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Analysis of Public Comments on the National Strategy to Support Family Caregivers

Perspectives and Priorities



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Executive Summary

This report presents findings from an analysis of public comments solicited by the Administration for Community Living (ACL) on the National Strategy to Support Family Caregivers, published on September 21, 2022. The Strategy was the culmination of several years of collaborative work by advisory councils established by the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act and the Supporting Grandparents Raising Grandchildren (SGRG) Act, work that involved hundreds of organizations and individuals contributing their time and energy. The outcome of all of this activity was a clearly articulated set of goals and outcomes.

Although the publication of the National Strategy was an important step, more work was needed. The Councils needed public feedback on the Strategy, to ensure buy-in; to check that they were on track; and to obtain guidance on how to focus their work as they move forward.

Thus, public comments were solicited: on October 1, 2022, a call for public comments on the Strategy was opened and widely publicized, closing on December 31, 2022. To collect responses, a semi-structured questionnaire was used to ask respondents about their views on the top priorities for the Councils, what was missing from the National Strategy, and any other issues they considered relevant to the Strategy.

Although all goals and outcomes were seen as priorities by some respondents, when analyzed in terms of the concentration of comments under each goal, it was apparent that Goal 3 (services and supports for caregivers) garnered by far the most comments. The second most important goal was Goal 4, financial and workplace security. Respondents also found Goal 1, raising awareness of and increasing outreach to family caregivers, important.

The specific issues that were seen as top priorities included the critical importance of addressing the affordability, quality, and supply of direct care workers; the need for long term services and supports more generally — and caregiver training and support, as well as access to respite, more specifically; and mechanisms for mitigating the financial and workplace impacts of caregiving, specifically through expanding paid leave policies; paying family caregivers or offering other financial benefits; and encouraging caregiver-friendly workplaces.

In response to the request for comments on what is missing from the Strategy, one category of responses concerned the need for accountability, with various suggestions about what the Councils can do to maintain the current momentum in advancing change. Many responses also targeted federal government actions, with respondents emphasizing its critical role — although a body of responses also highlighted the roles that states can play, as well.

Overall, the responses indicate broad support — and indeed, enthusiasm — for the National Strategy and provide useful guidance on key priorities moving forward.

Introduction

While publication of the National Strategy to Support Family Caregivers on September 21, 2022 marked a historic event, the critical work had only just begun. The National Strategy included multiple recommendations and agency- and sector-specific proposed actions, representing hundreds of hours of collaborative work by the advisory councils established by the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act and the Supporting Grandparents Raising Grandchildren (SGRG) Act. The recommendations for action incorporated extensive input from family caregivers, the care recipients they support, and a wide variety of stakeholder organizations in both the public and private sectors. However, the National Strategy was designed to be a dynamic and evolving blueprint for change in the lives of family caregivers and the organizations that serve them.

While every effort was made to obtain the broadest input from family caregivers and organizations at every level while the National Strategy was being developed, the RAISE Advisory Councils sought to both receive feedback on the Strategy itself and ensure continual input and improvement. To do so, it solicited a round of public comments on the newly-issued National Strategy shortly after its publication. On October 1, 2022, a call for public comments on the published Strategy was issued and widely disseminated. Comments were submitted over the three month period ending December 31, 2022, using a semi-structured questionnaire (see Appendix C).

Methodology

Appendix A (Table 3) contains a complete list of the data elements, including the text of the questions used to solicit feedback. Respondents were asked to select and comment upon one of the following components of the National Strategy:

- Project Narrative
- First Principles
- Federal Actions
- Actions for States, Communities, and Others

Alternatively, respondents were free to provide general comments that apply to the Strategy as a whole (Global Comments). There was no limit imposed on the number of forms that respondents could submit.

In addition to some non-identifying background information, respondents were asked to provide an open-ended response to each the following:

- What do you feel should be the Council's top three priority issues?
- What's missing from the National Strategy that should be included?
- Is there anything else you would like to add?

Respondent Overview

The Administration for Community Living (ACL) received 581 responses. Table 1 shows the distribution of respondents by category. Respondents could choose more than one category; in fact, over 200 respondents did so. Consequently, the numbers shown in the table do not sum to 581. The largest respondent category (46%) identified as advocates for family caregivers, followed by 44% of respondents stating they were family caregivers. Just over a third (37%) of respondents were employed by organizations serving family caregivers. Researchers (13%) and representatives of government (9%) represented the smallest respondent categories.

