

**Governor's Commission on Alzheimer's Disease and Related Disorders
Meeting Minutes 07-18-24**

Present: Carolyn Taylor Olson, Neely Bryant, Mary Beth Pinard, Mindy Clawson, Alecia Dimario, Luba Routsong, Dan Noyes, Colleen Nerney, Meg Polyte, Katherine Martin, Kaili Kuiper, Mark Boutwell, Ed DeMott, Rick Neu, Jeanne Hutchins, Jason Pelopida, Sen Randy Brock, Jane Dwinell, Angela Smith Dieng, Alicia Flemming, Simone Rueschmeyer,

TOPIC	NOTES	DECISION/ACTION
General Intro (10 mins)	<ul style="list-style-type: none"> • Welcome • Approve May minutes- Ed moved to approve, Rick seconded. All in favor, none opposed, none abstained. 	May minutes approved.
Navigating the Progression of Dementia	Lived Experience Advocate share	
State Dementia Services Coordinator Update	Slide Presentation	Questions, contact tiffany.smith@vermont.gov
Update on State Needs Assessment and timeline for creation of the State Plan on Aging	<p>-Assessment rolls out Aug 12 (online version) the hard copies will be available the following week.</p> <p>ADRD Questions:</p> <ul style="list-style-type: none"> • Do you provide unpaid assistance to spouse, family member or friend? For example, help with housework, cooking, transportation, dressing, bathing, managing money, etc. <ul style="list-style-type: none"> ➤ No ➤ Yes, the person I care for has Alzheimer's or other type of dementia ➤ Yes, the person I care for has other conditions that require help • What are the health conditions of your family member that require your care? <ul style="list-style-type: none"> ➤ -Alzheimer's or another form of dementia ➤ -Brain injury (i.e. from a stroke, fall, accident, etc.) ➤ -Physical disability ➤ -Chronic physical health condition or illness ➤ -No diagnosis ➤ -Other, please describe: ➤ -I prefer not to say 	Questions, contact Jason.pelopida@vermont.gov

New Subjective Cognitive Decline Data Brief	SCD brief published to website: https://www.healthvermont.gov/sites/default/files/document/hpdp-brain-health-scd-brief.pdf Sen Brock inquired 'How can VT prioritize demographic breakdown within SCD data points'	
ADRD Legislative Accomplishments	-S302 passed in June -Licensing board adopted Commission recommended language re: training for any individual in contact with residents to receive dementia capable communication	
2025 Legislative Priority Brainstorm	<i>What do you think we can do to improve the quality of services at the local level for people with ADRD and their care partners?</i> <i>What can we do to improve coordination between HCBS and medical providers for people with ADRD and their care partners?</i>	See group responses below
BOLD and VDH Alzheimer's Updates	'Save the Date' Brain Health Symposium November 1, 2024 9 am – Noon @ Waterbury State Office Complex -Promotional ads in development to improve self-identification of caregivers -look for BOLD Survey developed by PDA Evaluation (via email)	
Conflict Free Case Management and other DAIL Updates	In the 'transition phase' moving folks from HHA into AAA case management. Some AAAs experiencing challenges finding applicants to onboard as case managers.	
Member announcements	Dementia Friendly Communities: Middlebury, putting their Memory Café on hold- moving ahead in engaging their business sector. Middlebury holding a Non-Profit fair Aug 10 th - looking for a commission member to attend and share a table with the Alzheimer's Association	Luba Routsong is attending on behalf of the commission
Wrap Up		

Next meeting: **Thursday September 19th 9-11**

Meeting Attendee Menti Poll Responses:

What do you think we can do to improve the quality of services at the local level for people with ADRD and their care partners?

Better train health care providers, guidance for caregivers about a general disease pathway, better access to resources, financial support to build staffing at all levels, central resource repository.

Increase access and affordability of services. (Increase the capacity and number of services available.)

Increase the number of services available.

Activities to help with progression of disease, such as art, music, exercise.

Meet people where they are at within the communities i.e. meal programs and expand services at those sites to quickly implement services that will expand social, tactile arts and nutrition.

More social activities at local locations where seniors are already comfortable. Senior Centers, libraries, Adult Day centers...

