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AARP Oregon Testimony on HJM 4

February 3, 2017

TO: House Committee on Health Care, Rep. Greenlick, Chair

FROM: Jon Bartholomew, Government Relations Director, AARP Oregon

AARP Oregon is pleased to support House Joint Memorial 4. This proposal honors the hard work and sacrifices of the approximately 470,000 family caregivers in Oregon, the efforts by the Oregon Caregiver Respite Work Group that crafted recommendations to improve access to and effective use of caregiver respite in Oregon, and urges Congress to pass the RAISE Family Caregivers Act, which would lead to the creation of a national strategy to support family caregivers.

When we discuss “family caregivers,” who are we talking about? Family caregivers make it possible for older adults and people with disabilities of all ages to remain living in their homes and communities. They are informal caregivers who provide unpaid care to a relative or friend, often helping with activities of daily living such as eating and dressing. Family caregivers are the backbone of the long-term care system. An estimated 43.5 million Americans have provided unpaid care to an adult or child in the last year. In Oregon, an estimated 469,000 family caregivers provide about 437 million hours of unpaid care each year with an estimated value of \$5.7 billion. Caregivers come from all walks of life, but 60% of caregivers are women with an average age of 49. In addition to their family caregiving responsibilities, 56% of caregivers work full time.

The care provided by caregivers is wide-ranging and in some instances all encompassing. For many caregivers, the demands of caregiving can cause stress or loneliness, and may even cause a decline in their own health. Evidence shows that the stress of dementia care increases caregivers’ susceptibility to disease and health complications. Caregivers often report an increased incidence of emotional and physical difficulties in their personal life. Further, the longer a caregiver has been providing care, the more likely she or he is to report poor health.

Respite care is temporary, short-term care that provides relief from the extraordinary and intensive demands experienced by family caregivers. Respite services come in a variety of forms and include in-home paid care, adult day services, and overnight stays in a long-term care

setting. Research demonstrates that respite services reduce the stresses of caregiving and improve well-being for both family caregivers and the older adults for whom they provide care. Many caregivers, however, do not access respite care. Barriers to caregivers seeking and using respite care include lack of awareness, personal resistance to seeking outside help, lack of affordability, and shortages of high-quality providers.

Currently, most caregivers pay for respite out of pocket. Some Long Term Care Insurance policies, for the few people who have them, pay for respite. The Veterans Administration and Medicaid also sometimes pay for respite. There are two other notable programs that help caregivers access respite: The Family Caregiver Support Program (FCSP), which is federally funded under the Older Americans Act, and Oregon Project Independence (OPI), which is state funded.

FCSP is focused on the well-being of the caregiver. FCSP provides support to family caregivers of adults age 60 and older, as well as people providing care to people of any age with Alzheimer's disease, and a few other specific caregiving situations.

OPI covers services which offer temporary, substitute supports or living arrangements for care recipients which provide a brief period of relief for caregivers. Funds are extremely limited, wait lists exist based on priority, and respite is at the bottom of that priority list.

Because the need for respite was a recurring theme in the State Plan for Alzheimer's Disease in Oregon, the Senate Bill 21 workgroup, and the White House Conference on Aging, but nothing was happening, AARP decided to convene stakeholders to craft an action plan to determine what can be done in Oregon. We started by holding a summit in April, which was attended by over 70 stakeholders from around the state. About 25 people then formed a work group to craft the recommendations. The work group included family caregivers, academics, care providers, caregiver advocates, and others.

The work group held 14 community meetings across Oregon in the summer, so we could hear ideas and needs in different communities. We went to Albany, Astoria, Beaverton, Bend, Burns, Eugene, Hood River, La Grande, Lincoln City, Medford, Pendleton, Portland, Roseburg, and Salem. We heard from family caregivers, professionals working in the caregiving field, some elected officials, and others to determine is needed and what works in different parts of the state.

From all of this work, the report was published in November and it and the one-pager with the 15 recommendations is in front of you. I won't go into detail all the recommendations, but want to highlight a few.

- We were hoping to request some funding for services this year from the legislature, but we understand the budget constraints. That said, we will oppose any cuts to OPI.
- We have been told that DHS APD will open the rules on Adult Day Centers this summer, so that barriers to providing those services will be reduced.

- We are working with the business community to discuss what they can do to help family caregivers – and we are partnering with a Caregiving in the Workplace Summit with the Portland Business Journal on March 16th.
- Conversations are also happening with community colleges and health systems regarding the recommendations they can help with.

Another aspect of this Memorial is to urge Congress to pass the RAISE Family Caregivers Act. RAISE is an acronym for Recognize, Assist, Include, Support and Engage. In the last Congress, there was a Senate version and a House version. S 1719 had 5 GOP sponsors (introduced by Senators Collins and Baldwin) and 7 Dem sponsors. It passed the Senate on a unanimous voice vote in December of 2015. HR 3099 had a total of 127 cosponsors (78 Democrat, 49 GOP), and the chief sponsors were Rep. Harper, (R-MS) and Rep. Castor (D-FL). Three of Oregon's five members were sponsors. However, it never had a hearing in its House committee.

This bill directs the Department of Health and Human Services (HHS) to develop, maintain, and periodically update a National Family Caregiving Strategy. HHS shall convene a Family Caregiving Advisory Council to advise it on recognizing and supporting family caregivers. Essentially, this is about crafting a national plan to help family caregivers – something that is long overdue. We expect that this legislation will be reintroduced soon in the new Congress that just convened.

HJM 4 in front of you urges Congress to pass the RAISE Family Caregivers Act, and shows appreciation for the work of the Oregon Caregiver Respite Work Group, and that the legislature will consider the recommendations of it. And most of all, HJM 4 recognizes the sacrifices, compassion, and hard work of Oregon's family caregivers. I ask for your support for HJM 4.