Aging with an Intellectual and Developmental Disability:
Challenges and Management

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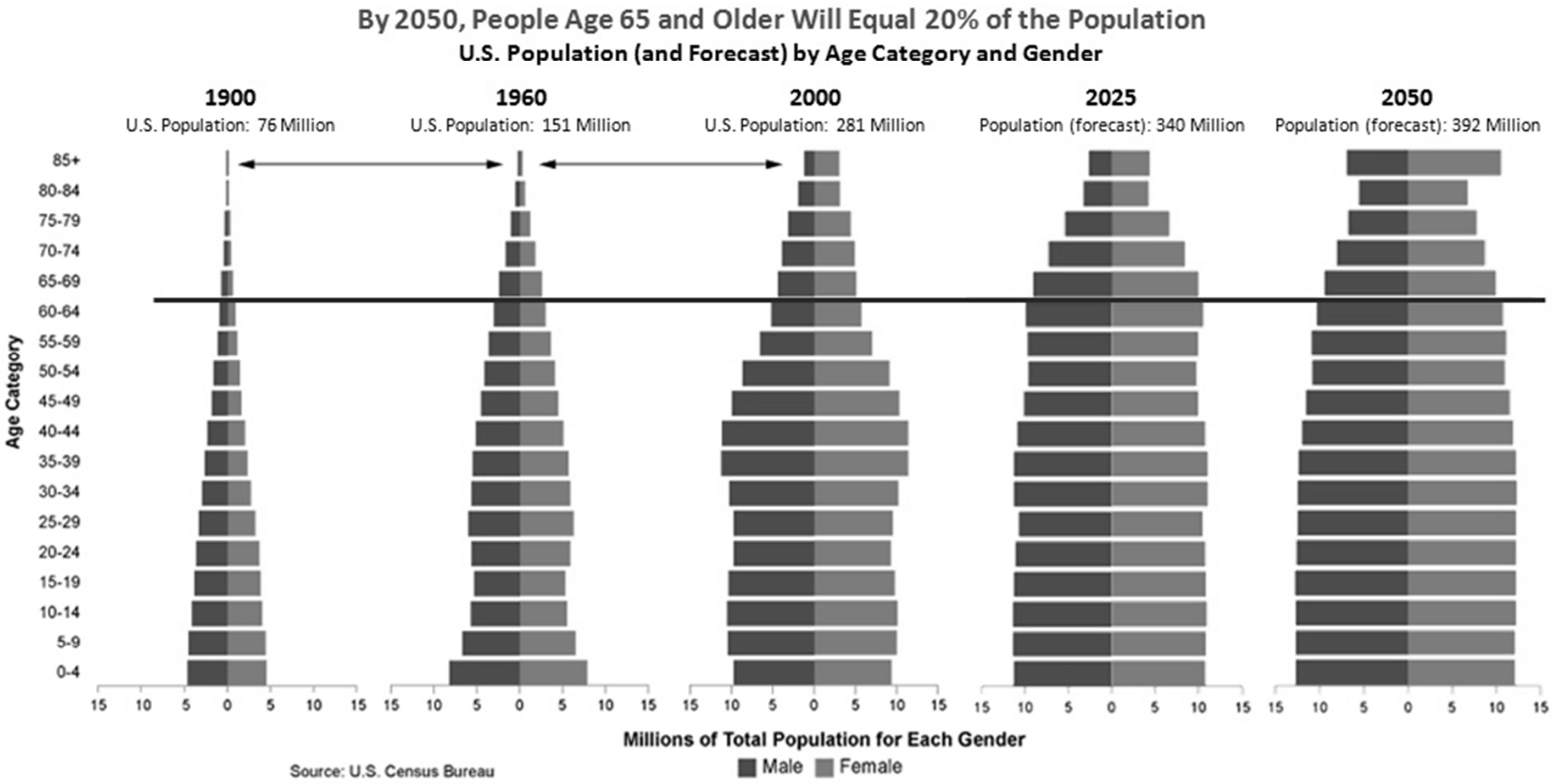
Learning Objectives

