CHANGING THINKING!

ADVISORY 25-1

KAER-ID and GUIDE

Precis

This advisory covers the KAER-ID component of GSA's KAER Tool Kit, developed to aid clinical and social care workers to identify, assess, diagnosis, and provide community-based supports to adults with intellectual and other neurodevelopmental disabilities. It provides information for Navigators, Practitioners, and program provision personnel with salient information on key aspects of addressing adults with intellectual disability as well how the use of KAER-ID within GUIDE activities.

BACKGROUND

The Gerontological Society of America's (GSA) KAER Toolkit for Brain Health is a framework that guides primary care teams in initiating conversations about brain health, detecting cognitive impairment, evaluating for dementia, and providing referrals to community resources, using the four steps of Kickstart, Assess, Evaluate, and Refer.[1] The KAER framework covers the following facets (See Figure):

- *Kickstart*: This step involves initiating conversations about brain health, observing and listening for patient or family concerns about cognition, and discussing potential risk factors.
- *Assess:* This step focuses on assessing the need for a full cognitive evaluation, using tools and strategies to identify potential cognitive impairment.
- *Evaluate:* This involves conducting or referring for a comprehensive cognitive evaluation to determine the presence and severity of cognitive impairment, and to diagnose dementia if appropriate.
- *Refer:* This step focuses on providing patients and families with referrals to appropriate community resources and support services, including educational resources, support groups, and care management.

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[1] GSA. (2020). The GSA KAER toolkit for primary care teams - REFER EVALUATE ASSESS KICKSTART - Supporting Conversations About Brain Health, Timely Detection of Cognitive Impairment, and Accurate Diagnosis of Dementia. https://pa-foundation.org/wp-content/uploads/GSA_KAER-Toolkit_2020_Final.pdf

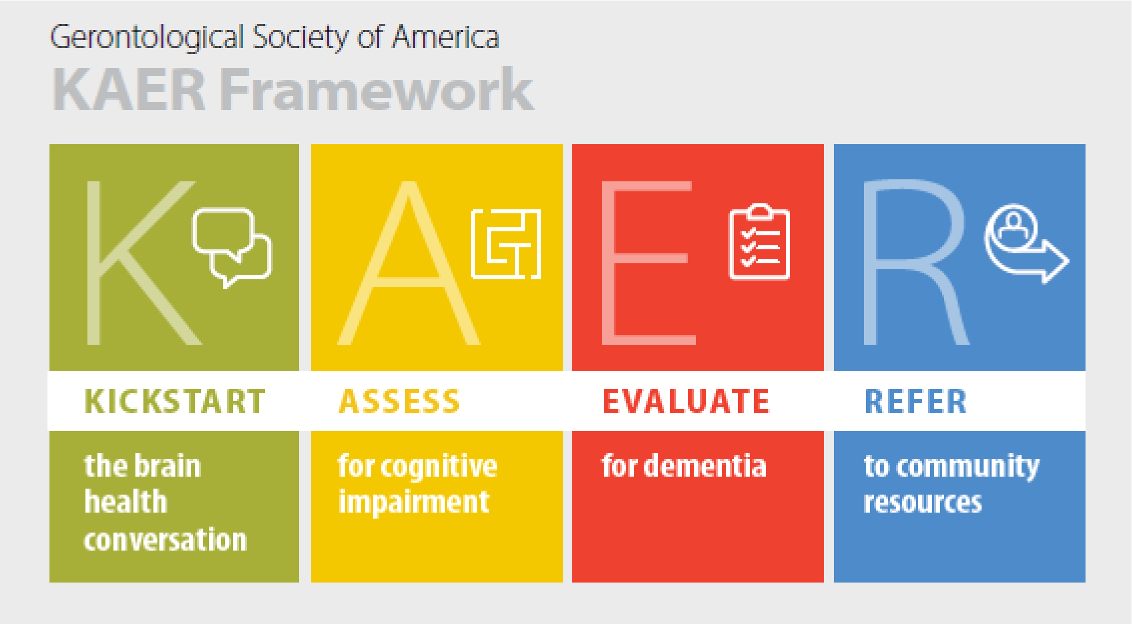

Figure 1: KAER logo (GSA)

The KAER toolkit is intended to improve health-related outcomes and well-being for people living with dementia and their families by promoting early detection, accurate diagnosis, and access to appropriate care and support. The Gerontological Society of America has a website with more information about the KAER Toolkit [https://gsaenrich.geron.org/kaer-toolkit-for-brain-health].

