ntg National Task Group on Intellectual Disabilities and Dementia Practices

NTG-NDSS Advisory on GUIDE and the Inclusion of Adults with Intellectual Disability & Down Syndrome and Dementia

Summary

This advisory provides a succinct summary of key elements of the GUIDE program that bear exploration with respect to the inclusion of adults with eligibly beneficiaries with intellectual disability, including Down syndrome, living with dementia and their caregivers. Noted are some of the basics and intents of the GUIDE program, a rationale for a focus in creating beneficiaries with Down syndrome (and other intellectual disabilities), commentary on training of navigators, use of instruments for assessing dementia impact and recommendations of locating beneficiaries and creating alignment with GUIDE Participants.

Background

On July 31, 2023, the Centers for Medicare & Medicaid Services (CMS) announced a new voluntary nationwide model – the Guiding an Improved Dementia Experience (GUIDE) Model – a model test that aims to support people living with dementia and their unpaid caregivers.[1] CMS announced that it would accept letters of interest for the GUIDE Model through September 15, 2023, and would release a GUIDE Request for Applications (RFA) for the model in the Fall of 2023. The model is expected to launch on July 1, 2024, and run for eight years.[2]

As CMS noted, the GUIDE Model will focus on dementia care management and aims to improve quality of life for people living with dementia, reduce strain on their unpaid caregivers, and enable people living with dementia to remain in their homes and communities. It is expected to achieve these goals through a comprehensive package of care coordination and care management, caregiver education and support, and respite services. It was designed to advances key goals of the National Plan to Address Alzheimer's Disease, which was established through the National

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[1] In GUIDE Model, the term "caregiver" is defined as a relative, or an unpaid nonrelative, who assists the beneficiary with activities of daily living and/or instrumental activities of daily living. Depending on the beneficiary's need, the assistance may be episodic, daily, or occasional.

[2] CMS. Guiding an Improved Dementia Experience (GUIDE) Model. (2023). https://www.cms.gov/priorities/innovation/innovation-models/guide

Alzheimer's Project Act (NAPA) and served to accelerate federal actions to optimize the quality of care for people living with dementia and their caregivers.

Despite its prevalence, many people living with dementia do not consistently receive high-quality, coordinated care. As a result, they experience poor outcomes, including high rates of hospitalization, emergency department visits, and post-acute care utilization. They also experience

high rates of depression, behavioral and psychological symptoms of dementia, and poor management of other co-occurring conditions.

CMS noted that dementia significantly impacts the family and other unpaid caregivers, who often provide significant amounts of assistance with personal care, finance, household and medication management, clinical coordination, and other care. Many caregivers for people living with dementia, who are often Medicare beneficiaries themselves, report elevated levels of stress and depression, which negatively affect their overall health and increase their risk for serious illness, hospitalization, and mortality.

Through the GUIDE Model, CMS plans to assess an alternative payment for participants that deliver key supportive services to people with dementia, including comprehensive, person-centered assessments and care plans, care coordination, and 24/7 access to a support line. Under the model, participants will assign people with dementia and their caregivers to a care navigator who will help them access services and supports, including clinical services and non-clinical services such as meals and transportation through community-based organizations.

The GUIDE Model, as designed by CMS, is intended to enhance access to the support and resources needed by unpaid caregivers, who will be connected to evidence-based education and support, such as training programs on best practices for caring for a loved one living with dementia. Grantees will also help caregivers access respite services, which enable them to take temporary breaks from their caregiving responsibilities. The model is also designed to reduce Medicare and Medicaid expenditures primarily by helping people with dementia to remain at home, and reducing hospitalization, emergency department use, and the need for post-acute care (as well as long-term nursing home care).

