Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals

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Intellectual and Developmental Disabilities and Dementia: Practical Strategies for Professionals

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Table of Contents

Section Page

List of Figures

List of Tables

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Purpose of The Guide

The purpose of this guide is to provide background and practical strategies that can be used by professionals—from both the intellectual and developmental disability (IDD) and aging communities—when working with people with IDD and dementia. Advances in medicine and technology are extending the lives of individuals with IDD, but their longer lifespan also increases their risk of developing dementia. People with IDD and dementia and their caregivers have many needs resulting in the need for specialized and targeted service delivery. Typically, a limited number of people with IDD and dementia live in any one community, compared to numbers in the general population.

The guide is organized into 15 sections that address a variety of methods to identify and provide services to people with IDD and dementia or who are at risk of developing dementia. The guide also includes tools professionals can share with family caregivers or other caregivers who work with this population. Each section includes specific strategies to support these communities and resources that professionals and caregivers can consult for further information.

The National Alzheimer's and Dementia Resource Center (NADRC) developed this resource at the request of the Administration on Aging within the Administration for Community Living (ACL). ACL funds the NADRC to provide it and its grantees expert technical assistance. Through the NADRC, ACL makes Alzheimer's disease and related dementias (ADRD) program information, tools, and trainings available to the Alzheimer's Disease Programs Initiative (ADPI) grantee community and the general public. This resource is intended to support the work of ACL's ADPI grantees and others who are dedicated to developing and delivering programs and services intended to support people with IDD and dementia. The NADRC's full array of dementia-related information, resources, and tools can be found at the NADRC website.

Section 1: Introduction

The needs of people with IDD and dementia often call for unique skillsets. This guide reviews practical strategies professionals can use to provide dementia-capable and culturally competent services and supports when working with people with IDD and caregivers/primary support people.

Most information on dementia and IDD is based on studies of people with Down syndrome, who have some of the highest rates of ADRD. New science also focuses on ADRD and autism: the relationship between the two conditions, symptoms and diagnosis, and approaches to care. That said, most of the recommendations contained within this document apply to all people with IDD who are living with ADRD. Notations are made throughout where items are specific to people with Down syndrome or autism.

Terminology Used in This Guide

The following terms are used throughout the guide:

- **Caregiver/Primary support person** can refer to a family member or professional who provides ongoing care, supervision, and support in a private home or residential care home.
- **Direct Support Professional (DSP)** is an increasingly used occupational title and refers to paid professionals who support people with disabilities to be more independent by aiding with activities of daily living, employment support, transportation, and accommodations. They facilitate access to resources and opportunities in the community. DSPs can be primary support people.[1]
- **Residential care home** is used to describe community-based residential living options that are not an independent home or home with a person with IDD's family. They offer staff support in a supportive setting that encourages the person with IDD to be engaged in their community and to benefit from home and community-based services.

Types of Disabilities

The following terms describing types of disabilities are used for the purpose of this guide:

- ***Developmental disability (DD)*** is defined by the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. §§ 15002)[2] as a severe, chronic disability in an individual 5 years of age or older; with onset before 22 years of age; and that results in substantial functional limitations in three or more areas of life activity such as self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent learning, and economic self-sufficiency.

- ***Autism spectrum disorder*** (ASD) is a type of DD. ASD is defined as an assortment of neurological differences that may contribute to sensory processing difficulties, repetitive behaviors, and challenges with social interaction, executive function, transitioning between activities, and communication.[3; 4] ASD's classification as a "spectrum" reflects the range of potential presentations of the condition. Some people with ASD may experience only minor challenges, while others may have more severe disabilities and require a high level of support. Some people with autism disapprove of referring to ASD as a disorder, preferring terms like "condition," "neurodiversity," or "difference".[5]

    - ***Why this guide focuses on ASD.*** There has been recent recognition that as people with ASD age they may also experience symptoms of dementia. Some research has suggested they are at increased risk for developing earlier onset dementia and types of dementia other than Alzheimer's disease (e.g., frontotemporal dementia).[5] Identifying dementia in people with autism can be complicated by the presence of overlapping symptoms.

- ***IDD*** is a subset of DD and is defined[6] as a disability that originates before the age of 18 and is characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills.

- ***Down syndrome*** is an IDD. It is a chromosomal condition that occurs when an individual has a full or partial extra copy of chromosome 21. Physical characteristics typically associated with Down syndrome include low muscle tone, shorter than average height, almond-shaped eyes that have an upward slant, and a single crease across the palm of the hand. However, each person with Down syndrome will experience a unique developmental trajectory. They may have varying degrees of these characteristics, or they may not have them at all.[7] All individuals with Down syndrome experience cognitive delays, and their level of disability can range from mild to severe.[7; 8]

    - ***Why this guide focuses on Down syndrome.*** Chromosome 21 plays a key role in the relationship between Down syndrome and Alzheimer's disease; the extra copy of chromosome 21, which defines Down syndrome, carries the amyloid precursor protein (APP) gene. This gene produces a specific protein called APP, a protein which has been shown to be involved with changes in the brain caused by Alzheimer's disease.[9]

Dementia and IDD by the Numbers

Dementia predominantly occurs among older adults with increasing age, although some individuals experience early onset of symptoms at a younger age.[10] Alzheimer's disease is the most common cause of dementia and accounts for an estimated 60%-80% of dementia cases.[10] Approximately 11% of U.S. adults aged 65 and older, or about 7.2 million adults aged 65 and older, are estimated to be living with Alzheimer's disease.[11; 12]

According to a report from the Institute on Community Integration, almost 8.4 million people with IDD were living in the United States in 2020.[13] Advances in medicine, screening, and living conditions have increased life expectancy for people with IDD. As such, from 2000 to 2030, the number of adults with IDD aged 60 and older is expected to nearly double, to 1.2 million.[14; 15] Research shows that age-related health problems among people living with IDD are similar to those in the general population, including the development of dementia.[16] Estimates vary as to the prevalence of dementia among people with IDD compared to the general population. Some experts report similar rates of dementia among the two groups,[17-19] while other studies found higher rates of dementia.[20] One study noted that although people with IDD and without co-occurring Down syndrome might have a higher prevalence of dementia at younger ages, the likelihood of developing dementia may be lessened with risk reduction approaches, like controlling blood pressure and treating depression.[21]

Down Syndrome and Dementia Prevalence

In 2018, the most recent year for which data were found, approximately 220,000 people living in the United States were estimated to have Down syndrome.[22] People with Down syndrome have experienced substantial gains in life expectancy in recent decades and now live an average of 60 years.[23; 24] Estimates of the number of older adults with Down syndrome are difficult to find, but one recent study suggested that approximately 2% of people with Down syndrome are aged 60 and older.[25]

There is consensus that among people with Down syndrome, dementia is more prevalent than among the general population, and it appears earlier in life.[19; 26-28] In one study, the average age of dementia onset was 55, but onset may occur as early as 40.[29] This longitudinal study followed 77 women with Down syndrome aged 35 and older at the start of the study. By the end of the 20-year study period, 97.4% had been clinically diagnosed with dementia.[29] Among those classified as having severe intellectual disability (ID), 100% had developed dementia.[29] Another study found that among people with Down syndrome 40% of people aged 45 and older and 49% of people aged 65 and older had a diagnosis of dementia.[30] Compared to the general population, people with Down syndrome are significantly more likely to die as a result of dementia (17% vs. 70%).[31]

As in the general population, prevalence rates of Alzheimer's disease among people with Down syndrome are reported to increase with age. Most people with Down syndrome have biomarkers for Alzheimer's disease by the age of 40, but not all of them will develop symptoms.[32] A recent study estimated that 23.3% of all adults with Down syndrome had Alzheimer's disease, with estimated prevalence increasing to nearly 80% among those aged 75 or older.[32] A meta-analysis of studies of adults with Down syndrome and Alzheimer's disease found the average age of onset of Alzheimer's to be 55 years and the average duration of disease to be 4.6 years.[33]

Autism Spectrum Disorder and Dementia Prevalence

Approximately 2.2% of the U.S. adult population was estimated to have ASD in 2017.[34] This is nearly 5.5 million adults. ASD diagnoses decline as people age,[35] but these lower levels may not reflect the real prevalence of ASD among adults. Researchers suspect that several factors may contribute to this decrease in diagnosed ASD at older ages, including lower levels of adult screening and research, difficulty identifying ASD in adults, different diagnostic criteria used in the past, the potential for symptoms to become less apparent with age, and earlier mortality.[35] Men are approximately 4 times more likely than women to be diagnosed with ASD.[36]

The relationship between ASD and dementia is not well understood.[35] Some studies report that people with ASD are more likely to be living with dementia and as much as 2.6 times more likely to be diagnosed with earlier onset dementia than the general population,[37; 38] while other research suggests that rates of dementia are similar between people with ASD and the general population.[39]

Some of the increased dementia risk for people with ASD may be explained by the prevalence of co-occurring ASD and ID, including Down syndrome. Researchers estimate that approximately 33% of people with ASD have co-occurring ID.[36; 40] In a study using Medicaid data from the state of California, researchers compared rates of dementia among adults with ASD only, adults with co-occurring ASD and ID, and adults with neither condition. Five-year prevalence of dementia for adults in the ASD-only group was 4.04%, compared to 5.22% for adults with both ASD and ID and 0.97% for adults with neither ASD nor ID.[38]

Other Intellectual and Developmental Disabilities and Dementia Prevalence

Other types of IDD may increase a person's likelihood of developing dementia. Fragile X syndrome (FXS) is a genetic condition that is a leading cause of ID.[41] FXS affects many of the body's systems, leading to cognitive, behavioral, neuropsychiatric, and physical symptoms. Some research has suggested a link between FXS and dementia, particularly Alzheimer's disease.[42] Cerebral palsy, a neurological condition that primarily affects a person's muscles and movements, can also cause cognitive and speech difficulties. Research on the connection between cerebral palsy and dementia is inconclusive. Some studies have found no increased risk of dementia among people with cerebral palsy,[43] while others identified an increased risk.[44]

Resources

- Alzheimer's disease in people with Down syndrome: What we know and what we can do about it (National Down Syndrome Society) Webinar features physicians and researchers who addresses diagnostic testing and why individuals with Down syndrome are at high risk for developing Alzheimer's disease.

- Intellectual and Developmental Disabilities and Dementia - Experiences of a Family Advocate and Promising Practices (NADRC) Webinar includes background information about the prevalence of IDD and dementia in the United States, barriers to good dementia care for people with IDD, and programming models for this population.

- Autism and Dementia Resource Library (National Task Group on Intellectual and Developmental Disabilities and Dementia Practices) This web-based resource compiles research on the links between ASD and dementia.

Section 2: Presenting Signs and Symptoms

Dementia symptoms may manifest differently in people with distinct forms of IDD. Because of the significant overlap between many symptoms associated with IDD and dementia, diagnosis of dementia can be difficult or delayed, particularly for people with severe/profound intellectual (and multiple) disabilities.[45; 46] Symptoms typically associated with dementia, like memory loss, may be masked by preexisting differences in cognitive functioning[47] and a person's "pattern of abilities".[19] In this section, we describe the signs and symptoms of dementia for people with IDD.

Adults with Down syndrome experience "accelerated aging," meaning certain conditions and physical features that are common for aging adults occur at an earlier age than the general population.[7] Identifying cognitive decline in people with Down syndrome can be challenging because cognitive difficulties can be related to lifelong deficits or to changes resulting from dementia.[29] Furthermore, the communication challenges typically faced by people with Down syndrome make recognizing the symptoms of dementia more difficult.[5] A number of early symptoms of dementia in people with Down syndrome have been identified, including memory loss, disorientation, and changes in personality, behavior, speech, and physical function.[48; 49] For example, in the early stages of dementia, people with Down syndrome may have decreased executive function, emotional changes such as fearfulness and sadness, and loss of everyday skills.[48] According to the Alzheimer's Association, "in people with Down syndrome, changes in overall function, personality and behavior may be more common early signs of Alzheimer's than memory loss and forgetfulness".[26] Any one of the symptoms included in the list below may not be the result of dementia, but a noticeable change in the person warrants further assessment.[45]

For people with IDD other than Down syndrome, including people with ASD or severe/profound intellectual (and multiple) disabilities, many of the symptoms of dementia are the same as those listed below, with the exception of late-onset seizures. For people with ASD, the signs of dementia are difficult to identify because there is substantial overlap in symptoms associated with both conditions.[37] For people with severe/profound IDs, dementia symptoms may also be challenging to distinguish from their preexisting conditions.[46] Some of the dementia symptoms found to be more common among people with ASD and severe/profound intellectual (and multiple) disabilities are included below.

Dementia Symptoms in People With IDD

Cognitive and Memory Changes

- Problems with attention or focus

- Forgetting everyday work and social events
- Not remembering names of people previously known
- Losing things and blaming others
- Difficulty learning new tasks
- Inability to make clothing decisions
- Getting lost in familiar environments
- Increased everyday problems with thinking, memory, and judgment
- Requiring supervision for activities that have not needed supervision before

Behavioral and Emotional Changes

- Exaggeration of longstanding behavioral traits
- More compulsive behavior
- Increased aggression, excessive fears, sleep problems
- Family members and staff finding they need to spend more time with them
- Decreased interest in leisure activities
- Decreased emotional recognition, empathy, and theory of mind (i.e., understanding that others have different perspectives)
- Decreased responsiveness
- Increased stimming or self-soothing behavior
- Increased agitation or irritability
- Increased sensory defensiveness or sensory seeking
- Apathy or showing more emotions than usual—crying more often, displaying signs of sadness or anxiety, or having strong reactions to everyday situations

Communication and Social Skills

- Loss of language and other communication and social skills

Daily Functioning and Routine

- Change in prior daily routine, sleeping, or eating habits
- Progressive loss of prior activities of daily living

Motor and Physical Decline

- Increased difficulty with visual/motor coordination
- Increased accidents and falls
- Loss of physical strength
- Increased and frequent choking incidents
- Significant weight loss or weight gain
- Increased incontinence

Sensory and Neurological Changes

- Changes in hearing and vision
- Late-onset seizures

Source: [5; 37; 46; 49-54]

Resources

- Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers (National Task Group on Intellectual and Developmental Disabilities and Dementia Practices, National Down Syndrome Society, and Alzheimer's Association) This booklet was created to empower families and caregivers with knowledge about the connection between Down syndrome and Alzheimer's disease, suggestions about how to carefully and thoughtfully evaluate changes that may be observed with aging, and guidance about how to adapt and thrive within an ever-changing caregiving role when a diagnosis is made.

- Dementia Guidebook for Individuals with Developmental Disabilities and Their Caregivers (Wisconsin Board for People with Developmental Disabilities) This guidebook was designed for individuals with IDD and dementia, their family members, and caregivers to help increase the quality of care and life for the individual with IDD and dementia.

Section 3: Assessing Whether a Person With IDD May Be Developing Dementia

The detection and diagnosis of dementia in people with IDD can be challenging and depending on the type and extent of disability, standardized assessment tools used with the general population may not be suitable for assessment of people with IDD. It is important to acknowledge the broad range of conditions that encompass IDD and comorbid medical and mental health conditions. Disability and health systems are typically siloed, making it difficult to coordinate care for a person with a complex array of conditions. This can be informed by the quality of a person's interactions with their providers and their varied knowledge of dementia and IDD, contributing to the complexity of dementia detection and diagnosis.

An accurate IDD diagnosis and intervention early in the person's lifetime can make a significant difference in their quality of life and can have a substantial impact on the dementia diagnostic process. Providers rely on prior medical records for measuring a baseline level of functioning, but there is wide variability in how people with IDD access health and mental health care across their lifespan. Some people may have never received a formal IDD diagnosis for a variety of reasons including lack of provider knowledge, shortage and high cost of specialists, and societal stigma that impacts use of the health system.[55]

As noted earlier in this guide, there is a direct link between Down syndrome and risk for developing Alzheimer's disease. Almost all people with Down syndrome have Alzheimer's biomarkers by age 40, and almost all have clinical symptoms of dementia by age 60.[56] Detecting dementia in someone with autism, however, is more complicated, and there is limited research exploring the link between ASD and dementia. ASD is experienced on a spectrum from mild to severe impairment, and associated with a wide range of co-occurring developmental, mental, and physical health conditions such as epilepsy, abnormal sleep patterns, motor difficulties, anxiety, and depression. A person with ASD may or may not have a co-occurring ID.[55] Although dementia prevalence is higher in individuals with co-occurring ID, some studies suggest that autistic adults may be protected against cognitive decline. Additionally, a comprehensive evaluation for dementia in autistic adults is challenging because of similarity of symptoms in both conditions such as impairment in communication, functional decline, and increased severity of behavioral and psychological symptoms.[5]

Preparing for an Evaluation

Prior to conducting an evaluation, a provider or interdisciplinary team should prepare to make the best use of the time with the person and their family members. Below are tips for health providers and family members.

Gather Information Beforehand

- Access prior health records including baseline cognitive and functional assessments whenever possible.
- Review the person's medical and developmental history.
- Send pre-visit questionnaire such as the NTG Early Detection Screen for Dementia to family member that asks about changes in function over time.

Make the Necessary Accommodations

- If possible, meet in a familiar setting with a provider who is known to the person. Sometimes a telehealth visit is a way to keep the person in an environment that is most comfortable.
- Consider the space needed to accommodate the person, family members, and staff who will be participating in the examination.
- Create a sensory-friendly environment with soft yet ample lighting, comfortable seating options, reduced noise, and a waiting area that incorporates calming elements.
- Identify any mobility needs in advance and make the space accessible for the person. If the space for the evaluation is difficult to find, plan on escorting the person and their family members.

Engage the Person During the Evaluation

- Build rapport early to assist with the person's engagement during the evaluation process.
- Use straightforward and concrete communication and avoid use of abstract language.

- Consider receptive and expressive language abilities and employ augmentative and alternative communication methods such as nonverbal cues, visual aids, task demonstrations, writing, and drawing.
- Use preferred communication devices such as a pocket talker or tablet.

Build in Extra Time

- Communicate with the family in advance regarding the variability of time needed for the evaluation.
- Monitor for fatigue and allow time for breaks.
- Note that it may take multiple visits to complete an evaluation.
- Have a plan in place if the examination is not going well and be prepared to end it.

Source: [35; 57; 58]

Diagnosing Dementia in IDD

Detecting a change in cognition, behavior, and functioning early in a person with IDD increases the opportunity for families and professionals to plan for the future; access treatments; and engage in more appropriate programming, services, and supports. It is important to recognize changes in behavior or personality as evidence of a possible dementia. A diagnosis of dementia is not based on a single test result or brain scan, but instead on the medical provider's assessment of all the information available including their observation of the symptoms, prior history, family history, other potential causes for the symptoms, and laboratory results.

Why Typical Dementia Diagnostic Criteria May Not Be Effective for Individuals With Intellectual and Developmental Disabilities

Dementia diagnostic criteria are applicable to all populations, but detecting cognitive impairment in people with preexisting and possibly severe cognitive impairment is difficult. Subjective report is usually an important part of making the diagnosis,[57] and because people with IDD may struggle with reporting cognitive symptoms, it may be challenging to map the symptoms the person with IDD is experiencing precisely onto diagnostic criteria.[57]

Traditional dementia screening tools such as the Alzheimer's Association's "10 Warning Signs of Dementia" or the AD8 [59] are often not effective for individuals with IDD because of differences in cognitive baseline functioning. Many of the standard diagnostic indicators (e.g., confusion about time or place, difficulty with problem-solving or communication, or misplacing items) may already be part of an individual's lifelong cognitive profile and may not be useful markers of change.[60]

For individuals with IDD, the key to identifying dementia lies in recognizing changes from their personal baseline, not in applying generalized diagnostic criteria. For example:

- A person with IDD may have always needed some help with daily tasks, but now requires significantly more assistance than before.
- They may have been independent in certain routines but have recently started struggling in those areas.

