

◦ **WEBINAR SERIES:**
AGING IN INDIVIDUALS WITH
INTELLECTUAL AND
DEVELOPMENTAL
DISABILITIES

CMS Medicare-Medicaid Coordination Office (MMCO)

Established by Section 2602 of the Affordable Care Act

- Purpose: Improve quality, reduce costs, and improve the beneficiary experience.
 - Ensure Medicare-Medicaid enrollees have full **access** to the services to which they are entitled.
 - Improve the **coordination** between the federal government and states.
 - Develop **innovative** care coordination and integration models.
 - Eliminate financial **misalignments** that lead to poor quality and cost shifting.
- Demonstration, technical assistance and evaluation activities include:
 - Program Alignment Initiative
 - Access to Medicare data for Medicare-Medicaid enrollees
 - State Demonstrations to Integrate Care for Dual Eligible Individuals: Financial Alignment Initiative
 - Initiative to Reduce Avoidable Hospitalizations in Skilled Nursing Facilities



Session 3

Dementia in Adults with Down Syndrome

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Outline for Session 3

1. What is Dementia
2. Dementia Criteria
3. Types of Dementia
4. Acute Dementia
5. Chronic Secondary Dementia
6. Chronic Non-Progressive Primary Vascular Dementia
7. Chronic Primary Neurodegenerative Pre-Senile Dementia
8. Chronic Primary Neurodegenerative Senile Dementia
9. Assessment
10. Staff outcomes.
11. Intervention strategies

Purpose of Session 3

- Increase awareness of the importance on developing observation skills on the changes that may be related to dementia
- Understand how Alzheimer's disease (AD) in the older down syndrome adult increases the risk of ACSC and hospitalization
- How, by implementing management strategies, this risk can be reduced

Myths about Dementia and ID/DD Adults

- Myths
 - ❑ High incidence of dementia in I/DD adults is a myth (same as the general population)
 - ❑ All DS older adults will be diagnosed with Alzheimer's disease

What is Dementia



SECTION I

Dementia

- There is no such thing as “just getting senile”
- Forgetfulness may accompany normal aging. Many older healthy adults have difficulty recalling names, where things were left, and reduced concentration.
- When memory loss and confusion begin to interfere with daily living, it is not a part of normal aging, but due to age associated changes or diseases

Dementia (cont' d)

- State of impaired memory with a loss of cognitive abilities and/or change in personality which are persistent and interfere with levels of social activities, routine activities of daily living, and/or occupational function
- The clustering of **behavioral changes, memory loss** and **decline in cognitive abilities** defines the type of dementia but does not imply causation or prognosis.

Three Dementia Criteria



SECTION 2

Dementia Criteria 1: Behavior Changes

- Apathetic (voluntary/willful refusal to cooperate)
 - ❑ Lack of motivation or behavioral initiation
 - ❑ Pervasive problem throughout course of AD
 - ❑ Most common behavior problem in AD
 - ❑ Anhedonia (lack of pleasure) and reduced self-initiated activities
 - ❑ Confused with depression
- Passivity and withdrawn (apathetic, and less responsive)
 - ❑ Two-thirds of mild AD
 - ❑ Decreased affectionate behavior
 - ❑ Decreased verbalizations
 - ❑ Predates cognitive changes

Dementia Criteria 2: Cognition

- Higher executive skills
 - ❑ Handling complex tasks, abstract thought, planning, problem solving
- Reasoning ability
 - ❑ Inability to respond to problems, reduced judgment
- Spatial and orientation ability
 - ❑ Organizing objects, finding way in familiar surroundings
- Language
 - ❑ Finding words, following conversation

Dementia Criteria 3: Memory Decline

- Store, retain, recall information (noticed early decline)
- Short term memory (storage and retaining effected early)
 - ❑ working memory – learning or training new information
- Long term memory (recall effected later in dementia)
 - ❑ episodic or context memory (recall specific events - time and place)
 - ▶ Example - When in Paris, personal feeling and emotions
 - ❑ semantic or factual memory (facts independent of context)
 - ▶ Example - Paris is the capital of France