The GUIDE Model aims to address the key drivers of poor-quality dementia care in five ways: (1) Defining a *standardized approach to dementia care delivery* for model participants – this includes staffing considerations, services for beneficiaries and their unpaid caregivers, and quality standards; (2) Providing an *alternative payment methodology to model participants* – CMS will provide a monthly per-beneficiary payment to support a team-based collaborative care approach; (3) *Addressing unpaid caregiver needs* – the model will aim to address the burden experienced by unpaid caregivers by requiring model participants to provide caregiver training and support services, including 24/7 access to a support line, as well as connections to community-based providers. (4) Respite services – CMS will *pay model participants for respite services*, which are temporary services provided to a beneficiary in their home, at an adult day center, or at a facility that can provide 24-hour care for the purpose of giving the unpaid caregiver temporary breaks from their caregiving responsibilities; and (5) Screening for Health-Related Social Needs – model participants will be required to *screen beneficiaries for psychosocial needs and health-related social needs* (HRSNs) and help navigate them to local, community-based organizations to address these needs.

Participants in the GUIDE Model (that is, those *grantees chosen to be part of the test of the model*) will establish dementia care programs (DCPs), using an interdisciplinary team approach, that will provide ongoing, longitudinal care and support to people living with dementia. GUIDE participants will be Medicare Part B enrolled providers and suppliers that are eligible to bill for Medicare Physician Fee Schedule services and agree to meet the care delivery requirements of the model. The CMS GUIDE model permits those participants that cannot meet the GUIDE care delivery requirements alone, to contract with other Medicare providers/suppliers to meet the care delivery requirements. These contracted providers/suppliers will be known as "Partner Organizations." To have sufficient model participation and improve the recruitment of diverse beneficiaries, CMS will permit organizations that do not currently offer comprehensive dementia care or have prior experience with alternative payment models to participate. To enable such participation, CMS will support model participation for these organizations by providing technical assistance and learning support as well as a pre-implementation year to prepare for model participation.

The eight-year model offers two tracks: (1) one for established programs, and (2) another for new programs. Established programs must have an interdisciplinary care team, including a care navigator, use an electronic health record platform that meets the standards for Certified Electronic Health Record Technology, and meet other care delivery requirements. New programs may not be operating a comprehensive community-based DCP at the time of model announcement and will have a one-year pre-implementation period to establish their programs.

As part of its health equity strategy, CMS expects that delivering equitable care and addressing health disparities in dementia will be crucial aspects of each participant's enactments of the GUIDE Model.[3] CMS has noted that dementia imposes significant financial, emotional, and logistical burdens on families, which are often exacerbated for certain racial and ethnic groups. Black and Hispanic populations have a higher prevalence of dementia, but they also are less likely to receive a timely diagnosis, have more unmet needs, are more likely to experience high caregiving demands, and spend a higher share of their family assets on dementia care. Inherent in such health equity deliverables, it is understood that some specific populations, expressing substantial risk for dementia and an associated high burden of care by families, will also be included.

Such populations include those older adults with intellectual disability, and particularly those with Down syndrome. The NDSS has noted that Alzheimer's disease affects about 30% of

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[3] CMS. Guiding an Improved Dementia Experience - Request for Applications (Version: 1). https://www.cms.gov/files/document/guide-rfa.pdf

adults with Down syndrome in their 50s, and that by their 60s, this number comes closer to 50%.[4] Providing care at home often extends the challenges that many families face. As they face their own aging, and the possibility of a spouse with impairments, the challenges of providing dementia care become more prominent. One critical difference between life-long caregivers (or perpetual parents) who live with their kin with Down syndrome now affected or debilitated by dementia) and spousal or offspring caregivers of older adults with dementia, is the nature of acclimation and assumption of caregiving responsibilities. Parents or other kin caregivers have multiple years' experience of caregiving, and with the onset of dementia challenged by new behaviors and diminishing capabilities. Often, their support needs mirror those of assumed caregivers, but also may involve long term disparities with receiving aid for caregiving.

Some of the disparities, beyond personal care, as the result of diminishing self-care capabilities. Such family caregivers may also be facing new challenges with dealing with heretofore absent problem behaviors which may now pose safety risks, increase self-neglect, and raise issues of continued capacity to care. These often include physical and verbal aggressiveness, self-injury, inappropriate sexual behavior, wandering, or getting lost. They also may have to contend with nuisance behaviors leading to increased frustration and anxiety for self and others. Studies also show that caregiver distress is often most impacted by symptoms of apathy followed by nighttime behavior, appetite/eating abnormalities, anxiety, irritability, disinhibition, and depression.[5,6] They are also faced with needs for respite, aid with adapting their homes, and providing supervision to ambulatory, cognitively impaired adults, whose physical conditions may progress to non-ambulatory care. Another factor is their diminishing ability to provide physical care due to their own aging and the progressive loss of ambulation of their offspring. This group of adults and their families are an integral part of any participants' efforts to expand their services with respect to health equity deliverables.

