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Building a National Strategy to Support Family Caregivers

Findings from Key Informant Interviews and Stakeholder Listening Sessions

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Introduction

Family caregivers are the glue holding together the delivery and financing of long term services and supports (LTSS) in the U.S. They play a critical role in ensuring that people needing LTSS can remain in their homes—as most strongly prefer. Remaining at home and delaying or avoiding hospital or nursing home placement saves money for families, private sector payers such as long term care (LTC) insurers and health plans, and for public payers such as Medicaid. Indeed, it is estimated that replacing family caregiving with paid services would cost roughly \$470 billion each year.¹ More recently, the COVID-19 pandemic has created renewed urgency and momentum to address caregiving issues, both highlighting and exacerbating the considerable challenges of family caregiving.

Family caregiving covers a broad spectrum of care needs, populations, and situations. It includes caring for aging and disabled adults and children with intellectual and development disabilities and other special needs. It also includes grandparent and kinship caregivers, youth caregivers, chosen family caregivers, long-distance caregivers, and much more. The needs of these caregivers are as diverse as the people for whom they are caring. And the challenges they face change continually throughout their caregiving journey.

That is why Congress authorized the creation of the RAISE Family Caregiving Advisory Council. Specifically, the **Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act** of 2018 directs the Secretary of Health and Human Services to develop a national family caregiving strategy. The Council comprises family caregivers and experts engaged in an in-depth information-gathering and research effort over the last two years to develop recommendations and an implementation plan for addressing this critical caregiving crisis. The Council has been supported with additional resources, technical assistance, and policy analysis by the National Academy of State Health Policy (NASHP) and The John A. Hartford Foundation.

The RAISE Council has developed and published recommendations in a newly-released [Report to Congress](#). The report's 26 key recommendations represent the first step to developing a national strategy to support family caregivers. The national strategy will outline critical actions that can be taken by both the public and private sectors to better support family caregivers in ways that reflect their diverse needs; it will serve as a roadmap for federal, state, and community action to better support family caregivers.

¹ RAISE Family Caregiving Advisory Council, Report to Congress. September 23, 2021.

About the RAISE Goals and Recommendations

The goals and recommendations are based on the real-life experiences of thousands of family caregivers and the organizations that serve them. The RAISE Council collected information from:

- More than 1,600 caregivers and organizations through a Request for Information (RFI) in the Federal Register in December 2019;
- Diverse family caregivers who participated in 12 focus groups over the summer of 2020; and
- Additional focus groups with over 40 stakeholder organizations serving family caregivers.

Many leading organizations informed the development of the Council's recommendations. The Administration for Community Living (ACL), in collaboration with The John A. Hartford Foundation, the National Academy for State Health Policy (NASHP), RRF Foundation for Aging, the Ralph C. Wilson, Jr. Foundation, National Alliance for Caregiving (NAC), LeadingAge LTSS Center @UMass Boston, Center for Medicare Advocacy, ADvancing States, and Center for Consumer Engagement in Health Innovation at Community Catalyst all contributed to the RAISE Act Council's work. Expert faculty also provided critical support to help inform the RAISE Act Council's recommendations.

The primary recommendations fall into five (5) broad areas, each of which is a major goal driving the national strategy:

- **Goal 1: Increasing Awareness of Family Caregivers.** Family caregivers' physical, emotional and financial well-being will improve as a result of expanded awareness, outreach, and education.
- **Goal 2: Engaging Family Caregivers as Partners in Healthcare and Long Term Services and Supports.** Family caregivers are recognized, engaged and supported as key partners with providers of health care and long term services and supports (LTSS).
- **Goal 3: Improving Access to Services and Supports for Family Caregivers.** Family caregivers have access to an array of flexible person- and family-centered programs, supports, goods and services that meet the diverse needs of family caregivers and care recipients.
- **Goal 4: Supporting Financial and Workplace Security for Family Caregivers.** Family caregivers' lifetime financial and employment security is protected and enhanced.
- **Goal 5: Generating Research, Data, and Evidence-Informed Practices.** Family caregivers are engaged stakeholders in a national research and data gathering infrastructure that documents their experiences, translates evidence into best practice, develops person- and family-centered interventions, and measures progress toward the National Family Caregiver Strategy.

Broadening Engagement

Momentum to support family caregivers is building as awareness is growing about the important role they play and the need to support them. Aging, caregiver support, disability, government, and advocacy organizations are rallying behind the RAISE recommendations in recognition of the critical need for a coordinated national effort.

Consequently, it is important to expand awareness of and engagement in the process of moving these recommendations into concrete action steps. To do so, a wide range of policymakers will need to engage with these recommendations, including policymakers at the federal, state, and local levels, as well as private sector players such as employers, healthcare systems, and service providers, along with private payers. These policymakers can support family caregivers most effectively by helping to fund and execute the detailed, evidence-based RAISE Act action steps found in this report.

This report summarizes findings from research involving a broad range of stakeholder organizations working with family caregivers in both the private and public sectors, in order to gain their insights into best practice models and action steps that can be included in the national strategy to meet the RAISE goals. Additional stakeholder groups such as the direct care workforce, county health care providers, employers, aging and disability organizations, faith-based groups, respite care providers, and others participated in a series of individual interviews and group listening sessions.

Research Objectives and Methodology¹

Research Objectives

The objective of all the research activities this past year was to help shape a roadmap for the National Strategy. As we explored with stakeholders what they felt should be priority action areas, we focused on critical topics that had emerged in the Phase I consumer focus group discussions (as well as the RFI analysis from Phase I). These topics included:

- Raising awareness on issues around family caregiving and helping family caregivers gain the tools to self-identify and access information and services;
- Meeting the needs of culturally and ethnically diverse caregivers;
- Identifying solutions and supports for working caregivers;
- Expanding the availability and use of respite care;
- Ensuring access to a high-quality, adequately-paid direct care workforce;
- Addressing the needs that family caregivers identified for training, self-assessment, and support; and
- Understanding how to better integrate and support caregivers into the health care, discharge, and after-care experience.

In conducting this research, we sought to connect with a diverse group of stakeholders to ensure our findings were broadly representative of a range of views about family caregiving across the country. To do so, we recruited a wide range of organizations to participate in key informant interviews and listening sessions, aiming to engage organizations that were not previously connected to or familiar with the work of the RAISE Council. We looked at organizations participating in existing coalitions, explored existing publications, webinars, and awareness campaigns, and completed location-specific searches of caregiving organizations. We reached out directly to individuals at organizations of interest and asked them to participate in a listening session or key informant interview based on their area of expertise. We also used LinkedIn and referrals from Council faculty to help identify individuals working in these areas of interest, especially if they represented voices that we had not previously heard from.

Phase I

The work took place in two components: Phase I was a series of stakeholder strategy sessions organized around each of the five RAISE goals. For Phase I, we convened important stakeholder organizations largely at the national level who could guide our thinking about issues relevant to implementation of the RAISE goals. This included organizations representing caregiver issues from various perspectives including aging, disability, provider groups, researchers, and others. Of the 60 organizations invited, 42 participated in one of six two-hour sessions held during the first two

¹ Given the number and breadth of recommendations, the interests of the stakeholders interviewed, the time allocated to discussions, and the focus of each conversation, not every topic or every RAISE recommendation within each of the five goals was discussed in depth. Their exclusions from this report should not be interpreted to mean that the subject is not important, but rather that it could not be addressed at this stage in an adequate manner.

weeks of December 2020. Those meetings sought to engage key organizations in the work of the Advisory Council and to brainstorm action steps that could address each of the five RAISE goals. Prior to the sessions, participants were invited to complete a brief on-line survey to generate ideas for action steps specific to the goal that was going to be discussed during their session. The list of ideas that emerged from the survey helped to spark further conversation within the session. See the list of organizations included in the Phase I strategy sessions, page 7.

Phase II

Phase II included both one-on-one key informant interviews and a series of stakeholder listening sessions. It aimed to delve deeper into some of the ideas emerging from the Phase I stakeholder meetings and to generate additional insights on concrete actions that could be implemented to achieve RAISE goals and recommendations. We began by identifying individuals to serve as key informants who could help identify the most important discussion topics within each of the issue areas we had prioritized, which helped us develop the discussion guide for the listening sessions. We also asked key informants to suggest other individuals who could contribute to the listening sessions. Overall, we conducted 17 one-hour key informant interviews, using the Zoom platform.

The Phase II stakeholder listening sessions were convened mostly in October 2021 and were organized either by topic or by stakeholder type, as shown in the workplan (Appendix A). Each was 90 minutes and had about 6-8 participants. Overall, we conducted 16 sessions and heard from **103 different stakeholder organizations**.

The workplan that drove the selection of participants and topics for the Phase II sessions was developed in consultation with NASHP and the RAISE team. It lays out the topics, populations and areas of inquiry for the 17 key informant interviews and 16 listening sessions (see Appendix A).