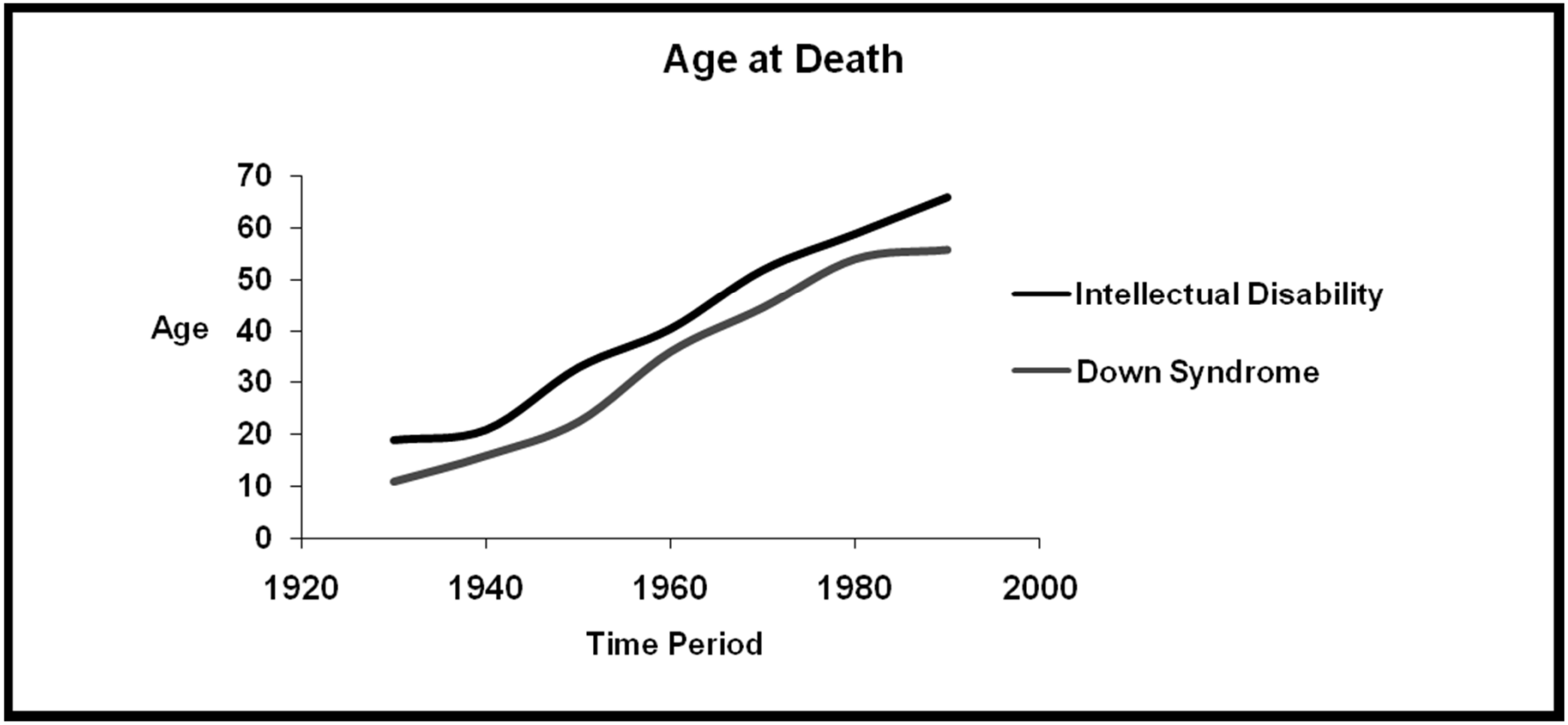
- Discuss the impact of aging for adults with IDD and their families
- Review the effectiveness of environmental, psychosocial, and pharmaceutical interventions for managing cognitive decline in patients with IDD
- Identify systems of care that may be used to address health problems such as dementia and cognitive decline that impact older adults with IDD
- Describe ways to modify the clinical approach to adjust for loss of function in the older adult with IDD

Changing US Population Demographics



Aging and Intellectual and Developmental Disabilities

- In 2002, an estimated 641,000 adults with IDD were older than 60.
- In 2002 about 75% of all older adults with IDD were in the 40-60 year old age range.
- The number of adults with IDD age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030 due to increasing life expectancy and the aging of the baby boomer generation



Carter & Jancar, 1983, Janicki, Dalton, Henderson, & Davidson, 1999

- Currently estimated life expectancy of a 1-year-old child with DS is between 43 and 55 years

Curr Gerontol Geriatr Res. 2012; 2012: 412-536.

- 25% of persons with Down syndrome are still alive at 65 years

Rubin & Crocker,2006; Yang Rasmussen & Friedman, 2002

What changes when we age?

- Our bodies and minds
- Our interests
- Our families, friends, and supports
- Our culture
- Our finances

