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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Acknowledgements

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 and aging communities—when working with individuals living with intellectual and developmental disabilities (IDD) and dementia. Although advances in medicine and technology are extending the lives of individuals living with IDD, their increasing years also place people living with IDD at high risk of developing dementia. People living with IDD and dementia have many needs, and they and their caregivers require specialized targeting and service delivery. The limited number of individuals living with IDD and dementia in individual communities and states suggests integrating people living with IDD and dementia into existing memory clinic and other dementia-specific services to yield the greatest benefit.

The guide is organized into 12 sections that address different aspects of identifying and providing services to individuals living 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 individuals living with IDD and dementia. In addition to strategies, each section includes resources that professionals and caregivers can consult for further information related to the specific section topic.

- **Section 1: Introduction**. Provides an overview of the terms and services referenced throughout the guide.

- **Section 2: Prevalence**. Discusses the prevalence of dementia among individuals living with IDD.

- **Section 3: Presentation: Signs and Symptoms**. Reviews the most common dementia symptoms for individuals living with IDD.

- **Section 4: Information Needed to Assess Whether an Individual May Be Developing Dementia**. Reviews information providers should consider when assessing individuals with living with IDD for possible dementia.

- **Section 5: Communicating with People Living with Intellectual and Developmental Disabilities and Dementia**. Provides suggestions for professionals and family caregivers that can be helpful when trying to communicate with individuals living with IDD and dementia, including nonverbal and verbal approaches and memory aid suggestions.

- **Section 6: Working with Family Caregivers**. Provides communication strategies to consider when working with family caregivers.

- **Section 7: Managing Stages of Dementia in People Living with Intellectual and Developmental Disabilities**. Summarizes the characteristics associated with the three stages of gradual decline among individuals living with IDD and dementia.

- **Section 8: Responding to Behavioral Symptoms**. Suggests tips for responding to and reducing behavioral symptoms among individuals living with IDD and dementia. This section includes examples that provide context for responding to a variety of behavioral symptoms.

- **Section 9: Environmental Modifications**. Provides a list of modifications group home staff or family members can consider to ensure that individuals remain comfortable and safe in their residences.

- **Section 10: Identifying People Living with Intellectual and Developmental Disabilities and Dementia in Your Community**. Provides strategies when trying to identify and reach people living with IDD and dementia in the community.

- **Section 11: Coordination of Care and Services for People Living with Intellectual and Developmental Disabilities and Dementia**. Provides care coordination and care management strategies that focus on helping individuals and families build plans for increased care and support for caregivers.

- **Section 12: Advance Planning and Decision-Making**. Reviews issues to consider when developing person-centered advanced care plans for individuals living with IDD and dementia.

This guide was developed by the National Alzheimer's and Dementia Resource Center, which provides technical assistance to Administration for Community Living (ACL)/Administration on Aging grantees, including Alzheimer's Disease Initiative-Specialized Supportive Services grantees, Alzheimer's Disease Supportive Services Program grantees, and Alzheimer's Disease Programs Initiative grantees.

Section 1: Introduction

The needs of people living with IDD and dementia are sometimes similar to other people with dementia but often call for unique skills, assessments, and approaches. This guide reviews practical strategies professionals can use to provide dementia-capable and culturally competent services and supports when working with people living with IDD and their caregivers.

Most information on dementia and IDD is based on studies of people with Down syndrome, a group with some of the highest rates of Alzheimer's disease and other dementia concerns. That said, most of the recommendations contained within this document are applicable to all persons living with IDD and Alzheimer's or other dementias. Notations are made throughout where items are specific to people with Down syndrome.

The population of individuals living with IDD and dementia includes individuals with a variety of disabilities and service and support needs. The following terms are used for the purpose of this guide.

Types of Disabilities

In the United States, *developmental disability (DD)* is defined by the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. §§ 15002)[1] 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.

- *Intellectual and developmental disability (IDD)* is a subset of DD and is defined as:

- a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.

Down syndrome is a chromosomal condition that occurs when an individual has a full or partial extra copy of chromosome 21. This additional genetic material alters the course of

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[1] https://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf

development and causes the characteristics associated with Down syndrome, including low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. All individuals with Down syndrome experience cognitive delays, but the IDD is usually mild to moderate. Each person with Down syndrome is a unique individual and may possess these characteristics to different degrees, or not at all (National Down Syndrome Society, 2019a). Chromosome 21 plays a key role in the relationship between Down syndrome and Alzheimer's disease. People with Down syndrome are born with an extra copy of chromosome 21, which carries the APP gene. This gene produces a specific protein called amyloid precursor protein (APP), a protein which has been shown to be involved with changes in the brain caused by Alzheimer's disease (Moran, 2013).

Intellectual Functioning and Adaptive Behavior

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. 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 and performed by people in their everyday lives. Standardized tests can also 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.

Home and Community-Based Services

Existing IDD services may differ from the services that older adults typically access. However, similar to aging programs, many of the services available to individuals living with IDD focus on maintaining or improving function and supporting independent living in the community. The following services are used by individuals living with IDD. More information on where individuals can access these services is provided in Section 11: Care Coordination of Services for People Living with Intellectual and Developmental Disabilities and Dementia.

Area Agencies on Aging (AAAs) are public or private nonprofit agencies designated by a state to address the needs and concerns of all older persons at regional and local levels. AAAs are primarily responsible for a geographic area, also known as a planning and service area, that is either a city, a single county, or a multicounty district. AAAs may be categorized as a county, city, regional planning council or council of governments, private, or nonprofit. AAAs coordinate and offer services that help older adults remain in their homes, if that is their preference, aided by services such as home-delivered meals, homemaker assistance, personal care, and other services that may make it possible for a person to remain in the community (ACL, 2017a).

Aging and Disability Resource Centers (ADRCs) provide information and assistance to individuals needing either public or private resources, professionals seeking assistance on behalf of their clients, and individuals planning for their future long-term care needs. ADRC programs also serve as the entry point to publicly administered long-term services and supports including those funded under Medicaid, the Older Americans Act, and state-funded programs (ACL, 2019a).

Centers for Independent Living (CILs) are consumer-controlled, community-based, cross-disability, private nonprofit agencies that provide an array of independent living services such as information and referral, independent living skills training, and peer counseling; and services that facilitate transition from nursing homes and other institutions to the community, provide assistance to those at risk of entering institutions, and facilitate transition of youth to postsecondary life (ACL, 2019b).

Residential care facilities provide assistance in acquiring, retaining, and improving self-help, socialization, or adaptive skills by a provider with round-the-clock responsibility for the residents' health and welfare in a residence that is not a single-family home or apartment (Larson et al., 2014).

Adult day services include regularly scheduled activities in nonresidential settings. Activities include assistance with or improvement in self-help, socialization, and adaptive skills that enhance social development and develop skills in performing activities of daily living and community living. Adult day services for individuals living with IDD may focus particularly on employment-related or educational instructions. Adult day services also include meals and day habilitation services that focus on enabling the participant to attain or maintain his or her maximum potential and are coordinated with any needed therapies in the individual's person-centered services and supports plan, such as physical, occupational, or speech therapy (CMS, 2011; National Adult Day Services Association, 2015).

Respite care service includes planned or emergency care provided to a child or adult with a special need to provide temporary relief to the family caregiver of that child or adult. Respite

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services may be provided in a variety of settings, including the home, adult day care centers, or residential care facilities (ACL, 2018).

   Participant- or self-directed services include services that are planned, budgeted, and purchased under the control of the individual. Under this approach, the individual is provided with the information and assistance needed to enable him or her to make informed decisions about care options (ACL, 2019c).

Section 2: Prevalence

Based on an analysis using nationally representative data from the National Health and Aging Trends Study and the National Study on Caregiving, there were approximately 4.0 million adults aged 65 and older in the United States living with dementia in 2015 (Figure 1). Dementia predominantly occurs among older adults with increasing age, although some individuals experience early onset of symptoms at a younger age (Chi et al., 2019). Alzheimer's disease is the most common cause of dementia and accounts for an estimated 60%-80% of dementia cases (Chi et al., 2019).