The researchers' recruitment efforts met with an enthusiastic response from a broad and diverse set of stakeholders. See the full lists of organizations we connected with (on page 7, for our Phase I Stakeholder Strategy Sessions, and Appendix B, our Phase II Key Informant and Listening Session Participants). These include national advocates, state and local advocates, employers, researchers, faith leaders, foundations, direct service providers, parent information centers, municipal, county, and state government officials, health systems, health providers, caregiver resource centers, business leaders, and coalitions. The organizations were also drawn from diverse location across 37 states. Organizations spanned a family caregiver resource center, serving parents of children with disabilities in rural Montana, a respite care provider in Honolulu, a memory disorder support organization in the Big Bend area of Florida, and a health system's family caregiver program in Detroit.

The organizations we spoke with also worked with many different types of family caregivers. For example, some served the disability and aging communities, as well as organizations supporting kinship families. In some cases, we dedicated listening sessions to organizations working with specific populations of family caregivers, including Indigenous and rural caregivers, as well as faith-based organizations that support family caregivers.

We intentionally sought out organizations that work with communities of color — examples include a Michigan home care agency that serves older South Asian individuals, a grassroots partnership supporting caregivers in Latinx and African American communities in the Chicago suburbs, and a research institute's Arizona-based Native American outreach program.

Phase I Stakeholder Strategy Session Participants

- AARP
- Access Living
- Alzheimer's Association
- American Bar Association
- American Network of Community Options and Resources (ANCOR)
- Association of Programs for Rural Independent Living (APRIL)
- Autism Society of America
- Benjamin Rose Institute on Aging
- Brookdale Foundation
- California Long-Term Care Education Center
- Caregive Action Network
- Center for Family Support, University of Pittsburgh
- Center to Advance Palliative Care
- Disability Policy Consortium
- Generations United
- Institute for Healthcare Improvement (The Conversation Project)
- Jewish Federation of North America
- Justice in Aging
- LeadingAge
- Little Lobbyists
- Lucille Packard Foundation for Children's Health
- Meals on Wheels America
- Medicare Rights Center
- Mental Health America
- National Association of Councils on Development Disabilities (NACDD)
- National Adult Day Services Association
- National Alliance for the Mentally Ill
- National Asian Pacific Center on Aging
- National Caucus and Center on Black Aging
- National Council on Aging
- National Council on Independent Living (NCIL)
- National Indian Council on Aging
- National PACE Association (NPA)
- National Patient Advocate Foundation
- National Council on Aging (NCOA)
- Scripps Gerontology Center, Miami University
- Services and Advocacy for Gay, Lesbian, Bisexual & Transgender Elders (SAGE)
- Sibling Leadership Network
- Institute on Disability and Human Development, University of Illinois
- Southeast Asia Resource Action Center (SEARAC)
- The Arc
- Well Spouse Association

In addition to these conversations with organizations serving a diverse range of family caregivers, we also connected with other sectors that impact the lives of family caregivers. We dedicated listening sessions to speaking with employers, experts in the direct care workforce, health systems, respite providers and county officials. For many of these participants, the listening sessions provided a unique opportunity for participants to connect with other stakeholders passionate about supporting family caregivers and those they care for. In addition to our research findings, these listening sessions illuminated the importance of dedicated spaces for caregiving stakeholders to connect, exchange insights, and collaborate.

Our research sought to bring more stakeholders into the RAISE Council's conversation, and the rich findings illustrate the importance of connecting with a diverse array of stakeholders. The entire research team is grateful to each of these organizations for sharing their time and insights.

Findings and Analysis

The more than 106 hours of transcripts were analyzed using NVivo, a qualitative analysis software program, to assure systematic analysis of data. A team of four researchers developed a coding tree organized by the RAISE goals and by major topics and themes within and across those goals. Each transcript was coded and reviewed separately by two researchers.

The Council directed us to identify the action steps that emerged from the stakeholder recommendations in support of each goal, and to differentiate those action steps based on whether they were intended for federal, state, or local governments, or for private sector entities (or some combination thereof).

In this section, we provide a broad overview of some of the major action steps that emerged from the key informant interviews and stakeholder discussions. Appendix C provides a complete list of recommended actions, along with quotes from the transcripts that further illustrate the concept behind those actions or the rationale and need underlying it.

Goal 1: Family caregivers' physical, emotional, and financial well-being will improve as a result of expanded awareness, outreach, and education.

Consensus emerged around the need for a federal-level interagency awareness campaign promoting the value of family caregivers, enabling them to self-identify and supporting their ability to find the services and supports they need. This national campaign would involve a well-curated and widely-promoted website, and create and disseminate culturally relevant materials aimed at supporting caregivers across all situations. In addition, specific efforts would target underserved populations such as persons of color, Asian-Pacific, Hispanic, LGBTQ, Indigenous, and other caregiver communities.

The awareness campaign would also have components specifically directed at employers and health care providers to educate them on the needs of family caregivers and the specific ways in which they can help support them. Examples of best practices in this regard are discussed further under Goals 2 and 4. Disseminating information and improving understanding of these topics by way of outreach to employers and health care providers would also be part of the overall awareness campaign.

Activities at the state, local and private sector level are also suggested to help raise awareness of the needs of and solutions for family caregivers. Some of these include:

- A state-based education and outreach campaign working with numerous stakeholders across the state;
- Development and implementation of an interagency Master Plan on Aging, similar to the one that was just completed in California; and
- Expanding state funding for “No Wrong Door” systems and state support for community- and faith-based organization in their work with family caregivers.

Additionally, there was support for the idea of creating community ambassadors/navigators to work with family caregivers in general and specifically to help reach excluded groups (e.g., minorities, and those living in rural areas) and help them navigate the resources that might be available.

“I’m concerned about the degree of shame that caregivers feel about... accepting support. Any kind of public awareness campaign that is culturally-sensitive and tailored to different communities could help... normalize this experience and reduce the shame... and then enable caregivers to more readily accept the help that’s available.” — *Health policy consulting firm*

“Where we struggle around supporting caregivers is the identification of caregivers. People in the role of a caregiver don’t know they’re caregivers, because they’re a role of, you know, a loved one or whatever that is.” — *Health systems provider*

“My vote for priorities would be along the lines of a large public education campaign... you can show different types of caregivers, all of us who are somewhat in a caregiver situation.” — *Family caregiver advocacy organization*

Goal 2: Family caregivers are recognized, engaged, and supported as key partners with providers of health care and LTSS.

Discussion and recommendations for Goal 2 focused on ways to strengthen the identification and engagement of family caregivers into healthcare and LTSS systems. This includes engaging the family caregiver into the care experience as the care recipient moves through the hospital, physician’s office, LTSS service system, and more. While there have always been challenges and disconnects in this regard, the COVID pandemic has further isolated caregivers from care recipients, particularly during hospital stays.

Several recommendations pertained specifically to the CARE Act, recommending both ways to strengthen it and to promote its wider adoption. The Caregiver Advise, Record, Enable (CARE) Act, which has been enacted by several states, aims to help family caregivers when their care recipient is in the hospital and as they transition to home. It requires hospitals to:

- Include the family caregiver’s name on the care recipient’s medical record;
- Inform family caregivers prior to discharge; and
- Provide the family caregiver with education and instruction about adequate support post-discharge.

Stakeholders felt that hospitals and health care systems are not properly staffed, trained or incentivized to identify family caregivers, engage with them, assess, and support their needs as intended or in accordance with best practices. In fact, one recommendation is to establish a stakeholder group at the federal level to develop strategies for incorporating caregivers into care planning, include them as part of a care team, develop quick caregiver identification tools for health care (and LTSS) professionals, and develop strategies for training medical and health care professionals to recognize and address the needs of family caregivers.

Participants felt that financial incentives—specifically the creation of new reimbursement codes for both private sector and public payers to cover time spent, engagement with, and assessment of the needs of family caregivers—is needed. Additionally, other recommendations included:

- Health care providers should pilot the use of caregiver assessments to improve identification caregivers' needs and how best to support them;
- Hospitals/health care systems should hire and train family caregiver engagement specialists;
- Hospitals should review and strengthen their protocols for incorporating the caregiver into the Electronic Medical Record system; and
- Hospitals, health systems, state hospital associations and research organizations should identify and promote best practices for family caregiver engagement.

Further, respondents discussed the importance of better training individuals across service settings — in both healthcare and LTSS settings — about the needs and experiences of family caregivers.

“I think enabling physicians to be reimbursed for the time they spend providing instruction and support to family members and to make this a [reimbursement] code that just doesn't apply to licensed providers, but would apply to case managers, to be working within primary care or another medical setting.”

