Growing Older: Implications for People with Intellectual Disabilities

Module Two: Alzheimer's Disease and Other Dementias Functional and Behavioral Changes

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Housekeeping & Introductions

Growing Older, Module Two: Alzheimer's Disease and Other Dementias …

- provides concrete information about the risks and manifestations of dementias in individuals with ID/DD and
- examines the challenges individuals and their caretakers face in coping with and understanding the process and implications of dementia.

Learning Objectives

- Identify the scope of physical and cognitive changes associated with the progression of dementia for people with intellectual disabilities
- Become familiar with the ways that Alzheimer's Disease & other dementias affect individuals with ID/DD
- Learn about early evaluation & assessment strategies for identifying & managing dementias to facilitate better supports
- Identify syndrome-specific concerns for individuals with Down Syndrome
- Differentiate between behavioral changes that may signal the onset of dementia and those that may indicate other, often treatable, mental or physical conditions

Definition: Intellectual/ Developmental Disability

- Intellectual limitation(s) that hinder independent functioning in daily activities such as self-care, communication, work, or education
- Intellectual limitation(s) developed before the age of 22 & expected to continue indefinitely
- Result in need for long-term adaptive and/or functional supports

Source: My Thinkers Not Working, National Task Group on Intellectual Disabilities & Dementia Practices, 2012 www.rrtcad.org/resources

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Intellectual/Developmental Disability vs. Dementia

- People with ID/DD: skills and cognitive abilities may be under-developed or absent; person has worked hard at developing skills that come "naturally" to others, progress may be slow but is measurable
- People with dementia lose existing skills & abilities over time; loss of skills and abilities usually worsens gradually and is frequently irreversible

Changing Demographics Require New Approaches

- Individuals with ID/DD are living longer -- and experiencing many of the risks associated with aging, including Alzheimer's Disease & other dementias
- Estimated that about 6% of people with ID/DD will be affected by some form of dementia by age 60
- People with Down Syndrome are at particular risk for developing Alzheimer's Disease
- For people with Down Syndrome: 25% experience dementia after age 40 and 50-70% after age 60

Sources quoted from: My Thinker's Not Working, National Task Group on Intellectual Disabilities & Dementia Practices, 2012 www.rrtcad.org/resources

Ongoing Research Provides New Information & Insights

- Numerous initiatives worldwide are examining the aging process in general & its implications for individuals with ID/DD in particular
- Self determination and person-centered planning values support continued community integration throughout the aging process
- Assessment and evaluation tools and protocol designed for individuals with ID/DD are being developed so that dementia process is identified early
- Early identification: comprehensive planning and supports; timely interventions, improved outcomes

Dementia & Individuals with ID/DD

What Is Dementia?

What Causes Dementia?

Who Is At Risk?

What is Dementia?

- A term that describes a generic process characterized by cognitive decline that impairs ability to function socially, personally, and productively, is persistent and progressive and is associated with chronic brain disorder
- A disease process -- not part of the normal aging process
- May be caused by various factors, including stroke, head injury, heart disease

SOURCE: Dementia, Aging, and Intellectual Disabilities: A Handbook, Janicki, Matthew P & Dalton, Arthur J. eds., 1999

Documenting Baseline Is Essential

- A baseline becomes the most important tool in assessing individuals with ID/DD for dementia
- Often difficult to assess individuals with ID/DD reliably due to lifelong histories of impaired abilities, particularly in communication and functional skills
- Standard assessment tools are typically based on a person's ability to self-report and are not always reliable if person with ID/DD has difficulty with communication
- Video recordings of the individual may be most useful tools over time for objective assessment

Groups at Higher Risk for Developing Alzheimer's Disease

- People with Down Syndrome who are over 40 years of age
- People with a family history of Alzheimer's Disease
- People who have suffered a serious head injury or a series of head injuries during their lifetimes, for example people with seizure disorders or those who have experienced frequent falls

SOURCE: Developmental Services Resource Guide on Aging and Dementia, Vermont Agency of Human Services . Retrieved from: www.ddas.vermont.gov/ddas-publications

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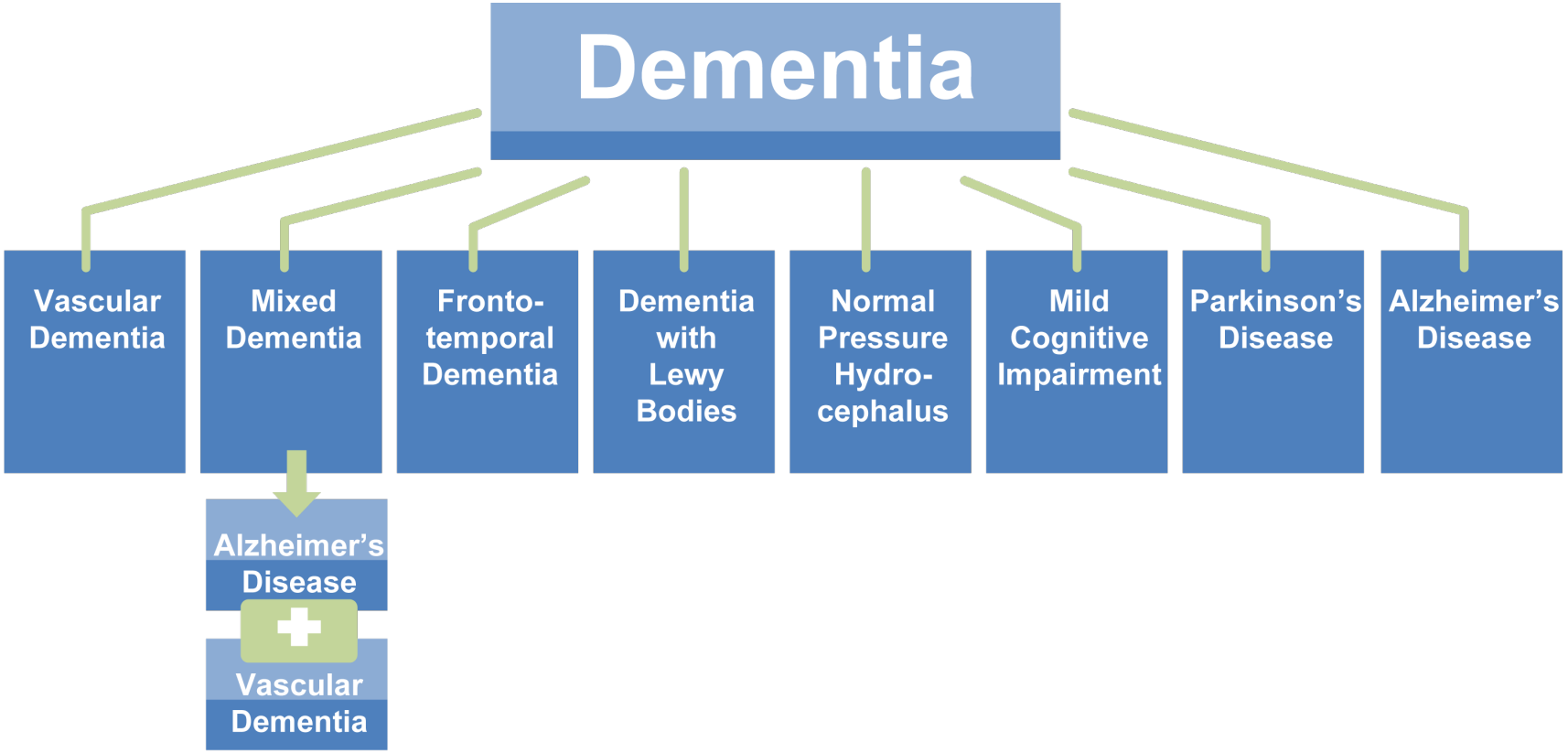
Types of Dementia

