Aging of Individuals with Intellectual and Developmental Disabilities (IDD)

Lieke van Heumen, PhD
Agenda

- Introduction to Aging with IDD
- Aging Challenges and Supports
- Questions
Common Thread

- Focus on creating positive and meaningful aging experience
- Application of life course perspective to aging/IDD
- Interventions informed by experiences of aging adults with IDD
Introduction to Aging with I/DD
Understanding aging

Biological, psychological, social, political, legal

Multiple indicators of age (Dannefer & Settersten Jr., 2010)

Lifelong (Elder Jr. et al., 2004)

Cumulative (dis)advantage (Dannefer, 2003)
Aging with disability

More people ‘aging with disability’ than ever before (Sheets, 2011)

Lifelong (early onset) v. late onset disability (Putnam, 2007)

12 million Americans with lifelong disabilities are aging (Sheets, 2011)

Aging with lifelong disability recent phenomenon (Mosqueda, 2004)

Little is known about disabled people’s lives over time (Heller & van Heumen, 2013)
Largest group of people aging with lifelong disability  
(Bigby, 2004)

Increasing life expectancy

• 641,000 people with developmental disability over age 60 in US.

• Numbers to double and potentially triple by 2030  
(Heller, 2013)
Population of older adults with I/DD (II)

Life expectancy similar unless

- severe intellectual disability
- Down syndrome
- cerebral palsy
- multiple disabilities (Haveman et al., 2009)
Alzheimer’s disease 15-20 years earlier
Earlier menopause (age 47 versus 52)
Earlier sensory, adaptive behaviors & cognitive losses
At greater risk for joint problems, seizures, tumors and heart disease  
(Haveman et al., 2009)
Transitions

Addressing chronic health conditions

Addressing long term services and supports

Retiring from employment

Addressing end-of-life care
Aging well for adults with I/DD

Living on your own terms
Adding value to society, family or friends
Maintaining health and cognitive function, maximizing mobility, retaining function, and reducing the impact of chronic disease/dysfunction  (Heller, 2004)
Challenges and supports
Health
Cascade of health disparities

- Impairment
- Adverse Childhood Experiences
- Poor Health Behaviors
- Poor Access to Health Care
- Greater Health Conditions Earlier

(Krahn, Hammond & Turner, 2006)
Health of older adults with I/DD (I)

Worse health and more unmet health care needs
More secondary conditions

- Obesity
- Constipation
- Poor dental hygiene
- Skin problems
- Osteoporosis and fractures
- Diabetes
- Incontinence
- High blood pressure
- Dementia
- Depression and other psychiatric issues
Higher rate of falls
- higher risk if female, have arthritis, seizures, polypharmacy, use walking aids, difficulty lifting/carrying ≥ 10 lbs

Cardiovascular disease one of the most common causes of death

Poorer health behaviors
- Sedentary behavior
- Fewer fruits and vegetables

(Hahn et al., 2016; Haveman et al., 2009; Hsieh, Rimmer & Heller, 2012)
Strategies to reduce disparities

Greater knowledge about impairment and treatments

Reduction in poverty and unhealthy environments

Improved health behaviors through health literacy and health promotion

Improved access, accessibility, equity, and effectiveness of health care

Better health and fitness in later life

(Krahn, Hammond & Turner, 2006)
Promoting health

Develop health care advocacy skills
Incorporate exercise into the daily routine
Encourage proper nutrition
Reinforce participation
Educate individuals, staff, & families
Creating a health promotion program
Health education program
Peer to peer program
My Health Passport: A Journey to Better Healthcare

If you are a health care professional who will be helping me, PLEASE READ THIS before you try to help me with my care or treatment.

My full name is: ________________________________
I like to be called: ______________________________
Date of birth: ______ / ______ / ______
My primary care physician: ___________________________
Physician’s phone number: __________________________

Attach your picture here!

