

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) DOWN SYNDROME MODULE

Form B1D: NTG — Early Detection Screen for Dementia

ADRC name: _____ Participant ID: _____ Form date: ___/___/_____
 Visit #: _____ Examiner's initials: _____



NTG-EDSD

(7) Sex:

	Female
	Male

Instructions:
 For each question block, check the item that best applies to the individual or situation.

(8) Best description of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

(9) Diagnosed condition (check all that apply)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

Current living arrangement of person:

- Lives alone
- Lives with spouse or friends
- Lives with parents or other family members
- Lives with paid caregiver
- Lives in community group home, apartment, supervised housing, etc.
- Lives in senior housing
- Lives in congregate residential setting
- Lives in long term care facility
- Lives in other: _____

(10) General characteristics of current physical health:

	Excellent
	Very good
	Good
	Fair
	Poor

(11) Compared to one year ago, current physical health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(12) Compared to one year ago, current mental health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(13) 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

(14) 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:

Geriatrician

Neurologist

Physician

Psychiatrist

Psychologist

Other:

(17) Reported date of onset of MCI/dementia

[When suspicion of dementia first arose]

Note approximate year and month:

(18) 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
(19) 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)				
(20) 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)				
(21) 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				
(22) 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
(23) Memory				
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				
(24) 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				
(26) 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., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

[Check column option as appropriate]

	⁽²⁷⁾ Chronic Health Conditions*	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
	Bone, Joint, and Muscle				
1	Arthritis				
2	Osteoporosis				
	Heart and Circulation				
3	Heart condition				
4	High cholesterol				
5	High blood pressure				
6	Low blood pressure				
7	Stroke				
	Hormonal				
8	Diabetes (type 1 or 2)				
9	Thyroid disorder				
	Lungs/breathing				
10	Asthma				
11	Chronic bronchitis, emphysema				
12	Sleep disorder				
	Mental Health				
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				
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)

(28) Current Medications**Yes No Indicate type**

- | | | |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment of chronic conditions |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment of mental health disorders or behavior problems |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment of pain |

For reviews, attach list of current medications, dosage, and when prescribed

- List is attached for reviews

(29) Comments related to other notable changes or concerns:**(30) Next Steps / Recommendations**

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

Acknowledgment: 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.

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National Task Group on Intellectual Disabilities and Dementia Practices

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