Figure 1. U.S. Population Age 65 and Older in 2015
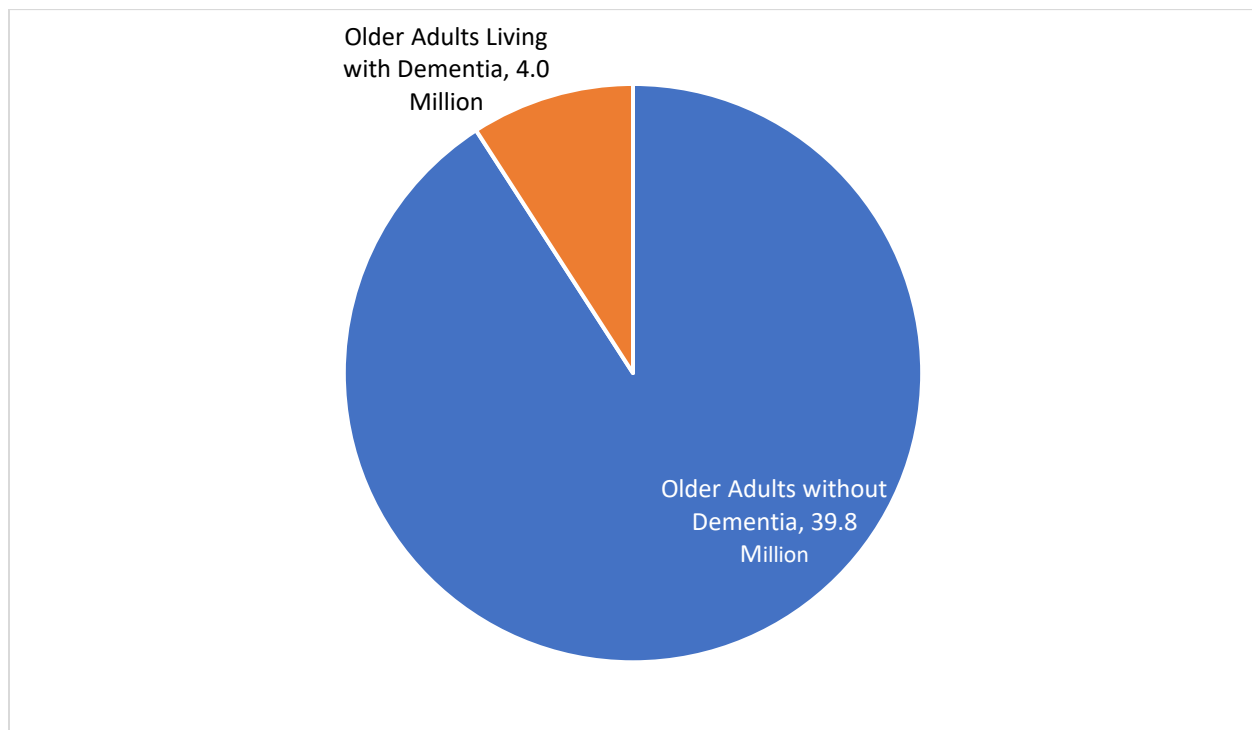
Source: Chi et al. (2019).

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 in later life (Heller et al., 2010; May & Kennedy, 2010; McCallion et al., 2013). However, the prevalence of dementia in people with Down syndrome at middle and early elderly ages is higher than in the general population (Ball et al., 2008; McCarron et al., 2014).

Figure 2. Aging, Intellectual and Developmental Disabilities, and Those with Down Syndrome Over Age 60
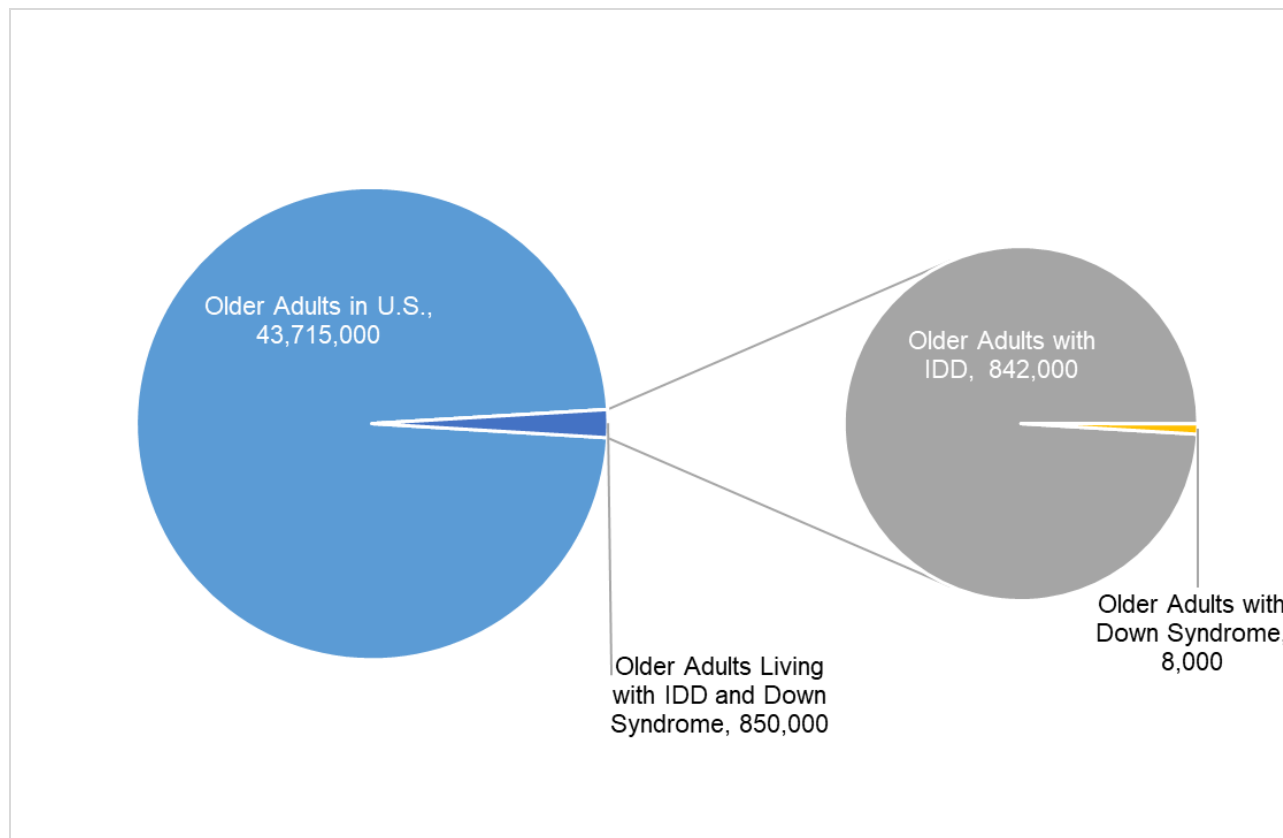
Source: Analyses of prior estimates (Ball et al., 2008; Coppus et al., 2010; de Graaf et al., 2017; McCarron et al., 2017; Presson et al., 2013; Strydom et al., 2010).

Down Syndrome Prevalence

Approximately 300,000 to 400,000 people in the United States are living with Down syndrome (National Down Syndrome Society, 2019b; Presson et al., 2013). As indicated in Figure 2, it is estimated that 2% of people with Down syndrome are aged 60 and older (de Graaf et al., 2017), and life expectancy has been increasing in recent years (National Down Syndrome Society, 2019b).

People with Down syndrome develop Alzheimer's disease and other dementias at higher rates and at a much younger age than the general population. The average age of onset is 55 but may occur as early as 40. For this population, the duration of dementia is usually 5 to 7 years with decline more abrupt in the early years, but duration in the later stages can be extended (McCarron et al., 2017; Strydom et al., 2010).

Prevalence rates of Alzheimer's disease among people with Down syndrome are reported to increase with age. Estimates based on a number of studies range from 10% to 25% in the 40 to 49

age group, 20% to 50% in the 50 to 59 age group, and 30% to 75% among those aged 60 and over (Ball et al., 2008). Perhaps the most dramatic data are found in a longitudinal study of 80 women with Down syndrome aged 40 and older at the start of the study. After 14 years of regular assessments, 89.6% had been clinically diagnosed with dementia, the average age of diagnosis was 55.41 years (SD = 7.14), and there was a median survival of 7 years after diagnosis (McCarron et al., 2014). One study also found that women with Down syndrome have an increased risk of dementia if they start menopause at an early age (Coppus et al., 2010).

Although individuals with Down syndrome are a relatively small subset of the populations both with dementia and with IDD, they have many needs and require specialized targeting and service delivery. Being successful at providing services to this population requires outreach to persons with Down syndrome and dementia and their families and service providers; a commitment to include training of the specific dementia issues of people with Down syndrome and dementia; and capacity in dementia care services to serve people with Down syndrome and dementia who may be under age 60 years, including skills and training in testing and diagnosis assessments designed for people with Down syndrome and dementia.

The prevalence for the age of onset for people living with IDD other than Down syndrome is similar to that for the general population—approximately 10% over age 65 (Alzheimer's Association, 2019). However, some researchers have reported dementia prevalence in this population to be two to five times higher than in the general population (Cooper, 1997; Strydom et al., 2013; Zigman, 2013).

Resources

- [Intellectual and Developmental Disabilities and Dementia - Experiences of a Family Advocate and Promising Practices](#). National Alzheimer's and Dementia Resource Center. Webinar includes background information about the prevalence of IDD and dementia in the United States, barriers to good dementia care for people living with IDD, and programming models for this population.