CMS has noted that it will actively seek out the participation of eligible organizations that provide care to underserved communities for participation in the GUIDE Model. To this end, CMS plans to offer a variety of financial and technical supports to ensure that participating safety-net providers can develop their infrastructure, improve their care delivery capabilities, and participate successfully in the model.

Under the GUIDE structures, there will be a focus on beneficiaries with dementia who are dually eligible for Medicare and Medicaid and, as with other patients supported by the model, help

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[4] NDSS. Alzheimer's Disease & Down Syndrome. https://ndss.org/resources/alzheimers

[5] Fonseca LM, Mattar GP, Haddad GG, Burduli E, McPherson SM, Guilhoto LMFF, Yassuda MS, Busatto GF, Bottino CMC, Hoexter MQ, Chaytor NS. Neuropsychiatric symptoms of Alzheimer's disease in Down syndrome and its impact on caregiver distress. J Alzheimers Dis. 2021;81(1):137-154. doi: 10.3233/JAD-201009

[6] Dekker, A.D., Strydom, A., Coppus, A,M,W., Nizetic, D., Vermeiren,, Y., Naude, P.J.W., Van Dam, D., Potier, M-C., Fortea, J., De Deyn, P.P. Behavioural and psychological symptoms of dementia in Down syndrome: Early indicators of clinical Alzheimer's disease? Cortex, 2015, 75, 36-61. doi: 10.1016/j.cortex.2015.07.032. Epub 2015 Aug 13.

them to remain safely in their homes for longer. Many adults with Down syndrome (and other intellectual disabilities) fall into this category of federal assistance recipients.

Eligible Beneficiaries

The GUIDE Model is designed to serve community-dwelling Medicare Fee-for-Service (FFS) beneficiaries, including beneficiaries dually **eligible for Medicare and Medicaid**, who have dementia. For the purposes of the GUIDE Model, a *caregiver* is defined as a relative, or unpaid nonrelative, who assists the beneficiary with activities of daily living and/or instrumental activities of daily living. Depending on the beneficiary's need, the assistance may be episodic, daily, or occasional.

Adults meeting the criteria for being able to receive services under the GUIDE model must meet one of the following:

- ***Has dementia***, as confirmed by attestation from a clinician on the GUIDE Participant's GUIDE Practitioner Roster (see "Dementia Diagnosis Attestation" for more information);
- Enrolled in Medicare Parts A and B;
- Not enrolled in Medicare Advantage, including Special Needs Plans (SNPs);
- Have Medicare as their primary payer;
- Not enrolled in the Program of All-Inclusive Care for the Elderly (PACE);
- Has not elected the Medicare hospice benefit; and
- Not a long-term nursing home resident (defined as residence in a nursing home that is not paid for under the Medicare skilled nursing facility benefit)

"Community-dwelling" is defined as living in a personal home, assisted living facility, **group home**, or other community setting and excludes beneficiaries who become a long-term nursing home resident, defined as a nursing facility stay that is not covered under the Medicare skilled nursing facility benefit. Beneficiaries will still be considered community-dwelling for purposes of this model if they are admitted to an acute care hospital or receive post-acute care in skilled nursing facility. "*Basic personal everyday activities"* include bathing, dressing, transferring, toileting, mobility and eating. "*Activities related to independent living*," include preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and communication.