These types of changes are often subtle and best recognized by those who know the person well, such as family members, long-time caregivers, or DSPs. [60]

Illustrative Examples

- *Ed*, who was previously independent in dressing, tying his shoes, riding the bus to work, and attending social groups, now consistently puts his shoes on the wrong feet, misses the bus, and forgets what day it is. These are significant declines from his previous level of functioning. But he may have never been able to subtract 100 minus 7 and count backward by 7 as in the MoCA screening tool. He may have never been able to remember five words and repeat them back, so specific tests designed for people of a typical IQ are not the indicative factors of dementia.
- *Peter*, who has always known the names of his support staff, now regularly calls them by the wrong names, a notable cognitive change that could signal early dementia.

Intellectual Functioning and Adaptive Behavior

Prior to diagnosing dementia, it is important to understand the person's preexisting intellectual functioning and adaptive behavior to discern what may be signs of dementia. Also called intelligence, *intellectual functioning* refers to general mental capacity, such as learning, reasoning, or problem solving. One way to measure intellectual functioning is an IQ test administered during the person's childhood. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning.

Adaptive behavior is the collection of conceptual, social, and practical skills that are learned early in a child's development and performed by people in their everyday lives. Standardized tests can determine limitations in adaptive behavior.

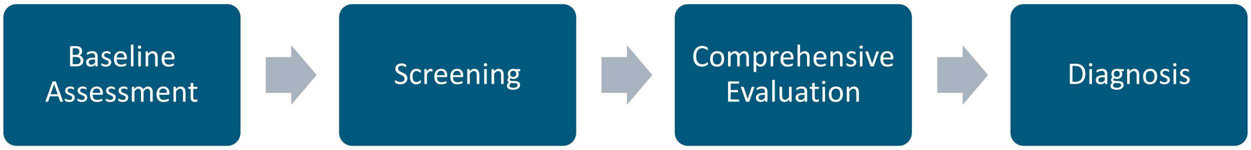
→ Conceptual skills—Language and literacy; money, time, and number concepts; and self-direction.

→ Social skills—Interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., lack of wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.

→ Practical skills—Activities of daily living (personal care), occupational skills, health care, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Understanding a person's baseline intellectual functioning and adaptive behavior can assist in the diagnostic process and determine whether recent changes may be a sign of dementia.

Diagnostic Process



Baseline Assessment

A baseline assessment of the person should be conducted before dementia is suspected, and ideally there should be ongoing annual assessments of cognitive and functional ability during a person's adult life.[61] Findings from prior cognitive and functional assessments can be used for comparison and can help differentiate between lifelong traits and dementia-related symptoms. For example, formal diagnostic evaluations for autism, Down syndrome, or other IDD conditions generally include assessment of language, verbal and nonverbal communication, and social interaction and behaviors.[62] Caregivers and primary support people can keep a record using videos that show the person speaking, interacting with others, performing daily activities, and engaging in favorite hobbies. These videos will demonstrate the person's talents, abilities, and motor skills.[61] Information about a person's baseline performance can provide a more accurate picture and avoid the possibility of diagnostic overshadowing (i.e., attributing symptoms to the person's disability).[61]

Screening

No single screening assessment is used by providers to determine whether a person is developing dementia. Selection of an assessment instrument should be made based on the person's condition, cognitive ability, tolerance, and fatigue level. Tests repeated over time with the person offer the opportunity to document changes in their performance. Longitudinal assessments can also be used to help discern whether the decline is progressive.[61] Assessments answered by a caregiver or primary support person may also identify changes observed over time. For example, a caregiver/primary support person can complete the National Task Group – Early Detection Screen for Dementia (NTG-EDSD) prior to the evaluation visit. The NTG-EDSD takes about an hour to complete and asks an array of questions about the person including their living arrangements, changes in physical and mental health, activities of daily living, sleep-wake patterns, communication, vision, hearing, and mobility.[5; 61]

Screening and Assessment Tools

Table 1 provides a list of instruments commonly used for assessment of dementia in people with IDD. Please note: This is not a comprehensive list, and the instruments below are designed primarily for professionals to administer in clinical settings.

Table 1. Screening and Assessment Tools

Measure	Instrument Description	Strengths/Weaknesses
Screening		
Dementia Screening Questionnaire for Individuals with Intellectual and Developmental Disabilities[63; 64]	Completed by caregivers who have known the person with Down syndrome for some time. Composed of 43 questions in three sections. Measures memories, confusion, feelings of insecurity, sleep problems, and behavior problems. Includes information about medical conditions, psychiatric conditions, and medication.	Strength: Current everyday functioning assessed, easy to administer/score, wide range of respondents considered appropriate, and easy to administer. Weakness: Less useful for more advanced stages of dementia.

Measure	Instrument Description	Strengths/Weaknesses
National Task Group-Early Detection Screen for Dementia (NTG-EDSD)[41; 65]	Comprehensive instrument used by family members and care providers who know person well to record observations of changes in function over time. Can take up to 1 hour to complete and some information can be obtained from person's health record.	Strengths: Provides useful information for evaluation and can be part of pre-visit preparation by the family. Findings can be used for care planning discussions and shared decision-making involving families and care providers.
Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)[66-68]	Brief 16-item questionnaire to be completed by a relative or friend who has known the person with IDD who can compare their current performance to 10 years ago.	Strength: Recommended as a useful tool to screen for cognitive decline in individuals with Down syndrome and seen as suitable for use in a primary care setting.
Montreal Cognitive Assessment[69; 70]	Brief screening tool completed by a professional to detect cognitive impairment by measuring executive function and other cognitive domains such as attention, memory, and language.	Strength: Shown to be more sensitive in detecting cognitive impairment in older autistic adults compared to other cognitive screening instruments such as MMSE.
Assessment		
Adaptive Behaviour Dementia Questionnaire[71]	Fifteen-item questionnaire used to detect change in adaptive behavior by comparing current functioning to typical functioning.	Strength: Detects change in everyday functioning, easy to administer and score, can be completed on a range of adults despite level of ID or cooperation. Weakness: Cognition is not part of the assessment and does not help with differential diagnosis.
Adult Independence Living Measurement Scale[72]	Short informant-rated assessment tool consisting of 19 items (goals) regarding the most important skills related to independent living.	Strengths: Findings are easy to implement because the total score is directly proportional to a person's degree of independence. Scale is user friendly.
Behavioral and Psychological Symptoms of Dementia in Down Syndrome (BPSD-DS)[64; 73]	Includes 52 items subdivided in 11 sections: anxious behavior, sleeping problems, irritable behavior, obstinate behavior, restless & stereotypic behavior, aggressive behavior, apathetic behavior, depressive behavior, psychotic behavior, disinhibited behavior, and eating & drinking behavior.	Strength: Changes in some items may indicate warning signs for AD in DS. Systematically evaluating BPSD in Down syndrome may increase understanding of changes among caregivers and (timely) adaptation of care/treatment.

Measure	Instrument Description	Strengths/Weaknesses
CAMDEX-DS[64; 74]	Test battery collects information on cognitive and functional decline, current mental and physical health and best level of functioning. The measure contains patient and informant interview questions and observational items.	Strengths: Comprehensive and thorough assessment that includes a measure of general disability. Facilitates process for differential diagnosis. Shown to lead to accurate diagnosis of Alzheimer's disease. Weaknesses: Floor effect and less effective for those at lower performance levels.
Test for Severe Impairment (Modified)[75; 76]	A 24-item cognitive test that takes 10 minutes to administer by a professional and tests language, memory, conceptual ability, and spatial skills.	Strengths: Most people with moderate and severe IDD should be able to score on the Test for Severe Impairment unless they are at an advanced stage of dementia. Weakness: The small number of items within each subscale may not always be sufficient to detect subtle changes over time.

Training Professionals to Screen for Dementia in People With IDD

Through their ACL-funded project, the Wisconsin Alzheimer's Institute developed, delivered, and evaluated the effectiveness of a training for professionals including DSPs, case managers, health care providers, and social services staff. The intention of the training was to increase participant knowledge and confidence in their ability to detect cognitive impairment and functional decline in people with IDD using the NTG-EDSD. Participants reported that it was feasible to administer the NTG-EDSD as a screening instrument. Initial findings demonstrated that participants' knowledge and confidence increased and to maintain these improvements, participants may benefit from periodic booster sessions.

Links to the training materials and NADRC webinar are in the Resources for this chapter.[65]

Conducting a Comprehensive Evaluation

A comprehensive evaluation should be conducted if the screening reveals a decline in function to determine whether a diagnosis of dementia is indicated. A number of factors can lead to a decline in function. A comprehensive evaluation helps to determine whether the underlying cause is something other than dementia such as another disease, nutritional or vitamin deficiencies, sensory impairments, change in daily routine or medications, or a significant event such as the death of someone close to them. Best practice is a comprehensive evaluation conducted by an interdisciplinary team with input from someone who knows the person well. All of the information gathered in the comprehensive evaluation is then synthesized and analyzed by a trained provider.

Components of a comprehensive evaluation are detailed in Appendix A and include[5; 61; 77] a thorough history and physical, developmental history, functional assessment and speech and language assessment.

Communicating With the Physician and the Interdisciplinary Team

Caregivers/primary support people are key to providing the information physicians and other professionals need to assess the person with IDD for dementia. Appendix C includes a behavior log template that can be used to document any changes in a person's behavior and function. Family members and others who know the person well can provide the following information:

- → Concrete detailed examples of any changes in behavior, interest in previously enjoyed activities, and general mood, particularly any heightened irritability or anger.
- → Examples of any difficulties noticed in ability to do things the person previously could do, including self-care activities including, but not limited to, dressing and managing personal care, participation in leisure activities, following routines, sleeping at night, and eating meals.
- → Photos or videos that illustrate what the person previously did that they can no longer do.
- → Information on any major life events in the last 12 months including changes in family and friend visit patterns, death or major illness of family or friends, and staff and peer changes where they live or work. Description of any new medical or psychiatric conditions, recent change in prescribed medications, sensory changes, falls, disorientation, or possible seizure activity.
- → Examples of things not remembered and contrast with other examples where they were previously remembered.[61; 78; 79]

Tools for Providers and Families

In addition to the Appendix A checklist for providers to use when collecting information from the family and conducting assessments of people with IDD at risk for dementia, Appendix B includes a checklist on postdiagnosis management.

Resources

- I Have Been Diagnosed with Dementia (Trinity Centre for Ageing and Intellectual Disability) This brochure explains dementia to someone with an ID in an easy-to-read format. The language can also be used to prepare providers for disclosure of diagnosis to the person and family.

- Things to Know about Health and Adults with Dementia (Seven Hills Rhode Island and the National Task Group on Intellectual Disabilities and Dementia Practices) This guide for people with IDD, family members, and caregivers provides an overview of the aging process, identifying changes, getting a diagnosis, responding to behavioral symptoms, and getting support.

- Screening for Dementia in Persons with Intellectual Disability and NADRC webinar (Wisconsin Alzheimer's Institute, University of Wisconsin School of Medicine and Public Health) This toolkit was developed for clinicians and caseworkers who are concerned about the presence of dementia in their clients with ID. It compares the incidence, prevalence, and clinical features of dementia of the Alzheimer type in adults with ID and outlines the modifications to diagnostic approaches that are needed to improve diagnostic accuracy. Many neuropsychological assessment measures that have been developed or adapted for use with adults with ID are reviewed.

- Primary Care Education about Down Syndrome Healthcare (National Down Syndrome Society) CARE Down Syndrome, an initiative of the National Down Syndrome, has a Clinical Education Hub for Healthcare Professionals that offers an online free continuing medical education course, clinical reference articles that discuss common health conditions, mental health disorders, and Down Syndrome Regression Disorder and a Resource Library.

- KAER Toolkit: Addressing Brain Health in Adults with Intellectual Disabilities and Developmental Disabilities (Gerontological Society of America; GSA) This toolkit adapts GSA's KAER framework for people with IDD [Kickstarting the brain health conversation, Assessing for cognitive impairment, Evaluating for dementia, and Referring to community resources].

Section 4: Managing Dementia and Co-Occurring Conditions

As a person with IDD is going through the dementia diagnostic process, or after they have received a dementia diagnosis, understanding the effect of dementia on preexisting physical and mental health conditions is essential. Caregivers/primary support people should also understand and monitor for co-occurring conditions that may emerge throughout the course of dementia.

Managing Preexisting Medical and Mental Health Conditions

Several medical conditions (Figure 1) more commonly develop in people with IDD than in the general population as they age.

Figure 1. Common Medical Conditions for People with IDD as They Age

- → Celiac Disease
- → Cervical Spine Disease
- → Dental Disease
- → Diabetes
- → Menopausal Disorders
- → Obesity
- → Osteoarthritis
- → Osteoporosis
- → Sleep Apnea
- → Thyroid Disorders
- → Vision and Hearing Deficits

It is important to monitor preexisting health conditions for any progression or shifts needed in their management, especially when the person with IDD starts experiencing cognitive decline. For example, diabetes management requires daily routines that may include regular glucose monitoring, insulin injections, taking medications, eating a healthy diet, consistent exercise, and weight management.[80] Even if a caregiver/primary support person has consistently been involved in managing diabetes with the person with IDD, the person with IDD may need additional support after the onset of dementia. People with IDD and dementia may forget to take their medication, miss an insulin injection before a meal, or forget to eat altogether. They may need additional support to prepare healthy foods and engage in safe physical activity. These changes may require revisiting diabetes management strategies and additional oversight and support of diabetes management activities.[80] Another example is sleep apnea, which is a common condition in people with Down syndrome.[81] Even if a person with IDD has used a continuous positive airway pressure (CPAP) machine for years, as dementia progresses, they may forget how to use the machine or become agitated while sleeping with the machine. The caregiver/primary support person may need to regularly help the person with IDD get reacclimated to using the CPAP machine or may need to consult a specialist to consider alternative options.[82]

We all experience sensory changes as we age, and people with IDD are no exception. People with Down syndrome are especially at risk for developing hearing loss, cataracts, and keratoconus, a condition of the eye that causes vision distortion from rounding of the outer layer of the eye.[82] Caregivers/primary support people should monitor for potential sensory changes and communicate changes to appropriate health care providers so that they can conduct screening and provide treatment, as needed. Changes in vision and hearing can be misinterpreted as confusion or changes in cognition, which could lead to misdiagnosis of dementia. For example, a person with IDD who has vision loss may get lost in familiar places, or a person with IDD who develops hearing loss may repeatedly ask the same question because they did not hear the response. Getting lost in familiar places and repeating questions or statements are early signs of dementia, especially Alzheimer's disease. It can be helpful for caregivers/primary support people to encourage the person with IDD to wear their glasses or hearing aids, if the person with IDD is forgetting to wear them or is regularly misplacing them. Regular screening and management by an eye doctor or audiologist may be helpful to address sensory changes as people age. Audiologists and speech therapists can provide strategies to address hearing loss for people with IDD including hearing aids, sign language, communication boards, and assistive technology.[83] If occupational therapy services are available, occupational therapists can provide adaptive strategies[84] to use in the home for people experiencing visual decline including the following:

- Using bright, even lighting throughout the home
- Installing motion-activated nightlights in hallways and bathrooms
- Reducing glare from windows and shiny surfaces
- Using high-contrast colors to distinguish objects from their background (e.g., dark plate on a white placemat)
- Applying colored tape to the edges of stairs or thresholds
- Reducing clutter and clearing pathways
- Using large-print materials (e.g., calendars, clocks, medication instructions).[60] Sensory regulation can also be managed through tactile, auditory, visual, and other tools such as weighted blankets and calming music.

Figure 2. Mental Health Conditions for Which People with Down Syndrome or Autism Spectrum Disorder are at Increased Risk

Down syndrome:

- Anxiety Disorder
- Depression
- Obsessive Compulsive Disorder

Autism spectrum disorder:

- Attention deficit/hyperactivity disorder
- Mood disorders
- Personality disorders
- Schizophrenia and other psychotic disorders
- Self-injury and suicide

As shown in Figure 2, people with IDD face an increased risk of developing specific mental health conditions as they age. People with autism have a higher likelihood of developing specific mental health conditions compared to the general population. If signs of depression or other mental health conditions appear, discussing them with a health or mental health professional and exploring treatment options is crucial. Because depression is a known risk factor for dementia and can impact overall functioning and well-being,[81] prompt attention and management are essential. [81;85]

Caregivers/primary support people need to be aware of the signs and symptoms of these conditions and discuss them with the person with IDD and a health professional. Monitoring for and managing co-occurring mental health conditions will support the person with IDD to have a higher quality of life and potentially address concerns around premature death. Nonpharmacological approaches are recommended for managing co-occurring mental health conditions, which include many of the same approaches provided in Sections 6 and 9 related to communication and managing behavioral symptoms, respectively.

As the person progresses through dementia, providers should be made aware of existing mental health conditions. Federal nursing homes must follow guidelines related to administering antipsychotic medications to people with dementia. If a person with IDD has been prescribed an antipsychotic medication to manage an existing mental health condition, staff and providers should be made aware so that they can assess the effectiveness of the medication.[86] This process is important to provide required documentation that the antipsychotic medication is clinically necessary.

Managing Physical and Mental Health Conditions After the Onset of Dementia

In addition to physical and mental health conditions that are present as a person with IDD ages, they can also develop after the onset of dementia. These conditions can include the following:

- Delirium
- Falls and subsequent traumatic brain injury (TBI)
- Incontinence
- Seizure disorders
- Swallowing and eating difficulties

Source: [57; 87]

New seizures can develop as a person with IDD progresses through dementia, especially a person with Down syndrome.[87] If a person had seizures when they were younger, they are at higher risk of developing seizures later in life.[57] Caregivers/primary support people should keep this in mind and watch for signs including involuntary jerking of limbs, body stiffening, or loss of consciousness.[87] Seizure activity may also be tied to unexplained falls. These situations should be discussed with a health care provider to consider whether testing and treatment is necessary.

If a person with IDD has dementia in addition to visual impairment or hearing loss, that can put them at higher risk for falls, which can result in TBI, bone fractures, and other physical injuries. Other factors can contribute to increased risk of falls, including the following:

- Arthritis
- Certain medications
- Impaired balance
- Loss of muscle mass

Source: [57, 87]

A caregiver/primary support person can consider several strategies to decrease risk of falls including the following:

- Ensuring adequate lighting
- Managing visual and hearing impairments
- Offering assistance when walking through unfamiliar places and uneven surfaces

- Providing shoes and clothes that fit properly
- Removing clutter, rugs, and other tripping hazards in walkways and living spaces
- Talking to the person with IDD and a health professional about using an assistive device such as a cane or walker

Source: [57, 87]

A home safety assessment done by a qualified professional such as an occupational therapist or a nurse can help increase accessibility of the home and avoid falls and subsequent injuries.

As dementia progresses, challenges with speech and language are common. The caregiver/primary support person may need to adapt their communication style. For example, instead of asking an open-ended question like, “What do you want to eat for breakfast?” they may need to provide clear, simple options with visuals. A better alternative would be, “Do you want to have oatmeal or eggs for breakfast?” It may also take longer for the person with IDD to respond, or they may respond in a different way. They may point or revert to using sign language or talking devices, especially if they have used those methods in the past. Further into dementia, this can progress into challenges with eating and swallowing.[87] People living with dementia may miss meals, forget whether they have eaten, forget how to use utensils, or forget how to chew and swallow certain foods.[87] Additionally, their brain may no longer be telling them when their body is hungry or thirsty, which can lead to people living with dementia losing weight and experiencing nutritional deficiencies and dehydration.[87] In some cases, challenges with swallowing can lead to aspiration pneumonia, which is when food or fluid moves into the lungs and leads to a lung infection.[87]

Several comorbid acute and chronic conditions cause pain (e.g., dental diseases, osteoarthritis) and the person with IDD may not be able to clearly communicate their pain or discomfort.[87] Communication can often present as:

- Agitation
- Grimacing or other facial cues
- Poor sleep
- Refusing to eat because of dental pain
- Refusing to move or participate in an activity

- Other similar behaviors that may seem out of character for the person

Source: [57, 87]

When these behaviors are present, the caregiver/primary support person should consider sources of pain and explore remedies, keeping in mind that the person with IDD may not have a clear sense of the source of their pain or be unable to communicate the source of their pain.