- Treatment and outcomes are different depending on type of dementia
- Causes, progression, and outcomes vary with each type—some may not be progressive and some are reversible with treatment
- Symptoms, functioning deficits, and presentation and progression vary depending on type of dementia



There are many types of dementia – different causes, symptoms, progression. Treatment is determined by the type of dementia.

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Types of Dementia

Alzheimer's Disease

- The most common form of dementia, accounting for 60-80% of cases
- Characterized by abnormal deposits of the protein fragment beta-amyloid (plaques or tangles)
- People with Down Syndrome are at particular risk for developing Alzheimer's Disease
- Progressive and irreversible loss of cognitive functioning

Types of Dementia

Vascular Dementia

- Multiple small strokes or changes in brain's blood supply
- Damage may occur anywhere in the brain
- Effect on functioning is variable depending on location and extent of damage
- Diagnosis is complicated because vascular issues are a common feature of Alzheimer's Disease
- No treatment available, although causes of stroke such as high blood pressure may be addressed to prevent future events

Types of Dementia

Mixed Dementia

- Combination of Alzheimer's and vascular dementia
- Alzheimer's Disease compromises vascular functioning, resulting in strokes
- Differential diagnosis necessary

Types of Dementia

Frontotemporal Dementia

- Involves damage to brain cells in the front and side regions of the brain
- Symptoms include personality & behavior changes, difficulties with communication
- Example is “Pick’s Disease,” characterized by Pick’s Bodies in frontal/temporal lobe
- No distinguishing microscopic abnormalities

Types of Dementia

Dementia with Lewy Bodies

- A pattern of decline similar to Alzheimer's Disease
- Includes Lewy bodies (abnormal protein deposits that form inside nerve cells of the brain)
- Alertness and severity of cognitive symptoms fluctuate daily
- Visual hallucinations, muscle rigidity, and tremors common

Types of Dementia

Normal Pressure Hydrocephalus (NPH)

- Caused by buildup of fluid in the brain
- Symptoms include difficulty walking, memory loss and inability to control urine
- NPH can sometimes be corrected with surgical installation of a shunt to drain excess fluid

Types of Dementia

Mild Cognitive Impairment (MCI)

- Problem with memory and cognitive skills severe enough to be noticeable but not severe enough to interfere with daily life

Parkinson's Disease

- Many people with the disease go on to develop dementia in later stages of the disease

Causes of Dementia

- Illnesses that attack brain cells:
  - Lyme Disease
  - Alzheimer's Disease
  - Parkinson's Disease
  - Huntington's Disease
  - High Fevers
  - Systemic Lupus

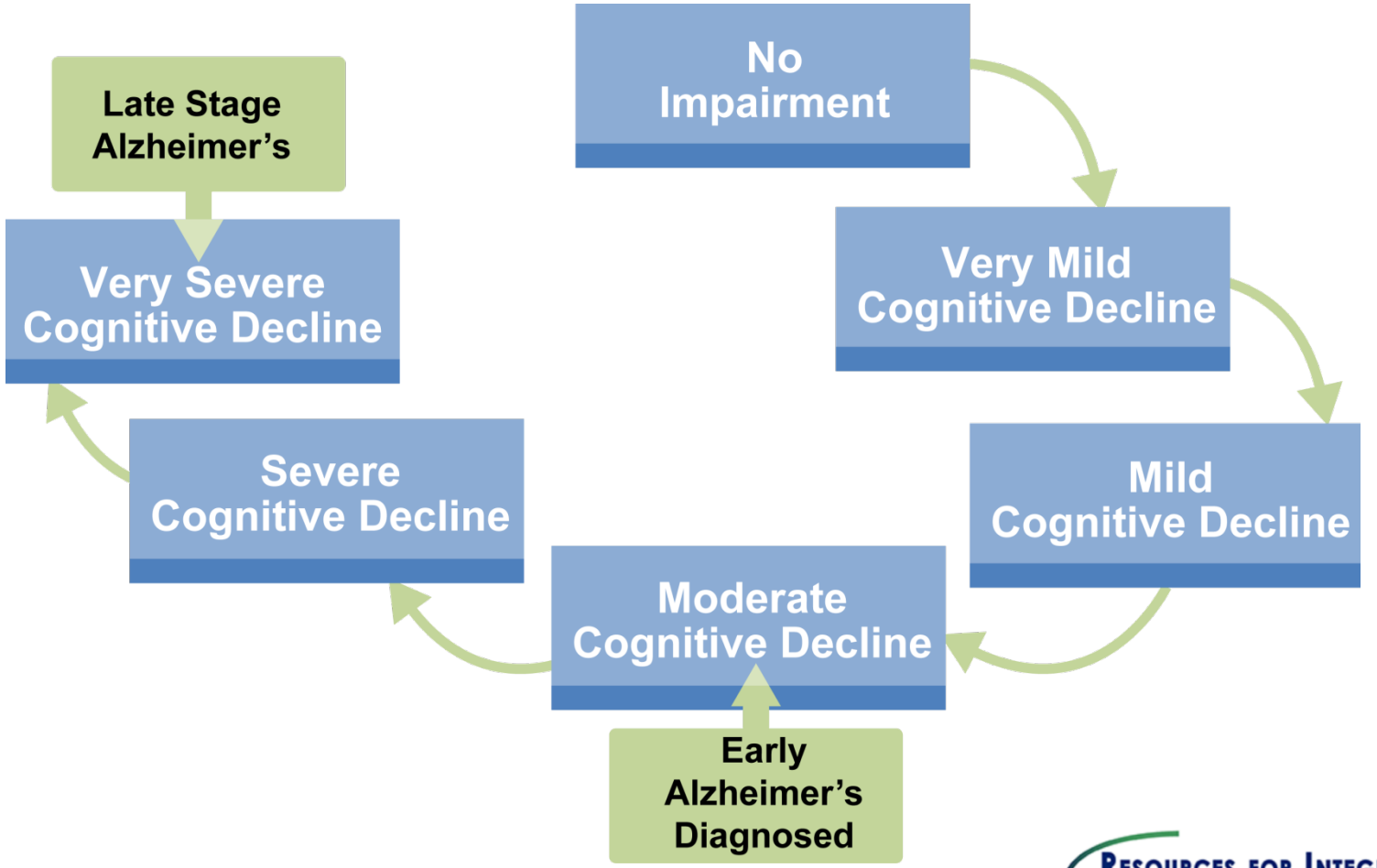
Causes of Dementia (cont.)

