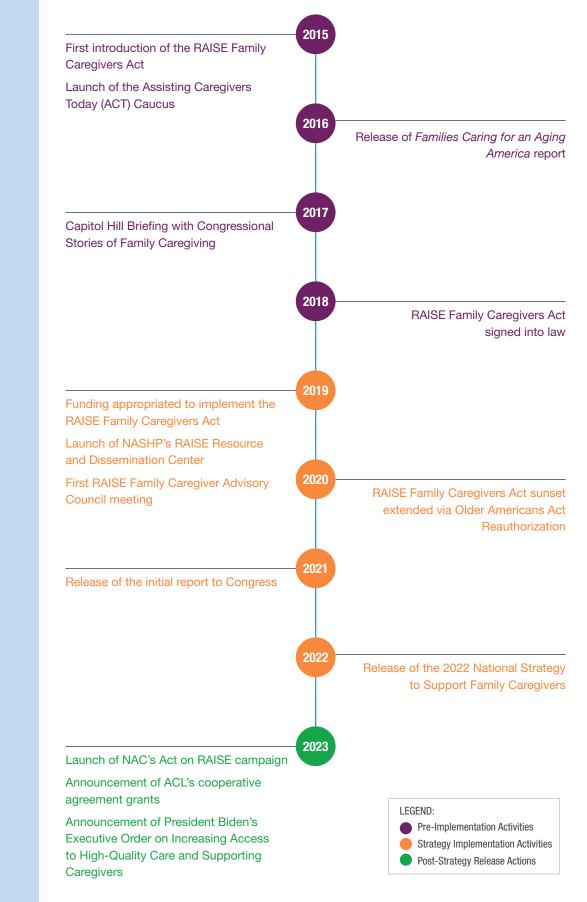




Assessing The National Strategy to Support Family Caregivers as a Model to Inform Efforts to Advance a National Plan on Aging



# Timeline of key activities leading to the National Strategy to Support Family Caregivers release and post-release actions.



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# **Executive Summary**

This report outlines the process by which the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act was developed, implemented, and deployed to achieve the first iteration of the 2022 National Strategy to Support Family Caregivers. The evolution of this process can inform similar efforts to advance a national plan on aging while building on existing efforts to drive multisector plans for aging across the United States.

The first section of this report provides an overview of the necessary catalyzing forces leading to the RAISE Family Caregivers Act, a summary of the process and implementation model deployed by the Administration for Community Living (ACL), and key partnerships with organizations and subject matter experts in the field needed to ensure the National Strategy to Support Family Caregivers came to fruition. The second section includes key takeaways and considerations for those interested in advancing national level coordination around state multisector plans for aging and/or a national plan on aging, such as:

- · Building a base of evidence to demonstrate urgency
- Establishing necessary partnerships to sustain momentum
- · Engaging policy and advocacy champions for legislative advancement
- Including stakeholders across sectors and disciplines and those with lived experience
- · Leveraging existing strategy development models for success

The progress that has been made to advance the concept of the National Strategy to Support Family Caregivers would not have been possible without precedence or preparation. Years of research, advocacy, education, and tireless efforts from policymakers, family caregivers as well as those in their care, and healthcare/social care subject matter experts elevated the need. Coordinated and strategic investment from philanthropic stakeholders and the private sector served as a catalyst to ultimately complete the 2022 National Strategy to Support Family Caregivers.

Although compromise at various levels of the process resulted in minor but important political challenges, some level of pessimism within the field about the "teeth" of the National Strategy to Support Family Caregivers, and the need to continually advocate for improvements within the National Strategy to Support Family Caregivers, the process itself garnered in an unprecedented level of momentum. The advocacy trajectory from building awareness to fostering widespread commitment to taking action on behalf of family caregivers tells an important story for advocates working to gain traction for other critical issues. Understanding this story requires awareness of the mile markers, milestones, speed bumps, and detours along the way.

The timeline of activities covered in this report spans nearly ten years–and the National Alliance for Caregiving (NAC) has had a unique role in championing, shaping, and supporting implementation activities throughout that time. The overview of events outlined in this report reflects that experience; the perspective gained can help inform tactics to advance similar efforts—such as a national plan on aging.

Years of research, advocacy, education, and tireless efforts from policymakers, family caregivers as well as those in their care, and healthcare/social care subject matter experts elevated the need. Coordinated and strategic investment from philanthropic stakeholders and the private sector served as a catalyst to ultimately achieve the 2022 National Strategy to Support Family Caregivers.