History. In 2015, GSA released a report on the detection of cognitive impairment and diagnosis of dementia.[2] The report, which was developed by the GSA Workgroup on Cognitive Impairment Detection and Earlier Diagnosis, underscored the value of detecting cognitive impairment and providing timely diagnostic evaluations for older adults. The report emphasized that various members of the primary care team, including physicians, physician assistants, nurses, and nurse practitioners, along with their office staff, play critical roles in preventive care, diagnosis, and follow-up for individuals with dementia and their families. The GSA Workgroup created a model that identifies four steps to achieve greater awareness of cognition and brain health in older adults, increase detection of cognitive impairment, initiate earlier diagnostic evaluation, and make referrals for educational and supportive community services for people with dementia. The four steps—Kickstart, Assess, Evaluate, and Refer (KAER)—were intended to

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[2] Morley JE, Morris JC, Berg-Weger M, Borson S, Carpenter BD, Del Campo N, Dubois B, Fargo K, Fitten LJ, Flaherty JH, Ganguli M, Grossberg GT, Malmstrom TK, Petersen RD, Rodriguez C, Saykin AJ, Scheltens P, Tangalos EG, Verghese J, Wilcock G, Winblad B, Woo J, Vellas B. Brain health: the importance of recognizing cognitive impairment: an IAGG consensus conference. *J Am Med Dir Assoc*. 2015 Sep 1;16(9):731-9. doi: 10.1016/j.jamda.2015.06.017.

improve health-related outcomes and well-being for people living with dementia and their families.

Primary care teams have varying degrees of familiarity with dementia-related clinical processes and may operate in different types of structures, organizations, and geographic regions. As such, care team members who are considering using the KAER Model in their clinical workflows may find certain steps to be more relevant than others and are encouraged to adopt processes that make sense within their clinical context. New approaches and tools are continually being researched and tested in the field. Users of the toolkit are encouraged to consider new validated tools as they become available, especially those that can better address gender, racial, ethnic, cultural, and language-related diversity; low literacy; sensory impairments; and intellectual disabilities.

ID Adaptation. In 2023, the GSA commissioned an adaptation of the KAER Model for application with adults with various neuroatypical conditions, primarily those with intellectual and developmental disabilities. The adapted component specifically addressed brain health in adults with intellectual disabilities and referred to it as the "KAER-ID Companion."[3] This companion toolkit was designed to help improve health outcomes and well-being for this population by providing resources and tools for primary care teams. As the KAER framework is a systematic approach to identifying and addressing cognitive impairment, it is particularly suited for use with older adults and lifelong cognitive impairments. The KAER-ID Companion adaptation focuses specifically on the needs of adults with intellectual disabilities and developmental disabilities, recognizing that they may experience unique challenges in accessing and understanding healthcare information.

To download or view *'Addressing Brain Health in Adults with Intellectual Disabilities and Developmental Disabilities: A Companion to the KAER Toolkit for Brain Health'* go to https://gsaenrich.geron.org/kaer-toolkit-for-brain-health

The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) played a key role in developing and implementing the KAER-ID Companion, providing intellectual property and technical assistance. The development and implementation of the KAER-ID Companion involved collaboration with several organizations [NTG, Ohio Council for Cognitive Health, Ohio Association of County Boards of Developmental Disabilities] and was financed by a grant to the GSA. The Companion has ID-specific content tailored to the needs of individuals with intellectual disabilities, including information on communication strategies, assessment

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[3] GSA (2024). KAER Toolkit - Addressing Brain Health in Adults with Intellectual Disabilities and Developmental Disabilities - The GSA KAER Toolkit for Brain Health Supporting Conversations About Brain Health, Timely Detection of Cognitive Impairment, and Accurate Diagnosis of Dementia.

methods, and referral pathways. Its aim is to provide a technical tool that would help improve the physical, social, and emotional well-being of adults with intellectual disabilities by increasing their inclusion in healthcare, health promotion, and disease prevention systems.

The KAER-ID Companion is being used as part of the Changing Thinking! intellectual disability training program for dementia care Navigators in the CMS's GUIDE Model. This companion document describes how the guidance in the KAER Toolkit can be applied to meet the unique needs of adults with intellectual disabilities (such as Down syndrome) and other neurodevelopmental, neurodiverse, and neuropsychiatric and neuro-sensory conditions (such as acquired brain injury, autism, cerebral palsy, fragile X syndrome, severe mental illness, and significant sensory impairments).[4] In large part the applications of KAER-ID are relevant to most situations when these other than intellectual disability conditions are present. Although the KAER framework for addressing dementia is largely the same for adults with intellectual disability (and for some of the other neurodiverse and neuropsychiatric conditions) as it is for the general population, adults with intellectual disability present unique challenges due to the presence of pre-existing impairments.

There is a wide range of cognitive and functional capacities among adults with these conditions and many individuals with intellectual disability have coincident conditions that further impair their functioning. Some adults may live independently while others may be moderately or fully dependent on others for performing various activities of daily living. However, a key unifying theme across these categories is that individuals have differences in cognition, communication, and function that complicate the identification and management of dementia.

Other similar conditions, termed neuroatypical conditions, often have similar presentations and similar challenges for diagnosing dementia and providing post-diagnostic supports. In-depth discussion of the features of various conditions, along with the risk for dementia, unique issues associated with each condition, and recommended assessment adaptations are provided in the 2022 report *Examining Adults with Neuroatypical Conditions for MCI/Dementia During Cognitive Impairment Assessments: Report of the Neuroatypical Conditions Expert Consultative Panel*.[5] Adults with many of these conditions, in addition to

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[4] Janicki, M.P., Hendrix, J., & McCallion, P., (2022). Examining older adults with neuroatypical conditions for mci/dementia: barriers and recommendations of the neuroatypical conditions expert consultative panel. Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring, 14(1), e12335. Doi: 10.1002/dad2/12335.

