

National Task Group Early Detection Screen for Dementia (NTG-EDSD): A tool to track cognitive and functional changes in adults with IDD

Dr. Ritabelle Fernandes
Associate Professor, JABSOM, UH

Objectives for Today's Session

- Describe the EDSD tool
- Understand the value of the ***NTG-EDSD*** as an administrative tool
- Provide suggestions for completing the form

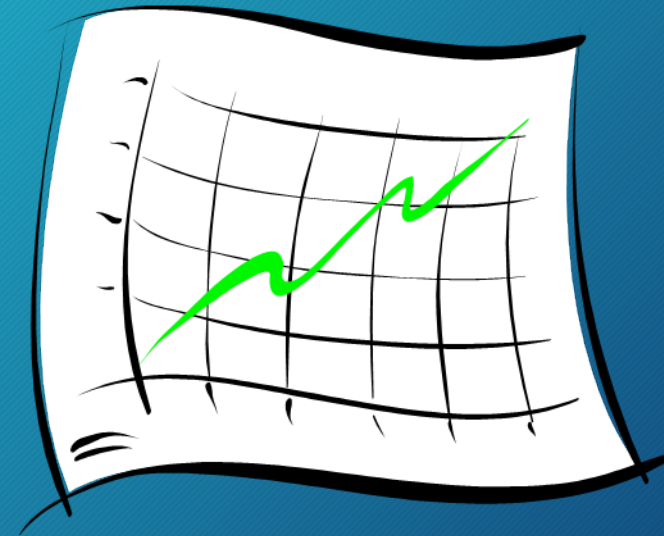


Risk of Dementia in ID

Most adults with ID are typically at no more risk than the general population.

Exception: Adults with Down syndrome are at increased risk!

- Younger (40's and '50's)
- More rapid progression.



Traditional Screening Tools Not Useful

Traditional screening instruments for detecting dementia in the general population are designed for people with average baseline intelligence and are not useful for detecting cognitive impairment in adults with DS.

Example:

- Mini-Mental Status Exam (MMSE)

Alternative:

- NTG - EDSD

NTG Early Detection Screen for Dementia (EDSD)


Adapted from:

- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (Deb et al., 2007), and
- Dementia Screening Tool (adapted by Philadelphia Coordinated Health Care Group from the DSQIID, 2010)

Down Syndrome begin age 40 then annually.

Non-DS begin at age 50.

Tool & manual available online in multiple languages: <https://www.the-ntg.org/ntg-edsd>

 **NTG-EDSD** v.1/2013.2

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 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.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.aadmd.org/ntg/screening).

(1) File #: _____ (2) Date: _____

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

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

(7) Sex:

<input type="checkbox"/> Female
<input type="checkbox"/> Male

(8) Best description of level of intellectual disability

<input type="checkbox"/> No discernible intellectual disability
<input type="checkbox"/> Borderline (IQ 70-75)
<input type="checkbox"/> Mild ID (IQ 55-69)
<input type="checkbox"/> Moderate ID (IQ 40-54)
<input type="checkbox"/> Severe ID (IQ 25-39)
<input type="checkbox"/> Profound ID (IQ 24 and below)
<input type="checkbox"/> Unknown

(9) Diagnosed condition (check all that apply)

<input type="checkbox"/> Autism
<input type="checkbox"/> Cerebral palsy
<input type="checkbox"/> Down syndrome
<input type="checkbox"/> Fragile X syndrome
<input type="checkbox"/> Intellectual disability
<input type="checkbox"/> Prader-Willi syndrome
<input type="checkbox"/> Other: _____

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

Current living arrangement of person:

<input type="checkbox"/> Lives alone
<input type="checkbox"/> Lives with spouse or friends
<input type="checkbox"/> Lives with parents or other family members
<input type="checkbox"/> Lives with paid caregiver
<input type="checkbox"/> Lives in community group home, apartment, supervised housing, etc.
<input type="checkbox"/> Lives in senior housing
<input type="checkbox"/> Lives in congregate residential setting
<input type="checkbox"/> Lives in long term care facility
<input type="checkbox"/> Lives in other: _____