- Disruption of oxygen flow to the brain due to:
  - Heart Disease
  - Strokes (CVAs)
  - Smoking
- Chronic poor nutrition and dehydration
- Metabolic disorders, liver or kidney diseases
- Drugs/alcohol abuse
- Traumatic Brain Injuries
- STDs, including AIDS
- Exposure to environmental & industrial toxins

Seven Stages of Alzheimer's Disease

- Stage 1: No impairment
- Stage 2: Very Mild Cognitive Decline
- Stage 3: Mild Cognitive Decline
- Stage 4: Moderate Cognitive Decline - Early Alzheimer's Disease is diagnosed
- Stage 5: Moderately Severe Cognitive Decline
- Stage 6: Severe Cognitive Decline (Moderately Severe Alzheimer's)
- Stage 7: Very Severe Cognitive Decline (Late Stage Alzheimer's)

Stages of Alzheimer's are progressive & irreversible



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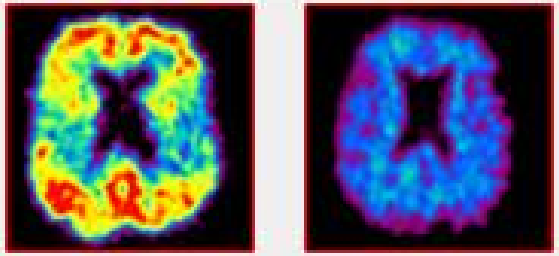
Brain Changes with Alzheimer's: PET Brain Scan



PIB Brain Scan

Red = Amyloid

The PET brain scan on the left is of a person with mild Alzheimer's disease, and the scan on the right is from a healthy adult. Red areas show the greatest levels of amyloid, and the dark blue indicates no amyloid. The other colors—in order like the colors of a rainbow—show progressively lower levels of amyloid.

Image credit:
University of Pittsburgh Medical Center

http://www.alz.org/research/science/earlier_alzheimers_diagnosis.asp#Brain

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Stage 1: No Impairment Noted

- Apparent normal functioning
- Memory loss may exist but is not evident in testing by a health care professional
- No impairment noticed by person, friends or family

Stage 2: Very Mild Cognitive Decline

- Person may forget familiar names
- Person may forget the location of common objects, such as keys or eyeglasses

Stage 3: Mild Cognitive Decline

- Friends & family notice differences
- Person experiences decreased ability to remember names
- Person has impaired retention when reading
- Person frequently loses objects
- Person experiences diminished ability to plan or multitask

Stage 4: Moderate Cognitive Decline: (Diagnosis of Early Alzheimer's Disease)

- Medical evaluation can detect that the person has a reduced memory of his/her personal history
- Person has difficulty remembering recent events
- Person's ability to do complex math and perform complex tasks is impaired
- Person may become withdrawn

Stage 5: Moderately Severe Cognitive Decline

- Mid-stage Alzheimer's Disease
- Person experiences major gaps in memory
- Person needs assistance in ADLs
- Person is disoriented around time and place
- Person is still able to recall his/her own name and the names of close family members

Stage 6: Severe Cognitive Decline

- Moderately Severe Alzheimer's Disease
- Person experiences significant personality changes
- Person has an imperfect recollection of his/her personal history,
- Person forgets the names familiar people, including spouse and close relatives and friends
- Person requires significant assistance with ADLs
- Person has sleep disruptions - "Sundowner Syndrome"
- Person experiences urinary or fecal incontinence
- Person may wander or get lost

Stage 7: Very Severe Cognitive Decline

- Late Stage Alzheimer's Disease
- Person has lost the ability to respond to his or her environment
- He/She is no longer able to generate recognizable speech
- Person may be incontinent
- Person may no longer be able to walk w/o assistance
- He/She may lose the ability to smile
- Person may display abnormal reflexes and muscle rigidity
- Person may experience impaired swallowing
- Person may have seizures

Global Deterioration Scale

- Worksheet for identifying the stages of Alzheimer's Disease

Source: Adapted by Dr. Doug Drummond from Reisberg B, Ferris SH, Leon MJ, et al. The global deterioration scale for assessment of primary degenerative dementia. American Journal of Psychiatry 1982;139:1136-1139.

Important: this was developed for people without a pre-existing intellectual or developmental disability -- provides information but is not a reliable diagnostic tool for someone with ID/DD and/or Down Syndrome

Global Deterioration Scale (GDS)

GLOBAL DETERIORATION SCALE (GDS)

Stage	Deficits in cognition and function	Usual care setting
1	**Subjectively and objectively normal**	Independent
2	• Subjective complaints of mild memory loss. • Objectively normal on testing. • No functional deficit	Independent
3	**Mild Cognitive Impairment (MCI)** • Earliest clear-cut deficits. • Functionally normal but co-workers may be aware of declining work performance. • Objective deficits on testing. • Denial may appear.	Independent
4	**Early dementia** • Clear-cut deficits on careful clinical interview. Difficulty performing complex tasks, e.g. handling finances, travelling. • Denial is common. Withdrawal from challenging situations.	Might live independently – perhaps with assistance from family or caregivers.
5	**Moderate dementia** • Can no longer survive without some assistance. • Unable to recall major relevant aspects of their current lives, e.g. an address or telephone number of many years, names of grandchildren, etc. Some disorientation to date, day of week, season, or to place. They require no assistance with toileting, eating, or dressing but may need help choosing appropriate clothing.	At home with live-in family member. In seniors' residence with home support. Possibly in facility care, especially if behavioural problems or comorbid physical disabilities.
6	**Moderately severe dementia** • May occasionally forget name of spouse. • Largely unaware of recent experiences and events in their lives. • Will require assistance with basic ADLs. May be incontinent of urine. • Behavioural and psychological symptoms of dementia (BPSD) are common, e.g., delusions, repetitive behaviours, agitation.	Most often in Complex Care facility.
7	**Severe dementia** • Verbal abilities will be lost over the course of this stage. • Incontinent. Needs assistance with feeding. • Loses ability to walk.	Complex Care

Adapted by Dr. Doug Drummond from Reisberg B, Ferris SH, Leon MJ, et al. The global deterioration scale for assessment of primary degenerative dementia. American Journal of Psychiatry 1982;139:1136-1139.

Provided by the Alzheimer's Drug Therapy Initiative for physician use.

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QUESTIONS?

Dementia and Down Syndrome: Risks and Vulnerabilities

Risk Factors for Alzheimer's Disease in People with Down Syndrome

- Living longer -- increases risk of Alzheimer's Disease
- Pre-existing genetic susceptibility
- Women with Down Syndrome have an increased risk of Alzheimer's Disease due to estrogen deficiency & earlier menopause

Risk Factors for Alzheimer's Disease for People with Down Syndrome (cont.)

