Supporting Care Partners of People Living with Dementia

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Better with Age, Gerontology and Education Research Initiative (GERI)

Faculty Grant Program Report

Supporting Care Partners of People Living with Dementia

Sherril Gelmon, DrPH, Walter Dawson, DPhil and Jenn Hollandsworth Reed, MPH

with

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PSU Institute on Aging

October 2023
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Executive Summary

Introduction: This report addresses the need to better support care partners of people living with dementia, including a proposal for a new Dementia Care Partner Hub (the “Hub”) that will facilitate care partner access to information, supports, services and activities. This work is the culmination of the “Supporting Care Partners of People Living with Alzheimer’s Disease and Related Dementias (ADRD)” project funded by the Portland State University Institute on Aging’s “Gerontology Education & Research Initiative” (GERI) faculty grant, conducted from June 2022 to October 2023. The project focused on addressing concerns and needs of care partners and people living with dementia from communities historically and currently underserved in the United States (Asian, Black, Indigenous, and Latinx) and organizations serving these communities.

Project Goals and Aims: This project sought to explore models of support for care partners of people living with ADRD with two overarching goals:

- Conceptualize a robust program of support that augments and complements current clinical and research programs, and reflects the needs of various communities that may be underserved and/or have difficulty accessing culturally specific services; and
- Frame key policy issues that encourage or hamper the delivery of care partner support and propose suitable advocacy strategies to achieve prioritization and funding of such services.

Dementia Care Partner Hub: This project has identified the need for the creation of a new Dementia Care Partner Hub (the “Hub”) that will augment the broad array of existing services and supports for care partners of people living with dementia. This information hub will function as the central node of a network of existing services. It is described in detail in the report; a brief overview includes:

- Web-based resource with complementary telephone access with focus on brain health, aging and memory loss focused on supporting care partners
- Housed at a “neutral” reputable site that can provide necessary administrative backup
- Conceptualized and governed by a coalition of leaders of relevant local organizations
- Staffed by a small team with skills in website development and maintenance, communications including social media, community outreach and engagement, and information management
- Care partner peer moderated discussion groups and responses to queries
- Engagement of professional advisors to review content
- Oregon-wide (with reach into Southwest Washington as feasible)
- Funded through combination of sources (to be determined by coalition) including government, philanthropy, health systems, community benefit resources

Ten role model programs that explicitly support care partners of people living with dementia were identified and elements were identified relevant to the Hub. The full report describes examples of resources to be offered by the Hub regarding: care partner supports, programs and services; information resources; and care and service coordination. For the Hub to become operational, attention will need to be given to elements such as key partners, an administrative home, implementation steps, and evaluation and improvement, all of which are discussed in the full report.

Responding to Community Assets and Needs: Focus groups and interviews with care partners of people living with dementia and leaders of organizations revealed several community assets and unmet needs. Collectively, these elements of the care partner experience inform the design of the Hub to ensure that it is responsive to the community assets and needs of historically and currently underserved communities, and that it can support Oregon care partners while ameliorating past inequities:

- Ongoing need for information about caregiving
- Unmet needs across communities
Caregiving affirms cultural and familial values
Evolution of care partner identity as dementia progresses
Strength and solidarity through cultural adjacency
Safety as a community practice
Legacy of past injustices affect care partners in the present.

Key Themes and Priorities: Representatives of organizations providing services and supports to people living with dementia and their care partners, as well as representatives from organizations serving selected historically and currently underrepresented communities, were invited to collaboratively generate priorities to better support care partners. Eight themes and associated priorities emerged. Four program/service priorities for supporting care partners included identification of:
• Specific strategies for supporting, educating and empowering care partners and their wellbeing
• Availability of programs and services with equity of access and design
• Information resources that are readily accessible, culturally appropriate, and acknowledge the universality of caregiving experiences and challenges
• Care coordination among providers and to address challenges of finding and navigating services

Four policy-related priorities for supporting care partners were identified related to:
• Policy areas such as a statewide dementia strategy, workforce development and staffing standards
• Funding to compensate dementia care partners, financial resources for care partners to pay for services, and expansion of health insurance programs to cover all aspects of dementia care
• Professional education/workforce development to ensure all health professions students, postgraduate trainees and health care professionals understand brain health/dementia and can support people diagnosed with dementia and their care partners
• Modification of data systems such as EHRs for dementia related screening, adaptation of personal health records to identify care partners, and use of technology to better support care partners

Policy Recommendations to Support Care Partners: Five state-level and three federal-level policy actions are recommended:
• State-level Recommendation 1: Increase state funding to compensate ADRD care partners (including family, friends, and hired care partners) through direct financial support.
• State-level Recommendation 2: Fund community organizations to ensure equity of access and in the design of all programs and services for ADRD.
• State-level Recommendation 3: Invest in and develop Oregon’s ADRD care workforce to ensure available and accessible care and support for the increasing number of Oregonians living with ADRD.
• State-level Recommendation 4: Create a professional certification for the relevant ADRD health workforce at the community college level.
• State-level Recommendation 5: Fund an information hub for ADRD-related care and support needs that provides links to community-specific resources including websites, telephone contacts, listings of various support services, and care options.
• Federal-level Recommendation 1: Support the use of technologies to support ADRD care partners through social support, data-driven programs and policies, and/or culturally relevant supports.
• Federal-level Recommendation 2: Expand public health insurance programs (e.g., Medicare, Medicaid, Veterans Health Administration, and Indian Health Service) to cover all aspects of dementia care, and acknowledge and support care partners.
• Federal-level Recommendation 3: Provide incentives for care coordination and navigation that will support care partners in providing care.

For further information, contact Dr Gelmon at gelmons@pdx.edu or Dr Dawson at dawsonw@ohsu.edu.
Introduction
This report addresses the need to better support care partners of people living with dementia, including a proposal for a new Dementia Care Partner Hub (the “Hub”) that will facilitate care partner access to information, supports, and activities. This work is the culmination of the “Supporting Care Partners of People Living with Alzheimer’s Disease and Related Dementias (ADRD)” project funded by the Portland State University Institute on Aging’s “Gerontology Education & Research Initiative” (GERI) faculty grant award to Drs. Sherril Gelmon, Walter Dawson and Allison Lindauer, with Dr. Jeffrey Kaye as a consultant, conducted from June 2022 to October 2023. The project has been supported by Jenn Hollandsworth Reed as Project Manager. Three doctoral students contributed to this work: Anaeliz Mina Colon, Sofia Chapela Lara, and Devlin Prince.

The project team gratefully acknowledges the participation and input of many individuals including dementia care partners who shared their time and experiences, and leaders of nonprofit and service organizations and government agencies that provide advocacy and services for people living with dementia and their care partners who offered their expertise as well as their time.

This report summarizes what has been learned from interviews with leaders of organizations providing services to care partners and people living with dementia, focus groups with care partners, a comprehensive review of the literature with in-depth exploration of potential role models, consultation with an expert group of interested parties, and priority setting with an expanded expert group. This work focused in particular on addressing concerns and needs of care partners and people living with dementia from communities historically and currently underserved in the United States (Asian, Black, Indigenous, and Latinx) and organizations serving these communities.

Project Goals and Aims
This project sought to explore models of support for care partners of people living with ADRD with two overarching goals:
• Conceptualize a robust program of support that augments and complements current clinical and research programs, and reflects the needs of various communities that may be underserved and/or have difficulty accessing culturally specific services; and
• Frame key policy issues that encourage or hamper the delivery of care partner support and propose suitable advocacy strategies to achieve prioritization and funding of such services.

This project had six aims:
• **Aim 1**: Determine caregiving priorities of people with lived experience as care partners for people with ADRD, as well as community agency representatives with specific attention to communities historically underserved in Oregon (Asian, Black, Indigenous, and Latinx), through environmental scans followed by focus groups.
• **Aim 2**: Identify promising role models of care partner support from other communities and other health conditions by completing a review of published and grey literature.
• **Aim 3**: Articulate perceptions of interested parties\(^1\) on priority topics and resources to inform current and future programming by convening an advisory group of interested parties.

\(^1\) The term “interested parties” is used rather than “stakeholders” following the guidance of the CDC’s “Inclusive Communication Principles” ([https://www.cdc.gov/healthcommunication/Preferred_Terms.html](https://www.cdc.gov/healthcommunication/Preferred_Terms.html)).
• **Aim 4**: Design an augmented program of care partner support that builds upon existing programs, including articulation of new resource needs.

• **Aim 5**: Create a formative evaluation plan to assess and monitor the implementation of the proposed program.

• **Aim 6**: Propose strategies for the prioritization and funding of care partner support services at the state and/or national level.

The aims, related activities, timing and deliverables are summarized in Table 1, below.

**Table 1: Project Aims, Activities, Timing and Deliverables**

<table>
<thead>
<tr>
<th>Aim</th>
<th>Activities</th>
<th>Timing</th>
<th>Deliverables</th>
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<td>1: Care partner priorities</td>
<td>• Environmental scan</td>
<td>July 2022 to May 2023</td>
<td>• Public-facing summary of key themes for care partners (Appendix A)</td>
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<td></td>
<td>• Interviews with interested parties</td>
<td></td>
<td>• Academic manuscript (in progress)</td>
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<td></td>
<td>• Focus groups with care partners</td>
<td></td>
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<td>2: Role model practices</td>
<td>• Systematic review of published and grey literature on models of care partner support</td>
<td>September 2022 to July 2023</td>
<td>• Summary of promising role models of care partner support (Appendix B)</td>
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<td>3: Perceptions of interested parties</td>
<td>• Meeting of interested parties</td>
<td>June to August 2023</td>
<td>• Executive summary for June 2023 meeting with interested parties (narrative in report)</td>
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<td></td>
<td>• Modified Delphi process to determine priorities</td>
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<td>• Report of priority-setting process (Appendix C)</td>
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<td></td>
<td></td>
<td></td>
<td>• Academic manuscript (in progress)</td>
</tr>
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<td>4: Program of care partner support</td>
<td>• Design of the “Hub”</td>
<td>August to October 2023</td>
<td>• Plan for the “Hub” including operational, governance, and resource needs (narrative in report)</td>
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<td>5: Formative evaluation plan</td>
<td>• Creation of formative evaluation framework</td>
<td>September to October 2023</td>
<td>• Proposed evaluation framework (Appendix G)</td>
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<td>6: Strategies for prioritization and funding</td>
<td>• Development of policy brief</td>
<td>September to October 2023</td>
<td>• Policy brief (Appendix H)</td>
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<td></td>
<td>• Draft of academic manuscript</td>
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<td>• Academic manuscript (in progress)</td>
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**Overview of the Dementia Care Partner Hub**

This project has identified the need for the creation of a new Dementia Care Partner Hub (referred to subsequently as the “Hub”) that will augment the broad array of existing services and supports for care partners of people living with dementia. This information hub will function as the central node of a network of existing services. It is described in greater detail later in the report; a brief overview is presented here to frame the following discussion for the reader:

• Web-based resource with accompanying telephone access with information about brain health, aging and memory loss focused on supporting care partners

• Housed at a neutral reputable site that can provide necessary administrative support
• Conceptualized and governed by a coalition of leaders of relevant local organizations
• Staffed by a small team with skills in website development and maintenance, communications including social media, community outreach and engagement, and information management
• Peer moderated discussion groups and responses to queries, involving individuals with lived experience as care partners
• Engagement of professional advisors to review content
• Oregon-wide (with reach into Southwest Washington as feasible)
• Funded through combination of sources (to be determined by coalition) including government, philanthropy, health systems, community benefit resources

The following sections address: goals and elements to be responsive to specific communities; scope of activities and supports; specific kinds and categories of supports for care partners; key partners; organizational home; implementation; and evaluation. Implementation of all or part of this proposal will require champions and funding. A major question to be addressed is how to make this coordinated approach to providing and accessing services a priority to ensure the development of an initiative that will be successful and sustainable. Given what has been learned through this project, it is vital that the Hub at its core a) serves multiple populations equitably, and has limited, if any, barriers to access; and b) engages multiple organizations and interest groups to ensure delivery of a comprehensive scope of resources while not duplicating other existing resources, programs and services.

This proposal has the potential to be of interest, and linked, to other current initiatives such as Oregon’s new BOLD (Building Our Largest Dementia infrastructure) grant; the new Oregon Center for Excellence in Behavioral Health and Aging (housed at PSU); possible new work related to the new federal GUIDE (Guiding an Improved Dementia Experience) program; the work of SPADO (State Plan for Alzheimer’s Disease & Related Dementias in Oregon); and the Governor’s Commission on Senior Services. These are addressed further in the sections that follow.

Responding to Community Assets and Needs
This work had a specific focus on identifying concerns and needs of care partners and people living with dementia from communities historically and currently underserved in the United States (Asian, Black, Indigenous, and Latinx) and organizations serving these communities. Four doctoral students from the OHSU-PSU School of Public Health who identify with these communities were recruited to work with these communities. In the invitations to focus groups, they identified their positionality as follows:
• To Asian American care partners: As a second-generation Filipino and Puerto Rican woman, I will be working alongside the Asian American community to explore their lived experiences.
• To Black care partners: As a Black man growing up in America and as a descendant of enslaved people, I am committed to bringing our experiences into research and will be working alongside the African-American community.
• To Indigenous care partners: My father was raised by white parents, and did not find out that he was adopted and also Native until he was 35 and I was in sixth grade. Even though he grew up on white culture, and so did I, it is important to me to honor my Native heritage; I identify as Haida, Creek, and white.
• To Latinx care partners: I was born and raised in Oaxaca, Mexico, and recently moved to Portland to study for a Ph.D. As a migrant, I have experienced difficulties assimilating and understanding the cultural differences in the United States. My interest in this project is not only professional but also personal.
The focus groups and interviews with care partners of people living with dementia and interviews with leaders of organizations revealed several community assets and unmet needs. Collectively, these elements of the care partner experience inform this proposal for the Dementia Care Partner Hub. A design that is responsive to the community assets and needs of historically and currently underserved communities will ensure that the Hub will support all Oregon care partners while ameliorating past inequities. The assets and needs are summarized below; a more complete description including illustrative quotations from focus group and interview participants is provided in Appendix A:

- **Ongoing Need for Information about Caregiving:** Care partners need early, accurate, and ongoing information related to dementia, caregiving for a person living with dementia, and taking care of themselves. Care partners seek to understand the diagnosis, prognosis, and course of dementia in order to better plan for disease progression. This information needs to be appropriate to the context of the communities that care partners belong to and the areas where they live.

- **Unmet Needs Across Communities:** As the disease progresses, people living with dementia have different nutritional needs and preferences. Care partners need transportation options that are dependable, cover a large geographic area, and can clearly communicate with the care partner and the person living with dementia. Care partners need trustworthy and affordable respite care for both short and longer breaks from caregiving. Caregiving can be extraordinarily expensive, and most publicly funded services impose restrictive eligibility requirements (including income, assets and diagnoses) resulting in multiple barriers that impede access to services and supports.

- **Caregiving Affirms Cultural and Familial Values:** Caregiving is an expression of the values that come from families and communities. Caring for a parent is a natural reciprocation of the care children once received. The experience of caregiving is an opportunity to express cultural values that honor and celebrate the person living with dementia as a treasured part of their community.

- **Evolution of Care Partner Identity as Dementia Progresses:** The relationship a care partner has with the person they care for changes as the disease progresses. Care partners grieve the loss of the marital or parent-child relationship as they navigate a new and changing identity as a care partner of someone living with dementia. Care partners feel conflicted when they engage in therapeutic lying to de-escalate tense situations or when they become upset. A person living with dementia may also impose an identity on the care partner, believing the care partner is another person.

- **Strength and Solidarity through Cultural Adjacency:** Care partners and people living with dementia find comfort and support in services and providers that share similar experiences, even if they come from different communities. This cultural adjacency comes from histories of migration to and within the United States, similar cultural values, and similar cultural practices and preferences.

- **Safety as a Community Practice:** Care partners strive to keep the person they care for safe and healthy. They are often supported by communities including neighbors who periodically check on the person living with dementia, family and friends who take precautions to avoid spreading COVID-19, and by accessing resources such as air conditioners and air filters distributed by community organizations to protect people against the effects of extreme heat and wildfire smoke.

- **Legacy of Past Injustices Affect Care Partners in the Present:** Cultural stereotypes lead to delayed diagnosis of dementia, inadequate health care, and provision of insufficient information. Historic practices that restricted entry into the licensed health professions affect the workforce today, resulting in access barriers for people living with dementia who speak and understand languages other than English. These same practices also have affected funding and location of services.

The Hub should serve all Oregon care partners, while being responsive to the specific assets and needs of historically and currently underrepresented communities. It will augment and complement current clinical, research, and social programs by connecting care partners to programs and services.
Community-specific information, for both communities defined by geography and by identity, will ensure that the Hub equitably serves care partners with differing needs. Key elements to achieving this equity goal include language access, culturally appropriate information, and the ability for care partners to access the Hub from wherever they live in Oregon.

