An estimated 469,000 family caregivers provide informal, unpaid care to older Oregonians, often with little assistance. Expanding high-quality, affordable respite services can help relieve the stresses and strains on family caregivers who are the backbone of long-term care in Oregon.

Improving Caregiver Respite Services in Oregon

Report of the Oregon Caregiver Respite Work Group

Table of Contents

The Oregon Caregiver Respite Work Group

The Oregon Caregiver Respite Work Group (Work Group) formed in May of 2016 to address growing concerns about the stresses on family caregivers and an acknowledgment that there are ways to improve access to and effective use of respite. Several processes – the State Plan for Alzheimer's Disease in Oregon, the Senate Bill 21 Work Group, and the 2015 White House Conference on Aging – highlighted the need to address the lack of access to respite and the need for caregivers to get some breaks from caregiving. The group came together to seek agreement on ways to help caregivers in Oregon get some relief from their caregiving responsibilities.

Members

The members of the Work Group were chosen for their expertise in the area of family caregiving and the roles they play with stakeholder organizations. Additionally, several of the Work Group members are currently or have been family caregivers.

The following individuals served on the Oregon Caregiver Respite Work Group:

Polly Bangs, Urban Excursions
Jon Bartholomew, AARP Oregon
Alison Bookman Skidmore, Volunteers of America
Jenny Cokeley, Oregon Home Care Commission
Jen Corbridge, staff for Rep. Alissa Keny-Guyer
Walt Dawson, Oregon Health Care Association
Annaliese Dolph, National Multiple Sclerosis Society
Regina Ford, Home care provider
Leslie Foren, Regence BC BS
Erin Grahek, Multnomah County Aging & Disability Services Division
Ruth Gulyas, Leading Age Oregon
Suzanne Hansche, We Can Do Better
Jan Karlen, Oregon Department of Human Services, Aging and People with Disabilities
Sara Kofman, Alzheimer's Association Oregon Chapter
Julie Luedtke, Northwest Senior & Disability Services
Mike McCormick, Oregon Department of Human Services, Aging and People with Disabilities
Deb McCuin, Oregon Department of Human Services, Aging and People with Disabilities
Cheryl Miller, Oregon Home Care Commission
Dave Nelson, Griswold Home Care
Pam Rinehart, Right Fit Senior Referral
Tom Sanders, Gerontology student at Portland State University
Vicki Schmall, AARP volunteer and caregiving expert
Tera Stegner, Grace Center Adult Day, Corvallis
Anna K. Williams, Providence Health & Services, Hood River

Work Group Process

The Oregon Caregiver Respite Work Group formed after an initial Oregon Caregiver Respite Summit held on April 15th, 2016 in Tualatin. The Summit was promoted to stakeholders across Oregon, and featured a keynote presentation by Jill Kagan, Executive Director of ARCH Respite. Over seventy people participated in the summit, and provided initial direction for the Work Group to explore. On May 19th, 2016, individuals who committed to participating in the Work Group held their first meeting.

The Work Group determined that its charge would be to focus on respite for caregivers of adults, with the hope that our recommendations would also have a positive impact for other caregivers, such as those for children with special needs, grandparents raising grandchildren, foster parents, and others. Work Group members felt that due to Oregon's adoption of the Medicaid K Plan, and its provision of "relief services" to Medicaid clients, our recommendations should target the needs of the non-Medicaid population.

The Work Group created two committees to gather information to inform the work of the full Work Group. The Best Practices and Innovations Committee researched funding streams, messages, and creative models of respite across the country. The Systems Barriers Committee took a deep dive into what the real barriers are to using respite in Oregon, including regulatory barriers and lack of funding.

Photos by Paul Rich Studio

Fourteen community meetings were held around Oregon in the months of June and July by the Work Group. These were held on the belief that what people need and are interested in may differ from community to community. The public was invited to participate in all of these meetings, and over 400 individuals attended, providing creative ideas and differing perspectives. Feedback from these events is incorporated into the rest of this report.

Photo by Paul Rich Studio

Special thanks to the following elected officials who attended these meetings or had staff attend:

- Sen. Tim Knopp
- Sen. Jeff Kruse
- Sen. Arnie Roblan
- Rep. Phil Barnhart
- Rep. Ken Helm
- Douglas Co. Commissioner Tim Freeman
- Lincoln Co. Commissioner Terry Thompson

After utilizing the research and public input, the Work Group agreed on the recommendations contained herein, and prepared this report. Ellen O'Brien, an independent consultant, was contracted to craft and finalize the report in consultation with the Work Group. Before finalizing the report, the recommendations were shared with Summit attendees, community meeting attendees, the AARP Oregon Diversity Advisory Committee, Jill Kagan at ARCH Respite, and other stakeholders to ensure we accurately captured their input. The Work Group greatly appreciates all the feedback we received.

For more information about this report, contact Jon Bartholomew at AARP Oregon: jbartholomew@aarp.org, and 503-513-7370.

Executive Summary

Family caregivers make it possible for older adults and people with disabilities of all ages to remain living in their homes and communities. Respite care is temporary, short-term care that provides relief from the extraordinary and intensive demands put on ongoing care providers. The Oregon Caregiver Respite Work Group produced this report to highlight the need for respite services and recommend approaches for expanding access to affordable, high-quality caregiver respite services. The report provides a brief overview of the role of caregiver respite and Oregon's respite programs and providers, and, importantly, an assessment of what's needed to address current gaps.

Caregivers and the role of respite services

An informal caregiver provides unpaid care to a relative or friend often helping with various activities of daily living such as eating and dressing. According to a 2015 report from AARP and National Alliance for Caregiving, an estimated 43.5 million Americans have provided unpaid care to an adult or child in the last year.[1] 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. [2]

Caregiving is demanding and caregivers need a break not only for their own health but for also for the wellbeing of the person receiving care. When caregivers have access to respite care they can take care of themselves, go to work, get to health care appointments, secure and prepare nutritious meals, and get rest. Respite offers more opportunity to meet other demands to shop and complete errands and necessary chores. Respite gives a caregiver an opportunity to do those things that are important to them, so that they will not lose sight of their own needs. Getting adequate sleep or simply relax and take a break from the pressures of caregiving can be immensely critical for the well-being of the caregiver.

Respite services come in a variety of forms and can include in-home paid care, adult day care services, or overnight services in a facility. Evidence shows that the stress of dementia care increases caregivers' susceptibility to disease and health complications.[3] Caregivers often report an increased incidence of emotional and physical difficulties in their personal life.[4] Further, the longer a caregiver has been providing care, the more likely she or he is to report poor health.[5]

Benefit of and barriers to using respite

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. Services can help caregivers continue to provide care at home and delay or prevent nursing home admissions. Recent studies have shown that respite, notably adult day services, can reduce caregiver distress.[6] Other research demonstrates that day care services are effective in decreasing caregiver burden and behavioral problems in persons with dementia. However, there are barriers to seeking and using respite care, including lack of awareness, personal resistance to seeking outside help, lack of affordability, and shortages of high-quality providers.

Caregiver support programs in Oregon

Today, two major programs (other than Medicaid) provide caregiver respite services: Oregon Project Independence (OPI), which is state funded and the Family Caregiver Support Program (FCSP), which is federally funded under the Older Americans Act and must meet federal "maintenance of effort" rules. In addition, for more than a decade, respite benefits also were provided to Oregon's family caregivers through the Lifespan Respite Program, but the program ended in mid-2010 due to lack of funding. OPI covers services which offer temporary, substitute supports or living arrangements for care recipients in order to provide a brief period of relief or for caregivers, but funds are extremely limited, wait lists exist based on priority, and respite is at the bottom of that priority list. FCSP is explicitly 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.

Recommendations

The work group identified several strategies to reduce barriers to using caregiver respite services. The recommendations are designed to expand access to high quality and affordable respite that can reduce the strains of family caregiving. The work group recommendations are targeted to: (1) enhancing education and awareness, (2) increasing the supply of providers, and (3) making respite more affordable.

Improving Education and Awareness

The first set of recommendations seeks to improve education and awareness and thereby reduce barriers to seeking and using respite.

> **Recommendation 1. Launch a public awareness campaign**. Because relatively little is known about the extent of public awareness of respite programs and services, we recommend launching a public outreach campaign. We propose activities to assess consumers' knowledge gaps, educate family caregivers about available services, and increase understanding of how respite services can both help caregivers continue to provide care at home and improve family well-being.
>
> **Recommendation 2. Prepare trusted messengers to increase awareness and promote the value of respite**. We propose leveraging medical professionals and social service professionals, including health care providers, religious leaders, employers and other community partners, to increase awareness and uptake of caregiver respite services.
>
> **Recommendation 3. Expand targeted outreach to veterans and their caregivers**. We also recommend targeted outreach to selected populations for whom additional sources of support may be available, including veterans who may qualify for VA services for caregivers, such as support lines, adult day health care, and respite.[7]
>
> **Recommendation 4. Improve data collection on family caregivers and respite**. Finally, we highlight the need to improve understanding of caregivers and their needs through more systematic data collection and analysis to inform program design.

Increasing the Supply of Providers

The second set of recommendations addresses the real and perceived shortages of high-quality respite services in Oregon. Our recommendations include strategies to:

Recommendation 5. Improve the quality and quantity of home care workers who can provide respite services. We recommend the Oregon Home Care Commission continue to implement strategies to expand and improve the home care workforce, including initiatives to create career ladders for home care workers. The Work Group calls on the Oregon legislature to provide funding as needed to achieve full implementation of the recommendations contained in the Commission's 2015 report on workforce development.

Recommendation 6. Update the administrative rules that govern adult day centers. We suggest a review of the regulatory rules governing adult day care to ensure that there are no unnecessary barriers to entry for new providers, such as the six-month waiting period for certification required for centers to become certified Medicaid providers.

