

Early Detection Screen for Dementia (EDSD): Testimonial and How to Administer

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Objectives

- Increase overall knowledge of the NTG-EDSD tool
- Increase understanding of how to complete the tool
- Increase understanding of when the tool could be administered
- Increase awareness of other individuals to involve when administering the NTG-EDSD tool
- Review the challenges in diagnosing dementia with individuals living with an intellectual developmental disability, and the rationale for using the NTG-EDSD tool



Items to consider...

- Who would you need to consult with to complete the NTG-EDSD?
- At what point should you take this tool to the physician?
- What is the best way for you to obtain the information?
- Who could you involve and in what capacity?



NTG-EDSD – Background Information

NTG-EDSD is...

- Informant-based rating tool
 - Adults with I/DD
- Administrative tool
 - Review of relevant information

NTG-EDSD is not...

- Clinical Assessment Tool
- Designed to diagnose dementia



Why it's important

- Increase our ability to gather and maintain information
- Increase collaborative efforts
- Increase proactive measures
 - Improving or maintaining quality of life
 - Adapt to needs
 - Social/Emotional
 - Environmental
 - Behavioral



Testimonial: How the NTG-EDSD has been used by Aptiv

- Residential Program
 - Adult Family Home (AFH)
- Recognition of change by staff
 - Collaborative effort



Testimonial (continued...)

- Changes in behavior
- ABC tracking
 - Antecedent : Behavior :
Consequence
- NTG-EDSD tool completion
 - Collaborative effort
- Information gathering/sharing
 - Diagnosis specific
 - Sundowning
- Next steps:
 - Medical appointment
 - Follow up
 - AFH staff
 - Residential Coordinator
 - Behavior Services
 - NGT-EDSD Administrator
 - Tool administered again



Plan of Action

- Continue to train staff using the NTG materials
 - Dementia and I/DD
 - Diagnosis specific
- Systematic roll out of NTG-EDSD administration throughout Residential Program
 - Evaluate
- Identification of next program to roll out EDSD administration



Helpful Information

Resources to have/use:

- Individual's medical records
 - Including lab tests
- Information regarding the living environment
- Information on personal functioning
- Information from others
 - Family
 - Staff

Limitations:

- The NTG-EDSD is not a diagnostic instrument
- There is no scoring system
- Opportunity for qualitative, not quantitative review of changes



NTG-EDSD Manual: Appendix A



National Task Group on Intellectual
Disabilities and Dementia Practices

National Task Group Early Detection Screen for Dementia

NTG-EDSD

Manual

Version 1 May 2013-e



NTG-EDSD

v. 1.0/2013.2

The **NTG-Early Detection Screen for Dementia**, adapted from the **D5QID**[®], 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 mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.8 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.aadmd.org/ntg/screening).

⁽¹⁾ File #: _____ ⁽²⁾ Date: _____

Name of person: ⁽³⁾ First: _____ ⁽⁴⁾ Last: _____

⁽⁵⁾ Date of birth: _____ ⁽⁶⁾ Age: _____

⁽⁷⁾ Sex:

☐	Female
☐	Male

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

⁽⁸⁾ Best description of level 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: _____



APPENDIX A: Instructions for Completing NTG-EDSD

Page 13 in NTG-EDSD
Manual

APPENDIX A: Instructions for the completion of the NTG-EDSD.

