

# GUIDELINES FOR STRUCTURING COMMUNITY CARE AND SUPPORTS FOR PEOPLE WITH INTELLECTUAL DISABILITIES AFFECTED BY DEMENTIA



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The willingness of families and individuals with intellectual disability to permit their photographs to be used in this publication is greatly appreciated.

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*Note: These guidelines are a product of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG). In 2011, U.S. President Barack Obama signed the National Alzheimer's Project Act (NAPA) which directed the federal government to develop a coordinated national strategy on dealing with Alzheimer's disease in the United States.*

To complement this federal initiative and to address the myriad requests for more specific information and practice models for providing quality care for people with intellectual disabilities affected by dementia, the American Academy of Developmental Medicine and Dentistry, the Rehabilitation Research and Training Center on Aging with Developmental Disabilities-Lifespan Health and Function at the University of Illinois at Chicago, and the American Association on Intellectual and Developmental Disabilities combined their efforts and created the National Task Group on Intellectual Disabilities and Dementia Practices.

The aims of the NTG were to update and augment the technological and clinical practices used by agencies in delivering supports and services to adults with intellectual disabilities affected by dementia, develop a workable early detection and screening instrument that could help identify behavioral markers of dementia, and recommend models of community-based support and long term care of persons with intellectual disabilities affected by dementia.

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# ABSTRACT

To assist families and organizations in their planning for extended care that accompanies the diagnosis of dementia, the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in the United States adopted a set of practice guidelines covering the period from when suspicions are aroused to when care ends with eventual death. These guidelines are drawn from the research literature as well as clinical experiences and demonstrated best practices. The guidelines delineate what actions should be undertaken and are presented in a manner that reflects the progressive nature of prevalent dementias. To enable the development of the most appropriate and useful services and care management for adults with intellectual disabilities affected by dementia, the NTG adopted the staging model generally accepted for practice among generic dementia services. The staging model follows the flow from a pre-diagnosis stage when early recognition of symptoms associated with cognitive decline are recognized through to early, mid, and late stages of dementia, and characterizes the expected changes in behavior and function. In keeping with the National Plan to Address Alzheimer’s Disease recommendations for earlier and more widespread efforts to detect possible symptoms, the guidelines cite the application of the NTG-Early Detection Screen for Dementia (NTG-EDSD) as a first step in documenting early signs of cognitive and functional changes among people with intellectual disabilities. The guidelines also provide information on nonpharmacological options for providing community care for persons affected by dementia as well as commentary on abuse, financial, managing choice and liability, medication and nutritional, issues.

Dementia is not an inevitable aspect of growing old; it is a condition..that has profound impact on the person, their family, other caregivers and their community.

# 1. INTRODUCTION

In 2011, American President Barack Obama signed the National Alzheimer’s Project Act (NAPA) which charged the federal government with developing a coherent and coordinated national strategy for dealing with Alzheimer’s disease in the United States. To complement this national initiative and to address the myriad requests for more specific information and best practice models for providing quality care for people with intellectual disabilities affected by dementia, three major American organizations created the National Task Group on Intellectual Disabilities and Dementia Practices (NTG).<sup>1</sup> The goals of the National Task Group were to identify a screening instrument that would help substantiate suspicions of dementia-related decline; formulate practice guidelines for health care and social supports; and recommend models of community-based support and long term care of persons with intellectual disabilities affected by dementia (National Task Group, 2012).

The NTG envisioned that purposive planning would enable adults with intellectual disabilities<sup>2</sup> affected by dementia to remain in community care settings. However, the NTG also recognized that the pathway from early recognition of Alzheimer’s disease or related conditions to its eventual outcome is a long and sometimes tortuous process. To aid organizations and families in their planning for the extended care that accompanies the presence of dementia, the NTG has formulated practice guidelines to develop services that

<sup>1</sup> These organizations included the American Academy of Developmental Medicine and Dentistry, the Rehabilitation Research and Training Center on Aging with Developmental Disabilities—Lifespan Health and Function at the University of Illinois at Chicago, and the American Association on Intellectual and Developmental Disabilities.

<sup>2</sup> The National Task Group has adopted a practical definition that characterizes adults with an intellectual disability affected by dementia as those adults who: (a) have intellectual limitations that significantly limit their ability to successfully participate in normal day-to-day activities such as self-care, communication, or work, (b) have developed the intellectual limitation during the ‘developmental period’ (before approximately age 22), (c) have a limitation that is anticipated to result in long term adaptive or functional support needs, (d) are eligible for State or Federal public support programs because they have been diagnosed as having an intellectual disability; and (e) are affected by dementia, and meet the criteria of having mild cognitive impairment, or have been diagnosed with possible, probable, or definitive dementia, as defined by the World Health Organization’s International Classification of Diseases or meet the diagnostic criteria of the American Psychiatric Association’s Diagnostic and Statistical Manual (NTG, 2012). The NTG recognized the distinction between intellectual and developmental disabilities, but also acknowledges that some adults with a developmental disability also have an intellectual disability and that in some jurisdictions these terms are used synonymously. For the purpose of this paper intellectual disability, as defined above, is the focus of these guidelines, unless otherwise specified.

A proactive versus reactive response to dementia care requires preparation, strategic planning, redesign, and integration of services. This also includes supports provided to families and other direct caregivers.

plan for the possibility of dementia and extend from that period when suspicions are aroused to when care ends with an adult’s eventual death. The NTG’s efforts with respect to defining quality community care practices are drawn from the guidance provided by the WHO (2012) in *Dementia: A Public Health Priority*, the prescriptions in the National Dementia and Intellectual Disabilities Action Plan (National Task Group, 2012), and from the call for the implementation of such care guidelines in the U.S. *National Plan to Address Alzheimer’s Disease* (US DHHS, 2012).<sup>3</sup>

With such purposive planning in mind, the NTG also endorsed and drew upon the original ‘Edinburgh Principles’ (Wilkinson & Janicki, 2002), as adapted, to serve as a conceptual framework for the guidelines. The Principles underscore that activities should:

- Promote quality of life.
- Use a person-centered approach.
- Affirm individual strengths, capabilities, skills and wishes.
- Involve the individual, their family and other close supportive persons.
- Access and make available appropriate diagnostic, assessment and service resources.
- Plan and provide services that effectively support the individual to remain in their chosen home and community.

<sup>3</sup> These NTG guidelines are compliant with Strategy 2.D (“Identify high-quality dementia care guidelines and measures across care settings”) and Action 2.D.1 (“Explore dementia care guidelines and measures”) as noted in the U.S. *National Plan to Address Alzheimer’s Disease* (DHHS, 2012), which note that guidelines “should be tailored to the stages of the disease, address the physical, cognitive, emotional, and behavioral symptoms of Alzheimer’s disease, and cover the myriad care settings in which care is delivered” (p. 18).

- Provide access to services and supports that are available to other persons in the general population affected by dementia.
- Undertake proactive strategic planning across policy, provider and advocacy groups.

These principles are consistent with the ‘Eight Common Principles for Supporting People with Dementia’, as noted by the World Health Organization (2012, p. 63)<sup>1</sup> and those articulated by Janicki, Heller, Seltzer and Hogg (1996) in the original AAMR-IASSID [American Association on Mental Retardation-International Association for

It is recommended that caregivers employ an early detection screening tool which can help to document the presence of certain behaviors or dysfunctions, as well as noted changes which may signal MCI or dementia, and where the data can be useful for starting that ‘critical conversation’ with a physician or other clinician.

the Scientific Study of Intellectual Disabilities] practice guidelines for dementia care applicable to adults with intellectual disabilities which emanated from an international consensus process. These original guidelines posited an evolutionary awareness and intervention process beginning with surveillance and identification and then progressing into elementary care management and follow-through. Given the continuing evolution of the field, current greater general awareness of dementia as an emerging public health challenge, and the greater sophistication now evident among care providers and service networks, an enriched set of statements on the application of new practices and technologies was deemed necessary.

*1 The eight principles include (1) know the early signs of dementia; (2) early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage; (3) communicate sensitively to support meaningful interaction; (4) promote independence and encourage activity; (5) recognize signs of distress and respond by diffusing a person’s anxiety and supporting their understanding of the events they experience; (6) family members and other caregivers are valued, respected and supported just like those they care for and helped to gain access to dementia care advice; (7) managers take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia; and (8) multi-agency team work to support persons with dementia.*



In undertaking this effort, the NTG acknowledged that dementia is not an inevitable aspect of growing old; it is a condition individually experienced that has profound impact on the person, their family, other caregivers and their community. Furthermore, most people with dementia can benefit from living in the community, ideally with people and in situations they value. While dementia as experienced by adults with intellectual and developmental disabilities is generally similar to that as experienced by other persons, there are exceptions. Some individuals with select conditions (Down syndrome, in particular) are more at risk for dementia, experience earlier age of onset, more rapid decline, and a briefer duration between diagnosis and death (Prasher, 2005; Stanton & Coetzee, 2004).

Adults with an intellectual disability affected by dementia undergo several transitions as the decline progresses and skills and abilities change. This creates challenges (as well as opportunities for creative solutions) to provide adequate support and resources during these transitions. To more effectively meet individual needs and support people as they attempt to remain in their homes and communities, critical system aspects include:

- Ensuring that formal services, out-of-home relocations, and family care supports are prepared for dementia.
- A specialized dementia-capable workforce and stage-based support strategies that maintain independence, function, and community

- participation for as long as is possible and reflect genuine community living.
- Support from dementia care programs, Alzheimer’s support programs, hospitals and hospice/palliative care programs with staff trained in aging and dementia care issues for people with intellectual disabilities and which are able to include people with intellectual disabilities and their families in their dementia focused offerings and technical assistance.
- Funding and public social policies that support home and community care.

Support from programs with staff trained in aging and dementia care is a critical aspect of the system.

The U.S. National Plan to Address Alzheimer’s Disease (US DHHS, 2012) affirms that there is an expressed need for community and social support guidelines with respect to aiding adults affected by dementias who currently live independently, reside with their families, or are in specialized dementia care settings. The NTG recognizes that such expectations apply equally well to adults with intellectual and developmental disabilities who are at risk or who have been diagnosed with dementia – including those living on their own, with families or other caregivers, or in receipt of specialized intellectual and developmental disabilities services. To this end, the NTG formulated

Formal diagnostics are the domain of specialists such as geriatricians, psychologists, neurologists, psychiatrists or others who have experience and expertise in evaluating adults with an intellectual disability.

actions that could be undertaken by family-based and advocacy organizations and care providers in order to plan for and support adults at risk of or affected by dementia living in the community. These guidelines, drawn from the research literature as well as clinical experiences and demonstrated best practices, delineate what actions could be undertaken and are presented in a manner consistent with the progressive nature of most dementias.

The guidelines are parsed initially into background and person-centered recommendations for tracking and adapting services in accord with a generally accepted model of staging of dementia. Secondly, consideration is given to general program models that can be employed enabling sound community care practices. Lastly, there are commentaries on ancillary issues (i.e. abuse, financial, liability, medication, and nutrition) of relevance to people with intellectual disabilities affected by dementia and their caregivers. Recommended actions are provided to help structure activities that may be undertaken by caregivers, organizations, and public policy bodies.

## 2. COMMUNITY CARE GUIDELINES

### 2.1 DISEASE/CONDITION PROGRESSION

With some noted variations, dementias affect people with intellectual disabilities in the same way as other adults in the general population. Among adults with intellectual disabilities, factors favoring more rapid decline include age and greater burden of psychotic symptoms (Wilkosz et al., 2010), gait deterioration (Patti et al., 2010), and presence of Down syndrome (Cooper, 2006). Adults with Down syndrome are at higher risk of dementia and show a significantly elevated prevalence with advancing age. Among adults with Down syndrome, early onset and often a more rapid progression of cognitive and functioning losses are evident (Evenhuis, 1997). Other characteristics presenting unpredictably include transitioning diagnostically from mild cognitive impairment (MCI) to dementia (Silverman et al., 2010), and an aggressive (i.e. rapidly progressive) form of Alzheimer’s disease that presents with rapid cognitive and physical decline (Gauthier et al., 2006; Schmidt et al., 2010). When aggressive forms of Alzheimer’s disease are present, these are generally associated with younger age of onset, poor nutritional status, and when initially assessed significantly impaired performance on measures of attention and executive function (Janicki, 2011). Adults with intellectual disabilities are as susceptible to the variety of dementias, as persons in the general population (Strydom et al., 2007; Strydom et al., 2010); although among some syndromes, such as Down, dementia of the Alzheimer’s type is most prevalent.

