



CHANGING THINKING!

ADVISORY 24-7

GUIDE CAREGIVERS

Precis

This advisory identifies caregivers, and proffers distinctions of caregiver of persons with intellectual disability from those caregiving for older adults who may be parents or spouses. It provides information for Navigators with respect to this distinction and proposes assessment aspects that can identify the relationship to dementia of long-term caregivers via a staging model. It also identifies areas where required service delivery may be modified to accommodate experienced long-term caregivers and the special needs of beneficiaries with intellectual disability.

BACKGROUND

Dementia affects more than 6.7 million adults in the United States, many of whom live with multiple chronic conditions and receive fragmented care. This often leads to high rates of hospitalization, emergency department visits, and the need for 24-hour care. People with dementia frequently experience depression, along with behavioral and psychological symptoms, further complicating their care needs. Informal caregivers, who provide constant support, face significant challenges, including mental, physical, emotional, and financial burdens. Notably, about 30% of dementia caregivers are Medicare beneficiaries themselves. These struggles disproportionately impact caregivers from Black, Hispanic, Asian, Native Hawaiian, and Pacific Islander communities as well as from the lifelong disability community. The GUIDE model seeks to address these issues by providing consistent funding for a standardized approach to dementia care. It aims to support caregivers and enable adults with dementia to remain safe in their homes, delaying or preventing nursing home placement. The GUIDE model strives to improve the quality of life for both individuals with dementia and their caregivers.¹

¹ CMS. Guiding an Improved Dementia Experience (GUIDE) Model. <https://www.cms.gov/priorities/innovation/innovation-models/guide#:~:text=The%20GUIDE%20Model%20focuses%20on,in%20their%20homes%20and%20communities.>

WHO ARE CAREGIVERS UNDER GUIDE?

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.²

In a paper issued in 2007, CMS clarified its authority to provide funding to caregivers. The paper noted that “Caregivers are broadly defined as family members, friends, or neighbors who provide unpaid assistance to a person with a chronic illness or disabling condition. The nature of the assistance could include helping the person with Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs); performing “medical” tasks such as administering intravenous drugs or caring for wounds; acting as the person’s legal representative; or other activities.”³

Who functions as the caregiver in situations when the beneficiary resides in assisted living or a group home? In the GUIDE model, when beneficiaries live in assisted living or a group home, the "caregiver" can be a relative or unpaid non-relative who assists or supplements the beneficiary with activities of daily living, even if the primary care is provided by staff at the assisted living facility. It is anyone who provides additional or supplemental support to the beneficiary beyond what the facility offers -- whether that is a family member, friend, or other designated person.⁴

According to CMS, a GUIDE caregiver is someone who helps the beneficiary with ADLs and/or IADLs. This is true, even when a beneficiary resides in assisted living or a group home. Their family or designated caregiver can still be considered part of the GUIDE program to receive additional support and coordination of care. The primary goal of the GUIDE model is to enhance support for caregivers of people living with dementia and to enable beneficiaries with dementia to continue living in the community and preclude institutional admissions.

WHAT SERVICES CAN BE PROVIDED TO CAREGIVERS UNDER GUIDE?

Caregivers can obtain an assessment to identify their individual health needs and those of the beneficiaries, and to help build a care plan that is tailored to provide the services they and the beneficiary need. A relative or unpaid nonrelative who helps as a caregiver can receive education and support such as direct communication with a dementia care navigator when they

² CMS. GUIDE Model Frequently Asked Questions. <https://www.cms.gov/priorities/innovation/guide/faqs#ben-cgs>

³ CMS. CMS Support for Caregivers (September 2007). <https://www.cms.gov/Outreach-and-Education/Outreach/Partnerships/downloads/CMSCaregivers91907.pdf>

⁴ AI Overview of the question posed to Google: “Who is the caregiver in GUIDE when beneficiaries reside in assisted living or a group home?” December 14, 2024.

need it. GUIDE Respite Services can be provided, up to an annual cap (\$2,500), so caregivers may take a break when they need to.

