National Strategy to Support Family Caregivers

Developed by:

The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council

&

The Advisory Council to Support Grandparents Raising Grandchildren

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Acknowledgements

The National Strategy to Support Family Caregivers was developed by the Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren (SGRG).

Both councils were formed in 2019; however, this strategy is the result of decades of engagement and hard work on the part of policymakers, advocates, philanthropic organizations, service providers, and family caregivers.

The members of the two councils would like to specifically recognize five organizations that generously provided financial, technical, and practical assistance at every step of the development of this strategy:

- The John A. Hartford Foundation (JAHF)
- National Academy of State Health Policy (NASHP)
- Community Catalyst
- The LeadingAge LTSS Center @UMass Boston
- National Alliance for Caregiving

In addition, more than 150 organizations across the private and non-profit sectors provided input in the form of white papers, briefings, and presentations or by participating in a series of listening sessions conducted by LeadingAge LTSS Center @UMass Boston and Community Catalyst to inform the development of the recommended actions. A complete stakeholder list is available in Appendix A.

Multiple federal agencies also contributed to the strategy through participation on one or both of the councils and/or by identifying specific actions that they will take under existing authorities to contribute to the advancement of a systemic approach to better recognize and support family caregivers. The councils would like to recognize the following federal agencies that contributed to its development:

- AmeriCorps
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    - Administration for Children and Families (ACF)
    - Administration for Community Living (ACL)
    - Centers for Disease Control and Prevention (CDC)

    - Centers for Medicare & Medicaid Services (CMS)
    - Health Resources and Services Administration (HRSA)
    - Indian Health Service (IHS)
    - National Institute on Aging (NIA), National Institutes of Health (NIH)
    - Office of the Assistant Secretary for Planning and Evaluation (ASPE)
    - Substance Abuse and Mental Health Services Administration (SAMHSA)
- U.S. Department of Labor (DOL)
- U.S. Department of Veterans Affairs (VA)

Creating the Strategy

The National Strategy to Support Family Caregivers (**Strategy**) is the result of three years of focused effort by two Congressionally mandated advisory councils: The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council and The Advisory Council to Support Grandparents Raising Grandchildren (SGRG) (collectively referred to herein as the **Advisory Councils**).

The two Advisory Councils were formed in 2019 to explore and document the challenges faced by family caregivers and kin and grandparent caregivers, respectively. Each was charged with providing actionable recommendations for supporting their corresponding caregiving populations in a holistic way both now and in the future. In addition, the RAISE Act directed the development of a family caregiving strategy.

In 2021, each Advisory Council delivered an initial report to Congress. The reports contained recommendations for increasing awareness and outreach; integration of caregivers in clinical settings and decision-making processes; expanding the availability of services for caregivers; reducing the financial challenges faced by family caregivers; and improving data, research, and the use of evidence-informed approaches in the field. The reports also offered testimonials from family caregivers to help illustrate why it is imperative that the nation do more to support them. During this work, it became clear that because family caregiving is such a varied activity that can affect people at any stage of life and often requires a wide range of skills and competencies, the best way to holistically support all family caregivers would be through a unified effort. As a result, the Advisory Councils collaborated to develop the Strategy.

Who are Family Caregivers?

The RAISE Family Caregivers Act defined “family caregiver” as “an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability or functional limitation.” In its initial report to Congress, the RAISE Advisory Council expanded that definition slightly to include unpaid individuals of all ages in its definition.

In its 2021 Report to Congress, the SGRG Advisory Council defined “kin and/or grandparent caregiver” to refer to any grandparent or relative adults who have primary responsibility for grandchildren or other children who cannot remain with their parents.

In the 2022 National Strategy to Support Family Caregivers, “family caregiver” includes anyone meeting those definitions.

Setting the Vision

According to the individual statements from Advisory Council members, when the goals of the Strategy are achieved, family caregivers of all ages and circumstances will be able to:

- “Be informed advocates … (and) obtain the services they desperately need to survive and thrive”
- “Access the right support at the right time”
- “Understand that the role (of family caregiver) is a competency, and their success relies on infrastructure available within a community”
- “Maintain their own vitality, health, and wellness”
- “Protect the bonds of family … and maintain strong family relationships”
- “Realize that they are not alone … and become empowered to step forward as advocates”
- “Navigate services that support their needs for providing a service of care”
- “Access emotional and financial support without judgment”
- “Reference a living document that reflects shared values”
- “Breathe again … ”

In addition, council members noted that supporting family caregivers helps to ensure that the people receiving support maintain their autonomy, independence, and right to self-determination.

Their first step was to articulate a shared vision. They began by describing a world in which family caregivers have the support needed to provide care without jeopardizing their own financial, emotional, and physical stability. Each council member submitted statements detailing their individual perspectives on what the Strategy should achieve—and the impact on family caregivers if the shared vision were realized. Their individual responses reflected the wide range of challenges and joys that are experienced by many family caregivers.

It is important to note that the Strategy is focused solely on the populations and issues addressed by the RAISE Family Caregiving Act and the Supporting Grandparents Raising Grandchildren Act; it does not address every type of caregiving situation. For example, although expanding access to affordable, quality childcare is crucial to supporting working parents, and parents are "family caregivers" in the literal meaning of the term, that issue is beyond the scope of this strategy.

Similarly, the Advisory Councils recognize that the Strategy does not fully address all aspects of family caregiving, as there is no one-size-fits-most solution to addressing the needs of more than 53 million individuals providing care in the U.S. Specific populations of family caregivers, especially those with more demanding and/or complex caregiving responsibilities (described by family caregivers as "more intense" responsibilities), likely will need additional support not described in this initial release of the Strategy.

A Note on Language

The Advisory Councils recognize that different stakeholder groups that will be served by this Strategy use different language to describe the role of a person who provides the support another person needs. For example, while many people use the term "caregiver," others prefer to use terms like "care partner" to describe the person who provides assistance, and some cultures do not have terms for people who provide informal support to others.

Similarly, different stakeholder groups prefer different terms to describe the tasks performed by these people to be "care," while others use "support," "assistance," or simply, "help."

To design a strategy broad enough to encompass all family caregivers and the myriad challenges they collectively face (and often overcome) in a manner that honors cultural norms and differences, the Advisory Councils blended their individual family caregiving-related definitions. This practical approach allowed them to create a broad concept that could be applied in a range of circumstances, while maintaining clarity for readers of the document. When working directly with individual family caregivers and care recipients, or different stakeholder groups, it is important to be aware of the wide range of language used to discuss the issues of family caregiving and to make an effort to use the language preferred by the individual/groups being addressed.

After thoughtful discussion within the Advisory Councils, which included both family caregivers and care recipients from a variety of circumstances, the following terminology was selected for the purposes of this document:

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

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

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

This all-encompassing approach is intended to reflect a vision for a comprehensive national response to supporting the nation’s family caregivers.

For more on how the terms used throughout the Strategy were selected, see the RAISE Family Caregivers Act Initial Report to Congress and the Supporting Grandparents Raising Grandchildren Act Initial Report to Congress.

Executive Summary

Background

Every single one of us, if we live long enough, is likely to experience being a family caregiver, needing a family caregiver, or both.

Each year, more than 53 million family caregivers provide the majority of support that makes it possible for older people and people with disabilities to live in the community (AARP and National Alliance for Caregiving, 2020). In addition, at least 2.7 million grandparents – and an unknown number of other kin and relative caregivers – carried the primary responsibility for caring for children whose parents were unable to do so (Annie E. Casey Foundation, 2019). When formal systems of caregiving break down (as we saw during the COVID-19 pandemic) or are not available in the first place, family caregivers step in—often on short notice—and cover whatever is needed: meals, transportation, chores, personal care, education, medical tasks, administrative assistance, language translation, and even IT support (AARP and National Alliance for Caregiving, 2020).

In short, family caregivers form the backbone of our nation's system of long-term care. They support a wide range of people, with a wide range of needs, such as:

- **Older adults and people of all ages with all types of disabilities** who may need assistance with bathing, toileting, dressing, and eating (also known as activities of daily living) or with things like grocery shopping and meal preparation, getting to doctor's appointments, home maintenance, or managing multiple medicines.

- **People with chronic health conditions**—such as cancer, diabetes, and arthritis who may need assistance navigating complex health care systems, managing symptoms and medication side effects, and maintaining quality of life.

- **Adults and children with I/DD** who may require assistance with ensuring that the individual's basic needs are met, while their rights are respected and protected. They also may need assistance with accessing and coordinating the supports needed for health, well-being, independence, and opportunities to participate fully in their communities, as well as integrated employment and self-determination, whether the individual with I/DD is living with the family caregiver or in their own home. Parents and other family members of people with I/DD often provide medical, behavioral, financial, and other daily supports beyond what most families provide, and they provide this assistance across the lifespan of the person with I/DD.

- **Children in the full-time care of relatives**, such as grandparents or close family friends, who may need special education, behavioral health services, and help to thrive due to previous adverse childhood experiences.
- **Medically fragile children and adults** who need round-the-clock care from a team that includes family caregivers and skilled nursing professionals working in close concert.
- **Older adults who are affected by Alzheimer's disease and related dementias (ADRD)**, including people with I/DD, who require assistance with activities of daily living.
- **Veterans with injuries and/or chronic conditions**, including traumatic brain injuries, limb loss, and mental health issues like post-traumatic stress disorder (PTSD).
- **People who live in nursing homes, board-and-care, and assisted living facilities**, and other residential care communities, who rely on family caregivers for assistance to maintain their health, safety, welfare, and well-being.

This is not an all-inclusive list—family caregivers provide many types of assistance not listed here. And, of course, some people supported by family caregivers may fit into more than one of these categories.

Costs of Caregiving

While family caregiving can be rewarding and personally satisfying, it often comes at significant personal cost to the caregiver (National Academies of Sciences, Engineering, and Medicine, 2016). However, those costs—financial, physical, and emotional—incurred by family caregivers are hard to measure.

The goal is always to provide support that meets the needs of the individual receiving it—as defined by that person—and to allow the individual receiving care to maintain autonomy, independence, and quality of life.

To date, data collection efforts have not captured the full range of caregiving. They often have been limited to specific caregiving situations, such as post-hospital-discharge caregiving. Some populations of family caregivers, such as kin and grandparent caregivers and long-distance caregivers, are often overlooked. The care provided differs from situation to situation and is intentionally tailored - the goal is always to provide support that meets the needs of the individual receiving it—as defined by that person—and to allow the individual receiving care to maintain autonomy, independence, and quality of life. These and other factors hinder the ability to capture the often ongoing, long-term nature of caregiving, especially for care recipients with long-term needs, such as those with dementia.

As a result, our knowledge about the impact of family caregiving is limited to selected outcomes like social isolation, loneliness, stress, depression, and quality of life. We know that family caregivers suffer from higher rates of depression than non-caregivers of the same age, and research indicates that family caregivers suffer a mortality rate that is 63 percent higher than non-caregivers (Schulz & Beach, 1999).

In recent years, additional attention has been given to measuring the financial impact of family caregiving, such as lost wages, reduction in workforce, and the out-of-pocket costs that caregivers often incur for meals, transportation, medical supplies, toys, educational tools, home modifications, and more. Family caregivers lose an estimated $522 billion in wages each year due to caregiving, and employers are losing an estimated $33 billion per year due to employees' caregiving responsibilities (Chari, Engberg, Ray, & Mehrotra, 2015).

Finally, when the challenges become overwhelming and family caregivers are unable to continue to provide support, the person they have been assisting often is left with no choice but to enter an institution. In addition to negatively affecting the health and well-being of the individual who has moved from the community, institutional care also carries a tremendous financial cost—most of which is borne by Medicaid. Ensuring family caregivers have the resources they need to continue to support older adults and disabled people in the community is critical to containing the rising costs of health care.

Purpose of the Strategy

The range of circumstances faced by caregivers is large, and every family caregiver is unique. However, they have at least one thing in common: each deserves and needs to be **recognized**, **assisted**, **included**, **supported**, and **engaged**.

To address this need, the initial National Strategy to Support Family Caregivers (Strategy) was developed in 2022 by the RAISE Act Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren (SGRG) (collectively, the **Advisory Councils**). It builds upon a framework prepared by each council's 2021 report to Congress to:

- **Align federal, state, tribal, local, and other stakeholder responses** around a set of goals and outcomes that are informed by thoughtful recommendations.
- **Foster collaborations** within and across stakeholder groups.
- **Optimize existing family caregiver support** efforts by reducing redundancy, improving information sharing, and infusing best practices systemwide.

- **Prioritize efforts to better serve** populations of caregivers who have not been reached historically.

- **Ensure** that all efforts to uplift caregivers are person- and family-centered, trauma-informed, and culturally competent.

Components of the Strategy

In addition to an overarching narrative, the Strategy includes two appendices; lists of actions, organized by goal, that can be undertaken by a wide range of stakeholders to achieve a vision where people can provide care and support to others without putting their own physical, emotional, and financial well-being on hold and at risk.

"**Federal Actions**" includes 345 commitments submitted by 15 federal agencies to support the 2022 National Strategy to Support Family Caregivers. While the federal actions are significant, they are constrained by the RAISE Family Caregivers Act requirement that they be "within scope of existing programs." Therefore, the federal actions within this strategy are limited to activities possible under existing budgets, programs, and authorities.

Note: As the Advisory Councils' respective reports to Congress made clear, at present, there are many identified needs of family caregivers that are not possible to fully address within the scope of existing federal programs. The Advisory Councils identify and describe for consideration other types of federal actions that would require new legislation under Family Caregiver Needs Requiring Legislative and Other Policy Changes.

"**Actions for Others**" includes actions for states, communities, and other stakeholders to support caregivers in ways that are aligned with the Strategy. These actions were distilled from eight separate convenings conducted by or on behalf of the Advisory Councils to gather, align, and aggregate independent actions that stakeholders can take to support the Strategy.

This is the first time that ideas from local and state agencies and nonprofit organizations are integrated with recommendations for the federal government in a combined initiative dedicated to family caregiving. The development of these lists also represents the first time that agencies across the federal government have formally worked together to coordinate family caregiver support planning.

For more information on public comments and input from stakeholders that informed the development of the Strategy, see Appendix B: Resources used in the development of the Strategy.

It is important to note that the Strategy is not—nor can it be—a timeline, a set of operating instructions, or a how-to manual. The Advisory Councils intentionally developed an approach that is flexible and broad; the Strategy presents a menu of priority actions organized under outcomes and goals to provide stakeholders with a range of options that can be implemented to meet local needs.

In addition to the lists of actions, the Strategy also provides a discussion of cross-cutting considerations, or "first principles," that must be embedded in all support to family caregivers: person- and family-centered care; the impact of trauma on families; and elevating direct care workers as essential partners to the family caregiver.

A First Step

The initial Strategy empowers communities, agencies, and other stakeholder groups to select actions for implementation, based on community and family caregiver needs and preferences, and in consideration of existing supports already in place, resource constraints, and other factors.

The Strategy is a significant milestone in our national effort to improve the way we support family caregivers, but it also is only the beginning. This will be a living document, updated regularly, based on the ongoing input of family caregivers and the people they support; the continued work of the Advisory Councils; communities, states and tribes, and federal agencies that are developing, implementing and adapting policies and programs to support family caregivers; and other stakeholders. All stakeholders are encouraged to look for opportunities to improve collaboration, reduce redundancy, and leverage the actions being undertaken by other organizations and/or sectors and to share recommendations to inform the first update to the Strategy, which will be published in 2024.

Introduction

Every day, millions of family caregivers put their own needs aside, often suddenly, to improve and maintain the quality of life for others. They support parents, spouses and partners, children with significant disabilities, children who cannot remain with their parents, and other family members. Both family caregivers and the people they support hail from every corner of the nation and reflect all of society (AARP and National Alliance for Caregiving, 2020).

The National Strategy to Support Family Caregivers is dedicated to America's family caregivers. It serves as an initial effort in changing systems so that family caregivers can receive the recognition, assistance, and support they deserve while engaging and including family caregivers in creating the change they envision.

Family Caregiving Today

According to the National Alliance for Caregiving (NAC) and AARP, at least 53 million people provide informal, and usually unpaid, care and support to older adults and disabled people of all ages in the United States (AARP and National Alliance for Caregiving, 2020). This support makes it possible for millions of people to live in homes in the community rather than congregate settings. Family caregivers also supplement the care of people who are hospitalized or living in nursing homes and other institutional settings (Avison, et al., 2018).

In addition, at least 2.7 million kin and grandparent caregivers have opened their arms and homes to millions of children who cannot remain with their parents (Generations United, 2018). These numbers are increasing rapidly due to growing populations of older adults and people with disabilities (including due to long COVID); the long-standing shortage of direct care workers, which has reached crisis proportions during the pandemic; the continuing opioid crisis and other issues that are creating thousands of new "grandfamilies" each year; and a variety of other factors.

The current U.S. system of long-term services and supports could not continue to function without the contributions of family caregivers. In 2017, the annual contribution of unpaid care of older adults from family members was estimated to be valued at $470 billion (Reinhard, Feinberg, Houser, Choula, & Evans, 2019). Currently, there are no estimates for the value of the countless hours that family caregivers devote to other types of care—for example, those providing 24/7 care to medically fragile children, those supporting the independence of people with I/DD, caregiving youth who help parents and grandparents, or family caregivers providing care to more than one person. Similarly, it is impossible to estimate the financial value of the care provided by kin and grandparent caregivers, many of whom are older adults (Generations United, 2018).

From our Listening Sessions

"One of the big stressors was money. Why aren't we paying our family caregivers? Why aren't we giving them a wage? When you think about any stressor they're having … a lot of it's going to be financially related."

Despite its many rewards, family caregiving often carries a considerable personal and financial cost (National Academies of Sciences, Engineering, and Medicine, 2016). These costs have long existed, but they came into the spotlight during the COVID-19 pandemic, when more people became family caregivers in response to closures of formal services and changes in the availability of informal supports (Beach, Schulz, Donovan, & Rosland, 2021). These new caregivers quickly began to experience the same challenges that have long been a reality for millions of caregivers across the nation. Because family caregiving often is time-intensive, and it takes place within family and other private spaces, it can leave the people who provide support isolated from friends, family, colleagues, and support systems. The pressures of the pandemic have only amplified the stress and loneliness that can accompany caregiving.

Many family caregivers struggle to balance their caregiving role with other family responsibilities and employment, and they often forgo rest and self-care. They also frequently bear out-of-pocket expenses (AARP and National Alliance for Caregiving, 2020). A 2016 caregiving cost study conducted by AARP found that three-quarters of family caregivers surveyed incurred out-of-pocket monetary costs as a result of caregiving. The estimated per family spending on family caregiving was roughly $7,000 per year ($6,594) (Rainville, Skufca, & Mehegan, November 2016). These and other challenges can have a long-term effect on caregivers' health, relationships, mental and emotional well-being, finances, and even their ability to provide support over time and/or care for themselves (AARP and National Alliance for Caregiving, 2020).

"The challenges and rewards of family caregiving are much more than any research study has ever captured. Families struggle, they look for help and support, they laugh, they cry. They do all of this for the family member that has the greatest need. Yet, the demands of work and the needs of other family members continue. Balancing all of the demands can be overwhelming."

-Alan Stevens, Ph.D., family caregiver & RAISE Family Caregiving Advisory Council Co-chair

Without the support of family caregivers, millions of people would find themselves with no choice but to move to more costly nursing homes and other institutional and congregate settings. Millions of children would enter the child welfare system (and be effectively in the care of strangers) (Generations United, 2018). In addition to having a negative effect on the health and well-being of the people receiving care, these changes would come at a significant cost to federal, state, and community social services budgets and the American taxpayer. Not only does the nation owe a tremendous debt to its family caregivers, but it has no acceptable alternative to family care. Consequently, family caregiving is an urgent public health issue of such magnitude that it requires a coordinated, iterative, and cross-sector response.

A Snapshot of Family Caregivers

Family caregivers represent a broad cross-section of the population—people of every background and in every corner of the nation are family caregivers (AARP and National Alliance for Caregiving, 2020). Family caregivers include spouses, parents, siblings, adult and minor children, grandparents and other relatives, and more, and people can assume family caregiving responsibilities at any stage of life (AARP and National Alliance for Caregiving, 2020).

