KICKSTART | ASSESS | EVALUATE | REFER

KAER Toolkit

Addressing Brain Health in Adults With **Intellectual Disabilities** and **Developmental Disabilities**

A Companion to the GSA KAER Toolkit for Primary Care Teams:
Supporting Conversations About Brain Health, Timely Detection of Cognitive Impairment, and Accurate Diagnosis of Dementia

GSA
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Advisory Board

Collaborating Organizations

ntg National Task Group on Intellectual Disabilities and Dementia Practices

OACB Serving People with Developmental Disabilities

Ohio Council for Cognitive Health

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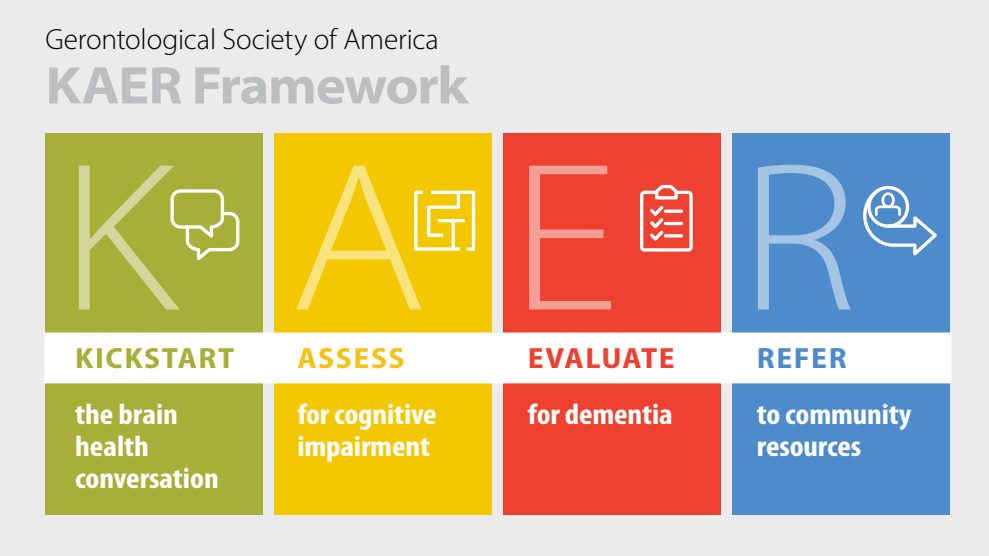
Eisai

Overview

The GSA KAER framework and *The GSA KAER Toolkit for Primary Care Teams* are designed to support the well-being of and positive health-related outcomes for people living with dementia and their families. The KAER Toolkit provides resources for **K**ickstarting the brain health conversation, **A**ssessing for cognitive impairment, **E**valuating for dementia, and **R**eferring to community resources.



This companion document describes how the guidance in the KAER Toolkit can be applied to meet the unique needs of adults with intellectual disabilities (ID) and developmental disabilities (DD; collectively I/DD). Although the KAER framework is largely the same for adults with I/DD as it is for the general population, adults with I/DD present unique challenges due to the presence of pre-existing impairments.

Adults with I/DD are a heterogeneous population with a wide range of abilities and needs. Intellectual disabilities affect intellectual functioning or intelligence and adaptive behaviors, including everyday social and life skills. Developmental disabilities include a broader category of disabilities that may affect intellectual and/or physical functions. Diagnoses that may be encountered within this broad grouping include autism spectrum disorder, cerebral palsy, Down syndrome, and ID (with or without dual diagnosis with a mental health condition).

There is a wide range of cognitive and functional capacities among adults with these conditions and many individuals with I/DD have coincident conditions that further impair their functioning. Some adults may live independently and hold part-time or full-time jobs 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*.[1]

Adults with I/DD have a wide range of living situations and life circumstances. Some live independently in the community, some live with family members who have cared for them since childhood (e.g., parents who are lifelong caregivers), and others live in group homes or other congregate care settings. Each of these living situations is accompanied by a unique circle of support for the individual that may include family, friends, housemates, spouses or partners, and paid care providers. Throughout this document, the term caregivers will be used to refer to this circle of support.

