

Welcome to today's panel!

- **First time using Webex?**

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- You can type questions about the material presented in the **Q&A** section.

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Planning for Growing Older and Adults with ID

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Training Objectives

- Participants will be able to discuss characteristics and information on aging, and intellectual/developmental disabilities (IDD).
- Participants will be able to discuss the importance of health care advocacy for adults with IDD including screening, working with the health care providers, systems challenges, daily health advocacy, and support.
- Participants will be able to discuss and implement practices of quality caregiving and supports for older adults with IDD including health care advocacy.



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What is Aging?

- Active process that occurs over an individual's lifespan
 - Generally considered progressive changes in the physiology of the body and mental processes - begins with birth and continues until death
 - Interaction of factors of aging with pre-existing conditions
 - Genetics
 - Lifestyle - Diet, exercise, smoking, support networks including family and friends
 - Environment - social and physical
 - Attitude
 - Unique to each individual within patterns of aging
- Gains and losses



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Why a Lifespan Approach?

- We become more of who we are as we age.
- All of our diseases, experiences, pre-existing conditions come together to make a difference in aging.
- Regardless of the pre-existing conditions, people with disabilities can age successfully.
- Risk factors in aging can be minimized through preventive activities across the lifespan.



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Aging Across the Lifespan

- Similar patterns for all adults regardless of pre-existing disability.
 - Each adult ages uniquely within patterns of aging.
 - Personalities do not change, each adult becomes more of who she or he has been absent disease process.

Aging Across the Lifespan (cont'd)

- Factors of genetics, lifestyle, environment, and attitude influence health and well-being old age.
 - Risk factors for age related and associated diseases and conditions based on combination of factors across the lifespan.
- All adults need proper nutrition, hydration, and exercise across the lifespan.
 - As adults age there is a continued need for exercise and attention to stamina - generally involving periods of low activity interspersed with periods of high activity.



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Mental Function and Aging

- IQ does not decline significantly
- No significant loss of memory
- Speed of recall may decrease
- Some interference with short term memory possible
- General cognitive function may be slowed somewhat???



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Personalities, Behavior, and Aging

- We become more ourselves as we age
- The older we are the more unique we are as a combination of factors of aging and our life experiences
- Personalities and behavior (how we exhibit our personalities) do not change substantially over a lifetime.
- Significant changes in personality and/or behavior usually indicate disease, side effects of medications, poor environmental fit, or mental health concerns.



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Aging and Intellectual & Developmental Disabilities

What You Need to Know

What is Intellectual Disability (ID)?

Characterized by

- Below normative intellectual functioning, due to cognitive impairment (organic or functional) present since birth or infancy
- Not a mental illness or psychiatric impairment
- Varies in degree and co-impairment
- Compensated by training, education, remediation, habilitation, supports for life activities

Down syndrome, an ID, is a chromosomal abnormality present at birth (#21) associated with ID - Occurs in 10-12% of the adult ID population 40+

Each individual, regardless of their pre-existing conditions, has the potential to age successfully compared to who the person has been throughout a lifetime.



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Aging and Intellectual / Developmental Disability (IDD)

- There are many conditions that may originate prior to birth, in early infancy or childhood, or before brain maturation (usually in the late teens).
- Some impair senses, cognition, mobility, or severely compromise health and function.
- An intellectual disability impairs cognitive and personal function over a lifetime.
- A development disability (which may include an intellectual disability) impairs normal growth and development over a lifetime.
- Developmental Disability is the umbrella term which includes Intellectual Disability.



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Challenges to Healthy Aging in Adults with IDD

- Lack of knowledge of medical history
 - Staff turnover
 - Family not available for information, historical documentation not kept or lost,
 - Health care provider turn over
- Lack of systems for advocacy in agencies and families
 - Information provided for the appointment



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Health Care Disparities & IDD

- Lack of knowledge & research about aging in adults with IDD
- Lack of training & expertise for health care providers on IDD, even less known about aging
- Aging for everyone still one of the stereotypes and prejudice allowed to be voiced (watch late night talk shows for example)
- In a society in which material wealth is highly valued especially for quality of life in later years adults with IDD more likely to be in poverty, existing on minimal income, and less family supports



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Myths and Stereotypes about Aging and IDD

- Lifetime accumulation of assumptions of lack of competency with double jeopardy
- Higher risk for mental illness which also increases the myths about aging with IDD
- Automatic assumption of dementia as normal aging for adults with IDD
- Assumption when functioning and cognitive decline occurs it is normal aging and not disease process



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Down Syndrome & Aging

Higher Risk but no Automatic Decline and
Disease Process in Adults with Down
Syndrome!!!

