Scaling Comprehensive Dementia-Care Models

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ALLIANCE
TO IMPROVE
DEMENTIA CARE

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The Alliance to Improve Dementia Care brings together a multi-sector coalition of leaders to advance timely detection, access to treatment and coordinated care, and health equity for people at risk for and living with dementia and their caregivers. Through expert workgroups, convenings, and collaborative initiatives, the Alliance amplifies and promotes the adoption of proven solutions and promising innovations. This report is informed by a consensus-building approach but may not reflect the views of all Alliance members.

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INTRODUCTION
IMPROVING LIFE AFTER DIAGNOSIS

Despite scientific progress over the past 25 years, dementia remains one of the toughest health-care challenges. Alzheimer's disease is the sixth-leading cause of death in the United States, and the number of deaths from all related dementias may be twice as high.[1] Years of investment and research in Alzheimer's disease and related dementias (ADRD) are sowing seeds of hope. New treatments aim to slow cognitive decline and manage symptoms. However, because of the complexity of dementia, people living with dementia will likely need a combination of drug treatments, comprehensive care, and supportive services to help them live their lives to the fullest after diagnosis.

Advocacy organizations, policymakers, researchers, and health-care professionals are developing ways to meet the complex medical and social needs of the estimated 7.2 million Americans living with ADRD and their families.[2] To advance the adoption of comprehensive dementia-care models, the Milken Institute Alliance to Improve Dementia Care (Alliance) convened a roundtable in June 2021. Leaders across industry, government, research, advocacy, philanthropy, health systems, and community-based organizations (CBOs) explored ways to improve and pay for comprehensive dementia care.

"COMPREHENSIVE" VS. "COLLABORATIVE" CARE MODELS

While these terms are sometimes used interchangeably, roundtable participants noted the distinction between "comprehensive" and "collaborative" dementia care that we affirm in this report. Comprehensive care refers to models that include all eight core care elements highlighted in Figure 1 and provide medical, neuropsychological, and social services to individuals across the stages of their dementia care journey. Collaborative care refers to models in which two or more professionals work together to deliver dementia care as a coordinated team and generally occurs when the lead clinician is not the individual's primary care provider. Comprehensive care can be delivered through collaborative or primary care models.
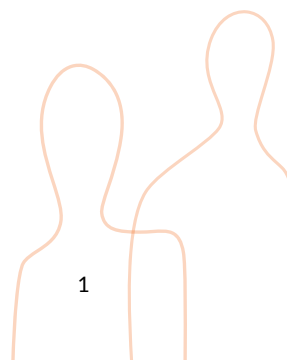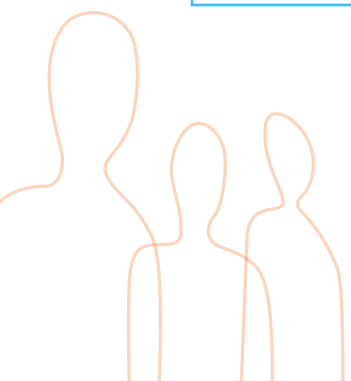
This report presents actionable recommendations to advance comprehensive dementia care and implement effective payment policies. These recommendations center around two overarching themes:

1. Developing a structured framework to test, implement, and scale comprehensive dementia-care models; and

2. Implementing effective payment policies to incentivize adoption and participation in comprehensive dementia-care models.

Earlier this year, the Alliance provided recommendations on *Building Workforce Capacity to Improve Detection and Diagnosis of Dementia*. The recommendations in this report focus on improving post-diagnostic care and payment policies under traditional Medicare, where we believe the need for reform is most urgent.[3] Future convenings may leverage these recommendations to advance comprehensive dementia care for beneficiaries covered by Medicare Advantage plans and for populations who are dually eligible for Medicare and Medicaid.

THEME #1

Developing a structured framework to test, implement, and scale comprehensive dementia-care models

Comprehensive dementia-care models can improve health outcomes, reduce costs, and support caregivers.[4] However, adoption of these models has been slow because of the wide-ranging needs of people living with dementia, the need for robust workforce training, inequitable access to health care, misaligned incentives, and inadequate payment. During the National Institute on Aging's 2020 National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers, leading experts identified four barriers that must be overcome to implement interventions successfully for people living with ADRD:[5]

1. Limited market demand,

2. Insufficient engagement of people living with ADRD and their caregivers,

3. Limited evidence regarding scalability and sustainability of ADRD care services, and

4. Difficulties in implementing successful innovations across different contexts.
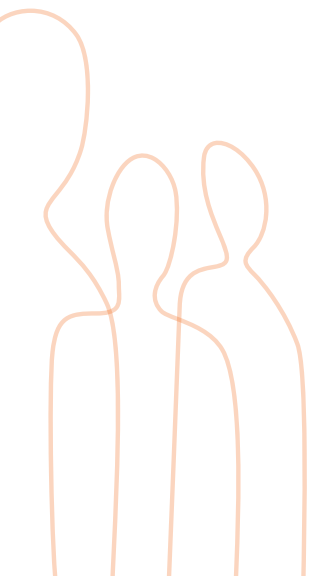
To scale comprehensive dementia-care models and make them accessible for all traditional Medicare beneficiaries, the Alliance recommends the following:

RECOMMENDATION #1

Ensure all dementia-care models contain a minimum set of core elements for comprehensive care and follow a population-health approach that tiers services to level of need

Comprehensive dementia-care models provide an approach to coordinated care. Researchers and practitioners have identified eight essential elements of comprehensive dementia care that improve outcomes and lower costs.[6] Roundtable participants agreed, and the Alliance recommends, that all comprehensive dementia-care models include the eight elements highlighted in **Figure 1**. This structured framework can reduce variations in care, align incentives, and improve care coordination.[7]

Figure 1: Eight Core Elements of Comprehensive Dementia Care
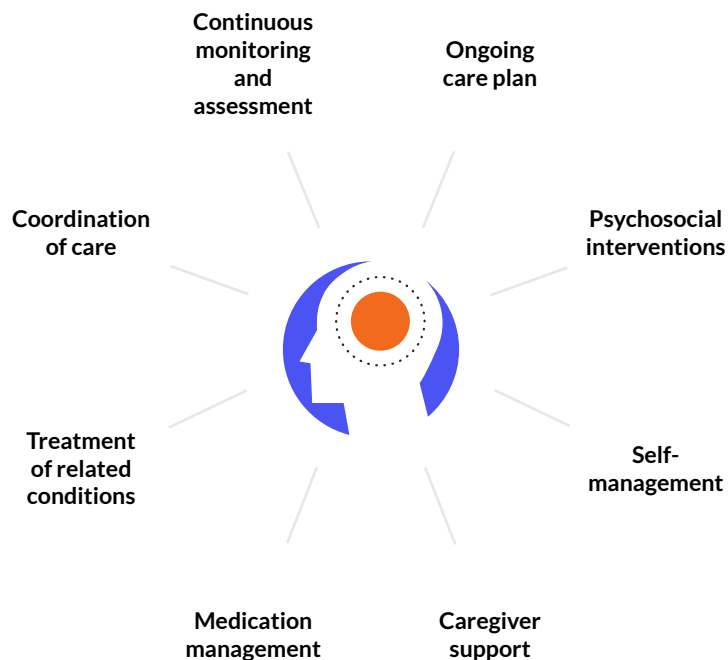
Note: See Appendix A for definitions and descriptions of each core element.