Given the nature of dementia, and its progression and complexities, the NTG recognizes the challenges faced by caregivers and provider organizations in accommodating the needs of affected adults. The NTG also recognizes the diversity of circumstances within which individuals live and service providers operate. In most instances, organizations

Case managers / care coordinators should identify caregiver support resources from within local disability organizations and other services, assess challenges the family is facing (including the caregiver’s own health needs), and be very adept in accessing dementia, health and aging specific supports for caregivers from other systems.

will confront a need to radically change their approach to services in order to best address the onset and evolution of dementia symptoms for people with intellectual disabilities in a supportive and respectful manner. A reactive response to dementia care requires preparation, strategic planning, redesign, and integration of services. This also includes supports provided to families and other direct caregivers.

To enable the development of the most appropriate and useful services and care management for adults with intellectual disabilities affected by dementia, the NTG concurs with the staging model in generally accepted practice among generic dementia services. The staging model, as shown in Tables 1a-1d, follows the flow from a pre-diagnosis stage, with early recognition of symptoms associated with cognitive decline, through to early, mid, and late-to-end stages of dementia progression. In each stage, examples of programmatic and therapeutic activities are offered that may be undertaken to compensate for and support the changes in function. The examples offer guidance for activities and actions that can be undertaken.

## 2.2 PRE-DIAGNOSTIC STAGE

### RECOMMENDED ACTIONS

1. **Make provisions for the ongoing information needs of individuals, friends, and families as well as staff training to be better understand the diagnostic process and progressive nature of dementia.**
2. **Use a detection/screening tool on a regular basis to capture early warning signs that may or may not indicate dementia.**
3. **Assess for medication induced adverse drug reactions or other conditions mimicking, exacerbating or masking dementia.**
4. **Dialogue with a healthcare professional or clinician about the screening tool results and, if the suspicions appear supported, seek a referral for a formal health assessment.**
5. **Advocate that trained professionals familiar with assessment and diagnosis of adults with intellectual disabilities and cognitive / functional decline become involved.**
6. **Have a person familiar with the adult with an intellectual disability and his or her history and communication method always accompany the adult to the assessment appointment(s).**
7. **Hold meetings with the individual, family members and others important to the person, if a diagnosis of dementia is obtained, to explain the diagnosis, prognosis, and begin to map out priorities for future support.**

Recognition of early symptoms of dementia is important for promoting early identification of changes through screening and assessment and the laying out of a systematic plan of care. Early detection can lead to effective interventions and coping strategies that may potentially delay some decline in function. In the pre-diagnostic stage, family members or staff familiar with the

individual may note subtle changes that may or may not be symptomatic of dementia. The individuals, themselves, may also raise questions about the changes they are experiencing. These changes or warning signs may include noticeable:

- Sporadic memory lapses
- Getting lost or misdirected
- Problems with gait or walking
- Confusion with familiar tasks or in familiar situations
- Increased frustration and lack of patience
- Changes in personality.

Such early warning signs, however, may go unrecognized, overlooked or possibly dismissed. Caregivers often wait to seek help until a point where everyday life is disrupted and care demands are increased by changed behaviors on a regular basis (Adams et al., 2008). Research has shown that the types of initial changes reported by caregivers include forgetfulness, loss of personal skills, and changes in personality. Also, challenging behaviors, such as wandering, becoming unusually argumentative or aggressive, and problems, such as changes in sleeping patterns, incontinence, and rummaging – generally indicative of mid-stage dementia – are usually identified by family caregivers (Jamieson-Craig et al., 2010). Diagnostic overshadowing<sup>1</sup> may also occur with changes attributed to the artifacts of intellectual disabilities. Identifying and clearly communicating such early changes is critical to implementing assessment, treatment and support services that are timely and appropriate.

Further, symptoms may vary depending on the nature and severity of the individual's intellectual disability. Memory impairments may be indicative of early signs among adults with mild or moderate intellectual disability, whereas gross function impairment may be indicative of early signs among adults with severe and profound intellectual disability. Etiology of the intellectual disability may also affect the nature of the early presentations of symptoms.

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<sup>1</sup> The tendency to attribute all behavioral and functional change to a certain diagnosis while other causes are not considered.

**Table 1a:**  
**Support Model for Addressing Dementia in Persons with Intellectual Disabilities**

PRE-DIAGNOSIS STAGE		
Functional change	Change indicator	Action
Sporadic memory, personality changes and or performance changes, confusion, other generic warning signs.	Individual shows distress or complains of losses.	Monitor behavior.
	Initial symptoms becoming evident.	Conduct screening.
	Screening shows correspondence with “warning signs.”	Refer for assessment. Assess for possible adverse drug reactions to medications.
	Assessment indicates symptoms are not related to dementia.	Follow prescriptive treatment (medication, nutrition, etc.) to address non-dementia conditions and symptoms.
	Assessment indicates symptoms are most likely related to dementia.	Begin planning and related education to help person, family, friends and roommates understand and cope with changes.  Listen and talk to the person about the changes they are experiencing using familiar terms that are consistently applied by everyone.  Continue to monitor for subsequent progressive changes in abilities.  Initiate support planning  Focus, in a planful manner, on encouraging continued engagement to keep the person as independent as possible.

Although memory loss may be indicative of dementia in the general population of adults with intellectual disabilities, early personality changes may be more indicative in adults with Down syndrome (Ball et al., 2006).

**Validating suspicions.** When some of the behaviors or changes in function occur, they raise suspicions among carers, particularly if the adult with an intellectual disability is genetically at risk or because of a history of brain trauma, of an age when such changes may signal cognitive impairment, or self-reports concerns over his or her functional status. To respond to such suspicions, it is recommended that caregivers employ an early detection screening tool which can help to document the presence of certain behaviors or dysfunctions, as well as noted changes

which may signal MCI or dementia, and where the data can be useful for starting that ‘critical conversation’ with a physician or other clinician.

Many variations of screening and assessment instruments exist that are applicable to adults with intellectual disabilities, some are easily used by caregivers and staff, others are more complex and require specialized training and professional qualifications (see Alyward et al., 1996). The NTG examined various instruments in general use for the assessment of behavioral and cognitive change, as well as for potentially diagnosing dementia, among adults with intellectual disabilities. After listening to the needs of provider organizations and family based groups, the NTG determined that the main need was for an easy-to-

use early detection and screening instrument that could be reliably used by both family and staff caregivers. A variant of one such instrument stood out – the Dementia Screening Tool (DST) which was an adaptation of the DSQIID (Deb et al., 2007).<sup>1</sup> The NTG adapted the DST, making some changes and adding a health status segment to create the NTG-Early Detection Screen for Dementia (NTG-EDSD). The NTG-EDSD was constructed so it could be easily completed by family caregivers or direct support staff with minimal orientation or training and could also be used to document and track serial changes over time. It can be used to contribute to the notation of ‘cognitive impairment’ among adults with intellectual disabilities as part of the annual wellness visit requirement under Patient Protection and Affordable Care Act (PPACA; PL 111-148). The NTG-EDSD can also be used to identify those individuals with dementia-like symptoms whose function and behavior are the results of other causes (such as thyroid disorders, medication interactions, depression, etc.) (see Esralew et al., 2013).

Changes in behavior that are often attributed to dementia may be possibly related to other causes, such as physical loss or debility (e.g., gait changes, falling, and sensory impairment), medical issues, adverse drug reactions, or pain. It is critical that other causes be eliminated prior to attributing the behavior manifested to dementia

The NTG concurs that a baseline be established in midlife (around age 40 for adults with Down syndrome and in the 50s for adults with other intellectual or developmental disabilities) in order to capture an individual’s optimal function and performance (British Psychological Society,

*1 The NTG-Early Detection Screen for Dementia (NTG-EDSD) was adapted from several sources, including the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) developed by Deb et al. (2007) and the Southeast PA Dementia Screening Tool (Philadelphia Coordinated Health Care Group, 2011) adapted from the DSQIID by the Philadelphia Coordinated Health Care Group. In addition of personal characteristic information and behavioral items, the NTG-Early Detection Screen for Dementia uses health status and comorbidity items adopted from the Longitudinal Health and Intellectual Disabilities Survey (LHIDS; Rimmer & Hsieh, 2012). The NTG-EDSD can be sourced at [www.aadmd.org/ntg/screening](http://www.aadmd.org/ntg/screening).*

2009; Janicki et al., 1996). As measures of decline in the general population are difficult to apply to adults with varying capabilities and function, it is recommended that the individual’s best performance be used as a base measure of change – i.e., the ‘baseline.’ This ‘baseline’ can be used as a measure against which future functional and cognitive decline can be assessed. The utility of the NTG-EDSD for use as a general baseline measure has yet to be fully investigated; however, it is expected to be helpful in cases where suspicions are aroused and its use is consistent with NAPA recommendations for earlier and more widespread efforts to detect possible symptoms. As there is a need for a brief universal clinical screening instrument, data derived from applications of the NTG-EDSD may contribute to the development of such an evidence-based instrument.

When suspicions are present, it is recommended to first employ the NTG-EDSD (or similar instrument) to record and note the areas of behavioral and functional change and comorbidities. Second, to review the results, and, third, to then have a conversation with a clinician or other professional around the results and, if the suspicions appear supported, to seek a referral for a formal cognitive health or dementia assessment. When completing the NTG-EDSD over successive times, collateral information should be also be gathered such as family history, incidents of seizures, loss of consciousness, unusual behaviors, and medication or drug usage, as well as type of diet and degree of hydration. Some clinicians may find it helpful to have a summary of suspicions and the functional and cognitive change data aggregated by a reliable informant and then sent ahead of an assessment appointment. Other clinicians may prefer that the information to be presented as on the NTG-EDSD form and key items highlighted as priority discussion points at the initial visit.

**Formal assessment and diagnosis.** Formal diagnostics are the domain of specialists such as geriatricians, psychologists, neurologists, psychiatrists or others who have experience and expertise in evaluating adults with an intellectual disability. Such diagnostics should be carried out within generally accepted practices by the professional

conducting the assessment (American Psychological Association, 2012; Moran et al., 2013). Referrals can be obtained via a number of routes including area agencies on aging, state developmental disabilities agencies, local intellectual disabilities services providers, family physicians, consulting psychologists, care coordinators, or dementia resource centers. Formal comprehensive geriatric clinic assessments are fruitful venues for such diagnostic processes (Bishop et al., 2013). In smaller communities and rural or remote locations, consultations may need to be arranged and conducted by professionals familiar with adults with intellectual disabilities affected by dementia via teleconference or videoconference. Development of regional teams may also improve access and assessment services for individuals and caregivers. In any formal assessment situation, persons familiar with the adult with an intellectual disability and his or her history and communication style should always accompany the adult to provide reassurances to the individual as well as to serve as a knowledgeable informant and to facilitate the exchange of information (Bishop et al., 2013).

Loss of function, personality and emotional changes, and or loss of activity may be the result of other diseases, physical or sensory problems (such as nutritional deficiencies, thyroid abnormalities, or hearing impairments) or a result of adverse life events. Seeking and obtaining well-trained and reliable diagnostic resources can aid in assessing adults with an intellectual disability and is crucial to accurate diagnosing and appropriate remedial treatment. Adults with an intellectual disability, particularly those with multiple complications or severe intellectual impairment, are often misdiagnosed and the course of treatment can be consequently misdirected (Janicki & Dalton, 1999).