The primary care provider, or other health care provider, should regularly review the medication list including nonprescription supplements with the person with IDD and their caregiver/primary support person. In some cases, medications can contribute to confusion or balance issues, leading to increased falls and decreased alertness.[87] In other cases, prescribed medications, over-the-counter medications, and herbal supplements can have negative interactions when combined.[87] A medication review is especially important during the dementia diagnostic process and when considering introducing medications to treat Alzheimer's disease.

Medications for Managing Symptoms of Alzheimer's Disease

Several medications have been approved to manage symptoms of Alzheimer's disease, including donepezil, rivastigmine, galantamine, and memantine.[88] These medications may also be used to treat other types of dementia, including Lewy body dementia. There has also been progress in the development of medications to treat Alzheimer's disease by slowing the progression of the disease[89] (e.g., Lecanemab). Although there presently are no studies that specifically focus on the use of these medications in the IDD population, people with IDD and their caregiver/primary support person can talk with their doctor to decide whether the medications would be appropriate for the person with IDD.

Resources

- Aging and Down Syndrome: A Health and Well-Being Guidebook (National Down Syndrome Association) The document provides a comprehensive overview of how individuals with Down syndrome can stay healthy as they age. It provides information on common medical conditions and medication management.

- Six Pillars of Brain Health (Health Matters Program for People with Intellectual and Developmental Disability) This two-page fact sheet promotes the importance of brain health for people with IDD and emphasizes that heart health is brain health. Brief infographics cover moving more, choosing to eat for brain health, taking an active role in health care, engaging in social activities, and getting enough quality sleep.

- Alzheimer’s Disease and Down Syndrome: A Practical Guidebook for Caregivers (National Task Group on Intellectual and Developmental Disabilities and Dementia Practices, National Down Syndrome Society, and Alzheimer’s Association) This booklet was created to empower families and caregivers with knowledge about the connection between Down syndrome and Alzheimer’s disease. The document provides information about medical conditions that are common for people with Down syndrome as they age and common physical symptoms that occur after the onset of Alzheimer’s disease.
- Down Syndrome and Dementia: A Guide for Families (Down Syndrome Australia) The document provides information about managing physical health and chronic health conditions as people with Down syndrome age.
- Mind and Memory Matters Dementia Resource Guide Book (Board for People with Developmental Disabilities) This document provides information on common medical conditions and associated screening recommendations.

Section 5: Identifying and Reaching People With Intellectual and Developmental Disabilities and Dementia in Your Community

Identifying people with IDD who are at risk for dementia can be challenging. One reason is that, as noted in Section 1, absolute numbers of people with IDD who are at risk for dementia are often relatively low within a given community. An estimated 842,000 adults aged 60 and over, or about 1%-3% of the adult population, live with IDD in the United States. Identifying a small subset of the population is more challenging than finding people who are affected by more prevalent conditions. For most older adults with IDD, rates of dementia are about the same as those for people without IDD. However, people with Down syndrome develop Alzheimer's disease and other dementias at higher rates and at a much younger age than the general population, with onset occurring as early as age 40.

Estimating the number of people in the community or service area who have IDD, and Down syndrome specifically, can help organizations begin to determine the scope of their outreach efforts. Providers may want to begin by determining the number of adults aged 35-60 and the number of adults over age 60 in the community. US Census data is a good place to start and can be searched by state, county, or city.[90] About 1%-3% of the population age 60 and over has IDD. About 1 in 1,000 people has Down syndrome.[24] Because early-onset ADRD commonly affects people with Down syndrome, the target population of people with Down syndrome should include those approaching age 40. In fact, a 2024 study of adults with Down syndrome on Medicare or Medicaid found that 23% had ADRD diagnoses.[32] To reach people with IDD at risk of dementia, aging and dementia service providers often start by building relationships within the IDD provider community. IDD providers are often serving an increasing number of older adults and are hungry for knowledge about dementia and dementia capability. Although the absolute numbers of people with Down syndrome are small compared to the overall population, because of the disproportionately high risk for dementia and the earlier average age of onset, dementia providers often choose to focus IDD outreach efforts on Down syndrome organizations.

Caregivers/primary support people are generally not familiar with dementia service providers. People with IDD who have lived independently in their community or at home with caregivers/primary support people are often unknown to dementia-capable home and community-based and state disability service systems. Reaching people with IDD and their caregivers/primary support people through IDD service organizations can be an effective way to identify people at risk and begin to build trust. Potential service recipients may be reluctant to accept help because they fear repercussions, including no longer being able to live or provide care independently and impacts to other services from which they benefit.

They may also attribute the symptoms of dementia to the underlying IDD or not know to whom or where to turn for help.

The following resources and strategies should be considered when trying to identify and reach people living with IDD and dementia in the community and their caregivers: [91; 92]

- State disability agencies typically have statistics on the number of people with IDD, sometimes at the community level. Local IDD providers may also have data or knowledge to share about local IDD populations.

- Start with the primary IDD advocacy and service organizations (e.g., The Arc, EasterSeals) in your community; they already have contact with many people with IDD and their families.

- Some caregivers/primary support people may prefer to continue working directly with the IDD providers with whom they are already familiar. Consider providing dementia training to IDD provider networks to enable them to better identify people with possible dementia and provide dementia-capable care directly.

- Often, aging and dementia service providers must first build partnerships with disability service providers and learn about each other's systems.

- Congregate meal providers, pharmacists, financial advisors, faith communities, state DD councils, hospital social workers, senior centers, allied health professionals (e.g., physical and occupational therapists), Meals on Wheels staff and volunteers, and community centers are other common points of contact who can help identify people with IDD.[93]

- DD service providers may know of physicians and other providers who focus on serving people with IDD and who can help with diagnosis and care planning. Those providers may benefit from information on dementia-capable community services to which they can make referrals.

- Consider engaging other provider systems, such as those caring for unhoused individuals or delivering mental health services. People with IDD are often disproportionately represented among these populations.

- If people are provided a telephone number or email address to contact for services, ensure that the person to whom they are referred understands the IDD community and culture and how it is impacted by dementia.

- When communicating with caregivers of people with IDD, place an emphasis on offering support to help them continue their caregiving if desired.

- Outreach posters/flyers/brochures for services and programs need to include images that are clearly of aging people with IDD and their caregivers (older parent and siblings).

- Encourage people with IDD and dementia and their caregivers to whom you are currently providing services to build awareness of IDD and dementia concerns and services among their acquaintances and communities.

Source: [16, 134]

Resources

- Aiding Older Caregivers of Persons with Intellectual and Developmental Disabilities (Center on Intellectual Disabilities, University at Albany) This toolkit provides best practice strategies for aging and dementia service agencies to connect with and work effectively with people living with IDD and their caregivers.

- 2020 Census Demographic Profile provides an overview of demographic characteristics for a specific geography. View data for counties, census tracts, and other geographies by first choosing a state to view.

Section 6: Communicating With People With Intellectual and Developmental Disabilities and Dementia

As a person with IDD progresses through the stages of dementia, the people involved in their care need to understand the ways in which their communication will change over time. The ability to communicate their wants and needs, and their ability to process and understand communication from others to them, becomes more challenging as the language areas of the brain are impacted by dementia.[94]

People with IDD and dementia may lose their ability to communicate as they would have before the onset of dementia. Certain behaviors can be a way for a person with IDD to communicate unmet needs including pain, hunger, confusion, or boredom.[78] Behavior can also be used to communicate distress, anxiety, or frustration.[78; 94] People who support the person with IDD and dementia may be confused by behaviors, labeling them "challenging" or "aggressive" and failing to understand that they are often driven by unmet needs that require identification and addressing. This section includes techniques and approaches that caregivers/primary care people and providers can incorporate into their communication with the person with IDD. It also includes information about how to talk with a person with IDD about their dementia diagnosis.[95]

Nonverbal communication (i.e., body language) may become the primary method of communication and needs to be a consideration as dementia progresses.[96] For example, caregivers/primary support people should avoid criticizing, correcting, or arguing with the person with IDD. Instead, consider listening to find the deeper meaning of what is being said, enter the person's reality, or redirect communication in a constructive manner. Below are some strategies to incorporate when interacting with a person with IDD and dementia. Each person is unique, and some approaches may work better than others.

Supporting Self-Advocates

As defined by The Arc, self-advocates are people with IDD who "exercise their rights as citizens by communicating for and representing themselves and others, with whatever supports they need" and "must have a meaningful role in decision-making in all areas of their daily lives and in public policy decisions that affect people with IDD."

As self-advocates progress through the dementia journey, they may find it more difficult to make their own medical decisions. This is why it is important for self-advocates to talk with their family members about their wishes and decisions for the future.

- **Engage the person with IDD in conversation:** Include the person with IDD in conversations with others. Talk directly to the individual face-to-face while maintaining good eye contact. Use clear, simple language and speak at a slow pace. Give the person time to process and respond to you. Consider using pictures or videos as prompts for conversation or to help the person understand what is being said.[53; 87; 97; 98]

- **Ask the person with IDD questions:** Ask one question at a time. Ask yes or no questions instead of open-ended questions. Give visual clues. Point, touch, or gesture to help the person understand what is being asked. If you do not understand a response, repeat the question and ask the person with IDD to share their response again.[87]
- **Listen to the person with IDD:** Listen to the person carefully. Allow time for the person to think about what they want to say and respond. Be patient and offer reassurance to encourage the individual to express their thoughts or feelings. Take time to listen to how the person with IDD is feeling. Look for the meaning behind the words and sounds. Listen to what they are thinking or may need. Emotions being expressed are often more important than what is being said.[16; 87; 97; 98]
- **Provide support to the person with IDD:** Offer instructions or provide cues one step at a time. Create meaningful opportunities for natural conversations. Enjoy being in the moment with the person. Introduce humor as appropriate to lighten the mood.[87; 98]
- **Use memory aids:** Many memory aid tools are available, so consider which type of tool(s) will be most helpful to the person with IDD. Personal memory albums are typically small, physical photo albums that include photographs and short descriptions of key memories or important topics for the person with IDD. Photos and videos taken on a cell phone can also be helpful memory aids for the person with IDD. Memory boards are another tool that can be used to display information about the person, their life, and what they enjoy. Memory boards can also be used to communicate daily or weekly schedules including meals, appointments, family visits, and other activities.[16; 53]

For health care providers, DSPs, and other professionals who may want to gather information from the person with IDD, additional considerations to keep in mind are listed below:

- **Consider the environment:** Provide a setting that is comfortable for the person. Consider asking about sensory differences ahead of time and adjusting the setting accordingly.[16; 57]

- **Consider whom to address:** Talk to the person directly to see whether they can respond. Ask the person with IDD for permission to have someone else interpret responses, if necessary.[16; 57]

- **Consider the approach:** Begin by asking easy, personable questions with no correct answer to build a positive relationship.[16]

- **Consider language and language tools:** Ask questions using vocabulary that is at an appropriate level for the person with IDD to understand. Encourage the person with IDD to use any assistive technology that they regularly use to communicate. Respect the person's choice not to use technology if that is their preference.[16]

Build a Positive Relationship by Asking Questions That Have No Correct Answer

→ "Who is your favorite sports team?" (provide options)

→ "Tell me about your favorite vacation."

→ "Who is your best friend?"

Several resources on how to talk with a person with IDD about dementia are available and are provided in the resources for this section's dementia diagnosis (e.g., parent, grandparent, friend), and others are specifically geared toward talking with the person with IDD about their own diagnosis. Below is a list of considerations that the caregiver/primary support person should keep in mind as they plan to share the diagnosis with the person with IDD. Section 8 of this guide shares considerations for future planning conversations including advance care directives, legal, financial, and end-of-life planning.

- Consider **who** should be part of the conversation
    - For the first conversation about the diagnosis, should it be one-on-one or in a group setting? Who should deliver the message? Who else should be part of the conversation? Who does the person with IDD feel comfortable with, trust, and respect? Does the person with IDD have a friend or a family member who has gone through this journey with their own family member and could provide helpful insight?
- Consider **when** the conversation should take place
    - Is there a particular time of day when the person with IDD is most alert and in a good mood? Is there a time when they will not be distracted and can focus on the conversation? Can the conversation happen before an activity that the person is excited about?

  - The conversation may need to happen more than once. After an initial conversation, it could be brought up when signs and symptoms present or as changes occur. Conversations may not always be planned and could come up during the day, so be prepared for when this happens.
- Consider **where** it will be most comfortable to have the conversation
  - Can the conversation be done in person, or will it need to happen virtually? Where is the person with IDD most comfortable? Is there a place that is quiet, with limited distractions, where the person with IDD can focus on the conversation? Are there certain comfort objects that they should have with them when the conversation happens?
- Consider **what** to say during the conversation
  - How will the conversation start? Would it be helpful to start out referencing results from recent doctor's appointments, or referring to signs and symptoms the person with IDD is experiencing?
  - How will dementia or the diagnosis be described? Consider focusing on changes in thinking, remembering, and making decisions. Also consider addressing feelings of confusion or fear that the person with IDD may be experiencing.
  - Several booklets are available to guide the conversation. Links to the booklets are available in the resources section for this topic area.
- Consider **how** to respond to questions:
  - Anticipate questions the person with IDD may ask. Think about how to respond to the questions. If you do not know the answer to a question, let the person with IDD know that you will help them find the answer.
  - Ask the person with IDD how they want to share this information with other people. Do they want to share with family and friends? Would they like someone else to share this information for them? If they want to share it, ask if they want to practice what they are going to say.

Source: [99]

Resources

- Let's Talk about Dementia (Down Syndrome Scotland) This is a booklet in an easy-to-read format that explains dementia and the impact on the brain. The booklet can be used to help a person with IDD understand their own dementia diagnosis, or a dementia diagnosis of a friend or family member.

- I have been diagnosed with dementia (Trinity Centre for Ageing and Intellectual Disability) This brochure explains dementia to someone with an ID in an easy-to-read format. The language can also be used to prepare providers for disclosure of diagnosis to the person and family.
- Signs of dementia (Alzheimer's Society) This is a booklet in an easy-to-read format designed to help people with IDD recognize the early signs of dementia in themselves and others. It uses plain language and visuals to make the information more accessible.
- Finding out you have dementia (Alzheimer's Society) This is a booklet in an easy-to-read format that was created to support people with IDD who have recently been diagnosed with dementia. The content includes a description of dementia and what the person with IDD can expect after a diagnosis.
- Talking about Dementia: A Guide for Families, Caregivers and Adults with Intellectual Disability (Seven Hills Rhode Island) The purpose of this document is to help families and caregivers talk about dementia with people with IDD in a respectful, clear, and supportive way. The document is geared toward family members, professional caregivers, and support staff working with people with IDD who may be concerned about or have recently been diagnosed with dementia. The content includes communication strategies, visual and interactive tools, advance planning, and emotional support.

Section 7: Responding to Behavioral Symptoms

Behavioral symptoms can fluctuate and take various forms, even for one person. One behavioral symptom may not look like or mean the same thing as another. It is therefore important to always gather insights from the perspective of the person with IDD and dementia. To respond to behavioral symptoms, first try to understand why they occur. Although it requires some detective work, the more providers know about the underlying causes of the behavior, the better they will be able to respond.

Possible Reasons for Behavioral Symptoms

- Reasons Related to the Person and How They Feel
    - Pain or discomfort
    - Effects of medications
    - Medical conditions
        - Dehydration
        - Delirium
        - Gastrointestinal disruptions
        - Illness (e.g., cold or flu)
        - Impaired vision or hearing
        - Inadequate sleep
        - Infection
        - Thirst/Hunger
    - Mental Health
        - Anxiety
        - Compulsions
        - Depression
        - Hallucinations
        - Paranoia

- Reasons Related to the External Environment
  - Unfamiliar surroundings
  - Too cluttered
    - Overstimulating environment (loud noises, too many people, physical space is too large, background disruptions)
  - Boredom (lack of engagement)
  - Lack of cues or information to help with orientation
  - Poor accommodation for visual perceptual changes (patterned carpet that looks like steps, no contrast between floors/walls, lighting that is too bright or not bright enough)
- Reasons Related to the Activity
  - Activity is complicated
  - Activity is unfamiliar
  - Require help initiating the first few steps of an activity
- Reasons Related to Caregiver Interaction
  - Express frustration or agitation because they don't understand what is expected of them or they are not able to communicate effectively

Source: [50; 53; 57; 60; 100]

Once a provider understands the "why" behind behavioral symptom(s), and the types of behavioral symptoms people with IDD and dementia may experience, they are ready to approach the behavior to better understand where opportunities exist to intervene. The following questions should be considered when thinking through what could have triggered a behavior, how the behavior presents, and how to best address the behavior.

Three Phases of Approaching a Behavior

- Before the Behavior
  - What was happening before the behavior? Was there anything going on in the background (noise, activities, motion)?

  - Did something trigger the behavior? Has there been a change in the person's physical, mental, or emotional status?
  - Where did the behavior happen?
  - When did the behavior happen? What time of day was it?
  - Who was present? What did they do?
- The Behavior
  - What exactly happened?
  - What was the person doing?
  - Was it sudden or gradual onset?
  - Who or what was it directed at?
  - How long did it last?
- Addressing the Behavior
  - What was the effect of the behavior on the person or on others? Was it harmful?
  - Are the person's needs being met?
  - What interventions were tried?
  - What worked and what failed? Can you adjust your approach?
    - Did the person come to terms with what happened in their own time?

Based on a model developed by McCallion and Janicki, 2002 .[101]

Although the process of approaching behavioral symptoms can be trial and error, the most effective strategy is to identify what happened (e.g., the antecedents) and take proactive steps to prevent it from happening again. Sometimes, more investigation is needed before a behavior is understood and the right approach to address it is selected.

Tips for Reducing Behavioral Symptoms

- Focus on the person's strengths and provide positive behavioral support by instilling feelings of trust and respect. The most important outcomes of care are happiness and optimization of life enjoyment.

- Try to look at the situation through the eyes of the person with IDD and dementia. Anticipate what the person will need based on similar past experiences, what you know about their health, environment, daily routine, communication habits, preferences, and any significant or traumatic life events.

- Maintain a structured daily routine as much as possible. Try to maintain the person's regular sleep/wake schedule, mealtimes, and personal care activities.
- Consider that behaviors may be triggered by an event or condition. If they see someone putting on a coat or getting their keys, they may think it's time to go. If someone is setting the table, they may think it's time to eat. And if clothes are laid out on the bed, they may think it's time to get dressed.
- Behaviors that seem challenging are often an attempt to communicate needs not being met, memories no longer being fully understood, or people and activities missed.
- Work with medical providers to review medications, including supplements, and reduce/eliminate those that are potentially problematic.
- It is important to seek help if there is a danger of injury to yourself or the person with IDD and dementia.[16]

Table 2. Specific Strategies for Common Behavioral Symptoms

Behavioral Symptom	Strategies for Responding
Anxious or Overstimulated	• Reassure the person that they are not alone by sitting quietly together. • Use noise-canceling headphones. • Take a walk with them and get some fresh air. • Model deep or meditation breathing. • Let the person know that they are needed. Say, "Can you help me with…?" • Distract the person with calming activities such as listening to music, knitting, sorting, or coloring.
Compulsive Behaviors (repetitively doing an action or behavior) ***Specific to Down syndrome**	• Look for and try to resolve cues of boredom, fear, uncertainty, or fatigue (i.e., irritability, fidgeting, or pacing). • Redirect the person and engage them in an activity.

Behavioral Symptom	Strategies for Responding
Frustration or Agitation	• Use clear and concise communication. • Avoid criticizing or correcting. • Ask yes/no questions to narrow down what is agitating the person. • Repeat what was said to clarify. • Offer a calm and soft voice if their agitation rises. • Use reassuring statements like "you're safe" and "I'm here to help you." It's also helpful to smile and nod, making sure the person feels secure.[53] • Interpret the person's gestures and other nonverbal signs. • Offer step-by-step instructions. • Provide visual cues to aid in communication. • Look for pain or discomfort. Consider if the person is hungry, too hot or too cold, needs to use the bathroom, or has another physical need. • Assist the person with changing into more comfortable clothing (remove tags, uncomfortable shoes, etc.). • Engage in activities that are meaningful and reinforce a person's sense of identity and purpose.
Hallucinations and Delusions	• Accept the person's reality. Don't try to reason or argue. • Consider the person's feelings.
Wandering	• Distract the person with a favorite activity. • Offer sensory stimulation. • Provide visual cues to help with navigation. • Participate in structured daily routines.