Two Categories of Dementia



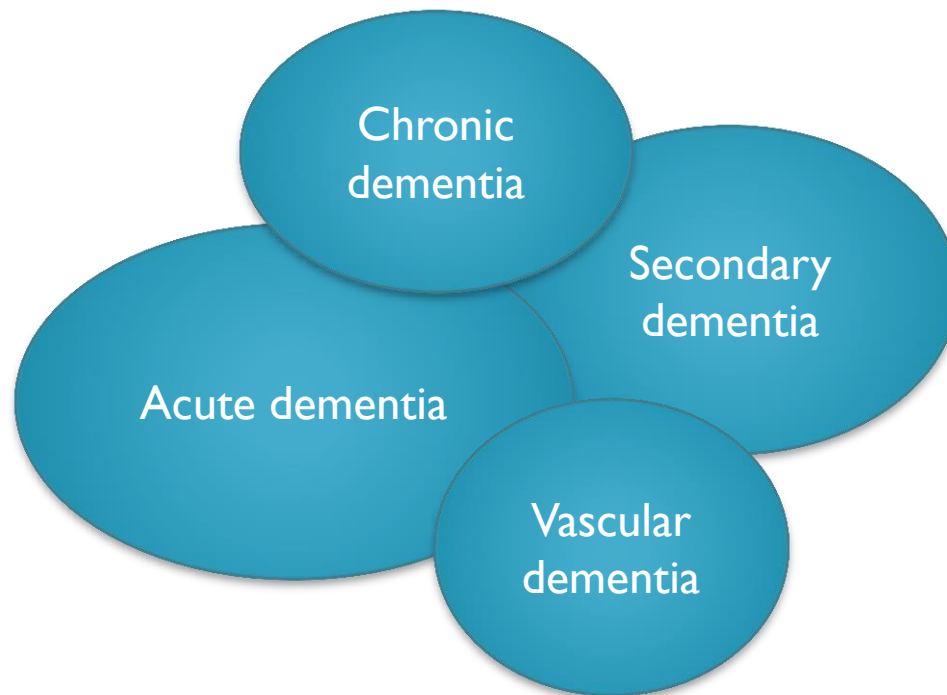
SECTION 3

Two Major Categories of Dementia

- Acute dementia - reversible
- Chronic Dementia - irreversible
 - Chronic secondary dementia
 - Chronic primary dementia
 - ▶ non-progressive – vascular
 - ▶ progressive – neurodegenerative

Overlapping Dementia

- An individual may have more than one dementia, making it harder to differentiate the types of dementia and intervention strategies. This should be noted for the I/DD aging population.



Acute Dementia



SECTION 4

Acute Dementia (reversible)

- Remove the cause and the symptoms disappear
- Causes:
 - delirium
 - depression
 - Dehydration
 - hypothyroidism
 - illness, inflammation, or infection
 - isolation (social)
 - lack of sleep
 - low body temperature
 - medication(s)
 - poor nutrition
 - sensory deprivation

Acute Dementia (cont' d)

- General I/DD populations are at risk for acute dementia, which may be confused with AD, increasing the difficulty in diagnosis and management (diagnostic over-shadowing)
- Older DS adult is at high risk of having age related and associated changes misdiagnosed as Alzheimer's (diagnostic over-shadowing)

Chronic Secondary Dementia



SECTION 5

Chronic Secondary Dementia

- Secondary condition to a primary disease
- Dementia symptoms may be unique to the primary disease
- Examples of primary diseases that have associated secondary dementias
 - ❑ AIDS
 - ❑ Alcoholism
 - ❑ Diabetes
 - ❑ Huntington's disease
 - ❑ Parkinson's disease
 - ❑ Syphilis

Chronic Non-Progressive (Vascular) Dementia



SECTION 6

Chronic Non-Progressive (Vascular)

- Caused by multi-infarctions or mini-strokes in the brain; accumulation of strokes leads to progressive decline in cognitive, memory and personality functions
- Causes: Lifestyle/Diet
 - Hyperinsulinemia (high insulin levels), dyslipidemia (high levels of fat), hyperglycemia (high sugar levels), hypertension
- Effects
 - Mini-strokes (clot/hemorrhagic) in various areas of the brain
 - New symptoms with each new incident (20% + of all dementias)
 - ▶ Can affect aging ID/DD adult population due to poor lifestyle (diagnostic over-shadowing)

Chronic Non-Progressive Example

- Mary, a 50 year old adult with Down syndrome and mild I/DD, is independent with full time job. Her employer describes Mary's work as good, but noticed that her speech is slightly slurred and she seems to have some problems finding words. He noticed this two days ago and it has not improved, nor has it worsened
- Note that the change occurred within a short time (two days) but did not worsen
 - Symptom of vascular dementia