The NTG recognized that, as with the general population (Cordell et al., 2013), clinical assessment instruments of cognitive function for persons with intellectual disabilities, many of which may include direct assessment as well as informant-based ratings, exist and are often used by clinicians to validate suspicions and help clinically track decline or changes. Such assessment instruments are

generally more heavily geared toward formally assessing memory, behavioral changes, and motor and visual spatial abilities, and often require their users to have extensive training and professional credentials (see Alyward et al., 1997). Such assessments are based on eliminating alternative hypotheses for the function and cognitive decline and generally are substantiated by review of performance in a variety of spheres (Burt & Aylward, 2000). Protocols may vary, but generally involve any of the prevalent measures noted in Table 2. The instruments noted are limited primarily to those with clinical applications.

As the diagnosis of Alzheimer's disease and some other forms of neurodegenerative disorders is tentative with designations such as 'possible' and 'probable', clinical determinations are made only after reversible causes and co-morbid confounding variables have been eliminated by laboratory workups and neuroimaging. Currently, the 'definitive' confirmation of a diagnosis of Alzheimer's disease can be made only after death, following the examination of brain tissue. Age-related functional decline often will continue to be a confounding element to the diagnosis so longitudinal tracking of a change in symptoms is important and integral to the process of assessment and diagnosis (i.e., as part of any care plan symptom progression should continue to be tracked).

Diagnostic information has useful applications. Knowing the type of dementia is helpful to formulating a plan of care, including options for a residence, expectations of length of stay, and assignment of staff or resources. For example, dementia of the Alzheimer's type will evidence stage-associated changes generally following those described in these guidelines and generally predictable with respect to sequencing and duration. With other types of dementias, such predictability may be less sure, and care practices may have to be varied to accommodate the peculiarities and challenges associated with the types of dementia. With respect to vascular dementia, there may be lengthy periods of stability of function but potentially precipitous change when further vascular accidents occur (Alzheimer's Association, 2012). This

**Table 2: Informant-report and objective measures for clinical assessment of dementia in people with intellectual disabilities**

Name of Measure	Instrument characteristic	Strengths/weaknesses
Adaptive Behaviour Dementia Questionnaire (ABDQ), Prasher et al. (2004)	15-item questionnaire used to detect change in adaptive behavior by comparing current functioning to typical functioning.	<p><b>Strengths:</b> Detecting change in everyday functioning, easy to administer and score, family member as informant, length of time must know adult is specified.</p> <p><b>Weaknesses:</b> No differential diagnosis, not useful to track intervention response.</p>
Assessment for Adults with Developmental Disabilities (AADS), 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'.	<p><b>Strengths:</b> Assesses current everyday functioning/ behavior, and behavior changes. Easy to administer, standardized administration, descriptive, indicates who needs further evaluation/care, many informants.</p> <p><b>Weaknesses:</b> No differential diagnosis. Questions are complex.</p>
Dementia Questionnaire for People with Learning Disabilities (DLD)*, Evenhuis (1992); Evenhuis (1996); Eurlings, Evenhuis & Kengen (2006); Evenhuis et al. (2007)  *Originally named the Dementia Questionnaire for Mentally Retarded Persons (DMR)	Made up of eight sub-scales: short term memory, long term memory, orientation (making up Sum of Cognitive Scores), speech, practical skills, mood, activity and interest and behavioral disturbance (making up a Sum of Social Scores).	<p><b>Strengths:</b> 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.</p> <p><b>Weaknesses:</b> 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.</p>
Dementia Scale for Down Syndrome (DSDS), Gedye (1995)	Measure of early, middle and late stages of dementia and includes the time course of the deterioration and a differential diagnosis scale.	<p><b>Strengths:</b> Differentiates typical from atypical functioning and determines how long signs have been present. Standardized administration. One form for 10 assessments.</p> <p><b>Weaknesses:</b> 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.</p>
Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID), Deb et al. (2007)	Comprised 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.	<p><b>Strengths:</b> Current everyday functioning assessed, easy to administer/score, wide range of respondents considered appropriate, length of time informant needs to know adult specified.</p> <p><b>Weaknesses:</b> For differential diagnosis just lists possible other conditions and medications.</p>

**Table 2 continued**

Name of Measure	Instrument characteristic	Strengths/weaknesses
Prudhoe Cognitive Function Test (shorter versions), Kay et al. (2003)	A 21 item informant administered cognitive test that takes 15 minutes to complete. It tests orientation, language, memory, and spatial and conceptual skills.	<p><b>Strengths:</b> Excellent correlation with an established test of cognitive function, the K-BIT. Those with moderate and severe handicaps can complete this test. There are 2 versions.</p> <p><b>Weaknesses:</b> People with profound intellectual disability are unable to complete items on this test.</p>
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.	<p><b>Strengths:</b> Most people with moderate and severe ID should be able to score on the TSI (Test for Severe Impairment ) unless they are at an advanced stage of dementia. Many report enjoying completing the scale.</p> <p><b>Weaknesses:</b> The small number of items within each subscale may not always be sufficient to detect subtle changes over time.</p>

type of dementia is generally associated with a step-wise progression of change, where there are periods of stability and then precipitous changes. With Lewy body dementia, neuropsychiatric symptoms are more prominent (Bjoerke-Bertheussen et al., 2012) while with fronto-temporal dementias (e.g., Pick’s disease) significant changes in personality and expressions of marked inappropriate social behavior may be more prominent (Mendez et al., 2008). Although evident, there is a dearth of literature detailing the sequelae of these other dementias among adults with intellectual disabilities.

Changes in behavior that are often attributed to dementia may be possibly related to other causes, such as physical loss or debility (e.g., gait changes, falling, and sensory impairment), medical issues, adverse drug reactions, or pain. It is critical that other causes be eliminated prior to attributing the behavior manifested to dementia. Physical and behavioral observations are critical as dementia progresses and the person deteriorates. Questioning ‘how do they look, act, react?’ can help identify alternative rationale for the changes in behavior.

In most cases, the assessment process will lead either to a diagnosis of mild cognitive impairment (MCI) or dementia, or to a recommendation for alternative assessments to determine the root cause of the changes in behavior.

Most often early symptoms, upon confirmation, reflect a trajectory of MCI. In contrast to dementia where cognitive skills are affected, mild cognitive impairment is defined by deficits in memory that do not significantly impact daily functioning and memory problems may be minimal to mild and hardly noticeable to the individual. However, MCI may often be the precursor to dementia.<sup>1</sup>

When the assessment has been undertaken, it is useful to ask and record a number of details about the assessment process and diagnosis. For instance, what types of measures or tests were used, what is the suspected type of dementia, what should be expected in the short and long term with respect to duration and function, and what co-morbidities were identified that have bearing on the nature and course of the dementia.

Whether the diagnosis is MCI or dementia, it is important that the individual and caregivers know that there are things they can do. Multidisciplinary team meetings with the individual, family, staff / caregivers, and others important to the person in order to explain the diagnosis and prognosis are critical. Such meetings can help

<sup>1</sup> The MCI to dementia conversion rate at least among adults with Down syndrome appears to be about 33% over an 18-month period and that aggressive behavior and physical and behavioral depression appears to show up more among adults with Down Syndrome showing MCI compared with adults with Down Syndrome but without symptoms of decline (Kinsky-McHale et al., 2010).

begin the planning to address future care needs and to implement appropriate plans of care. Additionally, following diagnosis, there is a need to review the capabilities, within an organization or family, of providing short- and long-term dementia care and to look for specific areas where environmental changes and training may help improve responses for the individual.

## 2.3 POST-DIAGNOSTIC STAGES

Each of the post-diagnostic stages described address recommended actions, symptoms, care focus, environmental modifications, training, and outcomes.

### 2.3.1 EARLY STAGE

#### RECOMMENDED ACTIONS

1. **Engage the individual and their family, and / or other caregivers or guardians in advance care planning (and prepare advance directives) consistent with state or other requirements.**
2. **Identify and plan to remediate the environmental challenges to help maintain community living.**
3. **Establish a daily regime that provides for purposeful engagement based on individual needs and preferences, yet is organized so as not to cause anxiety and confusion.**
4. **Provide ongoing clinical supports to address behavioral and psychological symptoms associated with dementia.**
5. **Redesign day activities and programs so that participation in valued activities and opportunities for interaction with others continues and respite for families and other caregivers is possible.**

Over the course of the early stage there is a need to actively support individuals by adapting the physical and social environments to accommodate their changing abilities, thereby helping them to maintain their community living situation.

**Symptoms.** Although abilities continue to fluctuate as dementia progresses, symptoms become more pronounced and constant including continued:

- Losses of memory that further effect performance in daily activities and social interactions.
- Increased confusion and anxiety.
- Communication difficulties.
- A reduced zest for life.

It is difficult to predict the duration of the early stage of dementia, unless there are pronounced behavioral or neurological (e.g., seizures) indicators. Individuals will vary and the symptoms that are associated with this stage will be equally individualized. Careful surveillance of change and indicators of the worsening of symptoms is indicated so as to be able to provide for supervision needs and other accommodations (Moran et al., 2013).

Engage the individual and their family, and / or other caregivers or guardians in advance care planning (and prepare advance directives) consistent with state or other requirements.

**Care focus.** The earlier stages of emergent dementia may last five to eight years, on average, and call for increased supervision and supports. There is an on-going need for a safe place to live with supervision involving staff or family caregiver support. Instituting a daily regime that provides for routine purposeful engagement based on individual needs and preferences is generally helpful. This helps reduce anxiety and confusion in the individual and can help prevent agitated or aggressive behavior. Support is needed to facilitate communication with peers / staff / family and community engagement. Opportunities should be proffered to the extent possible to continue to do things that have always been done and that are known to be of comfort, with the support and time needed to do them for oneself and / or with familiar others (Gaventa, 2010).

The NTG recommends that care and supports of adults with an intellectual disability affected by dementia take place as much as possible in community settings. In most instances, continued community living is viable and warranted both from a human rights and best practices perspectives. With appropriate supports and supervision most, if not all, adults with an intellectual disability can continue to reside in some type of community living setting and enjoy an enhanced quality of life. Threats to continued stay within the current living situation need to be identified and planning for remediation initiated. Similarly, medical follow-up for treatment of dementia and surveillance and management of co-morbid conditions should also

be planned for, and should occur in tandem with gradual increases in supports as dementia progresses. Given these considerations, care plans should be revised to emphasize

- Skill maintenance rather than skill acquisition
- Continuation of community participation, including in day programs
- Provision of spiritual support and engagement
- Standardization of routines so the person is able to manage their own day and living situation to the greatest extent possible (e.g., meal, activity, exercise, bathing, bed and wake times) and to aid overcoming resistance to care in later stages

**Table 1b:**  
**Support Model for Addressing Dementia in Persons with Intellectual Disabilities**

<b>POST DIAGNOSIS, EARLY STAGE</b>		
<b>Functional change</b>	<b>Change indicator</b>	<b>Action</b>
More pronounced changes in function, personality, and or attention to daily activities.	Progression of early stage symptoms.	Conduct functional assessments to measure continued changes. Monitor health for secondary co incident conditions.  Assess for possible adverse drug reactions to medications at each stage of change to rule out possible acute dementia from medications concomitant with dementia.
	Communication or word finding problems.	Prepare for non-verbal communication methods.  Ensure life story work begins.  Prepare advance directives and other documents related to later life care.
	Assessment indicates symptoms most likely represent progression towards mid-stage dementia.	Adjust daily routines, modify environment, review and adjust medications.  Engage in discussions on advanced care directives and on appropriate emotional, spiritual, and cultural support strategies for grief, loss, and end of life, including post-death rituals.  Introduce greater assistance with daily tasks, personal care and memory retention.  Establish plans for safety (e.g., wandering, ingesting harmful products, falling).  Explore resources for additional “in home” supports and specialized therapeutics.  Consider possible options for changes in residence (including where possible determination of individual’s desires).