Identifying meaningful change in functioning

- Not all change from baseline is meaningful for our purposes
- The ***NTG-EDSD*** identifies domains important to the recognition of meaningful change in functioning that alerts caregivers about the need to follow up:
 - A) by bringing up to the IDT/MDT the topic of the client's changes from usual functioning
 - B) by bringing up to the client's Health Care Provider (HPC) change from usual functioning
 - C) by recognizing that more information is needed, and additional tracking would be helpful

Rationale for development of the NTG-EDSD

- Need to equip family and professional caregivers with a tool to capture information about changes in cognition, behavior and daily functioning
- Provide caregivers with a format to share important information about the person they support with the consumer's/client's health care practitioner
- Train caregivers to recognize and report relevant signs of change
- For those eligible, the **NTG-EDSD** could be used as part of the Annual Wellness Visit

How do I complete the form?

- Who: The **NTG-EDSD** should be completed by someone who is familiar with the consumer. This is an administrative tool and not a clinical screen. It is best completed by whomever has everyday knowledge of the individual whose functioning is being rated
- Where: If the consumer attends day program, it may be helpful for the staff at day program to complete a separate record form or the day program's staff can be included in the completion of one rating instrument by providing input to family or residential support staff completing a form
- What: Gather medical and other chart materials in order to fill out some of the questions pertinent to medical and mental health status changes

Cover Page

Cover page

- 1. demographics
- 2. level of intellectual disability (if known)
- 3. developmental disorder (if known)
- 4. living arrangement

XC (32-bit)

(1)... x

1 / 6 85.4%

ntg
National Task Group
on Intellectual Disabilities
and Dementia Practices

NTG-EDSD

v.1/2013.2

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 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.B of the US National Plan to Address Alzheimer's Disease.

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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

⁽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: _____

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

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- Lives alone
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- 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 2

Page 2- Items 10-15

- In the opinion of the rater, how is the person's current physical and mental health and as how is the person's health compared with last year?

Page 2- Items 16-18

- Complete if the person has been diagnosed with Mild Cognitive Impairment (MCI)

Reader DC (32-bit)
Help
D-Final (1)... x

2 / 6 85,4%

NTG-EDSD - page 2

⁽¹⁰⁾ General characterization 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:

Page 3

Domains

- Activities of Daily Living
- Language and Communication
- Sleep-Wake cycle
- Ambulation



What is a Likert Rating?

- A Likert rating is composed of a series of four or more items that represent a range of choices for the same question
- You are probably most familiar with Likert Scales that ask you to rate something with number from 1-5, or ask you to indicate agree, somewhat agree, neutral, disagree, strongly disagree
- For the **EDSD** on pages 3-4, you are asked to indicate if something has always been the case, has always been the case but is worse, is a new symptom or does not apply
- ***Let's consider what each of these tells us as a way of capturing observations of change...***

Page 3

Page 3, Items 19-22

- Raters are now asked to check a column on a Likert Scale. The choices are:
- Always been the case
- Always but worse
- New symptom since last year
- Does not apply

bit)

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NTG-EDSD - page 3

[Check column option as appropriate]

	Always been the case	Always but worse	New symptom in past year	Does not apply
19^a 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 (lifting, toileting)				
Incontinent (including occasional accidents)				
20^a 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^a 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^a 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...

Pages 3-4

What do we mean by “Always been the case”?

- Kenan has always needed help bathing
- It has always been the case that he does not initiate conversations
- He always sleeps excessive amounts

By choosing “Always been the case,” you are indicating this is usual for the person and there has been no change

Always the Case but worse...

Pages 3-4

What do we mean by “Always the case but worse”?

- Rose has needed verbal prompts to complete showering and now she needs hand-over-hand assistance
- Rose has mobility problems—she previously used a walker --and now needs a wheelchair for anything further than short distances
- She previously needed her food cut up for her, but now she can only eat finger food

By choosing “Always been the case but worse” you are indicating the person has lost more skills and is less independent with an activity of daily living for which she has already had problems—the situation has gotten worse.

New symptom

Pages 3-4

What do we mean by choosing “new symptom”?

