research to date has been limited, in a small study of 143 patients in Italy who had recovered from COVID-19, nearly 90 percent of patients reported the persistence of at least one symptom after 60 days, 55 percent reported 3 or more symptoms, and 44 percent had a worsened quality of life.[27] The long-term sequelae of the disease are largely uncertain.

At the same time, medical procedures, routine health screenings, and emergencies are being deferred or avoided because of fears about COVID-19 infection, which may result in long-term effects as well. Again, definitive research is scarce, but there are indications that people are limiting their visits to doctors and emergency rooms. An analysis in May 2020 of 2.7 million patients across 23 states found that after the pandemic was declared a national emergency in March 2020, preventive screenings for cancer decreased by 86 percent (colon) and 94 percent (breast and cervical), as compared to mean preventive screening volumes for the three years prior.[28] A follow-up suggested that from March 15 to June 16, screenings for all three of these cancers were down by between 63 and 67 percent, relative to the number of screenings

expected based on historical averages.[29] According to the CDC's National Syndromic Surveillance Program, emergency department (ED) visits declined 42 percent early in the pandemic as compared to the same period last year, with the highest reductions in the Northeast, where the pandemic was initially most severe. According to the study, visits decreased for conditions such as nonspecific chest pain and acute myocardial infarction.[30] Anecdotally, doctors across the United States reported seeing fewer patients coming to the ED with symptoms of stroke and appendicitis, as well as heart attacks.[31–33] Reports suggest that many are delaying care for conditions that, if left untreated, could lead to increased morbidity.

In addition to the possible lasting effects on physical health, experts expect there will be a corresponding increase in substance abuse and mental health. In a recent paper, the authors write, "In the context of the COVID-19 pandemic, it appears likely that there will be substantial increases in anxiety and depression, substance use, loneliness, and domestic violence; and with schools closed, there is a very real possibility of an epidemic of child abuse." They argue that similar emergencies almost always lead to increases in depression, post-traumatic stress, and substance abuse, among other mental health disorders.[34] Studies already have indicated these effects. In a KFF Health Tracking Poll taken in July 2020, 53 percent of U.S. adults said that worry and stress related to the coronavirus has had a negative impact on their mental health, up from 39 percent in May.[35] Another survey completed in June 2020 found that among unpaid caregivers, 32.9 percent started or increased substance use to cope with pandemic-related stress or emotions, compared to 13.3 percent of the general population.[36]

Finally, many people who may have previously chosen to pursue long-term care in a facility may be more fearful due to the high incidence of infection and death at such facilities during the COVID-19 pandemic, and decide to remain home, relying on a caregiver instead. During the pandemic, family caregivers for those remaining at home were critical to the public health response. Their proximity to the care recipient may have ensured that someone noticed any symptoms exhibited; they were essential in facilitating contact tracing, particularly for patients with cognitive disabilities; and their presence allowed patients with chronic conditions or delayed procedures to remain home.

DEFINING THE POPULATION OF CAREGIVERS

According to a May 2020 report from AARP and the National Alliance for Caregiving, 53.0 million adults in the United States, or 21.3 percent, provide care to an adult or a child with special needs.[3] Of these, most are family caregivers, sometimes called informal caregivers—that is, relatives or friends

During COVID-19, family caregivers are critical to the public health response.

who have a relationship with the care recipient and are typically unpaid.[2,3] This group represents a significant segment of the U.S. population.

Caregiving is not defined by specific tasks or the amount of time spent, which is perhaps what makes it so difficult for people to understand or identify with the classification. Often the shift from providing simple assistance to a full-on caregiver is so gradual it can be virtually imperceptible. Some caregivers perform "cultural tasks" for their care recipient—for example, interpreting at the doctor's office or helping navigate the U.S. immigration system.[37] Depending on the status of the care recipient, the care needed can change significantly over months or years. Because of increasing life expectancy, accompanied often by the presence of long-term conditions and comorbidities, there is an indication that caregiving activities are becoming more intense, specific, and long-standing.[3,38,39]

Further, caregivers assist with many other daily tasks and general needs. Most caregivers monitor their care recipient's health and communicate with health care professionals, as well as advocating for their care recipient with providers, insurers, and other agencies.[3] In the United States, health care is delivered by a wide range of providers, including privately-owned, community, and government hospitals; independent physicians; urgent care centers; hospice services; community health centers and free clinics. The system is complex, and the cost of care can be high to patients, especially if they lack or have insufficient insurance coverage. One of the many strategies for controlling costs has been early hospital discharge, which results in a heavier reliance on follow-up care in the home rather than in the hospital.[40]

Almost half of the caregivers responding to a 2019 survey of family caregivers from the AARP Public Policy Institute reported that they perform complex medical/nursing tasks such as managing mobility assistive devices or operating ventilators and oxygen, in many cases without any prior preparation or training.[40,3] Many family caregivers said they worried about making mistakes, highlighting large gaps between medical professionals' expectations of family caregivers and caregivers' preparedness to take care of such highly specialized tasks. Further, caregivers' confidence in taking on these tasks varied by income level, with lower-income caregivers finding it more difficult than those with higher incomes to perform complex tasks, pointing to additional disparities.[40]

However, in many cases, family caregivers are well-positioned to support health care providers, therefore reducing the burden on the system and keeping costs down. This practice was likely

heightened by fears of new health risks throughout the COVID-19 pandemic, during which people who may once have moved to a rehabilitation center or care facility, instead chose to remain in their homes or live with loved ones.

