WEBINAR SERIES:
AGING IN INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES
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 1: Biological Aging and Health Care Disparities in the Intellectual / Developmental Disabilities (ID/DD) Population

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Purpose of Session 1

- Understanding the basics of aging in all populations
- Becoming aware of the disparities (unequal treatment) in the ID/DD population that limits access to quality health care
- Learning what barriers are causing disparities
- Becoming aware of the interventions for reducing these barriers
- Becoming aware of what influences the aging process in the ID/DD population
- Learning what the age related changes are and how they overlap with the ID/DD disabilities
- Understanding the role of the ID/DD network in reducing the high risk for hospitalization
Outline for Session 1

- Aspects of aging
- Determination of disparities in health care of the ID/DD population
- Barriers causing ID/DD disparities in health care
- What is aging in the ID/DD population
- Staff outcomes
- Possible strategies to overcoming barriers in health care disparities
SECTION 1: ASPECTS OF AGING
Aspects of Aging

- Inevitable – cannot stop aging
- Irreversible – cannot reverse aging; it is a progressive process
- Variable – rate of aging based on individual
- Linear – a continuous process decline
- Plasticity (compensatory) - the body has the ability to compensate for loss
Aspects of Aging (cont’d)

- Life long process from conception to death
- Two aspects of aging
  - Increase in vitality - birth to 30 years old
  - Decrease in vitality - 30 to death
- Senescence
  - Last developmental stage of life when a person increases susceptibility to fragility (illness, infirmity, or loss of independence) resulting in increase vulnerability to death.
  - Everyone will reach senescence but not everyone will become frail.
  - Frailty depends on the three determinates of aging: successful aging, usual or pathological aging
Three Determinants of Aging

- Genetics
  - Positive
  - Neutral-to-Negative
  - Negative genes

- Lifestyle

- Environment
Descriptors of Aging

- Successful Aging
- Usual Aging
- Pathological Aging
Successful Aging

- Little physical or mental functional decline from birth to about 70 years of age
  - Positive genes
  - Positive lifestyle
    - Good diet
    - Physical exercise
    - Mental exercise
    - Positive attitude
Usual Aging

- Physical or mental functional decline from the interaction of neutral or negative genes and poor lifestyle from birth to about age 70 causing a loss of some independence
  - Neutral to negative genes
  - Poor lifestyle
    - Poor diet
    - Little physical exercise
    - Little mental exercise
    - Neutral to negative attitude
Pathological Aging

- Serious functional limitations from the interaction of either genetically inherited or developmental traits with poor lifestyle causing a substantial reduction in daily activities
  - Negative genes
  - Negative lifestyle
    - Poor diet
    - No physical exercise
Terms to Describe Aging Changes

- Age Related Changes
- Age Associated Changes
- Age Associated Diseases
Age Related Changes

- Changes that are part of the normal aging process and experienced by everyone
- Successful aging
  - Sensory changes
  - Smaller bladder
  - Some bone loss
  - Some cardiovascular changes
  - Some memory change
  - Slowing of reflexes
Age Associated Changes

- Changes that occur at a higher incidence in older individuals and are caused by neutral or negative genes and/or poor lifestyle, increasing vulnerability for loss of independence
- Usual aging - not experienced by everyone
  - 33% loss of muscle mass
  - Vision / hearing impairment
  - Some confusion
  - Arthritis
Age Associated Diseases

- Changes caused by negative genes and poor lifestyle leading to diseases that reduce independence resulting in possible dependent care

- Pathological aging
  - Heart disease
  - Osteoporosis
  - Severe hearing/vision impairment
Summary

- **Successful Agers**—high level of age related changes
- **Usual Agers**—mixed levels of age related and age associated changes
- **Diseased Agers** - high levels of age associated changes
SECTION 2: DETERMINANTS OF DISPARITIES TO HEALTH CARE IN THE ID/DD POPULATION
Determinants of Disparities

- Difference in morbidity between individuals with ID/DD and the general population is the compounding effect of disparities, each adding to the other