Item #	Item Title	Comment
1	File#	For agency use
2	Date	Date form completed
3/4	Name of person	Fill in first and last name of person being screened
5	Date of birth	Provide day, month, year
6	Age	Age when form was completed
7	Sex	Indicate male or female
8	Best description of level of intellectual disability	Draw from any previously completed assessments or estimate if none ever done
9	Diagnosed condition	Draw from any previously completed assessments or estimate if none ever done
-	Current living arrangement of person	Pick most appropriate item
10	General characterization of current physical health	Pick most appropriate item
11	Compared to one year ago, current physical health is:	Pick most appropriate item
12	Compared to one year ago, current mental health is:	Pick most appropriate item
13	Conditions present	Indicate those diagnosed as well as observed
14	Significant recent [in past year] life event	Indicate those that occurred
15	Seizures	Pick most appropriate item
16	Diagnostic history	Complete this item only if the person has been formally assessed and diagnosed; use information provided in diagnostic report
17	Reported date of onset of MCI/dementia	Indicate month/year when first symptoms were noticed
18	Comments/explanation about dementia suspicions	Indicate any behaviors that triggered suspicions or referral for assessment
19	Activities of daily living	Pick most appropriate column item for each 'Always been the case' means the need, problem or behavior has been present for a very long time 'Always but worse' means the existing need, problem or behavior has further declined requiring more personal assistance 'New symptom in past year' means this need, problem or behavior was not present until recently 'Does not apply' means these needs, problems or behaviors are not present
20	Language & communication	Pick most appropriate column item for each



NTG - EDSD Document

Page 1: Fields 1 to 9

⁽¹⁾File #: _____ ⁽²⁾Date: _____

Name of person: ⁽³⁾First _____ ⁽⁴⁾Last: _____

⁽⁵⁾Date of birth: _____ ⁽⁶⁾Age: _____

⁽⁷⁾Sex:

☐	Female
☐	Male

⁽⁸⁾ Best description of level of intellectual disability

☐	No discernible intellectual disability
☐	Borderline (IQ 70-75)
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☐	Profound ID (IQ 24 and below)
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⁽⁹⁾ Diagnosed condition (check all that apply)

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☐	Fragile X syndrome
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☐	Other: _____

NTG - EDSD Manual Instructions

Item #	Item Title	Comment
1	File#	For agency use
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5	Date of birth	Provide day, month, year
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7	Sex	Indicate male or female
8	Best description of level of intellectual disability	Draw from any previously completed assessments or estimate if none ever done
9	Diagnosed condition	Draw from any previously completed assessments or estimate if none ever done
-	Current living arrangement of person	Pick most appropriate item

For each best:

Current

☐ Lives in congregate residential setting

☐ Lives in long term care facility

☐ Lives in other: _____



Page 2: Fields 10 to 18

(10) General characterization of current physical health:

Excellent
Very good
Good
Fair
Poor

(12) Seizures:

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

(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:

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:

Diagnoses:

☐ Geriatr

☐ Neurol

☐ Physi

☐ Psychia

☐ Psycho

☐ Other:

(17) Report (When is Note appr

(18) Comm suspici

NTG - EDSD Manual Instructions

10	General characterization of current physical health	Pick most appropriate item
11	Compared to one year ago, current physical health is:	Pick most appropriate item
12	Compared to one year ago, current mental health is:	Pick most appropriate item
13	Conditions present	Indicate those diagnosed as well as observed
14	Significant recent [in past year] life event	Indicate those that occurred
15	Seizures	Pick most appropriate item
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17	Reported date of onset of MCI/dementia	Indicate month/year when first symptoms were noticed
18	Comments/explanation about dementia suspicions	Indicate any behaviors that triggered suspicions or referral for assessment



	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				

NTG - EDSD Manual Instructions



19	Activities of daily living	Pick most appropriate column item for each 'Always been the case' means the need, problem or behavior has been present for a very long time 'Always but worse' means the existing need, problem or behavior has further declined requiring more personal assistance 'New symptom in past year' means this need, problem or behavior was not present until recently 'Does not apply' means these needs, problems or behaviors are not present
20	Language & communication	Pick most appropriate column item for each
21	Sleep-wake change patterns	Pick most appropriate column item for each
22	Ambulation	Pick most appropriate column item for each



NTG - EDSD Document

Page 4: Fields 23 to 26

	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)				

NTG - EDSD Manual Instructions

23	Memory	Pick most appropriate column item for each
24	Behavior and affect	Pick most appropriate column item for each
25	Adult's self-reported problems	Pick most appropriate column item for each 'Self-reported' means the adult has expressed one or more of these things
26	Notable significant changes observed by others	Pick most appropriate column item for each Assume that these are new behaviors