- [What is Alzheimer's Disease?](#) Alzheimer's Association. This video provides a general overview of Alzheimer's disease, including information about prevalence.

- [Dementia and Intellectual and Developmental Disabilities](#). Alzheimer's Disease International. Provides a general overview of Alzheimer's disease and other dementias for people living with IDD. This issue brief includes information about the prevalence of individuals with Down syndrome who have dementia.

Section 3: Presentation: Signs and Symptoms

Adults with Down syndrome experience "accelerated aging," during which certain conditions and physical features that are common for aging adults occur at an earlier age than the general population (Moran, 2013). 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 (Devenny et al., 2000). It is often difficult to distinguish dementia from new-onset behavioral disorders or psychiatric illnesses, which are common in older adults with Down syndrome (McCarron et al., 2014; O'Caoimh et al., 2013). A number of early symptoms of dementia in people with Down syndrome have been identified, including memory loss, disorientation, and changes in personality, behavior, and speech (Ball et al., 2008; Strydom et al., 2010). The list of symptoms is included below.

Dementia Symptoms in Persons with Down Syndrome

- Increased inability to stay focused
- Exaggeration of longstanding behavioral traits (most often stubbornness)
- Change in prior daily routine, sleeping, or eating habits
- Inability to make clothing decisions
- Getting lost in familiar environments
- Not remembering names of people previously known
- Increased aggression, unjustified fears, sleep problems
- Increased difficulty with visual/motor coordination
- Increased accidents and falls
- Difficulty learning new tasks
- Loss of language and other communication and social skills
- Progressive loss of prior activities of daily living
- Late onset seizures
- Frequent choking incidents
- Changes in hearing and vision

Source: Alvarez & Chawla, 2016; McCallion & Janicki, 2002.

Please note that for persons with IDD other than Down syndrome, the symptoms of dementia are the same as those listed in the table above, except that late onset seizures are much less likely.

Resources

- [Intellectual and Developmental Disabilities and Dementia](#), National Alzheimer's and Dementia Resource Center. This webinar addresses similarities and differences in warning signs and symptoms for the general population and individuals living with IDD with emphasis on Down syndrome, the philosophy of care, quality of life, models of care, family

caregiver support, care transitions, and common IDD vocabulary.

- [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 guide book has been designed for individuals with intellectual/developmental disabilities (I/DD) and dementia, their family members, and caregivers to help increase the quality of care and life for the individual with I/DD and dementia.

- [Talking About Dementia](#), Seven Hills Rhode Island. A guide for caregivers, families, and adults living with dementia and IDD.

- [A Caregivers Guide to Alzheimer's Disease](#), National Down Syndrome Society. A caregiver offers a personal and practical perspective on what it means to have a family member with Down syndrome and Alzheimer's disease.

Section 4: Information Needed to Assess Whether an Individual May Be Developing Dementia

As with the general population, early detection and diagnosis of dementia is challenging in persons with IDD. Standardized tools used with the general population are not recommended for use with persons with IDD. There is no single assessment used by providers to determine if an individual is developing dementia, but some useful tools are available (Burt & Aylward, 2000; National Collaborating Centre for Mental Health, 2007). Diagnosis 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 considered within the context for each individual including prior history and other potential causes of the symptoms observed. Recognition of a progressive change from baseline abilities for which there appears to be no other explanation is the cornerstone of a dementia diagnosis.

An individual's history is the basis of any dementia diagnosis. Providers should always look for evidence from previous assessments that might indicate the person's baseline level of functioning. The same test can then be repeated for comparison. Tests administered over time with the person living with IDD offer the opportunity to document changes in the person's performance. Reviews of test results over time may identify change, when an individual's adaptive functioning has been routinely tested for other purposes such as for work or day program or in annual physical examinations. Assessments answered by a caregiver or family member may also identify observed changes over time. Finally, the NTG-Early Detection Screen for Dementia (NTG-EDSD) is a useful tool to identify changes over time and may indicate a need for further evaluation. Links and information on other tools are available in the NADRC Evaluating Dementia Services and Supports: Instrument Resource List. These tools gather information useful for deciding whether a formal diagnostic process is needed and can inform that process.

Appendix A includes a checklist that providers can use when collecting information from the family and conducting assessments of individuals living with IDD at risk for dementia. Appendix B includes a checklist on postdiagnosis management.

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For Caregivers Communicating with the Physician and the Interdisciplinary Team

Caregivers of people living with IDD and dementia are key to providing the information physicians and other professionals need to assess the individual with IDD for dementia.

Caregivers can use a behavior log to document any changes in an individual's behavior and function. Appendix C includes a behavior log template that caregivers can consider using. Information included in a log could include:

- Concrete 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 doing things the person previously could do, including self-care activities such as dressing and managing personal care, participation in leisure activities, following routines, sleeping at night, and eating meals. Note any new toileting accidents or difficulties.

- 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, staff and peer changes where they live or work, difficulties experienced in friendships and other relationships, and favorite places and activities that they can no longer attend, regardless of reason.

- Description of any falls, disorientation, or possible seizure activity.

- Examples of things not remembered and contrast with other examples where this was previously remembered.

- Data from annual assessments where declines from previous assessments have been noted.

Resources

Table 1 provides a list of instruments often used to assess dementia in people living with IDD. The instruments noted are designed primarily for professionals to administer in clinical settings.

Table 1. Informant-report and objective measures for clinical assessment of dementia in people with intellectual and developmental disabilities

Measure	Instrument description	Strengths/weaknesses
Adaptive Behaviour Dementia Questionnaire, Prasher et al. (2004)	Fifteen-item questionnaire used to detect change in adaptive behavior by comparing current functioning to typical functioning.	• Strengths: Detects change in everyday functioning, easy to administer and score, family member as informant, specifies how long the informant must know the adult. • Weaknesses: No differential diagnosis, not useful to track intervention response.
Assessment for Adults with Developmental Disabilities, Kalsy et al. (2000); Oliver et al. (2011)	Measure of function with focus on behavior and performance related to cognitive and physical decline; 28 items with respect to "how often," "management difficulty," and "effect."	• Strengths: Assesses current everyday functioning/behavior and behavior changes. Easy to administer, standardized administration, descriptive, indicates who needs further evaluation/care, draws on information from several informants. • Weaknesses: No differential diagnosis. Questions are complex.
Dementia Questionnaire for People with Learning Disabilities*, Eurlings et al. (2006); Evenhuis (1992, 1996); Evenhuis et al. (2007) *Originally named the Dementia Questionnaire for Mentally Retarded Persons	Made up of eight sub-scales: short-term memory, long-term memory, orientation (contributing to Sum of Cognitive Scores), speech, practical skills, mood, activity and interest, and behavioral disturbance (contributing to Sum of Social Scores).	• Strengths: Designed for all levels of functioning as early screening instrument. Easy to administer as informant completion item or interview. Indication of dementia signs at one assessment and over repeated assessments. • Weaknesses: Level of functioning (e.g., IQ) required for norms. No differential diagnosis. Some concern among clinicians regarding its appropriateness for individuals in the severe and profound ranges of intellectual functioning.

(continued)

Table 1. Informant-report and objective measures for clinical assessment of dementia in people with intellectual and developmental disabilities (continued)

Measure	Instrument description	Strengths/weaknesses
Dementia Scale for Down Syndrome, Gedye (1995)	Measure of early, middle, and late stages of dementia and includes the time course of the deterioration and a differential diagnosis scale.	• Strengths: Differentiates typical from atypical functioning and determines how long signs have been present. Standardized administration. • Weaknesses: Normed only on adults with lower levels of functioning, which could affect sensitivity of scale in higher functioning adults. Two informants required; designed to be administered by psychologist.
Dementia Screening Questionnaire for Individuals with Intellectual and developmental disabilities, Deb et al. (2007)	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.	Strengths: Current everyday functioning assessed, easy to administer/score, wide range of respondents considered appropriate, length of time informant needs to know, adult specified. Weaknesses: For differential diagnosis just lists possible other conditions and medications.
Prudhoe Cognitive Function Test (shorter versions), Kay et al. (2003)	A 21-item cognitive test that takes 15 minutes to complete. It tests orientation, language, memory, and spatial and conceptual skills.	Strengths: Excellent correlation with an established test of cognitive function, the Kaufman Brief Intelligence Test. Those with moderate and severe handicaps can complete this test. There are two versions. Weaknesses: People with profound IDD are unable to complete items on this test.
Test for Severe Impairment (Modified), Albert & Cohen (1992)	A 24-item cognitive test that takes 10 minutes to administer, it 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. Many report enjoying completing the scale. Weaknesses: The small number of items within each subscale may not always be sufficient to detect subtle changes over time.