- Syndrome-specific brain development: decreased brain weight & size, reduced frontal lobe volume, and decreased dendrite branching during fetal development
- APOE gene located on chromosome 19 and its link to cholesterol / lipid metabolism: Institute of Behavioral Research study provides evidence that lowering cholesterol levels may reduce risk of early development of Alzheimer's Disease

Neuropathology in People with Down Syndrome

- People with Alzheimer's Disease and adults with Down Syndrome display similar brain deposits of plaques and neuro-fiber tangles characteristic of Alzheimer's Disease
- Neuro-pathologic changes consistent with Alzheimer's Disease appear early in people with Down Syndrome (ages 35-40)
- Measurable symptoms of dementia may not become evident until after 50

SOURCE: NY Institute for Basic Research.
http://www.opwdd.ny.gov/institute-for-basic-research/research

Dementia Considerations for People with Down Syndrome

- Tendency toward premature aging and increased risk of dementia due to Alzheimer's
- Some individuals have developed symptoms as early as their 40's
- Standard tests to diagnose dementia not designed to differentiate between dementia and cognitive impairments associated with Down Syndrome and ID/DD
- Cognitive abilities vary individually -- need assessment tools that take variations in baseline into account

Dementia in Down Syndrome

- Diagnosis requires a change in status over a period of 6 months
- Must be a change in both cognitive functioning and behavioral functioning
- Testing involves both person and caregiver or family member

Dementia and Down Syndrome Tests

- Down Syndrome Mental Status Exam (DSMSE)
- DSMSE tests includes recognition of simple designs, word object matching, and serial naming of objects (developed by J.V.Haxby 1989 and Silverman 2004 updated)
- Test for Severe Impairment (TSI) tests for cognitive function in people with severe impairments (Albert & Cohen,1992)
- Informant based assessments (questionnaire completed by caretakers to measure social and cognitive functioning suggestive of dementia)

Assessment & Diagnosis of Dementias

Standard Assessment Tools

Standard Assessment for Dementia

- Diagnostic criteria specifies decline in memory and in at least one of the following cognitive abilities:
- Ability to generate coherent speech and understand spoken or written language
- Ability to identify objects
- Ability to execute motor functions
- Ability to think abstractly, carry out complex tasks, make sound judgments

Dementia is often experienced differently for people with ID/DD

- Experience dementia at an earlier age with a more rapid decline, with a briefer duration between diagnosis & death
- Onset may manifest as changes in behavior before memory loss becomes evident
- History of a lifelong need for caregiving creates unique challenges for diagnosis and developing supports to sustain aging in place

Sources quoted by CARF from: My Thinker's Not Working, National Task Group on Intellectual Disabilities & Dementia Practices, 2012
www.rrtcad.org/resources

Standard Assessment Tools may not be valid for Assessing People with ID/DD

- May not be skilled or accurate self-reporters
- May have limited functional expressive and receptive language skills
- May not know the names of common objects due to ID/DD
- Impairments in abstract reasoning and judgment are common, even typical, features of ID/DD
- Individuals with ID/DD often have diminished or impaired functional skills in independent living

Pre-existing Impairments Must Be Considered in Dementia Diagnosis

- Most standard screening tools have limited value
- Diagnosis of Dementia for people in general population is based on assessment of memory loss or cognition decline
- Initial efforts underway to develop assessments and screening tools specifically for people with ID/DD
- Baseline of capabilities prior to possible symptoms of dementia remains the best tool

Recognizing Dementia in People with ID/DD

- Dementia diagnosis is based on a process of recognizing change or decline from prior level of function
- Changes in memory and cognition are often NOT the most obvious presenting symptom
- Changes in personality and behavior are frequently the early signs
- Frequent & early screening, including baseline screening, is essential

Standard Screening Tools are Inconclusive for Adults with ID/Down Syndrome

- Varied level of cognitive function due to ID/Down Syndrome
- Decline in individuals with ID/Down Syndrome can present in different ways
- Changes in cognition are accompanied by changes in behavior
- Difficult to establish cut-off score
- Aging caregivers may not be reliable reporters of information

What Can You Do? Proactive Responses and Planning

- Obtain a baseline of person's functioning and abilities at at early age – for people with Down Syndrome at 30
- Provide regular and ongoing evaluations of person's cognitive abilities using variety of tools beginning at age 35 for people with Down Syndrome
- Facilitate person-centered planning with individuals and caregivers to consider future care needs, identify resources and supports, develop collaborative networks

Why Document A Baseline?

- A baseline becomes the most important tool in assessing individuals with ID/DD for dementia
- Often difficult to assess individuals with ID/DD reliably due to lifelong histories of impaired abilities, particularly in communication and functional skills
- Standard assessment tools are typically based on a person's ability to self-report and are not always reliable if person with ID/DD has difficulty with communication
- Video recordings of the individual may be most useful tools over time for objective assessment

Baseline is Invaluable

- Individuals with ID/DD may not be reliable reporters of changes they notice; caregivers may not be objective reporters
- Baseline assessment provides valuable information on the person's typical skills, abilities, and behavior
- Assessment for dementia evaluates person's baseline functioning, looking for changes
- Distinguish between newly evident behavioral issues and behaviors that have been consistently evident as part of the person's baseline
- Changes in cognitive tests should be backed up with examination of changes in daily functioning

SOURCE: Burt, Diana B. & Aylward, Elizabeth H. Assessment Methods for Diagnosis of Dementia. Dementia, Aging, and Intellectual Disabilities, Janicki, Matthew P and Dalton, Andrew J., eds. 1999

Additional Supports for Reliable Assessment

- Assure caregivers understand risks, symptoms, and process of dementia and the elements of reliable diagnosis
- Facilitate regular, ongoing screenings for dementia
- Refer to professionals specifically trained in assessing individuals with ID/DD & Down Syndrome
- Assure that caregivers/family members who know the person well participate actively in assessment process
- Keep conversations open and continuous to assure collaboration

SOURCE: National Task Group, *Community Care Guidelines.* Retrieved from web: www.aamd.org/sites/files/NTG-communitycareguidelines-Final.pdf

NTG-Early Detection Screen for Dementia (NTG-EDSD)

- Developed by a National Task Group Screening Workgroup in 2010
- Goal was to develop a screening instrument that was easy to use, accessible to caregivers and staff, and linked to common signs of onset of dementia
- NTG-EDSD designed to detect cognitive decline in individuals with ID/DD as part of annual wellness visits
- Not a tool for diagnosis but provides important information to stimulate collaborative dialogue between health care practitioners and caregivers
- NTG-EDSD in PDF format can be retrieved from www.aadmd.org/ntg/screening

Evaluation & Assessment Tools (cont.)

