



**Guidelines for Dementia-related
Health Advocacy** for Adults with
Intellectual Disabilities and
Dementia of the National Task Group
on Intellectual Disabilities and Dementia
Practices

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Summary

Many adults with intellectual and developmental disabilities are living longer resulting from the positive effects of improved health care and quality of life. Concurrently, with advanced age, more adults with intellectual and developmental disabilities are and will be experiencing age-related health problems and also exhibiting symptoms of cognitive impairment and decline, some attributable to dementia.

Early symptoms of dementia can be subtle and in adults with intellectual disability are often masked by their lifelong cognitive impairment, combined with the benign effects of aging. A challenge for caregivers is to recognize and communicate symptoms, as well as find appropriate practitioners familiar with the medical issues presented by aging adults with lifelong disabilities.

Noting changes in behavior and function and raising suspicions with a healthcare practitioner, during routine or *ad hoc* visits, can help focus the examination and potentially validate that the decline is the result of the onset or progression of dementia. It can also help in ruling out reversible conditions that may have similar presentation of symptoms typical for Alzheimer's disease and related dementias.

To enable caregivers, whether family members or staff, to prepare for and advocate during health visits, the National Task Group on Intellectual Disabilities and Dementia Practices has developed these guidelines and 12 recommendations for dementia-related health advocacy preparation and assistance that can be undertaken by provider and advocacy organizations

It is anticipated that family members and staff working in the field will benefit from adopting these guideline and furthering the goal of enhancing quality of life for older adults with intellectual and developmental disabilities.



Background

An emerging public health concern is the increasing prevalence of adults with intellectual disability (ID) diagnosed with Alzheimer's disease and related conditions resulting in dementia (Janicki & Dalton, 1999; Jokinen et al., 2013; National Task Group on Intellectual Disabilities and Dementia Practices [NTG], 2012a; Sheehan, Ali, & Hassiotis, 2014; Strydom, Hassiotis, King, & Livingston, 2009; Watchman, 2014; World Health Organization [WHO], 2012).

Consequently, questions have been raised as to how formal (paid staff) and informal (family or friends) caregivers could best obtain help with accessing appropriate diagnostic and postdiagnostic supportive health services (Bishop & Lucchino, 2010; Bishop, Robinson, & Van Lare, 2013; Jokinen et al., 2013). In 2010, the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) was formed and charged to work in correspondence with activities emanating from the government's implementation of the National Plan to Address Alzheimer's Disease (U.S. Department of Health and Human Services [DHSS], 2012), as the nation lacked a coherent policy on enabling adults with ID to receive appropriate community-based diagnostic and dementia care services (Janicki & Keller, 2014).¹

¹ (Note: The National Task Group on Intellectual Disabilities and Dementia Practices was formed in 2010 with the support of the American Association on Intellectual and Developmental Disabilities, the (now named) Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago, and the American Academy of Developmental Medicine and Dentistry; its role was to examine and report on the needs of adults with dementia and intellectual disabilities, and after the

The NTG is a member of the Leaders Engaged in Alzheimer's Disease [LEAD] Coalition based in Washington, D.C.) As part of the NTG's activities, enabling family and paid staff caregivers to undertake dementia-related health advocacy was designated as a priority (NTG, 2012a). This was to be accomplished by an awareness campaign targeting caregivers who needed to access diagnostic services and healthcare providers (NTG, 2012a), by producing educational materials (NTG, 2013), by providing increased information to primary healthcare personnel (Moran et al., 2013), and by developing training curricula for service providers (Jokinen et al., 2013; NTG, 2014).

Older Adults with Intellectual Disability

These efforts emanated from the growing realization that increasing numbers of adults with intellectual and developmental disabilities in the United States were living into old age, paralleling the extended longevity of age peers in the general population (Heller, Janicki, Hammel, & Factor, 2002; Institute of Medicine, 2007). (Although the term *intellectual and developmental disabilities* is used generically, this guideline applies more specifically to those adults with intellectual disability, who experience intellectual and functional abilities that are below norm.) Population estimates have indicated that over 650,000 adults age 60 and older with intellectual and developmental disabilities live in the United States, this number is projected to double by 2030 (Centers for Disease Control and Prevention,

passage of the National Alzheimer Project Act in 2011 to track the progress of the National Plan to Address Alzheimer's Disease relative to intellectual disabilities [see Janicki & Keller, 2014].

2013; Heller & Caldwell, 2006; Tyler & Noritz, 2009).

Further, it is estimated that approximately 8% of this number of people may be affected by Alzheimer's disease and related dementias (NTG, 2012a). Many of these older adults live at home with aging caregivers or other family members, who are also experiencing age-related changes and increasingly need more day-to-day help (Haley & Perkins, 2004; Heller et al., 2002; Rizzolo, Hemp, Braddock, & Schindler, 2009). Others live in various community support settings where the increased presence of dementia is challenging care staff and administrators (Hogg, Lucchino, Wang, & Janicki, 2001; Janicki, McCallion, & Dalton, 2002; Rizzolo et al., 2009).

Until the latter part of the 20th century, life expectancy among most adults with ID was lower than among their age peers. Many adults with ID lacked the supports to live independently in the community. Over the past three decades as social conditions changed, advances in public policy and legislation and enhanced advocacy enabled adults with ID to survive well into their elder years and have the resources to enjoy life in normative community settings (Bittles et al., 2002). With a significant shift in public policies leading to greater support of self-determination over this period, increasing numbers of adults with ID have been able to live on their own, often unattached to any specific support agency (Heller & Caldwell, 2006; Heller et al., 2002; Tyler & Noritz, 2009).

Health, healthcare, and Dementia

Such independence, however, has also led to less formal attachments or access to healthcare providers, often compromising efforts at prevention and health-related oversight and treatment (NTG, 2012a; U.S. Department of Health and Human Services [USDHHS], 2002). With advanced age, many adults were also found to be at risk or susceptible to age-related physical and mental health problems, including neuropathologies, such as Alzheimer's disease and related dementias (Cooper, 1997; Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2001; Haveman et al., 2010; Iacono & Sutherland, 2006; Moran et al., 2013; Torr & Davis, 2007; WHO, 2012).

Adults with ID who have Down syndrome have been found to have a greater risk for Alzheimer's disease and demonstrate an earlier onset of symptoms when affected (Ball et al., 2006; Ball, Holland, Treppner, Watson, & Huppert, 2008; Evenhuis, 1997; Holland, 1999; McCarron, McCallion, Reilly, & Mulryan, 2014a; Oliver & Kalsy, 2005).

Even though they have an increased chance of developing early-onset Alzheimer's disease, other age-related conditions may present with symptoms that may appear similar to those of dementia, such as depression and thyroid dysfunction, or that may result from overmedication or undernutrition, which are amenable to treatment (Ball et al., 2006; Ball et al., 2008; Bishop et al., 2013; Holland, 1999; Prasher, 2005).

Health issues among older adults are gaining attention with the recognition that many are challenged by the same types of diseases and conditions as found among peers in their communities (USDHHS, 2002;

Sutherland, Couch & Iacono, 2002). It has been noted that older adults with ID experience varying differences in the prevalence of health risk factors, but that cardiovascular disease is as prevalent among people with ID and is as common a cause of death as in the general population.

Cardiovascular and respiratory diseases and cancer were the main causes of death in older adults with ID (Janicki, Dalton, Henderson, & Davidson, 1999). Many of these conditions preexisted later years and may have been left unattended. Further, with the progression of dementia it is more difficult to manage coexisting, chronic health conditions (Tilly, Wiener, Gould, & O’Keefe, 2011). Comorbidities in adults with dementia are a major concern, as declining cognitive function can preclude self-report of pain, discomfort, or debilitation. Comorbidities, such as seizures, cardiovascular and respiratory disease, gait disturbances, depression, and incontinence, are also significantly related to both the presence and stage of dementia (McCarron, Gill, McCallion, & Begley, 2005; Prasher, 2005).

Additionally, lifestyle and lifetime exposure to risk including smoking, diabetes mellitus, hypertension, coronary artery disease, and high cholesterol can contribute to ill health and lead potentially to dementia (Aggarwal, 2013). Thus, surveillance of health risk factors and health advocacy take a prominent role in both extending physical wellness, in the face of cognitive decline and ensuring that health issues do not compromise quality of life in older age.

Recognizing early signs and symptoms of cognitive decline and dementia is important, as it permits referrals for

assessments to rule out treatable causes. Alternative and in some instances treatable conditions that may present as symptoms of dementia include depression, seizures, hypothyroidism, hearing impairment, infections, and adverse side effects of medications, sleep apnea, heart disease, and anemia (Bishop et al., 2013; Janicki et al., 1997; Moran et al., 2013).

Acknowledging early signs and symptoms can also help determine proper interventions and lifestyle changes that may delay aggressive decline and health complications (McCarron et al., 2005; Oliver & Kalsy, 2005). Research indicates that the neuropathology of dementia may have its genesis some 10–12 years before the observable behavioral symptoms; therefore, the earlier these symptoms are recognized, the more effective the interventions may be (Norton, Matthews, Barnes, Yaffe, & Brayne, 2014).

Dementia and Intellectual Disability

Early symptoms of dementia can be subtle and in people with ID are often masked by their lifelong cognitive impairment and benign effects of aging (Oliver, 1999). Thus, many caregivers may be unaware of the key signs associated with onset of dementia in adults with ID and may not readily identify them when they occur. Generally, early warning signs may include behavioral challenges, such as the following: getting lost or misdirected, being confused in familiar situations, and exhibiting memory problems; difficulties with gait and balance; late onset seizures; and changes in personality (Henderson & Davidson, 2000; Janicki & Dalton, 1999; Moran et al., 2013; Prasher, 2005).

With the progression of dementia, these symptoms may become more prominent and include further gait deterioration, changes in mood, communication difficulties, sleep disturbances, wandering, incontinence, and lessening functionality in self-care (Patti, Galli, Ferrario, Freeland, & Albertini, 2010). At times, the early signs may indicate the presence of mild cognitive impairment (MCI), often a precursor for dementia, and may include notable aggressiveness and depressed emotional state (Cooper & Prasher, 1998, Kinsky-McHale Urv, Zigman & Silverman, 2012; Silverman, Krinsky-McHale, Schupf, & Zigman, 2010).

Among adults with Down syndrome, the onset of symptoms may exhibit earlier and be associated with a more rapid progression of cognitive and functioning losses (Cooper & Prasher, 1998; Evenhuis, 1997; Holland, 1999; Holland, Hon, Huppert & Stevens, 2000). Generally, factors influencing more rapid decline include age, psychotic symptoms, and gait deterioration (Patti et al., 2010; Wilkosz et al., 2009).

More aggressive forms of Alzheimer's disease are usually associated with younger age, poor nutritional status, and significantly impaired performance on measures of attention and executive function (Schmidt et al., 2010). The progression of MCI to dementia in adults with Down syndrome can be significant; one study found that this occurred in about 33% of the subjects over an 18-month period, apparently progressing more rapidly than in the general population (Silverman et al., 2010).