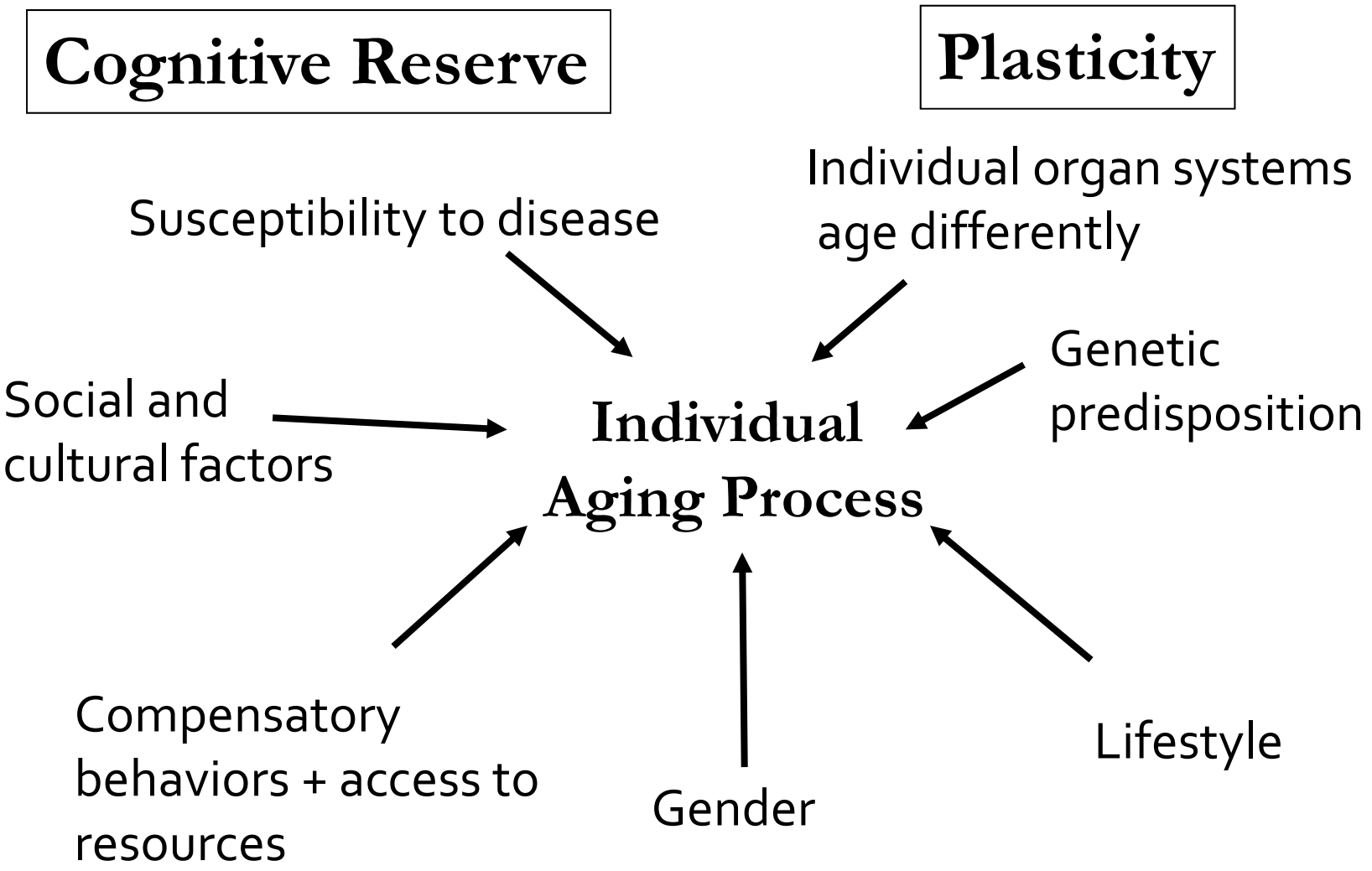
Expected Physical Changes of Aging

- **Osteopenia/Osteoporosis** – normal aging-related bone loss
- **Sarcopenia** – progressive loss of muscle mass
- **Presbyopia** – the lens of the eye becomes stiffer and less flexible, affecting the ability to focus on close objects (accommodation)
- **Presbycusis** – aging related change in the ability to detect higher pitches, more noticeable in those age 50+
- **Gustation** (i.e. the sense of taste) – decrements become more noticeable beyond 60+
- **Olfaction** (i.e. the sense of smell) – decrements become more noticeable after age 70+
- **Somatosensory System** – Reduction in sensitivity to pain, touch, temperature and proprioception
- **Vestibular** – Reduction in balance and coordination
- **Cognitive** – Reduction in short term memory loss, attention, and retrieval

Age-related Health Complications

- Seizures
- Osteoporosis
- Falls and fractures
- Behavioral challenges
- Visual and hearing deficits
- Dementia
- Gait dysfunction
- Cardiopulmonary disease
- Strokes
- Cancer
- Spinal disease
- Liver and Kidney disease
- GI disturbances

Diversity of the Aging Process



Successful Aging

Optimal Aging

"A kind of utopia, namely, aging under development enhancing and age-friendly environmental conditions"

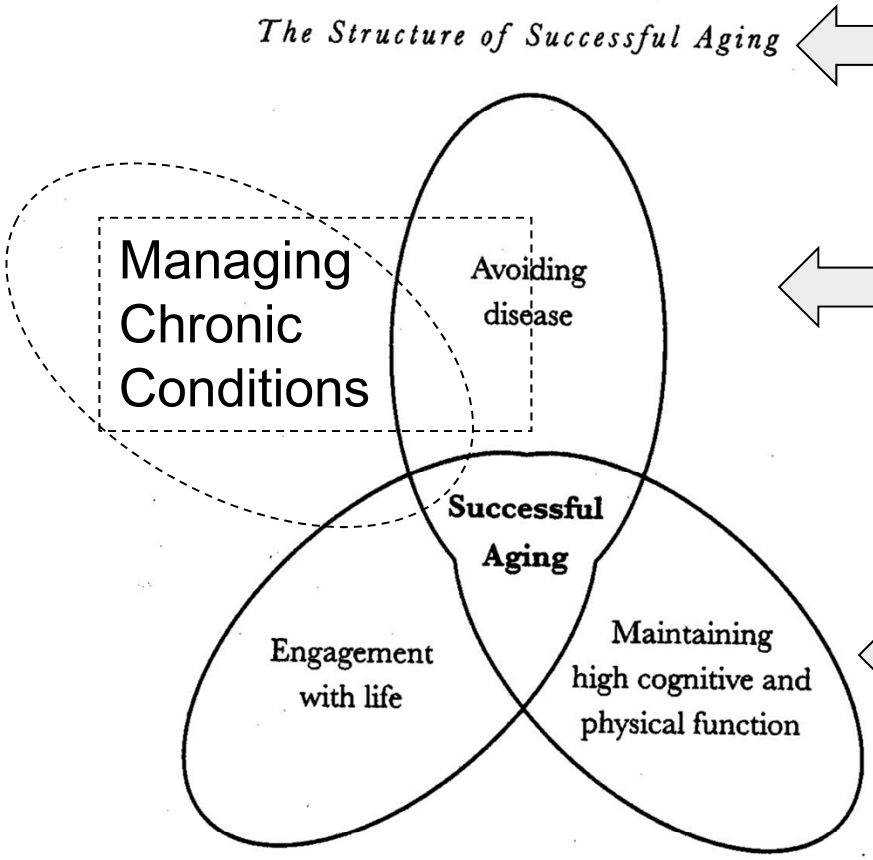
Baltes, P. B., & Baltes, M. M. (1990). Psychological perspectives on successful aging: The model of selective optimization with compensation. In P. B. Baltes & M. M. Baltes (Eds.), Successful aging: Perspectives from the behavioral sciences (pp. 1–34). New York: Cambridge University Press

