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

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NADRC
National Alzheimer's and Dementia Resource Center

ACL
Administration for Community Living

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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DARS
Virginia Department for Aging and Rehabilitative Services

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

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Virginia Dementia State Plan

Goal IV:

Provide access to quality coordinated care for individuals with dementia in the most integrated setting.

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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

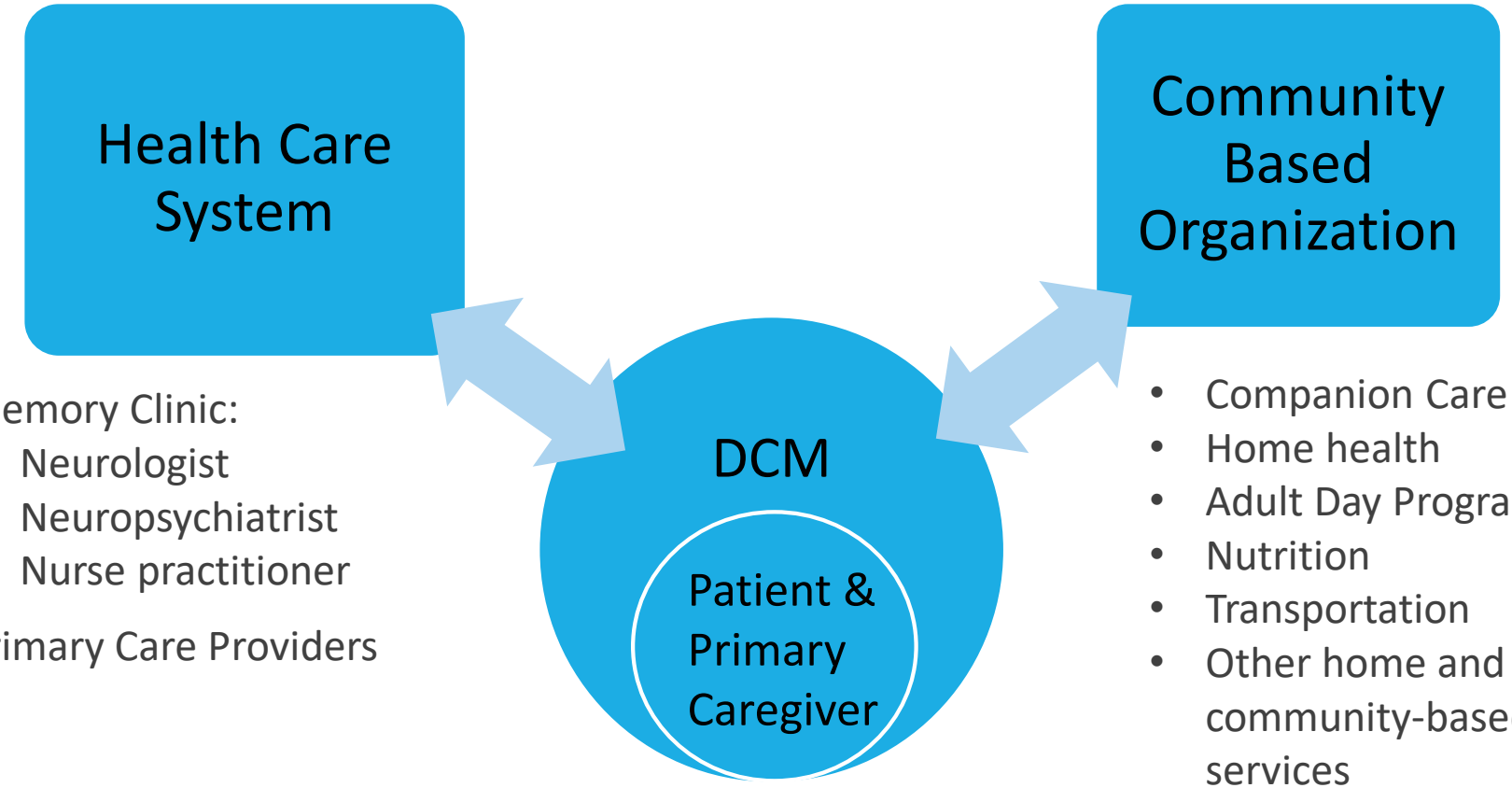
Care Coordination Model

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

Borson, S., & Chodosh, J. (2014). Developing dementia-capable health care systems: A 12-step program. *Clinics in Geriatric Medicine*, *30*, 395-420.