Some family caregivers assist others out of a wellspring of love and concern. Others provide care in response to tradition, culture, family expectations, or other factors (Zarzycki, Seddon, Bei, Dekel, & Morrison, 2022). More than half of all family caregivers (53%) feel they have no choice in taking on the role (AARP and National Alliance for Caregiving, 2020). Often, some combination of these reasons causes a person to become a caregiver.

An often-overlooked segment of the caregiving community is children, teens, and young adults who care for parents, grandparents, and siblings. Advocates refer to these young caregivers as “caregiving youth.” Research on caregiving youth remains limited, in part because many families are reluctant to volunteer information (National Alliance for Caregiving in Collaboration with United Hospital Fund, 2005). A 2005 study found that more than half of caregiving youth help with bathing, dressing, getting in and out of beds and chairs, toileting, and feeding. One in six child caregivers helps a family member communicate with doctors or nurses, and 15 percent of those aged 12 and older make calls and engage in care coordination. While data is still emerging, research also suggests that younger caregivers are more likely to support someone with a behavioral health condition (Reinhard S., et al., 2019).

It is important to note that some populations are disproportionately affected by caregiving issues. Although men are becoming family caregivers in greater numbers, 61 percent of family caregivers are women (AARP and National Alliance for Caregiving, 2020); caregiving responsibilities often exacerbate the financial security—including retirement security—disparities experienced by women. African American and Hispanic caregivers are more often in high-intensity care situations than white and Asian American caregivers (Choula, Snyder, & The John A. Hartford Foundation, 2020), but they also are more likely to report that caregiving provides them with a sense of purpose. On the other hand, Asian American and white caregivers report higher levels of emotional stress than African American or Hispanic caregivers (AARP and National

Alliance for Caregiving, 2020). Hispanic older adults are about one and one-half times as likely to have Alzheimer's or other dementias as compared to older adults who are white (Alzheimer's Association, 2021). The result is that caregiving disproportionally affects families of color. For example, Black and American Indian and Alaska Native children are more likely to live in grandfamilies (U.S. Census Bureau, 2019).

What Family Caregivers Do

Millions of people are able to live more independently, with dignity and self-determination while experiencing a better quality of life thanks to some form of assistance from family caregivers.

Today's family caregivers are often expected to perform highly complex tasks, including medical tasks, care coordination, administration, and technological support – activities that extend well beyond the help with activities of daily living that were the hallmark of family caregiving in years gone by (National Academies of Sciences, Engineering, and Medicine, 2016). Of the approximately 10.9 million individuals with LTSS needs living in the community and 1.8 million nursing home residents, 92 percent receive assistance from family caregivers and only 13 percent receive any form of paid assistance (Kaye, Harrington, & LaPlante, 2010).

The Advisory Councils convened as a result of these key pieces of legislation believe that their efforts are only **a first step in creating a systemic approach to supporting family caregivers**. Given the increasing numbers of older adults and people with disabilities and chronic conditions who are anticipated to need caregiver assistance in the future, the Advisory Councils contend that in addition to the implementation of the Strategy, significant future changes will likely be needed in the federal landscape to meet the vision of the RAISE Family Caregivers Act. This belief is aligned with public comments received by the councils.

See Family Caregiver Needs Requiring Legislative and Other Policy Changes below. For more information on public comments and input from stakeholders, see Appendix B: Resources used in the development of the Strategy.

Family caregivers generally provide this support without a formal assessment of their needs or the needs of the person receiving support. That means they may have to take on tasks they do not know how to do, did not expect to have to do, or do not feel comfortable doing. They often have limited access to training or assistance that could enable success. They often face legal barriers to providing care, such as when a grandparent opens their home to a child but lacks legal custody or the authority to make decisions on behalf of the child. This lack of formal recognition creates unexpected challenges with otherwise straightforward tasks such as accessing medical care or registering a child for school. Over time, these hurdles can make an already complex task both stressful and exhausting and even drain financial resources, especially over time.

Congressional Action

To address these complex challenges, and in response to decades of advocacy by multiple stakeholder groups, Congress passed the RAISE Family Caregivers Act of 2017 (P.L. 115-119). The RAISE Family Caregivers Act established the RAISE Family Caregiving Advisory Council and directed the development of this Strategy.

In September 2021, the RAISE Family Caregiving Advisory Council released its Initial Report to Congress. The report described the current landscape of family caregiving and proposed 26 recommendations for how the federal government, states, tribes, and communities—in partnership with the private sector—can better recognize, assist, include, support, and engage family caregivers. It was informed by over 1,600 responses to a formal Request for Information (RFI) which were analyzed by researchers at UMass Boston and Community Catalyst. The RFI analysis was made possible through funding from JAHF. The RAISE Family Caregivers Act Initial report to Congress made recommendations that were organized around five key goals:

- Improved awareness of and outreach to family caregivers
- Involvement of family caregivers in the care team
- Services and supports for family caregivers
- Financial and employment protections
- Data, research, and best practices

In a corresponding effort, in July 2018, Congress authorized the SGRG Act (P.L. 115-196). This legislation established a separate Advisory Council specifically to make recommendations and identify best practices to support a unique subset of family caregivers, many of whom are also older adults—those who have opened their homes to grandchildren or kin who are not able to remain with their parents. Sometimes these family caregiving situations are short-term; sometimes they are permanent. Often, they involve tremendous grief, loss, financial hardship, and/or trauma—and a resulting need for services and support—for both the children and adults involved.

In November 2021, the Advisory Council to Support Grandparents Raising Grandchildren released its Initial Report to Congress. The report was informed by over 300 responses to a second RFI specifically seeking input on the needs, challenges, best practices, and unaddressed gaps experienced by kinship families and grandfamilies. The SGRG Act Advisory Council developed a set of goals aligned with those of the RAISE Act Advisory Council, and these goals served as the framework for 22 recommendations set forth in its report. The report is a moving testimony to the resilience and grit of a generation of kin and grandparent caregivers who have put their physical, emotional, and financial well-being on hold to raise children within the embrace of loving homes.

A Combined Approach to Developing the National Strategy to Support Family Caregivers

As noted, as the Advisory Councils prepared their respective reports in 2021, it became clear the parallel statutory requirements between the RAISE and SGRG Acts presented an opportunity to bring together the issues of greatest concern to all family caregivers in a single, comprehensive response. Without this inclusive approach, there would remain the risk of ongoing lack of awareness of certain family caregiving issues and continued fragmentation of supports for specific populations. It also highlighted the magnitude of the issues facing so many Americans.

The development of the Strategy is an important initial step in identifying and addressing the family caregiving challenges most Americans will face in their lifetimes—whether providing care for a loved one or needing that care to remain in the community. This effort to develop a framework of systemic support for family caregivers is the first time that stakeholders representing an inclusive range of sectors and stakeholders (including family caregivers and people receiving care themselves) have collaborated with multiple agencies across the federal government to develop a shared path toward this single shared vision: **recognition and support for all family caregivers, regardless of age, background, circumstance, or location**.

Family Caregiver Needs Requiring Legislative and Other Policy Changes

The Advisory Councils anticipate that as the Strategy is implemented—and as the nation more fully comes to understand and respond to the challenges faced by family caregivers—society will embrace the cultural and policy shifts necessary to support them. As a result, over time, lawmakers likely will be called upon to propose legislative changes to better support family caregivers.

With this vision in mind, the Advisory Councils view this document as a **Call to Action** for lawmakers at the federal, state, and local levels and propose a list of recommendations for policymakers and legislators to enhance support for family caregivers in ways that are aligned with the Strategy. (See Table 1)

Table 1. Legislative and Other Policy Changes to Support Family Caregivers

Legislative or Policy Change
Increase funding for state, territorial, tribal, and local health departments to systemically embed family caregiving into public health infrastructure and planning
Provide funding for the development, implementation, and evaluation of a public health national and culturally competent awareness campaign regarding caregiving
Update language in existing federal caregiver-related legislation and authorities to ensure it reflects the current landscape of caregiving and aligns with the goals of the Strategy
Review current requirements of, and funding levels for, federal programs described in the Inventory of Federal Caregiver Support Programs & Initiatives
Encourage clinicians and providers to conduct formal assessments of family caregiving needs
Create incentives for health care systems to incorporate family caregivers into health care decision making for the person receiving care
Encourage Medicaid programs, programs offered by the VA, and Medicare Advantage programs to expand community-based long-term care options, including expanding self-directed opportunities to allow for the hiring of family caregivers, while also funding LTC services at rates that attract and retain a skilled direct care workforce[1]
Authorize specific benefit expansions in the Medicare program, including for respite, adult day services, home modifications, home delivered meals, and other long-term services and supports (LTSS) to enable individuals to safely age in place/remain in their homes
Increase funding for caregiver support services under the National Family Caregiver Support Program (NFCSP), the Lifespan Respite Program, and the Alzheimer's Disease Program Initiative (ADPI)
Create a job classification for direct care workers and standardize training and accreditation across states
Establish a federal interagency task force to develop a direct care workforce development plan
Change U.S. visa policies to allow au pairs to serve as caregivers of older adults and people of all ages with disabilities
Redesign the Medicaid eligibility process so that the care recipient does not have to deplete most of their assets to qualify for services and support
Financially support caregiving initiatives through federal funding opportunities, including expansion of Older Americans Act and Elder Justice Act funding opportunities
Pass federal paid family leave; expand the FMLA to include small employers and a broader definition of "family" to include grandparent and kin caregivers

Legislative or Policy Change
Include family caregiver out-of-pocket care expenses (products and services) as medical expenses eligible for tax credits
Introduce a range of incentives to encourage employers to adopt caregiver-friendly practices, including tax incentives
Develop tax deductions for paying for home and community-based services (HCBS), including by family members who are not claiming the care recipient as a dependent
Amend the Consolidated Omnibus Budget Reconciliation Act (COBRA) such that when wage earner(s) leave employment to care for family members, their benefits can continue at their previous level
Allow family caregivers who leave the workforce for caregiving to accrue Social Security credits to qualify for Social Security benefits
Allow kin and grandparent caregivers who have primary responsibility for a child to claim the federal Child Tax Credit
Launch a national public long-term care social insurance program that includes benefits for kin and grandparent caregivers
Extend health care coverage to children in the care of grandparents and kin who are not part of the child welfare system
Convene a task force to develop a consensus definition of family caregiver and a standardized set of survey questions that provide a minimum data set on the caregiver, person receiving care, and key characteristics of the caregiving situation

Framework for Systemic Caregiver Support

The aim of the Strategy is to advance a plan of action leading to recognizing, assisting, including, supporting, and engaging family caregivers. The Strategy includes four separate components which together provide a framework for making the respective recommendations of the Advisory Councils a reality for the nation's family caregivers.

Components of the Strategy

The Strategy includes four documents. This document provides the narrative discussion about how to drive the systemic change needed to take family caregiving from the sidelines of modern life to something that is recognized and supported as an essential contribution to society.

It describes how to achieve each of the 27 recommendations (restated as outcomes) described by the Advisory Councils in their respective reports to Congress. The narrative was developed based on transcripts and recordings of Advisory Council meetings, the reports to Congress by each council, analysis of the two formal public requests for information (RFI) about family caregiving, input from about 150 organizations through key informant interviews and listening sessions, plus other key documents developed to support the work of the Advisory Councils. Appendix B includes a list of additional sources that informed the development of the Strategy.

The narrative is organized around three components: **Goals** and **Outcomes** to support family caregivers, and **Indicators of Success**.

- **Goals**: Although the language used to describe them differs, the Advisory Councils shared five overarching goals. These goals provide the framework for the Strategy:
    - Goal 1: Increase awareness of and outreach
    - Goal 2: Advance partnership and engagement
    - Goal 3: Strengthen services and supports
    - Goal 4: Ensure financial and workplace security
    - Goal 5: Expand data, research, and evidence-based practices

  Many of the priority actions in the Strategy support multiple outcomes. Stakeholders can increase their impact by adopting actions that are identified in this document to support multiple areas.

- **Outcomes**: Based on the combined recommendations in their initial reports to Congress, the Advisory Councils developed 27 outcomes within the five goals. Within each outcome, the Strategy describes multiple priority actions.

Note: The Advisory Councils set forward a comprehensive, multi-sector approach to advocate for immediate and long-term changes that will be needed to achieve the cultural and systemic changes necessary to address the complex nature of family caregiving. In other words, the members contend that no single outcome will be sufficient by itself; however, each outcome is a driver of the momentum necessary to effect meaningful change.

- **Indicators of success**: With any large-scale undertaking to create change or improve how challenges are addressed, a set of guideposts to measure success is essential. Following the discussion of each goal and its outcomes, sample indicators of success are provided so any sector involved in implementing any of the actions can have a set of potential measures for their work.

A separate document, 2022 National Strategy to Support Family Caregivers: Federal Actions (**Federal Actions**), provides 345 federal actions submitted by federal departments and agencies as commitments to support one or more of the outcomes. This document addresses a key mandate of the RAISE Family Caregivers Act: requiring input from federal partners on agency actions that could be used to advance the development and implementation of the Strategy.

It's important to note that for the first iteration of the Strategy, the statute required that actions be within current programs.

The federal actions differ from one another significantly by agency, both in scope and detail. This reflects differing missions and authorities. Some of the federal actions are "new" activities within existing programs. Others are redesigned or reimagined from the current state. Additional actions at all levels—and collaboration across federal agencies to break down silos and leverage individual agencies' authorities and investments—will be necessary to achieve the vision described in statute and articulated by the Advisory Councils.

The wide range of federal responses in the initial Strategy also reflects the complexity of caregiver needs and myriad ways in which government programs and initiatives have sought in the past to address these issues. The Advisory Councils' intention for the future is that these responses will become increasingly aligned to form a truly holistic system of integrated services and supports.

A third document, 2022 National Strategy to Support Family Caregivers: Actions for States, Communities, and Others (**Actions for Others**), contains a list of more than 150 suggested actions that states, communities, and other stakeholders can take to advance the Strategy's goals. These practical actions, innovative ideas, and thoughtful suggestions represent the most current consensus from across multiple sectors and communities on how best to ignite widespread social change in how the nation honors and supports its family caregivers.

Finally, a fourth document, First Principles: Cross-Cutting Considerations for Family Caregiver Support, describes essential issues that must be centered in developing, delivering, and evaluating family caregiving services and supports:

1. **The need for person- and family-centered approaches**: As the U.S. builds a system of coordinated and interrelated responses to the needs of family caregivers, it is important that the family caregivers themselves—not systems or providers—remain the focal point of each encounter.

2. **Trauma and its impact**: The experience of trauma in the lives of caregivers and the people they support—including recent and decades-old traumas—has an impact on the caregiving journey in ways that must be recognized and proactively addressed.

3. **The direct care workforce**: Even though the Strategy focuses on family caregiving, the viability and well-being of the nation's professional caregivers (also known as direct care workers, direct service providers, and other similar names) has a direct influence on family caregivers, their options, and the quality of care provided to support the person receiving care. The COVID-19 pandemic has highlighted and exacerbated long-standing challenges faced by this sector. Only through the development of a robust, well-trained, and well-paid direct care workforce can we ensure family caregivers and the individuals they support have access to reliable, trusted, and affordable paid supports and assistance when and where they need it.

Family Caregiving Stakeholders: In addition to the federal government, caregiving stakeholders can include states, municipalities, payors, health care companies, faith-based communities, philanthropic organizations, public relations organizations, caregiver advocates and coalition leaders, organizations representing older adults, consumer groups, disability advocacy groups, educators, entrepreneurs, technology companies, employers, long-term care and health service providers, government (local and state) entities, policymakers, health system advocacy organizations, and academia, as well as the people supported by family caregivers.

How to Use the Strategy

The Strategy was written to address a wide range of potential stakeholders; not all outcomes will apply to all stakeholders. Each sector and stakeholder has a role to play in implementing the Strategy; the Advisory Councils recommend that each stakeholder begin by identifying and prioritizing the goals, outcomes, and actions that they can best support.

Every sector also should review the **Federal Actions** to look for ways to align their own actions with federal efforts and funding opportunities to reduce silos and redundancy. They should also review **Actions for Others** to similarly identify opportunities for collaboration at the state and local levels.

Finally, because many of the recommended actions will require cross-sector collaboration, an important step for all stakeholders will be to begin forming partnerships—within and outside their traditional networks—that can be used to achieve the goals of the Strategy.

In addition, the Advisory Councils offer the following suggestions for specific stakeholder groups:

- **Academic institutions and researchers** can consider the findings in the Advisory Councils' reports and the actions presented in the Strategy to formulate and advance agendas for research, data gathering, and analysis. They also can use this information to develop and disseminate new evidence-informed or evidenced-based interventions for family caregivers.

- **Business leaders and employers** can proactively champion recognition and support of family caregivers across a range of settings using the ideas and suggestions in this document. They may wish to identify actions that would enable them to better recognize and support their employees who are family caregivers and participate in data collection to ultimately improve workplace productivity and strengthen bottom lines.

- **Health care systems** consist of organizations and providers with a shared goal of promoting, restoring, and maintaining the health of patients. Such systems can use the suggestions that follow to identify ways that the needs of family caregivers can be incorporated into their existing workflows and processes, which were designed to solely support patients. They also can identify opportunities to include family caregivers and care recipients on decision-making boards and incorporate family caregiver awareness into training protocols and patient education materials.

- **Child welfare agencies** work in communities to strengthen families and keep children safe, however, their primary focus is often on children in formal foster care situations. The Strategy presents an opportunity to take note of and address long-standing gaps experienced by kin and grandparent caregivers outside the foster care system. These include improving recognition of kin and grandparent caregivers who are outside the formal foster care system and increasing access to services and assistance that could improve their ability to provide care to children in their homes.

- **Communities of faith and faith-based organizations (FBOs)** are trusted sources of information, support, and comfort for millions. By considering possible ways they can support the recommendations and actions in this section, FBOs can play an even more meaningful role in the spiritual and emotional well-being of the individuals within their congregations and communities.

- **Community-based providers of long-term services and supports** play a critical role in delivering essential services and supports for family caregivers. The recommendations and actions contained in this Strategy offer a roadmap for their own program development in support of family caregivers.

- **National, state, regional, and local philanthropic organizations** have an opportunity to advance recognition and support caregivers by identifying opportunities that align with their respective philanthropic goals and objectives.

- **States, tribes, and communities** have an opportunity to adopt actions and use them to strengthen recognition and programming for family caregivers and for similar state-level strategizing on behalf of caregivers.

- **Family caregivers, people receiving care, advocates, and members of the public** can use the document to work with legislators, program administrators, employers, and neighbors to adopt and administer person-centered and trauma-informed approaches that are based on caregivers' documented needs and preferences and grounded in cultural humility.

Related Resource: A Roadmap for States

After reviewing the Actions for Others document, states and state agencies should also review the extensive six-part RAISE Act State Policy Roadmap for Family Caregivers (Roadmap) developed by National Academy for State Health Policy (NASHP) under a generous three-year grant from The John A. Harford Foundation (JAHF) and RRF Foundation for Aging. The Roadmap was designed in response to the RAISE Act Advisory Council's Report to Congress. Its purpose is to assist state officials to better understand the state policy landscape for supporting family caregivers of older adults and to identify opportunities for innovation in their own states. The Roadmap contains six stand-alone sections:

- Section 1: Public awareness and outreach to family caregivers
- Section 2: Engagement of family caregivers in health care systems
- Section 3A: Increasing access to services and supports
- Section 3B: Strengthening the direct care workforce
- Section 4: Protecting and enhancing family caregivers' financial and employment security
- Section 5: Increasing data, research, and evidence-based practices to support caregivers

Disclaimer and Limitations

The development and release of the Strategy is a requirement of the RAISE Family Caregivers Act. It is not a budget document and does not imply approval for any specific action under Executive Order 12866, the Paperwork Reduction Act, or any other statute. The federal actions presented in the Strategy are subject to budgetary constraints and other approvals, including the weighing of priorities and available resources by the administration in formulating its annual budget and by Congress in legislating appropriations.