Support can come from local in-home respite providers, adult day centers, and other housing settings (that can accommodate 24-hour care). This would also include group homes, with open respite beds, operated by a local intellectual/ developmental disabilities service providers.⁵ Caregivers are also eligible to be aided by being enrolled in community-based services like meals, transportation, and obtaining limited home modification assistance. Caregivers also can be aided with managing behavioral health symptoms and to be linked to clinical and support services via care teams. Care navigators can also help with obtaining care supports via a 24/7 access to a care team member or helpline to ask questions or get support.⁶

An example of GUIDE program assistance provision:

Regina is a professional artist, teacher, and sole caregiver for her son, David, who has Down syndrome and dementia. Regina's husband had a heart attack a few years ago and passed away. David is an only child, and Regina does not have family nearby. Although Regina is in good health, she is 62 years old and beginning to experience and think more about age-related issues. As David's primary caregiver, Regina is responsible for the 24/7 supervision he requires, administering his medications, making and accompanying him to all medical appointments, completing the paperwork for his medical and home and community-based services, planning and facilitating his person-centered planning meetings and accompanying him to Special Olympic practices and other social events. As David's dementia is rapidly progressing and his self-care skills are deteriorating, Regina has had to take a more active role in bathing, dressing and feeding him. Regina is experiencing more physical, mental and emotional stress as she sees her once physically active, mentally acute, and personable son become nonverbal, agitated and depressed.

After a recent appointment, David's primary care physician referred Regina to her local GUIDE Participant organization. Following an assessment of Regina and David's support needs, the GUIDE Navigator set up a meeting with Regina, David, David's support coordinator through the state's developmental disability services agency, and himself. With Regina's permission, the support coordinator obtained a new Medicaid waiver that offered more hours of service and worked with a provider organization that assigned a staff person to take David on outings and spend time with him at home (which gave Regina some much needed respite). The Navigator

⁵ According to CMS, "the definition for long-term nursing home *** in GUIDE does not include ICF-IDDs so they would qualify for GUIDE if they met the other eligibility criteria."

⁶ CMS. Guiding an Improved Dementia Experience (GUIDE) Model - Services for people living with dementia & their caregivers Information for Patients & Caregivers. <https://www.cms.gov/files/document/guide-model-patient-caregiver-fs.pdf> (November 25, 2024).

also referred Regina to a support group of families of adult children with Down syndrome and dementia that has provided her with much needed support.⁷

GUIDE SERVICE COMPONENTS

Participants are required to provide the following:

1. **Comprehensive assessment** using approved screening tools (including the GUIDE required Clinical Dementia Rating [CDR] and the Functional Assessment Staging Test [FAST]) to aid clinicians to determine stage of dementia and evaluate caregiver burden and to screen for health-related social needs and an in-home evaluation that identifies psychosocial and safety needs.
2. **Care plans** created by care managers to address beneficiary and caregiver goals, preferences, and needs.
3. **24/7 access** to a care team member via a helpline or third-party vendor during off-duty hours.*
4. **Continuous monitoring** and support to review care plans, track progress toward goals, and identify emerging needs.
5. **Community-based referrals and coordination** for services, like home-delivered meals and transportation.*
6. **Care coordination and specialist support** that enable timely referrals to specialists to address comorbidities or other chronic conditions.
7. **Respite services** if the beneficiary has an unpaid caregiver, enabling temporary breaks from caregiving responsibilities, via an adult day center or facility with 24-hour care.*
8. **Medication management** conducted periodically to reconcile medications and avoid interactions or polypharmacy.
9. **Caregiver education and support** using training programs on best practices for caring for the beneficiary with dementia and for managing their own health.*

The care delivery requirements noted above with an * that the Participant must make available to caregivers may be provided via contract with a Partner Organization. These means that off-hour 24/7 helplines, referral and coordination, respite, and caregiver education can be vendorized. Services are divided into those directly provided to aid the caregiver, and those which directly aid the beneficiary.

⁷ Vignette adapted for as an intellectual disability situation from: Guiding an Improved Dementia Experience (GUIDE) Model - Services for people living with dementia & their caregivers Information for Patients & Caregivers

Those focused primarily on the beneficiary include (a) care coordination of access to medical specialists addressing ‘comorbidities and other chronic conditions,’ and (b) medication management.