Role Model Programs
Ten role model programs that explicitly support care partners of people living with dementia were identified; each offers selected elements relevant to the proposed Dementia Care Partner Hub. These are described in detail elsewhere (see Appendix B); they are:

- Aging Brain Care (ABC) program, Eskenazi Health, Indianapolis, IN
- Alzheimer’s and Dementia Care (ADC) program, University of California, Los Angeles, Los Angeles, CA and implemented in multiple other sites
- Care Ecosystem, developed at University of California, San Francisco and piloted/implemented in multiple other sites
- ConnectShareCare, Dartmouth College, Hanover, NH
- D-CHESS (Dementia–Comprehensive Health Enhancement Support System), University of Wisconsin – Madison, Madison, WI
- Integrated Memory Care (IMC) program, Emory University, Atlanta, GA
- Maximizing Independence (MIND) at Home, Johns Hopkins University, Baltimore, MD
- Program of All-Inclusive Care for the Elderly (PACE), based on the On Lok program in San Francisco, and now administered by the Centers for Medicare & Medicaid Services (CMS)
- VA Caregiver Support Program, Department of Veterans Affairs, nationwide
- WeCareAdvisor program, Drexel University, Philadelphia, PA

Many of these focus on clinical services and/or research, and include elements that are relevant to the care partner both in terms of how the care partner supports the person living with dementia and the care partner’s own physical and emotional wellbeing. Two (ConnectShareCare and WeCareAdvisor) have a specific focus on care partners.

Key Themes and Priorities
In addition to the focus groups conducted with care partners and interviews of leaders of organizations providing services to care partners and people living with dementia, consultation with expert interested parties was conducted. Representatives of organizations providing services and supports to people living with dementia and their care partners, as well as representatives from organizations serving selected historically and currently underrepresented communities, were invited to collaboratively generate priorities to better support care partners. The consultation was conducted as a modified Delphi process, which is an effective way for gaining consensus on priorities and giving all participants an equal voice in the process.

Eight themes emerged through the various methods of data collection (interviews, focus groups, literature review, meeting with interested parties, priority-setting exercise); these have been used throughout the analysis and the development of this proposal. These themes are not mutually exclusive, so elements of the proposal have been categorized in a theme for “best fit” recognizing this overlap.

The themes are:
- Care partner supports
- Programs/services
These themes collectively address the range of services/programs that would better meet the needs and concerns of care partners of people living with dementia. The themes are discussed in more detail later in the report. Priorities for supporting care partners were determined from the interviews, focus groups, and the Delphi priority-setting activity. The report on the Delphi activity is included as Appendix C. Each of the role model programs mentioned previously was reviewed in the context of the eight themes (see Appendix D), and examples from the role models’ work were included in the articulation of priorities. The 15 highest ranked priorities from the Delphi process for supporting care partners and associated thematic categories are reproduced below in Table 2.

**Table 2: Top 15 Priorities for Supporting Care Partners**

<table>
<thead>
<tr>
<th>Ideas</th>
<th>Thematic Category</th>
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<tbody>
<tr>
<td>Educating care partners about dementia disease process, ensuring timely and appropriate diagnosis, and stages of disease/symptoms (such as agitation and aggression)</td>
<td>Care Partner Supports</td>
</tr>
<tr>
<td>Increase funding including compensation of dementia care partners (family, friends, employed)</td>
<td>Funding/ Financing</td>
</tr>
<tr>
<td>Prepare all primary health providers to understand brain health/dementia, associated stigma, early diagnosis and screening, and support people diagnosed with dementia and their care partners</td>
<td>Professional Education and Workforce Development</td>
</tr>
<tr>
<td>Educating and empowering care partners and families about what to expect, what they might need, and resources to help them navigate and be supported</td>
<td>Care Partner Supports</td>
</tr>
<tr>
<td>How to serve people who do not have care partners</td>
<td>Care Coordination</td>
</tr>
<tr>
<td>Increase financial resources for care partners/PWLD for day programs, respite, other fee-based activities (non-means tested/Medicaid)</td>
<td>Funding/ Financing</td>
</tr>
<tr>
<td>Ensure equity of access and design of programs and services</td>
<td>Programs/ Services</td>
</tr>
<tr>
<td>Affordable in-home care</td>
<td>Programs/ Services</td>
</tr>
<tr>
<td>Facilitate immediate connections to supports, information, and resources at time of dementia diagnosis and as care partners need them</td>
<td>Care Partner Supports</td>
</tr>
<tr>
<td>Care coordination across primary care and specialty settings including referrals</td>
<td>Care Coordination</td>
</tr>
<tr>
<td>Easy access to day programs such as dementia cafes and adult day centers</td>
<td>Programs/ Services</td>
</tr>
<tr>
<td>Expand private and public health insurance programs to cover all aspects of dementia care</td>
<td>Funding/ Financing</td>
</tr>
<tr>
<td>Support care partner health, wellbeing, and work/life balance</td>
<td>Care Partner Supports</td>
</tr>
<tr>
<td>Create information resources, trainings, and services that are culturally and linguistically relevant, and address different learning styles and varied information needs at different stages of dementia</td>
<td>Information Resources</td>
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Create a “one stop shop” with community specific resources including websites, listings of various supports, options by community specific to geography, culture, etc. with resources updated in real time with up-to-date names and phone numbers

Information Resources

Further illustration and discussion of the themes with specific items related to program, service and policy priorities is provided in the following discussion.

Creation and Implementation of the Dementia Care Partner Hub

The conceptualization of the Hub built upon the results of interviews, focus groups, website reviews, and literature review. Specific areas of focus were then identified through a meeting with a group of interested parties, held in June 2023. This meeting fulfilled the third aim of this project, and was an opportunity to articulate perceptions on priority topics and resources to inform current and future programs/services by convening an advisory group of interested parties. Information was gathered from a variety of organizations through a review of websites, interviews with organizational leaders, and/or participation in the meeting of interested parties and subsequent priority-setting activity; these organizations are listed in Appendix E.

As described in brief earlier, it is anticipated that the Hub will include the following components:

- Web-based resource with accompanying telephone access with focus on brain health, aging and memory loss focused on supporting care partners
- Housed at a neutral reputable site that can provide necessary administrative backup (see Administrative Home, p. 11)
- Conceptualized and governed by a coalition of leaders of relevant local organizations (see Key Partners, p. 10)
- Staffed by a small team with skills in website development and maintenance, communications including social media, community outreach and engagement, and information management
- Capacity to create peer-moderated discussion groups and responses to queries, involving individuals with lived experience as care partners (modeled upon ConnectShareCare, described in the Role Models document in Appendix B)
- Engagement of professional advisors to review content
- Oregon-wide (with reach into Southwest Washington as feasible)
- Funded through combination of sources (to be determined by coalition) including government, philanthropy, health systems, community benefit resources (see Implementation, p. 13)

Details of the Hub will need to be determined by the guiding coalition of care partners and interested parties; elements that were articulated during the information gathering portions of this project are discussed below.

Care Partner Supports, Programs and Services

Care partners need information and access to many services and programs; the list below has been augmented with examples from organizations across the US that offer role model practices (see Appendix B for a description of these role model practices). The services, programs and information resources identified include:

- Information about Dementia and Caregiving: Caregivers receive information about dementia and caregiving from conversations with providers, pamphlets and books, support groups, websites, educational workshops, and from friends and other community information resources.
• **Navigation and Coordination:** Navigation assists care partners in identifying and accessing available services to support both care partners and the person living with dementia. Coordination ensures that everyone providing care and support for the person living with dementia, including health care teams, is aware of all relevant information.

• **Psychological Support and Recognition of the Care Partner Role:** Care partners receive psychological support from family, friends, support groups, and therapists who recognize the work they perform as care partners.

• **Leisure Activities for the Care Partner and the Person They Care For:** The ability to maintain participation in leisure activities contributes to a meaningful and content life. For the person living with dementia, this may also include services which tailor leisure activities as abilities decline with the progression of the disease.

• **Care Assistance:** Care partners are often helped by unpaid family and friends, and may reimburse family and friends for their time when they help. Some care partners are also able to afford to hire a professional care partner to assist periodically (privately or through a home health agency).

• **Day Services:** Adult day services provide care, social connection, meals, and leisure activities to people living with dementia for up to several hours per day. Depending upon the specific service, the care partner may or may not remain with the person they care for while at these services.

• **Transportation:** Transportation services allow the care partner and the person living with dementia to travel to medical appointments and go on social outings. These services include public transit, specialized medical transportation vehicles, and ride-sharing services.

• **Financial Support:** Financial support includes services that reduce out-of-pocket spending by care partners, as well as programs that provide money to care partners.

• **Legal Services and Financial Management:** Legal services assist the care partner in obtaining the legal authority (e.g., guardianship or conservatorship) to manage the affairs of the person living with dementia due to diminished capacity. Financial management ensures that care is appropriately paid for, and that the person living with dementia is protected from financial abuse and exploitation.

• **In-Home Care and Related Services:** In-home care and related services provide day-to-day services and supports, including activities of daily living (ADLs), household tasks, activities, and companionship. These services may be provided by a licensed home care agency or by family, friends or other individual. These services may allow someone to live in their own home longer rather than moving to a long-term care facility and offer brief respite for the care partner.

• **Home Health:** Home health services allow the person living with dementia to receive certain types of skilled rehabilitative services for an illness or injury in their own home, instead of travelling to a health care facility or moving to a long-term care facility.

There are a number of specific supports, programs and services that dementia care partners need to better support their caregiving activities. How to identify and obtain information about supports is often unclear for care partners. Information on how to obtain financial support to pay care partners for their time and effort dedicated to caregiving is important. Financial support includes services that reduce out-of-pocket spending by care partners, as well as programs that provide money to care partners. This might include providing links to ODHS website that provides overall eligibility for Medicaid-funded in-home care. The Hub might provide information on care partner health and wellbeing and what care partners need to maintain their health. It might also offer resources on how to access behavioral health services for care partners. Examples of care partner supports, programs and services that would be included in the Hub’s information resources are found in Appendix F.
Information Resources
Care partners need early, accurate, and ongoing information related to dementia, caregiving for a person living with dementia, and taking care of themselves. Care partners often seek to understand the diagnosis, prognosis, and course of dementia in order to better plan for disease progression. This information needs to be appropriate to the context of the communities that care partners belong to and the areas where they live. Information about dementia and caregiving can come from multiple sources including conversations with providers, pamphlets and books, support groups, websites, educational workshops, and from friends and other community information resources. Yet care partners may not know where to begin or feel overwhelmed when seeking out this information. The organization will ensure that this information is easily accessible. Specific information supports that could be available through the Hub or be complementary actions are presented in Appendix F.

Care and Service Coordination
Care and service coordination ensures that everyone providing care and support for the person living with dementia, including health care teams, is aware of all relevant information. Care partners need assistance with coordination of care and services; suggestions of ways to support care partners directly through the Hub include:

- Facilitate immediate connections to supports, information, and resources at time of dementia diagnosis and as care partners need them
- Post-diagnosis provision of teaching materials and resources for planning
- Care coordination for people living with dementia with various financing arrangements (Medicaid and Medicare dual eligibility, employer-based insurance, etc.)

Key informants also identified organizational and system changes required to better support care partners and people living with dementia. The Hub cannot likely address these, but the organizing coalition could consider strategies addressing service coordination, supportive services, and adaptation of technology (such as electronic health records) to better support care partners. Examples of organizational and system changes to better support care partners are found in Appendix F.

Key Partners
There are a number of key partners that will be needed to ensure the success and viability of the Hub in supporting care partners. They may play roles at different stages of the Hub’s existence including during the development stage and ongoing provision of supports. Perhaps most obvious, organizations and providers that provide care and support to people living with dementia and care partners are needed as partners. This might include consumer advocacy groups such as the Alzheimer’s Association or AARP Oregon, and it could include service providers such as adult day programs or in-home care agencies. These organizations have close contact with people living with dementia and their care partners and will be sensitive to evolving needs.

Governmental partners are also needed in the implementation and management of the Hub. State, tribal, and local government agencies serving older adults (including aging and disability-related services) are needed. These include the Oregon Department of Human Services, Office of Aging and People with Disabilities (APD), Oregon Health Authority (OHA), Oregon Department of Veterans Affairs (ODVA), Oregon Department of Consumer and Business Services (DCBS), as well as local area agencies on aging (AAs) and Aging and Disability Resource Centers (ADRCs). Tribal and county partners are also needed. Additional governmental initiatives that could be leveraged to support dementia care partners include the OHA’s recently funded BOLD grant, which is intended to build dementia infrastructure in Oregon. The new Oregon Center for Excellence in Aging and Behavioral Health, housed at PSU, could also be a
partner, along with the State Plan for Alzheimer’s and Dementias in Oregon (SPADO) and the Governor’s Commission on Senior Services (GCSS).

Charitable and philanthropic organizations are another potential partner in this work. These organizations could provide guidance on how to obtain support to enhance what the Hub is able to offer. There may be specific opportunities to build on the core support offered by the Hub, which a grant or other additional funding might facilitate. Oregon-based funders might include health system foundations, community benefit allocations, private philanthropic donors, and regional philanthropies with an interest in aging. It will be important to seek support to fund activities that are Oregon-wide in scope and recognize differences between rural and urban communities in terms of accessing services.

The wide variety of professionals who may work with people living with dementia and care partners are also important partners. These include health care professionals (e.g., geriatricians, primary care providers), as well as legal professionals such as elder law attorneys, and financial professionals who work with people on how to navigate paying for dementia care and services. Those working in banking can help prevent financial abuse – one of the largest sources of reported abuse in Oregon. Other professionals who may be engaged with the work of this organization come from faith, labor, social supports, and criminal justice. Faith-based organizations may be a particularly important partner in this work as entities that are a trusted source for information.

Civic organizations that provide social opportunities for people to gather and connect are another possible opportunity to support and promote the Hub, as well as creating opportunities to meet directly with care partners. Engaging with trade associations and professional societies that represent health care providers (such as seniors housing, long-term care, primary care, gerontology-related providers), and other professionals (such as law, finance, human services, criminal justice) will be another method to share knowledge about the Hub and ensure it has adequate support. Other public locations, such as grocery stores and local markets around Oregon where many older adults shop on a regular basis, could be partners in the Hub. Information booths at local farmers’ markets could be another opportunity to reach out to dementia care partners.

Other local government entities could be important partners in reaching various populations of care partners for outreach and dissemination. Libraries, community recreation centers, and senior centers continue to be an important component of communities around Oregon, and are a trusted resource for information related to caregiving needs. Other, less obvious partners might be post offices in rural and frontier communities, which serve as an informal location for people to connect socially with their community. Another less obvious partner might be law enforcement, who are often the first point of contact for people living with dementia who are wandering or are missing. Each of these potential partners could help care partners become aware of and access the Hub.

Higher education institutions and students may be important partners. Students in fields related to providing care and support for dementia care partners (nursing, social work, public health, etc.) offer a possible workforce source via internships and other work placements. This is a mutually beneficial arrangement for the Hub, students, and higher education institutions. Relationships with higher education institutions around Oregon with programs related to dementia, caregiving and health services should be cultivated (such as PSU, OHSU, WOU, OSU, SOU, EOU, Pacific University, Linfield University, and multiple community colleges).
Other community-based organizations and nonprofits that may also connect with people living with dementia and care partners should be engaged. These organizations may provide a location to carry out outreach around the organization’s offerings and the ability to interact with older adults. Examples include the Oregon Food Bank as well as local nonprofit organizations across the state that are important partners in their local communities. Organizations that serve historically and underrepresented communities are particularly important to achieving equity in the Hub.

Administrative Home
The organizational home for the Hub is important in order to ensure a “neutral” location that will be welcomed, welcoming, and accessible to all. It ideally will have the capacity to advocate for, and respond to, all interested parties. Options could include a new or existing nonprofit organization, a B Corporation, a university, or a government agency. The project team conducted additional interviews near the end of the project timeline with interested parties to explore these options and the following pros and cons were identified for these options:

- **Create a new nonprofit organization**: This would offer independence and a specific mission, but would require a major investment to be established, funded (initial and sustaining), and then substantial efforts to gain name recognition in relevant communities.

- **Existing nonprofit organization**: Such an organization would have an established structure, governance and stability, but the Hub would represent a new line of operations that may or may not fit with its mission, image and priorities. An existing nonprofit also may not have sufficient staff and resources to support the Hub and would require new funding (i.e. it is unlikely the new activity could simply be absorbed into operations).

- **B Corporation**: Certified B corporations are for-profit businesses that meet a higher standard of social responsibility, legal accountability, and public transparency. The bottom line of a B corporation emphasizes social responsibility rather than just profit. The mission of the Hub may not align with existing Oregon B corporations.