Current research indicates that most I/DD conditions do not increase the risk for developing dementia compared with the general population. It is estimated that 10% of older adults with I/DD have some form of dementia, with the prevalence varying among underlying conditions.[2] Importantly, Down syndrome does substantially increase risk for developing Alzheimer's disease (AD).[2] It is estimated that more than 50% of adults with Down syndrome 60 years of age and older have AD.[3] Adults with Down syndrome are more likely to have younger-onset dementia and experience a more rapid progression of cognitive and functional impairments than the general population.[4,5] The risk for dementia in selected forms of I/DD along with associated features are shown in Table 1.[1]

The emergence of dementia in adults with I/DD can have a substantial impact on their lives and the lives of their families and other caregivers as well as require specialized services. Interventions adapted to the needs of individuals who have I/DD with dementia and their families are often useful.[6]

To address the needs of adults with I/DD who develop dementia, the goals of this companion document are to:

- Raise awareness of unique needs of adults living with I/DD.
- Equip and encourage caregivers and health care teams to engage in appropriate brain health conversations with adults with I/DD.
- Promote brain health conversations and early detection of changes in cognitive and adaptive function for adults with I/DD.
- Assist with the identification of community supports and resource networks aimed at enhancing function and quality of life for adults with dementia and I/DD.

Table 1. Summary of Dementia Characteristics in Adults With I/DD or Other Neuroatypical Conditions Compared With General Population

Condition	Risk for Dementia	Dementia Type	Risk Features	Causal Features	Associated Features
Acquired/ traumatic brain injury	Potentially higher	Vascular; CTE	CTE high; stroke higher	Stroke; extensive head injury	Behavioral functions; senses; language; loss of prior function without other explanation
Autism spectrum disorder	Potentially slightly higher	Frontotemporal in some	Comorbid Down syndrome—higher risk	Unknown	Variability in communication abilities; loss of prior function without other explanation
Cerebral palsy	Not confirmed	Unknown	Younger onset	Coincident with seizures and intellectual disability	Post-impairment syndrome; loss of prior function without other explanation
Down syndrome	Definitive and high	Usually Alzheimer's disease	Younger onset	Genetic predisposition with coincident seizures	Seizures increase risk; precocious aging; loss of prior function without other explanation
Intellectual disability	Potentially higher	Mixed	Coincident conditions	Unknown	Loss of prior function without other explanation
Intellectual disability with dual diagnosis of a mental health condition	Potentially higher	Mixed	Coincident conditions	Coincident with intellectual disabilities and serious mental illness	Loss of prior function without other explanation
Severe mental illness	Potentially higher	Frontotemporal in some, Alzheimer's disease in others	Unknown	Unknown	Declines in memory and executive function
Sensory impairments	Not confirmed	Mixed	Unknown	Unknown	Reported coincidence; declines in memory and executive function

CTE = chronic traumatic encephalopathy; I/DD = intellectual disabilities and developmental disabilities.

Source: Reference 1.

Kickstart

the Brain Health Conversation

Early detection of cognitive decline is helpful for prompting thorough evaluations to identify and address potentially treatable underlying causes and, in the case of dementia, allow individuals and caregivers to plan for changes in function. Any dementia screening instrument should be a precursor to a broader clinical evaluation and used in conjunction with medical history, physical examination, and input from family members or caregivers.

Because assessments of cognitive decline require a determination of whether there is a significant change in function, it is critical to gather data about an individual's baseline functional abilities. Ongoing brain health conversations should include regular assessments of cognitive and functional capacity to gather such baseline data. Caregivers should consider first determining an optimal level of function (a "baseline"), and then maintain a record of behavior and function over time. One way is to compile a personal "life story" that can be used as a resource. Caregivers can be advised to create a baseline via a video diary of the adult with I/DD that includes recordings of the adult speaking, interacting with others, performing various activities of daily living, demonstrating fine and gross motor skills, and engaging in other activities that reflect the talents, abilities, and uniqueness of the individual. Videos can be readily recorded using smartphones and archived for future reference. Such an archive can be invaluable for future determinations regarding whether a change in function has occurred and whether it might be reflective of further cognitive impairment.

When communicating with adults with I/DD, health care providers should use strategies and language that the individual is able to comprehend to the extent possible and incorporate caregivers in conversations about the individual, as both informants and interpreters. Many conditions stemming from an I/DD are associated with problems with comprehension, oral communication, motor task performance, assessment-related visuals, and comfort with testing situations.[1] Expressive language skills may range from high verbal to monosyllabic or nonverbal. Receptive language abilities also vary widely and may not be fully apparent to unfamiliar persons. The health care team should aim to adapt their communication styles to accommodate these barriers and facilitate conversations (e.g., using visual materials, including gestures) and supplement the information provided by the individual with information from caregivers.

