

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 2: Age Associated Changes and Diseases in Intellectual / Developmental Disabilities (ID/DD) Population

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Outline for Session 2

- Section 1: Purpose of the session
- Section 2: Ambulatory Care Sensitive Conditions (ACSC)
- Section 3: Review Session
- Section 4: Hospitalization - higher risk for hospital admission than the general population
- Session 5: Age associated changes and diseases
- Section 6: Staff outcomes
- Section 7: Review of strategies

Section 1: Purpose of Session

- Increase awareness of risk factors for hospitalization
- The older ID/DD adult population is at greater risk than the general population in being hospitalized due to disparities in health care. The purpose of this session is to reduce the high rate of hospitalization by:
 - ❑ Increasing the awareness and the knowledge base of age associated changes in the older ID/DD adult,
 - ❑ Reducing the risk of these changes becoming age associated diseases by developing intervention strategies that will:
 - ▶ Reduce ACSC that may increase hospitalization or re-admission of the older ID/DD adult



**SECTION 2:
WHAT ARE AMBULATORY
CARE SENSITIVE
CONDITIONS (ACSC)**

Ambulatory Care Sensitive Conditions (ACSC)

- Clustering of serious health related changes or conditions that increase the older adult's vulnerability to being admitted to a hospital or residential care facility. Many of the ACSC can be prevented with recognition and intervention of specific conditions.
- Clustering of health related conditions that define the ACSC depends on many factors, including: gender, race/ethnicity, types of disabilities associated with a disorder, location, pre-existing conditions, etc.

ACSC (cont'd)

- Associated with older ID/DD adults account for a high rate of five to six time greater than the general population
- Associated, in part, with Down syndrome population are (not an inclusive list):
 - ❑ psychiatric disorders
 - ❑ seizure disorders
 - ❑ gastrointestinal disorders
 - ❑ tuberculosis
 - ❑ cancer
 - ❑ hepatitis
 - ❑ dental health

ACSC (cont'd)

- The major reason for the high rate of hospitalization from ACSC are the barriers that increase disparities in accessing health care for the ID/DD population.

Review of “diagnostic over-shadowing” from age related increasing risk for associated changes



SECTION 3: REVIEW

Review

- Changes related to the disability results in inappropriate or no interventions
- Pre-existing cognitive challenges assumed to be symptoms of dementia
- Pre-existing disability may be misdiagnosed as disease

Review (cont'd)

- Increased risk factors with earlier onset of symptoms
- Increased risk of inappropriate medical treatment
- Increased vulnerability to a more restrictive environment

Why the ID/DD population is at higher risk for admission or readmission to the hospital than the general population

