State Respite Legislation: Advancing Respite for Family Caregivers

ARCH Sustainability Learning Collaborative Webinar
November 12, 2019
International Short Break (Respite) Conference

Conference Details
• June 16-18, 2020 at Monona Terrace, Madison, WI
• Register at www.isba.me/registration
• Conference Website: www.isba.me

ARCH Respite Research Summit
• June 19, 2020, Monona Terrace
• Register at www.isba.me/registration
• More information at archrespite.org/respite-research#Summit

Lifespan Respite Grantee and Partner Learning Symposium
By invitation only for Lifespan Respite grantees and partners
• June 16, 2020
• More information and registration coming soon!
Resources: State Lifespan Respite Legislation and Opportunities for Funding

• Copies of State Legislation at
  lifespanrespite.wildapricot.org/State-Lifespan-Respite-Legislation

• Lifespan Respite Teleconference on State Funded Respite
  *Looking Beyond Federal Funding, Examples of State Funding for Respite*
  Recording and Resources available at
  lifespanrespite.wildapricot.org/confcalls#StateFunding

• Contact List for States with State Funding Support for Lifespan Respite Activities
Presenters

Jon Bartholomew
Senior Legislative Representative
State Advocacy and Strategy Integration (SASI)
AARP Government Affairs

Kathy Mayfield-Smith
President and Co-Founder
South Carolina Respite Coalition
CAREGIVER RESPITE ADVOCACY IN THE STATES

Jon Bartholomew
Senior Legislative Representative, SASI
AARP Government Affairs
# AARP State Caregiving Advocacy

<table>
<thead>
<tr>
<th>Section</th>
<th>Topics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Support and Education</td>
<td>CARE Act, CARE Act Implementation</td>
</tr>
<tr>
<td>Workplace Flexibility</td>
<td>Paid and Unpaid Leave, FMLA expansion, WORC, ELECT, Paid Sick Leave</td>
</tr>
<tr>
<td>Expanded Options for Care</td>
<td>Telehealth, APRN Scope of Practice, Nurse Delegation, Registries</td>
</tr>
<tr>
<td>Home and Community Based Services (HCBS)</td>
<td>MLTSS, Quality across settings, Antipsychotics, Improve/protect program/funding, Navigation</td>
</tr>
<tr>
<td>Financial and Legal Solutions</td>
<td>Guardianship, Caregiver Tax Credit, WINGS, Uniform Power of Attorney Act</td>
</tr>
</tbody>
</table>
Older Population Growth in the U.S.

Projected Population Growth by Age Group, 2015–2050

Source: Across the states: Profiles of long-term services and supports (2018)
AARP Public Policy Institute
Majority of Older People Will Need LTSS

Projected Lifetime LTSS Need for Persons Turning 65 in 2015, by Duration of Need

Family Caregivers: The Backbone of the LTSS System

Distribution of Older Adults (65+) Receiving LTSS in the Community, by Type of Care

- 66% Family Caregiving Only
- 26% Family & Formal Care
- 9% Formal HCBS Only

Family Caregiving in the U.S.

Valuing the Invaluable: Putting a Dollar Value to Family Caregiving

In 2013, about 40 million family caregivers in the United States provided an estimated 37 billion hours of care. The estimated value of their unpaid service was approximately $470 billion.

AARP Public Policy Institute
Caregiver Support Ratio

Source: The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers (2013), AARP Public Policy Institute
Caregiver Stress is Real

Experience of Alaska Caregivers Age 45-Plus
(n=397, Respondents Who Are Current or Past Caregivers)

- Stressed emotionally due to caregiving: 63%
- Stressed in trying to balance work and family: 55%
- Found it difficult to get enough rest: 50%
- Found it difficult to take care of household: 43%
- Found it difficult to exercise regularly: 42%
- Felt financially strained: 30%
- Experienced health problems: 29%
- Found it difficult to keep a healthy diet: 28%
- Found it difficult to visit the doctor: 25%

*Graph shows respondents who responded "yes" to each type of stressor.

Source: 2015 AARP Survey of Alaska Registered Voters Age 45 and Older on Caregiving
Respite Care Among Most Helpful

Source: 2015 AARP National Caregiving Survey of Registered Voters Age 40 and Older
A Respite Waiver Concept - RELIEF

• RELIEF (Respite: Living Independently, Energizing Families)
  – Extend Medicaid eligibility for a targeted set of respite and care coordination for family caregivers
  – Eligibility up to 400% of poverty (64% of the U.S. have incomes under this level)
  – States with state-funded programs could use that as match
  – States could use a sliding fee scale so that families could “buy-in” to services
  – Some elements of this proposal already approved in Washington state
RELIEF in Your State

• RELIEF could help divert those “at risk” of institutionalization from eventually needing full Medicaid benefits, and help the state get federal matching funds for state-funded respite and HCBS programs already in use.
RELIEF in Oregon
RELIEF in Oregon

Oregon Caregiver Respite Workgroup

• Formed after Respite Summit in April 2016
• Stakeholders from private, public, nonprofit sectors, including caregivers
• Reviewed research and literature
RELIEF in Oregon