Recommendation 7. Increase overnight respite options. The Work Group recommends establishing another working group to explore the feasibility of streamlining the process for overnight stays in licensed residential care settings and nursing facilities, and creating a new overnight model of respite.

Recommendation 8. Encourage hospitals, health systems, and Coordinated Care Organizations (CCOs) to consider ways to provide respite care. We recommend that health providers and CCOs partner with organizations to expand access to respite care or establish PACE programs. We also note that new community benefit requirements for hospitals create an opportunity for hospitals to work with communities in assessing local needs for respite services and to support and even develop programs to fill in gaps in needed services, work that could also possibly align with local Community Health Improvement Plan (CHIP) efforts.

Recommendation 9. Leverage community colleges and universities to expand access to respite. We recommend strategies for leveraging Oregon's community colleges and universities: they should explore opportunities to establish respite options, such as adult day centers, either on their own or in partnership with local non-profits. Such initiatives could provide practicum training opportunities for students and an affordable, high-quality respite option for community members.

Recommendation 10. Expand innovative models of delivering respite. The Work Group recommends providing and expanding Medicaid, OPI, or FCSP funding for innovative models of respite, such as camps, mobile programs, time-bank models, host homes, and co-op models.

Recommendation 11. Explore ways to support volunteer-based programs. We recommend that stakeholders consider ways to increase financial and other kinds of support for volunteer programs so as to expand their reach in Oregon.

Making Respite More Affordable

The third set of recommendations addresses the issue of affordability. We make recommendations for increasing state funding for existing and new programs to expand access to affordable respite care.

> **Recommendation 12. Increase state funding for existing respite care programs**. The Work Group recommends that the Oregon Legislature, beginning in 2017, provide state funding to supplement the federal dollars received for FCSP. These state funds should have fewer restrictions on their use, so as to allow for caregivers of individuals younger than 60 and without dementia to participate in the program. Additionally, we urge increased funding for Oregon Project Independence.
>
> **Recommendation 13. Explore the feasibility of developing a Medicaid waiver program to expand access to respite.** We recommend an effort to assess the feasibility of expanding access to respite care subsidies through a Medicaid waiver to reach older adults with income up to 400% of the federal poverty level.
>
> **Recommendation 14. Encourage employers to develop strategies to assist their employees who are family caregivers.** We recommend that private-sector employers assess caregiver needs among their employees and undertake strategies, including offering respite services, to help them balance caregiving and work.
>
> **Recommendation 15. Establish a system and funding for providing emergency respite.** The Work Group recommends that emergency respite be included in the implementation of other recommendations in this report. As stakeholders are discussing ways to increase the availability of overnight respite options, emergency respite—to address the needs of families in crisis who need services immediately—should be included.

Next Steps

Family caregivers are the backbone of long-term care in Oregon. With this report, the Work Group hopes to foster a conversation about the needs of family caregivers and how state government, private employers, and people and organizations in communities across Oregon can do more to address these needs. In the months ahead, the Work Group will present our recommendations and seek to develop the partnerships needed to advance policy. Our goal is to foster a more robust infrastructure for respite services that works to address the needs of older adults and their family caregivers.

Improving Caregiver Respite Services in Oregon

Report of the Oregon Caregiver Respite Work Group

November 2, 2016

Introduction

Family caregivers make it possible for older adults and people with disabilities of all ages to remain living in their homes and communities. For the older adults who are the focus of this report, informal caregivers provide assistance with daily living activities and household tasks, and, increasingly, complex medical tasks. The roles and responsibilities of family caregivers vary widely. Some caregivers provide only occasional help; others provide caregiving on a daily basis for many years without assistance. For many, caregiving for a frail older adult can be a rewarding part of family life. But caregiving—especially for people who are very frail or who have dementia—can create challenges and stresses, including physical harms, depression, isolation, and financial strain.

Supporting family caregivers is increasingly a focus of health care policy and practice. There is a growing consensus that health care and social service professionals need to know who family caregivers are, include them as partners, assess their needs, and connect them with needed supports. Among those caregiver supports are respite services—including in-home care, adult day care, and overnight respite in nursing homes or other facilities. Caregivers' needs and preferences vary, but for many, respite services can provide a temporary break that benefits both the caregiver and the person receiving care.

Despite the growing recognition of caregiver needs, the reality is that existing programs sometimes fall short of connecting caregivers to timely, appropriate, and affordable respite services. Part of the problem is that family caregivers don't always seek services: they worry that respite isn't a viable solution, that providers are not available, or that the services are too costly. Indeed, Medicare covers caregiver respite only for beneficiaries receiving hospice care.[8] Medicaid covers respite for people receiving home and community-based services, but most older adults are not covered by Medicaid. Older adults and their family caregivers usually must pay privately for respite services or seek financial assistance through Oregon's important, but limited, caregiver support programs.

The Oregon Caregiver Respite Work Group produced this report to highlight the need for respite services and recommend approaches for expanding access to affordable, high-quality caregiver respite services. The report provides a brief overview of the role of caregiver respite and Oregon's respite programs and providers, and, importantly, an assessment of what's needed to address current gaps.

The report includes 15 recommendations for improving respite services, including proposals to: (1) improve outreach to family caregivers, (2) expand the supply of high-quality respite care providers, and (3) make respite more affordable. We have made recommendations for both public- and private-sector action. Our recommendations are directed to Oregon's legislature and its state agencies, as well as health care providers, employers, and other community professionals who interact with family caregivers. We believe that these incremental proposals should be considered and further refined. These recommended strategies will build on existing efforts and significantly improve access to high-quality, affordable respite services that meet the needs of Oregon's families.

Family Caregivers and the Importance of Respite

Family caregivers

An informal caregiver provides unpaid care to a relative or friend often helping with various activities of daily living such as eating and dressing. Caregivers provide care for a variety of conditions from dementia, to advanced age, to physical disabilities, to developmental disabilities to cancer. According to a 2015 report from AARP and National Alliance for Caregiving, an estimated 43.5 million Americans have provided unpaid care to an adult or child in the last year.[9] 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.[10]

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.[11] Caregivers often report an increased incidence of emotional and physical difficulties in their personal life.[12] Further, the longer a caregiver has been providing care, the more likely she or he is to report poor health.[13]

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.***

Although caregivers come from all walks of life, AARP and the National Alliance for Caregiving report finds that 60% of caregivers are women with an average age of 49. The report also identifies that in addition to their family caregiving responsibilities, 56% of caregivers work full time. This presents a unique challenge to our workforce: caregivers report having to make various accommodations to balance caregiving responsibilities with work responsibilities.[14] This can include cutting back hours, taking a leave of absence, or early retirement.

Respite

Caregiving is demanding and caregivers need a break not only for their own health but for also for the wellbeing of the person receiving care. Respite care provides the caregiver with a short break to "provide relief from the extraordinary and intensive demands put on…care providers."[15] When caregivers have access to respite care they can take care of errands and household chores or simply relax and take a break from the pressures of caregiving.

*"**Respite care** is temporary, short-term care… The primary purpose of respite is to provide relief from the extraordinary and intensive demands put on ongoing care providers."*

Respite services come in a variety of forms and can include in-home paid care, adult day care services, or overnight services in a facility. Increasingly, new models of service delivery are being developed that are responding to the diverse needs and preferences of families. These models include co-operative models, camps, mobile programs, time-bank models, and host homes. In addition to paid services, family and friends and volunteers can provide relief to family caregivers by assisting with meal preparation or other household tasks, or providing companionship, for example.

*“**Adult day services** provide out-of-home, supervised group services with the goals of improving mood, wellbeing and quality of life of the caregiver and care recipient and enabling clients to remain at home for as long as possible.”*

The value of respite services

A growing body of research shows that supportive services for family caregivers, including education and skills training, for example, can improve wellbeing and quality of life for both caregivers and care recipients.[16] It has been challenging to demonstrate the effectiveness of respite services, however, because services and interventions vary widely.

Nonetheless, recent studies have shown that respite, notably adult day services, can reduce caregiver distress.[17] Another recent study demonstrates that day care services are effective in decreasing caregiver burden and behavioral problems in persons with dementia.[18] Other studies have measured the effects of respite services on care recipients’ wellbeing and quality of life, as well as the effect on preventing or delaying nursing home placement. Better evidence on community-based respite care will be helpful in identifying how to deliver respite services to achieve the best outcomes for caregivers and families. Improved data collection in existing programs can help advance policy and program development.

Measuring the outcomes of respite care. *Studies have measured the effects of adult day service use on caregiver health symptoms, positive affect, depressive symptoms, anger, and anxiety symptoms, as well as outcomes for care recipients.*

Caregiver Respite Programs in Oregon

In Oregon, there have been some innovative programs for caregivers that have provided and continue to provide needed breaks and relief from daily caregiving of a person in need of continual assistance and support from a family member or other informal caregivers. Today, two major programs provide caregiver respite services: Oregon Project Independence (OPI), which is state funded and the Family Caregiver Support Program (FCSP), which is federally funded under the Older Americans Act and must meet federal “Maintenance of Effort” rules.

In addition, for more than a decade, respite benefits also were provided to Oregon’s family caregivers through the Lifespan Respite Program, but the program ended in mid-2010 due to lack of funding. (A summary of the respite programs that have been and are currently available to caregivers in Oregon is provided in Table 1 below.) Oregon’s Medicaid program also provides respite services to family caregivers, including adult day care.

Oregon Project Independence

OPI serves seniors and people with physical disabilities by providing services while living in their own homes. Services are provided statewide through 17 local Area Agencies on Aging (AAAs) and include personal and home care, chore services, adult day care, home delivered meals and service coordination. OPI covers services which offer temporary, substitute supports or living arrangements for care recipients which provide a brief period of relief for caregivers, but funds are extremely limited, wait lists exist based on priority, and respite is at the bottom of the priority list. The funding gaps demonstrate that the demand for services exceeds the capacity of these programs. Beyond the wait list counts, however, little is known about how great the unmet need may be. It is likely that the number of family caregivers who might benefit from respite services exceeds the number who appear on the waiting lists. The focus of OPI is on the care recipient, not the caregiver, however caregivers benefit from the services provided.

