

## Insight on the Issues

# Valuing the Invaluable: 2023 Update

## *Strengthening Supports for Family Caregivers*

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**In 2021, about 38 million family caregivers in the United States provided an estimated 36 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately \$600 billion.**

Recognizing and supporting family caregivers is crucial to the health and economic and social well-being of both the caregivers themselves and the people who receive their care. Family caregivers provide needed day-to-day supports and services and manage complex care tasks for adults with chronic, disabling, or serious health conditions. Research finds that over half of older adults (i.e., ages 65 and older) living in the community—living in their own home, the home of a family member or friend, or any other community-based living arrangement outside of a nursing home—have difficulty carrying out daily living activities (such as bathing, getting in and out of a chair, or using the bathroom) without assistance over their lifetimes (Johnson & Dey 2022). Most all older adults (95 percent) receive some help with these activities from their family or close friends, and almost two-thirds rely solely on these family caregivers (Freedman & Spillman 2014). This report touches on the day-to-day experiences of family caregivers and highlights the economic value of unpaid family caregiving, which was an estimated \$600 billion in 2021.

In addition to helping with self-care or other everyday activities and giving emotional and social support, family caregivers handle complex medical and nursing tasks (such as performing wound care, giving injections, and managing medical equipment) in the home

(Reinhard, Young et al. 2019). Most family caregivers receive little instruction or support in taking on these complex medical and nursing tasks, which have been historically performed by trained professionals in health care and long-term care facilities. On top of caring for family members or friends with serious health conditions or disabilities, three-fifths of family caregivers are employed in the workforce (AARP and National Alliance for Caregiving 2020a, Lerner 2022).

Family caregivers may also be responsible for advocating for the preferences and interests of those individuals in their care, managing health insurance claims, communicating about care, and coordinating care with various health care and social service providers across care settings, and providing transportation to medical appointments. They also may hire

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## KEY TERMS

**Family caregiver:** Any relative, partner, friend, or neighbor who has a significant personal relationship with, and who provides a broad range of assistance for, an older person or an adult with a chronic, disabling, or serious health condition.

**Family caregiving:** Providing a wide array of help for an older person or other adult with a chronic, disabling, or serious health condition. Such assistance can include help with personal care and daily living activities (such as bathing, dressing, paying bills, handling insurance claims, preparing meals, or providing transportation); carrying out medical or nursing tasks (such as administering multiple medications, performing wound care, or handling medical equipment); locating, arranging, and coordinating services and supports; hiring and supervising direct care workers (such as home care aides); serving as an advocate for the family member or friend during medical appointments or hospitalizations; communicating with health and social service providers; and implementing care plans.

**Long-term services and supports (LTSS; also referred to as *long-term care*):** The broad range of day-to-day help needed by people with long-term conditions, disabilities, or frailty. This can include personal care (such as bathing, dressing, and toileting); complex care (such as medications or wound care); help with housekeeping, transportation, paying bills, and meals; and other ongoing social services. LTSS may be delivered in the home, in assisted living and other supportive housing settings, in nursing homes, and in integrated settings such as those that provide both health care and supportive services. LTSS also includes supportive services provided to family members and other unpaid caregivers (Reinhard, Accius et al. 2017).

**Family caregiver assessment:** A systematic process of gathering information about a family caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver as well as the caregiver's ability to contribute to the needs of the care recipient (Family Caregiver Alliance 2006, Feinberg, Houser 2012). A family caregiver assessment asks questions of the family caregiver; it does not ask questions of the care recipient about the family caregiver (Kelly, Wolfe et al. 2013).

and supervise direct care workers when the individual or family can afford some paid help.

In their role, family caregivers often experience positive effects and feelings of satisfaction and meaning; however, alongside such positive effects are challenging ones, starting with the typical feelings of being highly strained and overwhelmed (Miller 1989, Robertson, Zarit et al. 2007, Folkman 2008, Reinhard, Young et al. 2019). The emotional, physical, and financial toll on family caregivers is well documented in the research (Schulz, Eden et al. 2016). Common themes include

- emotional hardships on individual and family relationships;
- financial effects on family caregivers if they have to give up paid work to provide care or incur high out-of-pocket costs;
- physical demands of exhaustion and less time to take care of one's own health;

- concerns about being unprepared for the role, and not having a choice in taking on caregiving responsibilities; and
- feelings of worry, isolation, and helplessness in knowing where to seek help or in how to provide needed care and support to an adult relative or close friend with disabilities or complex health needs.

Family caregivers are at a higher risk for chronic loneliness, which has been shown to be predictive of increased morbidity and mortality (Hawkley and Cacioppo 2010). One of the top predictors of loneliness is being physically isolated; not surprisingly, this situation is common for family caregivers who provide intensive care—characterized by tending to someone with greater care needs, performing complex care tasks, or more weekly hours of care—to frail older relatives. Studies consistently show significantly worse outcomes for family caregivers who care for people with high care needs—such as

### Caregivers' Experiences in Their Own Words

Family caregivers' experiences, in their own words, are featured throughout this report. These experiences demonstrate the common threads in family caregiving as well as the great variety in experiences across family caregivers. We thank the family caregivers who shared their thoughts and stories.

Carri, early 30s, Texas, caregiver for her mother and grandfather:

*I am a full-time caregiver for my grandfather and part-time [caregiver] for my mother. Grandpa has Parkinson's disease and prostate cancer. Mom has multiple myeloma (a type of blood cancer commonly found in men). Most of the time, I feel like everyone in my family is depending on me for everything. Guess who is there to pick up the slack when my mom can't be there for my siblings, it's me. Guess who takes Grandpa everywhere (haircuts, dentist appointments, even hospital clinic visits to downtown Houston). That's right, I do.*

*I left my entire life, a life I loved, in Nashville, Tennessee, to be a caretaker in Texas. I am so grateful to have this time with my family, and I truly believe that caretaking is a calling. Unless you live this, you have no idea how tolling it can be physically AND mentally.*

*I feel like most of my energy goes to doing things for my family—that the other areas in my life get severely neglected (housework, cooking, etc.). I have no idea how I, and other caretakers, could get support with these things in our everyday life, but man... I think that these things are the biggest burdens that caretakers carry. These things and needing a vacation. LOL.*

individuals living with dementia, physical frailty, or multiple chronic conditions (Schulz, Eden et al. 2016). These outcomes are prevalent particularly among Black/African American family caregivers, regardless of income (Reinhard, Young et al. 2019).

The remainder of this report presents updated national and individual state estimates of the economic value of unpaid care by family and friends in 2021, the most current data available. The report also builds on the overview of family caregiver experiences and challenges and highlights trends in family caregiving. Lastly, the authors offer promising policy and practices along with policy and practice recommendations that would enhance the support and well-being of family caregivers and those individuals in their care.

### UPDATING THE NATIONAL ESTIMATED ECONOMIC VALUE OF FAMILY CAREGIVING

The estimated economic value of family caregiving is \$600 billion as of 2021, based on about 38 million caregivers providing an average of 18 hours of care per week for a total of 36 billion hours of care, at an average value of \$16.59 per hour. To provide reference of the magnitude of the total care hours in 2021, 36 billion hours of care is equivalent to 4.1 million years spent caring for a family or friend. The previous edition of *Valuing the Invaluable*, published in 2019 using 2017 data, estimated the economic value of caregiving to be \$470 billion (Reinhard, Feinberg et al. 2019). The term *family caregiving* here is defined by a range of tasks that include helping someone with

- activities of daily living (ADLs), such as eating, walking, using the toilet, getting dressed, and bathing;
- instrumental activities of daily living (IADLs) essential to living independently, such as cooking, transportation, housework, and managing finances; and
- complex medical and nursing tasks such as medication management, help with assistive

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Saving \$600 billion by setting aside \$100,000 a year would take a total of 6 million years. Further, \$600 billion would buy 20 million cars at \$30,000 each.

mobility devices, preparation of special diets, and wound care.

That many of these care tasks parallel those handled by long-term services and supports (LTSS) providers establishes the basis for the methodology of this economic valuation of family caregiving.

The estimated \$600 billion equates to about \$1,800 for every person in the United States (332 million people in 2021) (U.S. Census Bureau 2021). For perspective and comparison, the economic impact of \$600 billion is more than

- all out-of-pocket spending on US health care in 2021 (\$433 billion) (Centers for Medicare & Medicaid Services 2022);
- total US spending from all sources, including out-of-pocket spending, on home and community based LTSS (\$245 billion in 2020) (Chidambaram and Burns 2022); and
- the total spending from all sources of paid LTSS, including postacute care (\$531 billion in 2020) (Chidambaram and Burns 2022).