Adapted from Kristen Lees Haggerty et al., "Recommendations to Improve Payment Policies for Comprehensive Dementia Care," Journal of the American Geriatrics Society 68, no. 11 (November 2020): 2478-2485, https://doi.org/10.1111/jgs.16807.

In 2019, national experts participated in the [Payment Model for Comprehensive Dementia Care Conference](#) to review promising strategies for payment reform. Conference participants discussed six models of comprehensive dementia care that show compelling evidence of positive outcomes: the Benjamin Rose Institute Care Consultation model, Care Ecosystem, Maximizing Independence at Home program, Eskenazi Healthy Aging Brain Center, UCLA Alzheimer's and Dementia Care (ADC) program, and the Integrated Memory Care Clinic (see Appendix B for descriptions of each model).

These models can be adapted to varying levels of need and resources. During the Alliance roundtable, Gary Epstein-Lubow, MD, associate professor of psychiatry and human behavior and associate professor of medical science at Brown University's Warren Alpert Medical School, noted that "all [existing] models have all or almost all of the [eight] elements of comprehensive care. There are differences regarding their structure, such as staffing, scope of services provided, level of intensity—including networked engagement with CBOs, cost, and level of evidence for efficacy and effectiveness outcomes." **Table 1** highlights these differences.[8]

Table 1: Comparison of Six Comprehensive Dementia-Care Models

Structure and Process	Benjamin Rose Institute Care Consultation	Care Ecosystem	Maximizing Independence at Home	Eskenazi Healthy Aging Brain Center	UCLA Alzheimer's and Dementia Care	Integrated Memory Care Clinic
Key Personnel	SW, RN, MFT	Non-licensed care navigator, CNS, SW, Pharmacist	Non-licensed staff, RN, MD	Non-licensed staff, MD, SW, RN, psychologist	NP, PA, MD	APN
Face-to-Face Visits	No	No	Yes	Yes	Yes	Yes
Access 24/7/365	No	No	No	Yes	Yes	Yes
Patient Benefit	Yes	Yes	Yes	Yes	Yes	Non-significant findings but positive direction
Caregiver Benefit	Yes	Yes	Yes	Yes	Yes	Non-significant findings but positive direction
Cost Savings (gross)	$	$	None	$	$$$	$$$

Abbreviations: APN: advanced practice nurse; CNS: clinical nurse specialist; MD: medical doctor; MFT: marriage and family therapist; NP: nurse practitioner; PA: physician assistant; SW: social worker; RN: registered nurse; $: least cost savings; $$$ most cost savings
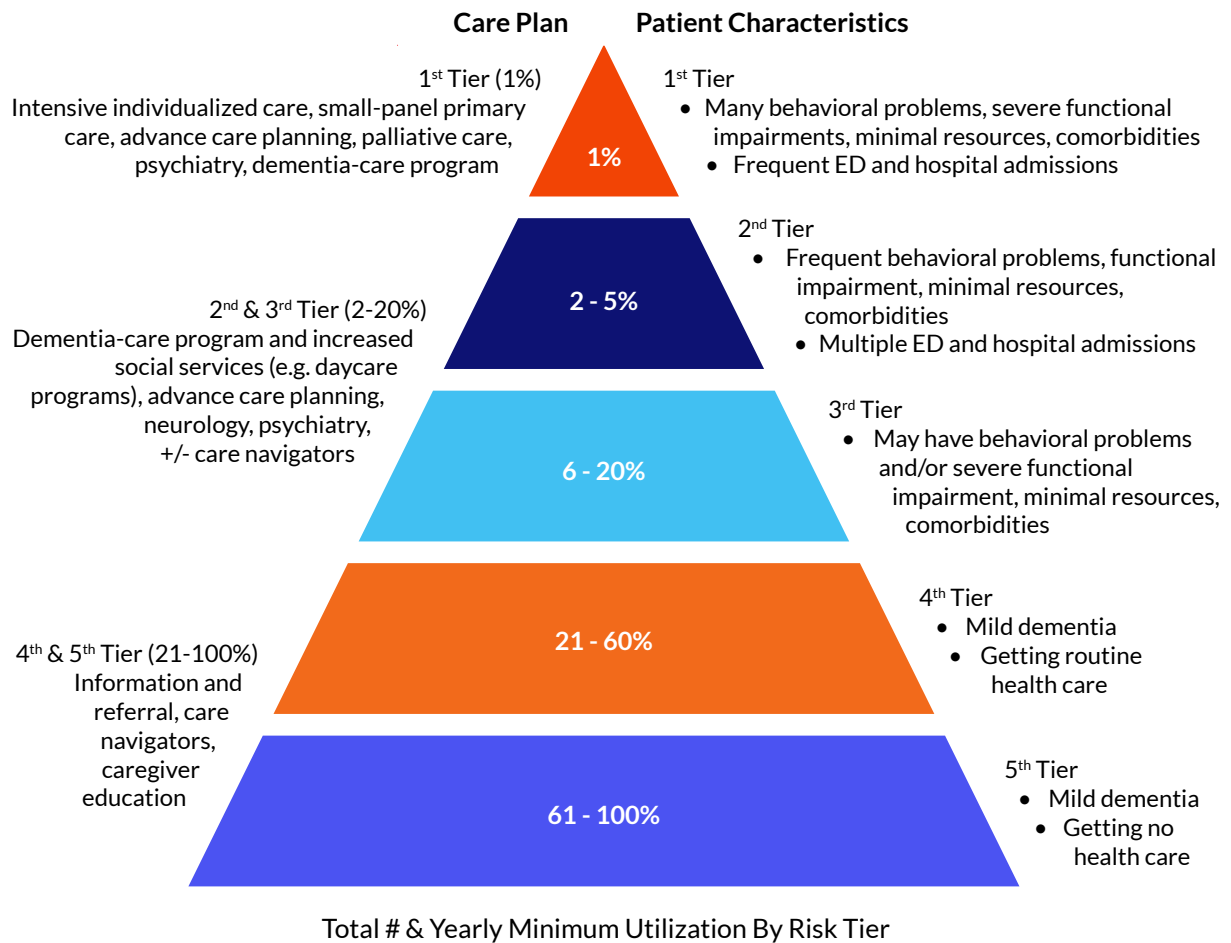
Note: See Appendix B for descriptions of each model.

Adapted from Kristen Lees Haggerty et al., "Recommendations to Improve Payment Policies for Comprehensive Dementia Care," Journal of the American Geriatrics Society 68, no. 11 (November 2020): 2478-2485, https://doi.org/10.1111/jgs.16807.

The needs and costs associated with dementia care are wide-ranging. A population-health approach can help clinicians adapt the core elements of comprehensive care to the unique needs of individuals and their caregivers across stages of dementia. **Figure 2** highlights how a population-health approach matches patient needs to a tier of services. Individuals with multiple comorbidities, emergency department (ED) visits, behavioral problems, and functional impairment may need expensive and medically intensive services (first-tier level of service). Conversely, individuals with mild dementia may require less intense medical care and more social supports, including caregiver education, disease education, referrals, and patient monitoring (fifth-tier level of service).

