Aging and Intellectual/Developmental Disabilities (IDD): What Do We Know, Where Do We Go?

Kathy Service RN, MS, FNP-BC, CDDN
kathyservice@gmail.com

- Discuss how process of aging affects two of your approaches with an older person w/IDD
- Describe effects of two social determinants of health (SDoH's) upon an older person with ID
- Analyze effect of health disparities upon the assessment upon an older person w/IDD who is showing a change

Normal & Inevitable

Cross-Cutting Issues

Reactive vs Proactive Approach

View + Plan

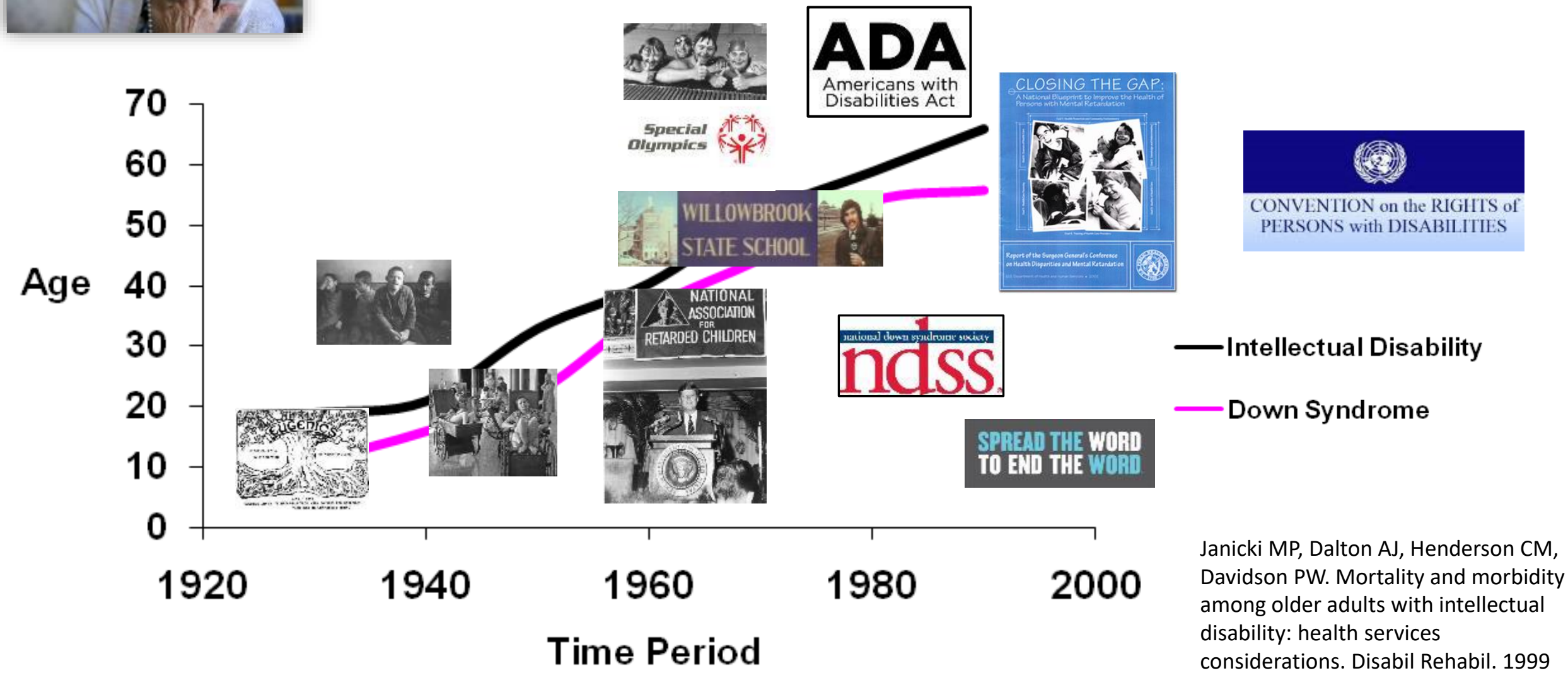
LIFE COURSE perspective

So what about aging”?

