Securing Respite Programs through State Advocacy and Research

Presented October 12, 2017 by Rachelle Cummins and Jonathan Bartholomew
Introductions
Rachelle Cummins- Director, State Research

Areas of Expertise: Survey Design and Analysis; Public Opinion on State and Local Issues

Rachelle is responsible for directing state research that supports planning, advocacy, and education efforts for AARP’s state offices and community presence. For nearly 25 years, she has led research efforts to understand public and member opinion on topics including health care, long-term care, caregiving, prescription drugs, financial security, fraud protection, utilities, livable communities, and more for AARP. For the last decade, Rachelle has led over a dozen research professionals to help create social change through collecting and leveraging public opinion at the state and local level. Rachelle’s work and that of her team can be found at http://www.aarp.org/research/state-surveys/. The body of work includes survey reports and fact sheets that focus on the needs, concerns and interests of AARP members and the 50+ population as a whole. Research is available for all 50 states, plus the District of Columbia, Guam, Puerto Rico and the U.S. Virgin Islands. Besides professional experience at AARP, Rachelle has a citation in Survey Methodology from the University of Michigan, University of Maryland, and Westat, Inc. She has a Master’s degree in Sociology from The George Washington University. Her undergraduate degree is in Sociology and Women’s Studies from Goucher College. Rachelle has extensive training in leadership and management including The Duke Leadership Program and over fifteen American Management Association seminars.

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Jonathan Bartholomew- Director, Government Relations, AARP OR

Jon Bartholomew is the Government Relations Director for AARP Oregon. In 2016, he led the Oregon Caregiver Respite Work Group, which made 15 recommendations for improving caregiver respite in Oregon. Prior to taking this position in 2014, he had been the Public Policy Director at the Alzheimer's Association Oregon Chapter, where he coordinated the creation of the State Plan for Alzheimer's Disease in Oregon. He has worked in public policy for 20 years, working on issues from after school program funding to media reform. Originally from Pennsylvania, he earned his Masters in Public Administration at the University of Washington.
Background
State of Family Caregivers

❤️ 17.7 million family caregivers are caring for someone over the age of 65+

❤️ These care recipients are often dealing with limitations in either physical, mental or cognitive functioning

❤️ By 2030, 72.8 million- more than one in five Americans will be 65 or older- with the greatest growth amongst the ‘oldest old’

Source: Families Caring for an Aging America
State of Family Caregivers, cont’d

❤ Increasing diversity of older Americans will further increase the need for family caregivers

❤ In less than 15 years almost 30% of older Americans will identify as a minority

❤ Differences in culture, income, education, environment, lifetime access to health care will have a significant impact on the need for care

❤ Developing effective ways to support family caregivers has never been more critical

Source: Families Caring for an Aging America
Importance of Respite Care

❤ Family caregivers play a critical role in the care of loved ones, but need regular breaks to maintain their own health and well-being

❤ Supporting family caregivers can significantly improve the quality of care delivered and quality of life of both the giver and recipient

Source: Families Caring for an Aging America
Impact of Respite Care

Respite care is one of the most needed services for Alzheimer’s caregivers and the delay in institutionalization offers billions in annual savings.

Respite care services for family caregivers significantly decreases the probability of nursing home placement.

Respite care services results in few hospital admissions for acute medical care.

Respite care has been shown to decrease caregiver related stress.

Caregiving in the USA Findings on Respite
Background on Caregiving in the USA

❤️ The purpose of Caregiving in the U.S. 2015 is to present a portrait of unpaid family caregivers today.

❤️ A national profile of family caregivers first emerged from the 1997 Caregiving in the U.S. study. Related studies were conducted in 2004 and 2009.

❤️ This study builds on those prior efforts, but was conducted against the backdrop of a societal shift in technology, requiring a shift to online data collection.

❤️ Caregiving in the U.S. 2015 establishes a new baseline for examining changes to caregiving in the future.

