Module IX

Aging
Mental Wellness and Aging in People with Intellectual/Developmental Disabilities
The purpose of this module is to discuss mental wellness among persons with IDD who are aging, considering the experiences of typical persons as well.
Learning Objectives

• Define and describe the components of wellness as it relates to aging
• List the types of changes that occur for people as they age
• Explain the factors affecting people with IDD as they age
• Explain how to enhance supports in consideration of these factors and the IDD
• Describe the age-related health problems attributed to genetically based syndromes
• Describe dementia, the prevalence among people with IDD and the challenges in diagnosing
• Describe the psycho-social aspects of aging with IDD and how to support a person to maintain healthy psycho-social contacts
The WHO (World Health Organization) acknowledges that aging is a lifelong process of change and there is no generally accepted age which defines exactly when people become old.
Understanding Aging

For some people, the types of changes that occur toward the end of their lives may require more care and support.

As people who have a dual diagnosis age, understanding and supporting their mental wellness is crucial.
A New Perspective

Clinical definition – “aging is a continuation of the developmental process and is influenced by genetic and other biological factors as well as personal and social circumstances.”

Holland, 2000
Aging

A Diverse Process

The accumulation of changes over time occur at different rates depending on an individual's genetics, environment, and lifestyle.

Physical and physiological changes make the body more susceptible to illness but no certain pathology is predictable without consideration to lifestyle variables. (Saxon et al., 2009)
Exercise

What words come to your mind when you hear the word “aging?”
Aging and IDD

Due to factors associated with their disabilities, people with IDD generally have poorer health, greater need for support, and experience greater health-related functional decline than do older people without IDD.

Bigby, 2004
For some people who have IDD, aging can be complicated by the occurrence of what appears to be premature aging and shortened life expectancy; particularly for people with profound and multiple disabilities and frequently those with Down syndrome.
Aging

Aging in the General Population

Aging in the general population increases vulnerability to certain health issues:

• Memory and Alzheimer’s disease
• Sensory problems: Eye and ear conditions
• Digestive and metabolic disorders
• Urogenital conditions such as incontinence and prostate cancer
• Dental conditions such as periodontitis, gingivitis and tooth loss
• Skin conditions – skin cancers, shingles, dry skin, pruritus, geriatric eczema

NIH, 2007
Concepts in Physical Aging

Skeletal system

Nervous system

Physical abilities are compromised

NIH, 2007
Learning and Memory
Common myths and stereotypes have long implied that older adults are not able to learn new material or that poor memory is part of aging. (Saxon et al., 2009)

People continue to have different learning styles as they age.
Life Expectancy

As a result of advances in health care and community supports, life expectancy is increasing for people who have intellectual/developmental disabilities.

For example, life expectancy for people with Down syndrome has increased dramatically in recent decades - from 25 in 1983 to 60 today.

Bigby, 2004
The Differences in Aging with an IDD

• Genetics
• Environmental Factors and Lifestyle
• Access to specialized health and mental health services for people who have IDD or dual diagnosis
• Communication
• Accelerated aging

Baxter et al, 2006 and Ringaert and Waters, 2005
Accelerated Physical Aging

There is evidence that people with IDD develop secondary conditions and diseases. As a result, they may age at a different rate than the general population.

Features of aging that can manifest as a gradual reduction in ability or capacity in an individual in the general population, can occur more rapidly in someone with IDD.

Kailes, 2006
Other age-related health issues are more frequent in people with particular genetically based syndromes.

- Mitral valve prolapse and musculoskeletal disorders in people with Fragile X syndrome
- Scoliosis in people with Prader-Willi syndrome
- Recurrent upper respiratory and ear infections in people with Cri du Chat syndrome
For many intellectual/developmental disabilities with genetic etiology, there are known, existing predispositions for specified medical, mental health, and behavioral challenges.

Sullivan et al, 2011
The most commonly known of these is the increased risk of precocious aging, dementia, and increased sensory loss in people with Down syndrome.

Wishart, 1996
Aging

The prevalence of certain mental health issues increases with aging, including anxiety, depression, dementia, and psychosis.

From the available research, it can be reasonably concluded that people who have IDD are more likely to develop a mental health issue as they age.

Patel, Goldberg & Moss, 1993
Prevalence of Mental Health Problems

The rate of psychiatric problems for people who have IDD is two to four times the rate of the general population as they age.

Torr & Davis, 2007
Aging

Dementia

The DSM 5 defines dementia as Neurocognitive Disorder. It involves the “loss of memory plus impairment in at least one other cognitive function, such as aphasia, apraxia, agnosia; and disturbance in executive function, which is severe enough to interfere with activities of daily living and represents a decline”.

APA, 2000, 2013
Dementia Prevalence Rate

22% of adults 40+ who have Down syndrome develop dementia.

The rate increases to 56% for adults 60+.

For individuals with other types of IDD the rate is comparable to that of the general population, 5% in adults 60+.

Janicki & Dalton, 2000 and Fletcher, et al., 2007
Challenges in Diagnosing Dementia

- Measuring decline in functioning
- Self-reporting observations
- No standardized criteria for dementia

Cooper, 1997
Case study: Maria is a woman with Down syndrome. She is in her 40s, and her health is failing. She suffers from digestive discomfort and sometimes has trouble hearing. She no longer has the energy to do the things she likes to do, and her favorite TV show, The Office, has gone off the air. Her life just seems to be slipping away. She gets crabby and takes her frustration out on staff, taking an occasional swing when she has energy and spitting at staff when she does not.

Exercise: Think about ways you could use these approaches to develop interventions to support Maria’s wellness: Positive Behavior Supports, Mental health interventions, and Person Centered Planning.
For people who have an intellectual/developmental disability, lifelong attention to preventable medical and mental health conditions is critical for healthy aging.
Best Practice Guidelines for Physicians

In 2011, Canadian Consensus Guidelines were developed for primary care physicians on evidence-based, best practice in preventative health care for people with IDD.

In 2014, these tools were adapted by Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities for use within the US health care system.
Primary Care Toolkit

The Canadian Primary Care Guidelines and Toolkit are available at:
http://www.surreyplace.on.ca/primary-care

The primary care tools adapted for use in the US health care system are available at:
http://vkc.mc.vanderbilt.edu/etoolkit/
The Social Aspects of Aging

As with all people, aging people with IDD deal with a variety of psychosocial changes and support as they age.

- increasing social isolation
- changing interests
- declining energy
- retirement

Continued.....

Temkin, 2009
Continued…

- cognitive decline
- financial and estate management
- loss of family and friends
- grief management
- acceptance of mortality
- lack of meaningful work or hobbies

Temkin, 2009
Social Value

Social value contributes to overall wellness for all people.

This includes people who have IDD who want to participate in and contribute to their communities in the same manner as all citizens.
Exercise

What social value did you experience from older people as you were growing up?

• Did you spend time around your grandparents?
• Were older people respected during your childhood?
• How can we ensure the people with IDD can continue to offer social value as they age?
Wellness

Wellness encompasses many components including:

• Promoting health and preventing illness, disease, and injury
• Optimizing mental and physical health
• Managing chronic conditions
• Engaging with life

WHO, 2000
Wellness

Key responsibilities for primary care and specialist health services:

1) Maintenance of the physical and mental health of people with IDD

and

2) Early detection and treatment of both physical and mental health problems

Pointdexter, 2002
Working Together

As people who have IDD age, there is ongoing need for collaborative supports and services to address the needs of the person in this stage of life to ensure that wellness is assured as an accepted part of aging for this population.