Source: [100,16]

Responding to behavioral symptoms should be specific to the individual. The following examples may be helpful in providing context on how to respond.

Example 1

Adrienne, a respite worker, is assisting with care of John, aged 58 years, a person with Down syndrome and dementia. On each respite visit, when she begins helping John out of bed and with dressing, he becomes upset, refuses to get out of bed, and shouts at Adrienne to go away. His mother usually intervenes and tells Adrienne to just let him stay in bed. However, when his mother helps him on days when Adrienne is not there, she reports that she does not have the same problem. Adrienne asks John's mother what is different on the days when she asks him to get out of bed. His mother explains that they have a longstanding relationship, and Adrienne can't hope to have the same success. Adrienne agrees but asks nevertheless what exactly happens when his mother awakens him and explains that she would like to learn from his mother and really try to avoid getting John upset. His mother explains that there is a wind-up music box on John's dresser that she usually starts up before he awakens, and she hums or sings softly with the music as he awakens. She then talks with him about what they are going to do that day and tells him about the weather and who might be visiting that day. Adrienne tries this the next morning and while it is still a little difficult to get John out of bed, he does not get upset and does not refuse.

Key Takeaway: Adrienne reduced conflict in the situation for John by asking his mother and learning about his regular routine and good communication to increase his level of comfort with the activity.

Example 2

Jeff is the respite worker for Joe, a 62-year-old man with IDD and dementia. Jeff tries to tell Joe stories about his previous work life because this was very successful with others he cared for. They would ask questions and sometimes it would evoke memories of their own past. Most of all it just seemed that Jeff's talking had a calming and consoling effect and sometimes when the person he was caring for was having difficulties it just took a story to help the individual by bringing some calm to the situation. For Joe this is not working; he doesn't seem to follow the stories Jeff is telling and Jeff notices that if he is walking around or doing things like putting clothes away as he talks, Joe loses interest. Jeff decides to be more purposeful in his storytelling. He sits down with Joe and makes sure that Joe can see his face when he is talking. He tries a couple of stories and finds two that Joe seems to pay more attention to. He simplifies the stories, uses shorter sentences than usual, uses hand gestures more to emphasize parts of the story, and repeats key points. Joe now seems to enjoy the stories more.

Key Takeaway: Jeff responded to Joe's difficulties by understanding his communication and stage-based needs, simplifying his language, giving more undivided attention, and reducing distractions so that his words were better understood. Jeff created a calm and respectful situation tailored to Joe's needs and preferences.

Example 3
Mary is the DSP for Julia, a 64-year-old woman with Down syndrome and dementia. Julia has been diagnosed with dementia for a number of years, and with advanced symptoms she has lost interest in the activities she used to enjoy and is unable to do many things for herself. Mary talks with Julia's sister Irene who is now her caregiver and asks about what Julia used to do for enjoyment. Irene gave her a lot of information and showed her a video of a vacation by the beach. Mary brought out some souvenirs from that trip and placed some sand and seashells in a basin. Mary and Julia watched the video together and Mary talked about taking a trip to the beach and helped Julia to run her hands through the sand and seashells in the basin just as she had on the video. Julia did not say anything but both Mary and Julia's sister agreed they saw her smiling several times, especially when she touched the sand.

Key Takeaway: Mary's effort to learn more about Julia's interests and then apply them to the situation helped comfort Julia and provided an enjoyable experience.
(Case Studies: McCallion et al, 2019)[16]

Resources

- Serving People with Intellectual or Developmental Disabilities (IDD) and Dementia online training (Minnesota Department of Human Services) This online training is designed to help case managers and certified assessors understand the impact that dementia has on those are living with IDD; what is different; how to best support the person, their families, and caregivers; and best practices.

- Behavior Symptom Management for Adults with IDD & Dementia PowerPoint training (The Arc Jacksonville) (To obtain a copy, contact Erin.Long@acl.hhs.gov) This PowerPoint training focuses on understanding that behaviors are a symptom of IDD and dementia; identifying what is causing a behavior; and selecting an appropriate strategy to use when a behavior is occurring, based on an individual's needs.

Section 8: Working With Family Caregivers

Family caregivers of people with IDD often have years of experience advocating for the person with IDD and navigating complex health care and service delivery systems to obtain necessary supports. When the person with IDD is younger, the focus is typically on building skills and gaining independence.[102] A dementia diagnosis necessitates a perspective shift toward maintaining skills and adapting to changing behaviors and abilities. Caregiving demands generally increase because of changes such as behavioral symptoms, nighttime wakings, and the need to learn about a new disease and connect with new providers.[103]

Like other caregivers of people living with dementia, family caregivers of people with IDD and dementia can benefit from education on the disease, disease progression, communication techniques, and behavioral symptom management. However, given their lifetime of experience providing care, existing dementia caregiver training materials are generally not appropriate for this population. Instead, materials should be adapted to respect caregivers' considerable expertise. It is important to encourage caregivers to regularly assess their own well-being and attend to their own mental, physical, emotional, and social needs.[94; 102] Respite services, with which lifelong caregivers are likely familiar, can be particularly valuable.[102; 104; 105]

To ensure that person-centered planning and services[1] are provided, when working with family caregivers, involve the person with disabilities and their entire care team in care discussions to the extent possible. Providers should also carefully consider how and when information is delivered to family and the person with IDD. The following suggestions can help.

Talking With Family Caregivers

- Appreciate a lifetime of caregiving. Adapt materials and trainings to respect their caregiving expertise.
- Avoid jargon and use plain language.
- Suspend judgment.

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[1] Person-centered planning and services allow for individuals to be involved to the maximum extent possible in their own advance planning, decision-making and problem solving. The process is based on their strengths, preferences, goals, medical needs, needs for home- and community-based services, and desired outcomes. Individuals can access one-on-one counseling to consider their options in a variety of settings. Primarily, this is a process directed by the person and can include a representative chosen by the person.[106; 107]

- Listen to the story/history.
- Acknowledge the potential grief of caregivers who have been focused on habilitation and progress and now must redefine what well-being is for the person living with dementia.
- Be sensitive to the feelings family caregivers may have about previous service system failures and how that may impact their openness to new services.
- Include the person with IDD and dementia whenever possible.

Source: [16; 108; 109]

In some cases, families of people with IDD and dementia may be reluctant to accept help. Providers should try to understand the reasons caregivers are reluctant to use services, which may include the following:

- They have had past negative experiences with the disabilities service system.
- They do not believe that anyone else can understand and provide care in the way they can or trust that professionals have the knowledge to appropriately address both IDD and dementia.
- They do not want to believe it is dementia.
- They worry that their family member will be taken away from them.
- They believe the services are unnecessary intrusions by strangers into their lives.
- They have had past negative experiences with the disabilities service system.
- They do not believe that anyone else can understand and provide care in the way they can or trust that professionals have the knowledge to appropriately address both IDD and dementia.
- Navigating services across multiple agencies in the aging/dementia and IDD networks is complex and overwhelming, and they may be concerned about how dementia services will affect their waiver benefits.

Providers should consider the following strategies to approaching and working with caregivers:

- Begin with their immediate concerns but recognize deeper concerns.

- Listen to what the caregiver says "works" in caring for their family member.
- Model good practice in care but do not insist that families do things your way.
- Place an emphasis on how you can help keep the person with IDD in their home/community, if desired.
- Use person-first language yourself (person with a DD, NOT developmentally disabled) but do not judge or correct a family member who uses other language.
- Intervene if you suspect abuse or if there is an immediate danger of injury to the person.

Source: [16; 108; 109]

Resources

- A Caregiver's Resource Guide for Rhode Islanders (Seven Hills of Rhode Island and the National Task Group on Intellectual Disabilities and Dementia Practices) This guide provides informal and professional caregivers with the foundation to begin planning for needed health care and supports. The resource includes sections on becoming a health care advocate; learning about screening, assessment, and diagnosis; learning about dementia; working with the health care provider; providing care; and caregiver tips.
- Dementia Guidebook for Individuals with Developmental Disabilities and Their Caregivers (Wisconsin Board for People with Developmental Disabilities) This guidebook has been designed for people with IDD and dementia, their family members, and caregivers to help increase the quality of care and life for the individual living with IDD and dementia.
- Alzheimer's Disease & Down Syndrome: A Practical Guidebook for Caregivers (National Task Group on Intellectual and Developmental Disabilities and Dementia Practices, National Down Syndrome Society and Alzheimer's Association) This guidebook is written for caregivers and provides an explanation for the connection between Down syndrome and Alzheimer's disease, the importance of establishing a baseline and obtaining an accurate diagnosis, common physical complications, tips for caregivers, meaningful activities, and advance planning.

Section 9: Advance Planning and Family Decision-Making

Advance planning for people with IDD and dementia is essential yet often overlooked. Historically, services for people with IDD have focused on younger populations, leaving significant gaps in preparing for aging, chronic conditions, and end-of-life care. As people with IDD live longer, they face new challenges such as the loss of aging parents, more complex medical needs, and limited access to tailored dementia care. Planning ahead—through person-centered conversations grounded in values and preferences—allows people with IDD to participate in decision-making and helps ensure that their care aligns with their wishes in later stages of life. Section 6 of this guide shares several considerations for how to talk to the person with IDD about their dementia diagnosis. These same considerations are useful when thinking about how to talk with the person with IDD about advance planning.

The time between diagnosis and death is frequently shorter for people with IDD and dementia, particularly in those with Down syndrome, making timely planning even more critical. Predicting the end of life is even more challenging than for people living with dementia who do not also have IDD.[110] It is crucial for people with IDD and dementia to engage in advance care planning as early as possible to ensure that their wishes are honored. [110-112]

Collaboration across disability, palliative, hospice, and dementia services—and recognition of the emotional, cultural, and relational dimensions of care—is essential to person-centered care.[110] Legal tools such as health care proxies, advance directives, special needs trusts, and tax-advantaged savings and investment accounts can support this process and protect the person's rights and benefits.

Guidance on Having the Conversation

- Involve people with IDD early in their advance care planning whenever possible and ask them who they would like to include in discussions.
- Encourage people with IDD to express their own needs and wishes. At least once a year, they can meet with family or trusted professionals to document their medical history and needs, preferred activities, important relationships, housing plans, decision-making supporters, interests, support needs, and goals.
- When timing conversations about end-of-life planning, consider both the readiness of the people involved and the importance of early planning.[110]

- Avoid medical jargon and instead use language the person with IDD and their caregiver/primary support person can easily understand.[60]
- Provide straightforward, accessible information about medical conditions, available interventions, and prognosis.[78]
- Foster an open, judgment-free environment where the individual and their caregivers feel comfortable discussing care preferences.[113-115]
- Acknowledge caregivers' concerns about the person with IDD's quality of life, and institutionalization and hospitalization. Explore alternatives.
- Recommend that families work with a trusted person (e.g., minister, social worker) to navigate any conflicts or difficult decisions around care.[78]
- Clearly document all conversations and plans, including who was involved, decisions made, and dates.

Care and Planning Considerations

- People with IDD may lose their ability to make decisions for themselves as dementia progresses. Planning for future care early helps document and honor their preferences.[110, 116]
- Care decisions for people with IDD and dementia can be complex. Encourage families to build a strong team of medical professionals, caregivers, and advocates and to continue to involve that team in end-of-life care decisions.
- Decisions about where care will take place—at home or in a care facility—are central and should be made carefully.
- State services that support continued in-home care often have waitlists and funding limitations. Encourage families to plan for these services well in advance of when they may be needed.
- Continued contact with peers, friends, family, and staff should be prioritized. Discuss options early and develop a plan to support continuity of care to the extent possible.
- For people with autism and dementia, sensory environment (light, sound, temperature) is important for comfort and well-being.[5] Consider these factors when determining care location.

- Consider the person with IDD's cultural and personal preferences, especially regarding spiritual care and end-of-life rituals.[87]

- At the end of life, focus on comfort, not curative treatment. Consider symptom management and emotional support as priorities.[110; 112]

Legal and Financial Planning

- People with IDD can consider a variety of decision-making arrangements, including supported decision-making agreements, limited powers of attorney, durable powers of attorney, and advance directives for health care.[117] Support families in drawing up legal documents. Those who cannot afford an attorney should be directed to their state's protection and advocacy program.[117] In cases where there is a legal guardian, identify people who can make decisions if the guardian is unavailable, and have the court designate a successor guardian.[117]

- Keep in mind that older parents may be experiencing their own health issues or cognitive decline, necessitating involvement of other family members, friends, or trusted individuals.

- Encourage families to connect with their state's IDD agency to learn about eligibility for public benefits,[118] as appropriate.

Understanding Predictors of Advancing Dementia

- Assess the person with IDD early to set a baseline and then annually to help monitor decline and stages.

- People with Down syndrome who have greater ID or who experience an onset of seizures are more likely to have dementia that progresses rapidly.[112]

- Similar to people with dementia without IDD, signs of advanced dementia may include worsening memory, inability to communicate, incontinence, total dependence on others for activities of daily living, breathing problems or pneumonia, changes in appetite and swallowing, and seizures.[112] Late-onset seizures are most likely related to the pathology in brain causing the dementia, However, it is possible that late-onset seizures are recurring if a person had seizures earlier in life.

- Some research suggests that assessment of stage 7 of the Functional Assessment Staging Tool AND acute medical complications or repeated hospitalizations can confirm advanced dementia in people with IDD. [110]

- New onset of difficult behaviors, such as agitation or paranoia, may signal a need for palliative care or medication adjustment.[60]

Training Providers

Many providers need training to deliver quality end-of-life care to people with IDD and dementia:

- IDD providers, particularly group homes, need training on pain management, managing nutrition and hydration, and other end-of-life care considerations.[110]
- Memory care facility staff need training on IDD and care for people with IDD and dementia.[60]
- Residential staff such as memory care and nursing facilities, need training on autism and dementia, particularly as it pertains to the sensory environment.[5]
- Palliative and hospice providers need training on communication with people with IDD and dementia.
- Caregivers/primary support people of people with IDD and dementia need training on end-of-life options and support.[110]

Resources

- Thinking Ahead: My Way, My Choice, My Life at the End (State of California Department of Developmental Services) Workbook and video created by California advocates with developmental disabilities. Contains words, symbols, and pictures that facilitate discussion with and decision-making by persons with developmental disabilities regarding their values, goals, and treatment preferences at the end of life. The video portion of the training serves as an instruction manual, containing vignettes that illustrate in simple, graphic format the purpose and use of the materials.
- Trainer's Guide: End of Life Care: Supporting Older People with Intellectual Disabilities and Their Families (New York State ARC) A two-volume guide for supporting older people with IDD and their families. To order: 518-439-8311; info@nysarc.org
- Let's Talk about Death (Down Syndrome Scotland) Easy-to-read materials to explain death to people living with IDD.

Section 10: Planning Meaningful Activities

The importance of being socially connected cannot be understated for people with IDD and dementia. Social networks and peer relationships, in particular, can provide needed support to people with IDD and dementia.[119] However, as dementia symptoms progress, people with IDD and dementia may experience changes in their ability to maintain social networks.[120] People living with dementia are also at risk of accelerated dementia symptoms when isolated or lonely, while engaging socially can improve quality of life and be a source of pleasure.[121] The benefits of social connection have been seen at The Arc of Jacksonville Specialized Aging Services (SAS)—an adult day center for people with IDD and dementia.[122] At the onset of dementia for those with IDD, families and staff observe changes in personality, such as withdrawing from activities or becoming more subdued. Engaging socially in activities at the SAS adult day center allows participants with IDD and dementia to develop relationships with others through everyday interactions and structured activities.[122] Participating in meaningful activities with others can help quell social isolation and increase social connectedness.

Activities for people with IDD and dementia can be structured so a person's abilities and strengths are emphasized, while also being adaptable for when abilities change. The need to have adaptable activities stems from the progressive nature of dementia.[94] As dementia symptoms advance, people with IDD may avoid certain activities or social situations.[94] Planning meaningful activities to encourage continued social engagement and mental stimulation becomes even more important.[98; 122] In the specific case of people with autism and dementia, it is necessary to balance the person's need for routine and predictability with activities that can be modified to meet their changing abilities resulting from dementia.

When developing meaningful activities for people with IDD and dementia, activities should be engaging and enjoyable and focus on an individual's strengths while also being mentally stimulating.[53] These types of activities may help to increase self-esteem for people with IDD and dementia.[94; 98] The aim is to continue activities that appeal to the person with IDD and dementia, even if activities are modified over time as dementia progresses.[78; 98] Activities with a multisensory component such as completing art projects with music in the background have been particularly impactful for participants at The Arc of Jacksonville SAS program.[122] When considering staff for activities, it is helpful to pair a person with IDD and dementia with a staff member who can match their energy level and specific support needs.[53]

The variety of activities that can be conducted is vast and can be tailored to each individual or small group based on their interests and abilities. Examples include the following:

- cultural activities such art shows, concerts, or neighborhood festivals and celebrations.
- physical activities such as walking, gardening, dancing, and singing.
- social activities centered around various topics such as current events, holidays, life cycle milestones, and reminiscence; and
- everyday chores like making a meal or doing laundry.

Source: [94; 98]

At The Arc of Jacksonville SAS Adult Day Center, the staff develop structured activities where each activity has a goal and description, materials needed, and instructions. The goal and description outline the purpose or intent of each activity, such as increasing socialization, maintaining physical abilities, or practicing proper nutrition. A thorough materials list for a complete week of SAS activities allows staff to shop one time and avoids unnecessary interruptions to the day because of missing items. Detailed instructions exist so any staff person or volunteer can run activities at the Center. In addition, to tailor activities to the needs and interests of participants, The Arc of Jacksonville completes an occupational therapy assessment with each SAS participant. They examine family and participant concerns and any current challenges. From that assessment, a personalized care plan is developed, and goals are established for each participant. Activities are adapted for each participant based on their abilities and interests.[122] To further meet the needs of participants, SAS implemented several other practices such as including a quiet sensory room for participants to take a break when they are over- or under-stimulated and ensuring that board games, puzzles, coloring sheets, and crayons are available if a person declines to participate in an activity.[122]

Resources

- Arc of Jacksonville Creating Supportive Spaces (The Arc of Jacksonville) (For a copy, contact Erin.Long@acl.hhs.gov) Presentation slides to assist in developing an adult day center specialized for people with IDD and dementia. Focus is on how visual-perception changes in people living with dementia impact daily functioning, practical environmental modifications to improve conditions for people with IDD and dementia, and strategies for structuring a day program to best support people with IDD and dementia.

- Arc of Jacksonville SAS Sample Schedule (The Arc of Jacksonville) (For a copy, contact Erin.Long@acl.hhs.gov) Sample activity schedule for participants at adult day center focused on IDD and dementia.

Section 11: Modifying the Environment and Approach to Care

Two of the most important environmental factors for people with IDD and dementia are safety and promoting independence. When modifying the environment, special attention should be given to assisting the person to feel supported, while capitalizing on their own strengths and sense of self-direction. Several environmental modifications can be considered to help people with IDD and dementia remain comfortable and safe at home. See Tables 3 and 4.