Source: Informed by the National Task Group on Intellectual Disabilities and Dementia Practices, 2013.

Additional Resources

- [Early Detection Screen for Dementia (EDSD)](#) ⧉, National Task Group on Intellectual and Developmental Disabilities and Dementia Practices. This screening tool is adapted from the Dementia Screening Questionnaire for Individuals with Intellectual and Developmental Disabilities. The purpose of the EDSD is to offer family and professional caregivers a resource to record their observations regarding changes in areas of cognitive and adaptive functioning known to be associated with dementia. The screen captures information to facilitate dialog and aid in shared decision-making. The webpage contains links to the early detection screening tools in various languages and a manual on how to administer.

- [Assessment and Diagnosis of Dementia in Individuals with Intellectual Disability: A Toolkit for Clinicians and Caseworkers](#) ⧉, 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 intellectual disabilities (ID). It compares the incidence, prevalence, and clinical features of dementia of the Alzheimer type in adults with ID (with an emphasis on Down syndrome) with that of the general population and then outlines the modifications to diagnostic approaches that are needed to improve diagnostic accuracy for adults with ID potentially affected by dementia. Many neuropsychological assessment measures that have been developed or adapted for use with adults with ID are reviewed.

- [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 explanation for the connection between Down syndrome and Alzheimer's disease, importance of establishing a baseline, obtaining an accurate diagnosis, common physical complications, tips for caregivers, meaningful activities, and advance planning.

Section 5: Communicating with Individuals Living with Intellectual and Developmental Disabilities and Dementia

Good intentions and efforts to maintain communication on the part of caregivers are often frustrated by poor understanding of the progression of dementia and by a lack of tools to respond more effectively. As a person living with IDD develops dementia, some communication strengths remain and reinforcing the great value in continued efforts to support those strengths is necessary (McCallion, 1999; McCallion & Janicki, 2002). There are verbal and nonverbal techniques and memory aids that providers should incorporate in day-to-day communications.

Nonverbal Techniques

1. Relaxing—before interacting with the person living with IDD and dementia, caregivers and family members should release their own emotions by using deep breathing relaxation techniques. This helps the caregiver, without becoming anxious, frustrated, or annoyed, to listen to and interact with the person even when they seem to make no sense or behave in an irrational fashion.

2. Maintaining eye contact.

3. Using a clear, low, loving tone of voice.

4. Touching—people living with IDD and dementia may have diminished visual and auditory acuity, so they often appreciate feeling the touch of another. Caregivers may know how the person felt about touch in the past and should carefully evaluate the individual's current comfort level with some simple touch for a short period.

Verbal Techniques

Certain verbal techniques also help to foster communication with people living with IDD and dementia:

1. Being supportive and nonconfrontational—Use nonthreatening words to build trust and avoid being critical of the person living with IDD and dementia.

2. Asking simple, concrete questions—Break down what is said into simple, concrete questions to promote communication.

3. Increasing time for responses—Talk slowly, pause frequently, and repeat key phrases when conversing with a person living with IDD and dementia because the person's reaction times are often greatly slowed.

4. Structuring, focusing, and simplification—Take more responsibility for structuring and focusing conversations to facilitate the individual's use of remaining cognitive and

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communication skills. Simplify instructions about tasks to remove demands that are now beyond the ability of the person living with IDD and dementia.

5. Encouraging and guiding—Use verbal (and nonverbal) cues to encourage and stimulate the person living with IDD and dementia to continue to communicate and to guide the person through communication sequences and activities they are having trouble completing; help the person to continue to do things for themselves.

6. Rephrasing and paraphrasing—Repeat the person's basic message using the same key words, tone of voice, and cadence of speech. This encourages continued communication by enabling the person living with IDD and dementia to hear what they said, by giving the person time to gather their thoughts in preparation for continuing the conversation, and to ensure that the message being conveyed is understood as intended.

7. Reminiscing—Encourage the person to explore and express pleasant memories from the past. Do not focus on the accuracy of these memories, but instead encourage them to express themselves.

8. Using ambiguity—Accept words that have no meaning to others and respond by using ambiguous or vague terms in responses to such words so that communication with the person living with IDD and dementia can be maintained.

9. Identifying the preferred sense—If the person living with IDD and dementia repeatedly communicates by using visual images such as "I see it over there. It makes me afraid," respond with simple questions such as "What else do you see, what color is it?" which encourages the person to use the preferred sense, sight.

10. Linking the behavior with the unmet human need— People living with IDD and dementia express basic needs through their behaviors; identify and respond to these needs.

Content adapted from: McCallion et al., 2008.

Memory Aids

Personal Memory Albums are small photo albums with easily turned pages. The albums contain photographs of a key memory on one page and a short statement about that memory on the page next to it. On *Personal Memory Charts* the same types of photographs and statements are placed on large, laminated pieces of cardboard posted on the person's bedroom walls at heights which take into account whether the person living with IDD and dementia is ambulatory or spends most of the day in a wheelchair (McCallion, 1999; McCallion et al., 1999).

Albums or charts are designed to promote positive interactions and to focus on maintaining previously learned information rather than imparting new information. The memory items address (1) facts that are important to the person living with IDD and dementia, (2) information on conversation topics the person likes or wants to talk about, and (3) facts that the person often gets confused.

To address facts that are important to the person living with IDD and dementia, information in a *Personal Memory Album or Chart* might include (1) the person: name, age, what they work(ed) at or things they like to do; (2) the person's family: names of family members and how they are related; (3) the person's daily life: days and times for important events; (4) people the person living with IDD and dementia now lives with: the names of roommates, other people in the home, or programs they attend.

Under conversation topics, caregivers are encouraged to identify three topics that are important to person living with IDD and dementia that he or she likes or wants to talk about. These topics may be from the person's present life or from her or his past. Topics that the person regularly attempts to discuss are often used.

The individual's forgetfulness of key facts can make communication difficult. To limit the impact of forgetfulness and confusion, key daily and weekly events such as meals, appointments, and family visits are often included in the Personal Memory Album or Chart.

Interview Approaches with People Living with IDD and Dementia

- Conduct interviews in a setting and manner that is comfortable for the individual.

- Question the individual, personally, to see whether he or she can respond.

- Begin by asking easy, nonthreatening questions with no "right" or "wrong" answer to build a positive relationship.

- Ask questions using vocabulary that the individual understands.

- Take time to listen to the individual; allow more time.

- If you do not understand a response, repeat the question (because paraphrasing might confuse the person) and ask the individual to state his or her response again.

- Encourage the individual to use any assistive technology he or she regularly uses to communicate. Respect the person's choice not to use the technology if that is his or her preference.

- Ask the individual for permission to have someone else interpret responses, if necessary.

- Ask the individual to expand on his or her responses if there is a possibility of a misunderstanding.

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- Do not accept responses blindly. Statements may need to be clarified to avoid misunderstandings.

- Recognize that some people can understand more language than they can express.

- Ask open-ended questions. If yes/no questions are used, then ask the question both ways to determine if the person is simply saying yes to everything.

Talking with Family Caregivers

- Suspend judgment.

- Listen to the story/history.

- Acknowledge the service system failures.

- Avoid jargon.

- Appreciate a lifetime of caregiving.

- Avoid person first "corrections."

- Be sensitive for vision and hearing impairment.

- Encourage but do not insist that person living with IDD and dementia be present but work toward inclusion.

Section 6: Working with Family Caregivers

To ensure that person-centered planning and services[2] are provided to this population, good communication must be a priority. Person-centered planning should involve the individual and his or her entire care team, including the health care proxy and family caregivers. To be effective, providers must understand strategies for communicating with people who have IDD and dementia. What, how, and when information should be delivered to family and other team members are important considerations.

In some cases, families of individuals living 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 believe the services are unnecessary intrusions by strangers into their lives.

- They worry that their son or daughter will be taken away from them.

- They do not believe that there are any services on which they can rely.

- They do not believe that anyone else can understand and provide care in the way they can.

- They have had past negative experiences with the disabilities service system.

- They have difficulties working with agencies they find complex and impersonal.

- They do not want to believe it is dementia.

A provider should consider the following strategies to approaching and trying to work with reluctant caregivers:

- Listen to what the caregiver says "works" in caring for their family member.

- Express appreciation for all the caregiver does and ask how you can help.

- Use person-first language yourself (person with a developmental disability, NOT developmentally disabled) but do not judge or correct a family member who uses outdated

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[2] Person-centered planning allows individuals to be engaged in the decision-making process about their options, preferences, values, and financial resources. Individuals in need of services or who are planning for the future have access to one-on-one counseling in a variety of settings, including within the home, community residence, acute care hospital, school settings, or several other settings based on the individual's needs (ACL, 2017b).

language—their family member was born in a different era.

- Begin with immediate concerns but recognize deeper concerns.

