

# 2022 National Strategy to Support Family Caregivers: Actions for States, Communities, and Others

## Developed by:

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

&

The Advisory Council to Support Grandparents Raising Grandchildren



*Technical assistance provided by the Administration for Community Living*

September 21, 2022

## Contents

Introduction & Purpose.....	1
Goal 1: Actions to Increase awareness of and outreach to family caregivers .....	3
Goal 2: Actions to advance partnerships and engagement with family caregivers .....	8
Goal 3: Actions to strengthen services and supports for family caregivers .....	13
Goal 4: Actions to ensure financial and workplace security for family caregivers.....	21
Goal 5: Actions to expand data, research, and evidence-based practices to support family caregivers .....	27
Acronyms and Abbreviations.....	34

## Introduction & Purpose

This document is a component of the 2022 National Strategy to Support Family Caregivers (**Strategy**), which 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 (**Advisory Councils**). It contains more than 150 **suggested actions** that states, communities, and other public and private stakeholders can take to holistically recognize, assist, include, support, and engage family caregivers in support of the Strategy. The actions were developed by members of the Advisory Councils in early 2022, based on the following:

**Goals of the National Strategy to Support Family Caregivers:** The Strategy outlines a series of approaches to achieving key outcomes in support of the 5 goals of the Advisory Councils:

- GOAL 1:** Achieving greater awareness of and outreach to family caregivers
- GOAL 2:** Advancing partnerships and engagement with family caregivers
- GOAL 3:** Strengthening services and supports for family caregivers
- GOAL 4:** Improving financial and workplace security for family caregivers
- GOAL 5:** More data, research, and evidence-based practices to support family caregivers

1. During focus groups and [caregiver interviews](#), family caregivers shared stories of their own experiences. Those stories informed the Strategy at every stage of its development, including to inspire many of the actions suggested in this document.
2. ACL published two requests for information (RFIs) in the *Federal Register* asking caregivers to express a need/concern, recommend a solution, and select from a list of issue areas that were important to them.
  - ◆ The RAISE Family Caregiving Act RFI received 1,613 unique responses, three-quarters of which were from family caregivers.
  - ◆ The SGRG Act RFI received 307 unique responses, half of which were from kin, grandparent, non-relative, and/or foster family caregivers.

The results of these RFIs contributed to the development of two suites of recommendations for supporting family caregivers of all ages, across circumstances, and in every corner of the nation. These recommendations were outlined in two reports to Congress in 2021:

- ◆ [RAISE Family Caregivers Act Initial Report to Congress](#)
  - ◆ [SGRG Act Initial Report to Congress](#)
3. Early in its work, the RAISE Family Caregivers Act Advisory Council created diagram that categorized multiple factors (drivers) that would affect the overall vision and goals of the council. This driver diagram became an internal planning tool during

council discussions. This tool enabled the Advisory Councils to identify and categorize multiple factors (drivers) that would achieve the overall vision and the goals of the council.

4. In 2020, the National Academy for State Health Policy (NASHP), under [a three-year grant from The John A. Hartford Foundation \(JAHF\)](#), collected and analyzed more than 800 recommendations from 27 key family caregiving reports written in the past decade. NASHP synthesized and inventoried the recommendations. The resulting document, [Inventory of Key Family Caregiver Recommendations](#), assisted the RAISE Act Family Caregiving Advisory Council in its recommendations to Congress.
5. NASHP, also with support from JAHF, commissioned Community Catalyst and UMass @Boston to undertake a series of 16 listening sessions and 17 key informant interviews with over 150 stakeholder organizations, including family caregivers, advocacy groups, and other entities with a role in supporting family caregivers. These interviews resulted in 50 hours of input from a wide array of voices. Community Catalyst and UMass @Boston also hosted 12 listening sessions with a total of 80 family caregivers representing a wide array of caregiving situations, including kin and grandparent caregivers and caregiving youth.
6. In 2020 and 2021, researchers from UMass @Boston produced three reports based on feedback from the family caregiver listening sessions and focus groups and an RFI analysis conducted at the request of the RAISE Family Caregivers Act Advisory Council.
  - ◆ [In Their Own Words-Family Caregiver Priorities and Recommendations: Results from a Request for Information](#) details and categorizes family caregiver priorities from the 1600+ RFI responses.
  - ◆ [Building a National Strategy to Support Family Caregivers: Findings from Key Informant Interviews and Stakeholder Listening Sessions](#) analyzes and presents the results of the key informant interviews and listening sessions.
  - ◆ [What Family Caregivers Need: Findings from Listening Sessions](#) details the twelve 60-minute listening sessions held with small groups of family caregivers of different caregiving situations.
7. In 2022, NASHP released [the RAISE Act State Policy Roadmap for Family Caregivers](#). This six-part compendium used the RAISE Family Caregivers Act recommendations as a framework to create a roadmap for 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.
8. To support these efforts, NASHP convened [a faculty consisting of state officials, advocates, and family caregivers](#) specifically to support the RAISE Act. From 2020 through the present, this group has provided technical assistance and insight to the RAISE Advisory Council. Some faculty members also contributed suggested actions for this document.

These actions are neither prescriptive nor all-inclusive. Rather, they are intended to provide a variety of options so that readers of the Strategy can easily envision a role for themselves or their organizations. Many of the actions contained in this document complement the 345

[commitments made by the federal government](#) in support of the Strategy. Therefore, federal agencies and programs may wish to review these actions to identify additional opportunities to collaborate, coordinate outreach, enhance program development and administration, and more effectively target family caregivers with available resources at more levels.

## Goal 1: Actions to increase awareness of and outreach to family caregivers

Increased awareness and recognition of family caregivers creates a better understanding, appreciation, and motivation for cross-disciplinary and cross-sector collaboration to affect changes—in new products, services, policies, and legislation—that recognize, assist, include, support, and engage family caregivers in meaningful ways.

**Vision for Goal 1:** To optimize the well-being of family caregivers by increasing the recognition of family caregivers among society and the number of people who self-identify as family caregivers who know where to go for trusted information.

In addition, many people do not think of themselves as “caregivers.” Instead, they consider themselves to be a parent, grandparent, sibling, child, spouse, partner, friend, or neighbor who is simply doing what needs to be done. As a result, they often do not look for resources and supports and are not counted in data collection efforts. Effective outreach is crucial to connecting family caregivers to the resources available to support them. This is particularly important in multicultural or immigrant communities and with family caregivers with limited English proficiency.

To create a system that truly supports families, multiple sectors—public and private—must work together. No single sector can do it alone. There is a particular need to engage the private sector—employers and industry—to better recognize and support employees who are family caregivers.

Advisory Council members noted that only when caregiving is widely recognized as a universal life experience will family caregivers themselves feel comfortable asking for and accepting the support they need.

Actions to increase awareness of family caregiving and outreach to family caregivers could include:

Increased awareness and recognition of family caregivers creates a better understanding, appreciation, and motivation for cross-disciplinary and cross-sector collaboration to affect changes—in new products, services, policies, and legislation—that recognize, assist, include, support, and engage family caregivers in meaningful ways.

- State agencies, municipal governments, and tribal leaders can ensure publications and websites include updated, accurate and culturally/linguistically appropriate representations of family caregiving and/or the supports and resources that are available. A first step can be to conduct an assessment of communication tools and develop a plan for improvement over time. (Also supports **Goal 3**)
- State entities, tribal councils, community leaders, CBOs, FBOs, and school districts can launch locally focused public outreach campaigns that align with the national caregiver awareness campaign described in the Strategy.
  - ◆ Implement these efforts in collaboration with local stakeholders such as Chambers of Commerce, Parks and Recreation Departments, and local health departments. To the extent possible, use meaningful local data about family caregiving prevalence and needs. (Also supports **Goal 5**).
  - ◆ Include family caregivers from target populations in the planning and release of these campaigns. (Also supports **Goals 2 and 3**).
  - ◆ Craft messages and products that are culturally competent, linguistically appropriate, accessible to people with disabilities, and sensitive to the specific populations for which they are intended.
  - ◆ Disseminate information through multiple distribution channels (social media, local news outlets, community advocates and faith leaders, materials created by schools and business, etc.) to reach family caregivers in a range of culturally and ethnically diverse communities.
  - ◆ Partner with leaders in tribal communities to include information and outreach about the unique needs of American Indian and Alaska Native family caregivers in existing community events and programs.
  - ◆ Conduct outreach to unserved and underserved communities using [ethnic media](#) and in-language campaigns, as applicable to inform caregivers and care recipients in target populations about the local, state, and federal supportive services and resources available to them.
- State agencies, tribal leadership, and municipal governments can issue official guidance (including to education, health, social services, law enforcement, corrections, emergency management, and human resources departments) defining “family caregivers” and “family” in the widest possible terms. This will increase awareness about the breadth of caregiving, maximize inclusion in supportive programs, and provide guidance on language and communication access. (Also supports **Goal 3**).
  - ◆ In the definitions of family caregiving, acknowledge grandparents, kin, close friends, neighbors, and others outside of the traditional family structure.
  - ◆ Use terminology that is inclusive of and welcoming to racially and ethnically diverse communities, American Indian and Alaska Natives, and LGBTQIA+ communities.