In addition, family caregivers often act as an integral component in the response infrastructure in disaster and emergency preparedness. In an unpublished survey conducted by RCI in 2019, nearly half of the family caregivers who responded found that disaster preparedness efforts targeting family caregivers were lacking. News stories about nursing homes in the early days of COVID-19 revealed how difficult it can be for caregivers to compile accurate information during emergencies.[41,42]

Aging American populace

Family caregivers span all generations, and, like the entire U.S. population, caregivers are aging.[3] Perhaps more importantly, the people they care for are reaching advanced ages that demand an even higher degree of support. As the population ages, the number of Americans suffering from Alzheimer's disease and related dementias continues to rise. Nationally, 5.8 million Americans over 65 are living with dementia, and that number is expected to rise to 13.8 million by 2050.[43] With more than nine out of 10 older adults with dementia relying on family caregivers at some point, the number of caregivers supporting them is growing in parallel.[43]

While dementia garners much national attention, it is hardly the only driver of increased caregiving. It is also caused by a rise in chronic conditions including diabetes and treatable cancers; physical and cognitive impairments such as Parkinson's disease, multiple sclerosis (MS), and amyotrophic lateral sclerosis (ALS); and the physical and emotional wounds of war among service members and veterans; among others.

The prevalence of chronic conditions is expected to increase as the baby boomers age and the share of the population over 85 doubles.[44,45] In fact, the fastest-growing cohort in the United States is adults over 80, who are the most likely to require care.[2] By 2030, as the baby boomer generation ages, roughly 20 percent of the U.S. population will be over 65, with an expectation that they could live an additional 18 to 21 years.[46,47] The nation is increasingly relying on an aging population in taking care of an even older population with no solution in sight. Concurrently, because of the Global War on Terrorism, along with veterans from the wars in Korea, Vietnam, and Desert Shield/Desert Storm, there is a growing number of current and former servicemen and women living today—many of whom suffer from visible or invisible wounds and need the support of a caregiver.

Alongside these demographic changes is the inadequate provision of long-term care services for many of those who need it. The United States does not have a cohesive, affordable system for long-term care, leaving those who need such care to piece together a makeshift solution. These aging or infirm individuals often struggle on their own, relying on family and friends for some tasks, using "gig workers" for others, and hiring direct care workers for specialized services such as medical and personal care. Those with financial limitations have even fewer options. In many cases, family members and loved ones find themselves searching for answers, seeking advice from friends and family in similar circumstances, or pursuing help from local governments and social service providers. They may consider the pros and cons of adult day care, assisted living communities, and nursing homes; but, in many cases, these options are unattainable due to high costs, demand outweighing supply, or limited reliability.[48] COVID-19 brought to light how untenable and fragile this patchwork system is for those with few options. The absence of a cohesive system that meets the needs of all Americans will become even more pronounced as the population grows older and less healthy.

At the same time that the need is likely to grow, the capacity of family members to provide care is waning. Families are shrinking, as fertility in the United States has pursued a downward trajectory for much of the last century.[49,50] With the exception of the baby boom in the 1940s, '50s, and '60s, fertility levels in the United States have hovered around replacement level.[49] This trend has led to a group of individuals who tend to be in midlife, with adult or semi-dependent children, but who are also caring for aging parents—known as the "sandwich generation."[51,52] Many of those who provide care to both children and parents find a third claimant on their time as well: their employer.[53] Due to the demands of the caregiving role, women in this role may forgo or reduce their earnings, may be passed over for promotions, and may be entirely pushed out of the labor force.[39]

Disparities in caregiving

Despite their prevalence, caregivers can often be marginalized and "otherized" in similar ways to other population subgroups. Othering has been described as "a set of dynamics, processes, and structures that engender marginality and persistent inequality across any of the full range of human differences based on group identities… Although the axes of difference that undergird these expressions of othering vary considerably and are deeply contextual, they contain a similar set of underlying dynamics."[54] Caregivers are sometimes dismissed by the dominant population as intrinsically different and therefore unrelatable, their needs ignored by employers, and their challenges in everyday tasks overlooked or sometimes exacerbated. The COVID-19 pandemic brought these affronts to the fore for caregivers whose circumstances caused greater risks for their families should they fall ill—essential workers, for example, who had to choose between earning money and risking the lives of their loved ones.

When caregivers are otherized or considered only as a subset of other population groups such as older adults or parents, it becomes much easier to exclude them from policy discussions, whether deliberately or inadvertently, or to otherwise minimize their power.[54]

In addition, "caregiver" is just one identity worn by those who provide support to family and friends. That identity often intersects with another identity, whether race, ethnicity, gender, or some other identifier. The prevalence, intensity level, and effects of caregiving vary widely by subpopulation.[2,3] It can be difficult to assess the effects by demographic group, as few caregivers fit neatly into any one category, but it is clear that—like other social determinants of health—caregiver well-being varies by gender, racial and ethnic identity, socioeconomic status, LGBTQ status, and likely many other contextual factors.