Table 1: Respondents by Category

Respondent Category	Number	Percent
Advocate for family caregiver	256	46%
Family caregiver	267	44%
Employment by an organization that serves family caregivers	212	37%
Chose more than one category	207	36%
Researcher on caregiving topics	74	13%
Other/chose not to say	56	10%
Employed by government program that serves family caregivers	54	9%

Most individuals (40%) chose to direct their comments to the National Strategy as a whole (global comments), rather than selecting one of the four (4) other response categories, as shown below. Another 25% directed their comments at the Project Narrative, which provided context and background to the Strategy, including detail on the role of Congress and the Advisory Councils in the process.

Table 2: Distribution of Comments, by Section

Section	Number	Percent
Global comments	232	40%
Project narrative	147	25%
Federal actions	89	15%
Actions for states, communities, and others	73	13%
First principles	40	7%

Findings

Top Priorities

This section describes what respondents identified as the “top three” priority issues that the National Strategy should emphasize, based on the responses to this question. All components of the National Strategy were identified as top priorities by some respondents, although some issues clearly predominated: these included the direct care workforce, the availability and accessibility of caregiving training and supports, the availability and accessibility of respite, and the need for some form of caregiver compensation. When analyzed in terms of the concentration of comments under each goal, Goal 3, services and supports for caregivers, garnered the most comments, by far. The second most important goal was Goal 4, financial and workplace security. Below we identify the goal, outcome, population, issue, or topic cited based on the coding categories used in the analysis.

It should be noted that the determination of which topics were “most important” is based on the number of times respondents identified an issue as among their top three priorities. Given the unrepresentative nature of the responses (only those who were made aware of and were motivated to respond to the solicitation participated) and the ability of respondents to respond multiple times, the count of responses in any given category can provide us with only an approximate indication of priorities among the wider community. Given this caveat, however, it was clear that there was broad consensus on the priority placed on certain issues, which are highlighted below.

Goal 3: Actions to Strengthen Services and Supports for Caregivers

Goal 3 of the National Strategy addresses many critical issues, including caregiver training and support, respite care, the direct care workforce, adult day services transportation, housing and safety, trauma-informed care, person-centered care, and more. There are nine recommendations contained within Goal 3 — more than in any of the other goals.

Not surprisingly, Goal 3 received by far the most attention in the comments. Moreover, individual recommendations under Goal 3 were frequently identified as priorities. The most frequently mentioned topics were:

- Improving the quality, supply, and wages of direct care workers
- Expanding access to and the availability of caregiver training and support
- Expanding access to and the availability of respite care
- Increasing the supply and affordability of long-term services and supports more generally.

Respondent verbatim comments illustrate the importance ascribed to these priorities and provide insights into strategies that respondents support for advancing toward those goals.

Direct Care Workforce

“Demand for direct care workers drastically exceeds the number of available workers. Federal agencies have a particular role to play in increasing wages, expanding benefits, providing career ladders, and addressing shortages through other strategies.”

“We strongly agree with the concept of making a career out of being a direct care worker. It is essential to make training consistent across...states...It is also important to create a path to job promotion and job retention. It is not going to be easy, but it is ...worth a national effort.”

Respite Care

“Respite care should become a state plan service under Medicaid.”

“Respite services for family caregivers are important to their mental and physical health and ability to continue providing care. Respite allows a social life as well... reducing social isolation and loneliness linked to disease and premature death.”

“The single most requested service from family caregivers is respite.”

Caregiver Training

“Caregivers need more than just...recognition. They need real, meaningful help offered by those who have been there, done that and have the stories to prove it.”

“The first rule is that the caregiver has to be supported for them to be an effective caregiver.... A parent/caregiver may know their loved one best but nearly all of the caregivers I’ve met would welcome more training and are desperate for more support.”

Finance Reform

“Some essential reforms, such as financing, may be politically challenging today, but nonetheless must be pursued, even incrementally, to create the environment and conditions for more transformative change.”