The Advisory Councils believe the Strategy presents a vision for meaningful change. While the Advisory Councils believe the recommendations for the federal government, states, communities, and other stakeholders are ones that have the strongest potential to positively impact the pressing public health issue of caregiver support and recognition and are necessary, the Advisory Councils do not have authority to require adoption by any agencies or entities.

The RAISE Family Caregivers Act calls for periodic updates to the Strategy. Comments on the Strategy are welcome and will play an important role in the first update. The Strategy will be formally open for comment for 60 days shortly after its release, and there will be additional opportunities for public input as the next iteration is developed.

Goal 1: Increase awareness of and outreach to family caregivers

Caregiving is a public health issue that receives inadequate recognition, and family caregivers are often the hidden heroes of the health care, long-term supports and services, and the child welfare systems. Improving support for family caregivers requires increased awareness of the roles they play and the challenges they face. In addition, there are many people providing support to loved ones who do not think of themselves as "caregivers;" they need to be empowered to identify the crucial role they play so that they can receive available training and assistance if they need it. Reaching these populations, those who have typically not had access to services, will require focused efforts to overcome mistrust of institutions, systems, and governments and use of culturally competent approaches. The Advisory Councils recognize that these efforts must be iterative. However, in coordination with the achievement of other goals, they will pave the way for greater recognition and support of family caregivers and better participation by caregivers in existing systems.

In any approach designed to increase awareness of family caregiving, communications channels and methods must reflect the communities for which the message is intended. Such outreach efforts should be coordinated across the public and private sectors with consistent overall themes, but the actual messages must be customized to meet the needs of local communities. It is also important to ensure that all language, pictures, graphics, videos, and other communications included in outreach materials promote a sense of safety, trust, and empowerment and can be understood by a wide variety of audiences. They should be created in partnership with their target audiences and take into consideration the language preferences, cultural values, historical circumstances, and types of family caregiving typical in each community. Because not all caregivers have access to the Internet, dissemination methods should be broad (e.g., electronic/web-based, in-person, print, podcasts, etc.).

Outcome 1.1: Americans are educated about and understand the experience of family caregiving.

From our Listening Sessions

> ***"Now is the time to address this issue. Caregivers are a national gem or a resource. Without them, it would cost us, I don't know how many billions more dollars than it is costing us right now … You're going to be in real trouble America, if we don't do something sooner … at the top of my list is to have some campaign so that we could turn on every TV station, open up Facebook, Twitter and just this would be an omnipresent message that we have to do something now."***

The Any Care Counts campaign is a caregiver identification campaign to recognize and support unpaid caregivers in Massachusetts by connecting them to available support resources in the state. It also includes free access to a culturally competent caregiving intensity index developed by ARCHANGELS.

Despite its many benefits to individuals and society, widespread public understanding of the breadth, depth, and complexity of family caregiving across the care continuum remains inadequate. Too often, caregivers report only learning exactly how complex it is after finding themselves unexpectedly plunged into the role. Even medical, educational, legal, financial, and social services professionals sometimes fail to fully comprehend the many needs, issues, and challenges faced by family caregivers. Such limited awareness is a partial contributor to many of the challenges faced by family caregivers, such as being excluded from care settings and health records, limited training and support, inadequate research, and inconsistent definitions and data.

Awareness Campaign

The priority action under Outcome 1.1 is a national, multi-pronged information campaign designed to bring family caregiving out of the shadows and make it a dinner table conversation in every home across the nation and respected at all points of service. **It should also serve as a reminder that each of us will likely experience being a family caregiver, needing a family caregiver, or both at some point, and the best way to prepare for that eventuality is through planning now**.

Because every family and community is unique, the campaign should offer a playbook with customizable, plain language messaging that can be adapted for specific segments of the population and reproduced in a range of accessible formats. Such a tool will include culturally competent messages that recognize that not all terms and recommendations resonate with different populations. All public campaigns should aim to increase family caregiver self-identification by highlighting all caregivers and caregiving situations. They should also emphasize that while family caregiving can be emotionally rewarding, it often comes at an emotional, physical, and financial cost to the caregiver.

Ideally, the campaign should be led at the national level through a public-private partnership in coordination with the federal government. This approach will ensure unified messaging, consistent data and evaluation, and uniform definitions of caregiving. It also will allow for integration of lessons learned and data from previous successful national education and awareness campaigns.

Civic organizations and businesses can help to advance the awareness campaign and boost general awareness of family caregivers by incorporating its messaging about the role and value of family caregivers into existing materials, work products, and business practices. For example, community organizations can blend messaging from the campaign with local data about caregiving needs to develop a mini campaign to recruit and mobilize volunteers to assist family caregivers in the community and promote local caregiver support resources. They also can conduct needs assessments as a first step in developing future tools and resources for local family caregivers. Philanthropic and faith-based organizations can adapt the campaign to create family caregiver support activities that reflect the preferences and values of their respective communities. Meanwhile, schools can ensure language on intake forms, websites, and other materials ensure kin and grandparent caregivers are represented in the language and imagery. This will help to raise awareness of the fact that many children today live with kin and grandparent caregivers. Finally, businesses that are open to the public, like coffee shops, restaurants, and retail stores, can incorporate caregiver awareness messaging into their own advertising, signage, store promotions, and staff trainings. This will ensure frontline staff, managers, and even other customers can recognize and respond appropriately to family caregivers they encounter in the course of a day. (Also supports **Outcome 3.5**) An additional benefit of raising awareness of caregiving in professional settings is that it also has the potential over time to increase awareness among employers of the needs of their staff who are also caregivers. These can include flexible work hours, time off on short notice, and paid leave for caregiving. (Also supports **Outcome 4.2**)

The campaign should be grounded in national, state, and local data about caregiving based on research and data collection activities described in **Outcome 5.1**. It should be timed to capitalize on existing caregiving-related observances such as National Family Caregivers Month or National Kinship Care Awareness Month.

Family Caregiving Information Platform

The awareness-raising campaign should include a central communications platform, ideally hosted by or in collaboration with the federal government. This platform would provide public and private entities a curated array of consistent family caregiving resources, data, quality indicators, caregiver identification tools, model policies, training materials, technical assistance, learning collaboratives, and a mechanism for finding available services and supports in the local community. Family caregivers themselves should also have access to this platform so that they can use it to share experiences and insights with one another. The existence of a centralized family caregiving information platform will ensure that users receive cohesive definitions, messaging, and resources in a single location. Meanwhile, campaign supporters and state governments would also have access to toolkits, talking points, and templates that could be adapted for local populations. National, state, regional, and local philanthropic organizations may wish to consider funding collaboratives to develop toolkits, templates, and related training materials that can be featured on the platform to support enhanced outreach and awareness. (Also supports **Outcomes 1.5**, **3.1**, **4.1**, **5.1**, and **5.3**)

As part of their participation in the national campaign, states may wish to conduct environmental scans to better understand the programmatic landscape for family caregivers at the state and local levels. Using the results from state programs and initiatives to support caregivers, states and their respective managed care plans may wish to create or enhance resource guides for health care systems, social service providers, and other stakeholders.

Outreach to Hard-to-Reach Populations

In addition to a general awareness-raising campaign, targeted outreach should focus on populations facing additional barriers that increase the challenges associated with family caregiving. These include kin and grandparent caregivers raising children impacted by trauma, family caregivers impacted by mental illness and/or substance use disorders, caregivers with disabilities, and caregiving youth. Targeted outreach should include federal outreach to states and grantees about available programs and initiatives to support caregivers along with outreach by states, communities, and professional associations, customized messages to the needs and preferences of the populations reached by each. States can also support the capacity of community-based organizations to conduct outreach and to help family caregivers to navigate the service delivery system.

Outreach to Professionals

A parallel campaign also should be initiated at the national level to educate professionals across a wide range of sectors who interface with family caregivers in the course of their work to improve their ability to identify and support family caregivers. These include, but are not limited to, medical, education, finance, and social services professionals. The campaign for professionals should also have a playbook that contains messages and content that can be adapted for specific audiences. This would allow for focused, but equally aligned, sub-campaigns that could educate a host of professionals often overlooked in education efforts that focus on family caregiver support. These can include retail workers, hospitality professionals, legal professionals, and public safety officers. Finally, community-based organizations should consider targeted information campaigns, using local data, to educate their elected officials and policymakers about issues related to caregiving. (Also supports **Outcome 1.5**)

Both the public and the professional campaigns should provide non-copyrighted images, graphics with imagery that reflects all family caregivers, and text that can be quickly adapted by other stakeholders. These materials should represent family caregiving as a broad experience that can affect anyone at any stage of life. It is critical to ensure that materials are accessible to and include and reference—through both language and images—all populations of caregivers. Finally, because family caregiving is constantly evolving, all outreach should be regularly reviewed and updated to ensure messaging is current, appropriate, relevant, and reflective of available supports in the state and/or community. As part of this, it is important to remember that ensuring language access goes beyond word-for-word translation into other languages; the message itself should be vetted to ensure that it resonates with the intended audience. (Also supports **Outcome 1.3**)

This case study includes lessons learned and details from the national campaign to promote CMS's **Medicare & You** and the development and launch of Medicare.gov in 1998. The outreach plan also included campaigns adapted to the needs of local populations.

More Than Words

All sectors can explore other approaches for raising awareness of family caregiving. One example is to adopt the inclusive and broad definition of "family, kin, and grandparent caregiver," as statutes and regulations permit, and to participate in, or initiate, observances related to family caregiving.

To further integrate the experience of family caregiving into all aspects of day-to-day life, local government entities and providers of supportive services for family caregivers, such as respite care, can partner with local media (TV, radio, print) to increase the prevalence of stories about caregiver experiences and to highlight available programs and services. (Also supports **Outcomes 1.3** and **3.1**) Greeting card companies, realtor associations, restaurants, and others could incorporate appropriate and evidence-based caregiver support in their products and services and employee training. (Also supports **Outcome 5.3**)

Retailers can offer caregiver discounts for select goods and services that can make family caregiving easier, or explore other ways to offset the expenses associated with family caregiving. (Also supports **Outcome 4.1**) Libraries can curate a "family caregiver corner" with books, films, resources, and other information specifically for or about family caregivers. Libraries also can devote time and space to offer family caregivers the opportunity to learn how to do online searches for information, training, and other resources to support their responsibilities. Communities of faith can create or expand "family ministries" to include family caregiving as a special focus. They also can hold special "caregiver outreach and recognition days" for their congregants at which local service providers can provide information about available services and supports. Schools can use "backpack campaigns" to include information about available services and supports for caregiving youth and/or for grandparent and kinship caregivers.

Area agencies on aging, state DD Councils, and other organizations in the aging and disability networks can ensure that staff are aware of available family, kinship, and grandparent caregiver support programs and services and trained in the importance of proactive caregiver identification and referral.

Aligned Actions

Federal agencies have committed to **51 specific actions** within the coming years in support of **Outcome 1.1**. See “**Actions for Others**” for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 1.

Outcome 1.2: Caregiver self-identification and knowledge of services is enhanced.

From our Listening Sessions

> ***“ … I keep using the analogy, until the word ‘caregiver’ resonates like the word ‘parent’, it’s really hard to enforce things because not everybody’s talking about the same thing...Until there’s that knowledge base about what these caregivers are and the support they need, I don’t think the sticks and carrots really matter … ”***

Many family caregivers assist others for years without realizing that their efforts extend beyond typical relationship expectations. By the time they realize that they are caregivers, they have often missed critical opportunities to learn family caregiving skills that could enable them to provide care while maintaining their own health and well-being. To address low rates of family caregiver self-identification, and in turn increase access to beneficial services, the Advisory Councils, using input from the key informant interviews, stakeholder listening sessions, and two formal requests for public input, identified three priority actions for boosting caregiver self-identification and knowledge of services.

Help Family Caregivers Self-Identify

The first priority action is to develop simple family caregiver self-identification tools that can be widely adopted. This could be a consistent question embedded in existing workflow, such as “do you help someone with shopping or daily activities?” Health care systems, social services agencies, schools, employers, and others should investigate and identify ways such tools can be incorporated into current processes to increase timely identification of family caregivers. For maximum impact, these tools should be promoted and used across all programs, regardless of funding source, and made available in conjunction with a multi-model public awareness campaign. (Also supports **Outcome 1.1**) To further boost caregiver self-identification, the broadest possible definitions of “family” should be used to include friends, neighbors, and others. This will ensure self-identification tools and related promotional materials are inclusive of families across a wide range of circumstances and communities.

Accessing Services

As people become aware of their role as family caregivers, it is critical that they learn about services and supports available to them within a short period of time. These self-identification tools should also include information on how/where to access services and supports in a particular state or community. Messaging conducted as part of other outreach campaigns about available services and supports should speak to this growing awareness and understanding of the importance of proactive and early requests for help. Hospitals/health care providers can conduct outreach to their patients' families to help them self-identify as family caregivers as part of their discharge planning, and in tandem with the CARE Act. (Also supports **Outcome 2.4**) Kinship care programs can periodically review their outreach and awareness programs to identify opportunities for improvement in helping new kin and grandparent caregivers self-identify as such. (Also supports **Outcome 3.10**) States can also look for opportunities to support community- and faith-based organizations in their efforts to boost self-identification in communities that typically do not recognize their efforts as part of family caregiving and, as a result, do not typically receive supportive services.

Partnering with Providers and Industry

Service providers have an important role in developing content, materials, and services specifically for a population of newly identified family caregivers. Professionals who engage with family caregivers must receive continuing education about available services and supports. They also must be prepared to respond to family caregivers with referrals to service providers that have the skills and knowledge to address their particular needs. This will require investments in combining information about family caregivers with existing continuing education, professional reading, conference materials, and certification/licensing requirements across a range of professions (e.g., medicine, law, education, social services, public services, and the hospitality industry).

The family caregiver stakeholders interviewed by UMass Boston and Community Catalyst agreed that the platform described in **Outcome 1.1** could offer information to the public and serve as a vehicle for educating professionals on caregiver identification and the family caregiving experience. Ideally it would feature training modules for employers and health care providers and other professionals who interact with family caregivers. These trainings would provide guidance and best practices on how they can support family caregivers in their respective environments. They could also include testimonials and stories to help professionals empathize with the experience of family caregiving. Such an initiative is more likely to be successful with widespread buy-in and engagement of partners across sectors of the U.S. economy.

Aligned Actions

Federal agencies have committed to **23 specific actions** within the coming years in support of **Outcome 1.2**. See “**Actions for Others**” for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 1.

Outcome 1.3: Outreach to family caregivers is improved.

From our Listening Sessions

> ***“I think one of the things that needs to happen is redefining and being more holistic about what we mean by ‘outreach’.”***

Family caregivers responding to the two public requests for information and the participants in the stakeholder listening sessions repeatedly described the above-noted challenges in finding family caregiving assistance. Many reported they learned too late about services—such as respite care—that could have helped them. Some caregivers were unaware of services because they have difficulty finding non-English language materials.

At present, while some supportive services for family caregivers are available, many caregivers are not aware of them—especially individuals who are new to the family caregiving role. By the time they come to learn about these services, they often find that they cannot access them for a host of logistical reasons (e.g., cost, scheduling, distance from home/work, lack of availability of child care or respite services, or they are not culturally competent). (The centralized family caregiving platform described under **Outcome 1.1** can also help to address this issue.)

Kinship navigators provide kin and grandparent caregivers in many states with a menu of trusted options and support and help to prevent unnecessary entries into foster care. They provide a model that should be translated across a range of sectors to increase effective outreach to caregivers in other caregiving situations.

A Needed Shift

For supports to become more widely reachable across the population, the nation must accept and acknowledge family caregiving as a universal experience. Only then will family caregivers themselves feel comfortable asking for and accepting assistance and accommodations for family caregiving. Professionals with whom they interact might also be better prepared to respond in a way that is meaningful. To provide the much-needed “course correction” for the many family caregivers who remain unreached by current outreach efforts, the Advisory Councils, using input from the key informant interviews and stakeholder listening sessions and the results of the RFIs, identified three linked actions, the outcomes of which will collectively increase outreach to populations of family caregivers that often are missed in current outreach efforts.

Researchers, health care and social services systems, and federal and state agencies can use a series of coordinated national and local information-gathering efforts to better understand and document the needs of specific populations and how best to reach them. (Also supports **Outcome 5.1**) The results of these efforts can then inform the development of outreach campaigns by different sectors that could dramatically increase awareness of family caregiving—especially in communities that typically do not receive caregiver support services.

Stakeholders across all sectors may wish to recruit and/or partner with trusted members of various communities to create a communication path between family caregiving communities and service providers. Examples include community health workers, peer health educators, *promotoras*, community resource coordinators, faith leaders, advocates, and trusted service providers such as barbers/hairdressers, teachers, cab drivers, librarians, and pharmacists. States, philanthropic organizations, and other funders can support these efforts by funding community-based organizations to conduct outreach and help family caregivers navigate service delivery systems. Primary care physicians, pediatricians, gerontologists, and similar medical providers can further support this by partnering with community-based organizations and FBOs to offer wrap-around caregiver support to their patients. Health care systems that are already offering navigation services related to family caregiving support during discharge planning may wish to share best case practices.

As more people begin to recognize themselves as caregivers, all sectors should take steps to ensure caregivers know (before they are in crisis mode) about—and have access to—person- and family-centered, and trauma-informed programs and services that are designed to meet the needs of the local community. (Also supports **Outcome 3.1**)

Aligned Actions

Federal agencies have committed to **10 specific actions** within the coming years in support of **Outcome 1.3**. See “**Actions for Others**” for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 1.

Outcome 1.4: Family caregiving—and caregivers—are embedded in federal, state, territorial, tribal, and local planning.

From our Listening Sessions

"I would love to see something that links people in a system and then can take them to their local communities … If we can connect people to services … It'd be nice to have a national [website] that was not for profit, and then got people to the right place."

While family caregivers and the people they support are sometimes included in the planning and policy development processes undertaken by federal, state, territorial, tribal, and local governments and other planning entities, this is not yet consistent across the nation. As a result, their needs are not fully understood or addressed. Sometimes, efforts to support family caregivers focus only on the caregiver and do not consider the needs of the person receiving care. Some efforts consider only specific family caregiving situations, such as supporting older adults, and the needs of other caregivers are left out. To truly change systems in a way that ensures families are supported across the lifespan and across family caregiving situations, caregiver voices and perspectives must be an integral part of planning efforts at all levels of society and government.

Reaching All Communities

Some populations of caregivers have traditionally been underrepresented in efforts to support caregivers, including caregivers of color and family members of people with I/DD. State and local governments, as well as providers of services, should ensure that everyone can access caregiver support. Such an approach will allow for more perspectives and input in any proposed change to ensure the needs of all family caregivers—including those who support people with disabilities—are included. Ways to do this include:

- Developing a language and communication access policy and plan,
- Adopting an ambassador program to create conduits between decision-making councils and communities, and
- Increasing representation of people with family caregiving experience on decision-making bodies.

Charting the LifeCourse, developed by Missouri Family to Family, provides guidance on delivering services for people with I/DD in ways that respect their cultural and personal preferences and needs.

California's Master Plan for Aging was developed through a range of stakeholder engagement initiatives including surveys, community events, webinars, legislative roundtables, and the creation of three advisory bodies comprised of subject matter experts, providers, and the public.

Those states that do not yet have in place a deliberative body specifically charged with considering the needs of caregivers, may want to consider establishing one (with caregiver representation, of course) to ensure that caregivers have a voice in planning and policymaking regarding services and supports. To increase contacts with groups that do not typically receive caregiver services, state and local entities are encouraged to ensure that planning efforts specifically include actions that support people who experience multiple forms of discrimination and who may face additional barriers because of disability status, race, ethnicity, sex, sexual orientation, and national origin (including limited English proficiency).

To reduce redundancy, state and local caregiver-related planning initiatives should be aligned with the Strategy. That means using consistent definitions of caregivers as described under **Outcome 5.1**, adopting the broadest possible definition of "family caregiving" across all external messaging (e.g., related to education, health, social services, child welfare, legal, financial), and developing state and community playbooks that support the Strategy.