Those focused primarily on the caregiver include (a) assessment of caregiver ‘burden,’ (b) 24/7 helpline access, (c) respite, (d) community-based referral for support services, and (e) caregiver education and support. Some are involved with both, such as comprehensive assessments, care planning, and on-going monitoring and support.

HEALTH EQUITY

How does CMS define "underserved communities" as related to the Health Equity Plan under the GUIDE Model? Consistent with the Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government dated January 20, 2021, “underserved communities” as used in the GUIDE RFA refers to populations sharing a particular characteristic, as well as geographic communities, that have been systematically denied a full opportunity to participate in aspects of economic, social, and civic life.⁸ This would include caregivers of adults with intellectual and developmental disabilities as an ‘underserved community’ as well as being part of an economically disadvantaged group.⁹

CAREGIVER SITUATIONS

Key content to convey to Navigators in trainings or educational materials should include several concepts differentiating caregiving in the intellectual disability space, from that typical of parental or filial caregiving. The following key concepts will help them understand the differences they may encounter when taking on a family/caregiver of a beneficiary with intellectual disability.

Points:

1. There may be a significant experience-based difference, from spousal [care partners] or filial caregiving,¹⁰ in caregiver capabilities from providing life-long care and oversight of an offspring or sibling with a cognitive impairment.
2. Caregivers of beneficiaries with an intellectual disability comprise a variety of caregiving situations, and include parents, siblings, other kin, or persons unrelated

⁸ Readers are advised to check for any updates related to this provision that may have occurred subsequent to January 20, 2025.

⁹ CMS. GUIDE Model Frequently Asked Questions. <https://www.cms.gov/priorities/innovation/guide/faqs#ben-cgs>

¹⁰ Spousal or care partner caregiving is when a spouse or other significant person in the life of the person with dementia who cohabits or maintains a close relationship with that person provides primary care. Filial caregiving refers to adult children or other relatives assuming primary care responsibilities (National Academies of Sciences, Engineering, and Medicine, 2016; National Research Summit, 2017).

- but who have befriended the adult and share a home. This includes caregivers who provide supplemental supports, and advocate and monitor the medical and home and community-based services of their adult children who live in group homes.
3. Most long-term caregivers have a system of care practices in place to accommodate the lifelong intellectual disability but may be still adapting to the new presentations resulting from dementia.

What follows is explanatory text in support of the above points.

Different life experiences

When Navigators assess home situations, it is important that they recognize the differences between caregivers of adults with lifelong neurodevelopmental conditions, such as intellectual disabilities, and those who have recently assumed caregiving roles due to a spouse or parent's dementia diagnosis. Additionally, it is helpful if they understand how caregivers are adapting to new care demands and managing the behavioral challenges associated with dementia onset and progression.

Caregivers of adults with intellectual disabilities often have a caregiving history distinct from that of spouses or children caring for a newly diagnosed adult with dementia. Their lifelong experience as 'perpetual parents' has allowed them to develop and adapt effective coping strategies over time. These caregivers are typically accustomed to providing continuous care, supervision, and support. In some cases, they may also juggle additional responsibilities, such as caring for a spouse or another household member.

Caregiving within the intellectual disability community has taken many forms and evolved over time. For much of their lives, parents have often provided care for their adult children with intellectual disabilities, but these dynamics frequently change as parents age.

After a diagnosis at birth or during childhood, caregiving typically occurs within the family, in contrast to historical practices where many children and adolescents with intellectual disabilities were institutionalized in public facilities or placed in private residential programs. For older beneficiaries, some may have spent part of their lives in congregate care, while others lived in group homes or housing (such as apartments) overseen by parent cooperatives or private or public provider agencies.

The shift toward deinstitutionalization allowed many adults to transition into community housing or return to their family homes. As they aged, individuals with an intellectual disability often became eligible for programs like Medicare and, earlier in life, Medicaid and waiver programs, due to their cognitive disabilities.