In addition, health care providers and other community members should aim to incorporate disability-inclusive person-first language when speaking with adults with I/DD and their caregivers. Person-first language is based on the premise that people have health conditions, but these conditions do not define them. For example, "people with diabetes" is preferred to "diabetic people" or "diabetics." (For more information about appropriate phrasing, see the Disability-Inclusive Language Guidelines from the United Nations.)

Assess

for Cognitive Impairment

Adults with I/DD and their caregivers may face many barriers in trying to obtain an accurate assessment of cognitive decline. Manifestations of new cognitive impairments or dementia may be mistakenly assumed to be symptoms of the underlying disability. Assessments may be complicated by pre-existing cognitive impairments or other challenges that impede communication.[1] Patients with sensory impairments (e.g., vision loss, hearing deficits) may require specifically adapted assessment tools such as large-print reading materials or assisted listening devices. Unfavorable reactions by members of the care team to adults with pre-existing cognitive deficits and lack of understanding regarding common behaviors and needs of adults with I/DD can further complicate assessments.

Assessments for cognitive impairment are often included as part of the Medicare Annual Wellness Visits, which are provided to Medicare-eligible adults. However, common tools used for these assessments may not be adequate or appropriate for adults with I/DD. Further, because dementia is more likely to manifest at younger ages in individuals with certain I/DD conditions, regular screenings for changes in cognitive and adaptive functioning from baseline may be called for during the middle-age years.

Initial assessments should capture information about the individual's personal history, including family and living situation, levels of functioning, key recent events, and any changes in behavior or function. Multiple longitudinal assessments may be needed to help document whether signs of decline are progressive and discern behaviors associated with an underlying condition from those that are associated with emerging changes in cognition. Recommendations for assessments for adults with various I/DD conditions are shown in Table 2.[1]

In the general population, assessments of cognitive function are typically based on population norms; thus, in most cases, these assessments are not appropriate for individuals who have pre-existing impairments in cognition or function. Cognitive assessment tools that are specifically developed for individuals with I/DD should be used for more accurate individualized assessments. The National Task Group on Intellectual Disabilities and Dementia Practices (NTG), which was formed to address issues specific to adults with I/DD and dementia, has developed numerous resources, including the NTG Early Detection Screen for Dementia (NTG-EDSD). (The NTG has also developed several other useful assets; see Resources.)

Table 2. Recommendations for Assessment of Cognition in Adults With I/DD

Condition	Frequency*	Measures	Adaptations	Barriers	Use of Informants
Acquired/ traumatic brain injury	Point measures	General CIA instruments	Verbal measures when vision affected; due to ABI effects use of non-normed measures	Variability of part of brain affected	Useful
Autism spectrum disorder	Longitudinal measurements	General CIA instruments; specialized ID instruments if appropriate	Visual testing; concrete instructions; serial assessments; individualize exam	Unfamiliar staff and clinic spaces	Useful
Cerebral palsy	Point measures	General CIA instruments; specialized ID instruments if appropriate	Accessible exam room; use measures not requiring task reproduction if fine motor skill impaired	Speech clarity; impaired fine motor fluency	Useful
Down syndrome	Longitudinal measurements	Specialized ID instruments	General CIA instruments with mild ID; special instruments with other ID; serial assessments	Speech clarity; comprehension; unfamiliar staff and clinic spaces	Required
Intellectual disability	Longitudinal measurements	Specialized ID instruments	General CIA instruments with mild ID; special instruments with other ID; serial assessments	Comprehension; unfamiliar staff and clinic spaces	Required
Intellectual disability with dual diagnosis of a mental health condition	Longitudinal measurements	Specialized ID instruments	General CIA instruments with mild ID; special instruments with other ID; serial assessments	Unfamiliar staff and clinic spaces	Required

*How often to take measures (Point: generally, at a single point in time; Longitudinal: several measurements over time).

ABI = acquired brain injury; CIA = cognitive impairment assessment; ID = intellectual disability; I/DD = intellectual disabilities and developmental disabilities.

Source: Reference 1.