Dementia and Health Advocacy

The onset of dementia can present certain difficulties for caregivers, whether family members or paid staff (Janicki, McCallion, & Dalton, 2000). Some of these challenges may include a lack of knowledge about early symptoms, difficulties with seeking out help for screening and assessment to obtain an accurate diagnosis and finding appropriate clinical services to aid with maintaining health status, as well as poor communication with medical and health services personnel during medical appointments and inadequate follow-up for treatment of comorbidities (Aggarwal, 2013; Iacono & Sutherland, 2006; Janicki et al., 2002; McCarron et al., 2005).

There may also be difficulties when locating appropriate assessment and diagnostic services that can help rule out conditions that mimic, mask, or exacerbate the symptoms of chronic dementia (Bishop et al., 2013, Henderson & Davidson, 2000; Llewellyn, 2011; Moran et al., 2013; Oliver & Kalsy, 2005; Pary, Rajendran, & Stonechipher, 2006). These difficulties may impede receipt of appropriate health and diagnostic services. Given the nature of the problems encountered, it may fall on family, friends, and staff to become advocates.

Dementia-related health advocacy

Being alert to suspicions, noting the areas of concern, locating the appropriate practitioner to make an assessment, arranging for assessment visits, and following through on dementia care and support recommendations all fall under the concept of *dementia-related health advocacy* (Bishop et al., 2013; Keller, 2013; Robinson, Dauenhauer, Bishop, & Baxter, 2012). The NTG posits that the aims of health advocacy

related to dementia and intellectual disability include the following: (a) representing the interests of adults suspected of having or being impacted by dementia; (b) aiding in ensuring that all health matters, irrespective of the presence of dementia, receive attention; and (c) initiating and following through on contacts with the health system.

The NTG (2012) recognized these difficulties as areas of concern, given the large number of adults with ID living by themselves, with family members, or with a spouse or house mates, as well as those living in co-housing assisted by paid staff. Despite the initiation of the Patient Protection and Affordable Care Act (Public Law 111–148, enacted on March 23, 2010), amended by the Healthcare and Education Reconciliation Act of 2010 (Public Law 111–152, and enacted on March 30, 2010), many adults living on their own may not yet be affiliated with care agencies or formal healthcare providers and thus may not routinely see health personnel or be under surveillance for at-risk conditions as they age (Heller et al., 2002; Janicki, Heller, Seltzer, & Hogg, 1996; Moran et al., 2013).

In contrast, those adults living in agency-sponsored housing often have more connections with healthcare services, but the staff may not be tasked with being health advocates. Because of the concerns that many preventable or treatable health conditions, including early signs of dementia, may go unrecognized or unreported, the NTG tasked one of its working groups to examine these challenges and suggest solutions.

The resulting guidelines set out a course for preparing caregivers, enabling enhanced interactions with healthcare practitioners, raising awareness and enabling

self-advocacy for health treatments, and offering an evidence-based prospectus that could aid caregivers to more effectively access healthcare services and practitioners (NTG, 2012a). With the implementation of the Affordable Care Act and its focus on wellness and annual cognitive assessments, these guidelines are even more relevant (Jokinen et al., 2013; Moran et al., 2013; Ne’eman, 2013).

The NTG Guidelines

The NTG guideline development process involves leaders and representatives from various stakeholder organizations related to health and intellectual disability, as well as members of various profession and multidisciplinary associations, such as the special interest groups within the American Association on Intellectual and Developmental Disabilities and the Gerontological Society of America. The process also tracks what is proposed within the National Plan to Address Alzheimer’s Disease, in this case *Strategy 2. D – Identify high-quality dementia care guidelines and measures across care settings* (USDHHS, 2014a).

Considering the range of issues related to healthcare advocacy and dementia, the NTG guidelines address enhancing awareness of early signs, as well as improving caregiver sensitivity to noting change in behavior and function, raising suspicions, obtaining appointments, aiding in the determination process, and implementing recommendations (see Table 1). The guidelines also address systemic factors, such as improving access to specialists, providing continuing education, benefiting from clinical assistance, and corresponding with the

annual wellness visit provisions of the Affordable Care Act. The core barriers to health advocacy and effective services provision are listed in Table 2.

The reference to *caregivers* is generic and includes both informal (e. g., family members, spouse, friends) and formal caregivers (e. g., paid staff). Additionally, the guidelines suggest a process for undertaking health advocacy, questions to raise during the annual wellness visit or at specific appointments to discuss concerns related to cognitive decline or health complications (see Table 3), and a set of recommendations for training content in healthcare advocacy and system integration with respect to dementia (see Table 4).

In these guidelines we have defined ***dementia-related health advocacy*** as a process that enables people functioning as caregivers, medical care advocates, or healthcare proxies, whether family members (including spouses, parents, or other relatives) or agency staff to advocate on behalf of a person with an intellectual disability, either in concert with the person or consistent with his or her advance directives, when seeking medical and other health and dementia- related services, participating in assessment and diagnostic sessions, or following up on recommendations for treatment of dementia or associated conditions.

The term ***provider*** has been used to refer to organizational deliverers of services and ***practitioner*** refers to any health services professionals. These guidelines aim to complement the NTG's other guidelines (see Jokinen et al., 2013; Moran et al., 2013) and

focus specifically on dementia-related health advocacy.

The following sections explain the issues and challenges in obtaining health assessments and diagnostic services to provide a guide for enabling caregivers to become effective advocates for health and dementia-related medical visits and assessments. They correspond to the factors, functions, problems, and key challenges and guidelines listed in Table 1. The factors noted reflect the key features that are found associated with each area; functions define a means of operating in which a person or organization may address concerns.

Information and Awareness (Caregivers)

Recognizing symptoms.

Effective dementia-related health advocacy may be impeded when caregivers are not able to recognize and communicate symptoms. Lack of adequate information about the implications of changes in function and behavior and inability to differentiate between expected and unexpected changes are additional impediments. Also, the degree of lifelong cognitive impairment and myths and stereotypes about those impairments may impede early recognition of changes (Bishop & Lucchino, 2010; Robinson et al., 2012).

Severity of cognitive impairment may also be a factor. Symptoms of dementia among adults with ID with mild or moderate levels of impairment may appear differently due to the pre-existing disability and communication difficulties. For example, symptoms may be perceived as stereotypic or

inappropriate (i. e., “challenging”) behaviors rather than symptoms of an underlying health-related or cognitive pathology. Symptoms among adults with ID with more

severe impairment levels may pose a different challenge: these cases are often difficult to discern because of the low rate of verbal communication and general

Table 1: Challenges for health care advocacy and access and guidelines for helping organizations

Area	Factor	Function	Problem	Guideline
Information and awareness of symptoms (Caregivers)	Observation of symptoms, change, or losses	Recognize behavioral changes as symptoms through development of observational skills.	Often early signs of dementia are missed because of caregiver’s lack of information.	Guideline #1: Provide caregivers with information on differential risk factors and signs associated with dementia in adults with intellectual disabilities.
	Documentation and reporting of changes or functional loss	Report accurately and specifically symptoms, including type, severity and frequency of behaviors, time of day, and environmental context. Report accurately activities of daily living and tracking the degree of caregiver support as the disease progresses.	Early symptoms of dementia may be subtle or complex or masked and can be missed when confounded by lifelong cognitive or sensory impairment.	Guideline #2: Increase caregivers’ awareness of symptoms (raise the index of suspicion) associated with dementia.
		Provide for agency policy and procedures on reporting and documenting.	Awareness of life history may be absent, or written. Records may be incomplete or unavailable.	Guideline #3: Ensure that life history and functioning information is retrieved, reconstructed, or developed when possible.
Information and awareness of symptoms (Practitioners)	Ensuring practitioner awareness	Determine background and experience with intellectual disabilities of practitioner.	Many communities lack health care practitioners who have extensive experience with adults with intellectual disabilities.	Guideline #4: Initiate cooperative continuing education programs in aging and intellectual disabilities for local health care practitioners and ancillary personnel.

			Often diagnoses are inaccurate as other factors may contribute to behavioral changes and be misinterpreted as dementia.	Guideline #5: Increase practitioners' understanding of the likely symptoms and presentation of dementia by adults with intellectual disabilities.
The referral and assessment process	Preparing for the appointment	Ensure that family/staff going to the health care appointment have specific information and are comfortable discussing the information with the health provider/practitioner.	Finding and accessing knowledgeable and experienced community health practitioners who can begin the diagnostic process can be challenging.	Guideline #6: Establish a regional directory of practitioners who are experienced with examining adult patients with intellectual disabilities.
		<p>Prioritize symptoms by those affecting quality of life of health and needing immediate attention.</p> <p>Send the correct person to the appointment, especially if it is a follow-up appointment with previous lack of success for symptom improvement or slowing of decline.</p> <p>Have person going practice for the appointment, if necessary.</p>	<p>As few health care practitioners have training or experience with adults with intellectual disabilities, it may be difficult to find a knowledgeable provider.</p>	Guideline #7: Assist caregivers through organizational support with finding health care providers who are knowledgeable and experienced with assessing adults with intellectual disabilities.
	During the appointment	<p>Prioritize presentation of symptoms.</p> <p>Take notes for later discussion with agency team and/or other family members.</p>	Organizing a referral or carrying out care suggestions can be challenging if the caregiver doesn't have access to others who can guide them.	Guideline #8: Establish a 'dementia specialist' or 'dementia team' on an agency or regional basis who/which can assist caregivers with gathering information and obtaining a referral for a dementia assessment (as well as consult within follow-ups).
Follow-up and clinical assistance	Follow-up after appointment	Ensure that the appropriate family member or staff receive information needed for the follow-up.	Caregivers may be reluctant to seek assistance in understanding the disease of dementia or be unfamiliar with	Guideline #9: Improve communication between caregivers and practitioners by training and instituting a process for

		Assign responsibilities for follow-up.	available resources.	dementia-related health advocacy amongst caregivers.
		Monitor follow-up, including making any further appointments.	Family and advocates often do not have the knowledge or expertise to work in partnership with health care providers of adults with ID and staff may not have sufficient support within their agency to successfully implement any post-diagnostic prescribed activities.	Guideline #10: Establish follow-up processes with assigned clinicians or advocates so that families have access to personnel who can help advise them.
		Develop and use a process of monitoring for results from the follow-up of the recommendations.		
Communication with health care personnel	Being comfortable discussing symptoms and assessment with practitioner. Seeking clinical services that provide health assessments.	Assure familiarity with terms and procedures and the medical assessment and review process.	Caregivers may be unfamiliar with the medical examination process or with some of the language used to describe medical conditions.	Guideline #11: Provide training or educational materials to caregivers on communication with health personnel.
		Aid the adults with developing an advance directive and organize a health proxy. Set up specialty clinics to provide assessment and diagnostic services.	State laws concerning advance directives and health proxy may not offer sufficient guidance on need for ensuring that all documents will be valid.	
			Lack of specialized and experienced clinicians who can assess and diagnose dementia in adults with ID	Guideline #12: Implement innovative approaches to health assessment as part of the planning and organizing of local dementia capable services.

Sources: (Bishop & Lucchino, 2011; Jokinen et al., 2013; Moran et al., 2013; NTG, 2012a)

functioning (Ball et al., 2008; Bishop et al., 2013; Evenhuis et al., 2001; Perkins, 2007; Service, Tyler, & Janicki, 2006).