Figure 2: Population-Based Dementia-Care Model

Care Plan

Patient Characteristics

1st Tier (1%)
Intensive individualized care, small-panel primary care, advance care planning, palliative care, psychiatry, dementia-care program

1%

1st Tier
- Many behavioral problems, severe functional impairments, minimal resources, comorbidities
- Frequent ED and hospital admissions

2 - 5%

2nd Tier
- Frequent behavioral problems, functional impairment, minimal resources, comorbidities
- Multiple ED and hospital admissions

2nd & 3rd Tier (2-20%)
Dementia-care program and increased social services (e.g. daycare programs), advance care planning, neurology, psychiatry, +/- care navigators

6 - 20%

3rd Tier
- May have behavioral problems and/or severe functional impairment, minimal resources, comorbidities

21 - 60%

4th Tier
- Mild dementia
- Getting routine health care

4th & 5th Tier (21-100%)
Information and referral, care navigators, caregiver education

61 - 100%

5th Tier
- Mild dementia
- Getting no health care

Total # & Yearly Minimum Utilization By Risk Tier

Adapted from David B. Reuben, "Payment Policies Needed to Scale Dementia Care Programs," presentation during Milken Institute Alliance to Improve Dementia Care Roundtable, June 7, 2021.

The [National Alzheimer's Project Act](#) (NAPA), enacted in 2011, established the [Federal Advisory Council on Alzheimer's Research, Care, and Services](#). This advisory council advises the secretary of the US Department of Health and Human Services (HHS) and Congress on priority actions to improve care for people with ADRD and their caregivers. In July 2021, the advisory council approved the recommendations put forth by the NAPA Subcommittees on Clinical Care, Research, and Long-Term Services and Supports (LTSS). The Alliance operates in collaboration with the advisory council, so the recommendations in this report aim to complement those proposed by the advisory council. To advance initiatives that deliver value-based programs, the NAPA advisory council adopted a recommendation to develop, evaluate, and use health-care models that align performance, the care experience of people living with ADRD and their caregivers, and payment ([2021 Clinical Care Recommendation #4](#)). Comprehensive dementia-care models strive to incorporate these three objectives and should be tested and implemented in diverse communities and health systems to advance this NAPA recommendation.

RECOMMENDATION #2

Implement quality measures to evaluate access, utilization, and outcomes of comprehensive dementia-care models, particularly for diverse communities disproportionately impacted by dementia and their caregivers

Measuring and tracking both health system and person-centered outcomes will create the evidence to scale high-performing innovations, replicate them across care settings, and ensure that providers consistently deliver high-quality care.[9] Shari Ling, MD, deputy chief medical officer at the Centers for Medicare & Medicaid Services (CMS), told roundtable participants that she believes "the true opportunity here is to focus on the delivery of value that prioritizes achievement and improvement of health outcomes that are meaningful for those we serve. Measuring quality and cost are two critical domains, regardless of who is delivering the care or how the care is delivered."

> **The true opportunity here is to focus on the delivery of value that prioritizes achievement and improvement of health outcomes that are meaningful for those we serve.**

Shari Ling, MD, Deputy Chief Medical Officer,
Centers for Medicare & Medicaid Services

Metrics applicable to health systems include emergency department visits, hospitalizations, long-term nursing home admissions, and 30-day hospital readmissions. Quality measures should also reflect the needs of people living with dementia and their caregivers. These needs include better care coordination and services that reflect individual preferences, such as telehealth access, appointments that accommodate caregivers, and inclusion in decision-making. Person-centered measures include behavioral symptoms, caregiver strain and depression, individually identified care goals, and days spent at home.

Tracking both health system and person-centered measures will ensure that care plans meet the needs of individuals while promoting continuous evaluation of needed resources. This person-centered approach should yield greater trust in the health-care and social-care systems and improve patient and family satisfaction. It may also help increase enrollment in future Medicare demonstration projects.

> **Recent investments have scaled palliative care models very rapidly and increased access to this care, but there are no required quality standards and therefore no consumer protections.**
>
> *Diane Meier, MD, Director Emerita and Strategic Medical Advisor, Center to Advance Palliative Care*

According to the Alzheimer's Association, dementia care and support services vary widely depending on race, ethnicity, geography, and socioeconomic factors.[10] Long-standing barriers include access to health care and LTSS, fewer health professionals who understand the unique needs of diverse communities, and historical mistrust in interventions, information, and policies.[11] Integrating equity measures into existing outcome metrics will ensure that comprehensive dementia-care models accommodate cultural norms and community preferences. In 2020, the NAPA Advisory Council adopted three cross-cutting recommendations to address issues facing people living with dementia and their caregivers during the COVID-19 pandemic.[12] Cross-Cutting Recommendation #3 aims to advance health equity by transforming how research, clinical care, and LTSS are provided and shifting to a model that more fairly distributes power over decision-making and policy development.[13] As discussed in the Alliance's *Better Brain Health through Equity* report, integrating health equity into dementia-care models can help address the underlying causes of disparities in dementia care.[14]

The [Age-Friendly Health System](#) initiative, created by [The John A. Hartford Foundation](#) and the [Institute for Healthcare Improvement](#), integrates equity into existing outcome measures (e.g., 30-day readmission rates, emergency department utilization). The Alliance recommends explicitly linking race and ethnicity data to quality and outcome measures in comprehensive dementia-care models. This will hold health systems accountable for reducing disparities and scaling these models across diverse communities.

As these models spread across communities, policymakers should provide oversight and regulations over health and social care systems to protect all patients. Some have warned that value-based payment (VBP) models, which seek to improve care while lowering costs, focus on measures that do not accommodate health systems that serve minority populations. For example, current benchmarks may result in financial penalties for practices that care for patients with high social risk factors and may promote quality measures that leave some populations behind.[15] To avoid perpetuating discriminatory practices, comprehensive dementia-care models should adopt equitable risk-adjustment metrics to incentivize efforts to reduce racial, ethnic, socioeconomic, and geographic disparities.[16] Diane Meier, MD, director emerita and strategic medical advisor at the Center to Advance Palliative Care, conveyed lessons from palliative care models to the roundtable. She noted that "recent investments have scaled palliative care models very rapidly and increased access to this care, but there are no required quality standards and therefore no consumer protections. This slows efforts to scale in health systems because accreditation requirements, oversight, and quality regulation incentivize attention to and investment in these care models."

Arthena Caston, an advocate living with early-onset Alzheimer's disease and an early-stage advisor for the Alzheimer's Association's Board of Directors, explained her first-hand frustrations with not being able to access care in her community. "I have to deal with physicians who are not connected through the same health systems, and when I travel from my home in Macon, Georgia, to Atlanta to see a doctor, it is very taxing."

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Arthena Caston, advocate living with early-onset Alzheimer's disease; Early-Stage Advisor, Alzheimer's Association Board of Directors

Roundtable participants provided several additional recommendations to ensure that comprehensive dementia care reflects diverse community needs and preferences:

1. Meet people where they are,

2. Promote trust and effective communication,

3. Improve cultural competence among existing providers, and

4. Leverage technology to improve access and accessibility.

The National Consortium on Aging Resources for Seniors' Equity Guide addresses meaningful inclusion in service planning and care delivery. It also provides a framework for dementia workforce training. The Health Resources & Services Administration (HRSA)'s online dementia curriculum offers skills training, dementia-care guidelines, factors to consider when treating dementia in diverse populations, and communication techniques.

Improving access to and utilization of health-care services, LTSS, and social services for all communities impacted by dementia is a key priority of the Alliance. These recommendations can help equitably scale comprehensive dementia-care models to close racial, ethnic, economic, and geographic disparities.