Aligned Actions

Federal agencies have committed to **13 specific actions** within the coming years in support of **Outcome 1.4**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 1.

Outcome 1.5: Public-private partnerships at all levels help drive family caregiver recognition and support.

From our Listening Sessions

> ***"We have ambassadors, we have champions, but when you talk about the systems that those individuals have to then go and … liaison between, that doesn't carry a lot of weigh… these need to be empowered paid administrators, managers, directors, within these communities that hopefully come from these communities so that they know what's available."***

Achieving national cultural change requires more than just the efforts of the federal government. To create a system that supports families, multiple sectors—both public and private—must work together. No single sector can do it alone. The RAISE Family Caregivers Act identified multiple areas of focus for the Strategy that would benefit from partnerships between public and private stakeholders. Benefits of such collaborations can include development of key products that would be difficult to capture otherwise (e.g., some kinds of research data); engagement of entities not traditionally focused on family caregiving (e.g., large employers), and an increase in awareness, protection from discrimination, and understanding of the issues facing family caregivers and the benefits for those who support them.

Wherever possible, opportunities to leverage the combined wisdom, talent, and resources of the public and private sectors should be explored. The family caregiving information platform described in **Outcome 1.1** is just one of many components of the Strategy that would benefit from broad public-private collaboration. While providing public resources, data, and information developed by federal, state, and other sources, the platform could also include training modules for a range of audiences about how to support family caregivers. These materials ideally would be developed in the private sector, with input from across various sources, to maximize the ability to align innovative training techniques with the goals of the Strategy. To increase alignment, federal agencies participating in such an effort can disseminate information and lessons learned back to the Advisory Councils for integration in future iterations of the Strategy.

State Planning

When state agencies develop federally mandated state plans (e.g., Medicaid state plans, state plans on aging, disability service plans, and state assistive technology plans), particularly those that address the needs of caregivers, public-private partnerships, particularly those that include employers and health care providers should be included into the planning process. In support of this, state units on aging, state councils on developmental disabilities, centers for independent living, and other community-based organizations can establish collaborations with major employers and state, regional, and local philanthropic organizations to create family caregiver coalitions with dedicated funding and projects in place to support family caregivers. (See Goal 4)

Aligned Actions

Federal agencies have committed to **17 specific actions** within the coming years in support of **Outcome 1.5**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 1.

The Massachusetts Caregiving Initiative is a public/private partnership to drive innovation in caregiver support. Its coalition of more than 30 member organizations has launched a wide range of data-driven tools and resources to benefit caregivers in the state since 2019.

Indicators of Success: Outreach and Awareness

As the actions under Goal 1 are implemented and each of the outcomes is attained, family caregivers will experience greater recognition as the following social changes take place:

- Society increasingly recognizes, appreciates, acknowledges, and celebrates the contributions that family caregivers make to the lives of others.

- When caregivers seek assistance, they have trusted and easily accessible sources of reliable, appropriate, and actionable information regarding available services and supports.
- More people understand and appreciate the challenges caregivers face.
- Caregiver identification (including self-identification) increases.
- Family caregivers feel more comfortable seeking assistance.
- Family caregivers participate actively in federal, state, territorial, and tribal planning.
- Family caregivers are recognized as subject matter experts on caregiving and sought out for input and guidance by decision-making authorities.
- Employers recognize the roles, responsibilities, and needs of employees who are caregivers and offer flexible policies (telework, flex time, paid leave) so that they can conduct caregiving responsibilities under unexpected or emergent situations without risk of losing employment.
- Family caregivers in communities that have not typically received caregiver support services have increased access to services because of improved outreach from those services.
- Professionals across a wide range of fields routinely recognize family caregivers when they meet them and are prepared to refer them to services and supports that are designed to meet their needs.
- Greater awareness of family caregiving and expanded outreach and education leads to measurable increases in caregivers' physical, emotional, and financial well-being.
- Accurate representations of family caregivers and the people they assist are increasingly reflected in media, advertising, and the arts.

Goal 2: Advance partnerships and engagement with family caregivers

Family caregivers are called upon to play an integral role in the support, care, and well-being of others. Yet, the systems with which they are regularly required to engage (e.g., health care, long-term services and supports, education, child welfare, legal systems, etc.) are often burdensome, complicated, time-consuming, minimally responsive, and confusing. They often do not value the crucial nature of the role caregivers play, do not recognize their experiences or expertise, and do not consider their time or needs. This was seen regularly during the COVID-19 pandemic, when family caregivers who were essential to the care of hospitalized patients were excluded from medical facilities because they were regarded as guests.

A holistic, person- and family-centered caregiver support system is one that—with the consent of the person receiving—carefully integrates the family caregiver into care processes within existing systems. At a minimum, they must be included in the aspects of decision-making and planning that affect them. The Advisory Councils developed five outcomes related to ensuring family caregivers are involved in the service systems with which their care recipients most often interact: health care, education, and social services. These outcomes reflect a future where approaches to care are no longer developed with the assumption that family caregivers will take on challenging tasks and roles without their consent or full understanding. Over time, and in coordination with the achievement of other goals, they will pave the way for partnerships and engagement of family caregivers that enable them to provide better care for as long as possible, to share information about the individuals receiving their care, and to receive appropriate services and supports to meet their own needs.

Outcome 2.1: Family caregivers are recognized as essential partners in the care teams of the person(s) to whom they are providing support.

From our Listening Sessions

"… Caregivers should be as much a part of the health care team as physicians, nurses, etc."

Multiple respondents to the family caregiving RFI noted that when a care recipient designates a family caregiver, that caregiver often goes on to play a key role in ensuring the medical, social services, and personal needs of the individual are met. One respondent referred to them as the "glue" that keeps the system together. For that reason, it is crucial that their role be recognized in health care and educational settings, particularly when care and/or educational plans are being developed for the individuals receiving support and those plans include tasks and responsibilities to be carried out by the caregiver. Too often, care plans are developed for individuals that require caregivers to perform certain tasks, such as medical tasks, personal care tasks, or transportation, without input from the caregiver.

Including family caregivers in the development of care plans and providing them access to information, with the approval of the person receiving support, has the potential to improve outcomes. An informed caregiver, particularly one trained in how best to support the needs and preferences of the individual, is better able to communicate changing needs to providers, manage medication, and assess health care options, such as whether to visit a hospital emergency room or an urgent care center during an acute incident—or to support the person for whom they care in doing so.

In the educational realm, kin and grandparent caregivers are often responsible for ensuring that a child completes their homework or attends health-related (including mental health) appointments. To recalibrate systems to facilitate caregiver success and better outcomes for the individuals receiving their care, the Advisory Councils identified two key approaches that should be undertaken in coordination with the federal government.

The priority action is to establish a consensus group made up of public and private health care, education, and social services leaders, family caregivers, people receiving care, and other related parties to develop strategies for systematically incorporating family caregivers into health care, social service, and academic systems. This should specifically include addressing barriers to caregivers being a part of "the care team," such as lack of recognition of caregiver roles, access challenges (broadband, transportation, etc.), and health reimbursement models that effectively create disincentives for medical providers to collaborate and engage with a patient's family caregiver. It should also consider legal barriers and issues and ensure that family caregivers support, but do not displace, the role of the person receiving support in decision making. A priority of such a group should include encouraging health care payers and others to create or leverage financial incentives, such as billing codes and approvals for who can be added to a health plan to enable payers, clinicians, and social services providers (including home health agencies) to partner with family caregivers in ways that continue to center the needs of the person receiving support, while also ensuring caregivers have a voice in decisions that will affect them.

A second priority action is to develop the infrastructure (and appropriate funding sources) necessary for researchers; national, state, regional, and local philanthropic organizations; health care systems; and others to measure and disseminate the quantitative and qualitative contributions that family caregivers make in supporting the health and well-being of people of all ages across a wide range of circumstances. A priority of such research should be more tools for culturally competent caregiver identification. (See **Outcome 5.1** for discussion)

To assist with integrating caregivers in medical settings, the Ontario Caregiver Organization created caregiver ID badges to visually recognize family caregivers in health care settings. They also created a toolkit to help systems integrate the badges into existing health care protocols.

Finally, while two separate outcomes under Goal 1 (**Outcomes 1.1** and **1.2**) describe the need for increased family caregiver identification across populations, there are also specific situations within existing systems where it is necessary for professionals to quickly identify a caregiver for efficient delivery of services. Examples include when first responders arrive on the scene of an accident, during triage in emergency departments, or when an adult who is not the parent brings a child to school. The need for such tools presents an opportunity for both public and private entities to fund and support the research and development of a range of evidence-based tools and technologies for effective, proactive caregiver identification and the integration of caregiver information into medical and school records, when appropriate. (Also supports **Outcome 5.3**)

As such tools become available, organizations can review existing practices, workflows, procedures, and industry standards to integrate them into existing workflows. This can mean adapting intake or screening protocols, surveying patient or client populations to identify existing family caregivers, and adapting messaging to ensure that caregivers are accurately reflected in those materials. (Also supports **Outcomes 1.1** and **1.3**)

To support such broad cultural change in existing systems, a range of educational materials, job aids, trainings, and new workflow documentation will be needed across health care, education, social services, emergency, and even financial sectors. Professional accreditation agencies can amplify such efforts by requiring implementation of tools to identify and support family caregivers as part of professional certification and accreditation.

Aligned Actions

Federal agencies have committed to **13 specific actions** within the coming years in support of **Outcome 2.1**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 2.

Outcome 2.2: Where appropriate, identifying services and supports needs for caregivers consistently starts with a review of family caregiver strengths and preferences using evidence-based assessments.

Many family caregivers find they are faced with a new reality for which they have no prior experience, nor do they know what reasonable expectations are to have of health care and other service providers. Accurately assessing the needs of family caregivers with evidence-based tools and protocols is critical to providing services that make a difference for the caregiver and empowers them to better meet the needs and preferences of the person they are supporting. In addition, the findings of assessments can also identify opportunities to address social determinants of health (SDOH). (See **Outcome 3.4** for further discussion of SDOH)

From our Listening Sessions

"With assessment tools, then they have to be free or very low cost … we've had a hard time accessing certain scales and then to get them in the languages that we need. So sometimes they're translated and of course, we would want to use the validated, translated version."

As the RAISE Act Initial Report to Congress made clear, talking with family caregivers in addition to the person they are supporting enables clinicians and providers to better understand each person's unique strengths, needs, preferences, and challenges. Such understanding can facilitate the development of a family-centered plan of care that addresses the needs of both members of the caregiving dyad.[2] This, in turn, has the potential to help family caregivers provide support for as long as possible.

The federal government, states, health care systems, and community-based organizations should make culturally competent caregiver assessments a standard part of care delivery, where appropriate. That means they would be included in quality measures, and providers would be compensated for time spent conducting an assessment. The assessments should be based on reliable and evidence-informed approaches. The outcomes of these assessments inform the development of a flexible, family-centered plan of care. It is critical to note that there exists a distinction below the assessment process, which uses structured, validated tools for determining a caregiver's strengths, ability, and needs, and person-centered planning, which is an inductive process that identifies issues important and unique to a given caregiver and weaves those findings into a support plan.

Researchers and academic institutions can support the adoption and use of caregiver assessments. There are several ways to do this, including by investing in efforts to better understand and assess specific instruments and mechanisms, translating instruments for cultural competency, training people to use and interpret the instruments, and integrating them into existing processes within health care and long-term services and supports systems. Integrating into existing processes will be key to avoid "additional burden" concern from health care systems.

For more on person-centered planning, see:

Five Competency Domains for Staff Who Facilitate Person-Centered Planning

Person-Centered Practices Self-Assessment for Governmental Agencies that Oversee Human Services

Policy makers, health care systems, and providers may need to be prepared for initial resistance to the widespread use of caregiver assessments. Many caregivers, in particular, kin and grandparent caregivers, have negative previous experiences with assessment tools being used in non-supportive ways. It is critically important that the assessment process—and the language used in describing it—not be perceived as punitive for grandparents and other caregivers, and instead, result in meaningful actions. (Some kin and grandparent caregivers are concerned that assessments will be used in a way that would lead to the inappropriate removal of children from their homes or a decision not to place the children with them, rather than focusing on what supports could be put in place to support them caring for the children.) Advocacy groups and health care associations may want to develop a communications campaign to raise awareness of how assessments can benefit caregivers. States and communities can play an important role by reviewing existing state grandparent assessments and the procedures around them for cultural sensitivity. Ensuring a common terminology across populations about the role and intended purpose of caregiver assessments will further integrate them in the delivery of services and supports.

Once culturally competent assessments are developed and tested, health care and social services systems must implement evidence-based practices for caregiver support at all points of health care delivery. That can include broad adoption of assessments as well as pilot projects in a variety of settings to identify caregivers in need of services and supports.

After assessments are integrated into the care experience, the outcomes must be available to providers of services so that they can adapt their efforts to encompass the needs of the caregiver. As evidence-based and -informed assessment tools become more available, health care, education, and social services systems must ensure that staff have the skills to use them (and operationalize the results) in ways that are culturally competent, trauma-informed, and person- and family-centered. To facilitate these shifts, health care and LTSS systems should consider hiring and/or training dedicated staff, ideally with lived experience, to increase caregiver engagement.

Caregiver assessments can do more than just identify the needs of the family caregiver. When aggregated and analyzed across all domains, the data from family caregiver assessments can be valuable tools for administrators and policymakers to develop new programs and services or form new partnerships for service delivery based on what family caregivers say they need, resulting in a more efficient and effective system of supports. (Also supports **Outcome 5.3**)

Aligned Actions

Federal agencies have committed to **9 specific actions** within the coming years in support of **Outcome 2.2**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 2.

Outcome 2.3: Where appropriate, family caregivers are included and considered in the development of care recipients' plans of care across a range of settings and circumstances.

From our Listening Sessions

> ***"I understand people definitely can't go back to medical school, but starting early, starting in the school system, starting in the medical schools, in the curriculum, making sure that caregiver knowledge and understanding is taught from the beginning."***

Family caregivers often are the de facto coordinators who help navigate systems of providers, services, and other supports. They make appointments, provide transportation, take notes, fill prescriptions, use electronic health records and patient portals, and carry out care plans. Yet, they are often excluded from routine health care encounters. Notably, **they may not even be included** in care transitions processes as patients move across settings such as hospitals, skilled nursing/rehabilitation facilities, and other types of long-term care settings. Involving family caregivers in care transitions and discharge planning activities to improve care coordination is the most basic level of engagement that family caregivers should expect.

It is important to note, however, that inherent in any discussion about providing access to health care information are legal implications relating to preserving the autonomy and self-determination of the person receiving support. Not all people who provide support are designated or equipped to make decisions on behalf of another person, nor should they have unfettered access to information such as health records and patient portals. All decisions about access to information should be made by the person receiving support.

The Sonoran Center for Excellence in Disabilities, funded by ACL, offers a 20-question caregiver assessment tool for caregivers of individuals with I/DD. The tool is specifically designed to support person-centered planning.

United Hospital Fund developed a toolkit for the implementation of New York's CARE Act. It contains a guide for a hospital discharge process that includes the family caregiver in a way that is designed to ensure the best outcomes for the patient while also respecting the preferences of the caregiver.

Improvements to care coordination can be achieved by ensuring that, when appropriate and supported by the care recipient, caregivers have a voice in all transition planning, regardless of the setting. Forty-four states have adopted the Caregiver Advise, Record, and Enable (CARE) Act, which seeks to address this challenge by requiring hospitals to do the following:

- Record the name of the family caregiver on the medical record,
- Inform the caregiver when the person they support is to be discharged, and
- Provide the family caregiver with education and instruction about the medical tasks they are expected to perform.

These requirements are the first step to ensuring caregivers can be a part of care transitions. Where possible and appropriate, states may want to explore options for incentivizing CARE Act implementation or allowing for enforcement of its provisions. States have an opportunity to explore options for more consistent and robust implementation of all provisions of the CARE Act, up to and including provisions for enforcement and monitoring by relevant regulatory agencies.

In addition to these considerations, health care and social service systems should routinely scan their policies and practices for unnecessary or outdated policies to make sure the needs of caregivers are reflected in those policies. Ideally, a caregiver should be identified prior to discharge and the results of the family caregiver assessment should be integrated into the discharge planning instructions, including referrals to supportive services, if appropriate. (Also supports **Outcome 2.2**) State and community agencies can support this effort by partnering with health care systems to develop and offer caregiver support services that address the specific challenges associated with hospital discharge and similar transitions.

Supported decision making (SDM) is one alternative to guardianship that ensures people with disabilities retain their decision-making capacity. With SDM, individuals retain their right to make decisions for themselves with the support of trusted friends and/or family members they choose. For more information, visit ACL's Supported Decision Making Program webpage.

Lessons learned from integrating family caregivers into settings transitions have the potential to benefit family caregivers in other settings. (Also supports **Outcome 5.3**)

There are multiple health care-centric care-coordination models proven to support people and their caregivers during transitions. For example, research has shown that coordinating care transitions is especially important for family caregivers of someone with dementia, especially where a change of location can result in more demands on the caregiver due to agitation, disorientation, or decompensating of the person receiving support. Other sectors can look to such models to translate caregiver-focused transitional programs to other settings, such as supportive services to people with long-term care needs and their family caregivers.

Aligned Actions

Federal agencies have committed to **9 specific actions** within the coming years in support of **Outcome 2.3**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 2.

Outcome 2.4 When policies are proposed or revised, the potential impact on family caregivers is anticipated and understood.

From our Listening Sessions

> ***"It's very hard for providers of social supports to collaborate with health systems… They live on different metrics than we do, and they don't understand what we're talking about… And it I think it requires some real training and more sort of collaboration among the community-based organizations to have the market power to be able to work with the health systems."***

Change in health care, social services, educational, and other systems is inevitable. When such changes occur, the opportunity presents itself to ensure the responsiveness of the system remains the same or is improved for the people it touches. The Advisory Councils found that the best way to achieve this is through engagement with individuals and their caregivers early and often in the processes driving change. Going forward, more attention should be paid to ensuring a thorough understanding of the downstream implications and results of changes to systems, policies, and/or practice to persons needing care and their family caregivers. This is the essence of person and family-centered care that is expanded upon in First Principles: Cross-Cutting Considerations for Family Caregiver Support.

As noted above, a key to achieving this is through representation of family caregivers on decision-making boards and committees that shape both policy and practice. Only through their engagement can systems ensure the lived experience and perspectives of caregivers are considered and included.

The federal government; universities; national, state, regional, and local philanthropic organizations; health care systems; school districts; and others can fund and/or disseminate research findings to increase understanding of how proposed policy changes can affect caregivers. As part of this effort, researchers should identify best practices for including caregivers in systems change. In addition, customer-serving organizations should adopt practices that help identify all potential stakeholders (including caregivers) at the initiation of proposed projects. State leaders may wish to explore means by which their state could champion involving caregivers in policy change. Certification, licensing, and/or accreditation bodies can help by requiring the full recognition of family caregivers as key to effective policymaking. In this regard, licensing and accreditation bodies can become leaders in ensuring the opportunity for participation and engagement of family caregivers across multiple settings and service delivery systems.

Aligned Actions

Federal agencies have committed to **6 specific actions** within the coming years in support of **Outcome 2.4**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 2.

Outcome 2.5: The education curricula of professionals who will potentially work with family caregivers include specific topics and coursework designed to ensure they have the skills to do so effectively.

Strengthening professional awareness and understanding of the needs of family caregivers is especially critical for any field that might engage with them, including (but not limited to) geriatrics, social work, public health, child development, palliative care, mental health, substance use, criminal justice, education, and pediatrics. When professionals who interact with caregivers have no training on how best to interact and engage with them, the ability to provide culturally and linguistically appropriate, person and family-centered care is inhibited. Training for these professionals should use the broadest possible definition of "family caregiver" to include kin and grandparent caregivers, caregiving youth, LGB caregivers, disabled caregivers, and caregivers in nontraditional family structures. A core competency in those trainings must be caregiver participation, where appropriate and desired, in the delivery of health care services. Trainings should be built upon available and emerging data and research on family caregiving (See **Goal 5**) and include understanding the role of family caregiver assessment and the availability of the appropriate tools and resources for facilitating referrals, assistance with navigating complex service delivery systems, and understanding the options for support that are available. The trainings should also feature family caregivers themselves as speakers/presenters to ensure that students can develop understanding and empathy for the lived experience of caregivers.

