CHANGING THINKING!

Advisory 24-6

Navigator Education

Precis

This advisory covers the requirements for training Navigators with a carveout on providing information on what Navigators should know about intellectual disability, aiding families of beneficiaries with intellectual disability, and specialized local resources aiding older adults with disabilities.

ROLE OF NAVIGATORS IN GUIDE

Under the GUIDE model, Participants assign people with dementia and their caregivers to a Dementia Care Navigator who will help them access GUIDE services and supports, as well as non-GUIDE services and supports (including clinical services and non-clinical services, such as respite, meals, home modifications, and transportation through community-based organizations).[1]

Broadly, Dementia Care Navigators collect pre- and post-diagnostic information and support for adults who have been referred for alignment with a GUIDE Participant, provide home assessment information to the interdisciplinary team and Practitioners, arrange appointment for medical or clinical services; provide information caregivers and family members and are a single point of contact with the Participant organization; provide for supports with basic strategies to support people with dementia to continue to live independently and not require admission to a skilled nursing facility; provide for supports for caregivers of adults with dementia to support them in understanding dementia and its consequences or with helping provide clinical supports to aid caregivers developing strategies to respond to behaviors associated with dementia; and provide opportunities to discuss any challenges being experienced by the caregiver, and aid them with planning for the future.[2]

Care navigation is an approach to personalized care management and care coordination that can help overcome barriers to care. Specifically, dementia care navigation functions include: working closely with caregivers; providing emotional support; tailoring education and resources; and coordinating with a clinical team around issues ranging from clinical questions to financial and legal

[1] CMS. Guiding an Improved Dementia Experience (GUIDE) Model. https://www.cms.gov/priorities/innovation/innovation-models/guide

[2] Partially drawn from: What is the role of the Dementia Navigator? Belfast Health and Social Care Trust (n.d.). https://belfasttrust.hscni.net/service/dementia-navigator/

decision-making.[3] Generally, Dementia Care Navigators are skilled in issues in neurodegenerative diseases and aging, how to review medication lists, skills in supportive listening and communication, how to complete assessments of patient function, behavior, and safety risks, how to identify and triage acute problems to the clinical team, and how to identify relevant community resources. Further, Dementia Care Navigators must be facile with conducting person-centered care planning, providing culturally competent care, and managing behavioral and psychosocial symptoms of dementia.[4]

WHO ARE DEMENTIA CARE NAVIGATORS

Dementia Care Navigators can be professionals and lay workers, including but not limited to community health workers, social workers, and registered nurses, as well as person specially hired and trained to fill these positions. While Dementia Care Navigators are not required to have specific credentials or professional accreditation within the GUIDE Model, preliminary investigations with Track 1 Participants are finding these organizations are staffing Dementia Care Navigator roles with seasoned professional personnel (such as OTs, nurses, and social workers) in the first instance, as they are more able to handle the initiation of a new program, managed an extended caseload, make quicker determinations of beneficiary needs, and make more efficiently mandated monthly contact time.[5]

On-boarding new hires necessitates more training demand and broader information content. For professionals, often caseloads of 100 or so are the norm for this group, while lessor caseloads (e.g., 50+) are more ideal for new hires and those with paraprofessional status. Participants also are noting that seasoned employees are retained for longer terms as Navigators. Information such as this leads to possible development of training content at two different levels, one for staff lacking experience in human services, and one for those with extensive experience.

PROFICIENCIES AND THE ROLE OF DEMENTIA CARE NAVIGATION

Individuals working as Dementia Care Navigators must possess skill sets that enable them to successfully meet the demands of the Participant organization for dementia care navigation, which would include the following characteristics:

- Have a personal style that relates well to a range of caregivers and their personal challenges
- Being able to assess a home and caregiving situation with the intent of reporting back to the interdisciplinary team
- Being able to synthesize diverse information from home visits and contacts with caregivers to accurately assess the home situation
- Be able to assess the nature and capabilities of the beneficiary with dementia and his or her current and anticipated needs

[3] Bernstein A, Harrison KL, Dulaney S, Merrilees J, Bowhay A, Heunis J, Choi J, Feuer JE, Clark AM, Chiong W, Lee K, Braley TL, Bonasera SJ, Ritchie CS, Dohan D, Miller BL, Possin KL. The Role of Care Navigators Working with People with Dementia and Their Caregivers. J Alzheimers Dis. 2019;71(1):45-55. doi: 10.3233/JAD-180957.

[4] GUIDE Model Frequently Asked Questions. https://www.cms.gov/priorities/innovation/guide/faqs#care-deliv

[5] Source: UCSF Care Ecosystem Implementation Meetings.