Chronic Primary Neurodegenerative Pre-senile Dementia



SECTION 7

Chronic Primary Neurodegenerative Pre-senile Dementia

- Prior to the age of 64
- Frontotemporal lobe diseases (Pick' s)
 - ❑ Not reported in the I/DD populations
- Dementia with Lewy Bodies disease (LBD)
 - ❑ Recent evidence suggests that LBD may occur in DS adults and may overlap with Alzheimer's disease
- Creutzfeldt-Jakob dementia
 - ❑ Not reported in the I/DD populations

Chronic Primary Neurodegenerative Senile Dementia
(Alzheimer's Disease)



SECTION 8

Alzheimer's Disease: Risk factors in the adult with Down syndrome

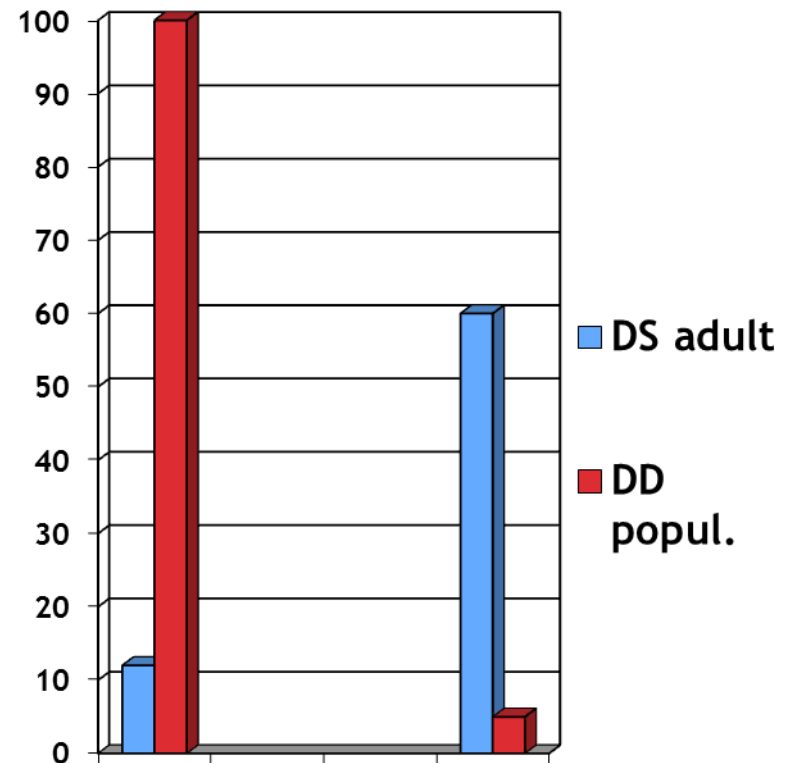
- ❑ 21st chromosome - mutated gene on this chromosome increases risks (mutated gene 100% in the Down syndrome population)
- ❑ Unknown if vascular diseases in adults with Down syndrome increases the risk of Alzheimer's disease
- ❑ Acute dementia may increase the risk of mimicking, masking or exacerbating Alzheimer's disease

Alzheimer's Disease: Risk factors in the adult with Down syndrome (cont'd)

- Symptoms may be misdiagnosed as Alzheimer's disease since other conditions such as acute dementia may mimic those symptoms
- Adults with Down syndrome are vulnerable to other conditions that could be mistaken for dementia

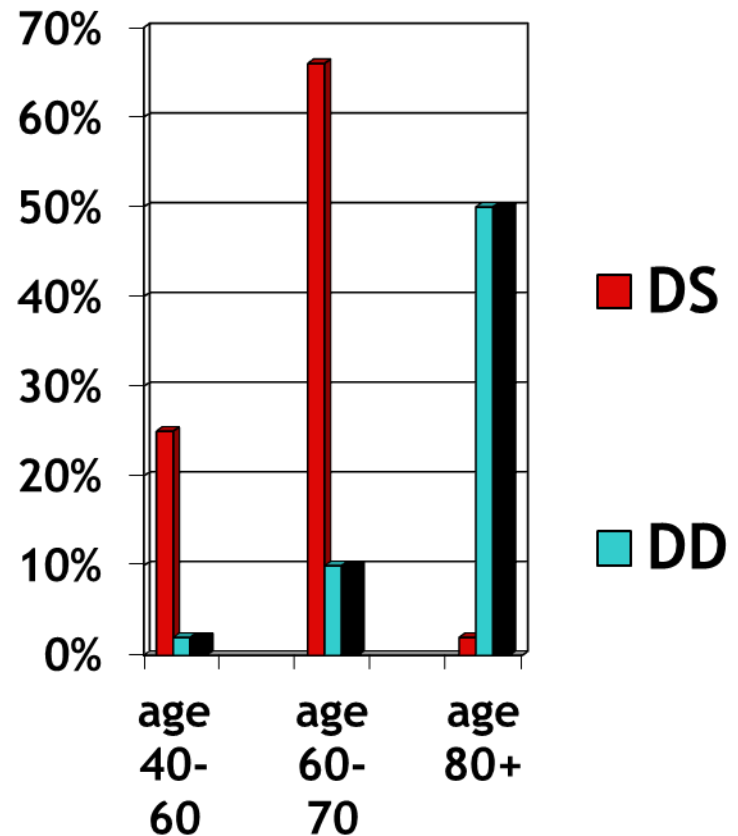
Alzheimer's Disease: Key Findings in DS Adults