What is Down Syndrome?

- One of the developmental disabilities, usually associated with Intellectual Disability (ID)
- 1 in 750 live births, genetic, older parent correlation
- Trisomy 21 (Chromosomal defect)
 - All cells of the body (95%)
 - Some of the chromosomes in all cells (2 - 3%)
 - All chromosomes in some cells of body, mosaicism, (2 - 3%)



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Down Syndrome & Aging

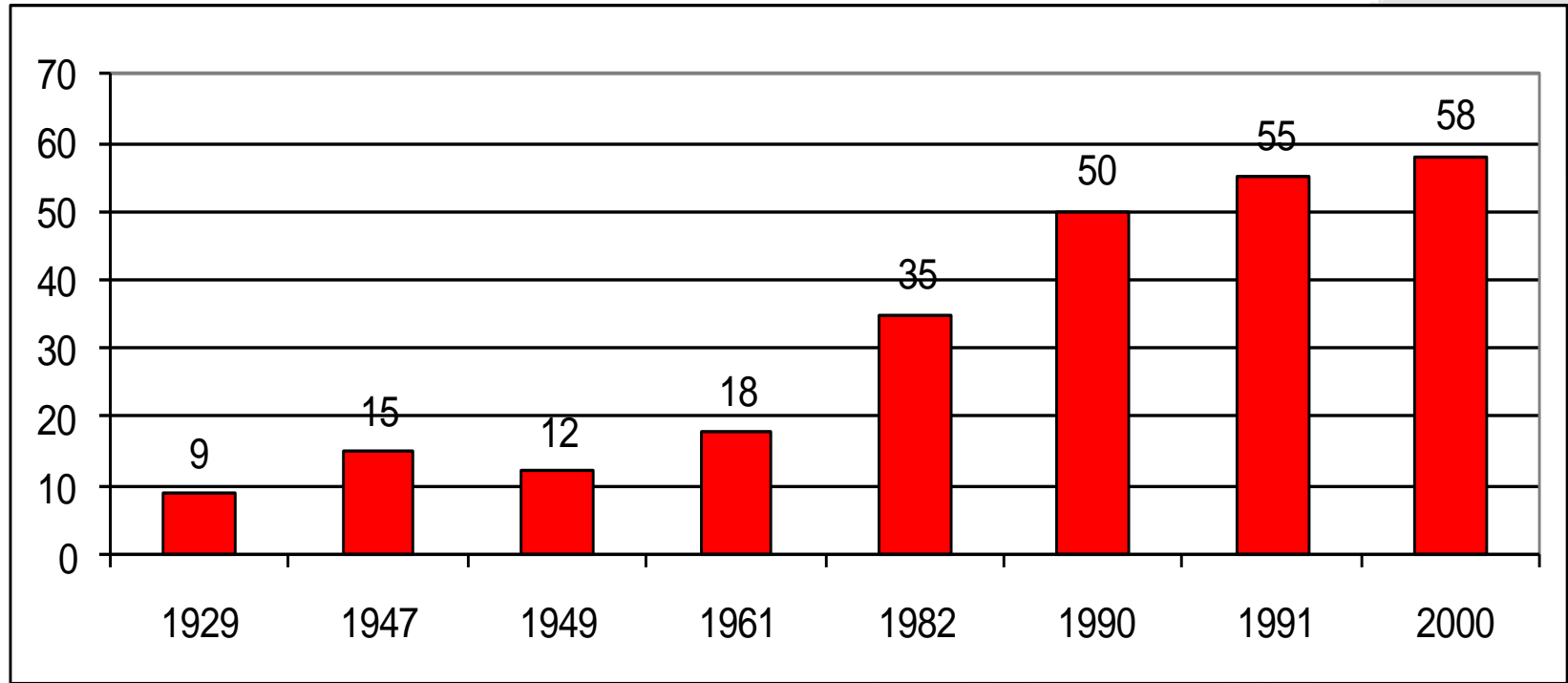
- Longevity is shorter than the general population
- Earlier aging into risks for diseases and conditions
 - Hearing & vision loss
 - Congenital heart disease
 - Adverse Effects of medications
- Early changes may result in:
 - Behavioral changes including intensity of behaviors as compared to their previous behaviors
 - Loss in function or cognitive capacity
 - Assumption of Alzheimer's dementia



