A Social-Medical Model for Dementia Care

Interdisciplinary Dementia Care Team of the
Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias,
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Executive Summary

The Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias (Council) convened a team on Interdisciplinary Dementia Care (IDC team) to address gaps in dementia care across the state.[1] During two years of research and discussions, the team identified critical shortcomings in the current system including fragmented services; poor integration of medical and social care; and a lack of support for both caregivers and primary care providers.

To address gaps in the dementia care system, the IDC team proposes a pilot program grounded in the evidence-based Care Ecosystem model. The proposed pilot will support people living with dementia and their caregivers through a coordinated network that includes clinical consultants, non-licensed care team navigators, primary care providers, and community-based aging and social service organizations. The model emphasizes adaptive, relationship-based care planning, navigation support, and interdisciplinary collaboration.

The pilot will be launched in at least one region by at least one healthcare system and evaluated over a defined period of time for impact, feasibility, and scalability. The participating healthcare system will collaborate with state officials to plan the pilot's implementation, aiming to lay the groundwork for a future statewide rollout. The ultimate goal is to have a program that ensures equitable insurance-agnostic access to high-quality, person-centered dementia care and caregiver support for all Massachusetts residents affected by dementia. A key feature of the vision is full integration with the state's robust aging services network, including its 24 regionally based Aging Services Access Points.

The IDC team outlines a seven-phase pathway from pilot to statewide adoption: 1) engaging in an economic modeling exercise; 2) establishing an implementation team; 3) developing an implementation plan with statewide alignment and scalability; 4) estimating costs and securing funding; 5) implementing and evaluating the pilot; 6) making the case for statewide implementation; and 7) transitioning leadership and operational responsibility to the state.

Introduction

This paper was developed by the Interdisciplinary Dementia Care (IDC) team of the Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias (Council). During its meetings convened from July 2023 through June 2025, the IDC team examined gaps in dementia care and identified potential solutions. The team focused on the importance of interdisciplinary care in the delivery of comprehensive, high-quality dementia care and support. In designing its proposal, the team reflected on the importance of integrating medical and social care for people affected by dementia. This paper briefly outlines the team's methodology and proposal. The proposal aligns with the Council's call for improved caregiver support and equitable, high-quality, person-centered care for all Massachusetts residents and families affected by dementia.

[1] Please see Appendix A to view a list of the Council's Interdisciplinary Dementia Care (IDC) team members.

This paper includes the following five sections:

I. Analysis and Findings

II. Proposed Integrated, Comprehensive Dementia Care Program

III. Pathway from Pilot Program to Broader Adoption

IV. Recommended Next Steps

V. Appendices: (A) Interdisciplinary Dementia Care Team Members; (B) Service Elements by Care Grouping; (C) Resources to Inform Economic Modeling Exercise; (D) Organizations to Explore for Potential Funding or Collaboration; and (E) Evaluation Domains, Metrics, and Targets to Consider

I. Analysis and Findings

The Council's Interdisciplinary Dementia Care team (IDC team) began its work by identifying gaps in the current dementia care system. These insights came from Council members, team participants, and individuals with lived experience who contributed through Council panels and focus groups. Next, the IDC team evaluated services and models to help build their knowledge about the benefits and challenges associated with delivering comprehensive, interdisciplinary dementia care. The team's central insight was that while interdisciplinary dementia care is essential for delivering quality care and reducing healthcare utilization and total medical expenses, it cannot be sustained without a supportive infrastructure.

Understanding Gaps and Systemic Challenges in Dementia Care

Numerous gaps were identified, which led the IDC team to examine the particularly pressing issue of **limited access to integrated, equitable, and high-quality dementia care**.

The team identified several critical areas where current systems fall short:

- Poor integration of dementia care with other medical care and social supports
- Inadequate person-centered care planning
- Uneven access to high-quality, equitable dementia care
- Insufficient polypharmacy risk management
- Gaps in primary care workforce education and availability
- Lack of early detection of dementia

Reflecting on the above gaps, the team identified the following systemic challenges:

- **Overburdened primary care practices**: Providers lack the time to form the sustained relationships necessary to meet the ongoing needs of people living with dementia and their caregivers.
- **Confused patients and consumers**: Although Massachusetts offers a wide array of services, people living with dementia and those supporting them often struggle to navigate them effectively.

- **Fragmented care and rising costs**: Many services address only one piece of the puzzle or overlap inefficiently, leading to suboptimal outcomes, caregiver stress, and increased costs across both community and healthcare systems.

Evaluating Services and Models to Inform Comprehensive Dementia Care

To better understand how dementia care could potentially be strengthened and better integrated into primary care, the team conducted a detailed analysis, including:

- identifying 40 key service elements,[2] their benefits, infrastructure requirements, and responsible professionals;
- reviewing established, evidence-based interdisciplinary care models;[3]
- investigating related programs in Massachusetts and other states for additional insight and validation;[4] and
- discussing options for feasible solutions with state government officials.

Conclusion: Infrastructure Must Support Interdisciplinary Collaboration

Based on its analysis, the IDC team concluded that effective interdisciplinary dementia care is contingent on the presence of a strong supporting infrastructure. After understanding the gaps and necessary infrastructure for effective care, the team set out to develop a proposal that will strengthen and augment the state's existing geographically based infrastructure in a manner that:

- focuses specifically on dementia care navigation and caregiver support;
- supports and enhances the capabilities of current providers;
- builds stronger collaboration among healthcare and community organizations;
- promotes seamless coordination between medical and community-based services; and
- reduces costs for healthcare systems; community-based service organizations; and state government.

II. Proposed Integrated, Comprehensive Dementia Care Program

Described below is the IDC team's proposal for integrated, comprehensive care in Massachusetts, which aims to:

- build a medical/social model of care by strengthening coordination between healthcare providers and community service providers;
- improve the health and wellbeing of people living with dementia;

[2] To view the 40 service elements, see Appendix B.