Down Syndrome Dementia Questionnaire

- Completed by a family member or caregiver who knows the person with ID/DD well
- Questions are scored based on person's ability to perform specific task or activity
- Distinguishes whether person was ever able to perform the task or if the person has recently become unable to perform task
- Retrieve from the internet at: http://www.kcdsg.org/files/content/Down%20Syndrome%20Dementia%20Questionnaire.pdf

It's Not Always Dementia . . .

Other illnesses and conditions can affect the behavior and memory of people with ID/Down Syndrome:

- Acute or chronic illness, pain, seizure disorder
- Life changes such as separation, bereavement, move to new residence
- Mental illness, particularly depression
- Nutritional deficits -- especially vitamin B-12 or folate deficiency
- Urinary Tract Infection
- Upper Respiratory Infection, pneumonia
- Vision or hearing loss
- Hypothyroidism
- Sleep apnea
- Reactions to medications

Changes Caregivers Should Watch For

- Onset of seizures for someone who does not have a history of a seizure disorder
- Personality changes/behavior changes
- Apathy or periods of inactivity
- Abnormal neurological signs
- No longer performing ADLs as before
- Speech deteriorates
- Disorientation - gets lost or confused easily

Reliability of Caregiver Reports

- Caregivers may not always be objective; may not be able to notice & document subtle changes over time
- Aging parents/family members may be experiencing health and cognition issues too, impairing ability to notice & document changes
- Caregivers may have varying thresholds of awareness - may dismiss certain changes without noting them as possible signs/symptoms of cognitive decline

Environmental Factors in Diagnosing Dementia

- Frequent staff changes may impact caregivers' abilities to provide reliable reports of changes in memory, skills, and behavior
- Level of supports adapt and increase to meet diminishing abilities -- person's diminishing skills may not be observed
- Risk of advanced stage of dementia before diagnosis made

Additional Factors in Diagnosis

- Opportunities for choice and decision-making limited and controlled in some environments --- evaluation of memory or judgment affected by lack of opportunity
- Individuals with ID/DD may have lived in sheltered environments with few intellectual demands -- subtle memory impairments more difficult to detect
- Risk of advanced stage of dementia before diagnosis made

Memory Problems -- NOT the First Symptom of Dementia for People with Down Syndrome:

- Personality change
- Uncooperative behavior
- Irritability
- Aggressive behaviors
- Inappropriate actions
- Giddiness

Questions?

Standard Assessment Tools

Designed to Assess/Evaluate Dementia In General Aging Population

The Self Administered Gero-Cognitive Examination (SAGE)

- A reliable tool for evaluating memory and cognitive ability
- A 15 minute written exam useful in early detection of Alzheimer's Disease
- Must be adapted for use with person with ID/DD
- Retrieve from the web at http://sagetest.osu.edu

The Self Administered Gero-Cognitive Examination (SAGE)

How Well Are You Thinking?

Please complete this form in ink **without** the assistance of others.

Name_____ Date of Birth _____/_____/_____

How far did you get in school? _____ I am a Man_____ Woman_____

I am Asian_____ Black_____ Hispanic_____ White_____ Other_____

Have you had any problems with memory or thinking? Yes_____ Only Occasionally_____ No_____

Have you had any blood relatives that have had problems with memory or thinking? Yes_____ No_____

Do you have balance problems? Yes_____ No_____

If yes, do you know the cause? Yes (specify reason)_____ No_____

Have you ever had a major stroke? Yes_____ No_____A minor or mini-stroke? Yes_____ No_____

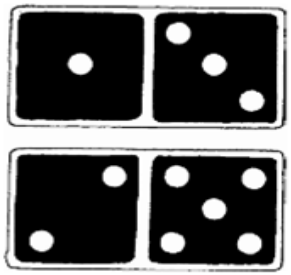
Do you currently feel sad or depressed? Yes_____ Only Occasionally_____ No_____

Have you had any change in your personality? Yes (specify changes)_____ No_____

Do you have more difficulties doing everyday activities due to thinking problems? Yes_____No_____

1. What is today's date? (from memory – no cheating!) Month_____ Date_____ Year_____

2. Name the following pictures (don't worry about spelling):



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CONTINUE NEXT PAGE

The Self Administered Gero-Cognitive Examination (SAGE)

Answer these questions:

3. How are a corkscrew and a hammer similar? Write down how they are alike. They both are… what?

_____

4. How many quarters are in $8.75 cents? _____

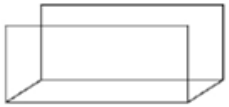
5. You are buying $1.95 of groceries. How much change would you receive back from a $5 bill?

_____

6. Memory Test (memorize these instructions). Do later only after completing this entire test:

At the bottom of the very last page: Write "I am done" on the blank line provided

7. Copy this picture:



8. Drawing test

- Draw a large face of a clock and place in the numbers
- Position the hands for 10 minutes after 11 o'clock
- On your clock, label "L" for the long hand and "S" for the short hand

CONTINUE NEXT PAGE

The Self Administered Gero-Cognitive Examination (SAGE)

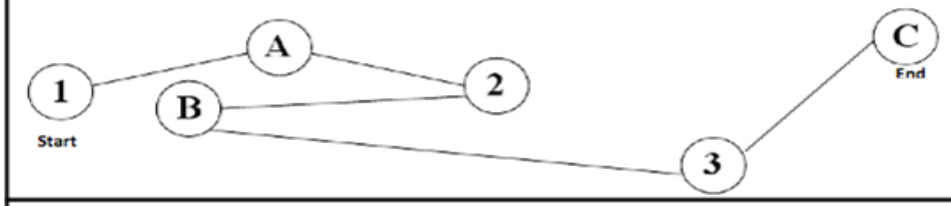
9. Write down the names of 12 different fruits or vegetables (don't worry about spelling):

_____ _____ _____ _____

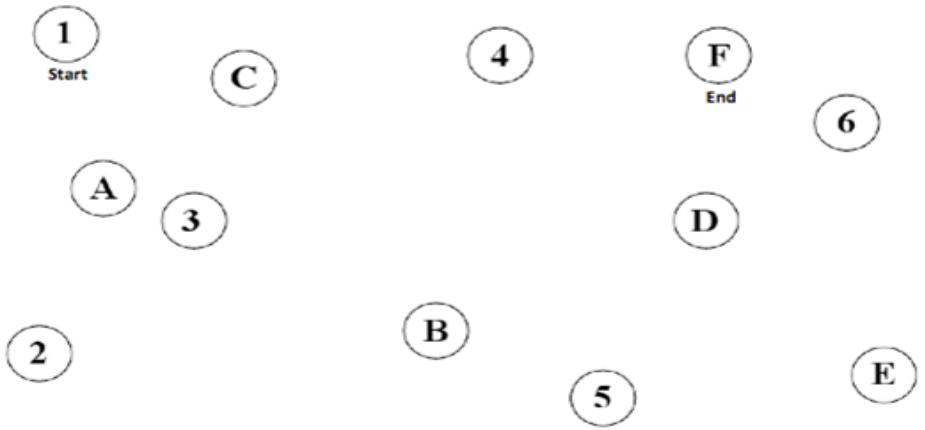
_____ _____ _____ _____

_____ _____ _____ _____

Review this example (this first one is done for you) then go to question 10 below: Draw a line from one circle to another starting at 1 and alternating numbers and letters (1 to A to 2 to B to 3 to C).