[5] Janicki, M.P., Hendrix. J., & McCallion, P., and Neuroatypical Conditions Expert Consultative Panel. (2022). Examining Adults with Neuroatypical Conditions for MCI/Dementia During Cognitive Impairment Assessments – Report of the Neuroatypical Conditions Expert Consultative Panel. The National Task Group on Intellectual Disabilities and Dementia Practices and the LuMind IDSC Foundation. https://www.the-ntg.org/screening-assessment. [Revision V. June 27, 2022]

having been diagnosed with dementia, may be Medicare beneficiaries eligible for GUIDE participation.

COMPONENTS OF THE KAER-ID COMPANION

1. *Component K: Kickstart the Brain Health Conversion*

This section primarily addresses the identification and preliminary assessment of cognitive conditions that may arise from various causes, with a focus on recognizing and addressing potentially treatable contributors to cognitive change or emerging impairment. It includes establishing a baseline to support the detection of changes that could lead to cognitive and behavioral decline.

While this process is important, within the context of GUIDE, it is generally assumed that beneficiaries have already been diagnosed with dementia. However, this section may still be useful to GUIDE Navigators and others by providing insight into how early signs of mild cognitive impairment or early-stage dementia are identified and verified.

> *TIP: Review this section for information on providing for baselines for adults with an intellectual disability by not yet affected by cognitive decline.*

2. *Component A: Assess for Cognitive Impairment*

Initial assessments should gather comprehensive information about the individual's personal history, including family and living circumstances, current functional abilities, recent life events, and any observed changes in behavior or functioning. In many cases, repeated longitudinal assessments are necessary to determine whether observed changes reflect a progressive decline and to distinguish between longstanding behaviors and those indicative of emerging cognitive impairment.

In the general population, cognitive assessments are typically norm-referenced, making them unsuitable for individuals with preexisting cognitive or functional impairments. Instead, assessment tools specifically designed for individuals with intellectual disability should be used to ensure accuracy and clinical relevance. One such tool is the **Early Detection Screen for Dementia (EDSD)**, developed by the National Task Group on Intellectual Disabilities and Dementia Practices.[6] The EDSD is intended for use as a screening tool and diagnostic aid in adults with intellectual disabilities.

The EDSD captures information on functional abilities and behavior, providing a structured way to initiate discussions about brain health and potential new signs of dementia. It

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[6] https://www.the-ntg.org/ntg-edsd

can be completed by caregivers or support staff to document the presence of key behaviors and support further evaluation. As a GUIDE Navigator, you may want to ask the caregiver to complete the EDSD in advance of your visit(s) or for use by the Practitioner to inform diagnostic planning.

As a GUIDE Navigator, you may find it useful to review the information on the completed EDSD with caregivers to help identify concerns that warrant further assessment or to inform the development of the dementia care plan. As the EDSD also collects detailed data on living arrangements, comorbid health conditions, medications, recent changes in physical and mental health, seizures, and sensory or mobility impairments, this information may complement other data you already have. In addition, as the EDSD includes ratings related to intellectual disability and various domains of functioning such as activities of daily living, communication, memory, ambulation, behavior, affect, sleep patterns, and self-reported concerns, this too may be helpful for team planning for the dementia care plan.

Although the EDSD was developed for use with adults with an intellectual disability, it can be helpful to use with beneficiaries diagnosed with dementia with other neurodevelopmental, neurodiverse, or neuropsychiatric or neurosensory conditions.

> *TIP: Using the EDSD, in addition to the GUIDE required tools (CDR, FAST), can aid you with capturing more fine-tuned information in the context of the adult's intellectual disability and what noted concerns on the form may be prominent issues for the caregiver.*

3. Component E: Evaluate for Dementia

Dementia is often a diagnosis of exclusion. When a decline in function is observed in adults with intellectual disability, a comprehensive evaluation is essential to determine the underlying etiology. To the untrained observer, such changes may appear to indicate dementia, but they may in fact result from other factors, including medical conditions, adverse medication effects, physical or sensory impairments (e.g., nutritional deficiencies, thyroid dysfunction, vision or hearing loss), or disruptive life events.

A dementia evaluation should aim not only to confirm the presence of dementia but also to identify its underlying cause—whether Alzheimer's disease or another neurological disorder. Additionally, the evaluation should assess for co-occurring conditions that may exacerbate cognitive decline, such as untreated pain, sensory deficits, or serious mental illness.

As a GUIDE Navigator you will not be asked to undertake a diagnostic assessment, but any information that you have gleaned from your interviews with the caregiver, or the beneficiary will aid the Practitioner with the confirmation of the diagnosis of dementia or with further examinations for other factors that may be impacting cognitive abilities or function.

Table 3 in the KAER-ID component identifies potentially co-occurring conditions that may impact behavior and functioning and which may affect how the confirming diagnosis is carried out. **Table 4** outlines key elements for a comprehensive evaluation of related or contributing factors and can be gathered during the caregiver interview.

