



## **Engaging on the RAISE National Family Caregiving Strategy**

**How to comment on the National Strategy and NAC policy priorities**

*Open comment period ends November 30, 2022*

[Click here to comment on the 2022 National Strategy to Support Family Caregivers](#)

## **Purpose of this document:**

With the release of the first ever [National Family Caregiving Strategy](#), there is an opportunity for the public to engage in the ongoing dialogue around how we can meaningfully support and recognize America's family caregivers via an open comment period. **This 60-day open comment period will close on November 30, 2022.**

It is critical that all key stakeholders with a focus on issues such as aging, disability, public health, patient advocacy, financial/economic security, equity, healthcare reform, mental health, community-based supports, social services, long-term care, chronic/serious illness, and beyond have a voice in this process. The Administration for Community Living (ACL) is expected to announce the second cohort of RAISE Advisory Council members in November 2022. These newly appointed Council members and others involved in updating and republishing the National Strategy will use comments submitted via this comment period to identify priorities of focus as the National Strategy evolves moving forward.

NAC hosts the [National Family Caregiving Advocacy Collaborative](#) (Advocacy Collaborative) which is a network of state and national family caregiving advocates working together to identify and address complex issues surrounding family caregiving across the lifespan. By working with this broad set of interdisciplinary experts from multiple sectors, NAC has identified a set of priorities that could lead to the implementation of many of the components identified in the National Strategy, as well as priorities that could use additional focus and attention. This document is designed to share some of those priorities, provide some high-level background on the process that went into developing the National Strategy, and instructions on how to comment.

Please feel free to look at the language below and determine if any of these priorities align with priorities your organization would like to see addressed in an updated and republished National Strategy. If not, please use this open comment period process to outline priorities you would like to see addressed as the National Strategy evolves, particularly over the next couple of years.

NAC will be working on an ongoing basis to support implementation efforts related to the National Strategy. If you would like to learn more about our policy and advocacy work, email Michael Wittke, V.P., Policy & Advocacy at [mike@caregiving.org](mailto:mike@caregiving.org). Let us know if you have any questions or would like to join the Advocacy Collaborative—it is free to join, and we meet quarterly to discuss and refine NAC's policy priorities related to the National Strategy.

## **About the RAISE National Family Caregiving Strategy:**

The RAISE Family Caregivers Act, which became law on Jan. 22, 2018, directs the Secretary of Health and Human Services to develop a National Family Caregiving Strategy. The strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers including:

- Promoting greater adoption of person- and family-centered care in all healthcare and long-term service and support settings, with the person and the family caregiver at the center of care teams
- Assessment and service planning (including care transitions and coordination) involving care recipients and family caregivers
- Information, education, training supports, referral, and care coordination
- Respite options
- Financial security and workplace issues

On September 22, 2021, the RAISE Family Caregiving Advisory Council released its [initial report to Congress](#). This report outlined the challenges faced by family caregivers, federal programs currently available to support them, and provided 26 recommendations for better supporting family caregivers. The recommendations were used to form the foundation of the National Family Caregiving Strategy, which included action steps to increase recognition and support for family caregivers.

On September 21, 2022, the [2022 National Strategy to Support Family Caregivers](#) was delivered to Congress. The Strategy includes nearly 350 actions the federal government will take to support family caregivers in the coming year and more than 150 actions that can be adopted at other levels of government and across the private sector to begin to build a system that ensures family caregivers – who provide the overwhelming majority of long-term care in the United States– have the resources they need to maintain their own health, well-being, and financial security while providing crucial support for others.

### **Components of the National Strategy**

- [2022 National Strategy to Support Family Caregivers](#) - An overview and description of the strategy's goals and intended outcomes
  - **Note – Page 22 and 23 in this document highlight legislative or policy changes that would need to be enacted to implement components of this National Strategy.**
- [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.

- **Note – This document contains actions that federal agencies have said they will take to implement components of this National Strategy.**
- [Actions for States, Communities, and Others](#) - More than 150 actions others can take.

**Instructions for providing public comment:**

The Administration for Community Living (ACL) has provided a [webpage](#) designed to collect public comment via portals where comments can be collected and aggregated. Your responses to the questions provided via the portals will help the incoming Advisory Council identify priorities for future updates of the Strategy. Below is an example of the portal which includes a menu of items you can use to provide comments.

If you would like to provide general comments that apply to the Strategy as a whole, you can select "Global Comment for all Four Components." When you have finished providing your comments, click "submit." If you would like to comment on another component of the Strategy, you can fill out this form again.

**There is no limit to the number of forms you can submit.**

**NOTE – THIS IS JUST AN EXAMPLE OF ITEMS FOUND ON THE ACL WEBPAGE, THIS DOCUMENT WILL NOT BE USED TO COLLECT AND SUBMIT COMMENTS.**

**[Click here to submit your comments on the National Strategy](#)**

Which component of the strategy are you addressing with your comment?

Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward?

1500 character(s) remaining

Are there issues that are not covered in this component that should be addressed in future updates?

1500 character(s) remaining

If you have additional comments on any aspect of the Strategy, please provide them below.

A rectangular text input field with a light gray background and a thin black border. On the right side, there are three vertically stacked buttons: an upward-pointing arrow, a square, and a downward-pointing arrow. Below the input field, there is a horizontal scrollbar with a left-pointing arrow, a square, and a right-pointing arrow.

500 character(s) remaining

## **Language NAC intends to submit on federal actions:**

Below is language NAC intends to submit specifically pertaining to the document outlining [Federal Actions](#) – there are nearly 350 actions that 15 federal agencies will take in the near term to begin to implement the Strategy.

**NOTE – You will see there is a character limit allowable on the ACL comment submission page. To help address that issue, below you will find two options to address the character limit. Option 1 is how NAC will submit and requires more than one submission. Option 2 is truncated language and can be used if you would like to submit only one comment.**

### **Option 1: (requires multiple submissions):**

#### **Submission #1**

*Which component of the strategy are you addressing with your comment?*

Select “Federal Action”

*Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward?*

A top priority for the Advisory Council should be a focus on accountability and transparency regarding federal actions

*Are there issues that are not covered in this component that should be addressed in future updates?*

The issues family caregivers face requires a comprehensive response across sectors. The National Strategy provides a unique road map to act in supporting America’s 53 million family caregivers. It is crucial to have accountability and transparency as the National Strategy is being updated and refined over the course of time that occurs between the release of the initial strategy and the publishing of the next version of the strategy. Increased accountability and transparency are especially important as stakeholders continue to champion and build on the foundation that has been established in the process of creating the 2022 National Strategy to Support Family Caregivers. Please help ensure that the public is allowed to follow this implementation process by requesting that those federal agencies which have made commitments are given time to speak out on their efforts by inviting agency leadership to participate and be included in the agenda for upcoming RAISE Advisory Council public meetings that are held in the span of time prior to the release of the updated strategy. Stakeholders should not be subjected to exceedingly long waits to receive updates on events that have taken place. The public must hear directly on an ongoing basis from agency leadership regarding their implementation progress or roadblocks they are facing as they work to enact the actions identified via the landmark National Strategy.

*If you have additional comments on any aspect of the Strategy, please provide them below.*

Please ensure that agencies working to implement federal actions are given the opportunity to provide updates to the public at least one time prior to the release of the updated strategy. We recommend that ACL develop an implementation dashboard to be used to educate agencies, policymakers, public policy stakeholders, and family caregivers about the implementation status of actions across agencies. This dashboard can help promote transparency and coordination as the National Strategy is refined.

## **Submission #2**

*Which component of the strategy are you addressing with your comment?*

Select "Federal Action"

*Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward?*

A top priority for the Advisory Council should be a focus on outcomes measures regarding federal actions.

*Are there issues that are not covered in this component that should be addressed in future updates?*

In addition to providing greater transparency on the successes and challenges in implementing identified federal level actions, we request that a process is developed and put in place that allows agency leadership to identify and report on anticipated and actualized outcomes of those actions. By providing outcomes measures, the National Strategy will have established efficacy that can be further refined, and an updated National Strategy can be developed with a clear picture of what is being accomplished as a result of the actions federal agencies are taking. We understand there are limitations on what can reasonably be accomplished given that agencies may only act on implementation efforts that can occur under existing authority. That fact should not suggest that what agencies seek to put into effect is not without merit. The public and the stakeholder community will benefit from understanding how federal agencies are measuring their progress. The outcomes measures established will also inform how the stakeholder community may shift their priorities and operations to align with successes and challenges outlined. If you have additional comments on any aspect of the Strategy, please provide them below.

## **Submission #3**

*Which component of the strategy are you addressing with your comment?*

Select "Federal Action"

*Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward?*



A top priority for the Advisory Council should be a focus on impact measures regarding federal actions

*Are there issues that are not covered in this component that should be addressed in future updates?*

To ensure that accountability and transparency are at the forefront of public interest, and as agency leadership communicates the intended outcomes of their critical contributions to America's family caregivers, it is essential to establish a process to communicate the meaningful impact on this population. As the National Strategy is being examined for future updates based on measurable outcomes, it is equally important to understand how these efforts will contribute to a more recognized, supported, and engaged family caregiver population. The National Strategy is undoubtedly a needed effort. To further advance policy and programmatic priorities, we request that a process is developed and put into place that allows agencies to identify and report on the impact of their efforts. This information will allow the public to build on what is possible under existing authority and potentially provide insight into pathways that can lead to additional action that is evidence based. Sound policy and programmatic innovation will rely on as much data as possible to provide information on the return on investment that will have been set in motion by the actions that occur under agency leadership. There are many critical issues related to this National Strategy, but the public would most benefit from regular reporting how those efforts are expected to result in impact—meaningful improvements in the lives of America's family caregivers.