- State governors, mayors, and other community leaders can use their tools of office to highlight the tremendous value that family caregivers bring and urge support and recognition. For example, proclamations signed during National Family Caregiver Awareness month create a product that can be shared by others and often result in media coverage, both of which help increase the reach of the message.
- Business leaders and civic organizations can recognize entities, including employers of all sizes, that actively recognize, assist, or support caregivers with a “family caregiver-friendly” designation. This allows the public to choose to patronize or apply for employment at these caregiver-friendly businesses. This can also increase public awareness and appreciation of caregiving. Examples of “caregiver-friendly” policies may include:
  - ◆ Discounts for family caregivers (Also supports **Goal 4**).
  - ◆ Special shopping hours for family caregivers (Also supports **Goal 3**).
  - ◆ Displays that highlight family caregiver-focused services and products (e.g., meal planning, assistive technology, medical supplies).
  - ◆ Expanded and rebranded care programs in gyms and retail stores to offer care and meaningful engagement to care recipients of all ages, including children and adults with disabilities. (Also supports **Goal 3**).
  - ◆ Feature diverse caregivers and the full range of family caregiving situations in print and media advertising.
  - ◆ Connect family caregivers with their state assistive technology programs so they can learn about [assistive technology options](#) that allow care recipients to communicate and live more independently. Examples include augmentative and alternative communication (AAC), fidget devices, electronic tablets, weighted blankets, noise-canceling headphones, etc. (Also supports **Goal 3**).
  - ◆ Train staff to recognize behavioral signs that a family caregiver or care recipient may have unique needs, such sensitivity to noise, dementia, speech aphasia, and memory loss, as well as when and how to offer and provide assistance to family caregivers. (Also supports **Goal 2**)
- State agencies, community leaders, school districts, health care providers, and others can identify opportunities to increase awareness in the local community of the unique strengths of--and challenges faced by--kinship families and grandfamilies. Kin and grandparent caregivers on the Advisory Councils noted such awareness efforts are critical to reducing stigma and common misconceptions about kinship families. Examples of possible approaches include:
  - ◆ Educate communities about the causes of kinship families and grandfamilies to correct common misunderstandings that often lead to negative perceptions.
  - ◆ Incorporate kinship families and grandfamilies into communication materials that are not “about” caregiving, such as advertisements, websites, and

recognition programs, to underscore that they are one of many types of families in the local community.

- ◆ Educate kin and grandparent caregivers about how to become foster parents and how they can receive services such as respite care if they choose to take that path.
  - ◆ Create resources such as booklets and brochures about kinship care, including materials specifically developed for the reading level and interests of children and teens in kinship families.
- Health care and social service systems can ensure that all intake forms adopt inclusive language to help family caregivers self-identify. For example, intake forms could include a field for the name of the designated family caregiver which could serve as a reminder to family members (and providers) that the assistance they are providing is a form of “family caregiving.” (Also supports **Goal 2**).
  - Health care and community-based service systems can partner to equip primary care providers and pediatricians with screening tools and accurate and timely information about family caregiving and local community supports so that they can make appropriate referrals. Especially important is up-to-date information about local respite options. (Also supports **Goal 3**).
  - CBOs can train first responders and emergency department personnel to identify family caregivers and grandfamilies during emergency situations so that they can effectively integrate family caregivers into the patient’s or child’s care team. (Also supports **Goal 2**).
  - Researchers, academic institutions, and funders can invest in research and education to better understand how cultural beliefs about caregiving affect caregiver identification and to identify the best ways to train and educate diverse family caregivers to prepare them for the role. (Also supports **Goal 3**).
  - Communities of faith can regularly survey parish memberships to proactively identify caregivers among their parishioners.
  - States can fund improvements to their No Wrong Door/Aging and Disability Resource Systems to expand their ability to support family caregivers and the people they support in making informed decisions about their long-term services and supports and to help them access public and private programs. (Also supports **Goal 4**).
  - States can configure their caregiver support programs, including those funded under the Older Americans Act National Family Caregiver Support Program, to expand and improve outreach, particularly to underserved populations. Specifically, they can budget for translation and interpretation of materials and events; refine requirements for outreach activities, such as the number of outreach events an organization must complete, the locations or populations that should be targeted; and types of media to utilize; and ensure outreach information is reflected in family caregiving program regulations and manuals.



- State agencies can compile a statewide inventory of existing resources and programs for family caregivers. This resource can be used to create a caregiver support locator function so that caregivers can quickly locate the services they need in their area.
  - ◆ Establish and support collaboration among state agencies, CBOs, FBOs, and municipalities to promote utilization of this support locator resource as well as other existing resources. (Also supports **Goal 3**).
- State agencies, CBOs, FBOs, and service providers can collaborate with national organizations to develop culturally appropriate toolkits and resource guides that can be used by local communities.
  - ◆ Develop materials with input from the communities they are intended to reach.
  - ◆ Distribute materials through trusted community channels such as: community ambassadors, community health workers; faith leaders and community leaders; hairdressers and barbers; pharmacists; primary care physicians and pediatricians; teachers. (Also supports **Goal 3**).
  - ◆ Include topics such as [naturalization resources](#), consumer rights, descriptions of local family/caregiver leave benefits within the state, the value of caregiver assessments and respite care; how to talk to children about caregiving, and how to navigate complex care systems with multiple points of entry, and other topics about which they may be unfamiliar. (Also supports **Goal 3**).
  - ◆ Create materials in multiple languages. (Also supports **Goal 3**).
- Community-based organizations can explore opportunities to partner with media and community relations companies to develop age-appropriate literature to help children in kinship families understand that they are not alone in their experiences. (Also supports **Goal 3**).
- Private payers (including health plans and health systems) can collaborate with CBOs to reach underserved populations of family caregivers (including caregivers of color and those in rural communities) and improve the reach of evidence-based programs. (Also supports **Outcome 5.3**).
- All stakeholders can seek out innovative ways to conduct outreach and data collection efforts that are specific to their sector. (Also supports **Goals 3 and 5**). Examples include:
  - ◆ *Colleges and universities*: Provide outreach targeted to students in a wide variety of majors, including but not limited to social work and psychology, to inform the next generation of professionals about the impact of caregiving on families.
  - ◆ *Faith-based organizations*: Identify family caregivers in their congregations and organize members to offer to bring them a meal, help with chores, or assist with respite.

- ◆ *Homeowners' associations*: Maintain lists of family caregivers who may need help with home maintenance or snow shoveling.
- ◆ *Restaurants and businesses*: Offer caregiver discounts, caregiver business hours, or special menu items that celebrate caregivers.
- State agencies, CBOs, FBOs, providers, and courts can strengthen provisions to ensure compliance with current federal law requiring access to services for older adults, people with disabilities, and caregivers with limited English proficiency. (Also supports **Goals 3 and 4**).

To create a system that truly supports families, multiple sectors—public and private—must work together. No single sector can do it alone. There is a particular need to engage the private sector—employers and industry—to better recognize and support employees who are family caregivers.