Oregon Project Independence, Program Data 2014[19]

- 2,802 people served
- Average age of clients served is 79 years
- OPI’s direct service annual cost per client was $1,621.00
- 62% of OPI consumers were at moderate risk and 29% were at high risk of moving to a greater level of care outside their home
- 50% of those screened for OPI need help with at least two activities of daily living, such as bathing, dressing or walking
- Consumers perceive their caregivers as stressed in 41% of those with a Risk Assessment

Family Caregiver Support Program

The ultimate goal of the FCSP is to improve the health and well-being of family caregivers by providing them with an array of flexible services designed to meet their individual needs. Unlike OPI, FCSP is explicitly 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. (FCSP also provides services for grandparents providing care to young children or adults with disabilities).

Nationally, existing program performance data suggests that caregivers are benefitting from the program. More than three-quarters of caregivers say that services provided through the national FCSP have allowed them to provide care for a longer period than otherwise possible. Additionally, 89% of caregivers reported that these services help them be better caregivers.[20]

Oregon's FCSP received $1.9 million in federal funding for fiscal year 2016 (October 1, 2015 - September 30, 2016). From that funding, $599,363 was used explicitly for helping 758 family caregivers receive respite.

A family caregiving story

"I care for Bonnie my wife of 51 years who has Parkinson's – which is a progressive mobility disease. It is one of the most difficult and rewarding things I have ever done, but we are as close to each other as we ever have been. We still hold hands out in public (although it's now a stability issue too).... Initially, the care I provided was mostly transportation to appointments and increased household chores, but after I retired the many symptoms of the disease progressed and the level of care also increased. Currently the care also includes most of the household chores, medicine reminders and constant observation/assistance with mobility. I cannot be away for more than an hour or two at a time." Tom, Oregon

Source: AARP Family Caregiving Stories at IHeartCaregivers, https://act.aarp.org/iheartcaregivers/stories/655/

Table 1. Oregon's Caregiver Respite Programs

Program	Description
Lifespan Respite Program	Oregon was the first state to adopt the Lifespan Respite Program. The purpose of this community-based program was to help individuals and families connect to respite providers and linking them to payment resources. Lifespan Respite allowed or encouraged entities in local communities to form respite programs that would consist of paid and volunteer staff. This program was intended to provide a short break for caregivers of aging relatives, individuals with special needs, people with a mental illness or other chronic condition regardless of age, income, race, ethnicity, special need or situation. This program was initiated in 1997 by the passage of HB 2013 and funded through state general funds. Local Lifespan Respite Networks also contributed and did fundraising such as applying for grants and other methods. Unfortunately, the program ended due to lack of funding in mid-2010. The statute and administrative rules authorizing the program have not been repealed, therefore it is a defunded program.
Family Caregiver Support Program (FCSP)	This program is primarily funded through the Older Americans Act and is implemented through local Area Agencies on Aging (AAA's). Each AAA decides which of the services listed below they will provide. Services under this program may include: • Information and assistance in gaining access to services and resources in the community, • Counseling, support groups and/or evidenced-based training to help caregivers make decisions and solve problems in their caregiving role, • Respite care that offers temporary substitute supports or living arrangements so the caregiver can have a brief period of relief from their role, and • Supplemental services that compliment or assist the caregiver, such as assistive technology, home modifications, incontinence supplies, legal assistance, and transportation. Caregivers served under this program include: • Caregiver of a person age 60 or older and the caregiver can be an adult of any age; • Caregiver of a person with Alzheimer's disease or other dementia of any age; • Caregiver of a child age 18 years or younger and caregiver is an older relative age 55 or older and the child lives with the caregiver; • Adult child with a disability who is 19 years of age or older and is financially dependent on the caregiver with whom they live. Even though there is no means test for financial eligibility, OAA requires that those with the greatest social and economic need are served first. Each AAA develops their own policies and procedures on how the program will be implemented, based on their Area Plans. All have a dollar limit per caregiver per year that can be spent. One AAA provides funding on a quarterly basis to caregivers and if they are in need of additional respite, that caregiver will need to reapply. Some of the AAA's will use a direct pay system to a provider or family member where an invoice is provided and the AAA pays the amount. Many AAA's also us a voucher system to provide to family caregivers so they can obtain their own respite relief. Some use a combination of both. Types of respite provided under the FCSP can be from another family member, friend or

Table 1. Oregon’s Caregiver Respite Programs

Program	Description
	someone from an in-home agency or a home care worker. Funds can also be used to minimize the cost of adult day services or a very short-term placement in a long-term care (LTC) setting such as an adult foster home, assisted living, or residential care facility. This program also allows up to 10% of the FCSP budget to be used for older relatives raising children. Respite for these caregivers can include day camps or overnight camps or other programs geared toward children that would allow the older relative to have a short break from this type of caregiving responsibility. Mid state fiscal year 2016, some AAA’s reported having used most if not all of their respite funding for the fiscal year. Others reported that they were close to spending their funds and others were providing respite services only to high-need individuals. There were only a couple of AAA’s that did not experience this shortfall of funds for respite care.
Oregon Project Independence (OPI)	OPI serves seniors and people with physical disabilities by providing services in their homes. These services may include personal and home care, chore services, adult day care, assistive technology, registered nursing services, home-delivered meals and service coordination. Services provided vary in areas. This program is funded through Oregon’s State General Fund. OPI was originally developed to provide in-home services to seniors to allow them to stay in their own home and delay placement into a long-term care setting. In 2014, a pilot program for younger people age 19 to 59 years was developed. This pilot is currently operating in certain areas in the state. Eligibility for OPI is based on level of need, and consumers at all income levels are eligible (there is no income eligibility limit). However, consumers pay a sliding scale fee that is based on their income. OPI consumers may not receive Medicaid federal benefits but can receive food stamps or be enrolled in a Medicare Savings Program (the Specified Low-Income Medicare Beneficiary Program). Due to limited funding, many AAA’s report running low on funds about half way through the year and develop a waiting list of clients and will serve those with the highest needs. Even though OPI is not considered a formal respite program, it does allow for a family caregiver or other natural support a brief break from caregiving when the OPI caregiver is in the home assisting the care receiver.
Veterans Benefits	Veterans of the United States armed forces may be eligible for a broad range of benefits and services provided by the U.S. Department of Veterans Affairs (VA). The VA offers a variety of benefits to veterans based on differing qualifying factors, but among them are services for home care, adult day programs, transportation to and from adult day programs, and respite services for family caregivers. Respite for individuals receiving veteran benefits is available at a veteran domiciliary. Two Eastern Oregon AAA’s have contracts with a VA hospital to provide OPI services to veterans who reside in their areas, and a VA hospital in Southern Oregon also has a contract with an adult day program in their area.
Not-for-Profit Organizations	Local chapters of the ALS Association, Parkinson’s Resources of Oregon, and the National MS Society will provide respite services for caregivers of individuals who have one of the conditions listed.

Table 1. Oregon's Caregiver Respite Programs

Program	Description
Private Pay	There are many options for people who pay privately for care. These options include adult day service programs, in-home care, LTC settings for overnight stays for a brief period of time. Another service in the Portland Metro area is Urban Excursions. Urban Excursions provides scenic rides and outings for those who are no longer able to drive, but enjoy getting out of their home for a change of scene.
Other Services	Other services that are available include: • Volunteer programs through churches and other non-profit organizations; • Senior centers and meal programs – especially in rural areas where care givers and care receivers can attend once or twice a week. Some senior centers will provide an activity for the care receiver while the caregiver can socialize with others or participate in another activity.

Barriers to Getting Respite

Although thousands of Oregon's seniors and their family caregivers receive some respite through existing programs, little is known about how many more may need services and the kinds of services that could serve them most effectively. Respite services may be underutilized for a variety of reasons including lack of awareness, personal resistance to seeking outside help, lack of affordability, and shortages of high-quality providers.

- ***Awareness.*** According to a 2014 report by the Family Caregiving Alliance, 33.4% of informal caregivers in Oregon don't know where to call to arrange for help in the home for an elderly relative or friend. Considering that the same report notes Oregonians are overwhelmingly white, it is likely that a good portion of people in diverse communities also do not know what care is available, and subsequently what value respite has in caregiving. Having knowledge of services and ability to access them vary among culturally and geographically diverse caregivers. Systemic barriers such as understanding how to navigate physicians, home health, pharmacists, skilled nursing facilities and all levels of care are particularly challenging for caregivers and especially challenging for people whose first language is not English. Caregivers learn by taking risks and often fear making a mistake in advocating for the care of their loved one.[21]

- ***Access to qualified providers.*** Shortage of highly skilled home care workers and limited respite service options and providers are barriers across the socioeconomic, cultural, and geographic areas. For example, Oregon has only 21 registered adult day services programs. This lack of access to services reduces the ability for them to effectively meet the needs of Oregon caregivers.