Dementia must be present in a beneficiary to make them be eligible for 'alignment to a GUIDE Participant' but may be at any stage of dementia—mild, moderate, or severe (mild cognitive impairment is not a dementia diagnosis and is not sufficient to meet this eligibility criteria). To confirm that beneficiaries have dementia that makes them eligible for the GUIDE Model, CMS will rely on clinician attestation rather than prior claims-based ICD-10 dementia diagnosis codes. A clinician on the GUIDE Participant's GUIDE Practitioner Roster must attest that based on their comprehensive assessment, beneficiaries meet the National Institute on Aging-Alzheimer's Association diagnostic guidelines for dementia and/or the DSM-5 diagnostic guidelines for major neurocognitive disorder. Alternatively, they may attest that they have received a written report of a documented dementia diagnosis from another Medicare-enrolled practitioner.

Beneficiary alignment is the linking of a beneficiary to a participant/provider so that services can be provided. The process of alignment is outlined in the CMS document, "Guiding an Improved Dementia Experience: Request for Applications" available at https://www.cms.gov/files/document/guide-rfa.pdf.

Implications for adults with Down syndrome and their caregivers

The CMS GUIDE model is designed to be inclusive and does not expressly exclude any group. CMS has noted that equitable care is a key component of achieving high-quality care for beneficiaries and is therefore critical to the GUIDE Model's success. CMS defines health equity as: "the attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, **disability,** sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes." The term "underserved communities" refers to populations sharing a particular characteristic, as well as geographic communities, which have been systematically denied a full opportunity to participate in aspects of economic, social, and civic life. As a special consideration, the GUIDE's Health Equity Adjustment (HEA) is designed to provide additional resources to GUIDE Participants that deliver care to beneficiaries from underserved communities. Thus, inclusion of adults with Down syndrome and their caregivers can benefit Participants. However, to be an aligned beneficiary in the program, adults with Down syndrome (or other intellectual disability) must meet the clinical criteria for the presence of dementia, be Medicare/Medicaid eligible, and their caregivers must have an expressed need for supports.

Down syndrome is the leading genetic cause of intellectual disability and automatically qualifies individuals for Social Security Insurance. Medicaid is the nation's primary payer of long-term services and supports, including HCBS programs, for individuals with intellectual or developmental disabilities.[7] Therefore, Medicaid is the major health insurance provider for this population which is at high risk for dementia, obesity, and premature mortality. Medicare, which can supplement Medicaid, is available for older adults and those who receive Social Security Disability Insurance (through their or a parent's eligibility). Medicare benefits usually start once people reach age 65 unless they qualify by disability before that age (having received Social Security Disability Insurance for at least 24 months related to their disability status). Medicaid provides a crucial service for adults with Down syndrome, including those who are aging.[8] In 2019, Medicare insured 582,868 adults with identified intellectual disability, autism, or Down syndrome.

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[7] GAO. Medicaid: Characteristics of and Expenditures for Adults with Intellectual or Developmental Disabilities. GAO-23-105457 Published: Apr 24, 2023. Publicly Released: Apr 24, 2023. https://www.gao.gov/products/gao-23-105457

[8] Rubenstein E, Michals A, Wang N, Scott A, Tewolde S, Levine AA, Tripodis Y, Skotko BG. Medicaid Enrollment and Service Use Among Adults with Down Syndrome. JAMA Health Forum. 2023 Aug 4;4(8):e232320. doi: 10.1001/jamahealthforum.2023.2320. PMID: 37566429; PMCID: PMC10422190.

Of 582,868 Medicare beneficiaries, 149,172 were Medicare only and 433,396 were dual-enrolled. Most Medicare enrollees are enrolled as child dependents (61.5%).[9] Medicare part A (hospital insurance) covers services provided by hospitals, skilled nursing facilities, hospice, and home health agencies, whereas part B (medical insurance) covers services and supplies needed to diagnose or manage medical conditions and preventive health services.[10]

Bayen et al (2021)[11] found that among 3,001,977 Californian Medicare beneficiaries, **353 individuals had DS with dementia (age 45–89 years)** or 0.00012%. They found that DS dementia was associated with increased level of multimorbidity (mean of 3.4 conditions in addition to dementia vs. 2.7 and 2.2 conditions for DS without dementia and AD, respectively), with more emergency room visits (88% vs. 76.5% and 54.4%) and with more primary care physician visits (91.2% vs. 87.3% and 81.3%). DS adults with dementia have higher health care costs than DS adults without dementia and adults with AD. Understandably, this group of adults would benefit significantly from being beneficiaries within the GUIDE program and services to their caregivers would more efficiently coordinate their health care needs due to dementia and help facilitate management of adult and geriatric care resources for these high-need high-cost individuals – and preclude more costly institutional admissions.