> *TIP: Becoming familiar with the various factors that may affect behavior and function in adults with an intellectual disability and dementia can help you better understand the home situation and factors contributing to the caregiver's concerns or distress.*

4. Component R: Refer to Community Resources

As a GUIDE Navigator you support individuals with intellectual disabilities and dementia, so that the information gathered through earlier assessment components—particularly any determination of dementia stage—play a critical role in shaping a person-centered dementia care plan. This plan serves as the foundation for identifying and coordinating appropriate post-diagnostic supports.

Post-diagnostic care can encompass a broad range of interventions. These may include counseling for individuals and their families, regular psychological and medical monitoring, early detection of behavioral or psychological symptoms, and periodic review and revision of the care plan. Other important elements include planning for advanced dementia and end-of-life needs, providing education to caregivers and staff, and evaluating the individual's overall quality of life.

Effective care planning depends on understanding the type of dementia diagnosed, the individual's current functional abilities, and their expected trajectory. For example, adults with Down syndrome are more likely to experience a faster progression of dementia. This increased rate of decline should be considered when identifying necessary supports, including potential residential placements.

The progression and care needs of individuals with intellectual disability and dementia are influenced by several factors—such as general health and stamina, the presence of other chronic or co-occurring conditions, access to health services, level of frailty, vulnerability to infections, and challenges related to self-neglect or harmful behaviors. Each of these must be weighed when determining the appropriate scope and nature of care.

A key part of your role as a Navigator involves linking the caregiver and the individual to additional sources of support. This includes GUIDE partner agencies that can offer respite and other forms of assistance, as well as community-based, non-GUIDE affiliated organizations that may provide resources to help caregivers manage day-to-day needs and maintain their own well-being.

Table 7 in the KAER-ID component offers a set of strategies tailored to managing dementia across its various stages in adults with intellectual disability. This resource can guide teams in developing care plans that are both individualized and responsive to the evolving needs of the caregiver and beneficiary.

> *TIP: Becoming acquainted with the agencies and organizations in your catchment area can help with making referrals for services covered by GUIDE or ancillary services that may aid the caregiver and beneficiary as defined in the dementia care plan.*

INTEGRATING THE GSA KAER-ID FRAMEWORK INTO THE CMS GUIDE MODEL FOR MEDICARE BENEFICIARIES WITH DEMENTIA AND INTELLECTUAL DISABILITY

The intersection of dementia and intellectual disabilities presents unique challenges in diagnosis, care planning, and service delivery. The GSA KAER-ID framework—which emphasizes **K**nowing the signs, **A**ssessing cognitive changes, **E**ducating stakeholders, and **R**eferring for appropriate services—offers a structured approach that aligns with the CMS GUIDE model. By integrating KAER-ID principles into GUIDE model activities, healthcare providers and Navigators can enhance the identification, assessment, and care coordination for Medicare beneficiaries with both dementia and intellectual disability.

Enhancing Dementia Assessment for Individuals with Intellectual Disability

Traditional dementia screening tools may not accurately capture cognitive decline in individuals with ID, particularly those with baseline developmental differences. The KAER-ID approach can be embedded within GUIDE's dementia progression assessment by:

- Training Navigators to recognize **atypical cognitive and functional changes** in adults with intellectual disability, including subtle shifts in daily living skills and social engagement.
- Utilizing **intellectual disability-specific cognitive screening tools** (e.g., the EDSD) alongside GUIDE required assessments to ensure accurate evaluation.
- Collaborating with **caregivers and intellectual disability service providers** to establish baseline cognitive function and track changes over time.

Tailoring Caregiver Support and Education

Caregivers of individuals with both dementia and intellectual disability often face additional complexities, requiring specialized education and support. GUIDE's caregiver assessment and care planning process can integrate KAER-ID by:

- Providing **targeted education** on how dementia manifests differently in individuals with intellectual disability, particularly in conditions like Down syndrome, which has a high risk for Alzheimer's disease.
- Offering **behavioral management training** to help caregivers adapt to dementia-related changes while considering the person's lifelong routines and sensory needs.
- Addressing **caregiver distress/stress and long-term planning**, ensuring families understand the trajectory of dementia and available resources that may aid them with specialized care.

Strengthening Service Coordination and Referrals

Individuals with intellectual disability and dementia often require a mix of medical, behavioral, and long-term support services. Integrating KAER-ID into GUIDE's referral and coordination activities can improve service access by:

- Establishing **stronger connections** between GUIDE Navigators and intellectual disability service agencies, ensuring a seamless transition to dementia-informed care.
- Incorporating **person-centered transition planning**, recognizing that individuals with intellectual disability may require different housing, guardianship, or end-of-life care considerations.
- Promoting **proactive referrals** to specialists, such as neurologists familiar with atypical dementia presentations in intellectual disability populations.

Advancing Research and Policy Alignment

The GUIDE model provides an opportunity to collect valuable data on how dementia progresses in individuals with intellectual disability, informing future research and policy. By incorporating the use of KAER-ID, GUIDE Participants can:

- Track **caregiver adaptation and service utilization**, helping refine best practices for this population.
- Support **cross-agency collaboration** to advocate for policies that improve dementia care equity for individuals with lifelong disabilities.
- Encourage **longitudinal studies** on dementia in intellectual disability populations, leading to earlier interventions and tailored treatment strategies.