- **Government agency**: This would have an established organizational structure and governance, but some communities (both cultural and geographic) might not be comfortable going to a government website because of historical and ongoing mistrust of government. Concerns were also expressed about changing government priorities that may occur with a change in leadership, which could have an impact on the sustainability of the Hub.

- **University**: This would have an established organizational structure and governance, and offer access to students and educational opportunities. However, the administrative complexity of universities may make it difficult to secure a long-term institutional commitment for support of the Hub, obtain consistent funding and staffing, and to maximize use of resources that flow through the university (given university policies and procedures for the management of external funding). Some communities may have a mistrust of universities because of a history of exploitation in research.

A coalition of interested organizations may be the best strategy to ensure representation of existing organizations in Oregon that are well established and recognized, and to avoid duplication of services. Leaders from these organizations who will champion the Hub could convene and enter into a memorandum of agreement that would define shared decision-making, resource allocation, and governance. A coalition creates the opportunity for organizations that serve specific communities to be central players in the Hub, and ensure that services and supports are designed to equitably reach care partners across Oregon.

It will be necessary to house the Hub at an organization that would serve as the administrative “home” and help provide fiduciary oversight, financial management, and other administrative services to help
build the capacity of the Hub. In order to be responsive to communities it is probably best not to host the Hub at any of the health systems due to access barriers created by health insurance and unique organizational missions, or at any of the specific community-serving agencies given their focus on specific communities or populations. Given feedback from key informants about various barriers to accessing services, as well as the importance of being culturally and community responsive, some potential locations that were suggested by key informants (and have not been discussed with these organizations) include:

- an existing, well-established nonprofit with a statewide focus, such as Age+,
- the Oregon Department of Human Services, which houses services for older adults (recognizing some concerns about government hosting),
- the PSU Institute on Aging, which houses the new Oregon Center for Excellence in Behavioral Health and Aging (perhaps as a sub-contractor to another organization given the concerns about hosting the Hub at a university).

Other organizations may also be viable hosts, and are not mentioned here as they were not identified during this project. There will need to be leadership from one or more organizational champions to convene interested parties, determine the viability of a coalition, and identify potential administrative homes.

Additional opportunities may emerge, for example, as OHA develops its scope of activity related to dementia with Oregon’s new BOLD grant; any upcoming funding to Oregon organizations that may be selected as sites in the new CMS GUIDE Model demonstration project; and any other new initiatives that bring new resources to Oregon that complement the intent of the Hub to reach and support dementia care partners across Oregon.

Initial Implementation Steps
The Hub should be established as a “one stop shop” that will provide resources including websites, listings of various supports, and options specific to communities defined by geography and culture, with resources updated in real time with current names and contact information for resources.

Acquiring adequate funding for the Hub is crucial to its success and long-term stability. Initial funding could be sourced from the State of Oregon as a seed grant to help make the Hub operational. However, relying primarily on state funding in the long-term may pose challenges in shifting political and policy environments. Oregon-based philanthropy could provide additional sources of funds, as could national funders with interests in aging, dementia, and caregiving issues.

A coalition of key collaborators and partners will be needed to ensure successful implementation and operation of the Hub both for start-up and over the long-term. Different collaborators will be needed at different points in time within the organization’s developmental process and operation. The coalition of collaborators will need to address leadership and governance structure, staff, and outreach to successfully build and implement the hub.

A community advisory group could be convened to provide guidance from individuals with lived experience as dementia care partners as well as people living with dementia or mild cognitive impairment. The membership of this group should be representative of the different regions of Oregon (e.g., Southern, North Coast, Eastern, etc.) as well as different communities within Oregon that are underserved and underrepresented within dementia care and research. While specifying the exact governance structure and staffing of the Hub is outside the scope of this report, the Hub should have the necessary organizational support to provide needed supports to care partners in Oregon.
Initial and continued outreach and promotion of the Hub will be essential to success including engagement with care partners from multiple communities across Oregon. The website should be highly visible, easily accessible, and navigable by care partners with limited free time. There also needs to be capacity for telephone access, for those individuals with restricted internet access. Outreach to specific communities and populations should be made throughout the Hub’s initial development and operation. Social media and other outreach communications should be provided in multiple languages to reach all Oregonians who are care partners. Local libraries, grocery stores, community and recreation centers, service clubs, faith-based organizations, senior centers, pharmacies, and rural post offices are all relevant outreach partners.

Public communications are also needed. The FlashAlert Newswire service should also be used to disseminate press releases to Oregon news media outlets when major milestones are accomplished, such as when the Hub is initially implemented and for significant updates. Social media posts should be made to the Hub’s social media accounts that reinforce the key messages of any press releases sent to FlashAlert Newswire, as well as more frequent posts that highlight individual components of the Hub. Targeted advertising on social media platforms can also be used to increase the likelihood that care partners will become aware of the Hub.

Implementation Plan
The plan to implement the Hub should include these steps:
- Self-identification of champions to initiate planning
- Assemble coalition of supporters
- Determine shared decision-making, resource allocation, and governance of coalition
- Seek and obtain funding to establish the Hub
- Identify administrative home and associated logistics
- Develop community advisory board
- Hire project manager and relevant staff (with skills in website development and maintenance, public communications including social media, community outreach and engagement, and information management)
- Build website/platform including telephone links
- Identify peer moderators and provide training
- Create initial peer-moderated conversation streams
- Develop and launch communications plan for outreach through social media and other channels
- Launch platform with relevant media communications
- Monitor activity
- Implement ongoing evaluation
- Continuous engagement and outreach with community partners and with dementia care partners
- Make regular improvements to respond to feedback
- Seek and obtain additional funding to sustain the Hub

Timing and sequencing of these activities would be determined by the guiding coalition.

Evaluation
The implementation of the Hub should be conducted in parallel with a robust monitoring and evaluation strategy in order to identify opportunities for improvement in a timely way. Evaluation activities should be written into funding requests at the standard rate of at least 10% of total budget. An initial framework for the design of the evaluation is presented in Appendix G; it articulates goals for the evaluation, key
questions, and an approach that builds from six core concepts to frame the evaluation. These core concepts are: Impact, Benefits, Partnerships, Sustainability, Satisfaction of Participants, and Effectiveness of the Hub operations. Each of these are high-level broad concepts with multiple indicators and connected to the larger evaluation questions. They form the foundation of the evaluation and provide the framework for subsequent reporting of results and action arising. Key observable or measurable indicators are suggested for each concept. Finally, various methods to collect the evidence and sources of that evidence are recommended.

Policy Recommendations to Support Care Partners
The Hub will not fulfill all needs that dementia care partners have for support and services. Many care partner needs are best addressed through policy changes, both within Oregon and nationally. Policy solutions are well-suited for addressing needs that require public financing or changes to healthcare standards and certifications. The following state- and federal-level policy recommendations were synthesized from focus groups conducted with care partners, interviews with leaders of organizations providing services to care partners and people living with dementia, consultation with expert interested parties, and a comprehensive literature review.

Five state-level policy actions are recommended:
- **State-level Recommendation 1**: Increase state funding to compensate ADRD care partners (including family, friends, and hired care partners) through direct financial support.
- **State-level Recommendation 2**: Fund community organizations to ensure equity of access and in the design of all programs and services for ADRD.
- **State-level Recommendation 3**: Invest in and develop Oregon’s ADRD care workforce to ensure available and accessible care and support for the increasing number of Oregonians living with ADRD.
- **State-level Recommendation 4**: Create a professional certification for the relevant ADRD health workforce at the community college level.
- **State-level Recommendation 5**: Fund an information hub for ADRD-related care and support needs that provides links to community-specific resources including websites, telephone contacts, listings of various support services, and care options.

Three federal-level policy actions are recommended:
- **Federal-level Recommendation 1**: Support the use of technologies to support ADRD care partners through social support, data-driven programs and policies, and/or culturally relevant supports.
- **Federal-level Recommendation 2**: Expand public health insurance programs (e.g., Medicare, Medicaid, Veterans Health Administration, and Indian Health Service) to cover all aspects of dementia care, and acknowledge and support care partners.
- **Federal-level Recommendation 3**: Provide incentives for care coordination and navigation that will support care partners in providing care.

More detail about each recommendation can be found in Appendix F, which presents a full policy brief intended for advocacy organizations and legislators wishing to take action to support care partners.

Dissemination
To date, the following presentations have been completed:
AcademyHealth Annual Research Meeting, Seattle, WA, June 2023:
- Sherril Gelmon, Walter Dawson, Kathy Kirkland, and Brant Oliver. “Policy Issues in Coproducing Support for Care Partners of People with Serious Illness.” Policy roundtable presentation.
• Walter Dawson, Sherril Gelmon, and Jenn Hollandsworth Reed. “Identifying Optimal Supports for Care Partners of People Living with Dementia.” Poster presentation. Alzheimer’s Association International Conference, Amsterdam, Netherlands, July 2023:
• Sherril Gelmon, Jenn Hollandsworth Reed, Anaeliz Mina Colon, Sofia Chapela Lara, Devlin Prince, and Walter Dawson. “Meeting the Needs of Care Partners of People Living with ADRD from Historically Under-Served Communities.” Poster presentation.
• Walter Dawson and Sherril Gelmon. “Supporting ADRD Care Partners from Historically and Currently Underserved Communities.” Featured research session. Institute on Aging Symposium, Portland, OR, October 2023:
• Sherril Gelmon, Walter Dawson, and Jenn Hollandsworth Reed. “Supporting Care Partners of People Living with Alzheimer’s Disease and Related Dementias.”

The following presentations will occur in the near future:
Gerontological Association of America Annual Scientific Meeting, Tampa, FL, November 2023:
Global Observatory on Long-Term Care in early 2024:
• Tentative invitation to present findings of this work in a webinar presentation.

A proposal for an oral presentation has been submitted and is under review for the Alzheimer’s Disease International Conference, Krakow, Poland, April 2024:

The project team intends to submit proposals for the Alzheimer’s Association International Conference, Philadelphia, PA, July 2024, and the American Public Health Association Annual Meeting, Minneapolis, MN, October 2024.

Written materials have been disseminated or will be disseminated as follows:
• Circulated the Delphi priority activity report to participants, and plan to write and submit a manuscript to a journal such as the Journal of Gerontology
• Sent the policy brief to key informants, and plan to write and submit a manuscript to a journal such as the Journal of Alzheimer’s Disease
• Plan to disseminate the policy brief to legislators (after the 2024 short session concludes)
• Post this report on the Institute on Aging website
• Write and submit a manuscript on coproduction in serious illness to a journal such as Health Affairs, building upon the AcademyHealth presentation, with colleagues from The Dartmouth Institute
• Write and submit a manuscript on the public health implications of dementia with emphasis on care partners of people living with dementia, for submission to the American Journal of Public Health
• Share the executive summary of this report with a link to the full report to key informants, networks affiliated with the Global Brain Health Institute (including the Atlantic Fellows), lived experience groups, and other contacts.

The Institute on Aging may wish to disseminate information from this report through its newsletter, FlashAlerts, social media or press releases.
Conclusion
The award of a Gerontology Education & Research Initiative (GERI) faculty grant through the “Better with Age” initiative at the Portland State University Institute on Aging supported the work described in this report. This has been a very productive 16-month project, which has seeded plans for continuing work. The relevance of this work to the lived experience of the project co-principal investigators makes the results personally meaningful, and we are hopeful that others will step forward to implement the recommendations presented.

Portland, OR
October 2023
Appendices

Appendix A: Key Themes from Interviews and Focus Groups

Appendix B: Role Model Programs that Support People Living with Dementia and Their Care Partners

Appendix C: Priorities to Support Care Partners of People Living with Alzheimer’s Disease and Related Dementias: Results of a Modified Delphi Process

Appendix D: Role Model Programs Thematic Matrix

Appendix E: Portland-Area and Oregon Community-Based Organizations Serving People with Dementia and Other Aging Populations

Appendix F: Examples of Information Resources Available through the Hub

Appendix G: Dementia Care Partner Hub Proposed Evaluation Framework

Appendix H: Policy Brief: Responding to the Needs of Oregon’s Dementia Care Partners: Recommendations for Policy Change
Appendix A: Key Themes from Interviews and Focus Groups

The following narrative describes seven themes that emerged from interviews and focus groups with care partners of people living with dementia.

Ongoing Need for Information about Caregiving for a Person Living with Dementia
Care partners consistently said they need early, accurate, and ongoing information related to dementia, caregiving for a person living with dementia (PLWD), and self-care. Information in healthcare settings is often provided in impersonal, written formats, focused on the medical implications of dementia, while neglecting to educate care partners about self-care and other topics that could support them throughout their journey.

[Health System] has information brochures pretty much everywhere. If you’re [at specialty clinic], there is a resource literature rack. None of it has, or very rarely -- I saw one over the course of the last 15 years -- some information about caregiver support. (Asian American care partner)

Care partners need and want to understand the diagnosis, prognosis, and course of dementia in order to better plan for changes that occur with disease progression. They often spoke of healthcare providers giving them inaccurate or inadequate information or relying upon printed materials which may not answer the specific or unique questions of care partners. While few things are certain with dementia, knowing what to expect as the disease progresses would help care partners feel more confident. Healthcare providers may also assume that care partners already understand what to expect, as was the case of a care partner who worked in healthcare (but in an area unrelated to dementia).

I think what [has] always been most important to me is knowing what to expect. ... I just wanted some idea of how fast, what the progression was going to be because I think a lot of people just have one idea of what dementia is ... Whenever I tell anyone that my mom has dementia, [they ask], "Oh, does she still know who you are?" ... Anyway, I think I would've really just liked to hear what I should expect. How long could she possibly be in her home? What are the things? ... I think sometimes, as a healthcare professional, people just expect you to know. And it's like, "Well, this is my mom. It's a little bit different... I'd like some guidance right now from you." (Adult child who cares for their parent)

Healthcare providers should also be aware that some care partners come from cultures where certain topics are less likely to be discussed publicly, so healthcare providers may need to be more proactive in sharing information about dementia rather than assuming that care partners will ask questions if and when they have them.

Now I feel like I can help other people, whereas at that point I didn’t know where to go, what questions to ask, and who even to talk to because again, culturally, my husband and I both came from cultures where we don’t share a lot of what’s going on in our families. Who do you talk to? (Asian American woman who cares for her Middle Eastern mother-in-law)

This information needs to be appropriate to the context of the communities the care partners belong to and the areas in which they live. Care partners need information that meets them where they are, literally and figuratively. While the focus group participants all lived within the Portland, OR metropolitan area, those in the suburbs and beyond noted the difficulty of traveling to Portland to obtain services and the need for accessible information about services located closer to home. Care partners also need
information delivered in modalities that can accommodate their work schedules, language proficiency, and literacy levels.

*Imagine going to any doctor or something and if you don't know how to read or write, they give you a packet of information, and these packets of information sometimes sit [at] home or whatever, and it goes around the family. Who will fill out the application for this person?* (Latina who works at a Latinx organization)

**Unmet Needs Across Communities**

Meals, transportation services, respite care, and financial support were all identified as unmet needs of care partners. Another unmet need identified by care partners was for referrals, navigation, and coordination across the myriad of services and providers who support PLWD.

*When my mother was hospitalized for what was finally identified as strokes and TIAs, I leaned on the medical social workers from the discharge team, and I have discovered that not all of those folks are well-educated on what’s available in the community for community resources. And that’s really distressing. I’m sad and angry. I’m sad because I’m sure they’re still short-changing other families with resources, and I’m angry that my family was shortchanged on resources.* (Asian American adult child who cares for their Asian parent)

*What I discovered, it’s part of my work to know these resources now, is that the more educated population, at least middle class, know about this resource. But the people who are in dire need often don’t. They do not know about it, they do not know where it’s located because nobody tells them. Again, they don’t know to ask the right question.* (Asian American woman who cares for her Middle Eastern mother-in-law)

As the disease progresses, PLWD may reject foods they perceive as bland or unfamiliar. Meal delivery services often provide foods that are intended to be palatable to most people, but they are unable to always fully accommodate certain dietary restrictions. As a result, care partners may discover that inappropriate or unacceptable foods have been provided, such as finding that a lactose-intolerant care recipient has a refrigerator full of cartons of expired milk.

Care partners need transportation options that are dependable, cover a large geographic area, and are able to communicate with care partner and PLWD in a way they can understand. Care partners spoke of transportation services that did not travel to needed geographic areas, provided language interpretation on their customer service phone lines but not during the actual ride, and services that failed to arrive on time or at all. The expense of transportation is also a barrier for low-income care partners.