- DS adults comprise 10-12% of the DD population; by age 60 they account for 60% of AD
- Late onset seizures in about 12%
- Type of dementia differs between DS and other types of intellectual disability



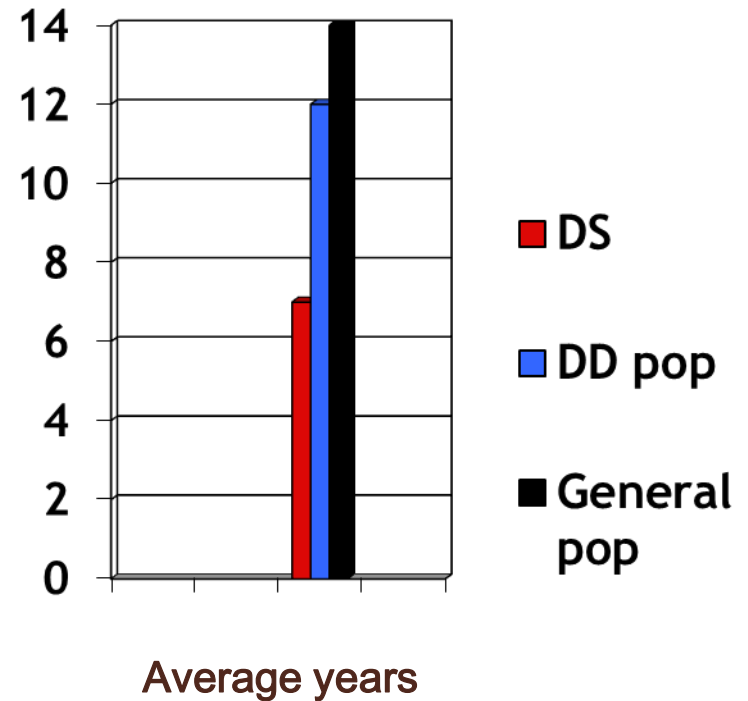
Age of Onset of Alzheimer's disease

- Average onset age about 53 for DS – 65 for others
- 25% of DS adults diagnosed with AD by ages 45-60
- 60-65% of DS adults diagnosed between 60-70 and <5% over 80+ years



Duration of Alzheimer's in Adults with DS compared to the I/DD and general population

- DS adults have a 5-8 year duration time for the disease from diagnosis to death
- The general and the mild to moderate I/DD populations have a duration of AD from 5-17+ years from diagnosis until death



Summary of differences between AD in DS adults and general population

Rate of Occurrence	<ul style="list-style-type: none">• Much higher prevalence & neuropathology indicative of AD in most
Onset and Duration	<ul style="list-style-type: none">• Earlier onset and shorter duration
Behavioral Changes	<ul style="list-style-type: none">• Personality change and memory loss
Neurological Signs	<ul style="list-style-type: none">• Late onset seizures

Why Increase in AD?

- In the past, Down syndrome young adults did not reach the upper age levels resulting in low incidents of AD
 - With the increases of life expectancy into middle age and beyond, the morbidity rate is increasing
- No inevitability about the onset of the disease, but studies do suggest that 40% of adults with Down syndrome will not develop clinical symptoms of Alzheimer's disease

Alzheimer's Disease: General Symptoms

- Slow and progressive, degenerative disorder of the brain that includes:
 - ❑ Short term memory loss (cannot remember what is told)
 - ❑ Personality changes (irritable, volatile)
 - ❑ Diminished self-care abilities (hygiene)
 - ❑ Cognitive impairment (loss of learned skills, disorganization, reduced ability to plan, difficulty finding words)

Alzheimer's Disease Example

- You notice that over the last 6 months there is a slow change in Tom's appearance and personality. He does not shave unless he is urged to do so, and it appears his ability shave properly has declined. At first the changes were not really noticeable until you look back over time
- Note that the changes were slow and not noticeable at first but noticed over time.