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Down Syndrome & Life Expectancy



Known Risk Factors for Adults with Down Syndrome

Down Syndrome

- Congenital heart disease
- Earlier onset for risk factors than the general population
- Aging into adverse side effects of medications
- Hearing impairment at birth, increased with age
- Adult onset leukemia
- Secondary condition of autism, autistic tendencies



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Disability Specific Risks to Rule Out

- **Down Syndrome** (risks about 20 - 25 years earlier than general population):
 - Hearing & Visual impairment
 - Vitamin B12 deficiency
 - Dehydration
 - Side Effects of Medications
 - Depression
 - Stroke
 - Seizures



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Cerebral Palsy and Aging

Cerebral Palsy (CP)

- Eating and swallowing disorder affecting nutritional intake
- Scoliosis
- Tuberous sclerosis
- Adverse Effects of Medications
- Arthritis/Osteoporosis
- Significant pain over the lifetime
- Respiratory



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Specific Developmental Disabilities & Aging

Each of us aging uniquely within patterns of aging.

Pre-existing conditions influence specific risk factors in each individual.

Always compare to who the person has been throughout a lifetime!

Potential Risk Factors for Persons with Autism

- **Genetics**- Possible pre-dispositions for disease/neurological impairments.
- **Lifestyle**- Difficulty with adjusting to change and loss of routine. Difficulty with developing social networks necessary for healthy aging.
- **Attitude**- Inability to deal with life stressors including sensory overload and demands.
- **Environment**- Inability to adjust to variety and environmental changes sometimes necessary in aging.



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Adult Outcomes

- Few studies specifically examine outcomes for ASD
 - Decreased probability of completing college
 - High unemployment
 - High underemployment
 - Poor employment stability
 - Poor wages
 - Inability to live independently and make personal life choices
 - Less peer social involvement
 - Greater risk of secondary psychological problems
- Outcome believed to be better for individuals with PDD-NOS & Asperger's, but few comparative studies conducted to date.



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Health Care Advocacy & You

You can make a positive difference
through health care advocacy

Health Care Advocacy: Why is it Needed?

- Ageism by health care providers
- Assumption of automatic loss and decline as part of aging untrue but commonly believed
- Assumption of dementia, especially in persons with Down syndrome
- Importance of giving voice

Diagnostic Overshadowing

Definition: Blaming loss, decline, and changes on the pre-existing diagnosis

- **Example** - Decline assumed to be a result of intellectual disability rather than disease process
- **Example** - Reported chest pain ignored because of the pre-existing diagnosis of ID
- Assumption of lack of cognitive capacity due to diagnosis of ID in combination with aging
- Lack of experience or verbal capacity for the adult with ID to report symptoms



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Other Pre-existing Conditions

- All pre-existing conditions interact with the aging process and the factors of aging.
- Recommendations-
 - Know each individual
 - Develop lifespan activities that prevent disease and changes that affect quality of life in old age
 - Advocate to make sure the pre-existing conditions do not influence health care providers to ignore symptoms of disease or assume dementia



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Factors of Aging

- **Genetics**- What pre-existing conditions and predispositions for diseases are genetically programmed for persons with Autism Spectrum Disorders?
- **Lifestyle**- How does the pre-existing disability affect lifestyles and opportunities?
- **Environment**- Does the pre-existing disability limit or shape the environmental choices?
- **Attitude**- How does the pre-existing disability affect attitude about aging and life? What adaptive behavior has been developed to deal with life stressors?



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4 Steps of Health Care Advocacy

#1. Observe

- Recognize that the functional and behavioral changes you observe are a form of communication.
- Screening as a tool for observation (EDSD)



- Behavioral
- Personality
- Activity level
- Unintended weight loss or gain (10%)
- Changes in wake/sleep patterns
- Diarrhea/constipation

4 Steps of Health Care Advocacy

#2. Report

- Document your observations
- Be accurate and specific
- To the right person
- Use correct forms and processes



Important components of reporting:

- Time of the day, who is present, where did it happen?
- How often do you observe this symptom?
- What was happening before? After?
- Making sure there is a system/process for reporting to the right person!