10. Do the following: Draw a line from one circle to another starting at 1 and alternating numbers and letters in order before ending at F (1 to A to 2 to B and so on).



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The Self Administered Gero-Cognitive Examination (SAGE)

Self Administered Gerocognitive Examination - SAGE© Form 2

Review this example (this first one is done for you) then answer question 11 below:

- Beginning with 1 triangle and 1 square
- Move 2 lines (marked with an X)
- To make 2 squares and no triangle
- Each line must be part of a complete square (no extra lines).

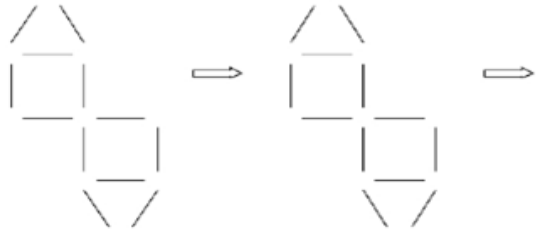
1 triangle, 1 square **(Example)**

Move these 2 lines **(Example)**

Put them here (at arrows)
Make 2 squares (answer) **(Example)**

11. Solve the following problem:

- Beginning with 2 squares and 2 triangles
- Move 4 lines (mark with an X)
- To make 4 squares and no triangles
- Each line must be part of a complete square (no extra lines).



2 squares, 2 triangles

Move 4 lines
Mark with an X

Draw answer here
4 squares

12. Are you done? _____

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D. Scharre MD, version 6.13 http://sagetest.osu.edu Page 4 of 5

STOP

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Mini-COG

- A 3-minute test that is useful in detecting mild cognitive impairment, dementia or an early stage of Alzheimer's Disease
- Research shows that the test has an 83 % rate of accuracy
- The test is in 3 parts: listening to three words, completing a clock drawing, and then recalling the words from part 1

Mini-Cog Questions

- Ask the person to listen carefully to 3 words such as ocean, book, desk and repeat them back
- Ask the person to draw a clock including all the numbers with the hands pointing to a specified time
- Ask the person to repeat the 3 previously stated words

Scoring the Mini-COG

- Word Recall Score: One point for each word recalled, maximum of 3 points
- Clock Drawing Score: Clock test is considered normal if all numbers are present and listed in correct order and the hands represent the correct time, maximum of 2 points

Total Score

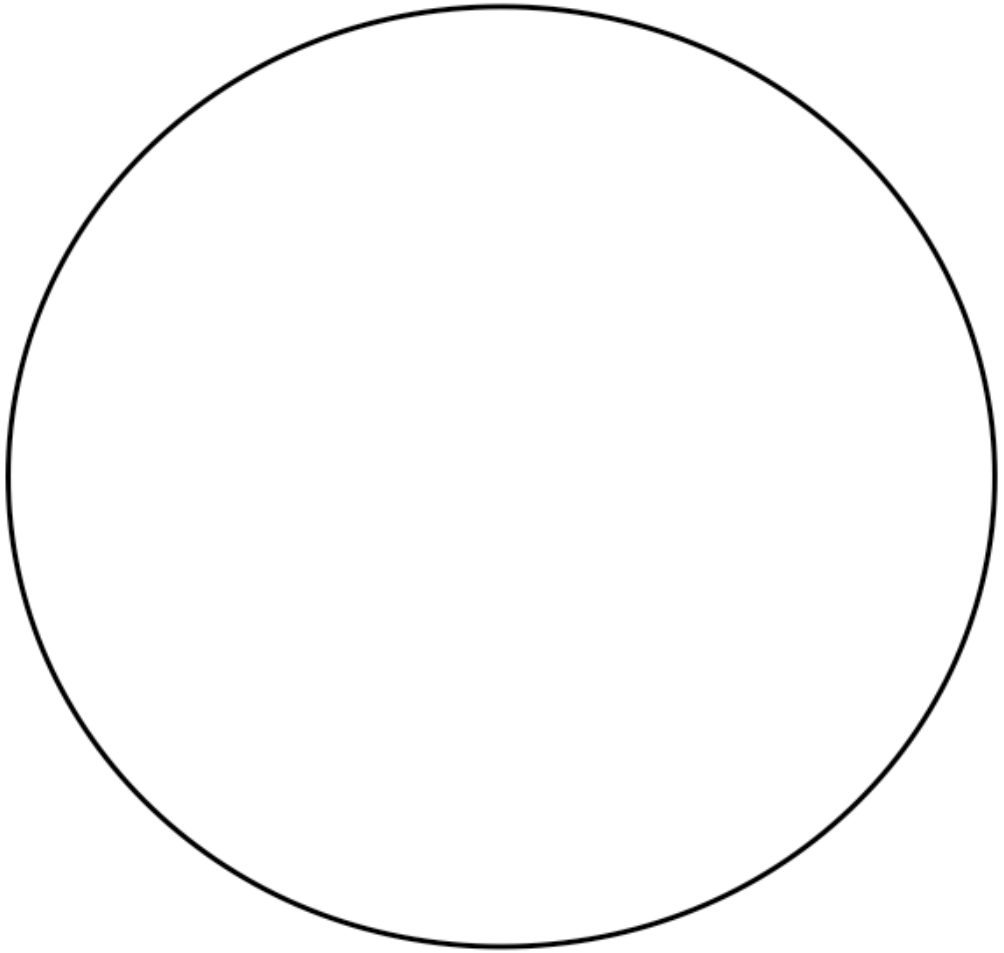
- 0-2 points: Symptoms of dementia may be present; additional assessments indicated
- 3-5 points: Negative for symptoms of dementia

Alzheimer's Clock Draw Test

- Drawing a clock by hand is a useful screening tool for early detection of a mild cognitive impairment
- Test differentiates between normal aging and possible dementia
- If the results indicate decline in abilities or unusual representation of a clock, further testing is indicated

Clock Drawing Test

Patient's Name: _____ Date: _____



Clock Drawing Test

Simple Balance Test

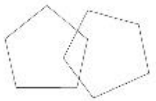
- Helps predict a decline in memory and brain function in people with dementia or Alzheimer's
- Research suggests link between physical performance and cognitive decline (Dr. Yves Rolland)
- People diagnosed with Alzheimer's Disease who exhibited an abnormal one-leg balance test experienced greater decline in brain function over 2 years than those with normal one-leg balance test

Mini Mental State Exam (MMSE)

- Useful assessment tool for people with higher intellectual functioning - person must have functional communication and orientation as a baseline -- not useful for people with pre-existing moderate to severe impairments
- Tests individual's orientation, attention, calculation, recall, language and motor skills
- MMSE is completed by a health care professional
- Retrieve sample from: www.health.gov/bc

Abbreviated version of the Folstein MMSE.