- Model good practice in care but do not insist that families do things your way.

- Express to supervisor any concerns related to the care you see provided by the family.

- Intervene if there is an immediate danger of injury to the person.

Resources

- [Talking About Dementia](#) , Seven Hills Rhode Island. A guide for caregivers, families, and adults with IDD and dementia.

- [Dementia Guidebook for Individuals with Developmental Disabilities and Their Caregivers](#) , Wisconsin Board for People with Developmental Disabilities. This guidebook has been designed for individuals living 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.

- [A Caregivers Guide to Alzheimer's Disease](#) , National Down Syndrome Society. A caregiver offers a personal and practical perspective on what it means to have a family member with Down syndrome and Alzheimer's disease.

Section 7: Managing Stages of Dementia in People Living with Intellectual and Developmental Disabilities

Alzheimer's disease and other dementias can be broadly characterized by a gradual decline that progresses through three stages: early, middle, and late. These stages are distinguished by their general features, which tend to progress gradually throughout the course of the disease, accompanied by incremental loss of abilities and skills and increased need for support, supervision, and assistance. Caregivers and providers of service to individuals living with IDD and dementia should have a general sense of where an individual may stand along the overall progression of dementia. This awareness can help with tailoring the care and services provided to the individual (National Down Syndrome Society, 2019c).

Table 2 provides recommendations for responding to dementia through the care environment, day programming, daily care, and communication. Additional resources are available following Table 2.

Table 2. Responding to Dementia in Persons with Intellectual Disabilities

Stage	Characteristics	Care Environment	Day Programming Recommendations	Day-to-Day Care Recommendations	Communication Recommendations
Early	• Preferably from an established and measured baseline and always in comparison to the person's prior functioning and behaviors; there are noticeable and increasing changes memory, ability to find their way, confusion with familiar tasks and situations, increased frustration and changes in personality. • Problems with walking and gait may become noticeable. • Particularly for persons with Down syndrome there may be late onset seizures.	• Lighting to avoid shadows and disperse direct sunlight with curtains or tinted glass. • Label cupboards and needed utensil and care products with visual cues. • Provide safe storage for kitchen tools, liquids, and powders (not food) using discreetly locked cabinets. • Install shutoff switches on appliances. • Ensure that valued activities may continue in kitchens and there is independence in bathrooms by making needed supplies visually available.	• Adjust daily routines. • Move from large to small group activities. • Focus on things known, activities previously valued, modify activities to reduce demands, and use familiar materials. • Improve signage to support wayfinding. • Support safety by providing safe places and safe activities.	• Adjust daily routines to be less demanding but support continued participation. • Offer help rather than "doing for." • 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.	• Simple direct language. • Let the person teach you their attention span. • Avoid talking for and filling in words. • Allow time for processing information. • Introduce topic, summarize, details. • Summarize and rephrase. • Reminisce. • Allow to express feelings. • Express support and caring. • Repeat important messages. • Give specific instructions and information before it is needed.

Table 2. Responding to Dementia in Persons with Intellectual Disabilities (continued)

Stage	Characteristics	Care Environment	Day Programming Recommendations	Day-to-Day Care Recommendations	Communication Recommendations
Middle	• Increased loss of abilities and often increases in challenging behaviors. • Memory loss becomes more pronounced as does disengagement with familiar and preferred activities. • Increased agitation, restlessness, repetitive talk/questioning, falls, pacing, wandering and shadowing of others. • Hallucinations/ delusions and sundowning for some. • Comorbid health conditions increase.	• 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. • Furniture with rounded versus sharp edges that is sturdy, simple, and versatile. • 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.	• Use multisensory approach—both stimulating and calming. • Support existing skills and memories rather than teach new things. • Tailor activities to likes/dislikes and previous experiences. • Activity ideas include reminiscence, trips in the community, walks, simple exercise, massage, Snoezelen, horticulture, pottery, art, music, aromatherapy. • Offered by trained staff trained. • Electronic alert systems so caregivers know when someone has left the program area or install door opening prevention devices (where not a needed exit).	• Reduce safety and wayfinding challenges. • Increase assistance with personal care, nutrition, safety, and supervision but seek opportunities to maintain even limited choice. • Routine monitoring AND treatment of comorbid health conditions. • Particular attention to additional assistance with toileting and other hygiene/ personal care activities so that dignity and personhood are supported. • Attention to facilitating continued valued relationships with family, friends, and staff.	• Speak only when visible. • Use the person's name and your name. • Avoid "Do you know who I am?" • Use overemphasis of gestures, facial expressions, and pointing to familiar objects. • Make sure you have been understood. • Wait for the person to respond. • If the person does not respond, repeat once. • Use a different, simpler way rather than repeating over and over. • Use people's names not "he" or "she." • Ensure predictable routine. • Familiar activities. • Use simple, easy-to-understand signs.

Table 2. Responding to Dementia in Persons with Intellectual Disabilities (continued)

Stage	Characteristics	Care Environment	Day Programming Recommendations	Day-to-Day Care Recommendations	Communication Recommendations
Middle (cont.)		• Replace standard showers or tubs with walk-in models. • Use electronic alert systems so caregivers know when someone has left the home or install door opening prevention devices (where not a needed exit for safety).			• Don't take it personally if the person responds negatively. • Listen and repeat. • Encourage and praise. • Use all available cues. • Avoid sudden changes in topic. • Avoid long and complex sentences.
Advanced	• Needs complete assistance with self-care. • Over time, the person becomes increasingly immobile. • Seizures, swallowing difficulties, and respiratory and breathing problems increase.	• Use equipment to preserve caregiver and the individual's safety and comfort when lifting or transferring. • As mobility becomes more impaired, modify environment and use adaptive equipment. • Adapt valued activities and experiences previously found stimulating.	• Often provided where the person lives to reduce need for transportation but should include outdoor activities if desired by the person. • Focused on making the person comfortable using activities like massage, Snoezelen, art, music, aromatherapy, and hand massage. • Offered by staff trained in dementia issues and comfort care.	• Care is best when it reflects what is known about the person's wishes for their final days and when comfort and continued quality of life are emphasized. Support of the people the person cares about will add to their sense of comfort. • Continued attention to assistance with toileting and other hygiene/personal care activities so dignity and personhood are supported.	• Speak only when visible. • Use his or her name. • Give your own name. • Voice low, affectionate, subdued. • Overemphasis, gestures, facial expressions. • Smile. • Speak slowly and clearly. • Assume person is hearing. • Do not speak as if person is not in room. • Keep talking even if no response.

Table 2. Responding to Dementia in Persons with Intellectual Disabilities (continued)

Stage	Characteristics	Care Environment	Day Programming Recommendations	Day-to-Day Care Recommendations	Communication Recommendations
Advanced (cont.)				• Routine monitoring AND treatment of comorbid health conditions. • Increased nursing care and prevention of secondary conditions and problems from malnutrition and dehydration or aspiration.	• Use touch. • Respond to seemingly meaningless speech. • Watch nonverbal communication. • Listen to music, read aloud. • Always say goodbye.

Adapted from Jokinen et al., 2013; McCallion & Janicki, 2002.

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 pre-diagnosis 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 are living with IDD; what is different; how to best support the person, their families, and caregivers; and best practices.

- [Serving People with Intellectual and Developmental Disabilities and Dementia: Online Training for Families and Persons Giving Care,]() Minnesota Department of Human Services. This online training is designed to help family caregivers learn more about dementia in people living with IDD.

Section 8: Responding to Behavioral Symptoms

Behavioral symptoms can be caused by the person's physical or emotional health, the environment, complexity of the task, or difficulty communicating. To respond effectively, it is important to understand the underlying cause of a behavior. The more you know about the person and their routine, the better you will be able to respond to behavioral symptoms.

Tips for reducing behavioral symptoms for the general population include the following and are also relevant for people living with IDD and dementia:

- Anticipate what the person will need based on what you know about their daily routine, family members, likes and dislikes, and any significant or traumatic life events.

- 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.

- Maintain a regular routine as much as possible. Try to maintain the person's regular sleep/wake schedule, mealtimes, and daily personal care activities.

- Be aware to recognize any discomfort or if they look uneasy. Consider if the person is hungry or cold, needs to use the bathroom, or has another physical need. Pay special attention for demonstration of physical or psychological pain.

- Look for and try to resolve cues of boredom, fear, uncertainty, or fatigue (i.e., irritability, fidgeting, or pacing) by:

  – Taking a walk with them and getting some fresh air.

  – Distracting them with calming activities such as listening to music, knitting, sorting, or coloring.

  – Letting the person know that they are needed. Say, "Can you help me with…?"

  – Reassuring the person that they are not alone, by sitting quietly together.

  More generally there is a need to realize that:

- The aim of care and of any responses to presenting behaviors is to instill feelings of trust, confidence, and respect.