- ***Personal resistance.*** Family caregiving is personal, and many families may be reluctant to seek help. Personal resistance can be driven by a sense of obligation to family members, both implied and perceived. Personal resistance by caregivers and/or care receivers differs across cultural and geographical areas. For example, in Latino cultures, it is a family obligation to care for elders. Asking for help outside of the family might be considered a sign of weakness.[22] African American caregivers are more likely to provide higher levels of personal care, but are also more likely to receive help from friends, family, or religious community members.[23] Similarly, caregivers in the LGBTQ community may be reluctant to access care for fear of discrimination. In rural areas, many families experience higher poverty, a migration of young people to urban areas (which creates a caregiver shortage), and lack of health and transportation resources. However, even if resources are available, some rural caregivers might not choose to access resources due to stigma, denial, or high value on independence.[24]

- ***Affordability.*** Most families who might benefit from respite services will have to pay privately for that care. At the fourteen community meetings around Oregon, the cost of respite services was identified as one of the largest barriers to receiving respite. About 57% of attendees indicated that cost was a barrier. Some populations are especially at risk of facing financial barriers to accessing respite services. Studies show that ethnic minority caregivers have a lower socioeconomic status than white caregivers and that white caregivers are more likely than non-white caregivers to pay for professional support.[25] Rural caregivers are also likely to have challenges in affording care both due to lower incomes and the cost of accessing care over long distances.[26] Many caregivers also work full or part-time, and often leave the workforce early in order to provide care.[27]

Reducing the barriers

Oregon's caregiver support programs, including OPI and FCSP, have helped to address some of these barriers. In addition, enhanced information and referral services help to connect caregivers with supportive services. With the emergence in the past few years of Oregon's Aging and Disability Resource Connection (ADRC), seniors and people with disabilities can receive person-centered options counseling and be connected to services that will best suit them. Options counseling is "a process whereby individuals and family members are supported to develop a plan for addressing long-term services and supports needs that aligns with their preferences and needs." Options counselors help families connect with public and privately funded services, including respite services and other caregiver supports, as needed.[28] This system reaches thousands of people needing long-term services and supports every year, but many family caregivers don't access these resources or don't find financial support and services they need.

Indeed, according to a 2014 report from the AARP Public Policy Institute that ranks states' systems for delivering long-term services and supports, it appears Oregon has room for improvement when it comes to supporting family caregivers. Oregon—one of the top ranked states on most measures of LTSS system performance—ranks only in the bottom quartile of states on one measure of supporting family caregivers: the percentage of family caregivers without much worry or stress, with enough time, who are well-rested.[29] Greater awareness of existing services and programs as well as new solutions are needed to ensure that caregivers are able to continue to provide valued care without risking their own health and quality of life. Expanding and increasing respite care options in the state of Oregon is one way to address this issue and offer greater support to family caregivers.

A heightened attention must be given to how barriers affect minority communities. For example, the Hispanic/Latino population in Oregon has grown 72% since 2000, and this trend is expected to continue. During the process of crafting this report, the work group reached out to a variety of organizations representing ethnic minorities and the LGBT community to spread the word about the community meetings. We learned that research is in the planning phase at Oregon State University on the different challenges caregivers experience in diverse communities. We helped the OSU researchers connect with the Oregon Community Health Care Worker Association (ORCHWA) to assist in finding diverse caregivers for focus groups. While the research results are not available at this time, we anticipate the findings will help inform strategies for addressing the barriers unique to minority communities.

Recommendations to Improve Caregiver Respite Services in Oregon

The work group identified several strategies to reduce barriers to using caregiver respite services. The recommendations are designed to expand access to high quality and affordable respite that can reduce the strains of family caregiving. The work group recommendations are targeted to: (1) enhancing education and awareness, (2) increasing the supply of providers, and (3) making respite more affordable.

Improving Education and Awareness

The first set of recommendations seeks to improve education and awareness and thereby reduce barriers to seeking and using respite. The objective of our recommendations is to better connect older adults and their caregivers to services that meet their needs.

- **Launch a public awareness campaign**. Because relatively little is known about the extent of public awareness of respite programs and services, we recommend launching a public outreach campaign. We propose activities to assess consumers' knowledge gaps, educate family caregivers about available services, and increase understanding of how respite services can both help caregivers continue to provide care at home and improve family well-being.
- **Prepare trusted messengers to increase awareness and promote the value of respite**. We propose leveraging medical professionals and social service professionals, including health care providers, religious leaders, employers and other community partners, to increase awareness and uptake of caregiver respite services.
- **Expand targeted outreach to veterans and their caregivers**. We also recommend targeted outreach to selected populations for whom additional sources of support may be available, including veterans who may qualify for VA services for caregivers, such as support lines, adult day health care, and respite.[30]
- **Improve data collection on family caregivers and respite**. Finally, we highlight the need to improve understanding of caregivers and their needs through more systematic data collection and analysis to inform program design.

Increasing the Supply of Providers

The second set of recommendations addresses the real and perceived shortages of high-quality respite services in Oregon. The objective of these recommendations is to increase the supply and variety of high-quality respite service providers. Our recommendations include strategies to:

- **Improve the quality and quantity of home care workers who can provide respite services**. We recommend the Oregon Home Care Commission continue to implement strategies to expand and improve the home care workforce, including initiatives to create career ladders for home care workers. The Work Group calls on the Oregon legislature to provide funding as needed to achieve full implementation of the recommendations contained in the Commission's 2015 report on workforce development.
- **Update the administrative rules that govern adult day centers.** We suggest a review of the regulatory rules governing adult day care to ensure that there are no unnecessary barriers to entry for new providers, such as the six-month waiting period for certification required for Centers to become certified Medicaid providers.
- **Increase overnight respite option**s. The Work Group recommends establishing another working group to explore the feasibility of streamlining the process for overnight stays in licensed residential care settings and nursing facilities, and creating a new overnight model of respite.
- **Encourage hospitals, health systems, and Coordinated Care Organizations (CCOs) to consider ways to provide respite care**. We recommend that health providers and CCOs partner with organizations to expand access to respite care or establish PACE programs. We also note that new community benefit requirements for hospitals create an opportunity for hospitals to assess community needs for respite services and develop programs to fill in gaps in needed services.
- **Leverage community colleges and universities to expand access to respite.** We also recommend strategies for leveraging Oregon's community colleges and universities: they should explore opportunities to establish respite options, such as adult day centers, either on their own or in partnership with local non-profits. Such initiatives could provide practicum training opportunities for students and an affordable, high-quality respite option for community members.
- **Expand innovative models of delivering respite**. The Work Group recommends providing and expanding Medicaid, OPI, or FCSP funding for innovative models of respite, such as camps, mobile programs, time-bank models, host homes, and co-op models.

Explore ways to support volunteer-based programs**. We **recommend that stakeholders consider ways to increase financial and other kinds of support for volunteer programs so as to expand their reach in Oregon. Making Respite More Affordable

The third set of recommendations addresses the issue of affordability. We make recommendations for increasing state funding for existing and new programs to expand access to affordable respite care.

- **Increase state funding for existing respite care programs**. The Work Group recommends that the Oregon Legislature, beginning in 2017, provide state funding to supplement the federal dollars received for FCSP. These state funds should have fewer restrictions on their use, so as to allow for caregivers of individuals younger than 60 and without dementia to participate in the program. Additionally, we urge increased funding for Oregon Project Independence.

- **Explore the feasibility of developing a Medicaid waiver program to expand access to respite.** We recommend an effort to assess the feasibility of expanding access to respite care subsidies through a Medicaid waiver to reach older adults with income up to 400% of the federal poverty level.
- **Encourage employers to develop strategies to assist their employees who are family caregivers.** We recommend that private-sector employers assess caregiver needs among their employees and undertake strategies, including offering respite services, to help them balance caregiving and work.
- **Establish a system and funding for providing emergency respite.** The Work Group recommends that emergency respite be included in the implementation of other recommendations in this report. As stakeholders are discussing ways to increase the availability of overnight respite options, emergency respite—to address the needs of families in crisis who need services immediately—should be included.

The Work Group's detailed recommendations follow below.

Recommendations: Improving Education and Awareness

Recommendation #1: Launch a public awareness campaign about the benefits of caregiver respite and how to find services.

Background

Family caregivers often do not identify as family caregivers, and do not seek out help until they are overwhelmed with caregiving responsibilities. Even if they do identify as caregivers, they often do not know about respite as something they could benefit from. If they are interested in respite, often they don't know where to find services. And if they know about services and where to find them, there is often personal resistance to using respite. All of these barriers to using respite can be addressed by a well-structured public awareness campaign.

A common theme that emerged from the community meetings around Oregon was that family caregivers were unaware of how to find respite providers. This was a top issue in the Portland metro area, but it was consistently found across the state. Only about half the participants in the meetings were aware of the existence of the Aging and Disability Resource Connection (ADRC) as their best source for finding respite. Participants also expressed distaste for the term "respite" and preferred the terms "a short break" or "caregiver relief," but there was no consensus on which term was most effective.

Another major barrier to using respite that was identified was personal resistance, either by the caregiver or the care recipient. For example, caregivers feel guilty about getting relief from caregiving, and care recipients often don't want someone coming into their home. Individuals feel vulnerable around new people, or experience separation anxiety when apart from their loved one.

Recommendation

What: The Work Group recommends that the State of Oregon provide funding for a public awareness and education campaign that addresses all these issues. The campaign should be a partnership between the OHA Public Health Division and the State Unit on Aging, so as to benefit from the knowledge and skillsets of each agency. Phase 1 of the campaign should focus on message testing to find the best ways to inform the public about the value of respite, how to access it (contacting the ADRC), and how to talk about it. Phase 2 should be an implementation phase, and should be funded sufficiently to reach the target audience. This work must include consideration of different messages, different messengers, and different languages for different minority communities.

Who: Partnership between the State Unit on Aging and the OHA Public Health Division.

When: Begin work in 2017, launch campaign in early 2018.

Cost: To Be Determined. In Phase 1, funding would be needed for focus groups, research, and message testing. In Phase 2, funding would be needed for materials and media buys.

Recommendation #2: Prepare trusted messengers to increase awareness and promote the value of respite.

Trusted messengers include health care providers, religious leaders, employers, and other community partners.

Background

When someone assumes the role of family caregiver, they often do not identify as a caregiver, and therefore do not look for assistance that can help make them better caregivers and take care of themselves. Every person has certain individuals in their lives who they trust, and can help them navigate the caregiving journey. These individuals need to be empowered with knowledge to help caregivers understand the benefit of and how to get much needed respite from caregiving.

