



## BRIDGING HEALTHCARE AND SOCIAL SERVICES FOR PEOPLE LIVING WITH DEMENTIA AND THEIR CAREGIVERS

### KEY POINTS

- As the number of people living with dementia (PLWD) grows, it is increasingly important to meet their complex and varied needs, as well as the needs of their caregivers, in a coordinated way. Bridging the social service supports provided through community-based organizations (CBOs) with the medical care that healthcare systems provide is an effective way to meet those needs.
- Programs that successfully bridge services from these two systems often provide the following core components as a part of their dementia care:
  - Early identification of possible dementia symptoms and referral for further evaluation.
  - Individualized care plans, ongoing check-ins, and regular reassessment of needs to ensure the changing needs of PLWD and caregivers are met throughout the disease process.
  - Tailored referrals to relevant resources, and assistance with accessing them.
  - Caregiver training, education, support, and respite throughout the progression of dementia.<sup>a</sup>
  - Medication management to ensure PLWD are taking recommended medications appropriately and caregivers are supported in this task.
- Barriers for implementing and/or expanding these programs include:
  - Lack of trained staff to provide dementia services.
  - Differing funding sources and payment structures between CBOs and healthcare systems.
  - Limited buy-in by CBOs and healthcare providers.
  - Challenges with communication, data sharing, and evaluation.
- Recommendations for CBOs and healthcare systems interested in providing these services include:
  - Improving the dementia-specific knowledge of professionals.
  - Utilizing multidisciplinary teams that include participation from CBOs and healthcare systems to aid in the distribution of care tasks across systems.
  - Developing and implementing care navigation capabilities or programs to serve as a central point of contact for the PLWD, the caregiver, and members of the care team.
  - Increasing the business acumen of both systems to facilitate reimbursement, including for nontraditional billers.

<sup>a</sup> This includes behavioral symptom management training to address changes that may arise for PLWD because of dementia.

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- Building structures that allow for the two systems to share data and communicate effectively.
  - Measuring the effectiveness of dementia care programs consistently.
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## BACKGROUND

People living with dementia (PLWD) often have complex health and social support needs, especially as their condition and comorbidities progress.<sup>1</sup> To meet these needs, PLWD and their caregivers may require the services of community-based organizations (CBOs) and healthcare providers. Although medical providers help PLWD manage comorbidities, such as diabetes or hypertension, they rarely have the time or training to address the long-term services and supports (LTSS) needed to help PLWD remain in the community.<sup>2</sup> The “aging network”—agencies and organizations at the federal, state, and local level that plan and provide services to older adults and their caregivers—can help meet LTSS needs.<sup>3</sup> Community-based providers, such as those in the aging network, can deliver resources like caregiver support, education about dementia, respite, and nonpharmacological approaches to behavioral symptom management, to PLWD and caregivers.

Implementing comprehensive care plans that address both health and social needs requires CBOs and healthcare systems to work together. Although PLWD and their caregivers often need both social services and healthcare, these systems typically operate independently and without established means of communication or coordination, leading to fragmented care.<sup>2,4</sup> Coordinating across all service providers involved in PLWD’s care through teamwork, information sharing, and goalsetting can lead to better outcomes for PLWD and caregivers.<sup>5,6</sup> Coordinated care may also lead to cost savings.<sup>7</sup>

Improving outcomes for PLWD and their caregivers through coordinated systems of care is a federal policy interest. This is illustrated by the National Plan to Address Alzheimer’s Disease’s goal of enhancing care quality and efficiency,<sup>8</sup> and through the implementation of the Centers for Medicare & Medicaid Services’ (CMS) Guiding an Improved Dementia Experience (GUIDE) Model.<sup>9</sup> The CBOs in the aging network are well situated to partner with healthcare providers and support the implementation of care coordination for PLWD and caregivers across the two systems.

## METHODS

This study aims to better understand promising practices for bridging CBOs and healthcare systems in the provision of comprehensive dementia care. The goal is to investigate how the two systems can work together to improve dementia care to answer the following research questions:

1. What are the components of community-based dementia care management, training, and education for PLWD and their caregivers that effectively partner with healthcare providers? How are effective programs structured?
2. What are best practices for aligning community-based service and healthcare systems to deliver comprehensive dementia care?
  - a. What are best practices for aligning these systems to facilitate coordination of care that maximizes the utility of both systems?
  - b. What are the barriers to alignment? Are there workforce enhancement solutions to addressing disconnects?
3. What are barriers to expanding the availability of these services and maximizing the benefit of dementia-specific service alignment?
  - a. What are the options for making these models and collaborations scalable and sustainable?
4. How are the alignments of the health and social service systems being articulated to facilitate the alignment of the care in a coordinated manner?

To address these questions, an environmental scan of peer-reviewed and grey literature was completed, and interviews were conducted with stakeholders in CBOs, healthcare systems, government agencies, and the policy field. Each of these methods is described in further detail in the **Additional Methodological Information** section. Interview respondents had different experiences with bridging the two systems. CBO stakeholders tended to have a background in the provision of social services in the medical field (e.g., medical social work), and healthcare systems stakeholders had a strong interest in social determinants of health and geriatrics. Interviews provided context for research findings, facilitated understanding of how perspectives may differ between the two systems, and highlighted specific challenges and successful practices. Comments and insights from interview respondents are integrated throughout the issue brief.

## FINDINGS

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***Dementia care programs that are successfully coordinating care across CBOs and healthcare systems commonly provide services related to identification of symptoms, care planning, referrals, ongoing reassessment of needs, caregiver support, and medication management.***

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### Core Components

#### ***Early Identification of Symptoms***

Early identification of dementia symptoms and timely diagnosis can improve care.<sup>10</sup> Early identification allows for treatment of reversible causes of cognitive decline, enables PLWD and caregivers to plan for the future and access support, helps maximize the independence of PLWD, and provides a better opportunity for pharmacological and nonpharmacological intervention.<sup>10</sup> CBOs and healthcare systems play a critical role in identifying dementia signs and symptoms and helping people get a timely diagnosis. Primary care physicians (PCPs) are often the first providers to receive concerns regarding PLWD's cognitive health.<sup>11,12</sup> Similarly, CBOs in the aging network often identify cognitive changes in their clients and make referrals for further evaluation. Just as PCPs can incorporate cognitive screenings into annual wellness visits for Medicare beneficiaries, CBOs can include brief screenings or questions about memory concerns as part of their service intake. CBOs may also train their staff and volunteers who have frequent contact with older adults, such as drivers who provide home-delivered meals, in the signs of cognitive decline and how to refer individuals who are showing symptoms of dementia for further services. Providers in both systems must know how to identify cognitive changes and have procedures in place to move people towards a diagnosis and help them access dementia-specific supports after a diagnosis.

