Oregon Family Caregiving Support Programs:

Options for Improvements

AARP Real Possibilities
Oregon

Acknowledgements

AARP Oregon would like to thank and acknowledge the contributions of the persons who helped bring this report to life. We are indebted to Pat Casanova and Sharon Lewis, Principals with Health Management Associates (HMA), who contributed their expertise in the area of caregiving and whose insights into state experiences helped show what is possible for Oregon. We would likewise like to thank key colleagues in our national office. Ilene Henshaw, Director of SASI's State Health and Family Team, and Glen Fewkes, Sr. Legislative Representative, provided thoughtful comments and edits throughout the development of this report.

TABLE OF CONTENTS

Oregon Family Caregiving Support Programs: Options for Improvements

Executive Summary

Because the availability and affordability of services for middle-income family caregivers are currently quite limited, this report will examine a number of ways that Oregon can provide services and supports to family caregivers whose income exceeds Medicaid's financial eligibility threshold.

This report first identifies family caregiver support programs and services that currently exist in Oregon. These programs and services include Oregon's system of Aging and Disability Resource Connections (ADRCs), Medicaid-funded Home and Community-Based services, Oregon Independent Choices Program, Oregon Project Independence, respite services and Oregon's Family Caregiver Support Program.

This report then takes a deep dive into how two states, Minnesota and Washington, have used innovative models to expand and improve upon their family caregiver support systems. AARP Oregon believes some of the measures these two states have taken and other best practices have the potential to be replicated here in Oregon.

In closing, this report offers a number of potential options for Oregon to explore in order to improve supports for family caregivers. These options include:

- Explore the feasibility of a Medicaid waiver program that expands access to respite services
- Increase state funding for existing programs that provide respite services
- Incorporate a caregiver assessment tool in the HCBS functional assessment process
- Expand caregiver education and outreach opportunities
- Increase family caregiver engagement during transitions
- Expand the use of telehealth supports
- Pursue strategies to assist working family caregivers, including Paid Family and Medical Leave

An Overview of Oregon's Family Caregivers

AARP's Public Policy Institute (PPI) estimates there are 469,000 family caregivers in Oregon who provide about 437 million hours of unpaid care each year with an estimated value of $5.7 billion.[1] A family caregiver broadly defined refers to "any relative, partner, friend or neighbor who has a significant relationship with, and who provides a broad range of assistance for an older person or an adult with chronic, disabling or serious health conditions.[2]

In November 2016, AARP Oregon conducted a telephone survey, the "Oregon Caregiving Survey: The Family Caregiver Profile," that questioned 1,000 state residents age 45 and older about their family caregiving experiences. One of the findings from this survey is that the typical family caregiver in Oregon is female, 55 years old and likely to be working, either part-time or full time.[3]

At the same time, Oregon's aging population is growing rapidly. In 2015, approximately 16% of the state's population was over the age of 65. By 2030 that percentage is projected to be 22.2%, rising to a projected 24.2% by 2050. In 2030 the number of Oregonians over the age of 85 is projected to be 130,000, an increase of 65% from 2015. By 2050, the number of people over the age of 85 is expected to reach 251,000, which is equivalent to three times the number of people over 85 living in Oregon in 2015.[4]

Continuing with our look to the future, the challenges and strains facing family caregivers will become even more problematic. As the US population continues to grow older, the growing demand for care will rapidly outpace the number of people available to provide caregiving help. AARP highlights the concept of the "caregiver support ratio" to demonstrate the growing gap in available caregivers relative to the need. In the year 2010, Oregon's caregiver support ratio was 6.9 caregivers per every care recipient. By the year 2030 that ratio declines dramatically to 3.9 and by 2050, it declines further still to 2.9 caregivers per every care recipient.[5]

---

[1] "Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain." *AARP Public Policy Institute* (blog), July 16, 2015. https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html.

[2] Ibid.

[3] "AARP Oregon Caregiving Survey: The Family Caregiver Profile." AARP Public Policy Institute. 2016. https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/2016-or-caregiving-profile-res-econ.pdf.

[4] Houser, Ari, Wendy Fox-Grage, and Kathleen Ujvari. "Across the States: Profiles of Long-term Services and Supports." 9th edition. 2012. https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf.

[5] Redfoot, D., Feinberg, L., & Houser, A. (2013). The Aging of the Baby Boom and Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers. Retrieved from https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf.