Health care providers of all kinds, doctors, nurses, social workers, etc. all should be provided more resources about the benefit of respite and where to find services that can be provided to caregivers. Often, it is in a health care setting that a person learns they will become a caregiver for a loved one. At that time, they are looking to their providers for information on what they should do. A well trained provider would be able to share an effective message about the value of seeking respite for both the caregiver and the care recipient. Providers should also be prepared to offer information about the ADRC as the most comprehensive resource for accessing and affording respite services.

Recommendation

What: The Work Group recommends that respite advocates engage with provider organizations to:

- Provide continuing education units about respite to providers at existing conferences.
- Work with existing sources of information that providers trust, such as medical journals and other news sources to keep information flowing to providers.
- The State Unit on Aging should ensure that health care providers’ offices are stocked with materials about the ADRC.
- Ensure all materials and strategies are culturally and linguistically appropriate and address the special needs of the LGBTQ community and other minority populations.

Besides health care providers, caregivers often receive guidance from a variety of other community contacts. These trusted messengers need to be prepared to provide quality information to caregivers about respite. We recommend that advocates reach out to and provide information about respite to the following:

- Clergy/Religious leaders
- Community Health Workers
- Non-profit service organizations
- First responders
- Employers, particularly Employee Assistance Programs (EAPs)
- Libraries

Multiple stakeholders should be involved in the implementation of this recommendation. However, if a new program within the Oregon Department of Human Services (DHS) is established to promote respite, they should take the lead on this initiative.

Who: Partnership between ADRC, AARP, and other community partners

When: Ongoing

Cost: Within existing resources

Recommendation #3: Expand benefits outreach to older veterans and their caregivers
Encourage Oregon's older veterans to apply for VA benefits for which they may be eligible, including home care, adult day care, and family caregiver respite services.

Background

Veterans of the United States armed forces may be eligible for a broad range of benefits and services provided by the U.S. Department of Veterans Affairs (VA). The VA offers a variety of benefits to veterans based on differing qualifying factors, but among them are services for home care, adult day programs, transportation to and from adult day programs, and respite services for family caregivers.

There are thousands of veterans in Oregon who could be receiving services that provide respite to their family caregivers from the VA, but have not applied for benefits. Approximately 326,000 Oregonians are veterans, but about 70% of them do not access any VA benefits. The Oregon Department of Veterans' Affairs (ODVA) encourages veterans to meet with their local Veteran Service Officer (VSO) to help veterans navigate the VA system and access their benefits. However, they have found that many veterans do not realize they are eligible for benefits or they feel they would be taking benefits away from someone "more deserving." Senate Bill 241, passed by the Oregon Legislative Assembly in the 2011 legislative session requires state agencies to ask if a customer or client is a veteran and to provide information to veterans from the ODVA and reintegration team within the Oregon Military Department. While it has not been the only factor, ODVA can point to a consistent and significant increase in claims filed since this legislation went into effect.

At the fourteen community meetings around Oregon about respite, the cost of respite services was identified as one of the largest barriers to receiving respite. About 57% of attendees indicated that cost was a barrier. Additionally, over 18% of attendees indicated that transportation was a barrier to using respite. VA benefits in many cases can address both of these barriers without using any state funds.

Recommendation

What: The Work Group recommends that the VA and ODVA collaborate on an outreach plan with multiple stakeholders to encourage veterans to meet with their local VSO. These stakeholders would include trusted messengers, such as AARP, health care providers, clergy, Employee Assistance Programs, and others.

Who: Partnerships between the U.S. Department of Veterans' Affairs, the Oregon Department of Veterans' Affairs, and other stakeholders

When: Ongoing

Cost: To be determined

Recommendation #4: Improve data collection on family caregivers and respite needs.

Background

The recognition of family caregivers as a population that needs support is a relatively new concept. At the federal level, the National Family Caregiver Support Program within the Older Americans Act was only established in 2000, and remains the highest profile program that singles out family caregivers as a population deserving help. Research has long shown the benefits of family caregiving in terms of keeping people in their own homes and preventing or delaying use of costlier government programs like Medicaid, but only recently has the negative impact of caregiving on caregivers been demonstrated.

Respite is one of the key ways to help relieve caregivers of the stress of caregiving. However, state agencies in Oregon do not collect much information about the use of respite through state services. In part this is because of the conflation of who benefits from a given service. Most data collected is focused on a care recipient, but certain services benefit the caregiver as well. For example, if Medicaid provides a client with some assistance with Instrumental Activities of Daily Living, it can help the caregiver take a few hours break from caregiving during that time. However, the data collected shows a benefit only for the care recipient in that instance.

To improve services and inform policy development, more and better information is need and more systematic data collection across the state is needed.

Recommendation

What: The Work Group recommends Oregon DHS improve their data collection and analysis of use of respite in Oregon. This information will then be used to make informed policy decisions on most effective use of state resources for helping family caregivers. Oregon DHS should convene a group to discuss what information about respite and family caregiving should be collected and how it should be performed. We recommend the data collected include all populations that benefit from respite, including family caregivers of older adults, as well as foster parents, grandparents raising grandchildren, and families with children with developmental disabilities. Data should also be explicitly collected regarding the impact of caregiving and supports on minority communities so as to inform appropriate approaches in those communities. A particular focus should be on using the data for benefit-cost analysis of caregiver supports.

Who: Oregon DHS.

When: Ongoing.

Cost: To be determined.

Recommendations: Increasing the Supply of Providers

Recommendation #5: Improve the quality and quantity of home care workers who can provide respite to family caregivers in the home.

Background

The most popular and common method family caregivers receive respite from a professional is through home care. There are several ways family caregivers can hire a home care provider – through a home care agency, through the Oregon Home Care Commission Registry, or through advertisements such as on Craigslist.com or bulletin boards.

Community feedback from the fourteen community meetings about respite held around the state indicated home care is the most popular method of receiving respite for family caregivers, with over 65% of the 400 participants indicating an interest in using home care. Many home care and personal support workers are members of ethnic minority communities, and provide services in languages other than English, which helps to alleviate barriers in those communities. However, family caregivers, as well as Area Agency on Aging staff, indicated there was often a shortage of quality home care workers available to provide respite, particularly in rural areas of the state. There are fewer options available for respite services in some areas because there is a lack of in-home agency presence.

A shortage of quality home care workers around the state is not a new concern. The 2015 Oregon Legislature passed Senate Bill 774, which directs the Oregon Home Care Commission to adopt a statewide plan to increase the workforce of home care and personal support workers available to provide in-home services to seniors, people with physical or intellectual or developmental disabilities, and individuals experiencing mental illness. The Oregon Home Care Commission (OHCC) is included in the Oregon State Constitution and is responsible for ensuring the high quality of home care services funded by the Department of Human Services for seniors and people with disabilities. OHCC created and maintains a statewide Registry of qualified homecare and personal support worker available to the public and provides training opportunities for workers. The scope of the OHCC, however, does not include workforce development for in-home care agencies. Consequently, the Work Group has included a recommendation (as part of recommendation #9 that relates to leveraging community colleges and universities) that encourages colleges and universities to enhance training for the in-home care workforce, and, in particular, to go beyond the OHCC to include home care workers employed by home care agencies.

The OHCC, with the assistance of the Worker Classification-Workforce Development Committee established by the OHCC, was charged with investigating potential strategies to increase the workforce comprised of home care and personal support workers. The committee's vision is that individuals will have access to supports and services from a qualified, trained, and diverse workforce. The committee, made up of in-home services consumers, stakeholders, community partners, advocates, subject matter experts, and OHCC Commissioners, has established a number of goals related to workforce development and retention.

The committee's report – published in November of 2015 and delivered to the Legislature – noted that:

> *"Increasing the home care workforce is urgent for multiple reasons. The senior population is the fastest growing population in the world. From 2009–2020, it is anticipated the senior population in Oregon will increase by 57 percent. There is already a shortage of workers available to provide assistance to individuals living at home, which will become even more pronounced as the population ages and the ratio of available workers decreases."*

The Worker Classification-Workforce Development Committee's report recommends:

1. Efforts to remove barriers for new home care workers to enter the workforce;
2. Ways to increase the number of home care workers on the registry maintained by the OHCC;
3. Strategies for creating a career ladder/lattice for home care workers; and
4. Assessing the feasibility and benefits of certifying home care workers.

Recommendation

What: The Work Group recommends that the Oregon Home Care Commission continue to implement the recommendations it presented to the legislature. The Work Group also recommends that the Oregon Legislature provide any necessary resources to the OHCC for the full implementation of the recommendations. We also recommend that a special focus be placed on recruitment of home care workers in ethnic minority communities to ensure a sufficient workforce who can provide respectful, culturally and linguistically appropriate services.

Who: Oregon Home Care Commission and related stakeholders.

When: Ongoing.

Cost: To be determined.

Recommendation #6: Update the Oregon Administrative Rules that govern adult day centers to ensure they do not create unnecessary barriers to entry.

Background

Adult day centers are a popular service for several reasons. They charge less than home care, so they serve as a respite option that more people can afford. Adult day centers provide socialization and enrichment that is not available if the care recipient is isolated at home. Also, because some people are not comfortable having a home care worker come into their home, adult day centers offer an option for respite that avoids that concern.

However, there are only about twenty adult day centers in the entire state, with only one east of the Cascade Mountains (in Redmond). In the Eugene area, there is only one (in Springfield), and it does not accept Medicaid clients. Most of these adult day centers are certified to accept Medicaid payments, and their business model requires them to do so to ensure enough clients to stay in business.

Adult day centers are governed by Oregon Administrative Rules (OARs) Chapter 411.66; they cover registration, certification, and standards.[31] These rules include a six-month waiting period after a center opens before they can become certified by the state to bill Medicaid. While this waiting period has some flexibility in practice, it is clearly a barrier to entry for some potential providers, which leaves communities and caregivers in need of services without an adult day center. These rules have not had a full review since 2007.

During a community meeting in Bend, we heard the story of a group of entrepreneurs who had qualifications, skills, and desire to open an adult day center in an area that lacks the service. When they discovered they would need to operate for six months before they could include certain people in need of the service, they decided against moving forward with their plan.