Successful Aging

- Avoidance of disease and (*additional*) disability
- Maintaining mental and physical function
- Sustained engagement in social and productive activities

Rowe, J. W., & Kahn, R. L. (1997). Successful aging. *The Gerontologist, 37,* 433-440

Rowe and Kahn Model



"Healthy Aging"

"avoid injury and promoting health"

"optimizing"

Source: Rowe, John W. and Kahn, Robert L. (1998). Successful aging. New York: Pantheon. 39.

Source: Marshall, V.M. & Altpeter, M. (2005). Cultivating social work leadership in health promotion and aging: Strategies for active aging interventions. Health & Social Work, 30(2), 135-144.

Modifiable versus Unmodifiable Factors for Successful Aging

Unmodifiable

- Age
- Gender
- Genetics
- Ethnicity

Modifiable Factors for Successful Aging

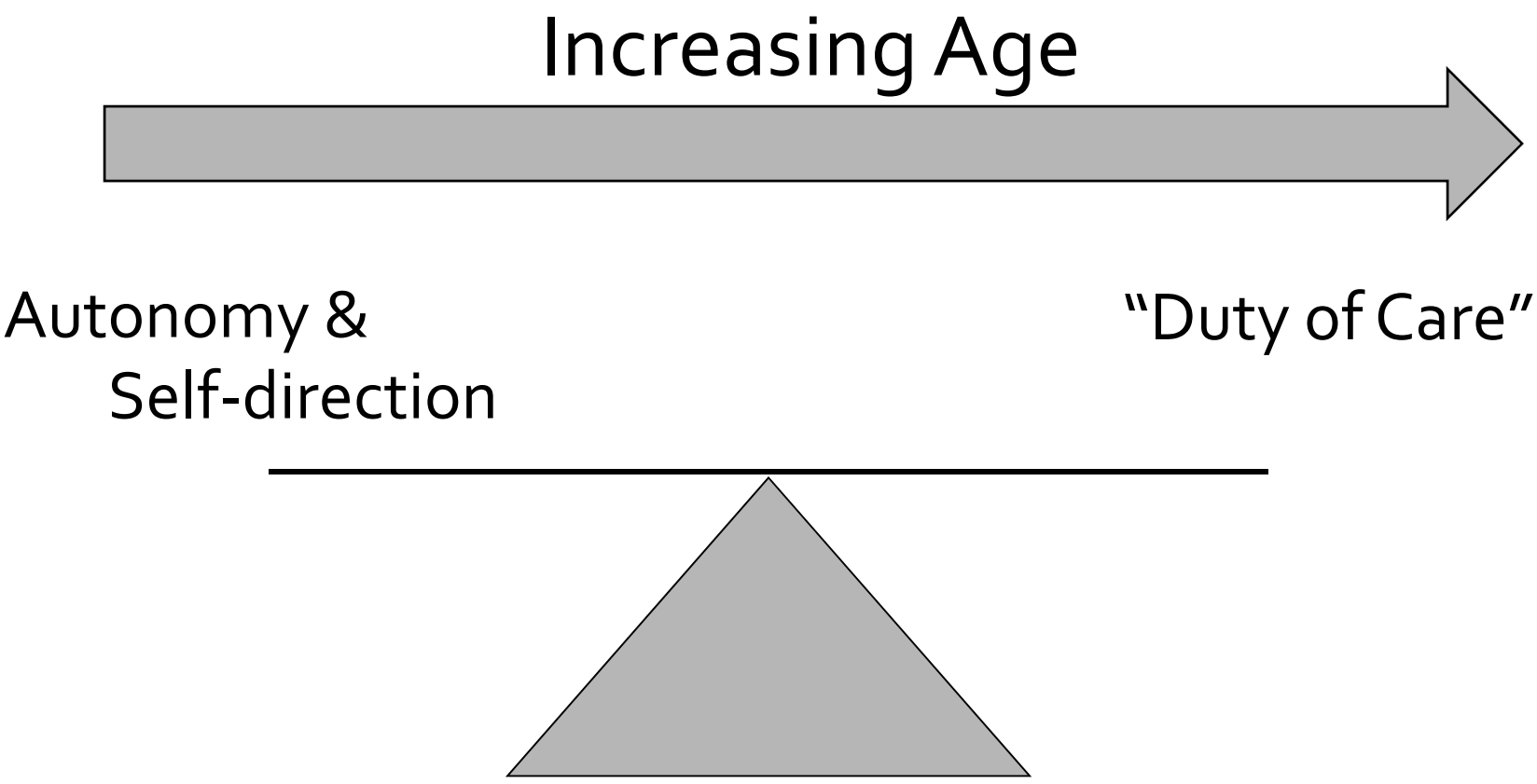
- Eat a balanced and healthy diet (and supplements)
- Maintain a healthy weight
- Exercise on a regular basis (include weight bearing exercises)
- Manage stress / allow time for relaxation
- Don't smoke (and avoid secondary smoking!)
- Education (promote lifelong learning)
- Occupation (esp. promotes curiosity, or working with people)
- Leisure activities (mental, social, physical)
- Enriching relationships (evolving)
- Living in a nurturing/clean physical environment