Care Coordination Model



Memory Clinic:
- Neurologist
- Neuropsychiatrist
- Nurse practitioner

Primary Care Providers

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

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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:

Person-centered Options Counseling	Education on dementia
Information and referrals to community-based organizations	Behavioral symptom management training and expert consultation
Eligibility assistance	Help with coordination of medical care

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

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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:

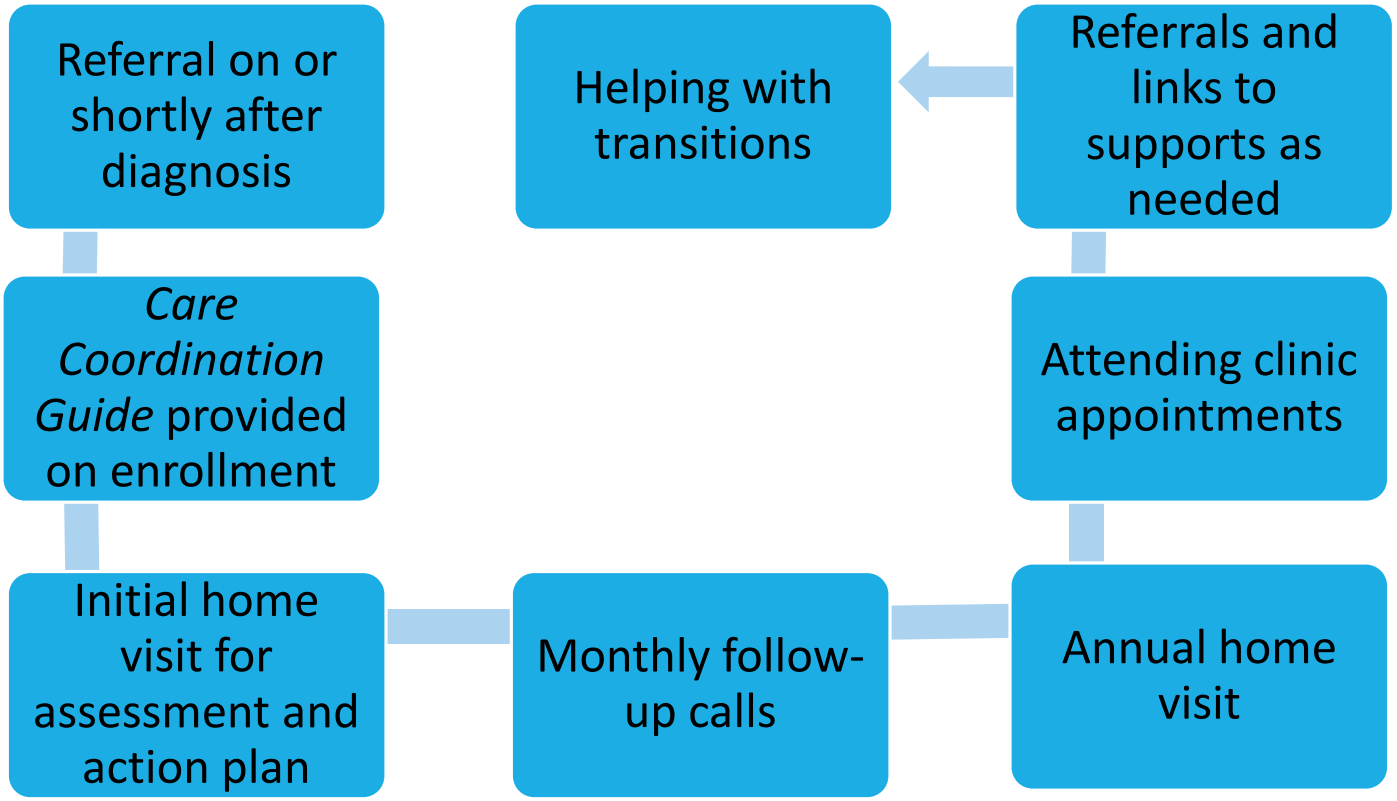
- Options counseling
- Dementia knowledge
- Long-term services and supports
- Elder abuse/mandated reporting
- Person-centered care
- Legal and financial planning