[3] The IDC team examined the following five models: (1) Benjamin Rose Institute (BRI) Care Consultation; (2) Care Ecosystem; (3) Collaborative Care for Older Adults with Alzheimer's Disease in Primary Care; (4) Maximizing Independence at Home (Mind at Home); and (5) UCLA Alzheimer's and Dementia Care (ADC) Program.

[4] Massachusetts programs examined included interviews with representatives from the Hospital to Home Partnership program; Massachusetts Child Psychiatry Access Program; and Behavioral Health Outreach for Aging Populations program. Additionally, Massachusetts programs examined through literature review included the Skilled Nursing Facility (SNF) at Home (aka rehab at home) programs and Hospital at Home program. Programs examined in other states via interviews included ACL-funded Care Ecosystem programs (social care only), which included the Cal Connect program of the California Department of Aging; and OCCK, Inc. in Kansas; and Care Ecosystem models implemented in healthcare systems across the country were examined through a combination of interviews and a literature review.

- reduce stress and burden on caregivers;
- enhance the skills and capacity of the dementia care workforce; and
- lower costs for healthcare systems; community-based organizations; and state government.

Piloting an Integrated Program Grounded in the Care Ecosystem Model

In light of its findings and commitment to bridge the gaps in dementia care, the IDC team is proposing a pilot program grounded in the proven and evidence-based Care Ecosystem model of dementia care, which has been subject to extensive randomized controlled trials and peer reviewed research. The Care Ecosystem model, developed at the University of California, San Francisco (UCSF), has been fully or partially implemented by more than 20 healthcare institutions nationwide. As described in more detail in the next section, the model includes non-licensed care team navigators, clinical consultants with dementia expertise, care protocols, and curated information. Care Ecosystem Resources such as online training modules, learning collaboratives, and a toolkit are available at no cost for organizations interested in implementing the model.

From 2019 through 2021, Ochsner Health in New Orleans, Louisiana implemented Care Ecosystem. According to a 2024 report, after 12-months, participants had significantly improved total cost of care relative to a control group with a mean cost savings of $5,700 annually per member. Participants also had lower emergency department, outpatient, and professional utilization. After factoring in program cost, the return on investment was strong at 5.85.

The IDC team's proposal enhances the Care Ecosystem model by drawing on the resources and expertise of the Commonwealth's robust network of community-based partners, notably the Aging Services Access Points and Councils on Aging, which have a presence in every region of Massachusetts.

The proposed pilot will serve as an evidence-based "proof of concept" for a scalable, cost-effective, and sustainable medical-social model for comprehensive dementia care in Massachusetts. It aims to overcome current barriers to dementia care. It does so by leveraging existing infrastructure and fostering interdisciplinary collaboration, which is essential for high-quality dementia care.

The IDC team envisions "statewide adoption" after completion of the pilot. Statewide adoption refers to the eventual, gradual rollout of a state-sponsored program that enables all primary care providers across Massachusetts to participate. In this vision, the program will be insurance-agnostic, removing barriers to care and enabling consistent, equitable access to integrated, high-quality dementia care services statewide.

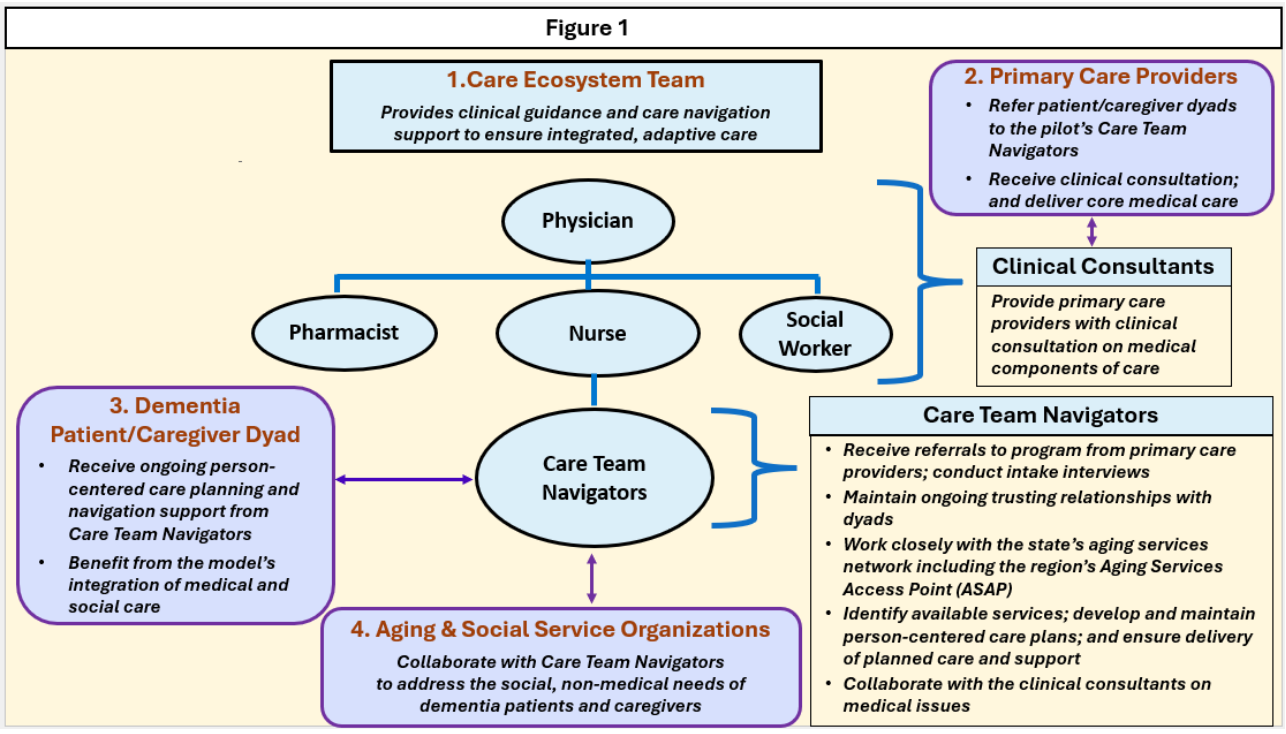
To help make the case for this vision, the IDC team proposes the pilot program be implemented by at least one healthcare system in at least one region of the state over a defined period, e.g., five years. The program will provide the healthcare system's participating primary care providers with access to expert clinical consultation; and deliver their dementia