RECOMMENDATION #3

Expand dementia-specific training beyond physicians and nurses to increase interprofessional coordination, provide continuous monitoring and assessment, and expand access to high-quality dementia-care services

The number of people living with dementia in the US is projected to double by 2040. There is a growing shortage of health- and long-term care providers with training in geriatrics and dementia care. According to the Alzheimer's Association, half of primary care physicians (PCPs) admit that the medical profession is unprepared to meet the growing demand for dementia care.[17] And, according to the American Geriatrics Society, older adults will require nearly 30,000 geriatricians by 2030, more than three times the number currently practicing.[18]

Given the time and resource constraints on PCPs, increasing the number of dementia-capable professionals will help meet the growing demand for care. Allowing health professionals and paraprofessionals to practice at the top of their licenses can expand workforce capacity. Individuals with fewer needs will receive appropriate, less intensive care, while PCPs and dementia specialists will have the capacity to care for those with more complex needs. To advance the current and future workforce through education, the NAPA Advisory Council adopted a new recommendation in July 2021 to develop and disseminate new training models to increase workforce readiness nationally (2021 Clinical Care Recommendation #2). Comprehensive
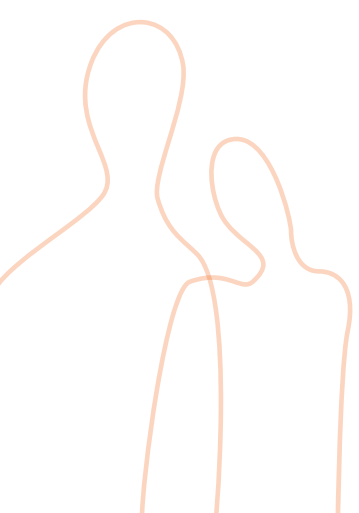
dementia-care models that support the training needs of all workers involved in dementia-care teams can better scale services across communities and care settings.

HRSA's online dementia training offers members of interdisciplinary care teams, including PCPs and direct-care workers, more than 25 training modules, many of which focus on outpatient dementia care.[19] Module nine focuses on interprofessional, person-centered care through collaboration among physicians, nurse practitioners, physician assistants, registered nurses, social workers, and occupational therapists.[20] The Gerontological Advanced Practice Nurses Association also offers online training for nurse practitioners that focuses specifically on dementia-care training.

Furthermore, HRSA's Geriatric Workforce Enhancement Program (GWEP) builds partnerships among academia, health systems, and CBOs to address health-care gaps and social determinants of health and to promote dementia-friendly communities for older adults.[21] The CARES Act (HR 748; passed in March 2020) reauthorized GWEP through 2025 and, in the fiscal year 2020, awarded $36 million to build geriatric knowledge across the care system.[22] Additional funding could fill workforce shortages by expanding training for licensed health- and long-term care providers and paraprofessionals practicing in diverse and rural communities.

GWEPs can also facilitate a "reverse pyramid" workforce model in comprehensive dementia care that elevates the role of care navigators, community health workers (CHWs), and social workers. This population-based approach will alleviate capacity constraints among PCPs and nurse practitioners by matching appropriately trained professionals and paraprofessionals to the medical and LTSS needs of individuals with dementia and their caregivers.

Roundtable participants suggested that certain care team members provide care navigation services to identify patient needs, provide disease education, facilitate treatment plans, and coordinate health-care services and LTSS.[23] However, comprehensive dementia-care models should first define the care navigator role and core competencies. Debra Cherry, PhD, executive vice president of Alzheimer's Los Angeles, noted during the roundtable that "care navigators are sometimes called dementia-care specialists, dementia-care managers, care consultants, and dementia-care coordinators. This complicates efforts to fill these positions because skills and licensure requirements are not clear." To improve dementia nomenclature, the NAPA Advisory Council adopted a new recommendation in July 2021 to standardize terminology across all organizations involved in its National Plan to Address Alzheimer's Disease (2021 Research Recommendation #3). A NAPA working group is developing strategies to standardize terminology across different audiences. These standardized terms will help uniformly scale comprehensive dementia-care models to areas where they currently do not exist.
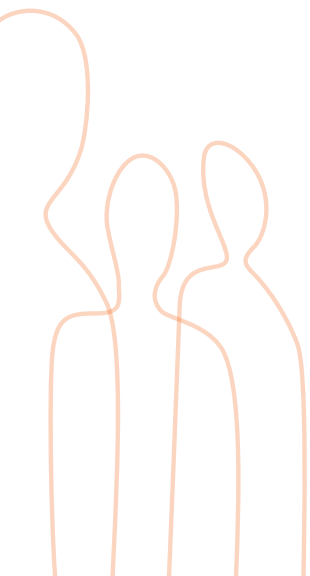
Case Study 1: Training a Collaborative Geriatrics Practice

The GWEP at Rush University Medical Center College of Nursing uses the Collaborative Action Team Training for Community Health–Older Adult Network (CATCH-ON) to unify academic, primary care, and CBO resources. The purpose of CATCH-ON is to prepare a geriatrics-collaborative workforce that optimizes person-centered health and wellness outcomes. This program trains clinicians, direct-care workers, caregivers, administrators, social workers, pharmacists, and occupational therapists.

This national program partners with 36 organizations serving rural and underserved populations. These organizations represent academia, primary care and delivery systems, and CBOs (e.g., Alzheimer's Association, Catholic Charities, Coordinated Care Alliance, Illinois Association of Area Agencies on Aging, and Shawnee Alliance).

This collaborative training program showed improvements in patient outcomes related to the 4Ms (What Matters Most, Mentation, Mobility, and Medication). These improvements include the following:

- Increases in caregiver education and support,
- Opioid screenings,
- Advanced care plans,
- Assessments for depression, dementia, and fall risk, and
- Decreases in high-risk medications.
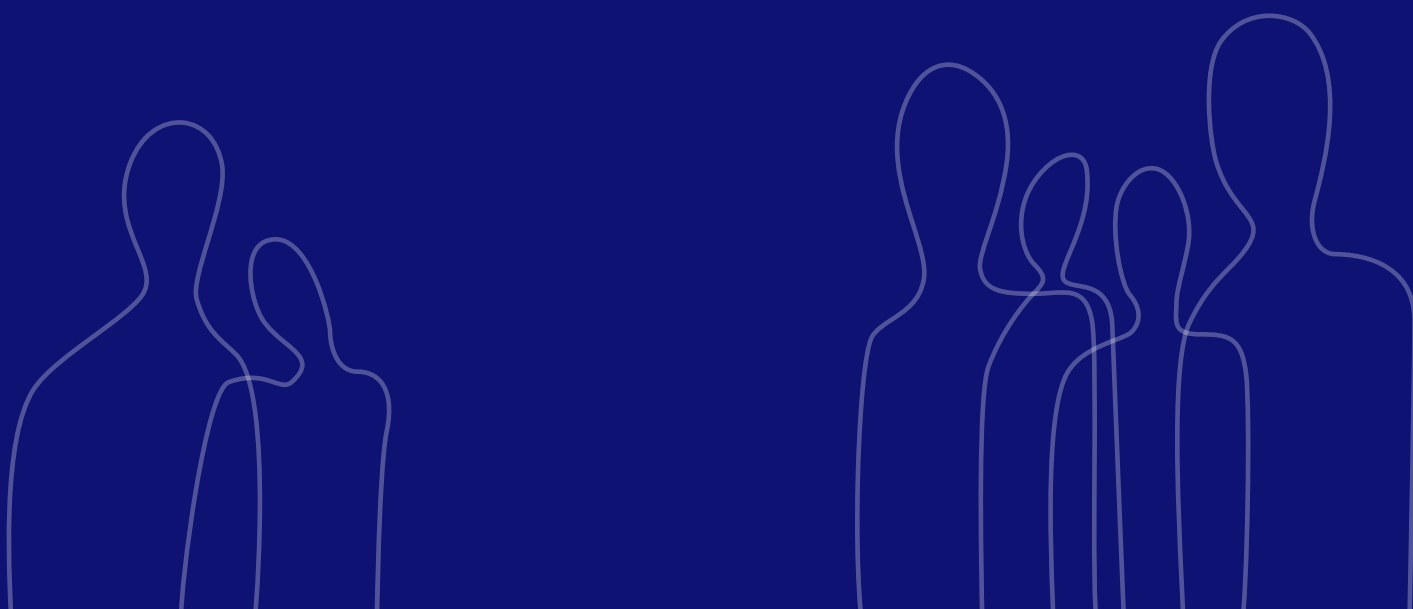
Supporting both paid and unpaid caregivers is essential to expand workforce capacity. Family caregivers should be considered members of the care team and receive training and support to provide essential LTSS. Raising awareness of training and support programs for family caregivers can help all communities provide resources and support. Best Practice Caregiving, a resource developed by the Benjamin Rose Institute on Aging and the Family Caregiver Alliance, profiles more than 40 proven dementia programs to assist caregivers, including skills training, sleep and stress management, and emotional support.[24] The UCLA Alzheimer's and Dementia Care (ADC) program also has 18 online caregiver training videos to manage behavioral scenarios.

