National Strategy to Support Family Caregivers

2026 UPDATE

Developed by:

The RAISE Act Family Caregiving Advisory Council and the
Advisory Council to Support Grandparents Raising Grandchildren

Coordinated by:

The Administration for Community Living,
an operating division of the U.S. Department of Health and Human Services



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Foreword

Family caregivers help older adults and people with disabilities live in their homes and communities, support loved ones with chronic illness, and step in as grandparents or other relatives when children need them.

This Strategy begins with a simple recognition. Families carry much of the responsibility for care, yet too often must navigate fragmented systems that fail to recognize or support them. The National Strategy to Support Family Caregivers provides a framework to strengthen caregiver supports, improve coordination, expand the evidence base, and address the direct care workforce families depend on.

Under President Trump's leadership, the U.S. Department of Health and Human Services (HHS) is working to Make America Healthy Again by confronting chronic disease and putting prevention first. Caregivers' health belongs in that mission. We must help them find support, protect their own well-being, and continue caring for those who rely on them.

We thank the RAISE Family Caregiving Advisory Council, the Advisory Council to Support Grandparents Raising Grandchildren, caregivers, care recipients, federal partners, and others whose expertise shaped this update. We also value the continued partnership of The John A. Hartford Foundation and the National Academy for State Health Policy (NASHP) in advancing implementation of the RAISE Act.

The measure of this Strategy is what it delivers for American families. By protecting caregiver health, expanding choice, strengthening the workforce, removing unnecessary barriers, and focusing resources on what works, we can make caregiving more sustainable, strengthen families, and build a healthier America.

Robert F. Kennedy, Jr.
Secretary
U.S. Department of Health and Human Services

Mary Lazare
Principal Deputy Administrator
Administration for Community Living

Executive Summary

The **2026 update to the National Strategy to Support Family Caregivers** strengthens the national framework for supporting family caregivers and the people they assist. Developed jointly by the RAISE Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren, with coordination by the Administration for Community Living, the update builds on the 2022 Strategy and adds a sixth goal dedicated to strengthening the direct care workforce.

The report describes a substantial and growing need for coordinated support. It cites an estimated 63 million Americans providing family care, while acknowledging that estimates vary with survey definitions and methods. Caregivers face fragmented service systems, limited access to respite and training, financial strain, and challenges balancing employment with caregiving. Grandparents and other relatives raising children, youth caregivers, and families in rural, frontier, and tribal communities face additional barriers.

Progress since 2022. The original Strategy included nearly 350 actions across 15 federal agencies and more than 150 recommended actions for nonfederal partners. A September 2024 progress report found that nearly all original federal actions were completed or underway, with agencies committing to nearly 40 additional actions. A separate 2024 report found that 72% of surveyed states used the Strategy to inform caregiver policy work. These findings demonstrate broad implementation activity, while continued evaluation is needed to assess results for families.

The update advances six priorities:

1. **Increase awareness and outreach.** Improve caregiver identification, use trusted communication channels, simplify referrals, and involve caregivers in policy and service planning.
2. **Strengthen caregiver partnerships.** Recognize caregivers as essential care team partners when desired and appropriate; document their roles; assess their willingness, capacity, and needs; and improve professional training. The update explicitly respects adult care recipients' choices about caregiver involvement and access to protected information.
3. **Improve services and supports.** Expand flexible respite, navigation, training, counseling, and peer support. Strengthen assistance for kinship families and grandfamilies, including those raising children outside the child welfare system.
4. **Protect financial and workplace security.** Promote caregiver-supportive employment practices, greater awareness of available resources, and access to financial planning and counseling. The revised goal explicitly includes the care recipients whom caregivers support.

5. **Strengthen data, research, and evaluation.** Standardize caregiver definitions and measures, expand longitudinal and cost-effectiveness research, and support evidence-based and evidence-informed practices. A new outcome calls for nationally representative data on youth caregivers.
6. **Expand access to a skilled direct care workforce.** Elevate workforce development into a standalone goal, recognizing that paid workers complement family care and enable respite, employment, and community living. Four outcomes address recruitment, training, retention, and workforce data. Priorities include competitive compensation, supportive workplaces, accessible training, and career advancement.

Implementation and accountability. The Strategy calls for coordinated action across federal, state, and local governments, healthcare systems, employers, schools, community organizations, researchers, and philanthropy. Its recommendations do not compel adoption. Success therefore depends on partners translating the framework into sustained action, reducing administrative barriers, and measuring improvements in caregiver health, financial stability, access to support, and care recipients' independence and choice.