patient/caregiver dyads with ongoing care planning and navigation services as well as integrated medical care and social support.

Integrated Model of Support and Communication

By emphasizing collaboration and bidirectional communication, the proposed pilot's integrated model will support ongoing, high-quality dementia care while addressing gaps in the current dementia care system. To achieve this, the proposed model will comprise four groups within the participating healthcare system's pilot region(s). Broadly stated and depicted in Figure 1 below, the four groups are:

1) ***The Care Ecosystem Team (Central Coordination)*** - Provides clinical guidance and care navigation support to ensure integrated, adaptive care.
2) ***Primary Care Providers (Frontline Medical Support)*** - Refer patients to the pilot program, i.e., the Care Ecosystem Team's Care Team Navigator; receive consultation; and deliver core medical care.
3) ***Dementia Patient/Caregiver Dyads (Ongoing Relationship-Based Support)*** - Benefit from ongoing person-centered care planning; navigation support; and integrated medical and social care.
4) ***Aging and Social Service Organizations (Community-Based Partnerships)*** - Address social care needs through ongoing collaboration with the Care Ecosystem Team's Care Team Navigators.



1. Care Ecosystem Team (Central Coordination)

The pilot program's operations will be enabled by **a small, centralized Care Ecosystem Team** that offers the healthcare system's participating primary care providers with clinical consultation and provides their patient/caregiver dyads with person-centered care planning and care navigation services. Members of the Care Ecosystem Team will meet regularly, e.g., weekly, to discuss and collaborate on patient/caregiver cases.

The proposed pilot's Care Ecosystem Team will consist of the following:

- **Part-time clinical consultants**, i.e., a physician, nurse, pharmacist, and social worker, will provide primary care providers with expert clinical advice to address the needs of their dementia patients.

- **Non-licensed Care Team Navigators** are a core part of the Care Ecosystem model. They will provide ongoing care planning and navigation support for dementia patients and caregivers. They will work closely with the pilot's clinical consultants, Aging Services Access Points, and other community providers, ensuring integrated medical and social care. Supervised by the pilot program's nurse, they maintain ongoing trusting relationships with patient/caregiver dyads, developing care plans that adapt to their evolving needs.[5]

2. Primary Care Providers (Frontline Medical Support)

The healthcare system's primary care providers in the pilot's region(s):

- refer patients to the pilot's Care Team Navigators;
- receive consultation from the pilot's clinical consultants; and
- continue to make all medical decisions and provide all medical care for their dementia patients:

Primary care providers will be kept up-to-date by the Care Ecosystem Team through such means as monthly reports and/or updates to shared patient records. While the Care Ecosystem Team will provide primary care providers with guidance to address medical needs, all medical decisions remain the responsibility of the primary care providers. The Care Ecosystem Team will:

- immediately alert primary care providers of any urgent medical need and if a patient requires medical attention and/or a medical decision;

- assist with discharge planning if a patient has a hospital or emergency department encounter; and

[5] According to one study of the Care Ecosystem model, 92 percent of caregivers reported that they could nearly always trust their Care Team Navigator and that the navigators were nearly always responsive (90%) and knowledgeable (79%).

- provide informed recommendations to primary care providers. For example, during the Care Ecosystem Team's regularly scheduled meeting, the team's pharmacist can review medication problems, and the nurse can assess patient symptoms (e.g., severe neuropsychiatric symptoms). This enables the team to provide informed advice to primary care providers on potential medication adjustments or specialist referrals.

3. **Dementia Patient/Caregiver Dyads (Ongoing Relationship-Based Support)**
    - The participating providers' dementia patients and their caregivers maintain a trusted ongoing relationship with the pilot program's Care Team Navigators.

4. **Aging and Social Service Organizations (Community-Based Partnerships)**
    - To address the social, non-medical needs of dementia patients and their caregivers, the Care Team Navigators will work closely with the state's robust network of community-based organizations including but not limited to the Aging Services Access Points and Councils on Aging, which are located in every region of the state.

III. Pathway from Pilot Program to Broader Adoption

The IDC team's proposed approach to scaling the medical-social care model from pilot to statewide implementation begins with leadership from at least one participating healthcare system and ends with a transition to state government ownership once the model is proven effective. The participating healthcare system will take the lead in designing, launching, and implementing the pilot program in at least one region of the state.

Successful transition from the pilot to a fully-funded, state-operated program requires a solid understanding of the pilot's shared value across stakeholders. It also requires early public/private collaboration and alignment, robust data, and a clear handoff strategy. As described in more detail below, the IDC team recommends a seven-phase strategy:

1. Engage in an Economic Modeling Exercise
2. Establish an Implementation Team
3. Develop an Implementation Plan with Statewide Alignment and Scalability
4. Estimate Costs and Secure Funding
5. Implement and Evaluate the Pilot
6. Make the Case for Statewide Implementation
7. Transition Leadership and Operational Responsibility

Phase 1: Engage in an Economic Modeling Exercise

Before establishing an implementation team for the pilot program, the IDC team recommends that one or more self-designated Council members or at least one affiliated stakeholder organization pursue and secure funding for a study that informs shared value across relevant community and healthcare partners. This study will include the following activities:

- Identify and assess the financial interests, incentives, and potential impacts for each partner group, including the participating healthcare systems; public insurers; private insurers; large employers, community-based service organizations; state-based organizations, individuals living with dementia; their caregivers; and families.