While the numbers vary among reports, women account for at least half of all caregivers, with some researchers estimating that as many as 61 percent of caregivers are female.[3,55] The stress of caregiving often weighs more heavily on women than their male counterparts for many reasons: their caregiving duties are likely to be higher-intensity tasks, they are more likely to co-reside with their care recipient, and they are more likely to earn lower incomes than men, among others.[39,56] Like women, minority caregivers are more likely to report higher intensity caregiving roles, due in part to higher rates of co-residence among minority caregivers.[3,57]

Likewise, individuals from minority communities are overrepresented among family caregivers: Hispanic, African American, and LGBTQ individuals are disproportionately likely to serve as family caregivers.[3,57–59] At least 30 percent of family caregivers identify as a racial minority, and this proportion is expected to increase as the older population itself becomes more diverse.[57] The prevalence of caregiving is highest among African Americans, 28.1 percent of whom report providing care in the past year.[3] They are followed by Hispanics (21.9%), white, non-Hispanics (19.8%), and finally, Asian Americans (19.2%).[3]

Although minority populations are overrepresented in caregiving roles, they are less likely to use formal caregiving supports such as paid services and more likely instead to rely on family and kin networks to help provide care.[57] Research has shown that both formal and informal support can improve caregiver health and other outcomes. Without formal support, informal family support may be especially helpful in protecting against poor health for minority caregivers,[57] and use of these supports increased among caregivers from 1999 to 2015.[38] Despite the higher burden and lower use of supportive services, African American and Latino caregivers are more likely to report having a positive attitude about their caregiving role.[57] One study suggests that

Women and minority caregivers are more likely to report higher intensity caregiving roles.

for African Americans in particular, where informal caregiving is more "normative largely because of a historical background of oppression, racism, and limited resource availability," the "social exchange" that takes place between caregiver and care recipient may result in lower depressive symptoms.[60,61]

Representation among caregivers also varies by age. Millennial caregivers, born between 1980 and 1996, are more diverse than older caregivers.[62,63] Only 44 percent of millennial caregivers are white, compared to 67 percent of older caregivers, and men make up a greater proportion of millennial caregivers than any other generation.[62] Latino and African American caregivers are more likely to be female, and, much like the Latino and African American populations in the United States overall, they tend to be younger, on average, than white caregivers.[57]

Almost half (47%) of caregivers are between 18 and 49 years old, and about one in four caregivers is a millennial.[3] One-third of these millennial caregivers are ages 18-24, another third are 25-29, and the final third are 30-34.[62] They are less likely to be married, have lower levels of education, and have a lower income than caregivers over 40.[63] Many millennial caregivers provide care to a parent or parent-in-law (43%), and another 22 percent provide care to a grandparent.[62] More than half of all millennial family caregivers are the sole caregiver to their care recipient.[62] In addition, millennial family caregivers are the most likely of any generation to be employed while performing their caregiving duties.[62] They face similar difficulties to older employed caregivers, such as cutting their work hours or turning down promotions.[62] Many millennial caregivers earn less income, find less support at work, and spend a higher proportion of their income on out-of-pocket costs for their care recipient.[62]

Although there is little research on caregiving among LGBTQ communities, there have been some studies of this particularly underrepresented population. Much like women and individuals from racial minority

> Despite higher burdens, African American and Latino caregivers are more likely to have a positive attitude about caregiving.

Millennial Family Caregivers by Age Group

30-34 yrs **34%** | 18-24 yrs **35%** | 25-29 yrs **31%**
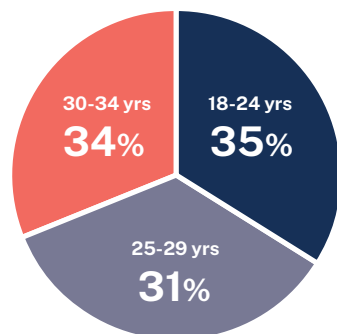
Millennial Family Caregivers by Race/Ethnicity
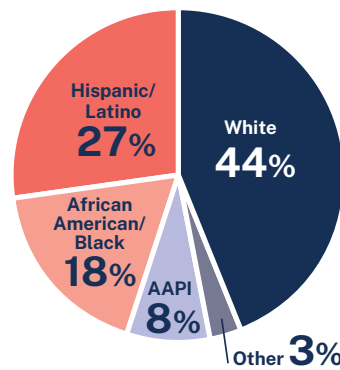
Hispanic/Latino **27%** | White **44%** | African American/Black **18%** | AAPI **8%** | Other **3%**

AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC: AARP. May 2020. https://doi.org/10.26419/ppi.00103.001

groups, LGBTQ individuals are overrepresented among family caregivers.[58] Compared to the non-LGBTQ population of family caregivers, LGBTQ caregivers are more likely to be male, younger than 65, and live alone.[58] In addition, they are even more likely than their non-LGBTQ counterparts to be non-white or Hispanic, to have lower socioeconomic status, and report higher levels of financial strain associated with caregiving.[58] A study of LGBT caregivers reported over a third (34%) are millennials, and of the youngest millennial caregivers (age 18-24) fully 17 percent identify as LGBT.[62]