#### Example from the Field

The Indian Health Service, part of the U.S. Department of Health and Human Services, is providing grant funds to tribal and urban Indian healthcare systems to develop and deliver comprehensive dementia care models for American Indian and Alaska Native PLWD and their caregivers. Two main goals of these models are to increase the awareness and recognition of dementia and to improve access to accurate and timely diagnosis.<sup>13</sup> Cherokee Nation Health Services in the Oklahoma City, OK region used a portion of their grant funds to hire a patient services navigator who is building partnerships with community service providers and raising awareness about dementia to promote early diagnosis through coordinated outreach.<sup>14</sup>

#### ***Person-Centered Care Plans***

Addressing the medical and social needs of PLWD in a coordinated manner can improve health outcomes, reduce care disparities, and delay institutionalization.<sup>15,16</sup> One way to address these needs is through the creation of a person-centered care plan that includes social prescribing, which is a strategy that aims to connect people to community resources.<sup>17</sup> Person-centered care, a model of care that is responsive to an

individual's goals and preferences,<sup>18</sup> has been shown to reduce agitation, improve neuropsychiatric symptoms, and positively impact quality of life for PLWD.<sup>19</sup> It is particularly useful when started in the early stages of dementia.<sup>19</sup> Incorporating caregiver strengths and needs into the care planning process can also be beneficial to both PLWD and caregivers. Caregivers play a crucial role in implementing care plans for PLWD, and improving caregiver self-efficacy can reduce burden, stress, and the likelihood of institutionalization.<sup>19-21</sup> Implementing a person-centered care plan requires CBOs and healthcare systems to work together. Each system should focus on the parts of the plan in which they have expertise. For example, a CBO may provide support groups or respite while a healthcare system may focus more on managing physical symptoms or comorbidities. Having representation from both systems helps ensure that PLWD and caregivers have their needs met.

#### Example from the Field

Nevada Senior Services' (NSS) Hospital 2 Home Care Transitions program in Las Vegas, NV works with PLWD who are transitioning out of a hospital setting. The program receives referrals from a hospital system and county social services, has dedicated space within the hospital for staff members, and has access to electronic health records (EHRs). Licensed social workers and case managers from NSS meet with the hospital discharge planners, PLWD, and, when applicable, the caregiver in the hospital to identify emergent needs, create a person-centered care plan, and ease the transition back home. Care plans are highly individualized and intended to reduce caregiver burden and ensure services are in place before the PLWD leaves the hospital. After immediate needs are met and the PLWD is safely home, NSS provides short-term respite and coaching to the caregiver and assists with LTSS.

#### Assistance With Accessing Relevant Referrals

Referrals to services within a person's community are an important part of effective care.<sup>22-28</sup> Rather than providing a list of generic resources, referrals should be selected based on the needs of the PLWD and/or caregiver.<sup>29</sup> There should also be a system in place that allows for "warm handoffs" between CBOs and healthcare systems, rather than placing the responsibility solely on the PLWD or caregiver to access services.<sup>11</sup>

A warm handoff is when one service provider makes a referral to another service provider, either over the

*"One of the things that I think is really necessary to bridge that gap [between CBOs and healthcare systems] is some kind of a closed loop referral system...There aren't too many community-based organizations I'm aware of that have gotten to that point, but I think that's what's really necessary to have fully integrated systems."  
—Community-based service provider*

phone or in person, with the PLWD or caregiver present. Warm handoffs help to ensure that PLWD and caregivers are aware of the referral and knowledgeable about next steps and give them an opportunity to ask questions or correct information.<sup>30</sup> Interview respondents from CBOs and healthcare systems agreed that closed loop referrals are best practice, but also noted that they are difficult to implement without shared communication or data platforms. Closed loop referrals are a form of bi-directional communication where both CBOs and health care providers are engaged in the referral process, track outcomes that align with their role in a PLWD's care, and report on progress to ensure each provider has a full understanding of the client. These kinds of referrals are beneficial

because they provide referrers with an awareness of whether a PLWD or caregiver is accessing needed services, which can help them understand barriers and trigger further support.<sup>31</sup>

#### Ongoing Check-Ins and Reassessment of Needs

It is important to regularly check in with PLWD and their caregivers and assess if there have been changes to care plan priorities or if new unmet needs have emerged.<sup>22,32-36</sup> Most programs have a minimum frequency of check-ins, but tailor how often they actively engage with PLWD and caregivers to meet the needs and preferences of the people with whom they are working.<sup>27,37</sup> For example, PLWD and caregivers may require

more frequent touchpoints and reassessments immediately following a diagnosis as they begin to understand its impact and plan for the future. Similarly, PLWD and caregiver needs may change more rapidly in the later stages of dementia, which would require more frequent contact and reassessment. Successful programs require someone on the care team to check in proactively and in a way that is responsive to the needs of the PLWD and caregiver, rather than expect the PLWD or caregiver to initiate contacts or follow an inflexible protocol.<sup>22,26,27,37,38</sup>

#### Example from the Field

Care Ecosystem is a 12-month evidence-based intervention that utilizes a care team navigator (CTN) to provide ongoing support to PLWD and caregivers.<sup>36</sup> The CTN checks in with the PLWD and/or caregiver via telephone at least monthly, but this may happen more frequently based on the client's needs and preferences.<sup>36</sup> During check-ins, the CTN, PLWD, and caregiver discuss progress on person-centered plans, address concerns and questions, and move through evidence-based protocols. PLWD and caregiver needs are formally reassessed at least every six months to result in a new care plan.<sup>39</sup>

In St. Louis, MO, Esse Health, the healthcare system partner, refers PLWD and caregivers who could benefit from participation in Care Ecosystem to Memory Care Home Solutions (MCHS), a local CBO. MCHS houses the CTN and a clinical team of social workers and occupational therapists to provide the program. They also provide ongoing reassessments of needs and support to the PLWD and caregiver. MCHS and Esse Health meet monthly to discuss referrals and next steps for clients.

