

# 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.

*Sources: Caregiving in the U.S. 2020. National Alliance for Caregiving and AARP Public Policy Institute; and US Health Resources and Services Administration, The 2017-18 National Survey of Children's Health.*

# Respite



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Benefits

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Access

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Barriers

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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

Consider	Consider Lifespan Respite approach as a state model
Make	Make permanent flexibilities currently approved for HCBS Medicaid Waivers granted to states under COVID-19
Ensure	Ensure respite is retained as a benefit in MLTSS
Add	Add respite as a benefit in traditional fee-for-service Medicare
Expand	Expand Medicare/Medicaid Hospice benefits to alternative settings

# Proposed Public-Private Partnerships for Expanding Respite Options

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

# For More Information



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## Lifespan Respite Technical Assistance Center



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