Lifelong caregiving

Families, who may have been extended caregivers, may also face new challenges, such as taking on new caregiving responsibilities for an adult child recently diagnosed or returning home after living elsewhere.

Lifespan caregiving may present with unique challenges that differ from those encountered in shorter term spousal or filial caregiving situations. These challenges may include:

- (a) the increasing demands of aging on caregivers, who are often a generation older than the beneficiary—typically in their 50s or 60s, while parent caregivers may be 20 to 30 years their senior—can significantly impact their ability to provide ongoing support.
- (b) burnout resulting from the evolving demands of caregiving as dementia progresses through its stages.
- (c) overwhelming physical demands, such as providing personal care for beneficiaries who may become non-ambulatory, incontinent, or aggressive.
- (d) compounded caregiving burdens, including new demands from other household members, such as a spouse or family member experiencing physical or cognitive impairments.

Caregiving situations

With the emphasis on being part of their natural communities, adults with an intellectual disability now reside in their family home, their own home, or in a group home.¹¹ Caregiving situations thus also reflect these living arrangements.¹² Depending on the beneficiary's need, the assistance may be episodic, daily, or occasional and can be primary or secondary. These are some examples of co-living situations and primary and secondary care:

- Parents or other kin serving as primary caregivers for the adult in the family home.
- A single parent serving as the sole caregiver in the family home.

¹¹ Leading Edge. (2023). GUIDE Model: A Funding Opportunity for Aging Services Providers. <https://leadingage.org/guide-model-a-funding-opportunity-for-aging-services-providers/>

¹² Jokinen N, Gomiero T, Watchman K, Janicki MP, Hogan M, Larsen F, Beránková A, Heloísa Santos F, Service K, Crowe J. Perspectives on family caregiving of people aging with intellectual disability affected by dementia: Commentary from the International Summit on Intellectual Disability and Dementia. *J Gerontol Soc Work*. 2018 May-Jun;61(4):411-431. doi: 10.1080/01634372.2018.1454563.

- Parents overseeing the out-of-home care of an adult or with others in shared housing, possibly in a home they financially support.
- Parents living separately from their adult son or daughter -- who lives in another setting under the aegis of a provider agency -- but function as his/her secondary caregivers.
- Parents providing care in the family home for a middle-aged adult with Down syndrome who has younger-onset dementia.
- A sibling or siblings caregiving for a younger or older sibling in the same household.
- Sibling and spouse co-caregiving for a grown sibling living with them.
- Non-kin surrogate-familial primary or secondary caregiving for an adult with an intellectual disability.

Another situation is when roles reverse and the caregiver may be a son or daughter (or other kin) with an intellectual disability who has assumed the responsibility of caregiving for a parent, sibling, or other relative who has dementia and is the beneficiary. Here the situation may be more complex, as the caregiver with an mild intellectual disability will benefit from aid to help them organize services for their aging parent or older sibling.

These extensive caregiving situations often involve unique dynamics, as lifelong caregivers are not entering a new caregiving phase but have been fulfilling this role for many years. Their long experience most likely makes them more attuned to changes in the loss of abilities and changes in behavior of the person for whom they care. However, the caregiver's age, health, and physical condition are critical factors that influence their ability to continue providing care.

Caregiver roles

Caregivers of individuals with an intellectual disability generally assume one of two primary roles, each aligning with the Beneficiary Model Tier outlined later in this advisory:

- Primary Caregivers provide direct care and daily support when an individual with dementia lives with them or remains under their personal supervision. For families of individuals with intellectual disabilities, caregiving has often been a lifelong commitment, and the onset of dementia has introduced additional challenges to long-established routines.

- Secondary Caregivers take on a supportive or supplemental role, focusing on advocacy, care planning, oversight, and occasional personal care when the individual resides in a separate setting, such as a group home or assisted living facility.¹³

Under the GUIDE model, secondary caregivers—including relatives, friends, or other designated individuals—are recognized as providing essential support beyond what the residential facility offers. Their involvement may range from episodic assistance to daily caregiving, depending on the beneficiary’s evolving needs.