Oregon Has Room for Improvement

The need for improvement in supporting family caregivers is underscored by two of the findings in the above mentioned 2016 "Oregon Caregiving Survey: The Family Caregiver Profile." This survey reveals that current and past family caregivers are feeling emotionally stressed (68%) and financially stressed (28%).[6]The survey also revealed that 71% of the respondents reported having to manage medications and 67% having to oversee other medical or nursing tasks. A significant majority of those surveyed (74%) also said that more caregiving resources and training was either very important or extremely important. These last three findings point to the need for CARE Act provisions which this paper addresses in the recommendations section. Furthermore, the survey reported that more than half (52%) of family caregivers were likely to be working either full or part-time, a data point that indicates family caregivers could benefit from programs that provide workplace flexibility such as paid family leave, which is also discussed in recommendations section.[7]

In addition, Oregon faces challenges many states do with respect to workforce shortages, budgetary constraints, and rapid growth in demand for services and supports that is outpacing the growth of available resources.[8]

In PPI's most recent (2017) Long Term Services and Supports (LTSS) Scorecard, Oregon's overall score came in at number four among all the states and was the top ranked state in the indicators that make up the category of support for family caregivers. The indicators include: support for working family caregivers, person-and family-centered care, nurse delegation, nurse scope of practice and transportation policies.[9] However, while Oregon is doing well in the support for family caregivers indicators, there are a number of other factors not measured in the Scorecard that are important in evaluating the degree of support a state is providing for family caregivers. Some of these indicators are the adequacy and affordability of services for private pay family caregivers, respite services, family caregiver assessments and telehealth services. AARP believes Oregon has room to improve its performance in all of these indicators and this paper provides recommendations on ways the state can realize improvements.

Programs and Services that Support Oregon's Family Caregivers

Oregon has been successful in taking advantage of federal funding and other opportunities to provide support for family caregivers, as well as establishing supportive state policies. However, except for establishing a No Wrong Door Aging and Disability Resource Center, (ADRC), most of these supports are available only for individuals who are Medicaid-eligible. For Medicaid-eligible individuals, the state offers a wide range of paid supports for individuals living at home,

[6] "AARP Oregon Caregiving Survey: The Family Caregiver Profile." AARP Public Policy Institute. 2016. https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/2016-or-caregiving-profile-res-econ.pdf.

[7] Ibid.

[8] "Improving Caregiver Respite Services in Oregon." November 2, 2016. https://olis.leg.state.or.us/liz/2017R1/Downloads/CommitteeMeetingDocument/95813.

[9]Reinhard, Susan, Jean Accius, Ari Houser, Kathleen Ujvari, Julia Alexis, and Wendy Fox-Grage. "Picking Up The Pace of Change."Longterm Score Card. 2017. https://bit.ly/2CoMO22

has inclusive eligibility criteria for Medicaid-funded services, and allows spouses and other family members to be paid to provide care. For individuals and families ineligible for Medicaid, options such as Oregon Project Independence and the Family Caregiver Support Program have limited funds available.

Oregon once had a system for caregiver respite that it no longer does. Oregon was one of the first four states to develop a Lifespan Respite program prior to the existence of the federal legislation, but in 2010 the program ended due to lack of funding. In November 2016, the Oregon Caregiver Respite Work Group produced a report recommending 15 strategies to reduce barriers to caregiver respite services in Oregon. The work group organized their strategies within three overall recommendations: (1) the enhancement of education and awareness (2) an increase in the supply of providers, and (3) making respite more affordable.[10]

Below are short descriptions of existing programs and services that serve Oregon's family caregivers:

Oregon ADRC: Oregon's Aging and Disability Resource Connection offers options counseling as well as information and referral services to everyone, regardless of income level. The ADRC is primarily information and referral-focused with services that are mainly phone-based and in-person through the Area Agencies on Aging (AAA). One of the shortcomings of Oregon's ADRC network is the limited availability of online planning information and the absence of interactive individualized planning tools on the ADRC website.

Medicaid-funded Home and Community-Based services for older adults and people with disabilities: In 2013, Oregon became one of the first states to implement the 1915(k) Community First Choice Option (CFCO), allowing the state to access an additional six percentage points of federal match for personal attendant care services.[11] With the exception of waiver case management offered under 1915 (b)/(c), Oregon moved all 1915(c) waiver HCBS into this state plan option. This expanded the availability of in-home and residential supports for Medicaid-eligible recipients and did away with caps on enrollment and services. The CFCO 1915(k) waiver includes payment to spouses and other relative family caregivers as well as offering payment for adult relative foster care.