— *Health policy research entity*

“That goes back to the clinician workforce education where we talk about how do we bring family caregivers into the conversation, being intentional about including them....And listening intently to those caregivers...It's a real culture change... it's a paradigm shift in terms of how we're looking at including caregivers.” — *Health system provider*

“So, as a nurse by training, I never quite formally learned how to assess caregiver needs, family member needs, as well as educating them about their loved-one's chronic illness. And I think that kind of stems up the pipeline in terms of when people are working as clinicians and not having that formal training or even awareness in their clinical rotations in terms of really interacting with the family, having a dedicated time and space for that in their clinical education.”

— *Health care provider*

“There's no one... assigned to monitor the Care Act documentation in the hospitals. So, I think having someone dedicated in terms of a clinician or administrator in these... areas would be essential.” — *Health system provider*

Goal 3: Family caregivers have access to an array of flexible person- and family-centered programs, supports, goods and services that meet the diverse and dynamic needs of family caregivers and care recipients.

Expanded federal funding was the action identified as having the most impact on achieving Goal 3—both with regard to strengthening existing programs and services as well as for creating new benefits under existing programs. Stakeholders support creating funding opportunities to create a community ambassador program—modeled after the Ryan White Act—to better reach excluded populations and the entities that serve them. Expanded Medicare benefits for respite, adult day care, and home modifications were also mentioned. Other suggestions for federal action included expanded family caregiver initiatives through increased funding for the Older Americans and Elder Justice Acts, for the National Family Caregiver Support Program, Lifespan Respite and Alzheimer’s Program Initiatives and Expanded Medicaid Access to Home and Community-Based Services (HCBS).

Stakeholders also recommended states expand access to HCBS through Medicaid expansions and state-funded programs. Medicare Advantage and other private health plans should expand benefits for respite care and other services to support family caregivers. Other suggestions focused on encouraging states and lenders to provide low-interest loans and grants to foster development of adult day services, along with encouraging states and municipalities to identify partners that could help them be more effective in developing supportive and low-income housing.

Several stakeholder sessions focused on the limited availability of direct care workers and the challenges faced in recruitment and retention. Specific action recommendations with regard to direct care workers include the following:

- Create a federal government-led interagency task force to design a Direct Care Workforce development plan;
- Publicize the value of direct care work;
- Improve pay for direct care work through increases to minimum/livable wages and payment under Medicaid;
- Fund research and demonstration programs to create greater understanding of the direct care workforce and ways to improve it;
- Improve data collection by the federal and state governments to ensure a better understanding of the workforce;
- Expand or create opportunities from state governments to pay family caregivers; and
- Invest in the direct care workforce through states and home care agencies and educational institutions by enhancing training and job advancement opportunities.

“I’m growing...tired of the empty rhetoric about the heroic nature of [direct care] work. It’s time to make some fundamental changes here. And that’s not a crisis. I mean, a crisis is sudden and temporary and unexpected. We’ve been having this conversation for 30 years. 30 years! It’s not a crisis. It’s a systemic failure.”

— *Advocate for direct care workers*

“I think we have ambassadors, we have champions, [but] ... these need to be empowered paid administrators, managers, directors... that hopefully come from these communities and know what’s available... being trained with advanced skills.”

— *Faith-based organization*

“Anything that’s directly related to getting cash and resources into the pockets of caregivers, that should always be our priority.” — *Advocate for LGBTQ elders*

“How do you recruit people? Pay them more than Starbucks. It’s not that complicated. In California, there’s signs everywhere because of the workforce shortage. You can work at the smoothie place for \$16 bucks an hour. Who’s going [to work for] a minimum wage of \$14 an hour. Most IHSS workers in California are at \$14 an hour. Why would I do this work that is so hard and so emotional, when I can go make a smoothie?” — *Policy and workforce advocacy organization*

“A comprehensive caregiver assessment is critical... It connects a key caregiver to...a caregiver consultant who can talk to them about all of those things, including respite if that’s what’s appropriate. They need a guide to help them steer that ship.”
— *Community-based organization*

Goal 4: Family caregivers’ lifetime financial and employment security is protected and enhanced.

An estimated one in six employees is juggling work and being a family caregiver², spending on average 20 hours a week providing a broad range of caregiver services.³ The cost to both business and the individuals who provide care is significant. One study found that 70% of working caregivers reported at least one mental health symptom and a similar proportion mentioned having to decrease work hours, take unpaid leave or rearrange work schedules in order to fulfill their caregiver responsibilities.⁴

The financial vulnerability that working caregivers face – along with these emotional burdens – was a critical concern that emerged in the Phase I focus groups with family caregivers, as well as a prominent theme emerging from the RFI analysis in Phase I.⁵ Therefore, several key informant interviews and stakeholder sessions focused on generating strategies to address these issues.

There was broad support for passing a federal paid Family and Medical Leave Act (FMLA), as well as for state-level initiatives. In addition, there was strong interest in expanding the FMLA definition of “family caregiver” to include “family of choice” and a broader range of family relationships, and for the FMLA to apply to small employers currently excluded under the law. Enabling family caregivers to receive direct pay for their caregiver role also emerged within the Goal 4 discussions, as it did under Goal 3. Respondents also mentioned the need for financial relief for the out-of-pocket expenses associated with being a family caregiver, through tax credits or other mechanisms.

A major theme was identifying ways to encourage employers to adopt caregiver-friendly workplace practices, such as offering tax credits or other financial incentives to employers who adopt one or more types of caregiver-friendly workplace practices. Other strategies involved partnerships and

² Gallup-Healthways. (2011). Gallup-Healthways Well-Being Index

³ National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S

⁴ U.S. Department of Health & Human Services, Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report, June 18, 2021.

⁵ <https://www.nashp.org/wp-content/uploads/2021/05/family-caregiver-listening-session.pdf> and <https://www.nashp.org/wp-content/uploads/2021/02/caregiver-priorities-and-recommendations-2.pdf>

promotional approaches: it was suggested that the federal government work with states and the private sector on a national campaign to promote caregiver-friendly workplaces, including voluntary certification programs, education and information for employers looking for best practices around caregiver-friendly workplace initiatives, and employer- and state-based coalitions to support employers' efforts to recognize and support working caregivers. Many also stressed the need for data to make the business case for the value of workplace programs to support family caregivers (as mentioned under Goal 5).

Some of the specific workplace programs identified by stakeholders included flexible work schedules, Employee Resource Groups (ERGs), benefits specific to caregiving such as an employer-paid care concierge service health insurance, coverage for respite, adult day care, caregiver training, and the like. Some felt that, while paid leave or leave without pay is critically helpful to address a caregiving crisis, it is of limited value for most caregiving situations that have extended durations and require on-going and changing support over time. To create a supportive workplace environment, training management to understand the needs, experiences, and value of family caregivers was also seen as critical.

Finally, some stakeholders felt that a larger, more structural and systemic change in our LTSS financing system is the best way to address the financial security of family caregivers—suggesting that stakeholders advocate for Congressional action to support broadscale reform in the shape of an LTSS social insurance program.

“When it gets to the point of [FMLA] eligibility requirements, [I suggest] it not be restricted to biological or legal family members... the older adults could designate who is eligible to receive these supports...” — *Advocacy organization*

“I’d like to add something to leave policies... employers shouldn’t define who a caregiver provides caregiving to. It’s not just about biology or a spousal relationship.” — *Advocacy organization for African American elders*

“Why don’t we have the tax credit for medical expenses... including all the long-term care-related ones and make it a refundable credit up to some percentage of people’s actual out-of-pocket costs?” — *Disability advocate*

“I like the idea of that tax incentive to an employer.... Because ultimately, you’re helping your employees who are going to work longer and be happier and provide better service.... So, tax credits are probably the way to do it.” — *Health systems provider*

“...even though you offer more PTO or FMLA ...people still need help with the challenge at hand. I can throw PTO at people all day... but I’m still trying to figure out how to help my family. [FMLA is] basically giving me more time to spend with them, but I still might be lost as a caregiver in terms of what I should be doing to help them....what resources to access.” — *Employer support service provider*

Goal 5: Family caregivers are engaged stakeholders in a national research and data gathering infrastructure that documents their experiences, translates evidence into best practices, develops person- and family-centered interventions, and measures progress toward the National Family Caregiver Strategy.

Recommendations for research actions were generated within each of the stakeholder sessions in Phase II. Additionally, in Phase I, a two-hour session specifically on research and data gathering priorities was convened. Priority topics for research pertained to:

- Demonstration of best practices for supporting working family caregivers;
- The return on investment to employers/business from various workplace strategies supporting employees in their caregiver roles;
- Best practices for engaging family caregivers in the health care and hospital experience, as well as throughout the LTSS system;
- The outcomes associated with health systems that employ caregiver engagement and supports;
- Data collection to better understand the current nature of the direct care workforce and how to recruit, retain and enhance it; and
- Research on caregiver assessment tools and best practices for implementing them.