Caregiving capabilities

Caregivers of adults with lifelong disabilities have spent decades providing care, shaped by their child’s physical, medical, and behavioral needs. Over time, they have developed an intuitive understanding of their child’s needs, emotions, and capabilities. However, with the onset of mild cognitive impairment or dementia, they may struggle to reconcile their well-established caregiving practices with the new and evolving challenges dementia presents.

Despite the difficult reality of a dementia diagnosis, most families remain deeply committed caregivers. However, their role inevitably shifts as they accommodate increasing cognitive decline, assist with ADLs and IADLs, adapt to behavioral changes, and take a more hands-on approach to daily planning. They must also navigate new responsibilities, such as managing healthcare coordination, ensuring social engagement, and implementing home safety measures that were previously unnecessary.

Navigators should approach family caregivers with respect, recognizing that their decades of experience often make them highly knowledgeable. It is essential not to assume they require training in basic caregiving. Instead, many families seek specific guidance on dementia-related challenges, including behavior management, dementia care strategies, home modifications, respite options, and medical considerations. Supporting caregivers effectively means offering tailored resources that acknowledge their expertise while equipping them with the tools needed to navigate this new stage of care.

Staging

The GUIDE Model integrates dementia staging into service alignment and payment structures by assessing both the beneficiary’s dementia progression and the caregiver’s capacity

¹³ Jokinen N, Gomiero T, Watchman K, Janicki MP, Hogan M, Larsen F, Beránková A, Heloísa Santos F, Service K, Crowe J. Perspectives on family caregiving of people aging with intellectual disability affected by dementia: Commentary from the International Summit on Intellectual Disability and Dementia. *J Gerontol Soc Work*. 2018 May-Jun;61(4):411-431. doi: 10.1080/01634372.2018.1454563.

to meet evolving needs (see Table 2, p. 14). Caregivers' ability to adapt to dementia-related challenges can often be understood through a series of stages.

As dementia or age-related decline progresses, caregivers must adjust their approach to address increasing limitations. Home-based caregivers often modify long-standing routines and take on additional daily responsibilities, while out-of-home caregivers may focus more on advocacy, monitoring, and coordinating services. Regardless of setting, dementia caregiving requires evolving strategies, emphasizing the need for strong post-diagnostic support and a structured care plan to guide caregivers through these transitions.

For Navigators conducting initial assessments, understanding a caregiver's current stage in their relationship to dementia is critical. Caregiver staging provides a structured way to assess caregiving dynamics, tailor support strategies, and recognize how dementia-related behavioral and functional changes disrupt even well-established routines. While lifelong caregivers may depend on familiar patterns for stability, dementia introduces complexities that demand flexible, innovative approaches.

Caregiver staging remains a valuable tool for both initial and follow-up evaluations, helping Navigators develop responsive and individualized care plans. As dementia progresses, caregivers often move between stages, and roles may shift among family members. This evolving process highlights the dynamic nature of dementia caregiving and the importance of continuous, adaptable support.

Caregiving staging consists of four key phases:

- *Diagnostic Phase:* Identifying the cause of functional changes through early assessments for dementia and addressing related factors.
- *Explorative Phase:* Accepting the dementia diagnosis and exploring available support options and resources.
- *Adaptive Phase:* Managing dementia symptoms and adjusting caregiving practices as needed.
- *Closure Phase:* Addressing aid associated with advanced dementia, resolving caregiving responsibilities, whether through decompression after end-of-life care or rebuilding and refocusing after the loss, depending on the caregiver's emotional connection to the beneficiary.

Understanding where caregivers are within these stages can aid the Navigator and the interdisciplinary team recommend appropriate services (see Table 1). For example:

- Caregivers in the Diagnostic Phase may benefit from basic education about dementia, counseling to support acceptance, and guidance on what to expect as the condition progresses.

- In the Explorative Phase, caregivers may need help exploring available services and planning for the future and what needs to be known about the progression of dementia.
- During the Adaptive Phase, the focus might shift to education and clinical aid on managing behavioral health symptoms and practical strategies for daily care and dealing with dementia related behavioral changes.
- For caregivers in the Closure Phase, support may include assistance with advanced dementia, grief counseling, guidance on end-of-life care, and resources to help them adjust to life after termination of caregiving.