Goal 4: Actions to Ensure Financial and Workplace Security for Caregivers

Goal 4 addresses steps to improve the financial and workplace security of family caregivers. This area received the second largest set of responses identifying the items as priorities. Specifically, respondents commented on:

- Policies relating to Outcome 4.1 (That “Family caregivers can provide care without negative impacts to their near- and long-term financial health.”) Specifically:
 - Expanding family and medical leave policies to provide paid leave, and
 - Establishing tax credits, Social Security credits, or other mechanisms for financial restitution for caregiving work.

- Separately, paying family caregivers for the care that they provide was identified as a specific priority.

Notably, comments relating to Outcome 4.1 ranked among the top four issues overall; in our analysis, these were broken down into comments relating to the Family and Medical Leave Act (FMLA) and those relating to other forms of credits or tax benefits for family caregivers. However, paying family caregivers was the fourth most frequently mentioned specific policy change identified overall, following concerns about the direct care workforce and the need for caregiver training and supports, and for respite; and the aggregated comments relating to the financial impacts of caregiving. Creating caregiver-friendly workplaces was also frequently identified as a priority.

Financial Impact

“The financial impact of caregiving is huge...We endorse policy and program solutions, with a broad definition of family applied.”

“Caregivers are forced to choose between staying employed or caring for their loved ones at home. When they forgo full time employment, their ability to build wealth fades. For veteran caregiving families, as they age and once their loved one dies, caregivers are further isolated and fall deeper into poverty.”

“Please...prioritize the need for paid leave...to ensure that all family caregivers can care for themselves or their family members without sacrificing their economic security.”

Paying Family Caregivers

“Family caregivers [including parents of minors and spouses] should have the option to be paid.... Allowing them to be a paid caregivers helps with the overall workforce crisis... [and] providing income for the work family members are already doing, helps the overall financial situation of the family.”

“[We need a] federal program modeled after California IHSS allowing parent caregivers to be paid for their children/family members.”

Caregiver-Friendly Workplaces

“I was not afforded the same favor as higher-ranking employees when members of their families were in need of care. There is a great disparity in the workplace.”

“Supporting employed family caregivers is critical in terms of paid leave, other employment protections, and workplace flexibilities at the state and local levels and from employers.”

Other Priorities

Goal 1, which relates to raising awareness of and outreach to family caregivers, was also seen as a top priority by a large number of respondents. Many respondents linked this priority with the importance of diversity, equity, inclusion, and accessibility (DEIA) as a top priority. As one respondent noted, *“resources simply cannot be just available; they must be attainable, understood by end-users, and reach diverse communities and individuals.”*

Kinship and Grandfamilies

A critical component of the family caregiver network are grandparents and other kinship caregivers who face unique challenges. For one, they express concern that they cannot access the financial and other supports they need, even though those supports are generally available to foster parents performing the same caregiving role as are the grandfamilies. Kinship caregivers also want access to caregiver training, respite care resources, and peer support so they can share strategies with others in similar situations. These caregivers also expressed the need for information and referral to resources about some of the specific and challenging conditions their children may encounter such as attachment disorders, specific types of intellectual and developmental disabilities, difficulties at school, and more. And finally, they expressed the need for legal help and guidance on a wide variety of issues.