*My husband went from four-wheeled walker to wheelchair to bedridden during the course of his decline. Because we’re over limit for the Oregon Health Plan, that meant I needed to find $200 every time I wanted to hire a wheelchair van to take him to a medical appointment.* (Asian American care partner)

Care partners need trustworthy and affordable care assistance and respite care for both short and longer breaks from caregiving. Caregiving can be extraordinarily expensive, and many services have income or asset limitations or are not covered by health insurance. Multiple care partners expressed concern over using formal, paid care or assistance, often centered around whether those workers would perform needed tasks and ensure the safety of their care recipient. Respite care allows care partners to take a
much-needed rest or attend important events such as weddings or the birth of a grandchild. The cost of respite care is often prohibitive, and care partners may rely upon family members and friends for this support.

I would expect that if my mom is at an appointment and she needs help filling something out, that [paid caregiver] would understand that. But instead, I asked them to take my mom to the dentist, and I [got] a call from my mom while I was [at work] ... So I called her back and said: “Well, what are you doing? How was your appointment?” Because it was an hour later. She said: “Oh, I’m still in the waiting room. I’m filling out my forms.” And I said: “Oh, could I talk to the receptionist? What’s going on?” [The receptionist] said: “Oh, I think she’s having some trouble.” It was on an iPad. So she was completely confused. [And I thought]: “There’s this person there. Why aren’t they helping?” (Adult child who cares for their parent)

Care partners also need support with basic needs, such as housing. The current housing crisis affects all populations, including care partners and their care recipients. The housing crisis is not limited to Portland, and disproportionately affects Native and immigrant communities across Oregon.

[Non-federally-recognized Tribal community] has one main site and in 1960 the Army Corps of Engineers came in and put some housing up. ... It's now a lot later and not a lot has been done since then. There are also other sites throughout the entire river where you have families and elderly living in subpar housing. You have them living in tents and broken-down RVs in even worse conditions. ...Throughout the summer, maybe that's okay, but our summers are getting a lot harsher now too, and it's hot out there. (Native American Tribal liaison for a government agency)

Caregiving Affirms Cultural and Familial Values

Everyone has values that came from their families and the communities they are part of, and caregiving is an expression of those values. Contrary to the deficits-focused language often used to describe historically and currently marginalized populations, care partners and people working for government agencies and community-based organizations highlighted the many strengths of their communities.

I think when you talk about Native Americans, we tend to go right for the generational trauma and all the bad stuff that’s happened. But the resiliency in the Oregon nine [federally-recognized tribes] is so strong, so strong, and just doesn’t show up in the news quite as much. And that’s really sad because the tribes are doing excellent things. (Native American Tribal liaison for a government agency)

Caring for a parent is often a natural reciprocation of the care children once received. While care partners acknowledged that caregiving could be difficult at times, they described it as being more like a duty they were proud to perform rather than a burdensome obligation.

I would feed her breakfast and then go to get dressed. When I came out she said: “When are you going to feed me??” [I said] “Mom, I just did, put the dishes in the dish washer, you just ate. ... I had to get used to that.” The first couple of times you sort of grind your teeth and go, “Oh.” But then I realized as my mom, when I was sick, took care of me and I’m sure she thought “That kid is sick again.” (Black adult child who cared for their parent)

The experience of caregiving is also an opportunity to express cultural values that celebrate the PLWD as a treasured part of their family and community. Care partners continue to involve their care recipient in
family traditions, even if they are unsure whether the care recipient will remember the tradition itself.
Caregiving also offers an opportunity for younger generations to get to know the care recipient and learn from them.

*In our community, we firmly believe that Elders are our history keepers, our culture keepers, and we need them in order to learn and to teach the future generations about Native ways, Tribal customs, Tribal practices specific to their Tribes, languages, recipes, food, ceremonies, all of it.* (Native American Tribal liaison for a government agency)

**Evolution of Care Partner Identity as Dementia Progresses**

The relationship a care partner has with the person they care for changes as the disease progresses. Care partners often grieve the loss of the marital or parent-child relationship as they navigate a new and changing identity as a care partner of a PLWD.

*I just need to find some peace with the situation. I mean, that’s what makes this the most difficult for me, is my resistance to what is happening. I am grieving the emotional support I used to have from my mom. She just does not respond in a way that makes me feel particularly loved or cared for. Even though I know my mom loves me, it’s just so different. She is so different now. Her personality has changed so much. And that is just something that I really struggle with ... I think that if I could find peace with that, then this wouldn’t be so difficult for me.* (Adult child who cares for their parent)

Beyond the loss of their core relationship with the care recipient, care partners are also keenly aware that, in the eyes of friends and acquaintances, their identities may shrink to just the care partner role. Care partners were adamant that while caregiving may be a large portion of their life, they are still whole and complete people who are more than a care partner.

*I get tired of just being seen as a care partner. And today I was thinking in my mind, care partner is a role that I play. It isn’t me. It isn't who I am. You really do get subsumed into this whole thing, and it becomes who you are. And that's just another part of it that wears on you.* (Partner who cares for their spouse)

Care partners also feel conflicted when they make decisions that contradict their own personal values but are nonetheless in the best interest of the care recipient. This can manifest when a person who prides themselves on being a truthful person engages in “therapeutic lying” and finds themself reacting in ways that are surprising, for example when contemplating a care facility placement for their care recipient.

*We're all in long-term relationships that die out. I think our relationships have been characterized by being honest, and yet all of a sudden after 50 years of honesty, I'm supposed to tell myself it's okay to do a little fib? That's a hard, hard transition.* (Partner who cares for their spouse)

A PLWD may also impose an identity on the care partner, such as when they believe the care partner is another person or an imposter of their loved one. The belief of someone being an imposter is a typical manifestation of Lewy Body Dementia. This can be similar to media portrayals where a PLWD mistakes their child for a long-deceased spouse, but it can also be more complex. These mistaken identities may be extremely distressing to both the care recipient and care partner, such as in the case of one care partner who reported that his wife called 9-1-1 when she believed him to be an intruder in their
bedroom. Even when the circumstances of a mistaken identity are more benign, it can still cause confusion and distress for the care partner.

Another thing I wish I'd known or understood more is why ... my husband thinks I'm a male who's one of his best friends, or somebody like that, over and over again. The neurologist explained to me that the neurons around facial recognition are clustered near each other, so that when he can't figure out what my face is, he will put the next closest thing, which would be an adult male friend who he feels close to, who's intelligent and witty... They're all nice people, but I'm not male. So, what is this about? I ended up showing him my chest one time, and then he wanted to understand why the pastor from church, which he thought I was, would want to change his gender. He asked very, very politely. He's very polite. But if I could have understood that a little earlier, it might've ... I don't know. I just kept kind of trying to understand, why does he think I'm Michael? (Partner who cares for their spouse)

Strength and Solidarity through Cultural Adjacency
Care partners and the PLWD they care for often find comfort and support in services and providers that share similar experiences, even if they may come from different cultural communities. This cultural adjacency comes from histories of migration to and within the United States, similar cultural values, and similar cultural practices and preferences. One care partner who described extensive race-based discrimination within the medical system eventually found a provider who was extremely helpful and supportive. The care partner believed that part of the provider’s supportiveness was derived from shared experiences of race-based discrimination, even though the provider was of a different (but still historically marginalized) race. Another care partner described the difficulty of directly discussing difficult family matters with strangers such as healthcare providers, and noted the importance of instead reaching out to trusted individuals from other cultures who are able to more comfortably directly access information.

Culturally, it doesn’t matter if it’s my culture, my husband’s [Middle Eastern] culture. We tend to ask friends. We trust friends and family. And if those people also don’t know unfortunately, then we are doomed. (Asian American woman who cares for her Middle Eastern mother-in-law)

I think, looking back, I wish we had first talked with other families that had similar experiences. Again, culturally it was difficult but we could have reached out to our Caucasian friends. It didn’t have to be... Knowing who to ask, what questions to ask, would’ve made a big difference. Both my husband and I work at universities, and now I realize that I probably could have talked to my colleagues [who] would have shared. (Asian American woman who cares for her Middle Eastern mother-in-law)

The importance of food was repeatedly mentioned by care partners. Food did not always need to be what is often conceived of as culturally specific. Care recipients valued food that traditionally came from the general geographic region associated with their culture, even if they did not previously eat that food themselves. Care partners of historically and currently marginalized communities found that their care recipients who rejected the typical American cuisine of some meal delivery services relished both the foods they had grown up with and the traditional (and flavorful) foods of cultures they had no exposure to earlier in life.

My [Asian] mother has a number of caregivers [who] are employed by-where she lives and they are either from the Philippines or Southeast Asia. I gave my mom a small rice cooker. So, although she doesn’t remember how to make rice, everybody on the second floor of her facility does. So she gets
her short grain rice if she wants it because they know how to help her make the rice. (Asian American who cares for their Asian parent)

**Safety as a Community Practice**

Care partners strive to keep the person they care for safe and healthy, and they are often supported in this goal by entire communities. This support comes from sources such as family and friends taking precautions to avoid the spread of COVID-19, and neighbors who help to ensure the safety of care recipients.

[My mom’s] next door neighbor was a nurse, she lived [several miles away]. But she would come all the way out there and check on her. Once I even called her, because my mom wouldn’t answer the phone. I said: “Would you go out there? Please go out there and check. Before I call the police or someone to check on my mom, go out there and check.” She said: “Your mom is okay. She was over in the community room, just chit chat with the little old lady.” (Black adult child who cared for their parent)

Community-based organizations and Tribal governments also provide holistic safety support for care partners and their care recipients. An employee of an organization that serves the Native community described how one local police department is familiar with an Elder who frequently wanders, and will drive the Elder to wherever their care partner is. Tribal values are also expressed through ensuring Elders and their care partners have what is needed to remain safely in their homes.

A couple of the grants that the state was offering were money for food. Well, [Tribe] had a whole surge of money for food. They chose to use that money to buy the 30-year shelf life food in case the big one hit. And so every Elder has enough food to last through the apocalypse. (Native American Tribal liaison for a government agency)

So we [government agency] partner with [government agency] and [they] got a ton of air conditioners and a ton of HEPA filters [after extreme heat and wildfire smoke]. ... It’s easy to talk to the Tribes about, “Well, what do you think about how these were distributed [in prior years]? Would you like to see them distributed differently the next time?” What we chose to do as an agency is to give an allotment to each of the Oregon nine [federally-recognized] Tribes. So I think [Tribe] got 200 HEPA filters, and then learning to not micromanage as the state and letting the Tribes have their sovereignty, for God’s sakes, let them make their own decisions. So [Tribe] decided how they were going to distribute the HEPA filters and the air conditioners that they got. Most of the time, it is prioritized for Elders, ... then people with disabilities or people with medical conditions are next on that list. Most of the Tribes did that. We don’t have to tell them to do that there. They know how to distribute. (Native American Tribal liaison for a government agency)

**Legacy of Past Injustices Affects Care Partners in the Present**

Cultural stereotypes often lead to a delayed diagnosis of dementia, inadequate health care, and insufficient information being provided. These disparities in care can be quite subtle, such as when a medical provider cut interactions short.

One older adult [served by Latinx community organization] says: “All the doctor gives me is medication. That’s all. Just gives me things for this and that.” She says: “But I don’t know if I’m losing my mind or if I’m just not remembering, but I don’t remember things.” (Latina who works at a Latinx organization)
While care partners primarily described subtle disparities in care, they also experienced overt racism in the course of their experience navigating the care and support systems.

*I even had a doctor say, “I’ve never treated a Black person before.” I said: “Pretend we’re just painted.”* (Black care partner)

Cultural stereotypes that are seemingly positive, such as older adults in some groups being respected for their wisdom, may be damaging if they cause healthcare providers to misinterpret symptoms of dementia.

*I didn’t really agree with their assessments, because they said that the person was perfectly capable of taking care of themselves, and I was a director for the [Native] Assisted Living at [reservation town]. I think I know when somebody’s needing assistance, and is not capable. What happens is sometimes they come in with this idea of what a Native American person is. ... So what happens is they look at this Elder, and they say: “Oh, Native Elders are these wise, all-knowing people.” When you get somebody that comes in, and this particular ... Elder would talk about ... about Mother Earth, and the Creator, and how things have changed, and it’s basically, he’s ... explaining how man’s out of whack with the climate, and everything. ... But when you’re around him, he tells it to you every single time. Doesn’t remember that he’s already told you, doesn’t always remember names. So, what he is doing is it’s the one thing that he can remember. That’s his safety, ... his safe zone. So, he goes there. ... I think they finally did get him [diagnosed] eventually, but it just took so long, because they kept saying, “Oh, he is capable of taking care of himself.”* (Native American who works at a Native community organization)

Historic practices that restricted entry into clinical professions affect the healthcare workforce today, resulting in language access barriers for many PLWD who speak and understand languages other than English. While some community-based organizations are able to provide health care in languages other than English, there is still a large unmet need for care provided directly in Spanish and other languages.

*You know, sometimes you go to the doctor, and nobody speaks Spanish, and there is no interpretation service. My insurance is with [organization], I don’t know about other hospitals, but if there is no interpreter, there’s a little screen that helps you. ... Because there are places where there isn’t anybody who speaks Spanish and there is no interpreter.* (Latina promotora)

These same practices have affected which services have been funded and where they are located. Care partners, as well as employees of community-based organizations and government agencies, noted that disparities in the ability to access services exist between the majority population and historically and currently marginalized populations, as well as in the evidence-based practice and research which drives those services.

*There’s been a real focus on more providing more evidence-based supports for communities, including for individuals with Alzheimer’s and related dementias. But there hasn’t been as much evidence or research that’s been done with the wider variety of very culturally specific groups. When you’re going out to try to translate it in a community can be really challenging. I do think there’s been progress over the last few years, but I think there’s lots of room for improvement.* (Employee of a government agency)
In [private memory care facility], somehow they get them a pass, and the bus picks them up. The people that will go to the appointment with the patient meet them at the doctor’s office, but the patients will go by themselves on the bus, which will pick them up at the house and then go to the appointment. On the contrary, that does not happen for us, the Latinos. It seems there is a network that provides rides, but it is very hard for our people to contact them. We need ... someone who speaks Spanish so when they call, they can say: “I need a ride to the hospital, and then they can communicate.” Language is an issue. (Latina promotora who also works as a paid caregiver at a memory care community)

When you talk about [non-federally-recognized Tribal community], those are the river people and they are nomadic, and they do not believe that the Columbia River Gorge is a state line, that’s a river. It was never the difference between Oregon and Washington. So you have people [who] constantly are crossing those lines backward and forth. To stay on Oregon State services versus Washington State services creates a lot of difficulties out in that area. Some Tribes have specific sources of funding for Tribal Elders, and [those] monies can be counted against them when applying for services. (Native American Tribal liaison for a government agency)

The authors thank all the care partners of people living with dementia who were willing to share their experiences, and contributed their ideas and time to the interviews and focus groups.

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Appendix B: Role Model Programs that Support People Living with Dementia and Their Care Partners

Aging Brain Care (ABC) Program
The Aging Brain Care (ABC) program was developed by Eskenazi Health in Indianapolis in 2008 to support primary care providers in the specialized diagnosis and management of patients with cognitive impairment caused by conditions such as Alzheimer’s Disease, delirium and cognitive and emotional problems that may arise after critical illnesses. The ABC team also supports caregivers and includes family members in all care decisions. The model combines research and clinical care, resulting in the rapid translation of research discoveries into clinical practice. Working closely with the patient’s primary care provider, the multidisciplinary care team (consisting of physicians, nurses, psychologists, care coordinator assistants and social workers) develops a personal treatment plan for each patient that includes medications and non-drug treatments to improve the quality of life for patients and caregivers.

Aging Brain Care services include diagnostic evaluation, a personalized brain care plan, and brain care management services. Diagnostic evaluation: A clinical and neurological exam, blood work, brain imaging, memory and mental status testing, and face-to-face family conference with the patient and family caregivers. Personalized brain care plan: Home-based care management coordination with community resources, tools to support patients and care partners in managing dementia and navigating the health care system. Brain Care Management Services: Patient and family education and counseling; data collection via standardized tools to identify and address changes in brain health; coordination of care transitions across multiple settings; design and delivery of person-centered, non-pharmacological interventions to reduce physical and psychological burden for both patients and care partners; modifications to physical and social environments; and Engagement of palliative and hospice care as appropriate (Eskenazi Health, n.d.).

One study showed that 51% of care partners of people living with dementia had a 50% reduction in care partners stress symptoms during their participation in the ABC program (LaMantia et al., 2018). Another analysis of the ABC program showed it led to a net savings per patient ranging from $980 to $2,856 annually, while the annual per patient cost for the program was approximately $618 (French et al., 2014).