- Older adults are characterized by **profound clinical heterogeneity**
- Large **interindividual differences** in biopsychosocial needs and increased multimorbidity that accumulates over the lifespan
- **Individual approaches** account for these factors above (“precision health”) PERSON-CENTERED
    - Kahkoska et al, 2023 p. 384. in the Journal of the American Geriatric Society
- **Precision medicine (aka Health) looks at the genetics, environment, and lifestyle of a person in order to select treatment that could work best for them**
  https://medlineplus.gov/genetics/understanding/precisionmedicine/definition/

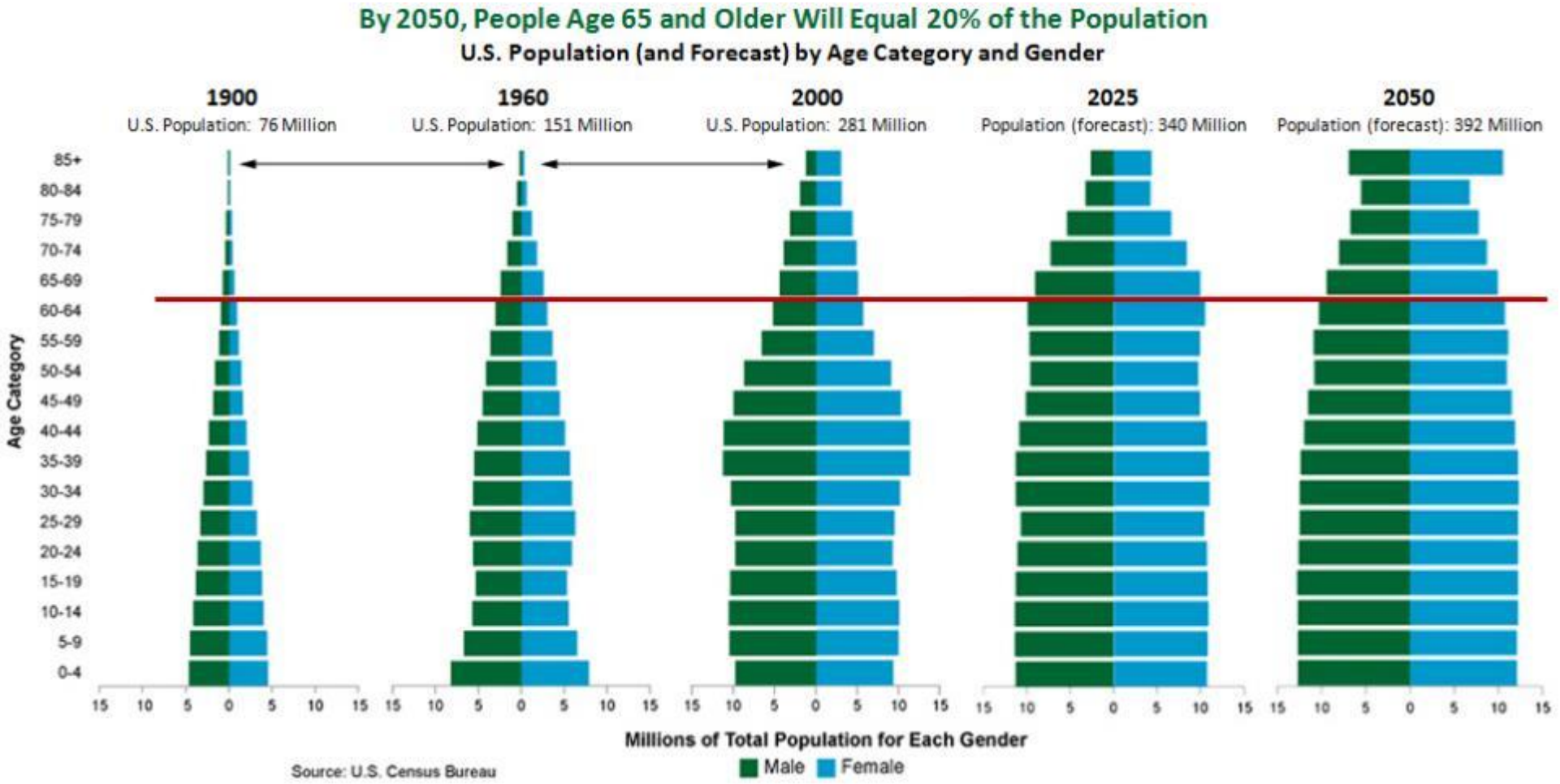
- Life Span AND Life Story - Guides

United States Life Expectancy



Janicki MP, Dalton AJ, Henderson CM, Davidson PW. Mortality and morbidity among older adults with intellectual disability: health services considerations. Disabil Rehabil. 1999 May-Jun;21(5-6):284-94.

