# The RAISE Act: Laying the Foundation for a National Caregiving Strategy Greg Link Administration for Community Living

2020 Home and Community Based Services Conference



Became law: 1/22/18

### **Three Key Elements**

Family Caregiving Advisory Council
 Report to Congress
 National Caregiving Strategy

Current Sunset: 2022

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**Family Caregiver** – "The term 'family caregiver' means an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability or functional limitation"

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The Family Caregiving Advisory Council (FCAC)

"...to advise and provide recommendations, including best practices to the Secretary on recognizing and supporting caregivers"

- The FCAC consists of:
  - Ex-officio federal members
  - Non-federal voting members (up to 15)
- Three subcommittees
  - Goal driven and topic based
  - Monthly meetings focus on Initial Report and National Strategy development
- Reports
  - An initial report;
  - Annual updates

The Initial Report to Congress

- An assessment and inventory of federally funded efforts to recognize and support family caregivers
- Recommendations to:
  - Improve/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/overlap.
- Identification of 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.

\*Deliverable #1

# Family Caregiving Strategy\*

- Developed jointly by Federal agencies and the FCAC;
- Identifies action Federal, state, local, communities, health and LTSS providers and others can take to recognize and support family caregivers (i.e., a *National* strategy);

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- Must be reflective of the diverse needs of family caregivers;
- Submitted to Congress and made available online; and
- Inclusive of the following.....

\*Deliverable #2

The National Caregiving Strategy (cont.)

- Promoting greater adoption of person- and family-centered care across settings
- Assessment and service planning
- Information, education and training supports, referral and care coordination
- Respite options
- Financial security and workplace issues
- Service delivery based on performance, mission and purpose of a program; eliminate redundancies



# RAISE Act Implementation: Progress to Date

#### Full Council Meetings

- Inaugural meeting: August 28 & 29, 2019
- Second meeting: February 11 & 12, 2020
- Third meeting: May 20 & 21, 2020
- Fourth Meeting: July 16, 2020
- Fifth Meeting: August 12, 2020
- Sixth Meeting: November 18, 2020
  - Open to the public, in-person and web-based formats
  - ACL website posts all meeting materials and recordings
- Request for Information (RFI)
  - Issued 12/7/19 (closed 2/7/20) 1,613 responses; 75% from caregivers!
  - Will inform development of the Initial Report, National Strategy and public listening sessions

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- Five Priority Areas
  - Awareness and Outreach for Family caregivers
  - Engagement of Family Caregivers as Partners in Healthcare and Long-Term Services and Supports
  - Services and Supports for Family Caregivers
  - Financial and Workplace Security for Family Caregivers
  - Research, Data and Evidence-Informed Practices
- Recommendations are the foundation for the National Family Caregiving Strategy



Recommendations focus on

- Increase public awareness and recognition of family caregiver needs
- Improving outreach
- Promote expansion of public/private partnerships
- Include family caregivers as essential members of the care team and in all relevant care coordination and transitions

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Recommendations focus on

- Increase the availability of high-quality, setting-appropriate, and caregiver-defined respite services
- Increase the availability of diverse counseling, training, peer support, and education opportunities for family caregivers
- Encourage use of technology, volunteers and volunteerism
- Improve the support of family caregivers during emergencies

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Recommendations focus on

- Increase and strengthen the paid LTSS and direct support workforce.
- Increase the availability, and use of, financial education and planning tools for family caregivers.
- Establish a national infrastructure using standardized data, questions, and a definition of "family caregiver" for obtaining analyzing, and disseminating information about caregivers and their experiences.

# Looking Ahead to 2021: Next Steps

- Complete the Council's Initial Report to Congress
  - Review and clearance
  - Dissemination plan and outreach
- Begin development of the National Family Caregiving Strategy
  - Based on adopted recommendations
  - Informed outreach and public input

# www.ACL.gov/RAISE

- Dedicated webpage for all RAISE Act-related activities and products
  - Read the RAISE Act statute
  - Council meeting information, materials and recordings
  - Progress Report
  - Link to Supporting Grandparents Raising Grandchildren webpage
  - Link to <u>NASHP's RAISE Family Caregiver Resource and</u> <u>Dissemination Center</u>





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Family Caregiving State Policy Academy: Leveraging State Resources to Support Family Caregivers





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RAISE Family Caregiver Resource and Dissemination Center

www.raisefamilycaregiving.org



#### Wendy Fox-Grage, MSG, MPA National Academy for State Health Policy Project Director



- Non-profit, non-partisan organization with offices in Washington, DC and Portland, ME.
- Supported by an Academy of regionally and politically diverse crossagency state leaders.
- Dedicated to working with states across branches and agencies to advance, accelerate, and implement workable policy solutions that address major healthcare issues.