- Three major disparities are:
  - Access to timely health care intervention (caregiver, health care professionals, hospital), i.e. – early recognition of healthcare issue
  - Access to appropriate health care intervention(s), i.e. – appropriate diagnosis or assessment of healthcare issue
  - Access to effective health care, i.e. access to appropriate health care services
Determinants of Disparities (cont’d)

- ID/DD populations are at greater risk for health concerns than the general population due to the cascading compounding of the three major disparities that result in:
  - Unrecognized complex health conditions due to the overlapping of their ID/DD associated disabilities with the age related and associated changes
  - Inadequate attention to care needs by caregivers
  - Inadequate focus on health promotion
  - Inadequate access to health care services
  - Frequent changes in providers resulting in inattention to health care status
Determinants of Disparities (cont’d)

- Interventions must address multiple levels: the persons with ID, the providers who support them, and the policies that will direct systemic changes.
- Cascading compounding of disparities increases health risks in individuals with ID/DD by being overrepresented in hospital admissions than the general population.
  - Five to six times greater.
To reduce the compounding cascade of disparities, systemic changes for sustained improvement must be addressed at multiple levels by incorporating four principles:

- Increase awareness of the barriers causing health disparities;
- Increase knowledge of the interactions of aging changes in persons with disabilities;
- Increase assessment skills to determine needs;
- Increase understanding of the types of interventions needed.
SECTION 3: OVERARCHING BARRIERS TO HEALTH CARE CAUSING DISPARITIES PLACING THE ID/DD POPULATION AT RISK
Overarching Barriers to Health Care

1. **Communication:** Limited verbal and non-verbal skills to express health care concerns or changes being experienced could deny participation in health care resulting in wrong diagnosis or inappropriate intervention.

2. **Caregiver involvement:** Lack of inclusion of the primary care provider by the health care professionals may result in wrong diagnosis or inappropriate intervention.

3. **Training:** Limited training, experience and comfort level of professional health care providers, especially in hospital admission or discharge, could result in suboptimal care.
SECTION 4:
AGING IN THE ID/DD POPULATION
Aging in the ID/DD Population

- Age related biological changes in individuals with mild to moderate ID/DD:
  - Same aging change
  - Same rate of aging change
  - Does not cause diseases or dysfunction
  - Generally, similar longevity as the general population *

- Pre-existing disabilities conditions that overlay aging changes, and influences of lifestyle, social / culture / economic, or medications may result in “diagnostic overshadowing”
  - Mimicking, masking, exacerbating symptoms of diseases/disorders

* exceptions are adults with Down Syndrome and Cerebral Palsy who experience early changes
Aging in the ID/DD Population (cont’d)

- Likelihood of “diagnostic overshadowing” may result in:
  - Changes related to the disability result in inappropriate or no interventions
  - Pre-existing cognitive challenges assumed to be symptoms of dementia
  - Pre-existing disability may be misdiagnosed as disease
Myths of Aging

- All individuals with ID/DD experience pre-mature aging
  - Only DS and CP experience early aging changes
- All Down Syndrome adults will have Alzheimer’s
  - Only 60% by age 60
- Majority of adult ID/DD individuals live in residential care facilities
  - Most live with parents
Interaction of Pre-existing Disability with Age Related Changes

- Increased risk factors with earlier onset of symptoms
- Increased risk for inappropriate medical treatment
- Increased vulnerability to a more restrictive environment
Interaction of Pre-existing Disability with Age Related Changes (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
Developmental Disabilities
Age Related Changes

Developmental Disabilities

Age Related Changes
Medications

Developmental Disabilities

Aging Changes

Medications
Developmental Disabilities

Age-Associated Changes

Aging Changes

Medications
Aging

Developmental Disabilities

Age associated changes

Aging

Aging Changes

Medications
Interaction of 4 Influences that Affect Aging

Genetics

Social/economic/Culture

Gender

Communication

Interaction of Four Influences that Affect Aging
AGING CURVES
General Aging Population

- **Maximum vitality**
- **Minimum vitality**
- **Vitality (increasing new cells)**

**% vitality**

- **Birth**
- **30**
- **Senescence**

**Conception**

**Death**
Aging General ID/DD Curve

Maximum vitality

General aging curve

% vitality

minimum vitality

100

vitality

Aging ID/DD curve

30

age

dead

death

conception

birth

senescence
DS and CP Aging Curve

% vitality

minimum vitality

conception

birth

age

senescence

0

30

100

↑ vitality

↓ vitality

Maximum vitality

General aging curve

Aging ID/DD curve

Down Syndrome/CP

death
Health Disparities

Persons with ID/DD experience poorer health because of health care disparities, not as a direct consequence of overlapping aging changes and disability.

