

Part I: Aging, Dementia, and IDD What do you need to know as a caregiver?

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National Task Group
on Intellectual Disabilities
and Dementia Practices

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▶ Aging, Dementia and IDD: What does it mean for you as the caregiver?

A. Understanding Aging, IDD, and Dementia, Dr. Kathleen M. Bishop (40 minutes)

B. Understanding Dementia and IDD, Kathryn Pears, MMPM (40 minutes)

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Agenda



Understanding Aging and IDD

Aging is aging is aging!

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Developmental/ Intellectual Disability

Developmental Disability

Umbrella Term: Can be cognitive or physical or both.

Severe & chronic. Disability occurs prior to birthdate of age 19 or 22 (depending on the state).

May or may not have low IQ.

Some developmental disabilities are largely physical.

- ▶ Example - cerebral palsy or epilepsy.

Can include a physical and intellectual disability.

- ▶ Example - Down syndrome or fetal alcohol syndrome.

Intellectual Disability

Disability related to cognitive (thought) processes.

Severe & chronic. Disability occurs prior to birthdate of age 19 or 22 (depending on the state).

Low IQ

The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation.

Developmental Disabilities (DD): An umbrella term that includes Intellectual Disabilities

- ▶ Level of intellectual ability below a measurable average standard as determined by American Association of Intellectual Disabilities (AAID)
- ▶ Caused in the developmental period of life by federal definition and most states by the birthdate of 22 and expected to last over the lifetime
- ▶ A lifetime expectation of needed supports due to severe disability affecting one or more areas of communication, learning, self-care, vocation, mobility, socialization and community participation, self-direction, capacity to live independently

Intellectual Disability (The most common type of Developmental Disability)

- ▶ Intellectual disability means significant limitations both in intellectual functioning and in adaptive behavior including
 - ▶ Conceptual (understanding concepts, expectations, and how to perform activities of daily living)
 - ▶ Social (interacting with others, able to give and ask for help, empathy and understanding, capacity to be with others)
 - ▶ and practical adaptive skills and shown during the developmental period (prior to birthdate of 22 by federal standards) that adversely affects life and function over the lifespan.
 - ▶ Diagnosis used for eligibility for services in the US

The slide features a white background with decorative geometric shapes in shades of pink and purple. On the left, a pink triangle points downwards. On the right, a purple rectangle is partially visible, and a pink triangle points upwards. A thin white line separates the pink and purple areas on the right side.

WHAT IS AGING IN ADULTS WITH IDD? IS IT DIFFERENT THAN AGING FOR YOU AND I?

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Aging does not ▶ equal disease!

We all age uniquely within patterns of aging with unique factors of aging and risk factors.

Universal Aging Process

- ▶ 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.
- ▶ Those who stay passionately engaged in life are more likely to age successfully



Aging and IDD

- ▶ We each age uniquely with individual risk factors based on genetics, lifestyle, physical and social environments, and attitude about aging
 - ▶ Myths and stereotypes of aging affect attitude and lifestyle
 - ▶ We typically become more of who we are as we age
 - ▶ The more we know about each person's history the more we can predict risk factors and provide preventive activities



Aging is aging is aging

All people age uniquely within patterns of aging

The combination of factors of aging means that each person's aging will be unique

We become more of who we are as we age

Any pre-existing condition, disease, or intellectual disability will interact with the aging process

All people have the potential for a good quality of life and health in old age, especially if they reduce risks through preventive activities

Aging and IDD

- ▶ Pre-existing conditions, diseases, and diagnosis affect aging. This includes:
 - ▶ Intellectual disabilities/developmental disabilities
 - ▶ Mental Illness and emotional trauma
 - ▶ Diseases and sickness over a lifespan including flu, pneumonia, heart disease, diabetes, arthritis



Aging and IDD

Interaction of the factors of aging and the pre-existing disability

- An accumulation across the lifespan
- By understanding this interaction we can predict risk for specific diseases and age-related conditions
- Understanding the specific IDD can help us develop preventive activities across the lifespan

The more severe the disability the increased likelihood for a shortened lifespan and reduced quality of life in relation to the general population

Lifespan Approach

Connecting all phases of life to the health and well-being of people with Developmental Disabilities.

What happens in childhood and young adulthood affects the quality of life in old age, including:

- Therapies
- Nutrition
- Weight-bearing exercise
- Exposure to sunlight
- Community involvement



Lifespan Approach to Aging

- ▶ Factors of aging:
 - ▶ Genetics/Heredity
 - ▶ Know familial risk factors and begin good choices early in life to minimize risks.
 - ▶ Lifestyle choices
 - ▶ Exercise especially weight bearing
 - ▶ Diet (moderation, moderation, moderation) weight management
 - ▶ Use it or lose it or overuse theory? (moderation)
 - ▶ Opportunities for learning
 - ▶ development of memory skills

Aging and IDD



Little research or knowledge available on aging in adults with IDD



Myths and stereotypes about adults with IDD combine with myths about older adults to create a double or triple disparity

May result in caregivers, health care providers, and adults with IDD assuming incompetence and loss in old age as inevitable thus missing clues for possible interventions

By taking this course you can help dispel these myths and stereotypes when you teach others

Challenges in healthy aging in adults with IDD

- ▶ Lack of knowledge about aging and IDD
 - ▶ No training and little research in medical schools or for clinicians
- ▶ Lack of knowledge family and personal medical history
 - ▶ History unknown especially if from other countries, English not the primary language
 - ▶ No baseline information
 - ▶ Family not available for historical information
 - ▶ Health care provider turnover
 - ▶ Staff turnover
- ▶ Lack of systems in organizations or advocacy supports on health care advocacy
 - ▶ Information not available for health care appointments and care

Aging and IDD

- ▶ We become more ourselves as we age with unique personalities and behaviors (within patterns of aging)
- ▶ Family and personal medical history gives us information to predict risk factors.
- ▶ An Intellectual/Developmental Disability (IDD) such as Down syndrome will increase specific risks
- ▶ For example if someone has a history of urinary tract infections increased fluids, plenty of rest interspersed with movement, and diet can help reduce affect on aging.

