



RAISE Act Family Caregiving Advisory Council: Overview of the Full Council Meeting on February 11 – 12, 2020

On February 11 and 12, 2020, members of the Family Caregiving Advisory Council convened for the second time as a full council to establish and refine the goals that will guide the creation of the National Family Caregiving Strategy. This strategy will include recommendations that government, communities, providers, and others are taking and may take to recognize and support family caregivers as required by the Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2018 (the RAISE Act). The Family Caregiving Advisory Council made great progress and unanimously agreed upon principles and goals to drive the creation of the National Family Caregiving Strategy.

Agenda Overview and Summary of Goals

The second convening of the RAISE Act Family Caregiving Advisory Council began with remarks from Lance Robertson, Administrator and Assistant Secretary of Aging at the Administration for Community Living (ACL), who commended the public for the Request for Information (RFI) responses received by the ACL. Assistant Secretary Robertson also reflected on the significant level of support for the council's work at the congressional and executive branch levels, nationally, and internationally; the council's commitment to fulfilling its task while recognizing that a job well done takes time; and the engagement of federal partners in this work.

Using the NAPA Plan as a Model

To assist the Family Caregiving Advisory Council in the development of the National Strategy, Helen Lamont, Ph.D., council member and Long-Term Care Policy Analyst at the U.S. Department of Health and Human Services, presented an overview of the decision-making process used by the National Alzheimer's Project Act Council (the NAPA Council). The 2011 National Alzheimer's Project Act (NAPA), legislation similar to the RAISE Act, directed the U.S. Department of Health and Human Services (HHS) to establish a council to create and maintain a national plan to overcome Alzheimer's disease. As such, the NAPA Council and National Strategy can serve as a model to guide the development of the National Family Caregiving Strategy.

Guiding Principles

Casey Shillam, Ph.D., RN, subcommittee chair, led the council in a discussion about guiding principles to consider in the development of recommendations. The council adopted the following guiding principles, creating a framework to help direct the Council's work going forward as they draft the recommendations and the National Strategy:

- (1) “Family caregiver” is an inclusive and holistic term that includes all who are caring for individuals across the life span with chronic or other health conditions, disabilities, or functional limitations
- (2) Promoting greater adoption of person- and family-centered care puts the person and family at the center of care teams, acknowledging the challenge of possible conflicting goals
- (3) Efforts to support family caregivers should further the autonomy, choice, and ability of caregivers and care recipients to engage meaningfully in their communities
- (4) Recommendations should recognize and support family caregivers in a fair and impartial manner, accounting for financial impact, and that respects and appreciates their complexity, diversity, and dignity
- (5) The national strategy will be a living document with ongoing actions, created in partnership with family caregivers, to be taken by federal, state, and local governments, communities, providers, and others while fostering cross-discipline and cross sector collaboration

Goals

Alan Stevens, Ph.D., subcommittee chair, led a discussion to assist the council in developing primary goals to help shape the council’s recommendations to Congress. The Council adopted the following goals:

- (1) Expand awareness, outreach, education, and access to programs, services, and products to optimize the physical, emotional, and financial well-being of family caregivers and care recipients
- (2) Recognize, include, and support family caregivers as key partners in the provision of health care and long-term services and supports
- (3) Protect, promote, and enhance financial and workplace security of family caregivers
- (4) Promote research, identification, and the adoption of evidence-based practices in caregiver support
- (5) Strengthen program administration, governance, and collaboration among all appropriate stakeholders to build a society that recognizes family caregivers

The council agreed that the wording of the above goals could be modified as they develop recommendations under each goal.

Driver Diagram

Bruce Finke, M.D, council member and Senior Advisor of the Office of Quality for Indian Health Services, led a discussion about the value of Driver Diagrams in developing actionable goals. A Driver Diagram is a visual display of a group’s philosophy on what “drives” or contributes to the fulfillment of a project goal. Nancy Murray, M.S., subcommittee chair, along with Dr. Finke, led a Driver Diagram exercise with the council to start brainstorming possible drivers for each of the goals outlined above.

Next Steps

Through a formal Request for Proposals process, the ACL has been accepting comments from the public on key questions related to the RAISE Act and family caregiving. The public comment period for the RFI closed on February 7, 2020. The Council will use this public input to inform its deliberations and development of recommendations. ACL is also working to develop an online portal to be used by council members to better facilitate collaboration.

The Council's work is being supported through a unique collaboration between The John A. Hartford Foundation, ACL, and the National Academy for State Health Policy (NASHP). With generous support from The John A. Hartford Foundation, NASHP created the [RAISE Family Caregiver Act Resource and Dissemination Center](#). The Center will continue to provide the Council with resources to inform and disseminate its work with state and federal policy makers, diverse stakeholders, and the public.