- Select activities that are meaningful and reinforce a person's sense of identity and purpose.

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- Happiness and optimization of life enjoyment for the person are the most important outcomes of care.

- Behaviors that seem challenging are often an attempt to communicate needs not being met, memories no longer being fully understood, and people and activities missed.

  – Ask yes/no questions to narrow down what is agitating the person.

  – Interpret the person's gestures and other nonverbal signs.

  – Try to look at the situation through the eyes of the person living with IDD and dementia.

  – Recall what caused similar incidents in the past.

  – Stay calm, and this will calm the person.

  – Speak in soothing tones.

  – Keep body language nonthreatening and relaxed.

  – Distract the person with a favorite activity.

  – Get help if there is a danger of injury to you or the person with dementia.

Sometimes more investigation is needed before a behavior is understood and the right approach selected.

- Understand the antecedents.

  – What was happening before the behavior?

  – Who was present?

  – What was happening?

  – Where did it happen?

- Understand 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?

- Understand the consequences.

  – What was the effect of the behavior on the person or on others?

– What interventions were tried?

– What worked and what failed?

– Did the person calm down in their own time?

The more we understand, the more opportunities there are to intervene. However, looking at the antecedents, what happened before the behavior of concern, is the most effective strategy. We are more likely to avoid concerning behaviors and the person being upset if we take proactive steps to avoid conflict and misunderstandings.

Responding to behavioral symptoms can 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 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 was still a little difficult to get John out of bed, he did not get upset and did not refuse.

> *Key Takeaway:* Adrienne reduced conflict in the situation for John by learning from his mother and relying on learned routines and good communication to increase his level of comfort with the activity. [Section 5: Communicating with Individuals with Intellectual and Developmental Disabilities and Dementia and Section 6: Working with Family Caregivers](#) provide additional information related to this scenario.

Example 2

Jeff is the respite worker for Joe, a 62-year-old man with an 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 different 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. Section 5: Communicating with Individuals with Intellectual and Developmental Disabilities and Dementia and Section 8: Responding to Behavioral Symptoms provide additional information related to this scenario.

Example 3

Mary is the respite worker 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. Section 5: Communicating with Individuals with Intellectual and Developmental Disabilities and Dementia and Section 7: Managing Stages of Dementia in People Living with Intellectual and Developmental Disabilities provide additional information related to this scenario.

Resource

- 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.

Section 9: Environmental and Care Approach Modifications

Several environmental modifications can be considered to help individuals living with IDD and dementia remain comfortable and safe in a residential setting, whether that setting is a group home or personal home (McCallion & Janicki, 2002; McCallion & McCarron, 2005).

The following modifications can be considered by group home staff or family members:

- Bathing: Staff or family should try to prepare the space

  – Lighting—Glare makes things look slippery/wet

  – Noise—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

  – Temperature—Ask the person to check the temperature before they get in

  – Safety—Nonslip mats, shower chairs, grab bars

  – Access to your supplies—Supplies should be close and ready to use so you are not leaving the person alone and unsure what is happening

  – Handheld shower head—Allows you to start anywhere, but do not start with the head and face

- Dressing and Personal Care

  – Clothes should be easy to put on and take off

  – Avoid things that the individual can put on "wrong"

  – Remove any clothing you do not want the individual to wear

  – Put away out-of-season clothing

  – Make sure there is space to sit

  – Provide privacy

- Mealtime

  – Small tables for dining (three to four people)

  – Mealtimes can be very noisy

    ▪ Try to minimize extraneous noise

    ▪ Set up quieter space to eat

- Create contrast, such as a dark placemat under a light-colored plate
- Avoid busy patterns on table coverings and dishes
- Use adaptive silverware, plates, and cup

- Approaches to minimize combativeness/agitation

  - Assess where and when any combativeness/agitation is happening
    - What is going on in that environment?
    - Can simple changes be made?
  - Quiet and 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)
  - Reduce danger to self and others—Lightweight items such as lamps should be secured or minimized

- Hallucinations and Delusions

  - Ask your client to show you where the sound or sight is located
    - Is there something in that area that is being misperceived?
  - Consider lighting, shadows, and reflective surfaces
    - Keep rooms well lit
    - Avoid shadows
    - Consider mirrors—They might be a source of agitation or confusion if images in mirror are not recognized
  - Avoid busy patterns on tabletops, curtains, and floors

- Repeated Questions

  - Keep commonly misplaced/requested items in the same place
  - Write things down for the person with 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

- 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/screen that minimizes the prompts that encourage leaving (e.g., other people putting their coats on in front of the person)

- Color

  - Reds and yellows are more accurately perceived than blues and greens

  - Choose solid colors or simple patterns

  - 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

- Flooring

  - Avoid patterned flooring

  - Avoid high-gloss finishes on floors

  - 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"

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 Checklist](#), 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.

- [Dementia and People with Intellectual Disabilities](#), National Down Syndrome Society. This video, primarily funded by the New York State Developmental Disabilities Planning Council, describes signs of dementia and offers advice to caretakers and institutions about

how best to support individuals living with intellectual disabilities through the stages of dementia. Includes a discussion of environmental issues.

Section 10: Identifying Persons Living with Intellectual and Developmental Disabilities and Dementia in Your Community

Identifying individuals living with IDD who are at risk for dementia can be challenging. As noted in Section 2 because of the low population prevalence rates, communities may not have very many people living with IDD who are at risk for dementia. Caregivers of people living with IDD may also be reluctant to ask for help because they may be concerned with being perceived as no longer able to provide care. The changes and symptoms associated with dementia are also new for caregivers and they may not know to whom or where to turn for help. Caregivers of individuals living with IDD are generally not familiar with the providers and services associated with dementia care. Of additional concern are those individuals living with IDD and caregivers who have previously managed living independently who may be unknown to dementia-capable service systems. Finally, symptoms suggestive of dementia may be attributed to the underlying IDD.

The following resources and strategies should be considered when trying to identify, reach, and serve people living with IDD and dementia in the community and their caregivers:

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

- Congregate meal providers, pharmacists, and barbershop/beauty salon operators are known to be key community contacts for directly distributing information to both people living with IDD and caregivers.

- Intellectual and developmental disability advocacy organizations (e.g., Chapters of ARC), intellectual and developmental disability service providers, and Alzheimer's organizations often have contact with some people living with IDD and who are suspected to have dementia and their caregivers.

- Developmental disabilities, aging, and dementia service providers should know of physicians and other providers who can help with diagnosis and care planning for people living with IDD. Those providers must be prepared to offer supportive counseling and referral to dementia-capable community services at the time of the visit.

- If people are provided with a telephone number or e-mail address to contact for services, ensure that the person to whom they are referred has specific knowledge of issues related to people living with IDD and dementia.

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

- Encourage individuals living with IDD and dementia and their caregivers to whom you are currently providing services to build awareness of intellectual and developmental disability and dementia concerns and services among their acquaintances and communities (Janicki et al., 1998).

Resource

- [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.

Section 11: Coordination of Care and Services for People Living with Intellectual and Developmental Disabilities and Dementia

Care for people living 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 that older adults tend to access. When individuals living with IDD develop dementia, they remain eligible for intellectual and developmental services and may also be eligible for some aging services. Caregivers and primary providers must learn what is available to the individual and be sufficiently informed to navigate successfully between the disability and aging systems.

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, and intermediate care facilities for individuals living with IDD. Institutional services serve a very small proportion of the population. Medicaid is 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.

Low-income older adults also access HCBS through Medicaid, but also can 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 AAAs to serve different regions of the state. AAAs coordinate and offer services that help older adults remain in their homes.

AAAs and 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, and other state programs. The Eldercare Locator at https://eldercare.acl.gov/Public/index.aspx can help individuals identify local AAAs and ADRCs. Additional information about accessing community-based services includes the following:

- A directory of Centers for Independent Living can be found at https://www.ilru.org/projects/cil-net/cil-center-and-association-directory 🔗

- The National Association of State Directors of Developmental Disabilities Services provides contact information for state IDD agencies at https://www.nasddds.org/state-agencies/ 🔗

Care Management Strategies

Care management should focus on helping individuals and families develop plans for increased care in support of caregivers (National Task Group on Intellectual Disabilities and Dementia Practices, 2013). Care managers should identify caregiver support resources from local disability and aging services organizations and other service providers, assess any challenges the family is facing (including the caregiver's own 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:

- Assisting with gathering information about the individual's past history, including services and supports used.

- Documenting needs and preferences and completing assessments of stress and coping for both the person living with IDD and their caregiver in support of the development of person-centered plans and identification of educational needs.

- Connecting the person living with IDD and their caregiver to any needed assessment services.

- Beginning the conversation about future desires in terms of care and decision-making.

- Facilitating communication and care planning with other family members and friends as needed.