- Modification of demand situations in the home or program to ease aggravation of dementia symptoms and the experience of declining independence
- Modifications in the home / day program and/ or its routine so that the individual's community participation and quality of life is maintained
- Proactive management of any related physical or mental health issues, including pain management, likely to impact upon or be impacted by dementia symptoms
- Sensitivity to and identified resources for staff and family caregivers who may experience compassion fatigue, stress and caregiver burden and grief.

During the early stage of dementia, relatively low-cost minor physical environment modifications can be helpful in creating a calm relaxing environment (e.g., declutter the environment; organize the household, keep familiar objects and possessions). Staff and family members should anticipate and plan for environmental modifications that likely support continued independence and reduce stress and demands on the individual as well as caregivers.

As housing that includes stairs can become increasingly problematic with dementia progression, thought should be given to how mobility aids (such as a second stair rail, or stair glide) might be used. In some homes, stairs, small bathrooms, thresholds, and other barriers may not easily accommodate walkers or wheelchairs. Also, given that brighter lighting has been found to positively affect cognitive decline, increasing lighting and reducing glare should be considered (Riemersma-van der Lek et al., 2008). Such barrier and environmental accommodations should first be considered before exploring alternative residences. Long range planning should also consider a need for specialized equipment required for late and end stage dementia. Table 4 identifies a number of evidence-based recommendations to consider.

In terms of communication strategies, all persons coming in contact with and supporting the person with dementia should reframe their communication approaches to reflect stage-based best practices (Bishop et al., 2013;

Staff and family members should anticipate and plan for environmental modifications that likely support continued independence and reduce stress and demands on the individual as well as caregivers.

Gerontological Society of America, 2012; McCallion, 1999). Early stage dementia is often marked by forgetfulness and increasing difficulty with managing conversations. Staff and family caregivers should take on a greater, yet respectful, role in those conversations by using simple and direct language; observing and listening to understand changed attention spans; offering additional information to help with understanding; and better managing conversation by purposefully seeking to be better understood and avoid disempowering steps (such as talking for the person or filling in his or her words).

To the extent that assistive devices (e.g., glasses, hearing aids) and technology (e.g., communication devices, motorized wheelchairs) have been part of the individual's life, there is a need to ensure that the equipment is still appropriate, ensure its continued use for as long as possible, and to consider if other devices (such as adaptive utensils) should be introduced. The use of memory aids (such as scrap or memory books and posters for an individual's room) should also be considered.

Throughout all stages of dementia care providers should provide feedback to the treating health care practitioners on the effect that pharmacologic and nonpharmacologic therapies have on the individual. Care providers should know what the treatment expectations are, how the outcomes and quality of feedback should be provided, as well as understand what the possible side effects might be.

**Training.** Keen observation skills are important attributes of an informed, proactive care provider. Specific instruction should be provided regarding how and what to observe. In the early stages of dementia, caregivers should be as fully informed as possible to help provide appropriate

Staff and family caregivers should take on a greater, yet respectful role in... conversations by using simple and direct language; observing and listening to understand changed attention spans; offering additional information to help with understanding; and..purposefully seeking to be better understood and avoid disempowering steps (such as talking for the person or filling in his or her words).

supports and reduce potential stress for everyone involved as dementia progresses. This should include expanding knowledge about the specifics of Alzheimer's disease and its progression among people with an intellectual disability, reviewing information and supports that may be available from other resource agencies (including spiritual supports), and instituting training related to grief and loss. Staff and family caregivers should also be provided with information and guidance on expectations of change and helpful tips on how to address select behaviors (Samus et al., 2012). What caregivers know should be verified and any insufficient knowledge noted, and when needed, additional training provided. Also, any staff training provided should be aimed at improving both the quality of life and the quality of supports provided (Kalsy, Health, Adams & Oliver, 2007).

Using existing training programs can be helpful in facilitating such education and training, several of which have been developed specific to intellectual disabilities and dementia (see, for example, McCallion & Janicki, 2002; Watchman et al., 2010). There are also services and supports available through the various organizations (such as the Alzheimer's Association [[www.alz.org](http://www.alz.org)], the U.S. Administration on Aging [[www.aoa.gov](http://www.aoa.gov)], and the National Institute on Aging [[www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)]) that explain the various types of dementia and link caregivers to written, on-line and or in-person resources.

Persons with intellectual disabilities who live independently or with families are generally able to

spend periods of time alone. However, a diagnosis of dementia can become a concern and, in time, increased supervision will be required. For instance, questions may arise regarding the ability to continue to travel about independently and use public transportation. Family members, friends, volunteers, and members of various community support networks may need to become involved to provide additional companionship and/or respite services.

Case management / care coordination tasks should focus on helping the individuals and families build plans for increased care and must also be a support for family members. Case managers / care coordinators should identify caregiver support resources from within local disability organizations and other services, assess challenges the family is facing (including the caregiver's own health needs), and be very adept in accessing dementia, health and aging specific supports for caregivers from other systems. Resources include credible websites, such as [www.eldercare.gov](http://www.eldercare.gov), and local organizations, such as state or regional aging and disability resource centers and local chapters of the Alzheimer's Association.

Advance directives should designate a medical guardian, and refer to specific treatments or situations such as the treatment of medical conditions, care and welfare decisions, basic care, life-supporting treatment, and life-saving treatment.

To facilitate the most favorable outcome, the individual's likes and dislikes should be determined, as well as his or her wishes for care now and in the future and who they identify as best able to express their wishes when they are no longer able to do so. To the extent possible, these expressions of choices should be formalized in advance directives and should influence all care planning, including end-of-life care (Coalition on Compassionate Care, 2008; Hollins & Tuffrey-Wijne, 2009; Kingsbury, 2009; McCallion et al., 2012;). Such advance directives should designate

a medical guardian, and refer to specific treatments or situations such as (a) the treatment of medical conditions, (b) care and welfare decisions, (c) basic care, (d) life-supporting treatment, and (e) life-saving treatment (Alzheimer Europe, 2009).

## 2.3.2 MID-STAGE

### RECOMMENDED ACTIONS

1. Provide increased assistance with personal care and hygiene when needed.
2. Secure appropriate residential supports and consider housing options to accommodate increasing losses in independent functioning.
3. Continue surveillance and periodic assessments to determine extent of change and progressive dysfunction as well as the possible development of co-morbid conditions.
4. Monitor any medications being taken to prevent adverse drug reactions.
5. Enhance training of staff and family as well as consultation to caregivers around coping with behaviors and adapting routines.
6. Institute planning for long-term services and supports.
7. Ensure protections are in place to preclude abuse or harm in both formal and informal settings.

During mid-stage dementia, the person may change dramatically and further demands may be placed on caregivers as the person experiences additional losses of abilities and expresses behavioral symptoms that present daily challenges. The mid-stage of dementia is likely to last 2-10 years for adults with intellectual disabilities affected by dementia (and is often less for adults with Down syndrome). During this stage, abilities frequently fluctuate and what works in managing behavioral symptoms one day may not work on other days. Simplification of approaches coupled with person-centered knowledge and routines is important. Staff and family caregivers at this stage often speak of

“losing” the person they once knew and wonder if they can continue to cope. Providing supports both for that sense of grief and loss as well as helping the primary caregivers “hold the memory” of who this person was is important (Swinton, 2012). Understanding this stage of the Alzheimer’s disease process, in combination with a repertoire of creative strategies, will support caregivers in their efforts to assist the individual. Respite services and or day services should be available to provide relief for family members providing care at home.

In some situations, alternate living arrangements may need to be considered. Active management of co-morbid conditions must also continue and, in particular, symptoms of depression should be monitored and treated.

**Symptoms.** Throughout the mid-stage, there is increased loss of abilities, as well as increased likelihood of the emergence of challenging behaviors, including:

- Short term memory loss and possible onset of difficulties recognizing family, friends and staff.
- Long term memories of people and events surfacing that the person incorporates as perceived reality.
- Disengagement from familiar activities
- Restlessness, pacing and agitation.
- Hoarding, wandering, and shadowing.
- Difficulties being understood and understanding.
- Repetitive talk or questioning.
- Challenging behaviors such as being verbally or physically abusive, “sundowning,” and hallucinations/delusions.

**Care focus.** Supervision needs to be increased as dementia moves into the mid-stage. Equipping the caregiver (staff or family) on how to provide increased levels of care (Administration on Aging, 2012). In some situations, alternate living arrangements may need to be considered. Active management of co-morbid conditions must also continue and, in particular, symptoms of depression should be monitored and treated.

**Table 3: Dementia focused environmental modifications**

Source: Adapted from McCallion & McCarron (2005) and Watchman (2007).

Home area	Action
Bathrooms	<p>Install devices to ease use (e.g., grab bars, raised toilet seats).</p> <p>Introduce bath / shower chairs.</p> <p>Use hand-held showers.</p> <p>Regulate water temperature on taps.</p> <p>Replace standard showers or tubs with walk-in models.</p> <p>Remain aware that modern bathroom equipment may become unrecognizable to the person with dementia.</p> <p>Widen doorways to accommodate walkers, wheelchairs, and lifts.</p>
Color	<p>Use color and contrast to create visual cues or reduce attention to specific areas throughout the home.</p> <p>Contrast colors in key places to create visual cues (e.g. white light switch with a dark colored switch plate; dark colored toilet seat on a white toilet; dark handrail against a light colored wall; dark placemat under a light colored dinner plate).</p> <p>Use tableware that offers contrasting colors to the foods being served (e.g., milk served in a white cup will appear to be empty to the person with dementia).</p> <p>Reduce visibility of exits, cupboards or other areas through use of color (e.g. exits and cupboards painted the same color as surrounding walls makes them less visible).</p> <p>Colors in the red to yellow range are more accurately perceived than blues and greens.</p> <p>Use solid colors or simple patterns instead of complicated or highly unusual designs.</p>
Flooring	<p>Use non-patterned flooring that has a matte versus high gloss finish.</p> <p>Provide floor markers to aid with wayfinding - people with dementia may develop the habit of looking down when walking.</p> <p>Eliminate scatter rugs and other loose floor rugs as potential risks for falls.</p> <p>Reduce or eliminate changes in the levels of flooring in the home to prevent falls and ease movement when mobility aids are used.</p>
Furniture	<p>Use furniture with rounded versus sharp edges that is sturdy, simple and versatile. Contrast furniture color with floors and walls.</p> <p>Arrange furniture to create clear pathways for movement.</p> <p>Secure lightweight items such as lamps.</p> <p>Use table tops / cloths that are smooth and pattern-free.</p> <p>Consider height and placement of objects and signage when a person is standing or seated.</p>
Illumination	<p>Use lighting to avoid shadows, a common source of visual illusions for persons with dementia.</p> <p>Disperse direct sunlight with curtains or tinted glass.</p> <p>Use indirect lighting to avoid glare as well as sudden changes in lighting levels (e.g. use dimmer switches and night lights).</p> <p>Reduce reflective surfaces (e.g. floor surfaces should not be buffed or waxed to produce shine).</p> <p>Consider lighting that eliminates bulb warm-up delays which produce low visibility.</p>

**Table 3 continued**

Home area	Action
Kitchens	<p>Label cupboards for visual cues, pictorially not with text.</p> <p>Create an open space (e.g. shelves that slide in when not in use).</p> <p>Provide safe storage for kitchen tools, liquids and powders that are not food stuffs by using discreetly locked cabinets.</p> <p>Install shut-off switches on appliances.</p> <p>Regulate water temperature on taps.</p>
Noise	<p>Improve acoustics through use of carpeting, acoustic tiles, curtains other sound absorbing materials.</p> <p>Reduce ambient sound levels associated with TV use and extraneous music.</p> <p>Design and encourage use of quiet spaces.</p>
Outdoors	<p>Provide access to safe outdoor space for walking and wandering (e.g. fenced yard with seating area, raised garden beds, and walking path that leads back to the house door).</p> <p>Install ramps or otherwise eliminate barriers to entrances / exits for people with gait difficulties or who use walking aids (e.g. walkers, wheelchairs).</p> <p>Install alert systems so caregivers know when someone has left the home or install door opening prevention devices.</p>

Often in specialized intellectual disabilities services, caregivers have received and now seek to apply behavioral training. However, in dementia the emphasis in behavioral approaches switches from management of consequences to prevention of antecedents in the belief that avoiding confrontations and difficulties may be of more critical concern than behaviors successfully managed (McCallion & McCarron, 2004). Altering communication style and keen observation skills are critical to the provision of dementia care at this stage. Case managers and care coordinators and other multidisciplinary team members can both teach and model such approaches.

