

Screening for Dementia in Persons Living with an Intellectual Developmental Disability

Amy Pope, LPC
Behavioral Health Supervisor
Community Care, Inc.

Jody Krainer, MSW, LCSW, MBA
NTG Affiliated Regional Trainer
Wisconsin Alzheimer's Institute

October 3, 2024



1

Webinar's Learning Objectives

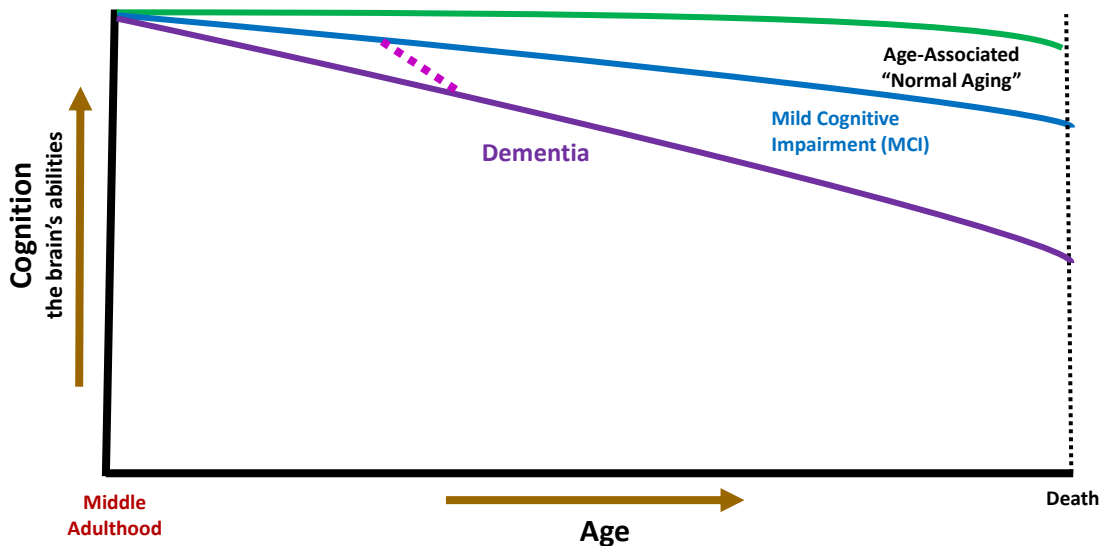
- Identify the challenges in detecting dementia in those living with an intellectual developmental disability (IDD)
- Provide an overview of National Task Group – Early Detection Screen for Dementia (NTG-EDSD or EDSD) tool
- Increase your knowledge on “how to”, and when to complete the NTG-EDSD tool
- Discuss Community Care Incorporated's experience with the NTG-EDSD tool
- Identify the benefits and drawbacks of the NTG-EDSD tool



2

1

The Aging Brain



3

Developmental Disability

- The term "developmental disabilities" is a broader category of often lifelong disability that can be **intellectual, physical, or both**.
- Our focus today is on those living with an **intellectual developmental disability (IDD)**
- Individuals living with IDD are also living longer. The average life expectancy for an individual with Down Syndrome born in:
 - early 1900's was 9 years
 - 1930 it was 19 years
 - 1983 it was 25 years
 - Today it is **66** years
- As a result, there is an increased risk for age-related health conditions, including the increased risk for dementia as they age

NIH: <https://www.nichd.nih.gov/health/topics/idds/conditioninfo/default>

Assessment and Diagnosis of Dementia in Individuals with Intellectual Disability: A Toolkit for Clinicians and Caseworkers – Dr. Gregory D. Pritchett, Psy.D. March 6, 2017

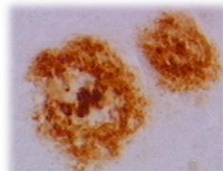
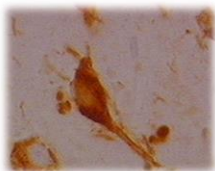


4

Genetic Risk for Alzheimer's Disease

• Alzheimer's Disease and Down Syndrome

- Individuals living with Down syndrome are born with an extra full or partial copy of chromosome 21, which carries the APP gene
- The gene produces a protein called **amyloid precursor protein (APP)**
- Too much APP leads to clumps called **beta-amyloid plaques**
- By age 40, most individuals with Down syndrome have the plaques, along with tau tangles