Training direct-care workers on dementia-care best practices can also help clinicians focus on treating complex patients and, ultimately, scale comprehensive dementia care. Several public- and private-sector organizations provide dementia-specific training to direct-care workers. Home Instead, the world's largest provider of home-care services, contracts with professional caregivers through its CAREGiver program. This program trains and equips paid caregivers to provide high-quality, at-home services such as meal preparation, personal care, transportation, and Alzheimer's care through continuing education credit opportunities and monthly webinars.[25] Healthcare Interactive also develops training products for family members and professional caregivers. CareAcademy develops state-approved training programs for home health aides, non-medical caregivers, and personal care aides. These programs include training to assist with personal care and activities of daily living, food preparation, communication, and infection control. CareAcademy also offers accredited nursing continuing education.

THEME #2

Implementing effective payment policies to incentivize adoption and participation in comprehensive dementia-care models

Although evidence supports the value of comprehensive care models, no current payment structure pays for all the needed elements of dementia care. Traditional fee-for-service Medicare presents multiple obstacles to scaling comprehensive dementia care. CMS and private payers should test new payment models to advance comprehensive dementia care. Six existing models of comprehensive dementia care show substantial evidence of positive outcomes, four of which have been tested by the Center for Medicare & Medicaid Innovation (CMMI). Several advocacy groups, lawmakers, and prominent researchers have called for CMMI to test a broadscale alternative payment structure for dementia-care management.[26] Participants in the Alliance's roundtable unanimously agreed. To move this process forward quickly, the Alliance recommends the following:

RECOMMENDATION #4

Test implementation of payment models for comprehensive dementia care in traditional Medicare, especially in underserved communities

The bipartisan *Comprehensive Care for Alzheimer's Act* (S.1125 and HR 2517) calls on CMMI to test an alternative payment methodology for dementia-care management. An alternative payment model (APM) can improve the complex health- and long-term care systems that people living with dementia must navigate—a core mission of the Alliance.

The Alliance recommends adopting an alternative payment methodology to reimburse providers for comprehensive dementia care using a value-based payment (VBP) model. VBPs incentivize providers and health systems to be more accountable for health outcomes and utilization costs for an identified patient population across the continuum of care. The Alzheimer's Association released a whitepaper that describes a proposed alternative payment framework for traditional Medicare in more detail. The whitepaper includes quality measures, eligibility criteria, payment methodology, patient assessment, and other design parameters.[27] Specifically, it proposes moving away from the traditional fee-for-service payment structure and toward a capitated payment in which providers receive a monthly per-beneficiary fee for dementia-care services based on the individual's needs and case complexity.[28]

The complex nature of dementia care requires an interdisciplinary team that can provide medical and home- and community-based services (HCBS). Traditional Medicare fee-for-service reimbursement creates payment barriers to team-based, coordinated care. Moreover, payment for services that may go beyond medical care, such as caregiver support or care navigation, is ineligible for reimbursement from fee-for-service Medicare.

> **Dementia-care models should "have the potential for widespread adoption, so they are not just housed in large health systems or academic medical centers but develop in small community health organizations and rural practices."**
>
> *Matthew Baumgart, Vice President, Health Policy, Alzheimer's Association*

During the roundtable, Matthew Baumgart, vice president, health policy, Alzheimer's Association, commented that dementia-care models should "have the potential for widespread adoption, so they are not just housed in large health systems or academic medical centers but develop in small community health organizations and rural

practices." Baumgart emphasized that the upfront cost to providers is the critical barrier to implementing the core elements of comprehensive dementia care. APMs would pay providers differently and increase access to dementia care and caregiver support. These APMs reward value-based care, facilitate care coordination, and reduce the use of high-cost care settings.

Existing comprehensive care models should be expanded and tested across a larger population. During the 2019 Payment Model for Comprehensive Dementia Care Conference, experts identified specific strategies to test in traditional Medicare. These strategies include mapping core elements to existing billing codes, determining specific services at each tier of the population-health model, and identifying where to increase or cross-subsidize revenues.[29] Future demonstration projects must include racially and ethnically diverse communities, different socioeconomic groups, and rural communities.

The Innovation Center tests innovative Medicare and Medicaid payment and service delivery models to reduce program expenditures while preserving or enhancing the quality of care furnished to beneficiaries.

Sarah Fogler, PhD, Deputy Director, Patient Care Models Group, CMMI

Comprehensive dementia-care payment structures must overcome long-standing barriers. Sarah Fogler, deputy director of the Patient Care Models Group at CMMI, discussed key learnings from the 54 demonstration models launched by CMMI. "The Innovation Center tests innovative Medicare and Medicaid payment and service delivery models to reduce program expenditures while preserving or enhancing the quality of care furnished to beneficiaries. To date, only four model tests have met the statutory requirements for expansion on a national scale. A critical part of eventual scalability is a robust model evaluation that requires a sufficient sample size and a well-matched comparison group not exposed to the intervention in order to make statements about the model's impact." To address these concerns, the Alliance recommends adjusting eligibility requirements to increase enrollment numbers. Strategies to increase enrollment include the following:

1. Improving the patient experience by optimizing communication and building trust,

2. Increasing outreach to diverse communities,

3. Ensuring patients with varying levels of need receive appropriate care, and

4. Expanding the number of social workers and nurse practitioners trained to manage larger patient panels.

Case Study 2: UCLA's Alzheimer's and Dementia Care Program

UCLA's ADC program focuses on the medical, behavioral, and social needs of people living with dementia and their caregivers through in-person, telephonic, and online dementia-care management.[30] Since 2012, 3,276 UCLA dementia patients have participated. In addition, more than 1,000 people with dementia have received the ADC at 16 program sites funded by The John A. Hartford Foundation and the Patient-Centered Outcomes Research Institute- and National Institute on Aging-supported Dementia Care Study (D-CARE). Among current enrollees at D-CARE-funded sites, 13 percent are African American and 9 percent are Latino, and 16 percent live alone.