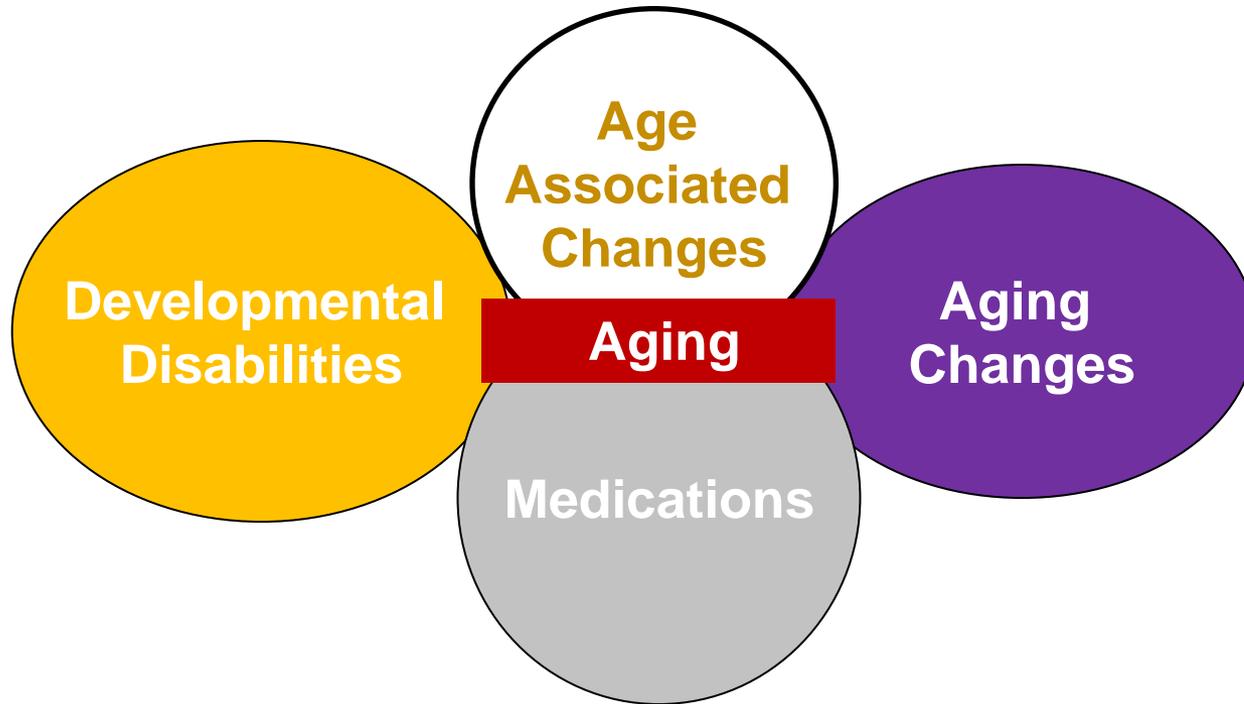


SECTION 4: HOSPITALIZATION

Hospitalization

- The ID/DD population is at greater risk for health concerns than the general population due, in part, to:
 - ❑ Overlapping of ID/DD associated disabilities with age associated and age related changes
 - ❑ High co-morbidity of age associated diseases
 - ❑ Health care disparity
- The increased health risk results in individuals with ID/DD being over- represented by five to six times the general population in hospital admissions.

Hospitalization (cont'd)



- Note: The decline in health of older ID/DD population is not due solely to disability, which changes little over time, but the interaction of the above influences.

Hospitalization (cont'd)

- Increased challenging behaviors due to communication difficulties
- Increased cost for treatment and interventions
- Increased staff/family frustration due to lack of communication and knowledge

How the age associated changes and diseases in the older ID/DD adult increases the risk for ACSC and hospitalization



SECTION 5: AGE ASSOCIATED CHANGES AND DISEASES

Prevalence of Diseases

ICPC code	Per 1000 patients	
	With ID (<i>n</i> = 868)	Control (<i>n</i> = 4305)
Epilepsy	172.8	3.2
Dermatomycosis	123.2	55.5
Diabetes mellitus	111.7	61.5
Acute infection of upper respiratory tract	109.4	62.4
Excess cerumen	95.6	29.5
Eczema by contact/other eczema	86.4	51.3
No illness	76.0	20.6
Insomnia/other sleeping disorder	69.1	20.4
Other infection of skin/subcutis/erysipelas	69.1	9.7
Medication/prescription/injection	67.9	23.0

Straetmans, Joseph; Henny Mj van Schrojenstein Lantman-de Valk; Francois G Schellevis; and Geert-Jan Dinan. 2007. Health problems of people with intellectual disabilities: the impact for general practice. *British Journal of General Practice* 57: 64–66.

