

# Family Caregiver Advocacy

November 16, 2022



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# Agenda



- Who Are Family Caregivers
- Federal Legislation to Support Family Caregivers
- Family Caregiver Issues
- Uplifting Caregiver Voices
- Q&A

# **Who Are Family Caregivers?**

# Family Caregiver Facts



- In 2019, at least 53 million people were providing informal, usually unpaid, care and support to aging family members and people of all ages with disabilities
- Lost income due to family caregiving is estimated to be \$522 billion each year
- Impact of COVID-19 pandemic increased momentum of caregiving as a public health issue



# Faces of RAISE

## #RAISEcaregiving

# **Federal Legislation to Support Family Caregivers**

# Federal Programming for Caregivers



- The [National Family Caregiver Support Program](#) funds a variety of supports that help family and informal caregivers care for older adults in their homes for as long as possible
- The [Lifespan Respite Care Program](#) works to improve the delivery and quality of respite services for caregivers of older adults and people with disabilities

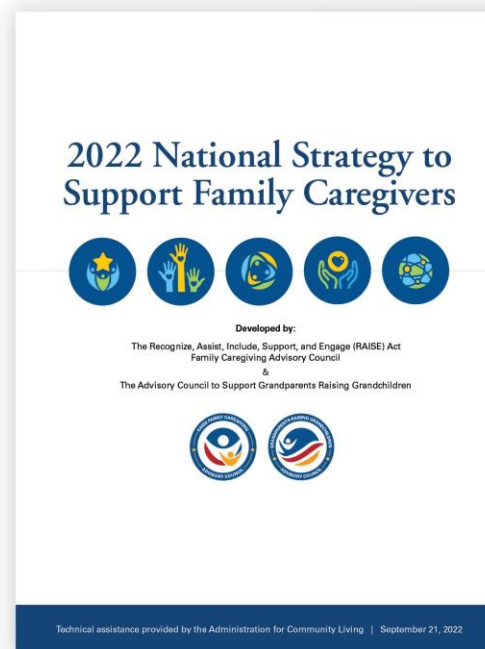
# Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act



## 2022 National Strategy to Support Family Caregivers

**Materials now  
available!**

[acl.gov/CaregiverStrategy](https://acl.gov/CaregiverStrategy)





# Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act



**GOAL 1** Increase awareness and outreach

**GOAL 2** Build partnerships and engagement with family caregivers

**GOAL 3** Strengthen services and supports

**GOAL 4** Ensure financial and workplace security

**GOAL 5** Expand data, research, and evidence-based practices

# RAISE Process



- The [RAISE Family Caregivers Act](#), which became law on Jan. 22, 2018, directs the Secretary of Health and Human Services to develop a national family caregiving strategy.
  - Appropriations started at around \$100k and has increased to \$400k
- The RAISE Family Caregiver [Resource and Dissemination Center](#)
  - RAISE Faculty has been guiding the process behind the scenes
- **Sunset Extension**
  - Older Americans Act provision extended RAISE authority 1 year
- **Public Meetings**
  - November 18, 2020, to bring the caregivers voice into the process
    - Listening sessions and [video vignettes](#)
  - September 21, 2021, to share our vision for the National Strategy

# RAISE National Strategy



On September 21, 2022, the **2022 National Strategy to Support Family Caregivers** was delivered to Congress.

- [2022 National Strategy to Support Family Caregivers](#) - An overview and description of the strategy's goals and intended outcomes
- [First Principles: Cross-Cutting Considerations for Family Caregiver Support](#) - Describes the four key principles that must be reflected in all efforts to improve support to family caregivers
- [Federal Actions](#) - Nearly 350 actions that 15 federal agencies will take in the near term to begin to implement the strategy.
- [Actions for States, Communities, and Others](#) - More than 150 actions others can take.

# Implementing the RAISE Act



- Public comment period ending November 30th
- State and local engagement on priority actions
- Publicizing the RAISE Act

# Family Caregiver Issues

# Awareness and Outreach



- Caregiving as a public health issue
- Empowering caregivers to identify the important role they play so that they can receive supports if they need them
- Need for accessible, linguistically and culturally competent communications and awareness campaigns

# Engagement



- Health systems and other institutions (legal systems, education, etc.) do not value or engage with family caregivers
- COVID-19 pandemic exacerbated this issue
- Need to fully integrate family caregivers in the care process

# Access to Services and Supports



- Education and training
- Respite care, counseling and peer support
- Trauma-informed and culturally appropriate services
- Increased funding for existing programs (Medicaid, ACL's National Family Caregiver Support Program, Lifespan Respite Program, Alzheimer's Disease Programs Initiative)



# Financial/Workplace Support



- Paid family caregiving and tax credits
- Paid leave and sick time for caregiving
- Caregiver-friendly workplaces
- Financial assistance with out-of-pocket costs

# **Uplifting Family Caregiver Voices**

# Reaching Underengaged Communities



- By 2030, nearly 3 in 10 older Americans will identify as a member of at least one diverse or underrepresented group
- Due to systemic racism, implicit bias, and other structural factors, caregivers in these groups do not receive appropriate and sufficient supports
- Must recognize and respond to the intersectional identities of caregivers

# Caregiver Identification



- Many caregivers don't identify as such
- Some cultures do not have terms for people who provide informal support to others
- Describe caregiving in terms of tasks, not title to be inclusive as possible

# Changing the Care Conversation Project



- Build the coalition and grassroots power of a diverse group of family caregivers to advance state and federal policy solutions that improve support for family caregivers
- Provide training, technical assistance and an online learning community as well as funding so organizations can participate in these activities
- Focus will be on building strategies/skills for moving policy change and on building policy expertise

# Including the Caregiver Perspective in Existing Advocacy



- Include family caregivers as a stakeholder group
- Identify family caregivers who are already part of your advocacy
- Follow the work of local, state, and national caregiver advocacy groups
  - Engage with local groups that support caregivers
  - Most states have a state caregiver coalition



# National Organizations



# Discussion & Questions



# **THANK YOU**

**For more information:**

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