### Summary of methodology

The 2021 estimates of caregiving incidence and intensity in this report are based on a meta-

analysis of four surveys of family caregivers between 2015 and 2019, adjusted to a common definition: caregiver age 18 or older; care recipient age 18 or older; providing care currently or within the past month; year 2019; and assisting with ADLs (such as bathing and dressing), IADLs (such as managing finances or providing transportation), or medical/nursing tasks (such as medication management or preparing special diets). These consensus estimates are then brought forward to 2021 using data from 35 states that fielded the Behavioral Risk Factor Surveillance System (BRFSS) caregiver module in 2021 and at least once between 2015 and 2019. BRFSS is the Center for Disease Control and Prevention's health-related telephone survey used to collect a range of health and behavioral information for Americans in all 50 states and the territories. For an overview of data sources and national estimates, see appendix A, page 24. For estimates of the number of family caregivers and economic value at the state level, see table B1, page 26.

The estimate of \$600 billion in 2021 continues a 25-year trend of growing economic value. Like the current study, prior studies have all found that the value of unpaid family care vastly exceeds the value of paid home care. Previous reports in the Valuing the Invaluable series have estimated the total economic value of family caregiving at \$354 billion in 2006, \$375 billion in 2007, \$450 billion in 2009, and \$470 billion in both 2013 and 2017. Earlier estimates showed steady growth in the economic value of family care—from less than \$200 billion in 1996 to about \$300 billion in 2004.<sup>1</sup>

### **TODAY'S FAMILY CAREGIVERS: IMPACT OF COVID-19 PANDEMIC ON FAMILY CAREGIVERS**

The COVID-19 pandemic laid bare the realities of the caregiving experience discussed earlier in this report. It heightened awareness of the need for comprehensive solutions in policy and practice to build supports targeting the family caregiver. The implications of the virus hit family caregivers on several fronts. Family caregivers and their care recipients lost access to paid care supports due to program closures and staff shortages, experienced isolation and loneliness while avoiding social interaction, juggled completing demands of working and schooling at home, and struggled with economic losses in income, housing and food security.

The COVID-19 pandemic, in fact, affected both paid and unpaid care, with efforts to mitigate the spread of the virus not only curtailing availability of home- and community-based paid care but also preventing family caregivers from assisting family members and friends in nursing homes—and pushing families to change caregiving routines to protect all involved. More than half of family caregivers experienced disruptions to care routines in the pandemic, with younger caregivers and African American/Black and Hispanic/Latino caregivers more likely to have faced these care disruptions (Truskinovsky, Finlay et al. 2022). In addition to managing interruptions in care routines, almost 40 percent of family caregivers increased the hours of care they provided in the pandemic. Family caregivers age 40 and under were more likely to provide higher hours of care than this same group of caregivers had in the past (AP-NORC 2020, Beach, Schulz et al. 2021).

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For those families caring for someone in a nursing home, almost 70 percent reported that they were unable to visit or provide care during the COVID-19 outbreak (AP-NORC 2020). Pandemic restrictions on visitors to nursing homes and other care facilities limited the ability of friends and families to engage in usual supports in a care facility and increased the likelihood that the person living in these settings would experience limited social and physical interaction. Family caregivers of individuals in facilities also noted the inability to ensure their care recipient had plenty of social stimulation and exercise during the pandemic and expressed concerns over staff's ability to fulfill care needs in their absence (Lightfoot, Yun et al. 2021). Changes in caregiving routines and pandemic-related economic impacts also led to new financial hardships for many caregivers, with a third reporting they lacked the financial resources for care (AP-NORC 2020). For many family caregivers who work (referred to as *working family caregivers* throughout, not to be confused with *paid caregivers*), disruptions in care routines led to disruptions in employment as well. In the pandemic, both family caregivers delivering more hours of care and family and friends newly assuming caregiving duties were more likely to experience a negative impact on employment including job losses, furloughs, and shifts to remote work (Truskinovsky, Finlay et al. 2022).

The pandemic spurred further social isolation and risk of loneliness for family caregivers. Significantly more caregivers reported severe loneliness and social isolation in the pandemic (Grycuk, Chen et al. 2022). Family caregivers who did not have strong social support networks pre-pandemic struggled even more to maintain connections (Bristol, Mata et al. 2021). These findings highlight how critical caregiver supportive policies are in buoying not just the physical and financial health but also the emotional well-being of family caregivers.

## PROMINENT ISSUES IN FAMILY CAREGIVING

At the societal level, the impact of family caregiving will escalate dramatically over the coming years. Noteworthy trends in US demography, which mirror ongoing demographic trends in Europe and Asia, are having a sizable impact on family caregiving (He, Goodkind et al. 2016). The US Census Bureau projects that by the year 2034, adults ages 65 and older will outnumber children under the age of 18 for the first time in American history. Given that trend, the share of potential caregivers is projected to continue shrinking relative to the number of older adults potentially at risk for needing long-term care in the United States (Redfoot, Feinberg et al. 2013, Vespa, Medina et al. 2020, OECD 2023). This fundamental demographic shift is due to the aging of the US population via longevity and a declining birth rate. Americans also have been delaying having children, which, when combined with increasing longevity, has led to a surge in the numbers of caregivers concurrently caring for an older adult and children or grandchildren (Medina, Sabo et al. 2020, Population Reference Bureau 2021).

The US population also will become more racially and ethnically diverse (Vespa, Medina et al. 2020) and so too is the population of family caregivers. These demographic trends of population aging, shifts in fertility and timing of first births, and the increasing racial and ethnic diversity of the US population help explain the following key prominent issues in caregiving:

- The balancing act of “sandwich generation” caregivers
- The impacts of caregiving on employment for working caregivers
- The impact of post-pandemic shortages in the direct care workforce on family caregivers and care recipients
- Meeting the needs of Black/African American, Hispanic/Latino, Asian American, and Native Hawaiian and Pacific Islander family caregivers

The following sections explore these topics in depth.

### **Sandwich generation caregivers**

The past two decades have seen heightened attention paid to the dual responsibilities of caregivers who are sandwiched between a younger generation—children or grandchildren they care for—and an older one—an older family member or friend for whom they also provide care. Early research narrowly defined sandwich generation caregivers as those in their 40s. But as increasing proportions of younger adults care for older family members, a trend that continued throughout the COVID-19 pandemic, the share of caregivers caring for two generations has grown to span a broader range of ages.

In 2019, roughly 30 percent of family caregivers of older Americans lived in a household with children or grandchildren, according to the Caregiving in the US survey (AARP and National Alliance for Caregiving 2020a), a significant increase from the 13 percent of sandwich generation caregivers estimated in 1999 (Wolff, Huang et al. 2018). Sandwich generation caregivers generally span ages 35 to 64, increasingly including Gen Z and millennial caregivers, and are more likely than other caregivers to be working while performing their caregiving responsibilities (Friedman, Park et al. 2017, Lei, Leggett et al. 2022).

As a result of such dual-generation care demands, sandwich generation caregivers

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report higher levels of emotional and financial strain. Many of them also report significant work impacts due to their care responsibilities (see below for more discussion of work impacts of caregiving) and that they lack supportive benefits at work, like paid leave (Weber-Raley 2019, Lei, Leggett et al. 2022). The pandemic highlighted the tension, as these caregivers faced reduced availability of community programs such as adult day care for older family members and schooling young children at home, resulting in unprecedented family demands. Sandwich generation caregivers may benefit from policies designed to assist caregivers financially, such as federal and state caregiver tax credits or grant programs, and those designed to help caregivers balance work and caregiving. The following sections explore the impact of caregiving on employment for sandwich generation caregivers and other working caregivers.

### **In Their Own Words...**

Tanet, 51, Georgia, caregiver for her adult son and her mother:

*I provide care for my disabled adult son. He has cerebral palsy and a feeding tube. In addition to caring for my son, my mother developed shingles in July, which was further complicated by a diagnosis of viral meningitis. As a result of my son's disability and the sudden illness of my mother, I had to resign from my position as an assistant city manager of a coastal Georgia city. It was a very humbling experience but despite my devotion to public service, my family comes first.*

## Family caregivers balancing work and care

As population aging drives growing shares of older workers in the labor force and the country sees a growing share of younger caregivers, family caregivers will increasingly be in the labor force in the future, facing the dual demands of employment and caregiving responsibilities (Toossi and Torpey 2017, Dubina, Kim et al. 2022). The majority (61 percent) of family caregivers of adults worked either full-time or part-time in 2019, with 54 percent in hourly wage positions (AARP and National Alliance for Caregiving 2020).

Family caregivers of adults with complex care needs may need to miss work to accompany their care recipients to healthcare visits and be present during hospitalizations (Wolff and Roter 2011, Reinhard, Levine et al. 2012, Wolff 2012, Bynum 2018). Hourly workers typically have less flexibility in scheduling, making it difficult to accommodate health care appointments. Without workplace benefits to support family caregivers—such as using sick days for family care, taking paid family leave, and accessing employee counseling and services such as respite care—employed family caregivers can experience heightened financial and emotional strain.