### **SECTION 1:**

# Laying the Groundwork for the 2022 National Strategy to Support Family Caregivers

### Introduction

Caregiving is a shared and timeless experience—as long as there have been families, there have been family caregivers, regardless of the age or condition of the person with serious health challenges. Caregivers are an essential component of our collective health and social care ecosystems. In fact, one in five Americans–53 million people–annually provide an estimated \$600 billion worth of informal, usually unpaid, care and support to aging family members and people of all ages.<sup>1</sup> Despite this ubiquity, the collective national commitment to recognize, respect, and improve supports for family caregivers and to alleviate widespread isolation associated with caregiving only recently emerged as a leading national priority.

The <u>2022 National Strategy to Support Family Caregivers</u> is a first-of-its-kind, multi-stakeholder call to action that identified nearly 500 policy, programmatic, or systemic opportunities for every level of society to bolster support for family caregivers in communities and across the country—caregivers across ages, conditions, racial/ethnic, geography, socio-economic status and other demographics across individual characteristics. This historic achievement reflects decades of cross-sector research, engagement, advocacy, and robust and enthusiastic public-private investment to implement the <u>Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act</u> (Pub.L. 115-119) passed by Congress in 2018.

A multisector plan for aging (MPA) refers to a state-led, multi-year planning process to address the needs of older adults, people with disabilities, as well as their family caregivers. While MPAs are currently being developed via state-led processes, state plans on caregiving were similarly developed prior to the creation of the National Strategy to Support Family Caregivers. Federal policymakers involved in driving a national plan on aging can support this movement in at least two ways: 1) champion the development and implementation of MPAs at the state level through congressionally-appropriated grants—potentially building on the recently introduced <u>Strategic Plan for Aging Act</u>; and 2) developing a strategic framework for a national plan on aging by leveraging a provision in the <u>Supporting Older Americans Act of 2020</u> regarding modernizing the interagency coordinating committee on healthy aging and age-friendly communities.

An important consideration when identifying tactics to advance a national plan on aging is the reality that the National Strategy to Support Family Caregivers was not created in a vacuum. In fact, the National Strategy to Support Family Caregivers was grounded in and modeled after the successful 2010 bipartisan effort to coordinate a strategic national plan to combat Alzheimer's disease.<sup>2</sup> The <u>National Alzheimer's Project Act (NAPA)</u>—served as a critical framework through which to build the National Strategy to Support Family Caregivers. Like the RAISE Family Caregivers Act, NAPA called for a partnership between several federal agencies, advisory council members, and recognized the need to update the strategy on an annual basis—which has been occurring regularly since 2012.

### Using Data and Evidence to Tell the Story

Individual stories are as unique as the family caregivers and the care recipients who tell them across the lifespan, and they are an essential ingredient for successful advocacy efforts. However, a solid base of evidence detailing broader trends among the country's family caregivers, as well as healthy aging, age-friendly communities, and person- and family-centered care initiatives, was a critical catalyzing force underpinning the need for a collective approach to support this population. Several data-driven efforts preceded and paralleled the push toward developing the National Strategy to Support Family Caregivers.

Since 1997, the National Alliance for Caregiving (NAC) and AARP have collaborated to survey—and tell the story of—the country's family caregivers via the <u>Caregiving in the U.S.</u> report series. At regular intervals, this study has highlights the varied experiences and situations of family caregivers in the United States over time, outlines the health and financial impacts many family caregivers face, and paints a vivid demographic picture about the national state of family caregiving. Specifically, Caregiving in the U.S. 2020 pointed to significant growth (9.5 million, or nearly 22 percent) in the overall numbers of family

 $<sup>{}^{2}</sup>https://www.collins.senate.gov/newsroom/senate-passes-collins-baldwin-raise-family-caregivers-action and the senate of t$ 

caregivers in the United States from the previous 2015 report, identifying an impossible-to-ignore demographic trend that had been occurring for decades.

In 2016, the National Academies of Science, Engineering, and Medicine (NASEM) published a landmark report, <u>Families</u>. <u>Caring for an Aging America</u>,<sup>3</sup> which demonstrated that family caregivers provide the majority of long-term care services for aging Americans and are critical to the health and financial well-being of older adults. The report also underlined that family caregiver challenges were among the most unrecognized of an aging nation. This milestone publication elevated the caregiving experience among the research and medical sectors and paved the way to establish an base of evidence make the case for a national commitment to improving support for family caregivers. Recommendation number one from that report specifically called for "The Secretary of the U.S. Department of Health and Human Services, in collaboration with the Secretaries of the U.S. Departments of Labor and Veterans Affairs, other federal agencies, and private-sector organizations with expertise in family caregiving to develop and execute a National Family Caregiver Strategy that, administratively or through new federal legislation, explicitly and systematically addresses and supports the essential role of family caregivers to older adults."