At times, caregivers may not know how to best express their suspicions (Ball et al., 2006; Bishop et al., 2013; Esralew et al., 2013; Evenhuis et al., 2001). Capability in recognizing and understanding symptoms is

important because it is often up to the caregiver to communicate these symptoms; workers in the health system may be unaware of the functional changes presented by aging people with ID (Jamieson-Craig, Scior, Chan, Fenton, & Strydom, 2010).

Adults with ID are as likely to experience the same age-related diseases and changes as their age peers in the general population (Bishop & Lucchino, 2010; Iacono & Sutherland, 2006; Moran et al., 2013). For some adults, however, complications, including verbal inability to report symptoms, blaming the cognitive impairment rather than possible disease or physical illness, and identifying pain as a “behavioral concern” create challenges for health practitioners. In addition, commonly held stereotypes, including not expecting adults with ID to be able to reliably self-report symptoms, may lead to overlooking insights into the problems the adults may have.

Practitioners may have limited access to information, training, or experience regarding adults with ID; and this limitation may also lead to inaccurate impressions. An informant should be present at health interviews who can relay any symptoms that have raised suspicions, particularly if the adult being examined is not a reliable self-informant (Pary et al., 2006).

Awareness of the meaning of symptoms adds value to the information to be presented or helps identify the basis for behaviors that otherwise might be initially misidentified. Caregivers need to know whether the suspicions they have are appropriate and what they need to do to confirm them. Within agencies, lack of familiarity with the individual because of

frequent staff turnover and the unavailability and lack of reliability of information can create a barrier to consistency in symptom recognition.

Viable strategies for working around these barriers need to be put in place for successful dementia-related health advocacy (Bishop et al., 2013; Evenhuis et al., 2001; Moran et al., 2013; Service et al., 2006; Wilkinson & Janicki, 2002). Assembling a list of questions about suspicions that can be discussed during a visit with the practitioner is a good starting point. At times agencies may not have yet acknowledged the difficulties that may present with dementia and do not have functional policies and practices in place that encourage early recognition and reporting of symptoms, noting of suspicions of decline, or encouraging early referrals to health practitioners for assessments and diagnostics.

The NTG recommends that caregivers should be provided with information and training on noting general symptoms, how to best document them, and how to best convey them during the health interview.

(See Table 1, Guidelines 1 and 2)

Familiarity with life history

Problems related to lack of information on the individual’s life history, both experienced and documented, can be a missing link in the assessment. Efforts should be undertaken to reconstruct, assemble, and present as much historical data as possible. Gathering history information, including family diseases, is needed to gain an overall picture of the adult’s behavior, function, and health and context for the symptoms. In many settings, however, such records may be

lacking and are not typically present when the aging adult is living at home (Janicki et al., 2002; Perkins, 2007).

Retrieving life histories to track development and possible exposure to pathogens and relate experiences with physical conditioning and history of nutrition may be difficult. Gleaning as much anecdotal information from family members or others

who have known the adult and reviews of rudimentary records can help in composing a life history.

Ideally some of this information can also be gleaned directly from the aging adult. The tendency for compliance, however (i.e., being agreeable and not revealing complaints), among those adults who have lived in congregate care settings, the degree

Table 2: Barriers for effective dementia-related health care provision

Barrier	Adverse Barrier Impact
Lack of information or knowledge enabling recognition of signs and symptoms by caregivers	Missing signals of behavioral change and possible further decline as condition remains unattended
Lifelong intellectual disability may mask early signs and symptoms of dementia	Missing signals of behavioral change and possible further decline as condition remains unattended
Confusion over which behaviors may be age-associated and which may be symptomatic of MCI or dementia	Delay in referral for a comprehensive assessment
Stereotypes of function held by health practitioners which may question self-report reliability and using the adult as an informant	Missing particularly pertinent information provided directly by adults related to dementia or other physical conditions
Lack of experience among caregivers with noting and recording signal behaviors that may be indicative of MCI or dementia	Pertinent information not accurately transmitted to practitioner
Absence of agency policies encouraging reporting of suspicions of cognitive decline	Missing signals of behavioral change and possible further decline as condition remains unattended
Inexperience of health practitioners with adults with intellectual disabilities experiencing cognitive decline	Inappropriate diagnosis offered which may not help with identifying best treatment possible
Agency staff flux leading to absence of reliable informants about the adult at the health interview or assessment	Key information on the adult and the behavioral or functional issues that led originally to suspicions not reported accurately and thus potentially delaying accurate diagnosis and identification of appropriate course of treatment

of severity of pre-existing intellectual disability, and the increasing cognitive impairment resulting from dementia can reduce the capability to accurately self-report history and symptoms (Perkins, 2007; Service et al., 2006).

Additionally, because of the high prevalence of lifelong comorbid conditions, including seizures (Aylward, Burt, Thorpe, Lai, & Dalton, 1997; McKhann et al., 2011) and mental health issues (Kwok & Cheung, 2007), some adults with ID are often prescribed multiple medications that can have long-term

consequences and that may impair memory and function, present as cognitive decline, and contribute to poor self-reporting (Evenhuis et al., 2001; Lucchino, 2012).

Caregiver awareness of symptoms and familiarity with the adult's life history are important starting points in assembling information to share at the healthcare interview (Bishop et al., 2013; Bishop & Lucchino, 2010; Moran et al., 2013; Perkins, 2007; Robinson et al., 2012; Service et al., 2006)

The NTG recommends that whenever possible caregivers document and retrieve life histories to ensure that this information is available as part of dementia-related health advocacy.

(See Table 1 – Guideline 3)

Information and Awareness (Practitioners)

Most healthcare practitioners may be unfamiliar with the complex healthcare needs of aging adults with ID (Jokinen et al., 2013; Moran et al., 2013; Perkins & Moran, 2010). Physicians' understanding of symptoms that adults with ID present may vary as training in medical schools on health issues of adults with ID is generally minimal or non-existent (Moran et al., 2013).

Healthcare practitioners rarely have training as to how aging affects adults with ID (Perkins & Moran, 2010) or exposure to textbooks containing such information (e. g. Saxon, Etten, & Perkins, 2014), where there is a dearth of knowledge about appropriate assessment and intervention (Bishop & Lucchino, 2011; Lucchino, 2008).

Most community health practitioners also have minimal experience in discerning symptoms of the presentation of dementia from those with ID, unless exposed to these topics through patient volume, specific training in aging and ID, or via their consulting to disability programs (Moran et al., 2013).

The NTG recommends establishing continuing education programs for local healthcare practitioners and ancillary personnel to create receptivity for dementia-related health advocacy.

(See Table 1 –Guideline 4)

For many years researchers noted that all adults with Down syndrome would be symptomatic of Alzheimer's dementia as they grew older; this often led to diagnostic overshadowing, where practitioners would often overlook other causes, assuming that if the syndrome was present then dementia followed (Bishop et al., 2013; Pary et al., 2006; Service et al., 2006) . This misunderstanding often was generalized to all adults with ID, irrespective of etiology. Contemporary research has shown that adults with etiologies other than Down syndrome are not at higher risk than their age peers (Evenhuis et al., 2001; Prasher, 2005; Service & Hahn, 2003).

Yet, among most practitioners, this misunderstanding continues, possibly leading to a high degree of misdiagnosis of the disease or lack of diagnosing other underlying conditions that mimic the symptoms of Alzheimer's dementia (Bishop & Lucchino, 2010; Moran et al., 2013).

Older adults are often overprescribed medications; these may increase the risk of adverse reactions that are unwanted side

effects due, in part, to drug-drug interactions from the overprescription (Lucchino, 2012; Mitchell et al., 2009). Some adults may have reactions that may lead to behaviors that mimic symptoms of dementia (e. g., emotional blunting, confusion, disorientation, or impaired cognitive function).

Because few practitioners are trained in understanding the long-term effects of medication use in this population, such overprescribing continues (Hanlon et al., 1998). Adverse effects that may mimic symptoms of dementia increase the risk that practitioners may attribute behaviors to dementia (Bishop et al., 2013; Bishop & Lucchino, 2010; Lucchino, 2012; Moran et al., 2013). Programs that provide information to practitioners to raise their awareness should include content on how medications may result in adverse drug reactions.

Practitioners may consult the “The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for The Evaluation and Management of Dementia in Adults with Intellectual Disabilities” (Moran et al., 2013) for more information on assessing adults with ID with suspected dementia. To increase understanding of how cognitive impairment can be differentiated from having a lifelong intellectual disability, how medications can adversely affect behavior and function, and what health issues are prevalent among older adults with ID:

The NTG recommends healthcare providers and health advocacy organizations develop and implement collaborative live or webinar-based continuing education programs involving local healthcare organizations, practitioners, and academic resources.

(See Table 1 –Guideline 5)

Referral and Assessment Process

Dementia-related health advocacy entails several aspects. These include pressing for a review of symptoms to determine cause and seeking out a practitioner to undertake a first assessment for cognitive impairment related to dementia.

Locating appropriate practitioners.

Many localities do not have a practitioner or clinic that may be an appropriate resource for assessing adults with ID who present with age-related health problems or who demonstrate changes associated with suspected dementia. This may be particularly true in rural and less populated areas. In these instances, options may be limited, but not insolvable.

At times, such resources may be found as part of an intellectual or developmental disabilities services agency, dementia assessment clinic, or in a practice of local practitioners with some experience with children or adults with ID. Local general practitioners may help with a referral to a specialist who has experience examining adults with dementia or may seek aid in conducting an assessment via telemedicine (Janicki et al., 1996; Jokinen et al., 2013; Moran et al., 2013).

The NTG recommends enabling this process by establishing and making available a directory of local or regional practitioners who are experienced in examining adult patients with ID.

(See Table 1 – Guideline 6)

In urban areas, caregivers may also encounter difficulties when seeking out

practitioners trained in geriatrics and familiar with the medical issues presented by aging adults with lifelong disabilities. Many general practitioners may not have had experience with differentiating recent symptoms of functional decline from baseline performance levels attributable to the patient’s intellectual disability (Bishop et al., 2013; Jokinen et al., 2013). To locate an appropriate resource for a dementia assessment, a trusted general practitioner may be helpful in obtaining a referral to a diagnostician who has expertise with older adults who have neurodegenerative disorders (Bishop et al., 2013; Janicki et al., 2002; Moran et al., 2013).

The NTG recommends local organizations have a process for aiding family and agency caregivers locate and obtain access to resources which are capable of undertaking assessments for dementia in their locality.

(See Table 1 – Guideline 7)

Also, a knowledgeable practitioner may be found by word of mouth or by contacting an intellectual or developmental disabilities provider agency. Other resources may be the local area agency on aging or the state’s agency responsible for intellectual and developmental disabilities services.

Preparing for the appointment.

Preparation should begin by assembling observations of symptoms that can be used to substantiate the suspicion of behavioral or cognitive changes. This preparation should include pertinent information drawn from life history and past medical history and any comparisons of current and previous functioning levels (Bishop et al., 2013; Esralew et al., 2013).

Recording information about the symptoms should be an ongoing process.

Staff from different shifts or programs or various family caregivers should be included in recording and noting specific symptoms of the individual. The information should include the time of day for occurrence of specific behaviors, the patterns of behaviors, and who was present when the symptoms occurred; the context of the behaviors and loss in functioning can be important clues to determining possible underlying causes (Bishop et al., 2013; Bishop & Lucchino, 2010; Moran et al., 2013). See Table 3 for suggestions of what to organize before the appointment and questions to ask.