In various surveys, caregivers report workplace disruptions due to their care duties; for many caregivers, those disruptions may include leaving a job altogether (AARP and National Alliance for Caregiving 2020a, Harrington and McInturff 2021, Lerner 2022). A 2019 survey found that 19 percent of working caregivers

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had to leave a job at some point to care for a family member or close friend, with younger, Black/African American, and Hispanic/Latino caregivers all more likely to have to give up a job for caregiving (Harrington and McInturff 2021). Many caregivers who left a job cite the lack of affordable and/or quality paid help as driving that difficult decision, demonstrating the key role of direct care workers in supporting family caregivers (Lerner 2022). Of particular concern are caregivers pursuing higher education, the majority of whom balance part-time work with school and caregiving duties. Sixty percent of student caregivers report financial strain because of these competing demands, leading many of these student caregivers to take out loans, borrow money informally, or work additional jobs (Skufca and O’Connell. 2020).

## In Their Own Words...

Angie, early 60s, Pennsylvania, caregiver to her parents and then her in-laws:

*I cared for my dad for two years in his home. I paid a daytime part-time caregiver out of pocket, as his income barely covered his household bills. I cared for my mom after Dad died, in my home. I paid all her living expenses and a portion of her full-time caregiver’s salary. I now care for my in-laws in their home. I quit my job to relocate across country. My husband closed his small business.*

### In Their Own Words...

Roger, mid-70s, New Hampshire, caregiver to his father for 17 years:

*I had a professional job. I worked 8 to 4 or 9 to 5 and could not participate and impress my supervisors to work at a higher level for promotion. I would have to be home at dinnertime to feed and accompany my father during the day. Me and my wife worked, so we had to take turns to come and check in on him or cater to him. I tried my best to keep my boss updated and informed of what was going on; however, I could not overdeliver because I had to be home. I could not stay after hours for important meetings. The last 5 to 10 years of my father living with us, my dad had multiple accidents. In 2010, my father had a heart attack and his needs increased and health routine care accrued. I had to miss more time at work and spend more time with my father. That caused me to miss opportunities at work for promotion. My father became heavily dependent on us for care.*

*He could not bathe himself, wash clothes, or feed himself, etc. He had multiple daily living needs. Everywhere we went, we wanted to bring him along—and so we did.*

*There was a visiting nurse that taught me how to draw blood. My wife was a lab scientist and did a lot of work drawing blood. When I could not, my wife jumped in. This was not something we routinely did, but we had to when necessary. Among the other care, when the nurse came in, they would go over many things and leave important instructions and information with us to help with medications, etc.*

Family caregivers who manage to balance work with caregiving still face a difficult juggling act. Most working family caregivers are employed full-time and working caregivers on average provide care hours that are equivalent to a part-time job (AARP and National Alliance for Caregiving 2020a, Lerner 2022). Working caregivers experience a range of workplace disruptions that go well beyond leaving a job—and that may still have significant impacts. In 2019, 7 in 10 working caregivers reported leaving work early, having to call out from work, not taking on additional work responsibilities, or declining promotions because of caregiving responsibilities. Almost 40 percent of working caregivers cite the emotional stress of balancing caregiving and work as their biggest challenge (Harrington and McInturff 2021).

Family caregivers who disrupt their careers or leave the labor force entirely to meet full-time caregiving demands can face substantial

economic risk and both short-term and long-term financial struggles. Risks include lost income, reduced career opportunities and savings, and subsequently lower Social Security and retirement benefits (Feinberg, Reinhard et al. 2011, 2016, GAO 2019). One recent study estimated the economic cost of forgone earnings by family caregivers of older adults at \$67 billion in 2013 (Mudrazija 2019). Newer research indicates that caregivers may experience disruptions in employment as they anticipate taking on caregiving responsibilities and that disruptions to employment may continue after the caregiver has stopped providing care (Maestas, Messel et al. 2022).

Although the economic impacts of caregiving-related employment disruptions are significant for working caregivers, the economic loss is also substantial for employers. When caregivers are unable to continue balancing work and caregiving responsibilities, employers are faced with the loss of valuable, experienced

### HOW CAN EMPLOYERS SUPPORT FAMILY CAREGIVERS IN THEIR WORKFORCES?

Employers of all sizes can implement a variety of workplace policies and practices, including many low- to no-cost options, to support their employees who are family caregivers. First and foremost is identifying the needs of caregivers in the employer's workforce, finding solutions tailored to the employer and its workforce, and formalizing a clear plan of action. Formal policies convey support for family caregiving in the workplace. Family supportive policies broadly have been shown to encourage employee retention, increase recruitment of new employees, and improve worker productivity (Respect A Caregiver's Time Coalition, AARP 2017, Skufca 2019).

The following are examples of potential policies and practices:

- Data collection to identify gaps in current workplace policies affecting family caregivers
- Paid time off for caregiving
- Flexible work arrangements, which could include telecommuting, job sharing, and cross-training employees
- Expert information about managing family caregiving and caregiving resources, which can include employee assistance programs; onsite experts; and expert workshops, webinars, and guides
- Peer resource sharing or support groups

Socialization of support for family caregivers in the workplace is an underappreciated element of any employer plan to improve support. Managers and employers must be aware of the available resources and policies, and employees must feel comfortable identifying their caregiving needs and asking for help balancing those needs with their work duties. Ongoing communication and marketing of formal policies and practices help set the stage for efficient socialization of support for working family caregivers (Respect A Caregiver's Time Coalition, AARP 2017, Skufca 2019, AARP, Public Private Strategies n.d., Roman, Scott et al. 2021).

workers and the cost of hiring new employees. Employers can mitigate this potential economic loss by implementing workplace policies and practices that support family caregivers' competing demands. The importance of supporting working caregivers extends to businesses of all sizes; a 2018 survey of small employers found that an overwhelming majority of them had direct experience with family caregiving and most small employers value family caregiving as important (Skufca 2019). There are many supportive policies that employers of all sizes can implement, including many low-cost options, to benefit and retain their caregiving employees.

A 2016 study found that employers could expect a return of \$1.70 to \$4.34 for every dollar invested in instituting flexible work

arrangements. Telecommuting, for example, produced a \$2.46 to \$4.45 return for every dollar invested in implementation (Respect A Caregiver's Time Coalition and AARP 2017). Employers may also benefit from introducing practices such as flexible work arrangements, employee assistance programs, and respite care programs. Additional information on state and federal paid and sick leave policies that support family caregivers is discussed in detail in the Promising Policy and Practice Supporting Caregivers section of this report.

#### **Direct care worker shortages and family caregiving**

Family caregivers often employ direct care workers to augment their care. Finding a direct care worker, coordinating visits, and

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ensuring that the direct care worker is aware of the specific health and emotional needs of the care recipient are sizable tasks that often fall to the family member or friend. A recent in-depth study of family caregivers of persons with dementia using paid care sheds light on the relationship between caregivers and direct care workers as well as the management tasks the caregiver takes on in this relationship (Reckrey, Watman et al. 2022). Caregivers note the need to train the paid care workers in the specific needs of the care recipient and the need for ongoing daily monitoring to ensure the workers are completing agreed-upon care tasks. Caregivers also work to build a relationship with the direct care worker, with many viewing established care workers as family (Reckrey, Watman et al. 2022). Despite the additional demand of management and monitoring tasks that paid care help may bring to the caregiver, the assistance is essential. A 2019 study of older adults receiving Medicare-funded home health care found that 87 percent had an identified need for family caregiving assistance, with almost 60 percent showing a need for help with five or more tasks (Burgdorf, Arbaje et al. 2019).

Direct care workforce shortages result in more hours of care and higher-intensity care by family caregivers—a situation that played out in the COVID-19 pandemic, when existing direct care worker shortages were exacerbated. A 2022 survey of Medicaid home- and community-based services (HCBS) state administrators found that all 50 states were still experiencing shortages in their direct care workforce in 2022, despite efforts to retain and attract workers via provider

payment rate increases (Watts, Burns et al. 2022). The aging of the US population, fueled by the overwhelming desire to age at home, will continue to drive demand for direct care workers. The direct care workforce is projected to grow from 4.6 million in 2019 to 5.9 million by 2028 (Campbell, Drake et al. 2021). The challenge, however, is in retaining workers in a field with an average turnover rate of 40 to 60 percent each year and providing sufficient pay and training to support their role caring for older adults with complex needs.