- Estimate the projected costs, savings, and potential return on investment for an intervention that supports integrated biopsychosocial care for persons living with dementia in the community through social-medical linked care navigation, care planning, and coordination. This work would be conducted through an economic modeling exercise that inputs relevant cost and impact information.

By weighing benefits and costs, this analysis will help justify forming an implementation team and plan for a pilot led by a healthcare system, with state officials participating as members of the planning team (Phases 2 and 3). The pilot and its evaluation will later inform a potential statewide, state-supported community-distributed program for persons living with dementia. Specifically, it will help us understand:

- How healthcare costs can be reduced while improving quality of life and health outcomes for patients.

- How supporting dementia caregivers can prevent costly patient care.

- How enhancing care coordination across healthcare and community-based organizations through a linked social-medical model can improve operational efficiency for both healthcare and social care providers.

- How ongoing support for dementia care planning and systems navigation for healthcare providers, community-based service providers, patients, and caregivers can avoid and reduce costly medical and social service utilization while increasing system capacity.

- How improved access to and quality of dementia care align with public and private payer savings and cost avoidance.

- How clinical consultation for primary care providers and care navigation for their patients can strengthen the dementia expertise of the healthcare and social care workforce while improving care delivery and provider satisfaction.

Importantly, the study will be designed to show how a linked social-medical dementia care model can be financially sustainable alongside the pilot's ultimate goal of delivering comprehensive high-quality, person-centered dementia care and caregiver support.

Please see Appendix C, to view resources that offer relevant insights, evidence, and examples that may help inform the design and execution of the proposed exercise.

Phase 2: Establish an Implementation Team

The participating healthcare system will form a dedicated implementation team responsible for developing and managing a detailed implementation plan for the pilot program. It will operate independently of both state government and the Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias (Council). However, as agreed upon by state government officials, key Council members and staff from the Massachusetts Executive Office of Aging & Independence and MassHealth will join staff from the healthcare system as members of the implementation team.

Phase 3: Develop an Implementation Plan with Statewide Alignment and Scalability

To guide development of the implementation plan, the following elements will be addressed to ensure alignment with state infrastructure, priorities, and long-term scalability:

- ***Developing a Regional Model with a Statewide Vision*** - The participating healthcare system's implementation team will collaboratively develop a detailed implementation plan focused on at least one region of the state over a defined period (e.g., five years). This plan will not only address the operational aspects of the medical-social model of dementia care but also ensure alignment with statewide infrastructure and policy priorities. Such alignment is essential for facilitating a smooth path toward statewide adoption and building early confidence among state government stakeholders.
- ***Assessing Fit within Existing State Systems*** - As part of this effort, the implementation team will assess how well the proposed model integrates with existing state systems. This includes identifying and proactively addressing any potential risks of misalignment with current government structures. For example, the team will examine whether the program will overlap or conflict with existing state contracts for care management or navigation, particularly those involving partnerships with community-based organizations. The team will also develop a risk response plan to anticipate and manage broader implementation challenges.
- ***Aligning with the State's Current Care Models*** - To further strengthen the plan, the team will draw insights from existing integrated care programs in Massachusetts, such as Senior Care Options (SCO) and the Program of All-Inclusive Care for the Elderly (PACE). These programs offer valuable lessons in effective care coordination and service delivery for older adults. In addition, the team will identify and leverage synergies between the pilot and existing programs such as the Alzheimer's Association's Dementia Care Coordination (DCC) program, the Massachusetts Behavioral Health

Outreach for Aging Populations (BHOAP) program, Hospital to Home programs, and the state's Home Care Program.

- ***Clarifying the Pilot's Role in Dementia Detection and Screening*** - The MA Advisory Council on Alzheimer's Disease and All Other Dementias recently identified early dementia detection and diagnosis as one of its top priorities. People living with dementia and their caregivers benefit greatly from receiving care planning, care, support, and potential treatment early in the disease's progression. However, early detection, screening, and diagnosis continue to be critical gaps in the system. The pilot's implementation plan will define the pilot's role in supporting or facilitating timely dementia screening and diagnosis, particularly for individuals identified by community-based organizations or state government programs. The implementation team will identify and assess potential collaborative approaches between the pilot program and the aging and social services network to ensure that individuals with suspected dementia are connected to appropriate specialists for evaluation.
- ***Establishing a Financial Case for State Investment*** - Financial considerations will be central to the plan, not only from the short-term perspective of the healthcare system's pilot program, but also from the longer-term perspective of a statewide program. The implementation team will estimate the program's financial benefits and return on investment and explore sustainable revenue streams beyond grant or state funding, e.g., by assessing opportunities for public and private insurance reimbursement through medical coding mechanisms. The plan will also include a methodology for assessing potential cost savings to MassHealth, particularly in serving individuals with dementia who are not currently enrolled in SCO or PACE. In addition to measuring direct cost savings for the state, the plan will include approaches to estimate long-term cost avoidance. Examples include a lower number of individuals who spend down assets to qualify for MassHealth and a reduction in future demand for state-funded long-term care facility placements.
- ***Laying the Groundwork for Statewide Adoption and National Influence*** - Through this collaborative planning process, the pilot will be positioned not just as an innovative care model for a single healthcare system, but as a fiscally responsible, scalable solution that aligns with state government priorities and paves the way for statewide adoption. Furthermore, the pilot program sets the stage for Massachusetts to position itself as a national leader in dementia care innovation, creating a model that can be replicated in other states and inform national public policy.