Economic effects of caregiving

When caregivers are healthy and can remain fully and gainfully employed, with the right support and benefits from their employers, the nation's economy benefits. Data from the 2011 and 2012 American Time Use Survey suggest that the 30 billion hours of care for older adults provided annually by family caregivers in the United States amounts to $522 billion in opportunity cost each year.[64] This contrasts with the costs of professional caregiving, which was estimated in 2011 to cost the nation $221 billion annually in unskilled paid care or $642 billion per year to replace with skilled nursing care.[64] In the future, as the needs increase for caregiving among the aging U.S. population, more family caregivers likely will face large opportunity costs alongside negative health impacts.[65]

Whether the care is provided by family caregivers or paid caregivers, it is expensive. In 2016, long-term care services and supports totaled $366 billion, or 12.9 percent of all personal health care spending. When Medicare spending is removed, the total drops to $286.1 billion, or 10.1 percent of personal health care spending.[66] In 2019, this figure includes such costs as nursing home care (average annual cost of $90,156 to $102,204, depending on room type); assisted living communities (base rate of $48,612); home health aides (average monthly rate of $4,385); and adult day care services (average monthly rate of $1,625).[67] A 2017 survey by the SCAN Foundation found that 57 percent of Americans expect to rely on Medicare for ongoing living expenses; however, Medicare is not intended to be a primary funding source for long-term expenses and provides limited access to personal care services.[68] For many families, these expenses simply are out of reach, leaving them scrambling to provide care themselves. According to the Congressional Budget Office, care provided by family caregivers to older adults was valued at $234 billion in 2011.[69] And this estimate does not include unpaid care provided to individuals under age 65.

Family caregivers bear great financial strain, even when they provide care themselves. A 2016 AARP report found that 78 percent of family caregivers have out-of-pocket costs related to caregiving, spending on average nearly

Whether the care is provided by family caregivers or paid caregivers, it is expensive. In 2016, long-term care services and supports totaled $366 billion, or 12.9% of all personal health care spending.

20 percent of their personal income.[70] According to a study by a financial services company, half of the caregivers financially providing for their care recipient are making personal financial sacrifices, with about one-third cutting back on their expenses. Nearly one-quarter of respondents have trouble paying their bills, and slightly less had to dip into their personal savings.[71] African American and Hispanic caregivers are more likely than white and Asian American caregivers to experience financial strain, identifying more "impacts" from a list of such choices as stopped saving, took on more debt, left bills unpaid, etc. These disparities are more pronounced among caregivers with household incomes of $50,000 or less.[3]

Financial strain is made worse by a lack of universal support from employers. Sixty-one percent of all caregivers report being simultaneously employed and caregiving.[3] Of these, 60 percent are employed full time. Employed caregivers report having flexible work hours (56%) or paid sick leave (58%), both of which could make accommodating their caregiving role easier.[3] However, these benefits are not uniform, and many employed caregivers must adjust their employment when taking on a caregiving role. About 60 percent of employed caregivers report that they have cut back their hours at a job, taken a leave of absence, or experienced other more significant, punitive workplace impacts.[3] Half of all caregivers who take time off from work to fulfill their role report losing income, and caregiving can also reduce overall earnings and retirement savings.[3]

> ### 60% of employed caregivers have cut back at work.
>
> Caregivers report losing income and reduced overall earnings and retirement savings.

There is a gender disparity as well. About two-thirds of male caregivers report being employed, while only a little over half of all female caregivers are employed.[3,39] Further, female caregivers are more likely to have hourly positions, whereas salaried caregivers are more likely to be male.[3] These trends are especially challenging since women are more likely than men to take on caregiving roles, and regardless of caregiving status, they earn less than men—on average—and are likely to have less retirement savings than men. Women over 50 who leave the workforce to care for an aging parent are estimated to lose more than $324,000 in wages and retirement savings.[72]

Also disproportionately affected are those workers taking part in the "gig economy," characterized by temporary or freelance work and short-term contracts as opposed to permanent positions with benefits.

The share of the U.S. workforce participating in the gig economy rose from 10.7 percent in 2005 to 15.8 percent in 2015, according to the U.S. Bureau of Labor Statistics, which has not released comparable numbers since then.[73] According to a study by Freelancers Union and Upwork, however, 35% of the U.S. workforce did freelance work in 2019, with only 25% of those freelancing to earn income beyond their full-time job.[74] Forty-six percent said freelancing provided flexibility needed because of personal circumstances. While traditional employment settings can pose difficulties for caregivers due to rigid disability benefits and leave policies, temporary employees have more freedom to make their own schedules but usually do not receive benefits. When they need extra time for caregiving tasks, they can spend it, but they do not earn any income during that time.

