Interim Study
Oklahoma’s Caregiving and Respite Care Programs
October 9, 2018
Committee: IS H18-011
Branch: House
Subject: COMBINED Oklahoma's caregiving and respite care programs

Description: Improving care and patient outcomes by exploring gaps and opportunities for efficiency gains in Oklahoma's caregiving and respite care programs. This study will look at existing caregiving and respite care programs and explore possible improvements to increase outcomes and streamline processes. There are many programs across the state and many hoops to jump through to access them. We can begin the process of working towards a more coordinated system, including respite care for caregivers.
AGENDA

Welcome and Overview of Oklahoma Caregiving
Rep Carol Bush
Rep Regina Goodwin

Community Viewpoints Of Respite Services

• Families of children with special needs
  Caregiver Perspective
  Aietah Stephens, Sooner SUCCESS
• Families of the senior population with special needs
  Caregiver Perspective
  Carol Carter, LIFE Senior Services
• Grandparents and other Relatives Raising Children
  Caregiver Perspective
  Ken Jones, OK Association of Area Agencies on Aging (O4A)

Conclusion
Chad Mullen, AARP Oklahoma

• Oklahoma Caregiver Needs Assessment Survey
• Benefits of caregiving and respite as an alternative to costly institutionalization
• Policy suggestions to balance caregiving and respite resources in Oklahoma

Questions
RESpite: Caring for the Caregiver
Who Is A Caregiver?

For our purposes, a caregiver is defined as an unpaid individual who provides ongoing care for someone with a chronic health condition or a disability.

- Spouse/Partner
- Friend/Neighbor
- Sibling
- Child caring for parent
- Parent of a child with special needs
- Grandparent or other relative raising a child
What is Respite?

• A much-needed, temporary break from the often exhausting challenges faced by family caregivers.

• Respite takes place when a caregiver has another person to temporarily care for their loved one.

• Respite can take many forms, from going away on a weekend, to having someone in their home for a few hours, or utilizing a day or evening program.
Benefits of Respite

- Improves family caregiver physical and emotional health
- Improves overall family well-being and stability
- Improves marriages, sibling, and other family relationships
- Reduces hospital costs and helps avoid or delay more costly foster care, nursing home, or other out-of-home placements
- Gives care recipient a break
Oklahoma Statewide Caregiver Respite Programs
Supporting Caregivers
Raising a Child with Special Needs

Aietah Stephens, MS
Executive Director, Sooner SUCCESS
Families

- often need multiple services from multiple providers
- are overwhelmed and are frequently the only “coordinator” of their child’s numerous services
- have difficulty locating needed services in their community
- must travel to several agencies while struggling with unreliable transportation, child care, illness and other challenges
Providers & Services

- managed independently through different sets of eligibility criteria
- often do not have the time or the experience to help families connect with other community resources
- are fragmented because the population is fragmented
- lack of comprehensive system fosters this fragmentation, issue specific approach

Achieving Success for All Children and Youth with Special Health Care Needs: A 10-Year Action Plan to Accompany Health People 2010” (2001)
Caring for Older Adults

October 9, 2018 – Caregiving Interim Study
Presented by Carol Carter, LIFE Senior Services
5950 East 31st St. Tulsa, OK 918-664-9000
Caring for Older Adults

• Caregiving often begins subtly, without notice.
• It intensifies as the care recipient’s needs increase.
• Caregiving often becomes all-consuming with disease progression, cognitive issues or Alzheimer’s disease.
Common Types of Caregivers

- Spousal and 24/7 caregivers
- Adult Children
- Working Caregivers
- Each have their own unique challenges.
- All could benefit from respite on a regular basis.
The Perils of Caregiving

• Significantly higher levels of depression, often with co-existing anxiety disorders, chronic disease and substance dependence or abuse.

• Chronic conditions at twice the rate as non-caregivers.

• High levels of stress, frustration, guilt, anger and exhaustion

• Lower levels of self-care. Lack of time and energy to exercise or prepare healthy meals. 72% don’t go to the doctor as needed.
The Perils of Caregiving

- Increased risk of heart disease
- Caregivers of loved ones with dementia experience compromised immune systems for three years after their caregiving ends.
- Increased mortality. 30% pass before the one they are caring for.
Respite is Vital

- Respite is vital. It helps caregivers better balance their lives and improves their physical and emotional health. Respite enables caregivers go to the doctor, have lunch with friends, enjoy a hobby or even just rest.

- Respite on a regular basis strengthens caregivers for the long run; helping them care for loved ones at home longer, and delaying or even avoiding the need for nursing homes altogether.
Types of Respite

• Companion care provides companionship and a watchful eye by an unlicensed individual. This can be through an agency or even a friend or family member who does not live in the home.

• A Personal Care Aide is a licensed CNA who can provide companionship as well as help with Activities of Daily Living like bathing, dressing and transferring. PCAs must be hired through an agency.
Types of Respite

• The Navigators is an outlet for individuals in the earlier stages of dementia. The group offers respite for the caregiver and friendships, support, and activities for the care recipient.

• Respite volunteers through the Alzheimer’s Association are trained and then matched with a family. They provide companionship respite once weekly for 2-4 hours.
Types of Respite

• Adult Day Health offers respite while the care recipient enjoys new friends, activities, music, movement and laughter. Medication management, meals and nursing oversight are also provided.

• ADH also offers auxiliary services for participants that simplify life for the caregiver – assisted showers, personal care, foot care, special therapies, hair salon, etc.
HCBS Saves the State $$$

- By investing in respite for family caregivers on the front end, nursing home care can be delayed or maybe even avoided entirely.