Phase 4: Estimate Costs and Secure Funding

The participating healthcare system will estimate costs associated with implementing the pilot program and seek and secure funding from one or more sources outside of state government. Referring to findings from the economic modeling exercise (Phase 1) and the implementation plan (Phase 3) as a guide, it will develop cost estimates and prepare programmatic and funding proposal(s) that are aligned with the goals, objectives, and strategies outlined in the plan.

Given that certain funding opportunities may have their own set of requirements not previously discussed by the implementation team, during this phase, the healthcare system will collaborate with state government officials as needed to discuss those requirements to ensure continued alignment.

To view a list of organizations to explore for potential funding or collaboration, please see Appendix D.

Phase 5: Implement and Evaluate the Pilot

Once funding is secured; and guided by the implementation plan and successful funding proposal, the healthcare system will implement the pilot taking full responsibility for overseeing and managing the pilot's operations. Through rigorous data collection including ongoing stakeholder feedback, the healthcare system will continuously document learnings and outcome data; analyze outcomes; and implement iterative improvements. Additionally, this data will serve as the evidence base to demonstrate the effectiveness, efficiency, cost-effectiveness, and potential scalability of the model.

Examples of metrics may include improvements in caregiver experience and quality of life of people living with dementia; reductions in avoidable emergency department visits, outpatient visits, hospitalizations, and long-term care placements; enhanced coordination of medical and social services; and decreases in overall healthcare costs or cost per patient. Other examples to consider include program scalability metrics related to operational performance (e.g., throughput, such as the number of existing and new patient/caregiver dyads served per month) and resource utilization (e.g., mean staff time per patient/caregiver dyad). To view a list of potential metrics to consider, please see Appendix E.

Phase 6: Make the Case for Statewide Implementation

The vision is that the healthcare system's evaluation of the pilot will be used to make a compelling case for transitioning to a statewide program. After the data analysis is complete, the healthcare system will present to state government officials a compelling case for launching a statewide rollout of the model.

Phase 7: Transition Leadership and Operational Responsibility

Once a strong case has been established, this phase ideally involves transitioning leadership and operational responsibility to the state. The intended outcome is for state government to take active steps to fund, oversee, and manage a gradual and sustainable statewide rollout of the program. This transition would mark the formal adoption of the program as a statewide standard of dementia care. It would require that the state develop a scalability and sustainability plan. The program's rollout would eventually include formal engagement with all 24 Aging Services Access Points to ensure that the program is embedded within the existing aging services infrastructure while maintaining fidelity to the Care Ecosystem-inspired model.

IV. Recommended Next Steps

(With reference to considerations outlined in Phases 1 through 4 above)

1. Seek and secure funding for an economic modeling exercise.
2. Launch the economic modeling exercise.
3. Form an implementation team and develop an implementation plan that aligns with statewide infrastructure and state government priorities.
4. Estimate costs and secure funding for the pilot.

V. Appendices

The remainder of this paper includes the following four appendices:

A. Interdisciplinary Dementia Care (IDC) Team Members
B. Service Elements by Care Grouping
C. Resources to Inform the Economic Modeling Exercise
D. Organizations to Explore for Potential Funding or Collaboration
E. Evaluation Domains, Metrics, and Targets to Consider

A Social-Medical Model for Dementia Care

V. Appendices

Appendix A

Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias

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Appendix B

Service Elements by Care Grouping

Detection and Diagnosis

1. Memory Screenings and Referrals
2. Neuropsychological Testing and Interpretation
3. Diagnosis of Dementia

Medication Management

4. Management of Medications: Effectiveness, Side Effects, Conflicts and Safety (Deprescribing and Prescribing)
5. Education on Pharmacologic and Nonpharmacologic Interventions

Patient/Caregiver Dyad Planning and Support

6. Development of Dementia Care Plan
7. Patient Assessment (Ongoing)
8. Care Coordination and Communication
9. Education about Memory Loss, Caregiver Issues and the Dementia Healthcare System
10. Basic Patient Monitoring
11. Basic Health Monitoring
12. Basic Medical Care
13. Home Safety Assessment
14. Patient and Caregiver Phone Follow-Up
15. Monitoring of Condition Progression
16. Patient Communication
17. Re-evaluation of Care Plan
18. Record Keeping
19. Family and Caregiver Support
20. Wound Care
21. Appointment Coordination

Specialist Services Required for Dementia Care

22. Design and Guidance of Exercise Programs
23. Advocacy in Health System
24. Referral for Outpatient Services
25. Psychotherapy and Counseling Services
26. Assistance with Speech and Language Skills
27. Functional Abilities Assessment
28. Fall Prevention and Mobility and Balance Training
29. Driving Evaluation
30. Swallowing Problems Care
31. Referral to Medicare Part A Services
32. Management of Ethical Issues

