



Dementia in Mentally Disabled Hard to Identify

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Action Points

- Note that this consensus statement addresses the evaluation and management of dementia in those with intellectual disabilities -- a population at particular risk of missed diagnosis.
- Be aware that most of the recommendations are based on expert opinion rather than randomized trial data.

A new consensus statement addresses the challenges of evaluating and managing dementia in older adults with "intellectual and development disabilities," such as [Down syndrome](#) or brain injury.

These patients have an increased risk of poorer outcomes, compared with the general population, in part because healthcare professionals often lack training and preparedness to adequately respond to their special needs, according to Julie A. Moran, DO, previously with Beth Israel Deaconess Medical Center in Boston, and colleagues. Moran is now with Tewksbury Hospital in Tewksbury, Mass.

Even trying to establish a baseline decline in everyday abilities in adults with intellectual disabilities can be challenging because cognitive functioning is highly individualistic, and also because of external factors such as poor record-keeping and contact with numerous healthcare professionals who often "presume that [the patient's] current level of ability represents [his or her] baseline level of functioning and, thus, miss signs of early decline," they wrote in the August issue of *Mayo Clinic Proceedings*.

"It's a relatively new phenomenon to have a large number of people with intellectual disabilities living into their 70s, 80s and beyond," Moran told *MedPage Today* in an interview. "Primary care and other general physicians typically didn't receive medical training specific to the needs of this patient population, particularly in terms of assessing their cognitive function. They need to be educated."

To address the multiple needs of these patients and their caregivers, the National Task Group on Intellectual Disabilities and Dementia Practices was formed. Its creation was a direct response to the [National Alzheimer's Project Act](#) that was signed into law in January 2011 by President Obama.

The recommendations for assessing patients with intellectual disabilities are intended to help provide healthcare professionals the information they need for the "detection of any cognitive impairment" -- a requirement that appears in the [Medicare Annual Wellness Visit](#) component of the Affordable Care Act.

Researchers recommend a nine-step approach for assessing health and function. These include:

- Taking thorough history, with particular attention to "red flags" that potentially indicate premature dementia such as history of cerebrovascular disease or head injury, sleep disorders, or vitamin B12 deficiency
 - Documenting a historical baseline of function from family members of caregivers
 - Comparing current functional level with baseline
 - Noting dysfunctions that are common with age and also with possible emerging dementia
 - Reviewing medications and noting those that could impair cognition
 - Obtaining family history, with particular attention to a history of dementia in first-degree relative
 - Noting other destabilizing influences in patient's life such as leaving family, death of a loved one, or constant turnover of caregivers, which could trigger mood disorders
 - Reviewing the level of patient safety gleaned from social history, living environment, and outside support
 - Continually "cross-referencing the information with the criteria for a dementia diagnosis"
- Moran and colleagues pointed out that current memory screening methods for individuals with intellectual disabilities are not standardized.

They suggested consulting a study by Alzheimer's Association outlining a variety of [cognitive screening tools that can be utilized in the primary care setting](#).

The National Task Group has plans in the pipeline to publish additional recommendations regarding screening techniques and how to provide additional support for these patients.

"There is no one-size-fits-all screening tool for this very heterogeneous group," Moran said. "Some adults with intellectual disabilities at baseline can't tie their shoes, while others can work and travel independently. It's very important to be able to detect longitudinal changes in cognitive function."

Has your practice seen an increase in the number of older adults with intellectual disabilities? Are you confident in the current knowledge and tools at your disposal regarding assessing them for cognitive decline? Tell us your experience by clicking [Add Your Knowledge](#) below. -- Sanjay Gupta, MD

UPDATE: This article, originally published Aug. 20, 2013, at 3:43 p.m., was updated with new material (Aug. 20, 2013, at 6:50 p.m.).

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