- All stakeholders can establish coalitions that bring together state officials, major employers, universities, philanthropic organizations, CBOs, FBOs, family caregivers and care recipients, and others with clearly articulated mission statements, work plans, sustainable funding, and projects. See [Massachusetts Caregiver Coalition](#) as a model. (Also supports **Goal 4**).
- States can convene or expand family caregiving taskforces to draw in stakeholders with lived experience and professional expertise to work together on behalf of family caregivers in the state. Activities can include developing an inventory of existing programs; recommended actions that improve family caregiver supports and address the other issues described in the Strategy; and ways to leverage the findings of the task force to increase funds for caregiver support services and/or pass supportive legislation.
- State agencies can develop and implement state plans (e.g., State Plans on Aging, State Developmental Disability Plans) for supporting family caregivers. These efforts should include representation from a broad range of stakeholders, including diverse caregivers and care recipients themselves.

## Goal 2: Actions to advance partnerships and engagement with family caregivers

Family caregivers help navigate complex, often fragmented systems of providers and services. They often serve as *de facto* care coordinators, physically perform, and/or either make, or support the person they care for in making, treatment decisions. Despite their integral role in the care of others, their own needs and preferences are rarely assessed using evidence-based tools; they are often excluded from care planning; and when systems change, the impacts of such changes on

**Vision for Goal 2:** To recognize, engage, and support family, kin, and grandparent caregivers as key partners in the provision of health care and long-term services and supports.

family caregivers are rarely considered. In addition, family caregivers and their needs are rarely identified or addressed in care plans. Actions like the following are needed to address systemic barriers to including family caregivers in care teams and ensuring their needs are represented in care plans.

### **Involvement of Caregivers as Part of the Care Team**

- Organizations employing medical providers and direct care workers can adopt systems, such as Health Insurance Portability and Accountability Act (HIPAA)-compliant dedicated messaging platforms, that allow family caregivers and other members of the care team to communicate directly and easily (with the approval of the care recipient).
- States can increase integration of family caregivers into care teams through considering the following:
  - ◆ Require training in how to engage with and interact with family caregivers as part of accreditation standards.
  - ◆ Add regulatory language that requires providers of health and social services to designate the family caregiver as part of the care team, if they have not done so already.
  - ◆ Allow flexibility for family caregivers to purchase and operate telehealth for care recipients (with the permission of the care recipient).
  - ◆ Define requirements to include caregiver information within health systems technology, such as electronic health records, and incorporate caregiver/user feedback when developing technology.
- Health insurance plans, payers, and others can create financial incentives, such as new billing codes for health care providers, to encourage and enable consultation with family caregivers as part of the care process (with the consent of the person receiving care).
- Health care and social service systems can champion the inclusion of caregivers in existing processes and protocols by taking the following steps:
  - ◆ Explore ways to incorporate family caregivers earlier in the care process.
  - ◆ Identify ways to include family caregivers in existing workflows and processes.
  - ◆ Ensure frontline workers can dedicate time to train family caregivers in how to support their loved one or share resources to help them learn. Examples include in-home or community-based visits to observe natural routines and scaffold support for caregivers or brief online/video training (2-3 minutes) that focuses on specific types of equipment, procedures, and/or tasks.
  - ◆ Create checklists for staff about family caregiving-related issues. Also, create information tools for family caregivers, such as key questions to ask providers

and contact information for caregiver services, such as: help desks, chat services, peer support networks, or other sources of live caregiver support.

- ◆ Develop job aids for health care professionals and discharge planners to integrate self-care for the family caregiver into a patient's care plan.
  - ◆ Extend the concept of a "post-surgery care coach" to support family caregivers when a patient comes home from the hospital; incorporate these services into discharge planning
  - ◆ Hire and train dedicated staff for family caregiver engagement (caregiver engagement specialists), including specialists trained in conditions such as Alzheimer's disease and related dementias.
  - ◆ Review and strengthen protocols for incorporating information about family caregivers and caregiving into electronic health records systems and the care process.
  - ◆ With the approval of the care recipient, include family members in care planning by discussing the patient's current condition and desired goals and outcomes for treatment and identifying any additional needed supports and services.
  - ◆ Collect data to determine the real-world return on investment of integrating family caregivers into the care team. (Also supports **Goal 5**).
  - ◆ Encourage managed care organizations (MCOs) or advocacy organizations to create an inventory of best practices for private industry family caregiver resources.
- Health care vendors can centralize patient data so that it can be accessed by family caregivers, providers, and homecare workers, with appropriate permission from the patient/person receiving support.
  - Health care IT firms can develop "identity and access management (IAM)" apps that aggregate information from multiple patient portals so that patients and caregivers can access an integrated dashboard of health information from multiple providers without having to use multiple passwords and log on credentials.
  - Customer-serving organizations can put in place policies, processes, and training designed to recognize, document, and engage kin, grandparent, and family caregivers as part of the care team, as appropriate.
  - Providers of Medicaid home and community-based services (HCBS) programs can educate themselves about the need to include family caregivers whenever appropriate and possible.
  - Schools, institutions of higher learning, and other learning centers can consider opportunities to share the lived experiences of family members as caregivers. Examples include guest lecturers, pre-recorded interviews, or similar opportunities.

- Municipalities and states can adopt policies that allow designation of family caregivers as essential workers during emergencies and as part of emergency planning.
- Professional organizations and societies can identify ways to acknowledge family caregivers' importance across all patient populations and develop guidelines that acknowledge the role of caregivers.
- Health care systems, MCOs, hospitals, and medical schools can study best practices and create policies that encourage appointment of family caregivers as board members to ensure their voices are included in all levels of policy planning.
  - ◆ Health care and customer-serving organizations can ensure best practices when making decisions by considering all affected stakeholders and developing validation criteria to anticipate and prevent unintended consequences.
  - ◆ Health care systems can ensure that policy-setting processes include documenting and responding to family, kin and grandparent caregiver needs.

### Caregiver Assessments

- States can increase use of family caregiver assessments by
  - ◆ Requiring providers to use evidence-supported caregiver assessment protocols.
  - ◆ Ensuring delivery systems and providers look critically at existing assessment tools to make sure they are trauma-informed and culturally competent.
- Health care and social services systems can bring in an objective third-party to assess family caregiver needs, particularly ways that caregivers could receive help and support.
- Government and third-party insurance payers can reimburse health care providers for conducting caregiver assessments.
- Health systems and other health care providers can pilot the use of caregiver assessments in a variety of care settings to improve identification of caregivers who need services and supports.
  - ◆ Explore the possibility of adding a caregiver module to off-the-shelf electronic health records to facilitate the use of assessments.
  - ◆ Assess and address the needs of culturally and socially diverse caregivers using measures such as the LTC Equality Index, which promotes inclusive care for LGBTQIA+ older adults in residential and senior housing.

### Care Transitions and Care Coordination

- States that have not yet done so can adopt and expand the CARE Act, which requires hospitals to inquire if a patient has a family caregiver, include them in the

discharge process, and teach them how to provide care after the discharge, if needed.

- States that have passed the CARE Act can consider requiring verifiable implementation of the state’s CARE Act for hospital accreditation.
- Health care organizations in states that have not implemented the CARE Act can ensure family caregivers are integrated into transition services when appropriate.
- Health care organizations and EHR vendors can provide functionality to enable viewing, printing, and sharing of health summaries, lab results, and medications for the following uses: sharing/data exchange between EHR systems or between Patient Health Record (PHR) and EHR systems; integrating caregivers into care transitions; and streamlining information access through technology linkages that allow a single sign-on to multiple patient portals by family caregivers (with permission of the patient).
- Health care systems can use the [patient navigator model](#) as a model for caregiving advocacy, especially those caregivers who face barriers to accessing systems of support.
- Providers can implement evidence-based practices for including caregiver supports at all points of health care delivery (inpatient, outpatient, LTSS, etc.) and transitions, including care coordination when care needs change and when caregivers relocate. (Also supports **Outcome 5.3**)
- Health care systems can partner with caregiver CBOs, such as AAAs, ADRCs, State Councils on Developmental Disabilities, and Centers for Independent Living to support family caregiver needs by assessing referral systems and taking steps to better include family caregivers where necessary.