Alzheimer’s and Dementia Care (ADC) Program
The ADC Program, based on the UCLA Alzheimer’s and Dementia Care Program, is designed to help persons living with dementia (PLWD) and their loved ones meet the complex medical, behavioral, and social needs of Alzheimer’s disease and other types of dementia. Dementia Care Specialists (DCCs) who are Advanced Practice Providers (nurse practitioners or physician assistants) are at the heart of the program and work with the patient’s primary care doctor and/or specialists to create and implement a personalized care plan with extensive PLWD and caregiver support. The program has expanded beyond UCLA to include these sites: Cheyenne Regional Medical Center, Cheyenne, WY; University of Utah Health, Salt Lake City, UT; Wellspan Health, Lebanon, PA; Jefferson Health, Philadelphia, PA; UC Davis Health, Sacramento, CA; Northwell Health, New Hyde Park, NY; Dignity Health Yavapai Regional Medical Center, Prescott, AZ; and the Wright Center for Community Health, Jermyn, PA.

The goals of the program are to maximize patient function, independence and dignity; minimize caregiver strain and burnout; and reduce unnecessary costs through improved care. The ADC program was developed to enable, empower, and support caregivers as well as provide disease management and...
care coordination to navigate the complicated health care system. The ADC program embraces three core tenets: care that supports the person living with dementia and caregiver dyad; co-management among a nurse practitioner or physician's assistant advanced practice provider (APP), dementia care specialist (DCS), and primary care or specialist clinicians to ensure that care is comprehensive and coordinated for the person with dementia and their family/caregivers; and partnership with community-based organizations (CBOs) and providers (Reuben et al., 2023).

Core elements include: an in-person visit with a Dementia Care Specialist; a personalized care plan developed with the referring physician; follow-up phone calls or in-person visits to make sure the plan is implemented or modified as needed; 24/7, 365-day-a-year access to caregivers for assistance and advice in order to avoid Emergency Department visits and hospitalizations; and ongoing patient monitoring with at least one annual in-person visit to ensure that ongoing and emerging needs are met.

**Care Ecosystem**
The Care Ecosystem model is a telephone- and web-based care program that provides education, support, and care coordination for people living with dementia and their care partners. It was developed and implemented at USCF in San Francisco, CA, has been replicated in other sites including Ochsner Brain Health and Cognitive Disorders Program in New Orleans, LA; HealthPartners Center for Memory and Aging, Saint Paul, MN; University of Colorado Health Seniors Clinic, Denver, CO; Harbor-UCLA Medical Center, Los Angeles, CA; Mass General Brigham Integrated Care Management Program, Boston, MA; Home Instead Center for Successful Aging, Omaha, NE. The current NIH/NIA Care Ecosystem five-year grant is coordinated by UCSF which is also a study site, and involves the previous sites in New Orleans, Saint Paul, Denver and Los Angeles, as well as Providence Oregon.

The services provided through Care Ecosystem include the use of care team navigators (CTNs), clinicians with dementia expertise (e.g., nurse, pharmacist, social worker), care protocols, and curated information and resources. A complete guide to the program is available through their toolkit (UCSF Memory & Aging Center, n.d.). The intervention has been shown to result in several positive outcomes including improved quality of life of individuals living with dementia, reduced visits to the emergency department, and decreased care partner depression and burden (Possin et al., 2019).

**ConnectShareCare**
ConnectShareCare is an online facilitated support network developed by Dartmouth College to help persons providing care or support to an adult with a serious illness better prepare to cope with surprises that arise after diagnosis and during bereavement. The two priorities of the network are connecting care partners to information and facilitating emotional support. In its first two years more than 200 members joined the network and recorded more than 3,500 online posts, moderated by peers. This model transforms peer-to-peer connections outside the traditional health care system into facilitated support networks. These networks extend the scope of services offered by the health system to support lay care partners, improving their resiliency and inviting them to share their expertise with others.

Supports offered through ConnectShareCare include: planning ahead resources (e.g., advance directive, living will), practical resources (e.g., housing, insurance, bills, legal, transportation, food), emotional resources (e.g., worry, loss of interest in usual activities, or anger), communication resources (talking with family or healthcare providers, access to interpreters, asking for, receiving, and providing help), and family resources (e.g., dealing with children or partners, or intimacy) (ConnectShareCare, n.d.).
**D-CHESS**
The Comprehensive Health Enhancement Support System (CHESS) was originally developed at the University of Wisconsin – Madison in 1989 to provide a computer-based health system to help patients and their families become more actively involved in their treatment. Early topics included Living with Breast Cancer, Living with HIV/AIDS, Adult Children of Alcoholics, Stress Management, Sexual Assault, and Academic Crises. In 2007 the first mobile CHESS app was designed to help adolescents manage their asthma. In 2008 A-CHESS, a second mobile phone app, was designed to provide monitoring, information, communication and support services to patients leaving alcohol treatment. In 2011, CHESS researchers, in collaboration with the Wisconsin Institute of Healthy Aging and local county Aging and Disability Resource Centers, developed the Active Aging Resource Center, a community-based information and community technology system that improved quality of life among older adults. D-CHESS (Dementia–Comprehensive Health Enhancement Support System), a computer-based system intended to improve the lives of caregivers, helps users to obtain information, communicate with other caregivers, get help with care decisions, and share information with experts (Gustafson et al., 2019).

**Emory Integrated Memory Program**
The Integrated Memory Care (IMC) program at Emory University is the only primary care practice in the U.S. specifically designed for people living with dementia and their care partners. The model helps families navigate the long road of dementia due to Alzheimer’s disease, frontotemporal degeneration, Lewy body disease, cerebrovascular disease, and other causes. Primary care customized for patients with dementia and the people who care about them. The IMC care team consists of nurse practitioners, physicians, a registered nurse, a social worker, a patient care coordinator, and more. The team develops an individualized plan of care for each person and their care partner with treatment recommendations. Patient education, potential and actual barriers to treatment goals, care partner and family support, and community resources may be discussed while developing the care plan.

Some of the services offered through Emory’s IMC program include longer appointments and individualized attention, family meetings to discuss care goals and needs, complete primary care by a nurse practitioner who specializes in dementia care, a geriatric nurse practitioner for behavioral and psychiatric symptoms, after-hours phone access (evenings and weekends) for established patients, prescription requests and refills by phone or online, collaboration with a patient and family advisory council, care coordination to organize health care needs, support for transitions of care to hospice or skilled nursing care, support groups, and practical education as well as stress management for family care partners (Integrated Memory Care, n.d.; Clevenger et al., 2018).

**Maximizing Independence (MIND) at Home**
Maximizing Independence (MIND) at Home is a comprehensive, home-based care coordination intervention for people with Alzheimer’s Disease or related dementias who live in the community and for their family caregivers. MIND at Home was developed by Johns Hopkins University, and is designed to systematically assess and help address unmet needs that may be barriers to persons with dementia remaining in their home, while maintaining their health and wellbeing and that of their care partner.

Services to address the individual needs of people living with dementia and their care partners through the MIND at Home program include how medications are organized, fall and other safety risks, available community resources and caregiver support. Patients and care partners work with a memory care coordinator, who is a nonclinical community worker, as well as a team that includes a geriatric psychiatrist, registered nurse and occupational therapist. The team conducts an in-home
assessment, and it plans and implements care based on six strategies: resource referrals, attention to environmental safety, dementia care education, behavior management skills training, as well as informal counseling and problem-solving (Shapiro, 2022).

**Program of All-Inclusive Care for the Elderly (PACE)**
The Program of All-Inclusive Care for the Elderly (PACE) provides comprehensive medical and social services to certain frail, elderly people living in the community. The PACE model is centered on the belief that it is better for the well-being of seniors with chronic care needs and their families to be served in the community whenever possible, and provides the structural support to do so. Most of the people who are in PACE are dually eligible for both Medicare and Medicaid. The national PACE program, administered by the Centers for Medicare & Medicaid Services, is modelled on the On Lok program in San Francisco. On Lok was founded in 1971 to create a program that would enable older adults to continue living in their community.

Services provide through the PACE model include all Medicare and Medicaid covered services: Adult day care, dentistry, emergency services, home care, hospital care, laboratory/x-ray services, meals, medical specialty services, nursing home care, nutritional counseling, occupational therapy, physical therapy, prescription drugs, primary care (including doctor & nursing services), recreational therapy, social services, social work, counseling, and transportation. PACE additionally provides any clinician-approved services deemed necessary to maintain a participant’s health (Centers for Medicare & Medicaid Services, n.d.).

**Department of Veterans Affairs (VA) Caregiver Support Program**
The Department of Veterans Affairs (VA) Caregiver Support Program offers clinical services to caregivers of eligible and covered veterans enrolled in the VA health care system. The program’s mission is to promote the health and well-being of family caregivers who care for veterans through education, resources, support, and services. It includes two programs. The Program of General Caregiver Support Services (PGCSS) provides caregivers of veterans with peer support mentoring, skills training, coaching, telephone support, online programs, and referrals to available resources. Caregivers who participate in PGCSS are called “General Caregivers” and do not need to be a relative or live with the veteran. The Program of Comprehensive Assistance for Family Caregivers (PCAFC) offers enhanced clinical support for family caregivers of eligible veterans who sustained or aggravated a serious injury (or illness) in the line of duty in the active military, naval, or air service during any service era.

Services through the PGCSS program include skills training, mobile support, one-on-one coaching, group support and coaching, self-care, peer support mentoring, telephone support, online programs, and referrals to available VA and community resources (U.S. Department of Veterans Affairs, n.d.). Care partner services provided through the PCAFC program include education and training, health insurance (if care partner is uninsured), mental health counseling, a monthly financial stipend, respite care and other services (U.S. Department of Veterans Affairs, 2023).

**WeCareAdvisor**
Drexel University developed an online resource, WeCareAdvisor, that provides caregivers helpful strategies to manage dementia-related behavioral and psychological symptoms, reducing care partner stress and enhancing confidence. WeCareAdvisor has an easy-to-use step-by-step approach to understanding why dementia-related behavioral and psychological symptoms (such as agitation, restlessness, irritability, repeated questions or other behaviors) occur and provides strategies that are customized to the family’s situation to help manage such behaviors.
The services provided through WeCareAdvisor include access to the program’s online platform, which seeks to help participants address dementia-related behavioral symptoms; disease education and potentially useful strategies; new ways of managing challenging behavioral symptoms of dementia; and contributing to research that is aimed at improving the lives of individuals living with memory loss and their care partners (We Care Advisor, n.d.; Gitlin et al., 2022).

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Appendix C: Priorities to Support Care Partners of People Living with Alzheimer’s Disease and Related Dementias: Results of a Modified Delphi Process

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October 2023

This report summarizes the results of a project to develop priorities to better support care partners of people living with Alzheimer’s Disease and related dementias. This project was conducted as part of a larger research project funded by the Gerontology Education and Research Initiative (GERI) faculty grant program of the Better with Age initiative, through the Portland State University Institute on Aging. The project employed a modified Delphi process. The Delphi process is an effective method for gaining consensus on priorities and gives all participants an equal voice in the process.

Representatives of organizations providing services and supports to people living with dementia and their care partners, as well as representatives from organizations serving selected historically and currently underrepresented communities, were invited to participate. Approximately 40 individuals were invited to participate, all of whom had been invited to participate in an earlier initial meeting (simultaneous in-person and virtual) to begin to generate priorities. An initial list of ideas was created from that meeting, organized into eight thematic categories: Care Partner Supports, Programs/Services, Information Resources, Care Coordination, Data Systems/Technology, Policy, Funding/Financing, and Professional Education/Workforce Development. These categories became the framework for the Delphi process (see Table 1). The process was conducted from July to September 2023.

Individuals received an email invitation to three surveys; they were invited each time regardless of participation in the previous surveys. In the first survey they received the list of ideas (mentioned above) and were invited to generate further ideas of priorities in the eight thematic categories. They could offer up to five ideas per category. There were 16 responses to the first survey.

These ideas were collated and synthesized to remove duplication and redundant items, and this revised list was shared in the second survey. The number of ideas generated from the first survey by thematic category is shown in Table C-1 below.

<table>
<thead>
<tr>
<th>Thematic Category</th>
<th># of Ideas from Survey 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Partner Supports</td>
<td>14</td>
</tr>
<tr>
<td>Programs/Services</td>
<td>12</td>
</tr>
<tr>
<td>Information Resources</td>
<td>11</td>
</tr>
<tr>
<td>Care Coordination</td>
<td>12</td>
</tr>
<tr>
<td>Data Systems/Technology</td>
<td>8</td>
</tr>
<tr>
<td>Policy</td>
<td>13</td>
</tr>
<tr>
<td>Funding/Financing</td>
<td>15</td>
</tr>
<tr>
<td>Professional Education/Workforce</td>
<td>15</td>
</tr>
</tbody>
</table>

Table C-1: Ideas Generated from the First Survey
Participants were invited in the second survey to review the list and rate each idea in terms of its importance on a five-point scale: 5=very important priority for care partners to 1=not important priority for care partners. There were 13 responses to the second survey.

The mean score for each idea was calculated, and in the final (third) survey participants were invited to indicate their top five priorities for each thematic category. There were 17 responses to the third survey.

A weighted score was created for each item that received a “Top 5” ranking to facilitate the overall assignment of priority to the ideas; where there were ties in scores those with more respondents were ranked higher. Each idea presented below was ranked by at least 60% or more of respondents to the third survey. Raw scores are not presented as the intent of the Delphi is a ranking, rather than a focus on absolute scores. The 15 ideas receiving the highest rankings overall are presented in Table C-2. More detail on priorities by thematic category is presented in Appendix C-1.

Table C-2: Top 15 Priorities for Supporting Care Partners

<table>
<thead>
<tr>
<th>Ideas</th>
<th>Thematic Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educating care partners about dementia disease process, ensuring timely and appropriate diagnosis, and stages of disease/symptoms (such as agitation and aggression)</td>
<td>Care Partner Supports</td>
</tr>
<tr>
<td>Increase funding including compensation of dementia care partners (family, friends, employed)</td>
<td>Funding/ Financing</td>
</tr>
<tr>
<td>Prepare all primary health providers to understand brain health/dementia, associated stigma, early diagnosis and screening, and support people diagnosed with dementia and their care partners</td>
<td>Professional Education and Workforce Development</td>
</tr>
<tr>
<td>Educating and empowering care partners and families about what to expect, what they might need, and resources to help them navigate and be supported</td>
<td>Care Partner Supports</td>
</tr>
<tr>
<td>How to serve people who do not have care partners</td>
<td>Care Coordination</td>
</tr>
<tr>
<td>Increase financial resources for care partners/PWLD for day programs, respite, other fee-based activities (non-means tested/Medicaid)</td>
<td>Funding/ Financing</td>
</tr>
<tr>
<td>Ensure equity of access and design of programs and services</td>
<td>Programs/ Services</td>
</tr>
<tr>
<td>Affordable in-home care</td>
<td>Programs/ Services</td>
</tr>
<tr>
<td>Facilitate immediate connections to supports, information, and resources at time of dementia diagnosis and as care partners need them</td>
<td>Care Partner Supports</td>
</tr>
<tr>
<td>Care coordination across primary care and specialty settings including referrals</td>
<td>Care Coordination</td>
</tr>
<tr>
<td>Easy access to day programs such as dementia cafes and adult day centers</td>
<td>Programs/ Services</td>
</tr>
<tr>
<td>Expand private and public health insurance programs to cover all aspects of dementia care</td>
<td>Funding/ Financing</td>
</tr>
<tr>
<td>Support care partner health, wellbeing, and work/life balance</td>
<td>Care Partner Supports</td>
</tr>
<tr>
<td>Create information resources, trainings, and services that are culturally and linguistically relevant, and address different learning styles and varied information needs at different stages of dementia</td>
<td>Information Resources</td>
</tr>
<tr>
<td>Create a “one stop shop” with community specific resources including websites, listings of various supports, options by community specific to geography, culture, etc. with resources updated in real time with up-to-date names and phone numbers</td>
<td>Information Resources</td>
</tr>
</tbody>
</table>

A limitation of the approach used is that participants were asked to rank five ideas in each of the eight themes in the third survey, so some ideas inevitably were ranked higher rather than if participants had
ranked the entire list. There were also different numbers of ideas in each category (as shown in Table 1), so caution should be used when making comparisons across categories as rankings across categories are not directly comparable. This may have influenced the overall rankings. Further comparison of priorities assigned in the second and third surveys were reviewed, resulting in the priority listing presented above in Table 2. The variations in rankings were taken into account in the overall synthesis of findings which is presented below.

**Next Steps and Future Directions**

This Delphi process identified a number of ideas that can inform policy and program development to better support dementia care partners in Oregon. A specific outcome could be the establishment a new resource to support dementia care partners in Oregon, by creating a central hub or “one stop shop” where dementia care partners are able to obtain the information they need when they need it, and identify community-specific resources. This hub would bring information on existing programs and services together into a central network – not duplicating existing activities but facilitating access to information through both Internet and telephone access. This should support care partners in carrying out their caregiving activities and help them feel they have access to the necessary supports to do so. Such a program was identified as a top idea during this process under the theme “Information Resources”. A detailed proposal for this “one stop shop” will be included in the final project report.

