ACL Dementia Grantee Developed Products

Virginia’s Collaborative Care Coordination Model and Eddy Alzheimer’s Services Training on Dementia Care for People with Intellectual and Developmental Disabilities

Jennifer Harvey
George Worthington

Part of the National Alzheimer’s and Dementia Resource Center webinar series sponsored by the Administration for Community Living.
Collaborative Care Coordination Model

VIRGINIA DEMENTIA SPECIALIZED SUPPORTIVE SERVICES PROJECT

National Alzheimer’s Disease Resource Center
Webinar July 24, 2019

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Dementia Services Coordinator
Partners

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Project team (2017)

**Department for Aging and Rehabilitative Services (DARS)**
- Mary-Margaret Cash, Assistant Commissioner, Community-Based Services Division
- Devin Bowers, Dementia Services Coordinator

**University of Virginia Memory and Aging Care Clinic (MACC)**
- Carol Manning, PhD, ABPP-CN, Director and Principal Investigator
- Scott Sperling, MA, PsyD, Neuropsychologist

**Jefferson Area Board for Aging (JABA)**
- Marta Keane, Executive Director
- Ginger Dillard, Director of Advocacy Services
- George Worthington, Manager, Community Resources
Goal IV:
Provide access to quality coordinated care for individuals with dementia in the most integrated setting.
Why care coordination?

Alzheimer’s Association discusses ‘active management’ of dementia to improve quality of life for people living with dementia (Vickrey et. al., 2206; Voisin & Vellas, 2009; Grossberg et. al., (2010):

- Appropriate use of available treatment options
- Effective management of coexisting conditions
- Coordination of care among physicians, health care and lay caregivers
- Participation in meaningful activities that provide purpose
- Opportunities to connect with others living with dementia
- Becoming educated about the disease
- Planning for the future
Care Coordination Model

Dementia Care Managers (DCM) within health systems are the single most effective innovation for improving dementia care

- Connect patients with community resources
- Coordinate care between community-based organizations and health care systems
- Deliver more intensive case management and promote stronger integration of health and social care services leading to better outcomes

Care Coordination Model

Health Care System

Community Based Organization

Memory Clinic:
- Neurologist
- Neuropsychiatrist
- Nurse practitioner

Primary Care Providers

DCM

Patient & Primary Caregiver

- Companion Care
- Home health
- Adult Day Programs
- Nutrition
- Transportation
- Other home and community-based services
Care Coordination Program

Eligibility criteria:

- Recent diagnosis of mild cognitive impairment or of a neurodegenerative disorder such as Alzheimer’s disease
- Resident of Virginia

Intended to serve at least 200 individuals living with dementia and caregivers over 3-year project period (no new enrollments in Year 3)

Program enrolled person with the diagnosis and a primary caregiver
# Care Coordination Program

**Program Provided:**

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person-centered Options Counseling</td>
<td>Education on dementia</td>
</tr>
<tr>
<td>Information and referrals to community-based organizations</td>
<td>Behavioral symptom management training and expert consultation</td>
</tr>
<tr>
<td>Eligibility assistance</td>
<td>Help with coordination of medical care</td>
</tr>
</tbody>
</table>

**Goal:** to help individuals living with dementia remain in their homes or in community settings for as long as possible.
Dementia Care Managers

Two Dementia Care Managers (DCMs)

Hired jointly by University of Virginia and Jefferson Area Board for Aging (one each)

Background in mental health or social work

Embedded in Memory and Aging Care Clinic

Day-to-day supervision by manager at Jefferson Area Board for Aging

Clinical supervision by Memory and Aging Care Clinic director
Training

Comprehensive training for DCMs in:

- Options counseling
- Dementia knowledge
- Long-term services and supports
- Elder abuse/mandated reporting
- Person-centered care
- Legal and financial planning
Person-centered Care Coordination

DCMs helped individuals living with dementia and their caregivers:

- navigate health system
- learn about dementia
- explore goals for care and create action plan
- Identify referrals and resources
Program

- Referral on or shortly after diagnosis
- Care Coordination Guide provided on enrollment
- Initial home visit for assessment and action plan
- Helping with transitions
- Monthly follow-up calls
- Referrals and links to supports as needed
- Annual home visit
- Attending clinic appointments
## Outcomes

