Community Clinical Linkages for the Screening, Diagnosis, and Care for Alzheimer's Disease and Related Dementias in Vermont

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VERMONT

DEPARTMENT OF HEALTH

Executive Summary
Community-Clinical Linkages Supporting ADRD Care in Vermont

Vermont faces unique challenges in supporting individuals with Alzheimer's Disease and Related Dementias (ADRD) due to its rural geography and aging population. With approximately 65% of adults aged 65+ living in rural areas, ensuring effective connections between healthcare providers and community resources is essential. This study examined how Community-Clinical Linkages (CCLs) - defined by the CDC as "connections between community and clinical sectors to improve population health" - can be strengthened to better serve Vermonters affected by ADRD. Through a comprehensive literature review and interviews with four key Vermont healthcare leaders, this study identified current practices, challenges, and opportunities for improving CCLs. Key findings include:

Current State of CCLs in Vermont
- Most organizations rely heavily on informal referral systems
- CCL implementation varies widely, from verbal recommendations to formal partnerships
- Pilot programs like Find Help in Lamoille County show promise for improving coordination
- Organizations generally lack robust systems for evaluating referral effectiveness

Key Barriers
- Health care providers face restrictions limiting referrals outside their networks
- Staff turnover frequently disrupts established relationships and referral pathways
- Resource knowledge tends to reside with individuals rather than in organizational systems
- Limited data sharing between organizations makes tracking outcomes difficult

Opportunities
1. Develop systematic approaches to screening and referrals, building on promising pilots
2. Create formal partnership structures with clear protocols and shared accountability
3. Build sustainable knowledge management systems to preserve institutional expertise

By addressing identified barriers while leveraging existing strengths in Vermont's healthcare ecosystem, these initiatives aim to create a more coordinated, accessible system of support for individuals with ADRD and their caregivers.

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Introduction

Vermont faces unique challenges in supporting individuals with Alzheimer's Disease and Related Dementias (ADRD) and their caregivers due to its rural geography and aging population. As of 2019, Vermont had the largest proportion of older adults living in rural areas among all states, with approximately 65% of adults aged 65 and older residing in rural communities. Rural residents often experience lower health care utilization for both primary and specialty care, despite having elevated health needs.

The Vermont Department of Health's Alzheimer's Disease and Healthy Aging Program (VADHAP) recognizes that improving connections between healthcare providers and community resources is essential to better serve Vermonters affected by ADRD. These connections, known as Community-Clinical Linkages (CCLs), are defined by the Centers for Disease Control and Prevention (CDC) as "connections between community and clinical sectors to improve population health."

Purpose and Objectives
This study was conducted to:

1. Deepen understanding of CCLs, both nationally and within Vermont
2. Examine how CCLs can effectively serve individuals with ADRD and their caregivers
3. Identify opportunities to strengthen and evaluate CCL efforts in Vermont
4. Inform VADHAP's CDC BOLD grant evaluation plan

Evaluation Questions
The study was guided by the following questions:

Primary Question: How effectively have community-clinical linkages enhanced coordination across healthcare systems, public health agencies, existing services, and community-based organizations in Vermont?

Additional Study Questions:

1. How do stakeholders in Vermont define and implement CCLs?
2. How can the quality of CCLs be evaluated for individuals experiencing ADRD?
3. How are individuals with ADRD in Vermont currently being served by existing CCLs?
4. What ADRD-related needs are being addressed through CCLs, and what gaps remain?
5. What factors facilitate or hinder the establishment of CCLs to support individuals with ADRD?
6. How does this work align with other state initiatives, including Community Health Worker programs?

Study Methods

To understand both the broader context of community-clinical linkages and their specific application in Vermont, we designed a two-phase study approach.

Comprehensive Literature Review: We examined CDC reports that outlined fundamental CCL frameworks and scoured academic literature for examples of successful implementation. We looked particularly for studies that demonstrated how CCLs have been used to support individuals with dementia and their caregivers, though we found this specific literature to be limited. The review helped us understand various CCL models, evaluation approaches, and potential challenges we might encounter in Vermont.