## What is NASHP?

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| Organizational Expertise   | <b>Core Functions</b>  |
|--|--|
| <ul> <li>Medicaid</li> <li>Public Health</li> <li>Children and Families</li> <li>Behavioral Health and Chronic Care</li> <li>Access and Eligibility</li> <li>Cross-sector state innovation and reform</li> </ul> | <ul> <li>Convene state health policy leaders</li> <li>Identify solutions</li> <li>Disseminate innovations</li> <li>Targeted technical assistance,<br/>webinars, briefs, meetings, and<br/>conferences</li> </ul> |



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#### **RAISE Family Caregiver Resource & Dissemination Center**





# Why Family Caregiving?

- Family caregivers play an important role in states' efforts to balance Medicaid LTSS systems
  - Family caregivers help Medicaid agencies deliver care that respects the enrollee's cultural and language preferences.
  - Caregiver support can <u>delay or reduce costly formal health care utilization</u>.
  - The economic value of family caregiving in 2017 was estimated to be <u>\$470 billion</u>, based on about 41 million caregivers providing an average of 16 hours of care per week, at an average value of \$13.81 per hour.
- Strong indicators suggest that family caregivers, and the Medicaid enrollees they care for, could benefit from additional supports
  - State examples:
    - ★ Training and education
    - ★ Counseling
    - Family caregiver benefit



#### **RAISE Family Caregiver Resource & Dissemination Center**

- Contains updates on RAISE Family Caregiving Advisory Council activities;
- <u>Blogs, reports, interactive maps and other resources</u> on family caregiving policy activity, including:
  - × NASHP report on Medicaid supports for family caregivers;
  - × Medicaid COVID-19 Appendix K tracker map;
  - × NASHP webinars on family caregiving featuring state officials
- Convenes <u>Faculty</u> experts to provide insight and expertise to the RAISE Family Caregiving Advisory Council;
- **o 2021: State Policy Academy on Family Caregiving**



State Policy Academy on Family Caregiving: Leveraging State Resources to Support Family Caregivers





## **State Policy Academy on Family Caregiving: Goal**

Through this Academy, NASHP will support state efforts to develop and/or strengthen innovative strategies to increase access to services and supports for family caregivers and the Medicaid beneficiaries for whom they provide care, focusing on home- and community-based approaches for older adult beneficiaries.



## **State Policy Academy on Family Caregiving: Overview**

- <u>Up to 5 state teams</u> will be selected by NASHP to participate in the Academy
- State teams will consist of up to four members led by a state official, including representation from
  - At least two state officials or administrators, such as:
    - ➤ Medicaid officials
    - ★ State Aging and Disability administrators
    - ✗ Legislators
  - May also include key stakeholders, such as:
    - ★ Family caregiver advocates
    - ➤ Community-based organizations
    - ▼ Providers
- State teams will receive 12 months of flexible technical support and \$40,000

Key Academy Dates: January 29, 2021 Applications due to NASHP

**February 15, 2021** Notification of selection to states

March 15, 2021 Academy begins



## Benefits of State Participation





## **Technical Assistance and Resources**

Guided by an analysis of state policy, regulatory, and administrative barriers, states will benefit from both individualized and peer-to-peer learning opportunities, including:

- Development of state-specific family caregiver policy action plans to support key state priorities;
- Individualized technical support from NASHP staff and expert consultation from national, state, and federal leaders;
- \$40,000 in support over the course of the Academy;
- Virtual workshops; and
- Facilitated discussions and webinars open only to Academy teams



# How does my state apply?





# **Application Guidelines**

#### **Required:**

Identify a core team of up to four members and collaborate with core team members to complete the RFA Application Questions

- Core team should identify a **team lead/point of contact** (must be a state official)
- Core team should contain at least **two state officials or administrators**, such as:
  - ★ Medicaid officials
  - State aging and disability administrators
  - Legislators
- Core teams may also include additional state staff or **key stakeholders**, such as:
  - ★ Family caregiver advocates
  - ▼ Employers
  - ★ LTSS providers

#### **Optional:**

Letters of Support



# **Application Guidelines**

All applications will be evaluated based on the extent to which they exhibit the following criteria:

• Specific & measurable policy goals and timeline activities

States' foundational planning for aging and disability policy changes

How Academy resources will be used to make progress on goals

Specific expertise/support that would help in progressing on Academy goals



## **Application Process**

- Assemble core team and complete the RFA Application Questions (available beginning December 15, 2020 at raisefamilycaregiving.org)
- NASHP will host an informational webinar on January 13, 2021 from 3PM-4PM EST
- Send completed applications to Luke Ehlers (lehlers@nashp.org) by 5pm EST on January 29, 2021
- States will be notified of their application status no later than mid-February 2021



For questions or more information, please contact Wendy Fox-Grage (<u>wfgrage@nashp.org</u>)

Access the RFA and Application materials beginning December 15, 2020 at raisefamilycaregiving.org