Appendix C

Resources to Inform Economic Modeling Exercise

- *Business Strategies to Support Comprehensive Dementia Care (Webinar Slides) and Recording*, June 18, 2025
- *The Scale of Benefit and Cost Effectiveness of the Care Ecosystem for Alzheimer's Disease relative to Lecanemab,* January 9, 2025
- *Dissemination of the Care Ecosystem Collaborative Care Model for Dementia,* January 6, 2025
- *Rate of Return (ROI) Calculators: ROI Calculator for the Business Case and Person-Centered Care*; *ROI Calculator for Healthcare Partnerships to Address Social Needs*
- *Strengthening Health Care-Community Partnerships with ROI Insights to Better Address Social Needs,* August 15, 2024
- *Care Ecosystem Collaborative Model and Health Care Costs in Medicare Beneficiaries With Dementia: A Secondary Analysis of a Randomized Clinical Trial,* September 18, 2023
- *Implementation and review of the care ecosystem in an integrated healthcare system,* August 24, 2023
- *Variations in Costs of a Collaborative Care Model for Dementia,* July 18, 2019
- *Comprehensive Dementia Care Programs for Patients and Caregivers: Evidence Roundup,* December 12, 2024
- *Model-Based Economic Evaluations of Interventions for Dementia: An Updated Systematic Review and Quality Assessment,* March 30, 2024
- *Care management improves total cost of care for patients with dementia,* 2024
- *Systemic Review on Navigation Programs for Persons Living With Dementia and Their Caregivers,* September 2, 2023
- *Making the Business Case for Value-Based Dementia Care,* February 15, 2023
- *Medication management for complex patients in primary care: application of a remote, asynchronous clinical pharmacist model,* May 21, 2021
- *Effect of Collaborative Dementia Care via Telephone and Internet on Quality of Life, Caregiver Well-Being, and Health Care Use: The Care Ecosystem Randomized Clinical Trial,* December 1, 2019
- *The Care Ecosystem Consortium Effectiveness Study* - Study launched on January 27, 2023; data collection is complete; study's expected completion is December 31, 2025
- *Dementia Care Navigation Roundtable, Business Case Workgroup* - Facilitator: John Sawyer, Ochsner Health. Developing a template business case with strategies for health systems and community organizations to promote equitable, quality dementia care navigation. For more information, contact: dementiacarenavigation@alz.org.

Appendix D

Organizations to Explore for Potential Funding or Collaboration

The list below offers a starting point for a healthcare or community-based organization to explore potential funding opportunities for implementing the proposed pilot. The list, which should not be considered exhaustive, includes organizations that have a history of providing grant funding or collaborating with healthcare organizations, state government agencies, or community-based organizations on healthcare or dementia-related initiatives.

None of the organizations listed below have been contacted or involved in the Interdisciplinary Dementia Care Team's work to date. They appear in no specific order and are included here solely as a reference for further research, inquiry, or relationship-building activities by potential pilot participants or grant applicants.

It is up to potential grant applicants to research specific grant eligibility requirements, explore upcoming funding opportunities, and consider reaching out to these and other organizations to assess potential collaborative opportunities. Noted for each organization are relevant priorities (especially those related to dementia), past grants, and key deadlines.

Nonprofit and Foundation Funding in Massachusetts

- **Blue Cross Blue Shield of Massachusetts Foundation**
    - ***Priority****:* Supports community-based organizations that serve those in Massachusetts who are economically, racially, culturally, or socially marginalized. They have interests in health equity and social needs.
    - ***Past Grants:*** Funded aging and community health projects, e.g., supportive housing for seniors. Not explicitly dementia-focused historically, but caregiver support aligns with their mission of health equity.
    - ***Deadline:*** Opportunities arise all year; however, typically grant cycles are in the spring and fall.
- **Point32Health Foundation**
    - ***Priority:*** Supports nonprofit organizations' work to advance equity in aging, prioritizing efforts that address systemic inequities and advance social and racial justice.
    - ***Past Grants:*** Funded dementia-friendly community efforts and caregiver respite programs in MA (e.g., support for Dementia Friendly Massachusetts initiative). They focus on systems change and collaboration.
    - ***Deadlines:*** Two grant cycles, typically in February and September.

- **The Boston Foundation**
    - ***Priority:*** Interests are broad including direct clinical services and broader public health initiatives, often emphasizing underserved communities and systemic health challenges.
    - ***Past Grants:*** Funded community health workers programs, mental health initiatives, etc., within Boston.
    - ***Deadlines:*** Rolling for some programs; formal cycles for others.
- **Health Foundation of Central Massachusetts**
    - ***Priority:*** Health programs in Central MA (Worcester County), often innovative service delivery and health equity.
    - ***Past Grants***: "The Synergy Initiative" provides funding for partnership-based projects targeting health issues. The "Activation Fund" supports one-year projects to help community organizations with capacity and effectiveness. Past grants have supported older adult services collaborations in the Worcester area.
    - ***Deadlines:*** Synergy Initiative applications are invited every 4–5 years, with about four projects funded per round; the last round (Round 6) was in 2023. Activation Fund grant opportunities are announced each January for 12-month periods starting July 1.
- **MetroWest Health Foundation**
    - ***Priority:*** Health of MetroWest region (Framingham/Natick and surrounding towns).
    - ***Past Grants:*** Support for dementia friendly community initiatives and caregiver training.
    - ***Deadlines:*** Semi-annual grant cycles.

National Nonprofit and Foundation Funding

- **John A. Hartford Foundation**
    - ***Priority***: Improving care for older adults, with current focus on age-friendly health systems, dementia caregiving, and serious illness care.
    - ***Past Grants:*** Funded the Center to Spread the UCLA Alzheimer's and Dementia Care (ADC) Program, the Alliance to Improve Dementia Care, and a package to improve dementia care in 2020.
    - ***Deadlines:*** Rolling; and accept inquiries year-round.