Family caregivers may want to seek professional assistance from someone who is available to help them by calling the local area agency on aging or other resource—perhaps someone attached to their relative’s day services program (Bishop et al., 2013; Heller & Caldwell, 2006; Henderson & Davidson, 2000; Robinson et al., 2012). Family caregivers can also consult generic Internet resources, such as the *Health Care for Adults With Intellectual and Developmental Disabilities Toolkit for Primary Care Providers* (Vanderbilt Kennedy Center, 2014) or those provided by the Alzheimer’s Association (2011) (see <http://www.alz.org>).

The NTG recommends agencies with staff resources or expertise designate a particular clinician (or alternatively drawing on a dementia resource team) as the means to help family or paid caregivers assemble the information that is needed.

(See Table 1 – Guideline 8)

Other resources for agency staff include a clinician or supervisor within their agency, someone from an Alzheimer’s disease organization, or a medical consultant used by the agency

Getting answers to questions.

To address suspicions of whether dementia is present family caregivers should have a conversation with a health practitioner during a routine or *ad hoc* visit. This conversation can be instrumental in validating suspicions and discussing symptoms to rule out reversible conditions

that may present with similar symptoms indicative of dementia (Esralew et al., 2013; Moran et al., 2013). Similar consultations may be appropriate for agency-based caregivers. Because many caregivers, advocates, and self-advocates often have little experience with the dementia diagnostic process, they should ask practitioners to explain in understandable terms their first impressions.

Whereas some caregivers may be knowledgeable about symptoms, many have had little training in how to report these symptoms to healthcare providers and may

Table 3 Organizing for the appointment and questions to ask

Preparing	
<p><i>Aim: To prepare background information, behavior and function notes, and assemble symptoms that will be discussed during the health interview and assessment.</i></p>	<p>Speak with others who know the adult to get agreement on information. Speak with the adult, if possible, to gain any insights into new issues. Gather pertinent medical history and current health status information. Collect data on current functioning and previous level of functioning. Collate a list of specific symptoms that need to be discussed. For specific behaviors, bring notations of the time of day and patterns for occurrence of behavior and who was present when the symptoms occur. Determine any relevant family medical history information that may be useful. Prepare a list of questions that can be asked of the practitioner. Ensure that staff who accompany the adult to the appointment are well briefed.</p>
Scheduling	
<p><i>Aim: To provide for the health appointment in a manner that will optimize the situation and allay concerns or anxieties in the adult so as to permit the interview and assessment to be carried out in the best possible atmosphere.</i></p>	<p>Try to schedule appointment for when the person is most functional (time of day, absent dysfunction from medications or recovering from challenging event). Try to allay fears or minimize anxiety over the appointment. Ensure that means of transport and access to appointment location do not raise stress level.</p>

	<p>Explain purpose of appointment and what the person may expect from the practitioner.</p> <p>Explain to practitioner’s office the need for promptness in meeting the appointment time and inquire about office protocols.</p> <p>Brief the practitioner’s office as to any limitations or behaviors that might impede the examination.</p>
<p>Questioning</p>	
<p><i>Aim: To be prepared with questions that can bring about a range of information resulting from the interview or assessment that will help with follow-up and next steps in altering or managing care.</i></p>	<p>Should the behavior we have noticed be a concern? Is it indicative of dementia or something else? If you think it may be dementia what should we do next?</p> <p>Is there any medication or other treatment that may be needed?</p> <p>Should we get a referral to a specialist?</p> <p>How often should (name of adult) be re-examined?</p> <p>What can we expect to see next?</p> <p>What shall we tell (name of adult)?</p>

need assistance in understanding and reporting them. It is helpful to use a standard means for collecting and collating symptom information that will be brought to the initial visit with a practitioner (Bishop et al., 2013; Moran et al., 2013).

The NTG has produced the NTG-EDSD (National Task Group–Early Detection Screen for Dementia; NTG, 2012b), an administrative early detection screen designed to be easily used by caregivers to record function and health information for the initial conversation with the health practitioner (Esralew et al., 2013; Jokinen et al., 2013). (The NTG-EDSD, in a number of languages, may be accessed at <http://www.aadmd.org/ntg>.)

Using a screening instrument can help recognize early signs of dementia (Lin et al., 2014) and often constitutes the first step in the process of obtaining a diagnosis or futures planning (Strydom, Chan, King, Hassiotis, & Livingston, 2013). Early screening results may also help determine that the adult meets a clinical, behavioral, or

functional threshold so as to be referred for assessment.

The NTG-EDSD can also be used to assemble relevant information for the cognitive impairment assessment as part of the annual wellness visit under the Affordable Care Act. As many practitioners may ask for repeated measures of function as a metric of decline, the NTG-EDSD may also be the basis for serial information recording, such that after the initial completion, it or a variant can be completed several more times over various intervals (Esralew et al., 2013).

Such serial recording can permit function and health information to compare over time, enabling the practitioner to more fully ascertain the degree of decline (Keller, 2014; Keller et al., in press). The information from the NTG-EDSD can be gathered from multiple sources including caregivers, both formal and informal, self-report from the patient, day and residential program staff or clinicians, and others involved in the individual’s day-to-day life (Bishop et al.,

2013; Robinson et al., 2012; Strydom et al., 2010). Reviewing the information on the NTG-EDSD with the practitioner can help focus the discussion and also identify behaviors that require further observation and assessment.

Diagnosing

Discerning dementia from other age-related dysfunction.

As functional decline is one of the most common complaints older adults with ID bring to a healthcare provider it is important to discern whether such decline is related to aging or to a disease. Decline can be either in performance, including self-care or activities of daily living (ADLs) skills (e. g., dressing or bathing) or function, changes in physical (e. g., gait) or cognitive (e. g., memory) performance. Decline may also be observed in changes in personality or emotional state. Functional decline is not just losses of specific ADLs skills, but also changes in social and interpersonal skills, especially with respect to the quality or type of skill (Henderson & Davidson, 2000; Pary et al., 2006; Service et al., 2006; Wallace & Dalton, 2006).

Seeking a diagnosis.

Numerous potential age-related and age-associated conditions and diseases can present dementia-like symptoms and create a challenge to getting an appropriate and accurate diagnosis. Because the eventual diagnosis of dementia is one of exclusion, the practitioner needs to rule out any alternative explanations for the symptoms and ascertain that neuropathological-based dementia

appears to be the cause of the behavioral or functional changes (Oliver & Kalsy, 2005; Pary et al., 2006; Prasher, 2005).

This process is commonly known as differential diagnosis (Pary, 2000). If the reason for the change in behavior and function is attributed to dementia, the practitioner will usually offer a diagnosis of *possible dementia* (strong suspicion based on presentation of symptoms) or *probable dementia* (strong evidence based on tests and clinical examinations). Getting a *definitive* diagnosis of dementia prior to death may be difficult as usually such a diagnosis is arrived at postmortem (Pary et al., 2006).

The diagnostic process often begins with a preliminary assessment of cognitive and physical functioning to confirm suspicions and to determine the presence of any neuropathological indicators associated with dementia. Because of pre-existing cognitive issues, standard cognitive instruments used in detection and progression in the general population make early-stage dementia detection difficult in people with ID. Thus, more hands-on assessments are usually undertaken, mostly by a medical practitioner or other qualified clinician.

The assessment will entail an evaluation of the presenting problem and as there may be only tentative conclusions about what may be causing the changes, it may not always immediately lead to a diagnosis. Assessments may require sequential visits and interviews during which the practitioner may track specific functions for evidence of change. The practitioner may formulate some tentative ideas about the rationale for the presenting problems, and

may request that certain diagnostic tests be undertaken.

These may include neuropsychological examinations, blood tests, assessments for delirium or depression, and brain scans (such as CT or MRI). An accurate diagnosis involves a confirmation of data from the assessment and a firm understanding of intellectual disability and causes of dementia.

Sharing information.

Once there is a diagnosis, information from the examination should be shared with the caregiver to aid in post-diagnostic supports. If it is MCI or early dementia, the practitioner should be able to provide the following information: Where is the adult in the progression of dementia? What can be expected in terms of duration and decline of functions? What type of dementia is it (Alzheimer's, vascular, other)? How may any comorbidities aggravate behavior or the progression? What medications might be useful (see Prasher, 2004)? What is the potential for any short- and long-term outcomes from prescriptive medications?

Caregivers and practitioners can use this information to assure accuracy in the determination of causes for decline and behavioral changes. Effective healthcare surveillance and appropriate medical treatment of dementia relies in part on the insights and observations provided by caregivers; thus, it is important for a family member or key staff to be involved with any discussions following the assessment (Moran et al., 2013; Service et al., 2006).

Mutual respect for the information each has to offer and good communication

between the caregiver and diagnostician can also help with useful interventions (McCallion, 1999; Moran et al., 2013; Service & Hahn, 2003). The practitioner should provide information on any limitations on activities and offer advice on symptom management techniques. Recommendations may also be provided for care practices or a referral to a dementia care coordinator, who can help with developing a care plan.

Caregivers should be given the results of the assessments and any recommendations for follow-up including additional appointments that may be needed. When an agency is involved, specific staff should be assigned responsibilities for any follow-up. A key aspect of dementia-related health advocacy is for caregivers to actively pursue a resolution to any assessment or diagnostic referrals or visits (Bishop et al., 2013; Robinson et al., 2013; WHO, 2012).

Challenges Due to Advanced Dementia

Late stage diagnostics and care.

A growing number of Americans are dying with advanced dementia, which is under recognized as a high risk for death and often results in suboptimal palliative care (Mitchell et al., 2009). Many adults who have complex physical and physiological needs also often receive poor quality end-of-life care (Sampson, Burns, & Richards, 2011). Unrecognized dementia may mean that an adult may decline significantly before an effort is made to have the person assessed. Significant global deterioration of function may occur, along with the presence of

marked coincident conditions (Mitchell et al., 2012).

Caregivers may need to be aided in accessing specialized clinical services and after diagnosis provided with specialized care supports and services, including palliative care for the adult (Dunkley & Sales, 2014; McCallion, McCarron, Fahey-McCarthy, & Connaire, 2012). People with advanced dementia often experience distressing symptoms, including challenging behaviors and significantly deteriorating cognitive functioning. Advanced dementia is also associated with gait dysfunction, swallowing dysfunction, disorientation and confusion, seizures, urinary tract infections, and immobilization. These problems may result in a higher frequency of hospitalization and emergency room visits (Mitchell et al., 2012).

To preclude later misunderstandings, advance care planning and decision-making as to the goals of care must be thoughtfully and carefully delineated including comfort and minimization of complications resulting from immobility (Comart & Mahler, 2013). Care goals and preferences must be put into an advance care directive, the legal document expressing the wishes related to palliative and end-of-life care to preclude potentially burdensome interventions being unnecessarily carried out (Mitchell et al., 2009).