### **Care experiences of racially and ethnically diverse family caregivers & LGBTQ family caregivers**

The current population of family caregivers reflects the growing racial and ethnic diversity of the US population. The US Census projects that by 2060, non-Hispanic white people will make up 44 percent of the US population (Vespa, Medina et al. 2020). The trend of growing diversity is highly relevant to family caregiving because Black/African American, Hispanic/Latino, Asian American, Native Hawaiian and Pacific Islander, and American Indian and Alaska Native family caregivers report distinct care experiences and specific support needs (Fabius, Wolff et al. 2020, Parker and Fabius 2020). Furthermore, the care recipients likewise have distinct care needs and health trajectories (Shippee, Dunn et al. 2020). Experts and policymakers have called for public policies that strengthen support for diverse groups of family caregivers to reflect their experiences with caregiving and address health care system inequities (Schulz, Eden et al. 2016, Janus and Doty 2017, The RAISE Act

### In Their Own Words...

Ayda, early 60s, Florida, caregiver to her bedbound father:

*My father is bedbound. Since the pandemic, I have been working from the home, which makes it very difficult. He does have a caregiver that comes a few hours in the afternoon (insurance won't approve any more hours), and, of course, is Monday to Friday. On the weekend I cannot go anywhere. I have to miss family events because of this [caretaking responsibility]; this has taken a great toll on my health. Sometimes I just break down and cry because I have to pay out of pocket to get a private caregiver for a few hours to go to church, grocery shopping, etc. I really need some guidance in how to cope with this. I'm so discouraged with the long-term state Medicaid, because of this, my dad has bedsores because they will not approve a special mattress, no one cares, I don't have a life for the past 4 years when my stepmom passed. I can sit here all night venting, so disappointed in the healthcare system, they all promise [help], and at the end of the [day] there is a catch and lies.*

Family Caregiving Advisory Council and The Advisory Council to Support Grandparents Raising Grandchildren 2022).

Care recipients more commonly live in the homes of Black/African American, Hispanic/Latino, Asian American, Native Hawaiian and Pacific Islander, and American Indian and Alaska Native family caregivers. But the caregiving experience varies significantly from there:

- More Black/African American and Hispanic/Latino caregivers are involved in high-intensity care, which is marked by tending to someone with greater care needs, performing complex medical and nursing tasks, or more hours of care per week.
- Black/African American caregivers often provide care alone with no other help.
- Hispanic/Latino caregivers tend to be younger and more often have children under age 18 still at home.
- Asian American caregivers more often have help from other unpaid caregivers; however, they more often report feeling they had no choice in providing care (AARP and National Alliance for Caregiving 2020).

Although Asian American caregivers may have more assistance in providing care, many find their role very emotionally stressful. Black and Hispanic/Latino caregivers, however, are more likely than other caregivers to report feeling a sense of purpose in caregiving, even when that care is intense (AARP and National Alliance for Caregiving 2020). American Indian and Alaska Native family caregivers report a sense of reward and satisfaction from caregiving that is attributed to cultural attitudes toward older persons and collective care, even despite experiencing some stress as well (Jervis, Boland et al. 2010, Strachan and Buchwald

**Black/African American, Hispanic/Latino, Asian American, Native Hawaiian and Pacific Islander, and American Indian and Alaska Native family caregivers report distinct care experiences and specific support needs. Furthermore, the care recipients likewise have distinct care needs and health trajectories.**

2022). Differences in emotional responses to the caregiving role may largely reflect cultural values specific to each of these caregiver groups (Whitney, Bell et al. 2023).

Research has shown that these distinctive cultural values shape use of LTSS and that these values persist to some extent across generations (Miyawaki 2016). Neighborhoods, however, have been shown to have meaningful impacts on the availability and range of LTSS services; that impact is felt more among Black/African American, Hispanic/Latino, Asian American, and Native Hawaiian and Pacific Islander older adults. For these groups in particular, where one lives often limits choice of care setting as well as access to quality home health and nursing home care (Travers, Naylor et al. 2021, Fashaw-Walters, Rahman et al. 2022, Shippee, Fabius et al. 2022). Access to culturally and linguistically congruent LTSS is vital to addressing economic disparities across racial/ethnic groups. The availability of meaningful community support can shape employment options and the capacity of the caregiver to augment their own income.

LGBTQ family caregivers make up roughly 9 percent of all caregivers in the country and face a distinctive set of challenges in caring

for LGBTQ partners, friends, and older family members (AARP and National Alliance for Caregiving 2020b). For many LGBTQ family caregivers, they provide care to chosen family and may face difficulties with legal authority in these cases or even in situations where partnerships have not been legalized. Written protections and legal planning documents are critical to ensuring legal authority for caregivers of chosen family members (Family Caregiver Alliance and Wenzel 2015).

Beyond legal concerns, LGBTQ caregivers and those individuals in their care also express concerns about overt marginalization and more subtle instances of exclusion and discrimination in health care and LTSS settings (Caceres, Travers et al. 2020, Rosa, Banerjee et al. 2022, Malta 2023). These instances highlight the need for inclusive language in health care and LTSS system documentation, cultural competency training for LTSS professionals, and greater awareness of the issues LGBTQ family caregivers and those they care for face in health care and LTSS settings.

In a national study of family caregivers, LGBTQ caregivers most often worked while providing care and experienced high levels of financial strain from caregiving. Most expressed feelings

### In Their Own Words...

Kurt, early 60s, Wisconsin, caregiver to his partner and his father:

*First, I had to care for my partner of 23 years as he developed leukemia and passed away from complications in May of 2018. My employer had told me not to worry about my job during this difficult time. I managed to do my job but not be as available 24/7, as I usually was. One month after my partner passed, I was replaced at work. I then moved in with my parents to help them get their house ready for sale. Not long after starting this work, my father fell and broke his hip, was diagnosed with Alzheimer's, skin cancer, and congestive heart failure. His health began to decline, and I, ended up being a primary caregiver for my father, alongside my mother. There was no way to take a job and care for my father. The pandemic then hit, my father began to fail, and in October of 2020 he passed away. I have yet to receive any sort of financial assistance. I am basically now homeless and hoping to get Wisconsin unemployment, which has been under consideration for 16 months.*

of isolation and emotional stress around their caregiving role and reported being in worse health than other family caregivers. The isolation many LGBTQ caregivers experience may be tied to increased stress (AARP and National Alliance for Caregiving 2020b).

These distinct experiences of Black/African American, Hispanic/Latino, Asian American, Native Hawaiian and Pacific Islander, American Indian and Alaska Native, and LGBTQ caregivers highlight the importance of respecting the traditions and cultures of—and including—all racial/ethnic, gender identity and sexual orientation groups in the provision of care. Programs and services should have as their guiding principles a commitment to address accessibility and affordability, meet the unique needs and preferences of diverse caregivers, and be inclusive.

### **PROMISING POLICY AND PRACTICE SUPPORTING CAREGIVERS**

The immediate care needs of the COVID-19 pandemic helped spur meaningful policy change at the federal and state levels to support caregivers and those in their care. Although much of this policy change was tied to the COVID-19 public health emergency (PHE) declared on January 31, 2020, many governments have found ways to implement ongoing policy change to aid family caregivers. With the PHE set to end on May 11, 2023, many of the flexibilities states made available to consumers and to family caregivers through Medicaid will expire.<sup>2</sup> It is incumbent on states, however, to continue transitioning to lasting policy change these flexibilities that support family caregivers. The pandemic brought to the forefront, for example, the importance of a person- and family-centered approach in LTSS to meet the needs of older adults and family caregivers. This approach centers on health and social service providers systematically identifying—and routinely assessing and addressing—the care goals, needs, and preferences of care recipients and their family caregivers, as well as delivering meaningful

and culturally appropriate supportive services and guidance tailored to their unmet needs (Bipartisan Policy Center 2018, Feinberg 2012).

Significant federal and state policy developments and meaningful steps, in both the public and private sectors, have taken place in the four years since the 2019 release of the last Valuing the Invaluable update. Advancements in LTSS, health care, and workplace policies have all contributed to better support the well-being of caregiving families. What follows is a look at some of those advancements, including policies and practices that continue pre-pandemic efforts to support family caregivers and those that stemmed from the COVID-19 PHE.

#### **Federal level**

##### ***Major initiatives***

- **National Strategy to Support Family Caregivers:** On January 22, 2018, the RAISE Family Caregivers Act (Public Law 115-119) was signed into law. This historic legislation directed the Secretary of Health and Human Services (HHS) to develop, maintain, and update a strategy to recognize and support family caregivers of an individual (of any age) with a chronic or other health condition, disability, or functional limitation. With input from family caregivers, those individuals in their care, stakeholders, and the public, the RAISE Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren released the National Strategy to Support Family Caregivers in September 2022 (National Academy for State Health Policy 2022, Administration for Community Living 2022). The National Strategy to Support Family Caregivers is a unified approach to improving recognition of and support for family caregivers. It is organized around five main goals:
  1. Increase awareness of and outreach to family caregivers.
  2. Advance partnerships and engagement with family caregivers.

3. Strengthen services and supports for family caregivers.
4. Ensure financial and workplace security for family caregivers.
5. Expand data, research, and evidence-based practices.

