



MIND & MEMORY MATTERS

Early Identification of Dementia in I/DD

In the United States, 6% of adults with I/DD will be affected by some form of dementia after the age of 60. For adults with Down syndrome, studies show that 50-70% will be affected by the age of 60. With early identification, there is potential to proactively address signs, delay symptoms and identify potentially treatable conditions that are causing symptoms. For all these reasons, the role of caregivers is especially important as advocates.

National Task Group-Early Detection Screen for Dementia (NTG-EDSD)

The NTG-EDSD is used by caregivers and providers in any setting for adults with I/DD who may be experiencing changes in thinking, behavior, and adaptive skills that could be related to dementia.

This tool is meant as a first pass screening to identify individuals who might need a more complete assessment.

The NTG-EDSD was not designed to diagnose dementia, but to help in the early identification and screening process, as well as to provide information to begin the conversation with health care providers.

When should the screening tool be used?



This instrument can be used annually or as needed with adults with Down syndrome beginning at age 40, and with other at-risk persons with I/DD when suspected of experiencing cognitive change.

Who should fill out the NTG-EDSD?

The form can be completed by anyone who is familiar with the adult (has known them for more than six months) such as a family member, support worker, or a behavioral/health specialist using information gathered through observation or from the adult's personal record.





MIND & MEMORY MATTERS

How to use the information you get from filling out the NTG-EDSD

The tool is a living document and can continue to be referenced over time.

- 1 If no signs or concerns are observed, then the form should be filled out and saved as a baseline for future reference.
- 2 If changes are observed, then the form can be used to start a conversation with your healthcare provider to determine next steps.
- 3 The information on the form can be shared with healthcare providers during any health visit, your annual wellness visit (provided under the Affordable Care Act) or as part of eligibility determination.
- 4 The form should be shared with all healthcare specialists who are part of the healthcare team to provide proactive treatment and appropriate support for the caregiver.

Early Signs of Dementia Include:

- Unexpected memory problems
- Getting lost or misdirected
- Problems with gait or walking
- New seizures
- Confusion in familiar situations
- Changes in personality