Continued home care may be a challenge when caregivers themselves are aged and the home is not amenable to primary bed care. Obtaining sound advice on care alternatives is part of health advocacy. Better understanding of clinical trajectory of end-stage dementia is an important step towards improving care of adults with

advanced dementia (Mitchell, Catic, Givens, Knopp, & Moran, 2013). This knowledge helps healthcare providers, patients, and families set more realistic expectations about what they will confront as the disease progresses and the end of life approaches (Mitchell et al., 2009). Family caregivers are advised to review *Advanced Dementia: A Guide for Families* (Mitchell et al., 2013).

Nutritional correlates.

Nutritional interventions are an integral part of post-diagnostic care. They become more important when dementia impairs cognitive and functioning abilities related to food choice and intake and compromises nutritional status. The adverse effects of dementia on weight and nutritional status are well documented, indicating that dementia causes weight loss (Albanese & Prina, 2014; Pivi, Bertolucci, & Schultz, 2012). Weight loss, which has multifactorial etiology, occurs before the symptomatic phase of dementia; the degree of weight loss and undernutrition increases with the severity of the disease.

Feeding problems worsen as dementia progresses. Aversive feeding behaviors, damage to the parts of the brain that control appetite and food intake, sensory dysfunction that reduces the sense of smell, oropharyngeal dysphagia (difficulty in transferring food from the mouth to the pharynx and esophagus) which can cause choking and food avoidance, loss of interest in eating, and poor oral and dental health that may cause pain—all these symptoms reduce food intake and contribute to weight loss (Allbanese & Prina, 2014). Dysphagia can also cause aspiration pneumonia (Pivi et al.,

2012), a hypercatabolic condition that can increase energy expenditure.

Weight loss and undernutrition predispose people, especially those who are immobile, to the development of pressure sores, infection, increased risk for falls, and frequency of hospitalization (Albanese & Prina, 2014; Mughal & Novak, In press). Overall, as these conditions adversely affect the course of dementia and the individual's health and survival, caregivers should carefully monitor nutrition, hydration, and weight variations.

Follow-up and Clinical Assistance

Carrying out the program of care.

Post-diagnostic dementia-related health advocacy should involve taking on the responsibility to implement any care recommendations, communicate the needs of the adult with others, participate in the person-centered planning process, and advocate for additional resources needed to support the individual with dementia. This may be undertaken in concert with staff designated as dementia coordinators who serve as care managers or solely by staff or family members who work or live with the adults and look after their welfare (Alzheimer Scotland, 2014; Nauert, 2014); alternatively specialist nurses may aid with latter stage care (Denning, Greenish, Jones, Mandal, & Sampson, 2012). For information on community care options and follow-up best practices, see "Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia" (Jokinen et al., 2013).

Other post-diagnostic functions include continuous monitoring of weight to detect weight loss and other risk factors for malnutrition and advocating for referrals to qualified health professionals for timely systematic nutritional assessment and collaboratively planned interventions (Prince, Siervo, Acosta, Guerchet, & Prina, 2014). Residences that do not employ full-time dietitians may have consultant dietitians and should have a protocol for nutritional screening or referrals to consultants.

Management of nutritional problems requires a multidisciplinary team of professionals working with the adults and their caregivers to deliver the best individualized care possible that meets the adults' health goals and preferences; in such situations, caregivers should be active participants and advocates. Given the complex feeding problems of adults with ID and dementia (i.e., difficulty in swallowing leading to choking, chewing but failing to swallow, and active resistance to hand feeding) (Pivi et al., 2012), education and training of caregivers on nutritional needs of individuals, balanced diet, ways to increase calories and protein intake, and managing aversive feeding behaviors may help delay the hazards of undernutrition (Prince et al., 2014).

Some caregivers may be reluctant to seek assistance in understanding the disease or be unfamiliar with available resources; in such instances, they should be aided with increasing their familiarity and willingness to follow through on any program plans or recommendations for care practices (Jokinen et al., 2013, Moran et al., 2013; Sullivan et al., 2006; Wilkinson & Janicki, 2002).

Agencies should aid this process by developing materials that might help caregivers keep track of the post-diagnostic recommendations and follow through on actions to be undertaken. Additionally, some family and staff caregivers may benefit from affiliating with support groups or other similar forums where experiences with care and support of dementia are shared and discussed.

The NTG recommends agencies and care organizations provide supports to caregivers to enable them with implementing postdiagnostic activities.

(See Table 1 – Guideline 9)

long-term services and supports (Janicki, McCallion & Dalton, 2000; McCarron et al., 2014b).

Agencies can facilitate this process by having dementia coordinators or other like personnel who can help both family and staff caregivers process the recommendations of clinicians and implement any recommended practices of procedures.

The NTG recommends that agencies assign specialist personnel to help and provide consultation to families and staff caregivers with post-diagnostic care.

(See Table 1 – Guideline 10)

Many caregivers may require assistance in obtaining formal assistance and supports for providing dementia-capable care and continued help with periodic reassessments to address identified behavioral and other functional problems (Holland, 1999; Janicki et al., 1996; Prasher, 2005). The primary agency responsible to design a program of care should take into account any information derived from the diagnostic process (diagnosis, type of dementia, stage, prognosis, and the relevant information) and include planning for residential care, daily activities, and frequency of follow-up medical visits, as well as communication, transitions, and advance directives (Janicki et al., 2002; Jokinen et al., 2013).

This planning should include an estimate of how the adult with dementia will likely be impaired by dementia and the possible duration so that any stage-dependent transitions in residences or other activities can be included in the planning process and integrated within the state’s

Long-term services and supports.

Consideration should be given to using available long-term services and supports. Under the Patient Protection and Affordable Care Act, states providing Home and Community Based Services (HCBS) are directed to “allocate resources and provide the necessary supports and coordination to be responsive to the person-centered needs and choices of older adults and people with disabilities in ways that maximize their independence and ability to engage in self-direction of their services, and achieve a more consistent and coordinated approach to the administration of policies and procedures across public programs” (USDHHS, 2014b).

Long-term services and supports (LTSS) include assistance with ADLs provided to older people and adults with disabilities who cannot perform these activities on their own as a result of a physical, cognitive, or chronic health condition, including dementia. LTSS may include care, case management, and service coordination to people who live

in their own home or a residential setting. They also include supports provided to family members and other unpaid caregivers. Obtaining advice on what LTSS supports may be available within the state is part of dementia-related health advocacy.

Communication With Healthcare Personnel

Communication in dementia-related health advocacy can take many forms including the following: Conveying information from the informant to the practitioner; being an interpreter for the adult with poor language skills; collecting information on any suspicions and having an internal conversation in the agency or home; facilitating the making of decisions; and sharing information after assessments with adults and their family members.

The NTG recommends expanding education and assistance to help people involved in health advocacy to enhance their ability to accurately communicate information.

(See Table 1 – Guideline 11)

Conveying information.

The transfer of information from family or staff caregivers to the healthcare provider should be two-way. Anyone attending the consult with the person with ID should be informed and familiar with the person and the presenting complaint. Sometimes, however, agencies send direct support staff as escorts for an adult with ID to the appointment without adequate preparation for the appointment, including a briefing on the specific symptoms or prioritization of the symptoms to be reported (Bishop et al., 2013; Bishop & Lucchino, 2010;

Janicki et al., 1996; Jokinen et al., 2013; Service et al., 2006).

When such lack of preparation occurs, compensatory procedures should be in place, such as having a complete packet of information on the presenting problem and the adult’s personal history and current status. Such a procedure should be in place to ensure that accurate and updated information accompanies the adult to be assessed (Bishop et al., 2013).

Communication may also involve the staff acting as an interpreter when the speech of the adult being assessed is difficult to understand.

Internal discussions.

Agencies should develop easy to follow procedures for dementia-related health advocacy within the agency. This would include a process for reporting symptoms or requesting medical consults. Communication within the agency and with caregivers enables quick responses to issues arising and amelioration of problems.

Communication could also involve a meeting of a healthcare professional and staff members to discuss the specific information to be related to the provider during the office visit (Bishop et al., 2013; Bishop & Lucchino, 2010; Robinson et al., 2012; Service et al., 2006).

Making decisions.

During any medical consult, the issue of who is authorized to make decisions for an adult who is unable to do so needs to be resolved. The question may arise as to who

can legally make the healthcare decisions and how those decisions are made with respect to informed consent if information is not available (Bishop & Lucchino, 2010; Moran et al., 2013). In all instances, whenever possible, the adult being referred or examined should be involved in any decision making and be encouraged to have in place an advance care directive.

When the individual's dementia progresses into the final stages, there will need to be a discussion about end-of-life care; and a previously developed advance directive will be useful in ensuring that the individual's wishes are respected (Towers & Wilkinson, 2014). At times, a proxy may need to be formally identified and asked to help make specific care decisions, including use of a feeding tube, ventilation, cardiac support, and referral to hospice (Jokinen et al., 2013; Moran et al., 2013).

Adding to the complexity is the question as to who can legally make healthcare decisions (i.e., a health proxy or equivalent) and whether those decisions can be considered informed consent if the information available is sparse or contradictory (Robinson et al., 2013; Service et al., 2006).

Uncertainties related to what assistance may be facilitated during the annual wellness visit under the Affordable Care Act complicate this aspect. When the adult is a dual beneficiary of both Medicare and Medicaid, it is unclear which program's benefits define specific rights. Agencies and families are advised to seek counsel on such matters before engaging in dementia-related health advocacy.

Sharing information.

The adult with ID should be involved in the referral and follow-through process. Communicating the outcomes of the results of any assessments or diagnostics is crucial. The decision on how to convey this information and how much of it is to be shared has to be carefully considered and assessed with respect to the degree the person will understand it and what may be the resulting impact.

Agencies should seek out guidance on communicating diagnostic outcomes and monitoring impact to avoid or minimize further alarm or concern on the part of the adult who may already have concerns about declining function. Compassionate reassurance and involving the adult in considering future options for care need to be given due consideration.

Geriatric Clinic and Specialist Team Resources

In areas it may be economically viable, establishing a clinic-based comprehensive geriatric or intellectual disability assessment service as an effective way in focusing on older adults' overall medical, social, psychological, and functional needs—beyond concerns of dementia—and in then obtaining prescribed appropriate care or supports (Boada et al., 2014; Chicoine, McGuire, & Rubin, 1999; Coppus, 2014; Henderson & Davidson, 2000; Prasher, 2005). The goal of such service is to use a comprehensive approach to develop an overall plan of care with long-term recommendations for interventions and follow up (Henderson & Davidson, 2000; Moran et al., 2013; Wallace & Dalton, 2006).

Inherent in this approach is chronic illness management and extensive knowledge of poly-pharmacy, nutrition, adverse effects of medications, quality of life, and differential diagnosis—all from a person-centered planning perspective (Alzheimer’s Disease International [ADI], 2014; Henderson & Davidson, 2000; Silverman et al., 2010; Sullivan et al., 2006; USDHHS, 2014b). An alternative approach to the geriatric clinic assessment approach is using a free-standing dementia care team—a clinic without walls (Janicki et al., 2002; McCarron & Lawlor, 2003; McCarron, McCallion, Reilly, & Mulryan, 2014b).

Analogous to the patient-centered medical home concept (Agency for Healthcare Research and Quality, 2014), under this model an agency or collective of agencies designate several of their experienced clinicians to become the experts

for the region and consult with caregivers beginning with preliminary screening and assessment, enabling the referral for any more sophisticated diagnostics, and continuing through to the post-diagnostic phase and consulting in the interventions (Bishop et al., 2013). Both approaches align well with dementia-related health advocacy efforts as they provide a focal point for communication and emphasis on wellness, health assessments, and the tracking of symptoms related to dementia.