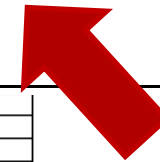
NTG - EDSD Document

Page 5: Field 27

	⁽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				

NTG - EDSD Manual Instructions

27	Chronic health conditions	Pick most appropriate column item for each Draw from any previously completed medical evaluations or current health notes in record
----	---------------------------	---



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



NTG - EDSD Document

Page 6: Fields 28 to 32

⁽²⁸⁾ Current Medications

Yes No Indicate type

- ☐ ☐ 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

☐ 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

Form completion information

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

NTG - EDSD Manual Instructions

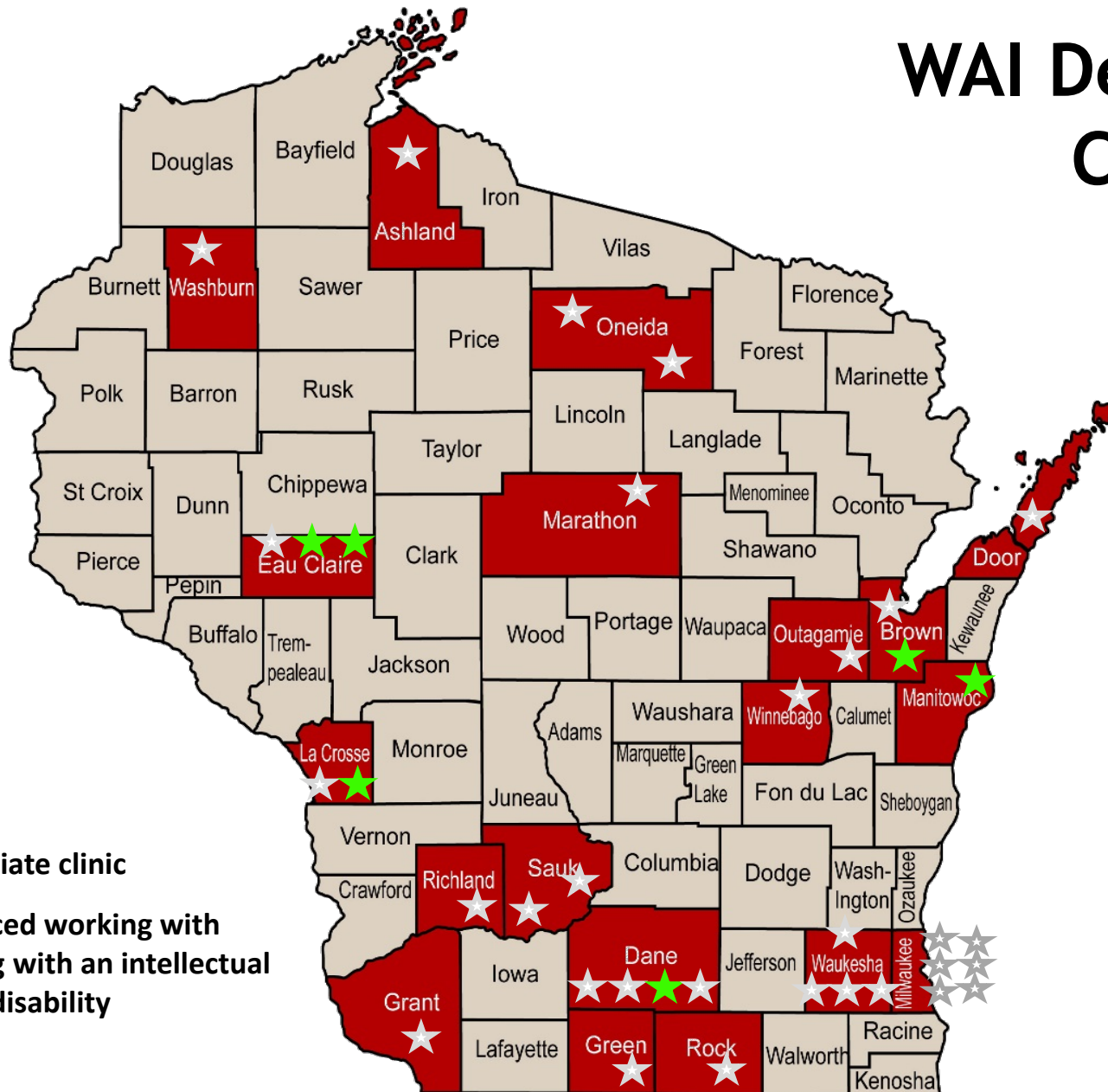
28	Current medications	This item is to help the physician or other clinician assess whether current medications may be the cause of behavioral or functional changes. Best to include a listing of current medication, with dosages, when sending or bringing form to assessment.
29	Comments related to other notable changes or concerns	Use this item to make comments of use related to behavior, function, or any events that may influence behavior
30	Next steps/recommendations	Check most relevant item
31	Date completed	Date form completed
32	Organization/agency	Name of organization providing services to the adult
-	Name of person completing form	Indicate your name
-	Relationship to individual	Indicate whether you are staff, a relative or someone else
-	Date(s) form previously completed	If the NTG-EDSD has been completed before, indicate when