A total of 27 outcomes are detailed under these goals. Under the outcomes, the strategy identifies nearly 500 federal, state, local, and other stakeholder actions that would support family caregivers across the public and private sectors, including in various health care, LTSS, and other settings. The National Strategy will be updated every two years (Administration for Community Living 2022).

- **Public Health Emergency (PHE) Acute Hospital Care at Home (AHCaH) Waiver:**

The Centers for Medicare & Medicaid Services (CMS) introduced regulatory flexibilities tied to the COVID-19 PHE that allowed qualifying hospitals to deliver acute care outside the physical hospital setting and in patients' homes. This waiver expanded Hospital at Home (HaH)—a long-standing US care model providing acute hospital care in patients' homes—by instituting a payment mechanism under Medicare for care episodes in home care settings. The AHCaH waiver serves eligible Medicare Fee-for-Service and nonmanaged care Medicaid beneficiaries. As of January 17, 2023, 260 hospitals in 37 states have been approved to participate in the AHCaH waiver (Centers for Medicare & Medicaid Services 2023, Reinhard, Caldera et al. 2022).

An AARP and ATI analysis of existing HaH programs found that many of them included few if any formal expectations, training, or supports for family caregivers. Although many of these programs have no formal requirement that family caregivers be present during the care episode, when they are present, it is vital that the program recognize them, obtain the caregiver's consent to the HaH or AHCaH, and adequately support

them and provide training (Reinhard, Caldera et al. 2022). The AHCaH waiver is now extended through December 31, 2024, AARP has outlined four Family Caregiver Considerations to be incorporated into any HaH policy and program design by federal policy-makers and HaH program operators. These considerations include the following:

- Ensure choice, access, and equity—seek caregiver assent to guarantee voluntary participation and ensure equity in the HaH patient population.
- Be clear and understandable to the patient and family caregiver—give accurate, complete information about the HaH program, delineate expectations of the caregiver, specify out-of-pocket costs, and clearly explain services.
- Recognize and support the family caregiver—do not expect caregivers to take on medical/nursing tasks, make services and supports available to meet the needs of both the patient and the family caregiver, lead care coordination efforts, encourage family caregivers to share observations, and set up all necessary care and services for a smooth transition at discharge.
- Allow for appropriate levels of research and learning—make data about HaH programs available to researchers, evaluate the impact of HaH programs on family caregivers, disclose any access and equity issues, and share learnings across programs.

### Medicare

- **Supplemental benefits under Medicare Advantage:** In 2019, Medicare Advantage plans—covering about one-third of Medicare beneficiaries in managed care—included additional flexibility to offer beneficiaries new and expanded supplemental services, such as LTSS and support services for family caregivers of enrollees, which Medicare does not routinely cover (Noel-Miller and Sung 2018). Since the 2019 update of Valuing

the Invaluable, the number of plans offering nonmedical supplemental benefits related to LTSS and supports for family caregivers of enrollees has greatly expanded. According to a 2022 report, 160 plans were offering support for enrollees' family caregivers as a new benefit, 729 plans began offering in-home support services, and 50 plans included adult day health services as a new benefit (ATI Advisory 2022).

### Medicaid

- **American Rescue Plan Act of 2021:** The American Rescue Plan Act of 2021 (ARPA) included a 10 percentage point temporary increase to qualifying states' federal medical assistance percentage (FMAP) for certain Medicaid HCBS expenditures. The temporary increase applied from April 1, 2021, to March 31, 2022, and the higher FMAP funds could be used to, among other things, address HCBS workforce issues, expand service capacity and help family caregivers and their care recipients on an HCBS waitlist (including by increasing the number of HCBS waiver slots to reduce or eliminate waiver waiting lists). To receive the increased FMAP, states were required to submit spending plans and narratives to CMS for approval. In June 2022, the period to spend the state funds equivalent to the amount of federal funds attributable to the increased FMAP was extended by a year; states now have through March 2025 to use the additional HCBS funding as detailed in the submitted state plan (Centers for Medicare & Medicaid Services 2021).

At the end of 2021, a tracker of state plans directing increased HCBS funding found that 30 state plans included initiatives to support family caregivers. State initiatives directed funding toward increasing respite care options, training and education for family caregivers, and direct payment to family caregivers (National Academy for State Health Policy 2021). According to a 2022 survey of state Medicaid administrators, 48 states used the FMAP increase to raise HCBS provider pay-

ment rates; just over half of these states plan to continue those increases. All states reported increasing self-directed HCBS opportunities that give Medicaid HCBS beneficiaries authority over hiring their direct care workers and setting payment rates. Forty-eight states introduced provisions allowing legally responsible relatives—such as a spouse, parent, or child—to become a paid direct care provider to a Medicaid HCBS beneficiary (Watts, Burns et al. 2022). Expanding opportunities to pay family caregivers helps states make the most out of their limited professional direct care workforce and makes family caregiving a sustainable arrangement for caregivers and care recipients who prefer to age at home (Murray, Edward-Orr et al. 2021). Prospectively, states could extend or make permanent policies developed under the COVID-19 public health emergency to support family caregivers or pay family caregivers to provide care or services.

- **Spousal impoverishment protections:** Spousal impoverishment protections were extended multiple times to ensure the spouse of a person receiving Medicaid HCBS isn't required to spend down all of their assets in order for the spouse to receive supportive services. Most recently, the 2023 Consolidated Appropriations Act extends these spousal impoverishment protections through fiscal year 2027 for Medicaid HCBS beneficiaries and their families (Library of Congress 2023).

### Veterans Affairs

- **Expanded supports for caregivers of veterans:** The VA MISSION Act, enacted in 2018, expanded the Department of Veterans Affairs (VA) Program of Comprehensive Assistance for Family Caregivers (PCAFC) to include family caregivers of veterans who served prior to September 11, 2001. As of October 2022, new regulatory changes further expanded the program to include family caregivers of veterans who served in any era. The PCAFC allows eligible family caregivers to receive a financial stipend,

training, access to health insurance, counseling, respite care, and legal and financial planning services (Department of Veterans Affairs 2022, Library of Congress 2018).

### Other initiatives

- Reauthorization of the Older Americans Act of 1965 (OAA):** The Supporting Older Americans Act of 2020, effective March 2020, authorizes OAA appropriations through fiscal year 2024. This reauthorization extends the RAISE Family Caregiver Act for one year and includes a provision to provide states with technical assistance to promote and implement the use of caregiver assessments, in line with the recommendation in the National Strategy to Support Family Caregivers to implement assessments and tie them back to referrals and caregiver support plans. This law also calls for a report on the caregiver assessments after three years that addresses use, the impact of these assessments on family caregivers and those individuals in their care (Library of Congress 2020).
- Lifespan Respite Care Program:** The Lifespan Respite Care Program Reauthorization Act of 2020, effective January 2021, authorizes \$10 million annually through fiscal year 2024 for the Lifespan Respite Care Program. This program offers accessible, community-based respite care to family caregivers of persons of all ages in grantee states. It also provides a way to coordinate provision of respite services to meet the needs of all and to ensure the quality of services delivered (ARCH National Respite Network n.d., Administration for Community Living 2023).
- Caregiving volunteer program:** The Consolidated Appropriations Act, 2023 included \$5.5 million for the National Volunteer Care Corps. Established in 2019, the Care Corps program places volunteers in communities to deliver nonmedical services to older adults and individuals

with disabilities to assist them and their family caregivers. This assistance allows the care recipients to stay in their homes and communities (Library of Congress 2017, Library of Congress 2023). The Omnibus bill also provides a \$1.5 million increase for subgrants to programs capable of building a network of screened and trained volunteer chaperones to accompany older adults and adults with disabilities in need to and from nonemergency medical appointments and outpatient procedures (Library of Congress 2023).

### State level

The pandemic drove policy change benefitting family caregivers and their care recipients at the state level too. The new challenges many people experienced during the pandemic highlighted the challenges of family caregivers, spurring continued progress in a number of policy areas. In addition, some temporary, federal policies implemented at the state level proved so effective that states have sought ways to extend these initiatives past the PHE.