*If you have additional comments on any aspect of the Strategy, please provide them below.*

Along with accountability and outcomes measures, information on impact together amounts to a better understanding of the effort that so many people have provided to establish this incredible and monumental effort. The public can use this information to go beyond what is currently possible under existing authority and contribute to a stronger implementation undertaking that will build on the foundation of this first ever National Family Caregiving Strategy.

#### **Submission #4**

*Which component of the strategy are you addressing with your comment?*

Select "Federal Action"

*Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward?*

A top priority for the Advisory Council moving forward should be a focus on equity as an organizing principle across federal actions

*Are there issues that are not covered in this component that should be addressed in future updates?*

Prioritizing equity as an organizing principle across federal actions: One of the organizing principles of the National Strategy is to “prioritize efforts to advance equity for unserved and underserved populations of family caregivers.” NAC applauds this critical focus area and the National Strategy’s efforts to embed examples of efforts to build equity for family caregivers. However, we strongly recommend the National Strategy be updated to identify the specific actions federal agencies will take to promote equity for unserved and underserved populations of family caregivers. NAC recommends these actions be explicitly organized as an equity agenda within the National Strategy to promote intentionality, transparency, and accountability about efforts to address the health and economic disparities experienced by family caregivers from historically marginalized communities.

### **Submission #5**

*Which component of the strategy are you addressing with your comment?*

Select “Federal Action”

*Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward?*

One top priority for the Advisory Council should be focused on highlighting the need for continued appropriations in the Health and Human Services Budget to ensure the National Strategy is regularly updated over time.

*Are there issues that are not covered in this component that should be addressed in future updates?*

Highlighting the need for continued appropriations in the Health and Human Services Budget to ensure the National Strategy is regularly updated over time: An undergirding priority around ongoing efforts related to ensuring accountability and transparency and measuring outcomes, impact, and equity regarding federal actions—as well as the entirety of the National Strategy—is the need to ensure that the Department of Health and Human Services (HHS) continues to include and incrementally increase appropriations requests in the HHS department budget to ensure ongoing support of the RAISE National Strategy process and to track implementation efforts. As the RAISE Advisory Council further addresses the critical issues faced by families by updating the National Family Caregiving Strategy, continued and increased appropriations are critical in the effort to track and refine actions that can be taken to recognize and support family caregivers moving forward. Therefore we request that HHS continues to prioritize the appropriations requests that will be needed to sustain the efforts of the RAISE Family Caregiving Advisory Council in updating the National Family Caregiving Strategy.

## **Option 2 (if you only want to submit comments once)**

*Which component of the strategy are you addressing with your comment?*

Select “Federal Action”

*Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward?*

1) It's crucial to have accountability and transparency as the National Strategy is being updated. Please ensure that agencies working to implement federal actions are given the opportunity to provide updates to the public at least one time prior to the release of the updated strategy. We recommend that ACL develop an implementation dashboard to educate the public about the implementation status of actions across agencies.

2) Please ensure process is developed and put in place that allows agency leadership to identify and report on outcomes of their actions. Outcomes measures will inform how the stakeholder community may shift their priorities and operations to align with successes and challenges outlined. To further advance policy and programmatic priorities, we request that a process is developed and put into place that allows agencies to identify and report on the impact of their efforts. This information will allow the public to build on what is possible under existing authority and potentially provide insight into pathways that can lead to additional action that is evidence based. Sound policy and programmatic innovation will rely on as much data as possible to provide information on the return on investment that will have been set in motion by the actions that occur under agency leadership. The public would most benefit from regular reporting how those efforts are expected to result in impact—meaningful improvements in the lives of America's family caregivers.

*Are there issues that are not covered in this component that should be addressed in future updates?*

An undergirding priority around ongoing efforts related to ensuring accountability and transparency and measuring outcomes, impact, and equity regarding federal actions—as well as the entirety of the National Strategy—is the need to ensure that the Department of Health and Human Services (HHS) continues to include and incrementally increase appropriations requests in the HHS department budget to ensure ongoing support of the RAISE National Strategy process and to track implementation efforts. As the RAISE Advisory Council further addresses the critical issues faced by families by updating the National Family Caregiving Strategy, continued and increased appropriations are critical in the effort to track and refine actions that can be taken to recognize and support family caregivers moving forward. Therefore we request that HHS continues to prioritize the appropriations requests that will be needed to sustain the efforts of the RAISE Family Caregiving Advisory Council in updating the National Family Caregiving Strategy.