Recently, another potential adult day center provider in the mid-Willamette valley was hoping to establish a center, with Medicaid being the projected source of payment for services. In this case, the six month wait period for Medicaid billing was a barrier because potential clients did not have the resources to pay privately for care. The provider would have no income or operating costs for six months, therefore prohibiting her from establishing the program. Other care settings do not have this delay requirement, and it is unclear what purpose it truly serves.

Recommendation

What: The Work Group recommends that Oregon DHS APD opens a rulemaking process on the adult day center OARs to modernize and update the rules based on lessons learned since adult day centers began operating in Oregon, and ensure that unnecessary barriers to entry into the field are eliminated.

Who: Oregon DHS APD and relevant stakeholders.

When: Early 2017.

Cost: Within existing resources.

Recommendation #7: Increase overnight respite options.

Background

Often, a few hours of respite are not enough to truly recharge a family caregiver to the point that their stress has been reduced. Additionally, family, work, and social commitments require family caregivers to travel for several days at a time. Access to overnight respite appears to be more limited than other forms of respite. Ensuring that your loved one is safe and cared for overnight or for several days is a difficult task.

Hiring a home care worker to stay overnight is difficult to find and expensive. Some long-term care settings will take people for short term stays, but they are reluctant to do so. This is because they must do all the same paperwork for intake and discharge for a three-day stay that they would for a three-year stay, and this can be burdensome. Long-term care settings do not receive higher reimbursement rates for providing short term stays.

Overnight and multiple day respite is a popular concept among caregivers. At the 14 community meetings held by the Work Group, over 50% of the attendees were interested in using this kind of service. One individual in Albany noted that he used to look forward to going to funerals in other states, because he knew he could convince someone to look after his loved one for the weekend. Many caregivers also note that they sleep poorly because they have to keep checking on their loved one, and quality of sleep is a major contributor to one's overall health.

Recommendation

What: The Work Group recommends exploring the feasibility of streamlining the process for overnight stays in licensed residential care settings (assisted living, residential care and foster care) and nursing facilities; and creation of a new overnight model of respite. We recommend establishing a workgroup that would:

- Review existing policies and procedures for community-based care settings (assisted living, residential care and adult foster care) and nursing facilities to outline requirements and the process that providers would follow to offer short "respite" stay within each of the service settings.
- Identify the steps in the process that could be streamlined/"waived" in order to make it more feasible for such settings to offer respite services.
- Identify actions needed to streamline the process, where feasible.
- Develop instructions for providers and state staff on how respite services can be provided under the new "streamlined process".
- Disseminate new process via multiple means (administrative alert, provider association communication vehicles, webinars, conferences)
- Brainstorm other models of overnight respite that could potentially be developed.

Who: Adults and People with Disabilities Program/Licensing staff, staff representatives from LeadingAge Oregon, Oregon Health Care Association, AARP, and the Alzheimer's Association, and provider representatives from community-based care settings and Nursing Facilities.

When: Workgroup formed in 2017 with work finalized by December 2017.

Cost: Within existing resources.

Recommendation #8: Encourage hospitals, health systems, and coordinated care organizations to consider ways to provide respite care, as a service or in partnership with local non-profit respite providers.

Background

Oregon's health system has been dominated in recent years by the mantra of the "Triple Aim" of Better Care, Better Health, Lower Cost. These are the guiding principles for our health care transformation and the role of the Coordinated Care Organizations (CCOs) in providing care to the Medicaid population. However, the Triple Aim is a worthy goal beyond the CCOs and should apply to the overall health care system in Oregon. Family caregiver respite can help achieve the Triple Aim.

Multiple studies indicate that family caregivers generally suffer poorer health as a result of being a caregiver. The Alzheimer's Association estimates that the approximately 178,000 family caregivers for people with Alzheimer's in Oregon (about 40% of the total population of family caregivers), have about $110,000,000 in higher health care costs annually due to their role as caregiver. It is well documented that the stress of family caregiving can lead to higher rates of depression, stroke, and heart attack.

If a caregiver experiences high stress levels or stress-related illness, the quality of care they provide will decrease. A happy, healthy caregiver is an effective caregiver. Along with caregiver training, respite can help prevent caregiver burnout and lead to better, more sustainable, provision of care.

Health care systems' role regarding respite is not a new idea. Today, Providence Health Systems partners with Volunteers of America at two adult day programs in Portland. At these sites, Providence offers participants in their Program of All-inclusive Care for the Elderly (PACE) the option of attending adult day programs, with medical care available on-site, and they benefit from the socialization and enrichment at the adult day center. Transportation is provided to and from the client's home by Providence Elder Place. The family caregivers for these clients benefit from the break from caregiving. PACE is jointly funded by Medicaid and Medicare (and serves beneficiaries who are dually eligible for these programs), and should be replicated in other parts of Oregon.

Providence also has a program in Hood River called Volunteers in Action which funds staff to organize volunteers to assist community members with basic services, including respite. They provide this as part of the community benefit requirement that non-profit hospitals must fulfill. As charity care decreases (due to increased numbers of insured individuals), hospitals need to look elsewhere to meet the community benefit requirement. Family caregiver respite is an opportunity to fulfill the requirement for community benefit while improving community health.

Recommendation

What: The Work Group recommends that hospitals, health systems, and CCOs should consider ways to provide respite care as a service, to make sustainable investments in community-based resources, or to partner with local non-profit respite providers to improve access to and quality of family caregiver respite throughout Oregon. Examples include:

- Hospitals, health systems, and CCOs examine how to provide respite through the PACE model.
- Hospitals, health systems, and CCOs work with communities to explore establishment of respite programs that can be supported through sustainable community benefit investment obligations, such as partnering with existing respite providers, supporting trained, paid health workers programs and volunteer programs that provide respite, providing space to community organizations interested in establishing respite programs, or setting up programs of their own.
- Hospitals, health systems, and CCOs work with communities in determining local needs for respite services, work that could also possibly align with local Community Health Improvement Plan (CHIP) efforts, and then making durable investments in developing sustainable programs that meet community needs.

Who: Oregon's hospitals, health systems, and Coordinated Care Organizations.

When: Planning begins in 2017, with service delivery commencing in 2018.

Cost: To be determined.

Recommendation #9: Leverage community colleges and universities to expand access to affordable, quality respite services

Background

At the community meeting in Roseburg, a participant suggested that perhaps Umpqua Community College could "get in the respite game" by setting up an adult day center on campus. As the conversations continued around the state, significant enthusiasm was expressed for this concept as it was fleshed out further. This concept addresses three barriers to using respite: (1) the lack of qualified providers, (2) the lack of services available in the community, and (3) the cost of services being financially out of reach for many. If a community college offered respite services, it could provide students in relevant programs with practical skills they will need in their career, it offers a new service to an underserved community, and because students are providing some of the services, the cost to the consumer would likely be lower than what a traditional provider would charge.

According to the National Center for Education Statistics, "The percentage of American college students who are Hispanic, Asian/Pacific Islander, Black, and American Indian/Alaska Native has been increasing."[32] This trend implies that Oregon's ethnic minority communities may benefit from increased training opportunities at their school.

This idea could take several forms. For example, a college could open an adult day center on campus, utilizing a mix of students and professionals. This could also provide students who are caregivers with a free or significantly discounted service that could help them continue their education, as some students have been known to drop out of school to take care of their loved ones.

A college in Oregon could also use the model created by Temple University's "Time Out Program." In this program, college students are trained to provide caring companionship and supervision while creating a safe and stimulating environment for the frail elderly. Additionally, they may help with meal preparation, laundry, changing bed linens, light grocery shopping, and assistance into the bathroom, as well as serve as medical escorts. They do not provide personal care (i.e. bathing, dressing, feeding), cleaning, transportation, or administer medication or therapies.

Colleges also could expand on existing practices that place students in relevant fields in practicums with community respite providers to earn credit while they learn. Some adult day centers in Oregon currently have relationships with the local college. For example, the Grace Center in Corvallis helps train students from Oregon State University on a regular basis.

In any of these potential models, students in marketing programs could also learn skills by creating a marketing campaign for the respite services. Each college could creatively find other ways to provide students with learning opportunities even if they are not in a program that is directly related to the provision of respite to caregivers.

Recommendation

What: The Work Group recommends that Oregon's community colleges and universities consider establishing respite services through the college as a learning opportunity for students, while also providing the community with a needed service at an affordable price. We encourage community colleges and universities in areas where there is a lack of respite providers to explore establishing respite options, such as adult day centers, either on their own or in partnership with local non-profits, to provide practicum training opportunities for students and provide an affordable, high-quality respite option for community members. The Work Group also recommends that colleges and universities work with community partners to develop/enhance training and curriculum to expand the availability of home care workers beyond the scope of the OHCC

- As all colleges have their own processes for planning, we encourage those with relevant programs, such as gerontology, allied health professions, Certified Nursing Assistant, social work, and others to use their long-term planning process to consider this recommendation.
- Colleges could consider phasing in their involvement, starting with what is immediately feasible (e.g., promoting Community-Based Learning and internship opportunities through existing adult day centers or other non-profit programs), while also exploring long-range opportunities to adopt more robust models, like setting up an adult day center on campus, as their own project or as a partnership with local non-profits.
- We recommend colleges consider respite as an educational opportunity and community service as they prepare bond proposals that would be voted on by their local community. More expansive programs, such as an on-campus adult day center would benefit from being included in a bond proposal.
- We recommend that colleges work with community partners such as local non-profit service providers, their local Area Agency on Aging, and local businesses, particularly health care providers, in appropriate roles such as outreach, referral, and training.
- Efforts should describe specific expectations to ensure access to respite and education that meets the needs of diverse populations.

Who: Oregon's community colleges and universities

When: Ongoing

Cost: To be determined

Recommendation #10. Expand innovative models of delivering respite services, such as camps and co-ops.