Similarly, the effects of caregiving status on employment must be caveated as of Spring 2020, when COVID-19 began its dramatic impact on the U.S. economy. The national unemployment rate rose dramatically, from a low of 3.5 percent in February to 14.7 percent in April, and the effect on caregivers is not yet known.[75]

The effects of caregiving on health

Family caregivers are relieving pressure on U.S. health care and long-term care systems by providing essential care to family members and friends for no pay. Without the estimated 53 million caregivers, providing roughly 24 hours of unpaid care per week, millions of people would rely on nursing homes and other forms of long-term care, putting increased strain on the medical system.[2,3] However, this benefit does not come without risk. Unsurprisingly, caregiving can create physical, mental, and emotional strain, and is exacerbated by a frequent lack of respite opportunity.

Many studies point to "caregiver burden," which in 2020 the *Caregiving in the U.S.* report began referring to as "intensity."[3] This concept is not universally defined but typically includes measures of emotional, physical, and financial challenges associated with caregiving.[56] Caregivers experience varying levels of physical, mental, and emotional strain as a result of their caregiving role. Thirty-six percent of caregivers report their caregiving situation to be highly stressful, with an additional 28 percent reporting moderate stress.[3] As a group, they are more likely than non-caregivers to report being in poor or fair health, and nearly one in four caregivers report that their health has worsened since taking on their caregiving role.[3,76] Between 2015 and 2020, the number of caregivers who consider their health to be excellent or very good declined even further, from 48 to 41 percent, with a greater effect felt by those who assist

Caregivers experience varying levels of physical, mental, and emotional strain.

with more caregiver tasks, provide more hours of care, or co-reside with their care recipient.[3] Health effects are exacerbated for those caring for someone with mental or emotional health issues, with 34 percent reporting declining health since beginning their caregiving role.[3]

Caregiver health is also associated with socioeconomic factors, consistent with the effects of socioeconomic status on health for all Americans. While less than half of all caregivers report excellent or very good health, it is higher for those with a household income exceeding $50,000.[3] In addition, caregivers who themselves rely on Medicaid for their health insurance are more likely to report poor or fair health.[57] Comparatively, among the general American adult population, those with an annual household income of less than $30,000 were 29 percent less likely to report excellent or good health than those with a household income of $75,000 or above.[77]

Caregivers Experienced Declining Health

AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC: AARP. May 2020. https://doi.org/10.26419/ppi.00103.001

Female caregivers are more likely than male caregivers to report high intensity,[56] demonstrating another gendered aspect of caregiving. Not only are women providing more care, they are also more likely to feel the effects of that care, whether physically, emotionally, or mentally. Studies have found a negative effect on the mental health of women in caregiving roles. Women who provide 36 or more hours of weekly care for an ill or disabled spouse are nearly six times more likely to report depressive or anxious symptoms than their non-caregiver counterparts.[78] In addition, women are more likely to be high-intensity caregivers, and tend to forgo activities they value as a result of their caregiving role.[3,38,56,79] Women who discontinue valued activities are likely to experience greater social isolation, which can have significant negative impacts on health and well-being, particularly increasing depressive or anxious symptoms.[80]

Female caregivers are also more likely to forgo other health services. Caregiving women are twice as likely as non-caregiving women to forgo their own needed medical care. Perhaps, as a result, they have worse health than non-caregiving women.[39] More than half of all female caregivers have one or more chronic conditions, and one-quarter report difficulty getting their own medical care.[39]

Of course, women are not the only group overrepresented in caregiving roles, and as such, they are not the only group at high risk for negative outcomes as a result of their caregiving role. Compared to cisgender heterosexual caregivers, lesbian, gay, and bisexual caregivers have poorer self-reported health.[58] In addition, older LGBTQ adults are at a greater risk of social isolation compared to their non-LGBTQ peers.[81] Being isolated can compound the other stresses and strains associated with taking on a caregiving role, potentially magnifying negative health outcomes.
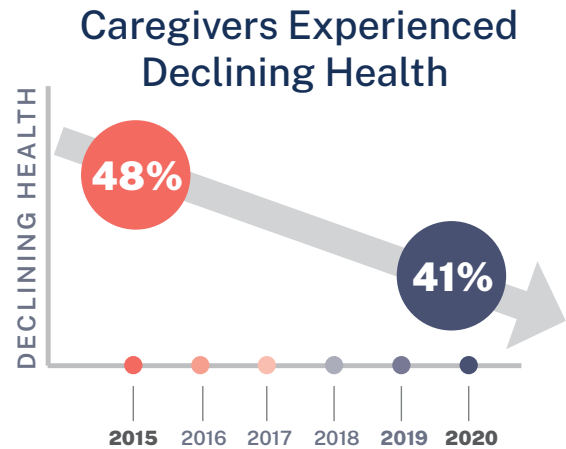
> # Being isolated compounds caregiver stress, potentially magnifying negative health outcomes.

Because caregiving can cause stress and result in caregiver strain, which can be alleviated by social support,[55,56,82] considering how this might be different among individuals who have faced oppression and marginalization throughout their lives is important to understanding caregiving more broadly.[81] In particular, acknowledging how LGBTQ caregivers receive and respond to support can deepen the understanding of caregiving in the United States. LGBTQ individuals tend to receive social support from both families of origin—biological family members—and, more commonly, "families of choice," which include same-sex partners and/or friends who can provide support.[58,81] The LGBTQ population faces unique challenges within medical institutions, which sometimes share information only with "next of kin" and refuse to share information with a care recipient's chosen family.[81] This is a challenge typically not faced, or faced to a lesser extent, by caregivers who are spouses, parents, or children of those receiving care.