- Offering respite and long term care through Home and Community-Based Services is significantly less expensive than nursing home care. The State can care for three people in their homes with HCBS for the same cost as just one person in a nursing home.
Expanding Use of HCBS

• Telling families about HCBS respite options is essential.

• Training social workers, discharge planners, and care managers to educate families about HCBS when nursing home care is being considered as a care option.

• DHS and OHCA workers could also help educate families when they are applying for Medicaid.

• This would also decrease the number of people being placed prematurely into nursing homes.
Grandparents and Other Relatives Raising Children

Ken Jones
ASCOG Area Agency on Aging Director
OK Association of Area Agencies on Aging Representative (O4A)
Grandparents and Other Relatives Raising Children (GRRC)

According to U.S. 2010 Census:

• Over 100,000 OK children live with grandparents or other relative adults as head of household

• 43,215 grandparents are responsible for raising their grandchildren

• 20% live in poverty
Grandparents and Other Relatives Raising Children (GRRC)

Additional information:

• The Older Americans Act (OAA) limits federal funding to 10% of caregiver services

• Two-thirds of GRRC are ineligible for OAA services
Grandparents and Other Relatives Raising Children (GRRC)

Additional information:

• Most of the time, the grandparents are the last available caregiver before the child ends up in State Child Welfare custody.

• The Lifespan Respite Grant is a valuable resource for those who are not eligible for OAA services or due to lack of funding.
SUPPORTING UNPAID FAMILY CAREGIVERS

Our Unsung Heroes

Chad Mullen
Associate State Director, Advocacy and Outreach
AARP Oklahoma

October 9, 2018
Lifespan Respite Survey – Top Findings

1. 52% of caregivers receive no services

2. 40% of caregivers would only use services “occasionally”

3. 34% of caregivers currently utilize respite care, while 57% wish they had it

4. 20% report needing home modifications
Lifespan Respite Survey – Top Findings

Which, if any, of the following problems are you experiencing due to your caregiver role?

- Feeling overwhelmed: 58%
- Loss of free time: 58%
- Exhaustion: 50%
- Loss of enjoyable activities: 40%
- Strained family relationships: 38%
- Depression: 35%
- Anxiety about aging: 32%
- Decline in physical health: 31%
- Loss of income: 30%
- Neglect of self and/or others: 30%
- Less marital closeness: 28%
- Sleep disorders: 28%
- Guilt, anger, resentment and/or denial: 26%
- Loss of friendships: 25%
- Work absenteeism and/or job loss: 18%
- More negative attitude toward the person you provide care for: 10%
- None: 10%
- Abuse of self and/or others: 1%

n=120
AARP Oklahoma Caregiver Profile

1. 524,000 unpaid family caregivers, ~25% are millennials

2. Provide 488 million hours of unpaid care annually

3. Valued at $6 billion

4. 26% of Oklahoma caregivers are caring for a parent and a child

5. 54% of Oklahoma caregivers are employed

6. 60% of Oklahoma caregivers use their own money to provide care
Caregiving is Stressful

Stressors Caregivers Face

- Felt stressed out emotionally due to your caregiving responsibilities: 67%
- Felt stressed out in trying to balance your job and family*: 63%
- Found it difficult to get enough rest: 57%
- Found it difficult to exercise regularly: 49%
- Found it difficult to take care of your household responsibilities: 43%
  - Found it difficult to maintain a healthy diet: 36%
  - Experienced problems with your health: 33%
- Felt strained financially due to your caregiving responsibilities: 33%
- Found it difficult to find time to visit your doctor: 25%

Source: 2017 AARP Oklahoma Caregiving Study
Respite Care Among Most Helpful

Helpfulness of Caregiver Services and Resources*
(n=845, Respondents who are Current, Former and Future Caregivers)

- Information about caregiver resources: 88% Very/Somewhat helpful, 12% Not helpful/Don't know
- Respite care: 85% Very/Somewhat helpful, 15% Not helpful/Don't know
- Assistance with chores: 78% Very/Somewhat helpful, 22% Not helpful/Don't know
- Assistance with transportation to medical appointments: 78% Very/Somewhat helpful, 22% Not helpful/Don't know
- Assistance with transportation: 77% Very/Somewhat helpful, 24% Not helpful/Don't know
- Assistance with meals: 74% Very/Somewhat helpful, 26% Not helpful/Don't know
- Assistance with managing medications: 72% Very/Somewhat helpful, 28% Not helpful/Don't know
- Connecting with other caregivers: 72% Very/Somewhat helpful, 28% Not helpful/Don't know
- Time off from work for caregiving tasks: 70% Very/Somewhat helpful, 30% Not helpful/Don't know

*Percentages may not add up to 100 percent due to rounding.

Source: 2015 AARP National Caregiving Survey of Registered Voters Age 40 and Older
Policy Recommendations to Improve Support for Family Caregivers, Lower Costs, and Improve Care

1. Streamline access to respite care and other caregiving services
   1. Explore a software solution
   2. Public/Private partnerships to create single contact point/center
   3. Better equip social workers and case managers

2. Better utilize home and community based services
   1. Expand availability of adult day services
   2. Implement presumptive eligibility
   3. Explore creative paid family leave solutions
Small Changes...Big Savings

1. Medicaid Reimbursement rate per person for a nursing home is $54,750 annually with a request by the industry to move that to $60,225

2. Average annual respite care expense is $1,400 per person

3. A $950,000 investment in caregiver support would be substantial

4. Improving balance in HCBS and Long Term Care by just 10% (1,500 patients) would save:
   1. $33 million annually if using home healthcare
   2. $58 million annually if using adult day services