Background

Oregonians have limited options for respite. Where communities *are* able to access adult day centers (ADCs), they can be an integral service for many families in need of respite. Unfortunately, ADCs are the only formal entity respite provider eligible for a Medicaid contract in Oregon. Yet, adult day does not necessarily meet all caregivers respite needs and they do not exist in many Oregon communities.

There are many existing innovative respite programs currently in Oregon, nationwide, and internationally that are changing the way people receive caregiver support. For example:

- Locally, serving Clackamas, Multnomah and Washington counties, there is a program called **Urban Excursions** which provides weekly social outings for seniors with Alzheimer's disease or other forms of dementia. This unique respite program is a door-to-door pick-up and drop-off service that allows the individuals receiving services to connect with peers in a social setting and participate in the community. Transportation barriers are eliminated due to the door-to-door service, caregivers are given a four-hour break, while caregivers can be guilt-free know their loved-ones are engaged in a fun outing.

- In California, a **Caregiver Co-operative Program** is operated by the Asian Community Center. This co-op model allows caregivers to "buy" caregiving time for their family member when they volunteer at least once a month. Once a week, the center opens and provides up to five hours of recreation, socialization, physical exercise, and mental stimulation to older adults with dementia and physical limitations. By implementing this co-op model, the financial burden of respite is eliminated while providing culturally-sensitive activity.

- Australia has an innovative program called **Host Home Respite**. The host-family respite program was developed to provide a service catering to the needs of people with dementia who are not suitable to mainstream respite care or who are reluctant to go to a kind of adult day program due to stigma or other reasons. This program is modeled after an existing Family Day Care model where smaller groups (approximately four to five families) open up their homes once per week to welcome members of their group for respite. The result is a more relaxed and family friendly atmosphere which may be more appropriate for some people while providing weekly respite for caregivers.

Recommendation

What: The Work Group recommends providing and expanding Medicaid, OPI, or Family Caregiver Support Program funding for innovative models of respite, such as camps, mobile programs, time-bank models, host homes, and co-op models. Medicaid should expand their contracts to include a breadth of respite services that offer the flexibility necessary to meet the individual needs of clients and caregivers. This would allow for the much needed development of innovative programs, allow access to existing respite programs not covered by Medicaid for low-income families, and encourage development of alternatives to ADCs, particularly in rural communities with no other respite options. Consideration should be made to create and support specialized respite models that meet the needs of diverse populations.

Who: Oregon DHS and stakeholders

When: Ongoing.

Cost: To be Determined.

Recommendation #11: Explore ways to support volunteer-based programs that provide caregiver respite and other caregiver supports.

Background

Volunteer programs that provide respite and other caregiver supports can be extremely valuable for caregivers under certain circumstances. Generally, volunteer programs are not the best choice if the care recipient has significant needs, but there are many families that can benefit from these services. Volunteer programs can provide services at little or no cost to families, while also providing the volunteers with a sense of purpose.

Several volunteer programs exist today in parts of Oregon, such as the Senior Companion program, Retired Senior Volunteer Program (RSVP), Friendly Visitor, and Senior Peer Counseling. These programs match volunteers with families in need, and can provide relief for the caregiver, some simple services for the care recipient, and some programs offer transportation to individuals. An example of where this is working well and could be expanded on is Clackamas County Social Services (CCSS). They operate a significant volunteer program, including RSVP, Senior Companion (SCP), Transportation Reaching People, Money Management, SHIBA and more. CCSS has funding and a new contract and funding with CareOregon to expand SCP to provide services in the metro area for CCO clients.

Recommendation

What: The Work Group recommends that several stakeholders consider ways to increase financial and other kinds of support for these volunteer programs so as to expand their reach in Oregon. Recruitment efforts should have specific goals to recruiting in diverse/minority communities. We recommend three sets of activities:

- First, Oregon DHS should examine the level of support it currently provides to volunteer programs and consider the cost-benefit of supporting volunteers. DHS should explore expanding technical assistance to anyone interested in providing respite services through a volunteer program, as well as providing modest funding.
- Second, health systems and CCOs should examine what they can do to support volunteer programs. An example of this in action is in Hood River, where Providence Hood River Memorial Hospital operates the Volunteers in Action program, using community volunteers to provide a variety of supports to caregivers in the region.
- Third, Oregon businesses should consider support for volunteer programs that provide respite and other caregiver supports. This support could be financial, allowing employees to be paid while volunteering, or by providing in-kind services or donations to the volunteer program.

Who:	Oregon DHS, health systems and CCOs, and Oregon businesses.
When:	Ongoing.
Cost:	To be determined.

Recommendations: Making Respite More Affordable

Recommendation #12: Increase state funding for existing programs that provide respite to allow them to serve considerably more families in need of respite.

Background

The National Family Caregiver Support Program (FCSP) is primarily funded through the Older Americans Act and is implemented through local Area Agencies on Aging (AAAs). There are multiple services that these funds can be used for, including respite. The unique aspect of the FCSP is that its focus is on the caregiver, not the care recipient. Often, but not always, the AAA provides a voucher to the caregiver to seek respite. Types of respite provided under the FCSP can be another family member, friend or someone from an in-home agency or a home care worker. Funds can also be used to minimize the cost of adult day services or a very short-term placement in a long-term care (LTC) setting such as an adult foster home, assisted living, or residential care facility.

Mid fiscal year 2015 – 2016 some AAAs reported having used most if not all of their respite funding for the fiscal year. Others reported that they were close to spending their funds and others were providing respite services only to high-need individuals. There were only a couple of AAAs that did not experience this shortfall of funds for respite care. These federal funds have restrictions that include the care recipient is over the age of 60 or has dementia. This prevents caregivers of younger people who have significant needs from being able to utilize these services. Currently, FCSP receives about $1.9 million per year from the federal government.

Oregon Project Independence (OPI) is a program providing a variety of services to Oregonians age 60 and older or have Alzheimer's disease or a related disorder who cannot receive Medicaid services. These services are intended to support their independence and allow them to remain in their home as long as they wish. To qualify for OPI, a person must need some type of in-home assistance based on an assessment done by a Case Manager. Additionally, a pilot program has begun to serve younger individuals with disabilities who are not receiving services through Medicaid. OPI is currently funded at approximately $20 million per biennium plus $6 million for the pilot program. With OPI, the qualifying individual is the care recipient, not the caregiver.

Individuals at or below Federal Poverty Level receiving OPI services pay a one-time participation fee of $25. Additionally, a monthly sliding scale fee is charged for services based on household income, after deductions for medical expenses. At the fourteen community meetings around Oregon about respite, the cost of respite services was cited as one of the most significant barriers to receiving respite. About 57% of attendees indicated that cost was a barrier. OPI helps caregivers get some breaks from caregiving at a lower cost than they otherwise could.

OPI is not considered a respite program, however, it does allow for a family caregiver or other natural support to get a brief break from caregiving when the OPI caregiver is in the home assisting the care receiver. OPI provides the following services that can provide a break for caregivers:

- In-home services provided to maintain, strengthen, or restore an individual's functioning in their own home;
- Assistance with tasks such as: housekeeping, laundry, meal prep, medication management, shopping, transportation, bathing/dressing, personal hygiene/grooming, ambulation/transferring, eating.

OPI also provides a variety of other services that allow individuals to remain in their homes longer such as home modifications and case management. One of the benefits of OPI often cited by people who are familiar with the program is that it has enough flexibility to provide appropriate services tailored to an individual situation. By helping older adults who need supportive services stay in their own homes longer, it delays when a family spends its resources down to the point of being eligible for Medicaid services. Any delay of entry to Medicaid long-term care helps save the state money over the long term. OPI is exclusively funded through the State General Fund.

OPI is administered by Area Agencies on Aging (AAAs) throughout Oregon. Most AAAs report that they run out of OPI funds about half way through each year and keep a waiting list of consumers who wish to receive help through this program. Additionally, there are many families who would benefit from OPI services but are not aware of the program.

Recommendation

What: The Work Group recommends that the Oregon Legislature in 2017 provide state funding to supplement the federal dollars received for FCSP. Additionally, these state funds should have fewer restrictions on their use, so as to allow for caregivers of individuals younger than 60 and without dementia to participate in the program. We recommend allocating $4 million per biennium to this item.

We also recommend that the legislature increase funding to OPI so it can serve many more individuals. Because funds run out about half way through the year, and there are many more people who could benefit from the program, we recommend increasing funding for OPI from $20 million to $50 million per biennium. Additionally, we recommend the pilot program be expanded statewide, which would take it from $6 million to $15 million per biennium. Combined, this would increase the total expenditures for OPI by $39 million per biennium to a total of $65 million. Cost savings would ultimately be realized by delaying entry into the Medicaid system and delaying entry into higher levels of care. In addition to funding, we recommend the Oregon Administrative Rules be revised for OPI to establish a higher priority to ensuring caregivers receive respite.

Who:	Oregon State Legislature, Oregon DHS.
When:	2017 Oregon legislative session.
Cost:	$43 million biennially.

Recommendation #13: Explore the feasibility of developing a Medicaid waiver program to expand access to caregiver respite services

Background

At the fourteen community meetings around Oregon about respite, the cost of respite services was cited as one of the most significant barriers to receiving respite. About 57% of attendees indicated that cost was a barrier. Individuals who are close to the financial eligibility level for Medicaid naturally are the most likely to cite cost as a barrier, and also could easily become eligible for full Medicaid long-term care benefits if they must pay for respite out of pocket.

Section 1115 of the Social Security Act gives the Secretary of Health and Human Services authority to approve experimental, pilot, or demonstration projects that promote the objectives of the Medicaid program. The purpose of these demonstrations, which give states additional flexibility to design and improve their programs, is to demonstrate and evaluate policy approaches such as:

- Expanding eligibility to individuals who are not otherwise Medicaid eligible;
- Providing services not typically covered by Medicaid; or
- Using innovative service delivery systems that improve care, increase efficiency, and reduce costs.