An interprofessional team delivers tailored care that considers the type of dementia, level of need, setting of care, language preferences, and clinical and behavioral symptoms.[31] This care team includes the following:

- Dementia Care Specialist—nurse practitioner or physician's assistant
- Dementia Care Assistant—bachelor's or master's level who assists with care coordination and follow-ups with non-urgent patients
- Clinic Office Staff—handles incoming calls and scheduling
- Physician Medical Director—provides medical direction and guidance for Dementia Care Specialist
- Program Manager—oversees and supports operations and helps collect outcome measures[32]

Care in the ADC program includes the following:

- Initial Assessment—The Dementia Care Specialist conducts a 90-minute, in-person assessment for patients and caregivers (with input from the PCP), which produces an individualized care plan and caregiver education, support, and referrals.
- Medical Treatment—The program manages the patient's dementia medical treatment plan to slow cognitive decline, manage symptoms, and reduce complications of dementia.
- Ongoing Monitoring and Care—The Dementia Care Specialist provides ongoing advice and services, including referrals to CBOs that receive payment vouchers for their services.

The program demonstrated positive outcomes for both patients and caregivers. After one year, dementia patients experienced fewer behavioral problems (e.g., agitation, irritability, apathy, and nighttime behaviors) and depressive symptoms.[33] Caregivers experienced reduced distress, less strain, and fewer depression symptoms. Dementia patients also experienced fewer emergency department visits, days spent in hospital, nursing home admissions to long-term care, and lower Medicare costs (among other measures):

- Hospitalizations: 12 percent reduction
- Emergency Department visits: 20 percent reduction*
- Intensive Care Unit stays: 21 percent reduction
- Hospital days: 26 percent reduction*
- Hospice in past six months: 60 percent increase*
- Total Medicare costs of care savings per participant: $2,404/year*
- Nursing home placement: 40 percent reduction*
- Caregiver confidence in handling complications: 72 percent increase

p<.05; based on National Opinion Research Center (NORC) external evaluation of CMMI Award using fee-for-service claims data[34] and UCLA accountable care organization data 9/2015-9/2017[35]

The program provides 80 hours of training for sites adopting the ADC, consisting of 22 online modules, one group training, intense remote training, and ongoing implementation support.

Case Study 3: UCSF's Care Ecosystem Model

The UCSF Care Ecosystem model uses care team navigators as the primary point of contact in a multidisciplinary care team.[36] Care team navigators are unlicensed paraprofessionals supervised by a clinician (e.g., a nurse or physician). They respond to caregiver needs, administer care protocols, and triage critical issues.[37] All care is delivered via phone and web. To date, 1,786 patients have received care across the seven health systems that have adopted the Care Ecosystem model. The model includes care team navigators; clinicians with dementia expertise in nursing, pharmacy, and social work; and dementia-care protocols and guidelines.

The program shows positive outcomes for patients and their caregivers and reduced cost of care. In one randomized controlled trial, the Care Ecosystem significantly improved quality of life, reduced caregiver burden and depression, and reduced emergency department visits. Ninety-seven percent of caregivers reported that they would recommend the program to another caregiver.[38] The estimated mean cost savings per individual with dementia to Medicare was $600 over 12 months.[39] Caregivers reported strong satisfaction with care team navigators' knowledge and responsiveness to patient and caregiver needs.[40]

The Care Ecosystem model, toolkit, and online training program enable health systems and clinics to provide dementia-capable care. Greater reliance on care team navigators alleviates PCP and nurse practitioner constraints while coordinating and prioritizing patient-centered care.
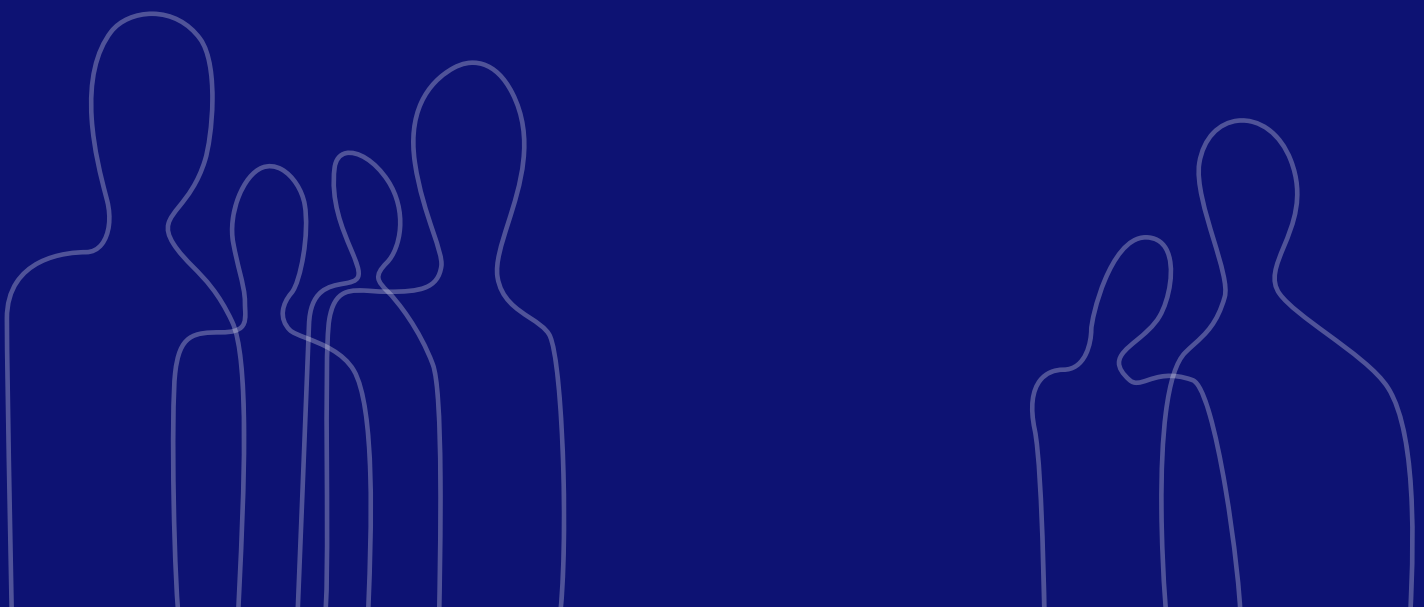
Under the Affordable Care Act, CMMI can only expand demonstration projects into permanent programs if they reduce spending or improve care quality without increasing spending. A recent analysis by the Medicare Payment Advisory Commission (MedPAC) found that in CMMI's first 10 years, almost all of its accountable care organizations and APMs generated small savings for the Medicare program. But after paying bonuses, savings were reduced, or expenditures rose. As a result, MedPAC recommended in June 2021 that "the Secretary should implement a more harmonized portfolio of fewer [APMs] designed to work together to support the strategic objectives of reducing spending and improving quality."[41]

In its whitepaper, the Alzheimer's Association proposes incorporating a dementia-care management model into CMMI's Primary Care First Model, with an emphasis on dementia care. Other roundtable participants recommended leveraging complex disease models such as the Comprehensive ESRD Care Model or Serious Illness Payment Model because the providers in these models may be better equipped to manage the complexities of dementia care. These models already follow patients, track outcomes, and provide evidence of successful and scalable models that save money and provide high-quality, comprehensive care.

RECOMMENDATION #5

Develop mechanisms to pay community-based organizations for services provided to individuals living with dementia and their caregivers

Comprehensive dementia-care models rely on CBOs to deliver services outside of clinical settings. CBOs provide direct services such as meal delivery, medication management, care and services coordination, and support with care transitions. They also offer assistance and support to family caregivers.[42] But these services are not reimbursed by traditional Medicare. The Alliance recommends that all comprehensive dementia-care models include payment to CBOs for providing these services.