A significant concern for the state has been the robust growth of the CFCO program expenses and the state is actively seeking ways to manage and control costs. In October 2017, Oregon implemented one cost saving measure by refining the functional eligibility assessment and regulatory definitions related to functional assistance.

[10] "Improving Caregiver Respite Services in Oregon." November 2, 2016. https://olis.leg.state.or.us/liz/2017R1/Downloads/CommitteeMeetingDocument/95813.

[11] "K Plan." Oregon Department of Human Services. 2018. https://www.oregon.gov/DHS/SENIORS-DISABILITIES/KPLAN/Pages/index.aspx.

Oregon Independent Choices Program: Oregon continues to maintain a small Medicaid HCBS 1915(j) cash and counseling program for individuals seeking fully self-directed services with employer and budget authority responsibilities going to the consumer.[12]
Oregon Project Independence (OPI): Oregon Project Independence is a program that offers case management and service coordination, personal and in-home care, adult day care, assistive technology, registered nursing services, home modifications, and home delivered meals to individuals not participating in Medicaid. Participants are assessed using the same functional assessment tools as waiver recipients. It is estimated that 96% of OPI participants would be financially eligible for Medicaid and over 60% would meet the functional eligibility criteria for the Medicaid-funded waiver.[13]
Oregon Family Caregiver Support Program (FCSP): Services in this program include caregiver counseling, caregiver supplemental services (which may include legal assistance, home modifications, transportation, assistive technologies, emergency response systems, etc.), caregiver support groups, evidence-based caregiver training, respite care, and information for caregivers that links them to services within their community. Oregon's FCSP program received $1.9 million in federal funding for 2016, of which $599,363 provided respite services to 748 family caregivers, however no state funds are used for this program.[14]

Caregiving Supports in Minnesota and Washington

Minnesota

With its strong national leadership in supporting older adults and caregivers, Minnesota has been a pioneer in using innovative models to expand and improve upon their family caregiver supports as part of their LTSS system. The state has been able to maximize federal matching dollars for all Medicaid-eligible populations while at the same time offering programs and services with a focus on the pre-Medicaid eligible population. Some key elements of Minnesota's LTSS system include a streamlined information and referral process through the Senior LinkAge (ADRC) Line.[15] This design brings in federal funds for the ADRC and the Senior

[12] "Oregon Independent Choices Program (ICP)." Paying for Senior Care: Understand Your Financial Options for Long Term Care. February 2018. https://www.payingforseniorcare.com/cash-and-counseling/or-independent-choices.html.
[13] Ibid.
[14] "Family Caregiver Support Program Standards." February 28, 2018. https://bit.ly/2R7HTL5
[15] Boston, Krista, and Stephanie Minor. "Supporting Seniors and Their Caregivers to Age Well and Live Well." PPT. Minnesota's Senior LinkAge Line. http://www.health.state.mn.us/healthreform/homes/collaborative/lcdocs/webinars/mnhelpwebinarada.pdf.

Health Insurance Program (SHIP) and allows Minnesota to claim Medicaid administrative costs for ADRC -allowable activities. Minnesota's ADRC network reaches across different agencies and funding sources to reach people who need supports at home, regardless of income. The state's ADRC grant funded program has established a true virtual system that provides assistance by phone, web and print formats. In addition, the ADRC program has created an on-line interactive LTSS planning tool. The state also leverages Older Americans Act Title III and SHIP funding.[16]

The state relies heavily on a data-driven process to help reach people and their caregivers at transition points, such as hospital to home, hospital to nursing facility, home to assisted living, and in the spend down process. Contacts with the care recipients and caregivers are made regularly to evaluate the burden of the caregiver and to provide consultation and/or respite services.

Minnesota has intentionally designed strategies to divert and support people before they turn to Medicaid for services. For example, Minnesota's ADRCs look at all the funding streams available to the individual to reach people before they begin to spend down to qualify for Medicaid. The goal is to expand access to people who are paying privately for services and to design programs and strategies that meet an increasing demand.[17]

One innovative program in Minnesota is the ***P.S. I Understand* program,** a family caregiver peer support program that matches family caregivers with former family caregivers who are at least one year past their caregiving experience.[18] The former family caregivers are volunteers who provide counseling, training and emotional support to the daily challenges faced by family caregivers. There is no cost associated with the P.S. I Understand Program, as the number of volunteer counselors who are involved with the program is relatively small and as such there is no need for funding at this time.