4 Steps of Health Care Advocacy

(Continued)

#3. Prepare for the health care appointment

- Hold a team meeting.
(residential/family/program/individual advocates)
- Meet with caregivers to bring together symptoms observed.
- Prioritize symptoms and concerns to be addressed.
- Checklist or form for the attending caregiver to bring to the appointment
- Gather all pertinent information in an organized format so that the information can be provided in a brief and concise manner.
- Make sure the person who goes with the individual is:
 - Included in the meeting
 - Able to communicate symptoms
 - Has some health care advocacy skills



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NTG Education & Training Curriculum on
Dementia and ID.

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4 Steps of Health Care Advocacy

(Continued)

#4. Follow-up after the appointment

- Follow-up recommendations with all caregivers
 - Make sure recommendations are understood.
 - Are there any follow-up the questions?
 - Continue observing and reporting.
 - Don't give up!
 - You may have to search out a new provider
 - Be as prepared for the follow-up as for the first appointment



Checklist for Ruling Out Causes for Decline in Older Adults with IDD

Differential Diagnosis

Sensory Processing and Differential Diagnosis

Rule out sensory impairments and challenges.

Seven senses: Responsible for our interaction with the external world.

1. Auditory (hearing)
2. Visual (sight)
3. Olfactory (smell)
4. Gustatory (taste)
5. Tactile (touch)
6. Proprioceptor (position) - the sensory feedback that informs us where the parts of our body are and how they are moving. Integrates input from the 5 senses.
7. Vestibular (balance) - related to and dependent on the proprioceptive system. The vestibular system is what gives us balance, allows us to stand and move through space without falling over.



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Behavioral Challenges

Some symptoms may present as behavioral problems rather than as health problems:

- Reduced sensory perception:
 - Hearing - refuse to participate in activities, inappropriate response to questions, confusion in noisy situations
 - Vision - unable to recognize familiar people, disorientation
- Menopause - memory impairment



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Behavioral Challenges (Cont'd)

Some symptoms may present as behavioral problems rather than as health problems:

- Multiple medications - confusion
- Delirium - sudden behavioral change which may fluctuate as the day progresses.
- Depression - lethargy, change in appetite or sleep, unnecessary worry over trivial issues.



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Tips for Health Care Advocacy in Your Agency

You are the expert!

Tips for Health Care Advocacy

- Be aware of myths and stereotypes about aging in persons with IDD
- Know the possible side effects and interactions for medications used by the individual
- Never assume it is the result of aging!
- Be persistent
- Develop systems of communication between residential, day program, and family or others in the adults life

Remember:

Successful Aging involves...

- Connecting all the factors of aging across the lifespan
- Building up reserves in body systems and factors such as a social support network
- Minimizing the effects of the pre-existing disability and the age-associated disability over the lifespan.
- Understanding potential risk factors and addressing them in childhood, young adulthood, before old age.



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Recommended Systems Changes

- Discuss possible risk factors before they occur
 - Document this discussion,
 - Develop a formal process
- Develop aging committees, long range planning for future needs
- The system needs changing for individuals to age in place!



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Lifespan Prevention

- Develop activities for healthy movement and weight bearing early in life
- Mentor good practices such as hydration, moderate diet, and exercise (You are the role model)
- Make the exercises fun and part of everyday life
- What you do will influence others around you.

Summary

- You can make a difference for you and others as each ages by understanding aging and developing prevention activities across the lifespan.
- Successful aging is possible for every person.
- Enjoy aging yourself and serve as a role model to others.
- Through health care advocacy and healthy practices across the lifespan
- **You can make a difference!**

Thank you!

- <https://aadmd.org/ntg/schedule>
- Queens, NYC September 18, 19, & 20
- Rhode Island, October 18th, 19th, & 20th
- Tallahassee, FL. October 23rd, 24th, & 25th
- Canton, NY (St. Lawrence Arc) & NY Third Age, November 1, 2, & 3
- St. Louis, MO. December 4, 5, & 6

Questions?

Please type your question into the chat box on the right hand side of the screen.



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