Revised 10/2017. Partially based on the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, 4th Edition) as revised (DSM-IV-R) and adapted from the





WAI Dementia Diagnostic Clinic Network



36 Affiliated Clinics in the Network



Indicates an affiliate clinic



Clinics experienced working with individuals living with an intellectual developmental disability

March 2019



In a Nutshell, to be Diagnosed with Dementia...



1. There needs to be a noticeable, **measurable decline** in the person's **cognitive** abilities; a decline from a **previous, higher level (their norm)**.
2. There needs to be a noticeable, **measurable decline** in the person's **function**; a decline from a **previous, higher level (their norm)**.
3. The changes are **not** due to a **medical reason**.

This can be challenging when evaluating someone living with an intellectual developmental disability.



Cholesterol Norms

Recommended Healthy Levels (Age 2 – 18 Yrs)

	DESIRABLE	BORDERLINE	HIGH RISK
Cholesterol	Less than 170	171 – 199	200 or more
LDL Cholesterol	Less than 110	111 – 129	130 or more
HDL Cholesterol	More than 60	36 – 59	35 or less

Recommended Healthy Levels (Age 19+ Yrs)

Total Cholesterol				
Men's Range	Less than 180	180 – 199	200 – 239	240 or more
Women's Range	Less than 180	180 – 199	200 – 239	240 or more
HDL Cholesterol				
Men's Range	50 or more	45 – 49	35 – 44	34 or less
Women's Range	60 or more	55 – 59	40 – 54	39 or less
Total Cholesterol/HDL Ratio				
Men's Range	4.0 or less	4.1 – 5.0	5.1 – 6.5	6.6 or more
Women's Range	3.3 or less	3.4 – 4.5	4.6 – 6.5	6.6 or more
LDL Cholesterol				
Men's Range	100 or less	100 – 129	130 – 159	160 or more
Women's Range	100 or less	100 – 129	130 – 159	160 or more

Screening Recommendations

Bad Cholesterol Level	199mg or less	200mg or more
Screening Frequency	Consult your physician for specific screening guidelines.	A complete cholesterol panel is recommended. See your physician.

We have established norms for many indicators on how the body is doing:

- Blood pressure
- Weight
- Blood composition
- Pulse
- Blood volume
- Heart rate
- Body Mass Index (BMI)

The norms were established through large research projects.

LDL (low density lipoprotein) = 'BAD' cholesterol

HDL (high density lipoprotein) = 'GOOD' cholesterol

Sources: National Cholesterol Education Program guidelines, 2010.



Measurable Cognitive Decline

to be diagnosed...

2. There needs to be a **noticeable, measurable decline** in the person's **cognitive** abilities; a decline from a **previous, higher level (their norm)**.



Standardized tests with norms are used to determine there has been a decline from a previous, higher level.

- Age
- Education

5. You have \$100 and you go to the store and buy a dozen apples for \$3 and a tricycle for \$20.

How much did you spend?

How much do you have left?

8. I am going to give you a series of numbers and I would like you to give them to me backwards.

For example, if I say 42, you would say 24.