The NTG recommends consideration of implementing innovative approaches to health assessment as part of the planning and organizing of local dementia-capable services.
(See Table 1 – Guideline 12)

Table 4. Recommendation for enhancing dementia-related health advocacy and system collaborations

Recommendations	Specific Strategies or Actions
<p>1. Develop webinars and other training opportunities for caregivers (staff or family), advocates, and self-advocates on how to collect health status information, prepare or and obtain access to health care visits, as well as apply useful interventions.</p>	<p>Training steps</p> <ul style="list-style-type: none"> a. Identify developers including potential partners (such as the Alzheimer’s disease associations and the aging network). b. Identify trainers, method of training, funding support, and future research possibilities to validate training. c. Develop pilot training curriculum. d. Present pilot training curriculum to identified participants. e. Conduct a regional needs assessment to validate training information to meet the identified needs. i. Conduct orientation and training on use of screening instruments, such as the NTG-EDSD. g. Revise training curriculum as appropriate based on survey of participants and input from experts within the NTG and other organizations. <ul style="list-style-type: none"> - Conduct pre- and post- tests to determine if training is effective and for possible future research. h. Develop a national training plan working with participating organizations and NTG members. i. Maintain ongoing development to meet training needs that are evolving and continuing.
<p>2. Suggested training topics</p>	<p>Training topics:</p> <ul style="list-style-type: none"> a. Overview of dementia including description, diagnosis process, and other age-related

	<p>conditions that can mimic dementia using easy to understand terminology for people without a health care background</p> <ul style="list-style-type: none"> b. Skills of observation and reporting c. Steps in developing positive partnerships with health care providers d. Differential diagnosis checklists for ruling out underlying causes for decline in adults with intellectual disability e. Strategies for developing agency specific policies and practices on dementia assessment and care <p>Practical aspects of caregiving for adults with intellectual disabilities and dementia to maintain quality of life using a person centered approach</p> <ul style="list-style-type: none"> f. Strategies for preparing advocates for the health care appointment g. Process for appropriate environmental and programmatic modifications that create an environment conducive to quality of life and continued functioning
<p>3. Increase dialogue among health care providers on ways to establish partnerships in health care for adults with intellectual disabilities, especially with respect to the diagnosis of dementia, through the use of national health care organizations.</p>	<ul style="list-style-type: none"> a. Collaborate on webinars with organizations representing health care providers to discuss ways of developing cooperation and partnerships. b. Advocate adding training on aging with intellectual disability in medical schools and universities. <ul style="list-style-type: none"> - Ongoing infusion in medical schools - Monitoring for ongoing inclusion in training curriculums for preparation of health care providers including physicians and nurses. Advocate at the state level for resources with continuing education programs to help develop more physicians and nurses with an expertise in aging with intellectual disabilities, including dementia care in this population. d. Promote collaborative research on best practices for health care advocacy, dementia diagnosis and care, and improving quality of life for adults with intellectual disability and dementia.
<p>4. Collaborate on developing resources that build partnerships through collaborative funding sources and sharing of best practice models.</p>	<ul style="list-style-type: none"> a. Pursue funding resources for training, infusion in health care providers' education, and research for collaboration. b. Develop collaborative webinars and forums on dementia and intellectual disabilities. c. Produce written materials on the issues related to dementia and intellectual disabilities including the need for training and resource development. d. Pursue discussions on the issues with a focus on preventing misdiagnosis, selection of screening tools that rule out underlying causes for decline other than Alzheimer's dementia, and caregiving supports.
<p>5. Collaborate on developing resources and training modules that are written in understandable terms for the advocate who has no health care training or experience including suggestions for the development of health care partnerships.</p>	<ul style="list-style-type: none"> a. Develop best practice policies and procedures to support advocacy. b. Pursue funding for infusion of practices nationally. c. Maintain ongoing monitoring of effectiveness of training and resources including research. d. Develop models for dissemination of training to rural areas, including teleconferencing and telemedicine.
<p>6. Collaborate with family advocacy groups and families to develop resources and guidelines for dementia-related health advocacy for families.</p>	<ul style="list-style-type: none"> a. Develop family friendly resources. b. Infuse information into schools and universities.

Sources: NTG, 2012a; www.aadmd.org/ntg

Training to Prepare for Healthcare Advocacy and System Interactions

The NTG recommends that agencies establish policies and practices that include training for any staff who may function as health advocates. It further proposes that organizations have a process for further cooperation and collaboration with local or regional health providers.

The rationale for this is that organizations, from both the disability and healthcare systems, need to effectively communicate and understand each other's structures and practices to address the health and dementia assessment and diagnostic needs of older adults with ID. Such collaborations or partnerships can involve helpful resources, including those within the aging network (e.g., aging and disability resource centers and area agencies on aging) (Bishop & Lucchino, 2010; Dodd, 2014; Jokinen et al., 2013; Moran et al., 2013).

Table 4 illustrates several functional processes that can be undertaken at the state, regional, and local levels to initiate and carry out training in ensuring accurate and timely diagnosis and production of useful interventions. Table 4 also provides recommendations on effecting system integration and collaboration and various entities involved with health care and dementia care provision.

Such efforts can include establishing partnerships with local and national healthcare organizations. Included are suggested ways to enable collaboration (a) on developing resources that build partnerships through collaborative funding sources and sharing of best practice models; (b) on

developing resources and training modules that are written in understandable terms for the advocate who has no healthcare training or experience, including suggestions for the development of healthcare partnerships; and (c) with family advocacy groups and families to develop resources and guidelines for dementia-related healthcare advocacy.

Conclusions

Demographic trends show that the proportion of people with complex or age-related health needs is growing and will continue to grow well into the future (Kaiser Commission, 2011; NTG, 2012a; Prasher, 2005; WHO, 2012). Evidence indicates that older people with ID may have similar or even higher rates of age-related conditions than their age peers (Evenhuis et al., 2001; Jokinen et al., 2013).

The *National Plan to Address Alzheimer's Disease* (USDHHS, 2012) has noted the need for a committed and trained work force to enable appropriate care and supports for the nation's growing number of people affected by dementia. The NTG has worked and is continuing to work in concert with the *National Plan's* goals and aims to create a series of recommendations and guidelines on improving the capacity of the nation's caregivers providing primary supports to adults potentially or already affected by dementia.

This would include more effective dementia-related health advocacy, especially with obtaining assessments for dementia and follow-up medical services, as well as implementing long-term care and supports (NTG, 2012a; USDHHS, 2012, 2013).

The NTG (2012a) has noted that it is essential for caregivers, whether family or staff, to be trained on increasing their familiarity with the aging of people with ID and risk factors for dementia and other age-related diseases or conditions, as well as the key functions involved in becoming effective health advocates.

The NTG's national training and education curriculum has described proficiencies required for persons employed to work with aging people with ID and affected by dementia. These proficiencies include knowledge of signs and symptoms of dementia, as well as the skills needed by healthcare advocacy for competent interaction with healthcare providers (NTG, 2014)

Whereas the recommendations and guidelines were originally developed as part of the NTG's efforts to address aims within the *National Plan to Address Alzheimer's Disease*, it is anticipated that state, regional, and national organizations will adopt these recommendations and guidelines as part of their efforts to address the growing gaps in services for caregivers and adults with ID. Education and training and collaboration across the networks can make a difference in the lives of older adults with ID affected by dementia, as well as in the lives of caregivers.

References

- Agency for Healthcare Research and Quality (AHRQ). (2014). Defining the PCMH [primary care medical home]. Retrieved from <http://pcmh.ahrq.gov/page/defining-pcmh>
- Aggarwal, N. T. (2013). Diverse populations, health disparities, and dementia. The 2013 NIH/ACL Alzheimer's Webinar Services, July 24, 2013. Retrieved from http://www.aoa.gov/AoA_Programs/HPW/Alz_Grants/docs/2013_07_24-DiversityHealthDisparitiesDementia-slides.pdf
- Albanese, E. & Prina, M. (2014). Undernutrition in dementia. In M. Prince, E. Albanese, M. Guerchet., & M. Prina (Eds.), *Nutrition and dementia: A review of available research* (pp 45 –52). London, UK: Alzheimer's Disease International.
- Alzheimer's Association. (2011). 2011 Alzheimer's disease facts and figures report. Retrieved from http://www.alz.org/alzheimers_disease
- Alzheimer's Disease International (ADI). (2014). *Nutrition and dementia: A review of available research*. London, UK: Author.
- Alzheimer Scotland. (2014). Scotland's national dementia strategy. Retrieved from http://www.alzscot.org/campaigning/national_dementia_strategy
- Aylward, E. H., Burt, D. B., Thorpe, L. U., Lai, F., & Dalton, A. J. (1997). Diagnosis of dementia in individuals with intellectual disability. *Journal of Intellectual Disability Research, 41*, 152 –164.
- Ball, S. L., Holland, A. J., Hon, J., Huppert, F. A., Treppner, P., & Watson, P. C. (2006). Personality and behavior changes mark the early stages of Alzheimer's disease in adults with Down's syndrome: Findings from a prospective population-based study. *International Journal of Geriatric Psychiatry, 21*, 661–673.
- Ball, S. L., Holland A. J., Treppner, P., Watson, P. C., & Huppert, F. A. (2008). Executive dysfunction and its association with personality and behaviour changes in the development of Alzheimer's disease in adults with Down syndrome and mild to moderate learning disabilities. *British Journal of Clinical Psychology, 47*, 1 –29.
- Bishop, K. M. & Lucchino, R. (2010). Module II: Matching needs to services for older adults with intellectual and developmental disabilities. *Cross Network Collaboration for Florida, ADRC Training*. Tallahassee, FL: Florida State Department of Elder Affairs.
- Bishop, K. M., Robinson, L., & Van Lare, S. (2013). Healthy aging for older adults with intellectual and developmental disabilities. *Journal of Psychosocial Nursing, 51*, 15–18.
- Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., Glasson, E. J. & Montgomery, P. D. (2002). The influence of intellectual disability on life expectancy. *Journal of Gerontology Series A: Biological Sciences and Medical Sciences, 57*, M470 –472.
- Boada, M., Tárraga, L., Hernández, I., Valero, S., Alegret, M., Ruiz, A. ... Becker, J., (2014). Design of a comprehensive Alzheimer's disease clinic and research center in Spain to meet critical patient and family needs. *Alzheimer's & Dementia, 10*, 409 –415.
- Centers for Disease Control and Prevention. (2013). *The state of aging and health in America 2013*. Atlanta, GA: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services.
- Chicoine, B., McGuire, D. & Rubin, S. S. (1999). Specialty clinic perspectives. In M. P. Janicki & A. J. Dalton (Eds.), *Dementia, aging, and intellectual disabilities: A handbook* (pp. 278 –291). Philadelphia, PA: Brunner-Mazel.
- Clarke, A., Hanson, E., & Ross, H. (2003). Seeing the person behind the patient; enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing, 12*, 697 –706.
- Comart, J., & Mahler, A. (2013) *How to talk to families about advanced dementia: A guide for health care professionals*. Boston, MA.: Hebrew Senior Life.
- Cooper, S. (1997). High prevalence of dementia among people with learning disabilities not attributable to Down's syndrome. *Psychological Medicine, 27*, 609–616.
- Cooper, S. A. & Prasher, V. P. (1998). Maladaptive behaviours and symptoms of dementia in adults with Down's syndrome compared with adults with intellectual disability of other aetiologies. *Journal of*