AD: Specific Early Stage Behavioral Changes in Mild to Moderate DS adults

- Key Early Stage - Slow Onset (1-2 years) (for other early changes see handout)
 - Difficulty with or loss of speech, loss of ability to find words, repetition of words, questions, or phrases
 - Decline in activities of daily living skills (ADL)
 - ▶ Key indicator in the early stage of Alzheimer's
 - Some deterioration in work performance
 - Changes in personality
 - ▶ Long periods of inactivity or apathy

AD: Specific Early Stage Behavioral Changes in Mild to Moderate DS adults (cont' d)

- ❑ Loss of interest in favorite hobbies
- ❑ Memory loss is not the first symptom of AD in the DS adult but occurs later (in the general population it is the key indicator)
- ❑ Noticeable decline in learned skills
- ❑ Changes in mental processes – slowing of thinking, reasoning and judgment (increase disorientation and confusion)

AD: Specific Mid-Stage Behavioral Changes in Mild to Moderate DS adults (cont' d)

- Severe change in personality
- Marked decline in long term memory
- Marked decline in mental processes - such as thinking, reasoning and judgment

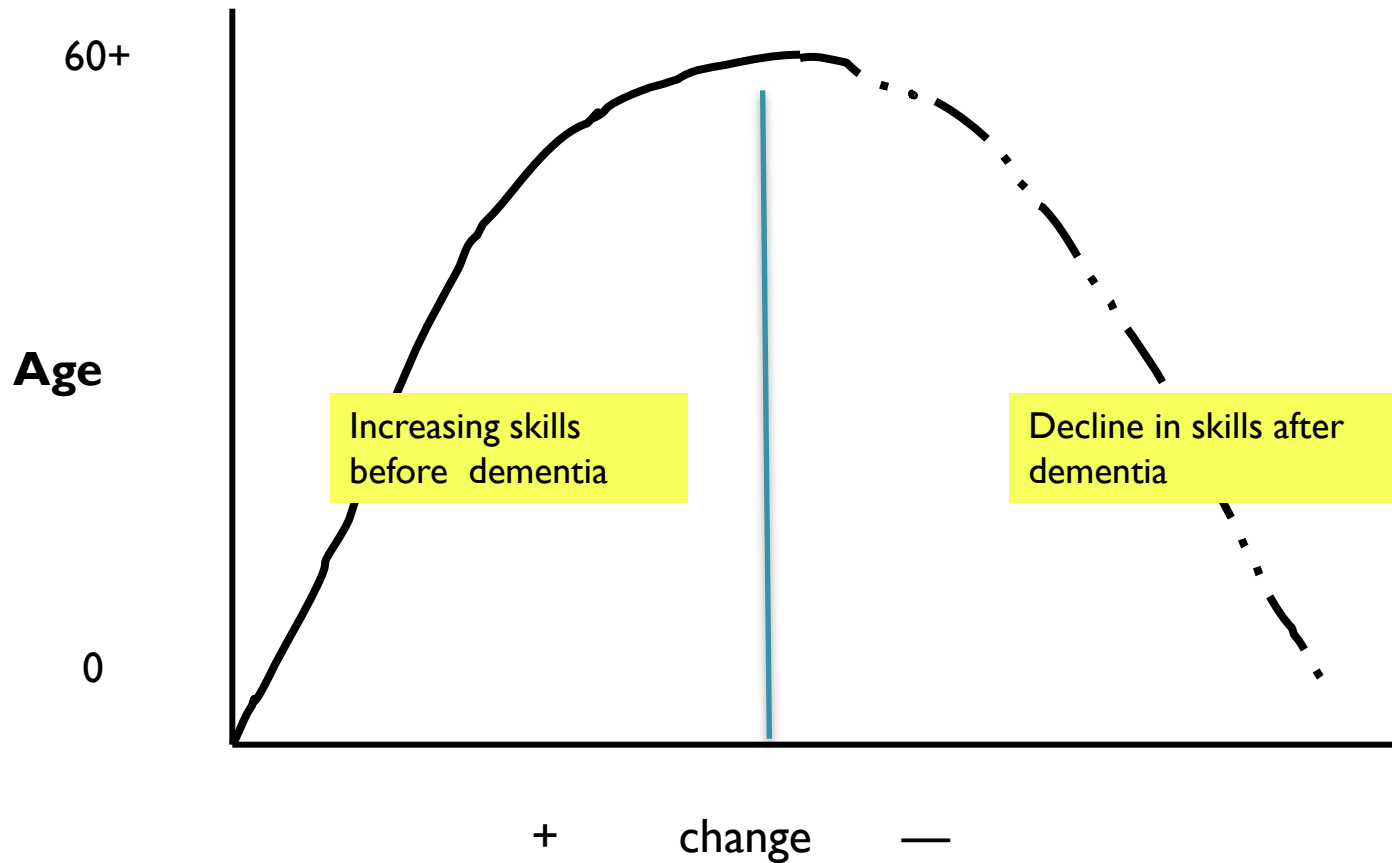
Suggested Interventions: Early to Mid Stages of Alzheimer's disease