Additionally, stakeholders suggested convening a federal task force to review data collection efforts across federal agencies to coordinate and standardize data items used, to enhance comparability and ensure that critical aspects of the caregiving experience are consistently collected. The objective would be to develop a uniform set of data questions that would easily enable questions about family caregivers to be integrated into existing national data collection efforts to improve our understanding of who is a family caregiver and expand the array of detailed data we have about them and their non-caregiving counterparts over time. Stakeholders also identified a need for a caregiver identification tool that could be used in service delivery settings to quickly identify and engage family caregivers, encouraging them to self-identify.

“I think it’s fascinating to look at outcomes when it comes to screening tests. So if you have caregivers in your organization taking care of a loved one at home, they’re more likely to have missed their mammogram this year or [their] colonoscopy in 10 years. So that’s something that you can really look at that really matters to overall... utilization of preventive care.” — *Large employer*

“We need to be able to quantify that. What are those health care costs for you the employer, if you don’t provide supports for your caregiving employees? Because yes, they can be more costly. Overall, they shouldn’t be, if you provide the right benefits.” — *Large employer*

“[We need] research-based interventions and... studies that show [how] involving the caregivers, educating and empowering them changes outcomes.” — *Health care provider*

Appendices

Appendix A: Phase II Work Plan

Appendix B: Phase II Stakeholder Organizations

Appendix C: Summary of Actions and Supporting Stakeholder Quotes

Appendix D: Best Practice Models

Appendix A: Phase II Work Plan

Population	Topics	Key Informant Interviews	Listening Sessions
Employers (including intermediaries, academics, and public policy representatives)	Financial and workplace accommodations: Strategies for advancing caregiver-friendly workplaces; How are the needs of diverse caregivers met? Making and disseminating the business case; Identifying and overcoming barriers; Strategies for making policy change.	5	3
Respite Care	Supply side issues: Increase the supply of quality, appropriate respite services; Expand use of vetted volunteers and volunteerism; Demand side issues: Raise awareness and acceptance of respite care; Identify barriers and strategies.	3	1
LTSS Providers/Direct Care Workforce	What will it take to grow, strengthen and sustain the direct care workforce? Meet with representatives of organizations that work with, support, advocate for and understand the direct care workforce. Explore strategies such as expanding the use of volunteers; strengthening the paid LTSS workforce; creating career ladders; and more	2	2
Health Care providers	How to include the family caregiver in the health care process. Explore with representatives from health care provider organizations and institutions that can provide insight into the implementation of the CARES Act in the 45 states where it is in place. While intended to provide inclusion for the family caregiver in their loved one's health care, what do we know about whether and how it is working? What improvements are needed? How can we better identify and integrate the family caregiver as a partner in the care team?	3	1
Counties	What specific resources and policy changes do counties need to better support family caregivers? How are counties supporting family caregivers through family-friendly workplaces?	1	1

(continued next page)

Phase II Work Plan (continued)

Population	Topics	Key Informant Interviews	Listening Sessions
Community-based and Faith-based Organizations (CBOs and FBOs)	Understand how CBOs/FBOs support family caregivers, including racially, ethnically and linguistically diverse populations to identify how they can more effectively address family caregiver needs. Are there examples of best practices? What are the biggest challenges? What is the role of FBOs in providing and expanding volunteerism to fill caregivers needs? Understand the unique aspects, benefits and limitations of these organizations as they support family caregiving. Identify how they engage diverse caregivers (e.g., grandparents/kinship care, non-English speakers, LGBTQ, etc.)	3	
Geographically-based Listening Sessions: Rural CBOs Urban/Suburban CBOs	Explore models of cooperation and collaboration and how CBOs do caregiver outreach and referrals to care. Issues explored as described above.		2
Population-specific Listening Sessions with CBOs	Specific sessions to explore these issues with organizations specifically serving the following populations: Aging, Disability, Indigenous communities, People of Color and Faith-Based Organizations		5
Total		16	17

Appendix B: Stakeholders Phase II, Key Informant and Listening Session Participants

- Alabama Department of Aging
- Alliance of Disability Advocates
- ALU LIKE, Inc.
- Alzheimer’s Orange County
- Apna Ghar Home Care
- Arizona Caregiver Coalition
- ATI Advisory
- Autism Self-Advocacy Network
- Best of Care Inc.
- Cariloop
- Caring Together, Living Better (CTLB), AgeOptions
- Center for Parent Information and Resources
- Chicago Department of Family & Support Services
- Claude Worthington Benedum Foundation
- Coalition to Transform Advanced Care (C-TAC)
- Colorado Cross-Disability Coalition
- Colorado Department of Health Care Policy & Financing
- Continuum of Colorado
- CVS Health
- Dana-Farber Cancer Institute
- Douglas County, NE Board of Commissioners
- Duke-Margolis Center for Health Policy, Duke University
- Easterseals Iowa
- Eastern Idaho Community Action Partnership (EICAP)
- Elizabeth Dole Foundation
- Epilepsy Foundation
- Family & Nursing Care
- Family First
- FamilyMeans
- Federal Reserve Bank of Kansas City/
New Mexico Caregivers Coalition
- Five County Area Agency on Aging
- Foster Kinship
- Global Coalition on Aging (GCOA)
- Hā Kūpuna (National Resource Center for Native Hawaiian Elders)
- Harvard Business School
- Health Management Associates
- Helper Bees
- Helping Hands of Vegas Valley
- Henry Ford Caregiver Assistance Resources and Education Program
- House Works, LLC
- Independent Living Research Utilization (ILRU)
- Integrated Benefits Institute
- Iowa CareGivers
- iRobot
- Jewish Family Service (JFS) of Saint Paul
- J-Sei
- KBH Advocacy
- L’Arche USA
- Learn Care Together LLC
- Little Tokyo Service Center
- L’Orech Yomim/Center for Healthy Living (LOY)
- Lunalilo Home
- MAC, Inc./ Maryland Living Well Center of Excellence
- Massachusetts Lifespan Respite Coalition
- Massachusetts Digital Health Initiative
- Massachusetts Executive Office of Elder Affairs
- MCM CPAs and Advisors, LLP

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Appendix B: Stakeholders Phase II, Key Informant and Listening Session Participants

(continued from previous page)

- Missouri Rural Health Association
- Montana Family to Family Health Information Center
- National Alliance for Direct Support Professionals (NADSP)
- National Association for Home Care & Hospice (NAHC)
- National Association of Counties (NACo)
- National Association of Nutrition and Aging Services Programs (NANASP)
- National Brain Health Center for African Americans, Balm in Gilead
- National Catholic Partnership on Disability
- National Disability Rights Network (NDRN)
- National Rural Health Association (NRHA)
- National Senior Corps Association
- Native American Outreach Program, Banner Alzheimer's Institute
- National Council on Aging (NCOA)
- Nevada Office of Aging & Disability Services
- New Mexico Caregivers Coalition
- North Dakota Respite Coalition
- Nourish for Caregivers
- Office of Hawaiian Affairs
- OK Cares
- Paralyzed Veterans of America
- Philadelphia Corporation on Aging
- Rethink First
- Rhode Island Department of Human Services
- Rural Dementia Caregiver Project, University of California San Francisco
- Services and Advocacy for Lesbian, Gay, Bisexual & Transgender Elders (SAGE)
- Silberman Aging, Hartford Center of Excellence in Diverse Aging
- South Carolina Respite Coalition
- Southern Caregiver Resource Center (SCRC)
- The Alzheimer's Project
- The Resource Exchange (TRE)
- The Urban Institute
- Torchlight
- The Renaissance Collaborative (TRC)
- Trellis
- United for Caregivers@Work
- United Methodist Health Ministry Fund
- United Way of Rhode Island/Family Caregiver Alliance of Rhode Island
- University of California San Francisco
- University of Iowa
- University of Minnesota Rural Health Research Center
- Us Against Alzheimers/Latinos Against Alzheimer's
- Vision for Equality
- Warrior Care Network, Wounded Warrior Project
- Washington County Disability, Aging, and Veteran's Services
- Well Spouse Association
- Wellthy
- Working Daughter
- Yale New Haven Health/Geriatric Emergency Department Collaborative
- Zen Caregiving Project

Appendix C:

Summary of Actions and Supporting Stakeholder Quotes

GOAL 1: FEDERAL ACTIONS

- Develop and implement an interagency federal campaign with multiple objectives. Create targeted campaigns for family caregivers, employers, and health care and other service providers. Raise awareness about what it means to be a caregiver and their value to self, family, and society.
- Use the awareness campaign to increase the number of people who self-identify as a caregiver.
- Create an easy-to-use tool to facilitate self-identification
- Use the awareness campaign to increase the number of caregivers who know where to go for services and supports that fit their needs.
- Create a national website and “help desk” to allow family caregivers to identify appropriate services and other resources.
- Create and distribute materials that direct caregivers to trusted sources of information on services and resources. Disseminate information through multiple distribution channels that reach caregivers in a range of culturally diverse communities.
- Fund and support the development of state plans on aging to coordinate activities to ensure that all family caregivers have access to services.
- Include modules in a newly-created website — Caregiver.gov — for employers and health care providers, providing guidance and best practices on how they can support family caregivers in their respective environments.