Aging in Adults with IDD

- One's life story
- What is expected? Aging with a prior lifelong disability
- Who are their supports?
- What personal, social, and health conditions exist?
- Bias/stereotypes/diagnostic over shadowing/ageism
- Self-efficacy theory

Life Course Health Promotion

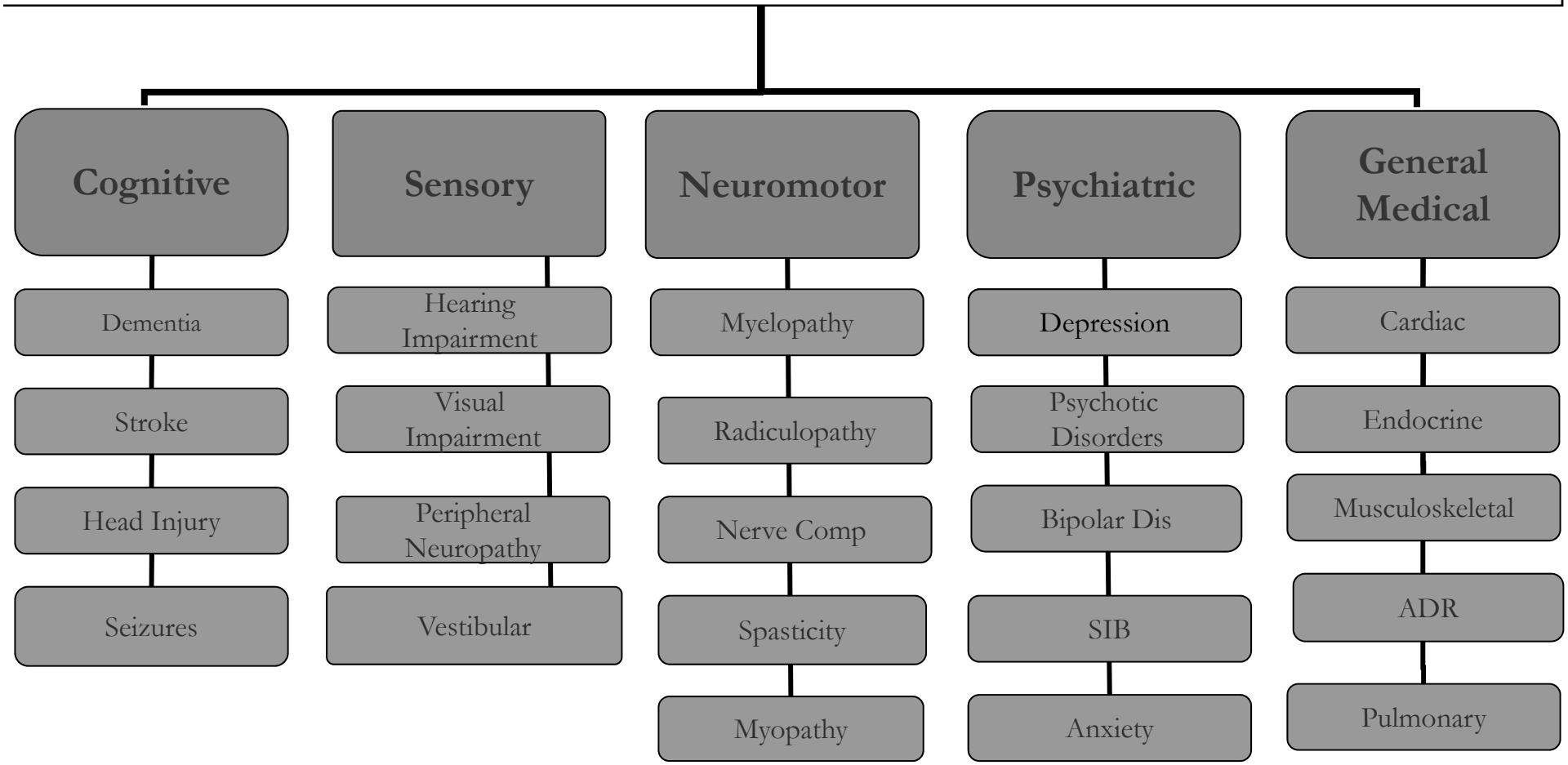
- A balancing act of guiding philosophies.



Optimizing Successful Aging for Older Adults with IDD

- Health promotion / health prevention – Wellness screenings (e.g. vision/hearing, dental checkups, cancer screenings, mammograms)
- Psychological well-being – advocate to ensure availability of optimal treatments / medications for those with dual diagnosis (e.g. anxiety, depression)
- Important to offer a range of new activities, that may result in continuing personal development and compensatory skill building
- Effective epilepsy management
- Avoiding Polypharmacy
- Involve families and support team

Functional decline is the decrement in physical and/or cognitive functioning and occurs when a person is unable to engage in activities of daily living



DD Specific Aging and Health Complications

Down Syndrome

- Sleep disturbances, depression, sensory loss
- Obesity
- Thyroid dysfunction, B12/folate deficiency
- Sleep Apnea
- Gait dysfunction
- Seizure Disorder
- Early onset Alzheimer's Disease