- Routine and familiarity is important – “age in place”
- Adaptations to environment or program
- Normal activities, but made simpler
- Structure and support to daily routines

Suggested Interventions: Early to Mid Stages of AD (cont'd)

- More guidance or supervision
- Explicit simple directions, instructions or cues
- Build on skills with similar activities
 - Use knowledge and activities that were learned early in life (see next slide)

Retrogressive Changes



Early skills learned are the last to be lost conversely the newest skills first to be lost

Alzheimer's Diseases: Specific Late-Stage Behavioral Changes in Mild to Moderate DS adults

- Late-stage (1 year)
 - ❑ Loss of basic skills (eating or drinking)
 - ❑ Loss of ability to walk
 - ❑ Total bowel and urinary incontinence

Alzheimer's Disease: Specific Behavioral Changes in the Severe to Profound Dementia Adult

- Changes may be very subtle and pass unnoticed because of non-verbal communication and the disabilities may mask symptoms of AD
 - Social withdrawal, reduced responsiveness
 - Apathy/behavior - personality changes
 - Impaired attention

Alzheimer's Disease: Prognosis

- Prevention
 - ❑ No intervention to prevent the onset or progression of AD
 - ❑ Exercising the brain and body may delay some of the memory and cognitive declines
- Treatment
 - ❑ No treatment available
 - ❑ Some medications may reduce memory loss
- Diagnosis
 - ❑ Presently there is no diagnostic procedure - only upon autopsy of the brain

Assessment for Alzheimer's Disease



SECTION 9

Assessment for Alzheimer's Disease

- Establishing a baseline to measure change is recommended
- Difficult to assess for AD because there are few assessment tools and I/DD individuals have difficulty responding to questions
- See handout for assessment recommendations

Staff Outcomes



SECTION 10

Staff Outcomes

1. Be aware of the causes of acute dementia and the importance of documenting possible causes to present to the health care practitioners
2. Have an understanding of the age differences of onset and duration of Alzheimer's disease between the older DS adult and the general population
3. Be aware of the percentage of older DS adults that will be diagnosed with Alzheimer's disease
4. Recognize the importance of establishing a base line of function and properly documenting change

Staff Outcomes (cont' d)

5. Be aware that the timing of symptoms of Alzheimer's disease in the DS adult are different than the general population
6. Become aware of the many conditions that may mimic, mask or exacerbate Alzheimer's disease by using the assessment check list in the handout
7. Understand the role as an advocate requesting a full assessment of an older DS adult who may express symptoms of Alzheimer's Disease

Intervention Strategies



SECTION II

Intervention Strategies

1. Develop a protocol to evaluate and document observed changes in older adults in the DS and general I/DD populations to be used by the formal and informal caregivers.
2. Develop an educational packet on Alzheimer's dementia in older DS to be distributed to the health care practitioners, hospital, and/or nursing home staff.
3. Develop a training program to educate formal and informal caregivers and older DS adults regarding the prevention of acute dementia, and the symptoms of Alzheimer's disease.
4. Develop an approach that includes the input of health concerns, and health care interventions from older DS and general I/DD adults.
5. Establish a base line evaluation protocol that includes the beginning age, the intervals between review, and at least 4 activities in which the older DS adult is involved
 - ❑ Video taping the individual is one of the most effective evaluation tools. The video can be shown to the professional health care practitioner documenting changes over time.