Local Expert Interviews: We identified and interviewed four key leaders representing different aspects of Vermont's health care and community support system. These included representatives from Blueprint for Health, which drives healthcare reform in the state; Bi-State Primary Care, which works with Federally Qualified Health Centers; Support and Services at Home (SASH), which coordinates care in housing communities; and Adult Day Services, which provides direct support to older adults and their caregivers.

Through hour-long conversations with each expert, we explored how CCLs function in Vermont's unique context, particularly in supporting individuals with ADRD. The interviews revealed both common themes and distinct perspectives based on each organization's role in the healthcare ecosystem. These conversations provided crucial insights into current practices, challenges, and opportunities specific to Vermont's rural landscape and aging population.

Together, these two phases of research – examining the broader literature and diving deep into Vermont's experience – allowed us to develop a comprehensive understanding of how CCLs can be strengthened to better serve Vermonters affected by ADRD.

Literature Review: CCLs and ADRD Care

This literature review broadly highlights principles and current approaches to Community-Clinical Links (CCLs) and includes literature specific to CCLs and Alzheimer's Dementia and Related Diseases (ADRD). It aims to understand CCLs and, more broadly, use this work and interviews with Vermont experts to identify actionable insights.

Key Literature Review Findings

Our review of academic literature and CDC reports revealed several important patterns in how CCLs are structured, implemented and evaluated across healthcare settings. While research specifically focused on CCLs supporting ADRD care is limited, the existing evidence points to promising practices and models that could inform Vermont's approach.

1. **CCLs exist on a continuum of intensity** from basic networking to full organizational merging, with most ADRD-focused CCLs centered around referral systems and educational partnerships.

2. **Two main models** emerge from the literature:

   - Education/training programs that prepare healthcare workers to make effective referrals

   - Centralized referral systems that coordinate care through a single point of contact or shared platform

3. **Research specifically examining CCLs for dementia care is limited**, with only two major studies identified.

4. **Evaluation approaches** vary based on program goals but commonly include:

   - Patient and provider satisfaction surveys

   - Referral tracking through centralized systems

   - Assessment of partnership strength and bidirectional engagement

Successful CCL programs demonstrate positive impacts on early screening rates, resource utilization, and satisfaction among both patients and caregivers.

Defining Community Clinical Linkages (CCL)

CCL is a broad term that can refer to a wide range of partnerships and programs connecting clinical and community activities. The CDC defines CCLs as: Community-clinical linkages are connections between community and clinical sectors to improve population health. CCLs can be placed on a continuum of intensity based on goals and objectives.[1]

Figure 2. Continuum of a Community-Clinical Linkage

Networking
Exchanging information

Coordinating
Exchanging information and altering activities

Cooperating
Exchanging information, altering activities, and sharing resources

Collaborating
Exchanging information, altering activities, sharing resources, and enhancing each other's capacity

Merging
Operating as one entity, where roles and cultures have blended

Least complex and intense → Most complex and intense

Adapted from Himmelman AT. *Collaboration for a Change: Definitions, Decision-Making Models, Roles, and Collaboration Process Guide.*

Examples across the continuum of linkages

Networking	Community resource shares pamphlets with clinics to distribute to patients.
Coordinating	A local health department, community Health Center and local YMCA decide to work together on efforts to reduce high blood pressure. The Local health departments decided to create a one-pager on effective prevention, the Community Health Workers then provide usual related services on top of information and referrals to YMCA. YMCA offers patients referrals 1 year family memberships.
Cooperating	Shared paid position dedicated to coordinating efforts, joint projects/ programs.
Collaborating	Skill Development training within participating entities to enhance capacity.
Merging	Organization undergoes complete organizational restructuring to integrate services into one entity fully.

