

# Family Caregiving Advisory Council Meeting

September 21, 2021



# Call to Order

Alison Barkoff

Acting Administrator and Assistant Secretary for Aging  
Administration for Community Living



# Looking Ahead to National Strategy Development

Greg Link, Director  
Office of Supportive and Caregiver Services  
Administration for Community Living



# Looking Ahead to National Strategy Development: Key Administration Priorities

Jessica L. Schubel

Director of Affordable Care Act and Health Care for the  
White House Domestic Policy Council



# Looking Ahead to National Strategy Development: A Legislative Backdrop

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# Looking Ahead: Legislative Backdrop for the National Strategy

September 21, 2021

RAISE Family Caregiving Advisory Council  
Administration of Community Living  
U.S. Department of Health and Human Services

Briefing From:

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C. Grace Whiting, President/CEO, NAC



# Caregiving Is a Dynamic Experience

*Allen, one of the family caregivers profiled in the new report to Congress, pictured with his wife and daughters in 2020. Photo courtesy of the family.*





A Dynamic, Impactful, Meaningful Strategy



# The Care Paradigm

**Caregivers are Partners & High-Quality Care Providers**

- ❖ VA Comprehensive Assistance for Family Caregivers
- ❖ §1915 Medicaid HCBS Waivers
- ❖ Managed Care (Medicare Advantage, Managed LTSS)
- ❖ Provider incentives, such as CPT billing codes for family support
- ❖ Regulatory guidance on caregiver roles in patient-focused drug development, clinical trials
- ❖ PACE Program
- ❖ Patient advocacy supports through groups like the Alzheimer's Association

**Healthy Families are Core to the Nation's Public Health**

**Caregivers Have Their Own Health and Wellness Needs**

- ❖ Older Americans Act National Family Caregiver Support Program
- ❖ Lifespan Respite Act
- ❖ Home- and Community-Based Caregiver Support Programs
- ❖ Behavioral Risk Factor Surveillance Survey (BRFSS)
- ❖ Workplace accommodations such as paid family medical leave and employee-caregiver programs
- ❖ Legal protections such as the American with Disabilities Act

# What's Next for the National Effort?



1. Awareness and Outreach for Family Caregivers



2. Engagement of Family Caregivers as Partners in Healthcare and LTSS



3. Services and Supports for Family Caregivers



4. Financial and Workplace Security for Family Caregivers



5. Research, Data, and Evidence-Informed Practice

# Awareness and Outreach

Goal 1: Family caregivers' physical, emotional, and financial well-being will improve as a result of expanded awareness, outreach, and education.

Recommendation 1.3 – Improve outreach efforts to family caregivers to ensure identification and access to services and supports.\*

## ✓ Happening Now: Caregiver Assessment in New Models of Healthcare Delivery

- Building on thought-leadership from groups like the Family Caregiver Alliance, managed LTSS providers are beginning to implement caregiver assessment in new models of care delivery to reduce costs.

## ❑ Happening Next: Public Health Infrastructure in Dementia

- The BOLD Infrastructure for Alzheimer's Act is currently implementing a public-health approach to dementia care with a focus on supporting caregivers.

## ❑ Reimagining Care: Caregiving as a Risk Screening Question

- Some have begun to examine the impact of [family caregiver assessment in primary care](#), laying the groundwork for a screening question like how we evaluate risks related to smoking, sexual activity, and diet.
- The U.S. Department of Veterans Affairs has recognized that mental and behavioral supports for caregivers can improve patient and family overall wellness.

\*Family Caregiving Advisory Council, Recommendations (2020), [https://acl.gov/sites/default/files/RAISE\\_SGRG/RAISE%20RECOMMENDATIONS%20FINAL%20WEB.pdf](https://acl.gov/sites/default/files/RAISE_SGRG/RAISE%20RECOMMENDATIONS%20FINAL%20WEB.pdf).

# Recognizing Caregivers as Partners



Goal 2: Family caregivers are recognized, engaged, and supported key partners with providers of healthcare and long-term services and supports.

Recommendation 2.2 – Identify and include family caregivers as essential members and partners in the care recipient’s care team.

## ✓ Happening Now: The State CARE Act Implementation

- Led by AARP, [the state CARE Act](#) now requires the inclusion of caregivers when medically complex patients move from hospital to home in more than 40 localities.

## ❑ Happening Next: Caregiver Roles in Biomedical Innovation

- The Food and Drug Administration requests input on patient and caregiver roles in the current reauthorization of the Prescription Drug User Fee Act.
- The U.S. House Energy & Commerce Committee has identified caregiving as a core pillar to [its 21<sup>st</sup> Century Cures 2.0](#) legislative proposal (Title II, Section 201).