Expand adult day services for all counties.

Expand adult day services.

More adult day services and home outreach

VT Adult Day expands across the state

More trained respite providers. Could be local people who get training so they can better help their friends/neighbors.

Workforce or lack thereof is a bottleneck to providing even basic care and support.

Work with local health care organizations to help steer hiring and recruitment of needed specialties.

Engage schools at every level to educate and encourage careers in supporting those with ADRD.

More funding for additional caregiver coordinator and caregiver program facilitator staff at AAAs.

Increase access to case management through outreach to older Vermonters so they know how and where to get access.

Integrated case management is key so people don't experience what Luba did trying to figure out What's Next.

Integrated Case Management: Assigning one Case Manager who is able to work with each system for that one person, instead of multiple people being involved making it more confusing.

Stronger relationships and coordination between primary care practices and AAA caregiver staff to facilitate care.

Diagnosis of dementia in primary care with connection to case management at diagnosis.

Support for navigating bureaucratic health programs and application processes.

Simplify Medicaid process

Easier system to access flexible funding for respite and other needs to support continued care in the home.

Training and coordination for everyone/every organization so that they're all on the same page and offering the same services.

Ensure that all community-based organizations have access to training and education to allow for shared learning, increased collaboration, and integrated care.

Dementia care training for all staff in local hospitals. Unacceptable that folks are told – we don't know how to deal with this - when someone with dementia is admitted for any reason.

Offer Trainings

Local events to educate citizens on ADRD.

Campaigns to end the stigma – normalize within communities.

Media campaign to raise awareness of family caregivers/issues/supports

Transportation!!!!

Provide a 'one stop' place that lists all resources/services in the state, broken down by region/city/town.

What can we do to improve coordination between HCBS and medical providers for people with ADRD and their care partners?

One provider overseeing/coordinating the care in consultation with others.

Need some streamlined system so each can see what the other is doing/prescribing.

A universal health record that allows any individual to record thoughts and concerns about a person being cared for – aspirational.
Easier avenues for team collaboration.

A shared HIPPA compliant database/portal that allows for the exchange of information in both directions.

Smartphrases for EMR that are geo-specific to allow providers to make referrals for individuals with cognitive issues and their caregivers.

Training for HCBS and medical providers and advocates on how the system should be working together.

Regional one page sheet with HCBS providers and their contact info to encourage warm hand off from Dr. Office.

All HCBS providers should maintain a current resource list of medical providers. All medical providers should maintain a current resource list of HCBS providers.

Making sure that HCBS informs PCP office of their involvement – clients don't always share this information and PCP staff don't know to have release of information forms signed to facilitate contact.

Education to the Providers to understand what services can be provided and that Caregiving is truly 24/7 but services are not.

Medical Providers need to understand what HCBS providers provide and how that will help their patient with an ADRD diagnosis.

Education to Providers on how to talk to the caregiver and asking the caregiver what they can and cannot do for the person thus understanding what services are truly needed in the home.

Providers need to understand the difference between ADL and IADL. It makes an impact on what services a person needs in their home.

Required training nodules for med students, residents and fellows.

Sharing of services. Would love to see more information given by Dr. Taylor about non pharmaceutical activities for slowing progression of the disease. Weight training class is an example.

A 'resource' that all medical providers can refer patients to that would provide the patient/caregiver with one-on-one guidance to resources and state with them throughout the journey.

Focused outreach and education of medical providers about local resources such as AAAs.

Create liaison positions that would help bridge the gap between the two groups, maybe bases in AAAs.

Create a team that would present to providers at hospital Grand Rounds or department meetings.

HCBS providers need an audience at VT Medical Society Annual meetings and other medical conferences to network, start conversations, etc.

An in-person, day-long meeting in each county where HCBS people and medical providers can actually talk to each other.

Joint and integrated trainings for current providers and for the longer term more bi-directional education as they are earning their degrees.

Survey the HCBS and medical providers to get their thoughts.

A webinar with HCBS and practice managers/administrators to educate/discuss the needs of active communications and collaboration.

How is the HIE currently being used?