#### *Caregiver Advise, Record, and Enable Act*

In the 2017 update of Valuing the Invaluable, 40 states, Puerto Rico, the US Virgin Islands, and the District of Columbia had enacted some version of the Caregiver Advise, Record, and Enable Act (CARE Act). Since then, five additional states passed CARE Act legislation, bringing the total to 45 states and territories with CARE Act laws in place. The CARE Act supports family caregivers when their relatives go into the hospital and as they transition home. State CARE Acts vary, but in general they require hospitals to (a) record the name and contact information of the patient's family caregiver (with the patient's permission) in the patient's electronic health record; (b) give advance notice to family caregivers about when the patient is to be discharged; and (c) educate and instruct family caregivers on any medical and nursing tasks (such as medication management, injections, and wound care) they are expected to perform for the patient at home.<sup>3</sup>

### **Financial relief for family caregivers**

Many states are exploring ways to offset the financial costs of caring for a family member. Several states have implemented caregiver tax credits or other reimbursement programs since the last edition of *Valuing the Invaluable*. Detailed here are some key, but not exhaustive, examples:

- In 2022, Maine implemented the Respite for ME: Family Caregiver Grants Pilot Program, which uses ARPA funding to give certain eligible family caregivers grants of up to \$2,000 to access respite care and other supportive services. Eligible caregivers include the following:

- Those caring for either someone age 60 or older or someone living with dementia and related diseases
- Family members age 55 or older, excluding parents, caring for children under 18 or an adult (age 18 to 59) experiencing disabilities

To be eligible, caregivers must also demonstrate they were negatively affected by or suffered financially from the COVID-19 pandemic (Maine Jobs and Recovery Plan n.d., Maine Office of Aging and Disability Services Care n.d.).

- Missouri's Shared Care Tax Credit offers eligible family caregivers of someone age 60 or older a nonrefundable tax credit of the lesser of \$500 or the equivalent of the caregiver's tax liability. The family caregiver must be registered as a certified shared care member with the Missouri Department of Health and receive no other compensation for caregiving. The family or friend receiving care must live in the caregiver's home for a total of more than six months in the tax year (Missouri Department of Revenue n.d.).
- North Dakota's Family Member Care Tax Credit offers relief of up to \$2,000 for eligible caregiver expenses, such as for adult day care, home health care, personal care, homemaker assistance, respite care, and

companionship services. The credit is limited to caregivers providing care to someone related to them by blood or marriage who is either 65 years or older or who has received a disability determination from the Social Security Administration, and who had federal taxable income of \$20,000 or less or \$35,000 if married (North Dakota Tax n.d.).

### **Workplace flexibility policies**

- **Paid family leave:** Since 2019, three more states, Colorado, Delaware, and Maryland, have enacted paid family leave programs, bringing the total number of states with paid family leave that covers caregiving, including care for older family members, to 11 and the District of Columbia. State paid family leave programs vary in eligibility and waiting-period requirements, qualifying family members or family-like relationships, amount of benefits paid, maximum length of paid leave, whether a worker's job is protected during the paid family leave period, and how the program is funded (Feinberg 2018, Feinberg 2019).
- **Paid sick leave:** A total of 14 states now require paid sick leave, and an additional two have enacted general paid time off laws that allow for paid sick leave, with eight of those states' laws specifically addressing paid sick leave in a PHE. Since the 2019 update, Colorado, New Mexico, and New York passed paid sick leave legislation. Several cities and localities have guaranteed access to paid sick days since 2015. As of November 2022, nearly 35 local jurisdictions in seven states (California, Illinois, Maryland, Minnesota, New York, Pennsylvania, and Washington) have passed paid sick-day legislation (National Partnership for Women & Families 2022).<sup>4</sup>

### **Beyond policy: research and technical developments**

Also relevant to the policy discussion is the continued development of new research and data collection on these issues since the release of the last *Valuing the Invaluable* update and, more generally, during the last few years. Here

are some updates to existing and new data sources covering caregivers; new research collaboratives are highlighted.

**National Study of Caregivers:** First fielded in 2011, the federally funded National Health and Aging Trends Study (NHATS) and its companion National Study of Caregiving (NSOC) examine a nationally representative sample of Medicare beneficiaries (ages 65 and older) and the family and other unpaid caregivers who help older adults with their daily activities. NSOC was conducted with NHATS in 2011, 2015, and 2017, but the survey is being conducted annually as of 2021. NHATS also released a COVID-19 Family Members and Friends File that examined the experience of family members or friends who helped NHATS participants during the COVID-19 pandemic (Johns Hopkins University and University of Michigan n.d.).

**Vanderbilt University Social Networks, Aging, and Policy Study:** The Vanderbilt University Social Networks, Aging, and Policy Study is a longitudinal study focused on the health and aging of older LGBTQ adults in the southern states of Alabama, Georgia, North Carolina, and Tennessee. The study is funded by the National Institute on Aging and includes three waves over four years. Findings from the first wave of the study were published in 2021 (Vanderbilt University and University of Texas at Austin n.d.).

**National Alliance for Caregiving Research Collaborative:** The National Alliance for Caregiving (NAC) Research Collaborative was convened to encourage and foster collaboration among family caregiving researchers across disciplines. The goal of this collaboration is to influence and promote policies and programs, through research, to improve the experience of family caregivers across the life span.

**Best Practice Caregiving:** Best Practice Caregiving is an online tool and database that helps family caregivers and organizations serving them compare evidence-based dementia caregiving programs. The tool, released in

2020, is a collaboration between the Benjamin Rose Institute on Aging, the Family Caregiver Alliance, and the Gerontological Society of America. The free tool's searchable database details more than 40 dementia caregiving programs across the country (Benjamin Rose Institute on Aging 2020).

**Public Health Center of Excellence on Dementia Caregiving:** The 2018 BOLD Infrastructure for Alzheimer's Act, which creates an Alzheimer's public health infrastructure across the country to implement effective Alzheimer's interventions focused on public health issues, established the Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC) to support and coordinate efforts related to dementia caregiving under BOLD. PHCOE-DC serves state, tribal, and local public health agencies by collecting and disseminating tools and materials, offering technical expertise to support agencies' work in identifying and implementing evidence-based interventions, and facilitating collaboration across agencies and other partners (Public Health Center of Excellence on Dementia Caregiving n.d., Centers for Disease Control and Prevention 2021).

### **Beyond policy: caregiver representations in the media and arts**

Family caregivers' stories are increasingly featured in national radio, television, movies, and print media, reflecting the commonality of the caregiving experience in the lives of more and more Americans (Bhattarai 2022, Floyd 2023, Singletary 2021, Span 2022). Millions of viewers followed the journey with Alzheimer's disease faced by Rebecca Pearson on the fictional television drama *This Is Us* and watched how her adult children managed caregiving tasks for their mother. It was a story about caregiving that rang true with so many families and caregivers. The value of seeing the caregiving experience in headlines, in major TV and radio news stories, and even on primetime is that it brings broader attention to all aspects, positive and negative, of the caregiving experience.

Media representations of family caregiving elevate the topic and shed light on the need for the types of supportive policies highlighted here. Celebrity advocacy, such as the lobbying in support of younger caregivers of older family members, which actor Seth Rogan and filmmaker Lauren Miller Rogan have undertaken (Washington Post Live 2022), shines a spotlight on the needs of caregivers and expands understanding of what family caregiving is. This understanding is essential to helping family members engaged in care to identify as a family caregiver; far too often, caregivers assume their care responsibilities are just their duty as a family member or friend. Media and artistic representations of caregivers and care recipients also serve to normalize the care experience and destigmatize the topics of disability and dementia (Hoffman, Sidani et al. 2022).

Family caregivers have also increased their presence and voice on social media—through Facebook groups aimed at offering peer support to family caregivers and the emergence of #dementia and #caregiving on TikTok (Wells 2022). The broad reach of social media offers caregivers an easy way to foster community and find support from any type of internet-enabled device. The short length of social media posts on Facebook, TikTok and Instagram allow busy family caregivers to quickly connect with other caregivers and learn from their experiences.

## **SELECT POLICY AND PRACTICE RECOMMENDATIONS**

### **National Strategy to Support Family Caregivers**

- Overall, the National Strategy to Support Family Caregivers should be turned into action to provide meaningful, tangible outcomes and support for family caregivers. In line with the actions outlined in the National Strategy to Support Family Caregivers, caregiver recognition and support are needed at all touchpoints within health care systems and LTSS. Validated

caregiver assessments—administered by persons trained in performing such assessments—should be incorporated at each of these touchpoints. It is critical to develop and train health care and LTSS providers on the use of culturally appropriate caregiver assessments that avoid bias or disparities. Black/African American, Hispanic/Latino, Asian American, American Indian and Alaska Native, and Native Hawaiian and Pacific Islander family caregivers have distinct needs and may express those needs in distinct forms, and this distinctiveness should be reflected in caregiver assessments.

These assessments are useful only if they connect family caregivers to supports and services. As such, it is critical that policies to implement caregiver assessments also include direction that the assessments result in care planning for the family caregiver and care recipient, referral to services and supports that meet identified needs, and training for the caregiver where appropriate.

- Inclusion of family caregivers in care planning for the care recipient is crucial at all levels of health care and LTSS, including for hospital discharge planning. The CARE Act, though it is specific to the hospital setting, provides a framework for what this inclusion should look like in all health care settings. CMS should update rules to incorporate the CARE Act’s provisions.