Several of the top priorities have implications for organizations whose scope includes educating and empowering care partners, and helping care partners identify necessary supports, information, and resources. This could include organizations such as AARP Oregon and the Oregon and Southwest Washington Chapter of the Alzheimer’s Association, as well as dementia care providers at health systems such as Oregon Health & Science University (OHSU) and Providence Health and Services. Such organizations are well positioned to support care partner health, wellbeing, and work/life balance, identify ways to serve people diagnosed with dementia who do not have care partners, and facilitate information about, and access to, day programs such as dementia cafes and adult day centers.

Attention to equity of access and equity in the design of programs and services is a moral responsibility for all organizations and individuals serving people living with dementia and their care partners. A related priority is the creation of information resources, trainings, and services that are culturally and linguistically relevant, and address different learning styles and varied information needs at different stages of dementia.

Other priorities will require action by provider organizations and educators in order to ensure primary care providers are better prepared to understand brain health and dementia and to support people diagnosed with dementia and their care partners. Care coordination across primary care and specialty settings including referrals will require action by provider organizations.

In addition, these results point to a number of potential policies and programs that could be implemented at the state and national levels to better support dementia care partners. For instance, the idea of “increase funding including compensation of dementia care partners (family, friends, employed)” has multiple possible applications in the Oregon policy context such as enhancing the flexibility of existing Medicaid waivers or increased funding of Oregon Project Independence (OPI), as well as increasing the number of people served by OPI. Other priorities will only be possible to implement if changes are made in financing and insurance to increase financial resources for care partners and people living with dementia for day programs, respite, and other fee-based activities; to ensure in-home care is
affordable and/or covered by private insurance/Medicare; and to expand private and public health insurance programs to cover all aspects of dementia care.

The results of this process can become part of a continuing dialogue on how to better support dementia care partners. In addition to sharing these results with those who participated in this Delphi process, we encourage participants to consider how they might use these ideas in their own work to support dementia care partners. Some of the policy and programmatic ideas identified through this process may be particularly relevant for certain partners and interested parties to advance or implement on their own. While they could move these ideas forward themselves, discussion of how they might use or advance these ideas can also inform the development or refinement of the “one stop shop” hub and policy recommendations proposed by this project’s team.

The complete report for the “Supporting Care Partners of People Living with Alzheimer’s Disease and Related Dementias” project will be available on the Better with Age website at Portland State University (PSU) in November 2023.

The authors gratefully acknowledge the support of the “Better with Age” initiative at the Portland State University Institute on Aging. This work was conducted with the support of a PSU faculty “Gerontology Education and Research Initiative (GERI) grant for 2022-2023.

The authors thank all participants who contributed their ideas and time to the process described here.
Appendix C-1: Priorities by Thematic Category

The eight categories of themes are presented in two groups: those related to program and service priorities for supporting care partners, and those related to policy-related priorities.

**Program/Service Priorities for Supporting Care Partners**

<table>
<thead>
<tr>
<th><strong>Theme: Care Partner Supports</strong></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Educating care partners about dementia disease process, ensuring timely and appropriate diagnosis, and stages of disease/symptoms (such as agitation and aggression)</td>
<td></td>
</tr>
<tr>
<td>Educating and empowering care partners and families about what to expect, what they might need, and resources to help them navigate and be supported</td>
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</tr>
<tr>
<td>Facilitate immediate connections to supports, information, and resources at time of dementia diagnosis and as care partners need them</td>
<td></td>
</tr>
<tr>
<td>Support care partner health, wellbeing, and work/life balance</td>
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<table>
<thead>
<tr>
<th><strong>Theme: Programs/Services</strong></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Ensure equity of access and design of programs and services</td>
<td></td>
</tr>
<tr>
<td>Affordable in-home care</td>
<td></td>
</tr>
<tr>
<td>Easy access to day programs such as dementia cafes and adult day centers</td>
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</tr>
<tr>
<td>Increase in affordable and trustworthy respite programs statewide with guaranteed funding</td>
<td></td>
</tr>
<tr>
<td>Create more residential options including memory care facilities, temporary and long-term supportive housing with capacity to manage behavioral concerns</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Theme: Information Resources</strong></th>
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</thead>
<tbody>
<tr>
<td>Create information resources, trainings, and services that are culturally and linguistically relevant, and address different learning styles and varied information needs at different stages of dementia</td>
<td></td>
</tr>
<tr>
<td>Create a “one stop shop” with community specific resources including websites, listings of various supports, options by community specific to geography, culture, etc. with resources updated in real time with up-to-date names and phone numbers</td>
<td></td>
</tr>
<tr>
<td>Create large public health and human services campaign to reframe dementia/brain health, educated the public, and acknowledge universality of caregiving experience and challenges, especially for communities expected to experience large increases in dementia prevalence and for individuals who may become a care partner in the future</td>
<td></td>
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<tr>
<td>Ensure provision of written translation and oral interpretation services in both primary care and specialty services</td>
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<table>
<thead>
<tr>
<th><strong>Theme: Care Coordination</strong></th>
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<tbody>
<tr>
<td>How to serve people who do not have care partners</td>
<td></td>
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<tr>
<td>Care coordination across primary care and specialty settings including referrals</td>
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</tr>
<tr>
<td>Better detection of dementia within multiple localities/systems, primary care, etc.</td>
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</tr>
<tr>
<td>Challenges of finding and navigating services</td>
<td></td>
</tr>
<tr>
<td>Have social workers with expertise in Alzheimer’s/dementia embedded within hospitals and other relevant settings</td>
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</tr>
</tbody>
</table>
Policy-Related Priorities for Supporting Care Partners

<table>
<thead>
<tr>
<th>Theme: Data Systems/Technology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adapt EHRs to prompt primary care and other providers for various actions such as screening for dementia, tracking dementia-related information, and following up on abnormal results</td>
</tr>
<tr>
<td>Use technology to support care partners through social support, data-driven programs and policies, and/or culturally relevant supports</td>
</tr>
<tr>
<td>EHRs should have prompts for identification of care partners and assessment of care partner wellness</td>
</tr>
<tr>
<td>Add a brain health metric to Oregon’s PCPCH (primary care home) recognition</td>
</tr>
<tr>
<td>Improve capacity of emergency departments to capture and share data about visits by people living with dementia and their care partners</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme: Policy</th>
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</thead>
<tbody>
<tr>
<td>Develop cohesive statewide strategy to address geriatric psychiatry services through policy and public funding</td>
</tr>
<tr>
<td>Create professional certification for relevant dementia health workforce at the community college level</td>
</tr>
<tr>
<td>Revise minimum staffing standards in long-term care facilities</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme: Funding/Financing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase funding including compensation of dementia care partners (family, friends, employed)</td>
</tr>
<tr>
<td>Increase financial resources for care partners/PWLD for day programs, respite, other fee-based activities (non-means tested/Medicaid)</td>
</tr>
<tr>
<td>Expand private and public health insurance programs to cover all aspects of dementia care</td>
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<table>
<thead>
<tr>
<th>Theme: Professional Education/Workforce Development</th>
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</thead>
<tbody>
<tr>
<td>Prepare all primary health providers to understand brain health/dementia, associated stigma, early diagnosis and screening, and support people diagnosed with dementia and their care partners</td>
</tr>
<tr>
<td>Help providers access relevant resources for diagnosis, adapting for culture / language / educational licensed attainment</td>
</tr>
<tr>
<td>Incorporate dementia education into health professions curricula for all health professions students and postgraduate trainees</td>
</tr>
</tbody>
</table>
Appendix D: Role Model Programs Thematic Matrix

This matrix summarizes a review of websites and selected citations for the ten role model programs, grouped by the eight thematic categories used throughout this report, with additional categories of relevant information. Where evidence was not found, the role model is not listed.

<table>
<thead>
<tr>
<th>Care Partner Supports</th>
<th>Alzheimer’s and Dementia Care Program (ADC)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aging Brain Care (ABC)</td>
<td>• Care partner support groups (UCLA Health, 2023).</td>
</tr>
<tr>
<td></td>
<td>• Care partner Training Videos – series of videos produced by the UCLA Alzheimer’s and Dementia Care program to help care partners understand how to better care for persons with dementia. Cover a range of topics (e.g., hallucinations, repetitive behaviors).</td>
</tr>
<tr>
<td></td>
<td>Alzheimer’s and Dementia Care Program (ADC)</td>
</tr>
<tr>
<td></td>
<td>• Care partner support groups (UCLA Health, 2023).</td>
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<td>• Care partner Training Videos – series of videos produced by the UCLA Alzheimer’s and Dementia Care program to help care partners understand how to better care for persons with dementia. Cover a range of topics (e.g., hallucinations, repetitive behaviors).</td>
</tr>
<tr>
<td></td>
<td>Care Ecosystem</td>
</tr>
<tr>
<td></td>
<td>Care plan covers physical and emotional health of the care partner (Meyer 2022a).</td>
</tr>
<tr>
<td>ConnectShareCare</td>
<td>ConnectShareCare</td>
</tr>
<tr>
<td></td>
<td>Care partner supports offered through ConnectShareCare include:</td>
</tr>
<tr>
<td></td>
<td>• planning ahead resources (e.g., advance directive, living will),</td>
</tr>
<tr>
<td></td>
<td>• practical resources (e.g., housing, insurance, bills, legal, transportation, food),</td>
</tr>
<tr>
<td></td>
<td>• emotional resources (e.g., worry, loss of interest in usual activities, or anger),</td>
</tr>
<tr>
<td></td>
<td>• communication resources (talking with family or healthcare providers, access to interpreters, asking for, receiving, and providing help),</td>
</tr>
<tr>
<td></td>
<td>• family resources (e.g., dealing with children or partners, or intimacy) (ConnectShareCare, n.d.).</td>
</tr>
<tr>
<td>D-CHESS</td>
<td>D-CHESS</td>
</tr>
<tr>
<td></td>
<td>Care partner-specific supports (Gustafson et al., 2019).</td>
</tr>
<tr>
<td></td>
<td>• Easing Distress – Collection of cognitive-behavioral, psychological, relaxation, and lifestyle strategies for coping with distress (audio meditations, cognitive reframing exercises, and more).</td>
</tr>
<tr>
<td></td>
<td>• My Journal – Private journaling feature for care partners, with prompts for writing and reflection.</td>
</tr>
<tr>
<td></td>
<td>• Discussion Group – Private, interactive online discussion group for care partners of people living with dementia for sharing and soliciting information, ideas, experiences, and support.</td>
</tr>
<tr>
<td>Emory Integrated Memory Program</td>
<td>Emory Integrated Memory Program</td>
</tr>
<tr>
<td></td>
<td>• Support groups</td>
</tr>
<tr>
<td></td>
<td>• Practical education</td>
</tr>
<tr>
<td></td>
<td>• Stress management for family care partners (Integrated Memory Care, n.d.; Clevenger et al., 2018).</td>
</tr>
<tr>
<td></td>
<td>• Counseling for Care partners (Emory Health Care, 2023).</td>
</tr>
<tr>
<td>Care Partner Supports</td>
<td></td>
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<tr>
<td>--------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------</td>
</tr>
<tr>
<td>Maximizing Independence (MIND) at Home</td>
<td>Provides informal counseling and problem-solving strategies to care partners (Shapiro, 2022).</td>
</tr>
<tr>
<td>Program of All-Inclusive Care for the Elderly (PACE)</td>
<td>• Care partner training</td>
</tr>
<tr>
<td></td>
<td>• Respite care</td>
</tr>
<tr>
<td></td>
<td>• Adult day care</td>
</tr>
<tr>
<td></td>
<td>• Support groups for care partners</td>
</tr>
<tr>
<td>VA Caregiving Support Program</td>
<td>Services through the PGCSS program include:</td>
</tr>
<tr>
<td></td>
<td>• skills training,</td>
</tr>
<tr>
<td></td>
<td>• mobile support,</td>
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<tr>
<td></td>
<td>• one-on-one coaching,</td>
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<tr>
<td></td>
<td>• group support and coaching,</td>
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<tr>
<td></td>
<td>• self-care,</td>
</tr>
<tr>
<td></td>
<td>• peer support mentoring (U.S. Department of Veterans Affairs, n.d.).</td>
</tr>
<tr>
<td>Care partner services provided through PCAFC program include:</td>
<td>• education and training,</td>
</tr>
<tr>
<td></td>
<td>• health insurance (if care partner is uninsured),</td>
</tr>
<tr>
<td></td>
<td>• mental health counseling,</td>
</tr>
<tr>
<td></td>
<td>• a monthly financial stipend,</td>
</tr>
<tr>
<td></td>
<td>• respite care and other services (U.S. Department of Veterans Affairs, 2023).</td>
</tr>
<tr>
<td>WeCareAdvisor</td>
<td>• Assists family care partners in management of dementia-related behavioral symptoms.</td>
</tr>
<tr>
<td></td>
<td>• Helps families assess, manage, and track behavioral symptoms and contributing factors.</td>
</tr>
<tr>
<td></td>
<td>• Provides tailored strategies for care partners to use that are in-home, non-pharmacologic behavior management.</td>
</tr>
</tbody>
</table>
| Programs/ Services | Clinical services, primarily diagnostic evaluations (Eskenazi Health, n.d.):  
|                   | • clinical and neurological exam;  
|                   | • blood work;  
|                   | • brain imaging;  
|                   | • memory and mental status testing;  
|                   | • face-to-face family conference with patient and care partner |
| Aging Brain Care (ABC) | Brain Care Plan (Indiana University, n.d.):  
|                       | • Establish and monitor goals for person living with dementia and care partners  
|                       | • Dementia Care Quality Targets - based on Healthy Aging Brain Care (HABC) Monitor for care partners (Monahan et al., 2016).  
|                       | • Depression Care Quality Targets:  
|                       | • Counseling on Diagnosis, Prognosis and Natural History on type of dementia (AD vs. Lewy Body, etc).  
|                       | • Brain Health Prevention ‘Bundle’ for people with MCI or at high risk of developing Dementia (physical exercise – 15 mins daily, brain exercises, diet, mindfulness, social activities, medication avoidance)  
|                       | • Caregiver Stress Prevention ‘Bundle’  
|                       | • Transitional Care Protocol  
|                       | • Connect the patient or the care partner with community resources (Alzheimer’s Association, respite care, and adult day care).  
|                       | • Behavioral Therapy Plan for Major Depression, Generalized Anxiety Disorder  
|                       | • Alternative Living Settings – counseling, education, and assistance with memory care, assisted living and/or nursing home placement.  
|                       | • Pharmacological Therapy Plan (ordered by memory care plan physician) – includes anti-dementia medications, antidepressants, sleep medications, etc. |
| Alzheimer’s and Dementia Care Program (ADC) | • Dementia Care Specialists (DCSs) who are Advanced Practice Providers (nurse practitioners or physician assistants) work with the patient’s primary care doctor and/or specialists to create and implement a personalized care plan with extensive person living with dementia and care partner support. Follow-up phone calls; in-person visits; 24/7/365 access to caregivers for assistance and advice; ongoing patient monitoring; at least one annual in-person visit |
| Care Ecosystem | • Care navigator works with care partners over the telephone and by email (Meyer 2022a).  
<p>|               | • Develop a care plan for care partners (Meyer 2022a). |</p>
<table>
<thead>
<tr>
<th>Programs/ Services (continued)</th>
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<tbody>
<tr>
<td><strong>Integrated Memory Care Clinic:</strong> Primary care customized to the needs of PWLD and care partners and includes specific supports including:</td>
</tr>
<tr>
<td>• Longer appointments and individualized attention,</td>
</tr>
<tr>
<td>• Family meetings to discuss care goals and needs,</td>
</tr>
<tr>
<td>• Complete primary care provided by a nurse practitioner who specializes in dementia care,</td>
</tr>
<tr>
<td>• Access to a geriatric nurse practitioner for behavioral and psychiatric symptoms,</td>
</tr>
<tr>
<td>• After-hours phone access (evenings and weekends) for established patients,</td>
</tr>
<tr>
<td>• Prescription requests and refills by phone or online,</td>
</tr>
<tr>
<td>• Collaboration with a patient and family advisory council, (Integrated Memory Care, n.d.; Clevenger et al., 2018).</td>
</tr>
<tr>
<td>• Care partner-only visits with nurse practitioners (Emory Health Care, 2023).</td>
</tr>
<tr>
<td><strong>Integrated Memory Care in the Community Program</strong> (Emory Health Care, 2023).</td>
</tr>
<tr>
<td>• Appointments with a nurse practitioner conducted at senior living community</td>
</tr>
<tr>
<td>• Occupational therapy evaluation and individualized plans to maintain function</td>
</tr>
<tr>
<td>• Weekly sessions with a dementia care assistant</td>
</tr>
<tr>
<td>• Care partners access to support, education, and counseling</td>
</tr>
<tr>
<td>• Care coordination and navigation</td>
</tr>
<tr>
<td><strong>Maximizing Independence (MIND) at Home</strong></td>
</tr>
<tr>
<td>• Work with care partners to avoid controllable factors related to hospitalizations focusing on problems w/ home safety, including falls; inadequate medication adherence and poor prescribing by health provider; missing medical appointments (Wiener et al., 2016).</td>
</tr>
<tr>
<td>• Connect care partners with available community resources and provide care partner support (MIND at Home, n.d.).</td>
</tr>
<tr>
<td><strong>Program of All-Inclusive Care for the Elderly (PACE)</strong></td>
</tr>
<tr>
<td>Services provide through PACE model include all Medicare and Medicaid covered services: Adult day care, dentistry, emergency services, home care, hospital care, laboratory/x-ray services, meals, medical specialty services, nursing home care, nutritional counseling, occupational therapy, physical therapy, prescription drugs, primary care (including doctor &amp; nursing services), recreational therapy, social services, social work, counseling, and transportation. PACE additionally provides any clinician-approved services deemed necessary to maintain a participant’s health (Centers for Medicare &amp; Medicaid Services, n.d.).</td>
</tr>
<tr>
<td><strong>VA Caregiving Support Program</strong></td>
</tr>
<tr>
<td>• Program of General Caregiver Support Services (PGCSS) provides a variety of supports to care partners. Not dementia-specific (U.S. Department of Veterans Affairs, n.d.).</td>
</tr>
<tr>
<td>• Program of Comprehensive Assistance for Family Caregivers (PCAFC) - <strong>enhanced clinical support</strong> for family care partners of eligible veterans who sustained or aggravated a serious injury (or illness) in the line of duty. Not dementia-specific (U.S. Department of Veterans Affairs, n.d.).</td>
</tr>
<tr>
<td>Program of Clinical/Research Services OR Specific to Care Partners</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Aging Brain Care (ABC)</strong></td>
</tr>
<tr>
<td><strong>Alzheimer’s and Dementia Care Program (ADC)</strong></td>
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<tr>
<td><strong>Care Ecosystem</strong></td>
</tr>
<tr>
<td><strong>ConnectShareCare</strong></td>
</tr>
<tr>
<td><strong>D-CHESS</strong></td>
</tr>
<tr>
<td><strong>Emory Integrated Memory Program</strong></td>
</tr>
<tr>
<td><strong>Maximizing Independence (MIND) at Home</strong></td>
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<tr>
<td><strong>Program of All-Inclusive Care for the Elderly (PACE)</strong></td>
</tr>
<tr>
<td><strong>VA Caregiving Support Program</strong></td>
</tr>
<tr>
<td><strong>WeCareAdvisor</strong></td>
</tr>
</tbody>
</table>