Commentary: The Value of Aligning KAER-ID with GUIDE Navigator Tools

By embedding the KAER-ID framework into the CMS GUIDE model, Navigators and interdisciplinary teams can ensure that Medicare beneficiaries with both dementia and intellectual disabilities receive timely, appropriate, and person-centered care. This integration enhances early detection, improves caregiver education, streamlines service coordination, and ultimately leads to better health outcomes and quality of life for this underserved population.

But the benefits of alignment extend even further. The KAER-ID component offers a structured, evidence-informed approach that helps Navigators interpret subtle changes in behavior and function—an essential need when standard dementia screening tools may not be reliable for individuals with intellectual disabilities. By organizing care around the KAER-ID phases—Kickstart, Assess, Evaluate, and Refer—Navigators can confidently guide caregivers through the complexities of diagnosis, planning, and ongoing support.

Importantly, this alignment also promotes continuity and equity in dementia care. Individuals with intellectual disability often experience delayed or missed diagnoses, fragmented services, and a lack of tailored supports. KAER-ID helps close these gaps by equipping Navigators with language, tools, and strategies to engage caregivers early, identify co-occurring conditions, and coordinate across multiple systems of care—including medical, behavioral, developmental, and social services.

Moreover, KAER-ID supports the relational work at the heart of the Navigator's role. It encourages authentic, empathetic conversations with caregivers, helping them move from uncertainty to informed action. When integrated into GUIDE workflows and documentation, the framework can help standardize best practices across teams, reduce caregiver burden, and support culturally competent, lifespan-oriented care planning.

In short, KAER-ID is not just another tool—it is a roadmap for more inclusive, proactive, and human-centered dementia care. When used within the GUIDE model, it strengthens the foundation for health equity and enables Navigators to make a tangible difference in the lives of caregivers and beneficiaries alike.

Notes:

Suggested citation: National Task Group on Intellectual Disabilities and Dementia Practices. (2025, April). *Changing Thinking! - Advisory 25-1 - KAER-ID and GUIDE*. Version 5. https://www.the-ntg.org/changingthinking.

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v.5 (April 21, 2025)