The NTG-EDSD is a screening tool for adults with I/DD that captures relevant information on function and behavior and is helpful for starting conversations about brain health and dementia. It can be used by support staff and caregivers to note the presence of key behaviors associated with dementia and to facilitate further assessments of function to inform diagnostic decision-making.[7] Primary care providers may ask families or other caregivers to complete the NTG-EDSD prior to visits so that any items noted can be discussed and used to construct a plan for further assessments.

The NTG-EDSD is used to collect data regarding the adult's living arrangements, diagnosed conditions (I/DD conditions and other chronic health conditions), medications, current physical health, changes in physical health, current mental health, changes in mental health, the presence of seizures, and impairments in vision, hearing, and mobility. Persons completing the NTG-EDSD are also asked to provide ratings of ID as well as various aspects of functioning, including activities of daily living, language and communication, sleep–wake patterns, ambulation, memory, behavior and affect, and self-reported problems. For assessments of function, the rater is asked whether the impairment: (1) Has always been present, (2) Has always been present and has worsened, (3) Is a new symptom in the past year, or (4) Does not apply.[7]

The NTG-EDSD is also recommended to use when determining and documenting impairments associated with Alzheimer's dementia when completing the CMS National Patient Registry and enrolling patients with Down syndrome or ID for prescription approval and access to FDA approved anti-amyloid drugs approved by the U.S. Food and Drug Administration for treating Alzheimer's disease.

Clinical Pearl 1

R.A., a 55-year-old woman with Down syndrome, was referred to a specialist by her health care provider's office. R.A.'s brother reported that she was becoming disinterested during usual family activities and less active in her favorite hobbies. The health care provider also reported noticing changes in her expressive language and gait. R.A.'s brother was asked to complete the NTG-EDSD and note any specific concerns. During the assessment, the specialist performed a general review of R.A.'s physical condition, including assessment of diet, medications, and routines. The specialist discussed with R.A. and her brother some items that were noted on the NTG-EDSD and reviewed the changes that were observed. Based on her initial observations, the specialist concluded that the changes were potentially symptomatic and asked R.A.'s brother to track her behaviors and return in 6 months. Given her suspicions, the specialist also referred R.A. to a regional memory assessment center, which had a clinician familiar with Down syndrome, for a neuropsychological review.

Evaluate

for Dementia

Dementia is often a diagnosis of exclusion. When an assessment reveals a decline in function in adults with I/DD, a thorough evaluation is needed to determine whether a diagnosis of dementia is appropriate. A decline in function or change in behavior may be due to a number of factors, including other diseases, medication adverse events, physical or sensory problems (e.g., nutritional deficiencies, thyroid abnormalities, vision or hearing impairments), or adverse or disruptive life events (Table 3).[3,8] Many syndromes and other etiologies of I/DD are frequently associated with secondary conditions that may further confound the assessment. Clinicians should be mindful to avoid diagnostic overshadowing, which occurs when a mental health symptom or behavioral problem is erroneously attributed to a pre-existing disability rather than conducting a thorough investigation.

It is important to determine whether any conditions that cause memory changes are present; this information is necessary to obtain an accurate diagnosis and because many of these conditions may be amenable to treatment that can reverse the declines in cognition or function, mitigate symptoms, and improve quality of life. An accurate diagnosis can support determination of eligibility for services, systematic provision of post-diagnostic supports, development of goals and plans, prescription of disease-modifying treatments, and eligibility for clinical trials.

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

*Depression can cause symptoms that seem similar to dementia and can co-occur with early dementia.

I/DD = intellectual disabilities and developmental disabilities.

Sources: References 3 and 8.

Clinical Pearl 2

F.W. is a 66-year-old ambulatory man with ID who uses a few words and mostly communicates by gestures and vocalizations. He is dependent on others for assistance for all activities of daily living. His current health problem list includes chronic constipation, dysphagia with hospitalization for aspiration pneumonia, cataract in the right eye, COVID-19 infection residuals, and history of anxiety and impulse control issues. Over the past few months, F.W.'s caregivers have reported behavior changes, including becoming more confused, uncooperative, and withdrawn. He has shown increased resistance with care and has impulsively hit staff. A consultant nurse practitioner conducted an evaluation, which revealed a strong history of depression and worsening of cataracts. Based on these findings, she recommended cataract removal along with an assessment by a psychiatrist with experience working with individuals with ID. The psychiatrist agreed that depression was likely present and initiated a plan for depression treatment.