- **The SCAN Foundation**
    - ***Priority:*** Transforming care for older adults, with emphasis on long-term care system reform, caregiver support, and innovative models.
    - ***Past Grants:*** Funded California's Community-Based Care Networks and national efforts like the "Better Care Playbook."
    - ***Deadlines:*** Invitation-based mostly; no fixed cycles.
- **RRF Foundation for Aging**
    - ***Priority:*** Improving quality of life for older people, with interest in caregiving, economic security, care coordination. Some grants are available only in Illinois.
    - ***Past Grants:*** Funded projects nationwide including New England; e.g., grants to improve dementia caregiver training.
    - ***Deadlines:*** Letters of Intent typically due Nov 1, Feb 1, and May 1.
- **Milken Institute**
    - ***Priority*:** Advances solutions in health, finance, aging, and innovation. While not a direct funder, it influences funding by advising philanthropists and fostering cross-sector collaboration. Priorities include scalable, evidence-based solutions.
    - ***Past Involvement****:* In the dementia space, it has led initiatives through its Center for the Future of Aging and Center for Strategic Philanthropy, focusing on brain health, early detection, and care innovation.
    - ***Approach:*** Alignment with their priorities and participation in convenings are key to engaging with their support network.
- **Milbank Memorial Fund**
    - ***Priority:*** State health policy, population health, health equity, chronic disease, evidence-based decision-making.
    - ***Approach****:* Rather than issuing open calls for proposals, they tend to identify strategic opportunities aligned with their mission and reach out to potential partners.
- **Gordon and Betty Moore Foundation**
    - ***Priority:*** Patient care improvements, notably in healthcare delivery and serious illness.
    - ***Past Grants:*** Funded palliative care models and caregiver tech solutions.
    - ***Deadlines:*** Rolling inquiries.

- **Robert Wood Johnson Foundation (RWJF)**
    - ***Priority:*** Health systems transformation, health equity, and community health.
    - ***Past Grants:*** Funded caregiver support research and care coordination projects.
    - ***Deadlines:*** No fixed schedule. Typically, new funding opportunities are announced through their website.
- **Leonard Davis Institute (LDI) Small Grants Program (UPenn)**
    - ***Priority*:** pilot research grants in health services and health policy research, with a focus on healthcare access and coverage, health equity, improving care for older adults, the opioid epidemic, and population health.
    - ***Deadline:*** Grant opportunities are typically announced in the fall.
- **Commonwealth Fund**
    - ***Priority:*** Healthcare system improvement, access and coverage, health equity, and innovation in care delivery.
    - ***Past Grants:*** Supported initiatives in Medicaid policy, primary care transformation, and reducing health disparities.
    - ***Deadlines:*** No fixed schedule. Grant opportunities are posted on their website as they become available.
- **BrightFocus Foundation**
    - ***Priority:*** Primarily biomedical research on Alzheimer's but includes some public health outreach.
    - ***Past Grants:*** While the primary focus is biomedical research, the Foundation has funded other research intersects with public health. One example is a study focusing on understanding how geographic and social factors influence Alzheimer's outcomes in underserved rural populations.
    - ***Deadlines:*** Deadlines vary each year by program.
- **UsAgainstAlzheimer's (A-LIST initiative)**
    - ***Priority:*** Advocacy, collaboration, activating communities; network of patients/caregivers via "A-List" initiative.
    - ***Past Work:*** While UsAgainstAlzheimer's does not provide grants, it collaborates with stakeholders, including government agencies, private sector partners, and other nonprofits in facilitating and supporting initiatives that address Alzheimer's and related dementias.
- **Alzheimer's Association (National and MA/NH Chapter)**
    - ***Priority:*** Primarily an advocacy and service organization; some grant programs for translational research. May be a potential source of in-kind support, e.g., materials or staff time.

Federal Government Grants

- **National Institutes of Health (NIH) – National Institute on Aging (NIA)**
    - ***Priority:*** Research on Alzheimer's care interventions, dissemination and implementation studies.
    - ***Past Grants:*** Funded the original Care Ecosystem trial and many pilot trials through the IMPACT Collaboratory.
    - ***Deadlines:*** Typically occur multiple times annually, with specific dates announced on their official funding opportunity web pages.
- **Patient-Centered Outcomes Research Institute (PCORI)**
    - ***Priority:*** Comparative effectiveness research that engages patients/caregivers in study design.
    - ***Past Grants:*** Funded the Dementia Care (D-CARE) study, a large-scale, pragmatic randomized clinical trial that measured effectiveness of health system-based and community-based dementia care interventions.
    - ***Deadlines:*** Cycle announcements throughout year (e.g., April/August 2025).
- **Administration for Community Living (ACL) – Alzheimer's Disease Program Initiative (ADPI) Grants**
    - ***Priority:*** Supporting state and community efforts to become dementia-capable.
    - ***Past Grants:*** Many states including Massachusetts have received multi-year grants to implement dementia interventions.
    - ***Deadlines:*** Typically, annual or biannual
- **Centers for Disease Control and Prevention (CDC)**
    - ***Priority:*** Public health infrastructure for dementia (education, data, risk reduction).
    - ***Past Grants:*** The Boston Public Health Commission received a CDC BOLD grant to strengthen dementia infrastructure beginning with the development of a citywide strategic plan.
- **Centers for Medicare & Medicaid Services (CMS) - Innovation Center (CMMI)**
    - ***Priority:*** Testing innovative payment and service delivery models for Medicare/Medicaid beneficiaries.
    - ***Past Initiatives:*** GUIDE model, drawing from UCSF's Care Ecosystem.
    - ***Deadlines:*** CMMI model announcements are irregular; monitoring recommended.

Corporate Philanthropy and Healthcare Organizations

- **Biopharmaceutical Companies (e.g., Biogen, Eli Lilly)**
    - ***Interest:*** Supporting community initiatives aligned with new Alzheimer's therapies and patient care pathways.
- **Health Systems Community Benefits**
    - ***Interest:*** Supporting initiatives that reduce burden on hospitals and improve community health.
- **Insurance Companies (Commercial) Philanthropy**
    - ***Interest:*** Some have foundations or community health grants.
- **Technology or Data Companies**
    - ***Interest:*** Occasionally fund health-related pilots; potential for tech donations or partnerships.