How many adults with Down syndrome might be potential beneficiaries? Using the California data derived from Bayen et al., which showed that about 40% of adults with Down syndrome in the age band 45-90 were noted to have dementia and extrapolating from the statistical projections for the US population of adults with Down syndrome aged 45-90 (N=10,400) noted by Presson et al.[12] and using the probable 40% of adults in this age band with DS dementia, **it is estimated that the number of potential beneficiaries across the US would be ~4,180** (or about .003/100,000). This estimate needs to be considered speculative, as there are no systemic prevalence figures for people with Down syndrome in the US to guide us, and there is an expectation that the prevalence of dementia will increase with each successive age band between 45 and 90, and older bands will be affected by higher mortality. It also reflects Medicare enrollees, and not the greater population of adults with Down syndrome. As Bayen et al. noted, they were not sure that the Medicare data reflected the full population of adults with Down syndrome in that age

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[9] Eric Rubenstein PhD, Salina Tewolde MSc, A. Alex Levine MPH, Lillian Droscha BS, Rachel Midori Meyer BA, Amy Michals MPH, Brian Skotko MD, MPP. Medicare, Medicaid, and dual enrollment for adults with intellectual and developmental disabilities. Health Research Service, First published: 24 January 2024. https://doi.org/10.1111/1475-6773.14287

[10] Centers for Medicare and Medicaid services. What's Medicare? (2024). https://www.medicare.gov/signup-change-plans/decide-how-to-get-medicare/whats-medicare/what-is-medicare.html]

[11] Eleonore Bayen, Kristine Yaffe, Laurent Cleret de Langavant, Yingjia Chen, Katherine L. Possin, (2021). The direct health care cost to Medicare of Down syndrome dementia as compared with Alzheimer's disease among 2015 Californian beneficiaries. Annals of Physical and Rehabilitation Medicine, 64(1),101430, ISSN 1877-0657,https://doi.org/10.1016/j.rehab.2020.07.011.

[12] Angela P. Presson, Ginger Partyka, Kristin M. Jensen, Owen J. Devine, Sonja A. Rasmussen, Linda L. McCabe, Edward R.B. McCabe. (2013). Current Estimate of Down Syndrome Population Prevalence in the United States. Journal of Pediatrics, 163(4), 1163-1168, https://doi.org/10.1016/j.jpeds.2013.06.013.

band. Also, it is doubtful that everyone with Down syndrome in this target age range would be enrolled in Medicare or be a dual eligible or would be in one of the GUIDE catchment areas during the 8-year period of the demonstration. However, this estimated number can help guide case finding and potential enrolment/alignment as beneficiaries in the GUIDE Participant geographic areas.

Alignment strategies

The GUIDE program uses the term 'alignment' to correspond with the determination process of appropriateness and need for receiving services from a GUIDE Participant. To help find potential beneficiaries by GUIDE Participants, which do not have an extensive consumer base (in contrast to intellectual disability/Down syndrome program providers), CMS intends to use Medicare data to identify potential beneficiaries for the GUIDE participants (that is, CMS will provide claims data from a three-year historical look-back period to identify beneficiaries who received Medicare services from a GUIDE Participant, have claims-based ICD-10 dementia diagnosis codes, and are eligible for the GUIDE Model). However, for participants seeking to identify potential beneficiaries with Down syndrome and their caregivers, we would recommend that GUIDE Participants partner with local providers of intellectual and developmental disabilities services (such as agencies serving adults with Down syndrome, chapters of the Down Syndrome groups, state and regional offices for persons with intellectual disability, and area agencies on aging and other providers within the local aging network) and identify potential beneficiaries. Conversely, family associations, provider agencies, and others advocating on behalf or serving adults with Down syndrome, whether aiding family caregivers, providing housing via group homes, or supporting adults living autonomously should contact the local GUIDE participant organizations via its referral resources (Navigators) to arrange for potential alignment to a GUIDE Participant. More specificity on the GUIDE processes is available at https://www.cms.gov/priorities/innovation/innovation-models/guide.