GOAL 1: ACTIONS FOR STATE, LOCAL AND PRIVATE ENTITIES

- States should support the Federal awareness campaign with parallel activities at the state level
- States should launch public outreach campaigns for family caregivers, in collaboration with local stakeholders
- States should support the capacity of CBOs to conduct outreach and to help family caregivers to navigate the service delivery system.
- States should establish and support collaboration among state agencies, CBOs, FBOs, and municipalities to share resources and promote utilization of existing resources.
- States should fund improvements to state-level No Wrong Door systems.
- States should create and distribute materials that direct caregivers to trusted sources of information on services and resources. Disseminate information through multiple distribution channels that reach caregivers in a range of culturally and ethnically diverse communities and that are culturally and ethnically appropriate and sensitive to the specific populations for whom they are intended.
- States should support CBOs and FBOs working to support family caregivers in diverse communities.
- States should create community ambassadors to act as liaisons from the communities to diverse and specific family caregiver groups.
- States should develop state plans for supporting family caregivers, involving a broad range of stakeholders.
- States’ units on aging should establish collaborations with major employers and local private philanthropy to create family caregiver coalitions with work plans, funding and projects to support family caregivers (Crosswalk Goal 4). See Massachusetts Caregiver Coalition as a model.

STAKEHOLDER QUOTES: GOAL 1

“I’m very concerned about the degree of shame that many caregivers feel about... accepting support. Any kind of public awareness campaign that is culturally-sensitive and tailored to different communities could help... normalize this experience and reduce the shame... and then enable caregivers to more readily accept the help that’s available.” — *Health policy consulting firm*

“Where we struggle as a health system around supporting caregivers, is the identification of caregivers. Our frontline staff don’t understand the definition of caregivers. People in the role of a caregiver don’t know they’re caregivers, because they’re a role of, you know, a loved-one or whatever that is.” — *Health systems provider*

“My vote for priorities would be along the lines of a large public education campaign... you can show different types of caregivers, all of us who are somewhat in a caregiver situation.” — *Family caregiver advocacy organization*

“I think having one overall campaign that addresses different issues would be the way to go... some of which is to raise awareness, but others are to self-identify folks that can say, ‘that’s me.’” — *Aging advocacy organization*

“I think it’s the clinicians, 100% providers definitely, but also Because the caregiver and the patient are at the front desk and they’re not even recognizing that the person with them is the caregiver.” — *Private foundation*

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

“Well, I think that if there’s a repository of best practices for any of the stuff that we’ve talked about, that would be something that I think would be helpful so we’re not trying to reinvent the wheel.” — *County commissioner*

“The way I think of it is the need for a national help desk for caregivers... there are resources, supports and services, but they don’t know how to navigate to them....” — *Family caregiver advocacy organization*

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

“So, we have to do a lot in terms of education. We have to do a lot in terms of awareness. And a lot in terms of messaging that’s targeted, that’s culturally tailored to the audiences that we are trying to speak to. And... I can’t think of any project initiative that we’ve done that we have not had to invest heavily in those three areas.” — *Faith-based organization*

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

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

“...I can’t tell you how often I meet with a family and they don’t know about resources that are right in their neighborhood. And why is that? Those are the kinds of things that we really need to be examining and understanding and, which is why going back to having community-based input...is so important...” — *Aging organization professional*

“...For a navigator, it’s not just giving you information, it’s not just dumping it on you, but it’s actually making sure those connections happen for you and doing the follow-up... So, having somebody [whose] job is to help you kind of make sure you get through those doors, not just knocked on the door...” — *Title VI provider organization*

“I think we have ambassadors, we have champions, but when you talk about the systems that those individuals have to then go and kind of liaison between, that doesn’t carry a lot of weight... these need to be empowered paid administrators, managers, directors, within these communities that hopefully come from these communities so that they know what’s available.” — *Faith-based organization*

GOAL 2: FEDERAL ACTIONS

- Ensure funding of caregiver-related research.
- Establish a consensus group to develop strategies for systematically incorporating caregivers into care planning and care teams.
- Develop a caregiver identification tool that health care and service providers can use to quickly identify people as family caregivers.
- Drive increased use of caregiver assessments.
- Conduct research to support use of caregiver assessments, including specific instruments and mechanisms for adoption and integration in the health care system.
- Create incentives for health care systems to incorporate family caregivers into decision-making and provider engagement processes (using both quality metrics and changes in Medicare/Medicaid reimbursement policies).
- Develop a strategy to train medical and other service professionals on family caregiving and publicize caregivers’ role in improving health. Create and disseminate training resources that can be widely utilized.

GOAL 2: ACTIONS FOR STATE, LOCAL AND PRIVATE SECTOR ENTITIES

- Encourage private philanthropy and health systems to identify the contribution that family caregivers make in supporting health of the care recipient (Crosswalk Goal 5).
- Encourage private sector health care organizations including health plans, payers and others to create financial incentives, such as new billing codes to health care providers to encourage and enable them to engage family caregivers.
- Implement evidence-based practices for caregiver support at all points of health care delivery (inpatient, outpatient, LTSS, etc.).
- Encourage healthcare providers to pilot the use of caregiver assessments in a variety of care settings to improve identification of caregivers in need of services and supports.
- Health systems should hire and train dedicated staff for family caregiver engagement (caregiver engagement specialist).
- States that have not yet done so should adopt and expand the CARE Act.
- Hospitals should review and strengthen protocols for incorporating the caregiver into electronic medical records systems and the care process.

- Hospitals, health systems, state hospital associations and research organizations should identify and promote best practices for family caregiver engagement in the health care process.
- Ensure that clinicians and other service providers are educated about the experiences and needs of family caregivers by incorporating this content into a range of educational opportunities.
- Private payors including health plans and health systems should collaborate with community-based organizations (CBOs) to reach a diversity of caregivers and improve the reach of evidence-based programs.

STAKEHOLDER QUOTES: GOAL 2

“If you don’t have a systematic, standardized way to identify caregivers, you’re not going to reach people most at risk.” — *Research organization*

“I think enabling physicians to be reimbursed for the time that they spend providing instruction and support to family members and to make this a [reimbursement] code that just doesn’t apply to licensed providers, but would apply to take case managers, to be working within primary care or another medical setting.” — *Health policy consulting firm*

“With assessment tools, then they have to be free or very low cost... we’ve had a hard time accessing certain scales and then to get them in the languages that we need. So sometimes they’re translated and of course, we would want to use the validated, translated version.” — *Service provider for underserved elders*

“That goes back to the clinician workforce education where we talk about how do we bring family caregivers into the conversation, being intentional about including them..., how to really be open to family members..., bringing them into the conversations. And listening intently to those caregivers... It’s a real culture change... it’s a paradigm shift in terms of how we’re looking at including caregivers.” — *Research organization*

“...A provider’s time is driven by scarcity and reimbursement. So, there is very limited support related to reimbursement for engaging in caregiving, planning, caregiving conversation...” — *Home care provider*

“We also should consider patient education officers are creating a caregiver experience... So, you know, there are different types of workforce members who have these skill sets, and I think it’s about prioritization and funding to make sure that we can really have that opportunity...” — *Health care researcher*

“It’s very hard for providers of social supports to collaborate with health systems... They live on different metrics than we do and they don’t understand what we’re talking about...And it I think it requires some real training and more sort of collaboration among the CBOs to have the market power to be able to work with the health systems.” — *Economic and social policy researcher*

“So, it’s about getting the incentives right... what is in it for a health system to collaborate with CBOs to make sure that frail older adults don’t keep coming back to the hospital? So, in theory... there’s supposed to be an incentive to prevent rehospitalization within 30 days. But it doesn’t seem to really be working. And unless the health systems have that incentive, unless they realize that there’s something in it for them, they’re not going to do it.” — *Economic and social policy researcher*

“So, as a nurse by training, I never quite formally learned how to assess caregiver needs, family member needs, as well as educating them about their loved-one’s chronic illness. And I think that kind of stems up the pipeline in terms of when people are working as clinicians and not having that formal training or even awareness in their clinical rotations in terms of really interacting with the family, having a dedicated time and space for that in their clinical education.” — *Health care provider*

“I understand people definitely can’t go back to medical school, but starting early, starting in the school system, starting in the medical schools, in the curriculum, making sure that caregiver knowledge and understanding is taught from the beginning.” — *Foundation spokesperson*

GOAL 3: FEDERAL ACTIONS

- Support funding for programs reaching excluded populations by creating community ambassador programs that provide specialized outreach to ethnically and culturally diverse communities; support community-based organizations focused on specific populations.
- Increase support for Medicaid to expand access to HCBS generally and access to more specific programs such as Money Follows the Person.
- Advocate for specific benefit expansions in the Medicare program, including benefits for respite, adult day services, and home modifications to enable individuals to safely age in place.
- Financially support family caregiving initiatives through federal funding opportunities, including expansion of Older American Act and the Elder Justice Act funding opportunities.
- Increase funding for the National Family Caregiver Support Program, Lifespan Respite Program, and the Alzheimer’s Program Initiative.
- Expand access to broadband nationally so all Americans can benefit from web-based resources and interactions.
- Encourage employers to incorporate future planning in employee benefit options.
- Advocate for the Consumer Financial Protection Bureau to develop financial planning tools specific to family caregivers and work to disseminate them.
- Publicize the value of direct care work.
- Improve worker pay by increasing Medicaid reimbursement rates and ensuring increases accrue to the direct care workforce.
- Standardize job titles and responsibilities across states to enable better understanding of workers and enhance job portability.
- Standardize training across states, via competency-based training with a common core for all direct care workers.
- Incorporate supplemental training modules to enable specialization and career advancement opportunities.
- Fund research and demonstration projects to create a more accurate understanding of the field and understand effective mechanisms for improving the direct care workforce.
- Create a federal government-level, interagency task force to work on a direct care workforce development plan, collaborating with states, possibly incorporating immigration reform, gray market, and student federal loan forgiveness programs.
- Increase the availability of programs paying family caregivers for providing direct care services.