#### Caregiver Support

Caregiver training, education, respite, and support are important components of high-quality dementia care.<sup>22,25-27,32,35,36,40</sup> Because healthcare systems are often not well suited to provide these services, collaboration with CBOs is important. Supporting caregivers throughout dementia progression and providing them with the skills needed to manage care responsibilities can improve their self-efficacy.<sup>41</sup> This may lead to delayed placement in a nursing home for the PLWD and improved quality of life for the PLWD and caregiver.<sup>41,42</sup> Respite can give caregivers a break from their role, help them reconnect with their interests, and build resiliency. This may improve health outcomes for both the caregiver and PLWD.<sup>43,44</sup>

#### Example from the Field

The Aging Brain Care (ABC) Program is typically housed within a healthcare system but was recently implemented by Area Agencies on Aging (AAAs) in Indiana.<sup>45</sup> In this community-based model of the program—named ABC Community—the care coordinators (called Dementia Care Coordinator Assistants or DCCAs) are employed by the AAAs. Experienced clinicians from the healthcare system provide the DCCAs with dementia care training, case conferencing, and support. DCCAs help identify caregiver stressors and provide targeted coaching and resources to address those stressors. Caregivers enrolled in ABC Community use the Caregiver Stress Prevention Bundle (CSPB) intervention, which consists of caregiver counseling, education, and referrals; development of a crisis plan; participation in weekly respite; and monthly support groups. Use of the CSPB has been shown to reduce caregiver stress.<sup>45</sup>

#### Medication Management

PLWD are at increased risk for polypharmacy (the use of multiple drugs to treat coexisting conditions), as they are often being treated for comorbidities as well as dementia.<sup>46,47</sup> Managing medication is a critical component of dementia care, but can be challenging for PLWD, and often falls to informal caregivers.<sup>25,35,36,48,49</sup> Medication management involves developing a complete and accurate medication list, having a medical provider review

the list for potential issues such as duplications or drug interactions, and developing strategies for adherence.<sup>50</sup>  
<sup>25,35,36,48</sup> This helps ensure PLWD are on the right medications to manage health conditions and are taking those medications as intended.<sup>51</sup> It can also give physicians a clearer overall picture to help limit adverse medication effects, as they do not always have immediate access to what others have prescribed, especially across different care settings or healthcare systems.<sup>49,50</sup> CBOs may not be able to provide comprehensive medication management for PLWD, but they can make direct connections to healthcare systems when PLWD and caregivers have questions about medications and can empower them to go to healthcare appointments prepared with medication information. Interview respondents from multiple stakeholder groups discussed medication management. As one healthcare system respondent said, “[CBOs can] assume greater clinical responsibility. If somebody is having questions about their medications when you are doing an in-home visit or you are assessing them...help them make those connections [to a healthcare provider].” One government agency respondent noted that their state has seen a growing interest from community pharmacists who are operating out of retail chains, grocery stores, and outpatient settings within the healthcare system in partnering to provide dementia care services. CBOs have also successfully partnered with schools of pharmacy for medication management.

### Example from the Field

Several evidence-based dementia care programs that align CBOs and healthcare systems include medication management as a component of their intervention.<sup>52</sup> Examples include Care Ecosystem, the ABC program, and the Alzheimer’s and Dementia Care (ADC) program. CBOs do not need a pharmacist on staff to assist with medication management. They can partner with local pharmacists or geriatric nurse practitioners affiliated with a healthcare system and use available tools, such as HomeMeds, to address this core component.<sup>53</sup>

## Multidisciplinary Teams

***Multidisciplinary care teams are necessary to effectively and efficiently serve PLWD and their caregivers but require coordination between CBO and healthcare systems.***

Many dementia care programs recognize the benefit of engaging a team of professionals to best serve PLWD and their caregivers.<sup>54,55</sup> Multidisciplinary dementia care teams may be comprised of physicians, nurses, social workers, occupational and physical therapists, pharmacists, CBOs, and more.<sup>56</sup> Caregivers and PLWD are also important members of the care team. Interview respondents from CBOs, healthcare systems, and government agencies agreed on the importance of multidisciplinary teams working in a coordinated way to ensure “the team is looking out for the big picture” of better care for PLWD. One way to do this is to bring CBOs and healthcare systems together before creating dementia care programs to explore opportunities to partner effectively and expand services. A policy analyst said the programs that “really get on the ground and co-design these concepts with community-based organizations are going to be the most impactful.” Bringing CBOs and healthcare systems together early in the process helps build buy-in and an understanding of roles.

*“I think [care coordination] needs to be built in, frankly, from both sets of services. I think if it's only built in from the community-based services, then there's often no one to reach in the clinical services. And the same can be true if it's only built in on the clinical side...I think of care coordination as a capability of an organization rather than as a particular service...And, so they're not overlapping [services], they're complementary capabilities.”*

*—Government agency respondent*

Recommendations in the literature and from interview respondents call for designating a staff member to serve as a central point of contact for the PLWD, the caregiver, and members of the care team.<sup>11,24,26,29,34,36-40,45,52,54,57-60</sup> This role is frequently referred to as the “Care Navigator.” Though the terminology and precise job description vary across dementia care programs, the core responsibilities are aligned. This person should be

someone who can effectively work with both systems and nurture a long-term relationship with PLWD and caregivers.<sup>40,61</sup> One healthcare system respondent concurred, saying these staff members need to know “how to not just interface with the social services system, but also the healthcare system, emergency departments, primary care doctors, psychiatrists, et cetera...” Interview respondents across all organization types noted that social workers tend to be assigned this role because they often have a “foot in the hospital and a foot in the community,” are adept at navigating both systems, and can help PLWD and caregivers access services throughout the course of dementia. Care Navigators should have strong interpersonal and communication skills, as well as knowledge of both clinical and community-based dementia services.<sup>27,38</sup> They are also typically required to go through training related to dementia.<sup>62</sup> The ABC program, for example, employs lay “Care Coordinator Assistants” who are selected primarily for their “aptitude for working with vulnerable older adults” and are provided training to build their dementia knowledge.<sup>26</sup> One government agency respondent noted that care navigation should be viewed as an organizational capability built into each system rather than a service provided by one or the other. This is an important consideration and allows for both sides to better communicate and coordinate care.

*“...the demands on primary care are so large and the specific demands of care for PLWD and their caregivers are so significant that...even an advanced, highly capable primary care delivery system is only going to partially meet those needs...”*

*—Government agency respondent*

PCPs play a vital role in caring for the overall health of PLWD, which positions them well to screen for dementia, identify unmet social needs, and connect PLWD and caregivers to community services.<sup>5,12,23,25,27,34,48,63</sup> One healthcare system respondent said that for dementia programs to have “an impact on the overall health and hospitalizations, readmissions, et cetera [of PLWD], they’ve got to be partnered with the primary care physician.” Despite this, multiple interview respondents from CBOs and government agencies commented on how busy PCPs are and how difficult it is to ask them to take on more. This further highlights the importance of building a

team that can share the work of caring for PLWD and supporting caregivers long-term.