The alignment strategy for persons with Down syndrome would mirror that of other potentially eligible beneficiaries. After a potentially eligible beneficiary is identified the next step is for the GUIDE Participant to schedule the person with dementia, or suspected dementia, for an initial comprehensive assessment visit. During the initial comprehensive assessment visit, which is similar to the Medicare service identified by CPT code 99483, Cognitive Assessment and Planning, the GUIDE Participant's interdisciplinary care team will assess the beneficiary and their caregiver (if applicable) across a number of required domains, including cognitive function, functional status, clinical needs, behavioral and psychosocial needs, and caregiver burden, with the goal of confirming a dementia diagnosis and creating a comprehensive care plan. During the assessment, if the interdisciplinary care team determines that the beneficiary has dementia and may be eligible to be aligned to the GUIDE Participant, then the care team must obtain the beneficiary's consent to voluntarily align to the GUIDE Participant. With situations where an adult with Down syndrome may lack the capacity to offer consent (due to intellectual disability or cognitive impairment due to dementia), there is a provision for the GUIDE Participant to identify and recognize the beneficiary's legal representative to prove consent.

Measures for determining alignment to tiers

CMS plans to assign aligned beneficiaries to one of five "model tiers," based on a combination of their disease stage, whether they have a caregiver, and if applicable, the degree of burden their caregiver is experiencing. Beneficiary and caregiver complexity, and correspondingly, care intensity and payment, will increase by tier.[13] To ensure consistent beneficiary assignment to tiers across GUIDE Participants, the GUIDE Participant are to use tools from a set of approved screening tools to measure dementia stage and caregiver burden. Approved tools have established scoring thresholds that correspond to mild, moderate, and severe disease stage or caregiver burden. Alternatively, the GUIDE Participant will have the option to seek CMS approval to use an alternative tool by submitting the proposed tool, along with published evidence that it is valid and reliable and a crosswalk for how it corresponds to the GUIDE Model's tiering thresholds. This would apply in certain situations involving an adult with Down syndrome and dementia.

According to the GUIDE model, the approved measurement tool set initially include two instrument that gauge dementia stage, the *Clinical Dementia Rating* (CDR)[14] and the *Functional Assessment Screening Tool* (FAST)[15], as well as one tool to report caregiver strain, the *Zarit Burden Interview* (ZBI).[16] For dementia staging (the CDR and the FAST) pick up on the capacities in cognitive functioning and activities of daily living (ADL) and/or instrumental activities of daily living (IADL). Both the CDR and FAST can apply to adults with intellectual disability or Down syndrome, but in most case they show significant impairment due to floor effects related to innate cognitive impairments. They will confirm deficits, but if GUIDE Participants are seeking precision with respect to dementia impairment, tools more specialized for use with adults with intellectual disability would be more appropriate. The Zarit Burden Interview has widespread application and has been used in the intellectual disability field to assess caregiver burden with reasonable reliability.

As CMS has noted, additional tools may be added to the approved measurement tool set throughout the course of the GUIDE Model. While these are the only specified assessment tools that CMS requires for model tiering and quality measure development, participants may use other assessment tools necessary to meet the care delivery requirements. As a critical mass of GUIDE Participants and partners evolve and broaden their beneficiaries, including eligibles with

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[13] CMS. Guiding an Improved Dementia Experience - Request for Applications (Version: 1). https://www.cms.gov/files/document/guide-rfa.pdf

[14] Morris JC. Clinical Dementia Rating: A Reliable and Valid Diagnostic and Staging Measure for Dementia of the Alzheimer Type. International Psychogeriatrics. 10 January 2005.

[15] Sclan SG and Reisberg B. Functional Assessment Staging (FAST) in Alzheimer's Disease: Reliability, Validity, and Ordinality. International Psychogeriatrics. 07 January 2005.