## Policy Development

- Municipalities and states can adopt policies that allow designation of family caregivers as essential workers during emergencies and as part of emergency planning.
- Professional organizations and societies can identify ways to acknowledge family caregivers’ importance across all patient populations and develop guidelines that acknowledge the role of caregivers.
- Health care systems, MCOs, hospitals, and medical schools can study best practices and create policies that encourage appointment of family caregivers as board members to ensure their voices are included in all levels of policy planning.
  - ◆ Health care and customer-serving organizations can ensure best practices when making decisions by considering all affected stakeholders and developing validation criteria to anticipate and prevent unintended consequences.
  - ◆ Health care systems can ensure that policy-setting processes include documenting and responding to family, kin and grandparent caregiver needs.

## Professional Education & Training

- State agencies can develop educational campaigns about the value of integrating caregivers into health care, social services, educational, and child welfare systems. These campaigns should be available in a variety of accessible formats and languages and should include diverse images and local data that reflects the caregiver community. Provide talking points for stakeholders to ensure consistent and accurate promotion of the campaigns.
- Health care systems can educate clinicians and other service providers about the experiences and needs of family caregivers by incorporating applicable content whenever possible. Examples of content may include:
  - ◆ Details about the role family caregivers play, challenges of long-term caregiving, the importance of early and meaningful engagement, and inclusive and accessible communication.
  - ◆ Stories of the lived experiences of busy caregivers to encourage understanding of their emotional journey as well as compassion, empathy, and validation during interactions.
- Health care systems can offer annual training to providers about HIPAA regulations to address the misperception that HIPAA precludes communication with family caregivers.
- CBOs can explore ways to educate professionals across a range of service industries about consumer rights as they apply to family caregivers.

## Goal 3: Actions to strengthen services and supports for family caregivers

Family caregivers need consistent access to an array of programs, supports, goods, and services that meet their diverse needs and those of care recipients. For these services to be effective, they must be person-centered, culturally competent, linguistically appropriate, and trauma informed – and more widely available.

**Vision for Goal 3:** To expand access to programs, services, supports, and products to family caregivers.

Too often, families spend valuable time and energy navigating multiple referrals and sources to obtain services and supports. Many are unable to fulfill their needs due to inconsistent eligibility requirements, waiting lists, large out-of-pocket costs, or supports that are not geared toward their situations. Streamlining access to resources is crucial.

Many family caregivers need more than support with caregiving tasks. A more holistic approach to supporting caregivers ensures access to appropriate and accessible housing, home repair support, healthy foods, transportation, and social engagement. These social

determinants of health contribute to caregivers' ability to maintain their own well-being and that of the care recipients.

In addition, caregivers need resources to help them plan for the future to meet care goals and honor the wishes of the person receiving support. Planning also can help caregivers conserve financial resources and maintain their financial well-being. (See more ideas under **Goal 4**.) In many cases, formal systems have not yet been put in place to support structures for caregivers to use in crisis response.

Finally, expanding and strengthening the direct care workforce is a fundamental component of improving access to support for family caregivers. Direct care workers provide essential services that help to meet the needs of a wide range of individuals including older adults, people with disabilities, and children and youth with serious long-term support needs. However, there is a shortage of paid workers, especially direct support workers such as personal care attendants, home health aides, and nursing assistants. They face low pay, a lack of benefits, and few opportunities for career development, which contributes to high turnover and creates significant challenges for family caregivers when looking for reliable, quality care.

The following are suggested actions for states, communities, and other stakeholders can take to address these and other issues and complement federal efforts to expand services and supports for family caregivers:

### Expanding Supportive Services

- States can prioritize a reform agenda that focuses on family caregivers and the direct care workforce. This can include the development of master plans for serving the aging population and legislative initiatives to create family caregiver and workforce commissions.
- States can continue to rebalance Medicaid spending to support caregivers in the community by funding HCBS rather than institutional settings when appropriate. Potential pathways include:
  - ◆ States can leverage new pandemic-related funding and flexibility within Medicaid to expand family caregiver supports.
  - ◆ Adopt self-directed models and vouchers which allow beneficiaries to select and pay for direct care workers—including family caregivers—to provide personal care, especially in rural areas and those with limited provider options.
  - ◆ Blend and braid the funding sources of Medicaid, OAA, state funding, and other grant programs to improve access to services for family caregivers.
  - ◆ Require public payors/Medicaid to cover respite services to ensure that families have access to it as a standard benefit.



- Using the [Inventory of Federal Caregiver Support Programs and Initiatives](#) as a model, states can compile their own inventories of family caregiver services to better understand what programs are available and to identify gaps/duplication and opportunities for collaboration.
- State agencies, municipalities health care systems, private funders, and others can explore increasing access to HCBS for family caregivers through pathways such as:
  - ◆ Expand state-funded programs to serve more low-income populations, rural areas, or others not currently eligible for HCBS waivers.
  - ◆ Ensure the financial viability of CBOs and FBOs, particularly those serving historically excluded and underserved populations.
  - ◆ Create opportunities for collaboration across systems and organizations that have (or potentially have) a role to play in supporting family caregivers. This may include hospitals, employers, communities of faith, state-based philanthropies, etc.
  - ◆ Explore ways to use OAA Title III funds to enhance or sustain dementia-care capabilities in local communities.
  - ◆ Explore avenues for providing low-interest loans and startup grants to encourage the development of adult day services as supports for family caregivers and care recipients.
  - ◆ Develop a universal application process that simplifies and streamlines processes for referral to and applying for services and supports across funding sources and agencies.
  - ◆ Build capacity and professional training tracks in the direct care workforce, particularly initiatives to encourage retention of trained workers so that family caregivers have greater access to assistance and respite opportunities.
- CBOs and FBOs can collaborate to create or bolster “community ambassador programs” to improve access to information and services for family caregivers from traditionally unserved and underserved populations.
- All stakeholders can explore innovative models that increase access to supports and services. Examples include:
  - ◆ Safe and reliable drop-in respite care programs that family caregivers can access during emergencies or unanticipated events
  - ◆ Help desks and hotlines that can address family caregiver stress
  - ◆ CBOs, FBOs, and research institutions can collaborate, create, and disseminate additional education and support options for family members with substance use disorders or anxiety and depression.
- States, counties, and municipalities can seek innovative ways of increasing the availability of a range of options for both in-home and out-of-home respite services, including vouchers, self-directed programs, and culturally specific programs. They

can also explore alternate respite models allowed under the Lifespan Respite Care Program and the National Family Caregiver Support Program. These can include volunteer and fee-for-service models, mobile adult day care models for rural communities, and more.

- School districts can develop a special orientation at the beginning of a new school year for kin and grandparents raising grandchildren. This can include distributing information about the programs and services available in their school district or in their planning and service area.
- States; national, state, regional, and local philanthropic organizations; CBOs, and FBOs can support the expansion and availability of respite care. Actions include:
  - ◆ Create greater awareness and acceptance of the need for respite care.
  - ◆ Develop and disseminate training resources to expand the capacity of respite care programs to meet the needs of family caregivers of individuals with medically complex care needs and those with intellectual and developmental disabilities (ID/DD)
  - ◆ Increase number of trained direct care workers and volunteers who can provide respite.
- State Respite Coalitions, where they exist, can consider focusing efforts on taking greater leadership roles in coordination, across systems and programs.
- CBOs can examine opportunities to establish volunteer respite programs.
- Managed care programs can cover respite as a regular part of their service package, if not already doing so. Plans can prioritize respite care as part of their supplemental services and advocate for use of those services by family caregivers.
- Advocacy or other organizations can create a ‘What respite means to me’ tool and add this resource to existing resource lists and websites.
- Faith-based communities and other community-based volunteer organizations can examine peer respite models and develop programs that leverage best practices. This can include:
  - ◆ Promote federally funded resources to community members, including the [National Respite Locator](#), the [Eldercare Locator](#), the [Disability Information and Access Line](#) (DIAL), and the [National Alzheimer’s Call Center](#)
  - ◆ Tap into church-based volunteer networks
  - ◆ Establish cooperative respite models that allow caregivers to “purchase” support for their family member with volunteer hours.
  - ◆ Provide adult day services in a supervised group setting within the community.
  - ◆ Develop other volunteer respite or peer support programs.