## Barriers and Promising Practices Related to Aligning Systems and Scaling Models

***Barriers to aligning CBOs and healthcare systems and scaling successful models include limited availability of a trained dementia care workforce, differences in funding sources and payment structures between the two systems, challenges with communication and data sharing, expectations and skills related to data collection and evaluation, and organizational buy-in.***

### ***Limited Availability of Dementia Care Workforce***

Both CBOs and healthcare systems struggle with insufficient staffing, which limits their ability to provide or expand these services. There is a significant shortage of clinical dementia specialists who can conduct a formal screening, provide a comprehensive evaluation, and diagnose dementia,<sup>64</sup> and PCPs often feel they do not have the time or ability to provide comprehensive cognitive assessments.<sup>65</sup> Non-clinical workforce availability, including staff in the aging network, is also limited.<sup>66</sup> Rural areas are especially prone to workforce shortages for both clinical and non-clinical dementia care professionals.<sup>66,67</sup> Without sufficient staff, CBOs and healthcare providers are unable to devote the necessary time to PLWD or caregivers they support.<sup>58</sup>

*“Everyone is very stretched for time. That’s certainly true on the healthcare side. I’m sure it’s true on the social services side as well.”*

*—Healthcare system respondent*

Inadequate compensation can lead to turnover and reduce the workforce, especially in CBOs.<sup>61,66</sup> Direct care workers who provide essential services to PLWD often have low pay, limited benefits, and low rates of retention.<sup>66,67</sup> This limits the ability of the aging network to provide critical dementia services like adult day programming.<sup>66</sup> High turnover within CBOs can also impact their ability to build partnerships with healthcare

systems. One healthcare system respondent said, “if you're trying to get relationships with a health system, a hospital, or a health plan...that kind of [staff] consistency is really important.”

Lack of dementia-specific training for CBO and healthcare systems staff impacts the ability of the systems to provide effective and ongoing care for PLWD and caregivers.<sup>66</sup> As previously noted, the number of people who have the clinical training and expertise to diagnose and provide effective medical care for PLWD is insufficient and the demand for these services is growing.<sup>64,66,67</sup> Opportunities for training through both clinical placements and educational courses that specialize in dementia care are lacking for medical students.<sup>66</sup> Outside of the healthcare system, training requirements for professionals who work with PLWD and caregivers are either lacking completely or inconsistent across fields.<sup>66</sup> One study showed that only a minority of states require dementia training for long-term care community administrators, direct care workers, and social workers, despite the fact that these professions often work with PLWD and caregivers.<sup>66</sup> The unavailability of specialized training diminishes the dementia care workforce.

### Promising Practices and Recommendations

The literature and interview respondents recommended training and workforce development as ways to mitigate the negative impacts of an insufficient workforce on PLWD and caregivers.<sup>33,38,52,62,63,67-71</sup> Dementia care programs commonly require dementia-related training for staff in the Care Navigator role,<sup>22,23,25-27,36,37,40,59,62,72</sup> but improving the dementia knowledge of any staff person that comes into contact with PLWD could improve outcomes. CBOs may choose to combine an initial training program for Care Navigators and other staff with ongoing supplemental training, case or care plan reviews, and professional development.<sup>22,23,36,40</sup> Some CBOs partner with organizations, such as the Alzheimer’s Association, to provide non-clinical training to team members.<sup>69</sup>

To improve the availability of dementia-capable providers in the healthcare system, clinical training on dementia should be built into professional development and education for the medical, allied health sciences, and social work fields.<sup>66</sup> This training should be provided by faculty who specialize in dementia care or organizations that have buy-in with healthcare providers, such as professional associations. One government

*“[Dementia care] is an area with specialized knowledge...We need to democratize that knowledge and get it into the delivery system, both in primary care and in the community-based organizations. We need to think about core skills or competencies and make that available.”*

*–Government agency respondent*

agency respondent discussed how they embedded healthcare system and PCP training into their state plan, saying, “We've started collaborating with our federally qualified health centers. We provide a continuing medical education training for them that outlines the various early detection strategies and clinical priorities to emphasize care within a community-based setting.”

Training for professionals in both CBOs and healthcare systems should include strategies for addressing behaviors related to dementia, communication techniques, and unique issues related dementia such as heightened risk of hospitalization, stigma, and caregiver burden.<sup>68</sup>

Beyond establishing a foundational level of dementia knowledge,

trainings can familiarize staff at CBOs and healthcare systems with one another’s work and multidisciplinary processes, which can enhance their partnership.<sup>32,70</sup> Federal initiatives like the Health Resources and Services Administration’s Geriatric Workforce Enhancement Program represent national efforts to address this growing need for well-trained and knowledgeable professionals to provide dementia care.<sup>66,67</sup>



## Example from the Field

In Georgia, the Georgia Memory Net (GMN) program depends on PCPs to identify memory concerns and refer PLWD to local Memory Assessment Clinics for further evaluation and care planning.<sup>23</sup> They partnered with the Georgia Academy of Family Physicians (GAFF) to identify PCP training needs related to dementia, and delivered training in collaboration with GAFF, the Georgia Chapter of the American College of Physicians, and the Gerontological Advanced Practice Nurses Association. After the dementia training, PCPs receive ongoing support through peer-to-peer education and expert consultation. This helps to ensure PCPs are comfortable identifying symptoms and referring PLWD for follow-up.

### ***Differing Funding Sources and Payment Structures***

Multiple published sources noted that some of the largest barriers to scaling dementia care models are related to existing payment structures.<sup>38,40,58,60,73-75</sup> Stakeholder interviews reinforced this finding, revealing that funding constraints presented barriers to both aligning and expanding dementia care services. Separate funding sources for medical and social needs and the limited funding of services related to social needs are both payment-related barriers.

### ***Separate Funding Sources Discourage Collaboration***

The current payment system for dementia care comprises multiple funding streams from federal, state, local, and private sources. Most people aged 65 and older have healthcare coverage through Medicare or Medicare Advantage. The social supports and services important to PLWD and caregivers, however, are often not covered by traditional payment structures, including Medicare.<sup>76</sup> Some PLWD and caregivers qualify for Medicaid, which provides limited support for home and community-based services and LTSS.<sup>77</sup> These state and federal funders reimburse qualified providers for medical services and, to a much lesser extent, social care services. CBOs are not typically eligible to bill Medicare. Medicare primarily provides services to the beneficiary, in this case the PLWD. Services to the caregiver, such as training and education, are limited.<sup>11</sup>

Funding from the Older Americans Act (OAA) supports CBOs in the delivery of services that help older adults age in place, such as congregate meals, in-home services, and respite care.<sup>78</sup> These services, directed to both PLWD and caregivers, are funded through discretionary federal grants to states that may be supplemented by state and local funds. However, these funds are often insufficient to meet the needs of CBOs that deliver social services to PLWD and caregivers. Moreover, some services funded through the OAA may have age restrictions.<sup>78</sup>

According to interview respondents, this separation of funding for medical and social needs results in the siloing of services. As one government agency respondent observed, the services provided by CBOs and healthcare systems are “confined to what their funding tells them they need to do, or to their reimbursement for services...There's just no driver towards that kind of coordination of care.” This siloing comes at a cost for PLWD and caregivers who may end up with fragmented care.