Cerebral Palsy

- Chronic Pain
- Dysphagia, aspiration, Esophageal strictures, gastritis
- Dental caries, erosion
- Motor dysfunction, inc spasticity and spinal cord dysfunction
- Osteoporosis
- Worsening bladder/bowel dysfunction

Autism

- Lifespan outcomes with Autism are unpredictable: some improve, some plateau, some lose skills
- Restrictive behaviors such as ritualistic, compulsive or self injurious behaviors tend to become more infrequent with age
- Seizures, accidental deaths (drowning, suffocation), earlier death from heart disease, aspiration pneumonia

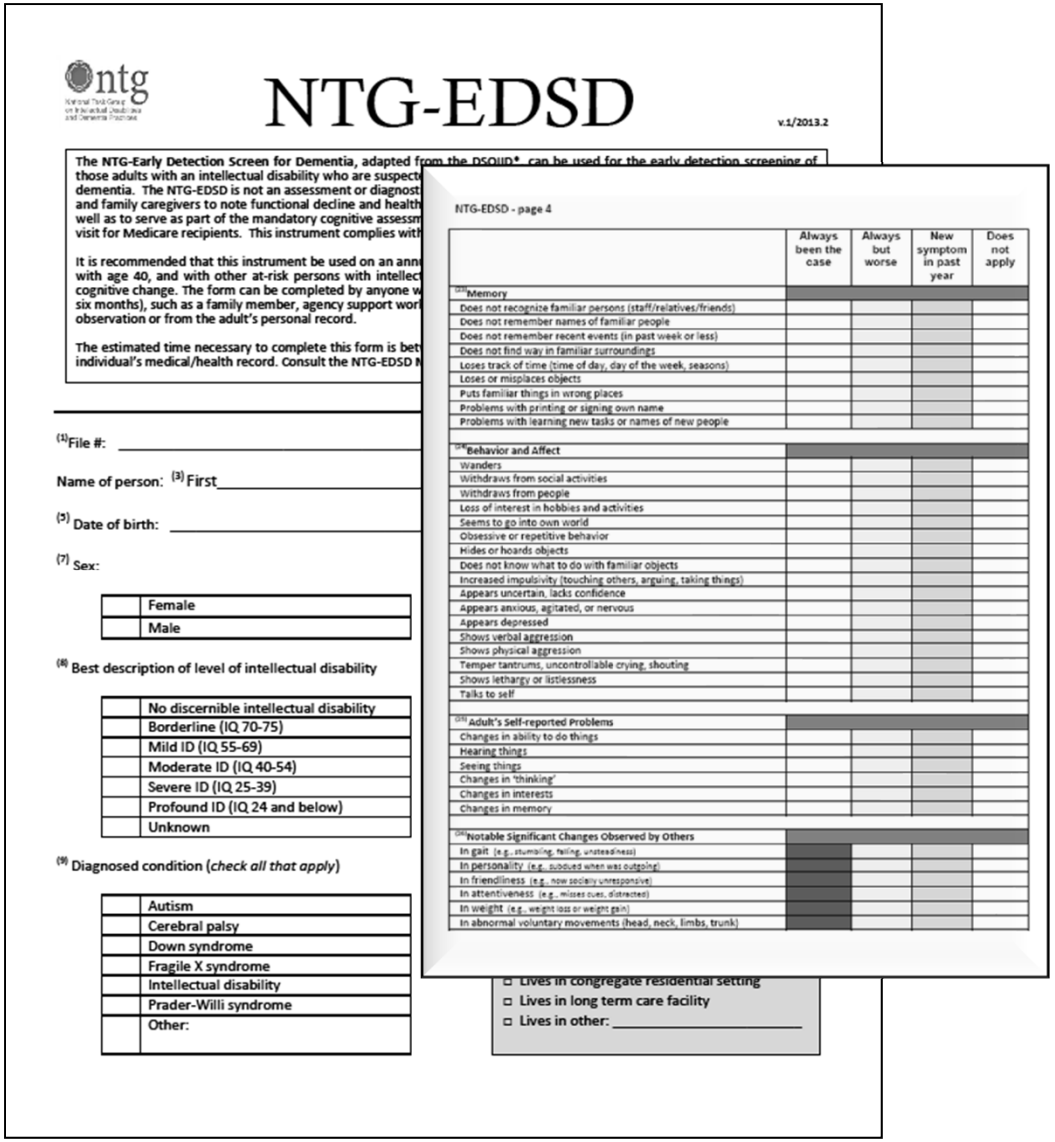
Diagnosis of IDD and Dementia

- Suspicion that pathologic decline in cognitive function is occurring; must be aware of prior baseline level of functioning
- Avoid Diagnostic Overshadowing
- Use of early warning screening and EDSD
- Neurocognitive assessments
- Workup and rule out / rule in accurate diagnosis
- Empiric diagnosis; Possible, Probable, Definite
- Usage of Biomarkers

Early detection/screening

NTG-Early Detection Screen for Dementia' (NTG-EDSD)

- Usable by support staff and caregivers to note presence of key behaviors associated with dementia
- Picks up on health status, ADLs, behavior and function, memory, self-reported problems
- Available in multiple languages
  - Use: to provide information to physician or diagnostician on function and to begin the conversation leading to possible assessment/diagnosis



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NTG-EDSD

v.1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspect dementia. The NTG-EDSD is not an assessment or diagnost and family caregivers to note functional decline and health well as to serve as part of the mandatory cognitive assessm visit for Medicare recipients. This instrument complies with

It is recommended that this instrument be used on an ann with age 40, and with other at-risk persons with intellec cognitive change. The form can be completed by anyone w six months), such as a family member, agency support wor observation or from the adult's personal record.