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



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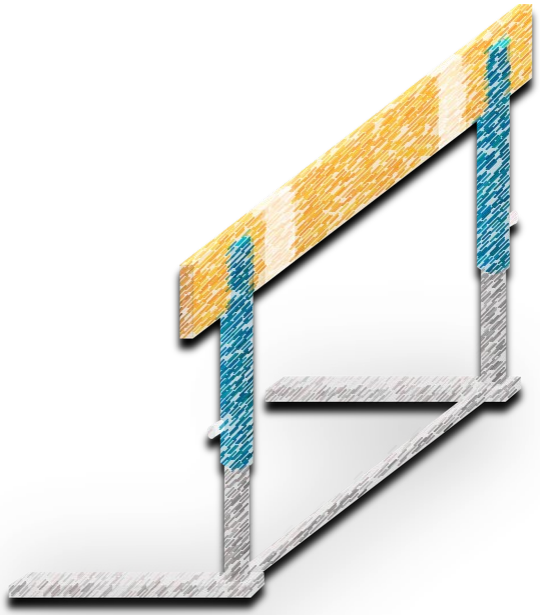
Outcomes

Validated tools administered at enrollment and at 12-month intervals

Person living with dementia	Care partner/caregiver
Reduced depression	Reduced depression
Improved quality of life	Improved quality of life
Reduction in behavioral symptoms	Reduced sense of burden
Helped prepare for future	Improved self-care
Helped adjust to diagnosis	Increased knowledge of community resources
Reduced stress	Reduced stress

Challenges

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



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Lessons Learned

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

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Awards

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

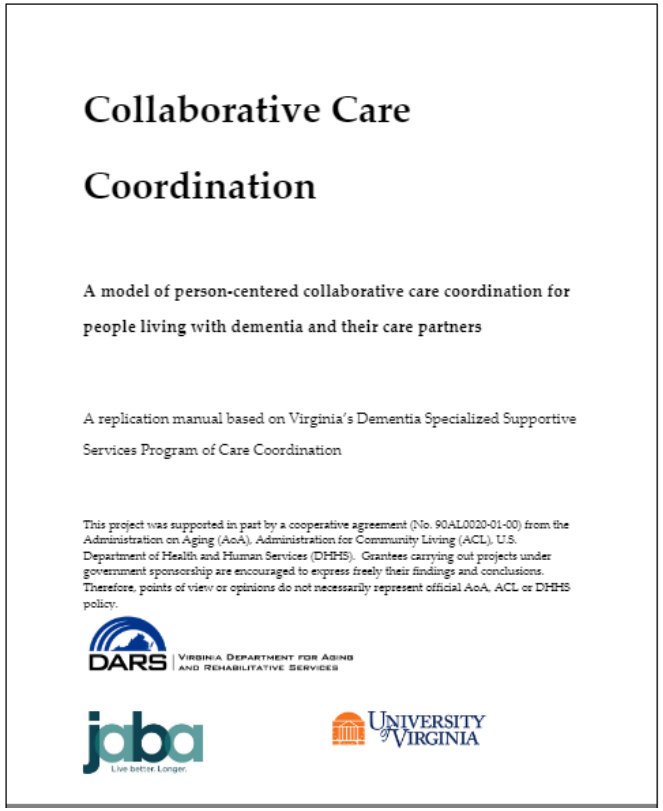
Resources

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

https://www.vadars.org/cbs/dementiaservices.htm#program

Includes:

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



Collaborative Care Coordination

A model of person-centered collaborative care coordination for people living with dementia and their care partners

A replication manual based on Virginia's Dementia Specialized Supportive Services Program of Care Coordination

This project was supported in part by a cooperative agreement (No. 90AL0020-01-00) from the Administration on Aging (AoA), Administration for Community Living (ACL), U.S. Department of Health and Human Services (DHHS). Grantees carrying out projects under government sponsorship are encouraged to express freely their findings and conclusions. Therefore, points of view or opinions do not necessarily represent official AoA, ACL or DHHS policy.