GOAL 3: ACTIONS FOR STATE, LOCAL AND PRIVATE SECTOR ENTITIES

- States should expand access to HCBS through expansions to Medicaid or state-funded programs serving low-income populations.
- States, municipalities, health plans and health systems should collaborate to ensure the financial viability of CBOs and faith-based organizations (FBOs), particularly those serving historically excluded and underserved populations.

- CBOs and FBOs should create or bolster community ambassadors to enhance connections with excluded populations.
- The state should create mechanisms for collaboration across organizations.
- In collaboration with a range of stakeholders, states should create a state plan for a comprehensive approach to supporting family caregivers.
- States, Medicare Advantage plans, CBOs and FBOs should find funding to support respite services. MA plans should prioritize respite care under the supplemental services they provide and advocate for use of those services by family caregivers.
- States should evaluate regulatory barriers to establishing adult day services as a respite care option.
- States, CBOs, FBOs, private sector providers, and employers should collaborate to create greater awareness and acceptance of the need for respite care.
- States, CBOs, FBOs and private philanthropy should support training resources that will expand the capability of respite care programs to meet the needs of family caregivers supporting care recipients with medically complex care needs and those with intellectual and developmental disabilities.
- States should provide low-interest loans and startup grants to encourage the development of adult day services as supports for family caregivers and the care recipients who use them.
- State advocates should seek out technical assistance and/or partner with organizations that can help the state be more active and effective in obtaining funds for supportive and low-income housing, such as Section 8 and Section 811 that are specific to people with disabilities.
- States should ensure access to broadband.
- States should establish a taskforce to identify ways to improve and disseminate web-based mechanisms for identifying services and providers.
- States, CBOs, health plans, and others should enable caregivers to access and utilize assistive technology.
- Employers, financial planners, and life/annuity/long term care insurers should incorporate future planning into financial planning more generally.
- States should create or expand opportunities to pay family caregivers.
- States should increase wages for direct care workers.
- States, home care agencies, and educational institutions should invest in the direct care workforce through enhanced training and job advancement opportunities.
- States should obtain better information about the direct care workforce. (Crosswalk Goal 5)

STAKEHOLDER QUOTES: GOAL 3

“I’m growing a little bit tired of the empty rhetoric about the heroic nature of [direct care] work. It’s time to make some fundamental changes here. And that’s not a crisis. I mean, a crisis is sudden and temporary and unexpected. We’ve been having this conversation for 30 years. 30 years. It’s not a crisis. It’s a systemic failure.” — *Direct care worker advocacy organization*

“We have 3,000 people on our waiver waitlist. And it takes about seven years to get off of that... And I know that doesn’t directly feed into the caregiver issues, but in one way it does.”
— *Community-based organization serving rural population*

“I’ll give you an example...[X] has been able to scale up that work because of a grant from ACL... we need more of that. More investments in community-based, community-led organizations who have that cultural competency, that language capability, that have relationships with organizations in order to overcome some of the trust issues.” — *CBO serving people of color*

“I think we have ambassadors, we have champions, [but] ... these need to be empowered paid administrators, managers, directors... that hopefully come from these communities and know what’s available... being trained with advanced skills.” — *Faith-based organization serving people of color*

“How do you recruit people? Pay them more than Starbucks. It’s not that complicated. You know, like in California, there’s signs everywhere because of the workforce shortage. You can work at the smoothie place for \$16 bucks an hour. Who’s going [to work for] a minimum wage of \$14 an hour. Most IHSS workers in California are at \$14 an hour. Why would I do this work that is so hard and so emotional, when I can go make a smoothie?” — *Advocacy organization for direct care workers*

“We would argue for competency-based training, so that training is not based on duration, or a number of hours, but is based on like a set of competencies and then we would also work more. Adult learner-centered training, just recognizing that people are adult learners and didactic methods aren’t always the best.” — *Research and policy advocacy organization*

“Do a public awareness campaign... and then also... a resource information hub for direct care workers that... provides education about these jobs, helps people understand what it means to do this work and they can see the career path and the opportunities, they can access training. So, trying to also, for the recruitment aspect, get the word out and help to spread more information and provide those resources for individuals who might be interested in pursuing the work.” — *State Medicaid agency*

“The title Direct Support Professional is not even recognized by the Bureau of Labor statistics.... When you’re setting rates for IDD service providers, they have to show an occupational title that’s recognized. So, they’re showing home health aide or personal care attendant for a direct support professional, and its inaccurate data. And we don’t even know how many IDD direct support professionals there are in this country because they’re not recognized by BLS.” — *Advocacy organization for direct care workers*

“Anything that’s directly related to getting cash and resources into the pockets of caregivers, that should always be our priority.” — *LGBTQ advocacy organization*

“[For] family caregivers, one of the biggest [needs] is just expanded services, more funding for more programming.” — *Community-based organization*

“If you don’t reimburse folks for those types of activities, they lose the concept of being valuable, in my opinion.” — *Disability advocate*

“I worry so much about losing competency and capacity of these groups... if we really want to be inclusive, and we want to build capacity for the existing resources that we have to continue to provide resources, we have to build that into the contract structure.” — *Community-based organization serving minority populations*

“[We have] our final draft of our first caregivers’ state plan. So, it’s intertwined with our mission for the office of healthy aging as the state unit on aging, but also looking at respite services in the state overall. We have goals and objectives of what needs to be done in the future.” — *State unit on aging*

“States that are a little bit further behind, I think even we’re still struggling when just developing the awareness of respite care services and making sure that not only providers, but caregivers are aware of it.” — *Community-based organization serving minority populations*

“We did a self-directed model and the family caregivers were offered training and almost as you universally, they said, ‘oh, we’ll do our own training. If I know how to do it, I could show somebody else how to do it.’ And they were much more eager to hire family and friends through a you know, that kind of a self-directed model.” — *Respite care program*

”... assisted technology efforts that might include things like touch screen tablets, videoconferencing and/or video phones...” We’ve been able to do that with some extra funding that we’ve gotten this past year. These methods are... they’re connecting family caregivers and their loved ones. But they’re also being able to be used as just intervention-type delivery of trainings and stuff like that.” — *State unit on aging*

“We have had some success with in the last two years, legislatively, we have been finally making inroads with our legislators to increase the state homecare budget with very specific utilization language tied to those reimbursement rate increases that the money has to flow to those workers. The next challenge though, is how do we annualize this and make this permanent?” — *Home care agency owner*

GOAL 4: FEDERAL ACTION

- Pass federal paid family leave; expand the FMLA to include small employers and a broader definition of “family.”
- Increase the availability of programs paying family caregivers for providing direct care services.
- Include family caregiver out-of-pocket expenses as medical expenses available for tax credit.
- In partnership with the private sector, establish a national campaign to promote caregiver-friendly workplaces.
- Promulgate promising practices associated with being a family caregiver-friendly workplace.
- Introduce a range of incentives to encourage employers to adopt caregiver-friendly practices, including tax incentives and a voluntary employer certification program for identifying and credentialing “caregiver friendly” workplaces.
- Encourage employers to offer financial planning advice through workplaces.
- Advocate for Congressional action to establish a public long term care social insurance program.

GOAL 4: ACTIONS FOR STATE, LOCAL AND PRIVATE SECTOR ENTITIES

- In the absence of federal action, states should work to expand policies supporting working caregivers, including enhanced FMLA and paid leave policies.
- States should expand Medicaid programs that reimburse family caregivers for providing care
- States should establish tax credits for family caregivers
- Employers and state agencies should create multi-stakeholder coalitions to support employers’ efforts to recognize, honor and support working caregivers.
- States should create incentives to encourage employers to be more caregiver-friendly, via tax incentives or certification programs.
- Employers, community-based organizations, and state agencies should collaborate to create a robust infrastructure for sharing resources that support family caregivers.
- Employers should work to systematically incorporate caregiver-friendly policies throughout their businesses, by extending flexible work opportunities beyond the COVID-19 pandemic, educating managers, incorporating caregiver-friendly resources into human resources (HR), and creating a culture supportive of caregivers.
- Employers should ensure the systematic inclusion of financial planning around family caregiving into existing Employee Assistance Programs (EAPs) and publicize the availability of such resources.