- Walt has episodes of incontinence which began 3 months ago.
- Walt has become lost while walking home from his program twice within the past 6 months
- He cannot remember the name of his new staff and began calling the new staff by the name of a worker who has not been at the home for several years.

By choosing “new symptom” you are indicating that this was not a problem last assessment but is a problem now and is a new sign of change

Does not Apply

Pages 3-4

What do we mean when we choose the rating “does not apply”?

- Joy does not need assistance in showering
- She does not need assistance in dressing
- Joy may have episodes of mild forgetfulness, but this does not interfere with her work or daily activities

By choosing “does not apply” we are indicating that this is an area in which Joy does not have a problem

Page 4

Domains (Items 23-26)

- Memory
- Behavior and Affect
- Adult 's Self-Reported Problems
- Notable significant changes observed by others

NTG-EDSD - page 4

	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)				

Chronic Health Conditions

- Bone, Joint and Muscle
- Heart and Circulation
- Hormonal
- Lungs and Breathing
- Mental Health
- Pain
- Sensory
- Other medical conditions

Based on the Longitudinal Health and Intellectual Disability Survey, University of Illinois at Chicago

NTG-EDSD - page 5

[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)

Page 6

- Gather information from the person's chart regarding current medication, dosage and when prescribed
- Background information
- Other changes observed but not covered in the rating form? This is your opportunity to share what you have observed.
- Next Steps

NTG-EDSD - page 6

⁽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

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	

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.

Essentials of a Diagnostic Workup

- Rule out delirium - sudden confusion, inattention, medical emergency
 - UTI, impaction, pneumonia, medications
- Rule out depression/anxiety - has there been a recent significant life event?
- Medication review - new meds, changes, interactions, anticholinergics*
- **History and physical** (including psychiatric, personal, past medical and family histories and mental state assessment)
- **Lab tests**
 - Evidence supports the following tests:
 - Complete blood cell count
 - Serum electrolytes
 - Glucose
 - BUN/creatinine
 - Serum B12 levels
 - Thyroid function tests
 - Liver function tests
 - Celiac screening if DS (tTG-IgA test)
- **MRI and/or CT scan (possibly)**

David

- David is a 57-year-old male with Down Syndrome who lives alone with staff supports
- We know that a psychologist has previously diagnosed him with Mild Cognitive Impairment
- He was rated as showing a variety of new symptoms including incontinence, word-finding problems, memory issues, changes in behavior, falls, sensory changes
- He has medical conditions including high blood pressure and high cholesterol

How would we complete Page 1 (cover page) for David?

- David is a 57-year-old male with mild intellectual disability and Down syndrome. He lives in an apartment in the community and is supported by staff

What are some things that the information on the cover sheet might alert us to consider?

- One of the things to think about as you proceed is that David is at high risk for Alzheimer's type dementia based on his being over 50 with Down syndrome

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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 #: **This is for your reference** (2) Date: **3/3/2021**
 Name of person: (3) First **David** (4) Last: **Smith**
 (5) Date of birth: **6/1/63** (6) Age: **58**

(7) Sex:

<input type="checkbox"/>	Female
<input checked="" type="checkbox"/>	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

<input type="checkbox"/>	No discernible intellectual disability
<input type="checkbox"/>	Borderline (IQ 70-75)
<input checked="" type="checkbox"/>	Mild ID (IQ 55-69)
<input type="checkbox"/>	Moderate ID (IQ 40-54)
<input type="checkbox"/>	Severe ID (IQ 25-39)
<input type="checkbox"/>	Profound ID (IQ 24 and below)
<input type="checkbox"/>	Unknown

(9) Diagnosed condition (check all that apply)

<input type="checkbox"/>	Autism
<input type="checkbox"/>	Cerebral palsy
<input checked="" type="checkbox"/>	Down syndrome
<input type="checkbox"/>	Fragile X syndrome
<input type="checkbox"/>	intellectual disability
<input type="checkbox"/>	Prader-Willi syndrome
<input type="checkbox"/>	Other: _____

Current living arrangement of person:

<input checked="" type="checkbox"/>	Lives alone
<input type="checkbox"/>	Lives with spouse or friends
<input type="checkbox"/>	Lives with parents or other family members
<input type="checkbox"/>	Lives with paid caregiver
<input checked="" type="checkbox"/>	Lives in community group home, apartment, supervised housing, etc.
<input type="checkbox"/>	Lives in senior housing
<input type="checkbox"/>	Lives in congregate residential setting
<input type="checkbox"/>	Lives in long term care facility
<input type="checkbox"/>	Lives in other: _____

How do we complete Page 2 for David?