① 87

① 649

① 8537

11. I am going to tell you a story. Please listen carefully because afterwards, I'm going to ask you some questions about it.

Jill was a very successful stockbroker. She made a lot of money on the stock market. She then met Jack, a devastatingly handsome man. She married him and had three children. They lived in Chicago. She then stopped work and stayed at home to bring up her children. When they were teenagers, she went back to work. She and Jack lived happily ever after.

② What was the female's name?

② What work did she do?

② When did she go back to work?

② What state did she live in?



HIGH SCHOOL EDUCATION		LESS THAN HIGH SCHOOL EDUCATION	
27-30	Normal	25-30	
21-26	MNCD*	20-24	
1-20	Dementia	1-19	
* Mild Neurocognitive Disorder			

SH Tariq, N Tumosa, JT Chibnall, HM Perry III, and JE Morley. The Saint Louis University Mental Status (SLUMS) Examination for Detecting Mild Cognitive Impairment and Dementia is more sensitive than the Mini-Mental Status Examination (MMSE) - A pilot study. Am J Geriatr Psychiatry 14:900-910, 2006.



In a Nutshell, to be Diagnosed with Dementia...



Measurable decline in cognitive abilities



Measurable decline in function (ADLs and IADLs)



Changes are not due to a medical reason

So, what are the challenges in diagnosing dementia with someone living with an intellectual developmental disability?



Overcoming the Challenges in Diagnosing Dementia in Persons Living with Intellectual Disability

- Establish their personal baseline, their “norm” by:
 - Completing the Early Detection Screen for Dementia (NTG-EDSD)
 - Maintain records on the whole person (cognitive, medical, social, vocational, legal, behavior, function...)
 - Technology: video tape, audio tape (better at capturing qualitative changes)



Early Detection Screen for Dementia (NTG-EDSD)

- National Task Group on Intellectual Disabilities and Dementia Practices recommends:
 - Begin doing at age of 40 years for those living with Down Syndrome
 - Other at-risk persons with an intellectual disability when there is suspicion of changes
 - Then annually thereafter
- Another train of thought is to do the screen at the age of 35 years for all individuals living with an intellectual disability, then annually and when a concern arises
- I have been advocating completing the initial screen at the **time of transition from secondary schools to post-school options.**



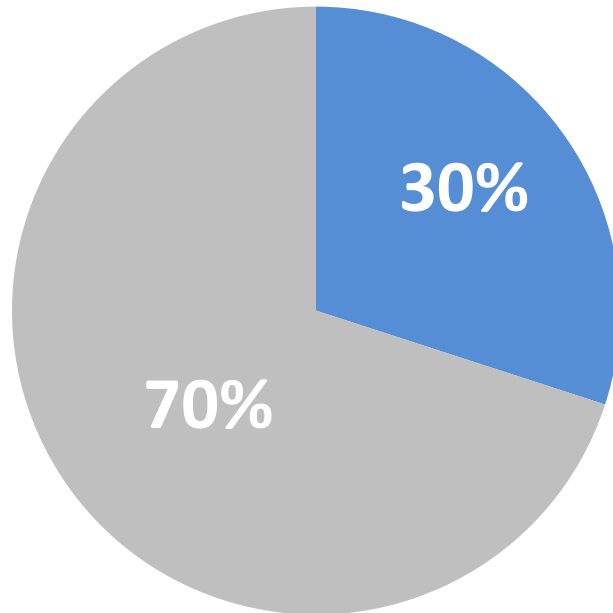
Early Detection Screen for Dementia (NTG-EDSD)

- Helpful in training caregivers to become good observers
- Serves as a ongoing record of health and function
- Multiple languages:
 - English
 - German
 - Italian
 - Greek
 - Spanish, North American
 - Dutch
 - French
 - Scottish
 - Japanese