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AlzPossible.org

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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

Eddy Alzheimer's Services

St Peter's Health Partners

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

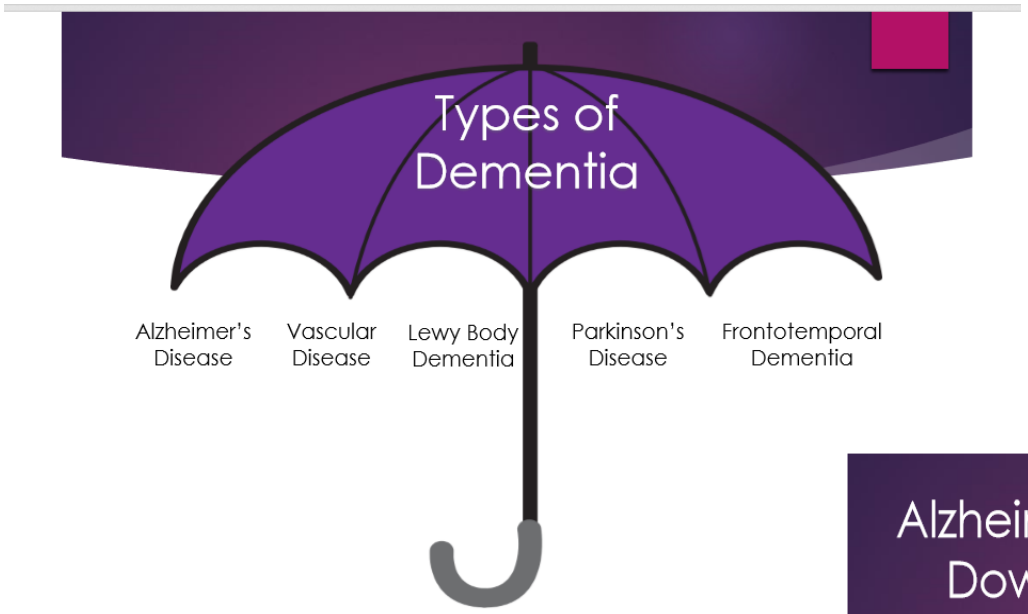
Foundations of Dementia Care Training

- 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

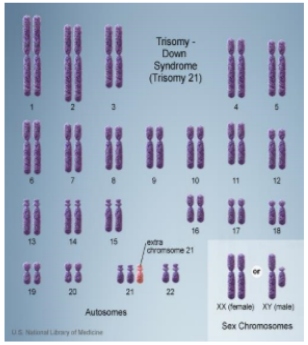
Foundations of Dementia Care Training

- 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



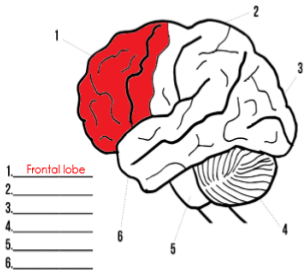
Alzheimer's Disease and Down Syndrome



- 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 of 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.

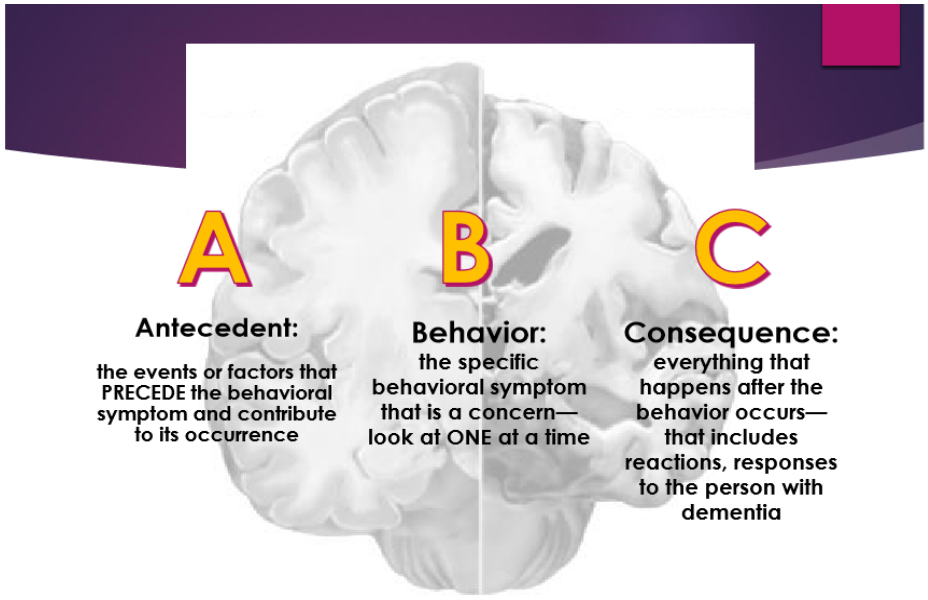
The 7 and 7 Rule

- 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.

Training components

Common Triggers of Behavioral Symptoms

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



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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