Caregivers should be encouraged to find strategies or be offered help to manage their emotions related to loss of the individual's abilities, to support one another, to see behaviors as part of dementia instead of failings of the individual, and to work on employing their own coping mechanisms. Community resources such as palliative care teams and / or spiritual caregivers can also be of help to primary caregivers as well as the individual.

Individuals with dementia, who are up during the night, leave the building without notice, challenge those around them, or hallucinate, can be taxing for caregivers. Other behaviors (e.g., wailing or crying, calling out, repetitive questioning) may also be burdensome and create tension. Some challenging behaviors, such as hoarding, shadowing, and rummaging, while somewhat less problematic, are to be expected and should be addressed in any care

Movement (change of housing) usually reflects an appraisal that (1) the current physical environment is not suitable, (2) the current housing resources provided (including staff or availability of family members) are not meeting needs, (3) others in the household are being adversely effected, and / or (4) the demands placed on the caregiver are beyond his or her capacities.

management strategies. Changes in sleep patterns, resistance to bathing, and expressions of heightened anxiety often present the biggest challenges, and staff and family caregivers will benefit from training in appropriate ways to manage them. Such proactive management of these behaviors can contribute to maintaining the current living situation for a longer time.

Non-pharmacological interventions should always be attempted first in addressing behavioral and psychological symptoms that emerge during mid-stage dementia (De Vreese et al., 2012). These can include the use of known and preferred activities and comfort, music, spiritual practices and/or religious rituals that a person may have been familiar with for years, as well as aromatherapy, massage therapy, and the like. Adapting activity levels / day programs should include:

- Redesign as “failure-free” and personally-valued activities that emphasize involvement with things already known rather than requiring new learning and the enjoyment of activities rather than their completion.
- Changes to activities and their sequencing suited to maintaining attention and interest.
- Inclusion in activities of valued items that orient to self, people, and environment (e.g., photos, scrapbooks).
- Engagement in valued aerobics-of-mind activities (e.g. completion of phrases), music, reading aloud to the individual, opportunities for tactile participation, such as in simple gardening and exercise.
- Providing types of foods more easily eaten without choking (e.g., a soft foods’ diet), and will require less assistance in eating.

Enhanced staffing or respite supports should be considered during the most challenging times. Support groups or counseling should also be available to caregivers and alternative approaches to problem situations explored. Resources available through the aging and the dementia specific networks should be considered as supplements to what intellectual disabilities services offer, as well as consultation sought from intellectual disabilities’ dementia

specialized programs. Respite supports can be in-home or out-of-home. Use of adult day services associated with the aging network can be of value.

All persons coming in contact with and supporting the person with an intellectual disability and dementia should continue to re-frame their approaches to communication to reflect stage-based best practices (McCallion, 1999). Mid stage dementia is often marked by forgetfulness and increasing difficulty with managing communication, including the ability to form and express sentences and to know when to listen and when to speak in a conversation. The individual may also talk of past persons or events as if current and become confused or agitated if contradicted; caregivers should develop common strategies to manage these situations. Staff and family caregivers must be prepared to speak when they can be seen; use their name and the person’s name in every communication (avoiding questions like “do you know who I am”); simplify language; and use overemphasis, gestures, facial expressions, and pointing to still familiar objects to support communication. Caregivers should be prepared to accept the responsibility to ensure they have been understood and above all, be patient while providing the person ample time to process what has been said and generate a response.

Non-pharmacological interventions should always be attempted first in addressing behavioral and psychological symptoms that emerge during mid-stage dementia.

The use of assistive devices and technology (e.g., glasses, hearing aids, communication devices, motorized wheelchairs) that have been part of the individual’s life should continue to be monitored to ensure that the equipment is still appropriate. Use of adaptive utensils and plate guards and simplification of meals may mean that some level of independence at meal times may be maintained. Continued use of memory aids is recommended (McCallion, 1999).

Thought should be given to amending or altering the physical environment so as to minimize any increase in confusion, agitation, and anxiety. Simplify the environment while also keeping it familiar, safe and supportive. Find a means to reinforce strengths and maintain autonomy as much as possible. Facilitate way-finding and orientation by providing access to areas that encourage self-direction as long as it is safe. However, limit access when abilities and understanding have diminished to the point that supervision is necessary.

**Training.** As dementia symptoms change, there will be a need for additional training of staff, or education of family caregivers. A particular frustration is that interventions that worked in the early stage may no longer be useful as dementia progresses. Training should address what to expect in mid-stage dementia, while accepting that the person they know is still there. Strategies should be employed that continue to find and reflect that person (things still remembered, activities enjoyed in the past, unconditional companionship) as well as identification of needs that are not being well-expressed (pain, hunger, discomfort, fear, grief, illness). Staff and families should know how to systematically and objectively gather information by noting behavioral changes and identifying potential precipitating factors, all essential to being able to change environments, staff approaches, and levels of activity. Timely access to ongoing clinical resources is also required to manage behavioral symptoms that emerge in mid-stage dementia.

**Outcomes.** Mid-stage dementia is often the most challenging for caregivers and people with dementia and is often the trigger for the consideration of an alternative residence (particularly if behavior has become increasingly problematic). Generally, behaviors such as wandering, hoarding, shadowing, verbal and physical aggressiveness, and paranoia can lead to quick caregiver burnout. Studies have shown that personal care (particularly around incontinence) and behavior management place the greatest demands on caregiver time during this stage. The dilemma is whether to continue supporting a caregiver who is experiencing increased stress and debilitation, or to

recommend a move out-of-home. However, as movement to an unfamiliar out-of-home residence or a change in the residential environment, may increase difficulties for the person with dementia (as it may promote disorientation, raise levels of anxiety, and lead to expressions of problem behaviors) compensatory initiatives should be explored.

Movement (change of housing) usually reflects an appraisal that (1) the current physical environment is not suitable, (2) the current housing resources provided (including staff or availability of family members) are not meeting needs, (3) others in the household are being adversely effected, and / or (4) the demands placed on the caregiver are beyond his or her capacities. Planning for a change in residence should consider challenges in each of the four areas noted above and determining whether some additional environmental modification should be made (see Table 4). Further considerations are what additional resources may be necessary (and for how long); how changes in managing the individual could improve the lives of others; and whether alternative ways of coping or new supports for the caregivers may increase their ability to manage.

Sometimes modifications of the environment or use of alternative caregivers are not possible and change of residence is required. Preparatory planning should consider this possibility and facilitate proactive rather than reactive planning of alternatives. Consultation with experts, listening to the caregiver's alternatives, finding supports for others in the home, and integration of efforts with other agencies, will reduce the trauma potentially associated with movement. Movement to another setting should be:

- A last resort.
- Planned for rather than abrupt.
- Have a clear person-centered purpose with a likelihood of continuation rather than be the precursor to additional moves.
- Undertaken in ways that maximize retention of familiar routines, places, people, and things.
- Inclusive of helping new caregivers to know the individual's story and who he or she is and has been, including formal transfer of information about the person and those connected to his or her life.

**Table 1c:**  
**Support Model for Addressing Dementia in Persons with Intellectual Disabilities**

<b>MID-STAGE</b>		
<b>Functional change</b>	<b>Change indicator</b>	<b>Action</b>
Significant changes in function, personality and orientation.	Assessment indicates symptoms related to further deterioration of function	Shift in nature of supervision and greater attention of personal care and direction over new activities.  Focus on activities and daily rituals preferred by the individual.
	Progression of mid-stage symptoms.  Emergence of behavioral and psychological symptoms of dementia.  Gait / walking problems.  Eating patterns / food choice changes.  Communication difficulties (e.g., loss of words, understanding).  Incontinence.	Adjust settings to reduce safety and wayfinding challenges.  Increase assistance with personal care, nutrition, safety and supervision.  Introduce specialized, nonpharmacological interventions to manage behavioral / psychological symptoms and reduce demands likely to result in behavioral challenges.  Access support from professionals (e.g., speech and language, occupational therapists) as appropriate.  Consider possible change in residence due to changing needs and need for additional support.  Access hospice care and/or palliative care support.  Introduce more aid with toileting and other hygiene/personal care activities.

## 2.3.3 LATE AND END-STAGE

### RECOMMENDED ACTIONS

1. **Reorganize care management toward non-ambulatory care.**
2. **Reassign staff to activities more structured around nursing and personal care including the support of family caregivers who wish to maintain the person at home.**
3. **Obtain support from palliative care or hospice specialists.**
4. **Institute procedures to maintain dignity, comfort, and address pain and symptom management.**
5. **Organize end-of-life supports and post-death arrangements.**

The late stage of dementia is characterized by greater cognitive inefficiency and functional deterioration. During this stage, adults face dramatic challenges with self-care and become progressively more dependent on others for personal care. Generally, this stage is of shorter duration and bodily function compromises often lead to illnesses and infections that may bring on death. This stage may last from one to three years on average.

As mobility is progressively lost, individuals will have significant difficulty moving about, maintaining balance, and may experience falls. Initially, ambulation aids such as a walker or wheelchair will be required. Eventually they will be unable to move about even with a wheelchair and will require total assistance. Continence will be further compromised, eating will become difficult requiring transition to soft or pureed diet, and personal care will predominate. Communication (expressive language) will become increasingly difficult and sporadic. As a result of increased medical episodes, short-term hospital admissions may also increase during this stage. Given these circumstances, if established, previously made advance directives should provide guidance for the difficult decisions related to care management encountered during this stage. In the absence of plans for a home death,

individuals may have to move to a new setting as the ability of families and staff to cope is exceeded. This move should be carefully planned as transfer trauma can further exacerbate the situation and result in increased stress experienced by the individual with dementia. In agencies with specialized group homes, often one home will be dedicated to persons in the end-stage. To assist with end-stage care, agencies or families can often access a hospice program. If hospice care is initiated, the role and availability of caregivers should be clearly identified and the linkages with families, peers in prior living situations, and staff respected in the provision of supports in the person's last days.

In the absence of plans for a home death, individuals may have to move to a new setting as the ability of families and staff to cope is exceeded. This move should be carefully planned as transfer trauma can further exacerbate the situation and result in increased stress experienced by the individual with dementia.

**Symptoms.** Although psychosocial needs continue to require attention, late stage dementia presents significant medical concerns marked by:

- Severe intellectual deterioration.
- Immobility.
- Falls.
- Seizures.
- Difficulties with swallowing.
- Respiratory and breathing problems.
- Complete loss of self-care skills.
- Conditions leading to death.

**Care focus.** This is a stage where some individuals still reside at home and a period that poses significant challenges to caregivers as their ability to cope with 24/7 care demands (e.g., incontinence, multiple medical complications, and hospitalizations) may be exceeded. The same may also occur in a residential service setting, such as a group home. Administrative decisions have to be made

as to whether to change residence to a more intensive care setting or to augment staffing with personnel more familiar with nursing and personal care. However, every effort should be made to take into consideration and honor, when possible, the previously identified wishes of the individual.

During the end stage, care should be exercised with respect to nutrition and hydration, as the adult will often not independently eat or drink. Food should be prepared to prevent choking. Careful observation of caloric and nutritional intake along with body weight should be maintained so as ensure that the individuals does not become under- or malnourished. The same applies to liquid intake, as dehydration can adversely affect the metabolism or mental state of the adult. Artificial nutrition and hydration may be needed. Adherence to cultural and religious values of the person and family and use of feeding tubes (or alternative approaches) and other life sustaining treatments may present challenges in the absence of advanced directives and other expressions of the person's wishes (McCarron et al, 2011; McCallion et al., 2012).