❤️ The core areas that we examined in this study include the following:

❤️ The prevalence of caregivers in the United States
❤️ Demographic characteristics of caregivers and care recipients
❤️ The caregiver’s situation in terms of the nature of caregiving activities, the intensity and duration of care, the health conditions and living situation of the person to whom care is provided, and other unpaid and paid help provided
❤️ How caregiving affects caregiver stress, strain, and health
❤️ Information needs related to caregiving
❤️ Public policy and caregiver support
Respite Care User Profile

✦ 15% (n=184) of all caregivers surveyed have used respite care

✦ 16% of current caregivers have used respite
✦ 15% of former caregivers used respite

✦ Respite care users are typically…
  ✦ Female (55%),
  ✦ 51 years of age
  ✦ Married (55%)
  ✦ Has attended college or graduated therefrom (63%)
  ✦ Owns their home (70%)
  ✦ Employed at some point while providing care (58%)

Source: Caregiving in the US 2015
Respite Care Users: Comparison of Respite Care Users vs. Non-Respite Care Users

Overall, our analysis shows that caregivers who use respite care are providing for care recipients who may be the most difficult to care for in terms of their condition.

<table>
<thead>
<tr>
<th>Care Recipient Illness</th>
<th>Respite Users</th>
<th>Non-Respite Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long-term physical condition</td>
<td>69%</td>
<td>58%</td>
</tr>
<tr>
<td>Memory problem</td>
<td>41%</td>
<td>24%</td>
</tr>
<tr>
<td>Alzheimer’s, dementia, or mental confusion</td>
<td>39%</td>
<td>19%</td>
</tr>
</tbody>
</table>

Source: Caregiving in the US 2015
Respite Care Users: Comparison of Respite Care Users vs. Non-Respite Care Users

❤ Overall, our analysis shows that the more ADL’s/IADL’s performed by the caregiver the more likely they were to use respite care.

<table>
<thead>
<tr>
<th>Help Provided</th>
<th>Respite Users</th>
<th>Non-Respite Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting dressed</td>
<td>54%</td>
<td>28%</td>
</tr>
<tr>
<td>Giving medicines</td>
<td>62%</td>
<td>43%</td>
</tr>
<tr>
<td>Advocating with providers/services/agencies</td>
<td>66%</td>
<td>47%</td>
</tr>
<tr>
<td>Cared for more than 40 hours a week</td>
<td>35%</td>
<td>20%</td>
</tr>
</tbody>
</table>

Source: Caregiving in the US 2015
Respite Care Users: Comparison of Respite Care Users vs. Non-Respite Care Users

<table>
<thead>
<tr>
<th>Working Caregivers</th>
<th>Respite Users</th>
<th>Non-Respite Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervisor knows about caring for someone</td>
<td>68%</td>
<td>54%</td>
</tr>
<tr>
<td>Flexible work hours are offered</td>
<td>63%</td>
<td>51%</td>
</tr>
<tr>
<td>Adjusted your work schedule to provide care</td>
<td>60%</td>
<td>47%</td>
</tr>
</tbody>
</table>

Source: Caregiving in the US 2015
## Respite Care Users: Comparison of Respite Care Users vs. Non-Respite Care Users

<table>
<thead>
<tr>
<th>Other</th>
<th>Respite Users</th>
<th>Non-Respite Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requested information about getting financial help for loved one</td>
<td>44%</td>
<td>25%</td>
</tr>
<tr>
<td>Had outside service provide transportation for recipient</td>
<td>48%</td>
<td>19%</td>
</tr>
<tr>
<td>Home modifications were made in loved one’s home</td>
<td>66%</td>
<td>28%</td>
</tr>
<tr>
<td>Health care professional asked about needed care for loved one</td>
<td>59%</td>
<td>27%</td>
</tr>
<tr>
<td>Health care professional asked about needed care for caregiver</td>
<td>33%</td>
<td>14%</td>
</tr>
</tbody>
</table>

Source: Caregiving in the US 2015
Multi-State Analytical Dataset Findings

Results were derived from AARP’s multi-state database of caregiving studies from 2014-2016

- 90% support State’s providing short term help from a home health aide. Support is higher among former caregivers.

