

# NTG-EDSD

v.2/2024.3

The **NTG-Early Detection Screen for Dementia**, adapted from the DSQIID,\* can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the cognitive impairment assessment that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.the-ntg.org/ntg-edsd)

<sup>(1)</sup> File #:	<sup>(2)</sup> Date:
Name of person: <sup>(3)</sup> First	<sup>(4)</sup> Last:
<sup>(5)</sup> Date of birth:	<sup>(6)</sup> Age:
<sup>(7)</sup> Sex:	
Female       Male	Instructions: For each question block, <u>check the item that</u> <u>best applies</u> to the individual or situation.
<sup>(8)</sup> Best description of level of intellectual disability (ID)	
No discernible intellectual disability	
Mild ID	
Moderate ID	
Severe ID	
Profound ID	Current living arrangement of person:
<sup>(9)</sup> Diagnosed condition ( <i>check all that apply</i> )	<ul> <li>Lives alone</li> <li>Lives with spouse or friends</li> <li>Lives with parents or other family members</li> </ul>
Autism	□ Lives with paid caregiver
Cerebral palsy	<ul> <li>Lives in community group home, apartment,</li> </ul>
Down syndrome	supervised housing, etc.
Fragile X syndrome	□ Lives in senior housing
Intellectual disability	□ Lives in congregate residential setting
Prader-Willi syndrome	Lives in long term care facility
Other:	Lives in other:

<sup>(10)</sup> General characterization of <u>current</u> physical health:

Excellent
Very good
Good
Fair
Poor

<sup>(11)</sup> Compared to <u>one year ago</u>, current <u>physical</u> health is:

Much better
Somewhat better
About the same
Somewhat worse
Much worse

<sup>(12)</sup> Compared to <u>one year ago</u>, current <u>mental</u> health is:

Much better
Somewhat better
About the same
Somewhat worse
Much worse

<sup>(13)</sup> Conditions present (*check all that apply*)

Vision impairment
Blind (very limited or no vision)
Vision corrected by glasses
Hearing impairment
Deaf (very limited or no hearing)
Hearing corrected by hearing aids
Mobility impairment
Not mobile – uses wheelchair
Not mobile – is moved about in
wheelchair

<sup>(14)</sup> Significant recent [in past year] life event (*check all that apply*)

Death of someone close
Changes in living arrangement, work, or
day program
Changes in staff close to the person
New roommate/housemates
Illness or impairment due to accident
Adverse reaction to medication or
over-medication
Interpersonal conflicts
Victimization / abuse
Other:

(15) Seizures

Recent onset seizures
Long term occurrence of seizures
Seizures in childhood, not occurring in
adulthood
No history of seizures

# If MCI or dementia is documented complete 16, 17, &18

(16) Diagnostic History
Mild cognitive impairment [MCI] or dementia previously diagnosed (Dx)?:
[ ] No
[ ] Yes, MCI
Date of Dx:
[ ] Yes, dementia
Date of Dx:
Type of dementia:
Diagnosed by:
Neurologist
D Physician
Psychiatrist
Psychologist
Other:
<sup>(17)</sup> Reported date of onset of MCI/dementia

 <sup>(17)</sup>Reported date of onset of MCI/dementia [When suspicion of dementia first arose]
 Note approximate year and month:

<sup>(18)</sup> Comments / explanations about dementia
suspicions:

# [Check column option as appropriate]

	Always been the case	Always but worse	New symptom in past year	Does not apply
<sup>(19)</sup> Activities of Daily Living				
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete,				
inadequately for weather)				
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)				
<sup>(20)</sup> Language & Communication				
Does not initiate conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
<sup>(21)</sup> Sleep-Wake Change Patterns				
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night				
Wakes earlier than usual				
Sleeps later than usual				
<sup>(22)</sup> Ambulation				
Not confident walking over small cracks, lines on the ground,				
patterned flooring, or uneven surfaces				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				