States and accrediting organizations can support these efforts by requiring professionals to receive training on family caregiving as a prerequisite to certification and including questions about family caregiving on licensure exams. Developers of continuing professional education curricula should create and disseminate training resources about engaging with family caregivers that use inclusive language and reflect the complexity of today's family caregiving landscape. (Also supports **Outcomes 1.1** and **1.3**) Health care organizations and other providers can create opportunities for professionals to gain knowledge of family caregivers' lived experiences to understand their emotional journey, and to expand their use of compassion, empathy, and validation when interacting with caregivers. Health care, long-term services and supports, and school systems, in turn, should ensure their respective workforces are educated about the experiences and needs of all kinds of caregivers by incorporating this content in culturally competent ways into onboarding, experiential learning programs, continuing education courses, and other professional development opportunities.

Respondents to the RFI noted that education of those professionals who engage with kinship families and grandfamilies would be especially beneficial (e.g., pediatricians, child welfare workers, mental health professionals, child care workers, and educators). Typically, when a child participates in educational, health care, and other supportive programs, their parent(s) are expected to represent that child to the various systems. As a result, when providers encounter kin and grandparent caregivers, they have few established practices on how to engage those caregivers to incorporate them in the provider's care delivery. Formal education on the unique strengths and challenges faced by kin and grandparent caregivers will facilitate the ability of professionals to develop culturally competent and strengths-based care and support plans for the children in kin and grandparent-led families.

Aligned Actions

Federal agencies have committed to **18 specific actions** within the coming years in support of **Outcome 2.5**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 2.

Indicators of Success: Partnership and Engagement

As the actions under Goal 2 are implemented, family caregivers will experience greater participation on care teams and in organizational processes, as the following social changes become increasingly widespread:

- Health care providers proactively identify if an individual presenting at a medical facility has a family caregiver and includes them in the care process.

- Caregiver assessments in medical settings are as commonplace as documenting height, weight, and blood pressure.

- Medical records include sections devoted to documenting the names, support, abilities, and preferences of caregivers.

- Professional messaging throughout health care, child welfare, education, and social services systems is inclusive of caregivers.

- Medical and paraprofessionals are trained on culturally competent and linguistically appropriate ways of engaging caregivers.

- When grandparent or other kin attend a school event or conference, educators quickly recognize if that person is a primary caregiver or a guest and are prepared to engage with them.

- Family caregivers have a better understanding of the care planning process and are better informed and prepared to assist the individual in need of their care.

- Family caregivers have access to training and support for self-advocacy when interacting with professionals involved in the life of the individual for whom they are caring.

- Educational terminology such as “parent-teacher conferences” are inclusive of non- parent caregivers.

- Care plans are no longer developed with the assumption that family caregivers will perform certain tasks or take on certain roles. Instead, caregivers participate in the process and—depending on their needs—receive referrals to services and supports that help them carry out their part of the plan.

- Systems are held accountable for disparities in access to paid services and supports.

- When a caregiver needs assistance, support, or training, professionals have the knowledge and resources to make referrals. This integrated network of support includes medical, legal, social services, and educational professionals.

Goal 3: Strengthen services and supports for family caregivers

As previously noted, family caregivers are a major provider of long-term services and supports for older adults, disabled people of all ages, and children whose parents cannot care for them. While some aspects of family caregiving come naturally, many of the tasks associated with today's family caregiving require a level of competency that people can master only through experience and training. Just as family caregivers provide support to others, they themselves often need support to allow them to continue in their roles.

To enable caregivers to provide support, now and into the future, the nation will need significant investments to ensure consistent access to an array of flexible services and supports, tailored to their needs and preferences, including high quality training about a wide range of topics; understandable instructions and communications about their responsibilities; flexible respite care, counseling, and peer support; and other accessible, culturally competent goods, services, and supports. These programs must be trauma-informed and culturally and linguistically appropriate to the populations they serve. Such investments will require action far beyond the present scope of the Advisory Councils and current federal programs.

In fact, the Advisory Councils heard repeated calls "loud and clear" from multiple stakeholders across the country and from some members of the Advisory Councils themselves for statutory and legislative changes to address the long-term care system in this country. Specifically, stakeholders have called for increased support for home and community-based services in Medicaid (generally and, more recently, for programs like Money Follows the Person) and by adding a long-term services and supports benefit in the Medicare program for respite, adult day services, and home modifications; and increasing funding and flexibilities for programs such as ACL's National Family Caregiver Support Program, Lifespan Respite Program, and Alzheimer's Disease Programs Initiative (which provides community-based support for people with ADRD and their family caregivers, as well as programs for professional caregivers who support people with ADRD), and the VA's Caregiver Support Program. The Advisory Councils believe such statutory changes will be increasingly necessary as the experience of family caregiving becomes more widely recognized and acknowledged as a function that every American will either provide or need. (Also supports **Outcomes 1.1**, **1.2**, **2.1**, and **5.1**)

The Advisory Councils developed ten shared outcomes specifically designed to strengthen the availability of a range of services and supports. Over time, and in coordination with the achievement of other Strategy goals, they will prepare the nation for expanding assistance to and support of family caregivers.

Outcome 3.1: Person- and family-centered, trauma-informed, and culturally appropriate caregiver services and supports are accessible for all family caregivers.

From our Listening Sessions

" … [For] family caregivers, one of the biggest [needs] is just expanded services, more funding for more programming."

A priority action identified by the Advisory Councils to prepare service providers for future expansions of services in response to rising demand is to invest more resources into overcoming barriers to access to services. Foremost of these are language and cultural barriers, suggesting providing translated or culturally adapted resources, services, and information to family caregiving communities that typically do not receive caregiving services should be a fundamental priority. (Also supports **Outcome 5.3**) For example, states, philanthropic organizations, community-based organizations, and faith-based organizations can review eligibility criteria for programs that use narrow definitions of "family" to explore ways to broaden those definitions to include caregivers who have other relationships with their care recipient, such as relatives beyond parents, grandparents, children, and spouses, as well as domestic partners, siblings, and/or other community members. Additionally, these sectors can evaluate existing resources to ensure they are culturally competent for their intended audiences.

The California Caregiver Resource Centers provide a model for a single point of entry for training and support and access to services for family caregivers.

Kin and grandparent caregivers need affordable legal and financial information, along with services from providers trained in trauma-informed care for children, and topics not typically associated with family caregiving, such as behavioral supports for children. They also need practical assistance with navigating school enrollment, pediatric care, and emergency planning. To address this, community-based organizations, faith-based organizations, and the organizations that fund them may want to prioritize the development and delivery of services for the populations of kin and grandparent caregivers in their communities.

Rural Populations

Caregivers in rural areas often lack access to needed services and supports. States can address this challenge by establishing task forces to identify and address barriers in hard-to-reach communities. Once barriers to access are documented and understood, states may want to consider expanding access to HCBS through expansions to Medicaid or other state-funded programs serving low-income populations. In parallel to these efforts, states, insurance payers, and health care systems can collaborate to ensure the financial viability of community-based organizations and faith-based organizations serving populations that have not in the past received caregiver support services. (See **Outcome 3.4** for information on other services that have the potential to improve health and well-being in these communities)

Washington State's Medicaid Transformation Project is using a Section 1115 waiver to create and continue to develop projects, activities, and services that improve Washington's health care system, including two caregiver support programs. The services within these cost-effective programs have improved the outcomes for caregivers and the people they support.

A common theme in the stakeholder input received by the Advisory Councils was the value of ambassador programs. Such programs can help build trust between local groups and providers of services. (Also supports **Outcome 1.3**)

To achieve further alignment, states, in partnership with a range of stakeholders, can create mechanisms for collaboration across organizations, such as communities of practice, to foster a cross-agency, interdisciplinary approach to supporting family caregivers. National, state, regional, tribal, and local philanthropic organizations and research institutions can expand the availability of culturally competent and adaptable evidence-based protocols by continuing to invest in translating and adapting existing evidence-based protocols and developing new ones. (Also supports Outcome 5.3)

Aligned Actions

Federal agencies have committed to **32 specific actions** within the coming years in support of **Outcome 3.1**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 3.

Outcome 3.2: Family caregivers can obtain respite services that meet their unique needs.

From our Listening Sessions

> ***" … I think even we're still struggling when just developing the awareness of respite care services and making sure that not only providers, but caregivers are aware of it."***

High-quality respite is one of the most requested needs of caregivers, but gaps in the availability and affordability of access are significant. For family caregivers, respite can mean different things and be received in numerous ways. Input from the Advisory Council members and stakeholder listening sessions all agreed on one fundamental fact about respite: it must be meaningful to the person receiving it. For example, some family caregivers might find a short time away from the actual caregiving situation to be what is needed most. Others might desire a break from other duties like homemaking, or from other tasks needed by the individuals for whom they are providing care.

Additionally, the concept of "respite" or a short break from family caregiving responsibilities might not be understood or valued in the same way across all cultures. Understanding these complexities is critical to developing respite services that are acceptable to different cultural and ethnic groups and fit a broad array of respite needs. For example, when developing respite programs and services for grandparent and kinship caregivers, it may be necessary to take a broader view of the types of activities that equate to respite. Additionally, where permissible under current statutory and regulatory guidelines, after-school clubs, youth sports, and camps could be marketed as respite programs if they are available in areas where kin and grandparent caregivers reside. Similarly, respite programs that meet the unique needs of caregiving youth, caregivers supporting people with complex medical needs, and those with I/DD must become more widespread and easier to access.

The VA's Building Better Caregivers offers a series of self-paced workshops that include access to an online "alumnus" community for peer-to-peer support to reinforce formal learnings.

States, insurance payers, community-based organizations, faith-based organizations, health care systems, managed care plans, and employers can collaborate to create greater awareness of the need for respite, in all its forms. They should develop respite opportunities that serve caregivers who would benefit most from this service and reflect the respite needs identified in the caregiving assessments mentioned earlier in the Strategy. Materials and messaging describing these programs and services should be developed in ways that resonate with the target populations and that align with their values and beliefs. Once services are developed, caregivers must be able to easily find the information they need when they need it. Information about respite services should be disseminated to caregivers through trusted repositories and programs, such as the Respite Locator and in the caregiving portal. (See **Outcome 1.1**)

State and local government agencies, insurance payers, managed care plans, community-based organizations and faith-based organizations, and other providers can consider expanding or prioritizing funding for payment that supports respite services, including training respite volunteers and ensuring direct care workers (DCWs) are trained and available to provide high-quality and flexible respite care. At present there are significant shortfalls in the number of DCWs available to provide respite care. Health care plans can prioritize respite care under the supplemental services they provide and advocate for use of those services by family caregivers. In addition, community-based organizations can explore establishing adult day services as a respite care option and promoting social respite models, like faith-based drop-in programs, which are more affordable and flexible than traditional adult day care or adult day health care. Researchers can also evaluate barriers, such as operating hours, compliance with accessibility requirements under multiple federal disability civil rights laws, and legacy licensing requirements to look for ways to expand the number of community settings where respite can be provided. (Also supports **Outcome 5.3**)

Take Another Break SC! offers a case study on how South Carolina optimized the delivery of federally-funded lifespan respite services across the state.

The 2019 Generations United report, A Place to Call Home, includes case study descriptions of caregiver-friendly housing models, such as Plaza West, an intergenerational housing model in Washington, D.C. Plaza West has 50 units designated for kin and grandparent caregiver-led households. Residents have access to on-site programs and referrals related to job training and employment, parenting, academic support, food assistance, furniture, clothing, recreation, physical and mental wellness, and legal aid.

Aligned Actions

Federal agencies have committed to **11 specific actions** within the coming years in support of **Outcome 3.2**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 3.

Outcome 3.3: A range of evidence-based education, counseling, and peer support services are available to family caregivers.

Numerous studies have shown that caregivers can experience elevated levels of stress and social isolation. Just as training helps caregivers feel more confident in their tasks, counseling and peer support from people who can empathize with their situation has been shown to improve outcomes for caregivers as well.

At present, education, counseling, and peer support designed specifically for unpaid caregivers are often difficult to find and access. For example, grandparents and other kin caring for children often are not offered access to the training and supports given to unrelated foster parents. One of the reasons for these gaps in access to trainings is because educational needs and preferences can differ significantly by population. Curriculum designers can explore opportunities to develop "bite-sized" trainings that allow a family caregiver to learn a specific skill rather than having to commit to a full curriculum. The Advisory Councils also noted that training programs that are flexible, available in-person or remote, feature the lived experience of other caregivers, and offer a choice of formats and languages, should be prioritized for development. These training modules should ideally be made available on the family caregiving website described under **Outcome 1.1** so that all caregivers and professionals who interact with caregivers have access to them. (Also supports **Outcome 3.6**)

These trainings should also be culturally competent to the populations they serve. For example, educational materials for kin and grandparent caregivers should use terminology specific to their needs rather than expecting viewers to translate. States, insurance payers, community-based organizations, faith-based organizations, and health care systems are encouraged to look to models that combine education with counseling and/or peer support when designing and commissioning programs. Where needed, trainings also should be trauma informed.

Aligned Actions

Federal agencies have committed to **12 specific actions** within the coming years in support of **Outcome 3.3**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 3.

Outcome 3.4: Family caregivers and families have safe places to live, nutritious food, and adequate transportation.

From our Listening Sessions

> ***"I've grown tired of trying to reach out because they always want me to come to them! I live in a campground in a very rural area! I can['t] make it anywhere!!! I'm stuck in bad situation that brings me down more every day I wake up!"***

All people should have access to adequate and safe housing, proper nutrition, and access to medical appointments and other transportation-related necessities. Without access to these fundamental requirements of daily living, family caregivers will face daily struggles. As a public health issue, effective family caregiver support efforts must include a focus on the five domains of the social determinants of health:

- Economic stability and security (including freedom from workplace discrimination)
- Education access and quality
- Health care access and quality
- Neighborhood and built environment
- Social and community context

To increase the effectiveness of high-quality, setting-appropriate, caregiver-defined services, numerous stakeholders can explore innovative ways to implement programs that support safe, accessible, and intergenerational housing, nutrition, transportation, elder wellness, and quality of life. For example, Asset-Based Community Development is a growing movement that assesses the resources, skills, and experience available in a local community and uses them as the foundation of sustainable community development.

Addressing the social determinants of health within the broader scheme of family caregiving is key to addressing longstanding health inequities among caregivers and their families in a holistic way. Policymakers can review the recommendations in Family Caregiver Needs Requiring Legislative and Other Policy Changes, which includes a list of specific legislative changes, aligned with the Strategy, that have the most potential to benefit caregivers.

To support this vision, states; insurance payers/health plans; community-based organizations; faith-based organizations; health care systems; and national, state, regional, and local philanthropic organizations can explore ways to increase the availability of wraparound services locally. For example, low-interest loans and startup grants within communities could encourage the development of programs like culturally competent adult day services. Service coordinators in low-income and public housing can be trained to understand and recognize the needs of family caregivers living in those communities. Communities of faith can explore opportunities to develop new ministries around key social determinants issues. State and local philanthropies can identify opportunities to fund specific initiatives designed to address these issues as well. (Also supports **Outcomes 3.2** and **3.3**)

Aligned Actions

Federal agencies have committed to **10 specific actions** within the coming years in support of **Outcome 3.4**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 3.

Outcome 3.5: Family caregivers have innovative tools and technology to assist them in their roles.

From our Listening Sessions

> ***"Develop software that functions just like Uber in tracking and vetting … the direct care service worker. Clients can rate the caregiver providing a greater level of accountability and performance. This also eliminates the need for care agencies as the direct care worker can be paid directly through the app as Uber drivers are."***

The pandemic highlighted the potential of technology to assist both caregivers and people receiving support. The flexibilities around telehealth, online training, counseling, and support groups that took place during the public health emergency provided opportunities to explore how technology can make family caregiving easier. States, health care systems, and insurance payers can leverage the lessons learned from the pandemic to make some of these changes permanent as part of their other efforts to support caregivers. They also can take steps to ensure that caregivers receive training that enables them to use these technologies successfully.

Those flexibilities only work, however, if caregivers have access to reliable, high-speed internet access, along with equipment and training to use it. The Federal Communications Commission's task force to improve health outcomes by providing land-based internet access to all communities is an important step in increasing caregivers' access to technological tools. In addition, the Affordable Connectivity Program (ACP) provides eligible households with a discount on broadband service and connected devices. States and local governments can support federal efforts to expand broadband infrastructure in their communities by supporting the reporting of performance metrics. Communities can establish a local task force to uncover caregivers' unmet technological needs as part of state planning. Internet providers and developers of infrastructure should prioritize supporting family caregivers in rural and hard-to-reach communities and expand access to technologies to support them. The recognition of supporting family caregivers and its importance is derived from a caregiver-aware business culture. (Also supports **Outcome 1.1**)

Community-based organizations, faith-based organizations, health care systems, insurance payers, and the IT industry can also actively seek out ways to embrace, promote, and fund caregiver access to future-focused tools and assistive technology, such as smart homes, wearable blood pressure and heart monitoring devices, automated pill dispensers, e-learning modules, task management apps, speech amplification and adaptation systems, and geo-tracking. National, state, regional, and local philanthropic organizations and research institutions can support these efforts by increasing research into evidence-based assistive technology models that benefit caregivers now and as new technologies emerge. (Also supports **Outcome 5.3**)

Aligned Actions

Federal agencies have committed to **9 specific actions** within the coming years in support of **Outcome 3.5**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 3.

Outcome 3.6: Volunteers of all ages and abilities are trained, vetted, and ready to assist family caregivers.

From our Listening Sessions

"Is it possible to create a national support hotline, perhaps staffed by volunteers who have been in a caring situation and/or experienced social workers who have an interest in kinship caregiving?"

Many family caregivers have great need for support, which is often unrecognized, unaffordable, and/or unavailable. Volunteers have long been a mainstay of the systems that provide respite, meal delivery, transportation, and social interaction, and are relatively cost-effective for both programs and families. Expanding volunteer opportunities can both increase the availability of direct supports for family caregivers and create a path for expanding the direct care workforce. State agencies, community-based organizations, and faith-based organizations can explore ways to support the coordination and training of volunteers. Community organizations can also develop and disseminate outreach materials to educate the public and professionals about volunteerism, mentoring, and peer-to-peer support programs as both a way of assisting family caregivers and as a means of developing valuable experience that can be applied professionally. To further support this, accrediting bodies and academic institutions can consider expanding programs that provide experiential credit for volunteer activities, offer intergenerational volunteer opportunities, or provide tuition credit or leverage community service hour requirements in educational institutions.

Community Care Corps is a national program that fosters innovative models in which local volunteers assist with non-medical tasks, provide companionship, and relieve overburdened family caregivers. The program benefits family caregivers, older adults, and persons with disabilities.

Aligned Actions

Federal agencies have committed to **2 specific actions** within the coming years in support of **Outcome 3.6**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 3.

Outcome 3.7: Family caregivers' and care recipients' needs are a key consideration in emergency response efforts.

From our Listening Sessions

"Make sure police emergency call responders are trained enough to recognize dementia-related emergencies."

Family caregivers, along with the people they support, are at greater risk during emergencies such as weather events, pandemics, natural and human-caused disasters, and economic instability. Yet, currently few formal systems for integrating the needs of caregivers and care recipients into emergency preparedness exist.

The HHS Office of the Assistant Secretary for Preparedness and Response (ASPR) offers a free web-based training to improve public health and emergency medical responders' capability to address the access and functional needs of community-dwelling older adults in disasters.

This course provides information, resources, tools, and strategies to help assess and address the needs of older adults in common disaster situations, including natural disasters and infectious disease outbreaks.