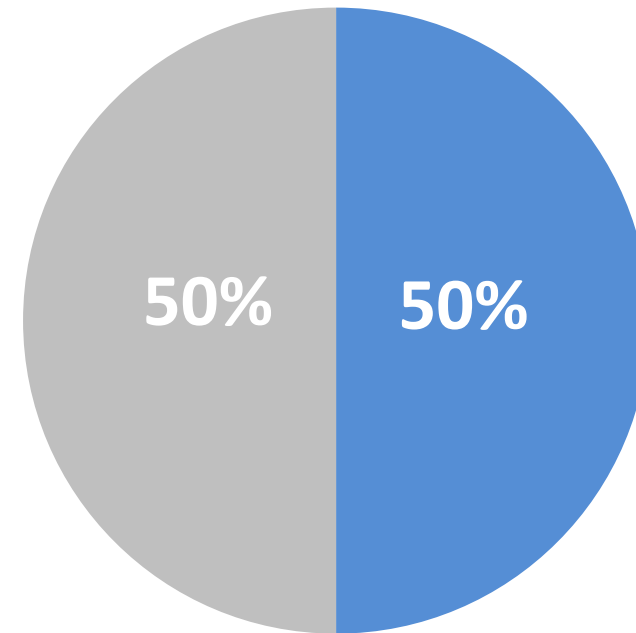
Prevalence of Alzheimer's Disease and Down Syndrome

Those in their 50's



- Are living with Alzheimer's disease
- Are NOT living with Alzheimer's disease

Those in their 60's



- Are living with Alzheimer's disease
- Are NOT living with Alzheimer's disease

National Down Syndrome Society: Aging and Down Syndrome: A Health & Well-Being Guidebook:
<http://www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf>





Case Application



NTG - EDSD Document

⁽¹⁾File #: _____ ⁽²⁾Date: _____

Name of person: ⁽³⁾First _____ ⁽⁴⁾Last: _____

⁽⁵⁾Date of birth: _____ ⁽⁶⁾Age: _____

⁽⁷⁾Sex:

☐	Female
☐	Male

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

⁽⁸⁾Best description of level of intellectual disability

☐	No discernible intellectual disability
☐	Borderline (IQ 70-75)
☐	Mild ID (IQ 55-69)
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☐	Severe ID (IQ 25-39)
☐	Profound ID (IQ 24 and below)
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☐	Autism
☐	Cerebral palsy
☐	Down syndrome
☐	Fragile X syndrome
☐	Intellectual disability
☐	Prader-Willi syndrome
☐	Other: _____

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- ☐ 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: _____

Page 1: Fields 1 to 9



Page 2: Fields 10 to 18

⁽¹⁰⁾ General characterization of current physical health:

Excellent
Very good
Good
Fair
Poor

⁽¹¹⁾ Seizures

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

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

Much better
Somewhat better
About the same
Somewhat worse
Much worse

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

⁽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

⁽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:

⁽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:

⁽¹⁸⁾ Comments / explanations about dementia suspicions:



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	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				

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	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)				

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	⁽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)



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⁽²⁸⁾ Current Medications

Yes No Indicate type

- ☐ ☐ 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

- ☐ 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

Form completion information

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

Revised 10/2017. Derived from the DSM-IV (4th Edition) Screening Questionnaire for Individuals with Intellectual Disabilities (Feb. 5, 2007) or adopted into the

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Case Application Discussion

- Overall, how did it go?
- How long do you think it would take to do, the initial, the annual follow-up, or at the time of change of condition?
- Do you like the tool? Why or why not?
- Any drawbacks or barriers to using the tool? Do you think it would be beneficial to use the tool? Why or why not?
- Do you think the NTG-EDSD would enhance your organization's service delivery? Why or why not?
- Other comments, thoughts, or questions?





**What needs to happen to make NTG-EDSD
a reality in your organization?**



Who Benefits?



References

- Esralew, L., Janicki, M.P., DiSipio, M., Jokinen, N., Keller, S.M. and Members of the National Task Group on Early Detection and Screening. (2013). *National Task Group Early Detection Screen for Dementia: Manual*. Available from www.aadmd.org/ntg/screening
- Visit: <http://aadmd.org/ntg> (American Academy of Developmental Medicine and Dentistry)



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Thank-you