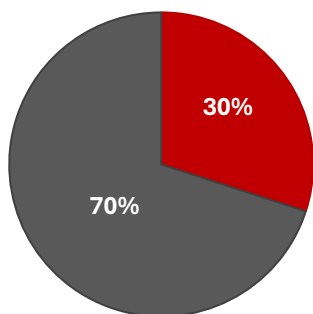
National Institute on Aging: *Eunice Kennedy Shiver*, National Institute of Child Health and Human Development



5

Prevalence of Alzheimer's Disease and Down Syndrome

Those in their 50's

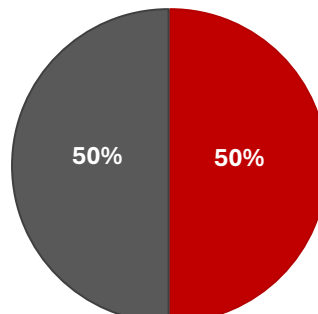


■ Are living with Alzheimer's disease
■ Are NOT living with Alzheimer's disease

Rate of dementia in general population:
0.4% at age 55-59 years

Ott A¹, Breteler MM, van Harskamp F, Claus JJ, van der Cammen TJ, Grobbee DE, Hofman A. (1995)

Those in their 60's



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

Rate of dementia in general population:
3.0% at age 65-74 years

2018 Alzheimer's Disease Facts and Figures:
<https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>



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>

6

Diagnosing Dementia



1. There needs to be a noticeable, **measurable decline** in the person's **cognitive** abilities; a decline from a previous higher level.
2. There needs to be a noticeable **decline** in the person's **function** (ADLs - activities of daily living, IADLs - instrumental activities of daily living); a decline from a previous higher level.
3. The cognitive/behavior changes are **not** due to a **medical** or **psychiatric** reason.



7

IDD and Dementia

- Detecting dementia in the IDD population is difficult:
 - Common medical problems that can mimic dementia (i.e., sleep apnea, hypothyroidism - 50% prevalence with Down Syndrome)
 - The tendency for dementia to be expressed differently (i.e., often marked by personality and behavior changes)
 - The premorbid cognitive deficits restrict or eliminate the use of standardized tools used in a typical dementia evaluation protocols
 - The starting level of functional skills is typically less

Assessment and Diagnosis of Dementia in Individuals with Intellectual Disability: A Toolkit
for Clinicians and Caseworkers – Dr. Gregory D. Pritchett, Psy.D. March 6, 2017



8

IDD and Dementia

- Detecting dementia in the IDD population is difficult:
 - Common medical problems that can mimic dementia (i.e., sleep apnea, hypothyroidism - 50% prevalence with Down Syndrome,)
 - The tendency for dementia to be expressed differently (i.e., often marked by personality and behavior changes)
 - The premorbid cognitive deficits restrict or eliminate the use of standardized tools used in a typical dementia evaluation protocols
 - The starting level of functional skills is typically less

Assessment and Diagnosis of Dementia in Individuals with Intellectual Disability: A Toolkit for Clinicians and Caseworkers – Dr. Gregory D. Pritchett, Psy.D. March 6, 2017



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)

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

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.

LDL (low density lipoprotein) = 'BAD' cholesterol

HDL (high density lipoprotein) = 'GOOD' cholesterol

Sources: National Cholesterol Education Program guidelines, 2010.

Biomarker Norms

We have established norms for many indicators on how the body and **brain** are doing:

- Blood pressure
- Weight
- Blood composition
- Pulse
- Blood volume
- Heart rate
- Body Max Index (BMI)
- Cognitive tools (i.e., MoCA, MMSE, the Clock Draw, RBANS, TRAILS...)
- Behavior Health (i.e., Geriatric Depression Screening – GDS)

The norms were established through large research projects.



Diagnosing Dementia

1. There needs to be a noticeable, **measurable decline** in the person's **cognitive** abilities; a decline from a previous higher level.



VAMC
SLUMS EXAMINATION
Questions about this assessment tool? E-mail slums@va.gov

Name _____ Age _____
Is the patient alert? _____ Level of education _____

1. What day of the week is it?
2. What is the year?
3. What state are we in?
4. Please remember these five objects. I will ask you what they are later:
Apple Pen Tie House Car
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?

MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 2.1.0 (Copyright) Copyright _____

VISUOSPATIAL / EXECUTIVE

Copy Color _____
Draw CLOCK (See past sheets) _____

Serial 7 subtraction starting at 100 [] 93 [] 86 [] 79 [] 72 [] 65

4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt** /3

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.
0 87 1 648 1 8537

11

IDD and Dementia

- Detecting dementia in the IDD population is difficult:
 - Common medical problems that can mimic dementia (i.e., sleep apnea, hypothyroidism - 50% prevalence with Down Syndrome,)
 - The tendency for dementia to be expressed differently (i.e., often marked by personality and behavior changes)
 - The premorbid cognitive deficits restrict or eliminate the use of standardized tools used in a typical dementia evaluation protocols
 - The starting level of functional skills is typically less

Assessment and Diagnosis of Dementia in Individuals with Intellectual Disability: A Toolkit for Clinicians and Caseworkers – Dr. Gregory D. Pritchett, Psy.D. March 6, 2017



12

Diagnosing Dementia



2. There needs to be a noticeable **decline** in the person's **function** (ADLs - activities of daily living, IADLs - instrumental activities of daily living); a decline from a previous higher level.

What skills do your clients have when it comes to...

IADLs	Driving	Yard work			
	Food preparation	Telephone use		ADLs	Dressing
	Housekeeping	Transportation			Bathing/grooming
	Laundry	Medication management			Toileting
	Finances				Eating
					Ambulation

**Not even in the
NTG-EDSD tool.**



13

Early Detection Screen for Dementia for those Living with IDD

- National Task Group - Early Detection Screen for Dementia or otherwise known as **NTG-EDSD** (Esralew et al 2013)
- Adapted from the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID), Deb et al (2007)
- The manual comes in multiple languages: English, French, Italian, and Spanish
- The form comes in multiple languages: English (paper and electronic), Dutch, Finnish, French, Greek, German, Italian, Japanese, Scottish, Spanish (No. American), and Spanish (European)

National Task Group Early Detection Screen for Dementia, NTG-EDSD, Manual



14

NTG-EDSD

- Takes 15 to 60 minutes to complete, four primary sections.
- Should be done by someone familiar with the person (knows them at least 6 months).
- Informant-based rating tool (particularly for support system members)
- An administrative screen that creates a visual overview and flagging system.
- Helps to establish the **person's baseline** (their norm).
- Helps the person's support system to become better observers.
- Serves as an **ongoing record of health and function**.
- Done annually or when cognitive changes are suspected
- **Not a clinical assessment tool or diagnostic instrument.**



National Task Group Early Detection Screen for Dementia, NTG-EDSD, Manual



15

NTG-EDSD and Other Perspectives

- National Task Group on Intellectual Disabilities and Dementia Practices recommends:
 - Begin doing at age of 40 years for those living with Down Syndrome
 - Begin with other at-risk persons with an IDD when suspected of experiencing cognitive change
- Then annually there after, or when changes are suspected.
- I have been advocating completing the initial screen is done at the time of **transition from secondary schools to post-school options**. Then annually at the age 35 years or when a concern arises.
 - I would suggest completing the NTG-EDSD on every new admission to establish their baseline.



16

National Task Group Early Detection Screen for Dementia

NTG-EDSD

Manual

Version 1 May 2013-f

Available at <https://www.the-ntg.org/ntg-edsd>

National Task Group Early Detection Screen for Dementia - 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 MC/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 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

Instructions, pages 13-14

R/O lab & medical tests, page 15

National Task Group Early Detection Screen for Dementia - Manual

APPENDIX B: Some of the laboratory and medical tests that might be used to rule out other sources of cognitive change among persons with intellectual or developmental disabilities

- Recent Primary Care Physician appointment/visit
 - Review of existing lab results and follow up on out of range values
 - DD Diagnosis
 - Recent Blood work (within 3 months) that includes
 - Liver panel (especially if on psychotropic medications)
 - Kidney function (BUN)
 - Complete Blood Count (CBC)- to account for some causes of potential delirium/Complete Blood Count
 - Comprehensive Metabolic Panel
 - Hepatic testing
 - Renal Function Test
 - Thyroid Studies(including TSH)
 - Vitamin B 12
 - Folic Acid
 - Hormone levels in women over 30
 - Sleep Apnea ruled out
 - If sleep apnea then investigate possibility of vascular dementia
 - Specifically for people with Down Syndrome, celiac: screening (total serum IgA if not done previously, and TTG)
 - Hearing/Audiology Testing
 - Electroencephalogram
 - Urinalysis
 - Chest X-Ray
 - Computerized Tomographic Scan
 - Magnetic Resonance Imaging
 - Vision Testing
- Explore conditions which are likely to involve pain/discomfort (including dental pain) and put in place a pain management protocol
- Explore medication side effects or interactions (pharmacist and/or PCP are most likely resources)
- Special thanks to Isabelle Grenon, Ph.D. and Melissa DiIorio, MSA for their assistance in compiling this list.