Existing CCL Models

Many CCLs rely on verbal physician referrals or referral systems and have demonstrated positive impact these relationships can have on patients, caregivers, clinics and community partners. Some of these models included:

Education and Training: In several studies[2-6] CHWs, and Clinical Staff are trained to better support their patients via direct referral to resources or referral to a referral system. Some examples include the CHW curriculum in Lohr et al., which trained CHWs to Link individual needs to community and clinical services (LINKS)[5]. Training included topics on emotional well-being techniques, cultural sensitivity, and cultural factors associated with social determinants of health, as well as how to address each area using referrals within the CHW position. In another example, physicians were recruited for training sessions hosted by the University of Carolina medical school faculty members; in these sessions, participants were provided with evidence-based dementia screening, methods of treatment, and community resources, among other dementia-focused topics.

Centralized Referral Systems: Centralized Referral Systems refer to a communicated system of referral-making between partners using a single entity for referral management. Vendor et al., 2001, did this using a single point of contact (SPOC) method[6]. This method consists of the development of a phone line to assist patients and caregivers. SPOC was staffed by registered nurses and social workers who would assess caller needs and provide information and make both internal and community references.

In other models, CCLs have been demonstrated using shared digital platforms to coordinate referrals[2,7]. In these examples either CHWs or staff coordinated by the referral program acted as intermediary, coordinating with patients and clinical staff on resources appropriate for the patients needs. They could also use the program to facilitate follow-ups after activity, patient satisfaction, and offer resources[2]. In Krist et al., 2020, their care planning platform that allowed for sharing of patient care plans, and progress with the patient, their clinical team and CHWs. This program also facilitated communication between patients and care team members.

Dementia Specific CCLs

Despite the long-standing use of CCLs across public health issues, literature on CCLs intentionally benefiting people with dementia and their caregivers is limited. This literature review identified two studies.

Vendor et al., 2001: SPOC was a phone line specifically for dementia patients and caregivers. In this study, 97% were satisfied with their SPOC experience. Only 9% reported using respite care offered in the community, and 20% used a support group; however, those who did had high satisfaction using personal care/chore services, educational programs, and respite care.

Lathren et al., 2013: Developed partnerships and training to better improve diagnosis and management of dementia. This study worked with several local Alzheimer's focused programs throughout NC and Project CARE (Caregivers Alternative to Running on Empty), a support groups for caregivers with dementia. Post training many physicians reported doing

more early screenings for cognitive impairment were completed, designating a staff person for dementia care, and referrals to Project CARE.

Evaluation Methods for CCLs
The effectiveness of CCLs can be evaluated in a variety of different ways depending on the targeted outcomes and goals.

Patient and Provider Surveys: Surveys have been used to indicate satisfaction levels of clinic care, the referral process, and utilization or satisfaction of the community service for all participants (ie. Patients, care team, community agencies). In another study[5], a well-being questionnaire was developed to assess baseline and periodically re-assessed along with a social determinant of health assessment. These considered whether needs from patients were being supported.

Central Referral Systems and SPOC: These systems can often collect information on the number of referrals, types of referrals and depending on the partnership it can communicate the use of referral and coordinate follow-up.

CCL Partnerships: Partnerships can be assessed using the CDC's continuum of community clinical linkages. The relationships between entities should be mutual and bidirectional. Evaluation of this can consider engagement between organizations, and can also include integration of services, data sharing and access to infrastructure and resources[1].

Vermont Context: Local Expert Interviews

To understand how community-clinical linkages function within Vermont's unique healthcare landscape, we conducted in-depth interviews with four experts representing key organizations in the state's health and social services network. These conversations revealed both the strengths of existing partnerships and opportunities for growth in supporting Vermonters affected by ADRD.