Validated tools administered at enrollment and at 12-month intervals

<table>
<thead>
<tr>
<th>Person living with dementia</th>
<th>Care partner/caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced depression</td>
<td>Reduced depression</td>
</tr>
<tr>
<td>Improved quality of life</td>
<td>Improved quality of life</td>
</tr>
<tr>
<td>Reduction in behavioral symptoms</td>
<td>Reduced sense of burden</td>
</tr>
<tr>
<td>Helped prepare for future</td>
<td>Improved self-care</td>
</tr>
<tr>
<td>Helped adjust to diagnosis</td>
<td>Increased knowledge of community resources</td>
</tr>
<tr>
<td>Reduced stress</td>
<td>Reduced stress</td>
</tr>
</tbody>
</table>
Challenges

- Integrating team across two distinct organizations
- Staff turnover/continuity
- Increasing complexity of casework
- Sustainability
Lessons Learned

- Value of home visits by the DCMs
- Realistic case loads essential
- Creating realistic expectations in participants/families
- Unified supervision for DCMs
Awards

- 2018 Commonwealth Council on Aging Best Practice Award
- 2018 n4a Aging Innovations Award—Health-LTSS Integration
Resources

Replication Manual for *Collaborative Care Coordination* available for download on:

[https://www.vadars.org/cbs/dementia services.htm#program](https://www.vadars.org/cbs/dementia services.htm#program)

Includes:

- Care Coordination Guide
- DCM job description
- List of training materials used
- Reference list of outcome measures
- Sample budget
Contact Information

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www.vadars.org/cbs/dementiaservices.htm

AlzPossible.org
Eddy Alzheimer’s Services

Dementia Training for People with Intellectual and Developmental Disabilities

Jennifer Harvey
This project was supported in part by grant number 90ALGG0012 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.
Objectives

- Participants of this webinar will be able to:
  - Describe the importance of quality dementia training for professional caregivers of people with intellectual and developmental disabilities; and,
  - Identify readily available tools and resources that can be used in practice settings.
Our Agency

- Support to caregivers, both family and professional
- Education
- Support Groups
- Ongoing case management
- Respite
- Services to individuals living alone with dementia
History and Need for Dementia Training

- Many agencies do not have a built-in dementia curriculum
- Individuals with I/DD are living longer due to better supports, healthcare, and community integration
- Individuals with Down Syndrome are at higher risk of developing Alzheimer’s disease
Target audience: Direct Service Providers (DSP), Administration, Behavioral Specialists, Social Work, Nursing, Psychology

Format: Three-hour training on-site for each agency

Assessment: IDD and Dementia Knowledge Scale from the Center on Intellectual Disabilities – University at Albany
Overview of dementia and specific conditions/diseases that cause dementia

Discussion of the brain
- Parts of the brain and what each part does
- Impact of dementia
- Strategies to use based on these cognitive changes

Role play exercise

Discussion of behavior and practical approaches
Training components

Types of Dementia

- Alzheimer’s Disease
- Vascular Disease
- Lewy Body Dementia
- Parkinson’s Disease
- Frontotemporal Dementia

Alzheimer’s Disease and Down Syndrome

- APOE4 is the first gene variation found to increase risk of Alzheimer’s disease
- Of the four risk genes, it has the greatest known impact
- This gene is located on chromosome 21
- People with Down Syndrome have an extra copy of this chromosome, putting them at higher risk
Training components

Frontal Lobe

- The “captain” or “boss”
- Makes sense of all the information the rest of the brain is gathering
  - Where information becomes response
- Emotions
- Appropriate responses
- Social cues and rules
- Organizing and prioritizing tasks

When dementia causes damage to the frontal lobe...

- I can’t dress myself.
- I go into the bathroom, but sit on the toilet without pulling down my pants.
- I abruptly walk away from an activity or conversation.
- I don’t sit down for lunch when you tell me to.
- I dash into the road without looking both ways.
- I call you a derogatory name.
- I reach out and touch my neighbor’s breast without their consent.
- I refuse to take my medication.