Positive effects of caregiving

There are, of course, positive impacts of caregiving. In a 2014 survey by the National Opinion Research Center, 83 percent of caregivers said that caregiving was a positive experience, and more than three-quarters said the experience strengthened their personal relationship with their care recipient.[83] Over half of family caregivers feel their caregiving role has given them a sense of purpose or meaning.[3] According to the American Psychological Association, family caregivers often point to a feeling of giving back to someone who has previously taken care of them and confidence that their loved one is receiving excellent care as additional benefits to their caregiving role.[84] Some academic research suggests that the stress experienced by caregivers may even be counterbalanced by the positive experiences, including closer interpersonal relationships.[85] This is more pronounced for African American caregivers, who as a group, demonstrate fewer depressive symptoms as a result of family caregiving.[86] However, it has also been suggested that the comparatively little stress reported by minority caregivers "may also be a function of differential cultural meanings attached to caregiving or other differences between caregivers that vary by race."[86]

> "I think a lot of people know about the negative side of caregiving, but there are so many positive and rewarding things, as well."
>
> Jessica, RCI REACH caregiver, on supporting her mom.

REORIENTING TO A SYSTEMS APPROACH

When RCI published *Averting the Caregiving Crisis: Why We Must Act Now* in 2010, the paper made recommendations for meeting the needs of the growing population of family caregivers.[87] The proposals were bold, and had policymakers pursued them aggressively, caregivers would perhaps be in a less vulnerable state now. They may have had a stronger safety net provided by either the federal or state and local governments; or they may have been in a better position and felt more prepared to provide care to their loved ones. As a nation, we may have gained further understanding of the stressors experienced by caregivers, and perhaps we would have a better idea about how to alleviate them. These remain key objectives in improving the lives of caregivers, and we must not lose sight of them.

Yet 10 years later, the situation facing family caregivers remains dire and the problems have grown:

- The population is aging and experiencing more chronic conditions, resulting in a growing need for care

- Health disparities among marginalized populations continue to grow, with caregiving status as a contributing factor

- The COVID-19 pandemic crystallized the additional risks borne by those who need care and the difficulties caregivers face providing that care during emergencies, as well as the reliance on family caregivers to reduce demand on the overburdened U.S. health care system

- Formal caregiving options can be inadequate, expensive, and often unavailable due to high demand, leaving family members with few viable options

- In many cases, caregivers are delivering health care interventions and treatment with limited or inadequate training

- While the traditional health care system has become more complex and costly, family caregivers can provide more integrated and seamless care at a lower cost

- Many prospective solutions are legislative, and the nation is divided on the question of who should bear the costs

Society has a greater understanding today about caregivers at a high level than it has previously, but there is little understanding about what kinds of support systems and interventions will have an impact on their lives.

> It's time for a fresh perspective—caregiving is dynamic, interacting with all of society.

Until researchers and policymakers consider the multiplicity of factors that affect caregivers and work collaboratively to address these issues, the problem will only continue to worsen.

To make meaningful progress for caregivers, a new perspective is needed. For too long, leaders have considered the multitude of challenges facing caregivers along only individual dimensions without acknowledging how each one interacts with the others. These silos include, among others, the impact of paid family leave; remote work environments; broadband internet access; housing for an aging population; telehealth; transportation; memory care for those with Alzheimer's or other dementias; support for parents of disabled children; military families; and the list goes on. If, instead of addressing each of these independently, we reorient to a multi-dimensional lens, or a systems mindset, we are more likely to see the entire landscape of interactions and unlock new solutions that can better meet caregiver needs and improve their well-being. Much like health care, education, poverty, and other complex societal challenges, caregiving is a dynamic issue that begins with the caregiver and their care recipient but interacts with every facet of society.

Smoking cessation provides a comparable example. Cigarette smoking declined among adults in the United States from 20.9 percent in 2005 to 15.5 percent in 2016.[88] This decrease is typically attributed to a confluence of interventions at all levels.[89] Many state and local jurisdictions implemented smoking bans in public spaces; federal, state and local tax authorities levied higher taxes on tobacco; some employers and insurance companies added coverage for smoking cessation treatment; corporate and other employers went further by eliminating smoking breaks or limiting areas where smoking was allowed; the government undertook anti-smoking education campaigns, and state and other organizations created quit lines.[89] No single solution is likely to have achieved the same reduction that a multi-tiered approach accomplished. Support for caregiver health and well-being will require a similar systemic approach.