- Being to reliably complete check-lists and forms documenting the level of care required by the beneficial as required by the Participant and GUIDE
- Being knowledgeable of diverse resources available within the immediate locality of the caregiver and corresponding these resources with the expressed needs of the caregiver.
- Being able to report in writing and orally and converse about the caregiving situation and beneficiary's needs with the interdisciplinary team, the Practitioner, Partner organizations, and others involved in providing care aid and support.
- Being able to use a standardized tool to conduct dementia screenings.
- Being able to complete interview in the home, by phone, or another locale, as needed to meet with caregivers to assess needs for services and program assistance under GUIDE
- Being able to maintain individual case records, complete documentation and collect identified data.
- Being knowledgeable of diverse medical, disability, and impairing conditions that may be compounding dementia care needs

GENERAL CONTENT EDUCATIONS AND TRAINING

The GUIDE Model requires that each Participant must ensure that its initial Care Navigator Training is a minimum of 20 hours and includes the following: (a) a *minimum of 10 hours of didactic instruction*, which may be a live (either virtual or in person) or a pre-recorded web-based training; and (b) a *minimum of 10 hours of experiential training*, which must be live (either virtual or in person). The Participants are required to "assess its Care Navigators following the initial Care Navigator Training to ensure comprehension."

The table covers the specific topics designated by CMMI that need to be covered in the training.

Mandated Training Topics for Care Navigators	
Topic	**Further Detail of Topic**
Background on Dementia	Overview of dementia as a medical condition; Progression of disease and balancing dementia with other co-morbidities
Overview of Assessments	Assessments available related to dementia; Recommendations for a successful assessment
Care Plan	What is a care plan; Including beneficiary in the development of plan
Person-Centered Planning	What person-centered planning means; How to incorporate into planning
Challenging Behaviors	Behavioral symptom management; Common behavioral changes due to dementia and how to address
Functional Needs	What are activities of daily living (ADLs) and instrumental activities of daily living (IADLs); Evaluation of ADLs and IADLs; Common changes in ADLs and IADLs due to dementia and how to address; Medication monitoring and maintaining a medication schedule

Advanced Care Planning	What is an advance medical directive and POLST form; How to assist beneficiary in advance care planning
Decision-Making Capacity	What is capacity for medical decision-making; What it means when a beneficiary does not have capacity for medical decision-making; supported decision-making
Safety	Considerations for safety at home, in public, and driving; elder abuse, neglect, and financial exploitation; access to weapons and dangerous substances
Communication	Communication strategies for persons with dementia and their caregivers
Coordination of medical care and community services	Communication with clinical providers; Supporting beneficiary in transitions between settings; Accessing community-based services and supports, including respite services; Working with case managers and other coordinators to address gaps and duplication in a beneficiary's community-based services and supports
Supporting a Caregiver	Caregiver strain and support (e.g.: peer-to-peer support, support group, 1:1 support); In-home caregiver training and importance of caregiver education
Diversity in Dementia	Treating dementia and communicating with diverse populations in a culturally competent way

Source: Guiding an Improved Dementia Experience (GUIDE) Model - Participation Agreement

The caregiver education under the GUIDE Model is not standardized except for this listing of training topics. Specific content has not been dictated. Participants have the option to establish their own programs and provide caregiver training themselves internally, or the participant can contract with a third-party vendor to provide these services

After the initial training, Dementia Care Navigators must take an additional two (2) hours of training each Performance Year in accordance with the following:

(1) the annual training may be developed and offered by the Participant or be a continuing education training offered by a third party;

(2) the annual training may be on a topic chosen by the Participant or the Care Navigator; and

(3) the Participant shall retain confirmation, in a form or manner that the Participant chooses, that its Care Navigator completed the annual training.

INTELLECTUAL DISABILITY SPECIFIC SUPPLEMENTAL EDUCATION

The intellectual disability supplemental education program aims to build on the foundational knowledge provided in the basic Dementia Care Navigator training, along with the experiential requirements mandated by the Centers for Medicare and Medicaid Services (CMS). This specialized supplement is designed to prepare Dementia Care Navigators to effectively assist families or formal

caregivers of beneficiaries with intellectual disabilities. The program seeks to orient navigators to the unique circumstances of home environments where intellectual disability is present and to address the distinct experiences of caregivers who have often been providing supervision and support for many years prior to the onset of dementia.

Structure and Content of the Supplemental Education

The program is structured into two main components:

- Main Package: A 1-hour training module divided into three content units.
- Ancillary Modules: Two additional 30-minute modules offering supplemental content.

The main package, titled *An Overview of Dementia and Adults with Intellectual and Developmental Disabilities,* is a web-based, self-guided instructional course delivered via the Articulate platform. Its content provides Dementia Care Navigators with essential information about the intersection of dementia and intellectual or developmental disabilities. The modules incorporate explanations, video and written vignettes, and technical material to highlight the differences between supporting families of individuals with intellectual disabilities and those of other beneficiaries, such as spouses or kin.