Introduction

Every day, millions of people put aside their own needs, often suddenly, to care for family members. These family caregivers include spouses supporting spouses, parents supporting children with significant disabilities or complex medical needs, adult children caring for aging parents, grandparents and other kin who step in to raise children, and youth who assist with the needs of family members. Family caregivers and the people they support hail from every corner of the nation and reflect every aspect of our society.

Federal efforts to support family caregivers have gained momentum in recent decades. In 2000, the reauthorization of the Older Americans Act created the National Family Caregiver Support Program and the Native American Caregiver Support Program.

Congress enacted the Lifespan Respite Care Act in 2006, followed by the Caregivers and Veterans Omnibus Health Services Act in 2010, and the National Alzheimer's Project Act in 2011. These milestones in federal support of family caregivers, coupled with growing efforts in states, communities, and across multiple sectors, help recognize family caregivers and address their complex needs.

Despite these notable advances, the United States lacked a clear, cohesive approach to coordinating efforts across public and private sectors. To address this gap, Congress passed the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2017, establishing the first federal Family Caregiving Advisory Council and calling for a national strategy to support family caregivers. In 2018, Congress authorized the Supporting Grandparents Raising Grandchildren (SGRG) Act, which established the Advisory Council to Support Grandparents Raising Grandchildren to make recommendations and identify best practices to support grandparents and other relatives who have opened their homes to children unable to remain with their parents.

The need for a cohesive strategy is supported by the realization that by 2030, 1 in 5 Americans will be 65 or older — and will outnumber children under 18. Meanwhile, about 46 million Americans live with a disability, representing more than 1 in 10 in the general population and 1 in 4 adults. In addition, nearly 1 in 5 children today have a disability or special healthcare need, including about 1.2 million children living with medical complexities.

In 2022, the Advisory Councils released the initial National Strategy to Support Family Caregivers (the Strategy). This first-of-its-kind roadmap, built through collaboration across the federal government and the private sector — along with considerable public input, including that of family caregivers — marked another important milestone in addressing the longstanding need for a comprehensive system of family caregiver support.

The Strategy included commitments from 15 federal agencies to nearly 350 actions to implement five goals and 26 outcomes identified by the Advisory Councils as essential for meaningful change on behalf of family caregivers. These actions included new demonstration programs to support family caregivers, efforts to collect and analyze data to better understand their needs, and educational materials and resources to increase their knowledge and confidence.

Recognizing that federal agencies alone cannot address the issue, the original Strategy also included over 150 recommended actions for states, communities, businesses, philanthropic organizations, and others.

Impact to Date

Two reports have documented the progress made by both the federal and non-federal sectors to implement the Strategy. In September 2024, the Administration for Community Living (ACL) released a report to Congress, *Progress Report: Implementation of the 2022 National Strategy to Support Family Caregivers*. Of note, this report stated that nearly all 350 federal actions had either been completed or were in progress. The report also listed nearly 40 additional actions that federal agencies had committed to since the Strategy's release. These actions included programs and initiatives to directly support caregivers, improve efficiency and coordination of services, and open doors to international engagement and collaboration.

Additionally, the progress report described partnerships and collaborations across government designed to accelerate progress toward the Strategy's vision. Government agencies, advocates, and stakeholder groups representing a wide variety of interests and industries, and family caregivers and care recipients came together to support the implementation and ongoing development of the Strategy.

In October 2024, NASHP issued its *National Strategy to Support Family Caregivers Progress and Impact Report: State and Community Actions*, focused on data gathered from multiple sources, including state government agencies, community-based organizations, national advocacy organizations, funders, philanthropic organizations, and others. Of note, NASHP's report found that 72% of surveyed states used the Strategy to inform their family caregiver-related policy work. Additionally, 15 of 26 states with multisector/strategic plans in place or in progress were using the Strategy to inform their work. States reported using the Strategy in a variety of ways, ranging from furthering work with governors' offices and state legislators to promoting cross-agency collaboration and engaging communities of interest.

2026 Strategy Update

The RAISE Act mandates regular updates to the Strategy, making it a living document that evolves over time to reflect the current landscape of family caregiver support and associated policies, research, and advocacy efforts. This first update builds on and expands the concepts outlined in the original Strategy.

The Advisory Councils worked together to develop this update with leadership from ACL and active participation from federal agencies. Additionally, significant technical support was provided by NASHP under its grant from The John A. Hartford Foundation.