### Information Resources

| **Aging Brain Care (ABC)** | Patient and family education and counseling when enrolled in the ABC Program (Eskenazi Health, n.d.).  
- Counseling on diagnosis, prognosis, and natural history on type of dementia (AD vs. Lewy Body, etc).  
- Connects the patient / care partner with community resources - Alzheimer’s Association, respite care, and adult day care (ABC Standardized Operating Plan, N.D.).  
- Info on alternative living settings – counseling, education, and assistance with navigating memory care, assisted living and/or nursing home placements (ABC Standardized Operating Plan, N.D.). |
| **Alzheimer’s and Dementia Care Program (ADC)** | Alzheimer's Caregiver Education Webinars - Free, live-stream webinar series that provides information about ADRD for CPs, loved ones, and others (UCLA Health, 2023). |
| **Care Ecosystem** | Provides information to care partners on:  
- Behavioral and safety issues,  
- Legal and financial issues,  
- Community resources.  
- Medical and medication needs (Meyer 2022a) |
| **ConnectShareCare** | Online network allowing for posts that is moderated by peers to facilitate information and facilitating emotional support (ConnectShareCare, n.d.). |
| Information Resources (continued) | Help care partners to obtain information, communicate with other care partners, help with care decisions, and share information with experts (Gustafson et al., 2019).  
- Library of Topics – Extensive on-site collection of informational readings on topics related to dementia and caregiving created by experts, and links to relevant external websites vetted for quality.  
- Personal Stories – Real-life accounts from CPs of family members with dementia, with prompts to explore 1) coping techniques, 2) in-depth descriptions of patient behaviors, symptoms, and caregiving stress, and 3) advice based on experiences.  
- Caregiver Tips – Quick tips from professional sources covering issues, such as coping with the emotional side of caregiving, relating to the patient, and helping with everyday activities.  
- A FAQ – a searchable list of FAQs and answers about ADRD, self-care, and stress reduction, symptom and behavior management, financial and legal issues, medical care, end of life, and more.  
Tools:  
- Respite Planner – an interactive tool for 1) thinking through potential benefits and barriers to respite and 2) respite planning.  
- Placement Decision Guide - to help care partners clarify situations and needs when considering placing a family member in a care setting.  
- Action Planner – Interactive tool for creating a step-by-step plan for any change for caregiver or patient, such as bringing in help or changing doctors, establishing a budget, starting a relaxation routine, and more. |
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<tbody>
<tr>
<td>D-CHESS</td>
<td></td>
</tr>
<tr>
<td>Maximizing Independence (MIND) at Home</td>
<td>Dementia care education and behavior management skills training for CPs (Shapiro, 2022).</td>
</tr>
</tbody>
</table>
| WeCareAdvisor | Provides:  
- Disease education  
- Step-by-step approach to understanding why dementia-related behavioral and psychological symptoms such as agitation, restlessness, irritability, repeated questions, or other behaviors occur.  
- Strategies customized to the family’s specific situation to help manage behaviors (We Care Advisor, n.d.; Gitlin et al., 2022). |
### Care Coordination

**Aging Brain Care (ABC)**
- Coordination of care transitions across multiple settings
- Palliative and hospice care as appropriate in care and support (Eskenazi Health, n.d.).
- Referral for In Home Services (Indiana University, n.d.).

**Alzheimer’s and Dementia Care Program (ADC)**
- Referrals to neurology, psychiatry, or geriatrics
- Referrals to community-based organizations (UCLA Health, 2023).

**Care Ecosystem**
Care navigator initially meets with a team of dementia care specialists, including: nurse practitioner, pharmacist, and social worker, to develop a care plan for patient and care partner (Meyer 2022a).

**Emory Integrated Memory Program**
- Integrated Memory Care Clinic:
  - Care team that consists of nurse practitioners, physicians, a registered nurse, a social worker, a patient care coordinator, and others (Integrated Memory Care, n.d.).
  - Support for transitions of care to hospice or skilled nursing care, when needed.
  - Referrals to specialists, as needed (Emory Health Care, n.d.).

**Maximizing Independence (MIND) at Home**
- Comprehensive, home-based care coordination intervention for PLWD living in the community and their family care partners (Samus et al., 2018). Patients and care partners work with:
  - A memory care coordinator, who is a nonclinical community worker,
  - A team that includes: a geriatric psychiatrist, registered nurse and occupational therapist.
  - The team conducts an in-home assessment, and it plans and implements care based on six strategies: resource referrals, attention to environmental safety, dementia care education, behavior management skills training, as well as informal counseling and problem-solving (Shapiro, 2022).

**Program of All-Inclusive Care for the Elderly (PACE)**
Comprehensive medical and social services (e.g., integrated interdisciplinary preventive, primary, acute, and long-term managed care and supports) for individuals 55 and older living in the community who are dually eligible for Medicare and Medicaid (Centers for Medicare & Medicaid Services, n.d.).

**VA Caregiving Support Program**
Referrals to available VA and community resources (U.S. Department of Veterans Affairs, n.d.).

### Data Systems / Technology

**Aging Brain Care (ABC)**
- Data collection via standardized tools to identify and address changes in brain health over time (Eskenazi Health, n.d.)

**ConnectShareCare**
- An online network to facilitate information sharing and support of care partners (ConnectShareCare, n.d.)

**D-CHESS**
- Computer-based system for use on computers or tablets that evolved from earlier CHESS systems, which is intended to improve the lives of dementia care partners through information resources and sharing (Gustafson et al., 2019).

**VA Caregiving Support Program**
- Telephone support and online programs are offered (U.S. Department of Veterans Affairs, n.d.).

**WeCareAdvisor**
- Online platform to provide support to care partners (We Care Advisor, n.d.).
**Policy**

<table>
<thead>
<tr>
<th>Care Ecosystem</th>
<th>In 2023, the care coordination services provided through the Care Ecosystem model became reimbursable under Medicare by any health system that adopts their use (CMS, 2023).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program of All-Inclusive Care for the Elderly (PACE)</td>
<td>Formalized care coordination for high need, high-cost population. Program embedded within Federal statutes (Title 42 U.S.C. 1302, 1395, 1395eee(f), and 1396u–4(f).) and Federal regulations (42 CFR Part 460).</td>
</tr>
<tr>
<td>VA Caregiving Support Program</td>
<td>US federal policy to support veterans through the Department of Veterans Affairs</td>
</tr>
</tbody>
</table>

**Longevity / Funding**

<table>
<thead>
<tr>
<th>Aging Brain Care (ABC)</th>
<th>Grant funding: CMS Innovation Center Award (LaMantia et al., 2017). Insurance payments for billable clinical services, health system support, and philanthropy (Center for Advanced Palliative Care, 2018).</th>
</tr>
</thead>
</table>
| Care Ecosystem | • Grant funding: CMS Innovation Center Award, National Institute on Aging (NIA), National Institute of Neurological Disorders and Stroke (NINDS) (Possin et al., 2019)  
• Other Funding: Private charitable donations at Ochsner Health (Meyer, 2022b). |
| ConnectShareCare | Grant funding: Gordon and Betty Moore Foundation, other awards to The Dartmouth Institute for Health Policy & Clinical Practice, Coproduction Laboratory |
| D-CHESS | Internal funds from Department of Medicine, School of Medicine and Public Health, University of Wisconsin–Madison (Gustafson et al., 2019). |
| Emory Integrated Memory Program | Grant funding: National Institute on Aging (NIA) |
| Maximizing Independence (MIND) at Home | Grant funding: National Institute on Aging (NIA) Private philanthropy |
| Program of All-Inclusive Care for the Elderly (PACE) | Medicare and Medicaid: Blends Medicare and Medicaid payments to pay for all health and LTC care of PACE participants. |
| VA Caregiving Support Program | Appropriations to US Department of Veterans Affairs to fund veteran health care services and supports |
| WeCareAdvisor | Grant funding: National Institute on Aging (NIA) |
### Enrollment / Access

<table>
<thead>
<tr>
<th>Program</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Aging Brain Care (ABC)</td>
<td>Health system patient</td>
</tr>
<tr>
<td>Alzheimer’s and Dementia Care Program (ADC)</td>
<td>Health system patient</td>
</tr>
<tr>
<td>Care Ecosystem</td>
<td>Initial: Study / Research participant – then Health system patient – Going forward, Medicare (CMS will pay for any of the services Care Ecosystem provided under the GUIDE Model if a health system adopts the program).</td>
</tr>
<tr>
<td>ConnectShareCare</td>
<td>Open to anyone</td>
</tr>
<tr>
<td>D-CHESS</td>
<td>Study / Research Participant</td>
</tr>
<tr>
<td>Emory Integrated Memory Program</td>
<td>Health system patient</td>
</tr>
<tr>
<td>Maximizing Independence (MIND) at Home</td>
<td>Study / Research Participant</td>
</tr>
<tr>
<td>Program of All-Inclusive Care for the Elderly (PACE)</td>
<td>Dual Eligibles Medicare-Medicaid (living near a PACE site)</td>
</tr>
<tr>
<td>VA Caregiving Support Program</td>
<td>US Veterans (who meet service requirements and health needs)</td>
</tr>
<tr>
<td>WeCareAdvisor</td>
<td>Open to anyone 21 years+</td>
</tr>
</tbody>
</table>

### Professional Education and Workforce Development

<table>
<thead>
<tr>
<th>Program</th>
<th>Description</th>
</tr>
</thead>
</table>
| Aging Brain Care (ABC)                       | • Participating nurses and social workers receive on-the-job training;  
• Care coordinator assistants (CCAs), who are specially trained community health workers, receive training in care for PWLD and depression (Center for Advanced Palliative Care, 2018). |
<p>| Alzheimer’s and Dementia Care Program (ADC)  | ADC ECHO Series to train healthcare providers on dementia care (ADC Program, n.d.).                                                           |
| Care Ecosystem                               | Unlicensed care team navigators receive 40 hours of training, work under supervision of and in collaboration w/ neuropsychologists, neurologists, social workers, nurses, and pharmacists (Meyer 2022b). |</p>
<table>
<thead>
<tr>
<th>Service Location</th>
<th>Host Location(s)</th>
<th>Service Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aging Brain Care (ABC)</td>
<td>Host Site(s): Eskenazi Health / Indiana University Health</td>
<td>Indianapolis, Indiana Metro Area</td>
</tr>
<tr>
<td></td>
<td>Service Area: Indiana University Health</td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s and Dementia Care Program (ADC)</td>
<td>Host Site: University of California, Los Angeles</td>
<td>Los Angeles, CA</td>
</tr>
<tr>
<td></td>
<td>Service Area: Los Angeles</td>
<td></td>
</tr>
<tr>
<td>Care Ecosystem</td>
<td>Host Site(s): University of California, San Francisco (UCSF), University of</td>
<td>Bay Area, CA, Omaha NE, New Orleans, LA, Portland, OR</td>
</tr>
<tr>
<td></td>
<td>Nebraska Medical Center (UNMC), Ochsner Health, Providence Health</td>
<td></td>
</tr>
<tr>
<td>ConnectShareCare</td>
<td>Host Site(s): Dartmouth College / Hitchcock Medical Center</td>
<td>Online, open to everyone; primary local focus New</td>
</tr>
<tr>
<td></td>
<td>Service Area: Online, open to everyone; primary local focus New Hampshire/Vermont</td>
<td></td>
</tr>
<tr>
<td>D-CHESS</td>
<td>Host Site: University of Wisconsin–Madison</td>
<td>Madison, WI Metro Area</td>
</tr>
<tr>
<td>Emory Integrated Memory Program</td>
<td>Host Site: Emory University</td>
<td>Atlanta, GA Metro Area</td>
</tr>
<tr>
<td>Maximizing Independence (MIND) at Home</td>
<td>Host Site: Johns Hopkins University</td>
<td>Baltimore, MD</td>
</tr>
<tr>
<td>Program of All-Inclusive Care for the Elderly (PACE)</td>
<td>Host Site: 300 PACE sites in 32 states</td>
<td>communities surrounding the 300 PACE sites</td>
</tr>
<tr>
<td>VA Caregiving Support Program</td>
<td>Host Site: Nationwide</td>
<td>Nationwide</td>
</tr>
<tr>
<td>WeCareAdvisor</td>
<td>Host Site: Drexel University, Philadelphia, PA</td>
<td>Online, nationwide</td>
</tr>
</tbody>
</table>
Selected Citations for Role Model Programs

**Aging Brain Care (ABC)**
Center for Advanced Palliative Care (2018). Case Study: Eskenazi Health’s Aging Brain Care Program, An Interdisciplinary Collaborative Care Model for People Living with Dementia. [https://www.capc.org/documents/download/554/](https://www.capc.org/documents/download/554/)


**Alzheimer’s and Dementia Care Program (ADC)**
Alzheimer’s and Dementia Care Program (2023). The Alzheimer’s and Dementia Care Program. [https://www.adcprogram.org/](https://www.adcprogram.org/)


UCLA Health (2023). UCLA Alzheimer’s and Dementia Care Program. [https://www.uclahealth.org/medical-services/geriatrics/dementia](https://www.uclahealth.org/medical-services/geriatrics/dementia)

**Care Ecosystem**


personalized, and scalable dementia care program: Early findings from the Care Ecosystem. *PLoS medicine*, 14(3), e1002260. [https://doi.org/10.1371/journal.pmed.1002260](https://doi.org/10.1371/journal.pmed.1002260)

UCSF Memory & Aging Center (n.d.). Building a Care Ecosystem. University of California, San Francisco. [https://memory.ucsf.edu/research-trials/professional/care-ecosystem](https://memory.ucsf.edu/research-trials/professional/care-ecosystem)

**ConnectShareCare**  
ConnectCareShare (n.d.) Dartmouth College. [https://connectsharecare.org/](https://connectsharecare.org/)

**D-CHESS**  

**Emory Integrated Memory Program**  


**Maximizing Independence (MIND) at Home**  


Program of All-Inclusive Care for the Elderly (PACE),


VA Caregiving Support Program


WeCareAdvisor

Appendix E: Portland-Area and Oregon Community-Based Organizations Serving People with Dementia and Other Aging Populations Consulted (Website Review, Interview or Invited Participant)