- Supporting self-advocacy and additional advocacy supports.

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

Resources

- [Practice Guidelines for the Clinical Assessment and Care Management of Alzheimer's Disease and Other Dementias Among Adults with Intellectual Disability](#), AAMR-IASSID Workgroup. The guidelines provide guidance to professionals for stage-related care management of Alzheimer's disease and suggestions for training and education of caregivers, peers, clinicians, and program staff.

- [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 pre-diagnosis 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 are living with IDD; what is different; how to best support the person, their families, and caregivers; and best practices.

- [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 intellectual and developmental disabilities and their caregivers.

- Eldercare Locator connects people and caregivers to local support resources, including dementia-specific services. Call 1-800-677-1116 or visit https://eldercare.acl.gov.

- A directory of Centers for Independent Living can be found at https://www.ilru.org/projects/cil-net/cil-center-and-association-directory

Section 12: Advance Planning and Family Decision-Making

Advance planning for individuals living with IDD and dementia is encouraged. The discussion can be guided by the state's legal or accepted practice frameworks to ensure that people living with IDD have opportunities to express their desires in a formal manner. Check with the state developmental disabilities services agency for educational materials and interventions to support both individuals living with IDD and their caregivers, family, peers, and staff.

Exploring, through person-centered planning, a person's values and preferences throughout life will offer the best guide to the person's wishes for care and supports in his or her final days. A 2016 summit of interdisciplinary experts in intellectual and developmental disability and dementia (McCallion et al., 2017; McCarron et al., 2018) recommended involving people living with IDD in decisions about their end-of-life care, drawing on statements of values in their person-centered plans, where available. Practitioners and family are encouraged to understand and honor the desires of individuals living with IDD and dementia. In jurisdictions where advance planning is encouraged there are likely to be legal or accepted practice frameworks and protocols in place to ensure that people living with IDD have opportunities to express their desires in a formal manner (see for example, Stein, 2007). There must also be educational materials and interventions to support both the individual with IDD and their caregivers, family, peers, and staff with person-centered planning and decision making (McCallion et al., 2017).

Resources

- [Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to End-of-life Care in Advanced Dementia](#), International Summit on Intellectual Disability and Dementia. Proposes use of palliative care services (including hospice) and recommends special efforts for enabling advanced directives and advance care planning prior to the extensive progression of dementia.

- [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 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 intellectual and developmental disabilities 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.

Conclusion

Aging and IDD service networks enable people of all ages who have chronic conditions and disabilities to remain in their homes and communities. As people living with IDD are living longer through medical advancement, aging and intellectual and developmental disability service systems need to increase capacity to provide this population with the services supports necessary to enable them to remain in the community.

The National Plan to Address Alzheimer's Disease (U.S. Department of Health and Human Services, 2018) called for a coordinated effort to develop the workforce in aging, public health, and IDD that are dementia-capable and culturally competent. This handbook on practical strategies in working with people living with IDD and their caregivers is intended to support such capability and competence.

The needs of people living with IDD and dementia, particularly those with Down syndrome, are sometimes similar to those of other persons with dementia but often call for unique skills, assessments, and approaches. The limited number of people living with IDD and dementia in individual states and regions calls for innovations in culturally competent dementia care and services, including their integration into existing memory clinics and other dementia-specific services. The guide's strategies and tools enable professionals to consider integrated approaches to service delivery for people living with IDD and dementia, while also providing information specific to their needs.

References

Administration for Community Living (ACL). (2019a). *Eldercare Locator: Aging and Disability Resource Centers.* Available at https://eldercare.acl.gov/Public/About/Aging_Network/ADRC.aspx.

Administration for Community Living (ACL). (2019b). *Centers for Independent Living.* Available at https://acl.gov/programs/aging-and-disability-networks/centers-independent-living.

Administration for Community Living (ACL). (2019c). *Alzheimer's Disease Programs Initiative – Grants to States and Communities.* Funding Opportunity, HHS-2019-ACL-AOA-ADPI-0325.

Administration for Community Living (ACL). (2018). *The Lifespan Respite Care Program.* Available at https://archrespite.org/images/lifespan101/Update_2018/Fact-Sheet_Lifespan_Respite_Care_2018.pdf .

Administration for Community Living (ACL). (2017a). *Area Agencies on Aging.* Available at https://acl.gov/programs/aging-and-disability-networks/area-agencies-aging.

Administration for Community Living (ACL). (2017b). *Person Centered Planning.* Available at https://acl.gov/programs/consumer-control/person-centered-planning.

Albert, M., & Cohen, C., (1992). The Test for Severe Impairment: An instrument for the assessment of patients with severe cognitive dysfunction. *Journal of the American Geriatric Society*, 40(5), 449-453.

Alvarez, N. & Chawla, J. (2016). *Alzheimer's Disease in Down Syndrome.* Available at https://emedicine.medscape.com/article/1136117-print

Alzheimer's Association. (2019). *2019 Alzheimer's Disease Facts and Figures.* Alzheimer's Association. Available at https://www.alz.org/media/Documents/alzheimers-facts-and-figures-2019-r.pdf .

Ball, S. L., Holland, A. J., Treppner, P., Watson, P. C., & Huppert, F. A. (2008). Executive dysfunction and its association with personality and behaviour changes in the development of Alzheimer's disease in adults with Down syndrome and mild to moderate learning disabilities. *British Journal of Clinical Psychology, 47*, 1–29.

Burt, D. B., & Aylward, E. H. (2000). Test battery for the diagnosis of dementia in individuals with intellectual disability. *Journal of Intellectual Disability Research, 44*(2), 175–180.

Centers for Medicare & Medicaid Services (CMS). (2011). *Updates to the §1915 (c) waiver instructions and technical guide regarding employment and employment related services.* Available at http://downloads.cms.gov/cmsgov/archived-downloads/CMCSBulletins/downloads/CIB-9-16-11.pdf.

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, Washington, DC. Available at https://aspe.hhs.gov/system/files/pdf/260371/DemChartbook.pdf

Cooper, S.A. (1997). High prevalence of dementia among people with learning disabilities not attributable to Down's syndrome. *Psychological Medicine, 27*(3), 609-616.

Coppus, A. M., Evenhuis, H. M., Verberne, G. J., Visser, F. E., Eikelenboom, P., van Gool, W. A., Janssens, A. C., & van Duijn, C. M. (2010). Early age at menopause is associated with increased risk of dementia and mortality in women with Down syndrome. *Journal of Alzheimer's Disease, 19*(2), 545–550.

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. *American Journal of Medical Genetics, 173*(10), 2710-2719.

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.

Devenny, D. A., Krinsky-McHale, S. J., Sersen, G., & Silverman, W. P. (2000). Sequence of cognitive decline in dementia in adults with Down's syndrome. *Journal of Intellectual Disability Research*, 44(6), 654-665.

Eurlings, H. A. L., Evenhuis, H. M., & Kengen, M. M. F. (2006). Dementia Questionnaire for People with Learning Disabilities. Available at http://www.pearsonclinical.co.uk/Psychology/AdultCognitionNeuropsychologyandLanguage/AdultGeneralAbilities/DementiaQuestionnaireforPeoplewithLearningDisabilities(DLD).aspx

Evenhuis, H. M. (1992). Evaluation of a screening instrument for dementia in ageing mentally retarded persons. *Journal of Intellectual Disability Research, 36*(4), 337–347.

Evenhuis, H. M. (1996). Further evaluation of the Dementia Questionnaire for Persons with Mental Retardation (DMR). *Journal of Intellectual Disability Research, 40*(4), 369–373.

Evenhuis, H. M., Kengen, M. M. F., & Eurlings, H. A. L. (2007). *Dementia questionnaire for people with learning disabilities (DLD)*. UK adaptation. San Antonio: Harcourt Assessment.

Gedye, A. (1995). *Dementia Scale for Down Syndrome – Manual*. Vancouver: Gedye Research & Consulting. Available at http://www.gedye.ca/

Heller, T., Stafford, P., Davis, L. A., Sedlezky, L., & Gaylord, V. (Eds.). (2010). People with intellectual and developmental disabilities growing old: An overview. *Impact: Feature Issue on Aging and People with Intellectual and Developmental Disabilities, 23*(1). Minneapolis: University of Minnesota, Institute on Community Integration.

Janicki, M., McCallion, P., Force, L., Bishop, K., & LePore, P. (1998). Area agency on aging outreach and assistance models for households with older carers of an adult with a disability. *Journal of Aging and Social Policy, 10*(1), 13-36.

Jokinen, N., Janicki, M. P., Keller, S., McCallion, P., Force, L. T. (2013). Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia. *Journal of Policy & Practice in Intellectual disabilities, 10*(1), 1-24.

