



The John A. Hartford
Foundation

RAISE Family Caregivers Act Council Meeting Summary

On August 28th and 29th, 2019, members of the RAISE Act Family Caregiving Advisory Council (the Council) convened for the first time to discuss their guiding values, establish their priorities moving forward, and begin their preliminary work supporting the creation of the national family caregiving strategy. The convening of the Council marks a significant first step in the effort to create a set of national recommendations to recognize and support family caregivers and the contributions they make in caring for friends, family, and neighbors across the lifespan.

The RAISE Family Caregivers Act of 2018 (the RAISE Act) directs the Secretary of Health and Human Services to develop a National Family Caregiving Strategy. This strategy will recommend actions that government, communities, providers, and others are taking and may take to recognize and support family caregivers in a manner that reflects their diverse needs, and will include:

- 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.

The RAISE Act also directs the Secretary to establish the Family Caregiving Advisory Council, which is charged in part preparing a report for the Secretary, which will include:

- An assessment and inventory of:
 - All federally funded efforts to recognize and support family caregivers and outcomes of such efforts;
 - Analysis of the extent to which federally funded efforts are reaching family caregivers and gaps in such efforts;
- Recommendations to:
 - Improve and better coordinate Federal programs and activities, including with state programs;
 - Effectively deliver services based on performance, mission, and purpose of a program while avoiding duplication or overlap;
- Identified financial, health, and other challenges faced by family caregivers and existing approaches to address them;
- An evaluation of the impact of family caregiving on Medicare, Medicaid and other Federal programs.

The Secretary will work with the Council to incorporate the Council's report and other relevant information into the National Strategy

To review the agenda for the meeting and the materials provided to Council members, please see *Appendix A*.

Council Members

The RAISE Act requires that the Council be made up of 15 voting members who reflect the diversity of family caregivers and care recipients, with at least one representative from each of the following constituencies:

- Caregivers;
- Older adults with long-term services and supports needs;
- Individuals with disabilities;
- Health care and social service providers;
- Long-term services and supports providers;
- Employers;
- Paraprofessional workers;
- State and local officials;
- Accreditation bodies;
- Veterans.

In addition, the RAISE Act requires that the Council include several non-voting Federal members who represent the Centers for Medicare & Medicaid Services, the Administration for Community Living, and Veterans Affairs, in addition to other relevant federal departments and agencies. For a complete list of both non-federal and federal Council members, and their bios, please refer to the *Appendix B*.

Agenda Overview and Summary of Goals

The inaugural RAISE Act Family Caregiving Advisory Council meeting began with remarks from Lance Robertson, Administrator and Assistant Secretary of Aging at the Administration for Community Living, and Eric Hargan, Deputy Secretary of the Department of Health and Human Services, both of whom emphasized the importance of the Council's work and the significance of federal investments in family caregivers. Throughout the first day, speakers shared results and strategies from advocacy efforts, national research, and state-driven task forces. Common among all presentations were the following threads: the importance of recognizing the diversity of family caregiver and care recipient needs; the need to support the wellbeing of family caregivers and care recipients; and the opportunity to better integrate family caregivers into, and empower them within, the health care system. During the second day of the meeting, Council members received an overview of existing federal programs and initiatives in support of family caregivers, which set the stage for the discussion of subcommittee roles and goals moving forward.

Guiding Values

Council members were asked to share the values that guide them in their work and as Council members. The following represents some of the common themes and core values discussed by the group, creating a framework to help direct the Council's work going forward as they create the report and the National Strategy:

- Prioritize honest communication, appreciation of all ideas, and accessible information;
- Breakdown barriers: foster cross-discipline and cross-sector collaboration;
- Practice excellence, exuberance, and empathy;
- Respect and appreciate the complexity, diversity, and dignity of family caregiving;
- Pursue a holistic, inclusive, and family-centered approach to resolving these issues;
- Gather information, be innovative, and take action.

Priorities

To start exploring and shaping priorities for the Council’s work, members broke into three subcommittees for smaller group discussion. Subcommittees reported out to the full group on their identified priorities, which will be revisited in upcoming subcommittee meetings:

Subcommittee 1: Assist Caregivers in Optimizing Care and Support for their Loved Ones

- Priority #1: Empowerment through resource identification and access
- Priority #2: Incentivize and support workforce development

Subcommittee 2: Enable Caregivers to Provide Care While Maintaining their Health and Well-Being

- Priority #1: Assessment to build a plan of care and support for family caregivers
- Priority #2: Increase and improve capacity to meet family caregiver needs:
 - i. Across the continuum of care/life
 - ii. Short term and long term workforce development and financial consideration
 - iii. Increase availability of resources and services
 - iv. Uptake of evidence-based practices

Subcommittee 3: Enhance Public Awareness, Education, and Engage Non-governmental Entities to Support Caregivers

- Priority #1: Create the Value Proposition for family caregivers for multiple audiences, work to identify gaps
- Priority #2: Identify and engage traditional and non-traditional partners

Next Steps

The RAISE Act was enacted in an effort to recognize and support the contributions family caregivers make to their families and to support family caregivers in this important service. The Council will begin its work by convening monthly subcommittee meetings starting in October, during which members will discuss and develop components of the report, and ultimately, the strategy.

The Council’s work is being supported through a unique collaboration between The John A. Hartford Foundation, the Administration on Community Living (ACL), and the National Academy for State Health Policy (NASHP). With generous support from The John A. Hartford Foundation, NASHP is creating the RAISE Family Caregiver Act Resource and Dissemination Center, which will launch on the NASHP website in October. The progress of the Council, and resources related to its work, will be tracked and shared with

state and federal policy makers, diverse stakeholders, and the public through this central web hub, and through related activities of the project.

Appendix A – Council Resources & Materials

Attach

Appendix B – Council Members and Bios

Attach Suggest linking to the member bios on ACL's web site at www.acl.gov/RAISE as opposed to listing them again here, in case they change we only have to update one place.