Appendix

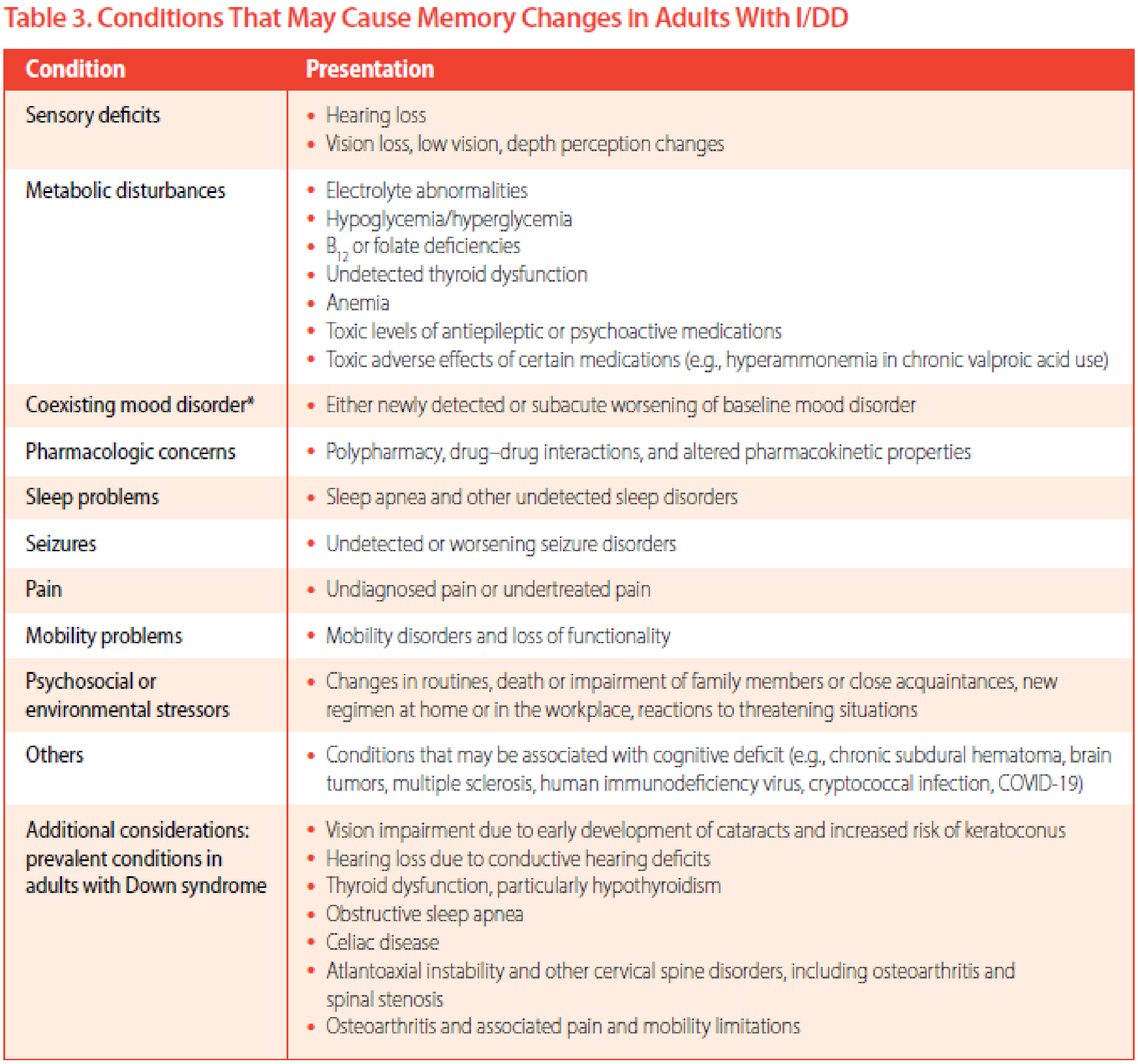
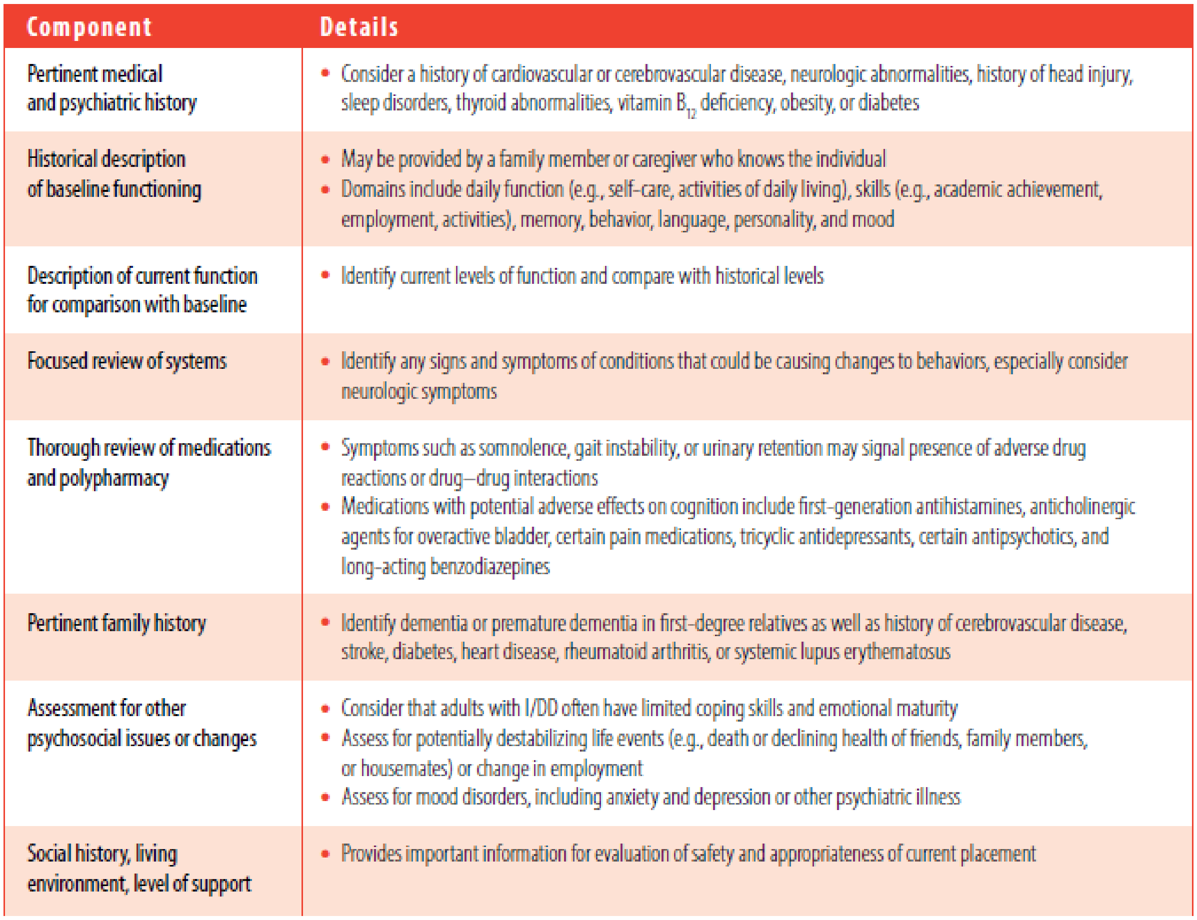