*If you have additional comments on any aspect of the Strategy, please provide them below.*

An organizing principle of the National Strategy is to “prioritize efforts to advance equity for underserved populations of family caregivers.” We strongly recommend the National Strategy identify specific actions taken by federal agencies to promote equity for these populations. These actions should be explicitly organized as an equity agenda within the National Strategy to promote intentionality about efforts to address the health and economic disparities experienced by family caregivers.

## **NAC's policy priorities for the strategy as a whole:**

The priority items listed below are issue-specific areas that may require additional legislative or policy action to implement components of the National Strategy. NAC will use this open comment period to encourage the RAISE Advisory Council to focus on these priorities as the National Strategy evolves. In general, these priorities fit within issue-specific categories such as:

- Access to Supports and Services
- Financial Security
- Family Caregiver Data Collection and Research
- Expanding or Improving Existing Programs under Health and Human Services
- Health and Wellness of Family Caregivers

**NOTE – You will see there is a character limit allowable on the ACL comment submission page. If you would like to ensure all these priorities are addressed in your comments, you will need to submit comments multiple times. If you only want to submit one comment, please select the top priorities you would like to see addressed that will fit within the character limit in each comment box.**

*\*Indicates priorities that are not specifically or fully addressed in the National Strategy*

### **Priority: Older Americans Act and Other Key Health and Human Services (HHS) Programs**

It is encouraging to see specific recognition in the National Strategy regarding the need to financially support caregiving initiatives through federal appropriations opportunities, including expansion of Older Americans Act and the Elder Justice Act appropriations opportunities.

As the strategy evolves, please prioritize additional focus on the need to build on the current federal infrastructure of supports and services for family caregivers and those in their care and highlight where further investment is needed under Older Americans Act Programs and other family caregiver-related programs under HHS such as:

- The National Family Caregiver Support Program (Title III E)
- OAA Title VI Part C Family Caregiver Supports
- Lifespan Respite Care Program
- BOLD Act Initiatives
- The Alzheimer's Disease and Healthy Aging Program
  - Including Healthy Brain Initiative Road Map Actions
- Community Care Corps Grants
- Health Resources & Services Administration (HRSA) Geriatric Workforce Enhancement Program (GWEP)

### **Priority: Paid Family and Medical Leave**

It is encouraging to see language in the National Strategy regarding the need to pass federal paid family leave and expand the FMLA to include small employers and a broader definition of “family” to include grandparent and kin caregivers.

As the strategy evolves, please continue to prioritize this issue and provide additional attention to the need to highlight core functions of a national Paid Family and Medical Leave program to ensure family caregivers across the lifespan can provide care or address their own medical needs without sacrificing their ability to work and ensure those functions are in line with the following principles:

- Provides caregiving and medical leave in addition to parental leave.
- Has a broadly inclusive definition of family and ensure that immediate, extended, and chosen family are covered under the definition of family caregiver.
- Are available to all workers, regardless of employer size, including part-time workers, self-employed workers, and low-wage workers.
- Includes sufficient wage replacement to ensure that people can afford to take caregiving, medical, or parental leave.
- Ensures job protection and include anti-retaliation provisions.
- Are flexible, easily accessible, and responsive to family caregiver needs, including allowing for intermittent use.
- Are sufficient to ensure that people have time to provide necessary care for loved ones and/or recover from their own serious medical conditions.
- Supplements and does not supplant the right to 12 weeks of unpaid leave under the FMLA regardless of whether the employee has or will also take employer provided paid leave for an FMLA-qualifying event.
- Are implemented and integrated to complement, not compete with, existing programs and policies.
- Are created with new appropriations sources and NOT carved out of or borrowed from funds dedicated to Social Security or other crucial federal programs.
- Ensures ability to utilize paid leave without jeopardizing eligibility for other federal programs.
- Ensures protections currently afforded through FMLA, the Americans with Disabilities Act (ADA), the Health Insurance Portability and Accountability Act (HIPAA) and other vital federal, state, and local programs must be maintained and complement new protections of a paid leave program.

### **Priority: Public Health Infrastructure Investment**

It is encouraging to see specific language in the National Strategy related to the need to increase appropriations for state, territorial, tribal, and local health departments to systemically embed family caregiving into public health infrastructure and planning as well as the need to provide appropriations for the development, implementation, and evaluation of a public health national and culturally competent awareness campaign regarding caregiving.