NTG-EDSD

v.2/2013.3

The NTG-EDSD is not an assessment or diagnostic instrument. It is recommended that this instrument be used on an annual basis with age 40, and with other at-risk persons with intellectual cognitive change. The form can be completed by anyone who is familiar with the individual (e.g., family member, agency support worker, or from the adult's personal record).

The estimated time necessary to complete this form is between 10-15 minutes. Consult the NTG-EDSD Manual for more information.

File #: _____

Name of person: (1) First _____

(2) Date of birth: _____

(7) Sex: _____

(8) Best description of level of intellectual disability (ID):

No discernible intellectual disability
Mild ID
Moderate ID
Severe ID
Profound ID
Unknown

(9) Diagnosed condition (check all that apply):

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

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

- 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: _____

Establish the individual's baseline, then do annually or when a concern arises.

NTG-EDSD - page 2

<p>^[14] General characterization of <u>current</u> physical health:</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>Excellent</td></tr> <tr><td>Very good</td></tr> <tr><td>Good</td></tr> <tr><td>Fair</td></tr> <tr><td>Poor</td></tr> </table>	Excellent	Very good	Good	Fair	Poor	<p>^[15] Seizures</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>Recent onset seizures</td></tr> <tr><td>Long term occurrence of seizures</td></tr> <tr><td>Seizures in childhood, not occurring in adulthood</td></tr> <tr><td>No history of seizures</td></tr> </table>	Recent onset seizures	Long term occurrence of seizures	Seizures in childhood, not occurring in adulthood	No history of seizures	<div style="border: 2px solid black; border-radius: 10px; padding: 5px; display: inline-block; color: red; font-weight: bold;">Feel free to write in comments</div>									
Excellent																				
Very good																				
Good																				
Fair																				
Poor																				
Recent onset seizures																				
Long term occurrence of seizures																				
Seizures in childhood, not occurring in adulthood																				
No history of seizures																				
<p>^[14] Compared to <u>one year ago</u>, current physical health is:</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>Much better</td></tr> <tr><td>Somewhat better</td></tr> <tr><td>About the same</td></tr> <tr><td>Somewhat worse</td></tr> <tr><td>Much worse</td></tr> </table>	Much better	Somewhat better	About the same	Somewhat worse	Much worse	<p style="text-align: center;"><small>If MCI or dementia is documented complete 16, 17, & 18</small></p> <p>General characterization of current physical health</p>	<p>Pick most appropriate item</p>													
Much better																				
Somewhat better																				
About the same																				
Somewhat worse																				
Much worse																				
<p>^[14] Compared to <u>one year ago</u>, current me</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>Much better</td></tr> <tr><td>Somewhat better</td></tr> <tr><td>About the same</td></tr> <tr><td>Somewhat worse</td></tr> <tr><td>Much worse</td></tr> </table>	Much better	Somewhat better	About the same	Somewhat worse	Much worse	<p>Compared to one year ago, current physical health is:</p>	<p>Pick most appropriate item</p>													
Much better																				
Somewhat better																				
About the same																				
Somewhat worse																				
Much worse																				
<p>^[14] Compared to <u>one year ago</u>, current me</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>Much better</td></tr> <tr><td>Somewhat better</td></tr> <tr><td>About the same</td></tr> <tr><td>Somewhat worse</td></tr> <tr><td>Much worse</td></tr> </table>	Much better	Somewhat better	About the same	Somewhat worse	Much worse	<p>Compared to one year ago, current mental health is:</p>	<p>Pick most appropriate item</p>													
Much better																				
Somewhat better																				
About the same																				
Somewhat worse																				
Much worse																				
<p>^[14] Conditions present (check all that apply)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>13</td><td>Conditions present</td><td>Indicate those diagnosed as well as observed</td></tr> <tr><td>14</td><td>Significant recent [in past year] life event</td><td>Indicate those that occurred</td></tr> <tr><td>15</td><td>Seizures</td><td>Pick most appropriate item</td></tr> <tr><td>16</td><td>Diagnostic history</td><td>Complete this item only if the person has been formally assessed and diagnosed; use information provided in diagnostic report</td></tr> <tr><td>17</td><td>Reported date of onset of MCI/dementia</td><td>Indicate month/year when first symptoms were noticed</td></tr> <tr><td>18</td><td>Comments/explanation about dementia suspicions</td><td>Indicate any behaviors that triggered suspicions or referral for assessment</td></tr> </table>	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	<p>Reported date of onset of MCI/dementia</p>	<p>Indicate month/year when first symptoms were noticed</p>
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																		
<p>^[16] Significant recent [in past year] life event:</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>Death of someone close</td></tr> <tr><td>Changes in living arrangements day program</td></tr> <tr><td>Changes in staff close to the person</td></tr> <tr><td>New roommate/housemates</td></tr> <tr><td>Illness or impairment due to accident</td></tr> <tr><td>Adverse reaction to medication or over-medication</td></tr> <tr><td>Interpersonal conflicts</td></tr> <tr><td>Victimization / abuse</td></tr> <tr><td>Other:</td></tr> </table>	Death of someone close	Changes in living arrangements 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:	<p>Comments/explanation about dementia suspicions</p>	<p>Indicate any behaviors that triggered suspicions or referral for assessment</p>									
Death of someone close																				
Changes in living arrangements 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:																				