*“For CBOs that may be AAAs where all of our revenues are cost reimbursement, this whole issue of addressing risk and funding a new program that is not eligible for Older Americans Act funding, that can be a deal breaker. That's where a lot of us who have interest never make it out of the gate.”*

*—Community-based service provider*

### ***Limited Funding for CBOs***

Limited funding, especially for CBOs, restricts the number of people who can be served and the types of services offered, and can lead to long waitlists for services and unmet needs.<sup>79,80</sup> A USAging survey of AAAs conducted in 2022 revealed that “scores of older adults across the country are at risk of being placed on waiting lists” for services, with nearly all AAAs (94%) reporting that older adults are not receiving services as often as needed.<sup>81</sup> Meals on Wheels America and the National Association of Nutrition and Aging Services Programs report that one-third of senior nutrition programs have a waiting list and 97% of local senior nutrition programs require more funding to match inflation.<sup>80</sup> One CBO respondent noted that OAA funds have

not matched the pace of growth in the eligible population in their large metro area; as a result, their area has a waitlist for services of 8,000 people. Another said, “The fact is, if [PLWD and caregivers] can't pay privately and they're not Medicaid eligible, we have too much demand for the funds we've got.”

### Updates to Medicare Do Not Address CBO Challenges

CMS has made recent changes to Medicare billing that some advocates believe may improve payment for dementia services through the healthcare system.<sup>82</sup> Updates to the Medicare Physician Payment Rule are intended to expand caregiver training and support.<sup>83</sup> The addition of new Principal Illness Navigation (PIN) codes further expands coverage of services to identify and meet social needs.<sup>8</sup> However, the changes do not fully address restrictions that have historically limited the availability of comprehensive dementia care, such as limits on who is eligible to bill for services.<sup>82</sup> Often, CBOs within the aging network do not qualify to use these codes. Interview respondents confirmed that providers continue to grapple with these limits on funding for social services.

### Promising Practices and Recommendations

To break down silos, funding sources must be structured to incentivize healthcare systems “to move beyond just the clinical care to whole person care...to invest resources and know that there’s a revenue behind that investment,” as noted by one government agency respondent. Healthcare systems need to better understand

*“[Healthcare systems should] take a little bit of risk to partner with community-based services. Rather than building out [their own social services], leverage healthcare dollars to pay for some of those services and support this workforce.”*

–Policy analyst

that investment in meeting the social-related needs of PLWD and caregivers leads to long-term cost savings. However, multiple respondents also noted that healthcare systems should recognize the expertise of CBOs and partner with them to provide social services, rather than trying to build their own program to address those needs. Payment models can be structured to encourage or require such partnerships. For example, according to one healthcare system respondent, their state has written a requirement into their Medicaid waiver contracts with health plans that PLWD receive referrals to the local AAA.

### **Example from the Field**

The University of California, Los Angeles’ (UCLA) ADC program may be used as a model for how CBOs and healthcare systems can partner in a mutually beneficial way. Community-based partners are reimbursed by UCLA on a fee-for-service basis through vouchers provided to PLWD and caregivers for specific services.<sup>84</sup>

Community Care Hubs can lower the risk for both CBOs and healthcare providers to build these partnerships and encourage each system to start working together. According to the Administration for Community Living (ACL), which helps run the Community Care Hub National Learning Community, a Community Care Hub “centralizes administrative functions and operational infrastructure including, but not limited to, contracting with health care organizations, payment operations, management of referrals, service delivery fidelity and compliance, technology, information security, data collection, and reporting.”<sup>85</sup> These hubs bring together community-based providers so that healthcare systems can work with a centralized organization to meet a wide variety of client needs.<sup>86</sup> One CBO noted that the Partners in Care Foundation has used its Community Care Hub to effectively bridge CBOs and healthcare systems across California.

Interview respondents agreed with the literature that funding sources such as Medicare and Medicaid should cover a wider menu of social services for PLWD and caregivers to complement, but not replace, OAA funding. One CBO advocated for Medicare to recognize social workers as key members of the workforce engaged in delivering social services and discharge planning across both systems. Another CBO respondent suggested that as payment structures are updated to permit a greater range of reimbursable expenses, these changes must

be more effectively communicated to CBOs and healthcare systems to ensure uptake. According to the respondent, CBOs and healthcare systems “need to learn how to bill for the things they can bill for” or risk missing opportunities to be reimbursed for services. “There are whole portions of the Medicare opportunity spectrum that nobody uses,” the respondent added. The respondent further recommended that CBOs become credentialed Medicare providers to allow them to bill for their services.

To ensure the uptake of successful dementia care that bridges CBOs and healthcare systems, researchers and advocates recommend revising the payment structure to cover the multidisciplinary services that characterize these models.<sup>60</sup> Some published sources suggest adopting flexible payment designs or alternative payment models (APM) capable of covering recommended services for dementia care both within and outside of the healthcare system. These include proposals to implement tiered payment approaches based on PLWD risk or need<sup>73</sup> and current efforts to incentivize healthcare providers, through physician fee schedule codes, to screen and refer for social needs.<sup>8,82</sup> Such an APM should specifically cover elements of dementia care that have been shown to improve health outcomes for PLWD such as continuous monitoring and assessment; ongoing care plans; psychosocial interventions; self-management; medication management; treatment of related conditions; coordination of care; and caregiver support.<sup>73</sup> These APMs should also set minimum quality standards, include reimbursement for training for all participating organizations, and reimburse for training and supports for caregivers.<sup>73,75</sup> CMS’ GUIDE Model demonstration aligns with these recommendations and offers an opportunity to test the payment model on a larger scale.<sup>9</sup>

### ***Lack of Organizational Buy-In***

Another barrier mentioned in the literature and by interview respondents is a reluctance to buy-in to a new method of care delivery that bridges the two systems. Each system may face high initial costs and time investment when adopting these kinds of care models due to required staff training and changes to organizational infrastructure, which could dissuade leadership from moving forward without evidence of return on investment.<sup>87</sup> Each system is also busy with their own work and may be reluctant to take on more. This can lead to uncertainty or hesitancy across the two systems about who should take the lead. One government agency respondent said, “I’m not sure there’s a [consensus] about who should actually create the alignment...Should it be the Area Agency on Aging? Should it be the independent healthcare systems who may not see dementia care as a priority of their system as much as they see other chronic condition care? That’s the challenge.”

### ***Promising Practices and Recommendations***

*“You can have the CEO on board. You can have the chief nursing officer on board. But if the floor nurses, the charge nurses, the discharge planners aren’t on board, you cannot have a successful [partnership]. It will not work.”*  
—Community-based service provider

One consistent recommendation from CBOs and healthcare systems to overcome this barrier is to appoint or identify champions within both systems who spearhead integration work and help bridge gaps. As a CBO respondent said, “you need a champion inside the hospital. You need somebody who really wants to take it on, really wants to do it, sees the value in it, and is in a position to champion the relationships and the things you’re doing together to the rest of the hospital and the health system.” These champions can help identify common goals, delegate responsibilities, and facilitate a shared

language between systems. These were emphasized as key aspects of securing buy-in by multiple respondents across healthcare systems, government agencies, and CBOs. However, to truly bridge these two systems, there must be buy-in at the executive level and from those doing the day-to-day work.