Assessments should become more focused on physical health aspects and directed toward amelioration of any confounding problems due to immobility (e.g. bedsores), pneumonia or respiratory distress, and any potential organ failures. At this stage, relatives should be engaged with any end-of-life decisions left uncertain by the lack of any lawful declarations made by the individual prior to his or her mental incapacity. These may involve decisions on the use of feeding tubes, DNRs (do not resuscitate orders) and or DNTs (do not treat orders) for conditions that arise.

In late and end-stage dementia, communication ability also continues to break down, including the ability to form words. There is evidence that many individuals are able to understand more than they can express so efforts at communication by staff and family members are still important. Important strategies include those previously mentioned for mid-stage, as well as talking even if there is no response, using touch, responding positively to any sound the person makes (as an effort to communicate) and always saying 'goodbye' when it is time to leave their presence.

...a "good death," meaning a death that minimizes pain, involves preferred supports and caregivers, and honors preferences and plans made earlier for last days and post-death rituals and practices.

In each person's plan of care, there is a need to anticipate the end stage of dementia. Resources will be needed to maintain the person where he or she has always lived and/or to plan for transition to a setting better able to cope with the demands of care (including addressing deteriorating health conditions and death). If the person is to die at home, staff, family and household peers need significant support to deal with the anticipation and caregiving in the days and moments leading up to death. If hospice is to be utilized, this should be seamless, with continuing involvement of those important to the person and the provision of required supports. The value of maintaining linkages with people, places, possessions, and rituals that the person has valued should not be lost in such transitions, nor should movement to an alternative setting mean loss of contact for peers, friends, family, and staff who value and care about the person.

In each person's plan of care, there is a need to anticipate the end stage of dementia.

**Environmental modifications.** With the loss of mobility and reliance on others to move, lifts and other equipment are required to safely support the individual with transferring positions or to maintain and change position. Lifts such as sling lifts or sit-to-stand lifts should be used for transfers to and from bed as well as in bathing. These devices may, however, cause distress if the person no longer recognizes them or their purpose and their use should explained in a gentle and respectful manner. Specialty mattresses and or bed linens should be used (and training provided to caregivers) to prevent bedsores. Use of specialized chairs or recliners (e.g., 'Geri' or geriatric chairs)

with appropriate specialist consultation may provide for greater comfort, decubitus protection, and safety when someone is increasingly immobile.

**Training.** Increasing immobility in the late and end stage of dementia poses challenges for family and staff caregivers and risk for injury during efforts to lift and turn the person. Training in appropriate lifting techniques and in the use of lifting technology (such as Hoyer lifts) is important. There should be increasing attention to improve communication among those hospital, nursing home and hospice/palliative care staff who are involved, as well as with community-based spiritual and cultural supports for individuals and families, as the person with dementia enters this final stage. As physical capacities decline, staff and caregivers will likely spend more time with nursing and personal care tasks. Training should be directed toward identifying and responding to symptoms and signs of distress and pain management and prevention of deterioration of body functions, elimination of discomfort, protecting the integrity of the body, and supporting nutrition and hydration, as well as preventing complications associated with inactivity (bedsores, pneumonia, etc.). Training of staff and family caregivers should be oriented more toward comfort, dignity of the person, relief of pain and discomfort symptoms and understanding the value and consequences

Training of staff and family caregivers should be oriented more toward comfort, dignity of the person, relief of pain..and understanding the value and consequences of decision-making around artificial nutrition and hydration.

of decision-making around artificial nutrition and hydration (McCarron et al., 2011; McCallion et al., 2012).

**Outcomes.** For the person, a “good death”, meaning a death that minimizes pain, involves preferred supports and caregivers, and honors preferences and plans made earlier for last days and post-death rituals and practices. As death will be a loss for friends, family and staff who have cared over time, service plans should include support and grief counseling for those involved (Friedman & Helm, 2010; Kaufmann, 2005; Markell, 2008). End-of-life decisions (e.g., the designation of decision-makers, and what the individual had requested for care) should be reviewed. During this latter stage, there is a need for greater collaboration among intellectual disabilities services, families, community supports and hospice/palliative care organizations in offering education and preparation for the needed decisions and in effectively supporting those last days.

**Table 1d:**  
**Support Model for Addressing Dementia in Persons with Intellectual Disabilities**

LATE AND END STAGE		
Functional change	Change indicator	Action
Notable changes in self-care, daily function with minimal orientation and mobility.	Assessment indicates loss of mobility and general awareness and need for non-ambulatory care.  Dependent on others for care.  Swallowing difficulties, bladder and pulmonary infections, skin breakdown, leg and lung clots.  Progression to death.	Introduce more personal care (at times skilled nursing care).  Focus on physical stimulation; prevention of secondary conditions and problems from malnutrition and dehydration and / or aspiration.  Support, prepare family, friends, staff and others for death.  Access hospice care and / or palliative comfort care support.  Provide comfort and pain relief.  Provide for post-death rituals for family, friends and staff.

## 3. PROGRAM/SUPPORT OPTIONS

The NTG recognized that there are a number of critical aspects of supporting people so that they may remain in their homes and communities. Not all community environments are the best location for an individual as dementia progresses. There is a need to balance remaining in place and creating alternative small home-like

environments where an individual can be safely supported as dementia progresses. The NTG also recognizes a number of support scenarios where an adult with an intellectual disability will need assistance and greater levels of support once dementia symptoms become pronounced. These include the following:

### 3.1 WHEN ADULTS LIVE IN A PRIVATE HOME WITH A FAMILY MEMBER OR OTHER CAREGIVER

Across the globe, adults with intellectual disabilities are most apt to live with their families, even though in some countries alternatives such as personal living arrangements are prevalent (Fujiura, 1998; Hogg et al., 2000). In the USA, for instance, it has been estimated that 75 percent of older adults with intellectual disabilities reside with their families (Braddock et al., 2011).

Family caregivers of adults with an intellectual disability and dementia have unique needs and are challenged to continue to provide dementia care at home. There may also be multiple members of the family involved in various aspects of care or willing to assist even when they live at a distance. Often times, families may be unaware of what is available and are confused by the requirements related to accessing services. Active outreach by and to families undertaking dementia care is critical to preparing them for what is to come and preventing social isolation. Talking with other families facing similar challenges in the decline of their relative is comforting and provides a sense of not 'going it alone'.

Respite options need to respond to both psychosocial and practical needs of family members and include support for required household tasks and activities while encouraging them to maintain personal interests. Flexibility in the design of respite services is necessary as each family's

situation and needs will differ (Jokinen et al., 2012). Agencies should aggregate several workers, with diverse specialties, into a 'home assist team', which can be detailed to examine the home environment and suggest modifications, assess capacities and activities in order to offer potential adaptations, and monitor physical and mental health status. Such teams can be particularly helpful and enable continued stay at home. They will be most successful when they incorporate the family caregiver and other informal supporters as full members of the team. Informal caregiving networks within a family's community, including extended family, neighbors, faith communities, and friends (i.e., others to whom a family may have turned in the past) should be drawn upon. It is important that intellectual disabilities services providers work with Alzheimer's Association chapters, aging and disability resource centers, hospital discharge planners, area agencies on aging, caregiver support programs, and other community agencies to help in accessing these supports. Table 4 highlights the critical concerns and provides suggestions on sources of information and assistance and examples of what is available.

Respite options need to respond to both psychosocial and practical needs of family members and include support for required household tasks and activities while encouraging them to maintain personal interests.

**Table 4: Living with family or other caregiver**

Critical concern	Information and Assistance Source	Examples
Family members seek out support to cope with dementia.	Useful guides issued by Alzheimer’s Association and other groups, as well as specialized information available from intellectual disability organizations, such as the National Down Syndrome Society	Information provided on dementia and signs and symptoms, stages, and what to expect in the future  Assistance in meeting eligibility requirements for services  Counseling on care options  Contact with other families who have experienced a decline of a family member with Down syndrome, and/or accessing respite care or home health aid
Outreach activities geared to families of adults with intellectual disabilities and dementia by organizations that offer familial support	Local respite services [such as the Alzheimer Society of Canada’s First Link© program* or AAA caregiver programs]	Pamphlets and other media designed to inform family caregivers and connect them with support  Accessible hours of respite care and connection with volunteers and companion programs
Adaptations to home to accommodate stage-related changes.	Guides to adapting home for dementia, such as those of the Alzheimer’s Association  Participant directed care programs through AAAs and state intellectual disability agencies where funds may be directed to home renovation	Provide memory aids to assist with wayfinding, remembering chores, activities, and basic skills  Ramps, shut off switches and emergency response systems

\* Alzheimer Society of Canada (2012) First Link® program is designed to get people with dementia and their caregivers connected to a circle of information and support as early in the Alzheimer’s disease process as possible. Note: AAA = Area Agency on Aging



## 3.2 WHEN ADULTS LIVE ALONE OR WITH A HOUSEMATE

As many adults with intellectual disabilities grow older, they may live by themselves or with one or more other people (see Table 5 for critical concerns, sources of information and assistance and examples). When mild cognitive impairment is suspected or early stage dementia present, continued independent living is possible as long as the early aspects of dementia do not jeopardize the person’s safety and the person can still function with some degree of independence. However, planning for next steps is critical at this stage while the persons themselves are

still able to indicate what their preferences for care are and to ensure that they are appropriately linked with service providers, particularly if they were previously unknown. In the early stages, outreach support (such as visitations) and other personal support arrangements should be provided. It is also timely to involve family and housemates in planning with the person for an alternative living arrangement that can provide the personal assistance and supervision required when dementia progresses from early to later stages.

**Table 5: Living alone or with housemates**

Critical Concern	Information and Assistance Source	Examples
Providing housemates and significant others with information about dementia.	Family oriented information. [e.g., Scottish Down’s Syndrome Association (n.d.) pamphlet on “What is dementia? A booklet about dementia for adults who have a ‘learning’ disability.”]	Informing room or housemates about what dementia is and how to help their housemate
Adaptations to home to accommodate stage-related changes	Participant directed care programs through state developmental disabilities agencies where funds may be directed to home renovation	Provide memory aids to assist with way-finding, remembering chores, activities, and basic skills  Ramps, shut off switches and emergency response systems
Deciding on alternative living arrangements for the future.	Materials designed to help families plan [e.g., “Futures Planning for Families Supporting Adults with Life-Long Disabilities” (Varnet, 2010)]	Holding discussions with adult affected, family members, and friends about where may be an alternative place to live
Identifying supports that may help maintain the person in their desired living situation.	Intellectual disability service providers  Aging and disability resource centers  Alzheimer’s Association chapters	Planning sessions involving the person affected with family, roommates, other supports and key agencies
Periodic monitoring of function to assess continued capability to remain in place.	Instruments that provide skill and capability assessment and environmental assessment.	Re-administration of instrument periodically and interviews with housemates and others involved with the adult with supports provided that reflect changing needs identified

Sharing helpful information with housemates on critical signs of change in function is crucial. This enables the housemates to be alert to significant diminishing abilities. Adults living on their own, or otherwise independently, will need help with coping and adapting to the early signals of change or decline. Spouses and friends will also benefit from assistance and learning more about the nature of dementia and what to expect in the following months or years. Information, in these situations, can be a powerful tool to enabling continued living in place, adapting to changes, and making future plans. A 'home-assist team', similar to the support network for those residing with family, should be created to assist the individual living

alone or with a housemate. It is critical to help the person consider the need for alternative future living arrangements and other advanced planning.

Eventually, the person will not be capable of living alone and the demands on housemates sharing an apartment may become too burdensome. Sometimes it is prudent for an adult affected by early stage dementia to move to a formal community residential setting, such as a group home, a cluster apartment, or similar supported living arrangement. Such changes should occur within a person-centered plan rather than occur abruptly in response to a perceived crisis.

