



## **RAISE Family Caregiving Advisory Council: January 2021 Meeting Summary**

On January 19, 2021, the RAISE Family Caregiving Advisory Council (FCAC) convened to hear presentations on Medicaid, listening sessions of family caregivers, and a federal inventory of family caregiver information and programs. The council also discussed the process for reviewing its initial Report to Congress.

The meeting began with a recorded video message from the council chair, Lance Robertson, Administrator and Assistant Secretary for Aging at the Administration for Community Living (ACL). Administrator Robertson reflected on the council's progress/accomplishments in 2020 and shared parting words and well-wishes, thanking the council for their commitment, along with the U.S. Department of Health and Human Services (HHS), ACL, and other partners who have supported the council's work. The council also took a moment to share parting words, well-wishes, and gratitude for Administrator Robertson's support and leadership.

### **Medicaid Supports for Family Caregivers Presentation**

Kitty Purington, Senior Program Director at the National Academy for State Health Policy (NASHP), delivered an informative presentation on ways state Medicaid programs could support family caregivers (see full [report](#)). Purington noted family caregivers' role in states conducting rebalancing efforts toward home- and community-based services (HCBS). Examples of HCBS that could support family caregivers include counseling and respite, education and training, care coordination, and reimbursement options that could include family caregivers. Purington noted that policy levers such as state plan options, 1915 (c) waivers, 1115 waivers, and Medicaid managed care presented opportunities to incorporate benefits for beneficiaries that support family caregivers.

Purington highlighted examples of states that had incorporated innovative supports, and noted opportunities at the federal level to support states in implementing family caregiver strategies. Purington concluded by noting potential options to support family caregivers of Medicaid beneficiaries such as partnerships with Area Agencies on Aging (AAA), and other similar organizations that offer training and counseling supports through waivers or managed care organizations; and support infrastructure for caregiver assessment. Purington also explained the importance of developing evidence-based practices to support programs and services, particularly in underserved communities.

## **[Caregiver] Listening Sessions Presentation**

Eileen Tell, CEO of ET Consulting and Fellow at LTSS LeadingAge Center at UMass Boston, presented on the caregiver listening sessions. After receiving caregiver input from ACL's Request for Information (RFI), on behalf of the FCAC Council, Tell worked with NASHP and the University of Massachusetts LTSS LeadingAge Center to conduct a series of 15 virtual listening sessions to gather detailed perspectives from caregivers. Listening sessions included family caregivers of diverse age, race, ethnicity, employment status, and family structure, with additional tailored groups such as Latinx, teen, and grandparent caregivers.

The presentation covered the major areas of inquiry from the listening sessions including:

- Respite
- Adult day care
- Information and referral
- Caregiver training and education
- Care transitions
- Financial wellbeing

The presentation examined how caregivers expressed a strong desire for respite services but were worried about finding quality respite caregivers. The Council also discussed caregiver concerns with referral systems and how they can be changed to earn caregiver trust. The presentation also addressed different preferences for training and education among caregivers, including behavioral and medical training in a hands-on or online setting.

Another area of concern covered in the presentation is caregiver perspectives on different financial supports including:

- Workplace accommodations
- Direct pay
- Tax incentives

Tell also addressed how the COVID-19 pandemic is impacting caregivers, describing both positives and negatives. While many caregivers appreciate additional workplace flexibility and greater availability of family to assist with care, they expressed that isolation, stress, difficulty adapting some therapies to a virtual setting, and other new responsibilities as challenges.

## **Overview & Discussion: Inventory of Federal Programs and Initiatives to Support Family Caregivers**

Greg Link from ACL shared updates on the compilation of an inventory of federal programs and initiatives that could support family caregivers. Information within the inventory is intended to address family caregivers, kinship/grandparent caregivers, and

other stakeholders. The inventory is currently planned to be made available to the public via a webpage in the future, with a high-level overview in the Report to Congress.

### **Initial Report to Congress: Overview of Council Review Process**

Sarah Markel of ACL explained the process for publishing the finalized first draft of the report to Congress. Members of the Family Caregiving Advisory Council will soon have the opportunity to review and provide edits to the first draft and collaboratively discuss changes. Once the report is finalized and passes clearance, the Council will vote on final approval.

### **Closing Remarks**

The meeting concluded with a discussion of the review process for the council's initial Report to Congress, and next steps involving development of the Family Caregiving National Strategy. The council subcommittees will meet in February 2021.