Trends indicating that the National Strategy to Support Family Caregivers was a needed priority were not unique to the United States. The 2018 report, <u>Global State of Care</u>, published by the International Alliance of Carer Organizations identified unpaid caregiving as "one of the most important social and economic policy issues worldwide."<sup>4</sup> The international report was intended to "facilitate policy discussions around the world by providing a global assessment of unpaid carer needs, sharing of best practices, and identifying the core elements of a global carer action plan." While the publication embraced a global approach, many of the findings and subsequent recommendations echoed those consistent in U.S. research and data-gathering efforts—trends that are reflected in national and state-level family caregiver support priorities. In fact, the report identified the RAISE Family Caregivers Act as one of the most significant actions of government recognition focused on the family caregiver population within the United States.

### Philanthropic/Private Sector Investments Spur Public-Sector Actions

The findings and recommendations outlined in the 2016 NASEM report also sparked a public-private sector collaboration and coordination effort that would evolve into support for implementation of the RAISE Family Caregivers Act. Such coordination was integral to the development of the National Strategy to Support Family Caregivers. Specifically, The John A. Hartford Foundation (JAHF) began what became a Grantmakers In Aging-convened funders collaborative<sup>5</sup> focused on coming together to share information and advice on projects to support family caregiving. Ultimately, that group advanced the concept of the National Strategy to Support Family Caregivers. The <u>National Strategy to Support Family Caregivers Action Guide for</u> <u>Philanthropy</u> was released as part of this initiative and funded by JAHF.

In 2017, a briefing on Capitol Hill served to foster broader awareness among and obtain buy-in from members of Congress about policy opportunities to improve support for family caregivers. <u>Congressional Stories of Family Caregiving</u><sup>6</sup> was hosted by the Gerontological Society of America with support from JAHF and conducted in partnership with AARP, the Alzheimer's Association, and NAC. It leveraged the findings from the NASEM report and engaged six members of Congress who shared their own caregiving stories and participated in discussions about potential national-level policy solutions focused on enhancing family caregiver support.

The briefing, Congressional Stories of Family Caregiving, leveraged the findings from the NASEM report and engaged six federal lawmakers in not only sharing their personal experiences as family caregivers, but also in discussions around potential national-level policy solutions to improve supports for the more than 50 million family caregivers across the country.

<sup>&</sup>lt;sup>3</sup>Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine; Schulz R, Eden J, editors. Families Caring for an Aging America. Washington (DC): National Academies Press (US); 2016 Nov 8. Available from: https://www.ncbi.nlm.nih.gov/books/NBK396401/ doi: 10.17226/23606 <sup>4</sup>https://carersworldwide.org/images/blogs/IACO-EC-GSoC-Report-FINAL-10-20-18-.pdf

<sup>&</sup>lt;sup>5</sup>The Family Caregiving Funders Community provides a forum for funders to invest in programs, models of care, research, communication and awareness, training, education, and advocacy for caregivers of older people. Started in 2016, the Community now includes more than 40 funders, and two pooled funds. Grantmakers in Aging recognizes the specific support of the John A. Hartford Foundation, Archstone Foundation, and the Ralph C. Wilson, Jr. Foundation. More information about the Family Caregivers Funders Community is available at: https://www.giaging.org/network/funders-communities/family-caregiving <sup>6</sup>https://www.caregiving.org/www.

In addition to championing the RAISE Family Caregivers Act, NAC worked at the state level with stakeholders involved in developing formal state strategies focused on family caregiving to outline needed engagement and resource development. NAC released the report, From Momentum to Movement: Developing a Unified Strategy to Support Family Caregivers Across the Nation, in 2021 to serve as a compilation of resources, and strategic guidance; it also identified core policy recommendations to help guide advocates in developing unified statewide caregiving strategies that address community-level needs.<sup>7</sup> The RAISE Family Caregiver Resource and Dissemination Center (mentioned below) developed a State Policy Roadmap<sup>8</sup> to encourage state efforts to improve supports and services for family caregivers which was released in 2022.