As the strategy evolves, please prioritize further focus on issues regarding public health by highlighting the role that the Secretary of Health and Human Services (HHS), in coordination with the Centers for Disease Control and Prevention (CDC) and the head of other agencies as appropriate, can play in identifying opportunities to award grants, contracts, or cooperative agreements to eligible entities, such as institutions of higher education, State, tribal, and local health departments, Indian tribes, tribal organizations, associations, or other appropriate entities for the establishment or support of regional centers to enable strategic alignment of care providers across settings to coordinate data collection, promote awareness, and offer training and education services for family caregivers by:

- Identifying and developing a protocol for entry-point service coordination for family caregivers across sectors.
- Strengthening, supporting, and mobilizing communities and partnerships to implement policies and practices that ensure the health and wellness of family caregivers as well as the persons receiving care by convening multi-sector stakeholders.
- Coordinating existing local supports and services to help family caregivers navigate and access services and supports, facilitating an integrated system of care focused on addressing social determinants of health and systemic inequities.
- Incorporating actions that can be prioritized to reach and support family caregivers into state health improvement plans.
- Ensuring family caregivers of all chronic or serious conditions are eligible for services.
- Ensuring family caregivers of those across the range of conditions are identified, assessed, and referred to services early in their care journey.
- Investing in programs increasing culturally competent health literacy to promote better health outcomes.
- Improving emergency preparedness and emergency response strategies to provide family caregivers with support and information during public health disasters, crisis, or other emergency situations.

**Priority: Public Health System Integration\***

As the strategy evolves, please highlight the need for the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) to use data collected via the Behavioral Risk Factor Surveillance System, the National Health and Nutrition Examination Survey, the National Health and Aging Trends Study, the Health Information National Trends Survey, and the National Health Interview Survey to strengthen state, territorial, tribal, and local health departments ability to systemically embed family caregiving into public health infrastructure and planning to do the following:

- Better understand the extent of health risk behaviors, preventive care practices, and the burden of chronic diseases (for family caregivers as well as those they care for)
- Monitor the progress of prevention efforts.
- Help public health professionals and policy makers make more timely and effective decisions.
- Develop, implement, and evaluate a national public health awareness campaign regarding caregiving.
- Establish science-based programs that prevent chronic diseases and reduce unhealthy behaviors in caregiving communities across the nation that improve health-related quality of life and save money in medical costs and lost productivity.

### **Priority: Federal-Level Research and Data Collection**

It is encouraging to see the stated goal in the National Strategy to expand data, research, and evidence-based practices.

As the strategy evolves, please continue to prioritize this issue by highlighting the need for additional research by public and private institutions by standardizing, expanding, and improving data collection by federal agencies such as HHS (ACL, CDC, FDA, NIH), DOL (BLS), VA (VHA), and the US Census Bureau taking into consideration the following needs:

- Strengthening family caregiver data collected via the Behavioral Risk Factor Surveillance System (BRFSS).
  - Including questions in the core sections of the BRFSS to gather family caregiver data.
- Exploring further use of tools such as National Health and Nutrition Examination Survey, the National Health and Aging Trends Study, Health Information National Trends Survey, Medical Expenditure Panel Survey, Panel Survey of Income Dynamics, Health and Retirement Study, and the National Health Interview Survey to understand how to achieve better health outcomes (for both the family caregiver and care recipient), how to achieve cost-savings, and how to ensure person and family centered care.
- Improving data collection on family caregiver health conditions and risk factors.
- Improving data collection on family caregivers of people with multiple conditions.
- Constructing additional channels on the local level that can gather detailed patient and family caregiver experience data to inform public health program and policy development.
- Collecting disaggregated data on diverse family caregiver populations and address the lack of segmentation and intersectionality in family caregiver research.



- Ensuring family caregiver data is collected on a consistent basis to track trends over time.

In addition, please prioritize the following:

- The need for the Assistant Secretary of Health and Human Services to develop a plan to implement recommendation 1-g from the National Academies of Sciences, Engineering, and Medicine’s “Families Caring for and Aging America” report: “Launch a multi-agency research program sufficiently robust to evaluate family caregiver interventions in real-world healthcare and community settings, across diverse conditions and populations, and with respect to a broad array of outcomes.”
- The need to convene a national task force to develop recommendations for a standardized set of survey questions that provide a comprehensive national level data set on improved health outcomes related to the family caregiver, person receiving care, key characteristics of the caregiving situation, and outcomes of policies that have been implemented on the national, state, and local levels.
- The need to improve equitable access to federally funded research by ensuring family caregivers and researchers can take part in every part of the scientific enterprise such as leading, participating in, accessing, and benefitting from taxpayer-funded scientific research by eliminating the optional 12-month publication embargo for federally funded peer-reviewed research articles and by making federally funded data published in peer-reviewed research articles immediately available upon publication.
- The need to increase appropriations for the National Institute of Nursing Research (NINR) to solve pressing health challenges and inform practice and policy – optimizing health and advancing health equity into the future by focusing on social determinants of health, population and community health, chronic disease prevention and health promotion and systems and models of care.
- The need to disseminate emerging research via a biennial summit on the science of caregiving to examine the importance of caregiving across the lifespan, as well as current and future directions for research to improve the health of patients and family caregivers.
- The need to increase appropriations for family caregiver research at The National Institutes of Health (NIH) Clinical Center to ensure the NIH Clinical Center improves recognition of family caregivers and further documents the effects of caregiving.
- The need to increase appropriations for family caregiver research at the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to generate new knowledge and to promote its effective use, strengthening the ability of family caregivers and families to support individuals with disabilities so they can more effectively perform activities of their choice in the community, and to expand society’s capacity to provide full opportunities and accommodations for its citizens with disabilities.