For private pay individuals, Minnesota has implemented five model projects that offer more intensive assistance at critical points of access along the pathway to long term care:

- Chisago County First Contact Pilot
  The First Contact Pilot Project, operated by the Central Minnesota Council on Aging, developed a service model to expand the role of the Senior LinkAge Line® and provide more seamless and timely access to services for older adults in Chisago County.[19] The project was designed to improve coordination between county human services staff and Senior LinkAge Line® staff, reduce the need for seniors or their family members to go through multiple intake processes, reduce the wait time required in order to make service connections and to realize these goals through the incorporation of state-of-the-art technology used by the MinnesotaHelp Network™ within the existing service system. An evaluation of this pilot

[16] "Minnesota Board on Aging State Plan: FFY 2015 - 2017." https://bit.ly/2rMB8jz
[17] Op. cit. Minnesota Board on Aging State Plan FFY 2015 – 2017
[18] Rudina, Parichay. "P.S. I Understand: Caregiver Peer Support." Wilder Foundation. February 19, 2014. https://www.wilder.org/articles/ps-i-understand-caregiver-peer-support?ID=75.
[19] "Chisago County First Contact Pilot Project." Wilder Foundation. Accessed 2018. https://www.wilder.org/wilder-research/research-library/chisago-county-first-contact-pilot-project.

program showed positive outcomes for consumers. They received more information and assistance during the initial call such as options for private pay and services were accessed more quickly.

- MnCHOICES
  MnCHOICES is a web-based application that integrates assessment and support planning for Minnesotans who need long-term services and supports. MnCHOICES embraces a person-centered approach to ensure services meet each person's strengths, goals, preferences and assessed needs. The goals of MnCHOICES are to promote timely consideration of support options reimbursed through Medical Assistance long-term service programs, provide greater consistency in how eligibility is determined for publicly funded LTSS, implement a single comprehensive assessment to determine needs and support planning, streamline support plan development, and determine eligibility for publicly funded programs and services for all ages and disabilities.[20]

- Live Well at Home Rapid Screen
  The *Live Well at Home* website is a resource tool for older adults and their family caregivers. This website provides information on everything from dealing with falls and memory concerns, to tips for family caregivers for coping with stress, to finding paid help so that older adults may continue to live at home.[21]

- Return to Community
  The Return to Community service helps people who are living in a nursing home and want to move home or to a new setting in their community.[22] Working with nursing facility staff, Senior LinkAge Line staff develop a list of services that people will need at home and provides counseling to help people look at all long-term care options based on where and how they want to live. AARP has produced a video on Return to Community highlighting this program.

- Long Term Care Consultation
  Long-Term Care Consultation services helps individuals in need of long term care make decisions about LTSS that reflect the individual's needs and preferences. A long-term care consultant identifies services and housing options that will help people who wish to remain in their homes and communities as well as those wishing to move out of a nursing home.[23]The long-term consultant is either a social worker or nurse who conducts a face to face visit with the individual in need of long term care to evaluate their needs and wants. The consultant will provide information about local long-term care services and support options including options that might help the individual pay for services.

---

[20] "MnCHOICES." Minnesota Department of Human Services. May 06, 2016. https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/mnchoices/.
[21] "Live Well at Home."http://www.mnlivewellathome.org/.
[22] "Return to Community Service." https://mn.gov/dhs/people-we-serve/seniors/services/nursing-homes/programs-services/return-to-community.jsp.
[23] "Long term care consultation services." https://mn.gov/dhs/people-we-serve/seniors/services/home-community/programs-and-services/ltcc.jsp

We believe Oregon should take a close and careful look at the innovative and creative family caregiver support programs that Minnesota has implemented to determine their feasibility for supporting Oregon's family caregivers.

Washington

Like Minnesota, Washington State has used innovative models to expand and improve supports for family caregivers as part of their LTSS system. In AARP's 2017 LTSS Scorecard, Washington was the number one ranked state in the delivery of long-term services and supports across all of the Scorecard's dimensions.[24]The state's Aging and Long-Term Support Administration and its division of Home and Community Services bring together under one administrative umbrella the Medicaid, the Older Americans Act, and state-funded LTSS for adults with physical and cognitive disabilities and their family caregivers. One of the state's goals is to help families delay the point at which they must apply for Medicaid, which benefits both consumers and the state budget.[25]