- States should expand Medicaid HCBS programs as well as state-funded programs supporting family caregivers.
- Employers should be encouraged to offer benefits as part of their overall benefit package that make LTSS more affordable for their working caregivers (e.g., respite care, adult day care, caregiver training, offering voluntary LTC insurance).

STAKEHOLDER QUOTES: GOAL 4

“An expansion of that definition of who is ‘immediate family’ is necessary for FMLA. I mean, you’ve been married to someone for 30 years and taking care of your father-in-law is just what you do, but it’s not protected under FMLA.” — *Private foundation*

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

“Employers shouldn’t define who a caregiver provides caregiving to. It’s not just about biology or a spousal relationship.” — *Advocacy organization for aging persons of color*

“Why don’t we have the tax credit for medical expenses... including all the long-term care-related ones and make it a refundable credit up to some percentage of people’s actual out-of-pocket costs?” — *Nonprofit caregiver advocacy organization*

“One of the big stressors was money. Why aren’t we paying our family caregivers? Why aren’t we giving them a wage? When you think about any stressor, they’re having.... a lot of it’s going to be financially related.” — *State agency*

“Some employers still don’t understand how many people are caregivers, even in today’s society.” — *Employee benefit research firm*

“I like the idea of that tax incentive to an employer.... Because ultimately, you’re helping your employees who are going to work longer and be happier and provide better service, So, tax credits are probably the way to do it.” — *Disability advocacy organization*

“It’s about money, money, money, money, money.... we got to find the money, and it’s got to be sustainable, and it’s got to be independent, and it’s got to fund services for middle class people. And without that... it will not address the fundamental problem. Social Insurance Program.” — *Caregiver advocacy organization*

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

“...if folks are afraid to raise their hand and call themselves a caregiver or to utilize a benefit for a caregiver because they’re afraid they’ll be fired, it’s not about awareness alone. It’s about infrastructure of support that enable that recognition.” — *Alzheimer’s advocacy organization*

“...an education campaign freed up some of the managers to be able to... have the mindset that they can allow [time off for caregiving].” — *State agency and business coalition*

“I think one thing that’s happened... with COVID is that it forced a lot more flexibility around work in terms of remotely different schedules and I think a lot of that was an awareness around caregiving, mainly around kids at home.... But recognizing... hey you were supporting [caregiving] families that work, but just making sure that definition also includes children with disabilities and older adults.”
— *Large Employer*

“Companies are offering different types of benefits, but they’re not...being used...like employee assistance programs... Because people don’t know what’s there, then they don’t want to ask for it.... And so, companies say, ‘well, I’m not going to spend all this money on it....” — *Employer coalition*

“An employer having a really good understanding...of what a family caregiver is and their responsibilities and what they have to do helps...employers can be more empathetic to the employee and will hopefully work with them.” — *Disability advocate*

“We have partnered with the AAAs and the State and others to show what resources are out there. It doesn’t cost them anything to be able to provide a site to go to or a list of resources.” — *State Agency and Business Coalition*

“A lot of the stress of caregiving is finances... so understanding and having tools to help with saving earlier, understanding what those needs are and options for long term care insurance.... I think is really critical.” — *Employer Coalition*

“And it was great to see the RAISE report to Congress, reiterate the importance of financial and workplace securities for caregivers... it is those kinds of protections that enable someone to raise their hands and say, ‘I am a caregiver, I want to be able to benefit from things like paid family and medical leave.’” — *Alzheimer’s Advocacy Organization*

“Caregivers are two and half times more likely to experience mental health issues and chronic conditions due to the demands and lack of resources.” — *Employee benefits researcher*

“12 million people have left their job this year alone. The women in the workplace is the lowest it’s been since 1988. Those two stats alone tell me that, you know, a majority of that could be from caregiving because unfortunately, a lot of it does fall on the women to handle those caregiving situations.” — *Employer intermediary*

GOAL 5: FEDERAL ACTIONS

- Develop a caregiver identification tool that health care and service providers can use to quickly identify people as caregivers and help them to also self-identify as caregivers.
- Fund research to promote utilization of caregiver assessment tools.
- Coordinate and support data collection and demonstrations to improve the direct care workforce.
- Support research on the value of working caregivers and the value to employers of investing in workplace supports.
- Support research and demonstration programs focusing on mechanisms to support family caregivers.
- Convene a task force to develop a uniform set of research questions to identify individuals as family caregivers. Promote integration of this newly developed caregiver question set into existing data collection tools to expand insights and trends into family caregiving.

GOAL 5: ACTIONS FOR STATE, LOCAL AND PRIVATE SECTION ENTITIES

- Private sector leaders (large employers) who have embraced caregiver-friendly policies (e.g., paid family leave) and business coalitions should identify and uplift caregiver-friendly employers and standardize the metrics of what makes a workplace “caregiver-friendly.”
- Business coalitions should encourage private-sector entities to utilize standardized data-collection tools.
- Academics, business leaders, private philanthropy and others should work to build the business case for caregiver-friendly workplaces by providing evidence on the Return on Investment (ROI) of workplace supports.
- Health systems should link caregiver supports to patient outcomes.
- Private philanthropy and academic research activities should support person-centered research that seeks input directly from caregivers and care recipients utilizing health systems.
- Private philanthropy needs to 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 should provide community-based organizations with the administrative and operational support to effectively build and standardize the evidence base for improved services and supports.
- States should collect more and better data on family caregiving and the long-term care workforce. (Crosswalk 5.3.)
- Private philanthropy, hospital systems, academic institutions and others should support additional research to identify best practices in support of the CARE Act.
- Hospitals should strive to identify a dedicated resource to serve as a caregiver experience officer/ambassador to develop and oversee best practices for engaging family caregivers in the hospital experience and support after discharge.
- Through state-level coalitions, states, CBOs, FBOs and philanthropic organizations should create and share resources to educate and support professionals working with family caregivers. (Crosswalk Goals 1 and 3.)

STAKEHOLDER QUOTES: GOAL 5

“All of the good family caregiver identification questions that I know of don’t use the term family caregiver. They describe the activity and then ask the person if they do that.” —*National advocacy organization*

“‘Are you a family caregiver?’ And someone can say ‘No.’ Because they don’t identify as a family caregiver, but asking like, ‘Oh, so you drove that person here today. How often do you do that? Do you clean their house? Do you do their groceries?’ Like, it’s a multitude of questions to help get that out there.” —*Caregiver support program*

“The thing I really see...is more data collection using a standardized question and definition of caregiving. The national infrastructure is not to just have caregiver surveys... but there is so much more opened up if we can piggyback even just... a small number of questions into other surveys that have already been established and have additional information that we would want to find out about family caregivers.” —*National advocacy organization*

“It will really, really be enlightening to see just how many people, or not, are doing this [direct care] work. Because that is really what is going to open the eyes and potentially the budgets on a state-by-state basis are learning just how few people there are doing this. Because... the fact that home carers work for multiple companies or agencies is the worst kept secret in the world.” —*Home care agency*

“We need employee data; we need to hear from the workers themselves to understand their issues and their challenges and what they need. And so, it’s really challenging to get that information.” — *State Agency on Health*

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

“One of the best ways to increase family caregiver research... is to either require or incentivize it.” — *National advocacy organization*

“We need to be able to quantify that. What are those health care costs for you the employer, if you don’t provide supports for your caregiving employees? Because yes, they can be more costly. Overall, they shouldn’t be if you provide the right benefits. So, I think that’s a piece of that data and... incentivizing them to pay attention to this issue.” — *Business coalition on aging*

“I think having some uniform [caregiver assessment] tools, then that way, we’re collecting the data all in the same way... So that way... ACL, they get all of the data they need.” — *Aging services agency*

“...it’s important. For states to develop strong data collection systems, the infrastructure to collect data on staffing turnover, vacancy rates, compensation training, there’s a wide range of variables that these data systems should call for backup.” — *Health care researcher*

“You have to survey; you have to be able to survey your employees and their families... [and it] has to be done by an uninterested party like the government or someone... And the research has to show that people are saying they need this and they don’t have it.” — *Employee benefits research firm*

“...we have a lot of tools, programming and support for caregivers. The biggest thing we struggle with is getting people to them because they don’t know they are caregivers. I would like to see a tool for our providers that successful in that light to come on.” — *Health systems provider*

“Michigan passed a law that required a research project on the long-term care workforce. We help with the direct care parts, but it’s a big step to being able to make a case and so, getting your state basically to commission a big study on the workforce. The understudied part of most studies is asking the workers themselves.” — *Health care researcher*