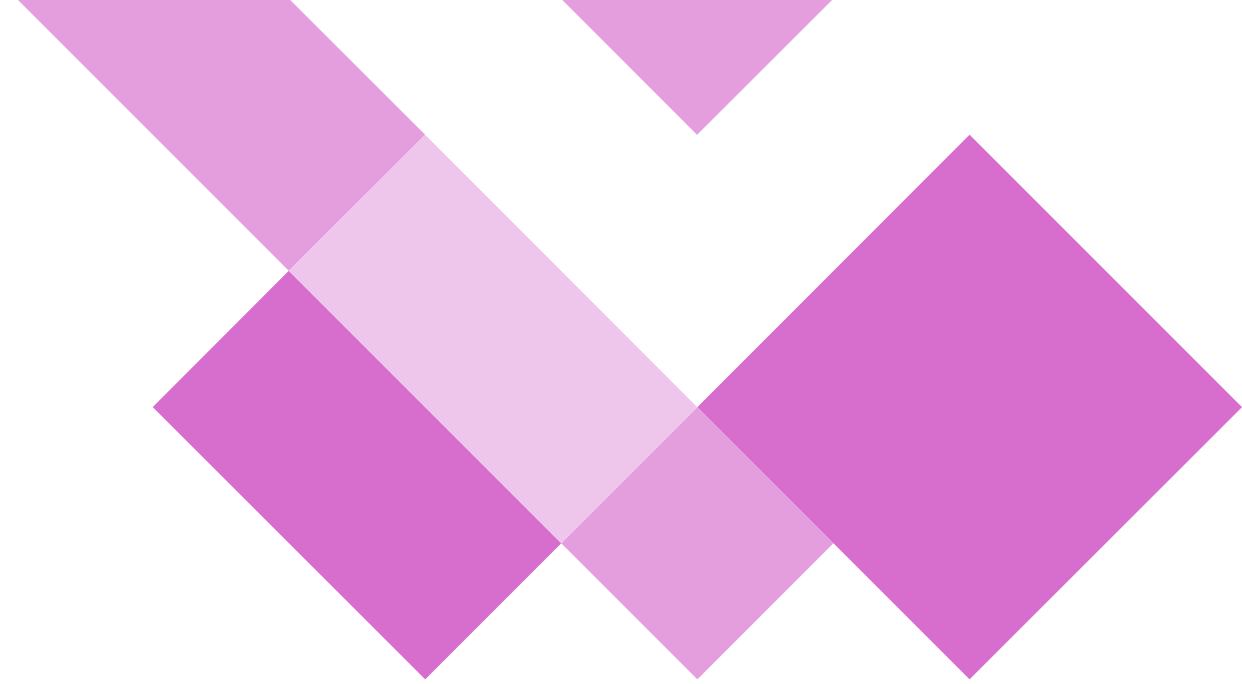


Dementia Services Coordination Update 7/18/2024

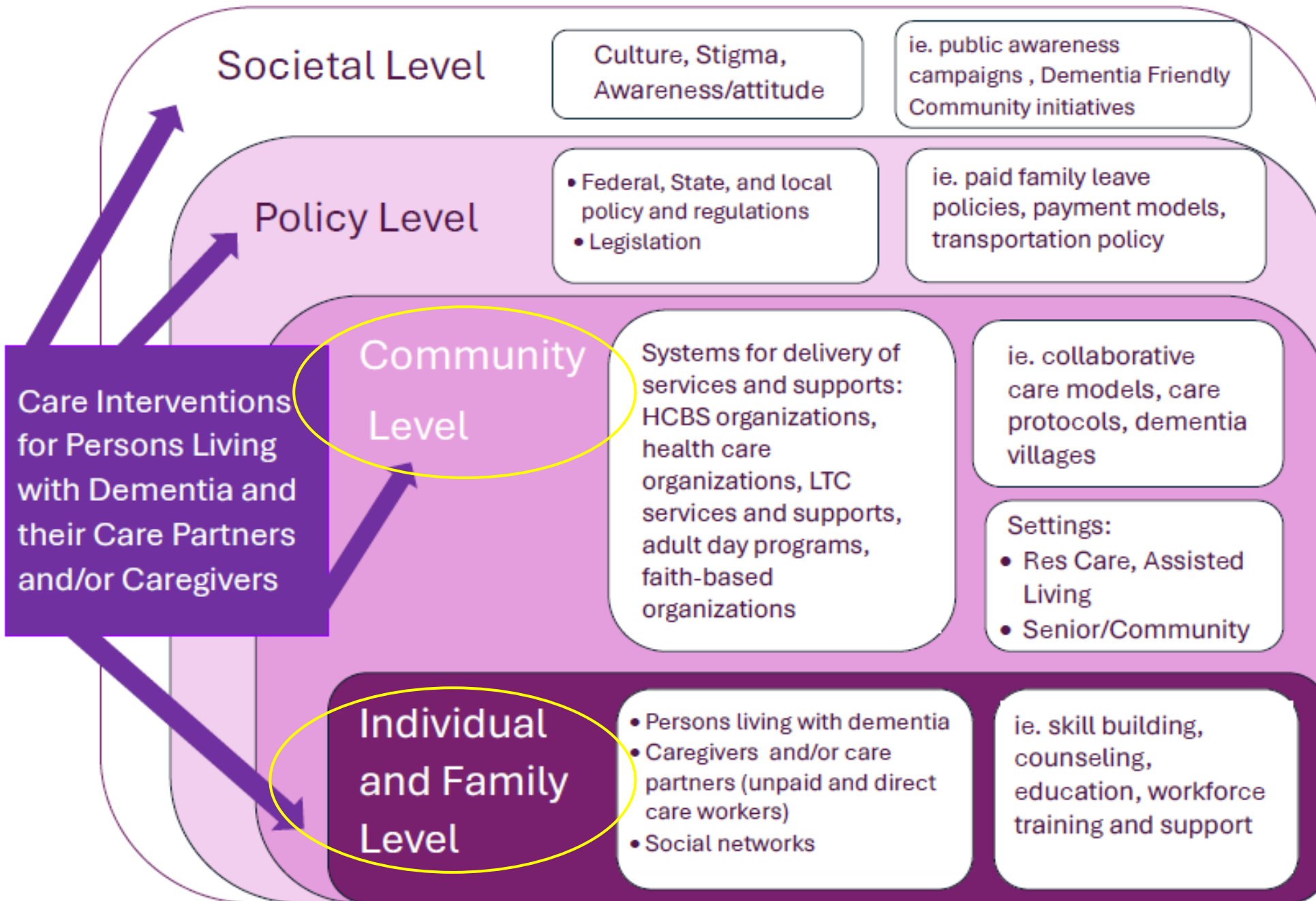
Tiffany Smith
Dementia Services Coordinator
State Unit on Aging, DAIL

Agenda

- **System Overview and Focus Areas**
- **Focus Area Update and Looking Ahead**
- **TCARE Impact Report 2024**



VERMONT DEMENTIA SERVICE SYSTEM



FOCUS AREAS

1. Individual and Family Level:

- What is available for individuals living independently
- What is available for caregivers
- Effective and timely supports, overall experience for the individual

2. Community Level:

- Systems for delivery of services and supports
- Information, Referral, Access, and Case Management

FOCUS AREA 1 Individual and Family Level:

Effective and timely supports, overall experience for the individual and or Caregiver

- Review of data and testimonials, from caregivers and HCBS organizations indicate that:
 - Supports/interventions are mostly ineffective and/or unsustainable.
 - Confusion around: what is available- for who, how to get it, and eligibility
 - Individuals and Caregivers have limited capacity to reach out to referrals/resources and often express ‘its not worth it’
- Through discussions with advocates and service providers there is a significant need for earlier intervention:
 - Engaging individuals in Health Promotion Disease Prevention (HPDP) programs
 - Increase access to Evidence Based Programs
 - Provide case management and practice ‘warm handoffs’ to partner organizations when needed.

Looking ahead-

- Scheduling visits (Summer/Fall) to Community focal points- meal sites, community/senior centers. The goal is to hear specifically about challenges and successes related to services provided in community that are utilized by individuals living with ADRD and Caregivers. Representatives from Alz Association, VDH, and myself will hear from community members, volunteers, and staff at locations across the state.