Interview respondents from both CBOs and healthcare systems agree that sharing common goals is a key aspect of bridging care. Even though the two systems ostensibly share the same goal of improving care, it can still feel like there is a mismatch or a lack of understanding related to each system’s culture. These misunderstandings can lead to breakdowns in communication. One CBO said, “It’s like we can’t quite

understand each other's systems well enough to think creatively..." Power dynamics between the two systems may also make it difficult to partner. One healthcare system respondent expressed that "social services people tend to be a little sort of shy or reticent about [interacting with healthcare systems], or may be worried about the power differential of, 'I'm a social services person and I'm trying to talk to a physician about my clients.'"

Using a common language or speaking in terms that are meaningful to both systems also emerged as a theme for these respondents. One healthcare system said, "If you go in and just talk social stuff in paragraphs with a doctor or a health system person, it's not going to go well. [CBOs have] got to be able to be succinct, get to the point, and say how it impacts their patient." Another healthcare system respondent agreed that CBOs need to be able to provide brief, timely, and direct communication. A CBO respondent said that hiring people with healthcare experience has helped them use the right language, build credibility with the healthcare systems, and foster these relationships.

A healthcare system respondent said that CBOs should come to conversations without bias, noting, "A lot of the community-based organizations, they come with a tainted view of the medical system that they're all just doing scopes and procedures to make money...But at least go [into conversations] assuming that they're looking to do the same thing you are." Building an understanding of common goals, shared responsibility, and collective vision is key to bridging these two systems and ensuring that each side buys in. One government agency respondent noted that their agency used a collaborative framework called the collective impact framework which facilitates the creation of shared goals and shared communication methods to ensure the two sides complement each other to create those mutual priorities.<sup>88</sup>

*"Community-based organizations need to understand the mindset, culture, and the language of the hospital. And the hospital people have to understand the language and culture of the not-for-profit, that CBO they're working with."*

*–Community-based service provider*

### Example from the Field

The Geriatric Resources for Assessment and Care of Elders (GRACE) model out of Indiana University brings together a multidisciplinary team of medical providers in concert with CBOs to improve patient care within the healthcare system and people's homes and communities.<sup>89</sup> While not dementia-specific, the model is applicable to dementia care. Indiana University developed an implementation approach for other organizations looking to replicate the GRACE model called the "ABCs of GRACE." This seven-step approach outlines best practices for implementation.<sup>90</sup>

- "A" stands for "Agree" and emphasizes the importance of key stakeholders coming together to agree that the goal or project is beneficial to both systems and to the people they are serving.
- "B" stands for "Building," which underscores the importance of identifying a strong champion and creating a collaborative approach to planning and development.

Indiana University makes the case that these steps, which include building buy-in from all stakeholders, are key to the successful implementation of care programs that bridge systems.

Having a shared understanding of each organization's role in care is imperative. As a government agency respondent remarked, "internally there is a huge misunderstanding of what [CBOs] do. There is this idea for some that the social workers and the care coordination folks are trying to sell something..." CBOs should clearly articulate the return a hospital or healthcare system can anticipate when investing resources in partnerships with CBOs. For example, CBOs might make the point that without sufficient attention to their social needs, PLWD are more likely to be re-hospitalized, which adds to healthcare system costs and workload for healthcare workers. Multiple CBO respondents noted that CBOs often do not have the level of business acumen required to make those assertions and would benefit from enhanced training, such as the modules

and resources offered through the USAgging Business Institute.<sup>91</sup> CBOs also need to know that they will get the referrals and reimbursement needed to justify a partnership and the costs they may incur when getting ready for implementation.<sup>92</sup> Both systems need to find the partnership mutually beneficial and need to follow-through on what is expected of them.

*“Framing the value proposition is so important. I think that really is an effective way to command [healthcare system] attention.”*  
–Community-based service provider

### **Communication and Data Sharing Challenges**

The literature suggests that regular communication across all members of the care team is critical for bridging CBOs and healthcare systems to deliver dementia care.<sup>5,37,38,40,45,48,55,58,70,93,94</sup> Frequent communication ensures all team members are aware of changes to a PLWD’s health status that may affect their care needs.<sup>95</sup> However, in practice, several barriers can impede communication between the two systems. Policy expert and CBO interview respondents described the difficulty of simply connecting with the right medical providers to coordinate care. Their challenges included identifying a healthcare system champion, maintaining partnerships when key personnel depart, and trying unsuccessfully to reach healthcare system personnel.

Technology-based solutions offer an option to facilitate regular communication between team members. Technology platforms and interoperable data systems have the added advantage of streamlining data sharing and making patient and referral information readily available to all team members. Sharing digital records is an effective way to facilitate this communication. However, although healthcare systems have widely adopted the use of EHRs, CBOs often have less of a digital infrastructure and may not have the capacity for data sharing or encounter barriers when trying to access these systems.<sup>11,26,27,57,60</sup> Multiple CBO respondents shared their experience being denied access to hospital EHR systems. Others tried various alternate arrangements, including paying to be credentialed to gain access to the EHR; accepting a system of one-way data sharing from the CBO to medical system; or relying on a separate shared registry that entailed duplicating data entry. Not all stakeholders interviewed expressed a strong need for interoperable data systems. While all CBO respondents cited the lack of shared data systems as a barrier to partnering with healthcare systems, healthcare system and government agency respondents were notably less likely to list this as a barrier.

### **Promising Practices and Recommendations**

*“I think what has been very impressive in the relationship is the communication. It's not without its snags, but we have regular meetings with [the partner CBO]. If there are issues, they're very willing to work with us. And we're willing to work with them to try and overcome those barriers...So the communication between the two entities is wonderful.”*  
–Healthcare system respondent

Regular meetings during which members of a care team discuss PLWD and caregiver needs, and review goals and care plans is one common approach suggested in the literature to ensure alignment of multidisciplinary team members.<sup>5,24,29,37,38,40,61,70</sup> Two healthcare systems respondents reported hosting regular multidisciplinary meetings with CBO partners. One healthcare system respondent detailed a “very specific process” used by their organization to keep all partners informed. In this case, they communicated via phone, text, or through EHR. They also recommended frequent in-person meetings to build relationships between staff. Engaging partners from both systems in opportunities for regular meetings results in the development of a more efficient network with greater knowledge of

available resources.<sup>38</sup> These meetings may also provide additional opportunities for professional development and cross-training.<sup>45,48,69</sup> Co-location, or arranging for team members to work out of one shared location, was also recommended, though less frequently, for its potential to increase communication and collaboration. Co-location of team members has been shown to enhance collaboration in non-dementia-specific models of integrated care.<sup>57</sup> Other dementia-specific programs note the advantages of co-locating team members and services not only for communication but also for the direct benefit of PLWD and caregivers.<sup>12,94</sup>

Sources in the literature and interviews stressed that having clear role definitions and protocols for communication, data sharing, and work processes reduced confusion and duplication of services between team members.<sup>5,38,58</sup> The literature suggested that clearly defining the partnership and associated roles could increase partner buy-in and consistent implementation of dementia care coordination interventions.<sup>38</sup> One healthcare system respondent devoted time early

*“I think it’s crucial that you have a system of checks and balances, maintaining those open pathways of care coordination between both systems.”*

*–Healthcare system respondent*

in their partnership with CBOs to establish processes for collaborating and communicating about PLWD needs. Another example, from the Partnership to Align Social Care’s toolkit on leading practices for integrated care, recommends that teams clearly define staff roles, data sharing and documentation processes, and accountability measures as part of the initial development of the scope of work.<sup>96</sup> Attending to these elements early in the partnership helps to establish shared expectations across team members.