The 7 and 7 Rule

- Try to use statements (not questions!) that have 7 words or less
  - “It’s time for lunch”
  - “Yes, I have a son.”
- Allow 7 (or more!) seconds for person to respond
- Repeat once, if necessary. You might want to simplify your statement.
-
Common Triggers of Behavioral Symptoms

<table>
<thead>
<tr>
<th>Related to Person with Dementia (PWD)</th>
<th>Related to the Caregiver</th>
<th>Related to the environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain or discomfort</td>
<td>Stressed</td>
<td>Too little stimulation</td>
</tr>
<tr>
<td>Underlying medical condition</td>
<td>Overwhelmed</td>
<td>Too much stimulation</td>
</tr>
<tr>
<td>Boredom</td>
<td>Body language</td>
<td>Poor lighting</td>
</tr>
<tr>
<td>Fright/fear</td>
<td>Quality of relationship with PWD</td>
<td>Difficulty finding way</td>
</tr>
<tr>
<td>Confusion or disorientation</td>
<td>Poor communication style</td>
<td>Too much clutter</td>
</tr>
<tr>
<td>Frustration</td>
<td>Not engaging</td>
<td>Too hot/cold</td>
</tr>
<tr>
<td>Anxiety/worry</td>
<td>Not aware of customs, traditions or generational courtesies</td>
<td></td>
</tr>
<tr>
<td>Hunger</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too hot/cold</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Training components

Meal Times

- Struggles with eating may be related to:
  - Trouble with eyesight, hearing, taste or smell
  - Too much going on in the environment
  - Physical discomfort or illness
  - No longer understanding how to eat or use utensils
  - Medications that decrease appetite

Meal Times: What can I do?

- Provide necessary support
- Try new foods
- Encourage finger-foods
- Provide smaller meals or snacks more throughout the day
  - Don’t get stuck on “three meals a day”
- Check oral health
  - Are teeth intact?
  - Are dentures in properly?

Meal Time: Environmental Considerations

- Small tables for dining (3-4 people)
- Meal times can be very noisy!
  - Minimize extraneous noise
  - Set up quieter space to eat
- Create contrast
  - A dark placemat under a light colored plate
- Avoid busy patterns on table coverings and dishes
- Use adaptive silverware, plates and cups
Training Development

- Worked with Dr. Phil McCallion, expert in IDD and dementia
- Minnesota Department of Human Services
  - Serving People with I/DD and Dementia: Online Training for Case Manager, Assessors and Providers
- National Task Group on Intellectual Disabilities and Dementia Practices
  - NTG Early Detection Screen for Dementia
- Several months of drafting materials and soliciting feedback
- Tapping into transferrable skills that IDD support staff and professionals already possess
Community Partnerships and Implementation

- Developed relationships with two local agencies who support individuals with IDD
  - The Center for Disability Services (CFDS) and Wildwood Programs (WW)
  - Both have multiple programs to support people with IDD in a large service area
  - Both identified dementia as a current and increasingly important issue

- Monthly trainings, alternating agencies and sites, over the course of the last year

- Offered other training opportunities to agency staff

- Offered separate training/event for family caregivers
Our progress so far…

- We have trained over 260 staff
- We have hosted three caregiver events, reaching approximately 20 family caregivers total
- Collecting pre/post-assessment data at all staff trainings using the IDD and Dementia Knowledge Scale
  - 63% of staff who completed both the pre and post-assessments demonstrated an increase in knowledge
  - 25% maintained their score from pre to post-assessment
  - 28% of those who attended a training did not complete one of the assessments
**Successes**

- **Buy-in from administrative and clinical staff**
  - Provided encouragement to managers and DSPs to attend training, particularly if actively supporting a person with dementia
- **Ability to provide additional services to staff and family caregivers**
- **Format of training was interactive and accessible to staff**
- **Identify key players and maintain a core team at each agency**
  - Offered opportunities for key players to participate in additional training, paid for by EAS
Challenges and Lessons Learned

- Length of training
- Reaching other agencies who serve IDD population
  - Do they identify dementia as a pressing issue for their agency?
  - Are they willing to make this training mandatory for staff?
- Is one training enough?
- Being at outsider
  - What does the Eddy have to offer, and why should they care?
- Expectations between agencies; establish a memorandum of understanding
- Sustainability and practical application of skills
Next Steps & Sustainability

- **Train-the-Trainer**
  - Staff at both CFDS and WW will be trained to provide curriculum
  - Curriculum has been manualized
  - Offered late July 2019, and likely next year as well

- **Behavioral consultations for residential and support staff**

- **Continued family support and programming**

- **Connections to other agencies in need of training**
  - Provided one training to a local ARC
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