States, communities, community-based organizations, faith-based organizations, and employers can work to address this issue by including the perspectives of family caregivers in emergency exercise and shelter-in-place planning. Family caregivers' support during a crisis should include linkages to community-based resources, culturally competent communications, advance care planning, medication support, help with care coordination, access to necessary Durable Medical Equipment (DME) and Assistive Technology (AT), and financial assistance. (Also supports **Outcomes 1.3**, **3.1**, and **4.1**) It also means embedding family caregiver identification tools into protocols used by all emergency responders. (Also supports **Outcome 2.1**)

Proactively building systems to support caregivers during times of crisis, in combination with advance planning on the part of caregivers, may help lessen the impact of emergencies on family caregivers and the people they support. Municipalities, public health departments, homeowners' associations, co-op boards, and faith-based organizations can do this by identifying caregivers in the community who may need additional help during emergencies and providing advance care planning workshops to them. One way to identify family caregivers is through a community census to identify and document the practical needs of local family caregiving populations. During an emergency, these needs can include powers of attorney (or other legal arrangements), access to durable medical equipment, assistive technology, refrigeration, and generators; mobility assistance; transportation; financial support; food; accessible emergency shelters; and information on emergency procedures that is understandable, culturally competent, and accessible to people with disabilities. The information gathered in a community census could also be used to inform and adapt local caregiver outreach efforts described in **Goal 1**.

To further support caregivers in emergencies, health care professionals and first responders should receive training in caregiver identification with an emphasis on emergency situations both in the community and in clinical settings. (Also supports **Outcome 2.1**) States, communities, and national, state, regional, and local philanthropic organizations can specifically fund services that support unanticipated caregiver needs during emergencies. (Also supports **Outcome 3.1**)

Aligned Actions

Federal agencies have committed to **10 specific actions** within the coming years in support of **Outcome 3.7**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 3.

Outcome 3.8: Family caregivers have the skills and tools necessary to prepare for the future needs of the person they support.

From our Listening Sessions

"What happens to my grandchildren if something happens to me?"

Planning for when they will no longer be able to support their loved one is something many caregivers find difficult. "Future care planning" activities are important, however, because they proactively ensure prudent resource management and sound decision making in the event of a crisis. Advance planning in general also ensures that family caregivers have the skills, resources, and legal authority they need as their responsibilities evolve. (Also supports Outcome 3.7) States, communities, health care systems, insurance payers, community-based organizations, and faith-based organizations can proactively develop and disseminate tools and resources that can make this difficult task easier. These tools must be trauma-informed and adaptable to the cultural and demographic needs of the target population. Employers can support these efforts by incorporating future planning in employee benefits options. Professional and HR associations may want to include the topic of future planning in caregiving-related outreach and education tools they develop.

To raise awareness of the importance of future care planning, community-based organizations, faith-based organizations, libraries, and social services providers can make available to the public financial planning tools for family caregivers developed by the Consumer Financial Protection Bureau. (Also supports **Outcome 4.1**)

Aligned Actions

Federal agencies have committed to **3 specific actions** within the coming years in support of **Outcome 3.8**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 3.

Outcome 3.9: An agile, flexible, and well-trained direct care workforce is available to partner with and support family caregivers.

The ability of family caregivers to support older adults, people with disabilities, and children who cannot remain with their parents is often directly affected by the availability of services and supports provided by direct care workers (DCWs). This workforce includes personal care attendants, home health aides, direct support professionals, residential workers, and others. These essential workers are an important source of respite care for family caregivers, as well as formal supports that complement care provided by family caregivers. Multiple respondents to the RFI noted that because it is difficult to find, hire, and retain DCWs, many family caregivers experience significant periods of time without a break from family caregiving responsibilities.

This is a long-standing and widespread issue that was significantly worsened by the pandemic, as discussed in the RAISE Advisory Council's initial report to Congress. Demand for DCW services currently exceeds the number of available workers. DCWs are one of the highest in-demand employment categories of professionals in the U.S. The critically needed expansion of this workforce will not happen without significant changes in how they are recruited, trained, paid, and supported.

In 2021, the Center for Health Care Strategies released Strengthening the Direct Care Workforce: Scan of State Strategies. The scan provides examples of state strategies aimed at strengthening the direct care workforce. Key resources include examples of legislative language supporting DCWs and direct care workforce training models, including, in some cases, information on how states fund training.

A recurring theme of stakeholder input was that the DCW workforce is critical to the success of family caregivers. The Advisory Councils call for the convening of an interagency task force to work on a direct care workforce development plan, collaborating with states, possibly incorporating other issues that impact the workforce such as immigration reform, and student federal loan forgiveness programs. States, state agencies, and managed care plans may want to consider exploring ways to support these efforts by increasing wages and benefits and ensuring those increases are received by DCWs themselves. Ideally, this should happen in tandem with federal increases in wages. (See Family Caregiver Needs Requiring Legislative and Other Policy Changes)

Stakeholders also recommended that multiple sectors—communities, health care systems, payers, child welfare systems, community-based organizations, and faith-based organizations—collaborate to build a robust labor force of DCWs and support alignment with the Strategy through:

- Creating consistent training requirements across states, via competency-based training with a shared set of principles for all direct care workers, including training on how to engage with family caregivers. (Also supports **Outcome 2.5**)
- Incorporating into existing training supplemental modules that enable specialization and career advancement opportunities (e.g., dementia care). (Also supports **Outcome 2.5**)
- Increasing the availability of programs that pay family caregivers for providing direct care services. (Also supports **Outcome 4.1**)
- Launching outreach campaigns that promote the social and economic value of direct care work. (Also supports **Outcome 1.1**)
- Convening interagency task forces to standardize job titles and responsibilities within and across states and sectors to enable better understanding of workers and enhance job portability. (Also supports **Outcome 5.1**)

To help drive the success of these activities, national, state, regional, and local philanthropic organizations and research institutions are encouraged to fund research and demonstration projects to advance understanding of the field and explore effective mechanisms for improving the direct care workforce. These should include increasing rates and payment structures to recruit and retain qualified DCW. (Also supports **Outcome 5.2**)

For further information on why it is critical that the nation support and sustain a well-trained and adequately compensated direct care workforce, see:

- First Principles: Cross-Cutting Considerations for Family Caregiver Support (a component of the Strategy), which discusses the direct care workforce, in addition to the impact of trauma, and person-centered planning.
- Community Supports in Crisis: No Staff, No Services explores how progress toward community living that has been made in services for people with I/DD over decades is now in jeopardy.
- State Strategies for Sector Growth and Retention of the Direct Care Health Workforce provides a series of multi-sector state and employer strategies to address recruitment and health sector retention of direct care workers while balancing workforce needs, job quality, and wages.
- Growing a Strong Direct Care Workforce: A Recruitment and Retention Guide for Employers (PHI) provides a range of strategies to help providers recruit and retain direct care workers and improve the delivery of care.

- 8 Essential Publications on the Direct Care Workforce (PHI) provides links to eight essential publications on the direct care worker crisis from PHI.

Aligned Actions

Federal agencies have committed to **11 specific actions** within the coming years in support of **Outcome 3.9**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 3.

Outcome 3.10: Kinship families and grandfamilies are recognized, supported, and valued within the child welfare system.

From the RFI about kinship families and grandfamilies

> ***"We experience so much from this never-ending nightmare of custody. The sleepless nights because of what the system has done to us. The days of not eating because we are too upset with what the system that is supposed to be protecting these children has done to us. This has caused so much damage ..."***

Two themes emerged from the RFI responses and SGRG Advisory Council discussions:

1. Kin and grandparent caregivers are often excluded from existing systems to financially assist families.

2. They struggle to navigate variable and disjointed federal, state, and local systems that, in the words of one respondent, "don't talk to one another." Each state has differing laws, procedures, and definitions that shape the experience of kin and grandparent caregivers, and those experiences are often not synchronized with federal programs.

The result of these intertwined issues is that some legal relationships, health and academic records, and case files are often not portable—even as children move to new homes and schools. This creates a cascade of stress, legal ambiguity, and financial hardship for more than 2.7 million kin and grandparent caregivers, many of whom are older adults and/or people with disabilities.[3]

Meaningful change in the child welfare system will itself require a dedicated strategy for aligning legal systems across states and with the nation. It will also require significant federal intervention to redefine eligibility criteria for programs (e.g., broaden the definition of family) that have traditionally not included kin and grandparent caregivers in informal relationships and to change the public narrative about kin and grandparent caregivers raising children outside of the foster care system. They should be accorded the same respect and status as licensed foster parents. And they should enjoy the same benefits and rights, including the same levels of financial and logistical assistance.

In the short term, there are actions states and communities can take now to explore and implement systems changes to better assist kin and grandparent caregivers and the children. States and/or communities can start by identifying and documenting existing inequities faced by kin and grandparent caregivers within specific state and local communities. Topics to cover include access to health care, access to financial resources, and data sharing. (Also supports **Outcomes 1.1** and **5.1**)

Family caregiving stakeholders can take steps to ensure that all websites, program descriptions, reports, media, and other materials use language and images that are inclusive of kin and grandparent caregiving situations and needs. (Also supports **Outcome 1.1**) States, health systems, communities, community-based organizations, faith-based organizations, school districts, and other stakeholders can prioritize the hiring of people with lived experience so that the child welfare system and the systems with which it interacts are infused with the real-world knowledge, experience, and voices of kin and grandparent caregivers. (Also supports **Outcome 3.1**)

The Colorado Child Welfare Family Advisory Council guides policymakers in the state on the design and delivery of high-quality child welfare services to youth and families. Members can be any of the following: biological parents, “grandfamilies” (non-certified grandparent), kinship family member providing non-certified out of home care, certified kinship foster parent, youth formerly in care and now out of care, foster parent (non-kinship), foster/adoptive parent (non-kinship), community partner providing services to youth in foster care.

A foundational belief of the SGRG Advisory Council is that children should grow up in the care of their own families. When it comes to keeping families together, there are several additional opportunities states and communities can leverage under existing law. For example, states can establish agreements, as allowable under Title IV-B of the Social Security Act, with tribes to provide culturally competent services to American Indian and Alaska Native Families. They can also look for ways to optimize use of Title IV-B funding (including Promoting Safe and Stable Families funds) to provide kinship-specific support services. State and legal advocacy groups may find it beneficial to develop guidance documents that explain how Title IV-B can be used to support kin and grandparent caregivers. (Also supports **Outcome 3.1**) They can also adopt the National Model Family Foster Care Standards (and ideally the more detailed National Association for Regulatory Administration Family Foster Care Licensing Standards) to address barriers to licensing kin and foster parents. (Also supports **Outcome 4.1**) Those states that use Temporary Assistance for Needy Families (TANF) for child support issues, may wish to broaden the term “family” so that it includes all kin and grandparent caregivers and form relationships with neighboring states so that program participation is transferable when a person moves across state lines.

To ensure the needs of kin and grandparent caregivers are reflected in all future planning, states can establish interagency child welfare task forces that include caregivers, children, child welfare professionals, attorneys, social services providers, medical professionals, and mental health experts to guide and inform the work of the child welfare system. (Also supports **Outcomes 3.1** and **4.1**)

States can use Title IV-B, subpart 2 funding to develop, enhance, and evaluate kinship navigator programs that serve kinship families both inside and outside the system. They can also explore participating in Title IV-E Guardianship Assistance program to facilitate child placements with relatives as a permanency option. (Also supports **Outcome 4.1**)

As previously noted, quality longitudinal data on kin and grandparent caregivers and the children they support is lacking. All stakeholders can collaborate to redress this imbalance through engaging in (or providing funding for) robust data collection efforts that are aligned with the goals of the Strategy. (Also supports **Outcome 5.1**) Such efforts should include data about children in the child welfare system and those children who have passed through the system and those children who come to the attention of the child welfare system but never enter the system. (Also supports **Outcome 5.1**)

Aligned Actions

Federal agencies have committed to **2 specific actions** within the coming years in support of **Outcome 3.10**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 3.

Indicators of Success: Services and Supports

As the actions under Goal 3 are implemented and the outcomes realized, family, kin, and grandparent caregivers will feel more confident in their ability to provide care because:

- Person- and family-centered, trauma-informed support are the norm.
- Information about services and supports for individuals needing care and to support those providing that care is available on a family caregiving information platform, so when a caregiver faces a new challenge, they immediately know where to turn.
- When family caregivers need a short break, they have a robust array of trained respite options available that are local, convenient, and affordable.
- Caregivers can tap into a community of fellow family caregivers who can empathize with their experiences and share insights from their own experiences.

- Technologies and tools to assist family caregivers are designed with caregiver input and tested by caregivers.
- Communities have robust pools of vetted and trained volunteers to assist family caregivers.
- Caregivers have a plan in place for what to do if they can no longer provide care.
- In emergency situations, first responders are prepared to identify and support family caregivers.
- Every family caregiver has an emergency kit that includes legal documents, if needed.
- Direct care workers have career paths, flexibilities, and compensation packages that make the field attractive to young people.
- Direct care workers will have the training they need to deliver high-quality care.
- Clear and consistent processes will exist for screening and hiring direct care workers.
- The default assumption, if a child is removed from their home, is to place them with kin first. (As a result of this, caseworkers would need special permission to place a child with non-relatives.)
- Child welfare agencies hire lived experience experts at both the leadership and caseworker levels, and that lived expertise informs all levels of decision making.
- The needs and perspective of informal kinship families—those who are raising children outside of the foster care system—are recognized by child welfare workers as equally important as foster families.

Goal 4: Ensure financial and workplace security for family caregivers

Personal finances and future financial security are a significant source of stress for family caregivers. Family caregivers face multiple financial threats associated with their family caregiving responsibilities. They experience significant out-of-pocket expenses and depletion of leave time as the majority of workplace policies do not allow sufficient paid time off or workplace flexibility to accommodate unexpected family caregiving duties. In addition, many are forced to leave the workforce in order to dedicate sufficient hours of care to a family member, which results in loss of income. Many are concerned about the ability to accommodate the needs of the person receiving support (including costs associated with health care, health supplies and equipment, housing, and support services) as well as their own financial security, now and into the future.

The RAISE Act State Policy Roadmap for Family Caregivers (Section 4: Financial and Workplace Security), developed by NASHP, provides examples of successful state strategies for improving financial and workplace security for employed caregivers.

Some programs do offer support that can help defray costs associated with home modifications, transportation, and legal fees, but those resources are limited and unevenly distributed across the nation. Financial assistance programs such as TANF are available to some kin and grandparent caregivers, but the amounts are often not enough to cover basic needs. Moreover, TANF is, by definition, a temporary benefit. Foster care maintenance payments, which are significantly higher than TANF, are not made available to most grandparent or kin caregivers. Altogether, there are many opportunities to ensure that family caregivers can provide care without putting their financial security—and that of their family—at risk.[4]

Outcome 4.1: Family caregivers can provide care without negative impacts to their near- and long-term financial health.

From our Listening Sessions

> ***"When it gets to the point of [FMLA] eligibility requirements, [I suggest] it not be restricted to biological or legal family members … the older adults could designate who is eligible to receive these supports from services apart from kin."***

Among input received by the Advisory Councils, the strongest recurrent theme focused on the need for the federal government to take the lead on several priority actions that, if implemented, have the potential to collectively change the financial landscape for family caregivers in this country. Participants in the key informant and family caregiver listening sessions repeatedly called for expansion of leave programs at the federal level and tax credits for family caregivers. These topics were also discussed extensively by the Advisory Councils and identified as a real need in relation to many aspects of family caregiving (out-of-pocket costs, paying for college, housing, etc.) As a result, the Advisory Councils see the current moment as a call to action for advocacy efforts to:

- Establish a national program of paid family leave for workers.
- Extend family leave programs so that they are available to all workers across the country.
- Provide refundable federal tax credits for family caregivers.

Those changes are outlined in Table 1, Legislative and Other Policy Changes to Support Family Caregivers.

Leave Programs, Discrimination Protections, and Tax Credits

Even in the absence of Congressional action, other sectors can still play a role in easing the financial shocks that can come with caregiving. If not already doing so, states and health plans may wish to explore opportunities to provide payment to family caregivers to the greatest extent allowed. (Also supports **Outcome 4.1**)[5]

State lawmakers can explore opportunities to launch leave programs for family caregivers. Such programs should include paid sick leave and paid family leave. States also can take action to broaden eligibility for leave and other related employment programs by using the broadest possible definition of family. Such action could ensure all types of caregivers, including grandparent and kin caregivers and non-relative caregivers, benefit from these programs.

State lawmakers can also take concrete action to protect family caregivers from employment discrimination through amending labor laws. As major employers themselves, states can lead by example by creating benefits packages for state workers that are caregiver-friendly.

States that are not currently offering tax credits to family caregivers may want to explore opportunities to do so. As of 2022, nine states allow family caregivers to claim some caregiving-related expenses as refundable tax credits. For further discussion on states that offer tax credits for family caregivers, see RAISE Act State Policy Roadmap for Family Caregivers: Financial and Workplace Security for Family Caregivers.

Public Education

A key theme of the RFI responses was that even when programs are available, family caregivers often struggle to learn about them. Planning for public education campaigns and other outreach about tax credits and employment programs should be included in the development of new programs. Such programs should then be promoted on the caregiving platform described under **Outcome 1.1**.

As state laws and benefits change over time, outreach campaigns should be developed to ensure that employers and employed family caregivers have access to up-to-date information about financial programs that could assist them. All sectors will need to contribute to ensuring that all populations of family caregivers are aware of and can benefit from these changes. If Congress expands programs for family caregivers, all sectors should commit resources to expand access for historically excluded populations of family caregivers. (Also supports **Outcomes 1.1** and **1.3**)

Aligned Actions

Federal agencies have committed to **7 specific actions** within the coming years in support of **Outcome 4.1**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 4.

Outcome 4.2: Family caregivers have access to employee-centered flexible workplace policies and practices that support work/life balance and professional performance when personal circumstances change.

From our Listening Sessions

> ***"If folks are afraid to raise their hand and call themselves a caregiver or to utilize a benefit for a caregiver because they're afraid they'll be fired, it's not about awareness alone. It's about infrastructure of support that enable that recognition."***

Nearly two-thirds of family caregivers who work full time say the stress of juggling work and caregiving is either the first or second biggest challenge they face. A study by the U.S. Government Accountability Office (GAO), Retirement Security: Some Parental and Spousal Caregivers Face Financial Risks, estimated that 68 percent of working caregivers who support either a spouse or a parent had to adjust their schedules, a decision that can affect career progression and financial security across decades, especially for women.

Legislative changes at the federal and state levels to leave programs and tax incentives are two priority ways to improve work-life balance for family caregivers. There is also much that employers can do to make it easier for family caregivers to maintain employment. This also benefits employers—investing in family caregiver support can pay off for employers both in terms of attracting talent and increasing retention.

Research and Employment Learning Collaboratives

Currently, very little high-quality research has been published on best practices for supporting family caregivers in the workplace. There is a real need for partnerships between states, employers, and researchers to create a robust infrastructure for sharing resources that support family caregivers, such as through learning collaboratives that can provide evidence to guide policy. Labor analysts and economists can support these efforts through research into the return on investment for supporting family caregivers. Stakeholders can help promulgate the findings of this research and spur further investigations. (Also supports **Outcomes 1.1** and **5.1**)

Caregiver-Friendly Work Culture

Employers can foster a culture that recognizes family caregiving and adopt policies and programs that make it easier for family caregivers to juggle caregiving and work. Examples include expanding the definition of family so that employee benefits like leave programs, health plans, and other programs better meet the needs of family caregivers.[6] This can also include adding flexible leave policies; allowing family caregivers to use flexible work hours, compressed work weeks, and telework; and structuring job descriptions around tasks that can be completed remotely, at flexible times of day.

Leave donation programs are an example of how a program can support family caregivers and raise awareness among non-caregivers of opportunities to support them. Promoting such programs in the workplace drives awareness among employees of the needs of family caregivers and helps create an organizational culture where they feel supported and welcome because caregiving is normalized. Researchers can support this effort by identifying and sharing best practices and research findings for employers on supporting family caregivers in the workplace. (Also supports **Outcomes 1.1** and **3.6**)

Employers can also consider adopting other caregiver-friendly workplace policies, such as joining an employer certification program for identifying and credentialing "caregiver friendly" workplaces, hosting family caregiver events and observances, featuring a wide range of family caregivers in employee handbooks and trainings, and providing easy to understand educational materials about Social Security, health insurance, and Medicare deductions, as well as eligibility for Medicaid and Children's Health Insurance Program (CHIP).