- Intellectual Disability Research*, 42, 293–300.
- Coppus, A. M. W. (2014). The outpatient clinic for adults with Down syndrome. In K. Watchman (Ed.), *Intellectual disability and dementia: Research into practice* (pp. 53–61). London, UK: Jessica Kingsley.
- Denning, K. H., Greenish, W., Jones, L., Mandal, U., & Sampson, E. L. (2012). Barriers to providing end-of-life care for people with dementia: A whole system qualitative study. *BMJ Supportive & Palliative Care*, 2, 103–107.
- Dodd, K. (2014). Staff knowledge and training. In K. Watchman (Ed.), *Intellectual disability and dementia: Research into practice* (pp. 204–221). London, UK: Jessica Kingsley.
- Dunkley, S. & Sales, R. (2014). The challenges of providing palliative care for people with intellectual disabilities: a literature review. *International Journal of Palliative Nursing*, 20, (279–284).
- Esralew, L., Janicki, M. P., DiSipio, M., Jokinen, J., Keller, S. M., & Members of the National Task Group Section on Early Detection and Screening. (2013). National Task Group Early Detection Screen for Dementia (NTG-EDSD) manual. *NADD Bulletin*, 16, 47–54.
- Evenhuis, H. M. (1997). The natural history of dementia in aging people with an intellectual disability. *Journal of Intellectual Disabilities Research*, 41, 92–96.
- Evenhuis, H., Henderson, C. M., Beange, H., Lennox, N., & Chicoine, B. (2001). Healthy ageing—adults with intellectual disabilities: Physical health issues. *Journal of Applied Research in Intellectual Disabilities*, 14, 175–194.
- Haley, W. E., & Perkins, E. A. (2004). Current status and future directions in family caregiving and aging people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1, 24–30.
- Hanlon, J. T., Schmader, K. E., Koronkowski, M. J., Weinberger, M., Landsman, P. B., Samsa, G. P., & Lewis, I. K. (1998). Adverse drug events in high risk older outpatients. *Journal of the American Geriatrics Society*, 46, 252–3.
- Haveman, M., Heller, T., Lee, L., Maaskant, M., Shooshtari, S., & Strydom, A. (2010). Major health risks in aging persons with intellectual disabilities: An overview of recent studies. *Journal of Policy and Practice in Intellectual Disabilities*, 7, 59–69.
- Heller, T. & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation*, 44, 189–202.
- Heller, T., Janicki, M. P., Hammel, J., & Factor, A. (2002). *Promoting healthy aging, family support, and age-friendly communities for persons aging with developmental disabilities: Report of the 2001 Invitational Research Symposium on Aging with Developmental Disabilities*. Chicago, IL: The Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Department of Disability and Human Development, University of Illinois at Chicago.
- Henderson, C. M., & Davidson, P. W. (2000). Comprehensive adult and geriatric assessment. In M. P. Janicki & E. Anselmo (Eds.), *Community supports for aging adults with lifelong disabilities* (pp. 373–386). Baltimore, MD: Paul Brookes.
- Holland, A.J. Down’s syndrome. In M.P. Janicki & A.J. Dalton (Eds.), *Dementia, aging, and intellectual disabilities: A handbook* (pp. 183-197). Baltimore, MD: Paul Brookes
- Holland, A. J., Hon, J., Huppert, A., & Stevens, F. (2000). Incidence and course of dementia in people with Down’s syndrome: Findings from a population-based study. *Journal of Intellectual Disability Research*, 44, 138–146.
- Hogg, J., Lucchino, R., Wang, K. Y., & Janicki, M. (2001). Healthy ageing – adults with intellectual disabilities: Ageing and social policy. *Journal of Applied Research in Intellectual Disabilities*, 14, 229–255.
- Iacono, T., & Sutherland, G. (2006). Health screening and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 3, 155–163.
- Institute of Medicine. (2007). Disability trends. In M. J. Field & A. M. Jette (Eds.), *The future of disability in America* (pp. 65–97). Washington, DC: National Academies Press.
- Jamieson-Craig, R., Scior, K., Chan, T., Fenton, C., & Strydom, A. (2010). Reliance on carer reports of early symptoms of dementia

- among adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 7, 34–41.
- Janicki, M. P. & Dalton, A. J., (Eds.) (1999). *Dementia, aging, and intellectual disabilities: A handbook*. Philadelphia, PA: Brunner-Mazel.
- Janicki, M. P., Dalton, A. J., Henderson, C. M., & Davidson, P. W. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation*, 21, 284–294.
- Janicki, M. P., Heller, T., Seltzer, G. B., & Hogg, J. (1996). Practice guidelines for the clinical assessment and care management of Alzheimer's disease and other dementias among adults with intellectual disability. *Journal of Intellectual Disability Research*, 40, 374–382.
- Janicki, M. P., & Keller, S. M. (2014). Viability of a dementia advocacy effort for adults with intellectual disability: Using a national task group approach. *Journal of Policy and Practice in Intellectual Disabilities*, 11, 176–191
- Janicki, M. P., McCallion, P., & Dalton, A. J., (2000). Supporting people with dementia in community settings. In M. P. Janicki & E. F. Ansello (Eds.), *Community supports for aging adults with lifelong disabilities*. Baltimore, MD: Paul Brookes.
- Janicki, M. P., McCallion, P., & Dalton, A. (2002). Dementia-related care decision-making in group homes for persons with intellectual disabilities. *Journal of Gerontological Social Work*, 38, 179–195.
- Jokinen, N., Janicki, M. P., Keller, S. M., McCallion, P., Force, L. T., & National Task Group on Intellectual Disabilities and Dementia Care Practice (2013). Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 10, 1–24.
- Kaiser Commission. (2011). Medicaid and the uninsured issues paper: Improving access to adult primary care in Medicaid. Retrieved from www.kff.org/medicaid/upload/8167.pdf.
- Keller, S. M. (2013). Dementia in adults with intellectual and developmental disabilities. Webinar on People with Intellectual or Developmental Disabilities and Dementia – 2013 NIH/ACL Alzheimer's Webinar Series (June 25, 2013). Retrieved from http://www.Aoa.gov/AoA_Programs/HPW/Alz_Grants/docs/2013_06_25-IntellectualDevelopmentalDisabilitiesDementia.pdf
- Keller, S. M. (2014, June). *Serial assessment of function in adults with intellectual and developmental disabilities and dementia*. Paper presented at 12th Annual Education Conference of the American Academy of Developmental Medicine and Dentistry, Princeton, NJ, June 17, 2014.
- Keller, S. M., Esralew, L., & Janicki, M. P. (In press). Dementia: Screening, evaluation, diagnosis, management. In I. L. Rubin, J. Merrick, D. E. Greydanus, & D. R. Patel (Eds.), I. L. Rubin & A. Crocker (3rd ed.), *Health care for people with intellectual and developmental disabilities across the lifespan*. Dordrecht, Germany: Springer.
- Kinsky-McHale, S., Urv, T., Zigman, W., & Silverman, W. (2010, August). *Neurological symptoms associated with mild cognitive impairment in adults with Down syndrome*. Paper presented as part of the symposium, Transitions in neurological and cognitive phenotypes and dementia status in people with Down syndrome, at the 118th annual convention of the American Psychological Association, San Diego, CA, August 14, 2010.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Milton Keynes, UK: Open University Press.
- Kwok, H., & Cheung, P. W. H. (2007). Co-morbidity of psychiatric disorder and medical illness in people with intellectual disabilities. *Current Opinion in Psychiatry*, 20, 443–449.
- Lin, J. D., Chen, W. X., Hsu, S. W., Lin, L. P., Lin, F. G., Tang, C. C. ... Chou YC. (2014). Primary caregivers' awareness and perception of early-onset dementia conditions in adolescents and young and middle-aged adults with Down syndrome. *Research in Developmental Disabilities*, 35, 1934–1940.
- Lucchino, R. (2008). *Aging and intellectual and developmental disabilities*. Santa Fe, NM: New Mexico Chapter Alzheimer's Association.
- Lucchino, R. (2012). *Introduction to adverse effects and interactions of medications*. Agency Webinar Series, March 8, 2012, sponsored by the Program on Aging and

- Developmental Disabilities (PADD), Strong Center for Developmental Disabilities, Golisano Children's Hospital, Rochester, NY.
- Llewellyn, P. (2011). The needs of people with learning disabilities who develop dementia: A literature review. *Dementia, 10*, 235–247. doi: 10.1177/1471301211403457
- McCallion, P. (1999). Maintaining communication. In M. P. Janicki & A. J. Dalton (Eds.), *Dementia, aging, and intellectual disabilities: A handbook* (pp. 261–277). Philadelphia, PA: Brunner-Mazel.
- McCallion, P., McCarron, M., Fahey-McCarthy, E., & Connaire, K. (2012). Meeting the end of life needs of older adults with intellectual disabilities. In E. Chang & A. Johnson (Eds.), *Contemporary and innovative practice in palliative care* (pp. 255–267). Rijeka, Croatia: Intech.
- McCarron, M., & Lawlor, B. A. (2003). Responding to the challenges of ageing and dementia in intellectual disability in Ireland. *Aging & Mental Health, 7*(6), 413–417. doi:10.1080/13607860310001594655M.
- McCarron, M., Gill, M., McCallion, P., & Begley, C. (2005). Health co-morbidities in ageing persons with Down syndrome and Alzheimer's dementia. *Journal of Intellectual Disability Research, 49*, 560–566.
- McCarron, M., McCallion, P. Reilly, E., & Mulryan, N. (2014a). A prospective 14-year longitudinal follow-up of dementia in persons with Down syndrome. *Journal of Intellectual Disability Research, 58*, 61–70.
- McCarron, M., McCallion, P., Reilly, E., & Mulryan, N. (2014b). Responding to the challenges of service development to address dementia needs for people with an intellectual disability and their caregivers. In K. Watchman (Ed.), *Intellectual disability and dementia: Research into practice* (pp. 241–269). London, UK: Jessica Kingsley.
- McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R. Jr., Kawas, C. H., Klunk, W. E., & Phelps, C. H. (2011). The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging—Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's and Dementia, 7*, 263–269.
- Menne, H. L., Ejaz, F. K., Noelker, L. S., & Jones, J. A. (2008). Direct care workers recommendations for training and continuing education. *Gerontology & Geriatrics Education, 28*, 91–108.
- Mitchell, S. L., Black, B. S., Ersek, M., Hanson, L. C., Miller, S. C., Sacks, G. A., Teno, J. M., & Morrison, R. S. (2012). Advanced dementia: State of the art and priorities for the next decade. *Annals of Internal Medicine, 156*, 45–51.
- Mitchell, S. L., Catic, A. G., Givens, J. L., Knopp, J., & Moran, J. (2013). *Advanced dementia: A guide for families*. Boston, MA: Hebrew Senior Life. Retrieved from <http://www.hebrewseniorlife.org/workfiles/IFAR/DementiaGuideForFamilies.pdf>
- Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., Volicer, L., Givens, J. L., & Hamel, M. B. (2009). The clinical course of advanced dementia. *New England Journal of Medicine, 361*, 1529–1538.
- Moran, J., Keller, S. M., Janicki, M. P., Singh, B., Rafii, M., Kripke, C. & Members of the National Task Group Section on Health Care Practices, Evaluation, Diagnosis, and Management. (2013). Position paper on evaluation and assessment for medical care of adults with intellectual disabilities with dementia. *Mayo Clinic Proceedings, 88*, 831–840.
- Mughal, D. T., & Novak, P. (in press). Nutrition and individuals with intellectual disability. In I. L. Rubin, J. Merrick, D. E., Greydanus, & D. R. Patel (Eds.), I. L. Rubin & A. Crocker (3rd ed.), *Health care for people with intellectual and developmental disabilities across the lifespan* Dordrecht, Germany: Springer.
- National Task Group on Intellectual Disabilities and Dementia Practices (NTG). (2012a). "My thinker's not working": A national strategy for enabling adults with intellectual disabilities affected by dementia to remain in their community and receive quality supports. Retrieved from <http://www.aadmd.org/ntg/thinker>
- National Task Group on Intellectual Disabilities and Dementia Practices (NTG). (2012b). NTG early detection screen for dementia. Retrieved from <http://www.aadmd.org/ntg>