- The need to fund the newly authorized Research, Demonstration, and Evaluation Center for the Aging Network under the Older Americans Act and administered by the Administration for Community Living.
- The need to support an effort to standardize collection of family caregiver outcomes. This could help with federal survey measurement and be a guide to family caregiver survey/cohort studies.
- The need for family caregiver registries to document family caregivers in EHRs that's routinely collected. Documentation would allow for EHR studies to follow family caregivers to understand readiness for care, care burden, caregiver health outcomes and dyadic health outcomes, cost of care, and more.
- The need to gather data on family caregiver prevalence via the U.S. Census.

### **Priority: Expansion and Improvements in the Infrastructure of Formal/Direct Care Providers**

It is encouraging to the level of attention in the National Strategy given to the need to build out the system of direct care providers. Specifically, it is promising to see language related to the need to create a job classification for direct care workers and standardize training and accreditation across states and highlighting the need to establish a federal interagency task force to develop a direct care workforce development plan.

As the strategy evolves, please continue to prioritize the need to improve the infrastructure of formal care providers by doing the following:

- Highlighting the need to implement educational programs for family caregivers across all chronic conditions, allowing for the training and development of additional skills that would allow them to augment a care team and complement, not compete with, a clinical visit.
- Highlighting the need to establish partnerships among care providers, community-based organizations and/or faith-based organizations, and state/county/local public health departments with the purpose of both expanding existing family caregiver programs and establishing new, innovative family caregiver support programs that can reach family caregivers across the range of all chronic conditions.
- Highlighting ways the CDC's Primary Care and Public Health Initiative can foster linkages between public health and primary care by integrating family caregiver population health risk factor data into medical residency program curricula and competencies, increasing clinician understanding of public health problems and national initiatives offering potential solutions, and increasing clinician awareness and use of CDC resources.

### **Priority: Home and Community-Based Services (HCBS)**

It is encouraging to see language in the National Strategy regarding the need to develop tax deductions for paying for home and community-based services (HCBS), including by family members who are not claiming the care recipient as a dependent. It is also

encouraging to see language regarding encouraging Medicaid programs, programs offered by the VA, and Medicare Advantage programs to expand community-based long-term care options, including expanding self-directed opportunities to allow for the hiring of family caregivers, while also funding LTC services at rates that attract and retain a skilled direct care workforce.

As the strategy evolves, please further prioritize this issue specifically by focusing on the need to expand and strengthen HCBS by:

- Ensuring full implementation and enforcement of the HCBS settings rule for both residential and non-residential services, including adequate appropriations, technical assistance, appropriate individualized transportation options to ensure community integration, and other necessary supports to states.
- Promoting and expanding the Medicaid Consumer-Directed Care Program (also known as Cash and Counseling), available under Home- and Community-Based Services Waiver Program.
- Making permanent, within any Medicaid-funded Home and Community-Based Services (HCBS) program, protections against spousal impoverishment.
- Ensuring that states have plans to provide services to individuals with IDD who live with aging family caregivers or who are in other crisis situations and allow reimbursement for future planning services.
- Ensuring that amount, duration, and scope of HCBS are provided based on individual need identified through a person-centered planning process.
- Making permanent the Medicaid HCBS Money Follows the Person Program.

### **Priority: Medicare and Medicaid Access & Eligibility**

It is encouraging to see the National Strategy include language regarding the need to authorize specific benefit expansions in the Medicare program, including for respite, adult day services, home modifications, home delivered meals and other long-term services and supports (LTSS) to enable individuals to safely age in place/remain in their homes.

