

QUICK GUIDE FOR USING THE NTG- EDSD BY SUPPORT & CARE STAFF

The NTG-EDSD is a brief checklist that staff and other caregivers can use to record behaviors that they suspect may be changing and want to discuss with a clinician or use for dementia care planning.



National Task Group
on Intellectual Disabilities
and Dementia Practices

www.the-ntg.org

What is the EDSD? This easy-to-use checklist enables direct support professionals and other service providers to record suspected behavioral changes and differences that they observe for adults with an intellectual disability, including setting a 'baseline.' The EDSD is also used by healthcare providers and others as a record of changes in abilities and behaviors over time. This information helps to determine if there are changes in capabilities as the person ages. For ease of use, the EDSD has been translated into many languages, including English, Spanish, and French.

What information is collected? Observations from multiple sources, including care teams, healthcare providers, and caregivers can be noted directly on the same form. The EDSD also enables services/support providers to record information about issues including (a) medical or behavioral conditions, (b) questions about observed changes, (c) how the person acts when doing daily tasks, (d) whether the person is having memory problems or forgetting how to do things, (e) medication use, and (f) whether behaviors are new or have been there for some time.

How can you use it? As a service/support staff, complete the form and then check with anyone else who may also have helpful information. Then review the information with your team or with a clinician about what questions to raise with the healthcare provider or diagnostician about the changes you are observing. It is also helpful for use in a review for dementia care planning.

Can it diagnose? No. Clinicians or healthcare providers provide a diagnosis of a mild cognitive impairment or dementia and determine

what these or something else is responsible for any notable changes in thinking or behavior. Often, clinicians or providers will need to run some tests before making a diagnosis. The EDSD is helpful because it helps track changes and highlight areas that require further examination – those suspicions about something that warrants further investigation. This checklist is a starting point and the personal observations captured will be helpful when determining whether there are changes in thinking or behavior and what can be done to treat the person.

When should you use the EDSD? This checklist should first be used with adults with Down syndrome around age 35 and with adults with another intellectual disability around the mid-50s. The first time the EDSD is used, the 'baseline' records the person's skills and abilities before any observed changes. This baseline is helpful to compare changes over time. The checklist should be re-done every year or every other year. If areas of concern are noted, then the checklist can be redone more often. Even as much as every six months or as recommended by a healthcare provider.

More information, including the NTG-EDSD checklist, can be downloaded for free at www.the-ntg.org/ntg-edsd.

The mission of the NTG is to advocate for services and supports for people with intellectual disability and their families who are affected by Alzheimer's disease and dementias.