**Table 6: Living in small group settings**

Critical Concern	Information and Assistance Sources	Examples
Adaptations to home to accommodate early stage changes.	Guides to adapting home for dementia (e.g., Alzheimer’s Association publications) Participant directed care and other programs through State intellectual disability agencies where funds may be directed to home renovation	Provide memory aids to assist with way-finding, remembering chores, activities, and basic skills Ramps, shut off switches and emergency response systems
Information and education of staff, housemates, spouses, or others involved with the adult.	Family oriented information. [e.g., Scottish Down’s Syndrome Association (n.d.) pamphlet on “What is dementia? A booklet about dementia for adults who have a ‘learning’ disability.”] Caregiver (staff & family) intellectual disability-specific training (e.g., McCallion & Janicki, 2002).	Informing about communication and how to provide assistance when needed
Periodic monitoring of function to assess continued capability to remain in place.	Instruments for skill and capability assessment.	Re-administration of instrument periodically and interviews with housemates and others involved with the adult with supports provided that reflect changing needs identified
Assessment of impact upon housemates and primary caregivers.	Support group and or Interviews with housemates.	Determination that nighttime wandering, verbal or physical outbursts, and other disruptive behavior are having a deleterious effect on housemates and impinging on their mental health
Preparation of staff.	Education and training packages or programs (e.g., Fahey-McCarthy et al., 2008; McCallion & Janicki, 2002).	Training on stages of dementia, communication approaches, day to day care, modification of activities, management of co-morbid health concerns and preparation for end of life care.

### 3.3 WHEN ADULTS LIVE IN A GROUP HOME OR APARTMENT

Some adults with intellectual disabilities affected by dementia live in group homes or other supported living arrangements (see Table 6 for critical concerns, sources of information and assistance, and examples). It is important for organizations providing these services to consider and determine their commitment to an aging-in-place or in-place-progression model (Janicki, McCallion & Dalton, 2002; Janicki et al., 2005).<sup>1</sup> If the organization's governing body is not committed to supporting individuals through the progression of dementia, a person centered plan should be developed, identifying how current needs will be met and what anticipated needs will require an outside referral. This referral should be carefully planned with those outside services required and implemented with the best interest of the individual the prime focus. Such planning may help to avoid abrupt changes that can further compromise the limited coping mechanisms of the individual.

When a commitment is made to enable the person to continue to live in this setting, it is referred to as 'aging-in-place'. In these instances strategies have been determined to modify dementia-related care as the person experiences

*1 The premise for the 'aging in place' model is that the adult affected by dementia progresses through stages of disease (or dementia) at home and a range of appropriate supports are adapted and provided relevant to each stage of need. The premise for the 'in-place progression' model is that specialized staff and a specialized environment can best provide for long term care and that such care addresses the higher demand stages of Alzheimer's disease (or dementia).*

progressive decline with individual supports adapted and modified at each stage of dementia to permit the individual to remain within that home for as long as possible (often until death).

Agencies committed to 'aging-in-place' should pay particular attention to any environmental modifications required, special or augmented training for staff,

Greater interaction with social and medical day care programs and with dementia specific programs and senior centers in the community will likely increase the value of day programs in an overall intellectual disabilities and dementia strategy.

installation of safety features, and adaptations to services in other spheres of the adult's life and the eventual need for 24/7 staff. At some point an assessment may indicate that continued stay may be inappropriate due to safety concerns; planning for movement to a setting more appropriate for dementia care and supports will be need to be undertaken. Planning of ongoing supports needed for the primary caregiving staff and housemates is crucial and should be done with their collaboration.

### 3.4 WHEN ADULTS LIVE IN A SPECIALIZED ‘DEMENTIA-CAPABLE’ RESIDENCE

Some agencies maintain a home or multiple homes which specialize in dementia care (see Table 7 for critical concerns, sources of information, assistance and examples). While individual homes, where one or two persons are diagnosed with dementia, but the other residents are not, may follow an ‘aging-in-place’ model, other homes where all of the residents have some degree of dementia use an “in-place progression” model. This model usually involves a cluster of persons with varying levels of dementia residing in one or more specialty group homes. When more than one specialty dementia care home is operated by an agency, the individuals may move among the homes depending upon functional level and the level of support needed. How and when the person is moved should receive careful review and consideration.

Movement to another home with a similar internal design and appearance is preferable so as to minimize confusion and anxiety.

Such specialty homes can be developed by agencies when there is a commitment to continued community care with a concurrent interest in creating a dementia-capable<sup>1</sup> care environment. With a large number of people affected by dementia, such multiple homes can provide stage-related levels of supports. One home can provide for adults with moderate decline resulting from dementia, another can provide care for those with significant decline resulting from dementia, and another can provide care for those

1 ‘Dementia-capable’ means being skilled in working with people with dementia and their caregivers, knowledgeable about the kinds of services that may help them, and aware of which agencies and individuals provide such services.

**Table 7: Living in specialized dementia care homes**

Critical Concerns	Information and Assistance Sources	Examples
Physical design set up to accommodate changing needs and challenges associated with stage of dementia.	Specific designs that make a home ‘dementia capable’.	Increasing safety and security in homes as means to accommodate changing needs (e.g. mobility) and symptoms (e.g., wandering)
Staff expertise is stage contingent.	Assignment of staff with differing capabilities.	With non-ambulatory residents, staff are chosen who can provide more intensive personal care
Resident mix is assessed at certain intervals to ascertain the capacity of the service to meet individual needs and capabilities.	Administrative team decision meetings, along with family or advocates.	Service and program aspects may differ depending on remaining functions and decisions may be made to accommodate residents in a home with similar demand characteristics
Preparation of staff	Education and training packages or programs (e.g. Fahey-McCarthy et al., 2010; McCallion & Janicki, 2002)	Training on stages of dementia, communication approaches, day to day care, modification of activities, management of co-morbid health concerns and preparation for end of life care

with profound decline (or needing terminal care) resulting from dementia. Caregivers who have received specialty training can staff these homes, which may be defined by stages, and the physical environment can be adapted or designed to accommodate progressive decline in physical and mental abilities.

Agencies providing such care homes should set or adopt criteria for admission and movement from one level of care

Like other adults, persons with intellectual disabilities have a right to know about their physical or mental health condition.

to another and follow generally accepted standards for training of staff and adaptations, designs of the specialty environments, and allocation of clinical support staff.

### 3.5 WHEN ADULTS ATTEND DAY SERVICES PROGRAMS

With respect to day programs, some agencies are currently organized for large group activities. When dementia becomes more prominent, there is a need to reorganize to better support *small* group activities and flexibility in hours of involvement for the individual with dementia (e.g. partial versus full days). Table 8 provides suggestions on how day programs should be modified to support people with an intellectual disability and dementia (Nickle & McCallion, 2005).

To prepare for such a redesign, day programs should work more closely with aging and Alzheimer/dementia specific service providers and begin to focus on maintaining the individual’s previously learned skills and enjoyable activities rather than the addition of new skills and experiences. Staffing should become dementia-capable and training will be needed in particular to address

Day programs should..begin to focus on maintaining the individual’s previously learned skills and enjoyable activities rather than the addition of new skills and experiences.

wandering management, health related concerns and incontinence to reduce the likelihood that people dementia will be discharged and no longer able to attend the program. Greater interaction with social and medical day care programs and with dementia specific programs and senior centers in the community will likely increase the value of day programs in an overall intellectual disabilities and dementia strategy and create opportunities for cross-programming and shared resources.

**Table 8: Day program modifications**

Environment	Programming
<ul style="list-style-type: none"> <li>• Small group and one-on-one spaces</li> <li>• Dementia appropriate lighting (reducing shadows), noise abatement, flooring (reducing glare and avoiding patterns), way-finding cues</li> <li>• Fully accessible with adaptive toilets and a bathroom area (able to deal with toileting accidents)</li> <li>• Spaces to wander safely inside and outside with sitting areas</li> <li>• Gardens, kitchen, Snoezelen area, memory room, beauty salon</li> </ul>	<ul style="list-style-type: none"> <li>• Multi-sensory in approach; both stimulating and calming</li> <li>• Support of existing skills and memories rather than teach new things</li> <li>• Tailored to the likes and dislikes and previous experiences</li> <li>• Reminiscence, trips in the community, walks, simple exercise, massage, Snoezelen, horticulture, art, music, aromatherapy, hair/make-up/personal grooming (activity not training oriented)</li> <li>• Offered by staff trained in dementia care practices</li> </ul>

# 4. ANCILLARY ISSUES

## 4.1 ABUSE

A significant number of older adults are abused, neglected, or exploited in the United States (Stahl, 2012). A number of these are adults with intellectual and developmental disabilities, some of whom may have MCI or dementia. With diminished capacity, persons affected by dementia become vulnerable to different kinds of abuse or mistreatment, which can take varied forms: emotional, physical/sexual, and financial. Organizations should take special precautions against abuse from staff or family caregivers and others in the person's environment.

*Emotional abuse or mistreatment* may take the form of verbal exchanges of a demeaning or threatening manner, deprivation of emotional support, or withholding of treatment or medication for anxiety, paranoia, or other unsettling behavior. Often this may happen when caregivers are not informed or trained in communication techniques, or sufficiently supervised to prevent inappropriate interactions with adults affected by dementia.

*Physical and sexual abuse or mistreatment* may take the form of physical contact, either by unnecessary rough handling, hitting, and sexual violation. Such abuse may be purposive and used as means of coercion, or reactive to either verbal or physical outbursts by the adult with dementia. Staff or caregivers may also inadvertently revert to the use of abusive controls (e.g., improper use of chemical or physical restraints) out of frustration or as a means to control and or impose their will on the person supported. In all cases of physical abuse, such behavior is inappropriate and may be illegal under existing statutes. Physical abuse may take the form of sexual abuse, when staff or caregivers take advantage of the incapacity of the adult and violate him or her sexually. Physical abuse or mistreatment is more likely when there is lack of training or insufficient supervision. Prevention of abuse or mistreatment should be the responsibility of every

administrator and supervisor irrespective of reporting relationships.

*Financial abuse* may take the form of misappropriation of funds provided for the care and support of the individual or deprivation of services or care resulting from the misappropriation of funds. This may include the theft of checks or other deposits made by families, trusts, or government authorities in support of care of the individual or allowances for any discretionary spending, billing for services when the services are not provided, or the expropriation of any funds held in trust or on behalf of the individual for later life care or funerals. Persons affected by dementia may be particularly vulnerable as they experience diminished self-surveillance of their financial affairs.

*Neglect* is also a form of abuse; it is the refusal or failure to fulfill any part of a person's obligations or duties to a person under their care. It typically involves the refusal or failure to provide the person with dementia with such life necessities as food, water, clothing, shelter, personal hygiene, medicine, comfort, and or personal safety. *Self-neglect* also is a form of abuse. This occurs when an adult with dementia who lives alone loses the ability to care for him or herself, lacks support resources, and poses a threat to his or her health, safety, and well-being. Signs of neglect include malnourishment, evidence of a lack of hygiene or dressing in filthy clothing, or living in unsanitary or hazardous conditions.

Abuse, mistreatment, and neglect can also result from a lack of support for primary caregivers. Ongoing contact by other caregivers and friends is crucial in preventing situations that lead to abusive behavior. Primary caregivers should have the opportunity to talk with trusted others about the frustrations and problems of caregiving, as well as receive occasional relief from caregiving.

Whatever the source, abuse, mistreatment, and neglect should not be tolerated and any instances immediately reported to the appropriate authorities. Organizations providing services to people affected by dementia, either

directly or by support of informal caregivers, should have in place appropriate abuse prevention and reporting policies and procedures.

## 4.2 FINANCIAL

For the most part adults with intellectual and developmental disabilities are eligible for Medicaid and its associated benefits, which can be used to support formal residential options and a range of therapeutic services. Many states still operate small group homes supported by both Medicaid and state appropriations and as adults age these homes have become valuable resources for continued care in community settings. For those adults residing at home with their families, the recent Olmstead Decision related Department of Justice settlements with States and the *Jimmo et al. vs. Sebelius* class action law suit<sup>1</sup> settlement will make it easier for many adults including those with intellectual and developmental disabilities affected by dementia to receive services in the community and to have Medicare pay for qualified home-based care. Also of import is the application of the

1 The U.S. Department of Health and Human Services, Medicare contractors, and administrative review boards were determined to be arbitrarily limiting coverage for patients who did not show long-term improvement in their conditions, even though Centers for Medicare & Medicaid Services (CMS) regulations provide that these services should be covered.