By tailoring interventions to the caregiver’s stage, care teams can provide more effective support, helping both the caregiver and the beneficiary navigate the complexities of dementia care. (Table 1 – on page 12 -- provides more information on the care factors and outcomes for each stage)¹⁴

CAREGIVER SERVICE REQUIREMENT DISTINCTIONS AND INTELLECTUAL DISABILITY

Services provided under GUIDE to support caregivers and beneficiaries are designed to address case management, healthcare provision, and the evolving needs of beneficiaries as dementia progresses and advanced stages lead to significant functional decline. While most services under GUIDE apply broadly to all populations, certain areas may require specialized focus when beneficiaries have an intellectual disability. The table below highlights specific adaptations for this population.

One of the most significant service variations lies in the comprehensive assessment. Current assessment tools may lack the sensitivity to detect changes and needs in adults with lifelong cognitive impairments, making it difficult to accurately identify stages or subtle cognitive shifts. For such cases, experts propose the use of specialized instruments developed in the field of Down syndrome and intellectual disabilities as acceptable alternatives.

Another key area of differentiation is in referral services, where greater emphasis may be needed in terms of care coordination and specialist support, Navigators could benefit from additional training on conditions commonly associated with Down syndrome and intellectual disabilities. This knowledge would support focused surveillance, early detection, appropriate

¹⁴ Jokinen N, Gomiero T, Watchman K, Janicki MP, Hogan M, Larsen F, Beránková A, Heloísa Santos F, Service K, Crowe J. Perspectives on family caregiving of people aging with intellectual disability affected by dementia: Commentary from the International Summit on Intellectual Disability and Dementia. *Journal of Gerontological Social Work*. 2018 May-Jun. 61(4), 411-431. doi: 10.1080/01634372.2018.1454563.

screening, and the application of established treatment protocols. Additionally, it is essential to monitor polypharmacy, which is prevalent in the intellectual disability population, due to the heightened risk of adverse effects from unreviewed or inappropriate medication regimens. Regular medication reviews—beginning with an initial review at enrollment and followed by periodic re-evaluations—are critical to ensuring safe and effective care.

Table 1. Support-staging model of family-based dementia caregiving in intellectual disability.

Dementia support stage	Carer factors and supports	Outcomes/goals
(1) Diagnostic phase (seeking validation of the cause of change in behavior and or abilities)	<ul style="list-style-type: none"> • Conferring or seeking help in understanding changes in behavior and function • Seeking diagnostic source and following through on diagnostic requirements 	<ul style="list-style-type: none"> • Validating suspicions • Tracking behavior and function • Engagement in assessment and diagnostic process • Obtaining a diagnosis
(2) Explorative phase (accepting the diagnosis and considering support options)	<ul style="list-style-type: none"> • Being informed and educated about dementia and comorbid conditions • Understanding information on diagnosis and its implications • Talking with adult about diagnosis • Getting information on care practices • Planning for future care needs 	<ul style="list-style-type: none"> • Better understanding of disease and its progressive nature. • Plan of care formulated with persons affected • Alternative living arrangements identified in event needed • Advanced care directives identified • Treatment decisions
(3) Adaptive phase (managing symptoms of dementia)	<ul style="list-style-type: none"> • Monitoring behavior and function • Adapting care practices to changes in behavior and function • Getting ongoing advice for supports and home modifications • Self-care strategies • Psychosocial counselling including grief and loss 	<ul style="list-style-type: none"> • Home modifications made • Routines and tasks adapted to reflect changes • Service adaptations made to accommodate family needs • Respite instituted • Coping with changes • Better quality of life
(4) Closure phase (resolving caregiving issues and relief from responsibilities, and redefining next steps in life)	<ul style="list-style-type: none"> • Finding advanced stage care setting as needed • Working with palliative and hospice care services • Understanding end-of-life issues • Supporting end-of-life decisions • Planning funeral rites • Accepting end-of-life • Obtaining bereavement/grief supports 	<ul style="list-style-type: none"> • Setting located for advanced care as needed • Supportive palliative and hospice care services engaged • End-of-life decisions are respected • Celebration of life rituals held • Caregiver reflection on experiences and moving forward in life

The caregiver education component also warrants specialized consideration. Certain behavioral and psychological symptoms of dementia (BPSD) may be particularly common among beneficiaries with intellectual disabilities. Educational programs for caregivers should incorporate evidence-based

pharmacological and non-pharmacological interventions drawn from the intellectual disability and dementia literature to address these challenges effectively.