### Implementing the RAISE Family Caregivers Act

While the RAISE Family Caregivers Act achieved passage in 2018, <u>Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI)</u> championed bipartisan legislative efforts to create a national plan to support family caregivers beginning in 2015. Following the lead from the Senate, the House of Representatives introduced a companion bill, in 2015, under the leadership of Gregg Harper (R-MS). Securing bipartisan and bicameral support for the RAISE Family Caregivers Act indicated that the legislation was politically viable. The two pieces of legislation received nearly 130 co-sponsors across both congressional bodies.

Also in 2015, the Assisting Caregivers Today (ACT) Caucus formed as a bipartisan, bicameral, Member-led initiative to focus on increasing visibility to family caregivers and the challenges and opportunities that caregivers of all ages face.<sup>9</sup> Members of the ACT Caucus, in collaboration with national advocacy organizations, ultimately leveraged multisector support for the RAISE Family Caregivers Act, which passed Congress and was signed into law in 2018.

While passage of the RAISE Family Caregivers Act was a critical milestone toward developing and implementing the National Strategy to Support Family Caregivers, significant additional advocacy and collaboration efforts among organizations was necessary to ensure momentum. Notably, the RAISE Family Caregiver Act was signed into law absent any funding mechanisms and administered through an agency without sufficient appropriations to implement the Act's requirements. Furthermore, the timeline to achieve the required activities outlined in the Act was short—only three years. Advocacy organizations pushed for appropriated funds to implement the RAISE Family Caregivers Act while public, private, and philanthropic stakeholders once again leveraged previous collaborative efforts to maintain momentum toward implementation.

Recognizing the limitations posed by the lack of appropriated resources to support implementation, JAHF approached ACL to offer support for implementing the RAISE Family Caregivers Act. Through this collaborative effort that was built on JAHF's long and successful history of supporting other ACL initiatives that aligned with its philanthropic goals, JAHF funded a three-year project led by the <u>National Academy for State Health Policy (NASHP</u>) to administer the RAISE Act Family Caregiver Resource and Dissemination Center to support the Family Caregiving Advisory Council and other efforts to develop the national

strategy. Specifically, ACL, JAHF, and NASHP maintained coordination to advance RAISE implementation efforts while initial federal appropriations were being approved by Congress. It is important to note that NASHP also later received support from the Ralph C. Wilson Jr. Foundation and the Research Retirement Foundation who joined JAHF to advance this work.

This support, along with collaboration across ACL and external stakeholders (including a <u>RAISE Family Caregiving Faculty</u>) allowed NASHP to curate existing and develop new essential resources to inform the Advisory Council's efforts. Modeling work after NAPA, NASHP identified more than 800 recommendations reflecting multi-stakeholder input from 27 key state, national, and international caregiving reports spanning nearly a decade. This effort populated an initial inventory of policy recommendations for members of the Family Caregiving Advisory Council to consider.<sup>10</sup> Additionally, ACL and NASHP adapted the NAPA Driver Diagram<sup>11</sup> as a framework through which to consider these recommendations. According to interviews with key JAHF, NASHP, and ACL administrators, identifying and adapting an applicable model through which to implement the RAISE Family Caregivers Act was an integral part of advancing this work.

NAC worked with policymakers, specifically Senator Susan Collins, to include a short-term, but necessary, oneyear extension of the RAISE Family Caregivers Act.

<sup>8</sup>https://nashp.org/state-tracker/state-family-caregiving-task-forces/

<sup>10</sup>https://nashp.org/inventory-of-key-family-caregiver-recommendations/

<sup>&</sup>lt;sup>7</sup>https://www.caregiving.org/wp-content/uploads/2021/02/NAC\_50state-Strategy\_Report\_NAC-FINAL\_02\_2021.pdf

<sup>&</sup>lt;sup>9</sup>https://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2015/bipartisan-congressional-caregivers-caucus.html

<sup>&</sup>lt;sup>11</sup>https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-advisory-council/napa-advisory-council-meetings/napa-past-meetings/napa-2018-meeting-material/january-2018-meeting-presentation-napa-driver-diagram

# The Path from Statute to a National Strategy to Support Family Caregivers

Because the RAISE Family Caregivers Act was signed into law in early 2018 without any federal appropriations, national advocates (including NAC) championed funding while JAHF worked alongside NASHP and ACL to fund and begin implementation activities in mid-2019. Lawmakers modestly funded the RAISE Family Caregivers Act (currently at \$400,000 annually), which allowed ACL to hold the first RAISE Advisory Council meeting in August 2019. However, the early philanthropic support enabled the Assistant Secretary for Aging and Administrator of ACL to begin developing the requisite <u>2021 report to</u>. <u>Congress</u><sup>12</sup> and eventually the first iteration of the National Strategy to Support Family Caregivers.