To increase efficiency in these efforts, employers may wish to create communities of practice with state agencies modeled on the Massachusetts Caregiving Initiative (See box). Such an initiative could promote caregiver-friendly workplaces in the state (or industry) and promulgate promising practices associated with being a family caregiver-friendly workplace. (Also supports **Outcomes 1.1** and **5.3**)

Benefits That Attract and Retain Family Caregivers

Employers can also consider family caregiver issues and needs when designing benefits packages. Examples include providing advanced planning support for family caregivers or prioritizing Employee Assistance Programs (EAP) that include support to family caregivers in their roster of available services. To ensure that workers have current information on local services, community-based organizations, faith-based organizations, and others, community organizations should consider attending employee benefits fairs and other events to disseminate information about existing services and help increase family caregiver identification. (Also supports **Outcome 1.2**)

> The Massachusetts Caregiving Initiative released the Massachusetts Employer Toolkit to Support Working Caregivers. The toolkit includes a business case for supporting caregivers, employee questionnaires, best practices, a case study, and descriptions of state-based resources to assist caregivers.

Educate Managers on Supervising Family Caregivers

New managers and supervisors should receive training on the needs of family caregivers in the workplace. Such trainings should encompass the full range of family caregivers in the workplace from caregiving youth with part-time jobs to full-time professionals juggling career and caregiving—and everything in between. Human resources organizations and curriculum developers should develop management trainings on the issues faced by family caregivers, including caregiving youth, when they are caring for someone with a chronic condition or who is at the end of life. Authors and publishers of business management books and periodicals should explore topics and themes about “caregiving in the workplace.” When firms update management trainings, it is important to include language and visuals that reflect all caregivers. (Also supports **Outcome 1.1**)

Aligned Actions

Federal agencies have committed to **7 specific actions** within the coming years in support of **Outcome 4.2**. See “**Actions for Others**” for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 4.

Outcome 4.3: Family caregivers have access to and use of financial education and advance planning tools.

From our Listening Sessions

"A lot of the stress of caregiving is finances … so understanding and having tools to help with saving earlier, understanding what those needs are, and options for long-term care insurance … I think is really critical."

Caregivers often need assistance with long- and short-term financial planning. That assistance must go beyond bookkeeping basics and recognize the fact that family caregivers need help planning. The financial requirements of their role often exceed their available resources, and many family caregivers put their careers on hold or lose income. In addition, the available systems of support, such as TANF and other safety net programs, are often difficult to navigate and/or access. This is even more critical for specific populations of family caregivers, such as those with more intense caregiving responsibilities, parents of children with complex health care needs, and kin and grandparent caregivers.

Concerns about financial security were a recurring theme of the RFI responses and among the participants in the focus groups. Of particular concern to many family caregivers is how care recipients will be supported in the event the family caregiver is no longer available to provide care. Many kin and grandparent caregivers also have continual concerns about how to meet the costs of health care, health supplies/equipment, school supplies, housing, and other needs for the individuals receiving their care. As a result of these complex and interdependent challenges, family caregivers need a range of information and resources to support sound financial decisions and future planning for themselves and the individuals in their care. (Also supports **Outcome 3.1**)

Increase Access to Planning Services

Advance planning and decision-making supports are crucial legal and financial tools for family caregivers. Without these supports, family caregivers and the individuals receiving their assistance are at risk if they are no longer able to provide care. At particular risk are children who are in the care of kin and grandparent caregivers without a clear legal arrangement such as custody or guardianship.

Work/Life Resource Navigators are a phone/text/email-based benefit that an increasing number of employers are now offering. The trained coaches focus on topics like caregiving, paying bills, budget optimization, trauma-informed care, and understanding assistance programs and options.

The child welfare system, legal aid programs, and community-based, or faith-based organizations can work to address these issues by providing greater access to pro bono and low-cost services and supports that focus specifically on developing legal and financial arrangements for people who are supported by caregivers. (Also supports **Outcomes 3.1** and **3.6**)

Employers can ask their Employee Assistance Program (EAP) vendors to offer caregiver support services such as financial planning, as part of the confidential information, support, and referral services these programs offer. Employers can include caregiving employees with consultations with financial advisors, who are trained in trauma-informed support, as part of their benefits package. (Also supports **Outcome 3.1**) Communities and social services providers can also promote the availability of financial planning services to family caregivers.

Aligned Actions

Federal agencies have committed to **7 specific actions** within the coming years in support of **Outcome 4.3**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 4.

Outcome 4.4: Long-term services and supports are more affordable, allowing family caregivers to reduce their out-of-pocket costs.

The quality of life of older adults and individuals with all types of disabilities is closely tied to the services they receive in home and community-based settings. Among these services are residential supports, personal care services, mental health services, and community living supports. While Medicaid is the largest public provider of covered long-term care services, on average, more than half of long-term care costs are paid out of pocket by individuals and families. When families cannot afford these services, family caregivers are often called upon to fill the gaps, which can increase family caregiver stress.

From our Listening Sessions

> ***"I would urge everyone to focus on overall long-term care financing reform. That's where the likely real change is going to be. I would suggest the council needs [to work with] other entities within the government … That's going to be the key. Also bring in some of the experts from Washington State and see what's worked, what hasn't worked."***

The WA Cares Fund is investigating ways of making LTC affordable for all workers in the state. Starting in July 2026, each person who is eligible to receive the benefit can access care costing up to $36,500 (adjusted annually) over their lifetime. To access benefits, an individual must need assistance with at least three ADLs.

Affordable Supports and Services

An area of consensus among the focus group participants was the need for a national long-term care insurance program. Such a program would enable employees to pay a monthly premium for guaranteed coverage of a flexible set of goods and services necessary for maintaining status in the community. In support of this, employers may wish to offer benefits that make long-term services and supports more affordable for their family caregiver employees. Examples include leave donation programs, respite programs, onsite adult day care, family caregiver training, and voluntary long-term care (LTC) insurance.

States and insurance providers also can partner to develop more tools for consumers that protect against the costs of long-term care, such as health savings accounts, affordable stand-alone policies, hybrid life insurance models, annuities with LTC benefits, and term-life insurance that converts to LTC insurance at age 65.

Advocates, researchers, and policymakers should continue to research barriers to funding LTC. States may wish to explore ways to expand Medicaid HCBS programs, as well as state-funded programs supporting family caregivers. Insurers may wish to explore partnerships with HCBS providers to test offering HCBS as Medicare Advantage supplemental benefits. The two papers commissioned by the Advisory Councils speak to opportunities for both programs to proactively address the needs of family caregivers:

- Medicaid Supports for Family Caregivers by Neva Kaye and Salom Teshale, Ph.D.
- Medicare and Family Caregivers by Judith A. Stein, J.D., and David A. Lipschutz, J.D.
- State officials seeking to better understand the state policy landscape for supporting family caregivers can review the RAISE Act State Policy Roadmap for Family Caregivers developed by NASHP.

Aligned Actions

Federal agencies have committed to **1 specific action** within the coming years in support of **Outcome 4.4**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 4.

Indicators of Success: Financial and Employment Protections

As the actions under Goal 4 are implemented, family caregivers will experience greater financial security as the following social changes take place:

- Older adults, people with disabilities, and their families will no longer have to deplete their savings/assets to qualify for Medicaid to access much needed long- term services and supports; they will be able to stay in their own homes where they most often want to receive care and live.

- Caregivers have access to high-quality and appropriate financial education and planning services and support, such as time off and flexible work schedules for caregiving.

- Family and kinship caregivers see their experiences reflected in new policies that reduce the financial consequences of family caregivers.

- Instead of feeling forced to give up their own careers, family caregivers will be able to help their family members access services and supports to help meet their needs.

- Caregivers are able provide care without being anxious about their financial status later in life.

- Caregivers do not have to choose between paying for their own necessities and caregiving expenses.

- If they are employed, family caregivers can better balance caregiving and meaningful employment.

- Caregivers feel comfortable talking to their colleagues and management about caregiving at work.

- Managers receive training in how to support employees on their teams, including those with caregiving responsibilities.

- Caregivers who provide financial management for another have more accessible and available tools and technologies that make it easier and more effective to safeguard the assets of someone else.

- Caregivers who leave the workforce to provide care can access needed services and take time off work for caregiving without losing Social Security “quarters of coverage.”

- Caregivers with primary responsibility for care have access to paid leave and flexible work policies

- Long-term care insurance options are available across the lifespan that reduce the burden on family caregivers and support community living.

Goal 5: Expand data, research, and evidence-based practices to support family caregivers

As the RAISE Act initial report to Congress found, the experience of caregiving can leave family caregivers financially, emotionally, and physically depleted. Yet, despite a growing body of research, there is limited infrastructure for the collection of comprehensive, population-based data about the prevalence of caregiving and the context in which care is provided, or the financial, emotional, and physical impacts of caregiving.[7] In addition, we lack a national research infrastructure that is inclusive of the full range of family caregiving (e.g., episodic, chronic, long-distance, etc.), the relationship between the family caregiver and the person receiving care, and all caregiving conditions and disabilities.

Most national surveys do not contain questions that identify family caregivers. Data sources that do include family caregivers often use inconsistent definitions that make it hard for researchers to synthesize data sets to achieve outcomes, such as determining the economic value of caregiving and the opportunity costs for family caregivers. There is still much to learn and document about how public policies can improve well-being for family caregivers, especially over time. Identification of family caregivers continues to pose a challenge, which could have long-term impacts on public spending and allocations for the delivery of services.

As of 2022, there is no major body of work to provide information about the experiences of caregiving youth. Similarly, there is little information on the impacts of sibling caregiving or the needs of children who live in families where the parents are full-time family caregivers to other relatives. There is very limited available research on family caregivers who themselves identify as disabled. Nor are family caregivers included in biomedical clinical trials or medical device development, which means the nation has scant information on the extent to which the presence of a trained family caregiver affects efficacy of medical and social services interventions. When studies do assess family caregiver experiences, they often mistakenly assume the family caregiver perspective reflects the patient experience, when in fact, they can be markedly different.

Goal 5 is a prerequisite to the success of the Strategy and should be among the highest priority efforts by all sectors. These efforts will need to be iterative. In coordination with the achievement of other goals, these efforts can ensure that the nation has the knowledge and data necessary to adequately recognize, assist, and support family caregivers.

Outcome 5.1: A national infrastructure will exist to support the collection of population-based data, using standardized wording of the definition of family caregiving and standardized wording of questions that address the core characteristics of the family caregiving experience.

From our Listening Sessions

> ***“As more data emerges to show that caregivers are kick ass people and that they are really good workers … the education goes up, the stigma goes down and we start making some headway.”***

Over the past three decades, scientific research has significantly increased our understanding of family caregiving, but critical gaps in knowledge remain. Much of what is known about family caregivers is based on single research site, smaller-scale studies or surveys conducted with convenience samples. Additionally, a single, well-accepted definition of the term “family caregiver” has not emerged from the field. Yet, available data, as demonstrated in both Advisory Councils’ reports to Congress, strongly suggest the urgency of increased support to family caregivers. Current data also point to the need for more standardized, population-based studies to confirm the prevalence of family caregiving in the U.S., identify the contextual factors in which families provide care, document the impacts of providing care on people with disabilities, as well as impacts to the overall family structure and family relationships, and to evaluate existing and new care models and programs intended to provide support to family caregivers.

Enterprise Data Strategy

While other aspects of the Strategy call for collective, organic efforts across and within sectors, desired outcomes related to Goal 5 likely require a different approach. Because data, research, and identification and promulgation of evidence-based practices inform the success of the other goals of the Strategy, the Advisory Councils have identified the need for an enterprise data strategy which should be developed through a public-private partnership composed of three key groups:

1. Those federal and state bodies that collect and maintain data related to health care delivery and outcomes, health care utilization and associated cost, and demographic and epidemiological data, as well as data on a wide collection of lifestyle variables including health behaviors, employment, and income.

2. Private entities capable of either providing analogous data, such as actuaries, major employers, health insurers, and private entities capable of integrating data from multiple sources using advanced technology while assuring complete data privacy and security.

3. Academic institutions, technology start-ups, think tanks, researchers, nonprofit organizations, and national philanthropic organizations.

Governing Body

An enterprise data strategy should be informed and led by a governing body that would determine a process for understanding which data sets have the most utility for understanding family caregiving needs and supports. The governing body should work quickly to determine a process for standardizing data and creating a common data structure. This should include a uniform set of research questions to identify individuals as family caregivers. Questions about the family caregiving experience should also be integrated into existing data collection tools to expand insights into prevalence and trends in family caregiving. (Also supports **Outcomes 1.1**, **1.3**, and **5.3**)

Refer to The Changing Landscape of Family Caregiving in the United States by Vicki A. Freedman and Jennifer L. Wolf for a discussion of data sources and the challenges associated with measuring and defining family caregiving.

Such efforts will ensure that when researchers design studies, a common set of categories of data with a consistent taxonomy is used. The development of a body of knowledge using common terminology and data sets will allow researchers to compare data across caregiving populations and sectors. For example, as described in the RAISE Act initial Report to Congress, multiple surveys currently exist to count the prevalence of family caregiving. Each study has variations that prevent aggregating the data to create a full picture of the prevalence of caregiving. They use differing definitions of caregiving (e.g., “caregivers of older adults,” “grandparent-led households,” etc.), they define ages of care recipients differently (e.g., adults only vs. care recipients of all ages), and each uses a different time span for length of care (e.g., years vs. months). As a result, researchers cannot compare or combine data sets to identify the actual number of family caregivers in the U.S. In addition to consistent data definitions, a consistent data structure would standardize these disparate sources of information so that they could be aggregated and used to better understand and predict outcomes.

Data consistency and aggregation allows researchers to study population groups over time, homing in on actions and interventions for specific types of caregiving at precise stages of illness, helping family caregivers in the short term, and eventually longitudinally. Additionally, this consistent approach will allow data sharing between previously disparate partners so that older studies can be replicated and used to advance current research. It will also enable economists to continue to quantify how caregiving support impacts health care and social services outcomes and spending.

Data Storage and Access

Once a standardized data structure is determined and agreed upon, the participants in the partnership would need to develop processes for creating a shared repository designed to store, process, and secure large amounts of data with differing structures side-by-side. The ability to store that data in a range of formats and sizes will allow for flexibility as new types of data about caregiving emerge. From this pool of data, researchers would then be able to draw information and material for a variety of uses, such as research and prevalence studies, building algorithms, predictive analytics, and machine learning. To safeguard privacy of individuals and competitive data owned by firms participating in the effort, this process would need to include security measures such as information assurance and data safeguarding procedures.

In 2008, the Federal Aviation Administration (FAA) and the aviation industry developed the Aviation Safety Information Analysis and Sharing (ASIAS) program to promote an open exchange of safety information to continuously improve aviation safety. Over 200 public and private entities participate, which allows the FAA to draw together a wide variety of airline safety data and aviation information sources from across government and private industry. Its data set currently includes 99 percent of all U.S. air carrier operations in U.S. airspace.

Once the data is gathered, there would be a need to increase the analytical capability and information-sharing of researchers authorized to access the information. This will allow for analysis of non-related datasets into such topics as how family caregiver supports, like respite, affect nursing home admission rates. The governing body can also promote integration of caregiving-related queries into existing data collection tools to expand insights and understanding of trends in family caregiving.

Outcome 5.1 also calls for the establishment of a baseline of data that documents the impact of caregiving on finances, productivity, and profits so that these findings can be disseminated as part of **Outcome 1.1** and shape the development of services under **Outcome 3.1**. To achieve this, the outcome of 5.1 will depend on participation from stakeholders who may not think of themselves as part of the caregiving ecosystem, like retailers, financial institutions, and transportation providers.

State agencies and national, state, regional, and local philanthropic organizations are encouraged to collaborate with major employers to collect systemic data related to caregiving and ensure it reaches academic institutions. For example, researchers looking for the impact of paid leave on nursing home placements and reducing health care costs would benefit from data about use of leave from large employers who provide paid leave.

As the Advisory Councils have noted, there is no one-size-fits-all solution to supporting family caregivers. Other entities such as local chambers of commerce, unions, human resources societies, and insurance companies can also advocate for and participate in coordinated data collection and sharing for the purposes of creating a unified means of measuring and documenting the needs of family caregivers and what interventions support them.

Aligned Actions

Federal agencies have committed to **17 specific actions** within the coming years in support of **Outcome 5.1**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 5.

Outcome 5.2: Family caregiver research facilitates the development and delivery of programs and services that support and enhance the health and well-being of the family caregiver and the person receiving support.

From our Listening Sessions

> ***"One of the best ways to increase family caregiver research … is to either require or incentivize it."***

The availability of evidence-based and evidence-informed interventions is important for the delivery of an array of person-centered, trauma-informed services and supports described under **Outcome 3.1**. In addition to creating an enterprise data strategy related to caregiving to support **Outcome 5.1**, major research institutions and philanthropic organizations may wish to partner in a parallel effort with other stakeholders in the research community to establish a national research agenda on caregiving. This agenda should prioritize research goals for the coming decade and ensure that those goals are aligned with the Strategy and that the data collected is interoperable with the enterprise structure described above. Priorities of the research agenda could include:

- Advancing research on the modeling and measurement of the total value of family caregiving and translating these models and measurements into research leading to findings to guide business models, health systems, insurers and payers, and employers. (Also supports **Outcomes 2.1**, **4.1**, **4.2**, and **4.3**)
- Developing models for the sharing of health information with family caregivers that honor and promote self-direction and autonomy for the person receiving support. (Also supports **Outcomes 2.2** and **2.3**)
- Encouraging the study of family caregivers in the workplace, including the role of the employer and the value of employers investing in workplace caregiving/family supports. (Also supports **Outcome 4.2**)

- Stimulating the next generation of family caregiver support programs (i.e., interventions) that build on the approaches and mechanisms proven effective in prior research but are adapted to the needs of family caregivers in communities that have traditionally not been represented in caregiver support programs.

- Promoting the development and use of culturally competent and meaningful family caregiver assessment tools.

- Aligning existing protocols in health and social service provider systems to facilitate rapid transition from research to services. (Also supports **Outcomes 2.2** and **5.3**)

- Promoting research of cutting-edge technologies and devices that could assist family caregivers with caregiving tasks or reduce an individual's need for care and family caregiver burden. These technologies would need to be designed with participation from people with disabilities and could include assistive technology for monitoring the location and physical condition of the person receiving support, remote home monitoring, and/or web-based applications to facilitate the delivery of evidenced-based programs. (Also supports **Outcome 3.5** and **5.1**)

- Coordinating and supporting data on the need and value of the direct care workforce, as well as programs that support and develop the careers of direct care workers. (Also supports **Outcome 3.9**)

- Increasing translation and dissemination of promising and evidence-supported practices and models of care to support family caregivers when they are identified in health care and long-term services and supports delivery settings. (Also supports **Outcome 5.3**)

- Capturing the potential health care/taxpayer dollar savings over time with expansion of coverage for long-term services and supports within not only Medicaid but also Medicare and private insurance over time, and how that could lower costs and improve health and quality of life. (Also supports **Outcome 4.1**)

- Coordinating and supporting data on children and kin and grandparent caregivers of children outside the child welfare system, including those who come to the attention of the child welfare system but are diverted to the care of grandparents or other kin without the benefit of supports and services. (Also supports **Outcome 5.1**)

Once an agenda is established to allow for information sharing between institutions and ongoing support and maintenance, stakeholders may wish to create a caregiving research portal that uses open architecture design principles and can be accessed by a range of researchers. Developers may want to include a "public domain" view so that caregivers and non-research-based stakeholders of evidence-based practices can review findings and participate in discussions. States can support this by collecting more and disaggregated data on family caregiving and the long-term care workforce and sharing that data with researchers. Community-based organizations can collect and report data on their work, through financial incentives (such as funding administrative cost, data collection, and research learning) or through non-financial incentives (such as technical support and training) that directly support their programs and services. These funded resource incentives should ensure best practices about the collection of data are followed.