- Although the raters indicated his health is “good,” they also indicated it is *somewhat worse* than last year
- Compared with last year he *appears sadder and more anxious*. Staff rated him as somewhat worse in his mental health compared with last year
- His vision and hearing are corrected by eyeglasses and hearing aids
- This past year a *family member died*, and his *favorite staff left during COVID and did not return*
- He was diagnosed with Mild Cognitive Impairment in 2016 based on lessened productivity at work, less interest in keeping up with chores at home and lessened interest in socializing with others

⁽¹⁰⁾ General characterization of current physical health:

<input type="checkbox"/>	Excellent
<input type="checkbox"/>	Very good
<input type="checkbox"/>	Good
<input checked="" type="checkbox"/>	Fair
<input type="checkbox"/>	Poor

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

<input type="checkbox"/>	Much better
<input type="checkbox"/>	Somewhat better
<input type="checkbox"/>	About the same
<input checked="" type="checkbox"/>	Somewhat worse
<input type="checkbox"/>	Much worse

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

<input type="checkbox"/>	Much better
<input type="checkbox"/>	Somewhat better
<input type="checkbox"/>	About the same
<input checked="" type="checkbox"/>	Somewhat worse
<input type="checkbox"/>	Much worse

⁽¹³⁾ Conditions present (*check all that apply*)

<input type="checkbox"/>	Vision impairment
<input type="checkbox"/>	Blind (very limited or no vision)
<input checked="" type="checkbox"/>	Vision corrected by glasses
<input type="checkbox"/>	Hearing impairment
<input type="checkbox"/>	Deaf (very limited or no hearing)
<input checked="" type="checkbox"/>	Hearing corrected by hearing aids
<input type="checkbox"/>	Mobility impairment
<input type="checkbox"/>	Not mobile – uses wheelchair
<input type="checkbox"/>	Not mobile – is moved about in wheelchair

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

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

⁽¹⁵⁾ Seizures

<input type="checkbox"/>	Recent onset seizures
<input type="checkbox"/>	Long term occurrence of seizures
<input type="checkbox"/>	Seizures in childhood, not occurring in adulthood
<input checked="" type="checkbox"/>	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: 2016

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:

5/1/2016 (SIB, observation, collaterals)

⁽¹⁸⁾ **Comments / explanations about dementia suspicions:**

What did we learn when we completed Page 3 for David?

Activities of Daily Living (19)

David is independent in his activities of daily living. We know this because the staff has checked off the column “Does not apply”. However, he has been exhibiting a relatively “new symptom” of urinary incontinence (accidents)

Language and Communication (20)

David has displayed new signs of change in his communication skills in the form of word finding difficulties and his tendency to lose track in the middle of conversations

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

Ratings for David's Page 3

Sleep (21)

Here several changes are reported as “new symptoms”. David is sleeping less compared with before, he is waking frequently. When he is awake, he appears confused. Staff have reported several episodes of middle-of-the-night wandering from his home

Ambulation (22)

- No significant problems reported with balance or walking except that he has fallen twice

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

What did we learn when we completed Page 4 for David?

Memory (23)

- David appears to be displaying several memory changes including problems with new learning, not remembering the names of familiar people, losing track in the middle of conversations, and misplacing objects

Behavior and Affects (24)

- David is more withdrawn, impulsive, repetitive/compulsive, depressed and wanders

Adult Self-reported Problems (25)

- David has noted his own memory change and he reports having a harder time doing things

	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)				✓

What did we learn when we completed Page 5 for David?