Appendix E

Evaluation Domains, Metrics, and Targets to Consider

A robust evaluation plan is critical for measuring the pilot program's success and to inform future policy. It is essential that metrics are clearly aligned with the pilot's objectives. Listed below are five potential "**evaluation domains"** along with their goals:

1. **Healthcare Utilization Outcomes**
   Goal: Reduce avoidable acute care use among people with dementia in MA
2. **Patient Outcomes and Quality of Care**
   Goal: Improve patient well-being and care processes
3. **Caregiver Outcomes**
   Goal: Alleviate caregiver burden and improve support
4. **Cost and Utilization (Economic Outcomes)**
   Goal: Demonstrate cost-effectiveness and potential savings
5. **Scalability**
   Goal: Gauge the pilot's potential for broader system integration

For each evaluation domain, listed below are some metrics and targets to consider:

1. Healthcare Utilization Outcomes

(Goal: Reduce avoidable acute care use among people with dementia in MA.)

- **Emergency Department (ED) Visit Rate:** Consider tracking the number of ED visits per participant per year for dementia-related issues (falls, behavioral disturbances, infections, etc.). A potential benchmark could be a 25% reduction in ED visit rate compared to baseline or a control group. Prior studies (e.g., Care Ecosystem RCT) have shown reductions in ED use, which may be replicable in Massachusetts. This area aligns with concerns around high dementia-related ED utilization in the state.
- **Hospitalization Rate:** One option is to measure all-cause hospital admissions per participant annually. Based on other Care Ecosystem interventions, a 20% reduction could serve as a reference point. Hospital readmissions within 30 days could also be tracked reflecting that care navigation supports smoother transitions and fewer readmissions.
- **Long-Term Care Placement:** It may be useful to observe the percentage of participants who transition to long-term care, and the timing of this transition. Even during a relatively short pilot, any trend toward delayed institutionalization, e.g., by 3–6 months, may signal success in helping individuals remain in the community longer.

- **Connection to Support Services:** It might be helpful to track how quickly and frequently participants connect with resources like Aging Services Access Points. For example, documenting contacts or service uptake (e.g., Meals on Wheels, homemaking) within the first 90 days could offer insights into how well the navigation process improves timely access to existing supports.

2. Patient Outcomes and Quality of Care

- **Quality of Life (QoL):** Instruments like the QoL-AD could be administered at intervals to assess patient well-being. In a progressive illness like dementia, even stabilization, or slower decline compared to a control group, for example, could be considered a meaningful outcome.
- **Neuropsychiatric Symptom Management:** Tools such as the Neuropsychiatric Inventory (NPI) may help track behavioral symptoms like agitation or anxiety. A reduction in frequency or severity could reflect earlier intervention and symptom management.
- **Advance Care Planning Completion:** Tracking the proportion of participants with documented care preferences (e.g., healthcare proxies, advance directives) may offer insight into how the program supports future planning. Increasing completion rates beyond 75% might suggest progress toward person-centered care.
- **Timely Diagnosis & Treatment:** Although participants typically enroll post-diagnosis, earlier detection facilitated through community awareness or provider education could be another area to explore. Trends in referrals or diagnosis timing might reflect an indirect effect of the pilot.

3. Caregiver Outcomes

- **Caregiver Burden Score:** A validated scale (e.g., Zarit Burden Interview) could be used at regular intervals. Changes in scores might indicate shifts in caregiver stress, and prior studies have shown reductions in burden with similar programs.
- **Caregiver Depression and Health:** Screening tools like PHQ-9 and self-rated health surveys could be used to explore caregiver well-being. Observing trends in depression scores or self-reported health could offer insight into potential impacts of care navigation.
- **Caregiver Experience/Satisfaction:** Feedback might be gathered through surveys or interviews about caregiver experience, perceived support, and ability to manage care. High satisfaction and a strong sense of support may reflect positively on the model. Benchmarks from past programs (e.g., >85% reporting improved management or >90% trusting navigators) might serve as useful comparisons.

4. Cost and Utilization Metrics (Economic Outcomes)

- **Total Cost of Care per Patient:** Claims data could be used to explore cost differences before and during the pilot. Reductions in per-member-per-month (PMPM) costs may indicate economic impact. For instance, prior implementations reported PMPM savings in the hundreds of dollars, which could serve as a reference point.
- **Cost Savings Breakdown:**
    - *Acute Care Cost Savings:* Decreases in ED and hospital usage may translate into measurable cost reductions.
    - *Long-Term Care Cost Impact:* Delayed nursing home placement might eventually reduce Medicaid expenditures. Even early qualitative observations or projections could be informative.
    - *Out-of-Pocket and Caregiver Economic Impact:* Optional metrics might include reductions in ER co-pays or indirect savings such as caregivers staying in the workforce longer.
- **Program Utilization and Efficiency:**
    - *Navigator Caseload and Contact Frequency:* Consider tracking average monthly contact per participant.
    - *Issue Resolution Rate:* Monitoring resolution of common problems may help assess program responsiveness.
    - *Referral Completion Rate:* A high rate of successful service uptake (e.g., >80%) could suggest effective follow-through on referrals.

5. Scalability Metrics

- **MassHealth Engagement Metrics:** Potential indicators include the proportion of pilot enrollees on MassHealth.
- **Model Fidelity and Workforce Metrics:**
    - *Navigator Retention and Training Efficacy:* Retention rates and skill assessments could be tracked to gauge role sustainability.
    - *Primary Care & Specialist Feedback:* Provider surveys may offer insight into the program's value from a clinical perspective. Positive provider feedback can support scalability discussions.
- **Scalability Cost Projections:** Cost estimates for expanding the model statewide (e.g., per 1,000 dementia patients) could be developed to inform feasibility and budget alignment. Comparing projected savings and costs could potentially help stakeholders evaluate long-term value.