Changes in Central Nervous System

- Older Adults with Down syndrome
 - ❑ Higher prevalence of seizures (epilepsy) between the ages of 20- 30 years old, but can occur in older adults
 - ❑ Late-onset seizures after the age of 50 in 75
 - ▶ 85% of adults with Down Syndrome diagnosed with Alzheimer's disease
 - ❑ Usually tonic-clinic seizures most common (Grand Mal) but others may occur

Changes in Senses: Vision

- Overlapping age related changes with associated changes in vision in the older adult with Down syndrome (DS)
 - ❑ Earlier occurrence in DS adult
 - ❑ Cataracts: clouding of vision
 - ❑ Keratoconus : degenerative disorder of the eye causing substantial distortion of vision with multiple images, streaking and sensitivity to light

Changes in Senses: Hearing

- Overlapping age related changes with associated changes in hearing in the older adult with Down syndrome
 - ❑ Earlier occurrence in DS adult
 - ❑ Conductive hearing loss - ear tubes decrease in size
 - ❑ Excess cerumen - high build-up of wax in ear
 - ▶ Interferes with hearing and balance

Changes in Senses: Vision and Hearing Changes Overlapping

- Accumulative overlapping age related changes with the associated changes in vision and hearing may increase the risk for age associated diseases
 - May mimic or mask dementia or result in age associated diagnostic overshadowing

Changes in Senses: Body's Temperature Regulation

- Age related changes in body's temperature regulation may increase the risk for age associated diseases
 - Age associated hyperthermia increases risk for seizures
 - Communication issues in ID/DD adults may exacerbate age associated hyper – hypothermia
 - ▶ Mimicking dementia

Changes in Senses: Thirst

- Age related changes in thirst may increase the risk of age associated diseases
 - ❑ Increase risk of age associated dehydration
 - ▶ Mimicking acute dementia
 - ❑ Reduced communication may mask dehydration

Changes in Senses: Taste and Smell

- Age related changes in taste and smell may increase the risk of age associated diseases
 - ❑ Reduced communication may compound the problem in adults with Down syndrome
 - ❑ Possible age associated appetite decline increases risk for age associated nutrition problems – including mimicking acute dementia

Changes in Senses: Pain Problems with Communication Issues

- Reduced verbal communication in adults with Down syndrome may mimic or mask disease(s) or discomfort - resulting in behavior changes
- Caution must be exerted before medications are to be prescribed to alleviate the symptom of pain without finding the cause
- Caution must be exerted before medications are to be prescribed for symptoms of a supposed problem, unless the problem has been verified

Changes in Senses: Summary

- Effects of the overlapping age related and associated risk changes for loss of senses
 - ❑ Possible increase in age associated falls
 - ❑ Behavior or personality changes
 - ❑ Isolation - reduced socialization
 - ❑ Acute dementia (especially in DS adults)
 - ❑ Depression
 - ❑ Inappropriate social response

Changes in Skin

- Age related changes that may increase the risk for serious skin problems
 - Dermatomycosis
 - ▶ Fungal infections
 - ▶ Psoriasis
 - ▶ Skin rash
 - ▶ Eczema
 - ▶ Erysipelas (bright-red, butterfly-shaped rash appearing across the bridge of the nose and the cheeks)
 - Decubitus – Bed sores in older Cerebral palsy adults
- The cause for age associated skin problems may be related to environment (dry) and/or the onset of

Changes in Muscles

- Overlapping age related, age associated changes with ID/DD disabilities increases the risk of serious loss of muscle tone
- Age associated loss of muscle tone in the older adult with Cerebral palsy (CP)
 - ❑ Progressive weakness with aging
 - ❑ Weak upper body
 - ❑ Increased falls (possible broken bones)
 - ❑ Reduced activities due to increase fatigue

Changes in Bone

- Age associated loss of bone increases the risk for:
 - ❑ Osteoporosis
 - ▶ High risk in older adults with CP and DS
 - ❑ Increased risk of broken bones from falls
 - ❑ Increased risk of dental problems (gum diseases / abscess tooth)
 - ❑ Increased lower back pain

Changes in Joints

- Overlapping age related with age associated changes in joints increases the risk for age associated problems
 - ❑ Limited communications may result in pain not being recognized but expressed as behavior changes
 - ❑ High risk in older adults with Cerebral palsy
 - ▶ Osteoarthritis
 - ▶ Spondylosis (degenerative osteoarthritis of the joints in the spine)
 - ▶ Increase in contractures (locked joints)
 - ▶ Kyphosis of the Spine (risk for severe pain and discomfort, breathing and digestion difficulties)

Changes in Joints (cont'd)

- Arthritis: Cross Culture
 - ❑ African-American females and Native American males and females have a higher incidence of Rheumatoid arthritis than whites.
 - ❑ Females, in general, have a higher incidents of Rheumatoid arthritis than males.