The 2026 update to the Strategy includes revisions to Goals 1 through 5 and a new Goal 6 focused on the direct care workforce shortage.

While the Advisory Councils believe the recommendations for the federal government, states, communities, and other stakeholders have the potential to positively impact the pressing issue of caregiver support and are necessary, they do not have the authority to require adoption by any agencies or entities.

Goal 1: Increase Awareness of and Outreach to Family Caregivers

Overview

The first step in improving support for family caregivers is increasing awareness of the role caregivers play and the challenges they face. Although family caregiving plays a critical role in health outcomes, family caregivers too often are not recognized in the healthcare, long-term services and supports (LTSS), and child welfare systems. In addition, many people who provide family caregiving support to others do not think of themselves as "family caregivers" and often do not know that training, assistance, and other supports are available when they need them.

Recent research indicates that people who self-identify as family caregivers are more likely to report having confidence in accessing services and supports, though this does not necessarily mean they are aware of all available resources or can easily navigate complex systems. However, emotional strain and isolation become barriers to self-identification, engagement, and persistence in seeking support. Changing this requires healthcare and service providers, government agencies, employers, and community-based organizations to take focused approaches to successfully recognize, identify, reach out to, and effectively support family caregivers.

Goal 1 of the Strategy aims to increase awareness of family caregiving and to build and strengthen communication channels and methods to reach and include family caregivers in policy development and planning. While such outreach efforts should be coordinated across the public and private sectors with consistent overall themes, the actual approaches and messages must meet the unique needs of local communities and populations.

In the years since the Strategy's release, public awareness campaigns focused on family caregiving have helped shine a light on the importance of family caregiving and the availability of supports. National Family Caregivers Month, for example, has grown into a robust platform for recognition and education.

While the Councils made no changes to Goal 1 and its outcomes as they appeared in the original Strategy, they called out several opportunities for further advancement in this area. For example:

- **Many family caregivers are still unaware of available services.** In a national poll released in 2024, 67% of U.S. residents over age 50 were not familiar with area agencies on aging — even though these agencies are often the gateway to essential services. Awareness gaps are particularly pronounced in rural and frontier communities, especially where limited broadband access and fewer outreach channels constrain information dissemination.
- **More work is needed to educate healthcare professionals** to prevent missed opportunities to formally identify caregivers. Without routine caregiver screening protocols or standardized documentation practices, caregivers remain invisible to clinical and social service systems, despite the role they play in health outcomes.
- **Fragmented and inconsistent messaging limits engagement.** Family caregivers frequently encounter inconsistent eligibility criteria, program requirements, and access points across federal, state, employer, and nonprofit systems. This can create confusion, increase administrative burden, and discourage follow-through, particularly for caregivers already experiencing time and financial strains.
- **Barriers to caregiver participation in planning efforts persist.** Many caregivers are unaware of opportunities to participate in advisory bodies or community forums. Those who want to participate face logistical challenges — including lack of compensation, childcare, or transportation — that disproportionately exclude lower-income caregivers from sustained engagement.
- **Family caregiving policies in the private sector remain heavily stratified by socio-economic standing.** While some employees benefit from flexible scheduling and employer-sponsored caregiver benefits, service-sector workers, part-time staff, and gig workers often lack access to comparable supports. This exacerbates financial strain and increases stress, especially among lower-income caregivers.

Council Priorities

The Advisory Councils recognize the ongoing need for:

- **Effective use of multi-media communications channels** — TV, radio, social media, and trusted community messengers — to reach caregivers of varied backgrounds, values, and communication styles and increase awareness of available services, normalize talking about family caregiving and its impacts, and reduce stigma for caregivers who seek supports.

- **Building caregiver needs into policies and protocols**, such as incorporating caregiver identification fields into electronic health records, developing standardized referral pathways, and integrating key concepts in screening tools and educational materials in healthcare and community-based settings can help engage individuals who do not use the term "caregiver" to describe their role.
- **Cross-sector collaboration** to help ensure that available support capacity adjusts to increased demand, is consistent and effective, and reduces the likelihood that caregivers encounter a dead end once they seek help. These collaborations can involve state, local, and federal agencies, healthcare providers, philanthropic organizations, faith institutions, employers, and schools.
- **Active engagement of family caregivers in policy planning activities** for public health, service delivery, outreach, transportation, housing, and other sectors. For example, caregiver councils can provide meaningful input on the potential impact of state and local policies and planning.
- **Promotion of caregiver-friendly policies and practices across sectors**, including family caregiving coalitions, caregiver-friendly workplace practices, public-private partnerships for data and resource sharing, and innovative grant models, such as Community Care Corps, to help foster broader collaboration among nonprofits, funders, and governments.