Andrew Renda, MD, vice president, Bold Goal and Population Health Strategy, Office of Health Affairs and Advocacy at Humana, identified social determinants of health (SDOH) as an important component of any comprehensive care model. "Often, these are the rate-limiting factors in achieving positive health outcomes, especially in the dementia space. Whether it is access to food, transportation to appointments, or housing quality, patients need all of these services, and payment for these services is essential."

To expand the availability of LTSS, the NAPA Advisory Council adopted a new recommendation in July 2021 to expand access to HCBS through Medicare, addressing SDOH (2021 LTSS Recommendation #1.B). Roundtable participants agreed that all comprehensive dementia-care models should include HCBS to help individuals with dementia living at home, support caregivers, and address inequities affecting access to care.
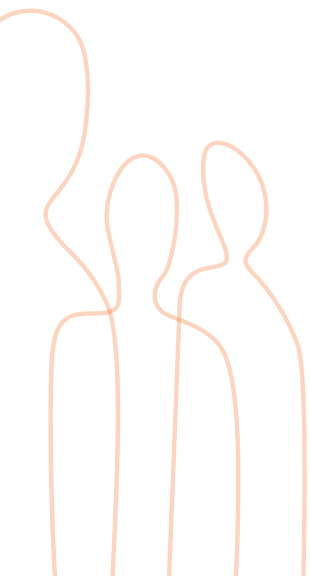
The Alliance recommends that comprehensive dementia-care models pay CBOs for their services. CBOs such as Area Agencies on Aging (AAAs) rely on funding sources such as the discretionary Older Americans Act. As Nora Super, executive director of the Alliance to Improve Dementia Care, pointed out in a blog post, "these funds have remained flat or declined, despite upward growth in the number of people—older adults and people with disabilities living in the community—who could benefit from community-based organizations' support."[43]

> ## Whether it is access to food, transportation to appointments, or housing quality, patients need all of these services, and payment for these services is essential.

Andrew Renda, MD, Vice President, Bold Goal and Population Health Strategy, Office of Health Affairs and Advocacy, Humana

Under the capitated payment structure put forward in Recommendation #4, health systems will likely act as the primary custodian of funds. They will bear the financial risk of paying for all dementia services. Health systems should identify CBOs that can deliver services outside clinical settings. It is difficult for health systems and plans to pay CBOs efficiently because many CBOs do not have the infrastructure to bill directly for their services. In response, networks of CBOs called community-based integrated care networks cover large geographic areas and offer a single point of contracting and accountability with health systems.[44]

The Aging and Disability Business Institute created a Network Readiness Assessment tool to help organizations build, sustain, and grow a network of service providers that contracts with health entities.[45] It provides the requirements for health systems and managed care organizations to contract with CBO networks for dementia-specific services and prioritizes networks in underrepresented communities.

Technology that collects data and automates referrals and claims processes can help integrate CBOs into the care continuum. Different models adopt different approaches to pay CBOs. Unite Us, for example, is a technology platform that connects health and social care, coordinates care networks, tracks outcomes, and automates referrals to community partners. These platforms also provide a back-office system to submit claims for services. Trellis, an AAA located in Minneapolis, built the technology and CBO networks to partner with health-care organizations for HCBS.[46]

Case Study 4: Capitalizing on a Statewide Network to Improve Health for Older Adults

Juniper, a program of Trellis, developed a statewide network of CBOs to offer health promotion classes across Minnesota. Juniper classes help people living with dementia and their caregivers get fit, manage their health, and prevent falls. Local organizations provide in-person or online classes.[47]

Since 2016, more than 24,000 people have participated in classes and more than 160 CBOs have delivered classes. The network has trained nearly 700 class leaders. Through grant funding and health-care partnerships, Juniper pays providers for each participant who completes a course.

Trellis develops payer relationships with health-care organizations to provide a sustainable source of payment for classes. The total cost to deliver these classes is, on average, $300 per participant. In 2019, Trellis signed contracts with Blue Cross Blue Shield of Minnesota (BCBS) and HealthPartners to provide classes to their dual-eligible members—that is, those covered under both Medicaid and Medicare. The BCBS agreement is unique in that BCBS shares member contact information with Trellis. Juniper sends information to each member through a co-branded mailing and contacts each person via phone to provide information about classes and answer questions. Juniper uses a hot-spotting approach to schedule classes where health plan members live or can easily access them.

Juniper also partners with the provider arm of HealthPartners. This partnership enables Juniper to enroll people in classes through direct clinician referrals. Through funding from the Minnesota Department of Health, Juniper employs a CHW at the HealthPartners Neuroscience Center, who is co-located with physicians, nurse practitioners, and others. The CHW is available to respond quickly to referrals and enroll patients in a broad range of HCBS. Soon, the CHW will lead Juniper non-narcotic pain classes within the community health clinic. Juniper saw promising results with 116 referrals during the first five months of the program.

A robust network of service providers ensures the availability of classes and other services. This is essential to the success of partnerships with health-care organizations. Trellis is adding HCBS such as meals, chore help, and caregiver support to its menu of services that health-care organizations can purchase, including for its members with dementia and their family caregivers. Trellis's investment in building the network is paying off as Juniper's program staff cultivates partnerships with additional health-care organizations.
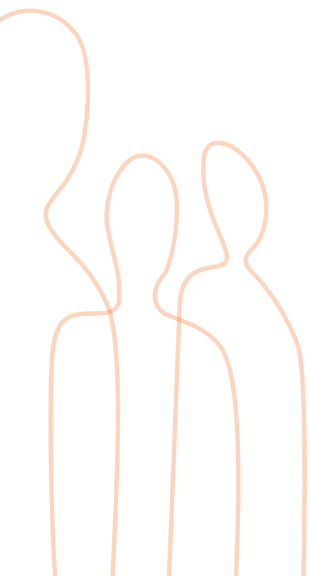
Comprehensive dementia care can ensure more coordinated and affordable care. But investment in the infrastructure to drive this change requires a promising business case. Roundtable participants recommended identifying the data needed to create the business case to showcase how CBOs can help avoid or reduce high-cost services, decrease provider workload, improve patient outcomes, and reduce caregiver stress. This dataset will provide health systems with guidance to pay CBOs appropriately. The Aging and Disability Business Institute created a resource guide, which highlights data needed to calculate the cost-benefit analysis.[48] Expanding data needs to include dementia-care services—which can be more complex than traditional HCBS—could help advance payment for needed services.

CONCLUSION

The complex and progressive nature of dementia is challenging our health- and long-term care systems to deliver high-quality and affordable care for people living with dementia and their families. Long-standing issues related to workforce, payment, equity, accessibility, fragmentation, and LTSS have slowed the dissemination of solutions to advance comprehensive dementia care. This report's recommendations address all of these issues. Adopting a population-health approach and including the minimum set of eight core elements in all models will ensure that people at different stages of their care journey receive appropriate care. It also offers a baseline for scaling these models nationally. New payment models will achieve multiple objectives: encourage providers to coordinate care; pay CBOs for the services they provide; align incentives among payers, providers, and patients; and ensure that individuals living with dementia and their caregivers receive more seamless, coordinated health- and long-term care.

The Alliance supports efforts to test and implement a scalable demonstration project under traditional Medicare using a population-health approach. This will require collaborating, developing the workforce, integrating health equity into quality measures, and advancing payment structures. With each expert roundtable and related report, the Alliance aims to offer new insights, thoughtful recommendations, and achievable solutions to address current gaps in our health- and long-term care systems as we build momentum to improve the lives of people living with dementia and their caregivers.