Table 3. Conditions That May Cause Memory Changes in Adults With I/DD

Condition	Presentation
Sensory deficits	• Hearing loss • Vision loss, low vision, depth perception changes
Metabolic disturbances	• Electrolyte abnormalities • Hypoglycemia/hyperglycemia • B_{12} or folate deficiencies • Undetected thyroid dysfunction • Anemia • Toxic levels of antiepileptic or psychoactive medications • Toxic adverse effects of certain medications (e.g., hyperammonemia in chronic valproic acid use)
Coexisting mood disorder*	• Either newly detected or subacute worsening of baseline mood disorder
Pharmacologic concerns	• Polypharmacy, drug–drug interactions, and altered pharmacokinetic properties
Sleep problems	• Sleep apnea and other undetected sleep disorders
Seizures	• Undetected or worsening seizure disorders
Pain	• Undiagnosed pain or undertreated pain
Mobility problems	• Mobility disorders and loss of functionality
Psychosocial or environmental stressors	• Changes in routines, death or impairment of family members or close acquaintances, new regimen at home or in the workplace, reactions to threatening situations
Others	• Conditions that may be associated with cognitive deficit (e.g., chronic subdural hematoma, brain tumors, multiple sclerosis, human immunodeficiency virus, cryptococcal infection, COVID-19)
Additional considerations: prevalent conditions in adults with Down syndrome	• Vision impairment due to early development of cataracts and increased risk of keratoconus • Hearing loss due to conductive hearing deficits • Thyroid dysfunction, particularly hypothyroidism • Obstructive sleep apnea • Celiac disease • Atlantoaxial instability and other cervical spine disorders, including osteoarthritis and spinal stenosis • Osteoarthritis and associated pain and mobility limitations

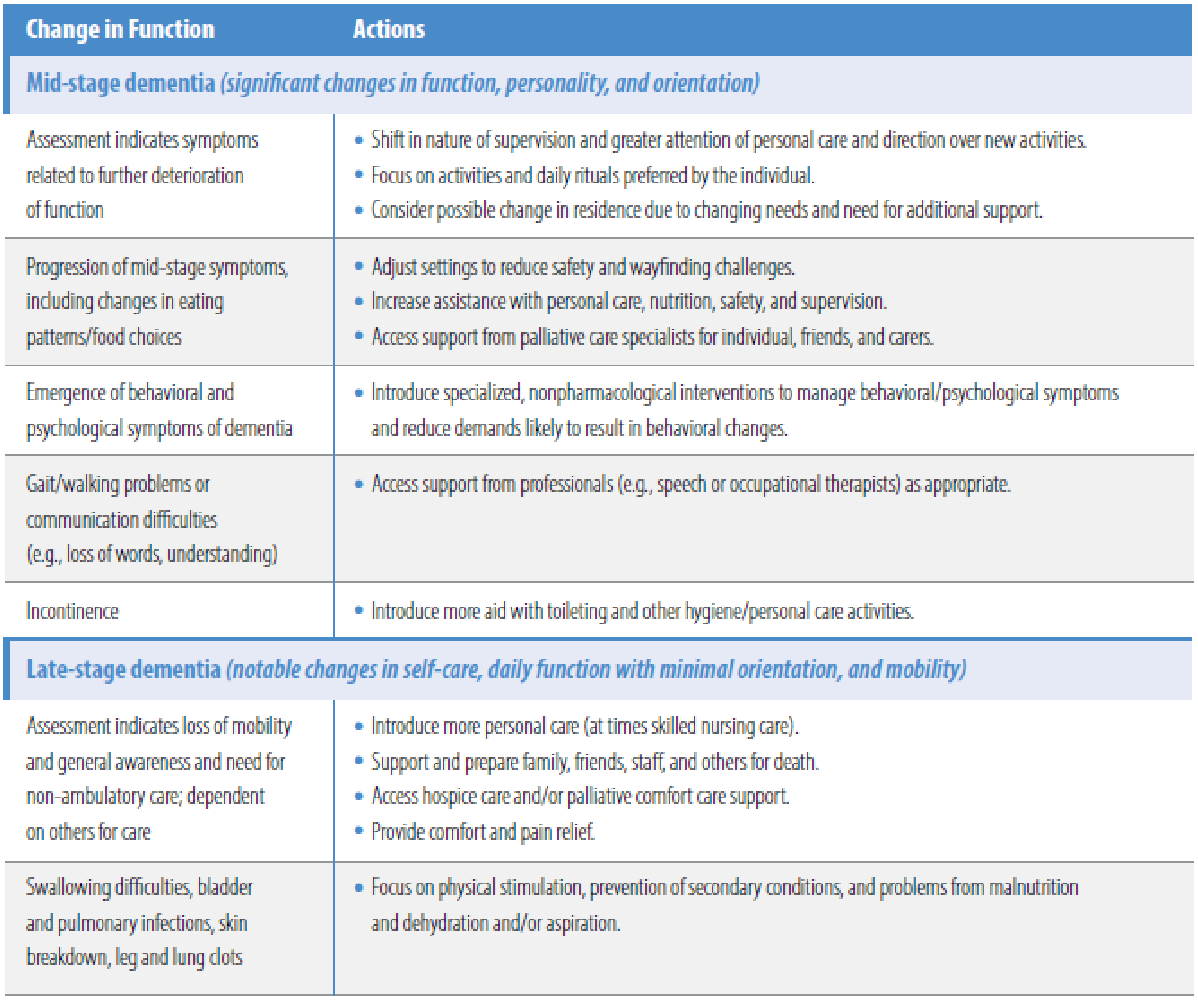
Table 4. Components of an Evaluation for Dementia in Adults With I/DD