Shared initiatives should be created across agencies and organizations that involve the aging, disability, and dementia care systems, whether for family supports, day respite, residential, or other supports and services.

medical-home and accountable care organization concepts under the Affordable Care Act which emphasize seamless chronic care management, including among families, providers, and disabilities system authorities (Weedon et al., 2012). Requirements for seamless care coordination and management among multiple providers will benefit families providing in-home care for adults with intellectual and developmental disabilities affected by dementia. State developmental disabilities authorities should continue to seek out and help define the mechanisms for optimizing Medicaid and Medicare financing of various aspects of long-term dementia-capable care in community settings.

## 4.3 MANAGING CHOICE & LIABILITY

There are concerns among both families and providers about liability issues in supporting choice in dementia care. One aspect of liability is how to handle the information about the diagnosis of dementia. Another is decision-making related to life planning, as well as where one may live and what one may do over the course of a day or week that is meaningful. With respect to the former, diagnostic information should be handled in accord with any privacy provisions under US federal and state laws or certification or regulatory agency policies. Another aspect is under what conditions is the diagnosis discussed with the

person affected. Like other adults, persons with intellectual disabilities have a right to know about their physical or mental health condition. How information is divulged or explained should reflect decisions about the ability of the person to understand the information provided and what effect the disclosure of this information may have on them. This is true for everyone and the emphasis should be on effective and respectful disclosure rather than denial of information. Participating in later life planning and in determining the aspects of advance directives and end-of-life planning is also crucial to respecting the dignity and

rights of adults affected by dementia and should occur while the adult is cogent, can benefit from counsel, and can still participate in life decisions.

With respect to the latter, enabling decision-making is crucial to fulfilling the dignity and rights of adults affected by dementia. Choice and liability are best managed when providers enable the individual and family to be part of the decision-making process about dementia care and supports.

## 4.4 MEDICATION

There are two major issues related to medications. The first is the efficacy and applicability of Alzheimer's-related medications and the second is the production of pseudo-dementia stemming from adverse drug reactions (ADRs).

Currently two categories of medications are in use in the American general population to aid in extending clarity and deferral of memory loss symptoms. One is the anticholinergic medications (e.g., Aricept®, Razadyne®, and Exelon®) and the other is the antiglutamatergic medication (e.g., Namenda®). Usually anticholinergic medications are prescribed during the early to mid-stage and are used to reduce memory loss; the available data do not support that these medications work with all individuals affected by Alzheimer's disease and there is evidence of a diminishing effect over time. The same holds true for antiglutamatergic medications, except that there are reports of a better efficacy in the mid-to-late stage of the disease. There is also some evidence that the combination of the two types of medications may have a compounding efficacy in early to mid-stage producing better results than either one alone. However, use of any of these medications is a matter for discussion between the person with dementia and their physician and these guidelines are not intended to provide recommendations on medication use.

It is important to note that extrapolations from generic study data to adults with Down syndrome and other intellectual disabilities and dementia are complicated. The research reported to date on the efficacy of these medications is mixed (Moran et al., 2013). Some research

Monitoring of...side effects in people with intellectual disability is difficult, and if...medications are being utilized, an initial base line should be completed on cognition, memory, and behavior prior to their use and a monitoring schedule established.

has shown that both anticholinergic and antiglutamatergic medications are effective (Kerins et al., 2008; Kishnani et al., 2009), but other research has shown that they are not effective (Hanney et al., 2012). Data on the treatment outcomes with adults with other intellectual disabilities (not Down Syndrome) is lacking. As for the general population with dementia, use of these medications should be based upon the judgment of the practitioner, taking into account their function in symptom relief, and the reaction to them by the adult with dementia. Adverse drug reactions for anticholinergic medications have been documented, including an increased risk in mimicking cognitive loss, memory reduction, increase in constipation, and urine incontinence (Kerins et al, 2008). Monitoring of such side effects in people with intellectual disability is difficult, and if these medications are being utilized, an initial base line should be completed on cognition, memory, and behavior prior to their use and a monitoring schedule established to allow for comparison for possible changes.

Adverse drug reactions from various medications have been reported to result in dementia-like behaviors (Gurwitz et al, 2003; Hanlon et al, 1997; Kongkaew et al., 2008), often because higher levels of a medication remain in the system of older adults for a longer period of time than is found for younger age adults. These ADRs may be caused by: a) age-related biological changes in the body reducing the ability of older adults to metabolize medications, b) drug-to-drug interactions due to an

increase in the number of medications taken related to an increase in chronic diseases and disorders, or c) an increase in the number of over-the-counter medications consumed, also, leading to drug-to-drug interactions. The usage of seizure and psychoactive medications also can contribute to the higher risks of developing ADRs. Many ADRs may mimic, mask, or exacerbate signs or symptoms of diseases and disorders, including cognitive impairment, and may result in misdiagnosis of a health problem (Gurwitz et al., 2003; Hanlon et al., 1997; Kongkaew et al., 2008).

The risk for ADRs in adults with intellectual disabilities is presumed to be high because: a) the higher concentration of medications in their body for a longer time and from a much earlier age, (age 30 instead of age 70), b) the high prevalence of chronic health issues increasing drug-to-drug interactions, c) the interactions of the underlying disorder with medications affecting how ADRs will be expressed, and, most importantly, d) the exacerbation of ADRs with the early age related changes experienced. Alterations in symptoms may be attributed to the underlying intellectual disability rather than an ADR, so care providers should

Consultations with a nutritionist and other clinical supports are recommended to plan for individually tailored interventions.

remain vigilant to ensure that diagnostic overshadowing doesn't occur otherwise serious illness or even death may occur. Additionally, with medications there is a phenomenon termed "aging in". Because of the age-related changes found in many older adults, there will be a reduced ability to metabolize medications. Medications that they may have been taking for many years may start to produce ADRs that may go unrecognized because they had not previously presented a problem. Providers should increase the awareness of staff and family to changes that may be associated with ADRs and produce documentation that can be used by health care professions to evaluate the causes of changes observed in older adults with intellectual disabilities (Deb et al., 2008; McGilvery & Sweetland, 2011).

## 4.5 NUTRITION

Weight loss and under-nutrition are common complications that occur with dementia. Weight loss may occur in the early stages of dementia before diagnosis and is a sign that the individual's food or energy intake is insufficient for his or her needs. Under-nutrition adversely affects an individual's functional abilities, resistance to infections, and general overall health status and independence. As dementia progresses, the person increasingly becomes more dependent on caregivers to meet nutritional needs. Yet malnutrition is preventable, or can be ameliorated, if early intervention strategies are set up and management of emerging problems is rapid and appropriate. Consultations with a nutritionist and other clinical supports are recommended to plan for individually tailored interventions to address problems.

There are five general types of feeding difficulties: initiating the feeding, maintaining attention, getting food into the mouth, chewing food, and swallowing food (Chang & Roberts, 2011). As dementia progresses, the person may have impaired ability to use eating utensils and recognize food and know what he or she should do with it. Impairment of fine motor skills and visual problems may make it difficult for the person to get food from the plate to the mouth. Poor oral health and the inability to coordinate chewing and swallowing can also affect food intake. Psychological, medical, and social issues, including depression and the side effects of medication, can cause somnolence and agitation that can affect food intake. Additionally, environmental factors such as the atmosphere in the dining room, loud noises, and social conversations among people can affect food intake. Cultural factors

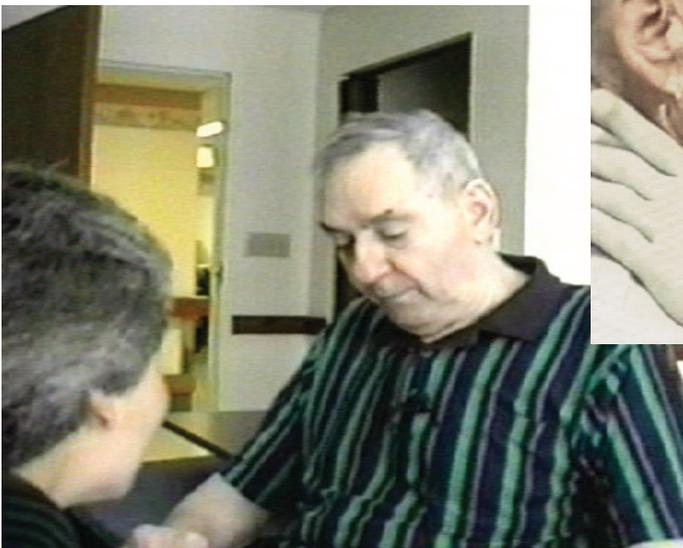
also affect food preferences, utensils used, expression of feeding difficulties, and the way caregivers address them. Eating problems (e.g., difficulty chewing and swallowing) can lead to aspiration pneumonia.

Small changes in the dining environment and experience should be employed to help alleviate feeding problems (e.g., improving lighting, accompanying meals with soft music, allowing more time for dining, and reducing loud conversations or other noises, as well as use of color examples noted in Table 4). Foods should be prepared to ease chewing and swallowing and as dementia progresses (e.g., food cut into bite-size pieces, the serving of soft foods or ground / pureed foods). Serving foods that are difficult to chew thoroughly (e.g., raw vegetables) should be avoided. Caregivers should be alerted about signs of problems with swallowing and signs of choking and taught the Heimlich maneuver in case of an emergency (Medline Plus, 2012).

Some simple practices should be employed to address a decreased appetite. These include preparing favorite foods, increasing physical activity, or planning for several

small meals rather than three large ones per day (as the person's activity level decreases, he or she may not need as many calories). If the person's appetite does not increase and/or he or she is losing weight, caregivers should consult a physician.

Particularly challenging are the nutrition issues as the person enters the late and end stage of the dementia decline process. Difficulty holding food in one's own mouth, chewing and swallowing concerns, agitation and distress, spitting, and food inhalation/aspiration are all stressful for the person, the family and staff. Influences of cultural and religious values of the person, the family and, at times, staff emotions and relationships and a lack of undisputed outcome data to support or discourage use of feeding tubes (or alternative approaches) present formidable clinical and care challenges (McCallion et al., 2012). For these reasons, providers should pay special attention to maintaining nutrition and hydration, and appropriate body weight.



## 5. CONCLUSIONS

These guidelines were developed to help address the burgeoning care demands being experienced by families and provider organizations as the number of older persons with an intellectual disability affected by dementia increases. The guidelines are suggestive of common-sense as well as those drawn from practical experience and the research literature. They are designed to enable an improvement in quality care for persons with an intellectual disability affected by dementia as they live out the balance of their lives.

To provide care for individuals affected by dementia, intellectual disability services will need to plan and reorient practices. This includes ensuring the incorporation of person-centered principles, the value of family and staff relationships in care, maintenance of community living for people with deteriorating abilities, and services directed by the individual affected to the extent possible. Integrated supports and targeted services rather than standard care packages need to be developed for individuals, their families and other caregivers.

On a systems level, organizations and families should emphasize innovative program and services development (even in times of limited resources) to address this insidious disease and maintain quality in the lives of adults with intellectual disabilities first affected and then devastated by dementia. Shared initiatives should be created across agencies and organizations that involve the aging, disability, and dementia care systems, whether for family supports, day respite, residential, or other supports and services. States and localities should advocate for the inclusion of the concerns and needs of people with intellectual disabilities within any legislative actions, state and local budgetary allocations, and state plan initiatives related to dementia.

NTG anticipates that these guidelines will be used throughout the United States and complement any similar efforts undertaken by the federal government and the federal Advisory Council on Alzheimer's Research, Care, and Services in response to the National Alzheimer's Project Act. These guidelines may also be applicable for policy-makers, service providers and families in other countries concerned with supporting their older-aged populations of adults with intellectual disabilities who have dementia.

Information can be a powerful tool to enabling continued living in place, adapting to changes, and making future plans.

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