

Improving Caregiver Respite Services in Oregon – In Brief

Oregon Caregiver Respite Work Group • November 2, 2016

The Oregon Caregiver Respite Work Group produced a report to highlight the need for respite services and recommend approaches for expanding access to affordable, high-quality caregiver respite services. The Work Group aims 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. Below is a summary of the report.

Who are family caregivers for older adults?

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

What is respite care? Who provides it? Who benefits?

- Respite care is temporary, short-term care that provides relief from the extraordinary and intensive demands experienced by family caregivers.
- Respite services come in a variety of forms and include in-home paid care, adult day services, and overnight stays in a long-term care setting.
- Caregivers often report an increased incidence of emotional and physical difficulties in their personal life due to caregiving. The longer a caregiver provides care, the more likely she or he is to report poor health. Evidence shows that the stress of dementia care, in particular, increases caregivers' susceptibility to disease and health complications.
- 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.
- Barriers to caregivers seeking and using respite care include lack of awareness, personal resistance to seeking outside help, lack of affordability, and shortages of high-quality providers.

Caregiver respite services in Oregon

- Two major programs (other than Medicaid) provide respite to caregivers: The Family Caregiver Support Program (FCSP), which is federally funded under the Older Americans Act, and Oregon Project Independence (OPI), which is state funded.
- FCSP is focused on the well-being of the caregiver. FCSP provides support to family caregivers of adults age 60 and older, as well as people providing care to people of any age with Alzheimer's disease, and a few other specific caregiving situations.
- OPI covers services which offer temporary, substitute supports or living arrangements for care recipients which provide a brief period of relief for caregivers. Funds are extremely limited, wait lists exist based on priority, and respite is at the bottom of that priority list.

The Oregon Caregiver Respite Work Group's Recommendations

Improving Education and Awareness

1. **Launch a public awareness campaign** to assess knowledge gaps and educate family caregivers about available services—including different messages, messengers, and languages for effective outreach to diverse communities.
2. **Prepare trusted messengers to increase awareness and promote the value of respite.** Leverage health care providers, religious leaders, employers and other community partners to increase awareness and uptake of caregiver respite services.
3. **Expand targeted outreach to veterans and their caregivers** who may qualify for VA services for caregivers including adult day service and support lines.
4. **Improve data collection on family caregivers and respite** to improve understanding of caregivers and their needs and to inform program design.

Increasing the Supply of Providers

5. **Improve the quality and quantity of home care workers who can provide respite services.** The Oregon Home Care Commission should continue to implement strategies to expand and improve the home care workforce, including initiatives to create career ladders for home care workers.
6. **Update the administrative rules that govern adult day centers** to ensure there are no unnecessary barriers to opening centers, e.g. the 6-month waiting period for Medicaid certification.
7. **Increase overnight respite options** by exploring 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.
8. **Encourage hospitals, health systems, and Coordinated Care Organizations (CCOs) to consider ways to provide respite care** by partnering with community organizations or establishing PACE programs.
9. **Leverage community colleges and universities to expand access to respite.** Such initiatives could provide practicum training opportunities for students and an affordable, high-quality respite option for community members
10. **Expand innovative models of delivering respite.** Provide Medicaid, OPI, or FCSP funding for innovative models of respite, such as camps, mobile programs, time-bank models, host homes, and co-op models.
11. **Explore ways to support volunteer-based programs.** Increase financial and other kinds of support for volunteer programs so as to expand their reach in Oregon.

Making Respite More Affordable

12. **Increase state funding for existing respite care programs.** Beginning in 2017, increase total funding for FCSP by providing state funding to supplement the federal dollars received, and increase funding for OPI.
13. **Explore the feasibility of developing a Medicaid waiver program to expand access to respite.** 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.
14. **Encourage employers to develop strategies to assist their employees who are family caregivers.** Employers should assess caregiver needs and undertake strategies, including offering respite services, to help employees balance caregiving and work.
15. **Establish a system and funding for providing emergency respite.** 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.

To receive the full report or for more information about it, contact
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