Goal 2: Advance Partnerships and Engagement with Family Caregivers

Overview

Family caregivers play important roles in maintaining and improving the health and well-being of the individuals they support. They help manage medications, coordinate appointments, oversee education planning, and assist with essential activities of daily living (ADLS), such as bathing, dressing, eating, and toileting, and independent activities of daily living (IADLS), such as meal preparation, medication management, transportation to appointments, and grocery shopping. They do this often while working part-time or full-time jobs and juggling other family and community responsibilities.

However, too frequently this work goes unrecognized and unsupported by healthcare and service providers. Family caregivers often feel isolated and left out of decision-making processes, adding to the stress and strain of family caregiving. For example, hospitals may fail to notify caregivers before patient discharge, or healthcare providers may not consider caregiver schedules and availability when scheduling follow-up appointments.

Goal 2 of the Strategy aims to better integrate and empower family caregivers — across care teams and care settings — in decision-making and policy development processes in all areas of healthcare, education, and social services systems.

Policies such as the Caregiver Advise, Record, Enable (CARE) Act, which mandates hospitals to recognize and engage family caregivers, have improved integration within care teams. While this policy holds promise, it only applies to hospital settings, and its use varies by state. More widespread implementation of the CARE Act and application of similar principles across care settings are needed to help ensure that family caregivers become integral partners in the care teams of the people they support.

Council Priorities

The Advisory Councils focused their discussions on strengthening the Goal 2 outcomes based on the following priorities:

- **Greater engagement and recognition of family caregivers** of all ages and types as essential partners in care teams of the people for whom they provide support.
- **Increased leverage of policies and processes** — including managed care plan contracts, electronic health records, and provider training — to better identify caregivers, provide or refer them to services, coordinate care, and train caregivers on performing medical tasks.
- **Greater use of family caregiver assessments** as a routine part of care planning to understand caregiver willingness and capacity to assist in delivering care, as well as unique needs and preferences of caregivers and care recipients.
- **Identification and replication of best and promising practices** for engaging caregivers as part of the care team, so that care team integration becomes a commonplace and expected practice of care across the country.
- **Systemic identification and documentation of the identity of family caregivers**, including their roles in the support of the care recipient.

Goal 2 Revisions

The Advisory Councils recommend revised outcomes under Goal 2. Additions to the original outcomes are shown in italics. Deletions are shown in strikethrough.

Outcome 2.1 – *In addition to the care recipient,* family caregivers are recognized, *supported, and engaged* ~~as essential partners in~~ *as co-leaders* of the care team~~s of the person(s) to whom they are providing support~~, *when desired and appropriate, including clear documentation of caregivers and their roles in the health record.*

This revision reflects the importance of both documenting the presence of family caregivers in the health record and allowing caregivers to share information with and ask questions of the healthcare team. It also makes clear that adult care recipients have the right to determine to what extent caregivers are included in the care team or given access to protected health information.

Outcome 2.2 – *Engagement of family caregivers is driven by an assessment of their ability, needs, and preferences.* ~~Where appropriate, identifying services and supports needs for caregivers consistently starts with a review of family caregiver strengths and preferences using evidence-based assessments.~~

This revision highlights the interconnected nature of the caregiver-care recipient relationship. Consulting caregivers and formally assessing their ability and willingness to provide care as well as their own healthcare needs help ensure that caregivers have the knowledge, support, and resources to continue in their roles.

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

This revision adds the word "desired" to reflect the right of adult care recipients to determine the extent to which caregivers are involved in care planning. It also emphasizes the importance of care coordination and care navigation to the caregiver experience.

Outcome 2.5 – *Professionals who engage with family caregivers receive education and training that improves their ability to provide effective support and appropriate referrals.* ~~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.~~

This revision adds specific recommendations for the training of healthcare professionals to ensure they know how to identify, engage, and support family caregivers. This includes expanding their knowledge of local services that can assist caregivers to continue in their roles.

Goal 3: Strengthen Services and Supports for Family Caregivers

Overview

While many aspects of family caregiving may involve assistance with less complex tasks such as grocery shopping, meal preparation, and transportation, others require special experience or training (such as wound care, medication management, or personal care). Just as family caregivers provide vital assistance, they may require training, services, and supports to continue in their family caregiving roles.

