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When Dementia Looks Different: Transitions for Older Adults with Intellectual and Developmental Disabilities

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Individuals with intellectual and developmental disabilities (IDD) are living longer lives then they have ever before (Bishop et al., 2015). Increased longevity means an increase in age-related changes and disorders such as dementia. Strydom et al. (2009) found that individuals with IDD are two to three times more likely to be diagnosed with dementia compared to other populations. The prevalence of dementia and Down syndrome was found to be even higher, with 75% of adults with Down syndrome over the age of 65 having a diagnosis of dementia (Wissing et al., 2022). One of the biggest challenges loved ones and caregivers face is confirming a dementia diagnosis. Neurologists may be hesitant to diagnose someone who has IDD with dementia and may attribute concerns to age-related decline. A major challenge in diagnosing dementia in this population is that signs of change, whether physical, emotional, or cognitive, rely heavily on caregiver and family reporting, as many individuals with IDD cannot reliably communicate these concerns (Duncan et al., 2023). Despite these challenges, early detection and accurate assessment of dementia are essential for ensuring individuals and their caregivers receive appropriate support.

Dementia screenings are typically recommended when an adult self-reports cognitive changes. Limited verbal or non-verbal adults may have difficulty self-reporting changes to a medical professional. Additionally, the clinical presentation of dementia in people with IDD may differ from the general population, with changes in personality and behavior occurring first, rather than observable difficulty with memory and cognition (Wissing et al., 2022; Zeilinger et al., 2013). As such, providers who are unfamiliar with dementia in the IDD population may have difficulty identifying signs of dementia. In addition to difficulty initiating the diagnostic process, dementia assessment for people with IDD also poses challenges. Dementia screenings must emphasize identifying changes from an individual's personal baseline, in the absence of comparison to neurotypical population norms (McCallion et al., 2019; Zeilinger et al., 2013). Therefore, it is essential to utilize screening tools designed for the IDD population.

The National Task Group's "Early Detection Screen for Dementia" (NTGEDSD) is widely gaining acceptance as the primary dementia screening tool for IDD, due to its reliability, relevance of the information gathered, and its accessibility as a free online tool available in multiple languages (Silverman et al., 2020; Zeigler et al., 2013; Zeigler et al., 2022). Caregivers with extensive knowledge of an individual can provide essential information about a person's typical behaviors and abilities, as well as changes to their baseline. It is recommended that dementia screenings for people with IDD are completed before concerns for dementia arise (Deb & McHugh, 2010; McCallion et al., 2019; Strydom et al., 2013; Uberti & Corti, 2013; Zeilinger et al, 2013).

This proactive approach to screening helps establish a baseline level of functioning and allows for earlier detection (Dodd et al., 2025; Jokinen et al., 2013). Early detection of dementia in people with IDD is critical to ensure that the individual and their caregivers receive the appropriate medical and social support to navigate this disease (Janicki & Keller, 2014; Janicki & Keller, 2015; Silverman et al., 2022; Wissing et al., 2021; Zeilinger et al., 2013). While we have emphasized the need for tailored assessment approaches and proactive planning, the current studies available in best practices are rarely focused on the dementia and IDD population, instead focusing on each population separately. Delivery of effective care requires caregivers to understand and know the person well, understand dementia and maintain an awareness of its progression, and consequently be able to deliver care in the present while simultaneously thinking ahead (Dodd et al., 2025). The focus of care for a person with IDD experiencing dementia symptoms will shift from goal-oriented approaches to skill preservation, maintaining autonomy, and ensuring the presence of quality-of-life indicators.

Non-pharmacological approaches to dementia management emphasize environmental modifications to reduce stressors, implementation of structured routines, and continuous assessment of an individual's internal needs (e.g. sleep, hunger, pain, thirst, discomfort). (International Summit/ Autism Work Group, 2024). According to Ghamari et al. (2025), environmental considerations are critical in impacting progression of the disease while enhancing quality of life. Strategic design of an individual's environment should account for changes in their spatial perception and motor coordination. Some essential features may include non-slip flooring, handrails, accessible bathrooms, and consideration of sensory sensitivities (e.g. lighting, noise). In addition to essential safety components, the integration of personalization and familiarity may offer therapeutic benefits to evoke memories and stimulate cognitive engagement.

Building on the support strategies outlined above, it is equally important to consider how both individuals with IDD and their caregivers experience transitions as dementia progresses. Transitions often occur across many areas of life including daily routines, living situations, supports, and relationships. These transitions can be especially complex due to communication challenges, behavioral changes, and the need for specialized supports. Planning ahead and supporting gradual changes can help individuals feel safer and maintain a sense of familiarity. Maintaining consistency in routines, trusted caregivers, and daily activities help to preserve quality of life as well as reduce confusion or anxiety (Jacobs et al., 2023). For families and caregivers, these transitions are emotionally complex and can be physically and mentally demanding.

Many caregivers face uncertainty about how best to support their loved one as dementia progresses. They may be questioning when to introduce additional care, how to communicate changes, or whether residential placement may be needed (Hughes et al., 2024). Dennehy et al. (2023) found that caregivers of adults with IDD and dementia often experience grief, guilt, and stress, especially when services are fragmented or difficult to navigate. Access to clear information, supportive professionals, and respite opportunities can make a meaningful difference. Additionally, caregiver education about dementia symptoms and behavioral changes can build confidence and reduce distress.

Egan et al. (2021) describe transitions for this population as ongoing processes rather than a single event. Collaborative, interdisciplinary teamwork among healthcare professionals, behavioral specialists, and direct support staff can help ensure continuity and reduce service gaps (Ashbourne et al., 2021). Post-diagnostic supports, such as shared planning meetings and written transition plans, are key elements of effective care. Ultimately, the focus of transition planning should always center on the person, honoring their preferences and history, while also supporting the wellbeing of caregivers. Through early planning and collaboration, individuals with IDD and dementia can experience greater comfort, stability, and dignity through each stage of change.