APPENDIX A

Definitions of Comprehensive Dementia-Care Elements

Source: Kristen Lees Haggerty et al., "Recommendations to Improve Payment Policies for ComprehensiveDementia Care," Journal of the American Geriatrics Society *68, no. 11 (November2020): 2478-2485, https://doi.org/10.1111/jgs.16807.*

Caregiver support—Identify one or more caregivers to include in evaluation, decision-making, and care planning; provide culturally sensitive support and assistance designed to help the caregiver(s)

Continuous monitoring and assessment—Continuously monitor and assess cognitive, functional, behavioral, and psychological needs and safety and the level of caregiver stress

Coordination of care—Coordinate transitional and other health-care services across hospitals, nursing homes, ambulatory care, and community-based settings

Medication management—Use evidence-based medication management, including deprescribing medications with adverse cognitive effects; includes efforts to increase medication adherence and education about opportunities for participation in research

Ongoing care plan—Develop and implement a care plan that is regularly evaluated and modified as needed, including advance care planning, wishes about the place of residence, and attention to end-of-life care

Psychosocial interventions—Implement interventions to prevent or reduce the burden of cognitive, functional, behavioral, and psychological challenges and caregiver stress, including care practices from innovative technology solutions

Self-management—Provide self-management tools to enhance the skills of the person living with dementia and caregiver in managing Alzheimer's disease and related dementias, navigating the health-care system, and engaging in activities related to person-centered goals

Treatment of related conditions—Take steps to prevent and treat conditions related to Alzheimer's disease and related dementias, such as depression, falls, and delirium

APPENDIX B

Description of Six Comprehensive Dementia-Care Models

The Benjamin Rose Institute Care Consultation model is a telephone-based program utilizing bachelor's or master's degree-level social workers or nurses for individuals living with dementia and their caregivers. This model has demonstrated beneficial changes in psychosocial outcomes for both patients and caregivers (e.g., reduced symptoms of depression, embarrassment about memory problems, care and caregiving strains, and social isolation).

The Care Ecosystem utilizes a team of non-licensed care team navigators as well as advanced practice nurses, social workers, and pharmacists to implement care plan protocols via telephone and internet. In a clinical trial, the Care Ecosystem model improved the quality of life of individuals living with dementia as well as reduced emergency department utilization and caregiver depression and burden.

The Eskenazi Healthy Aging Brain Center initially employed a nurse practitioner dementia-care manager for delivery of nonpharmacological and pharmacological care to patients in collaboration with their primary care provider. This program demonstrated effectiveness on quality measures and patient outcomes (e.g., reduced behavioral symptoms and caregiver stress by half at 12 months). Most care within the program is provided by non-licensed staff.

The Integrated Memory Care Clinic is a patient-centered medical home providing comprehensive primary and dementia care led by advance practice nurses for individuals with dementia and mild cognitive impairment. It demonstrated success in delivering high-quality care and is associated with reduced emergency department utilization and rates of ambulatory-sensitive hospitalizations.

The Maximizing Independence at Home program is a comprehensive home-based care coordination intervention provided by non-licensed personnel, registered nurses, and physicians. The program demonstrated success in delaying transitions from home to residential care and reducing caregiver burden.

The University of California, Los Angeles (UCLA) Alzheimer's and Dementia Care (ADC) program uses a co-management model with nurse practitioner dementia-care specialists and primary care and specialty physicians. In a large case series and cost comparisons with a matched control group, the program demonstrated reduced total Medicare costs, decreased nursing home placement compared with matched patients, and improved end-of-life care and patient and caregiver outcomes.

APPENDIX C

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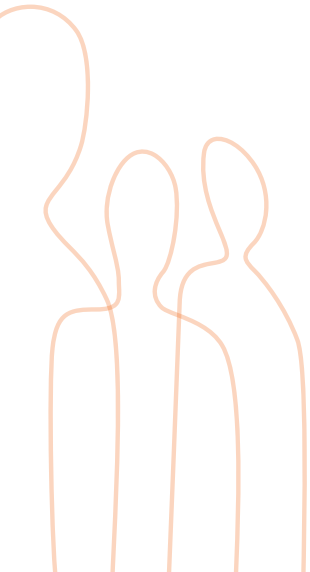
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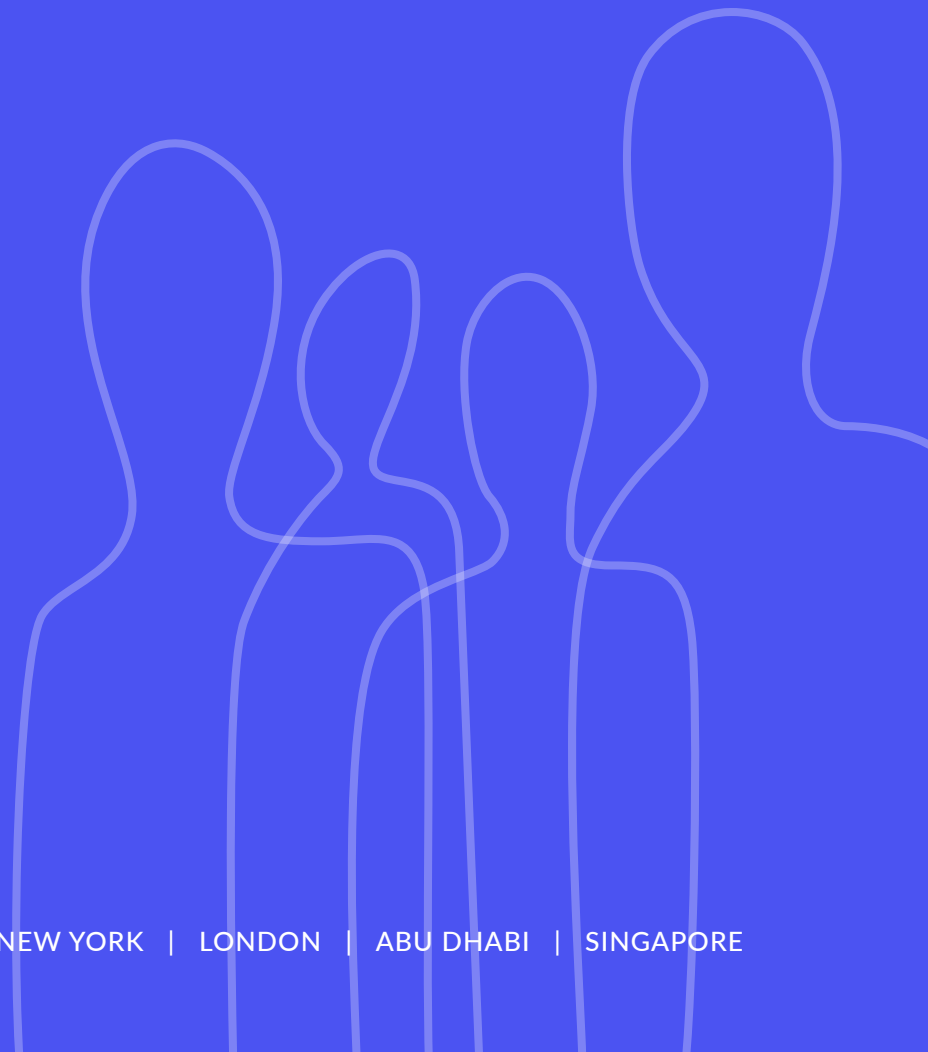
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