Respite Presentation

for the RAISE Family Caregiving Advisory Council

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Family Caregiving is Lifespan!

Majority of family caregivers caring for an adult care for someone ages 18-75 (54%).

- 20% of family caregivers care for someone ages 65-74;
- 20% care for someone ages 50-64;
- 14% care for someone ages 18-49.

Nearly 14 million children have special health care needs.

Respite

Benefits
Access
Barriers
Strategies
Respite is...

Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

*Lifespan Respite Care Act definition*

*PL 109-442*
Types of Respite

- In-home respite
  - Consumer-directed
  - Home care agencies
  - Volunteer programs

- Out-of-home respite
  - Adult day care or child care centers
  - Facility-based (hospital, nursing homes, assisted living)
  - Community or faith-based
  - Provider’s or other family’s home
Respite may help --

- Improve family caregiver stress levels, which in turn, benefits caregiver physical and emotional health
- Improve overall family well-being, family relationships and stability
- Reduce social isolation
- Reduce hospital costs and avoid or delay more costly foster care, nursing home or other out-of-home placements
- Give care recipient a break, too!
Respite: Too Little, Too Late

- Just 14 percent of family caregivers report having used respite, though 38 percent feel it would be helpful (2020 Caregiving in the US, NAC/AARP).
- Of those who do, they often receive too little, too late.
Respite Barriers

- Limited government funding
- Cost
- Shortage of qualified providers
- Limited respite options, appropriate or preferred services
- Reluctance to use respite, ask for help, or self-identify as caregiver
- Access issues
  - Transportation
  - Multiple funding streams with confusing and restrictive eligibility
  - Lack of information
Paying for respite

- Medicaid Waivers
- Medicare Advantage Plans
- Family Caregiver Support Program
- Veterans Programs
- Lifespan Respite
- State Funded Respite Programs
- Disability or Aging organizations
- Self-pay or long-term care insurance
Proposed Strategies
Lifespan Respite ... a system of services

*Lifespan Respite Definition:*

Coordinated **SYSTEMS** of accessible, community-based respite services for all family caregivers regardless of age or special need.
Federal Lifespan Respite Care Program

U.S. Administration for Community Living administers competitive state grants for required uses of funds:

- Development or enhancement of State and local Lifespan Respite systems
- Planned or emergency respite for all ages
- Training and recruitment of providers/volunteers
- Provision of information to caregivers about respite services, and assistance in gaining access
Lifespan Respite Grant Activities

- Statewide Respite Registries
- Connecting families to respite
- Volunteer and Faith-based Respite
- Promoting Informal Respite Opportunities
- Consumer-directed Respite Voucher Programs
## Proposed Public Sector National Strategies for Expanding Respite Options

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<thead>
<tr>
<th>Consider</th>
<th>Consider Lifespan Respite approach as a state model</th>
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<tr>
<td>Make</td>
<td>Make permanent flexibilities currently approved for HCBS Medicaid Waivers granted to states under COVID-19</td>
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<td>Ensure</td>
<td>Ensure respite is retained as a benefit in MLTSS</td>
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<td>Add</td>
<td>Add respite as a benefit in traditional fee-for-service Medicare</td>
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<tr>
<td>Expand</td>
<td>Expand Medicare/Medicaid Hospice benefits to alternative settings</td>
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# Proposed Public-Private Partnerships for Expanding Respite Options

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<th>Address</th>
<th>Address the Respite provider shortage through innovative recruitment and expanded training opportunities</th>
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<td>Provide</td>
<td>Provide incentives to private insurance to include respite as a benefit</td>
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<td>Support</td>
<td>Support business roundtables to encourage employer support for respite</td>
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<td>Encourage</td>
<td>Encourage the expansion of an evidence-base for respite</td>
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For More Information

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