Advances in solutions and interventions also remain siloed into disease- and population-specific "verticals" that reduce the likelihood of shared learning. This trend makes it far less likely that programs proven to help a caregiver of someone with AIDS, for example, will ever find their way to a caregiver struggling to effectively help someone with Alzheimer's disease, cancer, post-traumatic stress, or opioid addiction. And yet, the challenges facing all these caregivers—and many others—have more similarities than differences. Likewise, demographic trends indicate that the profile of a typical caregiver is changing—while many are middle-aged women caring for an aging parent, there are many others as well, spanning a plethora of subpopulations.[2,3,38]

Reorienting to a systems approach will account for all the various changes taking place in American life, including not only demographic shifts but also changing gender norms, the growing frequency of dual-career families, increasing longevity, and many others. We need to build bridges among researchers and program developers, cutting across differences in disease and populations, to orient toward common solutions. This will require all parties, including funders, to rethink how interventions are developed, how grants are awarded, and how outcomes are measured—not a minor shift. However, this kind of realigned ethos throughout the field will boost and hasten progress for caregivers and, optimally, reduce burdens borne by employers, the health care system, and families.

Technology can break down but also highlight barriers

Over the past decade, society has streamlined some caregiving tasks but has not prioritized supporting caregivers, as individuals with their own needs, more broadly. The support needed by a caregiver goes beyond ensuring that tasks are completed; it includes respite care, nurturing resiliency, developing coping skills, and many more. While these supports remain wanting, some caregivers have benefited from 21st century technological advances, especially related to tasks such as transportation, shopping, food preparation, and the like. For those who had access, the value of such modern era breakthroughs became clear during the shelter-at-home measures made necessary by the COVID-19 pandemic in early 2020, as technology helped facilitate activities of daily life. For many others who lacked access, the pandemic brought to light yet another disparity. In many communities, especially urban centers, stores delivered groceries and most anything else someone might need, within hours if necessary. Many local restaurants transformed their operations to offer curbside pickup or delivery, and others took orders through delivery platforms.

However, before the start of the pandemic, one in four caregivers reported it was very difficult to get affordable services such as delivered meals, transportation, or in-home health services in their recipient's community, and another 33 percent reported moderate difficulty.[3] For caregivers who *can* access these services—who often live in a more isolated environment—these providers can be lifelines. Ride-sharing apps allow people to get to and from the doctor on their own, even if they cannot drive. Health care providers and pharmacies often connect directly for prescription management, and many pharmacies deliver medication directly to the patient. Many companies deliver ready-to-eat food ranging from multi-course meals to frozen soups and smoothies. Those who prefer to cook can order from companies that simplify the process by shipping all the ingredients needed for specific recipes. Virtual assistants housed in smart speakers or embedded in smartphones can help set reminders for taking medications or can turn out the lights. Many smart speakers

and smartphones have video capabilities that allow caregivers to see their care recipients, which can be a comfort.

Video can be especially reassuring to caregivers who are not local. According to the University of Michigan Health and Retirement Study, Americans live an average of 18 miles from their mother, and only 20 percent live more than a couple of hours' drive from their parents.[90] However, those with college and professional degrees are much more likely to live farther from their parents than those with a high school education, pursuing job opportunities in cities.[90] According to AARP and the National Alliance for Caregiving, 11 percent of caregivers live more than one hour away from their care recipient.[3] For these individuals, caregiving from afar can be an especially stressful experience, especially when inadequate internet access interferes. The Federal Communications Commission has estimated that 21.3 million Americans lack access to broadband internet, but the number could be as high as 42 million Americans, according to a study from BroadbandNow.[91] Limited access to high-speed internet in rural communities is frequently cited, but a recent analysis by the Brookings Institute of the Census Bureau's American Community Survey found that 13.9 million metropolitan households live without an in-home or wireless broadband subscription,[92]—a digital divide brought into high visibility by the COVID-19 crisis. According to Pew Research Center, only slightly more than half of households with incomes under $30,000 have access to broadband internet.[93] This digital disconnect is hidden in plain sight, often affecting lower-income families and resulting in limited access to some of the modern advances that can benefit caregivers.

LOOKING AHEAD

A decade ago, the Rosalynn Carter Institute for Caregivers (RCI) published *Averting the Caregiving Crisis: Why We Must Act Now*, an ambitious position paper that laid out a dozen recommendations* to address what it called an "emerging caregiver crisis."[87] Thanks in large part to the dedication of caregiver advocates, there have been some promising legislative accomplishments—including passage of the RAISE Family Caregivers Act, VA MISSION Act, and the Caregivers and Veterans Omnibus Health Services Act of 2010, along with widespread adoption of the Caregiver Advise, Record, Enable (CARE) Act—but the changes largely have been intermittent and fragmented. Ten years since the report's publication, progress in addressing caregiver needs has been piecemeal when a systemic change is needed. The time has come to support caregiver health and well-being in the same way we approach any other public health concern. We cannot simply stand by while the problem grows larger; instead, caregiver health and well-being must be addressed as one component of a complex ecosystem that requires rebalancing.

*Policy changes since *Averting the Caregiving Crisis* https://www.rosalynncarter.org/looking-back/

Tackling caregiver health and well-being through a systems approach will require building a community of existing and new partners and collaborators.

Since 1987, RCI has developed evidence-based programs to serve more caregivers in more ways and more places, including caregivers in rural areas, caregivers of those with cancer, and those caring for children with disabilities, among others. Today, RCI's programs support caregivers of injured service members and veterans as well as those with Alzheimer's disease and other dementias and ALS. We are pursuing programs and supports of all types, to meet the needs of diverse caregivers and their loved ones. As just one example, we are helping to create collaborative understanding between caregivers and first responders. Caregivers must be seen as critical partners in emergency preparedness and response and included in preparedness planning. In addition, we are advocating for additional research and investing in innovative data collection methods that will enable a deeper understanding of caregiver needs, helping us map solutions.