Table 3. Home and Activity Environmental Modifications for People with IDD and Dementia

Home Area/Activity	Environmental Modifications
Bathing	• Check the lighting (glare makes things look slippery/wet). • Ensure that the temperature of the room is warm. • Convert standard showers and tubs to be walk-in. • Install safety devices (e.g., nonslip mats, shower chairs, grab bars). • Ask the person to check the water temperature before they get in. • Use a handheld shower head (allows you to start anywhere, but do not start with the head and face). • Vent fan or sound of shower is distracting and makes conversation difficult, so explain what is happening before bathing begins and be prepared to turn off the fan or the shower if person becomes confused so they can hear what you have to say. • Supplies should be close and ready to use so you are not leaving the person alone and unsure what is happening.
Color	• Choose solid colors or simple patterns. • Reds and yellows are more accurately perceived than blues and greens. • Create contrast when possible. – A dark-colored handrail on a light-colored wall – A white light-switch with a dark switch plate around it – A colored toilet seat in an otherwise white-tiled bathroom – A dark placemat under a light-colored plate

Home Area/Activity	Environmental Modifications
Dressing	• Clothes should be easy to put on and take off (avoid things that the person can put on "wrong"). • Consider the clothing material (scratchy clothing or tags can be problematic for people with ASD). • Remove any clothing you do not want the person to wear (put away out-of-season clothing). • Make sure there is space to sit. People with Down syndrome need to have their legs and feet well supported to avoid sliding down and potentially falling. • Provide privacy.
Flooring	• Avoid patterned, high-gloss finishes. • Clearly mark changes in floor levels, such as a step down into another room. • Use a black mat on the floor in front of a door you'd like to remain "off-limits."
Mealtime	• Use small tables for dining (three to four people). • Sit with the person and model eating. • Provide signs and helpful information at eye level. • Try to minimize extraneous noise and set up a quieter space to eat. • Create contrast (e.g., a dark placemat under a light-colored plate). • Avoid busy patterns on table coverings and dishes. • Use adaptive silverware, plates, and cup.

Source: [16]

Table 4. Environmental Modifications for Common Behavioral Symptoms

Behavioral Symptom	Environmental Modifications
Anxious or Overstimulated	• Provide quiet space. Minimize confusion and noise (e.g., sitting in the living room, watching people come and go, might not be a good location for this person to spend time). • Offer noise-canceling headphones.

Behavioral Symptom	Environmental Modifications
Frustration or Agitation	• Keep commonly misplaced/requested items in the same place. • Write things down for the person with IDD and dementia and others who provide support. • Use a memory book (familiar pictures that will support conversation or answer questions). • Use a digital clock that has both the date and day of week spelled out and am/pm. • Use labels. • Reduce danger to self and others—Lightweight items such as lamps should be secured or minimized.
Hallucinations and Delusions	• Keep rooms well lit. • Avoid shadows. • Consider that a mirror might be a source of confusion if images in the mirror are not recognized. • Avoid busy patterns on tabletops, curtains, and floors.
Wandering	• Edges of furniture should be rounded and not sharp. • Rocking chairs might be a good outlet for energy. • If there are specific times when the person tends to "leave" provide an alternative activity that minimizes the prompts that encourage leaving (e.g., other people putting their coats on in front of the person).

Source: [16]

Resources

- Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia (National Task Group on Intellectual Disabilities and Dementia Practices) The guidelines delineate what actions should be undertaken and are presented in a manner that reflects the progressive nature of prevalent dementias beginning with the prediagnosis stage when early symptoms associated with cognitive decline are recognized and continuing through to the early, mid, and late stages of dementia.

- Home Safety (Alzheimer's Association) Provides tips for creating a safe home environment, which can prevent dangerous situations from occurring and help maximize independence for as long as possible.

Section 12: Managing Stages of Dementia in People With Intellectual and Developmental Disabilities

Dementia can be broadly characterized by a gradual decline that progresses through three stages: early, middle, and late. These stages are identified by general characteristics that illustrate incremental loss of abilities and skills and an increased need for support, supervision, and assistance. Caregivers/primary support people and service providers should have a general sense of where the person with IDD is within the progression of dementia. If family members are unsure, they can discuss staging with a health care provider who knows the person with IDD, and then share that information with other caregivers/primary support people, as appropriate.

Mild cognitive impairment (MCI) typically precedes the early stage of dementia. This term is used in the general population for people who are showing signs of memory loss and other cognitive impairment that is more significant than normal signs of aging but cannot yet be diagnosed as dementia.[123] Over time, MCI typically progresses to dementia in the general population. Although this term is not widely used in the IDD population, it is to understand.

Although there is a general progression through the stages of dementia, the speed of each person's dementia journey will be unique to them. There is limited information on the duration of each stage of dementia for people with IDD. One study found that nearly all patients with Down syndrome who exhibited early signs of dementia—but had not yet received a dementia diagnosis—progressed to clinically diagnosed dementia within 5 years of follow-up.[124] This study also showed that women with Down syndrome tend to progress through the stages of Alzheimer's disease faster than men.[124]

Using information presented in previous sections, Table 5 provides details on the general characteristics of each stage of dementia, suggestions for adapting the care environment, and recommendations for day programming, daily care, and communication. This table can be used by caregivers/primary support people, DSPs, health care professionals, and others to support the person with IDD through their dementia journey. The table indicates where characteristics and recommendations listed are more relevant to people with Down syndrome or autism. Additional resources are included following Table 5.

Table 5. Stages of Dementia in Persons with Intellectual Disabilities

Stage	Characteristics	Care Environment Adaptations	Day Programming Recommendations	Day-to-Day Care Recommendations	Communication Recommendations
Early	• Noticeable and increasing changes in memory. Difficulty recalling recent events and learning new information. • Repeating themselves. Difficulty with word finding. Vocabulary becomes smaller and simpler. • Confusion with familiar tasks and situations. Difficulty following instructions. • Challenges finding their way around. Looking lost, confused, or distracted. • Misplacing things or difficulty finding things in their usual location • Increased frustration and changes in personality.	• Adjust lighting to avoid shadows. • Disperse direct sunlight with curtains or tinted glass. • Label regularly used items with visual cues. • Provide signs and pictures at the person's eye level. • Provide safe storage for kitchen tools, cleaning supplies, and toxic alcohol using discreetly locked cabinets. • Install shutoff switches on appliances. • Ensure that valued activities in kitchens can continue. Ensure there is independence in bathrooms by making needed supplies visually available.	• Adjust daily routines. • Move to smaller group or one-on-one activities. • Focus on topics known to the person and activities that the person enjoys. • Modify activities to reduce demands and use familiar materials. • Match the energy of the person. Intentionally assign staff who can match the energy of the person. • Improve signage at eye level to support wayfinding. • Support safety by providing safe activities in safe places. • Talk with the person about sharing their diagnosis with friends and peers.	• Adjust daily routines to be less demanding but support continued participation. • Offer help rather than doing everything for the person. • Give extra time and limit range of choices so that independence may still be supported. • Install devices to ease use (e.g., grab bars, raised toilet seats, water temperature regulators). • Review and adjust medications as needed. • Use memory aids to assist with wayfinding, remembering chores, activities, and basic skills.	• Use simple, direct language. • Pay attention to the person's attention span and adjust communication accordingly. • Avoid talking for the person and filling in words. • Allow extra time to process information. • Summarize and rephrase. Repeat important messages. • Share memories and reminisce. • Allow the person to express their feelings. Express support and care. • Give specific instructions and information before it is needed.

Stage	Characteristics	Care Environment Adaptations	Day Programming Recommendations	Day-to-Day Care Recommendations	Communication Recommendations
Early (continued)	• Decreased work performance or participation in day program activities • Problems with walking and gait may become noticeable. • Late-onset seizures (Down syndrome).				
Middle	• Increased loss of abilities and often increases in behavior as communication. • Memory loss becomes more pronounced. Daily forgetfulness and confusion. Increased difficulty recognizing people and recalling names. • Deterioration or loss of some or all household chores or other daily tasks.	• Change lighting to avoid glare and sudden changes in lighting levels. • Reduce reflective surfaces (e.g., floor surfaces should not be buffed or waxed to produce shine). • Avoid patterned flooring and table surfaces. • Provide furniture that is sturdy, simple, and versatile with rounded edges instead of sharp ones.	• Ensure a predictable routine with familiar activities. Clearly communicate transitions. • Overcommunicate about upcoming changes and address any discomfort or anxiety. • Be flexible to the needs of the person. If they do not want to participate in an opportunity, try to find an alternative. • Use multisensory approaches—both stimulating and calming.	• Reduce safety and wayfinding challenges. • Increase assistance with personal care, nutrition, safety, and supervision but seek opportunities to maintain choice and decision making. • Model safe eating and drinking, including chewing fully before swallowing • Routine monitoring and treatment of comorbid health conditions.	• Speak only when in front of the person and visible to them. • Use the person's name and your name. • Avoid quizzing questions such as "Do you know who I am?" • Use gestures, facial expressions, and pointing to familiar objects.

Stage	Characteristics	Care Environment Adaptations	Day Programming Recommendations	Day-to-Day Care Recommendations	Communication Recommendations
Middle (continued)	• Increased level of assistance needed for some aspects of personal care (e.g., bathing, toothbrushing, shaving). • Dependent on prompts and reminders from caregivers to get through an average day. • Disorientation to concepts of day of week, recurring events, routine schedule. • Poor judgment and safety awareness. • Difficulty navigating familiar places, getting lost. Increased social isolation and disengagement with familiar and preferred activities.	• Contrast furniture color with floors and walls. • Use color and contrast to create visual cues or reduce attention to specific areas throughout the home. • Reduce visibility of exits, cupboards, and areas with increased safety challenges. • Replace standard showers or tubs with walk-in models. • Install door opening prevention devices, that can be disengaged for emergency evacuation. • Use electronic alert systems so caregivers know when someone has left home. • Consider less restrictive interventions before restricting the person's autonomy.	• Monitor for overstimulation and consider using noise-canceling headphones and providing a calm space. • Support existing skills and memories rather than teaching new things. • Tailor activities to likes, dislikes, and previous experiences. • Activity ideas include reminiscence, community trips, walks, simple exercises, massage, Snoezelen, horticulture, pottery, art, music, aromatherapy. • Install door opening prevention devices, considering emergency evacuation safety.	• Particular attention to additional assistance with toileting and other hygiene and personal care activities to support dignity and personhood. • Pay attention to maintaining continued valued relationships with family, friends, and staff. • Avoid drastic temperature changes when bathing, dressing, and toileting.	• Wait for the person to respond. If the person does not respond, use a different, simpler way to say something rather than repeating. If they still do not respond, redirect to another topic. • Do not take it personally if the person responds negatively. If they are resisting or being stubborn, be positive and smile, so they understand you are there to help. • Use simple, easy-to-understand signs that are at eye level for the person. • Listen and repeat what the person says. • Smile, nod, and say "yes." Validate and then redirect, as needed

Stage	Characteristics	Care Environment Adaptations	Day Programming Recommendations	Day-to-Day Care Recommendations	Communication Recommendations
Middle (continued)	• Increased agitation, restlessness, repetitive talking and questioning, falls, pacing, wandering, and shadowing others. • Hallucinations, delusions, and sundowning. • Urinary incontinence, possibly fecal incontinence. Swallowing dysfunction. Worsened gait and mobility.		• Use electronic alert systems so staff know when someone has left the program area. • Consider less restrictive interventions before restricting participant autonomy.		• Avoid sudden changes in topic. • Avoid long and complex sentences.
Late	• Profound memory impairment, including both short-term and some long-term memories. • Difficulty recognizing family and friends. • Major loss of language abilities – using few words and vocalizations.	• Use equipment to preserve caregiver's and the person's safety and comfort when lifting or transferring. • As mobility becomes more impaired, modify the environment and use adaptive equipment.	• Provide programming where the person lives to reduce the need for transportation. • Include outdoor activities, if desired by the person. • Listen to music or read aloud.	• Care is best when it reflects what is known about the person's wishes and when comfort and quality of life are emphasized. Support of family and friends will add to their sense of comfort.	• Speak only when in front of the person and are visible to them. • Use their name and give them your name. • Use a calm, affectionate voice. • Speak slowly and clearly.

Stage	Characteristics	Care Environment Adaptations	Day Programming Recommendations	Day-to-Day Care Recommendations	Communication Recommendations
Late (continued)	• Needs complete assistance with self-care. • Over time, the person becomes increasingly immobile—primarily in a wheelchair or bed-bound. • Seizures, swallowing difficulties, and breathing problems increase. Complete incontinence of bladder and bowels. Weight loss.	• Adapt valued activities and experiences. • Consider palliative or hospice care.	• Focus on making the person comfortable using activities like massage, Snoezelen, art, music, aromatherapy, and hand massage. • Offered by staff trained in dementia and comfort care.	• Assistance with toileting and other hygiene and personal care activities so dignity and personhood are supported. If the person is bed-bound, ensure regular repositioning to reduce pressure injuries. • Routine monitoring and treatment of comorbid health conditions. • Increased nursing care and prevention of secondary conditions from malnutrition, dehydration, or aspiration.	• Smile. Overemphasize gestures and facial expressions. • Assume the person is listening to you even if they are not responding. • Do not speak as if the person is not in the room. • Respond to seemingly meaningless speech. • Watch for nonverbal communication. • Tell the person when you are leaving and when you might see them again. • Consider sensory needs. Use touch if they have been comfortable with touch in the past.

Source: [16; 53; 94]

Resources

- Alzheimer's Disease and Down Syndrome A Practical Guidebook for Caregivers (National Task Group on Intellectual and Developmental Disabilities and Dementia Practices, National Down Syndrome Society, and Alzheimer's Association) This booklet was created to empower families and caregivers with knowledge about the connection between Down syndrome and Alzheimer's disease. The document provides information about the natural progression and stages of Alzheimer's disease.

- Mind and Memory Matters Dementia Resource Guide Book (Board for People with Developmental Disabilities) This guidebook provides comprehensive information for people with IDD and their caregivers/primary support providers to navigate and advocate for their own health care when they are concerned about memory or cognition. The document includes a section on stages and common behaviors during each of the stages.

- Intellectual Disability and Dementia: A Caregiver's Resource Guide for Nebraskans This guide was designed to provide caregivers/primary support people of people with IDD an overview of dementia and provide information about caregiving and support options available in Nebraska. There is a specific section focused on staging Alzheimer's disease.

Section 13: Coordinating Care and Services for People With Intellectual and Developmental Disabilities and Dementia

Care for people with IDD and dementia is often fragmented both within and between aging and IDD service systems. Existing IDD services, and the settings in which they are delivered, may differ from the services available to older adults. When people with IDD develop dementia, they remain eligible for intellectual and developmental services and may also be eligible for some aging services. Caregivers and primary care providers must learn what is available to the person in both service networks and be capable of navigating successfully between the disability and aging systems.[16]

Accessing Services

The service system for people living with IDD includes the following categories: in-home support services that are nonmedical, non-institutional residential care facilities, community habilitation or therapeutic services, adult day services, transportation, and intermediate care facilities for individuals living with IDD. Services delivered in institutional settings serve an extremely small proportion of the population. Medicaid has been the primary source of funding for these services. Individuals living with IDD may also access home and community-based services (HCBS) through state-only programs that generally support county government–operated residential or group homes, day programs, and other community supports. In some states Medicaid also supports specialized medical clinics for people living with IDD, and these may be a source of more specialized health assessments. The services provided under Medicaid or through other state-funded programs are often habilitative in nature and focus on helping this population acquire and improve skills to be more independent in the community; these services may not fully meet the needs of people who develop dementia.[16]

Low-income older adults can access HCBS through Medicaid but may also be able to access services funded by the Older Americans Act (OAA), such as respite care. State Units on Aging are responsible for developing and administering state plans on aging and allocating OAA funding, including working with local Area Agencies on Aging (AAAs) to serve different regions of the state. AAAs coordinate and offer services that help older adults remain in their homes. AAAs and Aging and Disability Resource Centers (ADRCs), centers that provide information and referral assistance to individuals, are available entry points where individuals can access publicly administered long-term supports including those funded under Medicaid, the OAA, including the National Family Caregiver Support

Program, and other state and federal programs,[16] such as the Lifespan Respite Care Program.

Additional information about accessing community-based services includes the following:

- Eldercare Locator connects people and caregivers to local support resources, including dementia-specific services, local AAAs and ADRCs. Call 1-800-677-1116.
- Click the following link for a directory of Centers for Independent Living.
- The National Association of State Directors of Developmental Disabilities Services provides contact information for state IDD agencies.

Care Management Strategies

Care management should focus on helping individuals and families develop plans for increased care for the person with IDD and dementia, including supports for caregivers. Care managers can identify caregiver support resources from local disability and aging services organizations and other service providers, assess any family challenges (including the caregiver's health needs), and assist in identifying and accessing dementia-, health-, and aging-specific supports for caregivers from other service and support systems. Among the key tasks are the following:

- Gathering information about the person's past history, including services and supports from which they have previously benefited.
- Developing person-centered plans and identification of educational needs which address the needs and preferences of both the person with IDD and their caregiver.
- Connecting the person with IDD and their caregiver to any necessary assessments.
- Beginning the conversation about future care and decision-making.
- Facilitating communication and care planning with other family members and friends as needed.
- Supporting self-advocacy and additional advocacy needs.

- Preparing the person with IDD, the caregiver, and other people in their lives for the transitions that will occur during the course of dementia, including responses to changing needs, discussions about end-of-life concerns and decision points and preparation for care transitions.

Resources

- Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia (National Task Group on Intellectual Disabilities and Dementia Practices) The guidelines delineate what actions should be undertaken and are presented in a manner that reflects the progressive nature of prevalent dementias beginning with the prediagnosis stage when early symptoms associated with cognitive decline are recognized and continuing through to the early, mid, and late stages of dementia.

- Serving People with Intellectual or Developmental Disabilities (IDD) and Dementia online training (Minnesota Department of Human Services) This online training is designed to help case managers and certified assessors understand the impact that dementia has on those who are living with IDD; what is different; how to best support the person, their families, and caregivers; and best practices.

- ONE Caregiver Resource Center (ONEgeneration) A centralized platform to support caregivers and adults with IDD who may be at risk of, or are living with, ADRD.

- Aiding Older Caregivers of Persons with Intellectual and Developmental Disabilities (Center on Intellectual Disabilities, University at Albany) Best practice strategies for aging and dementia service agencies to connect with and work effectively with people with IDD and their caregivers.

- Autism spectrum disorder in adults: Diagnosis and management (National Institute for Health and Care Excellence) This guideline offers general principles of care, identification and assessment, interventions for autism and delivery of care.

- Eldercare Locator connects people and caregivers to local support resources, including dementia-specific services. Call 1-800-677-1116 or visit the Eldercare Locator website.

- Click the following link for a directory of Centers for Independent Living.

Section 14: Making Referrals for Home and Community-Based Services

HCBS help people with IDD integrate into their communities by providing supports that focus on independence and functional ability, similar to programs for older adults . The number of people benefiting from long-term services and supports (LTSS) through state IDD agencies has grown significantly over the past 2 decades. The majority of people with IDD receive LTSS while living with a family member. For example, Medicaid waiver recipients with IDD increased from 1,381 in 1982 to 954,314 in 2020. In 1988, 9 of 10 people with IDD receiving Medicaid-funded supports lived in an institutional setting, while in 2020, 9 of 10 lived in home and community-based settings.[53; 125]

Some common HCBS that may be helpful for people with autism or other IDs are listed below.[125]

- *Adult Day Services*—Adult Day Services offer structured health, social, and habilitation programs in community settings for people with disabilities or older adults, aiming to maintain autonomy, improve quality of life, and support aging in place.[126] For people with IDD or autism, these services may emphasize employment, education, meals, and therapies aligned with personalized care plans. Provided in community settings, these programs typically run for 4 or more hours a day, one or more days a week, and are tailored to each person's service plan. The activities help participants reach their full potential.[127]
  - Locate an Adult Day center
- *Aging and Disability Resource Centers*—The aging and disability networks are made up of local, state, and national organizations and committed advocates working to support older adults and people with disabilities. They serve as entry points to services funded by Medicaid, the OAA, and state programs with some organizations focusing on specific needs and others offering broader support.[128] U.S. State Disability Agencies & Services Directory | Disability Resources
- *Area Agencies on Aging*—An AAA is a state-designated public or nonprofit organization that serves older adults at the regional or local level. Each AAA covers a specific geographical area, which could be a city, county, or multi-county district. They coordinate services, such as home-delivered meals, homemaker help, and other supports, to help seniors live independently and choose the care and living arrangements that fit their needs.[128]

  - Find your local AAA by visiting the Eldercare Locator website or calling 1-800-677-1116.