AARP has crafted a proposal called RELIEF (REspite: Living Independently, Energizing Families), a limited respite care benefit that would be made available to those with incomes up to 400% of the federal poverty level (FPL). Oregon could construct a sliding fee scale so that those of higher incomes would be able to "buy-in" to these services. Also, current funding for respite, such as through Oregon Project Independence, could be used to match federal funding. The service could be structured to provide family caregivers with a "bank" of time for a given year. Respite services could be accessed in 4-24 hour increments throughout the year, until the bank of time is depleted.

Both the federal and state government would benefit by providing a more cost-effective alternative of limited Home and Community Based Services (HCBS) that would prevent, delay or slow the process of persons spending down to full-benefit Medicaid eligibility. The waiver could also reduce the number of persons who need longer term and higher cost HCBS waiver services or nursing home care funded by Medicaid. Some states might also be able to obtain federal matching funds for previously unmatched funds used to provide state-funded HCBS.

Recommendation

What: The Work Group recommends that in 2017, Oregon DHS engage with decision makers and other stakeholders to explore the feasibility of applying for a RELIEF waiver under Section 1115. DHS should explore development of a Section 1115 Medicaid waiver that would allow the state to provide respite services to individuals with income up to 400% of the federal poverty level. Factors that need to be considered include conflicts with other Medicaid waivers, the general fund costs and potential savings, and the record of success in states that have already considered this concept.

Who: Oregon DHS.

When: 2017.

Cost: Within existing resources.

Recommendation #14: Encourage employers to develop services and strategies to assist employees who are family caregivers

Background

Because the number of employees with eldercare responsibilities is on the rise, employers need to better understand the impact of family caregiving on work, including how employees manage work and caregiving responsibilities. Often, the most valuable employees are in their 40's and 50's, and the average age of a family caregiver is 49. An estimated 61 percent of family caregivers of adults age 50 and older are currently employed either full-time (50 percent) or part-time (11 percent).[33] U.S. businesses lose up to $33.6 billion per year in lost productivity from full-time working caregivers. Costs associated with replacing employees, absenteeism, workday distractions, supervisory time, and reductions in hours from full-time to part-time all take a toll. The average annual cost to employers per full-time working caregiver is $2,110. Nearly seven in ten (68 percent) working caregivers report reducing their professional productivity to accommodate caregiving. This may include arriving late/leaving early or taking time off, reducing work hours, changing jobs, or stopping work entirely.

Studies have documented that eldercare programs can benefit both employers and employees, improving worker retention, productivity, stress levels, and health among workers. Effective workplace programs include referral to caregiver resources in the community, on-site support groups for working caregivers, and discounted back-up home care for emergency needs. Employers have found eldercare benefits to be a competitive advantage both in new employee recruitment and retention of existing employees. A recent report notes that for every dollar invested in flexible work schedules, businesses can expect a return on investment of between $1.70 and $4.34, and for every dollar invested in telecommuting option, a return of between $2.46 and $4.45.[34] Additionally, many large employers in Oregon have onsite day care for children, but none, as far as we know, have an adult day center onsite or offers employees a discount at a local provider.

Recommendation

What: The Work Group recommends that employers should examine their policies to see how they can help their employees who are family caregivers for older adults. Employers should determine how many of their employees are caregivers, and if their Employee Assistance Program is versed on providing resources and advice to caregiving employees. Where they do not exist, employers should explore establishing policies such as paid family/medical leave, flexible work schedules, and offering eldercare benefits. Additionally, large companies should explore providing an onsite adult day center, similar to the provision of onsite child care, if there is a critical mass of employees who could benefit from such a service.

Who: Oregon’s private-sector and public-sector employers.

When: Ongoing.

Cost: To be determined.

Recommendation #15: Establish a system and funding for providing emergency respite to family caregivers in crisis.

Background

Sometimes respite is needed in an emergency situation to prevent the exacerbation of a family crisis. When emergencies arise and a family caregiver becomes ill or cannot provide care for other reasons, emergency respite becomes an invaluable resource. Emergency respite, sometimes also known as crisis care or crisis respite, is short term care that may last from one hour to several weeks depending on the needs of the primary caregiver and may take place in-home or out-of-home. Emergency respite services not only provide the temporary care a family might need, but link families to more comprehensive support services if necessary. When dealing with the most vulnerable families, these services have also been shown to help prevent abuse or neglect.

Oregon has no specific provisions for providing emergency respite.

Recommendation

What: The work group recommends that emergency respite is included in the implementation of other recommendations in this report. As stakeholders are discussing ways to increase the availability of overnight respite options, emergency respite should be explicitly included. As rules are being written or revised on increased funding to existing programs, some funds should be set aside to provide for emergency respite. Additionally, DHS should explore streamlining and expediting the exception process for Medicaid HCBS so that emergency respite can be attained for Medicaid consumers quickly.

Who: Oregon DHS and stakeholders.

When: 2017.

Cost: To be determined.

Next Steps

Family caregivers are the backbone of long-term care in Oregon. With this report, the Work Group hopes to foster a conversation about the needs of family caregivers and how state government, private employers, and people and organizations in communities across Oregon can do more to address these needs. In the months ahead, the Work Group will present our recommendations and seek to develop the partnerships needed to advance policy. Our goal is to foster a more robust infrastructure for respite services that works to address the needs of older adults and their family caregivers.

Notes

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[1] AARP Public Policy Institute, and National Alliance for Caregiving, *Caregiving in the U.S., 2015 Report*, June 2015.

[2] See the AARP DataExplorer, Long-Term Services and Caregiving, Economic Value of Family Caregiving.

[3] Alzheimer's Association, *Alzheimer's Disease Fact and Figures, 2016*.

[4] *Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study*. U.S. Department of Health and Human Services, 2014.

[5] CDC/NCHS, National Health Interview Survey, January–June 2014, Family Core component.

[6] Zarit, Steven H. et al. "Effects of Adult Day Care on Daily Stress of Caregivers: A Within-Person Approach." *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 66B.5 (2011): 538–546. *PMC*. Web. 17 Oct. 2016.

[7] See the information on the Veterans Administration website at: http://www.caregiver.va.gov/support/support_services.asp

[8] Medicare pays for inpatient respite care in a nursing home, hospice inpatient facility, or hospital. Medicare does not yet cover short-term, home-based respite care as an alternative to inpatient respite care in hospice.

[9] AARP Public Policy Institute, and National Alliance for Caregiving, *Caregiving in the U.S., 2015 Report*, June 2015.

[10] See the AARP DataExplorer, Long-Term Services and Caregiving, Economic Value of Family Caregiving.

[11] Alzheimer's Association, *Alzheimer's Disease Fact and Figures, 2016*.

[12] *Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study*. U.S. Department of Health and Human Services, 2014.

[13] CDC/NCHS, National Health Interview Survey, January–June 2014, Family Core component.

[14] Caregiving in the U.S., 2015 Report, AARP Public Policy Institute, and National Alliance for Caregiving, June 2015.

[15] Legislative Administration Committee, Policy and Research Office, *1997 Summary of Major Legislation*, *69th Oregon Legislative Assembly*, p. 79.

[16] Richard Schulz and Jill Eden, Editors, *Families Caring for an Aging America*, Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine, 2016, pp. 5-26-5-27.

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[18] Vanderpitte, S. et al. "Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review," *Int J Geriatr Psychiatry*, (2016): 1099-1166.

[19] Oregon Project Independence, Summary Report, 2014.

[20] National Family Caregiver Support Program Process Evaluation, Lewin Group, 2016.

[21] Richard Schulz and Jill Eden, Editors, *Families Caring for an Aging America*, Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine, 2016.

[22] Hispanic Family Caregiving in the U.S.: Findings from a National Study, Evercare and National Alliance for Caregiving, November 2008.

[23] See the discussion of Cultural Diversity and Caregiving provided by the American Psychological Association: http://apa.org/pi/about/publications/caregivers/faq/cultural-diversity.aspx, and demographic

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statistics of caregivers, including caregivers by race and ethnicity, provided by the National Alliance for Caregiving at: https://www.caregiver.org/caregiver-statistics-demographics
the Family Caregiver Alliance Caregiver Statistics: Demographics.

[24] See the discussion of Rural Caregiving provided by the American Psychological Association: http://apa.org/pi/about/publications/caregivers/faq/cultural-diversity.aspx.

[25] See the discussion of Cultural Diversity and Caregiving provided by the American Psychological Association: http://apa.org/pi/about/publications/caregivers/faq/cultural-diversity.aspx.

[26] See the discussion of Rural Caregiving provided by the American Psychological Association: http://apa.org/pi/about/publications/caregivers/faq/cultural-diversity.aspx, and also see Caregiving in Rural America, Easter Seals and National Alliance for Caregiving, 2014.

[21] Richard Schulz and Jill Eden, Editors, *Families Caring for an Aging America*, Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine, 2016.

[28] See the discussion of options counseling at the ADRC Technical Assistance website: https://www.adrc-tae.acl.gov/tiki-index.php?page=OptionsBenefits

[29] AARP Public Policy Institute, *Raising Expectations 2014: A State Scorecard on Long Term Services and Support for Older Adults, People with Physical Disabilities, and Family Caregivers*. 2014

[30] See the information on the Veterans Administration website at: http://www.caregiver.va.gov/support/support_services.asp

[31] See Department of Human Services, Seniors and Persons with Disabilities Division, Oregon Administrative Rules, Chapter 411, Division 66, at: https://www.dhs.state.or.us/policy/spd/rules/411_066.pdf

[32] National Center for Education Statistics, *Fast Facts*, at: http://nces.ed.gov/fastfacts/display.asp?id=98

[33] Lynn Feinberg and Rita Choula, *Understanding the Impact of Family Caregiving on Work*, AARP Public Policy Institute, 2012.

[34] *Determining the Return on Investment: Supportive Policies for Family Caregivers*, AARP and ReACT, 2016.