- ◆ Encourage and support schools and colleges to give credits for providing respite as part of a volunteer service requirement.
- All stakeholders can proactively use the widest possible definition of respite, meaning it can include any activity that provides the caregiver with a meaningful break. For example, respite services can:
  - ◆ Give a short break from any caregiving task.
  - ◆ Engage socially with the care recipient so the caregiver can focus on other tasks.
  - ◆ Teach a child who lives with a grandparent or kin caregiver to ride a bike, skateboard, or play a video game.
  - ◆ Cover housekeeping tasks that would otherwise fall to the caregiver.
  - ◆ Create space in the caregiver’s day for a nap or a walk.

### Whole-person Approach

- States and communities can work together to support family caregivers in addressing needs that are not “about” caregiving, but which contribute directly to health and wellbeing of the caregiver and the care recipient. These can include providing appropriate and accessible housing, home repair support, healthy foods, transportation, and social engagement.
- States can take advantage of technical assistance from and/or partner with organizations that can help them more effectively obtain funds for supportive and low-income housing, such as Section 8 and Section 811 that are specific to people with disabilities.
- States can maximize opportunities to ensure and expand caregivers and the people they support have access to web-based information. Suggested approaches include:
  - ◆ Establish a taskforce to identify ways to improve and disseminate web-based tools for identifying services and providers in the community
  - ◆ Adopt programs that provide computers, software, and internet technologies to individuals who need these tools.
  - ◆ Participate in efforts to expand broadband availability.
  - ◆ Partner with insurance payers to enable caregivers to access and use assistive technology.
- Communities can leverage existing programs like home-delivered meals or other delivery services to create “wellness check” programs to maintain health and safety for vulnerable community members.

## Emergency Planning and Disaster Response

- Health care systems can train employees and providers on how to respond to family caregiver and care recipient needs during emergencies and disasters.
- Long-term care providers can ensure that they seek input from family caregivers and care recipients when developing emergency planning procedures and ensure that all community members know what to expect in case of emergency. This includes continuity of service operations; how caregivers/recipients will be kept informed and whom to call; processes for equipment maintenance and replacement and replenishment of supplies; transportation alternatives, and how the service will address essential basic needs such as access to medicine.
- CBOs, FBOs, and other community/volunteer groups can put together essential survival packages and deliver to families in need during emergencies. (Also supports **Outcome 3.6**)

## Legal and Financial Services

- Financial institutions and national advocacy organizations can collaborate to curate or develop financial planning resources geared for family caregivers. Institutions can disseminate these resources in several ways, such as printed brochures distributed during in-person banking and as reminders and links within other resources related to financial planning, including eligibility for Medicaid and other benefit programs.
- Stakeholders can work together to expand legal services for kin/grandparent caregivers:
  - ◆ States can encourage attorneys who specialize in the custody/guardianship of children in kin/grandparent care to provide pro bono services.
  - ◆ Family and juvenile court systems can work to provide educational seminars to assist kin and grandparent caregivers who come through their systems to understand their rights and obligations.
  - ◆ Legal assistance programs can add pro bono succession planning for children in kinship families as part of the menu of services supported by the Older Americans Act to assist with advance planning.
  - ◆ States can encourage state and local bar associations to train and develop a corps of attorneys who are willing to handle pro bono cases to assist kin and grandparent caregivers in developing documents to establish and protect their rights, including succession planning and/or a determination of custody should the caregiver no longer be able to perform that duty, and to apply for benefits and services that may be available for the children.
  - ◆ Local legal services programs, including local protection and advocacy programs, can work with community organizations on outreach to kin or grandparent caregivers to inform them of their rights and obligations. Local legal services programs can also work with state and local courts and bar associations to ensure adequate representation for the caregivers.

- Employers, financial planners, and life/annuity/long term care insurers can incorporate future planning and considerations for family caregiving circumstances into all financial planning services more generally so that caregivers have necessary documents in place when the unexpected happens.

### Expanding and Strengthening the Direct Care Workforce

- States can prioritize a direct care workforce reform agenda that incorporates stakeholder input to inform state legislation and policy. This can be done through establishing legislative initiatives, master plans on aging, and direct care workforce collaboratives within state Medicaid, aging and disability agencies.
- States can launch a communications campaign to publicize the value of the direct care work to taxpayers, employers, and businesses. (Also supports **Goal 1**)
- States can coordinate workforce policy and resources across agencies, including partnerships between the states' departments of labor, workforce boards, and community college systems.
- States can address the recruitment and retention of direct care workers through the following activities:
  - ◆ Increase wages, benefits, and training for direct care workers under Medicaid that provides for a livable income.
  - ◆ Create quality incentive payments and workforce quality licensing designations for providers that promote a positive and robust work environment.
  - ◆ Create interoperable training programs that can be used across agencies and states.
  - ◆ Create state registries of direct care workers.
  - ◆ Collaborate with the federal government and other states to collect consistent data on outcomes of existing workforce efforts. (Also supports **Goal 5**).
- Home care agencies and educational institutions can partner with state agencies to support the above efforts through activities such as:
  - ◆ Set clear and consistent quality and care delivery standards.
  - ◆ Enhance training and job advancement opportunities.
  - ◆ Create career paths that includes opportunities to transition into related careers.
  - ◆ Create peer mentoring opportunities.
  - ◆ Expand credentialing options, including offering options for maintaining credentials when moving to a new state or jurisdiction.

- ◆ Participate in national data collection efforts to more fully understand the issues affecting the direct care workforce at the state and local levels. (Also supports **Goal 5**).

### Additional Actions to Support Kin and Grandparent Caregivers

- Child welfare systems can improve their outreach, engagement, and supports to relatives by:
  - ◆ Lead their agencies with a [“kin-first” philosophy](#).
  - ◆ Develop written policies and protocols that reflect equity for children with kin and recognize their unique circumstances.
  - ◆ Identify and proactively engage kin for children at every step.
  - ◆ Create a sense of urgency for making the first placement a kin placement.
  - ◆ Prioritize kin licensing.
  - ◆ Support permanent families for children.
  - ◆ Create a strong community network to support kinship families and grandfamilies.
- CBOs and FBOs can partner with legal groups to:
  - ◆ Create training programs for judicial professionals to educate them about kinship/grandparent needs.
  - ◆ Create toolkits for court officials to give to families with resources and information.
- Training programs for new foster parents can consider creating tailored versions specifically for kinship and grandparent caregivers rather than expect kin and grandparent caregivers to “translate” materials made for other audiences.
- Instructional designers can prioritize trainings for kin and grandparent caregivers that are flexible, available in-person or remote, feature lived experience, and offer a choice of formats. Possible topics include trauma, behavioral supports, legal relationships, access to benefits; managing relationships with birth parents, supporting family members with substance use disorders or serious mental illness, talking with children about their birth parents.
- All stakeholder organizations, including those not focused on kinship families, can review materials and trainings for appropriate (non-stigmatizing) and consistent language about caregivers.
- Mental health professionals can develop expertise to work more effectively with clients in kinship families and grandfamilies: managing relationships with birth parents; interacting with family members with substance use disorders or serious mental illness; and talking with children about their birth parents.

- Health care providers, especially those who accept Medicare and Medicaid, can ensure they offer flexible timing options for mental telehealth, mental health, and tele-trainings (e.g., weekend and evening appointments).

## Goal 4: Actions to ensure financial and workplace security for family caregivers

Personal finances and future financial security are a significant source of stress for family caregivers. Many of them worry about how to cover current and future costs associated with health care, health supplies and equipment, housing, and other services to accommodate the needs of the person receiving support. Family caregivers, especially parents of children with lifelong disabilities, worry about the future.

**Vision for Goal 4:** To alleviate the financial challenges associated with family caregiving, prevent financial ruin, and reduce out-of-pocket expenses for the caregiver, including employment protections.

Family caregivers often must respond to the immediate health and financial needs of the person receiving support with little time to prepare. This can increase both emotional and financial stress. The financial implications of caregiving can unfold for decades and affect future generations because it is often so hard for caregivers to put money aside for the future.