- 77% say it is very important to have respite services in community. Support is higher among former caregivers.
State Advocacy Work: Respite in Oregon
Family caregiving is the foundation of Oregon’s system of LTSS

- About 469,000 unpaid caregivers in Oregon
- Valued at $5.7 billion per year
- 89% of people 65+ want to stay in own home.
Respite is an identified unmet need

- 2014 AARP LTSS Scorecard ranked OR 41st for caregiver stress
- State Plan for Alzheimer’s Disease in Oregon noted need for respite
- LTC 3.0 (SB 21) noted need for respite
Lack of Access

- 20-ish Adult Day Centers in Oregon that take Medicaid. A handful of private pay
- Too few home care workers
- LTC settings don’t want short term stays
Oregon Caregiver Respite Workgroup

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

♥ Held 14 community meetings around Oregon in June/July
Oregon Caregiver Respite Workgroup

Key findings

- Emotional stress was top issue for most, but physical and financial stresses were noted by a majority, as well as lack of access to resources.
- A majority did not know about the ADRCs, even though many people who attended work for them.
- People interested in all models – home care, adult day, short term stays.
**Oregon Caregiver Respite Workgroup**

- **Key findings (cont.)**
  - “Respite” doesn’t connect. “Short break” top, but “caregiving relief” also popular.
  - Portland Metro and I-5 corridor said biggest barrier is not knowing where to find services.
  - Elsewhere, top concern was lack of services.
  - Cost a major concern across the state.
  - Personal resistance also a major concern.
Oregon Caregiver Respite Workgroup

- Report published in November 2016
- Passed HJM 4 which honors family caregivers, says the legislature will consider the work of the Workgroup, and urges Congress to pass the RAISE Family Caregivers Act
- Not a good year to ask for more funding - $1.6 billion shortfall
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
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
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
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
Download the report at
action.aarp.org/oregonrespite
Policy Implications
AARP Recommendations

❤️ National Strategy To Support Family Caregivers

❤️ Federal Level

❤️ A national strategy should be developed to support family caregivers. Public and private sectors, including family caregivers, should advise and make recommendations on how to best address the challenges facing families in their caregiving roles.
AARP Policy Recommendations

 Necessary Programs And Services To Assist Caregivers

 Federal and State Level

 Federal and state governments should ensure that long-term services and supports (LTSS) programs cover services—such as respite care and adult day services—that supplement caregiving by relatives, friends, and neighbors.
AARP Policy Recommendations

❤️Federal and state governments should offer a range of culturally appropriate services geared to the needs of diverse family caregivers, such as:

❤️caregiver assessments to help improve targeting of supportive services, caregiver training programs, support groups, family meetings, and counseling (such as counseling for nutrition and mental health);
❤️home-modification programs and assistive technologies;
❤️respite care; and
❤️income support and transportation.
AARP Policy Recommendations

Education and training programs should ensure that family caregivers are well trained and prepared to perform not only difficult LTSS tasks such as bathing, but also to handle medical and nursing tasks, such as medication management and wound care.

Supplemental programs and support services should reflect the multicultural and language access concerns and needs of diverse populations of caregivers.
AARP Policy

 Yosemite Federal and state governments should establish and coordinate information and referral systems to let caregivers know about the full range of available LTSS, including caregiver support services.

 Yosemite Federal and state governments should offer a range of culturally appropriate services geared to the needs of diverse family caregivers.

 Yosemite The Joint Commission should ensure that surveyors are trained to assess family caregiver training and support programs.
AARP is the nation’s largest nonprofit, nonpartisan organization dedicated to empowering Americans 50 and older to choose how they live as they age. With nearly 38 million members and offices in every state, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands, AARP works to strengthen communities and advocate for what matters most to families with a focus on health security, financial stability and personal fulfillment. AARP also works for individuals in the marketplace by sparking new solutions and allowing carefully chosen, high-quality products and services to carry the AARP name. As a trusted source for news and information, AARP produces the world’s largest circulation publications, AARP The Magazine and AARP Bulletin. To learn more, visit www.aarp.org or follow @AARP and @AARPadvocates on social media.