Interviewees included:

Dr. John Saroyan, **Blueprint for Health**

Heather Skeels, **Bi-State Primary Care**

Casey Doerner, **SASH**

Kristen Bolton, **Adult Day**

Key Interview Findings

Our interviews with Vermont stakeholders revealed key insights into how CCLs function at the local level and identified both challenges and opportunities for strengthening these connections. Three major themes emerged from our analysis:

1. **CCL implementation shows broad spectrum**

   - Most organizations rely heavily on referrals as their primary linkage mechanism
   - Current referral practices range from informal verbal recommendations to formal organizational agreements
   - Pilot programs like Find Help in Lamoille show promise for improving referral coordination
   - Organizations generally lack robust systems for evaluating referral effectiveness

2. **Cross-organizational barriers limit service coordination**

   - Healthcare providers often face restrictions that limit their ability to refer outside their networks
   - Organizations struggle to navigate competing priorities while trying to find resources for patients
   - Formal partnerships face challenges in merging different organizational cultures and processes
   - Current systems make it difficult to coordinate care across different networks and organizations

3. **Individual knowledge drives current system**

   - Staff turnover frequently disrupts established relationships and referral pathways

- Resource knowledge tends to reside with individual staff rather than in organizational systems

- Organizations rely heavily on personal connections rather than standardized processes

- Limited data sharing between organizations makes tracking outcomes difficult

These findings suggest opportunities for more systematic approaches to building and maintaining CCLs while highlighting the importance of addressing both structural and practical barriers to effective implementation.

Full Summary of Responses

The following is a summary of each interviewee's responses organized by interview question.

Can you tell us about your role and organization?

Interviewees included local experts with varying experiences in this work, serving the needs of the Vermont population in different ways.

Blueprint for Health is a health care reform program that provides team-based primary and specialty care. Dr. John Saroyan oversees the organization more broadly.

Bi-State works with all 11 FQHCs in the state, serving about 198,000 patients in 2023. Heather improves programmatic, clinical, operational, and financial performance and works directly with health center medical directors and other staff.

SASH offers team-based care coordination through Community Health Workers (CHW) and Wellness nurses in affordable housing communities throughout Vermont. They serve about 5,000 people and are in every county in VT. Casey oversees operations and supports staff around the state.

Adult Day offers direct services for older adults and caregivers and primarily serves Addison County. Kristen is the Executive Director of Elderly services, with Project Independence Adult Day Health as its primary service. Kristen also does advocacy work at the state level.

The CDC defines Community-Clinical Linkages as "Connections between community and clinical sectors to improve population health." How would you define "Community Clinical Linkages," and how do they fit into your work?

Throughout the expert interviews, interviewees defined and identified broad ranges of how CCLs fit into their work. CCLs can be network-specific and dependent on geographic location.

Blueprint for Health recognized CCLs in more formal capacities, as they referenced the buying of programs to merge services, Blueprint can also assist in linkages by disseminating funding to partners.

Bi-State Referrals to resources may be made verbally, and it can be difficult to receive the status on outgoing referrals from a provider or even the patient's use of services. These linkages may not include a memorandum of agreement, which allows communication between services via HIPAA regulations.

SASH sees CCLs as a critical component of its model. Through partnerships, SASH works to help coordinate care (e.g., Organizing transportation to providers or setting appointments). It can also use information provided by physicians to support in-home care.

Adult Day is referred to through funding programs such as Medicaid and VT Moderate Needs Programs. Currently, they partner with other case management companies and the VA, which works with nurses and handles referrals.

What linkages currently exist at your organization/in your work? Can you describe what they look like and how they came to be?

Throughout the state, CCLs are demonstrated in a spectrum of ways. Some used memorandums to allow healthcare providers and their teams to connect with care coordinators, on-site support teams, and community partners. Some used verbal referrals, while others built more structural partnerships.

Blueprint for Health is acquiring existing programming to merge into their system. Dr. Saroyan was unable to speak to linkages that exist at the local level.

Bi- State believes that providers currently make referrals to organizations and resources that they are aware of. There may be insufficient or no formal IT systems to track if a patient uses resources offered. Lamoille Health Partners is currently piloting a program called Find Help. Find Help is a centralized referral system that creates linkages to care.