Inclusion of family caregivers should extend to nontraditional health care settings as well. Regulatory flexibilities under the PHE have resulted in an increase in hospitals operating AHCaH programs under the CMS waiver. As noted previously, few if any of these programs have explicit guidance for inclusion of family caregivers. HaH programs should supply information on the expectations of family caregivers and secure their assent for participation during patient intake. These programs should also provide all supports and services that family caregivers may need during the acute care episode and in the discharge transition. Congress and the CMS should incorporate family caregiver considerations into potential

future legislation or rulemaking regarding the AHCaH program, and private operators are highly encouraged to do the same.

- It is crucial to give families greater access to high-quality respite care to sustain family caregiving. Family caregivers devote so much time and emotional energy to providing care, often balancing that care with child-rearing and work; they need opportunities for relief. When asked in a recent listening session what support they needed, family caregivers overwhelmingly cited the need for quality respite care services (Tell, Nadash et al. 2021). It is essential that the quality of respite services be a key consideration in any policies to expand their availability. The AmeriCorps Seniors Senior Companion Program is one innovative example of efforts to expand the reach of respite care to all families.
- Policymakers should ensure that all publicly funded programs and caregiver support services (at the federal, state, and local levels) account for the diverse needs of family caregivers and care recipients, particularly for the needs of Black/African American, Hispanic/Latino, Asian American, Native Hawaiian and Pacific Islander, and American Indian and Alaska Native family caregivers and their care recipients. Culturally appropriate programs and services may require consideration of cultural differences in approaches to family, aging, and health care; language access for those who do not speak English as their primary language; and recognition of the distinct and often intersectional identities of family caregivers and older Americans in data collection. Special attention also should be paid to the needs of family caregivers and care recipients historically underserved, such as persons in rural areas or persons identifying as LGBTQ. Family caregivers in these communities likewise have specific needs that influence their experiences with caregiving supports and LTSS.

### Financial relief

- To ease the financial costs of caregiving, policymakers should provide financial assistance and relief to family caregivers through a federal or state tax credit. Few family caregivers are able to claim their care recipients as dependents under current federal tax laws, yet family caregivers spend significant amounts out of pocket to meet the needs of those in their care. These out-of-pocket expenditures may cover home modifications, respite care, transportation, and adult day care. Younger caregivers, who have fewer lifetime financial resources, and Black/African American and Hispanic/Latino caregivers report higher strain from these out-of-pocket costs (Skufca, Rainville 2021). State or federal tax credits to offset some of these out-of-pocket costs would help alleviate that financial strain for eligible caregivers.
- Policymakers should consider reforms that would protect and, if possible, improve Social Security benefits for people who provide caregiving to children, older adults, and others.
- Publicly funded HCBS programs should use participant-directed (sometimes referred to as *consumer-directed*) service models that permit payment to family caregivers. Such models allow consumers and their families to choose and direct the types of services and supports that best meet their needs and preferences. As discussed in the Promising Policy and Practice Supporting Caregivers section, all states now offer self-directed opportunities to Medicaid HCBS beneficiaries, and almost all now temporarily allow legally responsible adults, such as a spouse, parent, or adult child, to become a paid caregiver under these consumer-directed models (Watts, Burns et al. 2022).

## Work/family

- Policymakers should strengthen the federal Family and Medical Leave Act (FMLA) and state FMLAs, including expanding protections to apply to small employers with fewer than 50 employees and covering all primary caregivers. FMLA laws should cover all family and affinity relationships, as many family caregivers are caring for kin or longtime friends.
- Family and medical leave needs to be paid so caregivers can afford to take time off from work to care for themselves or a loved one. Many working caregivers cannot afford to take unpaid leave to care for an ill family member.
- Employers should be required to provide a reasonable number of earned sick days that workers can use for short-term personal or family illness or to take relatives to medical appointments. The continued expansion of state sick leave laws offers another workplace flexibility to help family caregivers balance the needs of their care recipients with their workplace duties.
- Family-friendly workplace flexibility policies that accommodate employed family caregivers should continue and be strengthened. Such policies include flexible work options and telecommuting, job sharing, use of existing leave for caregiving duties, referral to supportive services in the community, and caregiver support

programs in the workplace. Access to workplace flexibility and benefits enables employed family caregivers to meet both care needs and workplace responsibilities—and helps them remain in the workforce.

- Policymakers should prohibit discrimination against workers with family caregiving responsibilities. This should include requirements for employers to provide reasonable accommodations to family caregivers without retaliation.

## CONCLUSIONS

As demonstrated throughout this report, family caregivers play an essential role in providing long-term care in the United States. Whether they care for someone in their home, coordinate home health care remotely, or care for someone who lives in a nursing home, they fill a valuable role in a fractured LTSS system that increasingly relies on care recipients' family and friends. In 2021, the estimated economic value of family caregivers' unpaid contributions was approximately \$600 billion. This rise from the 2019 Valuing the Invaluable publication's estimate, based on 2017 data, was driven in part by increases in wages overall and the cost of home care in the intervening years. The economic impact of caregiving has grown larger over time.

This estimate, in fact, remains conservative, for it does not consider the financial cost of care or account for the complexity of care provided by

Whether they care for someone in their home, coordinate home health care remotely, or care for someone who lives in a nursing home, family caregivers fill a valuable role in a fractured LTSS system that increasingly relies on care recipients' family and friends.

Policies should not only enable training for providers, direct care workers, and families but also support the economic well-being of family caregivers.

many caregivers. A 2021 survey of caregivers found that, on average, family caregivers spend roughly a quarter of their incomes in out-of-pocket costs for caregiving activities, which is not captured in this estimated economic value (Skufca, Rainville 2021). This estimate does not account for the opportunity cost of the foregone wages of caregivers who cut back hours or give up paid employment nor lost lifetime income tied to these employment disruptions. Finally, of course, any such estimate would not factor in the emotional and physical cost of care.

The estimate also does not account for the great variation in the intensity and nature of care that family caregivers provide. More than half of family caregivers reported performing medical/nursing tasks, and a quarter of family caregivers give more than 41 hours of care each week (AARP and National Alliance for Caregiving 2020a). Both cases could lead to a higher economic value of caregiving for that caregiver, either through the higher wage rate to hire a direct care worker with the appropriate level of training to perform medical/nursing tasks or through the increased

number of hours of care a direct care worker would need to provide.

Although many important federal and state policy developments have taken place since the 2019 Valuing the Invaluable report—many driven by the COVID-19 pandemic—such developments should be only the beginning, for family caregivers need further support. Some of these advances will sunset after the public emergency and the future of these initiatives remains unclear. More policy action is needed to help caregivers at all levels of the health care system. Policies should not only enable training for providers, direct care workers, and families but also support the economic well-being of family caregivers. The National Strategy to Support Family Caregivers offers a unified, clear plan for implementing coordinated supports for family caregivers across a range of areas—health care, social support, and economic—and highlights an array of actions at all levels of government and in the private sector, including some that are underway. Steps must be taken to build on the actions, goals, and outcomes in the National Strategy.

## Appendix A: Sources and Methodology Overview

Each survey in table A1 has a different definition of the term *caregiving*, which is defined by the target population, the question that identifies caregivers, and other characteristics of the survey. As has been the case for past *Valuing the Invaluable* reports, the meta-analysis adjusts the data from multiple sources to a common definition:

- caregiver age 18 or older;
- care recipient age 18 or older;
- providing care currently or within the past month;
- providing assistance with activities of daily living (ADLs; e.g., bathing, dressing), instrumental activities of daily living (IADLs; e.g., managing finances, transportation), or medical/nursing tasks (e.g., medication management, preparing special diets); and
- year 2019.

More detail about the sources, adjustments to the common definition, and other methodology can be found in the Detailed Methodology document, available online at <http://www.aarp.org/valuing>.

The meta-analysis approach is preferred because it takes into account more information than any one particular survey. Also, the adjustment to the common operational definition brings the different estimates into a tighter cluster (see table A2). This increases confidence that the Valuing prevalence, hours, and economic value estimates are not significantly under- or overestimated based on a single outlier data source.

To present consistent state and national estimates of the economic value of caregiving, the number of family caregivers and the economic value of caregiving were estimated separately at the state level and then summed to get national estimates. At the state level, the economic value was calculated as (number of caregivers in 2015-19) × (hours of care per caregiver per week) × (52 weeks/year) × (economic value of one hour of family care).