STANDARDIZED MINI-MENTAL STATE EXAMINATION (SMMSE)

	QUESTION	TIME ALLOWED	SCORE
1	a. ***What year is this?***	10 seconds	/1
	b. ***Which season is this?***	10 seconds	/1
	c. ***What month is this?***	10 seconds	/1
	d. ***What is today's date?***	10 seconds	/1
	e. ***What day of the week is this?***	10 seconds	/1
2	a. ***What country are we in?***	10 seconds	/1
	b. ***What province are we in?***	10 seconds	/1
	c. ***What city/town are we in?***	10 seconds	/1
	d. ***IN HOME – What is the street address of this house?*** ***IN FACILITY – What is the name of this building?***	10 seconds	/1
	e. ***IN HOME – What room are we in? IN FACILITY – What floor are we on?***	10 seconds	/1
3	**SAY:** ***I am going to name three objects. When I am finished, I want you to repeat them. Remember what they are because I am going to ask you to name them again in a few minutes.*** Say the following words slowly at 1-second intervals - **ball/ car/ man**	20 seconds	/3
4	***Spell the word WORLD. Now spell it backwards.***	30 seconds	/5
5	***Now what were the three objects I asked you to remember?***	10 seconds	/3
6	**SHOW** wristwatch. **ASK:** ***What is this called?***	10 seconds	/1
7	**SHOW** pencil. **ASK:** ***What is this called?***	10 seconds	/1
8	**SAY:** ***I would like you to repeat this phrase after me: No ifs, ands or buts.***	10 seconds	/1
9	**SAY:** ***Read the words on the page and then do what it says.*** Then hand the person the sheet with CLOSE YOUR EYES on it. If the subject reads and does not close their eyes, repeat up to three times. Score only if subject closes eyes	10 seconds	/1
10	**HAND** the person a pencil and paper. **SAY:** ***Write any complete sentence on that piece of paper.*** (Note: The sentence must make sense. Ignore spelling errors)	30 seconds	/1
11	**PLACE** design, eraser and pencil in front of the person. **SAY:** ***Copy this design please.***  Allow multiple tries. Wait until person is finished and hands it back. Score only for correctly copied diagram with a 4-sided figure between two 5-sided figures.	1 minute	/1
12	**ASK** the person if he is right or left-handed. Take a piece of paper and hold it up in front of the person. **SAY:** ***Take this paper in your right/left hand*** (whichever is non-dominant), ***fold the paper in half once with both hands and put the paper down on the floor***. Score 1 point for each instruction executed correctly.	30 seconds	
	Takes paper correctly in hand		/1
	Folds it in half		/1
	Puts it on the floor		/1
	TOTAL TEST SCORE		/30

Note: This tool is provided for use in British Columbia with permission by Dr. William Molloy. This questionnaire should not be further modified or reproduced without the written consent of Dr. D. William Molloy.

Provided by the Alzheimer's Drug Therapy Initiative for physician use.

Source: www.health.gov/bc

RESOURCES FOR INTEGRATED CARE

Resources for Plans and Providers for Medicare-Medicaid Integration

Screening and Comprehensive Diagnostic Exams

- Early screen for warning signs followed by complete exam
- Components to include are: family and personal history, medication history
- Full physical and neurological and psychological exam
- Annual vision and hearing screens
- Vital signs, sleep and weight monitoring
- Lab tests : CBC, FBC, LFT'S, ESR, TFT, folate and B12 levels, urinalysis, drug levels, EKG, chest x-ray (CT and MRI if indicated)
- Determine dementia or alternative diagnosis based on test results
- Use a multidisciplinary approach

More Suggested Annual Screenings for Health Maintenance & Baselines

- Mobility and orthopedic screening to rule out gait or balance disorders (*especially important in syndromes associated with gait/balance abnormalities such as C.P., Fragile X, Noonan's*)
- Fall risk assessment—especially if history of 2 or more falls in a year, evaluate med profile for drugs that may impact balance

Suggested Screenings (cont.)

- Atlanto-Axial instability screening in Down Syndrome (baseline as adult with C-Spine x-ray repeat annually if symptomatic)
- Osteoporosis screen with bone density scan
- Medication regime review for potential interactions or contraindications (review at least every 6 month or if problem noticed)

Differential Diagnosis

Dementia vs. Depression

Differential Diagnosis: Dementia vs. Depression

- High risk for misdiagnosing dementia and depression in adults with ID/DD
- Dementia & dementia secondary to depression are often mistaken for each in the general population (10-20% of the time)
- Symptoms of depression overlap with those of dementia
- Depression may be a prodromal syndrome prior to development of dementia
- Some neurological symptoms in adults with depression may indicate an underlying organic process

Source: Burt, Diana B. Dementia and Depression. From Dementia, Aging, and Intellectual Disabilities: A Handbook, Janicki, Matthew P & Dalton, Arthur J. eds., 1999.

Symptoms of Depression & Alzheimer's Overlap in People with ID/DD

DEPRESSION

- Decline in ADLs
- Change in sleep habits
- Appetite changes
- Behavior changes, including aggressiveness & agitation
- Memory loss or decline
- Apathy
- Moodiness

ALZHEIMER'S DISEASE

- Decline in ADLs
- Changes in sleep habits
- Increased agitation and & irritability
- Increased apathy or withdrawal
- Periods of inactivity
- Memory loss or decline

SOURCE: Burt, Diana B. Dementia and Depression. From Dementia, Aging, and Intellectual Disabilities: A Handbook, Janicki, Matthew P & Dalton, Arthur J. eds., 1999.

RESOURCES FOR INTEGRATED CARE
Resources for Plans and Providers for Medicare-Medicaid Integration

Challenges to Differential Diagnosis Depression vs Dementia

- Individuals with ID/DD may not be able to consistently and accurately describe their experiences and feelings -- lack the ability for self-assessment
- Reports by caregivers may be influenced by caregiver's tolerance level, beliefs about the individual's behavior, setting in which behavior is observed, and caregiver's own psychological needs
- Symptoms of weight loss/gain and sleep changes may be result of psychotropic medications
- Some symptoms of depression - i.e., self-injury, may be part of individual's typical behavior pattern

Differential Diagnosis Affects Treatment Outcomes: Depression vs. Dementia

- Changes resulting from depression are often treatable and reversible
- Depression may be a precursor to onset of dementia —diagnosis of depression may mask diagnosis of early dementia
- Accurate diagnosis is essential for person-centered planning and development of future supports

Assessment Challenges in Differential Diagnosis

- Difficult to assess the impact of life changes that individuals may be experiencing
  - Death of parents or long-term caregiver
  - Change in living environment
  - Loss of familiar routines and relationships
  - Change in work environment
- Individual is often unable to self-report reliably and accurately about what he or she is feeling

Improving Outcomes

- Use a standard classification system for dementia and Down Syndrome
- Educate caregivers on how to recognize changes
- Early diagnosis affects outcome
- Long-term follow-up should begin at age 35
- Assess cognition and ADL skills & monitor for changes at least annually
- Recognize need for an intellectually stimulating environment
- Remember memory loss is not the first sign—you'll see behavioral & skill changes first

Questions?