Securing an annual appropriation to continue the work of ACL and the RAISE Advisory Council again required coordinated and persistent federal engagement from organizational and individual family caregiver advocates and the ongoing buy-in from key lawmakers and staff. NAC worked with policymakers, specifically Senator Susan Collins, to include a short-term, but necessary, one-year extension of the RAISE Family Caregivers Act as part of the 2020 Older Americans Act reauthorization (Pub.L. 116-131).<sup>13</sup> Securing an annual appropriation to continue the work of ACL and the RAISE Advisory Council again required coordinated and persistent federal engagement from organizational and individual family caregiver advocates and the ongoing buy-in from key lawmakers and staff.

With the federal allocation to implement key activities outlined in the RAISE Family Caregivers Act, the work toward convening the appropriate stakeholders to develop the National Strategy to Support Family Caregivers became a true public-private effort. Core components of that effort, which are detailed in the initial report to Congress, included recruiting, selecting, and convening both federal and non-federal members of the Family Caregiving Advisory Council, coordinating several annual public meetings of the council, and pursuing an extensive process of public engagement to inform both the recommendations outlined in the initial congressional report and the National Strategy to Support Family Caregivers.

Initial opportunities for public engagement entailed a Requests for Information (RFI), conducting more than a dozen focus groups with 80 participants, convening more than 20 stakeholder listening sessions with 145 stakeholder organizations representing multiple sectors, and conducting 17 key informant interviews between 2019 and 2021 where NASHP was responsible for data collection regarding these efforts. Additionally, multiple federal agency representatives were included on the Advisory Council and both U.S. Department of Health and Human Services (HHS) and White House Domestic Policy Council representatives regularly participated in Advisory Council convenings.

Successfully identifying and deploying the RAISE Family Caregiver Advisory Council stakeholders through a strategic, coordinated, flexible, and streamlined model of engagement was essential to developing the 2022 National Strategy to Support Family Caregivers. However, the implementation process included multiple milestones and deliverables that were critical to informing the final strategy as well as advocacy efforts. Advisory Council members, ACL administrators, and key stakeholders embraced an iterative process to identify unifying characteristics of family caregivers, driving the need for a more holistic approach to supporting family caregivers across the lifespan.<sup>14</sup> Family caregivers were engaged in multiple ways throughout the process of developing the Advisory Council's initial report to Congress and the National Strategy to Support Family Caregivers.

Accompanying the initial report to Congress were several additional resources that were important to informing the ongoing development of the 2022 National Strategy to Support Family Caregivers. Specifically, the ACL released a comprehensive Inventory of Federal Caregiver Support Programs and Initiatives intended to increase awareness and understanding about programs to support family caregivers and to avoid duplication of effort when developing the National Strategy to Support Family Caregivers.<sup>15</sup> The council also released two reports exploring the role of both Medicare<sup>16</sup> and Medicaid<sup>17</sup> in supporting family caregivers and care recipients. Furthermore, in an effort to build awareness and communicate the individual stories

<sup>15</sup>https://acl.gov/sites/default/files/RAISE\_SGRG/FedCaregiverSupport-Inventory(ACL).docx

17 https://nashp.org/medicaid-supports-for-family-caregivers/

<sup>12</sup>https://acl.gov/RAISE/report

<sup>&</sup>lt;sup>13</sup>https://acl.gov/sites/default/files/about-acl/2020-04/0lder%20Americans%20Act%200f%201965%20as%20amended%20by%20Public%20Law%20116-131%20on%203-25-2020.pdf

<sup>&</sup>lt;sup>14</sup>https://acl.gov/sites/default/files/RAISE-InitialReportToCongres2021\_Final.pdf (pages 10-11)

<sup>&</sup>lt;sup>16</sup>https://medicareadvocacy.org/wp-content/uploads/2020/06/Medicare-and-Family-Caregivers-June-2020.pdf

of family caregivers, "Faces of Family Caregiving" featured written and video vignettes from a diverse group of 26 family caregivers from across the nation representing a range of family caregiving situations and needs.<sup>18</sup> A landmark report "In Their Own Words—Caregiver Priorities and Recommendations: Results from a Request for Information" was also released, reflecting both the qualitative and quantitative analysis and discussion of the trends identified throughout the RFI process.<sup>19</sup> All of these accompanying efforts required extensive support, input, and effort from various organizational and individual stakeholders. These materials are housed on ACL's website.