Key Topics Covered

- *Unique Needs and Supports*: The modules identify the specific characteristics of intellectual and developmental disabilities, and the caregiving supports required by beneficiaries.
- *Implications for Navigators:* The course examines the challenges and considerations for care navigators working with this special population, offering guidance on utilizing state and local disability resources.

Training Format

The program has adopted a uniform training modality designed to enhance understanding and application through the following elements:

- *Explanatory Content*: Core information is presented through accessible, well-organized modules.
- *Branching Scenarios*: Learners encounter variations of real-world situations they may face as navigators.
- *Video Vignettes*: Brief visual clips are used to reinforce learning points by illustrating actual caregiving scenarios.
- *Interactive Questions*: Embedded questions assess comprehension, and the practical application of the material covered.
- *Certification Quiz:* A final quiz evaluates overall knowledge retention and is used to certify completion of the module.

This comprehensive approach ensures that Dementia Care Navigators are well-prepared to meet the specialized needs of beneficiaries with intellectual and developmental disabilities, ultimately improving the quality of care and support provided, and ultimately mitigating admission to a long-term facility.

Learning Objectives:

At the conclusion of this supplemental module participants will be able to:

1. Recognize intellectual disability in beneficiaries.

2. Describe the varied impact of dementia on the daily life of beneficiaries with intellectual disability and variations in caregiver experience from providing lifelong care.

3. Identify local resources in the disability community that can benefit the family and beneficiary.

Module 1 - Unit 1: **Dementia and Adults with Intellectual Disability** – content

- Overview of intellectual disability and varied developmental disabilities with risk for dementia, including Down syndrome
- Confounding impact of co-incident conditions on dementia trajectories and progression
- Historical factors impacting on beneficiaries with intellectual disability and dementia
- Case scenarios – identifying intellectual disability
- Unit quiz
- Information on Resources

Module 1 – Unit 2: **Caregiver Perspectives and Care Settings** – content

- Working with family 'perpetual' caregivers of beneficiaries living at home – different approaches than with spousal/parent caregiving
- Working with formal caregivers in group home and alternate care settings
- Perspectives of caregivers related to the care of beneficiaries with intellectual disability and dementia
- Differences for 'perpetual' caregivers with advance care planning
- Assessing caregiving environments
- Scenarios – identifying unspoken needs
- Unit quiz
- Information on Resources

Module 1 – Unit 3: **Community Resources/Disability Networks** – content

- Review of aging network and intellectual disability
- Review of intellectual/developmental disabilities system
- Review of other community resources
- Conjoint resources from state intellectual/developmental disabilities agencies
- Scenarios – locating resources/matching to family needs
- Unit quiz

- Information on Resources

Completion credits and certification

One (1) continuation education credit and certificate of completion after successful completion of module and module quiz

Other supplementary modules.

These specialty modules are offered to help Dementia Care Navigators gain skills (1) in undertaking periodic assessment of behavior and function using an instrument specific for adults with intellectual disability with dementia (suspected or diagnosed) and (2) in understand more in-depth the various intellectual disabilities and how the interaction of a specific intellectual disability and dementia affects care planning.

1. **Assessing intellectual disability and dementia using the EDSD** – ~(0.5 credit)

Learning objectives:

At the conclusion of taking this module, the Dementia Care Navigator will be able to:

1. Administer the EDSD
2. Summarize the key findings for the interdisciplinary team and Practitioner
3. Suggest interventions or specific follow-up as part of the dementia care plan

Content

- Explanation of instrument
- Video on administration
- Interpretation of findings
- Translation of findings to dementia care planning
- Unit quiz
- Resources

2. **Implications of types of intellectual disability and coincident conditions** – (0.5 credit)

Learning objectives:

At the conclusion of taking this module, the Dementia Care Navigator will be able to:

1. Recognize significant differences among various intellectual disabilities
2. Describe various co-incident conditions associated with various intellectual disabilities
3. Identify behavioral trajectories and dementia progression factors associated with various intellectual disabilities

Content

- Review of Down syndrome and Alzheimer's disease and other specific etiologies
- Review of prevalent BPSDs and intellectual disability
- Review of expectations of medical conditions and functional decline
- Review of effectiveness of various interventions and intellectual disability

- Unit quiz
- Resources

Completion credits and certification

One-half (0.5) continuation education credit and certificate of completion after successful completion of each of the two supplementary modules and module quiz. The certificate will be issued by the National Task Group.

-30-

The development of this product was supported in part by the Special Olympics Systems Change for Inclusive Health Subgrant, funded by the Centers for Disease Control and Prevention. The contents of this project are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the US Department of Health and Human Services.

11/Dec/2024