Oregon Caregiver Respite Workgroup

• Held 14 community meetings around Oregon in June/July 2016
RELIEF in Oregon

Oregon Caregiver Respite Workgroup

- Report published in November 2016
  - action.aarp.org/oregonrespite
- Passed HJM 4 which honors family caregivers, says the legislature will consider the work of the Workgroup, and urged Congress to pass the RAISE Family Caregivers Act
RELIEF in Oregon

Work Group Recommendations

• Education and Awareness
  • Public awareness campaign about caregiving, value of getting breaks, and how to find respite. Need to use different terminology.
  • Work with trusted messengers like medical providers to provide information about why to use respite and where to get it.
  • Work to encourage veterans to apply for benefits
  • Improve data collection and analysis about respite
RELIEF in Oregon

Work Group Recommendations

• Increasing the supply of providers
  • Revisit Adult Day Center rules
  • Continue work on workforce development of home care workers
  • Explore the creation of a new overnight model
  • Explore streamlining process for overnight stays in LTC settings while preserving protections
RELIEF in Oregon

Work Group Recommendations

• Increasing the supply of providers (cont.)
  • Explore colleges in underserved areas setting up programs, or collaborating with community partners
  • Explore hospitals/CCOs developing programs or collaborating with community partners
  • Explore using public funds for alternative models of respite, such as mobile programs, camps, etc.
  • Provide funding for volunteer programs like Senior Companions
RELIEF in Oregon

Work Group Recommendations

• Make respite more affordable
  • Expand funding for Family Caregiver Support Program and Oregon Project Independence considerably *(protected funding)*
  • *Explore a Medicaid 1115 waiver that would allow Oregon to provide respite to up to 400% of poverty level*
  • Encourage employers to provide caregiver supports
  • Create funding specific to “emergency respite” and establish protocols for making it available
RELIEF in Oregon

RELIEF Legislation - 2019

- Oregon DHS submitted a “Policy Option Package” to be part of the Governor’s recommended budget for 2019-21 biennium based on RELIEF model
- Did not make it into the budget
- AARP partnered with Alzheimer’s Association to promote a “budget note” directing DHS to craft the RELIEF waiver
- Ways and Means co-chairs said we needed a bill
RELIEF in Oregon

RELIEF Legislation

• Found a bill sponsor, and introduced SB 1035
  – https://olis.leg.state.or.us/liz/2019R1/Measures/Overview/SB1035
• After successful policy committee hearing, bill sat in Ways and Means committee
• At the end of the session, the Ways and Means co-chairs turned the language into a budget note in the DHS budget bill
RELIEF in Oregon

RELIEF Legislation

• DHS has been meeting with stakeholders, using SB 1035 as a guide to craft the waiver
• Formal advisory group to convene in December
• Waiver proposal to be finalized by end of December
• To be submitted to CMS for approval early in 2020
Jon Bartholomew
AARP Government Affairs

jbartholomew@aarp.org

@JonB_AARP
State Legislative Advocacy SC Respite Coalition Experience

ARCH Webinar:
State Respite Legislation: Advancing Respite for Family Caregivers

November 12, 2019

PRESENTED BY:
Kathy Mayfield-Smith, MA, MBA
Board President and Cofounder
SC Respite Coalition
Respite Awareness Day (Valentine’s Day)

• Annual Advocacy Day at the State House
• Family Caregivers (older adult, younger adult, child) told their stories & the difference respite made
• Caregivers met with their legislators to tell their stories
• Provided written information to all legislators: respite/caregiver facts, benefits of respite, faces of respite
Other Education and Advocacy

• Presentation of State Respite Plans
  – Take A Break SC and Take Another Break SC

• Public Awareness:
  • List-serv notices; E-blasts, Newsletter articles;
  • Facebook, twitter, etc.
  • Caregiver feature stories

• Advocating within the agencies
State-funded Respite Voucher Program

Line-item Budget Request
2012 Lt. Governor’s “Tour on Aging”

- Held 10 regional community forums to hear directly from older adults and caregivers
- Lifespan grant Director staffed the forums
- Respite was a major theme in all of the meetings
SCRC actively participates in these forums:

• Executive Director, Board or volunteers participated in all regional meetings
• Provided information/data on respite
• Notified family caregivers of meetings and encouraged to tell their stories
Budget Line-Item Request

- Lt. Gov added 2 recurring line-item requests to the LGOA (now SCDOA) SFY2014 budget:
  - $3 million for caregiver supports (e.g., meals, transportation)
  - $3 million for respite vouchers
- LGOA led requests & legislative support
STATE-FUNDED VOUCHER PROGRAM

Working with Partners

• Foundation of Lifespan Respite in SC
• Coordinating the message (AARP and Alzheimer’s Association)
• Key to building support across constituencies
Advocacy Successes

• 2014 – Line-item passed ($3 million, non-recurring); LGOA implements for Older Adults the Family Caregiver Support Programs

• 2015 – Line-item reduced ($2 million, but recurring

• 2016 – LGOA broadens Voucher program to Lifespan; adds SC Respite Coalition to serve children, young adults ($100,000)
Advocacy Successes

• 2017 – Line-item increased ($2.4 million)

• 2018 – Line-item maintained ($2.4 million, recurring), SC Respite Coalition increased to $200,000)

• 2019 – Line-item maintained; SCRC level maintained
Questions?

Kathy Mayfield-Smith
klmayfie@mailbox.sc.edu
803-777-0930