Changes in Cardiovascular System

- Little change - blood pressure remains in normal range
 - ❑ Blood pressure is lower in DS adults than the general population
- DS adults may be at more risk
 - ❑ Some arteriosclerosis (smoking and alcohol increases arteriosclerosis) - higher in males
 - ❑ Atherosclerosis - poor diet
 - ❑ Possible mitral valve prolapse (valve leakage)

Changes in Digestive System

- Mouth
 - Age associated conditions may reduce appetite or cause unrecognized pain
 - Poor dental conditions from tooth decay and gum infection
 - ▶ High risk in older Cerebral palsy adults and profound/severe ID/DD individuals
 - Dry mouth from medications
 - ▶ Difficult in swallowing - swallow food with water
- Esophagus
 - High risk in CP adults
 - ▶ Increased difficulty in swallowing
 - ▶ Increased risk for aspiration pneumonia (food particles inhaled)

Changes in Digestive System (cont'd)

- Gastroesophageal Reflux Disorder (GERD) or heart burn
 - ❑ Older adults with Down syndrome at higher risk
 - ❑ May not communicate pain from heart burn
- Curling
 - ❑ Reduced esophagus muscle tone results in food lodged in esophagus causing reverse movement into throat and possible choking or aspiration pneumonia
 - ❑ Increase risk for older adults with Cerebral palsy

Changes in Digestive System (cont'd)

- Intestines
 - Increase risk in DS adults (pain unreported)
 - ▶ Chronic constipation – no bowel movement more than three days
 - ▶ Increase in fecal incontinence
 - ▶ Weakening of anal muscles - possible staining of undergarments
 - ▶ Celiac disease (gluten intolerance): excessive diarrhea, nausea, abdominal distension, or unexplained lethargy

Changes in Nutrition

- Age associated effects of poor nutrition
 - ❑ Anemic- decrease iron absorption
 - ❑ Chronic constipation - no bowel movement more than three days
 - ❑ Increased weight (obesity) – high caloric intake
 - ❑ Acute dementia – anemia (low RBC count)
 - ❑ Increase risk for osteoporosis – reduced calcium and Vitamin D
 - ❑ Dehydration- acute dementia, increase ADR to medications

Changes in Nutrition: Obesity

- Obesity in older adults with Down syndrome
 - ❑ 70.58% of males and 95.83% of females with Down syndrome are obese
 - ❑ 49.29% males and 62.96% females from other ID/DD subjects are obese
 - ❑ Only 40% of males and 32% females from general population are obese
- Health problems associated with obesity
 - ❑ Increased blood pressure
 - ❑ Possible increase risk of diabetes two
 - ❑ Increased risk of heart problems
 - ❑ Possible increased risk for Alzheimer's disease

Changes in Sleep

- Older DS adults at high risk for obstructive sleep apnea - disorder leads to poor quality, non-restorative sleep
 - ❑ Signs: snoring, gasping noises, daytime sleepiness, morning fatigue (difficulty getting out of bed), excessive napping and fragmented sleep
 - ❑ Untreated: leads to irritability, poor concentration, behavior changes and impaired attention
 - ❑ Health problems: strain on the heart and lungs and high blood pressure

Changes in Sleep (cont'd)

- Causes of Disturbed Sleep Patterns in general ID/DD populations
 - ❑ Noise
 - ❑ Worry or anxiety
 - ❑ Pain/illness
 - ❑ Medication(s)
 - ❑ Dementia
 - ❑ Fear of incontinence
 - ❑ Uncomfortable bed
 - ❑ Change - address, room, location of bed or roommate