#### Example from the Field

To strengthen collaboration and referrals to community partners, the ADC program at UCLA established memoranda of understanding with its five primary community partners for “specific services that would benefit PLWD and caregivers.”<sup>27</sup>

As noted earlier, interview respondents recommended establishing a shared data system that facilitates automatic, closed loop referrals and information exchange between CBOs and healthcare systems. Given the amount of patient-related communication and decision-making conducted via systems like the EHR and the time-consuming nature of data entry, the desire to use one common system is understandable. Regarding privacy restrictions, one CBO respondent noted that Health Insurance Portability and Accountability Act (HIPAA) requirements are “just a slice of the Kennedy Kassenbaum Act, which was designed to facilitate universal communication on healthcare information exchange. It’s all about healthcare exchange. And instead, it’s kind of backed its way into a privacy rule that has become the focus; so, we’ve set up barriers.” This respondent and others offered suggestions for addressing privacy concerns while allowing for the use of a common data system. “I’m hopeful that maybe in the future there’ll be some technology solutions that don’t require us to actually be inside each other’s systems to be able to share data, but we’re not there yet,” said one CBO respondent. Another suggested that “what we need is for the health information exchanges to have funding to write software that puts [both systems’] portals together.”

#### Example from the Field

For the GMN program, the development of a “robust technology platform” was essential to the success of the statewide initiative.<sup>23</sup> The platform hosted clinical and referral data, with the option for various partners to access specialized views relevant to their own roles. GMN also used their platform to track PLWD outcomes for program evaluation. One feature of GMN that respondents found concerning, however, was the system structure to only permit PCPs to make referrals to the affiliated dementia care services, potentially limiting access for PLWD who may not be connected to a PCP.

### ***Differences in Data Collection, Priorities, and Evaluation***

Multiple sources emphasized the importance of quality improvement efforts and program evaluation.<sup>5,12,23,24,38,52,66,69,70</sup> The regular collection, analysis, and sharing of quality data improves the delivery of services, PLWD outcomes, and dementia care system design.<sup>38,52,66</sup> These data have the potential to add to the field’s understanding of which dementia care programs should be scaled and how.<sup>52</sup> Without collecting and tracking data, providers risk missing opportunities to not only identify the most effective care models, but also

to identify PLWD and provide them with high-quality care.<sup>60</sup> Monitoring and evaluation generate information that can be shared across partners for both process improvement and adjusting patient care plans. Programs make use of quality measures to monitor performance, evaluate client status and needs, or both.<sup>5,23,38,70</sup> However, one CBO respondent noted that because they are not required to collect data for many of their services, they “don’t have a good handle on [their] outcomes,” which is something that healthcare systems want to see when they are considering a partnership. Moreover, although the collection of quality metrics is ubiquitous within hospitals and other health settings, community-based settings may need additional support to collect quality or outcome data.<sup>55</sup> One government agency respondent noted that the federal government had a role to play in “finding measures that matter” for a variety of audiences and helping organizations understand the best ways to capture those outcomes.

### Promising Practices and Recommendations

Respondents offered examples of outcomes that they are currently collecting. One CBO respondent with a successful partnership with a hospital system shared that they collect data on rehospitalizations, which helped highlight the benefit of the partnership. A healthcare system respondent agreed that they are interested in impacts related to hospitalizations and readmissions. However, these data points may not be as meaningful or relevant to CBO providers, or PLWD and their caregivers. As participants of a recent panel for the Agency for Healthcare Research and Quality noted, traditional quality and outcome measures used by healthcare systems often do not reflect the priorities of aging adults.<sup>60</sup> Improving data collection across systems and building a mutual understanding of what is most important to collect could lead to more effective collaboration that meets PLWD needs.<sup>60,97</sup>

Multiple respondents reinforced the need for partners to work together to determine the meaningful

*“What’s going to be critical to sway the decision makers to continue the program, to see value in it, whether it’s decreasing readmissions or decreasing caregiver stress? [Both systems should] decide what are those critical success factors so that you’ve got everybody on board with a common goal and what you need to track.”*

*—Healthcare system respondent*

measures for these programs. Failing to focus on outcomes that are relevant to all stakeholders can be a barrier to effective system alignment.<sup>60,97</sup> Respondents recommended engaging partners from both systems early in the planning process to establish the partnership’s critical indicators of success. One healthcare system respondent suggested that doing this helps the partnership work because “from the start, everybody kind of agrees they’re working together on it, to build the program, to get it started, to track what’s meaningful, and then do continuous improvement.” A CBO respondent suggested that an area in which the field is lacking is in making data related to dementia care program outcomes broadly

available, not just between local partners, but across organizations nationally. Having access to this broader data set would offer “the ability to look at how people fare under certain sets of circumstances,” which in turn could provide guidance for selecting approaches to care.

### Example from the Field

The ABC Community in Indiana program maintains a monthly dashboard to track key program metrics—such as new enrollments, completed and missed appointments, crisis planning, and caregiver time off—to spot areas of potential improvement.<sup>24</sup>

## DISCUSSION

There are clear benefits to PLWD and their caregivers when they receive dementia care that bridges CBOs and healthcare systems. These kinds of models lead to higher quality person-centered care, which helps people live in their homes and communities longer. They also improve coordination between CBOs and healthcare systems and shift the burden of accessing support away from PLWD and caregivers and onto the systems. Respondents noted that CBOs and healthcare systems involved in successfully bridging the gap between the two systems often experience greater efficiency and are better able to focus on their core services and what they do best. As one healthcare system respondent said, “There are only so many hours in the day. Why not rely on a partner that has it and does it right? That’s the benefit for us.”

*“If we succeed [in bridging CBOs and healthcare systems], the benefit is we’ve inverted the burden. So, the burden is on the systems to figure it out and not on the individual who’s already in crisis...”*

*—Government agency respondent*

There are challenges to these collaborations, however. Respondents said that the most important way healthcare systems can better partner with CBOs is to increase their awareness of the services and resources CBOs offer and appreciate the value that they add to care for PLWD and caregivers. A government agency respondent said that there is often a misunderstanding about what CBOs do. Two interviewees noted that it is important for healthcare systems to lean on CBOs to provide social services rather than trying to do it on their own, because CBOs are the ones with the expertise in this work and their communities.