Goal 3 of the Strategy aims to ensure consistent access to an array of flexible services and supports tailored to family caregivers' needs and preferences, including high-quality training, counseling, peer support, and other services geared to rapidly changing caregiver needs and situations. A key element of these supports is respite care, which provides short-term relief to primary caregivers of a child or adult with support needs. Time away from family caregiving responsibilities can support caregiver well-being, with benefits that extend to care recipients and families. As the number of family caregivers continues to grow, so too does the demand for respite care.

Since the Strategy's release, states and other sectors have made measurable progress — often with federal support or technical assistance — to strengthen services and supports for family caregivers. However, important opportunities exist to continue this progress. For example:

- **Expanded access and refinement of caregiver navigation services** can connect caregivers, including grandparents and other kin, to tailored resources and supports at the right time.
- **Caregiver assessment and coordination of services help support caregivers in their roles.** Integrating these tools into referral platforms can improve coordination and responsiveness.
- **Flexible program models offer new options for service delivery.** Flexible program designs improve satisfaction and utilization. Promising strategies include "bankable" respite care hours, services in non-traditional settings, and adjustable scheduling.
- **Caregiver supports, including respite care,** that leverage the ability for family caregivers to choose and select the providers of services increase the likelihood of utilization of needed supports.

Council Priorities

In the analysis of public comments on the original Strategy, top priorities for additional actions clustered in three key areas:

- **Many family caregivers do not receive respite care or even know it is an option.** Barriers to access include a lack of trust in unfamiliar providers, difficulty finding and paying for quality providers, and program policies that limit eligible providers.
- **Most kin and grandparents who are raising children do so outside of the foster care system** and therefore may not have access to the legal, financial, and other supports from that system.
- **The shortage of direct care workers (DCWs) has a direct impact on family caregivers,** increasing stress and strain and endangering their own health as well as the health of care recipients.

Based on this, the Advisory Councils prioritized two outcomes for revision and expansion, while they recommend a third (original 3.9) for elevation to a new Goal 6. They also wanted to emphasize the critical role respite care plays for family caregivers and the barriers they face in accessing this essential service.

Goal 3 Revisions

The Advisory Councils recommend the following deletion.

Outcome 3.9 (3.10 in the original Strategy) – Kinship families and grandfamilies are recognized, supported, and valued ~~within the child welfare system~~.

Kinship and grandparent caregivers have specific needs when raising children whose parents are absent or otherwise unable to care for them. Grandparents and other kinship caregivers voice the need for:

- Legal assistance to obtain legal authority to make decisions and access services on behalf of the children
- Financial assistance to help meet the children's needs
- Supportive services, such as caregiver training and resources, to address the children's behavioral and developmental needs
- Support from peers who are also raising children

These needs are especially pronounced in kinship and grandparent families raising children outside of the child welfare system.

Goal 4: Ensure Financial and Workplace Security for Family Caregivers

Overview

Current and future financial security, as well as employment concerns, can be significant sources of stress for family caregivers. Seven in ten family caregivers in the U.S. are in the workforce, and 60% experience work disruptions due to their caregiving responsibilities. Caregivers also often incur significant out-of-pocket family caregiving-related expenses, which can impact their financial stability and ability to plan for their own retirement or long-term care. In kinship families, some previously retired adults must return to work to make ends meet or need to prematurely access savings or retirement funds while others may need to leave employment to care for children with special or medical needs.

When workers lack adequate support to balance family caregiving and work, employers may experience increased absenteeism, reduced productivity, and workforce turnover. Among the estimated 8.8 million employed family caregivers, family caregiving reduced work productivity by one-third on average, or an estimated $5,600 annually per working family caregiver.

Recognizing these challenges, many states, businesses, communities, and organizations are exploring ways to better support working caregivers. This may include educating employers on the value of offering supports to employees who are caregivers, making information available to employers about caregiver supports, or facilitating workplace policies that provide flexible options for time off, including paid time off for family caregivers. These measures can promote economic stability for caregivers and increase workforce retention, two aims of Goal 4.