To identify underlying conditions that may be present, health care providers should conduct a thorough evaluation that considers a range of issues in addition to a physical exam and cognitive assessment (Table 4).[3] The cognitive assessment should be conducted with dementia screening and assessment tools that are designed for use with adults with I/DD and that compare current levels of function with baseline levels (Table 5).[9] Some of these tools may be used without specialized training but with some basic understanding of I/DD, while others require specialized training to administer to assure accuracy in interpretation.

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

I/DD = intellectual disabilities and developmental disabilities.

Source: Reference 3.

After conducting a thorough evaluation (potentially with serial assessments) and referrals to specialists as needed, clinicians can synthesize the available information to determine whether a diagnosis of dementia is warranted. The rapidly developing science around the use of biomarkers may also play a greater role in informing the diagnosis of dementia associated with disease-based brain changes.

The information gathered during the assessment and diagnostic process, including a determination of dementia stage where possible, can also be useful in helping develop a dementia care plan and recommending post-diagnostic supports.

Table 5. Examples of Dementia Screening and Assessment Tools for Adults With I/DD

Tool	Description	Strengths and Weaknesses
Adaptive Behaviour Dementia Questionnaire (ABDQ)	A 15-item questionnaire that detects change in adaptive behavior by comparing current functioning to typical functioning	Strengths: Detecting change in everyday functioning; easy to administer and score; family member as informant; length of time informant must know adult is specified. Weaknesses: No differential diagnosis; not useful to track responses to interventions.
Assessment for Adults With Developmental Disabilities (AADD)	Composed of 28 items respective of "how often," "management difficulty," and "effect" to measure function with focus on behavior and performance related to cognitive and physical decline.	Strengths: Assesses current everyday functioning/behavior and behavior changes. Easy to administer; standardized administration; descriptive; indicates who needs further evaluation/care; many informants. Weaknesses: No differential diagnosis. Questions are complex.
Dementia Questionnaire for People With Learning Disabilities (DLD)	Cognitive and social scores based on 8 subscales. Cognitive score is based on short-term memory, long-term memory, and orientation; social score is based on speech, practical skills, mood, activity and interest, and behavioral disturbance.	Strengths: Designed for all levels of functioning as early screening instrument. Easy to administer as an informant completion item or interview. Indication of dementia signs at one assessment and over repeated assessments. Weaknesses: Level of functioning (e.g., IQ) required for norms. No differential diagnosis. Some concern among clinicians regarding its appropriateness for individuals in the severe and profound ranges of intellectual functioning.
Dementia Scale for Down Syndrome (DSDS)	Measure of early, middle, and late stages of dementia. One form for 10 assessments, includes time course of deterioration and a differential diagnosis scale.	Strengths: Differentiates typical from atypical functioning and determines how long signs have been present. Standardized administration. Weaknesses: Normed only on adults with lower levels of functioning that could affect sensitivity of scale in higher functioning adults. Two informants required; designed to be administered by a psychologist.
Dementia Screening Questionnaire for Individuals With Intellectual Disabilities (DSQIID)	Composed of 43 questions in 3 sections. Measures memories, confusion, feelings of insecurity, sleep problems, and behavior problems. Includes information about medical conditions, psychiatric conditions, and medication.	Strengths: Current everyday functioning assessed; easy to administer/score; wide range of respondents considered appropriate; length of time informant needs to know adult specified. Weaknesses: For differential diagnosis only lists possible other conditions and medications.

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Tool	Description	Strengths and Weaknesses
National Task Group Early Detection and Screen for Dementia (NTG-EDSD)	A brief screening instrument that is relatively quick to administer, drawing from informant and clinical records data, making them suitable for use in a variety of health care settings; embedded in it is a variant of the DSQIID.	Strengths: Applicable for use by family carers and staff; can identify key changes noted in behaviors associated with symptoms of dementia; best with early stages. Available in multiple languages. Weaknesses: Lacks data on scoring and is not definitive as it only is used as a screen prior to more formal assessments.
Prudhoe Cognitive Function Test (shorter versions) (PCFT)	A 21-item informant-administered cognitive test that takes 15 minutes to complete. It tests orientation, language, memory, and spatial and conceptual skills.	Strengths: Excellent correlation with an established test of cognitive function, the Kaufman Brief Intelligence Test (K-BIT). Those with moderate and severe handicaps can complete this test. Weaknesses: People with profound intellectual disability are unable to complete items on this test.
Test for Severe Impairment (modified) (TSI)	A 24-item cognitive test that requires 10 minutes to administer. Tests language, memory, conceptual ability, and spatial skills.	Strengths: Most people with moderate and severe intellectual disabilities should be able to score on the TSI unless they are at an advanced stage of dementia. Many report enjoying completing the scale. Weaknesses: The small number of items within each subscale may not always be sufficient to detect subtle changes over time.