*“First, they have to be patient. Hospitals are really hard. They’re really hard. It takes years to evolve these relationships and people in hospitals change.”*

*—Community-based service provider*

When asked how CBOs can work better with healthcare systems, interview respondents emphasized how important it was for CBOs to continue their outreach and relationship-building with healthcare systems. One government agency respondent said, “I do think there need to be established relationships with the clinical entities in their catchment area. It can’t be random phone calls and trying to reach into a busy doctor’s office or dementia care program.” CBOs that have

successfully built these relationships reiterated that it takes patience and consistency.

Several respondents thought one way to build these relationships is to bring people together in coalitions that maximize resources to benefit PLWD and caregivers. This helps everyone see that they are on the same team and are working toward the same goals. The push for dementia-friendly communities and healthcare systems may be one opportunity to bring these two systems together with a common purpose. A government agency respondent noted that efforts to create dementia-friendly healthcare systems in her state are “allowing those health systems to align their work for people living with dementia and caregivers specific to community resources...It’s a great way to connect services that may otherwise not have been known [to each other].”

Interview respondents commented on opportunities for the federal government to support this work. Most respondents said it is important to create grants, projects, or funding opportunities that explicitly require the two sides to work together. Although previous funding opportunities may have encouraged partnerships, respondents felt they were not intentional enough about requiring the partnerships, which can lead each system to stay in their respective “silo.” As one government agency respondent said, “if the government could assist in breaking those silos of funding...I think that would go a very long way. Often, we have to make the case as to why these funding streams should collaborate and align. But if they were established to align from the front end, I think it would make it a lot easier for us to work together across the various programs.”

Respondents from a variety of perspectives reiterated that the federal government should make more funding available to support comprehensive dementia care programs. They noted that the current Medicare reimbursement system does not support the sort of team-based care delivery that is required to create and deliver models that bridge both systems. Two respondents noted that the federal government should continue advocating for health plans, including Medicare Advantage plans, to partner with CBOs.



Several respondents noted that the federal government should focus on funding the implementation of real-world dementia programs. These programs should also help organizations build their capacity and ability to sustain the work after funding ends. The Alzheimer’s and Dementia Programs Initiative (ADPI) through ACL may provide a model for this work. These ADPI cooperative agreements allow states and communities to test evidence-based and evidence-informed dementia programs in their communities to see what works and how. They also provide opportunities for grantees to build their capacity and plan for sustainability of successful programs.

*“Require hospitals and healthcare systems to partner with CBOs and spell out exactly what that means, otherwise hospitals will continue to make assumptions that CBOs are going to be there to pick up the pieces.”*

*–Policy analyst*

## CONCLUSION

With a growing population of PLWD and an insufficient dementia-trained workforce, the need for multidisciplinary approaches to deliver dementia care is becoming more acute. Several dementia care programs that align social services and healthcare have demonstrated promising outcomes, such as improved

*“We need more investment and understanding of what high-quality care looks like in dementia care, not ideal care. We’ve got a lot of work on ideal care in dementia care, but we need an understanding of quality of care that is scalable and translatable. It’s not as aspirational but is real.”*

*–Government agency respondent*

quality of life for PLWD and decreased caregiver strain. When well-executed, these programs can address the complex needs of PLWD and their caregivers while distributing care tasks across a coordinated team with relevant expertise and resources. Several barriers must be overcome to facilitate widespread uptake of coordinated dementia care. Insufficient training and education that leads to workforce shortages, outmoded payment models, lack of organizational buy-in, limits on communication and data sharing between systems, and differences in data collection and evaluation all impede progress toward transforming dementia care to

cohesively address medical and social needs. Future efforts to improve dementia care must address these barriers while centering the goals and needs of PLWD and their caregivers.

More research should be done to ensure PLWD and caregivers are being served effectively and efficiently. Half of interview respondents thought that future research should focus on translating science to practice and implementing what is thought of as best practice in the real world, including in CBOs and healthcare systems. As one government agency respondent said, “A lot of that research work really should be in the implementation. And honestly, it has to work within existing communities with existing resources...I think that kind of work is the way we’re going to get to better systems.” Others noted that it is important to build the business case for models that align CBOs and healthcare systems. Future research could be conducted to see if spending money upfront to build out these models leads to better financial outcomes for systems and better health and wellbeing for PLWD and caregivers.

## ADDITIONAL METHODOLOGICAL INFORMATION

### Methods for Conducting Environmental Scan

An experienced librarian conducted searches of PubMed, Web of Science, and CINAHL using the search terms in Exhibit A-1 for peer-reviewed literature published after 2014. RTI, the Office of the Assistant Secretary for Planning and Evaluation (ASPE), and ACL collaborated to develop the list of search terms. Key search terms included words related to dementia, community-based care, medical care, and alignment. One hundred twenty-two (122) abstracts were provided and reviewed for relevance and 51 were selected for full-text review. Information extracted from each article was organized into an Excel-based data tracker.

RTI identified grey literature sources from publicly available media and industry reports, as well as existing programs and examples from National Alzheimer’s and Dementia Resource Center grantees. The same search terms were used to identify relevant literature (Exhibit A-1). RTI focused on literature from the last five years with the aim of including the most current approaches. We identified 38 grey literature sources and reviewed them systematically for relevance. These were categorized based on recommendations relevant to bridging community-based and healthcare system-based services. Data were organized in an Excel tracker.

### Exhibit A-1. Environmental Scan Search Terms

Literature Search Terms
“dementia*” OR “ADRD” OR “Alzheimer’s” OR “cognitive decline” OR “cognitive impairment” OR “cognitive disability” OR “Alzheimer” OR “neurocognitive disorders” OR “neurological” OR “organic brain dysfunction”
AND
“HCBS” OR “community*” OR “social service”
AND
“medical” OR “healthcare”
AND
“coordinate*” OR “align*” OR “integrate*”

### Methods for Conducting Stakeholder Interviews

We conducted 12 structured interviews with stakeholders in July 2024. The stakeholders included:

- Individuals who lead CBOs that partner with healthcare systems to provide care to PLWD and caregivers;
- Individuals who work within healthcare systems that collaborate with CBOs;
- Individuals who work within government agencies that support dementia care; and
- Individuals whose work focuses on research, policy, and practice initiatives to improve care for PLWD and caregivers.

We sent an initial list of potential interviewees and their areas of expertise to ASPE and ACL for approval. Once approved, individuals were sent an email invitation to participate in a virtual interview; all but one individual accepted the invitation, and an alternate interviewee was invited to participate. Interviews were conducted via Zoom, recorded, and transcribed. A thematic analysis of interview topics was completed using an inductive approach.

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