As the strategy evolves, please continue to prioritize the need to authorize these specific benefit expansions and increase appropriations and capacity including the following:

- Respite
- Adult day services
- Home modifications
- Congregate and Home-delivered meals
- Home care and direct care services
- Transportation
- Family caregiver support
- Legal Consultation

In addition, please prioritize the following:

- Highlight the need to incentivize state implementation and ensure protection of Medicaid expansion as authorized by the Affordable Care Act.
- Highlight the need to oppose requirements that Medicaid beneficiaries be employed to receive benefits.
- Highlight the need for the Centers for Medicare and Medicaid Services (CMS) to provide thorough, timely, and consistent review of all state plan amendments and waivers and waiver amendments to ensure compliance with the Americans with Disabilities Act (ADA) and Olmstead.
- Highlight the need to redesign the Medicaid eligibility process so that the care recipient does not have to deplete most of their assets to qualify for services and support.
- Highlight the need to support expansion and improved access for the State Health Insurance Assistance Program (SHIP) which is a national program that offers one-on-one assistance, counseling, and education to Medicare beneficiaries, their families, and family caregivers to help them make informed decisions about their care and benefits.
- Highlight the need to expand capacity to help low-income family caregivers with LTSS legal planning.

**Priority: Provider Reimbursement\***

As the strategy evolves, please highlight the need to support experimentation with reimbursing providers for time spent supporting family caregivers by:

- Promoting innovations in payment of supports and services for family caregivers.
- Promoting incentives for healthcare systems to incorporate family caregivers into healthcare decision making for the person receiving care.
- Promoting the need to better educate patients, family caregivers, and providers about existing reimbursable services aimed at supporting family caregivers.

**Priority: Family Caregiver Assessments**

It is encouraging to see language in the National Strategy regarding the need to inspire clinicians and providers to conduct formal assessments of family caregiving needs.

As the strategy evolves, please continue to prioritize the need to strengthen and expand the use of family caregiver assessment tools by taking into consideration that in addition to capturing and sharing information about the family caregiver, providers should conduct a standardized, formal assessment of the family caregiver's willingness and ability to provide care to the patient. While some home- and community-based providers have used a family caregiver assessment tool under Medicaid waiver programs and/or Older Americans Act, these tools are not specifically tailored to the Medicare program. Highlight that CMS should consider a Medicare-specific assessment tool, building on

effective instruments used by states and even other nations. Despite limitations, these existing tools may offer guidance to CMS in providing one standard instrument for providers to use.

### **Priority: Healthcare Discharge and Transition**

It is encouraging to see that the National Strategy extensively refers to the need to strengthen issues related to care discharge and transition processes.

As the strategy evolves, please continue to prioritize the need highlight efforts to ensure family caregivers receive discharge instructions in all cases where a patient is discharged to the home from a post-acute care setting considering the following:

- Family caregivers should receive a copy of discharge instructions in all cases where the patient is discharged from an acute-care setting to a post-acute setting.
- Improvements in interaction with home health providers who are many ways are best positioned to provide instruction to a family caregiver, as they observe the patient in the home and can offer training with an understanding of the functional challenges facing patients in day-to-day life.
- CMS should consider extending the discharge instruction requirements to all providers who are discharging a patient into the hands of the family caregiver.
- Where a family caregiver has been identified, all healthcare settings should notify the family caregiver when a patient changes settings, if that family caregiver is not present during discharge or transition.

Additionally, please highlight the need to strengthen the implementation of the state-based CARE ACT (which generally requires hospitals to provide patients an opportunity to identify a family caregiver and have their name and contact information recorded in the hospital's health record for notification upon discharge or transfer to a facility and offer the family caregiver instructions on how to perform the medical/nursing tasks that are included in the discharge plan) by including family caregivers for all persons with medical complexities, ensuring implementation by tracking uptake, evaluating outcomes, and expanding discharge instructions to include coordination among home and community-based providers.

### **Priority: National Resource Center on Family Caregiving\***

As the strategy evolves, please highlight the need for the Office of the Assistant Secretary of Planning and Evaluation (ASPE) in the Department of Health and Human Services (HHS), in partnership with the Department of Veterans Affairs (VA) and the Department of Labor (DOL) under Title II of the Older American's Act (OAA) to award a grant to or enter into a cooperative agreement with a public or private nonprofit entity to establish and operate a National Resource Center on Family Caregiving that can focus on program evaluation, training, technical assistance, materials and dissemination, and research; and promote quality and continuous improvement in the support provided to

family caregivers of those with medical complexity across the life course and across a range of federal agencies.

### **Priority: Workplace Protections**

It is encouraging to see language in the National Strategy regarding the need to protect family caregivers against workplace discrimination.

As the strategy evolves, please continue to prioritize this issue and highlight the need to pass workplace protections for family caregivers by passing legislation to ensure prohibition of discrimination or retaliation against:

- An applicant based on family caregiving responsibilities.
- An employee because of family caregiver responsibilities

### **Priority: Tax Credits**

It is encouraging to see language in the National Strategy regarding the need to include family caregiver out-of-pocket care expenses (products and services) as medical expenses eligible for tax credits. It is also encouraging to see language regarding the need to introduce a range of incentives to encourage employers to adopt family caregiver-friendly practices, including tax incentives.