- *Centers for Independent Living* (CILs) are consumer-controlled, community-based, cross-disability, private nonprofit agencies that provide an array of independent living services. Designed and operated and run by individuals with disabilities, CILs provide services to help people with disabilities live independently, make their own choices, and participate fully in society.[129]
  - Access a graphic about how centers for independent living make community living possible.
  - Click here for list of independent living centers by state.
- *Intermediate Care Facilities* offer the highest level of intervention and support for people with IDD including 24-hour supervision, health and rehabilitative services, and individualized program plans developed by an interdisciplinary team. These facilities are an optional Medicaid benefit that states can provide.[130]
- *Participant or Self-Directed Services*—Those that are planned, budgeted, and purchased under the control of the individual. Through this approach, the person is provided with the information and assistance needed to enable them to make informed care options decisions. The principles of consumer control are infused in every ACL program. Several initiatives aim directly at advancing consumer control and are included on the ACL *Consumer Choice and Control* webpage and listed below:
  - Person-Centered Planning allows individuals to be engaged in the decision-making process about their options, preferences, values, and financial resources.
  - Supported Decision Making is an alternative to guardianship that keeps control in the hands of the individual while providing assistance in specific ways and situations that are beneficial *to the person.*
  - Transportation—Accessible transportation is a critical component of community living for older adults and people with disabilities. Through an inclusive transportation program, ACL works with communities across the country to give travelers a voice in the planning process and to improve transportation options.
  - Veteran Directed Care Program—This program provides veterans with opportunities to self-direct their LTSS and continue living independently at home.

- *Respite Care Services*—Provide temporary relief to family caregivers of adults or children with special needs. Respite services may be planned or in response to an emergency and can be provided in a variety of settings, including the home, adult day care centers, or residential care facilities. The Lifespan Respite Care Program, enacted by Congress in 2006 under Title XXIX of the Public Health Service Act (42 U.S.C 201) and reauthorized in 2020 empowers coordinated state systems to provide accessible, community-based respite care services. Respite supports family caregivers of children and adults across all age groups, disabilities, and chronic conditions. As an essential component of home and community-based long-term services and support, which contributes to healthier families and the health and well-being of caregivers and care recipients.[131]
    - ARCH National Respite Network—Helping caregivers rest and recharge, this organization helps families locate respite and crisis care services, assist and promote the development of quality respite and crisis care programs, and serve as a strong voice for respite in all forums.[132]

Residential Care Homes—Many options are available for individuals with IDD to live in settings other than their own independent home or a family home. These settings typically offer varying levels of staff support, including up to 24-hour care. They are generally designed to promote community involvement and encourage the use of community-based services rather than relying solely on specialized or agency-provided supports, though the use of such services may still be part of the support plan. The names used for this type of settings vary and include group homes, individual residential alternatives, supervised apartments, Adult Family Care, Adult Residential Care Homes, Domiciliary Care, Adult Foster Care, Group Homes, Community-based Waiver Homes, and Transitional Housing.[53; 133; 134]

For example, The Arc of Jacksonville uses Residential Community Home[135] to describe a "supportive living environment that provides not only housing, but also a sense of belonging, security, and friendship. Each home offers private bedrooms, shared meals, personal care, leisure activities, and individualized wellness plans that may include medications, therapies, and nutrition guidelines. Residents are supported in maximizing independence through self-care, participation in household activities, and development of community safety skills, creating a warm, inclusive setting that truly feels like home."

Resources

- Accessible Housing—The Arc accessible housing webpage lists the resources below to support housing for people with disabilities.

- Key Federal Housing Initiatives: Key programs at the U.S. Department of Housing and Urban Development (HUD) that seek to increase affordable housing for people with disabilities include:
    - Section 811 Supportive Housing for Persons with Disabilities Program. Section 811 is the only HUD program dedicated to producing affordable, accessible housing in the community for non-elderly, very low-income people with significant disabilities.
    - Section 8 Housing Choice Vouchers. HUD's Section 8 Housing Choice Voucher program helps very low-income families, the elderly, and people with disabilities afford rental housing in the private market. About one in three households using Section 8 vouchers are headed by a non-elderly (under age 62) person with a disability.
    - National Housing Trust Fund. The National Housing Trust Fund is a new, dedicated fund that provides grants to states to build, preserve, and rehabilitate housing for people with the lowest incomes.
- *Autism Housing Network (AHN)*—A project of the Madison House Autism Foundation, the AHN aims to provide a central hub of housing information, developer tools, and resources to build more neuro-inclusive communities. (Autism Housing Network (no date). [136]
    - Click here to explore array of existing and emerging housing models. Help finding other community living options can be found using services like Choice Respect independence: CRi; Dignity Dedication Respect Choice: DDRC; and, My Goodlife: goodlife innovations, or by contacting the local/state chapter of The Arc.

Section 15: Creating a More Dementia Capable Workforce: Training and Skills Building for Direct Support Professionals

DSPs are skilled paid workers who assist people with IDD with a variety of activities to help them live independently and participate fully in their communities.[137] The type of activities in which DSPs support people with IDD include daily living support (e.g., housekeeping, meal preparation), health and medication management, skill development, emotional and behavioral support, and advocacy.[137] DSPs work in a variety of settings, including peoples' homes, care facilities, places of employment, and day programs, and their duties are tailored to the unique needs of the individuals they support.[138]

Although DSPs are skilled in providing support to people with IDD, they often have limited knowledge of the unique needs related to aging, and dementia specifically. Because they focus on different populations, disability and aging networks have unique histories and identities. As people with IDD are living longer, professionals in the disability network are learning more about the needs of older adults and in the aging network they are learning more about how to support them as they age.

DSPs should have a basic understanding of dementia so that they can identify the signs and symptoms and alert family members to changes they notice. DSPs often have close, day-to-day interactions with the person with IDD and could be the first to recognize when the person with IDD is struggling with tasks that they have typically been able to do or acting out of character. DSPs should share their observations with family members, because that information can assist physicians in possibly making a dementia diagnosis.

Several introductory dementia courses for DSPs are included in the resources for this section. These courses often include an explanation of dementia, types of dementia, signs and symptoms of dementia, stages of dementia, communication strategies, and caregiving approaches. Having this foundational knowledge will help the DSP feel more confident and competent as they provide support to the person with IDD as they age.

If the person with IDD has received a dementia diagnosis, their DSPs should be informed of the diagnosis. Knowledge and understanding of the diagnosis can empower the DSP to support the person with IDD in the best way possible. It is important to ask the person with IDD, whenever possible, if they are comfortable sharing the diagnosis, with whom they want the information shared, and how they want the information shared. If the person with IDD does not have capacity to make this decision, their legal decision-maker should consider the option that is in their best interest. The caregiver/primary support person may consider sharing the changes they have noticed with the DSP and explain how the DSP may need to change their approach. For example, the DSP may need to assist the person with IDD to select weather-appropriate clothing and provide more cueing while the person with IDD is dressing.

Behavior symptom management is a crucial skill for DSPs to learn to best support people with IDD and dementia. As the person with IDD progresses through dementia, they may lose verbal communication skills and begin expressing their needs through behaviors that can often signal unmet emotional or physical needs, such as pain, hunger, or confusion.[78] When misunderstood, they may show distress or frustration, which can be misinterpreted by DSPs as challenging or aggressive behavior.[120] A variety of trainings and resources are available to help DSPs better understand how to recognize and address behavioral symptoms of dementia. Training on behavioral symptom management often includes background on behaviors as symptoms of dementia, identifying what is causing the behavior, and person-centered strategies to address behaviors.

Resources

- Basics of Intellectual and Developmental Disabilities and Dementia for Direct Care Professionals (MemoryLane Care Services) (For a copy, contact Erin.Long@acl.hhs.gov) This is a training developed for DSPs and others providing day-to-day care to people with IDD and dementia. The content includes basic information about dementia, communication strategies, person-centered care skills, and environmental changes to support high-quality care for the person with IDD and dementia.
- Screening for Dementia in Persons with Intellectual Disability (Wisconsin Alzheimer's Institute) This training includes five sessions for professionals who work with people with IDD to improve their understanding and utilization of the NTG-EDSD tool.
- Serving People with IDD and Dementia (Minnesota Department of Human Services) This is an online training for professionals working with people with IDD and dementia on how to best support the person, their families, and caregivers/primary support people.
- Dementia Friends IDD Version (Dementia Friendly America) Dementia Friends is a global movement to raise awareness and share basic information about dementia. The curriculum has been adapted specifically to educate professionals about people with IDD who develop dementia.
- Supporting Someone with Dementia (National Intellectual Disability Memory Service) This document is a simple overview of how to provide person-centered

care to a person with IDD and dementia. It includes information about communication and relationships, meaningful activities, self-care for the carer, and tips on brain health.

- Behavioral Symptom Management Training (The Arc) (For a copy, contact Erin.Long@acl.hhs.gov) This training provides an overview of common triggers for behaviors in adults with IDD and dementia and practical strategies to help professionals and caregivers interpret and respond to behaviors effectively. The training also addresses specific challenges such as aggression, elopement, repetitive questioning, difficulty with personal care, and sleep disturbances, offering concrete tools to promote safety and quality of life.
- Training Checklist for a More Dementia Capable Workforce (The Arc) (For a copy, contact Erin.Long@acl.hhs.gov) This document is a checklist of training opportunities for DSPs working within the IDD population or working with aging programs. Training topics include dementia basics, screening for dementia, behavior symptom management, dementia capable care, and effective communication strategies.
- Supporting People with Intellectual Disabilities and Dementia (Neighbor Network of Northern Nevada) (For a copy, contact Erin.Long@acl.hhs.gov) This curriculum includes a six-part training series and a one-time abbreviated session. The curriculum uses a customized approach to tailor training formats, discussions, and activities to suit each unique audience, including direct support staff, professionals, unpaid caregivers, and other community groups concerned with prioritizing person-centered care and support of people with intellectual disabilities as they age.
- Adapting Activities Across the Dementia Journey PowerPoint PDF (The Arc Jacksonville) (For a copy, contact Erin.Long@acl.hhs.gov) This training aims to equip learners with practical strategies to support individuals experiencing the progression of dementia through meaningful engagement. This training identifies activity types that align with the cognitive and functional abilities present at each stage of dementia, ensuring that interventions remain person-centered and accessible. The session highlights the therapeutic benefits of purposeful engagement in reducing distress, enhancing communication, and promoting dignity across the dementia journey. Learners will also explore how to incorporate sensory-based approaches and “just-right challenge” activities that stimulate abilities without overwhelming, creating opportunities for success, connection, and improved quality of life.

Conclusion

Aging and disability service networks enable people of all ages who have chronic conditions and disabilities to have self-determination and remain living in their homes and contributing to their communities. As long-term support services have evolved and HCBS providers have expanded their capacity, most people with IDD live in community settings rather than institutions.[139-141] To continue meeting the needs of people with IDD as they age, it is essential that aging and disability networks be equipped to provide responsive, person-centered care. The 2024 update to the National Plan to Address Alzheimer's Disease (NAPA)[142] called for a coordinated effort to develop the workforce in aging, public health, and IDD that are dementia-capable and culturally and linguistically appropriate. NAPA also called for efforts to educate families and service providers of people with IDD about changes that may indicate the onset of dementia. This guide is intended to contribute to and elevate the dementia capability of the aging and disability networks. The aging and disability networks have historically operated separately from one another, with different funding streams, federal rules and regulations, and local structures. To provide more holistic support to people with IDD and dementia, disability service providers need to build capacity in the aging space, and aging service organizations need to build capacity in providing support to people with IDD. This guide should be seen as a resource to both aging and disability network providers to understand and accommodate the ever-changing landscape.

Although the focus of this Guide is on practical strategies, it is important to acknowledge the growing body of scientific research that informs dementia diagnosis and treatment. Advances in biomarker research—including brain imaging (e.g., CT scan, MRI, PET scan), genetic testing, and fluid biomarkers such as blood tests[143]—offer promising tools for identifying dementia earlier and informing a more accurate diagnosis for people with IDD. Notably, Down syndrome–associated Alzheimer's disease is a specific condition that may respond to anti-amyloid monoclonal antibodies (e.g., Lecanemab)[144] and slow the progression of the disease.

Together, these strategies and scientific advancements offer a path forward for more informed and effective care for people with IDD and dementia.[142]

References

1. Office of Disability Employment Policy. (2025). *Direct Support Professionals (DSPs)*. U.S. Department of Labor. Retrieved from https://www.dol.gov/agencies/odep/program-areas/individuals/DSP
2. Public Law 106–402 (2000). https://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf
3. National Institute of Mental Health. (2025). *Autism Spectrum Disorder*. U.S. Department of Health and Human Services, National Institutes of Health. Retrieved from https://www.nimh.nih.gov/health/publications/autism-spectrum-disorder
4. World Health Organization. (2025, September 17). *Autism*. World Health Organization. Retrieved from https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders
5. International Summit Autism/Dementia Work Group. (2024). Autism, aging, and dementia: A consensus report of the Autism/Dementia Work Group of the 2nd International Summit on Intellectual Disabilities and Dementia. 2nd International Summit on Intellectual Disabilities and Dementia, Toronto, Canada.
6. Eunice Kennedy Shriver National Institute of Child Health and Human Development. (n.d.). *Intellectual and Developmental Disabilities (IDDs)*. NICHD Information Resource Center. Retrieved from https://www.nichd.nih.gov/health/topics/factsheets/idds
7. National Down Syndrome Society. (2019a). *Down Syndrome*. National Down Syndrome Society. Retrieved from https://www.ndss.org/about-down-syndrome/down-syndrome/.
8. Grieco, J., Pulsifer, M., Seligsohn, K., Skotko, B., & Schwartz, A. (2015). Down syndrome: Cognitive and behavioral functioning across the lifespan. *Am J Med Genet C Semin Med Genet, 169*(2), 135-149. https://doi.org/10.1002/ajmg.c.31439
9. Antonarakis, S. E., Skotko, B. G., Rafii, M. S., Strydom, A., Pape, S. E., Bianchi, D. W., Sherman, S. L., & Reeves, R. H. (2020). Down syndrome. *Nat Rev Dis Primers, 6*(1), 9. https://doi.org/10.1038/s41572-019-0143-7
10. Chi, W., Graf, E., Hughes, L., Hastie, J., Khatutsky, G., Shuman, S., Jessup, E. A., Karon, S., & Lamont, H. (2019). *Older adults with dementia and their caregivers: Key indicators from the National Health and Aging Trends Study*. Assistant Secretary for Planning and Evaluation. https://aspe.hhs.gov/system/files/pdf/260371/DemChartbook.pdf
11. Alzheimer's Association. (2025). *2025 Alzheimer's Disease Facts and Figures. Special Report: American Perspectives on Early Detection of Alzheimer's Disease in the Era of Treatment*. Alzheimer's Association. https://www.alz.org/getmedia/ef8f48f9-ad36-48ea-87f9-b74034635c1e/alzheimers-facts-and-figures.pdf
12. Alzheimer's Association. (2025). 2025 Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 21*(4), e70235. https://doi.org/10.1002/alz.70235
13. Residential Information Systems Project. (n.d.). *Key Questions: How many people have IDD*. University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. https://risp.umn.edu

14. Bradley, V., Hiersteiner, D., Li, H., Bonardi, A., & Vegas, L. (2020, March). *What Do NCI Data Tell Us About the Characteristics and Outcomes of Older Adults with IDD? Data Brief*. Human Services Research Institute and National Association of State Directors of Directors of Developmental Disabilities.
15. Keller, S. (2019, Nov 15). *Aging in adults with intellectual and developmental disabilities; concerns and hope*. https://www.cpofnys.org/wp-content/uploads/2019/11/6-SKeller-Aging-Dementia-And-Down-Syndrome.pdf
16. McCallion, P., Knowles, M., & Gould, E. (2019, July). *Intellectual and developmental disabilities and dementia: Practical strategies for professionals.* . RTI International. https://www.the-ntg.org/publications-2/intellectual-and-developmental-disabilities-and-dementia%3A-practical-strategies-for-professionals
17. NHS Northern England Clinical Networks (National Health System, U. (n.d.). *Dementia in Intellectual Disability Disorder Diagnosis and management Information for GPs*. U.K. National Health System. Retrieved from https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/12/IDD-GP-Guide-short-v1.9.pdf
18. Janicki, M. P., McCallion, P., Splaine, M., Santos, F. H., Keller, S. M., & Watchman, K. (2017). Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to Nomenclature. *Intellect Dev Disabil, 55*(5), 338-346. https://doi.org/10.1352/1934-9556-55.5.338
19. Hanney, M., Jebur, I., & National Health System (NHS). (2018). *Dementia in intellectual disability disorder: Diagnosis and management information for GPs*. NHS Northern England Clinical Networks. https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/12/IDD-GP-Guide-short-v1.9.pdf
20. Patel, P., Sun, W., Mataruga, A., Fung, K., & Balogh, R. (2025). The Incidence and Prevalence of Dementia Among Ontario Adults With and Without Intellectual and Developmental Disabilities. *Int J Geriatr Psychiatry, 40*(2), e70050. https://doi.org/10.1002/gps.70050
21. Takenoshita, S., Terada, S., Kuwano, R., Inoue, T., Cyoju, A., Suemitsu, S., & Yamada, N. (2020). Prevalence of dementia in people with intellectual disabilities: Cross-sectional study. *Int J Geriatr Psychiatry, 35*(4), 414-422. https://doi.org/10.1002/gps.5258
22. de Graaf, G., Buckley, F., & Skotko, B. (2024, May 4, May 3). *People living with Down syndrome in the USA: BIRTHS AND POPULATION*. Retrieved from https://docs.downsyndromepopulation.org/factsheets/down-syndrome-population-usa-factsheet.pdf
23. Chicoine, B., Rivelli, A., Fitzpatrick, V., Chicoine, L., Jia, G., & Rzhetsky, A. (2021). Prevalence of Common Disease Conditions in a Large Cohort of Individuals With Down Syndrome in the United States. *J Patient Cent Res Rev, 8*(2), 86-97. https://doi.org/10.17294/2330-0698.1824
24. National Down Syndrome Society. (n.d.). *Facts, Myths, & Truths About Down Syndrome*. NDSS. Retrieved from https://ndss.org/myths-truths
25. de Graaf, G., Buckley, F., Dever, J., & Skotko, B. G. (2017). Estimation of live birth and population prevalence of Down syndrome in nine U.S. states. *Am J Med Genet A, 173*(10), 2710-2719. https://doi.org/10.1002/ajmg.a.38402