- National Task Group on Intellectual Disabilities and Dementia Practices (NTG). (2013). Frequently asked questions. Retrieved from <http://www.aadmd.org/ntg>.
- National Task Group on Intellectual Disabilities and Dementia Practices (NTG). (2014). Education and training curriculum on intellectual and developmental disabilities. Retrieved from <http://www.aadmd.org/ntg>
- Nauert, R. (2014). Program helps people with dementia stay at home. Psych Central. Retrieved from <http://psychcentral.com/news/2014/02/11/program-helps-people-with-dementia-stay-at-home/65730.html>
- Ne’eman, A. (2013, September). The Affordable Care Act and the IDD Community. An overview of the law and advocacy priorities going forward. Retrieved from <http://www.autisticadvocacy.org/wp-content/uploads/2013/09/ACA-ASAN-policy-brief.pdf>
- Norton, S., Matthews, F. E., Barnes, D. E., Yaffe, K. & Brayne, C. (2014). Potential for primary prevention of Alzheimer’s disease: An analysis of population-based data. *Lancet Neurology*, 13, 788–794. doi:10.1016/S1474-4422(14)70136-X
- Oliver, C. (1999). Perspectives on assessment and evaluation. In M. P. Janicki & A. J. Dalton (Eds.), *Dementia, aging, and intellectual disabilities: A handbook* (pp. 123–138). Philadelphia, PA: Brunner-Mazel.
- Oliver, C. & Kalsy, S. (2005). The assessment of dementia in people with intellectual disabilities: Context, strategy and methods. In J. Hogg & A. Langa (Eds.), *Assessing adults with intellectual disabilities: A service provider’s guide* (pp. 98–107). Oxford, UK: BPS Blackwell.
- Pary, R. (2000). Differential diagnosis of functional decline in Down’s syndrome. *Habilitative Mental Healthcare Newsletter*, 11(6), 37–41. Retrieved from <http://www.riverbendds.org/index.htm?page=declinepar>.html
- Pary, R. J., Rajendran, G., & Stonechipher, A. (2006). Overview of Alzheimer’s disease in Down syndrome. In V. P. Prasher (Ed.), *Down syndrome and Alzheimer’s disease: Biological correlates* (pp. 1–36). Oxford, UK: Radcliffe.
- Patti, P. J., Galli, M., Ferrario, D., Freeland, R. & Albertini, G. (2010). Movement and dementia in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 23, 410.
- Perkins, E. A. (2007). Self and proxy reports across three populations: Older adults, persons with Alzheimer’s disease, and persons with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 1–10.
- Perkins, E. A., & Moran, J. A. (2010). Aging adults with intellectual disabilities. *Journal of the American Medical Association*, 304, 91–92.
- Pivi, G. A. K., Bertolucci, P. H. F., & Schultz, R. Z. (2012). Nutrition in severe dementia. *Current Gerontology and Geriatrics Research*. Article ID 983056, 7 pages. Retrieved from <http://www.hindawi.com/journals/cggr/2012/983056/>
<http://dx.doi.org/10.1155/2012/983056>
- Prasher, V. (2005). *Alzheimer’s disease and dementia in Down syndrome and intellectual disabilities*. Oxford, UK: Radcliffe Publishing.
- Prasher, V. P. (2004). Review of donepezil, rivastigmine, galantamine and memantine for the treatment of dementia in Alzheimer’s disease in adults with Down syndrome: implications for the intellectual disability population. *International Journal of Geriatric Psychiatry*, 19, 509–515.
- Prince, M., Siervo, M., Acosta, D., Guerchet, M., & Prina, M. (2014). Improving nutrition for people with dementia. In M. Prince, E. Albanese, M. Guerchet., & M. Prina (Eds.), *Nutrition and dementia: A review of available research* (pp. 53–81). London, UK: Alzheimer’s Disease International.
- Rizzolo, M. C., Hemp, R., Braddock, D., & Schindler, A. (2009). Family support services for persons with intellectual and developmental disabilities: Recent national trends. *Intellectual and Developmental Disabilities*, 47, 152–155.
- Robinson, L., Dauenhauer, J., Bishop, K., & Baxter, J. (2012). Growing health disparities for persons who are aging with intellectual and developmental disabilities: The social work linchpin. *Journal of Gerontological Social Work*, 55, 175–190.

- Sampson, E. L., Burns, A., & Richards, M. (2011). Improving end-of-life care for people with dementia. *British Journal of Psychiatry, 199*, 357–359.
- Saxon, S. V., Etten, M. J., & Perkins, E. A. (2014). *Physical change & aging: a guide for the helping professions* (6th ed.). New York, NY: Springer Publishing Co.
- Schmidt, C., Redyk, K., Meissner, B., Krack, L., von Ahsen, N., Roeber, S., Kretzschmar H., & Zerr, I. (2010). Clinical features of rapidly progressive Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders, 29*, 371–378.
- Service, K. P. & Hahn, J. E. (2003). Issues in aging: The role of the nurse in the care of older people with intellectual and developmental disabilities. *Nursing Clinics of North America, 38*, 292–312.
- Service, K. P., Tyler, C. V. & Janicki, M. P. (2006). Geriatric care. In I. I. Rubin & A. Crocker (Eds.). *Developmental disabilities: delivery of medical care for children and adults* (2nd ed., pp. 575–589). Baltimore, MD: Paul H. Brookes.
- Sheehan, R., Ali, A., & Hassiotis, A. (2014). Dementia in intellectual disability. *Current Opinion in Psychiatry, 27*, 143–148.
- Silverman, W., Krinsky-McHale, S., Schupf, N., & Zigman, W. (2010, August). *Progression from mild cognitive impairment to dementia in adults with Down syndrome*. Paper presented as part of the symposium, "Transitions in neurological and cognitive phenotypes and dementia status in people with Down syndrome," at the 118th annual convention of the American Psychological Association, San Diego, CA, August 14, 2010.
- Strydom, A., Hassiotis, A., King, M., & Livingston, G. (2009). The relationship of dementia prevalence in older adults with intellectual disability (ID) to age and severity of ID. *Psychological Medicine, 39*, 13–21.
- Strydom, A., Shoostari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., & Maaskant, M. (2010). Dementia in older adults with intellectual disabilities—epidemiology, presentation, and diagnosis. *Journal of Policy and Practice in Intellectual Disabilities, 7*, 96–110.
- Strydom, A., Chan, T., King, M., Hassiotis, A., & Livingston, G. (2013). Incidence of dementia in older adults with intellectual disabilities. *Research in Developmental Disabilities, 34*, 1881–1885.
- Sullivan, W., Heng, J., Cameron, D., Lunsy, Y., Cheetham, T., Hennen, B., & Swift, I. (2006). Consensus guidelines for primary health care of adults with developmental disabilities. *Canadian Family Physician, 52*, 1410–1418.
- Sutherland, G., Couch, M. A., & Iacono, T. (2002). Health issues for adults with developmental disability. *Research in Developmental Disabilities, 23*, 422–445.
- Tilly, J., Wiener, J. M., Gould, E., & O'Keefe, J. (2011). Making the long-term services and supports system work for people with dementia and their caregivers. Retrieved from http://www.adrc-tae.acl.gov/tiki-download_file.php?fileId=31471
- Torr, J., & Davis, R., (2007). Ageing and mental health problems in people with intellectual disability. *Current Opinion in Psychiatry, 20*, 467–471.
- Towers, C. & Wilkinson, H. (2014). Planning ahead: Supporting families to shape the future after a diagnosis of dementia. In K. Watchman (Ed.), *Intellectual disability and dementia: Research into practice* (pp. 161–182). London, UK: Jessica Kingsley.
- Tyler, C. & Noritz, G. (2009). Aging adults with intellectual and other developmental disabilities. *Clinical Geriatrics, 31*, 85–88. U.S. Department of Health and Human Services (USDHHS). (2002). *Closing the gap: A national blueprint to improve the health of persons with mental retardation*. Washington, DC: Author.
- U.S. Department of Health and Human Services (USDHHS). (2012). *National plan to address Alzheimer's disease*. Washington, DC: Author. U.S. Department of Health and Human Services (USDHHS). (2013). *2013 Update to the national plan to address Alzheimer's disease*. Washington, DC: Author. U.S. Department of Health and Human Services (USDHHS). (2014a). *2014 Update to the national plan to address Alzheimer's disease*. Washington, DC: Author.
- U.S. Department of Health and Human Services (USDHHS). (2014b). Section 2402(a) of the Affordable Care Act – Guidance for implementing standards for person-centered planning and self-direction in home and

community-based services programs. Memo to Heads of Operating Divisions from Secretary Kathleen Sibelius, Department of Health and Human Services (June 6, 2014), Washington, DC. Retrieved from <http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf>

Vanderbilt Kennedy Center. (2014). Health care for adults with intellectual and developmental disabilities toolkit for primary care providers. Retrieved from <http://vkc.mc.vanderbilt.edu/etoolkit/>

Wallace, R. A., & Dalton, A. J. (2006). Clinician's guide to physical health problems of older adults with Down syndrome. *Journal on Developmental Disabilities, (Supplement)*, 12(1), 1–45.

Watchman, K. (2014). *Intellectual disability and dementia: Research into practice*. London, UK: Jessica Kingsley.

Wilkinson, H., & Janicki, M. (2002). The Edinburgh principles with accompanying guidelines and recommendations. *Journal of Intellectual Disability Research*, 46, 279–284.

Wilkosz, P. A., Seltman, H. J., Devlin, B., Weamer, E. A., Lopez, O. L., Dekosky, S. T., & Sweet, R. A. (2009). Trajectories of cognitive decline in Alzheimer's disease. *International Psychogeriatrics*, 22, 281–290.

World Health Organization (WHO). (2012). *Dementia: A public health priority*. Geneva, Switzerland: Author.