Aligned Actions

Federal agencies have committed to **20 specific actions** within the coming years in support of **Outcome 5.2**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 5.

Outcome 5.3: Promising and evidence-informed practices are promoted, translated, and disseminated to support family caregivers in the delivery of health care and social services.

There are few proven interventions available for family caregivers at the present time. Those that have been developed tend to focus on family caregivers of people with dementia, and most of those programs have yet to be translated for delivery in real-world settings. The nation must commit to funding and conducting consistent research into culturally adaptable family caregiver interventions for a range of circumstances and translating existing research for delivery in clinical and social services systems (defined widely to include all health care settings, community-based organizations, and home-based care providers).

From our Listening Sessions

> ***" … This question of, what do we know about what works in terms of supporting family caregivers around the transitions and care that will produce better outcomes? And I think that's a big, big, big question and unknown."***

Some policymakers have expressed concern that greater research and data on caregiving would lead to a demand for services that could outstrip ability to fund such services. However, until economists and data scientists can determine the economic value of caregiving and costs in terms of lost opportunities, tax revenue, and spending and reduced productivity, states have incomplete data on the actual return on investment in supporting family caregivers. Advocates suspect that when all factors are considered, supporting family caregivers may prove to be the efficient financial model for providing long-term services and supports.

Researchers and the entities that fund them can lead this effort through designing and advocating for research into interventions and models that are aligned with the Strategy. These interventions should be person- and family-centered, trauma-informed, and adaptable to a range of caregiving circumstances, needs, and cultural sensitivities. (Also supports **Outcome 3.1**) A key component of these efforts should be the coordination and support for data collection and demonstrations to improve the direct care workforce. (Also supports **Outcome 3.9**)

Advocates, funding entities, researchers and administrative leaders have a critical role in the prioritization of the development and testing of family caregiver identification tools that health care and service providers can use to efficiently identify patients and clients as family caregivers, including efforts to support a person's ability to self-identify as a family caregiver with comfort. This could include:

- Innovations in which family caregivers are identified and engaged via electronic health records (EHR), with the consent of the person receiving support.
- Models of care that seamlessly integrate care provided by health care providers with community-based social service providers. (Also supports **Outcome 1.2**, **2.1**, and **2.2**)
- Independent evaluations of family caregiver services and supports, so promising practices can be identified and scaled up.

All available technologies should be explored as a means of supporting wider availability of existing evidence-based programs, most of which were designed for in-person delivery, which has become increasingly difficult.

The findings of research advances suggested above can be used to support various aspects of the Strategy. For example, public relations and media professionals supporting the campaigns described under **Outcome 1.1** can use caregiver assessment tools to advance awareness of the availability of proven ways of supporting family caregivers. Health care systems and hospitals may wish to identify a dedicated resource to serve as a family caregiver experience officer/ambassador to develop and oversee best practices for engaging family caregivers in the entire medical experience, including pre-hospital services, pre-discharge planning, and post-discharge care in support of **Outcome 2.3**. Through state-level coalitions, states, community-based organizations, faith-based organizations, and philanthropic organizations can create and share toolkits to educate and support professionals working with family caregivers to support **Outcome 2.5**.

Aligned Actions

Federal agencies have committed to **15 specific actions** within the coming years in support of **Outcome 5.3**. See "**Actions for Others**" for more than 50 additional actions that states, communities, and other stakeholders can take to support Goal 5.

Indicators of Success: Data, Research, and Evidence-Based Practices

As the actions under Goal 5 are implemented, the supports and services offered to family caregivers will increasingly be developed using rigorous data and research practices. Examples of such changes include:

- State, tribal, local, and federal programs have information collection processes on family caregiving across the lifespan that are consistent and comparable between programs and governmental entities.
- A formal data collection process, coordinated at a national level, leads to a body of evidence to develop, plan, and coordinate resources, services, and supports, and helps to identify and document the economic value of family caregiving.
- Researchers can document the needs and impact of caregiving on different types of family caregivers across the lifespan.
- A core set of family caregiver questions is available to add to existing national and state surveys.
- Surveys are available in a variety of formats and languages so that as many family caregivers as possible can participate.
- Family caregivers and the people receiving support are involved as research partners in the design and the delivery of services and plan a prominent role in the successful utilization, evaluation, and sustainment of needed services.
- Family caregivers see themselves fully represented in evidence-based practices that will improve their health and well-being and the health and well-being of those for whom they care.
- Family caregiver support programs (i.e., interventions) are adapted to the real-world experiences of today's caregivers.
- Family caregiving programs and interventions are evaluated to inform the evidence base for promising practices and lessons learned (i.e., what works and what does not).

- Researchers have access to consistent data that allows them to measure progress toward achieving the goals of the Strategy.
- Organizations can scale up practices and supports that are proven to be impactful and cost-effective.
- Researchers have data on the number of and well-being of children in grandfamilies outside of the foster care system.

Conclusion

The 2022 National Strategy to Support Family Caregivers proposes an ambitious list of approaches that, if acted upon, would begin to move the nation toward ensuring that family caregivers are recognized, assisted, included, supported, and engaged across the lifespan. National change for caregiving in this country will require participation from individuals and a range of stakeholder sectors: federal government, states and tribes, philanthropic organizations of all sizes, community-based organizations, faith-based organizations, school districts, health systems, insurance payers, researchers, universities, and every one of us. As each sector and individual takes steps to achieve the vision of the Strategy, the Advisory Councils urge that five foundational issues remain front of mind:

1. **Every American who lives long enough is likely to become a family caregiver, need a family caregiver, or both.**

2. **Family caregivers and care recipients must be included.** At every step of the way, entities must engage family caregivers and the people they support in the planning, execution, and evaluation of any activities designed to advance the vision of this Strategy. Such an approach will ensure that outreach, engagement, policies, services and supports, and new initiatives are accessible, person- and family- centered, trauma-informed, and can meet the needs of the populations they are intended to serve.

3. **Actions to support family caregivers must be aligned.** It is critical that actions of stakeholders be aligned with the Strategy to optimize success. The Advisory Councils reviewed and considered thousands of suggestions, recommendations, actions, and ideas. The information included within the 27 outcomes of this Strategy is a distillation of the best approaches identified through a range of data collection efforts, including focus groups, interviews, briefings, and formal requests for information. While the Advisory Councils understand that further iterations of this strategy will be necessary ongoing, the outcomes and actions contained here represent promising initial steps informed by the most up-to-date understanding of how best to immediately and consistently address the support needs of millions of family caregivers in a range of circumstances.

4. **Cross-cutting considerations.** Stakeholders are urged to read the overview of cross-cutting considerations that affect family caregiving and adopt the essential practices to support infusing person- and family centeredness, trauma-informed care, and support for direct care workers into caregiver services and supports. See First Principles: Cross-Cutting Considerations for Family Caregiver Support.

5. **There is much more work to be done.** The publication of the Strategy is a beginning, not the end. As government and stakeholders in the public and private sectors begin to implement the Strategy, they must also look for opportunities to collaborate within and across sectors, leverage resources (and authorities, within government agencies) to create the greatest impact, and continue to seek opportunities to achieve the outcomes identified by the Advisory Councils.

The U.S. sits on the precipice of unprecedented demographic changes that will result in a greater need for family caregivers. This first National Strategy to Support Family Caregivers provides the foundation to motivate and inform independent undertakings by all stakeholders and sectors, as well as guide and direct outcomes toward a unified vision—one in which *family, kin, and grandparent caregivers* are recognized and supported for their tremendous, and often life-changing, efforts on behalf of others.

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1 For specific discussion on how fostering an agile, flexible, and well-trained direct care workforce can benefit family caregivers, see Outcome 3.9 under Goal 3: Strengthen services and supports for family caregivers.

2 For a literature review on the impact of caregiver dyads on outcomes, see Jacops R, Hopkins CS, Fasolino T (2022) Patient-Caregiver Dyad: A Systematic Review Informing a Concept Analysis. Int J Nurs Health Care Res 5: 1298. DOI: https://doi.org/10.29011/2688-9501.101298

3 See the Supporting Grandparents Raising Grandchildren Act Initial Report to Congress. Released by The Administration for Community Living, November 2021.

4 For additional information on TANF, see https://www.gao.gov/assets/gao-12-2.pdf

5 For a discussion on the existing research on how caregivers benefit society of family caregiving, see “Societal Benefits” in Families Caring for an Aging America.

6 The Family Medical Leave Act only applies to grandparents, parents, spouses and children. Siblings, aunts, uncles are not included – as well as other non-traditional family members and domestic partners.

7 Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine; Schulz R, Eden J, editors. Families Caring for an Aging America. Washington (DC): National Academies Press (US); 2016 Nov 8. Available from: https://www.ncbi.nlm.nih.gov/books/NBK396401/ doi: 10.17226/23606

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Appendix A: Participating Non-Federal Stakeholders

The following individuals served as non-federal members of the Advisory Councils.

RAISE Act Family Caregiving Advisory Council

- Ben Bledsoe, M.H.A., President/CEO of the Consumer Direct Care Network
- Joe Caldwell, Ph.D. family caregiver and the Director of the Community Living Policy Center at the Lurie Institute for Disability Policy, Brandeis University
- Diane Caradeuc, family caregiver and federal government retiree
- James S. Cheely, family caregiver and project manager with a general contracting company from Glasgow, Kentucky
- Jisella Dolan, family caregiver and Global Chief Advocacy Officer for Home Instead Senior Care®
- Brenda Gallant, R.N., Executive Director of the Maine Long-Term Care Ombudsman Program
- Catherine Alicia Georges, Ed.D., RN, FAAN, family caregiver and former AARP National Volunteer President
- Rhonda J.V. Montgomery, Ph.D., family caregiver and co-founder of TCARE, Inc.
- Nancy Murray, M.S., family caregiver and President of The Arc of Greater Pittsburgh and Senior Vice-President of Achieva.
- James Murtha, III, MSW, person with a disability and receiver of family caregiving, mental health therapist, policy advocate for disability rights, and volunteer with the Christopher and Dana Reeve Foundation
- Casey R. Shillam, Ph.D., RN, family caregiver, dean, and professor at the University of Portland School of Nursing
- Alan B. Stevens, Ph.D., former family caregiver, Vernon D. Holleman-Lewis M. Rampy Centennial Chair in Gerontology at Baylor Scott & White Health
- Deborah Stone-Walls, family caregiver and member of USAging
- Theresa Tanous, M.H.A., family caregiver and federal government retiree
- Carol Zernial, M.A., Executive Director of the WellMed Charitable Foundation

Advisory Council to Support Grandparents Raising Grandchildren

Jaia Peterson Lent, deputy executive director of Generations United

- Ethlyn McQueen-Gibson, D.N.P, M.S.N, R.N.-B.C., associate professor and director of Gerontology Center of Excellence at Hampton University
- Martha R. Crowther, M.P.H, Ph.D., associate dean for research at the University of Alabama, College of Community Health Sciences
- Patrick Donavan, supervisor with Muskingum County (Ohio) Adult and Child Protective Services
- Gail Engel, grandparent and founder of Grand Family Coalition
- Sarah Hedden, B.S., M.S.W, J.D., attorney with the Kinship Care Legal Services Program at the Center for Elder Law & Justice in Buffalo, New York
- Bette Hoxie, former director of Adoptive and Foster Families of Maine, Inc. & the Kinship Program
- Toni Kleckley, M.A. D.Th., grandparent and founder and executive director of Trans4mation Now Inc., and the Grandparents Educating Minds program
- Yvonne S. Lee, M.S.W., professor at West Virginia State University
- Linda Miller, R.N., director of the Iowa Department on Aging
- Sharon Olson, grandparent and past president of the Minnesota Kinship Caregivers Assoc.
- Sarah L. Smalls, grandparent and family resource coordinator for Formed Families Forward
- Charlotte Stephenson, grandparent and advocate

Focus Groups and Key Informant Interviews

Representatives from the following organizations provided input to the focus groups and/or interviews.

- AARP
- Access Living
- Alabama Department of Aging
- Alliance of Disability Advocates
- ALU LIKE, Inc.
- Alzheimer's Association
- Alzheimer's Orange County
- American Bar Association
- American Network of Community Options and Resources (ANCOR)
- Apna Ghar Home Care
- Arizona Caregiver Coalition
- Association of Programs for Rural Independent Living (APRIL)
- ATI Advisory
- Autistic Self Advocacy Network
- Autism Society of America
- Benjamin Rose Institute on Aging
- Best of Care Inc.
- Brookdale Foundation
- California Long-Term Care Education Center
- Caregiver Action Network
- Cariloop
- Caring Together, Living Better (CTLB), AgeOptions
- Center for Family Support, University of Pittsburgh
- Center for Parent Information and Resources
- Center to Advance Palliative Care
- Chicago Department of Family & Support Services
- Claude Worthington Benedum Foundation
- Coalition to Transform Advanced Care (C-TAC)
- Colorado Cross-Disability Coalition
- Colorado Department of Health Care Policy & Financing
- Continuum of Colorado

- CVS Health
- Dana-Farber Cancer Institute
- Disability Policy Consortium
- Douglas County, NE Board of Commissioners
- Duke-Margolis Center for Health Policy, Duke University
- Eastern Idaho Community Action Partnership (EICAP)
- Easterseals Iowa
- Elizabeth Dole Foundation
- Epilepsy Foundation
- Family & Nursing Care
- Family First
- FamilyMeans
- Federal Reserve Bank of Kansas City/New Mexico Caregivers Coalition
- Five County Area Agency on Aging
- Foster Kinship
- Generations United
- Global Coalition on Aging (GCOA)
- Ha Kupuna (National Resource Center for Native Hawaiian Elders)
- Harvard Business School
- Health Management Associates
- Helper Bees
- Helping Hands of Vegas Valley
- Henry Ford Caregiver Assistance Resources and Education Program
- House Works, LLC
- Independent Living Research Utilization (ILRU)
- Institute for Healthcare Improvement (The Conversation Project)
- Integrated Benefits Institute
- Iowa CareGivers
- iRobot
- Jewish Family Service of Saint Paul (JFS)
- Jewish Federation of North America
- J-Sei
- Justice in Aging
- KBH Advocacy
- L'Arche USA

- LeadingAge
- Learn Care Together LLC
- Little Lobbyists
- Little Tokyo Service Center
- L'Orech Yomim/Center for Healthy Living (LOY)
- Lucile Packard Foundation for Children's Health
- Lunalilo Home
- MAC, Inc. Maryland Living Well Center of Excellence
- Massachusetts Digital Health Initiative
- Massachusetts Executive Office of Elder Affairs
- Massachusetts Lifespan Respite Coalition
- MCM CPAs and Advisors, LLP
- Meals on Wheels America
- Missouri Rural Health Association
- Montana Family to Family Health Information Center
- National Alliance for Direct Support Professionals (NADSP)
- National Association for Home Care & Hospice (NAHC)
- National Association of Counties (NACo)
- National Association of Nutrition and Aging Services Programs (NANASP)
- National Brain Health Center for African Americans, Balm in Gilead
- National Catholic Partnership on Disability
- National Council on Aging (NCOA)
- National Disability Rights Network (NDRN)
- National Rural Health Association (NRHA)
- National Senior Corps Association
- Native American Outreach Program, Banner Alzheimer's Institute
- Nevada Office of Aging & Disability Services
- New Mexico Caregivers Coalition
- North Dakota Respite Coalition
- Nourish for Caregivers
- Office of Hawaiian Affairs
- OK Cares
- Paralyzed Veterans of America
- Philadelphia Corporation on Aging
- Rethink First

- Rhode Island Department of Human Services
- Rural Dementia Caregiver Project, University of California, San Francisco
- Silberman Aging, Hartford Center of Excellence in Diverse Aging
- South Carolina Respite Coalition
- Southern Caregiver Resource Center (SCRC)
- The Alzheimer’s Project
- The Renaissance Collaborative (TRC)
- The Resource Exchange (TRE)
- The Urban Institute
- Torchlight
- Trellis
- United for Caregivers@Work
- United Methodist Health Ministry Fund
- United Way of Rhode Island/Family Caregiver Alliance of Rhode Island
- University of California, San Francisco Healthforce Center
- University of Iowa
- University of Minnesota Rural Health Research Center
- Us Against Alzheimer’s/Latinos Against Alzheimer’s
- Vision for Equality
- Warrior Care Network, Wounded Warrior Project
- Washington County Disability, Aging, and Veteran Services
- Wellthy
- Working Daughter
- Yale New Haven Health/Geriatric Emergency Department Collaborative
- Zen Caregiving Project

Appendix B: Resources Used in the Development of the Strategy

- Building a National Strategy to Support Family Caregivers: Findings from Key Informant Interviews and Stakeholder Listening Sessions by Pamela Nadash, Ph.D.; Taylor Jansen, M.S.; Eileen J. Tell, M.P.H.; and Marc Cohen, Ph.D.

- In Their Own Words-Family Caregiver Priorities and Recommendations: Results from a Request for Information by Pamela Nadash, Ph.D.; Taylor Jansen, M.S.; Eileen J. Tell, M.P.H.; and Marc Cohen, Ph.D.

- Inventory of Key Family Caregiver Recommendations

- Medicaid Supports for Family Caregivers by Neva Kaye and Salom Teshale, Ph.D.

- Medicare and Family Caregivers by Judith A. Stein, Executive Director, and David A. Lipschutz, Associate Director, of the Center for Medicare Advocacy

- RAISE Act State Policy Roadmap for Family Caregivers

- RAISE Family Caregivers Act Initial Report to Congress

- Recordings and transcripts of meetings of the Advisory Council to Support Grandparents Raising Grandchildren

- Recordings and transcripts of meetings of the RAISE Family Caregivers Act Advisory Council

- SGRG Act Initial Report to Congress

- Supporting Family Caregivers of Older Adults with a History of Trauma: Implementation Recommendations for the National Family Caregiving Strategy by the Jewish Federations of North America

- Supporting Grandparents Raising Grandchildren: Resources for Consumers and Professionals

- What Family Caregivers Need: Findings from Listening Sessions

Acronyms and Abbreviations

- AT: Assistive technology
- ACF: Administration for Children and Families
- ACL: Administration for Community Living
- ADL: Activities of daily living
- ADPI: Alzheimer’s Disease Programs Initiative (ACL)
- ADRD: Alzheimer’s disease and related dementias
- ASPE: HHS Office of the Assistant Secretary for Planning and Evaluation
- ASPR: HHS Office of the Assistant Secretary for Preparedness and Response
- CARE Act: Caregiver Advise, Record, and Enable Act
- CDC: Centers for Disease Control and Prevention
- CFPB: Consumer Financial Protection Bureau
- CHIP: Medicaid and Children’s Health Insurance Program (CMS)
- CMS: Centers for Medicare & Medicaid Services
- CSP: Caregiver Support Program (VA)
- DCW: Direct care workforce (or workers)
- DOL: U.S. Department of Labor
- DME: Durable medical equipment
- EAP: Employee assistance programs
- ED: U.S. Department of Education
- FAA: Federal Aviation Administration
- FBO: Faith-based organization
- FEMA: Federal Emergency Management Agency
- GAO: U.S. Government Accountability Office
- HCBS: Home and community-based services
- HHS: U.S. Department of Health and Human Services
- HRSA: Health Resources and Services Administration
- I/DD: Intellectual and developmental disabilities
- IHS: Indian Health Service
- JAHF: The John A Hartford Foundation
- LGB: Lesbian, gay, bisexual
- LTC: Long-term care
- NAC: National Alliance for Caregiving
- NASHP: National Academy for State Health Policy

- NFCSP: National Family Caregiver Support Program (ACL)
- NIA: National Institute on Aging
- NIH: National Institutes of Health
- OAA: Older Americans Act
- PTSD: Post-traumatic stress disorder
- RAISE: Recognize, Assist, Include, Support, & Engage Act of 2017
- RFI: Request for information
- SDM: Supported decision making
- SAMHSA: Substance Abuse and Mental Health Services Administration
- SGRG: The Supporting Grandparents Raising Grandchildren Act
- TANF: Temporary Assistance for Needy Families
- VA: U.S. Department of Veterans Affairs