26. Alzheimer's Association. *Down Syndrome and Alzheimer's Disease*. Alzheimer's Association. Retrieved from https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome
27. National Institute on Aging. (2020, November 30). *Alzheimer's disease in people with Down Syndrome*. National Institute on Aging, National Institutes of Health. Retrieved from https://www.nia.nih.gov/health/alzheimers-causes-and-risk-factors/alzheimers-disease-people-down-syndrome
28. Oliver, C., Adams, D., Holland, A. J., Brown, S. S. G., Ball, S., Dodd, K., & Carr, J. (2022). Acquired mild cognitive impairment in adults with Down syndrome: Age-related prevalence derived from single point assessment data normed by degree of intellectual disability. *Int J Geriatr Psychiatry, 37*(2). https://doi.org/10.1002/gps.5674
29. McCarron, M., McCallion, P., Reilly, E., Dunne, P., Carroll, R., & Mulryan, N. (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. *J Intellect Disabil Res, 61*(9), 843-852. https://doi.org/10.1111/jir.12390
30. Bayen, E., Possin, K. L., Chen, Y., Cleret de Langavant, L., & Yaffe, K. (2018). Prevalence of Aging, Dementia, and Multimorbidity in Older Adults With Down Syndrome. *JAMA Neurol, 75*(11), 1399-1406. https://doi.org/10.1001/jamaneurol.2018.2210
31. McGlinchey, E., McCallion, P., & McCarron, M. (2020). Down syndrome and dementia: advances in the field. *Curr Opin Psychiatry, 33*(3), 278-283. https://doi.org/10.1097/yco.0000000000000589
32. Rubenstein, E., Tewolde, S., Michals, A., Weuve, J., Fortea, J., Fox, M. P., Pescador Jimenez, M., Scott, A., Tripodis, Y., & Skotko, B. G. (2024). Alzheimer Dementia Among Individuals With Down Syndrome. *JAMA Network Open, 7*(9), e2435018-e2435018. https://doi.org/10.1001/jamanetworkopen.2024.35018
33. Iulita, M. F., Garzón Chavez, D., Klitgaard Christensen, M., Valle Tamayo, N., Plana-Ripoll, O., Rasmussen, S. A., Roqué Figuls, M., Alcolea, D., Videla, L., Barroeta, I., Benejam, B., Altuna, M., Padilla, C., Pegueroles, J., Fernandez, S., Belbin, O., Carmona-Iragui, M., Blesa, R., Lleó, A., Bejanin, A., & Fortea, J. (2022). Association of Alzheimer Disease With Life Expectancy in People With Down Syndrome. *JAMA Netw Open, 5*(5), e2212910. https://doi.org/10.1001/jamanetworkopen.2022.12910
34. Dietz, P. M., Rose, C. E., McArthur, D., & Maenner, M. (2020). National and State Estimates of Adults with Autism Spectrum Disorder. *J Autism Dev Disord, 50*(12), 4258-4266. https://doi.org/10.1007/s10803-020-04494-4
35. Janicki, M. P., McCallion, P., Jokinen, N., Larsen, F. K., Mughal, D., Palanisamy, V., Santos, F., Service, K., Shih, A., Shooshtari, S., Thakur, A., Tiziano, G., & Watchman, K. (2025). Autism and Dementia: A Summative Report from the 2nd International Summit on Intellectual Disabilities and Dementia. *J Autism Dev Disord*. https://doi.org/10.1007/s10803-025-06843-7
36. Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Res, 15*(5), 778-790. https://doi.org/10.1002/aur.2696
37. Rhodus, E. K., Barber, J., Abner, E. L., Duff, D. M. C., Bardach, S. H., Caban-Holt, A., Lightner, D., Rowles, G. D., Schmitt, F. A., & Jicha, G. A. (2020). Behaviors Characteristic of Autism Spectrum Disorder in a Geriatric Cohort With Mild

Cognitive Impairment or Early Dementia. *Alzheimer Dis Assoc Disord, 34*(1), 66-71. https://doi.org/10.1097/wad.0000000000000345

38. Vivanti, G., Tao, S., Lyall, K., Robins, D. L., & Shea, L. L. (2021). The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder. *Autism Res, 14*(10), 2189-2199. https://doi.org/10.1002/aur.2590
39. Torenvliet, C., Groenman, A. P., Radhoe, T. A., Agelink van Rentergem, J. A., Van der Putten, W. J., & Geurts, H. M. (2023). A longitudinal study on cognitive aging in autism. *Psychiatry Res, 321*, 115063. https://doi.org/10.1016/j.psychres.2023.115063
40. Micai, M., Fatta, L. M., Gila, L., Caruso, A., Salvitti, T., Fulceri, F., Ciaramella, A., D'Amico, R., Del Giovane, C., Bertelli, M., Romano, G., Schünemann, H. J., & Scattoni, M. L. (2023). Prevalence of co-occurring conditions in children and adults with autism spectrum disorder: A systematic review and meta-analysis. *Neurosci Biobehav Rev, 155*, 105436. https://doi.org/10.1016/j.neubiorev.2023.105436
41. National Task Group on Intellectual Disabilities and Dementia Practices (NTG). (n.d.). *NTG-EDSD Screening Tool*. NTG. Retrieved from https://www.the-ntg.org/ntg-edsd.
42. Esralew, L. (2023). *Fragile X Syndrome, IDD, and Dementia*. International Summit on Disability and Dementia, Toronto, Canada. https://www.the-ntg.org/_files/ugd/8c1d0a_e84da022107c450cbeb141985cff21be.pdf
43. Smith, K. J., Peterson, M. D., O'Connell, N. E., Victor, C., Liverani, S., Anokye, N., & Ryan, J. M. (2019). Risk of Depression and Anxiety in Adults With Cerebral Palsy. *JAMA Neurol, 76*(3), 294-300. https://doi.org/10.1001/jamaneurol.2018.4147
44. Mahmoudi, E., Lin, P., Kamdar, N., Gonzales, G., Norcott, A., & Peterson, M. D. (2022). Risk of early- and late-onset Alzheimer disease and related dementia in adults with cerebral palsy. *Developmental Medicine & Child Neurology, 64*(3), 372-378. https://doi.org/10.1111/dmcn.15044
45. Hayes, J. (2023, May 15). Recognizing the symptoms of Dementia with IDD. https://www.benrose.org/resource/recognizing-the-symptoms-of-dementia-with-idd/
46. Wissing, M. B. G., Fokkens, A. S., Dijkstra, R., Hobbelen, J. S. M., van der Putten, A. A. J., De Deyn, P. P., Waninge, A., & Dekker, A. D. (2022). Dementia in People with Severe/Profound Intellectual (and Multiple) Disabilities: Practice-Based Observations of Symptoms. *J Ment Health Res Intellect Disabil, 15*(4), 364-393. https://doi.org/10.1080/19315864.2022.2061092
47. Firth, N. C., Startin, C. M., Hithersay, R., Hamburg, S., Wijeratne, P. A., Mok, K. Y., Hardy, J., Alexander, D. C., & Strydom, A. (2018). Aging related cognitive changes associated with Alzheimer's disease in Down syndrome. *Ann Clin Transl Neurol, 5*(6), 741-751. https://doi.org/10.1002/acn3.571
48. Lautarescu, B. A., Holland, A. J., & Zaman, S. H. (2017). The Early Presentation of Dementia in People with Down Syndrome: a Systematic Review of Longitudinal Studies. *Neuropsychol Rev, 27*(1), 31-45. https://doi.org/10.1007/s11065-017-9341-9
49. Washington, S. E., Bodde, A. E., Helsel, B. C., Bollinger, R. M., Smith, N., Ptomey, L. T., Ances, B., & Stark, S. L. (2024). The association of dementia risk symptoms and

functional activity in adults with Down syndrome. *Alzheimers Dement (N Y), 10*(4), e70007. https://doi.org/10.1002/trc2.70007

50. McCallion, P. (2025, July 21). [Personal interview].
51. Klein, C. B., McQuaid, G. A., Charlton, R. A., Klinger, L. G., & Wallace, G. L. (2023). Self-reported cognitive decline among middle and older age autistic adults. *Autism Res, 16*(3), 605-616. https://doi.org/10.1002/aur.2877
52. Wissing, M. B. G., Ulgiati, A. M., Hobbelen, J. S. M., De Deyn, P. P., Waninge, A., & Dekker, A. D. (2022). The neglected puzzle of dementia in people with severe/profound intellectual disabilities: A systematic literature review of observable symptoms. *J Appl Res Intellect Disabil, 35*(1), 24-45. https://doi.org/10.1111/jar.12920
53. Dewitt-Smith, A. (2025, August 8). [Personal communication].
54. Listwan, T. A., Krinsky-McHale, S. J., Kovacs, C. M., Lee, J. H., Pang, D. I., Schupf, N., Tycko, B., Zigman, W. B., & Silverman, W. (2024). Prodromal Alzheimer's disease can affect activities of daily living for adults with Down syndrome. *Alzheimers Dement (Amst), 16*(1), e12562. https://doi.org/10.1002/dad2.12562
55. Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M. E. S., Fuentes, J., & Frazier, T. W. (2022). Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. *Pediatr Res, 91*(5), 1028-1035. https://doi.org/10.1038/s41390-021-01465-y
56. Rafii, M. S., Schlachetzki, Z., Barroeta, I., Head, E., Fortea, J., & Ances, B. M. (2025). Down syndrome and Alzheimer's disease: insights into biomarkers, clinical symptoms, and pathology. *Lancet Neurol, 24*(9), 753-762. https://doi.org/10.1016/S1474-4422(25)00237-6
57. Walaszek, A. (2025, June 11). [Personal interview].
58. Anemone, R. (2024, April 12). Creating Sensory-Friendly Health Care Environments for Autistic Patients. Retrieved Jul 22, 2025, from https://autismspectrumnews.org/creating-sensory-friendly-health-care-environments-for-autistic-patients/
59. Galvin, J. E., Roe, C. M., Powlishta, K. K., Coats, M. A., Muich, S. J., Grant, E., Miller, J. P., Storandt, M., & Morris, J. C. (2005). The AD8: a brief informant interview to detect dementia. *Neurology, 65*(4), 559-564. https://doi.org/10.1212/01.wnl.0000172958.95282.2a
60. Such, A. (2025, Aug 7). [Personal email communication].
61. Gerontological Society of America. (2024). *KAER Toolkit: Addressing Brain Health in Adults with Intellectual Disabilities and Developmental Disabilities*. Gerontological Society of America. Retrieved from https://www.kaerbrain.org/Portals/KAER/Files/IDD_KAER%20Toolkit_Update_Dec2024_FNL.pdf?ver=zqFDXR_f20LS22iaJ-43fA%3D%3D
62. Janicki, M. P., McCallion, P., Jokinen, N., Larsen, F. K., Service, K. P., Mughal, D. T., Watchman, K., Gomiero, T., & Keller, S. M. (2025). Autism, Diagnostics, and Dementia: A Consensus Report From the 2nd International Summit on Intellectual Disabilities and Dementia. *Int J Geriatr Psychiatry, 40*(6), e70110. https://doi.org/10.1002/gps.70110

63. Deb, S., Hare, M., Prior, L., & Bhaumik, S. (2007). Dementia screening questionnaire for individuals with intellectual disabilities. *British Journal of Psychiatry, 190*(5), 440-444.
64. Zeilinger, E. L., Zrnic Novakovic, I., Komenda, S., Franken, F., Sobisch, M., Mayer, A. M., Neumann, L. C., Loosli, S. V., Hoare, S., & Pietschnig, J. (2022). Informant-based assessment instruments for dementia in people with intellectual disability: A systematic review and standardised evaluation. *Res Dev Disabil, 121*, 104148. https://doi.org/10.1016/j.ridd.2021.104148
65. Walaszek, A., Albrecht, T., LeCaire, T., Sayavedra, N., Schroeder, M., Krainer, J., Prichett, G., Wilcenski, M., Endicott, S., Russmann, S., Carlsson, C. M., & Mahoney, J. (2022). Training professional caregivers to screen for report of cognitive changes in persons with intellectual disability. *Alzheimers Dement (N Y), 8*(1), e12345. https://doi.org/10.1002/trc2.12345
66. Burton, J. K., Fearon, P., Noel-Storr, A. H., McShane, R., Stott, D. J., & Quinn, T. J. (2021). Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) for the detection of dementia within a general practice (primary care) setting. *Cochrane Database Syst Rev, 7*(7), CD010771. https://doi.org/10.1002/14651858.CD010771.pub3
67. Prado Mattar, G., Uchida, R. R., Haddad, G. G., Shiozawa, P., Reboucas da Silva, M. F., Hoexter, M. Q., Busatto, G. F., de Campos Bottino, C. M., Fonseca, L. M., & Forlenza, O. V. (2022). Screening for Dementia and Cognitive Decline in Adults With Down Syndrome: A Novel Approach Using the Informant Questionnaire on Cognitive Decline in the Elderly. *Alzheimer Dis Assoc Disord, 36*(2), 162-167. https://doi.org/10.1097/WAD.0000000000000495
68. Australian National University National Centre for Epidemiology and Population Health. (n.d.). *Informant questionnaire on cognitive decline in the elderly*. Australian National University Retrieved from https://nceph.anu.edu.au/research/tools-resources/informant-questionnaire-cognitive-decline-elderly
69. Groot, I. Z., Lever, A. G., Koolschijn, P. C., & Geurts, H. M. (2021). Brief Report: Using Cognitive Screeners in Autistic Adults. *J Autism Dev Disord, 51*(9), 3374-3379. https://doi.org/10.1007/s10803-020-04782-z
70. Edge, D., Oyefeso, A., Evans, C., & Evans, A. (2016). The utility of the Montreal Cognitive Assessment as a mental capacity assessment tool for patients with a learning disability. *British Journal of Learning Disabilities, 44*(3), 240-246. https://doi.org/10.1111/bld.12157
71. Prasher, V., Farooq, A., & Holder, R. (2004). The Adaptive Behaviour Dementia Questionnaire (ABDQ): screening questionnaire for dementia in Alzheimer's disease in adults with Down syndrome. *Res Dev Disabil, 25*(4), 385-397. https://doi.org/10.1016/j.ridd.2003.12.002
72. Zorzi, S., Dalmonego, C., De Vreese, L. P., & Gomiero, T. (2023). Adult Independence Living Measurement Scale: Psychometric validation of a scale to estimate personal skills for independent living in people with intellectual and developmental disabilities. *J Intellect Disabil Res, 67*(6), 560-572. https://doi.org/10.1111/jir.13028
73. Dekker, A. D., Ulgiati, A. M., Groen, H., Boxelaar, V. A., Sacco, S., Falquero, S., Carfi, A., di Paola, A., Benejam, B., Valldeneu, S., Fopma, R., Oosterik, M., Hermelink, M., Beugelsdijk, G., Schippers, M., Henstra, H., Scholten-Kuiper, M., Willink-Vos, J., de

Ruiter, L., Willems, L., Loonstra-de Jong, A., et al. (2021). The Behavioral and Psychological Symptoms of Dementia in Down Syndrome Scale (BPSD-DS II): Optimization and Further Validation. *J Alzheimers Dis, 81*(4), 1505-1527. https://doi.org/10.3233/JAD-201427

74. Beresford-Webb, J. A., Mak, E., Grigorova, M., Daffern, S. J., Holland, A. J., & Zaman, S. H. (2021). Establishing diagnostic thresholds for Alzheimer's disease in adults with Down syndrome: the Cambridge Examination for Mental Disorders of Older People with Down's Syndrome and Others with Intellectual Disabilities (CAMDEX-DS). *BJPsych Open, 7*(3), e79. https://doi.org/10.1192/bjo.2021.36
75. Albert, M., & Cohen, C. (1992). The Test for Severe Impairment: an instrument for the assessment of patients with severe cognitive dysfunction. *J Am Geriatr Soc, 40*(5), 449-453. https://doi.org/10.1111/j.1532-5415.1992.tb02009.x
76. McCarron, M., Carroll, R., Mulryan, N. M., Reilly, E. M., Dunne, P., McGlinchey, E., & McCallion, P. (2018). The Test for Severe Impairment. In V. P. Prasher (Ed.), *Neuropsychological Assessments of Dementia in Down Syndrome and Intellectual Disabilities* (pp. 145-160). Springer International Publishing. https://doi.org/10.1007/978-3-319-61720-6_8
77. Watchman, K., Janicki, M. P., Members of the International Summit on Intellectual, D., & Dementia. (2019). The Intersection of Intellectual Disability and Dementia: Report of The International Summit on Intellectual Disability and Dementia. *The Gerontologist, 59*(3), 411-419. https://doi.org/10.1093/geront/gnx160
78. Seven Hills Rhode Island. (2020). *Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders, 2020* Retrieved from https://nadrc.acl.gov/details?search1=201
79. National Task Group. (2022, Jun 20, 2025). *NTG FAQ: Some Basic Questions about Adults with Intellectual/Developmental Disabilities Affected by Alzheimer's Disease or Other Dementias*. National Task Group on Intellectual Disabilities and Dementia Practices. https://apd.myflorida.com/waiver/docs/Frequently%20Asked%20Questions.pdf
80. Rawat, P., Sehar, U., Bisht, J., & Reddy, P. H. (2023). Support Provided by Caregivers for Community-Dwelling Diabetic Hispanic Adults with Intellectual Disabilities and Comorbid Conditions. *Int J Mol Sci, 24*(4). https://doi.org/10.3390/ijms24043848
81. Torr, J. (n.d.). *Down syndrome and dementia: A guide for families*. Down Syndrome Australia. https://www.downsyndrome.org.au
82. Moran, J. (2023). *Aging and Down syndrome: A health and well-being guidebook (2nd ed.)* (2nd ed.). National Down Syndrome Society. https://ndss.org/resources/aging-and-down-syndrome-health-well-being-guidebook
83. American Academy of Audiology. (n.d.). *Intellectual and developmental disabilities and hearing loss. Accessed 9/17/2025.* . American Academy of Audiology. Retrieved from https://www.audiology.org/consumers-and-patients/hearing-and-balance/intellectual-and-developmental-disabilities-and-hearing-loss/
84. H2 Health. (2024, September 18). *Better vision through occupational therapy for dementia*. Retrieved from https://www.h2health.com/better-vision-through-occupational-therapy-for-dementia/

85. Hand, B. N., Angell, A. M., Harris, L., & Carpenter, L. A. (2020). Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults. *Autism, 24*(3), 755-764. https://doi.org/10.1177/1362361319890793
86. Texas Health and Human Services. (n.d.). *Evidence-based best practices for antipsychotic medication use in nursing facilities*. https://www.hhs.texas.gov/sites/default/files/documents/ebbp-ap.pdf
87. Moran, J. A., Hogan, M., Srsic-Stoehr, K., Service, K., & Earle-Hahn, J. (2019). *Alzheimer's disease & Down syndrome: A practical guidebook for caregivers. . Retrieved May 27, 2025.* . National Down Syndrome Society. Retrieved from https://ndss.org/resources/alzheimers-disease-down-syndrome-practical-guidebook-caregivers
88. Arvanitakis, Z., Shah, R. C., & Bennett, D. A. (2019). Diagnosis and Management of Dementia: Review. *JAMA, 322*(16), 1589-1599. https://doi.org/10.1001/jama.2019.4782
89. Cummings, J., Apostolova, L., Rabinovici, G. D., Atri, A., Aisen, P., Greenberg, S., Hendrix, S., Selkoe, D., Weiner, M., Petersen, R. C., & Salloway, S. (2023). Lecanemab: Appropriate Use Recommendations. *J Prev Alzheimers Dis, 10*(3), 362-377. https://doi.org/10.14283/jpad.2023.30
90. United States Census Bureau. (2020). *2020 Census Demographic Profile*. United States Census Bureau. Retrieved from https://www.census.gov/data/tables/2023/dec/2020-census-demographic-profile.html#data
91. Spreat, S. (2020). Persons with Intellectual Disability in Prison. *Journal of Intellectual Disability and Offending Behaviour, 11*(4), 233-237. https://doi.org/10.1108/JIDOB-03-2020-0006
92. McCallion, P. (2023). *Basics of Intellectual and Developmental Disabilities and Dementia for Direct Care Professionals, (Memory Lane Care Services).* . Memory Lane Care Services.
93. McCallion, P., Jokinen, N., & Janicki, M. P. (2017). Aging. In M. L. Wehmeyer, I. Brown, M. Percey, K. A. Shogren, & M. Fung (Eds.), *A Comprehensive Guide to Intellectual and Developmental Disabilities* (pp. 639-654). Paul Brookes Press.
94. National Down Syndrome Society. (2023). *Alzheimer's disease and Down syndrome: A practical guidebook for caregivers*. NDSS. Retrieved from https://ndss.org/caregiver_guide_eng?token=1WW4Wp1l83CUbUn16MRsexh67O8Qq2oFIBOO5VwSb5c
95. The Arc. (n.d.). *Self-advocacy position statement*. The Arc. Retrieved from https://thearc.org/position-statements/self-advocacy/
96. Alzheimer's Society. (2022, January 19). *Non-verbal communication and dementia*. Alzheimer's Society. Retrieved from https://www.alzheimers.org.uk/about-dementia/stages-and-symptoms/dementia-symptoms/non-verbal-communication-and-dementia
97. Alzheimer's Society. (n.d.). *Learning disabilities and dementia*. Alzheimer's Society. Retrieved from https://www.alzheimers.org.uk/about-dementia/types-dementia/learning-disabilities-dementia
98. National Intellectual Disability Memory Service. (2020). *Supporting someone with intellectual disability and dementia*.