Despite promising advancements towards Goal 4, challenges remain, including:

- **Workplace benefits, wages, and protections vary by income level, industry, and job type.** Some workers are significantly less likely to have access to paid leave, flexible scheduling, or remote work options that benefit family caregivers. Even when policies exist, workplace stigma often discourages use. Small and mid-sized employers may lack the capacity or awareness to adopt caregiver-friendly practices.
- **Many caregivers face challenges accessing resources or navigating complex financial systems.** Many caregivers are unaware of financial information and available resources, or they may lack access to them. Even when resources exist, legal, financial, and LTSS systems can be difficult to understand and navigate without professional guidance. Further, family dynamics can often inhibit discussions about long-term care and estate planning, and the use of financial planning tools and resources remains low.
- **Affordable support options remain limited.** Nearly half of family caregivers report experiencing at least one negative financial impact due to family caregiving — such as taking on debt, draining savings, or delaying retirement — and many caregivers incur substantial out-of-pocket expenses related to care. Given these and other challenges, the economic costs and consequences of caregiving can persist well beyond the caregiving period itself.

Council Priorities

The Advisory Councils emphasize the following key priorities within Goal 4 for this revision.

- **Strategies to address access to financial and workplace supports** across geography, income, and employment status, including policies and programs to improve family caregivers' economic security and ability to stay in the workforce.
- **Increased access to financial planning tools and counseling** that help caregivers prepare for care recipients' and caregivers' own long-term services and support needs while also protecting family caregivers' financial stability.

- **Increased awareness among employers** of public supports available to their employees and encouraging employers to inform their employees about available community resources such as aging network services, children's programming, and relative caregiver supports.
- **Consideration for caregiver experiences** and needs when developing workplace benefits, financial literacy initiatives on family caregiving, and support programs to strengthen the broader family caregiving infrastructure.

Goal 4 Revisions

The Advisory Councils recommend revising Goal 4. Additions to the original are shown in italics. Deletions are shown in strikethrough.

Goal 4: Ensure financial and workplace security for family caregivers *and the care recipients they support.*

The Advisory Councils added "care recipients" to reflect the importance of ensuring the care recipient's preferences, needs, and well-being are considered and respected.

Goal 5: Expand Data, Research, and Evidence-Based Practices to Support Family Caregivers

Overview

Goal 5 aims to ensure that policy and program decisions affecting caregivers are grounded in high-quality data, robust research, evidence-informed practices, and caregiver experience. The overall success of the Strategy depends on the realization of the outcomes of this goal.

Despite a growing body of research on family caregiving, currently available data does not reflect the full range of family caregiving situations, including the age of the family caregiver and care recipient; duration of family caregiving; types of tasks and responsibilities undertaken; quality and nature of the relationship between the family caregiver and care recipient; geographic factors, like rural/urban and long-distance caregiving; and health status of the family caregiver, including presence of disabilities.

Differences in survey design and research methods and a lack of standardized criteria for inclusion or types of information collected have led to wide variations in estimated numbers of family caregivers. For example, the Caregiving in the US 2025 survey, released by AARP and the National Alliance for Caregiving, included family caregivers who help with personal needs, household chores, companionship, or finances for adults of any age and found that 63 million Americans met their criteria as a family caregiver. RAND's 2023 Caregiving Survey included people who provided eight types of assistance for someone over age 18 with illness, injury, or

condition. The RAND survey estimated that 105.6 million Americans over age 18 qualified as caregivers. While neither survey directly surveyed youth caregivers under the age of 18, the Caregiving in the US survey collects household-level information on the presence of caregiving youth. Furthermore, the Caregiving in the US survey includes caregivers of children under 18 with disabilities or medical complexities.

Recognizing that family caregiving encompasses a broad array of caregiving situations, the actions outlined in the Strategy and this update will help build the infrastructure to inform policies and programs that support family caregivers. This effort must proceed incrementally and iteratively, in coordination with actions across the other goals, to ensure the nation has the knowledge and data to adequately recognize, assist, and support family caregivers.

Council Priorities

The Advisory Councils recognize the following priorities as essential to achieving the outcomes under Goal 5.

- **Standardized family caregiver definitions and measures** across national, regional, and local surveys improve data comparability, strengthen quality and reporting, and ensure family caregivers are consistently recognized.
- **Expanded longitudinal data on family caregiving can provide important insights** into how family caregiving responsibilities evolve over time and impact health, financial security, and workforce participation. This data can also advance our understanding of how caregiver health, socioeconomic status, income, education, and social support impact their caregiving experiences.
- **Comprehensive data collection across federal data systems and tools can help ensure caregivers are consistently identified** and that their needs and outcomes are systematically considered in care delivery and financing structures.
- **Technical assistance and resources can help strengthen states' capacity** for family caregiver data collection, including implementation of caregiver-focused survey modules, data integration, and development of dashboards that inform program management, policy decisions, and public accountability.
- **Expanded cost-effectiveness research on family caregiver interventions can strengthen understanding** of effects on health outcomes, healthcare and service use, and larger economic impacts. Interventions to research may include respite care, caregiver training, and care navigation services.
- **Research should reflect the full range of family caregiving experiences** — including family caregivers supporting individuals with disabilities, chronic conditions, and mental health needs — to ensure policies and programs are responsive to the full range of caregiving situations. A 2025 Government Accountability Office report found that national