Source: Reference 9.

to Community Resources

If a diagnosis of dementia is made, referral to resources in the community is needed to ensure that the adult with dementia and caregivers receive appropriate post-diagnostic supports and services. The diagnosis should be shared with the adult's health care providers and other entities that may be involved in the care of the individual, such as an I/DD services agency. Many state developmental disability agencies provide case management and other support services for people with I/DD and can be asked to aid in prolonged aftercare. (To locate contact information for specific state agencies, see the National Association of State Directors of Developmental Disabilities Services.) Many organizations that serve the general population of adults with dementia can provide valuable supports and services to adults with I/DD. These organizations include the affiliates or chapters of the Alzheimer's Association as well as other dementia services agencies. An additional resource is the aging network's State Units on Aging and local Area Agencies on Aging (information on the individual entities can be found on the website of ADvancing States). State Departments of Health and Human Services or Adult Protective Services may also provide resources to support adults with I/DD and dementia; (these entities usually can be found in local services directories maintained by the local area agency on aging). Community providers that serve adults with I/DD and other disabilities may also be useful resources to obtain support for individuals with I/DD and dementia and their caregivers.

Although research regarding pharmacologic and nonpharmacologic approaches for supporting adults with I/DD and dementia is limited, there is general agreement that approaches used for the general population should be adapted to meet individual needs and modified as dementia progresses.[10] Post-diagnostic care may include a range of interventions, including creation of a dementia care plan, post-diagnostic counseling for individuals and their families, psychological and medical surveillance, periodic reviews and adjustments to the dementia care plan, early identification of behavioral and psychological symptoms of dementia, reviews of care practices and supports for advanced dementia and end of life, supports such as education to caregivers and staff, and evaluation of quality of life (Table 6).[2,10] Individuals in formal living situations (e.g., group homes) will likely have their individual care plans evolve to address their dementia as well as other preexisting diagnoses.

Table 6. Post-Diagnostic Supports for Adults With I/DD and Dementia

Post-Diagnostic Stage	Key Strategies
Immediately post-diagnosis	• Post-diagnostic counseling/support and education offered to the person and caregivers/support staff to help empower them to effectively manage dementia, its implications, and the probable course/trajectory. • Early identification of behavioral and psychological symptoms of dementia and reviews of care practices and supports for these symptoms.
Ongoing	• Periodic, regular, planned reviews of the care plan to identify changes in health, function, and quality of life from the perspective of both the person with I/DD and informants. • As-needed adjustments to activities and care practices to provide quality person-centered care. • Supports and education offered to caregivers/support staff on an ongoing basis, from both specialist and mainstream services, with continuing provision of information. • Psychological and medical surveillance throughout the course of decline to address dementia-related needs and conditions (e.g., seizures in Down syndrome) and non-dementia comorbid conditions.
Advanced dementia	• Review care practices and supports.

I/DD = intellectual disabilities and developmental disabilities.

Sources: References 2 and 10.

Care planning should consider the diagnosis of the individual's type of dementia, current function, and abilities as well as anticipated trajectory when determining post-diagnostic supports and services. For example, adults with Down syndrome are more likely to have rapidly progressing dementia, which should be accounted for when determining appropriate interventions and supports, including potential residential supports. The anticipated trajectory and care needs of adults with I/DD and dementia depend on many factors, including the person's overall general health and stamina, presence of other chronic diseases or coincident conditions, type of dementia, level of fragility and frailty, lack of or access to health services, susceptibility to acute conditions (e.g., infections), and mitigating self-abuse or neglect.[11]

Supports and services provided to adults with I/DD and dementia should also consider the adult's living situation and caregiver needs. For example, some individuals may have been cared for during their whole lives by their parents who are approaching advanced age and have their own care needs that may impact their ability to manage the individual with dementia. Care planning should seek to identify supports that would help adults with I/DD and dementia maintain their desired place of residence for as long as possible, while also considering movement to alternative living arrangements if care needs exceed that residence's capacity to provide the required level of care. Conversations about advance directives and other documents that impact decision-making and care provision should be incorporated into care planning discussions. Several resources from the NTG are available to support care planning for adults with I/DD, including *Dementia Care Plan for Adults With Intellectual Disability Living With Dementia*.