[16] Bedard M, Molloy DW, Squire L, et al. The Zarit Burden Interview: A New Short Version and Screening Version. The Gerontologist. October 2021. 41(5): 652-657.

intellectual disability or Down syndrome, an agreed upon set of measures tailored to this population could be adopted. Such standardization of equivalencies would contribute to agreement that the data set being used for the GUIDE program evaluation would reflect the inclusion of the assessment of services to families/caregivers of adults with Down syndrome.

Education and training of ‘navigators’

Navigators are defined broadly under the GUIDE model. CMS notes that to serve as a ‘care navigator’ under the GUIDE Model, although an individual must satisfy the select training requirements, CMS does not require individuals to have specific professional backgrounds or certifications. CMS believes that registered nurses, licensed clinical social workers, and community health workers would all be well-suited to this role, although at briefings, the CMNI team noted that specialty workers experienced with the intellectual disability or Down syndrome community would qualify.

The GUIDE program requires that individuals employed as navigators complete a comprehensive training program, particularly since this role can be filled by a non-practitioner lay person such as a community health worker (CHW). The purpose of the training is to provide a foundation for care navigators prior to delivering services to beneficiaries. The GUIDE Participant must deliver this one-time training when a care navigator joins the care team, regardless of the care navigator’s professional background. CHWs can help health care organizations improve health care quality, reduce provider burden, and strengthen relationships and trust within the communities for which they provide care. The CHW job title is sometimes—but not always—used interchangeably with titles of lay health worker, *promotora*, community health representative, peer health educator, or care/patient navigator, among other titles. These roles may provide services for differing audiences, disease types, community make-ups, or other known issues. The expectation is that the equivalent of direct support professionals, with specialized training and appropriate education, would fulfill the role on a CHW when providing services in disability communities.

With respect to the training, CMS requires a minimum of 20 hours, including a minimum of 10 hours of didactic instruction plus a minimum of 10 hours of experiential training, e.g., job shadowing of experienced care navigators, supervised interactions with beneficiaries, case studies, or on-the-job training. The minimum of 10 hours of didactic instruction may be live or a web-based training. The minimum of 10 hours of experiential training must be live, not asynchronous. The GUIDE Participant must develop an assessment for care navigators to take after the training to ensure comprehension. The content of the training is generic and involves exposure the following topics:

- **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 them.
- **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.

To the extent possible, the CMS permits the GUIDE Participant to use a combination of training programs that are already available to meet this requirement. An applicant with an established dementia care program may already provide staff trainings that are in large part consistent with the proposed training topics, but they may need to modify, or add to, their training program to comply with model requirements. For potential navigators who may be collaborating with partners or the GUIDE Participant and focusing on the intellectual disability community, the NTG's National Intellectual Disability and Dementia Training Curriculum and two-day workshops primarily fulfill the knowledge and skill requirements noted in the GUIDE training requirements.[17]

Recommendations

The GUIDE Model will have two participant tracks, one for established dementia care programs and one for new dementia care programs. The purpose of the two tracks is to allow established programs to begin their performance in the GUIDE Model on July 1, 2024, while giving organizations that do not currently offer a comprehensive community-based dementia care program, including safety net organizations, time and support to develop a new program. The new program development is intended to help to increase beneficiary access to specialty dementia care, particularly in underserved communities.

We encourage local/regional intellectual disabilities organizations and providers to

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[17] NTG's National Intellectual Disability and Dementia Training Curriculum. www.the-ntg.org/education

(a) Reach out to existing dementia care GUIDE Participants and work our partner agreements to coordinate and provide dementia care services to families and caregivers, and to those adult lining along, of adult with intellectual disability and dementia in need and embed their services within the aegis of GUIDE Participant care planning and provision; and

(b) Reach out to those GUIDE participants with deferred tracks, to incorporate dementia care services into their planning and interorganizational partnership agreements once they are authorized to begin providing services under the GUIDE Model.

Resources

NDSS. Aging and Down Syndrome

NDSS. Alzheimer's and Down syndrome

NTG. Community care practices

NTG. Assessments

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