surveys that collect data on caregiving were not designed to provide information on the number of youth caregivers, although other research indicates that as many as 3 to 5 million minors may serve as caregivers for family members. In addition, incorporating quantitative and qualitative data is necessary to fully comprehend caregiving trends.

- **Evidence-based research should include both youth caregivers and kinship caregivers** to expand cross-sector supports. Data and research on youth and kinship caregivers can promote the development of school-based and cross-sector interventions and data collection strategies that recognize and support their unique needs and circumstances.

Goal 5 Revisions

The Advisory Councils recommend revising the wording of Goal 5 and one of its outcomes. They also recommend adding an outcome. Additions to the original Strategy language are shown in italics. Deletions are shown in strikethrough.

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

The Advisory Councils updated Goal 5 to expand options for interventions rooted in research to support family caregivers.

Outcome 5.3 – ~~Promising~~ *Emerging* and evidence-informed practices are promoted, translated, *replicated,* disseminated, *and sustained* to support family caregivers~~ in the delivery of health care and social services~~.

The Councils recommended this change to reflect the importance of using data to identify, scale, and sustain existing evidence-based practices to reach more caregivers.

New Outcome 5.4 – Nationally representative data on caregiving youth (minors) are available.

The Advisory Councils added this new outcome to address the specific needs of caregiving youth.

New Goal 6: Increase Family Caregivers' Access to a High-Quality, Well-Trained Direct Care Workforce to Complement the Care they Provide

Overview

While family caregivers provide most of the long-term support for older adults and people with disabilities in the U.S., direct care workers (DCWs) provide essential services that complement those supports. These include respite care and other assistance that help safeguard family caregivers' health and well-being. In some cases, DCWs enable family caregivers to continue to work outside the home (if they choose) to maintain financial stability.

Care provided by DCWs can help make it possible for older adults and people of all ages with disabilities to live in and fully participate in their communities. However, the country continues to face a shortage of DCWs. Addressing this shortage is essential to ensuring the well-being of family caregivers and care recipients.

Current Challenges and Opportunities

The direct care workforce is a critical pillar of the aging and disability services sector. DCWs include people in various occupations and roles, including personal care attendants, home health aides, direct support professionals, nursing assistants, respite care professionals, and more. These critical professionals offer a broad range of assistance with ADLs and IADLs essential to a person's ability to live, work, socialize, volunteer, and participate in their community, including faith-based activities.

While an estimated 5.4 million DCWs support older adults and people of all ages with disabilities in the U.S., more than 88% of provider organizations report staffing challenges, with many turning away new referrals due to inadequate staffing. By 2032, the U.S. will need another 800,000 DCWs to meet demand. The DCW shortage is influenced by several factors, including working conditions, job satisfaction, economic stability, education and career pathways, and work environment.

Many DCWs face economic instability, with median hourly wages often well below other entry-level jobs. Additionally, a lack of clear career advancement opportunities and limited access to affordable training programs exacerbate the challenges of recruiting and retaining workers. Turnover among DCWs providing home care reached 75% in 2024. The result is a chronic shortage of trained professionals.

Council Priorities

The Advisory Councils recognize the interconnection between a strong direct care workforce and supporting family caregivers and care recipients.

In their 2021 reports to Congress, both Advisory Councils recognized the need to strengthen and expand the paid direct care workforce. Goal 3 (Outcome 3.9) of the Strategy included a variety of recommendations to address workforce shortages, including creating new training programs and worker registries. This included recommendations for clear, consistent quality and care delivery standards, enhanced training and job advancement opportunities, and expanded credentialing options.

Despite some progress since the release of the Strategy, the workforce crisis continues and has even worsened, including in rural, frontier, and tribal communities. Infrastructure constraints in these communities — including limited training opportunities and broadband access — further complicate the availability of DCWs.