SASH connects patients to clinical teams through a memorandum with patients. This allows SASH to conduct team meetings with SASH staff, members of the care team, and local partners. These memorandums also connect the housing agencies, PCPs, VT home health and Hospice, hospitals and other agencies to SASH. The organization also conducts annual evaluations with each site. In these evaluations the staff rates coordination, experiences and offers feedback. In the past OneCare typically requests these reports but Casey was open to sharing evaluation results and collaborating with this group as well.

Adult Day works with patients on a daily basis. Its staff has a unique ability to identify abnormalities in behavior and can work closely with a primary care team. Similarly, social

workers can contact a geriatric psychologist for further information on medication and side effects.

Adult Day services are often self-sought by patients on their own, with some marketing done through local advertising. Outside of this, patients are referred by case managers who write the referrals and ensure reimbursement through Medicaid or the Moderate Needs Program. Additionally, some referrals come from doctors' offices and the VA.

How are people with ADRD and their care givers in Vermont being served by CCLs? What groups are and are not being served? What needs are being addressed?

For many interviews this was a challenging question, as their systems for CCLs did not include ways to measure this. Organizations who were not focused explicitly on ADRD or older populations, may not include measures at all, especially if it's not required by the state or funders.

Blueprint for Health emphasized that Blueprint could play a stronger role in helping to identify early signs of ADRD and connect individuals with resources and support for diagnosis. Dr. Saroyan also notes that within community health teams, there is no limit on how often CHWs can contact individuals. For those patients with frequent contact, this can be supportive in addressing social isolation and maintaining communication on health. However, not all CHWs have this capacity and flexibility, as it is dependent on funding.

Bi-State There are also no measurements or requirements from the state or funders to report on any ADRD-related measures.

SASH provides mini cognitive tests, which are shared with the primary care team to assess for cognitive changes. This is done to screen for early cognitive changes and assist them with care if needed. Casey also noted that rural areas have been more challenging to support through this work, as finding higher levels of care can be challenging.

Adult Day specifically supports ADRD through a UVM partnership to provide clinical services. UVM is hosting a pilot program starting in October, attempting to broaden their reach but this still only serves a small number of people.

Payment for Adult Day services is made through some direct pay, community Medicaid, and the Medicaid waiver program for people who qualify for nursing home care but don't want to be in a nursing home. The Moderate Needs Program has income requirements but has less challenging clinical requirements and allows people who are not as disabled to attend. The option for payment is an indicator of who will use these services.

Adult Day serves primarily white patients, those lower in socioeconomic status, and those with disabilities. Kristen also expressed that they also don't serve as many people with vision impairments, developmental disabilities, and the LGBTQ community.

What changes or improvements would you like to see to increase CCLs in your work? What are some barriers and facilitators?

Some of the barriers discussed were systems or policy barriers that prevent organizations from sharing data or referrals. Staff turnover or retention was also a common facilitator or barrier – individuals often hold knowledge of linkages and resources that is lost when they leave. This is related to a lack of systems to store and track linkages. The BOLD program was mentioned as a facilitator in creating connections and relationships between organizations.

Blueprint for Health noted that territorial issues are a barrier to CCLs. Dr. Saroyan discussed that specific health systems are unable to refer outside of their own health systems. This limits the patients' choices in the types of services they have access to and makes it difficult if the system they are seeing is unaccepting or underperforming.

A facilitator for CCLs in Blueprint was the retention of staff with varying experience levels. He notes that if you want to do something high-level, then you need people to stick around.

Heather Skeels, from Bi-State emphasized that solutions should not rely on clinical practices alone to create these linkages. A goal should be to get the public involved and get the information directly to patients.

One barrier that Heather addresses is the prerequisites to getting into a memory clinic. Doctors may not have time to be with patients at each step, but informed caregivers and community members support them in this if they have that knowledge.

SASH identified challenges in communication and collaboration. They further discussed shifts in Home Health Agencies limiting services, which has led them to work with large entities like AAA, but there has been less willingness to collaborate on AAA's end. Working within rural communities has also made transportation difficult, as transportation options are limited to supporting medical needs. Because of this, social needs aren't being supported via existing transportation services.