Building on the initial report to Congress, ACL released the 2022 National Strategy to Support Family Caregivers only a year later.<sup>20</sup> The caregiver landscape was further expanded when ACL combined its actions with findings and recommendations in a companion project, <u>Supporting Grandparents Raising Grandchildren (SGRG)</u>. SGRG was established through separate legislative and administrative actions.

The National Strategy to Support Family Caregivers leveraged the years of action and engagement of the Advisory Councils, policymakers at all levels of government, national advocacy organizations, and thousands of individual family caregivers around five primary goals:

- 1. Increase outreach and awareness
- 2. Build partnerships with family caregivers
- 3. Strengthen services and supports
- 4. Ensure financial and workplace security
- 5. Expand data, research, and evidence-based practices

The National Strategy to Support Family Caregivers also identified more than 350 actions federal agencies committed to take over three years and more than 150 actions available to numerous other sectors, including state governments, communities, philanthropic organizations,<sup>21</sup> health care organizations, and services providers, to advance supports for family caregivers. Notably, the National Strategy to Support Family Caregivers also identifies key legislative actions to improve supports for family caregivers. These actions are identified in the National Strategy to Support Family Caregivers as beyond the purview of federal agency authority, and they inform a call to action for federal, state, and local lawmakers to enhance support for family caregivers.

The volume of content in the National Strategy to Support Family Caregivers demonstrates how large the scale of the issues facing this population is and how these issues can be addressed across the lifespan. The strategy is comprised of four documents:

- 2022 National Strategy to Support Family Caregivers An overview and description of the strategy's goals and intended outcomes
- First Principles: Cross-Cutting Considerations for Family Caregiver Support Describes the four key principles that must be reflected in all efforts to improve support to family caregivers
- Federal Actions Nearly 350 actions that 15 federal agencies will take in the near term to begin to implement the strategy
- <u>Actions for States, Communities, and Others More than 150 actions others can take</u>

An important factor to consider when looking at the National Strategy to Support Family Caregivers as a model for a national plan on aging is that the language in the RAISE Family Caregivers Act required that the strategy be updated every two years to reflect changes in the landscape. We identify NAPA in this report as an important consideration because that process shows how much has been done to iterate on the Alzheimer's plan over several years.

### **Catalyzing Forces**

Given the breadth of stakeholder engagement necessary during a limited timeframe, public-private collaboration was essential to ensuring that feedback and comments could be adequately distilled and addressed to inform National Strategy to Support Family Caregivers recommendations. For example, during the 2019 RFI process, the Advisory Council benefited from NASHP's

coordination with researchers at the LeadingAge LTSS Center at the University of Massachusetts in Boston to conduct a timely and formal analysis of more than 1,600 responses that ultimately informed recommendations in the report to Congress. Further analysis took place after a <u>request for public comments</u> was announced post release of the National Strategy to Support Family Caregivers; <u>comments were published</u> in early 2024. This feedback will help inform the next iteration of the strategy.

Due to the widespread interventions needed across sectors, it was critical that a process was established to prioritize and activate a coalition of stakeholders capable of engaging in advocacy. Once the National Strategy to Support Family Caregivers was released, NAC launched a targeted campaign in 2023 to engage stakeholders and ensure accountability around implementation of actions within the strategy. In addition to the philanthropic support to NASHP, JAHF also supported NAC to launch an advocacy campaign called Act on RAISE.

The <u>Act on RAISE</u> campaign (named to reflect title of the RAISE Family Caregivers Act) is singularly focused on driving implementation of the actions outlined in the National Strategy to Support Family Caregivers by bringing together stakeholders across the caregiving continuum (aging groups, patient advocacy groups, disability groups, and caregiving groups) and provide engagement opportunities. The goals of the campaign are to accelerate the implementation of the National Strategy to Support Family Caregivers and strengthen federal-level coordination needed to implement the intent of the RAISE Family Caregivers Act.