## ❑ Reimaging Care: Reimbursement for Caregiver Inclusion

- Providers rarely receive reimbursement for time spent with the caregiver, but small successes in dementia, oncology offer insight into future reimbursement models.
- Some payers such as [BlueCross BlueShield](#) have also examined claims data to determine the cost of not supporting caregivers within their health systems.

# Income Security for Caregivers

Goal 4: Family caregivers' lifetime financial and employment security is protected and enhanced.

Recommendation 4.2 – Advance the development and broad adoption of employee-centered flexible workplace policies and practices that support work/life balance and maintain performance when personal circumstances change.

- ✓ **Happening Now: Federal Paid Family and Medical Leave**
  - Provisions in the American Families Plan and proposals from Congressional leaders such as the Committee for Ways & Means would offer wage replacement for workers with caregiving responsibilities.
- ❑ **Happening Next: Tax Credits for Caregivers**
  - The bipartisan “Credit for Caring” Act would offset caregiving expenses for caregivers in the workforce and those without paid jobs, boosting income for middle class families.
- ❑ **Reimagining Care: Universal Family Care**
  - Developed by Caring Across Generations, the Universal Family Care proposal would offer families new flexibilities – and recognize the value of care work.

# Family-Centered Support

Goal 3: Family caregivers have access to an array of flexible person- and family-centered programs, supports, goods and services that meet the diverse and dynamic needs of family caregivers and care recipients.\*

New models of care support are emerging to meet the needs of modern families:

- Analyzing existing and generating original research, the [Diverse Elders Coalition's research and training](#) is working to address unmet family caregiving needs in diverse communities.
- Building on new research on youth caregivers, the [Elizabeth Dole Foundation](#) has launched the Hidden Helpers program to better support children and youth with care responsibilities.
- [The Community Care Corps](#), led by national leaders at Caregiver Action Network, USAging, and Altarum Institute, among others, created new state/local infrastructure.
  - In Maryland, for example, the [Caregiver Services Corps](#) allowed volunteer caregivers to provide rapid response to people in need during the COVID-19 pandemic.

\*Family Caregiving Advisory Council, Recommendations (2020), [https://acl.gov/sites/default/files/RAISE\\_SGRG/RAISE%20RECOMMENDATIONS%20FINAL%20WEB.pdf](https://acl.gov/sites/default/files/RAISE_SGRG/RAISE%20RECOMMENDATIONS%20FINAL%20WEB.pdf).

# Research and Data Gathering

Goal 5: Family caregivers are engaged stakeholders in a national research and data gathering infrastructure that documents their experiences, translates evidence into best practices, develops person- and family-centered interventions, and measures progress toward the National Family Caregiver Strategy.

- Public health leaders in the United States are examining how to expand the [Behavioral Risk Factor Surveillance Survey](#) and other data collection tools to better understand caregiving need.
- Federal centers that fund caregiving research, such as the [National Institute of Nursing Research](#), have identified that additional research is needed on family caregiving.
- Global leaders through Embracing Carers and the International Alliance of Carer Organizations are working to centralize data on family caregivers around the world:
  - IACO's [Global State of Care Report](#) profiles caregiving best practices in France, Australia, Canada, Germany, India, Italy, Spain, the United Kingdom and the United States.
  - Community efforts are moving forward to estimate the worldwide prevalence of caregiving to support a Global Action Plan for Carers and build partnerships with the United Nations and the World Health Organization.

# A More Efficient System

*Sec. 3(b) -- **The Strategy shall** identify recommended actions that Federal (under existing Federal programs), State, and local governments, communities, health care providers, long-term services and supports providers, and others are taking, or may take, to recognize and support family caregivers in a manner that reflects their diverse needs, including with respect to the following...*

*(6) Delivering services based on the performance, mission, and purpose of a program while eliminating redundancies.*

*Might look like*

- ✓ Continuation of the RAISE Family Caregiving Advisory Council past the current sunset date, with expanded representation from federal agencies and centers, such as:
  - National Institutes of Health – National Institute of Aging, National Institute of Nursing Research, and others
  - Food and Drug Administration – Center for Drug Evaluation & Research, Center for Devices & Radiological Health, and others
  - Social Security Administration
- ✓ [www.caregiving.gov](http://www.caregiving.gov)
  - A centralized clearinghouse of resources and information for caregivers and those who support them



# Thank You for Your Leadership!

 [www.caregiving.org](http://www.caregiving.org)

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# DISCUSSION

# Closing Remarks and Adjourn

Alison Barkoff

Acting Administrator and Assistant Secretary for Aging  
Administration for Community Living



Thank you