FOCUS AREA 2 Community Level:

Systems for Delivery of services and supports: Information, Referral, Access, and Case Management

- In February of 2024, monthly meetings were scheduled with each AAA caregiver support leads to discuss service and support coordination for OAA and DRG* eligible individuals living with ADRD and Caregivers of individuals living with ADRD
- In May of 2024, Each AAA lead has joined the [National Caregiver Champion Collaborative](#)
- In SFY24, 3 AAAs have added an additional person to their caregiver support team.
- In review: intake/prioritization processes for OAA target populations: individuals in greatest social and economic need, individuals living with ADRD and Caregivers of individuals living with ADRD
- SUA providing technical support and guidance to improve data collection of OAA and DRG services.

Looking ahead-

- Building a partnership with the VT Dementia Family Caregiver Center
- Opportunities to utilize Social Workers via the UVM Bridges program
- Explore effective national models of care coordination ie. [Care Ecosystem](#), [CMS GUIDE Model](#), Virginia's [NWD Cognitive Impairment Identification Tool](#) and [other Dementia Capable Tools](#)

*Older Americans Act and Dementia Respite Grant

TCARE Impact Report

January 2020-
December 2023

Vermont	Screeners	Assessments	Follow-Ups
Age Well	60	62	9
CVCOA	3	4	0
Northeast Kingdom	27	28	27
Senior Solutions	22	7	0
SVCOA	38	20	0
Totals	150	121	36

January 2024-
July 17 2024

Vermont	Screeners	Assessments	Follow-Ups
Age Well	20	16	13
CVCOA	0	0	0
Northeast Kingdom	6	5	2
Senior Solutions	6	0	0
SVCOA	16	8	1
Totals	48	29	16

T-Care data for all VT participants in program from inception to 6/17/2024

<u>Feelings of depression</u>	Lowered	Maintained	Elevated
VT State Results	12%	78%	10%
National Average (AAAs)	32%	58%	10%



VT Average of **90%** of participants **lowered or maintained** feelings of depression while caregiving. National average of 90%

<u>Stress burden</u>	Lowered	Maintained	Elevated
VT State Results	10%	79%	11%
National Average (AAAs)	31%	60%	9%



VT Average of **89%** of participants **lowered or maintained** their stress burden while caregiving vs. National average of 91%

T-Care data for all VT participants in program from inception to 6/17/2024

<u>Objectivity burden</u>	Lowered	Maintained	Elevated
VT State Results	12%	78%	11%
National Average (AAAs)	31%	60%	9%



VT Average of **90%** of participants **lowered or maintained objective scores** while caregiving vs. National average of 91%

<u>Relationship burden</u>	Lowered	Maintained	Elevated
VT State Results	10%	80%	10%
National Average (AAAs)	24%	62%	14%



VT Average of **90%** of participants **lowered or maintained** their relationship burden while caregiving vs. National average of 86%

T-Care data for all VT participants in program from inception to 6/17/2024

<u>Intention to place, now</u>	Lowered	Maintained	Elevated
VT State Results	2%	91%	6%
National Average (AAAs)	7%	81%	11%



VT Average of **93%** of participants **lowered or maintained** their intent to place in facility while caregiving vs. National average of 88%

<u>Identity Discrepancy burden</u>	Lowered	Maintained	Elevated
VT State Results	14%	78%	12%
National Average (AAAs)	31%	58%	10%



VT Average of **89%** of participants **lowered or maintained** their identity discrepancy burden while caregiving vs. National average of 89%



Thank you

Tiffany Smith

Tiffany.smith@vermont.gov

ADRD Question

26. Do you provide unpaid assistance to spouse, family member or friend? For example, help with housework, cooking, transportation, dressing, bathing, managing money, etc.

- No
- Yes, the person I care for has Alzheimer's or other type of dementia
- Yes, the person I care for has other conditions that require help

ADRD Question

3. What are the health conditions of your family member that require your care?

- Alzheimer's or another form of dementia
- Brain injury (i.e. from a stroke, fall, accident, etc.)
- Physical disability
- Chronic physical health condition or illness
- No diagnosis
- Other, please describe:
- I prefer not to say