“So, the recommendation health services research really to devote some research dollars, too. This question of, what do we know about what works in terms of supporting family caregivers around the transitions and care that will produce better outcomes? And I think that’s a big, big, big question and unknown.” — *Health care researcher*

“You need more research that helps employers understand it’s in their self-interest and in the interest of their productivity mechanisms, in the interest of their higher retention, in their interest of reducing absenteeism, reducing presenteeism, all these various “isms” that they currently intuitively know and understand” — *Academic-based researcher*

“...there’s a huge audience that would be willing to take a look at something like that. If we had some tangible measures information so that businesses can tie it back into their workforce.” — *Large employer*

“We need to understand people’s attitudes, beliefs, and perceptions about the CARE Act in their organizational system from their standpoint, but also from caregivers and patients. We need more work done in terms of interviews from their perspective.” — *Health care researcher*

Appendix D: Promising Models

GOAL 1

Raising Awareness

[AIDs/HIV Program Models: The Ryan White Program](#). “That’s a federally-funded program through HRSA, as well as CDC also provides funding toward that.....They have everything from case management... led by psychiatrists and licensed social workers to non-clinical case management..... And that is all paid, paid reimbursable work. And we just don’t have that when we look at caregiving or even other larger diseases that are disproportionately impacting our communities.”

[Own Your Future LTC Awareness Campaign](#) publication

[HHS Own Your Future LTC Awareness Campaign Final Report](#)

[Medicare Part D roll-out as a model](#) and [other research](#). “One example of this is way back when, for those of us who remember, when Medicare Part D was starting. It really required an amazing effort to engage everyone to let Medicare beneficiaries know all of a sudden there was this drug benefit, and you had to sign up for it, and there’s this whole extra help subsidy that you also need to know about. It really required the engagement of everybody from disease groups, to Medicare beneficiaries, to healthcare providers, to pharmaceutical companies, and pharmacies, and pharmacists, and pretty much everybody. It was done. If you think back, you may have questions about the way the benefit is rolled out. Everybody knows about it. It can work. You can engage at every level from the very local level to the national level.”

“I think there’s a lot of foundations who are now interested in group funding. If you get some of the big ones on grant makers in aging, grant makers in health to help talk about the public private partnership there, get some additional dollars or groups.”

“One thing we didn’t talk about at all and I think might be valuable is the.... National Governors Association. They may be an important partner. Just that if we go like a campaign that engages at every level down to the community, then they may be an important resource.”

GOAL 2

Successful Implementation of the CARES Act

[New Jersey Hospital Association Support](#). “We did learn that the more a hospital association has been on board.....from the beginning and has been just a completely different picture in terms of implementation, training and support for health systems. “

Henry Ford Health System

“We’re instituting social determinants of health assessments... and we’re using that information to drive towards solutions. So, you may not have the best caregiver support and resources out there, but don’t let that stop you from assessing your caregivers and understanding what your caregiving burden is... we are partnering with our local United Way and creating sort of a closed loop referral system. So, we’re identifying the resources on the hospital-based side, referring them out.... And then getting a documentation system... and really using that to drive Michigan 211 to invest in the areas of social determinants that we’re finding are a problem for our patient populations.”

Assessing and Addressing the Needs of Culturally and Socially Diverse Caregivers (Crosswalk to Goal 5)
[The Long Term Care Equality Index](#). “Our Long Term Care Equality Index, the LEI, for short, is attempting to... have groups sign up and benchmark themselves against what policies and procedures and training and so forth, they’re doing related to LGBT folks to then help them to get better. To help them to implement better policies, and procedures, and training, and so forth, such that they will become more LGBT- affirming, as in their various residential settings.”

GOAL 3

Family Caregiver Training

[Schmieding Center](#). “This is a program in Northwest Arkansas... [it has] a caregiver, affiliate family caregiver training program that really serves two purposes. It trains family caregivers in how to care for their loved-ones. And it also becomes a job training program. So that often happens for these folks, who most of them are generally very low- income and low-skilled, is this is now a career for them.... it was funded because Mr. Schmieding gave the University of Arkansas \$10 million to build a caregiver training program.”

“There are opportunities at hospitals, for example. So, you’re lying around a hospital bed for three days after surgery with nothing to do except watch reruns on the TV. What if they had caregiver training [videos] during some of that time.”

Model For Caregiver Training Access Point and Support

[California Resource Center](#) as a model for a single point of entry for caregiver training and support and access to services. “So, again, programs like the Caregiver Resource Centers of California were one of the best practice models when they developed the Title III Family Caregiver Support Program, back in 2000.”

Caregiver Support

[Montgomery County, Maryland](#). “Montgomery County is a good example. “They have a county caregiver support program that is operated out of there like aging resource center. And I would say that kind of the range of supports that are available through OAA programs are probably something that counties are involved in those places where counties play a role in supporting the AAA.”

Caregiver Self-Assessment/Stress

[Archangels Caregiver Intensity Tool](#). Quick and easy to use self-assessment tool

Direct Care Workforce

[Prepare to Care Iowa](#): “Iowa had a task force that was looking at the education training for direct care workers and trying to streamline it and they developed, I think... a PCAS, I don’t know what it stood for now. PCAS, it focused on two paths that people could take and option one was more medical side of things, it’s called Prepare to Care. And that was their hospital aides and CNAs in nursing homes. The other was more the social HCBS side of things. And we had, support really from the disability side of things and homecare and the nursing home, the long-term care side of things. They could cross train, again too because we got different levels of care within a single entity. Sometimes people have to switch and work and serve a different population or age group. It’s nice to have that portability too.”

Enhance Funding Opportunities for CBOs, FBOs And Other Community Organizations Serving Family Caregivers

[Trellis, Innovations for Aging](#). “But another part of our organization, we have a subsidiary called Innovations for Aging, where we are trying to help our community partners diversify their revenue streams, specifically from health plans, so that they don’t have to solely rely on government funding and help build capacity.”

GOAL 4

Supporting Working Family Caregivers

[Worklife Partnership](#). “What are relevant benefits? What are individuals looking for? And oftentimes, our jobs are structured with these set of benefits that are desired by management, but don’t fit the needs of the people that are getting the benefits... There’s some great work being done around that, Worklife Partners out of Denver is great on that....”

Model For Raising Awareness and Recognizing Caregiver Friendly Workplaces

[National Working Daughters’ Day](#). “We launched the first National Working Daughters Day to raise awareness that working daughters are out there needs support. And this year we’re just about to kick off what I think might be the first list of best companies to work for, for Working Daughters.”

Financial literacy for Family Caregivers

[SageCents to foster financial planning literacy](#). “We offer a financial wellness App called SAGE Cents and it’s just financial education, help people, increase their, their knowledge around retirement and savings and this than that, but we wove in caregiving into that, as well.”

State Government, Employers and State-based Foundations Collaborate to Advance Issues to Meet Family Caregiver Needs

[Massachusetts Caregiving Initiative](#). “The Mass Caregiving Initiative was created to support caregivers in their communities and workplaces by partnering with the public and private sectors to drive innovation in the Commonwealth. The Initiative has three focus areas:

Employers: [The Massachusetts Caregiver Coalition](#) emphasizes helping employers support their employees who are family caregivers. Launched more than a year ago in partnership with the Mass Business Roundtable and others, it continues its work to drive public/private collaboration in order to recognize, honor, and support caregivers. **Community:** We are working with partners such as the Executive Office of Elder Affairs and [Mass Home Care](#) to address the needs of caregivers and their supporting communities. **Innovation:** Working with partners to highlight solutions that leaders and organizations can use to lessen caregiver stress and support caregivers. This includes an Innovations in Caregiving Webinar Series that will publicize research data and highlight innovative approaches, products, and services that respond to the data points and empower caregivers.”

GOAL 5

Improved Caregiver Assessment and Data Collection

[Archangels Caregiver Intensity Score](#). “...for the Caregiver Resource Centers, we developed a new interactive database for family caregivers that we know have all 11 sites use across the board... we’re measuring apples to apples. And the data that we’re collecting for those family caregivers having to go through the intake and assessment process, is so rich... we are now able to measure people’s depression, burden, isolation anxiety on an across-the-state. We also are able to identify that the caregivers that come to us, that we’ve been able to assess, have more complex caregiving issues...”

MULTIPLE GOALS

Comprehensive State Plans on Aging

[California Master Plan on Aging](#). “California has created a Master Plan for Aging. That was one of the first executive orders issued by Governor Newsome. It’s a start. I’ll tell you it doesn’t take a heck of a lot regarding the ages of workers and that’s a whole other conversation, but I think it was essential. Though, I want to see the one thing in there as it creates like an ongoing working group, so it legitimizes the conversation, that this is a big issue that needs to be studied and looked at. I mean, I think that, that makes all the sense in the world.”