99. Seven Hills Rhode Island, & National Task Group on Intellectual Disabilities and Dementia Practices. (2018). *Talking about dementia: A guide for families, caregivers and adults with intellectual disabilities. A Supplemental Module to Intellectual Disability and Dementia: A Caregiver's Resource Guide for Rhode Islanders*. Seven Hills Rhode Island. https://onecaregiverresourcecenter.org/wp-content/uploads/2023/12/TalkingAboutDementia7.10.18.pdf
100. Such, A. (n.d.). *Behavior Symptom Management for Adults with IDD & Dementia*. The Arc.
101. McCallion, P., & Janicki, M. P. (2002). *Intellectual disabilities and dementia. A two cd-rom training package*. NYS Developmental Disabilities Council.
102. Wisconsin Board for People with Developmental Disabilities. (n.d.). *Dementia Resource Guide Book*. Wisconsin BPDD. Retrieved from https://wi-bpdd.org/wp-content/uploads/2018/10/Dementia_Guide_Book_Full_compressed.pdf
103. Hughes, M., Hanna, K., Wiles, A., Taylor, E., & Giebel, C. (2024). The experiences of caring for someone with dementia and a learning disability: A qualitative systematic review. *Dementia (London), 23*(5), 817-849. https://doi.org/10.1177/14713012231225797
104. Massachusetts Down Syndrome Congress (MDSC). (n.d.). *Today & Tomorrow: A guide to aging with Down Syndrome*. MDSC. Retrieved from https://mdsc.org/resource/today-tomorrow-a-guide-to-aging-with-down-syndrome/
105. Down Syndrome Resource Foundation. (n.d., Oct 6). Thinking clearly about down syndrome and Alzheimer's. https://www.dsrf.org/resources/blog/thinking-clearly-about-down-syndrome-and-alzheimers/
106. Administration for Community Living (ACL). (2024). *Person Centered Planning*. ACL. Retrieved from https://acl.gov/programs/consumer-control/person-centered-planning
107. Administration for Community Living (ACL). (n.d.). *What is Person-Centered Counseling?* ACL. Retrieved from https://nwd.acl.gov/person-centered-counseling.html
108. Lightfoot, E. (2006). Social work practice with older adults with developmental disabilities. In.
109. McCallion, P., & Ferretti, L. A. (2021). Psychosocial concerns among ageing family caregivers (Translator, Trans.). In Editor (Ed.),^(Eds.), *Book Psychosocial concerns among ageing family caregivers* (pp. 249-259). Springer Nature Switzerland AG. https://doi.org/10.1007/978-3-030-56934-1_15
110. McCallion, P., Hogan, M., Santos, F. H., McCarron, M., Service, K., Stemp, S., Keller, S., Fortea, J., Bishop, K., Watchman, K., & Janicki, M. P. (2017). Consensus statement of the International Summit on Intellectual Disability and Dementia Related to End-of-life Care in Advanced Dementia. *Journal of Applied Research in Intellectual Disability, 30*(6), 1160-1164. https://doi.org/10.1111/jar.12349
111. McCarron, M., Allen, A. P., Mulryan, N., Leigh, M., O'Reilly, L., McCarthy, C., Dunne, P., Reilly, E., & McCallion, P. (2022). Living and Dying Well with Dementia. In R. J. Stancliffe, M. Y. Wiese, P. McCallion, & M. McCarron (Eds.), *End of Life and People with Intellectual and Developmental Disability: Contemporary Issues, Challenges,*

Experiences and Practice (pp. 179-209). Springer International Publishing. https://doi.org/10.1007/978-3-030-98697-1_7

112. Ferretti, L. A., McCarron, M., & McCallion, P. (2022). Building Shared End-of-Life Supports and Cross-Training for Hospice/Palliative and Intellectual Disability Services Providers. In R. J. Stancliffe, M. Y. Wiese, P. McCallion, & M. McCarron (Eds.), *End of Life and People with Intellectual and Developmental Disability: Contemporary Issues, Challenges, Experiences and Practice* (pp. 211-233). Springer International Publishing. https://doi.org/10.1007/978-3-030-98697-1_8
113. Diaz, M. A., Angus, F. C., & Bickenbach, J. E. (2024). Perceived barriers and facilitators to good end of life care: Focusing on people with intellectual disabilities. *J Appl Res Intellect Disabil, 37*(2), e13186. https://doi.org/10.1111/jar.13186
114. Stancliffe, R. J., Wiese, M. Y., McCallion, P., & McCarron, M. (2022). Experience of End-of-Life Issues by People with Intellectual Disability. In R. J. Stancliffe, M. Y. Wiese, P. McCallion, & M. McCarron (Eds.), *End of Life and People with Intellectual and Developmental Disability: Contemporary Issues, Challenges, Experiences and Practice* (pp. 29-57). Springer International Publishing. https://doi.org/10.1007/978-3-030-98697-1_2
115. McCarron, M., Kelly, K., McCallion, P., Burke, É., Haigh, M., & Wormald, A. (2022). Supporting People with Intellectual Disability at End of Life: Moral Distress Among Staff Caregivers During COVID-19. In R. J. Stancliffe, M. Y. Wiese, P. McCallion, & M. McCarron (Eds.), *End of Life and People with Intellectual and Developmental Disability: Contemporary Issues, Challenges, Experiences and Practice* (pp. 235-264). Springer International Publishing. https://doi.org/10.1007/978-3-030-98697-1_9
116. The Arc. (n.d.). *Expressing Wishes for the Future*. The Arc. Retrieved from https://futureplanning.thearc.org/pages/learn/where-to-start/expressing-wishes-for-the-future
117. The Arc. (n.d.). *Future decisions*. The Arc. Retrieved from https://futureplanning.thearc.org/assets/Future%20Decision%20-%20Center%20for%20Future%20Planning-bfbeb59e1a0ac03013d58e3da8c96fd29f46d753cfa8ecd9c1cbe65267f6c8d2.pdf
118. The Arc. (n.d.). *Future Planning 101*. The Arc. Retrieved from https://futureplanning.thearc.org/pages/learn/future-planning-101
119. Sheth, A. J., Kramer, J. M., Magasi, S., Heller, T., Nishida, A., & Hammel, J. (2021). "It's not the same without you:" Exploring the experience and perception of transition for people with intellectual disabilities and dementia. *British Journal of Learning Disabilities, 49*(3), 365-372. https:/doi.org/10.1111/bld.12412
120. Jacobs, P., Watchman, K., Wilkinson, H., Hoyle, L., & McGenily, L. (2023). Experiences of people with intellectual disability and dementia: A systematic review. *J Appl Res Intellect Disabil, 36*(2), 241-258. https://doi.org/10.1111/jar.13063
121. Curelaru, A., Marzolf, S. J., Provost, J. K. G., & Zeon, H. H. H. (2021). Social Isolation in Dementia: The Effects of COVID-19. *J Nurse Pract, 17*(8), 950-953. https://doi.org/10.1016/j.nurpra.2021.05.002
122. Such, A. (2025, June 12). [Personal interview].
123. Esteba-Castillo, S., Garcia-Alba, J., Rodriguez-Hildago, E., Vaquero, L., Novell, R., Moldenhauer, F., & Castellanos, M. A. (2022). Proposed diagnostic criteria for mild

cognitive impairment in Down syndrome population. *J Appl Res Intellect Disabil, 35*(2), 495-505. https://doi.org/10.1111/jar.12959

124. Videla, L., Benejam, B., Pegueroles, J., Carmona-Iragui, M., Padilla, C., Fernandez, S., Barroeta, I., Altuna, M., Vallldeneu, S., Garzon, D., Ribas, L., Montal, V., Arranz Martinez, J., Rozalem Aranha, M., Alcolea, D., Bejanin, A., Iulita, M. F., Videla Ces, S., Blesa, R., Lleo, A., & Fortea, J. (2022). Longitudinal Clinical and Cognitive Changes Along the Alzheimer Disease Continuum in Down Syndrome. *JAMA Netw Open, 5*(8), e2225573. https://doi.org/10.1001/jamanetworkopen.2022.25573
125. Residential Information Systems Project. (2025). *Where do people who get supports live?* University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. https://risp.umn.edu
126. Centers for Medicare and Medicaid Services (CMS). (2016). *Key Message and Tips for Providers. Found at: Key Message and Tips for Providers: Adult Day Care*. Retrieved from https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/key-messages-Adult-Day-Care-%5BApril-2016%5D.pdf
127. National Adult Day Services Association. *Consumers*. NADSA. Retrieved from https://www.nadsa.org/for-caregivers/consumers/
128. Administration for Community Living. (n.d.). *Aging and Disability Resource Centers*. ACL. Retrieved from https://acl.gov/programs/aging-and-disability-networks/aging-and-disability-resource-centers
129. Administration for Community Living (ACL). (2025, April). *Paragraph 2. Centers for Independent living*. ACL. Retrieved from https://acl.gov/programs/aging-and-disability-networks/centers-independent-living
130. Medicaid.gov. (n.d.). *Intermediate Care Facilities for Individuals with Intellectual disability*. Centers for Medicare & Medicaid Services. Retrieved from https://www.medicaid.gov/medicaid/long-term-services-supports/institutional-long-term-care/intermediate-care-facilities-individuals-intellectual-disability.
131. Administration for Community Living (ACL). (2025, January). *Lifespan Respite Care Program*. ACL. Retrieved from https://acl.gov/programs/support-caregivers/lifespan-respite-care-program
132. ARCH National Respite Network and Resource Center. (n.d.). *ARCH National Respite Network & Resource Center home page*. ARCH. Retrieved from https://archrespite.org/
133. CRI (Choice. Respect. Independence). (n.d.). *Community Living Options: Find the Right Fit for Individuals with IDD*. CRI. Retrieved from https://mycri.org/service-lines-cri-disability-mental-health/community-living-options-find-the-right-fit-for-individuals-with-idd
134. McCallion, P. (2025, Aug.). [Personal communication (email)].
135. The Arc Jacksonville. (n.d.). *Community Homes*. Retrieved from https://arcjacksonville.org/programs/community-homes/
136. Autism Housing Network. (n.d.). *Home is possible...Inspiring a Future Where Everyone Finds their Place in the World*. Retrieved from https://www.autismhousingnetwork.org/

137. National Alliance for Direct Support Professionals. (2024). *National Alliance for Direct Support Professionals (NADSP)*. NADSP. Retrieved from https://www.nadsp.org
138. U.S. Department of Labor, O. o. D. E. P. (n.d.). *Direct support professionals (DSPs)*. U.S. Department of Labor. Retrieved from https://www.usa.gov/agencies/office-of-disability-employment-policy
139. Larson, S. A., van der Salm, B., Pettingell, S., Sowers, M., & Anderson, L. L. (2021). *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2018*. University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from https://ici-s.umn.edu/files/yFXkkmRteg/2018-risp-full-report?preferredLocale=en-US
140. Friedman, C. (2019). The Influence of Residence Type on Personal Outcomes. *Intellect Dev Disabil, 57*(2), 112-126. https://doi.org/10.1352/1934-9556-57.2.112
141. Larson, S. A. (2022, June). *Are large institutions for people with intellectual or developmental disabilities a thing of the past?* . University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. (Policy Research Brief. https://publications.ici.umn.edu/community-living/prb/29-2/main
142. U.S. Department of Health and Human Services. (2024). *National Plan to Address Alzheimer's Disease: 2024 update*. Office of the Assistant Secretary for Planning and Evaluation. https://aspe.hhs.gov/sites/default/files/documents/dc2ff0be0e08df15971fce57cb8e5c7a/napa-national-plan-2024-update.pdf
143. Granholm, A. C., & Ledreux, A. (2021). Biomarkers show value of studying dementia in Down syndrome. *Nat Rev Neurol, 17*(10), 599-600. https://doi.org/10.1038/s41582-021-00558-w
144. Hillerstrom, H., Fisher, R., Janicki, M. P., Chicoine, B., Christian, B. T., Esbensen, A., Esralew, L., Fortea, J., Hartley, S., Hassenstab, J., Keller, S. M., Krinsky-McHale, S., Lai, F., Levin, J., McCarron, M., McDade, E., Rebillat, A. S., Rosas, H. D., Silverman, W., Strydom, A., Zaman, S. H., et al. (2024). Adapting prescribing criteria for amyloid-targeted antibodies for adults with Down syndrome. *Alzheimers Dement, 20*(5), 3649-3656. https://doi.org/10.1002/alz.13778

Appendix A: Provider Checklist for Assessing People With Intellectual and Developmental Disabilities at Risk for Dementia

Establish a baseline:

- Administer screening instrument periodically that includes a cognitive, health, and functional assessment and a behavioral baseline.
- Baseline screening should begin at 40 years of age for people at increased risk for premature aging, such as Down syndrome, and at 50 years of age in individuals with other intellectual and developmental disabilities.

Gather a history from the person whenever possible and confirm with a reliable informant.

- Ask about longstanding cognitive and functional abilities and when they first noticed changes. Ask for specific details because this will aid in the diagnosis.
    - What could the person do previously regarding self-care activities such as dressing, eating, and managing personal care? What change have they noticed?
    - Have there been any new toileting accidents/difficulties?
    - Has there been any new sleep difficulty?
    - Has there been a change in sexual activity?
    - What could the person do previously regarding daily activities such as taking the bus, preparing meals, and going to work? What changes have they noticed?
    - What could the person do previously regarding following routines such as getting ready in the morning, bedtime routine? What changes have they noticed?
    - What activities or hobbies did the person enjoy previously? What changes have they noticed?
    - Has there been a change in the person's mood (for example, anxiety, sadness, irritability, suicidal statements, self-harm)?
    - Have there been any new concerning behaviors (for example, aggression, self-harm behavior, refusal of care)?
- Ask about any major life events in the last 12 months such as:
    - Change in health
    - Change in living or work environment
    - Change in medications

  - Changes in ability to go to favorite places or do favorite activities
  - Changes in patterns of visits by family members and friends
  - Changes in staff or peers where they live and work
  - Death or major illness of family or friends
  - Recent breakup with boyfriend/girlfriend

Conduct caregiver assessment:

- Identify primary caregiver
- Assess caregiver’s capacity to manage person’s physical, emotional, financial, and social needs
- Assess for abuse or neglect including financial exploitation

Conduct a thorough history and physical exam including:

- Any changes in mood or behavior
- Any seizure activity in the last 12 months
- Change in appetite or weight loss/gain
- Changes in gait or walking difficulties
- Changes in vision or hearing or dental concerns
- Falls within the last 12 months
- History of memory loss
- Mental status exam
- Reported or suspected pain
- Sensory processing impairments
- Sleep difficulties
- Substance abuse
- Swallowing difficulties

Obtain medical records of any prior medical assessments

Medication Review

Order lab tests:

- Celiac disease screen (specifically for adults with autism)
- Complete blood count
- Electrolytes
- Thyroid dysfunction
- Vitamin deficiencies

Order diagnostic tests:

- Dementia biomarkers may be indicated (e.g., FDG PET, CSF, or blood-based biomarkers for Alzheimer's disease)
- MRI or CT scan to evaluate for cerebrovascular disease and focal atrophy

Make referrals:

- Occupational therapy assessment
- Psychiatric assessment
- Sleep study to assess for sleep apnea
- Speech and language assessment
- Vision or hearing testing
- X-rays or other imaging to assess for arthritis or degenerative changes

Report any suspected abuse or neglect to Adult Protective Services or law enforcement.

Source: [5; 57; 16; 77]

Appendix B: Provider Checklist for Postdiagnosis Care and Management

- Counsel person and caregivers/support staff about the condition, probable course/trajectory, advance care planning.

- Request social work consultation for:
  - Ongoing education and support for person and caregiver/primary support person
  - Care management
  - Benefits assessment and counseling
  - Referral to financial or legal services
  - Referrals to adult day services, respite services, residential care, or other services
- Monitor for behavioral and psychological symptoms of dementia and review care approaches with caregivers.

- Provide regular medical checkups to address dementia related conditions (e.g., seizures in Down syndrome) and comorbid medical conditions.

- Assess for changes in health, function, and quality of life.

- Conduct quality of life evaluations from both the perspective of the person with ID and the caregivers semiannually or if change in person's condition.

Source: [57; 16]

Appendix C: Behavior Log

Behavior: ______________________

- When did the behavior occur?
- How frequent is this behavior?
- Who was present?
- Where was this and what was happening at the time?
- What intervention was tried?
- What was the result?

Behavior: ______________________

- When did the behavior occur?
- How frequent is this behavior?
- Who was present?
- Where was this and what was happening at the time?
- What intervention was tried?
- What was the result?

Behavior: ______________________

- When did the behavior occur?
- How frequent is this behavior?
- Who was present?
- Where was this and what was happening at the time?
- What intervention was tried?
- What was the result?

Source: [16]

Appendix D: Individualized Care Plan

The Arc of Jacksonville creates an individualized care plan (see below) for each participant who attends their SAS adult day program. The care plan includes a summary of the participant's needs and specific goals. Each goal is written in SMART format where the goal is **S**pecific, **M**easurable, **A**chievable, **R**elevant, and **T**ime-bound. Accompanying each goal is a training step that is used to help the participant reach their goals. Target completion dates and progress notes are also included. The plan is reviewed regularly and is signed by the participant, their guardian or parent, and staff who write and review the care plan notes.

Individualized Care Plan

Participant Name: ______________________

Date of Plan: __________________________

Review Date: __________________________

Team Members Present: ______________________________________

Primary Contact/Responsible Staff: _____________________________

Overall Focus / Summary of Participant Needs:

(Brief paragraph describing the participant's strengths, preferences, areas of concern, and general goals for quality of life. This can also include results from NTG-EDSD screening, cognitive baseline screening, and any other relevant signs of changes, decline, or observations.)

Goal 1: [Insert Specific Goal]
*(SMART format: Specific, Measurable, Achievable, Relevant, Time-Bound) *

Example Goal: [Dave will participate in at least two meaningful group activities per day with peers at the program (ex: music, walking group, or memory games) for the next 12 weeks, to maintain social engagement and a sense of purpose.

- Training Step 1: ____

Example Training step: [Staff will offer Dave a visual schedule and provide a choice of at least two preferred options to support participation.]

- Training Step 2: ____

Target Completion Date: ______________

Progress Notes:

____

____

Goal 2: [Insert Specific Goal]
(SMART format: Specific, Measurable, Achievable, Relevant, Time-Bound)

- Training Step 1: ____

- Training Step 2: ____

Target Completion Date: ______________

Progress Notes:

____

____

Goal 3: [Insert Specific Goal]
*(SMART format: Specific, Measurable, Achievable, Relevant, Time-Bound) *

- Training Step 1: ______________________________________

- Training Step 2: ______________________________________

Target Completion Date: _____________

Progress Notes:

____

____

Review Plan

Next Review Date: ______________________

Notes/Recommendations for Follow-Up:

____

____

Participant Signature: ______________________

Parent/ Guardian Signature (If applicable): ______________________

Note Writer Signature: ______________________

Note Reviewer Signature (Second staff member): ______________________

Appendix E: Sample Training Checklist for a More Dementia Capable Workforce (Direct Support Professionals) From the Arc Jacksonville

DSPs Working Within the IDD Population

- ☐ IDD & Dementia 101: Dementia Basics Training
- ☐ NTG-EDSD Screening Training
- ☐ Behavior Symptom Management Training[100]

DSPs Specifically Working Within Aging or Dementia Programs

- ☐ All trainings listed above
- ☐ At least one of the following:
  - ○ NTG Dementia Capable Care 2-Day Training
  - ○ Teepa Snow’s Positive Approach to Care for Dementia and IDD
- ☐ Alzheimer’s Association Trainings
  - ○ 10 Warning Signs of Alzheimer’s
  - ○ Effective Communication Strategies
  - ○ Understanding and Responding to Dementia Related Behavior
- ☐ Riverside Center for Excellence in Aging and Lifelong Health Trainings
  - ○ Meeting a Person Where They Are
    - ▪ Let’s Get Started
    - ▪ Lesson 1: Understanding Dementia
    - ▪ Lesson 2: Asking WHY
    - ▪ Lesson 3: Accepting Their Reality
    - ▪ Lesson 4: Adapting
    - ▪ Lesson 5: Communication