Here at RCI, we recognize we will not be able to take on this enormous problem on our own. Tackling caregiver health and well-being through a systems approach will require likeminded allies building a community of existing and new partners and collaborators. With employers, caregiver advocates, policymakers, payers, health care providers, and others coming together, exchanging ideas and data, we can gain a better understanding of the true challenges facing caregivers and the solutions that will alleviate them. Many of the diverse stakeholders that attended RCI's *Caregiving in the 21st Century: A National Conversation* in November 2019 took part in these discussions, but the conversations need to continue and expand.

For our part, RCI will keep an open mind, continue asking bold questions and following the answers toward meaningful impact. The following questions are designed as first step to encourage dialogue as we explore a new direction for caregiving so that when another decade has passed, we can point to meaningful improvements for caregivers:

Approaching caregiving as a public health issue:

- How do we challenge the health care system to screen for at-risk caregivers?

- How do we challenge the public health community to build a systems approach to supporting family caregivers?

- What is the true effect of access to caregiver support?

- What are the protective factors for caregivers that reduce caregiver challenges or increase benefits?

- What are the optimal intervention combinations or the order? What can we learn about interventions that have been tried without success, and where are those learnings being captured?

- How can we evaluate interventions at each level of the prevention pyramid to assess their success beyond a single, discrete caregiver group and to determine how long any improvement lasts?

- How can data be leveraged to design for impact when creating and delivering programs? And how can it be harnessed to construct better programs and do away with unproven interventions and misconceptions?

- What is the best way to reach caregivers with vital information?

Caregiver status as a social determinant of health:

- How well do we understand how being a caregiver can impact one's health and how having a healthy caregiver impacts one's health?

- What will incentivize additional research into the impact of caregiver status and/or access to caregiver supports as a risk factor for other issues?

- What characteristics are confounding factors—i.e., combine with caregiver status to create additional stressors and make the population more vulnerable?

- Is there active research into the epidemiology of caregiving to facilitate understanding of the underlying health factors and identify the most at-risk communities?

- What can we learn from the study of other diseases and social determinants of health to better address the needs of caregivers?

- How can family caregivers be better integrated into the formal medical system?

- Are there ways to creatively modify our existing social architecture to alleviate caregivers' everyday pain points?

Defining the population:

- What gets in the way of identification of caregivers, whether self-identification or the recognition by providers?

- How do we help both caregivers and communities see the beauty of caregiving in a way that makes self-identification possible and reduces stigma?

- If caregivers are an at-risk population, what data can help identify risk factors to enable early intervention and better support the caregiver?

- Who are we missing in our current efforts, and what needs to change? What is the research agenda needed in order to better understand caregivers?

Economic and policy concerns:

- What is the return on investment for caregiving support? What are the cost savings for individuals, employers, the health care industry, and government at all levels?

- What will help employers create programs and policies that keep caregivers at work?

- What can be done to help employers understand the benefits of recruiting and retaining workers who serve or have served as caregivers?

- Which federal, state, and local policies need to change to support caregivers?

- Within both state and federal government, where should caregiving policy and funding be housed to ensure coordination?

More than three decades ago, RCI was established to bring awareness to the challenges facing caregivers. When RCI was founded, caregiving was rarely discussed, largely hidden behind closed doors. Today, that stigma is minimized—though it still exists in some pockets—but that does not mean our work is complete. For every person suffering from disease, a chronic condition, or long-term health effect, a caregiver stands beside them, and often that caregiver is silently struggling. In many ways, the circumstances around caregiving run parallel to another health crisis Mrs. Carter has focused on since President Carter was governor of Georgia: mental illness.[94] After nearly half a century, America has begun to consider the many different factors that contribute to mental illness. We will have failed if it takes the same amount of time to make inroads in caregiving.

The needs of caregivers are largely universal. They need to be able to access self-care; they need to be supported by a "care team" that can assume some of their burden; they need clear communication from providers so they have a firm grasp on what they need to do; they need to build problem-solving skills; and they need compassion and understanding from their communities.

Since RCI's inception, the institute has been a catalyst for change. We now find ourselves in a national moment in which previously entrenched systems are embracing inevitable change. We are encouraged to seize this opportunity—to be more inclusive, to consider a systems approach to meet the needs of this growing population, to focus not only on individual caregivers but the entire public health system that surrounds them, reorienting both policies and practice to meet the needs of caregivers as well as care recipients. We are committed to engaging deeply, challenging ourselves and others as we collaboratively work toward bold and broad solutions that will improve the lives of caregivers and, in turn, all of society.

> In many ways, the circumstances around caregiving run parallel to another health crisis Mrs. Carter has focused on since President Carter was Governor of Georgia: mental illness. After nearly half a century, America has begun to consider the many different factors that contribute to mental illness. We will have failed if it takes the same amount of time to make inroads in caregiving.

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