National Task Group Early Detection Screen for Dementia, NTG-EDSD, Manual

19

NTG-EDSD - page 3

<p>^[19] Activities of Daily Living</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>Needs help with washing or dressing</td></tr> <tr><td>Needs help with dressing</td></tr> <tr><td>Dresses inappropriately (e.g., inadequately for weather)</td></tr> <tr><td>Undresses inappropriately (e.g., in public)</td></tr> <tr><td>Needs help eating (cutting food, mouthful amounts, choking)</td></tr> <tr><td>Needs help using the bathroom (finding, toileting)</td></tr> <tr><td>Incontinent (including occasional accidents)</td></tr> </table>	Needs help with washing or dressing	Needs help with dressing	Dresses inappropriately (e.g., 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)	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="text-align: center;">Always been the case</td> <td style="text-align: center;">Always but worse</td> <td style="text-align: center;">New symptom in past year</td> <td style="text-align: center;">Does not apply</td> </tr> </table> <p>Activities of daily living</p>	Always been the case	Always but worse	New symptom in past year	Does not apply	<p>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</p> <p>'Always but worse' means the existing need, problem or behavior has further declined requiring more personal assistance</p> <p>'New symptom in past year' means this need, problem or behavior was not present until recently</p> <p>'Does not apply' means these needs, problems or behaviors are not present</p>
Needs help with washing or dressing													
Needs help with dressing													
Dresses inappropriately (e.g., 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)													
Always been the case	Always but worse	New symptom in past year	Does not apply										
<p>^[20] Language & Communication</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>Does not initiate conversation</td></tr> <tr><td>Does not find words</td></tr> <tr><td>Does not follow simple instructions</td></tr> <tr><td>Appears to get lost in middle of conversation</td></tr> <tr><td>Does not read</td></tr> <tr><td>Does not write (including printing own name)</td></tr> </table>	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)	<p>Language & communication</p>	<p>Pick most appropriate column item for each</p>					
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)													
<p>^[21] Sleep-Wake Change Patterns</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>Excessive sleep (sleeping more)</td></tr> <tr><td>Inadequate sleep (sleeping less)</td></tr> <tr><td>Wakes frequently at night</td></tr> <tr><td>Confused at night</td></tr> <tr><td>Sleeps during the day more than usual</td></tr> <tr><td>Wanders at night</td></tr> <tr><td>Wakes earlier than usual</td></tr> <tr><td>Sleeps later than usual</td></tr> </table>	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	<p>Sleep-wake change patterns</p>	<p>Pick most appropriate column item for each</p>			
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													
<p>^[22] Ambulation</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td>Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces</td></tr> <tr><td>Unsteady walk, loses balance</td></tr> <tr><td>Falls</td></tr> <tr><td>Requires aids to walk</td></tr> </table>	Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces	Unsteady walk, loses balance	Falls	Requires aids to walk	<p>Ambulation</p>	<p>Pick most appropriate column item for each</p>							
Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces													
Unsteady walk, loses balance													
Falls													
Requires aids to walk													

Feel free to write in comments

National Task Group Early Detection Screen for Dementia, NTG-EDSD, Manual

20



Always been the case	Always but worse	New symptom in past year	Does not apply
----------------------	------------------	--------------------------	----------------

[23] Memory				
Does not recognize faces				
Does not remember names				
Does not remember recent events				
Does not find way in familiar places				
Loses track of time (e.g., forgets date)				
Loses or misplaces objects				
Puts familiar things in unfamiliar places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				

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

[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)				