Component	Details
Pertinent medical and psychiatric history	• Consider a history of cardiovascular or cerebrovascular disease, neurologic abnormalities, history of head injury, sleep disorders, thyroid abnormalities, vitamin B_{12} deficiency, obesity, or diabetes
Historical description of baseline functioning	• May be provided by a family member or caregiver who knows the individual • Domains include daily function (e.g., self-care, activities of daily living), skills (e.g., academic achievement, employment, activities), memory, behavior, language, personality, and mood
Description of current function for comparison with baseline	• Identify current levels of function and compare with historical levels
Focused review of systems	• Identify any signs and symptoms of conditions that could be causing changes to behaviors, especially consider neurologic symptoms
Thorough review of medications and polypharmacy	• Symptoms such as somnolence, gait instability, or urinary retention may signal presence of adverse drug reactions or drug–drug interactions • Medications with potential adverse effects on cognition include first-generation antihistamines, anticholinergic agents for overactive bladder, certain pain medications, tricyclic antidepressants, certain antipsychotics, and long-acting benzodiazepines
Pertinent family history	• Identify dementia or premature dementia in first-degree relatives as well as history of cerebrovascular disease, stroke, diabetes, heart disease, rheumatoid arthritis, or systemic lupus erythematosus
Assessment for other psychosocial issues or changes	• Consider that adults with I/DD often have limited coping skills and emotional maturity • Assess for potentially destabilizing life events (e.g., death or declining health of friends, family members, or housemates) or change in employment • Assess for mood disorders, including anxiety and depression or other psychiatric illness
Social history, living environment, level of support	• Provides important information for evaluation of safety and appropriateness of current placement

Table 7. Strategies for Managing Dementia in Adults With I/DD

Change in Function	Actions
Prediagnosis *(sporadic memory, personality changes and/or performance changes, confusion, other generic warning signs)*	
Individual shows distress or complains of losses	• Monitor behavior.
Initial symptoms becoming evident	• Conduct screening.
Screening shows correspondence with "warning signs"	• Refer for assessment. • Assess for possible adverse drug reactions.
Assessment indicates symptoms are not related to dementia	• Follow prescriptive treatment (medication, nutrition, etc.) to address non-dementia conditions and symptoms.
Assessment indicates symptoms are most likely related to dementia	• Begin planning and related education to help person, family, friends, and roommates understand and cope with changes. • Listen and talk to the individuals with I/DD about the changes they are experiencing using familiar terms that are consistently applied by everyone. • Continue to monitor for subsequent progressive changes in abilities. • Initiate support planning. • Focus, in a planful manner, on encouraging continued engagement to keep the person as independent as possible.
Early-stage dementia *(more pronounced changes in function, personality, and/or attention to daily activities)*	
Progression of early-stage symptoms	• Conduct functional assessments to measure continued changes. • Monitor health for secondary coincident conditions. • Assess for possible adverse drug reactions at each stage of change to rule out possible acute dementia from medications concomitant with dementia.
Communication or word-finding problems	• Prepare for nonverbal communication methods. • Ensure life story work begins. • Prepare advance directives and other documents related to later life care.
Assessment indicates symptoms most likely represent progression toward mid-stage dementia	• Adjust daily routines, modify environment, review and adjust medications. • Engage in discussions on advance care directives and appropriate emotional, spiritual, and cultural support strategies for grief, loss, and end of life, including post-death rituals. • Introduce greater assistance with daily tasks, personal care, and memory retention. • Establish plans for safety (e.g., wandering, ingesting harmful products, falling). • Explore resources for additional "in home" supports and specialized therapeutics. • Consider possible options for changes in residence, including (where possible) determination of individual's desires.



Change in Function	Actions
Mid-stage dementia *(significant changes in function, personality, and orientation)*	
Assessment indicates symptoms related to further deterioration of function	• Shift in nature of supervision and greater attention of personal care and direction over new activities. • Focus on activities and daily rituals preferred by the individual. • Consider possible change in residence due to changing needs and need for additional support.
Progression of mid-stage symptoms, including changes in eating patterns/food choices	• Adjust settings to reduce safety and wayfinding challenges. • Increase assistance with personal care, nutrition, safety, and supervision. • Access support from palliative care specialists for individual, friends, and carers.
Emergence of behavioral and psychological symptoms of dementia	• Introduce specialized, nonpharmacological interventions to manage behavioral/psychological symptoms and reduce demands likely to result in behavioral changes.
Gait/walking problems or communication difficulties (e.g., loss of words, understanding)	• Access support from professionals (e.g., speech or occupational therapists) as appropriate.
Incontinence	• Introduce more aid with toileting and other hygiene/personal care activities.
Late-stage dementia *(notable changes in self-care, daily function with minimal orientation, and mobility)*	
Assessment indicates loss of mobility and general awareness and need for non-ambulatory care; dependent on others for care	• Introduce more personal care (at times skilled nursing care). • Support and prepare family, friends, staff, and others for death. • Access hospice care and/or palliative comfort care support. • Provide comfort and pain relief.
Swallowing difficulties, bladder and pulmonary infections, skin breakdown, leg and lung clots	• Focus on physical stimulation, prevention of secondary conditions, and problems from malnutrition and dehydration and/or aspiration.

Note: The tables were extracted from the GSA's KAER-ID Component document.

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