One way Washington is attempting to meet this goal is through the "Washington State Medicaid Transformation" 1115 demonstration waiver which CMS approved in the fall of 2016. This demonstration waiver includes two new benefits for family caregivers.[26] The Medicaid Alternative Care (MAC) benefit provides support for unpaid family caregivers who provide care for Medicaid beneficiaries not utilizing Medicaid-funded LTSS. The MAC benefit includes training, support groups, respite services, home-delivered meals as well as help with housekeeping. The second benefit, Tailored Supports for Older Adults (TSOA**)** targets individuals who are not eligible for Medicaid due to financial status but who have been determined to be at risk of future Medicaid LTSS use. The TSOA option provides similar supports and benefits to unpaid family caregivers without requiring individuals or families to spend down to Medicaid eligibility.[27]

The respite services included in this demonstration are similar to a waiver concept developed by AARP called RELIEF that is designed to support family caregivers whose income exceeds Medicaid eligibility. More information on the RELIEF model is provided below.

Washington's statewide network of access points for Medicaid program/financial eligibility determinations and case management services, along with its residential quality assurance programs, consolidated management functions and other community-based resources are regarded by the state's Health Care Authority as the main drivers of the state's success in supporting family caregivers.

---

[24] Op. cit., Long-Term Services and Supports (LTSS) State Scorecard 2017 Edition
[25] Rector, Bea. "Washington State's Support for Family Caregivers." PPT. December 9, 2014. http://www.agingwashington.org/files/2014/11/NCSL-family-caregivers-final.pdf.
[26] "Medicaid Transformation." Washington State Health Care Authority. 2018. https://www.hca.wa.gov/about-hca/healthier-washington/medicaid-transformation.
[27] Ibid.

Washington has found many other ways to support family caregivers. One of these ways is through the adoption of the Tailored Caregiver Assessment and Referral (TCARE®) Personal Caregiver Survey developed by the University of Wisconsin.[28] The Personal Caregiver Survey asks the family caregiver to reflect on their experiences and then rates the responses to a series of statements based on identified rating scales in each section. This survey is used to help caregiver specialists get a better understanding of the caregiver's situation so that they can create an individualized plan to meet the caregiver's unique needs.

Washington launched a Family Caregiver Support Program (FCSP) in the year 2000 to assist unpaid family caregivers who were caring for adults, with services offered either for free or at a low cost sliding fee scale. Some of the many FCSP services include: specialized caregiver information, caregiver screening and needs assessment, consultation and care planning, respite care, counseling, support groups and referrals for physical and mental health/wellness programs.[29] In 2012 – 2013, the FCSP was expanded to add more family caregivers to its rolls. In the year before the expansion, the state allotted FCSP with $6.3 million in state funds. In State Fiscal Year (SFY) 2012, the program was awarded an additional $3.4 million in state funds in order to serve 1500 new family caregivers. In SFY 2013, the program was expanded once more with an allocation of $1.5 million in order to serve an additional 750 new caregivers.[30] An evaluation of the FCSP over a six-month period revealed that the program had achieved a very high success rate, with 84% of family caregivers showing statistically significant improvements in key outcomes such as lower levels of stress, a decrease in the severity of depression and greater comfort in their caregiving role.[31]

As is the case with Minnesota, we believe the programs and services that Washington has developed should be reviewed and analyzed to determine if they could be replicated here in Oregon.

Note: Washington also uses the Kinship Navigators program that supports grandparents caring for their grandchildren.

Note: The cost associated with the TCARE survey is based on the type of organization using TCARE and the number of completed assessments, with multiple pricing tiers. The program is funded by its customers which are State Departments of Aging, Area Agencies on Aging, healthcare insurers or healthcare provider systems.

Options for Oregon to Improve Supports for Family Caregivers

➢ Explore the Feasibility of a Medicaid Waiver Program to Expand Access to Caregiver Respite Services

We encourage Oregon's Department of Human Services (DHS) to explore the development of a Section 1115 Medicaid waiver that would allow the state to provide respite services to individuals with incomes up to 400% of the federal poverty level. Some of the factors that need

[28] "Tailored Caregiver Assessment and Referral (TCARE)." Rosalynn Carter Institute For Caregiving. 2007. http://www.rosalynncarter.org/caregiver_intervention_database/miscellaneous/t_care/.
[29] Op, cit. Washington State's Support for Family Caregivers
[30] Ibid.
[31] Ibid.

to be considered include potential conflicts with other Medicaid waivers, along with the costs and potential savings of general fund dollars.