Interventions may include education for the adult's family members, caregivers, and housemates, as well as supportive accommodations.[12] Services may be provided by a variety of caregivers, depending upon the adult's living situation. Family members who have been primary caregivers throughout the adult's life are often challenged with managing diminishing capabilities and may require assistance or supports to address changing levels of care. Staff who care for adults with I/DD in supported living situations may require education and training in generally accepted dementia care practices; the realities of dementia progression among independently living adults with I/DD may require services from aging or social services organizations or agencies. Regardless of the living situation, early detection, screening, and diagnosis of cognitive impairment is necessary for developing a successful dementia care plan and the required post-diagnostic supports. However, not all health care providers or supporting entities are specifically prepared to address the needs of adults with I/DD so it may be challenging to find suitable post-diagnostic support provision. This same challenge may be prevalent in rural areas or in jurisdictions with scarce public investment in supports for people with disabilities with or without dementia.[13]

Recommended strategies for managing dementia in adults with I/DD across the care trajectory are shown in Table 7.[9] It is essential that caregivers for adults with I/DD and dementia receive education that changes in behavior are a manifestation of changes in the brain. Additionally, they should be trained in techniques for managing behavioral and psychological symptoms of dementia so that they can continue to support the person in a safe and comfortable environment.

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.

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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.

I/DD = intellectual disabilities and developmental disabilities.

Source: Reference 9.

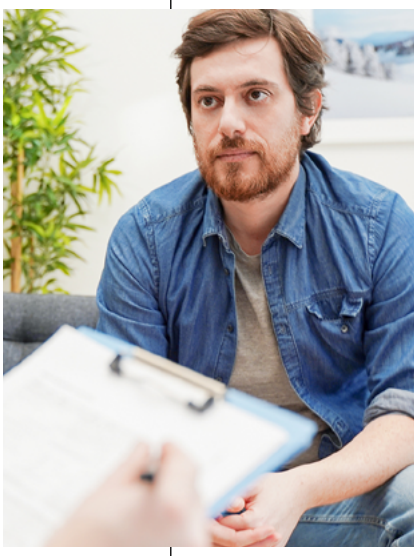
Detailed guidance for post-diagnostic supports and services for adults with I/DD is provided by several statements and guidelines:

- *Quality Care for People With Intellectual Disability and Advanced Dementia: Guidance on Service Provision*
- *Consensus Statement of the International Summit on Intellectual Disability and Dementia on Valuing the Perspectives of Persons With Intellectual Disability*
- *Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to Post-Diagnostic Support*
- *Supporting Advanced Dementia in People With Down Syndrome and Other Intellectual Disability: Consensus Statement of the International Summit on Intellectual Disability and Dementia*

More details about how to address challenges for supporting adults with I/DD and dementia, including information and awareness, referral and assessment processes, clinical care and follow-up, and communicating with health care teams can be found in *Guidelines for Structuring Community Care and Supports for People With Intellectual Disabilities Affected by Dementia* and *Guidelines for Dementia-Related Health Advocacy for Adults With Intellectual Disability and Dementia*.[4,9]

Summary

Adults with I/DD are a diverse population who face a wide range of challenges as they grow older. Among these concerns are personal challenges such as failing health; difficulties with mobility, sight, and hearing; and losses in their personal lives. These issues often are compounded by changes in cognitive abilities and overall functioning. Thus, any evaluations of loss of cognitive and adaptive function in this population are complicated by pre-existing impairments and life situations associated with aging. Given this context, a thorough approach to assessment and differential diagnosis is required. This companion document adapts the GSA KAER framework and *The GSA KAER Toolkit for Primary Care Teams* to meet the distinct needs of aging adults with I/DD. All providers of supports for aging adults with I/DD are encouraged to consider the lived experiences and life histories, the nature of the primary I/DD and secondary conditions, and the context of presenting behaviors and changes in function before undertaking assessments, as they keep in mind that individualized care requires understanding of the unique circumstances, abilities, and strengths of adults in this population.