Other barriers included staffing turnovers and a lack of engagement from partners due to other priorities. Facilitators who were mentioned included VDH and DAIL as resources.

Adult Day shared that one facilitator for this work was the Project ECHO program and how it will help PCPs become more comfortable diagnosing ADRD and referring people to their services. Kristen also identified that communicating with clinicians and attending trainings

on clinical issues has supported her personal knowledge of aging and ADRD and has overall supported her work with this population. Kristen also works through the BOLD network to advocate for Adult Day.

Barriers include the reliance on PCPs to refer patients to services. PCPs aren't making these decisions early enough. Other barriers include the inability to provide data on the benefits of their services, the lack of statewide services, and the lack of in-house nurse practitioners or physician assistants.

Key Opportunities

Based on our findings from both national literature and local expertise, three primary opportunities emerged for strengthening community-clinical linkages in Vermont. These opportunities focus on systematic approaches to coordination and referral that have shown promise both nationally and locally.

1. Develop systematic approaches to screening and referrals

Interview findings and national literature both emphasize the importance of standardized referral processes. The Find Help pilot in Lamoille County offers a promising model for tracking and coordinating referrals. Partnering with Blueprint for Health could also be an avenue to develop standardized screening protocols. Expanding this type of systematic approach could help address the currently fragmented referral landscape while providing better data on service utilization and gaps.

2. Create formal partnership structures

Both our literature review and local interviews highlighted the challenges of maintaining effective partnerships without formal structures in place. Adult Day services is in the process of forming a formal clinical partnership through their work with UVM, which will enhance their ability to provide comprehensive care. There's an opportunity to develop more systematic approaches to partnership, including data sharing agreements, clear communication protocols, and shared accountability measures. The BOLD program provides a foundation for facilitating this more structured approach.

3. Build sustainable knowledge management systems

A consistent theme across interviews was the challenge of maintaining institutional knowledge and referral relationships when staff turnover. This aligns with findings from the literature about the importance of systematizing CCL processes rather than relying on individual relationships. Creating more robust systems for documenting and sharing knowledge about resources and referral processes could help address this challenge.

VADHAP is well-positioned to advance these priorities and has already identified concrete steps to address these priorities through the BOLD program. Initial actions include exploring innovative service delivery models through Adult Day programs, collaborating with Blueprint for Health to enhance early ADRD diagnosis capabilities, and engaging with emerging care models, like the state's first Community Nurse Model, to strengthen community-clinical connections. By focusing on these targeted interventions while addressing identified barriers, Vermont can work toward a more coordinated, accessible system of support for individuals with ADRD and their caregivers.

As other states and organizations work to strengthen their own CCLs supporting individuals with ADRD, VADHAP hopes this analysis of current practices, challenges, and opportunities will provide useful insights. The combination of national research and local expertise presented here offers a framework for understanding and improving CCLs that can be adapted to other contexts, while highlighting important considerations for implementation.

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Appendix

This evaluation was conducted by Professional Data Analysis (PDA), led by Anne Schwalbe and supported by Monique Harris.

Interview Protocol

Community-Clinical Linkages for people with ADRD and their care givers in Vermont: Local Expert Interview Protocol

Questions:

1) Can you tell us about your role and organization?

2) The CDC defines Community-Clinical Linkages as "Connections between community and clinical sectors to improve population health." How would you define "Community Clinical Linkages" and how do they fit into your work?

3) What linkages currently exist at your organization/in your work? Can you describe what they look like and how they came to be?

4) How are people with ADRD and their care givers in Vermont being served by CCLs?

   a. What groups are being served? Not served?

   b. What needs are being addressed? Not addressed?

5) What changes or improvements would you like to see to increase CCLs in your work?

   a. What are some of the barriers to establishing effective CCLs to support people with ADRD and their care givers?

   b. What are some facilitators, what has been helpful?