- David's medical conditions include high cholesterol, hypertension, thyroid problems, depression and urinary incontinence

For possible further consideration:

- His high cholesterol and HTN put him at greater risk for stroke, cardiac problems and cognitive changes
- His thyroid problems can contribute to mood issues
- Depression can contribute to concentration, attention and memory problems
- Are his episodes of incontinence due to urinary tract or prostate problems or is he misjudging when he needs to use the toilet?

[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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
2	Osteoporosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Heart and Circulation					
3	Heart condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
4	High cholesterol	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	High blood pressure	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Low blood pressure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
7	Stroke	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Hormonal					
8	Diabetes (type 1 or 2)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
9	Thyroid disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Lungs/breathing					
10	Asthma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
11	Chronic bronchitis, emphysema	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
12	Sleep disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Mental health					
13	Alcohol or substance abuse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
14	Anxiety disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
15	Attention deficit disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
16	Bipolar disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
17	Dementia/Alzheimer's disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
18	Depression	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	Eating disorder (anorexia, bulimia)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
20	Obsessive-compulsive disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
21	Schizophrenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain / Discomfort					
23	Back pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
24	Constipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
25	Foot pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
26	Gastrointestinal pain or discomfort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
27	Headaches	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
28	Hip/knee pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
29	Neck/shoulder pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sensory					
30	Dizziness / vertigo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
31	Impaired hearing	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32	Impaired vision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Other					
33	Cancer – type:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34	Chronic fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
35	Epilepsy / seizure disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
36	Heartburn / acid reflux	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
37	Urinary incontinence	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38	Sleep apnea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
39	Tics/movement disorder/spasticity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
40	Dental pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

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

What do you do with the Ratings from the EDSD?

- Look for patterns
- What are areas in which change has been noted?
- What is the extent of change?
- Is something being done to currently address identified issues?
- Bring findings from the *EDSD* to the IDT/MDT



Sharing Findings with Members of the IDT

- Discuss observations captured through **EDSD** ratings
- Reconcile any discrepancies across settings
- Request additional information, if necessary
- Brainstorm possible approaches
- Operationalize a plan of action
- Is it time to refer to the HealthCare Provider or other professionals?
- Evaluate the effectiveness of the plan



Sharing findings from EDSD can advance important conversations

- Raise neurocognitive disorder or competing problems for exploration as possible explanation for change. In addition to dementia, the following can be contributing to observed changes:
 - Depression
 - Delirium
 - Sensory loss
 - Unaddressed pain
 - Psychosocial stressors



Types of Decisions that May Follow from Use of the EDSD



Modification of residence



Change in residence



Changing staffing support



Changing programming



Developing a positive daily routine



Identifying items and activities for stimulation

Utilize to determine care and support needs of the individual

- What types of visual and verbal cuing, role modeling or other supports help the individual remain as independent as possible?
- What does the person need in order to be safe?
- What does the person need in order to be comfortable?
- What does the person need in order to have the best Quality of Life (QoL)



What did the team do with findings from the EDSD rating for David?

- David is at higher risk for Alzheimer's due to his age and Down Syndrome
- We might want to explore how sensory changes impact his functioning
- We might want to explore if he is a candidate for balance and gait training
- We might consider helping him develop a positive daily routine by providing him with choices within a scheduled and structured day

⁽²⁸⁾ **Current Medications**

Yes	No	Indicate type
<input checked="" type="checkbox"/>	<input type="checkbox"/>	Treatment of chronic conditions
<input checked="" type="checkbox"/>	<input type="checkbox"/>	Treatment of mental health disorders or behavior problems
<input type="checkbox"/>	<input checked="" 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 6 months

Form completion information

⁽³¹⁾ Date completed	⁽³²⁾ Organization / Agency
3/2/2021	
Name of person completing form	
Relationship to individual (staff, relative, assessor, etc.) SLS staff	
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.

Take Home Messages

- Family and staff are in the best position to recognize everyday changes in memory, thinking, behavior skills and ADLs for the people whom they know and support
- The **NTG-EDSD** is an administrative screening tool that can be used to capture information about observed changes in functioning of individuals with IDD
- Findings from the **EDSD** can aid and promote healthcare advocacy
- Findings can be shared with members of the Interdisciplinary Team and Health Care Providers to make decisions about services, supports and treatments