This passport has important information so you can better support me when I visit/stay in your hospital or clinic. Please keep this with my other notes, and where it may be easily referenced.

My signature: ____________________________ Date completed: ______ / ______
You can talk to this person about my health: ____________________________
Phone number: ____________________________ Relationship: ____________________________

I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)
Dementia
Higher prevalence in Down Syndrome

- 22% of people 40 years and older
- 56% of people 60 years and older

Prevalence in people with other types of ID over age 60 similar to general population (Strydom et al., 2009, NTG, 2012)
Earlier onset

- Mean age in Down Syndrome: 52.8 years
- Mean age other ID types: 67.2 years

Early symptoms not as noticeable

Faster disease progression in Down Syndrome

- 2-7 years
- < 2 years in aggressive Alzheimer’s disease

(Strydom et al., 2009; NTG, 2012)
Signs of dementia in adults with I/DD

- Forgetfulness
- Loss of skills
- Personality changes
- Sleep disturbances
- Wandering
- Aggressiveness
- Verbal outbursts
- Argumentative
- Incontinence
- Hoarding
- Late-onset seizures  
  (Jamieson-Craig et al., 2010; Menendez, 2005)
Challenges with identifying dementia

- Individuals with I/DD might be unable to report symptoms
- Norms and tools general population not useful
- No average premorbid level of functioning
- Diagnostic overshadowing and underrepresentation (Strydom et al., 2009)
Current state of affairs

Limited recognition of dementia in I/DD
Limited experience with specific presentation
Limited screening and assessment

No diagnosis, misdiagnosis, misdirected course of treatment (NTG, 2012)
Conduct early and regular screening

- Establish baseline of optimal functioning
- Create comparative data to determine decline 
  (NTG, 2012)

If screening positive, refer for clinical assessment

If assessment positive, refer for full diagnostic evaluation
Early Detection Screen for Dementia

http://aadmd.org/ntg
Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia

Practice Guidelines for the Evaluation and Management of Dementia in Adults with Intellectual Disabilities

Guidelines for Dementia-Related Health Advocacy for Adults With Intellectual Disability and Dementia
Resources National Down Syndrome Society

- Aging and Down Syndrome. A Health and Well-Being Guidebook

- Alzheimer’s Disease and Down Syndrome: A Practical Guidebook for Caregivers
Environmental modifications

Simplification of the environment
Way finding and orientation
Furniture
Noise
Illumination
Color
Flooring
Bathroom management
Kitchen safety
Supports for wandering
Assistive Technology
Social Relations
Supportive networks evolve across the life course

Social networks are important for older people (Cavanaugh, 1999)

Supports and opportunities are needed to develop and maintain a supportive social network to age with

Inclusion requires connection to others (Bigby, 2005)

A greater focus is needed in practice
Promoting social networks

Persons with ID need ongoing support to develop social networks
Acknowledge and maintain informal ties
Encourage and help build informal networks
Skilled inclusion/relationship worker
Continuous social network mapping (Bigby, 2008)
Social network mapping (I)

- Relatives
- Peers with disabilities
- Support staff
- Friends and acquaintances

Person with disability
Social network mapping (II)
Death and Dying
Engage with loss, grieving and end-of-life

Appropriate death education and bereavement counseling lacking (Blackman, 2003; Botsford, 2000)

People with ID need assistance in expressing loss and grieving

Need for involving adults with IDD in planning (Ronneberg et al., 2015; Watchman, 2005)
• Resources in IDD and Coping with Grief, Death and Dying:

http://rwjms.rutgers.edu/departments_institutes/boggscenter/projects/documents/EndofLifeResources11.11.11.pdf
Life story work

Use life story work to inform everyday support (Meininger, 2005)

Create life book

- Family
- Residential history
- Childhood
- Disability experience
- The present
- Future wishes
- End of life planning
Questions
Contact

lvheumen@uic.edu
(312) 413-5557