TERMINOLOGY

We have primarily adopted the terminology used in various GUIDE Model resources. To facilitate alignment between GUIDE terminology and the terms commonly used within the intellectual and developmental disabilities (I/DD) system, in Table 2 we provide the following crosswalk:

GUIDE Service		End-Point	Modification for ID
1	Comprehensive assessment	Determining stage of dementia and evaluating caregiver burden.	Use of instruments specifically designed to identify stage of dementia in adults with intellectual disability
2	Care plans	Defining beneficiary and caregiver goals, preferences, and needs.	Like other caregivers
3	24/7 access	Accessing to team member	Like other caregivers
4	On-going monitoring and support	Updating care plans, assessing progress on goals.	Like other caregivers
5	Referrals for services	Making referrals for additional services	Distinct use of local support services from intellectual disability providers
6	Care-coordination and specialist support	Ensuring co-incident conditions addressed	Identifying usual co-incident conditions associated with various intellectual disabilities
7	Respite services	Providing relief for caregivers	Like other caregivers, when day services used – more focus on intellectual disability providers
8	Medication management	Reviews of medications	Specialized reviews due to the history of polypharmacy among adults with intellectual disabilities
9	Caregiver education	Building capacity of caregiving	Focus more on adapting caregiver to handle BPSDs and other facets of dementia
10	Alignment	Process of GUIDE Participants agreeing to provide care to beneficiaries	Accepting /enrolling an eligible adult into a service

Note: This table was developed specifically for the Changing Thinking! Project; it can be reproduced with attribution.

CAREGIVER AND BENEFICIARY MODEL TIERS

For GUIDE, CMS created a series of tiers defining the level of aid required to provide day-to-day caregiving (See Table 3). The ‘Beneficiary Model Tier’ is determined via assessment and is a combination of beneficiary disease stage, presence of a caregiver, and if applicable, their caregiver's needs. These Tiers are linked to payment variations.

This aspect is covered in more detail in *Changing Thinking! Advisory 24-1* (Beneficiary Model Criteria & Tools); <https://www.the-ntg.org/changingthinking>.

	Tier	Criteria	Corresponding Assessment Tool Scores
Beneficiaries with a caregiver	Low complexity dyad tier	Mild dementia	CDR= 1, FAST= 4
	Moderate complexity dyad tier	Moderate or severe dementia AND Low to moderate caregiver strain	CDR= 2-3, FAST= 5-7 AND ZBI= 0-60
	High complexity dyad tier	Moderate or severe dementia AND High caregiver strain	CDR= 2-3, FAST= 5-7 AND ZBI= 61-88
Beneficiaries without a caregiver¹⁵	Low complexity individual tier	Mild dementia	CDR= 1, FAST= 4
	Moderate to high complexity individual tier	Moderate or severe dementia	CDR= 2-3, FAST= 5-7

Source: CMS. Guiding an Improved Dementia Experience - Request for Applications - Version: 1, p. 23 (Nov 7, 2023)

-30-

Suggested citation: National Task Group on Intellectual Disabilities and Dementia Practices. CHANGING THINKING! Advisory 24-7. GUIDE Caregivers. V. February 3, 2025. <https://www.the-ntg.org/changingthinking>

V. 2/3/2025

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.

¹⁵ Note: Beneficiaries may live independently in their own home or in a community setting such as an assisted living facility or group home. Their caregiver does not have to live with the beneficiary to qualify for participation in the model. In some cases, the caregiver may live in a different home, or in a different state; but they must be actively participating in supplementing the beneficiary's care.