AARP Oregon
Adelante Mujeres
Africa House, IRCO
AGE+
Alzheimer’s Association, Oregon & SW Washington
Asian Health and Service Center
Asian Pacific American Network of Oregon (APANO)
Centro Cultural
Clackamas County Social Services
Coalition of Communities of Color
Coalition of Community Health Clinics
Cohen Caregiving Consultants
Diverse Elders Coalition
Familias en Acción
Friendly House
Governor’s Commission on Senior Services (GCSS)
Immigrant and Refugee Community Organization (IRCO)
Institute on Aging, Portland State University
Jessie F. Richardson Foundation
Latino Community Association
Layton Aging & Alzheimer’s Disease Research Center, Oregon Health & Science University
Multnomah County Aging, Disability & Veterans Services Division
Multnomah County Family Caregiver Support Program
Native American Rehabilitation Association of the Northwest (NARA)
Native American Youth and Family Center (NAYA)
North by Northeast Community Clinic
Northwest Portland Area Indian Health Board (NPAIHB)
Oregon Commission on Asian & Pacific Islander Affairs (OCAPIA)
Oregon Commission on Black Affairs (OCBA)
Oregon Commission on Hispanic Affairs (OCHA)
Oregon Department of Human Services: Aging and People with Disabilities (APD); Tribal Affairs
Oregon Health Authority, Older Adult Behavioral Health Initiative
Oregon Latino Health Coalition
Our House
Pacific Islander and Asian Family Center, IRCO
Portland Area Indian Health Service
PreSERVE Coalition
Providence Elder Place
Safe + Strong Oregon
SAGE Advocacy and Services for LGBT Elders
Self Enhancement, Inc. (SEI)
Senior Health, Providence Health & Services
State Plan for Alzheimer’s Disease & Related Dementias in Oregon (SPADO)
Urban League
Vancouver Avenue Baptist Church
Virginia Garcia Memorial Health Center
Volunteers of America
Washington County Disability Services
Appendix F: Examples of Resources Available through the Hub

Care Partner Supports, Programs and Services
Specific supports that will be identified and linked through the Hub should address:
- Navigating health services
- Navigating social services
- Navigating financial/legal supports
- Support groups
- Peer support such as community-specific gatherings of care partners
- Care partner health and wellbeing
- Financial resources/cash benefit to do what you need to do (requires changes in Health insurance/Medicare/Medicaid)
- Behavioral health services for care partners
- Embedded links to relevant community-specific resources (bidirectional)
- Provide assistance with documentation burden for care partners to access Medicaid, Medicare and other programs

Programs and services that should be possible to search through the Hub include:
- Day services/memory cafes/companions/home care/respite
- Support groups
- Education of care partners and families
- Transportation to activities and services
- Various alternatives for permanent housing
- Food, clothing, equipment
- Dementia friendly primary care as well as specialty care
- Behavioral health services for care partners
- Affordable in-home care
- Financial and legal advisors/navigators
- Availability of behavioral health services for people living with dementia
- Use technology to support care partners through social support, data-driven programs and policies, and/or culturally relevant supports

Information Resources
Specific information supports that could be available through the Hub or be complementary actions include the following strategies:
- Educating care partners about dementia disease process, ensuring timely and appropriate diagnosis, and stages of disease/symptoms
- Educating and empowering care partners and families about what to expect, what they might need, and resources to help them navigate and be supported
- Create large public health and human services campaign to reframe dementia/brain health, educate the public, and acknowledge universality of caregiving experience and challenges, especially for communities expected to experience large increases in dementia prevalence and for individuals who may become a care partner in the future
- Range of information resources generally available
- Benefits of involvement in research (clinical trials, etc.)
• Population-specific resources (younger onset, veterans, LGBTQIA+, rural, immigrant, and historically and currently underserved populations)
• Information on how to choose a long-term care facility, adult day care, respite, home care provider, companions
• Financial information/education
• Legal information/education
• Design content for information hubs at libraries, grocery stores, community and recreation centers, service clubs, faith-based organizations, senior centers, pharmacies
• Recognize existence of informal channels (gray market) for accessing resources, goods and services
• Identify potential issues of elder abuse and neglect (financial, legal, emotional, physical, sexual)
• Provide information about educational opportunities (continuing, formal, one-time) for professionals and others working with people living with dementia

Organizational and System Changes – Outside the Scope of the Hub
Key informants identified organizational and system changes required to better support care partners and people living with dementia:
• Clinical care coordination among primary and specialty providers
• Service coordination across various sectors (clinical, social services, home care, meals, transportation, etc.)
• Coordination between clinical and service organizations and individuals
• Build capacity of organizations to help meet needs of care partners, and coordinate with other organizations engaged in complementary work
• Ensure provision of written translation and oral interpretation services in both primary care and specialty services
• Recognition, communication and decision-making by and among providers to address care partners’ (spouse, partner, family) needs, assets, and challenges and demonstrate more understanding and support
• Streamline technology-based systems for access to services and information to reduce the burden on care partners
• Create easy access by care partners to EHRs, portals and other records
• Build EHR prompts for identification of care partners and assessment of care partner wellness
• Adapt EHRs to prompt primary care and other providers for various actions such as screening for dementia, tracking dementia-related information, and following up on abnormal results
Appendix G: Dementia Care Partner Hub Proposed Evaluation Framework

Goals:
• To determine the effectiveness of the Dementia Care Partner Hub (the “Hub”) in enhancing access to supports for care partners of people living with dementia.
• To understand the roles and involvement of key interested parties in building the network of services which is the Hub.
• To identify opportunities for improvement of the Dementia Care Partner Hub in order to better meet the needs of care partners and people living with dementia.

Key questions:
1. Does the Hub enhance access to resources (e.g., information, services, etc) for care partners?
2. Are key partners involved?
3. Is the Hub effective?
4. How could the Hub be improved and/or expanded?

The Hub evaluation is built upon the following evaluation framework (adapted from Gelmon, Foucek, & Waterbury, 2005):

I. Core Concepts: What are the major areas the Hub addresses? Six core concepts will frame the evaluation of the Hub: Impact, Benefits, Partnerships, Sustainability, Satisfaction of Participants, and Effectiveness of the Hub operations. Each of these are high level and broad concepts with multiple indicators and connected to the larger evaluation questions. They form the foundation of the evaluation and subsequent reporting of results.

II. Key Indicators: What can we observe or measure to generate evidence? The indicators all relate to a specific concept. These are necessary to answer the evaluation questions and can be collected via qualitative and/or qualitative methods. There may be multiple questions across multiple methods that provide evidence on individual indicators.

III. Methods: How will we collect the evidence? and Sources: From whom or where will we obtain this information? Sources of information will include surveys, interviews, focus groups, website analyses, and document reviews.

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Key Indicators</th>
<th>Methods &amp; Sources</th>
</tr>
</thead>
</table>
| Impact      | • Capacity to reach care partners in multiple communities (geographic, demographic, SES, educational level, etc.)  
• Capacity to engage relevant organizational partners  
• Provision of information/networks/connections previously unavailable or of which care partners were unaware  
• Enhanced knowledge among health and social service providers of resources, programs and supports  
• Engagement of care partners in Hub design and operations  
• Recruitment of peer mentors/advisors  
• Use of the Hub by care partners to access information | • Website analytics  
• Log of telephone calls/emails  
• Tracking of peer mentors / advisors engaged  
• Surveys of users  
• Focus groups with users, peers, providers  
• Tracking of outreach efforts |
| Benefits    | • Access  
• Information relevant to all care partners  
• Community-specific information  
• Referrals  
• Navigation  
• Care coordination  
• Breadth of information  
• Impact on care partner burden  
• Sense of community (among care partners) | • Quarterly review of scope of information  
• Surveys of users  
• Tracking of contacts/information referrals (monthly, quarterly, annually) |
| Partnerships | • Partnership development and continued engagement  
• Number of partners  
• Scope, representation and relevance of partners  
• Communication patterns  
• Mechanisms of collaboration  
• Strength and reciprocity of relationships  
• Networks of relationships and partnerships | • Website analytics  
• Interviews/focus groups with key partners  
• Tracking of partnership activities and accomplishments  
• Tracking connections and links from partner sites to the Hub |
| Sustainability | • Initial funding  
• Identification of new funding sources  
• Value of the Hub to organizational partners/funders  
• Contributions of the Hub to supporting care partners  
• Program improvements and/or expansion | • Initial funding secured  
• Long-term funding secured  
• Document review  
• Interviews/focus groups with key partners |
| Satisfaction of participants | • Relevance of information  
• Ease of access via modalities  
• Reported satisfaction by users  
• Complaints/issues  
• Engagement with peers  
• Referrals to friends/family | • Surveys of users  
• Log of feedback / complaints / issues |
|-----------------------------|---------------------------------------------------------------------------------|---------------------------------------------------------------------|
| Effectiveness of the Hub operations | • Responsiveness of [program] staff/peers  
• Timeliness of communications  
• Relevance and timeliness of website information  
• Resource management  
• Factors or conditions that facilitated the implementation of the Hub  
• Factors or conditions that impeded the implementation of the Hub operations | • Log of telephone calls/emails  
• Tracking of response times for follow-up  
• Surveys of users  
• Interviews/focus groups with key partners  
• Mentions in news and social media |
Appendix H: Policy Brief: Responding to the Needs of Oregon’s Dementia Care Partners: Recommendations for Policy Change

Sherril Gelmon, Walter Dawson and Jenn Hollandsworth Reed
OHSU-PSU School of Public Health, OHSU Department of Neurology and PSU Institute on Aging

October 2023

“Our professional caregiver shortage is extreme; I feel we’re not getting enough qualified people to care for our most vulnerable population.” (Representative of an organization providing services to people living with dementia)

“I’m mad for the people that aren’t getting help.” (Care partner of a person living with dementia)

The Issue: Alzheimer’s disease and related dementias (ADRD) are the most expensive conditions in the United States with annual health and long-term service and support costs expected to surpass $345 billion in 2023. In Oregon, there will be a projected 22% increase in the number of people living with ADRD from 65,000 to over 84,000 by the year 2025. In support of these individuals, more than 168,000 estimated ADRD-specific care partners provide 317 million hours of care per year; this uncompensated care has a value of more than $7.2 billion. ADRD places enormous burdens on families and care partners as well on the public programs that fund ADRD services. Further, responsibility for caregiving is disproportionately provided by women, individuals of low socioeconomic status, and racial and ethnic minority populations, who more often rely upon, and also provide, most informal care and support.

Throughout the COVID-19 pandemic, care partners for people living with dementia experienced increased burdens due to reduced supportive services and programs, and increased isolation from curtailed access to typical support service. While most services have returned to typical operations, the pandemic’s reverberations continue to affect the availability of services. Therefore, the need to better support ADRD care partners through policy actions is high; much can be done in Oregon and nationally to enhance existing activities and close the gaps across populations, especially for historically underserved groups. Dementia-related policy is shaped at both state and federal levels, and both perspectives need to be addressed when recommending policy actions. This brief summarizes policy actions identified through a research project conducted within the “Better with Age” Gerontology Education and Research Initiative (GERI) of the Portland State University Institute on Aging in 2022-2023.

Data Collection and Analysis: Twenty-four systematic interviews and five focus groups were conducted with organizations providing services that support people living with dementia and care partners. These data collection efforts centered on four communities historically underserved in the United States (Asian, Black, Indigenous, and Latinx). Organizational leaders and care partners also participated in a modified Delphi priority setting process to identify priorities for supporting care partners. A comprehensive literature review provided additional foundational information. The findings from these data collection efforts identified several themes and specific areas of need to better support care partners (see Table 1).

These findings also identified several policy-related priorities for supporting care partners, which in turn informed development of several specific policy recommendations, which are presented below.
Table 1: Areas of Needed Support

- Information on the disease process
- Navigation and coordination within and across systems
- Access to clinicians, care teams, health/personal records
- Legal and financial issues
- Screening and hiring companion/in-home caregivers
- Respite care
- Psychological and physical health support for care partners
- Flexibility of work, schedule, social engagements

State-level Recommendations: Several opportunities exist to address the specific needs of ADRD care partners within the Oregon policy context. Five recommendations are outlined below that could be implemented in Oregon through the legislative and/or rulemaking processes (e.g., Oregon Administrative Rules) in order to better support care partners.

State-level Recommendation 1: Increase state funding to compensate ADRD care partners (including family, friends, and hired care partners) through direct financial support. One way to accomplish this might be to expand the scope of Oregon Project Independence (OPI), which already provides some financial support for people under the age of 65 who are living with ADRD (younger onset dementia) who are not Medicaid-eligible. Since OPI has been moved under Oregon’s newly updated 1115 Medicaid Waiver, federal dollars can now be leveraged to match general fund appropriations for this program.4

State-level Recommendation 2: Fund community organizations to ensure equity of access and in the design of all programs and services for ADRD. Providers and organizations that provide services for ADRD may be unfamiliar with how people living with ADRD and their care partners who are members of historically underrepresented communities communicate their experiences and needs.5,6 Organizations embedded within historically underrepresented communities should be funded to provide direct services to people living with ADRD and their care partners, and also to provide training in culturally competent communication and ADRD screening to organizations without this expertise. This funding would allow providers and organizations to better and more equitably serve all Oregonians with ADRD and their care partners.

State-level Recommendation 3: Invest in and develop Oregon’s ADRD care workforce to ensure available and accessible care and support for the increasing number of Oregonians living with ADRD. This might include efforts to better prepare all primary health providers to understand brain health and dementia, associated stigma, early diagnosis and screening, and to be knowledgeable on supports available for people diagnosed with dementia and their care partners. It could also include helping providers access relevant resources for diagnosis that are adapted for culture language of communities served. Initiatives could include investments to augment core curriculum content in health professional education programs, and support of interprofessional continuing education programs to enhance understanding of how to diagnose and manage ADRD in the primary care setting. This workforce investment would also support care partners and reduce their burden through ensuring they can turn to a relevant, well-prepared workforce for services and supports.

State-level Recommendation 4: Create a professional certification for the relevant ADRD health workforce at the community college level. This could help to attract and retain a highly qualified workforce that will better meet the needs of a diverse and growing ADRD population in Oregon. A
specific focus should be on preparing certified individuals who identify with historically underrepresented communities (both cultural and social). This would bolster the dementia workforce by ensuring ADRD-specific training is available and provided to Oregon workers.

**State-level Recommendation 5:** *Fund an information hub for ADRD-related care and support needs that provides links to community-specific resources including websites, telephone contacts, listings of various support services, and care options.* Resources must be available through both web and telephone contacts, and maintained to ensure current organizational contact information. Best practices also suggest a role for peer consultation and peer-moderated discussion groups. This hub would be an Oregon-wide, easily accessible platform for care partners to identify and obtain the information they need to carry out their care-related activities and feel supported – and be available 24/7/365 whenever it is needed. This hub is not intended to replace any existing programs, but rather to build upon and complement existing supports offered in Oregon.

**Federal-level Recommendations:** Several opportunities for policy change are federal in scope. Three recommendations that federal policymakers could implement to address care partner needs are offered.

**Federal-level Recommendation 1:** *Support the use of technologies to support ADRD care partners through social support, data-driven programs and policies, and/or culturally relevant supports.* One way to implement this is through enabling care partners to access the electronic health records of their person living with dementia so the care partner is able to more effectively navigate the care process. This also has implications for advanced care planning, which has been shown to be an effective method for improving outcomes for people living with dementia and care partners alike. This change would recognize and reconsider the care partner as central to the care and support process.

**Federal-level Recommendation 2:** *Expand public health insurance programs (e.g., Medicare, Medicaid, Veterans Health Administration, and Indian Health Service) to cover all aspects of dementia care, and acknowledge and support care partners.* The recent announcement of the GUIDE Model to cover dementia care partner supports through Medicare is a positive action. These benefits will be voluntary and rolled out in the years ahead. There is a need for more comprehensive supports which are accessible beyond these programs. Program coverage would remove individual out-of-pocket expenses for many routine activities for people living with dementia.

**Federal-level Recommendation 3:** *Provide incentives for care coordination and navigation that will support care partners in providing care.* This might include enhanced financial reimbursement to providers and health systems who meet certain quality metric targets focused on care partners and ADRD care and support. For example, Medicare could reimburse health systems that use a dementia care navigator who assists care partners and people living with dementia in navigating health, social services, and other needed non-clinical supports. Similarly, there could be enhanced Medicare reimbursement for use of advanced care planning codes which include the care partner in the conversation with the provider.

**Conclusion:** Care partners are often overlooked in the caregiving process. These recommendations offer several actionable ways for policymakers to improve ADRD care and support, while also directly supporting care partners. These recommendations will require bold action by legislators and other policymakers. There is a clear role for providers and advocacy groups to assemble a coalition and build the case for these changes, both in Oregon and nationally. Policymakers and groups that support people
living with dementia and their care partners can effectively work together and substantially improve the lives of Oregon care partners.

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**References**