Citation: Gloria L. Krahn, Laura Hammond, and Anne Turner 2006. A CASCADE OF DISPARITIES: HEALTH AND HEALTH CARE ACCESS FOR PEOPLE WITH INTELLECTUAL DISABILITIES. Mental Retardation and Developmental Disabilities Research Reviews. 12: 70–82
Individuals with mild to moderate developmental disabilities experience the same:

- Aging changes
- Rate of change
- Longevity as the general population
  
  Exceptions are individuals with Down Syndrome and Cerebral Palsy.
Aging Differences in Gender and Culturally Diverse Individuals

- Basic aging process affects both males and females, but because of their genetic differences and influences during development, there are differences in aging expression.

- Differences among male racial groups (whites non-Hispanic, white Hispanic and African-Americans) which are influenced by culture, genetics, and social-economic factors.
SECTION 5: OUTCOMES FOR STAFF
Outcomes for Staff

- To understand that age related biological changes do not cause diseases or dysfunction
- To understand that individuals with mild to moderate developmental disabilities experience the same:
  - Aging changes
  - Rate of change
  - Longevity as the general population
    - Exceptions are early aging related changes in adults with Down Syndrome and Cerebral Palsy
- To understand that the overlay of disabilities with changes due to aging, lifestyle, social / culture / economic, or medications may modify the aging process, either mimicking or masking diseases or disorders
Outcomes for Staff (cont’d)

- To understand that the developmentally disabled older adult may not be able to verbally express these changes because of communication problems and may thus express frustration through behavior.
- To understand that the ID/DD populations are at greater risk for health concerns due to the cascading compounding of the three major disparities and the barriers, then the overlapping of the disabilities and age related and associated changes.
Outcomes for Staff (cont’d)

- Staff must be aware of the signs of normal aging changes occurring in the ID/D adult.
- Aging changes are normal and do not cause disorder or diseases, but increases a person’s vulnerability to decline in cognitive and physical functioning.
- ID/D population the underlying disabilities interact with the normal aging changes, increasing vulnerability to a potentially greater loss of cognitive or physical function over time, if interventions are not applied.
SECTION 6: DEVELOP STRATEGIES TO OVERCOME BARRIERS IN HEALTH CARE DISPARITIES
Develop Strategies to Overcome Barriers in Health Care Disparities

- Training programs must be developed enabling the primary care provider or the older ID/DD adult to have a better understanding of the aging process, allowing them to better communicate with the health care practitioners on aging changes they are experiencing, thus avoiding the risk for the mimicking, masking or exacerbating serious health care problems – early intervention

- Develop a better coordinated system for an effective continuum of care for the older ID/DD adult while moving through the health care system from: community to hospital, to residential care facilities, and back to community in reducing possible re-admission – access to healthcare
Develop Strategies to Overcome Barriers in Health Care Disparities (cont’d)

- Cooperative agreements in the continuum of care system must be developed in providing training to the residential care facilities and/or hospital staff on the needs of the older ID/DD adult that includes: admission process, stay, and discharge process – **effective services**

- Develop an advocacy program that includes proper documentation of the health concerns that are provided to the professional health care practitioners, reducing possible misdiagnosis or delivery of inappropriate services in the continuum of care process - **timely intervention**
IN SUMMARY
In Summary

Barriers causing disparities
- Limited communication
- Limited caregiver involvement
- Limited training

Disparities increases health risk
- Timely access to health care
- Appropriate intervention services
- Access to effective health care

Principles for reducing disparities
- Increasing awareness of barriers
- Increasing knowledge of aging
- Increasing assessment skills
- Increasing understanding of interventions