As the strategy evolves, please continue to highlight the need to pass legislation to ensure that expenses for goods, services, and supports related to assistance of any Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL) incurred by family caregivers are eligible for credit against their taxes each taxable year, including the highlighting the need to ensure that family caregiver out-of-pocket care expenses (goods, services and supports) at any dollar amount are considered medical expenses that are eligible for refundable tax credits.

### **Priority: Improve Access to Research for Family Caregivers and their Care Partners and Better Integrate Family Caregivers into Research Design and Medical Product Development\***

As the strategy evolves, please strengthen language that highlights the need to institute reforms and ensure federal research appropriations are tied to recognizing the value – the contributions, the expertise, the health impact – of what family caregivers do and as partners in research by creating a more equitable research enterprise in the US. Also, please promote the need for the development of patient and family friendly remuneration policies and practices that consider family situations and enable appropriate compensation for family caregiver time helping patients participate in trials and for acting as research advisors and stakeholders.

In addition, please consider the following:

- Highlight opportunities to build on existing legislation such as the Food and Drug Administration Safety and Innovation Act and the 21<sup>st</sup> Century Cures Act which

have positioned the U.S. Food and Drug Administration (FDA) as a leader in defining methods and opportunities for capturing patients' views on the most burdensome aspects of their conditions as well as what matters most to them in terms of benefit expectations.

- Highlight opportunities to build on the Patient-Centered Outcomes Research Institute (PCORI) leadership as it relates to viewing patients as partners in research, rather than simply as subject of research.
- Highlight opportunities to build on the Patient-Focused Drug Development (PFDD) initiative which sought to hear directly from individuals with lived experience about what it is like to live with their medical conditions.

### **Priority: Palliative Care and Hospice Education and Training\***

As the strategy evolves, please highlight the need to pass legislation to improve palliative care and hospice education and training to:

- Increase and improve workforce training by expanding interdisciplinary training in palliative and hospice care and establish programs to attract and retain providers.
- Strengthen education and awareness via a national campaign to inform patients, families, and health professionals about the benefits of palliative care and the services that are available to support patients with serious or life-threatening illness.
- Enhance research by directing NIH to use existing authorities and funds to expand palliative care research to advance clinical practice and improve care delivery for patients with serious or life-threatening illness.

### **Priority: Engaging the Centers for Medicare and Medicaid Innovation\***

As the strategy evolves, please prioritize the need to highlight the following recommendations focused on ways that the Centers for Medicare and Medicaid Innovation (CMMI) can address improvements in the beneficiary experience via patient and consumer involvement by:

- Addressing CMMI's statutory authority and responsibilities to provide a lens to consider opportunities to engage with patients. Under Section 1115A, CMMI is required to consult with federal agencies, as well as clinical and analytical experts with expertise in medicine and healthcare management. CMMI is also required to use "open door forums" or "other mechanisms to seek input from interested parties" and addressing ways that CMMI might expand this perspective, valuing insight on the lived experiences from individuals in underserved communities, and highlighted consultation as an area where CMMI can directly include patients, as well as their families and family caregivers.
- Addressing the need for CMMI to use a broad definition of the phrase "consumer advocate," to include individuals like family caregivers and families, improving the beneficiary experience.

**Priority: VA Caregiver Support Program**

It is encouraging to see federal actions identified by the Department of Veterans Affairs (VA).

As the strategy evolves, please consider further highlighting opportunities to build on the VA Caregiver Support Program (CSP) and determine how this program may serve as a model for opportunities that could be implemented in other sectors, particularly by following the implementation of the VA Mission Act of 2018.

**Priority: Mental Health\***

As the strategy evolves, please further prioritize the need to highlight reforms and new programs in mental and behavioral health to support family caregivers who are facing mental health challenges and for those that are family caregivers to individuals with mental health or substance abuse challenges. This includes the need to introduce legislation to address social isolation and loneliness, particularly among caregivers.

**Priority: Social Security Credits**

It is encouraging to see language in the National Strategy regarding the need to allow family caregivers who leave the workforce for caregiving to accrue Social Security credits to qualify for Social Security benefits.

As the strategy evolves, please continue to prioritize this issue by highlighting the need to pass legislation to ensure Social Security credits and ensure that family caregivers that do not receive monetary compensation and provide care to a dependent relative are eligible for continued Social Security benefits.

**Priority: Enhancements in the family caregiver support infrastructure across federal agencies\***

As the strategy evolves, please prioritize the need to pass legislation that includes provisions regarding education and training for family caregivers, pandemic preparedness, health literacy grants, increased shared-decision making, as well as increased diversity in clinical trials and patient-family caregiver experience data which would go a long way to enhance the federal support infrastructure for family caregivers.