The estimated time necessary to complete this form is bet individual's medical/health record. Consult the NTG-EDSD M

(1) File #: _____

Name of person: (3) First_____

(5) Date of birth: _____

(7) Sex:

	Female
	Male

(8) Best description of level of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

(9) Diagnosed condition (*check all that apply*)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

NTG-EDSD - page 4

	Always been the case	Always but worse	New symptom in past year	Does not apply
(10) Memory				
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people				
Does not remember recent events (in past week or less)				
Does not find way in familiar surroundings				
Loses track of time (time of day, day of the week, seasons)				
Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
(11) Behavior and Affect				
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities				
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression				
Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness				
Talks to self				
(12) Adult's Self-reported Problems				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
(13) Notable Significant Changes Observed by Others				
In gait (e.g., stumbling, falling, unsteadiness)				
In personality (e.g., subdued when was outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

- Lives in congregate residential setting
- Lives in long term care facility
- Lives in other: _____

http://aadmd.org/ntg/screening

Challenges to diagnosis and care

- Individuals with IDD may not be able to report signs and symptoms
- Subtle changes may not be observed
- Commonly used dementia assessment tools are not relevant for people with IDD
- Difficulty of measuring change from previous level of functioning
- Conditions associated with IDD maybe mistaken for symptoms of dementia – Diagnostic overshadowing
- Aging parents and siblings
- Lack of research, education and training

Realistic Goals of Dementia Treatment

- Attenuate cognitive and functional decline
- Prevent / decrease behavioral and psychiatric symptoms
- Delay nursing home placement
- Lengthen period of self-sufficiency
- Reduce caregiver burden
- Palliative and End of Life Care

Community Care Needs of Adults with ID and Dementia

- Dementia is a condition that lessens an individual's ability to self-direct and be left alone – thus long-term living on ones' own may not be an option as the disease progresses.
- Aging in Place/In Place Progression/Aging Out
- What are the needs?
  - In home supports (to family caregivers and the person)
  - Advanced planning for alternative care
  - Diagnostic, medical and behavioral health care
  - Support groups for caregivers (family or staff)
  - Dementia capable community housing
  - Day care programs and respite for family caregivers
  - Usage of technology / telehealth

This animation shows how we achieve maximal "smartness" early in life and need to work against those forces that negatively affect our cognition (cognitive reserve idea) .