AARP has crafted such a model called RELIEF (REspite: Living Independently, Energizing Families), a limited respite care benefit that would be made available to those with incomes greater than Medicaid eligibility up to 400% of the federal poverty level (FPL). As mentioned above, Washington is one state that has embedded this concept into its 1115 demonstration waiver by adding respite services and other benefits for individuals who are not Medicaid eligible. One option for Oregon would be to construct a sliding fee scale so that people with incomes above Medicaid eligibility would be able to "buy-in" to respite services. In addition, current funding for respite, such as through Oregon Project Independence, could be used to draw down federal matching funds.[32] The program could potentially 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.

Another option would be to amend the existing 1915(k) waiver in order to include OPI participants. There may also be value in seeking a detailed fiscal analysis related to enrollment of some or all of the Medicaid eligible OPI population in the Aged and Physically Disabled (APD) waiver.

➢ Increase State Funding for Existing Programs that Provide Respite

We encourage the Oregon Legislature to provide funding to supplement the federal dollars received for the National Family Caregiver Support Program (FCSP). These state funds should have fewer restrictions on their use than Oregon Project Independence, so as to allow for caregivers of individuals younger than 60 and without dementia to participate in the program. We recommend allocating at least $4 million per biennium to this program. This could be directly tied to the waiver recommendation above.

We also recommend that the legislature increase funding to Oregon Project Independence (OPI) so it can serve more individuals. Because OPI 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. In addition to funding, we recommend the Oregon Administrative Rules be revised for OPI to establish a higher priority for ensuring that caregivers receive respite.

➢ Incorporate a Caregiver Assessment Tool in the HCBS Functional Assessment Process

We recommend the use of a comprehensive family caregiver assessment tool that can be administered by a health care professional, such as a social worker or a nurse. We believe that

[32] "Oregon Project Independence." https://www.co.washington.or.us/HHS/DAVS/upload/OPI_Overview_0117-1.pdf.

incorporating caregiver assessment questions into the HCBS functional assessment process could result in improved person-centered planning. Such a tool could also help maintain the natural supports provided by family caregivers. As described above, Washington State's Tailored Caregiver Assessment and Referral is a well-researched validated instrument. California, Massachusetts, Minnesota and Pennsylvania also have comprehensive tools.[33] The Family Caregiver Alliance has analyzed caregiver assessments across the country, identifying measures and creating an inventory of measures resource.

➢ Expand Caregiver Education and Outreach Opportunities

While Oregon currently offers education and training for family caregivers through organizations such as Oregon Care Partners and the Oregon Alzheimer's Association, we believe that with 469,000 family caregivers in the state, there is a need to expand these opportunities. The Oregon Caregiver Training Workgroup report, published in 2014, made a number of important recommendations, including the need to increase the scope, access to, and usefulness of trainings.[34] We believe a follow-up to these recommendations would be helpful to ensure that effective trainings are available to all Oregonians who are serving as family caregivers.

In addition, because the public knows relatively little about the extent of caregiver programs and services, we recommend launching a public awareness campaign. Such a campaign could include activities to assess consumers' knowledge gaps, educate family caregivers about available services and increase understanding of how caregiver support services can both help caregivers continue to provide care at home and improve family well-being.

➢ Increase Family Caregiver Engagement during Transitions

The CARE (Caregiver Advise, Record, and Enable) Act is one means of supporting family caregivers during a care transition. Enacted in Oregon in 2015, the legislation provides people who are admitted to a hospital with the opportunity to designate a family caregiver who will be helping them post discharge with their medical or nursing tasks.[35] Once a family caregiver is designated, the hospital is responsible for notifying the caregiver when their loved one is going to be transferred to another facility or is going to be discharged to home. The Act also requires the hospital to provide the family caregiver, prior to discharge, with instruction or training for caring for their loved one at home.

We recommend that that the Oregon Health Authority take steps to ensure that Oregon's hospitals are fully complying with the requirements of the CARE Act. Some steps that the

---

[33] "Program Description." Tailored Caregiver Assessment and Referral (TCARE). March 2017. https://acl.gov/sites/default/files/programs/2017-03/Tailored_Caregiver_Assessment_and_Referral__ISR_08_20-2014.pdf

[34] "Oregon Caregiver Training: Work Group Report." June 2014. https://www.oregon.gov/DHS/SENIORS-DISABILITIES/ADVISORY/GCSS/CommissionMeetingsFull/06-2014/Oregon Caregiver Training Report.pdf.

[35] Bartholomew, Jon. "Oregon Senate Provides Final Passage of the CARE Act." May 27, 2015. https://www.thelundreport.org/content/oregon-senate-provides-final-passage-care-act.

