

1. 2022 National Strategy to Support Family Caregivers:

https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyToSupportFamilyCaregivers.pdf

Enter Responses Below:

- 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) with spaces**

The Committee on Aging (CONA) of the American Psychological Association appreciates the attention and detailed consideration that the RAISE Act Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren have given to this national strategy. The 3 most important topics/issues to focus on are:

-outreach to individuals, families and communities who are engaged in provision of care but who do not define themselves as “caregivers” or their involvement as “caregiving”

-attention to identifying and disseminating research-supported best practices that are identified as having highest utility for implementation at the community level

-coordination of services across areas of service (e.g., financial support, psychoeducational programs

- Are there issues that are not covered in this component that should be addressed in future updates? **1500 character(s) with spaces**

Acknowledging the unique needs and concerns of kinship networks for LGBTQI+ individuals, along with identifying national public/private partnerships for these communities are entirely missing from this document. At minimum, SAGE and the National Resource Center for LGBT Aging should be included both within this document and as an advisory group.

- If you have additional comments on any aspect of the Strategy, please provide them below. **500 character(s) with spaces**

2. 2022 National Strategy to Support Family Caregivers: Actions for States, Communities, and Others:

https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyFamCaregivers_ActionsSCO.pdf

Enter Responses Below:

- 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) with spaces**

Moving forward, we propose that the Advisory Councils should focus on awareness, accessibility, and dissemination of caregiving research and resources. When addressing societal concerns like caregiving, it is necessary to first identify disparities that exist within the population. Who in the community are underserved, and how can

the proposed actions ensure movement toward culturally sensitive and responsive care and support? When addressing actionable steps, it is also important to acknowledge what systems already exist (e.g., Medicaid) and how realistic, system-based approaches could tangibly support caregivers. In terms of accessibility, we recommend a focus on continuing to broaden the definition of caregiving and focusing on ways to accommodate caregivers. By increasing public awareness of these broader definitions, resources and accommodations can be properly allocated and benefit more caregivers. Lastly, dissemination of caregiving research and resources/support should be a major focus. This may look like improving education/training efforts for caregivers in underserved communities. It may also be helpful to more clearly suggest ways to collaborate with community members and institutions to help improve methodological and dissemination strategies. In caregiving research, it may also be helpful to highlight community-based participatory approaches as well as ethical issues that researchers may have (e.g., appropriate compensation for participants).

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It will benefit the utility and reception of the document to elaborate on the proposed actions for states, communities, and others to take. The document addresses what people, communities, and stakeholders should do, yet there is less of a focus on how people, communities, and stakeholders might implement these actions and why these would benefit caregivers/care receivers. For example, phrases like “create opportunities for collaboration” (p. 15) or “create strong community network” (p. 20) were stated without referencing how to implement these strategies. Moving forward, we recommend providing more concrete, actionable steps for potential stakeholders to take. For example, a helpful addition to the document would be a guide for securing funding or volunteers for relevant efforts. Additionally, it is necessary to recognize that the proposed strategies are not universally applicable or accessible. It is essential to acknowledge the barriers that exist regarding access to resources and to address these barriers within the various sections of the document. We recommend first identifying/recognizing disparities in caregiving (e.g., women, spouses, and racially minoritized caregivers experience the most negative physical and mental health outcomes), and addressing how systems can support at-risk communities and funnel resources in an equitable manner.

- If you have additional comments on any aspect of the Strategy, please provide them below. **500 character(s) with spaces**

We recommend being more intentional with chosen verbiage regarding culture. Using language like “cultural competence” may imply that there is a way to become “competent” in understanding the vastly complex, subjective lived experience of someone based solely on their cultural identity. Rather, using language like “cultural responsiveness” or “cultural sensitivity” may reflect a more accurate aim.

3. First Principles: Cross-Cutting Considerations for Family Caregiver Support:

https://acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyFamCaregivers_FirstPrinciples.pdf

Enter Responses Below:

- 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) with spaces**

The components we identified as the most important include the following:

- 1. Addressing trauma and its impact on families is important as a cross cutting consideration, particularly raising awareness of the impacts of mental health and trauma experienced by caregivers and care recipients. Challenging dementia related behaviors can be exacerbated by trauma. Moreover, the experience of transitioning into a caregiver/care recipient role can be a traumatic experience that is rarely appropriately acknowledged and/or addressed in care settings.*
- 2. Advancing equity, accessibility, and inclusion for family caregivers in underserved communities is important, more specifically being more culturally sensitive in healthcare settings to respond to caregivers and care recipients. Moreover, addressing the health disparities of care recipients will directly influence caregivers.*
- 3. Elevating direct care workers as family caregiving partners by addressing the workforce shortages, including compensation and benefits. Ensuring that direct care workers make a livable wage will improve care and quality and influence the experience of family caregivers.*

- Are there issues that are not covered in this component that should be addressed in future updates? **1500 character(s) with spaces**
 - *The given cross cutting principles should underly every dissemination and action effort, it is a very important document that everyone implementing the strategies should reference; however, it could also stand alone as a resource. As such it would benefit from more information on its purpose, why it is important, and how it can be used. Additionally, more links and references to other resources and sections of the strategy to address “how” to implement strategy and actions are needed.*
 - *This would be a good opportunity to include mental health and trauma and normalize mental health conditions that often arise.*

- If you have additional comments on any aspect of the Strategy, please provide them below. **500 character(s) with spaces**

There is a need to discuss/reference the “how” for these principles as well as considerations on ensuring that the right stakeholders/constituent groups are

considered and/or afforded the opportunity to provide input. For example, a checklist or tool to ensure equity, diversity, and inclusion have been considered in all areas of the work.

4. Global comments for all four components:

Enter Responses Below:

- 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) with spaces**

The components we identified as the most important include the following:

The National Strategy to Support Family Caregivers covers major concerns that caregivers face. Three concerns stand out to focus on moving forward: a) financial needs of caregivers, b) the process of service development and delivery and the need for culturally specific materials, and c) the need for better data. The strategy correctly points out that caregivers make financial sacrifices with regard to work and with regard to expenditures. The need for increased FMLA, and for paid leave is pressing. Delivery of information and services is key to successful intervention for caregivers. This includes publicizing programs, assistance with program enrollment, and program delivery where the caregiver is (often at home with the care recipient). A key component of the National Strategy involves obtaining better information from federal sources to identify the scope of problems. National data (to address prevalence) and smaller studies (to understand specific caregiving processes) may yield information that is necessary to understand the scope of the problems and to generate effective programs.

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It is recommended that the strategy addresses how to help caregivers focus on specific needs given the abundance of resources and information that may be provided to them. The number of resources whether online or in print may be overwhelming and time consuming to caregivers. If resources were able to be broken down via circumstance, it could help families better access those resources needed. For example, resources could be broken down by insurance coverage of the care recipient (private, Medicare, Medicaid), by state, by medical condition (dementia, cancer), by cultural sensitivity, by relationship to the care recipient, etc.

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Caregiving often occurs in a network of caregivers, rather than a sole caregiver. Coordinating the network is a key component of meeting all the caregivers' needs. Many individuals provide care from a distance, sometimes with differing state policies in the two locations. Providing access to programs across state lines is necessary. Caregivers' relationship to the care recipient (e.g., spouse, child) also require policies and programs specific to life stage.

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