One major critique of the National Strategy to Support Family Caregivers was that the RAISE Family Caregivers Act didn't authorize the development of new programs or funding tied to implementation. This criticism is valid given that the only policy advancements that could be made in the near future were dependent on what could be done under existing authority–particularly pertaining to what could be done on the federal level. It is important to note that many of the outcomes identified in the strategy will require additional legislation or policy change to achieve the sufficient infrastructure investments needed to integrate family caregivers on the systems level.

However, a major advancement occurred in 2023 when <u>ACL announced funding for new cooperative agreements grants</u> in support of the 2022 National Strategy to Support Family Caregivers. The project period for these new grants spans from 2023 to 2027. Funds for this initiative were drawn from Title III-E formula funds and use the demonstration authority found in Sec 373(i) of the Older Americans Act. Each of these grants is intended to support implementation of each of the five goals outlined in the National Strategy to Support Family Caregivers within the aging, tribal, and kinship support programs funded under Title III-E and were awarded to five separate entities—Community Catalyst, Regents of the University of California, San Francisco, USAging, University of Southern California, Leonard Davis School of Gerontology, and the National Alliance for Caregiving.

### **SECTION 2:**

# Key Considerations for Advancing a National Plan on Aging

The future of the RAISE Advisory Council relies on ongoing reauthorization and additional federal funding, driven by continued and sustained advocacy from within the field. The evolution and achievements from this process can inform future advocacy efforts to advance multisector plans for aging in the states and/or a national plan on aging—elevating the national dialogue and establishing a sense of urgency to act on a societal level.

Efforts to advance multisector plans for aging in the states and/or a national plan on aging will likely involve the need to ensure a level of commitment to facilitate the process within the federal government and gather stakeholder feedback from a variety of subject matter experts. Following are key considerations for funders, advocates, subject matter experts, and policymakers as they explore future opportunities to support older adults, people with disabilities, and family caregivers.

The future of the RAISE Advisory Council relies on ongoing reauthorization and additional federal funding, driven by continued and sustained advocacy from within the field.

<sup>24</sup>The Strategic Plan for Aging Act was introduced on February 28, 2024. At the time of publication, no republican sponsors were identified. https://www.gillibrand.senate.gov/news/press/release/gillibrandcasey-introduce-landmark-strategic-plan-for-aging-act/

### **Developing a Case for Advocacy**

An evidence-informed foundation clearly delineating the need for action can serve as an important catalyst for broad engagement and investment. Demonstrating a broad base of existing activities and their impact in multiple states advancing concurrent actions–such as the state-level multisector plan for aging activity underway in 24 states–can also serve as a foundation to foster federal action.

For example, numerous studies, reports, and legislative analyses collectively underscored the need to advance the national, cross-cutting strategy to support family caregivers. Materials including NAC/AARP surveys (i.e., Caregiving in the U.S.), the NASEM report (Families Caring for an Aging America), International Alliance of Carer Organizations (Global State of Care), and NASHP's summary of existing legislative recommendations to support family caregivers contributed to building a case for collective national action in different ways as they are all intended to reach various audiences.

Advocates promoting the need for a national plan on aging can look to numerous existing state efforts to inform a federal approach. As state leaders endeavor to work across traditionally siloed sectors and holistically plan to better meet the needs of an aging population, national advocates can apply these state strategies to inform a broader national planning effort.

### **Building a Bipartisan Base of Policy Champions**

Broad-based planning efforts take time to develop and implement and often span multiple election cycles. To maintain momentum across changing political dynamics, it is important to engage policymakers across the political spectrum as champions. For example, as co-sponsors of the RAISE Family Caregivers Act, Senators Baldwin and Collins were able to assume the leadership in both Republican and Democratic-led legislative sessions. Furthermore, advocates and lawmakers organized the bipartisan Assisting Caregivers Today (ACT) Congressional caucus to engage lawmakers in sharing their personal caregiving experiences outside of political parameters.

State-level, multisector plans for aging have also enjoyed support from governors across the political spectrum. Additionally, the issue has received congressional attention. In February 2024, Senators Kirsten Gillibrand (D-NY) and Bob Casey (D-PA), chair of the Senate Committee on Aging, introduced the Strategic Plan for Aging Act. This proposal would initiate a nationwide grant program under the Older Americans Act (OAA) to incentivize and support states' efforts to create their own strategic plans for aging. While the <u>Strategic Plan for Aging Act</u> does not include Republican co-sponsors when introduced,<sup>22</sup> the bill can serve as a launching point for congressional leaders and the dozens of endorsing organizations to build bipartisan support. Additionally, the grant program authorized in the legislation would be administered through the Older Americans Act–a bill that is traditionally a bipartisan effort.