Kalsy, S., McQuillan, S., Oliver, C., & Hall, S. (2000). *Manual for the 'Assessment for Adults with Developmental Disabilities' (A.A.D.S.) questionnaire*. Birmingham, UK: University of Birmingham.

Kay, D. W. K., Tyrer, S. P, Margallo-Lana, M.-L., Moore, P. B., Fletcher, R., Berney, T. P. & Vithayathil, E. (2003). Preliminary evaluation of a scale to assess cognitive function in adults with Down's syndrome: The Prudhoe Cognitive Function Test. *Journal of Intellectual Disability Research, 47*(3), 155-168.

Larson, S. A., Hallas-Muchow, L., Aiken, F., Hewitt, A., Pettingell, S., Anderson, L. L., Moseley, C., Sowers, M., Fay, M. L., Smith, D., & Kardell, Y. (2014). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2012*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Available at https://risp.umn.edu/RISP_FINAL_2012.pdf .

May, M. E., & Kennedy, C. H. (2010). Health and problem behavior among people with intellectual disabilities. *Behavior Analysis in Practice, 3*(2), 4–12.

McCallion, P. (1999). Maintaining communication. In M. P. Janicki, & A. J. Dalton, (Eds.), *Mental retardation, aging, and dementia: A handbook* (pp. 261-277). New York: Taylor & Francis.

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, 3*0(6), 1160-1164.

McCallion, P., & Janicki, M. P. (2002). *Intellectual disabilities and dementia*. Albany, NY: New York State Developmental Disabilities Council.

McCallion, P., & McCarron, M. (2005). Environmental modification and dementia: Key recommendations. *The Frontline of Learning Disability, 64*(Winter), 28-29.

McCallion, P., Zendell, A., Ferretti, L.A., & Aldrich, D. (2008). *Facing the challenges: Addressing needs for persons with intellectual disabilities.* Albany, NY: NYS OCFS. A CD-ROM.

McCallion, P., Swinburne, J., Burke, E., McGlinchey, E., & McCarron, M. (2013). Understanding the similarities and differences in aging with an intellectual disability: Linking Irish general population and intellectual disability datasets. *International Review of Research in Mental Retardation, 45*, 225–256.

McCallion, P., Toseland, R. W., Lacey, D., & Banks, S. (1999). Educating nursing assistants to communicate more effectively with nursing home residents with dementia. *The Gerontologist, 39*(5), 546-558.

McCallion, P., Zendell, A., Ferretti, L. A., & Aldrich, D. (2008). *Facing the challenges: Addressing needs for persons with intellectual disabilities*. Albany, NY: NYS OCFS. A CD-ROM.

McCarron, M., Carroll, R., & McCallion, P. (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. *Journal of Intellectual Disability Research, 61*(9), 843-852. DOI: 10.1111/jir.12390

McCarron, M., McCallion, P., Coppus, A., Fortea, J., Stemp, S., Janicki, M., & Watchman, K. (2018). Supporting advanced dementia in people with Down syndrome and other intellectual disability: Consensus statement of the International Summit on Intellectual Disability and Dementia. *Journal of Intellectual Disabilities Research, 62*(7), 617-624.

McCarron, M., McCallion, P., Reilly, E., & Mulryan, N. (2014). A prospective 14-year longitudinal follow-up of dementia in persons with Down syndrome. *Journal of Intellectual Disability Research, 58*(1), 61–70.

Moran, J. (2013). *Aging and Down Syndrome.* National Down Syndrome Society*: A health & well-being guidebook*. Available at http://www.ndss.org/PageFiles/2594/Aging%20and%20Down%20Syndrome%20A%20Health%20and%20Well-Being%20Guidebook.pdf .

National Adult Day Services Association. (2015). *About adult day services.* Available at http://nadsa.org/learn-more/about-adult-day-services/.

National Collaborating Centre for Mental Health (UK). (2007). *Dementia: A NICE-SCIE guideline on supporting people with dementia and their carers in health and social care*. Leicester (UK). Available at National Institute for Health and Clinical Excellence: Guidance.

National Down Syndrome Society. (2019a). *Down Syndrome*. Available at https://www.ndss.org/about-down-syndrome/down-syndrome/.

National Down Syndrome Society. (2019b). *Down Syndrome Facts*. Available at https://www.ndss.org/about-down-syndrome/down-syndrome-facts/.

National Down Syndrome Society. (2019c). *Alzheimer's disease & Down syndrome a practical guidebook for caregivers*. Washington, DC: NDSS. Available at http://aadmd.org/sites/default/files/NDSS_Guidebook_FINAL%20%281%29%20%5B11%27 2%2718%5D.pdf.

National Task Group on Intellectual Disabilities and Dementia Practices. (2013). *Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia*. Available at http://aadmd.org/sites/default/files/NTG-communitycareguidelines-Final.pdf.

O'Caoimh, R., Clune, Y., & Molloy, W. (2013). Screening for Alzheimer's disease in Down Syndrome. *Journal of Alzheimer's Disease and Parkinsonism, S7*(001).

Oliver, C., Kalsy, S., McQuillan, S., & Hall, S. (2011). Behavioural excesses and deficits associated with dementia in adults who have Down syndrome. *Journal of Applied Research in Intellectual Disabilities, 24*, 208-216.

Prasher, V.P., Holder, R. & Asim, F. (2004). The Adaptive Behaviour Dementia Questionnaire (ABDQ): Screening questionnaire for dementia in Alzheimer's disease in adults with Down's syndrome. *Research in Developmental Disabilities, 25*(4), 385–397.

Presson, A. P., Partyka, G., Jensen, K. M., Devine, O. J., Rasmussen, S. A., McCabe, L. L., & McCabe, E. R. (2013). Current estimate of Down Syndrome population prevalence in the United States. *The Journal of Pediatrics, 163*(4), 1163-1168.

Stein, G. L. (2007). *Advance directives and advance care planning for people with intellectual and physical disabilities*. Report for U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation. Available at https://aspe.hhs.gov/system/files/pdf/75361/adacp.pdf.

Strydom, A., Chan, T., King, M., Hassiotis, A., & Livingston, G. (2013). Incidence of dementia in older adults with intellectual disabilities. *Research in Developmental Disabilities*, *34*(6), 1881–1885.

Strydom, A., Shooshtari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., Jokinen, N., Courtenay, K., Bass, N., Sinnema, M., & Maaskant, M. (2010). Dementia in older adults with intellectual disabilities— Epidemiology, presentation, and diagnosis. *Journal of Policy and Practice in Intellectual Disabilities*, 7, 96–110.

U.S. Department of Health and Human Services. (2018). *National plan to address Alzheimer's disease: 2018 update*. Available at https://aspe.hhs.gov/system/files/pdf/259581/NatPlan2018.pdf.

Watchman, K., & Janicki, M. (2017). The intersection of intellectual disability and dementia: Report of The International Summit on Intellectual Disability and Dementia. *The Gerontologist*. https://doi.org/10.1093/geront/gnx160.

Zigman, W. B. (2013). Atypical aging in down syndrome. *Developmental Disability Research Reviews*, 18, 51–67.

Appendix A: Provider Checklist for Assessing Individuals Living 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 and individuals at increased risk for premature aging, such as Down syndrome and beginning at 50 years of age in individuals with other intellectual and developmental disabilities.

- Gather history from the individual 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 general mood?

- Ask about any major life events in the last 12 months such as:
    - Change in living or work environment
    - Change in health
    - Death or major illness of family or friends
    - Recent breakup with boyfriend/girlfriend
    - Changes in staff or peers where they live and work
    - Changes in patterns of visits by family members and friends

- – Changes in ability to go to favorite places or do favorite activities
- 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
- Conduct a thorough history and physical exam including:
  - – Mental status exam
  - – History of memory loss
  - – Changes in vision or hearing or dental concerns
  - – Change in appetite or weight loss/gain
  - – Swallowing difficulties
  - – Sleep difficulties
  - – Changes in gait or walking difficulties
  - – Reported or suspected pain
  - – Falls within the last 12 months
  - – Any seizure activity in the last 12 months
- Obtain medical records of any prior medical assessments
- Order lab tests:
  - – Complete blood count
  - – Electrolytes
  - – Vitamin deficiencies
  - – Thyroid dysfunction
  - – Celiac disease screen
- Order diagnostic tests:
  - – PET, MRI, or CT scan
- Make referrals:
  - – Vision or hearing testing
  - – Sleep study to assess for sleep apnea
  - – X-rays or other imaging to assess for arthritis or degenerative changes

— Psychiatric assessment

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

Sources: McCallion & Janicki, 2002; Janicki et al., 1996

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:

    – Benefits assessment and counseling

    – Referral to financial or legal services

    – Referrals to adult day centers, respite services, residential care, or other services

    – Ongoing education and support for person and caregivers

    – Care management

- 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: Watchman & Janicki, 2017.

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?
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