By adding a new goal entirely focused on the direct care workforce, the Advisory Councils call for more comprehensive action across multiple sectors that benefit care recipients and their caregivers, while engaging DCWs and service providers to shape recruitment and retention solutions. The Councils recommend a multi-faceted approach that focuses on key aspects such as outreach and recruitment, training, and retention, with the goal of better preparing and sustaining DCWs through more visible and supportive career paths. To encourage and monitor progress toward Goal 6, the Advisory Councils outline four outcomes as well as a number of recommended actions that the public sector, employers, community-based organizations, and other stakeholders can take to address workforce needs and better support family caregivers and people for whom they provide care.

Goal 6 Outcomes

Outcome 6.1 – Recruitment results in more DCWs hired across service delivery models.

While efforts are underway to identify and recruit more DCWs, the sector requires additional approaches to meet the support needs of family caregivers and care recipients. Aligning federal, state, and local initiatives can expand opportunities across all service delivery models, support career progression, enhance coordination with family caregivers, and strengthen worker well-being. Examples may include widening workforce entry through new and innovative entry points, developing worker and matching service registries, and strengthening connections between family caregivers and the paid direct care workforce.

Outcome 6.2 – Training prepares DCWs to deliver high-quality, person-centered support and effectively coordinate with the care recipient and caregiver.

Education and training are essential to ensure the continued availability of DCWs. Training and certification programs improve the skill sets of DCWs, help ensure high-quality care, and provide opportunities for career advancement. High-quality training programs that are accessible to DCWs expand recruitment and retention opportunities and support Outcomes 6.1 and 6.3 as well. Training needs should be competency-based for the entry level of a profession and allow for instruction regarding specific skills based upon the individuals being served.

Increased access to adequate training improves DCW competency to deliver high-quality care. Proper training equips workers with the tools to handle challenging situations, reducing stress and errors in caregiving. Training tailored to specific communities — including older workers and workers with disabilities — also allows more people to support themselves with meaningful work. Mentorship also plays an important role in engaging and encouraging DCWs to remain and advance in their fields.

Outcome 6.3 – Retention is achieved through flexible job structures, safe and supportive workplaces, and competitive compensation.

Retention challenges among DCWs are well-documented and stem from compensation, benefits, and working conditions. About one-third of home care workers work part-time and lack access

to employer benefits, and many rely on Medicaid or other public assistance. Direct care work should be a path to self-sufficiency. Unpredictable work schedules add to job insecurity and turnover. Employers that offer paid leave, health benefits, flexible scheduling, and retirement plans report better retention.

Career pathway programs, including mentorship and peer support opportunities, that offer advancement opportunities, credentialing support, and wage increases tied to skill development have increased retention. Comprehensive retention strategies may also include mentoring and peer support, particularly for home care workers who often work in isolation. Coordinated efforts on the federal and state levels can address these barriers to stabilize the workforce and ensure long-term sustainability in direct care services.

Outcome 6.4 – Data collection and research illuminate the full scope of the direct care workforce to help guide policy.

Reliable data and sound research are fundamental to understanding and addressing complex issues such as workforce supply and demand, quality, drivers of recruitment and retention, and the relationship between family caregiving and the direct care workforce. A better understanding of workforce trends and the drivers of attrition in the direct care workforce (such as burnout, injuries, and benefit loss) could lead to actionable solutions.

Federal and state momentum in this area is growing, and partnerships among stakeholder organizations are also helping to advance a shared research agenda. The Together in Care initiative published briefs that summarize existing data and identified critical gaps, such as workforce interventions and caregiver-worker dynamics. States have also piloted promising data collection approaches, including tracking metrics for family caregivers.

Expanding the current understanding of how the direct care workforce interacts with family caregivers can strengthen both the direct care workforce and the quality and availability of supports to family caregivers.

Conclusion

Meaningful and lasting change for family caregivers requires "all hands on deck." This includes federal, state, and local governments in close collaboration and coordination with a host of private-sector entities, including healthcare systems, advocacy and philanthropic organizations, school systems, higher education, researchers, employers, and many others.

The first National Strategy to Support Family Caregivers was acknowledged as an unprecedented roadmap for better recognizing and addressing the complex needs of family caregivers. With this update, the Strategy continues to evolve in response to evolving challenges, new opportunities, and lessons learned through implementation.

The Advisory Councils envision the Strategy continuing to serve as a framework for the nation's collective efforts on behalf of family caregivers. This update strengthens that foundation by incorporating new insights and emerging priorities to ensure the Strategy remains responsive to the needs of family caregivers, care recipients, and those who support them.