### **Prioritizing Public-Private Partnerships to Sustain Momentum**

Public and private-sector support is essential to advancing a comprehensive, transparent, collaborative, co-design process to develop national strategies. Philanthropic support, specifically from JAHF, was instrumental in catalyzing advocacy and implementation activities for both the RAISE Family Caregivers Act and the National Strategy to Support Family Caregivers. This support allowed for the augmentation of materials that provided feedback, insight, and evidence from various levels of expertise that would not have otherwise been possible.

As efforts progress in support of a national plan on aging, it is important to ensure that a core group of leading organizations (policy, advocacy, philanthropy, academia, public sector entities) are coordinating early in the development process. Champions of a national plan on aging can look to both RAISE and NAPA to identify critical activities and inflection points to target support and funding efforts.

### Pursuing Multisector Stakeholder Support and Including Individuals with Lived Experience

By nature, high-level, multisector planning efforts involve and engage multiple stakeholders and interest groups. Champions for these initiatives must ensure that affected sectors and stakeholders are aware of–and on board with (or at least not opposed to)–the overarching goals, vision, and mission of the endeavor. Additionally, responsible advocacy ensures that affected

stakeholders are regularly engaged as progress occurs. Managing expectations for advocacy achievements and progress is also important as these processes can take time. For example, the National Strategy to Support Family Caregivers was designed to address issues across the life course and span multiple sectors, disciplines, and demographics, which were engaged through the RAISE Family Caregiver Advisory Council and Act on RAISE campaign.

Furthermore, input from affected individuals and constituency groups should inform initiatives at all phases of development and implementation. Family caregiver interviews, public comments, testimonials, and vignettes threaded the RAISE Family Caregivers Act reports to Congress and development of the National Strategy to Support Family Caregivers. Because MPAs on the state level are developed with cross sector stakeholders, public-private partnerships have paved the way for a learning community to foster learning and ensure buy-in is gained where needed. On the national level, interagency coordination can highlight and expand on existing frameworks for success and gather input from experts and individuals with the experience needed to translate outcomes that can be achieved from the local and family level to the federal and national level.

### **Incorporating and Augmenting Existing Efforts**

As momentum builds around advancing a national plan on aging, it is critical to consider existing planning activities–including but not limited to federally mandated state and area plans on aging, age- and dementia- friendly community initiatives, age-friendly public health, Healthy People 2030, the National Strategy to Support Family Caregivers, the National Plan to Address Alzheimer's Disease–and understand how existing (mandatory) planning efforts would be affected and could inform broader planning efforts. A national plan on aging could also align with the efforts to implement the LTSS Scorecard as one measure to track progress. However, these endeavors are unique from one another.

Coordination on the national level as it pertains to multisector plans for aging would provide a space to synthesize priorities outlined in state plans, gather feedback from the public to identify gaps, incorporate buy-in across stakeholders at various levels within society and government, and define priorities that delineates between what is most appropriate to occur on the state, local, or community level, where attention is needed from the private sector, and where agencies or Congress can play a role on the federal level. Reflecting on the nuances, strengths, opportunities, and vulnerabilities in each effort is important as advocates build and promote a broader strategy to develop a national plan on aging. Reflecting on the nuances, strengths, opportunities, and vulnerabilities in each effort is important as advocates build and promote a broader strategy to develop a national plan on aging.

### Conclusion

As policymakers, funders, and other stakeholders embark on the journey to advance a national plan on aging, it should be kept in mind that there is no one-size-fits-all approach for such a process. Much of the success when it comes to advancing such an effort via legislation depends on often unpredictable political environmental factors.

A major success factor for the National Strategy to Support Family Caregivers was establishing the issue as a priority that could span presidential administrations. A large majority of the initial efforts to establish the National Strategy to Support Family Caregivers took place during the Obama Administration and leading up to the Clinton-Trump election season. Given the bipartisan nature of the RAISE Family Caregivers Act, the legislation was ultimately signed into law under the Trump Administration. As of 2024, the National Strategy to Support Family Caregivers and issues facing family caregivers remains a priority under the Biden Administration.

The need for a model that can be sustainable over time is reflected in the fact that the 2022 version of the National Strategy to Support Family Caregivers is the first iteration of what must be an evolving framework to reflect changes in the landscape. It's likely this will hold true for the effort to advance a national plan on aging.