	Always been the case	Always but worse	New symptom in past year	Does not apply
<sup>(23)</sup> Memory			1	
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people				
Does not remember recent events (in past week or less)				
Does not find way in familiar surroundings				
Loses track of time (time of day, day of the week, seasons)				
Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
<sup>(24)</sup> Behavior and Affect				
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities				
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness Talks to self				
(25) Adult's Self-reported Problems				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
<sup>(26)</sup> Notable Significant Changes Observed by Others				
In gait (e.g., stumbling, falling, unsteadiness)				
In personality (e.g., subdued when was outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., new second unesponsive)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

## [Check column option as appropriate]

	<sup>(27)</sup> Chronic Health Conditions*	Recent	Condition	Lifelong	Condition
	Chi one nearth conditions	condition	diagnosed in	condition	not present
		(past year)	-	condition	not present
	Pana laint and Musala	(past year)	last 5 years		
4	Bone, Joint and Muscle				
1	Arthritis				
2	Osteoporosis				
0	Heart and Circulation Heart condition				
3					
4	High cholesterol				
5	High blood pressure				
6	Low blood pressure				
7	Stroke				
•	Hormonal				Τ
8	Diabetes (type 1 or 2)				
9	Thyroid disorder				
10	Lungs/breathing				Γ
10	Asthma				
11	Chronic bronchitis, emphysema				
12	Sleep disorder				
10	Mental health				Γ
13	Alcohol or substance abuse				
14	Anxiety disorder				
15	Attention deficit disorder				
16	Bipolar disorder				
17	Dementia/Alzheimer's disease				
18	Depression				
19	Eating disorder (anorexia, bulimia)				
20	Obsessive-compulsive disorder				
21	Schizophrenia				
22	Other:				
	Pain / Discomfort				1
23	Back pain				
24	Constipation				
25	Foot pain				
26	Gastrointestinal pain or discomfort				
27	Headaches				
28	Hip/knee pain				
29	Neck/shoulder pain				
	Sensory				
30	Dizziness / vertigo				
31	Impaired hearing				
32	Impaired vision				
	Other				
33	Cancer – type:				
34	Chronic fatigue				
35	Epilepsy / seizure disorder				
36	Heartburn / acid reflux				
37	Urinary incontinence				
38	Sleep apnea				
39	Tics/movement disorder/spasticity				
40	Dental pain				

\*Items drawn from the Longitudinal Health and Intellectual Disability Survey (University of Illinois at Chicago)

### NTG-EDSD - page 6

(28) Current Medications			
Yes	No □	<b>Indicate type</b> Treatment of chronic conditions Treatment of mental health disorders or behavior problems	
		Treatment of pain	
For reviews, attach list of current medications, dosage, and when prescribed <ul> <li>List is attached for reviews</li> </ul>			
<sup>(29)</sup> Comments related to other notable changes or concerns:			

### <sup>(30)</sup> Next Steps / Recommendations

- Refer to treating physician for assessment
- □ Review internally by clinical personnel
- □ Include in annual review / annual wellness visit
- □ Repeat in \_\_\_\_\_ months

# Form completion information

<sup>(31)</sup> Date completed	(32) Organization / Agency			
Name of person completing form				
Relationship to individual (staff, relative, assessor, etc.)				
Date(s) form previously completed				
Date(s) form previously completed				

Acknowledgement: Derived from the DSQIID (\*Dementia Screening Questionnaire for Individuals with Intellectual Disabilities; Deb, S., 2007) as adapted into the Southeast PA Dementia Screening Tool (DST) – with the assistance of Carl V. Tyler, Jr., MD – and the LHIDS (Longitudinal Health and Intellectual Disability Survey; Rimmer & Hsieh, 2010) and as further adapted by the National Task Group on Intellectual Disabilities and Dementia Practices as the NTG Early Detection Screen for Dementia for use in the USA and other countries.