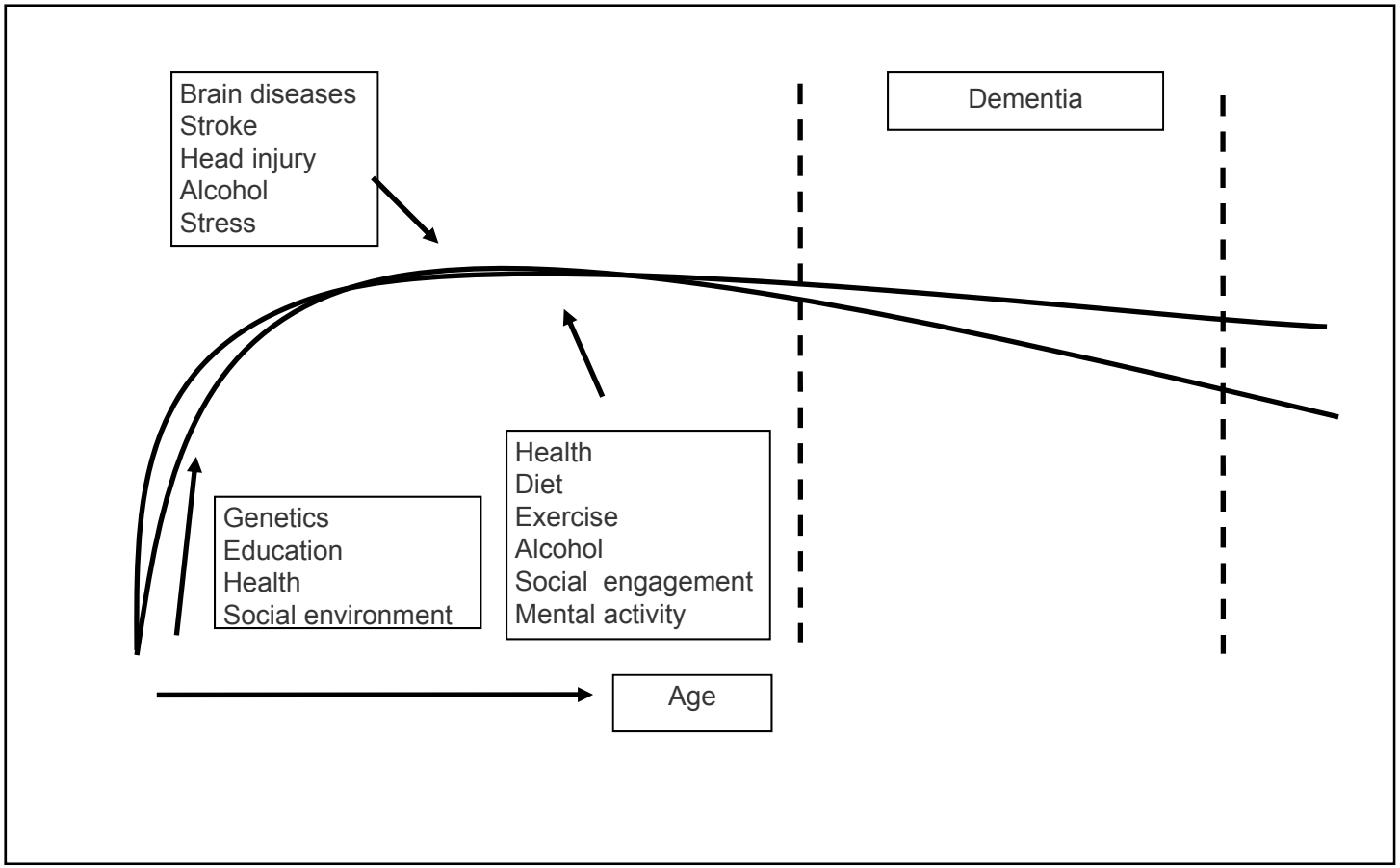

Figure adapted from Richards M and Deary I *J. Ann. Neurol*. 2005.

Health promotion and disease prevention does work for older adults

- Longer life
- Reduced disability
  - Later onset
  - Fewer years of disability prior to death
  - Fewer falls
- Improved mental health
  - Positive effect on depressive symptoms, social connectedness
  - Delays in loss of cognitive function
- Lower health care costs
- Requires systemic involvement for it to be most effective

Where do we go from here?

- Education and training
- Local, regional, and national resources
- Research
- Proving that we make a difference
- Health care provider support
- Awareness, sensitivity, and advocacy

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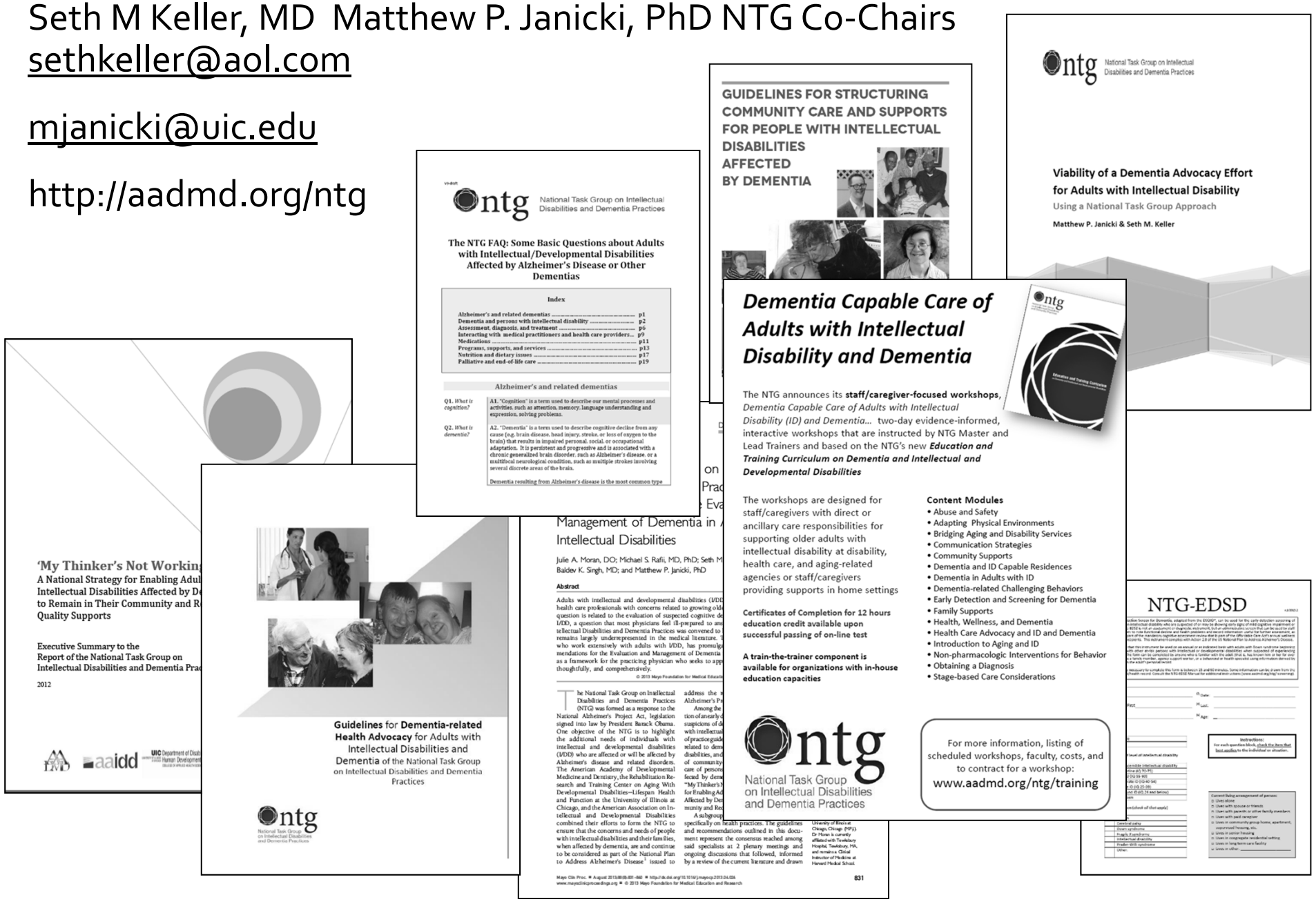

Thank You!!