Common age-related Conditions

- ▶ Stroke
 - ▶ Side effects of medications ★
 - ▶ Nutritional deficits and imbalances
 - ▶ Alcohol and drug abuse
 - ▶ Hypothyroidism
 - ▶ Dehydration, malnutrition
 - ▶ Cardiovascular disease
 - ▶ Environmental challenges
 - ▶ Sensory impairments
- ▶ Depression
 - ▶ Lyme disease
 - ▶ Normal pressure hydrocephalus
 - ▶ Sleep apnea
 - ▶ Osteoporosis
 - ▶ Arthritis

★Anticholinergics

Developmental Disabilities, Aging, and Risk Factors

- ▶ Universal aging that may be impacted by the pre-existing diseases and conditions over a lifetime
 - ▶ Specific developmental disabilities affect risk factors including autism, down syndrome, and cerebral palsy
 - ▶ “Successful aging” is possible for adults with IDD as in the general population
- ▶ Always compare to who the person has been throughout a lifetime
 - ▶ Personalities do not change unless there are traumatic experiences, diseases, or mental health
 - ▶ We tend to become more of who we are, not less (a group of 8-year old's is more alike than a group of 80-year old's
 - ▶ The more you know each person the more you can find clues of today's problem

- ▶ One of the developmental disability usually associated with Intellectual Disability
- ▶ One in 750 births with higher risk for older parents and genetic predisposition
- ▶ Most people have 2 chromosome 21's in every cell of the body, people with Down syndrome have three chromosome 21's in all or most cells of the body.
- ▶ Common physical characteristics and risk factors because of the trisomy 21



What is Down syndrome?

Risks for Adults with Down syndrome

- ▶ Risks for shortened life expectancy compared to general population
- ▶ Earlier onset of age-related risk for diseases and conditions (about 20 to 25 years earlier)
 - ▶ Vision and hearing loss
 - ▶ Adverse side effects of medications
 - ▶ Pain from arthritis, osteoporosis
 - ▶ Heart disease
 - ▶ Respiratory
 - ▶ Alzheimer's disease

Risks for Adults with Down syndrome with earlier aging into risks (20 to 25 years earlier)

- ▶ Need to change how we think about older adults, especially with Down syndrome
- ▶ Early changes may result in behavioral changes or increased “inappropriate” actions
- ▶ Automatic and false assumption of Alzheimer’s disease or a related dementia (ADRD)
- ▶ Loss of function and ability which may have reversible solutions but are ignored because of assumptions of aging related loss normal
- ▶ Remember successful aging for each person is possible through advocacy and thinking positively about aging for each person

Dispelling Myths on Aging and Down syndrome

- ❑ Adults with Down syndrome do have a shorter lifespan, higher risk for Alzheimer's disease and Related Dementias (ARD), and an earlier aging into risk factors than the general population. However,:
 - ❑ The current research indicates that approximately 60% of people with DS will be diagnosed with AD by the age of 60. This is like the general population at the age of 85.
 - ❑ IT IS NOT 100% AND NOT INEVITABLE! NEVER ASSUME LOSS IS AUTOMATICALLY DUE TO ARD OR ANOTHER TYPE OF DEMENTIA.
 - ❑ Life expectancy for adults with DS continues to increase from about 9 years in the early 20th C to about 60 years today.
 - ❑ Dementia written in the health care chart is not a specific diagnosis but indicates significant cognitive and functioning loss from who the individual has been. (Remember to always compare to the individual him or herself and not to the general population).
 - ❑ Differential diagnosis is essential for everyone, especially for adults with DS.

Adults with Down syndrome and dementia

- ▶ Current longitudinal research indicates about 60% of people with DS are diagnosed with Alzheimer's disease (or the inaccurate and incomplete diagnosis of dementia) by age 65
- ▶ Earlier aging into risk factors of aging about 20 - 25 years earlier than the general population
 - ▶ Higher risk for misdiagnosis of AD as health care providers assume AD in any adult with DS
 - ▶ Less likely to have a complete differential diagnostic process unless knowledgeable caregivers
 - ▶ High risk other reversible conditions are not screened or treated



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This is why visual
information is so important?
What do you know about Kay
from this photo?
You are the expert and need
to work in partnership with
your health care providers.

REMEMBER OUR STRENGTHS AND GIFTS

KNOWLEDGE OF EACH PERSON OVER A LIFETIME OR AT LEAST SOME OF THE LIFE STORY


GOOD AT DOCUMENTING

GREAT AT GOAL OF INDIVIDUALIZING EVEN IF WE DON'T MEET IT

MORE FUNDING THAN MOST HUMAN SERVICE SYSTEMS
MOST WILLING TO LEARN AND CHANGE

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A life well led, health care advocacy through a team approach with training and supports is our goal for everyone regardless of underlying disease or conditions

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