Oregon Health Authority can undertake to ensure that family caregivers are receiving the support they need include:

- Integrating the provisions of the law into the state's hospital survey and licensing process;
- Sending reminder notices to hospitals throughout the state and their associations about the CARE Act and educate or re-educate hospital leaders and staff about how to comply with it, including copies of any materials prepared for hospitals regarding this law;
- Ensuring that hospitals adopt and maintain written discharge policies that include elements of the CARE Act
- Establishing a pathway for consumers to express concerns about their experience with the law and have them addressed, such as through a designated 800 number or an email address, or whether the state will use existing consumer complaint processes;
- Collecting data from hospitals to track implementation of the law; and
- Otherwise ensuring effective oversight.

In addition, we recommend that OHA consider developing a standard reporting form upon which each hospital shall submit compliance information to OHA annually. Upon submission to OHA, such information will be considered government records and may be made available to the public at the discretion of OHA and according to state law. The standard reporting form could include requests for information such as:

(A) Number of patient discharges;

(B) Number of patients offered to designate a caregiver;

(C) Number of patients electing to designate a caregiver;

(D) Number of caregivers notified in advance of patient discharge or transfer;

(E) Number of caregivers offered instruction related to the patient's after-care needs;

(F) Number of caregivers who received instruction related to the patient's after-care needs;

(G) The prevalence of different types of instruction provided to caregivers related to the patient's after-care needs, including the number of caregivers who received live demonstrations as part of the instruction; and

(H) The reasons why any caregivers did not receive instruction related to the patient's after-care needs.

We believe that the implementation of these steps directed at compliance with the CARE Act and our recommendations of the reporting information could go a long way to ensure that family caregivers are being supported when their loved one is transitioning from hospital to home.

We also recommend that OHA and state policymakers urge healthcare provider networks to utilize United Hospital Fund's Transitions in Care–Quality Improvement Collaborative (TC—

QuIC).[36]The goal of this initiative is to examine how chronically ill patients are transitioned from one care setting to the next and how that transition could be improved by systematically involving family caregivers. This Collaborative has demonstrated successful outcomes for both family caregivers and the individuals relying upon them.[37]

This Collaborative has increased the number of family caregiver assessments, decreased time between admission and medication reconciliation, educated families prior to discharge, and supported family caregivers post-discharge. The success of this program is evidenced by the high level of family satisfaction with discharge and transition practices, recording a measurement of 9.5 on a scale of 10. Additionally, some providers have reported "an expansion of organizational capacity to work with family caregivers and a heightened awareness of caregivers' potential role and impact in improving care transitions. Some teams described the effects of TC–QuIC as an organizational 'culture shift."[38]

➢ Expand the Use of Telehealth Supports

AARP Oregon believes that telehealth holds the promise of multiple solutions to help people access health care as well as long term services. Telehealth can also be a valuable tool in making it easier for family caregivers to care for their loved ones. We strongly encourage OHA, lawmakers and health care industry stakeholders to consider the needs and preferences of consumers and especially family caregivers when considering telehealth legislative and regulatory proposals.

The Journal of Telemedicine and Telecare published a review of studies related to caregiver telehealth, providing evidence of how telehealth services have benefitted family caregivers. This educational review uncovered thirty-three articles focused on family caregivers of adult and older patients, looking at video, web-based, telephone-based and telemetry/remote monitoring. [40] Six main categories of interventions were delivered via technology: education, consultation (including decision support), psychosocial/cognitive behavioral therapy (including problem solving training), social support, data collection and monitoring, and clinical care delivery. More than 95% of the studies reported significant improvements in the caregivers' outcomes and caregivers' satisfaction with telehealth interventions.[39]

There is also evidence that telehealth services can be helpful for Oregon's family caregivers through an intervention called Star-C Telemedicine (TM). Star-C Telemedicine is an evidence-based telehealth intervention used to assist family caregivers of persons with Alzheimer's and dementia.[40] A Star-C Telemedicine pilot in Oregon was funded by the Oregon Alzheimer's

[36] Levine, Carol, Deborah E. Halper, Jenniver L. Rutberg, and David A. Gould. "Engaging Family Caregivers as Partners in Transition." 2013. file:///C:/Users/tbarton/Downloads/TC-QuIC_Report_FINAL.pdf.
[37] Ibid.
[38] Ibid.
[39] Chi, Nai-Ching, Demiris, George. "A systematic review of telehealth tools and interventions to support family caregivers". 2014;21(1):37-44. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4486048/
[40] Ibid.