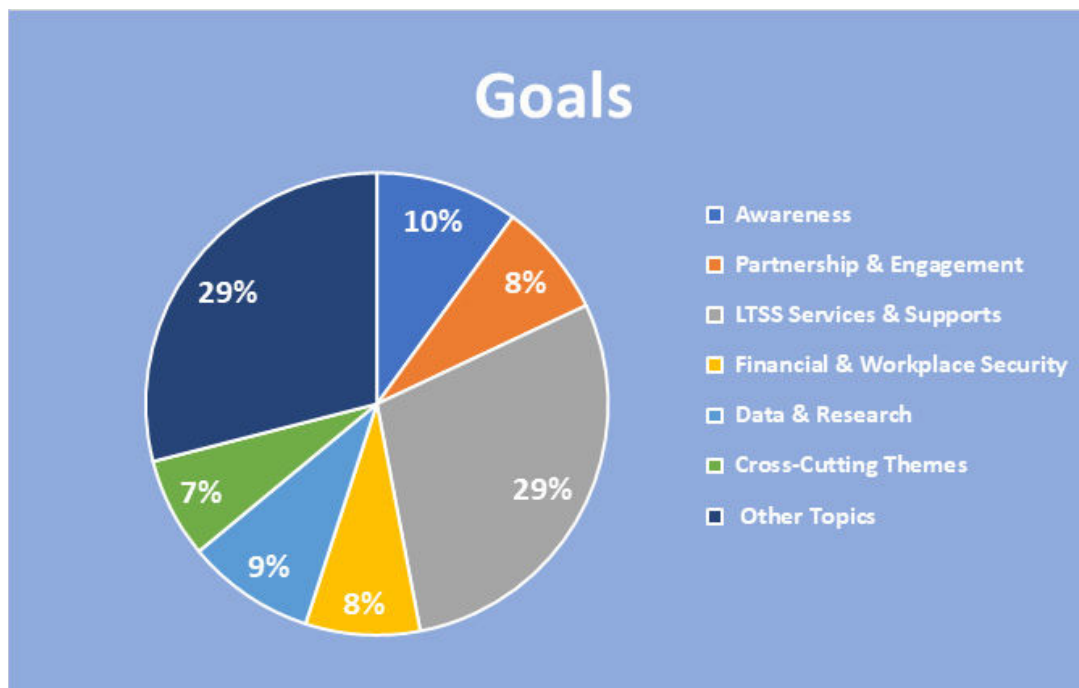
“Ensuring that those of us who provide kinship care have access to the same training and respite resources as foster care families.... We’re thrown into these situations with very little support. You can save costs and streamline the system by just opening certain doors for us.”

What’s Missing?

In addition to soliciting respondent opinions regarding what the Councils should prioritize as they move forward, the Councils also invited public comments to identify topics and issues of critical importance that are missing from the 2022 National Strategy, along with ways that the Strategy could go further on areas addressed by the current draft. Despite its 102 pages, the nearly 350 commitments made by 15 federal agencies to support the family caregivers, and recommendations for states, communities, and other stakeholders, respondents identified several areas that they felt needed more attention.

Input on this question was received from 502 respondents, with many respondents indicating that they had nothing to add. Responses were coded and analyzed using the same methodology used for the “top priority” question. Figure 1 shows the distribution of responses by goal and other categories. The largest response category had to do with Goal 3, LTSS services and supports (29%) and other topics (29%). The next largest (and roughly equal categories) include Goal 1, awareness (10%), Goal 5, data and research (9%), Goal 2, partnerships and engagement, Goal 4, financial and workplace security (8%), and finally cross-cutting themes (7%).

Figure 1: What's Missing from the National Strategy by Category



More specifically, the responses that mapped to Goal 3 identified specifics regarding:

- Direct care workforce
- Respite care
- Caregiver training and support
- Pay for family caregivers
- Diversity, equity, and inclusion
- Financial impacts and financial reform.

In addition, respondents frequently raised the needs of specific populations that they felt needed greater attention in the National Strategy than had been provided. These included:

- Individuals with intellectual and developmental disabilities
- Spousal caregivers
- People with mental illness and their caregivers
- Children with disabilities who age out of the care and services system.

Furthermore, other topics respondents felt were missing included support for research that evaluates the return on investment (ROI) for employed-based caregiver support programs and benefits, and identifying ways to share best practices and progress specific to housing and “right to die” practices.

“Throughout the strategy there is minimal acknowledgment of family caregivers for people with intellectual and developmental disabilities, especially children. These caregiving situations are unique in that they are often the longest, and sometimes the most intense, journeys family caregivers endure with compounding stress and challenges through the years.”

“The Strategy should continue to focus across the lifespan and more explicitly address the unique needs of caregivers of children and young adults with special needs, and adults between the ages of 18-60 with physical and intellectual/developmental disabilities, chronic conditions, and mental illness, and youth caregivers.”

What’s Missing: The Federal and Congressional Role

Several responses identifying missing issues related to federal government actions that were not included in the national strategy. This section describes findings from the analysis of those comments.

Probably the most important topic raised here regarded the need for accountability around the National Strategy and the role the federal government (and, specifically, the ACL) can play in ensuring and tracking its implementation. One approach suggested was to create a federal inter-agency task force for implementation that would include public meetings, progress reports, and perhaps a publicly-available “dashboard” tracking the status of implementation across federal agencies with a commitment on actions toward the National Strategy.