Financial planning tools and resources for people with disabilities, including special needs trusts and other financial products and services, can empower the family caregiver and the person receiving support. Family caregivers also struggle to balance their caregiving responsibilities with employment. More than half of working age adults are family caregivers. Many of them have had to miss work because of their caregiving roles, and some of them have ultimately had to reduce their working hours, take a leave of absence, or leave the workforce altogether. Flexible policies and practices can provide caregivers with employee benefits and the tools to balance work and caregiving role and allow them to remain in the workforce longer.

In addition, the cost of long-term services and supports themselves can create challenges. Medicare does not cover these expenses, and few people have private long-term care insurance or other mechanisms to pay for care. Medicaid is the primary payer of LTSS, covering just over half of all spending for such services and supports in the nation. However, access is limited to Medicaid HCBS services that enable family caregivers to continue to provide care, and most people receiving support from family caregivers do not meet the financial eligibility requirements for public assistance.

Public input to the Councils suggested that a significant portion of the long-term actions related to financial security require Congressional changes or federal regulatory action.

(See the Strategy for a resource list of legislative changes that are aligned with the Caregiving Advisory Councils' recommendations.) These changes are anticipated in future years as the overall culture increasingly recognizes the value of supporting caregivers. In the interim, states, communities, and other stakeholders can take actions to advance financial protection for caregivers and pave the way for future change. These include:

- States can promote a culture within agencies/systems that fosters recognition of family caregiving and what it entails. By describing caregiving and its duties, rather than assuming the concept is familiar, agencies/systems can encourage caregivers to recognize their role and start to self-identify as a caregiver. As a result, they are more likely to connect to training programs, financial resources and other supports to address financial challenges. (Also supports Outcome 1.1)
- State agencies, CBOs, and FBOs can review all outreach materials, website content, and intake forms related to financial issues for cultural sensitivity and to ensure that they do not perpetuate harmful stereotypes. (Also supports **Outcome 1.1**)
- Businesses can implement a “Caregiver Credit” program of discounts and other incentives for long-term care-related products, school supplies, and other items commonly purchased by family caregivers for their care recipients. (Also supports **Outcome 1.1**)
- AAAs can promote Title III E services to support family caregivers. They can also seek out or enhance non-traditional partnerships, such as with banks and financial planners, by reaching out with information and ideas for financial programs to benefit and support caregivers. (Also supports **Outcome 1.3**)
- States and human resources organizations can invest in developing outreach materials to educate employers and employees about available benefits programs that support caregivers, such as leave, workplace flexibility, anti-discrimination laws, and tax credits. (Also supports **Outcome 1.3**)

## Financial Planning

- School districts can partner with college and university admission programs to provide kin and grandparent families information on the financial aspects of attending college. They can also distribute the [Consumer Financial Protection Bureau](#) (CFPB) suite of tools on how to pay for college, compare college courses, and financial offers as well as how to apply for student loans.
- Public/private partnerships can explore ways to advance interest-free loans through targeted, tax-free funded donations or tax advantaged savings accounts (such as ABLÉ accounts).
- Software companies and application developers can develop and/or refine financial education and planning toolkits for kin, grandparent, and family caregiver populations.
- Financial counselors, coaches, and advisors can volunteer to assist kin, grandparent and family caregivers apply for the services and benefits they're qualified to receive.



- Financial institutions can explore partnerships with CBOs and Kinship Navigator programs to develop financial planning tools designed for kin and grandparent families who will be applying for college.
- Employers, banks, and credit unions can develop Caregiver Master Classes for financial education and planning. These should be short, incremental trainings for busy family caregivers. Other tools include Lifelong Learning Institutes at universities, where classes are free and within the community.
- CBOs and Volunteer Income Tax Assistance (VITA) sites can refer kin, grandparent, and family caregivers to financial counselors. They can also distribute resources such as CFPB’s [Your Money Your Goals](#) toolkit which was designed to help people plan for financial goals. (Also supports **Goal 3**).
- Caregivers themselves may want to review the [Life Course Framework](#), which is available for all types of caregivers and any age of care recipient. It helps individuals and families think about their current realities and goals for different aspects of their lives and engage in future or long-term planning to achieve those goals.

### Employment Protections, Flexibilities, and Leave Policies

- States should enact legislation to prohibits discrimination against caregivers in the workplace.
- States can consider expanding on the federal FMLA program by expanding the definition of caregiver, the length of leave available, the size of employers covered, and family caregiver protections.
- Employers and state agencies can create multi-stakeholder coalitions to support employers’ efforts to recognize, honor, and support working caregivers. (The [Massachusetts Caregiver Coalition](#) is a good example of this.)
- States can conduct assessments to better understand how many caregivers in the state have access to paid leave either through public or private programs. (Also supports **Outcome 5.1**)
- States can create incentives to encourage employers to be more caregiver-friendly via tax incentives for businesses and/or certification programs.
- States can make family responsibilities “good cause” for leaving a job, allowing caregivers who quit a job for caregiving to be eligible for unemployment insurance.
- Employers of all sizes can leverage AARP’s [Supporting Caregivers in the Workplace: A Practical Guide for Employers](#) to facilitate efforts to adopt supportive workplace policies and best practices for caregivers:
  - ◆ Commit to embracing flexibilities and lessons learned during the pandemic, notably that the workday can be defined beyond traditional hours.
  - ◆ Create flexible workplaces that allow for remote and telework options, leave sharing, job sharing, and comp time. This also includes structuring position

descriptions in such a way as to optimize the success of workplace flexibilities.

- ◆ Add employer-determined flexibilities for family caregivers, as they define their new normal in the wake of the pandemic.
  - ◆ Promote Employee Assistance Program (EAP) programs that offer meaningful support for caregivers as part of existing packages of free and confidential services to employees who have personal and/or work-related problems.
  - ◆ Encourage culture change to remove potential stigma associated with participating in EAP programs through the workplace. (Also supports **Outcome 1.1**)
  - ◆ Offer flex spending plans that help caregivers pay for certain extraordinary health care expenses, while allowing spending accounts to roll over.
  - ◆ Develop specific messaging on the impacts of family caregiving, which can lead to greater awareness among employees of the financial implications.
  - ◆ Offer flexible Human Resources (HR) options, such as caregiver flex time.
  - ◆ Distribute information and build awareness, either through HR or EAP, on the of types of tax credits available to caregivers
- CBOs can educate EAP vendors about locally available family caregiver resources, especially Kinship Navigator Programs and peer groups, so that employees who use EAP programs have an opportunity to learn about caregiver services that may benefit them. (Also supports **Outcome 1.3**)
  - Employers can expand benefits packages that make LTSS more affordable for working family caregivers (e.g., respite care, adult day care, caregiver training, offering voluntary LTC insurance, and allowing sick leave for family caregiving). (Also supports **Outcome 3.1**)
  - HR associations can educate their memberships and other employers about challenges family caregivers face so that managers and supervisors understand the needs of their caregiving employees:
    - ◆ Explain that changes in caregiving situation can lead to unexpected requests for leave benefits and flextime.
    - ◆ Encourage them to make available services and supports that benefit caregivers, both in the workplace (such as EAPs) and in the community. (Also supports **Outcome 1.1**)
    - ◆ Encourage them to support workplace job transitions through development of core competencies for position descriptions and structured assignment transitions. This can improve employees' productivity and confidence.

## Financing Long-Term Services and Supports

- States can explore options for expanding LTSS financing beyond state Medicaid programs. Examples to explore include [Washington's publicly funded long-term care program](#) or Hawaii's publicly funded family caregiver cash benefit called [Kupuna Caregivers Program](#).
- States can create a plan to expand access to long-term care insurance coverage, through citizen education campaigns, expanded tax credits for policyholders and employers who provide some level of benefit, and providing subsidized plans to state employees.
- LTC insurance providers can explore ways to improve affordability of services and supports for kin, grandparent, and family caregivers.
- States can identify ways to reduce the amount of time caregivers and beneficiaries spend filling out repetitive forms to apply for programs that help to fund long-term services and supports.
- States can expand Medicaid programs through self-direction or consumer-direction programs that can reimburse family caregivers for providing care.
- States can consider ways to reduce [spousal impoverishment](#) through efforts such as protecting the maximum amount of combined resources for the spouse living in the community, as allowed under federal law.
- States can evaluate existing safety net programs to identify services to assist those at risk of going onto Medicaid and provide targeted services for these family caregivers.
- States can develop a plan to provide some health and mental health coverage to all children, so kin and grandparent caregivers are not forced to relinquish their parental or custodial rights for the child to receive critical mental health support.