Disease Center and was tested in 2016.[41] The early findings for Star-C-TM, support for caregivers of dementia patients, suggest that using technology-based support is an acceptable option for caregivers to fill a gap in caregiver support. The caregivers who completed the post-intervention testing were satisfied with the results of the program. All of the participants noted they preferred a telehealth, or telehealth with one in-person visit, over an in-person (only) intervention. The quantitative measures showed reduced burden, and qualitative findings revealed program acceptance.[42] There are other barriers to the implementation of Star-C Telemedicine (TM) such as a lack of awareness, the availability of training staff after hours and increasing the supply of hardware. Although more work is needed to make this program scalable and sustainable, the potential for caregivers is significant.

This program and other telehealth programs would be more effective if broadband were more available and affordable across Oregon. This could be accomplished through a variety of means, such as a public broadband network, the use of analog whitespace that once was used by television broadcasting, or public investment in broadband in other ways.

➢ Pursue Strategies to Assist Working Family Caregivers

AARP Oregon strongly believes that family support is a key factor in determining an older person's ability to remain in his or her home and community and out of institutional care settings such as nursing homes. However, the care provided by family members comes at a cost, both to the caregiver and to their families. While some legal protections—such as the national Family and Medical Leave Act (FMLA) — provide a useful benefit for many employees to maintain job security while experiencing a "serious medical condition" or caring for a parent, spouse or child with a serious condition—FMLA is unpaid leave and does not provide a source of income to replace lost wages. [43]

In addition, the financial impact on working caregivers who leave the labor force due to caregiving demands can be severe. Estimates of income-related losses sustained by family caregivers ages 50 and older who leave the workforce to care for a parent are $303,880, on average, in lost income and benefits over a caregiver's lifetime.[44]

Because working caregivers often must divert attention away from their jobs to tend to caregiving responsibilities, we urge the Legislature to enact a law establishing a paid family

---

[41] Lindauer, Allison, and Nicole Bouranis. "STAR-C Telemedince: Extending the Boundaries of Caregiver Support." https://www.ohsu.edu/xd/outreach/oregon-rural-health/about/rural-health-conference/upload/Thu-Lindauer-Using-Telehealth-to-Provide-Caregiver-Support.pdf.

[42] Lindauer, Allison, Deniz Erten-Lyons, Jeffrey Kaye, Katherine Mincks, Nora Mattek, Hiroko Dodge, and Linda Teri. "Star-C-Telemedicine: Accessible Caregiver Support." *Alzheimers & Dementia*13, no. 7 (2017). doi:10.1016/j.jalz.2017.06.2603. https://www.alzheimersanddementia.com/article/S1552-5260(17)32856-X/fulltext

[43] "Family and Medical Leave Act." https://www.dol.gov/whd/fmla/.

[44] Reinhard, Susan, Lynn Friss Feinberg, Rita Choula, and Ari Houser. "Valuing the Invaluable." July 2015. https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf

leave program similar to those that exist in California, New Jersey, New York, Rhode Island and most recently Washington State.[45]

We also urge state legislators to encourage employers to consider ways to support their family caregiver employees. Employers can begin by examining their current leave policies, determine how many of their employees are family caregivers, and ensure if and how their Employee Assistance Programs are providing resources and assistance to family caregiving employees. Employers could be urged to explore establishing policies such as paid family/medical leave, flexible work schedules and offering eldercare benefits. Additionally, large companies could explore providing an onsite adult day center similar to onsite childcare centers.

Conclusion

Oregon has a long history of national leadership in developing integrated community care for older adults and people with disabilities, as well as in supporting their family caregivers. It has also excelled at ensuring broad access to Medicaid-funded home and community-based services. To build on this strong foundation, we believe there are multiple opportunities to address the needs of family caregivers of individuals who are not currently Medicaid- eligible. Lessons from both Minnesota and Washington point to the effectiveness of a coordinated and systemic approach that acknowledges the important role of family caregivers in reducing reliance upon more expensive publicly-funded LTSS. We encourage Oregon's lawmakers and OHA to study the successful and evidence- based caregiver support programs and systems summarized in this report to determine the feasibility of their replication in our state.

AARP Oregon welcomes the opportunity to work with OHA and Oregon lawmakers towards this important goal.

[45] "State Family and Medical Leave Laws." July 19, 2016. http://www.ncsl.org/research/labor-and-employment/state-family-and-medical-leave-laws.aspx.