Respondents also noted that, while the strategy is full of suggestions for collaboration, this is “easier said than done.” Some suggested that infrastructure development across federal agencies may be needed to facilitate this, along with identifying a lead agency that could shepherd the caregiver strategy.

Comments specific to the Administration for Community Living (ACL) include the following:

“Revise ACL grant rules (e.g., Dementia Capable, Lifespan Respite) to reduce administrative burdens, extend grant periods and increase ...funding to allow states to hire staff to support grant work and an independent robust evaluation to meet meaningful long-range goals.”

“ACL should influence states or state agencies to create incentives to adopt the recommendations.”

“Guidance from ACL on how states can incorporate elements of the Strategy to align with their plans on aging and other caregiver initiatives, including support establishing public-private family caregiver coalitions, would be appreciated.”

Other federal actions suggested pertain to changes to Medicare, Medicaid, and/or Medicare supplemental coverage. These include changes such as the following:

- Make Home and Community-based Services (HCBS) a mandatory component of Medicaid
- Make “Money Follows the Person” permanent
- Institute other Medicaid changes, by:
 - Streamlining eligibility and spend-down rules
 - Expanding the ability to pay family caregivers.

Respondents suggested that respite care should be included as a mandatory benefit—in some cases as part of the Medicare program and in other cases as part of the Medicaid programs. To better address mental health care needs, increased payment rates within Medicare/Medicaid for mental health services were mentioned.

“We suggest CMS expand the option to pay family members who provide personal care services under section 1905(1)(24) ...Current policy allows states to pay for extraordinary care...but prohibits payment under 1905(a) This creates fractured delivery system and confusion amongst participants and their caregivers.”

“[Medicare should] add a code for caregiver-focused health risk assessment. I have taken my mom to probably 100 doctor appointments and no one ever asked me about my health. If this is supposed to be used, it seems Medicare needs to educate doctors.”

“We ask CMS to provide states with the option to waive estate recovery for LTSS participants, this policy can result in...delaying enrollment in HCBS and place more strain on family.”

The most far-reaching recommendations, however, are those that pertain specifically to caregiver support initiatives that would require Congressional action to put into place. Many of the items included in the Public Comments had also emerged in stakeholder and caregiver conversations during the development of the National Strategy. These include some of the following:

- Establish a federal tax credit for family caregivers
- Implement immigration reform to expand the direct care workforce
- Expand family-friendly benefits for federal employee caregivers (including access to paid leave) so that the federal government can become a model for employers nationally
- Expand funding to support implementation of the National Strategy, including creating federal grants for states to implement national strategy goals including wage increases for direct care workers
- Establish a new Office of Caregiver Health at HHS
- Ensure that tribal entities are eligible for funding under programs supporting older adults and caregivers.

Illustrative quotes include the following:

“Recommendations are only as good as the willingness of the Administration and Congress to implement them. Expecting the states and communities to move forward...without funding from the federal government is foolhardy.”

“While the RAISE Strategy recommends that private sector employers step up and expand their support of employee caregivers, there is no parallel recommendation that the federal government strengthen its commitment to employee caregivers... Providing support to federal employees would reduce their burden...and signal a strong commitment of the federal government to leading efforts on behalf of caregivers.”

“The federal government should make changes to the immigration system so that it is easier for people to come to the U.S. ...to serve as a caregiver for a person with a disability...the changing of visa policies to allow au pairs to serve as caregivers...is mentioned in the narrative...but not in the recommended federal actions.”

“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...which would go a long way to enhance the federal support infrastructure for family caregivers.”

What’s Missing: The State Role

Finally, some of the public comments mentioned actions that states should take on, most notably the following:

- Pay family members as caregivers for their family members as part of the state Medicaid programs
- Adopt the Paid Family Leave and Medical Act, the CARE Act, and Medicaid expansion in states that have not yet done so
- Where the CARE Act has been adopted, improve implementation
- Track state implementation of the National Strategy and share best practices
- Include family caregivers and a wide range of community-based organizations in state planning (and at all levels)
- Improve data collection on caregiver-related services and outcomes.