Supporting Autonomy and Community Life for Aging Individuals with ID/DD & Down Syndrome & Dementia

Edinburgh Principles

- Developed by Edinburgh Working Group on Dementia Practices at a collaborative meeting called by University of Stirling (Scotland), University of Albany (USA) & University of Illinois at Chicago (USA) in February 2001
- Tasks: define internationally applicable working practices for community supports for people with ID/DD affected with Alzheimer's Disease and/or other dementias

For more information: www.albany.edu/aging/IDD/edinburgh.htm

Edinburgh Principles (cont.)

- Adopt an operational philosophy that promotes quality of life
- Affirm that individual strengths guide decision-making
- Involve the individual and family in all planning and services
- Ensure availability of appropriate diagnostic and service resources
- Plan and provide supports to optimize remaining in the community
- Ensure that people with an intellectual disability have access to same dementia services provided to others in the population
- Ensure that community dementia services planning also involves a focus on adults with ID/DD
- Ensure generic, cooperative, and proactive strategic planning across relevant policy, provider, and advocacy groups involves consideration of the current and future needs of adults with ID/DD affected by dementia

Implementing the Edinburgh Principles

- Implement person-centered, strength-based approaches to planning for individuals with ID/DD at risk for dementia
- Initiate timely conversations with individual, caregivers, family to identify supports necessary for person to age in place
- Implement regular, ongoing assessment and evaluation protocols to monitor for early signs of dementia; assure reliable reporting and assessment by qualified professionals
- Become informed of resources and supports for aging individuals with ID/DD available in your community

Advocacy is Essential

- Assure that people working with individuals with ID/DD in healthcare settings understand who the person is:
  - How does the person communicate?
  - What are his/her capabilities? How does he/she communicate his/her needs?
  - What does he/she need help with? Toileting, dressing, eating?
  - Special diet needs and preferences?
  - What does he/she need to feel safe and confident?

Conversations with Caregivers

- As caregivers age, they may no longer be able to provide a previous level of support
- Encourage family caregivers to identify their personal goals for retirement and health care
- Discuss their plans for their family member's care - who will care for this person in their absence?
- Help family caregivers to develop a "wishlist" for their family member and help them to prioritize and actualize these wishes
- Collaborate to identify community resources to make their plans and wishes reality

Source: Aiding Older Caregivers, www.albany.edu/aging/IDD

Optimize Quality of Life

- Support and enable the person's existing abilities - don't try to teach new skills
- Establish routines and maintain them - predictability & familiarity help person to feel more secure
- Safety first - increased staff, closer supervision; monitor nutrition intake closely, review environment regularly for risks - trip hazards, poor lighting
- Encourage exercise if person's condition permits it - can help maintain physical and mental abilities
- Support socialization - plan activities that the person enjoys - provide memory aids to help the person recall names of familiar people

Collaborative Efforts for Learning More

National Task Group (NTG) on Intellectual Disabilities and Dementia Practices www.aadmd.org: excellent resource for information, current research, handbooks & publications, collaboration between:

- Collaboration between American Academy of Medicine & Dentistry (AADMD)
- Rehabilitation & Training Center on Aging and Developmental Disabilities - University of Chicago
- American Association on Intellectual and Developmental Disabilities (AAIDD)

National Task Group (NTG)'s Projects & Initiatives

Charged with the following tasks:

- Develop early detection screen for dementia related changes in people with ID/DD
- Develop practice guidelines for health care and supports around dementia in adults with ID/DD
- Identify models of community-based support and long-term care for people with ID/DD

Publications:

- My Thinker's Not Working
- Guidelines for Structuring Community Care and Support for People with Intellectual Disabilities Affected by Dementia.
- PDFs and additional information available at www.aadmd.org

Learn as Much as You Can

- Developmental Services Resource Guide on Aging and Dementia, 2008: Useful handbook developed by the Vermont Agency of Human Services, retrieve PDF at www.ddas.vermont.gov
- Aiding Older Caregivers of Persons with Intellectual and Developmental Disabilities: Provides practical information and identifies resources for developing supports and planning for future needs of individuals with ID/DD & their caregivers. Retrieve PDF from: www.albany.edu/aging/IDD/documents/Aiding_older_caregivers.pdf
- Aging and Down Syndrome: A Health and Well-Being Guidebook: Comprehensive information on medical concerns, advocacy, developing supports for people with Down Syndrome, retrieve PDF at www.ndss.org/Global/Aging%20and%Down%20Syndrome.pdf

Useful Websites

- Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Maintained at the University of Illinois at Chicago, includes resources such as a bibliography on dementia care, fact sheets and background materials, assessment tools and instruments, links to dementia reports and guidelines, information on meetings, conferences, and workshops, contact information for researchers in these fields. www.rrtcadd.org
- School of Social Welfare, University at Albany, State University of New York (SUNY), Intellectual Disabilities, Aging, and Dementia: A website dedicated to providing resources for staff caring for aging individuals with intellectual disabilities. Includes links to assessment tools, research articles, training opportunities, and other useful information and supports. http://www.albany.edu/aging/IDD/r-id.htm

More Useful Websites

- Institute on Aging, University of Wisconsin – Madison: Provides resources, articles, and research on policies and practices in health care for the aging http://aging.wisc.edu
- Institute on Community Integration, UCEDD, University of Minnesota: Offers resources, information and training opportunities for individuals with intellectual disabilities and their families and caregivers. Information and opportunities for services, education, and consultation services. www.ici.umn.edu

Post Test: True or False?

1. Dementia is a process characterized by cognitive decline and impaired ability to function. T/F
2. Standard assessment tools for dementia are reliable tools to assess dementia in ID/DD population. T/F
3. Alzheimer's disease is a rare form of dementia unlikely to affect individuals with Down Syndrome. T/F
4. People with Down Syndrome are dying at younger ages than previously. T/F
5. DSMSE, TSI, and Caretaker Questionnaire are useful tools in diagnosis of dementia in ID/DS population. T/F

Post Test: True or False (cont.)

6. A baseline of capabilities prior to dementia is an effective tool to diagnose and recognize symptoms of dementia in DD/ID population. T/F
7. Symptoms of depression and Alzheimer's can be similar in individuals with ID/DD. T/F
8. The Edinburgh Principles recommend institutionalization of individuals with ID/DD who have mild to moderate dementia. T/F
9. The first sign that a person with Down Syndrome may be experiencing dementia is usually a change in behavior. T/F
10. Planning future supports for an individual with ID/DD should not include the individual since it would be upsetting for him. T/F

Correct Answers

1. True
2. False
3. False
4. False
5. True
6. True
7. True
8. False
9. True
10. False

Questions/Discussion