## Tax Deductions and Other Financial Assistance Programs

- States and municipalities can offer “refundable” state and local tax credits to family caregivers.
- States and communities that do offer tax credits to caregivers can explore ways to ensure that all eligible taxpayers are aware of these tax incentives. (Also supports **Outcome 1.3**).
- Financial counselors and advisors can provide information on setting up [ABLE accounts](#), tax-free savings accounts that individuals with disabilities and their families can use to cover qualified disability expenses.
- States can collaborate at the regional level to administer Temporary Assistance for Needy Families (TANF) and Supplemental Nutrition Assistance Program (SNAP) consistently and adopt a shared universal baseline income support for children & families.

- States can develop universal financial assistance application forms and methods of submission to save caregivers' time and reduce risk of errors on forms.
- States can consider ways to reduce the negative financial consequences that often come with taking in a relative family member who is unable to live alone or a non-relative child/grandchild outside of the foster system. Possible examples include:
  - ◆ Develop de facto custodian statutes to assist kin and grandparent families with custody issues.
  - ◆ Identify legal options for defining relationships and responsibilities for caregivers of children.
  - ◆ Extend tax credits for family, kin and grandparent caregivers as compensation for years spent out of the workforce while providing care. These credits can also enable caregivers to qualify for Social Security later in life.
  - ◆ Do not consider grandparent income when establishing benefits eligibility for children in informal kin and grandparent caregiving situations.
- States can take other actions to reduce the financial impact of caregiving. For example, states can make legal changes so that grandparents have the right to:
  - ◆ Request child support from the non-custodial parent.

### Child and Dependent Care Tax Credit: The Benchmark for State Tax Credit Policies

State credits often use the federal [Child and Dependent Care Tax Credit](#) (CDCTC) as a starting point for state initiatives. The CDCTC is available to caregivers who care for a child under 13, a spouse who is incapable of self-care, or a dependent adult. The CDCTC can reduce a caregiver's tax liability by up to \$3,000 for one qualifying individual or \$6,000 for two or more, though the [average credit amount](#) is about \$565. Caregivers may claim a [percentage](#) of the cost of items primarily used for the well-being of the person receiving care, determined by their total income. The CDCTC is nonrefundable, so caregivers can only receive a credit up to the amount they owe.

Since the credit is nonrefundable, caregivers cannot receive cash payments from the tax credit. Caregivers with lower gross tax liabilities have lower potential maximum credits, so middle and upper-middle income caregivers claim most of the credit's benefits and file a [disproportionate amount](#) of CDCTC claims. Additionally, the take-up rate is low for caregivers of adults. In 2017, roughly 159,000 people claimed the CDCTC for care of an adult and 156,000 for both an adult and a child, just 2.5% and 2.4% of the total CDCTC claimants, respectively. These caregivers earned credits worth a total of \$119 million out of a total of \$3.2 billion for the credit as a whole.

- ◆ Pursue the biological parents for child support paid to the grandparent, where applicable/desired.
  - ◆ Pursue the biological parent(s) for child support when applying for TANF.
  - ◆ Exercise the federal “good cause” exemption which could allow kinship families and grandfamilies to receive public assistance without requiring them to also seek child support from the child’s biological parents.
- States can share best practices for implementing the National Family Caregiving Support Program (NFCSP) (See **Goal 1**).

## Goal 5: Actions to expand data, research, and evidence-based practices to support family caregivers

Despite [a growing body of research showing the increasing role of family caregivers](#), limited infrastructure exists 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.<sup>1</sup> For example, the current national research infrastructure does not take into account the full range of caregiving (e.g., episodic, chronic, long-distance, etc.), the relationship between the caregiver and the person receiving care, and all care conditions and disabilities.

**Vision for Goal 5:** To promote research, identification, and the adoption of evidence-based practices in caregiver support.

Most national surveys do not contain questions that identify family caregivers. As of 2022, no major body of work explored the experiences of caregiving youth, and little information exists on the impacts of sibling caregiving or the needs of youth who live in families where the parents are full-time caregivers to others. Similarly, only very limited available research looks at caregivers who themselves identify as disabled. Family caregivers also are not included in biomedical clinical trials or medical device development, which means the nation has scant information on how the presence of a trained family caregiver influences efficacy of medical and social services interventions.

In addition, data sources that do include caregivers often use inconsistent definitions that make it hard for researchers to synthesize data sets to determine things the actual value of family caregiving and the potential opportunity costs for caregivers. An enterprise data management approach is needed to collect data on family caregiving that are consistent and comparable between programs and governmental entities. This will help ensure researchers can easily find, analyze, and utilize data to develop, plan, and coordinate

<sup>1</sup> 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

resources, services, and supports. It can also help identify and document the economic value of family caregiving.

Even though Goal 5 is the last goal of listed in the Strategy, validated and consistent data about the prevalence of family caregiving is a necessary component of other goals. As a result, improved data collection around family caregiving should be considered to be among the highest priorities.

### **Consistent Definitions and Data Sets**

- Researchers can develop a core set of standardized family caregiver questions that to add to national surveys.
- States can ensure their definitions of “family caregiver” are flexible and broad enough to encompass populations that are often missed or undercounted (e.g., grandchild caring for a sick grandparent) and are inclusive of terminology used to describe caregiving activities in other cultures.
- National, state, regional, and local philanthropic organizations and research institutions can improve quality of LTSS by funding or otherwise encouraging coordinated and consistent measurement development for HCBS and family experiences of care, especially for caregivers of people with Alzheimer’s disease or other cognitive or intellectual disabilities.
- All states can administer the optional Caregiver Module of the Behavioral Risk Factor Surveillance System (BRFSS), a system of health-related telephone surveys from the CDC that collect state data about health-related risk behaviors, chronic health conditions, and use of preventive services.
- State agencies and CBOs can collaborate to collect data at a single point of entry to save administrative costs and reduce the risk of data entry errors and inconsistencies.
- National, state, regional, and local philanthropic organizations; research institutions; business leaders; and others can work together to establish a set of standards for data collection to enable researchers and other key stakeholders to better evaluate research results.
- Private sector leaders (such as large employers) who have embraced caregiver-friendly policies (e.g., paid family leave) and business coalitions can advocate for widespread adoption of standardized metrics for evaluating the efficacy “caregiver-friendly” workplace programs. Such efforts have the potential to ensure that smaller employers and those just beginning to offer caregiver programs can easily align their efforts with other companies and/or research initiatives, reducing information silos and encouraging the sharing of success stories.
- State agencies and CBOs can support the expansion of research using national caregiving-related data sets.

- National, state, regional, and local philanthropic organizations; research institutions; and CBOs can create a caregiver data repository that caregivers can opt into to share data with researchers. The [University of Southern California Family Caregiver Support Center](#) provides a model.
- Business coalitions can encourage private-sector entities to use standardized data-collection tools, forms, and definitions of terms.
- Philanthropic organizations, researchers, CBOs, and other stakeholders, such as standards development organizations (SDOs), terminologists, and family caregiving interest groups can partner to:
  - ◆ Encourage widespread adoption of a core minimum data set with standardized data (including standardized caregiver definitions, and data attributes).
  - ◆ Educate stakeholders about the value of a coordinated approach to data collection about caregiving. (Also supports **Outcome 1.1**)
- States can adopt standardized, [evidence-based or evidence-informed](#) family caregiver assessments and use the results to develop person-centered and family-centered care plans. Tracking outcomes from those plans can help identify information that organizations can use to determine future resource needs and identify programming gaps.
- Researchers can make available to other researchers in-progress caregiver research via social networking sites for scientists and researchers. (See above **Goal 1**).
- Researchers and states can collaborate to collect more data on interactions between family caregivers and the long-term care workforce and share that information with other states. (Also supports **Outcome 5.3**)
- State agencies, health care systems, insurance payers, and CBOs can adopt interoperative and flexible technologies that allow public and private programs to streamline their efforts and collaborate with each another. For example, they can:
  - ◆ Build internet-based interfaces that can be shared by multiple agencies. These systems can host application and identification forms that enable family caregivers to provide information for use on several forms and applications. This can reduce the risk of inconsistent or incomplete reporting
  - ◆ Adopt tools and processes for reducing risks associated with handling of Personally Identifiable Information (PII). Examples include data-anonymizing techniques (such as character shuffling, encryption, or term substitution) and tools that reduce the risk of data breaches (such as fillable forms that do not store information in a database).
- State agencies, health care systems, insurance payers, and CBOs should embrace and participate fully in data collection efforts of the federal government that can facilitate future support to caregivers. For example, they can:

- ◆ Proactively seek opportunities to participate in the development, testing and deployment of new data collection and research efforts.
  - ◆ Set aside fiscal resources for data collection and reporting efforts.
  - ◆ Explore ways to participate in efforts to increase broadband speed and access data in communities with low access rate. (Also supports **Outcome 3.5**)
  - ◆ Encourage local health departments to commit to adopting and using the Behavioral Risk Factor Surveillance System (BRFSS) questions as part of their data collection programming.
- Private philanthropy can include adequate funding for administrative costs to provide incentives for CBOs to include data collection and research learning as a part of their programs and services.
  - Funders can also provide CBOs with the administrative and operational support to effectively build and standardize the evidence base for improved services and supports.
  - States can collaborate to establish data-collection methods that jointly support understanding the economic value, and opportunity costs, of family caregiving.
  - States can work with managed care plans and researchers to convene a community of practice/learning collaborative and create a collection of vetted best practices for different purposes at the state Medicaid level.
  - States can implement evidence-informed programs for family caregivers and collect data on those programs to assist researchers with translation and adaptations.
  - States can develop state evaluations of family caregiving programs to identify programs that warrant additional study and adaptation.
  - CBOs can partner and utilize the [Best Practice Caregiving Database](#) as a model to create databases of in-kind community-tested programs to facilitate program and service development, delivery, and use.
  - CBOs and/or research institutions can translate identified best practices for culturally competent use with diverse populations, including kin and grandparent caregivers.
  - States can collaborate with managed care plans and researchers to create evidence-based trainings for staff of participating plans.
  - State legislatures can include evidence-based approaches to service delivery in state-funded caregiver support programs.
  - States and organizations can build partnerships with universities and academic institutions to expand research and funding for evidence-supported family caregiving. Best practices include:
    - ◆ Developing standardized language for funding announcements to facilitate collaboration across research entities and sectors using the outcome data.



- ◆ Presenting findings at the national level, including to the Advisory Councils and at major conferences, so that evidence-based practices have the best chance of being adopted nationwide.
  - ◆ Sharing data on academic research and evidence-based outcomes with other states.
  - ◆ Ensuring evidence-based approaches identified in research are communicated to policy makers for implementation.
- Caregiving stakeholder organizations can develop a model like [pivotal ventures investments and incubation](#) to advance evidence-based and evidence-informed “incubator projects” that have promising societal impact for family caregivers and care recipients within the public domain.
  - College and university research programs can consider opportunities to expand and obtain funding for research into evidence-based interventions to support caregiving families.
  - CBOs and schools can disseminate kin and grandparent caregiver-specific evidence-based programs and evidence-informed practices through non-traditional places such as libraries, recreation/daycare centers, and afterschool programs. (Also supports **Outcome 1.3**)
  - Researchers can expand and standardize information collected from family caregivers including demographics, prevalence and nature, costs of care, health status, specific needs of diverse/multicultural caregivers, and level of unmet need.
  - State Medicaid programs can incorporate caregiver feedback as part of quality assurance for state Medicaid programs.
  - Researchers can design studies to include family caregivers across racial and ethnic populations by oversampling underrepresented groups as well as examining and comparing their outcomes across groups.
  - Academics, business leaders, and national, state, and regional philanthropic organizations can work to gather consistent data that builds the business case for workplace supports and encourages more businesses to adopt such supports. (Also supports **Goal 4**)

### Research Topics for Future Consideration

During discussions led by the Caregiving Advisory Councils, several topics emerged about which council members noted a need for additional understanding and knowledge. These topics are provided below. Students, researchers, and institutions (national, state, regional and local philanthropic organizations; publishers; conference organizers; etc.) may wish to consider soliciting, funding, creating, and/or widely disseminating work in these areas:

- Assess the effects on caregivers when individuals with disabilities (particularly those with high support needs) are integrated into the workforce through competitive, integrated employment practices.

- Assess availability, use, and impact of paid leave on caregivers in the state.
- Evaluate best practices for direct care worker (DCW) workforce training, recruitment, and retention
- Explore the roles of entities such as health care systems, insurance companies, FBOs, and tribal communities in expanding research and gathering data about family caregivers.
- Investigate and determine:
  - ◆ Number of children in kin and grandparent-led families who encounter the child welfare system and their outcomes.
  - ◆ Outcomes of caregiver assessments over time.
  - ◆ The return on investment for supporting family caregivers across all domains: training, support, employment, financial assistance, etc.
  - ◆ Person-centered outcomes, especially the totality of outcomes that truly reflect the end users' or the caregivers' perceived value of a particular intervention, not only the financial incentive
  - ◆ Capability of local direct care workforces to meet the needs of the state.
  - ◆ Testing existing evidence-based practices in multiple modes of delivery, such as in person, by mail, video, and/or phone.
- Expand evidence-based research on respite that can be disseminated to the appropriate populations or groups.
- Collect data to show who may need services but doesn't meet current eligibility requirements.
- Translate clinical-based interventions or care coordination models into more human services or social service settings.
- Translate and adapt other evidence-based approaches (not developed specifically for caregiving) for use by family caregivers.
- Develop a family caregiver study program that uses an interdisciplinary track of courses from multiple academic disciplines.
- Identify which care events trigger an assessment update and/or contingency plans
- Determine where and how cultural expectations and caregiving competencies intersect and interact.
- Collect statistical data on how many people are providing care, their demographics, and the context in which care is provided.
- Determine the commonalities regarding the role of the family caregiver across all populations.

- Conduct longitudinal studies that research family caregiving over time to identify and document the health-related changes related to caregiving.
- Begin studies about caregiving populations and groups that have not yet been the subject of research.
- Conduct environmental scans to develop an understanding of what currently exists that could be implemented; analyze data to figure out why the evidence-based practices are not being used.

## Acronyms and Abbreviations

- AAAs: Area agencies on aging
- ACL: Administration for Community Living
- ADRC: Aging and Disability Resource Centers (ACL)
- ADRD: Alzheimer's disease and related dementias
- BRFSS: Behavioral Risk Factor Surveillance System
- CBOs: Community-based organizations
- CDC: Centers for Disease Control and Prevention
- CDCTC: Child and Dependent Care Tax Credit
- CFPB: Consumer Financial Protection Bureau
- CMS: Centers for Medicare & Medicaid Services
- CSC: Caregiver Support Coordinator (VA)
- DCW: Direct care worker
- DIAL: Disability Information and Access Line
- EAP: Employee assistance program
- EBPs: Evidence-based practices
- EDM: Enterprise data management
- EHR: Electronic health records
- FBOs: Faith-based organizations
- HCBS: Home and community-based Services
- HHS: U.S. Department of Health and Human Services
- IAM: Identity and access management
- ID/DD: Intellectual and developmental disabilities
- JAHF: The John A Hartford Foundation
- LGBTQIA+: Lesbian, gay, bisexual, transgender, questioning, intersex, asexual, and others
- LTSS: Long-term services and supports
- MCOs: Managed care organizations
- NASHP: National Academy for State Health Policy
- NFCSP: National Family Caregiver Support Program (ACL)
- OAA: Older Americans Act

- OAEC: Older Adults Equity Collaborative
- RAISE: Recognize, Assist, Include, Support, & Engage Act of 2017
- RFI: Request for Information
- SGRG: The Supporting Grandparents Raising Grandchildren Act
- SNAP: Supplemental Nutrition Assistance Program
- TANF: Temporary Assistance for Needy Families
- VA: U.S. Department of Veterans Affairs
- VITA: Volunteer Income Tax Assistance