Conclusion

Overall, respondents expressed enthusiasm for the Strategy, often offering thanks for the efforts made in developing the Strategy and for the opportunity to comment. Many noted that the Strategy touches on an expansive range of key issues. As one respondent said, “The Strategy is comprehensive and much-needed for reshaping the caregiver paradigm.” The strong endorsement by respondents of many Goals and Outcomes identified under the strategy also testifies to the hard work done by the Councils and the extent to which the Strategy resonates with the broader community of caregivers and caregiver-serving organizations. So, too, did respondents endorse the cross-cutting principles of the National Strategy — in particular, the need to incorporate DEIA into all facets of implementation.

These findings not only support the salience of the Strategy, they also provide guidance on how the Councils can focus their work going forward. Although all the Goals and Outcomes described in the Strategy play important roles in advancing the well-being of caregivers — and were endorsed as such by respondents, including some of the components with more indirect impacts, such as the need for data and research — certain issues rose to the top. These include the critical importance of addressing the affordability, quality, and supply of direct care workers; the need for long term services and supports more generally — and caregiver training and support, as well as access to respite more specifically; and mechanisms for mitigating the financial and workplace impacts of caregiving, specifically through expanding paid leave policies, paying family caregivers or offering other financial benefits, and encouraging caregiver-friendly workplaces. The support for improving outreach and awareness around family caregiving was also identified as a priority by many.

In response to the request for perspectives on what is missing from the Strategy, a significant category of responses concerned the need for accountability, with various suggestions about what the Councils can do to ensure that they keep up the momentum in advancing change. Many responses were also targeted to the federal government, with respondents emphasizing its critical role (although a body of responses also highlighted the roles that states can play as well).

Overall, the responses indicate broad support for the National Strategy and provide useful guidance on key priorities moving forward.

Appendix A: Analytic Strategy

The analysis involved two key steps: developing the coding tree and then ensuring that the codes were correctly applied to the content. The researchers first developed coding categories based the goals and outcomes included in the National Strategy. However, some responses did not fit easily into those categories. Furthermore, some sub-topics emerged as significant, requiring new codes to capture their independent importance to respondents. Thus, additional categories were created as patterns emerged in the analysis, suggesting refinements and sub-topics to better classify the respondent comments.

Using a qualitative data analysis software, NVivo, the team of researchers each independently tested and refined the codes based on a subset of 100 responses. In addition, they checked their coding tree against the National Strategy to ensure inclusion of all important topics. They then independently applied these codes to the data, compared their application of the codes, reconciled any differences, and adjusted the codes to obtain the final coding tree. Responses were then hand-coded individually by the researchers working each independently on a set of 200 responses for each of the questions, then switching roles to cross-check the accuracy of the coding.

Appendix B: Project Team

The research team was led by **Pamela Nadash**, PhD, Associate Professor of Gerontology at the University of Massachusetts Boston, and part of the LeadingAge LTSS Center @UMass. Dr. Nadash has a long history of policy-focused research on issues around LTSS, both in the US and internationally. She is an experienced quantitative and qualitative researcher and a skilled focus group moderator, with specific expertise in web-based focus groups.

Eileen J. Tell, MPH, CEO of ET Consulting is the co-principal investigator. Ms. Tell is an LTSS research expert in both qualitative and quantitative research with consumers, family caregivers and LTSS stakeholders. Since 2000, she has been a subcontractor on numerous LTSS projects for U.S. Department of Health and Human Services/ASPE/ACL.

The team also included two graduate research assistants: **Maryssa Pallis** and **Shan Qu** are both PhD students in the Department of Gerontology at the University of Massachusetts Boston.

Marc Cohen, PhD, Co-director of the LeadingAge LTSS Center @UMass Boston and the Research Director of the Center for Consumer Engagement in Health Innovation, provided project oversight and guidance.

Appendix C

Table 3: Data Elements for Comments on the National Strategy

Data element	Response option
Submission ID	Numeric
Please let us know how you are involved in caregiving. Which of the following best describes your role? (Select all that apply.)	<ul style="list-style-type: none"> • A Family Caregiver • An advocate for family caregivers • A researcher on caregiving topics • Employed by an organization that serves family caregivers • Employed by government program that serves family caregivers • Other/chose not to say
Which component of the strategy are you addressing with your comment?	<ul style="list-style-type: none"> • Global comments • Project narrative • Federal actions • Actions for states, communities, and others • First principles
Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward?	Open-ended
Are there issues that are not covered in this component that should be addressed in future updates?	Open-ended
If you have additional comments on any aspect of the Strategy, please provide them below.	Open-ended