Changes in Hormones

- Hypothyroidism - reduced thyroid function
 - Older DS adults are at risk for an age associated decline in thyroid function
 - ▶ Possible short term memory loss
 - ▶ Fatigue
 - ▶ Sleep disturbance (too much or not enough)
 - ▶ Feeling cold, reduced body temperature
 - ▶ Unresponsive
 - ▶ Symptoms of acute dementia (possible misdiagnosis as Alzheimer's disease)
- Diabetes 1 and 2
 - DS children are at risk for Diabetes 1, but as they age there is an increased risk in comorbidity with Diabetes 2

Changes in Respiration

- Cerebral Palsy Adults
 - ❑ Increased difficulty in breathing (dyspnea) and muscle control making speaking more difficult.
 - ❑ Increased vulnerability to pneumonia
 - ❑ Increased upper respiratory infections
- Down Syndrome Adults
 - ❑ Many of the respiratory disabilities in Down syndrome children overlay the age related changes in older Down syndrome adults resulting in late onset age associated respiratory problems (breathing)

Changes in Excretory System

- Incontinence – Age related changes to increase age associated vulnerability to age associated incontinence
 - ❑ Reduced bladder size
 - ❑ Reduced strength of contraction
 - ❑ Reduced muscle tone
 - ❑ Increased frequency of infection
 - ❑ Possible reduced control

Changes in Excretory System (cont'd)

- Causes of age associated incontinence
 - ❑ Depression
 - ❑ Acute dementia
 - ❑ Chronic dementia
 - ❑ Medication(s)
 - ❑ Disease/dysfunction
 - ❑ Attention

Changes in Male Reproductive System

- Prostate Cancer
 - Age associated problems with similar prevalence as in the general population (symptoms include difficulty in urination, reduced flow of urine, reduced force of urine flow)
 - ▶ Male ID/DD adults may not report reduced ability to urinate due to lack of communication skills
- Enlarged non-cancerous prostate
 - Benign Prostate Hyperplasia (BPH)
 - ▶ Age related change with similar symptoms as prostate cancer
 - ▶ Male ID/DD adults may not report reduced ability to urinate due to lack of communication skills



SECTION 6: OUTCOMES FOR STAFF

Outcomes for Staff

- To understand that age associated changes increase the risk for age associated diseases or dysfunction
- To understand that the overlapping of an individuals disabilities with the age related and age associated changes in the mild to moderate ID/DD population may increase possible ACSC increasing the risk of hospitalization or readmission.

Outcomes for Staff (cont'd)

- To understand that this overlay may be further modified by lifestyle, social / culture / economic, or medications that either causes, mimics, masks, or exacerbates diseases or disorders leading to an increase in ACSC
- To understand that the ID/DD adult may not be able to verbally express changes due to communication problems and thus may be expressed as frustration through behavior change.

Outcomes for Staff: Summary

- Staff must be aware that age associated changes occurring in the ID/DD adult may increase vulnerability to disorders or diseases, increasing the risk for ACSC

Strategies to reduce ACSU and hospitalization



SECTION 7: REVIEW OF STRATEGIES

Review of Strategies

- To better coordinate the continuum of care as ID/DD adults enter and move through the health care system from community to hospital, to residential care facilities, back to community and possible re-admission
- Reduce ACSC by train formal and informal caregivers on identifying and intervene in the underlying age associated changes increasing the risk of ACSC
- Enabling the primary care provider or the adult with ID/DD to have a better understanding of the aging process, allowing them to better communicate with the health care professional the aging changes they are experiencing.

Review of Strategies (cont'd)

- Provide training to the residential care facilities and/or hospital staff on the needs of the older ID/DD adult that includes inclusion in:
 - ▶ Admission
 - ▶ Stay
 - ▶ Discharge process
- Increasing advocate's role in providing documentation of health care concerns to the professional health care practitioners in reducing misdiagnosis or inappropriate services