TABLE A1  
Sources of Data on Caregiver Prevalence and Hours

Survey	Data Years	Citation
American Time Use Survey	2017-18	Bureau of Labor Statistics, “Unpaid ElderCare in the United States--2017-2018 Summary,” 2019, <a href="https://www.bls.gov/news.release/elcare.nr0.htm">https://www.bls.gov/news.release/elcare.nr0.htm</a> .
Behavioral Risk Factor Surveillance System	2015-19, 2021	AARP Public Policy Institute, unpublished analysis of data from the 2015-19, 2021 Behavioral Risk Factor Surveillance System, 2021, <a href="https://www.cdc.gov/brfss/data_documentation/index.htm">https://www.cdc.gov/brfss/data_documentation/index.htm</a> .
Caregiving in the U.S.	2019	AARP Public Policy Institute, unpublished analysis of Caregiving in the U.S. survey data. 2019 data (2020 report) available at: <a href="https://www.caregiving.org/research/open-data/">https://www.caregiving.org/research/open-data/</a>
The Long-Term Care Poll	2018	AARP Public Policy Institute, unpublished analysis of data from the AP-NORC’s 2018 Long-Term Care Poll, <a href="https://www.norc.org/Research/Projects/Pages/long-term-care-poll.aspx">https://www.norc.org/Research/Projects/Pages/long-term-care-poll.aspx</a> .

TABLE A2

**Adjusted and Unadjusted National Estimates of Caregivers and Care Hours**

Source	Year	Unadjusted Number of Caregivers (source year)	Adjusted Number of Caregivers (2019)	Average Hours per Caregiver per Week	Total Adjusted Number of Care Hours
American Time Use Survey	2017–18	39.1 million	47.1 million	6.2	14.8 billion
Behavioral Risk Factor Surveillance System	2015–19*	47.7 million	43.9 million	19.3	44.0 billion
Caregiving in the U.S.	2019	47.9 million	30.4 million	23.7	37.5 billion
The Long-Term Care Poll	2017*	39.2 million	40.5 million	16.8	34.0 billion
<b>National Estimates (2019), Adjusted to 2019</b>			<b>41.6 million</b>	<b>18</b>	<b>36.7 billion</b>

\*All years of BRFSS data are adjusted to 2019 in the “unadjusted” column. The Long-Term Care Poll was fielded in 2018 but estimates were weighted to the 2017 population, so we use that baseline for adjustments.

The number of family caregivers was based on a weighted average of the four data sources, adjusted to the common definition, and multiplied by a state factor based on sources with state-specific prevalence data (2015–19 BRFSS; additional sources from the 2019 *Valuing the Invaluable* report) to account for significant variation in the age structure and age-adjusted prevalence of caregiving across states.

The economic value of 1 hour of care was estimated at the state level as the average of the state minimum wage, median home health aide wage, and median private pay cost of hiring a home health aide.

The national average value per hour of \$13.81 is the average value for all care hours across all states. In the states, the average value per hour ranges from \$11.84 in Louisiana to \$21.88 in Washington (see appendix B for state data).

## Appendix B: State Data

TABLE B1

## Number of Family Caregivers, Hours, and Economic Value of Caregiving, by State, 2021

State	State Population	Number of Caregivers	Number of Care Hours (millions)	Value per Hour	Economic Value (millions)
Alabama	5,050,000	700,000	660	\$12.66	\$8,300
Alaska	734,000	94,000	88	\$19.23	\$1,680
Arizona	7,260,000	850,000	800	\$18.20	\$14,500
Arkansas	3,030,000	420,000	390	\$14.77	\$5,800
California	39,100,000	4,400,000	4,100	\$19.76	\$81,000
Colorado	5,810,000	600,000	560	\$20.07	\$11,200
Connecticut	3,620,000	420,000	390	\$18.43	\$7,200
Delaware	1,005,000	124,000	116	\$16.33	\$1,890
District of Columbia	669,000	74,000	69	\$19.83	\$1,370
Florida	21,800,000	2,700,000	2,600	\$15.50	\$40,000
Georgia	10,790,000	1,260,000	1,180	\$13.82	\$16,300
Hawaii	1,447,000	154,000	144	\$18.09	\$2,600
Idaho	1,904,000	210,000	193	\$15.75	\$3,000
Illinois	12,690,000	1,290,000	1,210	\$17.70	\$21,000
Indiana	6,810,000	790,000	740	\$14.61	\$10,800
Iowa	3,200,000	330,000	310	\$16.80	\$5,200
Kansas	2,940,000	340,000	320	\$14.30	\$4,500
Kentucky	4,510,000	610,000	570	\$15.19	\$8,600
Louisiana	4,630,000	630,000	590	\$11.84	\$6,900
Maine	1,377,000	166,000	155	\$18.81	\$2,900
Maryland	6,170,000	760,000	710	\$17.61	\$12,500
Massachusetts	6,990,000	780,000	730	\$20.65	\$15,100
Michigan	10,040,000	1,200,000	1,120	\$17.39	\$19,600
Minnesota	5,710,000	530,000	500	\$20.14	\$10,000
Mississippi	2,950,000	470,000	440	\$12.72	\$5,600
Missouri	6,170,000	800,000	750	\$15.47	\$11,600
Montana	1,106,000	112,000	105	\$16.86	\$1,760
Nebraska	1,964,000	179,000	168	\$16.96	\$2,800
Nevada	3,150,000	340,000	320	\$16.01	\$5,100
New Hampshire	1,388,000	168,000	157	\$17.96	\$2,800
New Jersey	9,270,000	1,010,000	940	\$18.71	\$17,600
New Mexico	2,120,000	270,000	250	\$15.31	\$3,800
New York	19,860,000	2,200,000	2,100	\$18.69	\$39,000
North Carolina	10,570,000	1,280,000	1,190	\$13.79	\$16,500
North Dakota	778,000	62,000	58	\$17.24	\$1,000
Ohio	11,760,000	1,460,000	1,370	\$15.61	\$21,000
Oklahoma	3,990,000	490,000	460	\$14.50	\$6,600
Oregon	4,260,000	470,000	440	\$19.73	\$8,700
Pennsylvania	13,010,000	1,490,000	1,390	\$15.63	\$22,000
Rhode Island	1,097,000	121,000	113	\$18.95	\$2,100
South Carolina	5,190,000	710,000	670	\$13.92	\$9,300
South Dakota	896,000	80,000	74	\$18.12	\$1,350
Tennessee	6,970,000	930,000	870	\$14.16	\$12,300
Texas	29,600,000	3,100,000	2,900	\$14.02	\$41,000
Utah	3,340,000	340,000	320	\$17.08	\$5,500
Vermont	647,000	70,000	66	\$18.73	\$1,230
Virginia	8,660,000	980,000	920	\$15.51	\$14,300
Washington	7,740,000	820,000	770	\$21.88	\$16,800
West Virginia	1,786,000	250,000	230	\$12.74	\$3,000
Wisconsin	5,880,000	580,000	540	\$16.97	\$9,200
Wyoming	579,000	58,000	54	\$16.77	\$910
<b>Total US</b>	<b>332,000,000</b>	<b>38,000,000</b>	<b>36,000</b>	<b>\$16.59</b>	<b>\$600,000</b>

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- 1 Mitchell LaPlante and colleagues found that the value of unpaid personal assistance provided to adults (ages 18 and older) with disabilities approached \$168 billion in 1996; the value of paid formal assistance in the home was \$32 billion. In 1997, Peter Arno and colleagues estimated the national economic value of informal caregiving to be \$196 billion, compared with \$32 billion for paid home care in that year. The Congressional Budget Office (CBO) adjusted this estimate for inflation to \$218 billion in 2004 dollars. An updated estimate by Arno was \$306 billion in 2004. See Mitchell P. LaPlante, Charlene Harrington, and Taewoon Kang, “Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults at Home,” *Health Services Research*, 37, no. 2 (2002): 397–413; P. S. Arno, C. Levine, and M. Memmott, “The Economic Value of Informal Caregiving,” *Health Affairs* 18, no. 2 (1999): 182–8; D. Holtz-Eakin, “The Cost and Financing of Long-Term Care Services,” CBO Testimony before the House Subcommittee on Energy and Commerce, April 27, 2005; P. S. Arno, “Economic Value of Informal Caregiving: 2004,” presented at the Care Coordination & Caregiver Forum, Department of Veterans Affairs, NIH, Bethesda, MD, January 25–27, 2006.
- 2 Some state flexibilities can extend six months past the end of the PHE, now May 11, 2023.
- 3 As of January 2023, states that have enacted the CARE Act are Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Georgia, Hawaii, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Puerto Rico, Rhode Island, Texas, Utah, US Virgin Islands, Virginia, Washington, West Virginia, and Wyoming. Tennessee has implemented provisions of the CARE Act by regulation. South Dakota passed a version of the CARE Act that is limited to mental health treatment facilities.
- 4 Local jurisdictions with paid sick days include seven cities in California (San Francisco, Oakland, San Diego, Berkeley, Emeryville, Santa Monica, and Los Angeles); Seattle, Tacoma, and Spokane, Washington; Washington, DC; New York City and Westchester County, New York; Philadelphia, Allegheny County, and Pittsburgh, Pennsylvania; Montgomery County, Maryland; Minneapolis and Bloomington, Minnesota; and Chicago, Illinois.

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