Resources

General Resources

Administration for Community Living

The ACL helps support Aging and Disability Networks as part of its mission to maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers.

National Alliance for Caregiving

The NAC is a non-profit coalition of national organizations focusing on issues of family caregiving and its members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations.

National Institute on Aging

The NIA leads the federal government in conducting and supporting research on aging and the health and well-being of older adults, including Alzheimer's disease in people with Down syndrome.

National Task Group on Intellectual Disabilities and Dementia Practices

The NTG, which has issued dementia guidelines, is dedicated to providing for advocacy on behalf of adults with intellectual and developmental disabilities affected by dementia and their families and caregivers, as well as providing education and training on dementia and intellectual disabilities, informational materials, guidelines care practices and screening/assessment, and being a technical assistance resource.

Dementia-Specific Resources

ADvancing States

ADvancing States is an organization representing the interests of the state units on aging and works to design, improve, and sustain state systems delivering long-term services and supports for older adults, people with disabilities, and their caregivers.

Alzheimer's Association Local Chapter Listing

The Alzheimer's Association provides an online tool to find a local chapter and become involved with the Association in the community.

Alzheimer's Foundation of America

The mission of the AFA is to provide support, services, and education to individuals, families, and caregivers affected by Alzheimer's disease and related dementias nationwide, and fund research for better treatment and a cure.

Dementia Friends USA

Dementia Friends USA aims to expand awareness and understanding about dementia.

Global Council on Brain Health

The GCBH is an independent collaboration with AARP created to provide the general population with trusted information about how to maintain and improve brain health.

Disability-Specific Resources

The Arc of the United States

The Arc is a national community-based organization advocating for and with people with intellectual and developmental disabilities and serving them and their families, with chapters in most states.

Down Syndrome Medical Interest Group

The DSMIG-USA is a group of health professionals committed to promoting the optimal health care and wellness of individuals with Down syndrome across the lifespan; members are professionals from a variety of disciplines who provide care to individuals with Down syndrome and/or their families.

Global Down Syndrome Foundation

GLOBAL is a public non-profit dedicated to significantly improving the lives of people with Down syndrome through research, medical care, education, and advocacy.

National Down Syndrome Society

The NDSS is a national organization that offers support to people with Down syndrome, their families, friends, teachers, and coworkers, and educates the public about Down syndrome; it maintains chapters in various parts of the United States.

National Alliance of Direct Support Professionals

The NADSP is a non-profit organization that aims to elevate the status of direct support professionals by improving practice standards, promoting system reform, and advancing their knowledge, skills, and values. Its list of member organizations may be sources of information, supports, and services.

National Association of State Directors of Developmental Disabilities Services

The NASDDDS represents the state agencies in 50 states and the District of Columbia providing services to children and adults with intellectual and developmental disabilities and their families and promotes systems innovation and the development of national policies that support home and community-based services for individuals with disabilities and their families.

National Down Syndrome Congress

The NDSC is a national organization serving as a resource of support and information for anyone touched by or seeking to learn about Down syndrome.

National Resource Center for Supported Decision-Making

The NRC-SDM aims to provide accurate and helpful information, resources, and stories about supported decision-making to those who need it. Resources include research, state-by-state legislation guides, and webinars addressing supported decision-making.

Books About Dementia in Adults With I/DD

Ann Has Dementia
Hollins S, Blackman N, Eley R
A story told in pictures about an adult with dementia who is being cared for at home until she moves to residential care. Beyond Words publishes books and provides training to support people who find pictures easier to understand than words.

Dementia, Aging, and Intellectual Disabilities: A Handbook
Janicki, M P & Dalton, A J (Eds.)
A textbook covering all facets of dementia and intellectual disability. The editors take a practical approach to diagnosis, assessment, treatment, management, and care, making the book a useful guide for both students and trained professionals.

Jenny's Diary
Watchman K, Tuffrey-Wijne I, Quinn S
A resource to support conversations about dementia with people who have a learning disability.

Let's Talk About Dementia
Down's Syndrome Scotland
A booklet about dementia for people with Down syndrome published by Down's Syndrome Scotland.

Mental Wellness in Adults With Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges
McGuire D, Chicoine B
A resource for adults with Down syndrome and their caregivers to support mental and emotional health and well-being.

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