Feel free to write in comments

[Check column option as appropriate]



Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
------------------------------	-------------------------------------	--------------------	-----------------------

Bone				
1 Arthritis				
2 Osteoporosis				
Heart				
3 Heart disease				
4 High blood pressure				
5 High cholesterol				
6 Low back pain				
7 Stroke				
Horm				
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)

Feel free to write in comments

NTG-EDSD - page 6

<p>⁽²⁾ Current Medications</p> <p>Yes No Indicate type</p> <p><input type="checkbox"/> Treatment of chronic conditions</p> <p><input type="checkbox"/> Treatment of mental health disorders or behavior problems</p> <p><input type="checkbox"/> Treatment of pain</p> <p>For reviews, attach list of current medications, dosage, and</p> <p><input type="checkbox"/> List is attached for reviews</p>	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.
<p>⁽²⁾ Comments related to other notable changes or concerns</p>	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
<p>⁽²⁾ Next Steps / Recommendations</p> <p><input type="checkbox"/> Refer to treating physician for assessment</p> <p><input type="checkbox"/> Review internally by clinical personnel</p> <p><input type="checkbox"/> Include in annual review / annual wellness visit</p> <p><input type="checkbox"/> Repeat in _____ months</p>	30	Next steps/recommendations	Check most relevant item
Form completion information			
<p>⁽³⁾ Date completed</p>	31	Date completed	Date form completed
<p>⁽³⁾ Organization / Agency</p>	32	Organization/agency	Name of organization providing services to the adult
<p>Name of person completing form</p>	-	Name of person completing form	Indicate your name
<p>Relationship to individual (staff, relative, assessor, etc.)</p>	-	Relationship to individual	Indicate whether you are staff, a relative or someone else
<p>Date(s) form previously completed</p>	-	Date(s) form previously completed	If the NTG-EDSD has been completed before, indicate when

Acknowledgement: Derived from the DSQID ("Dementia Screening Questionnaire for Individuals with Intellectual Disabilities"; Deib, S., 2007) as adapted into the Southeast PA Dementia Screening Tool (DST) – with the assistance of Carl V. Tyler, Jr., MD – and the LINDS (Longitudinal Health and Intellectual Disability Survey; Remmer & Hoch, 2010) and as further adopted 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.

© NTG 2024.3
National Task Group on Intellectual Disabilities and Dementia Practices
www.the-ntg.org/ntg-edsd

National Task Group Early Detection Screen for Dementia, NTG-EDSD, Manual

23

Red Flags

• “Signal items” are those items throughout the **NTG-EDSD** that are linked to the general warning signs of Mild Cognitive Impairment or early dementia, include:

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



National Task Group Early Detection Screen for Dementia, NTG-EDSD, Manual



24

Community Care Inc. and NTG-EDSD Why Screen

- Help members and their families plan for the future.
- Based on early diagnosis, the member with dementia/neurocognitive disorder may also be able to make choices about how care is to be planned and delivered based on her/his preferences.
 - ✓ Decisions regarding care and treatment
 - ✓ Place of residence
 - ✓ End of life decisions and advance directives



25

Community Care Inc. and NTG-EDSD Who and How

- At Community Care both the Care Manager and Nurse Care Manager are trained in the utilization of the screen.
- Care Teams work with family members, guardians and residential provider agencies to get the screen completed and provided back to the teams for review.
- Once reviewed determination is made if it will warrant a referral to Primary Care.



26

Community Care Inc. and NTG-EDSD Challenges/Benefits

- Teams with Community Care have seen the screening outcomes lead to early diagnosis for members- which allows for the ability to plan/prepare.
- At times teams have seen feedback be provided from Primary Care that member has IDD or TBI so no further work-up is needed.
- Limited family and new providers/placement can pose issues with the rule of knowing the member for at least 6 months.
- Getting the form completed in its entirety.



27

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

- Establish their personal baseline, their “norm” by completing the NTG-EDSD
- Consider more than one person filling out the NTG-EDSD
- Do the NTG-EDSD annually and when cognitive changes are suspected
- Maintain records on the whole person (cognitive, medical, social, vocational, legal, behavior, function...)
- Technology: video tape, audio tape (captures qualitative changes)



28

National Task Group's Website

- NTG-EDSD Form and Manual (multiple languages)
- Quick Guide for Using the NTG-EDSD by Families
- Quick Guide for Using the NTG-EDSD by Support and Care Staff
- Physician's Quick Guide for Using the NTG-EDSD



<https://www.the-ntg.org/ntg-edsd>