Changing US Population Demographics



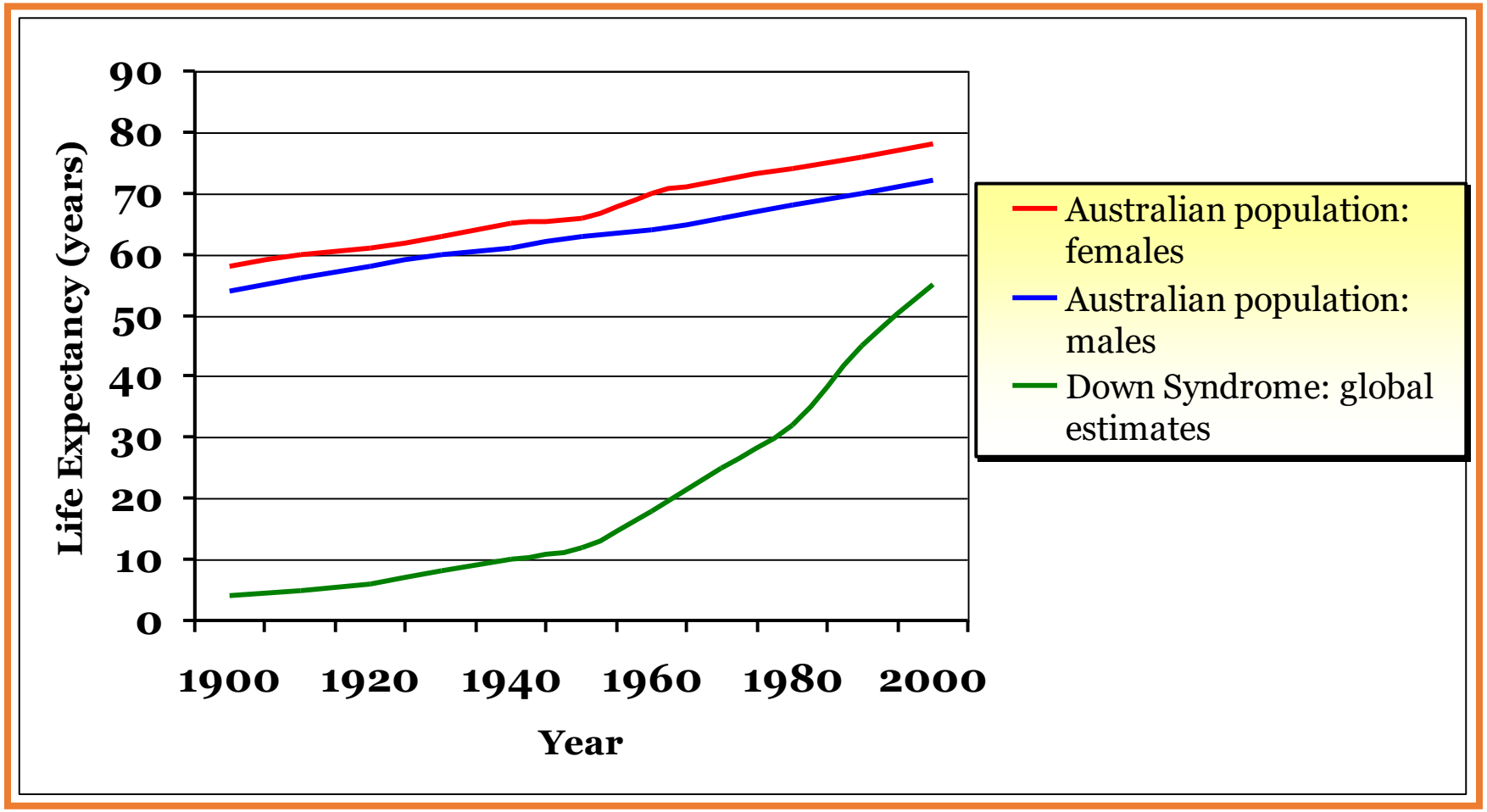
Why?

- 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

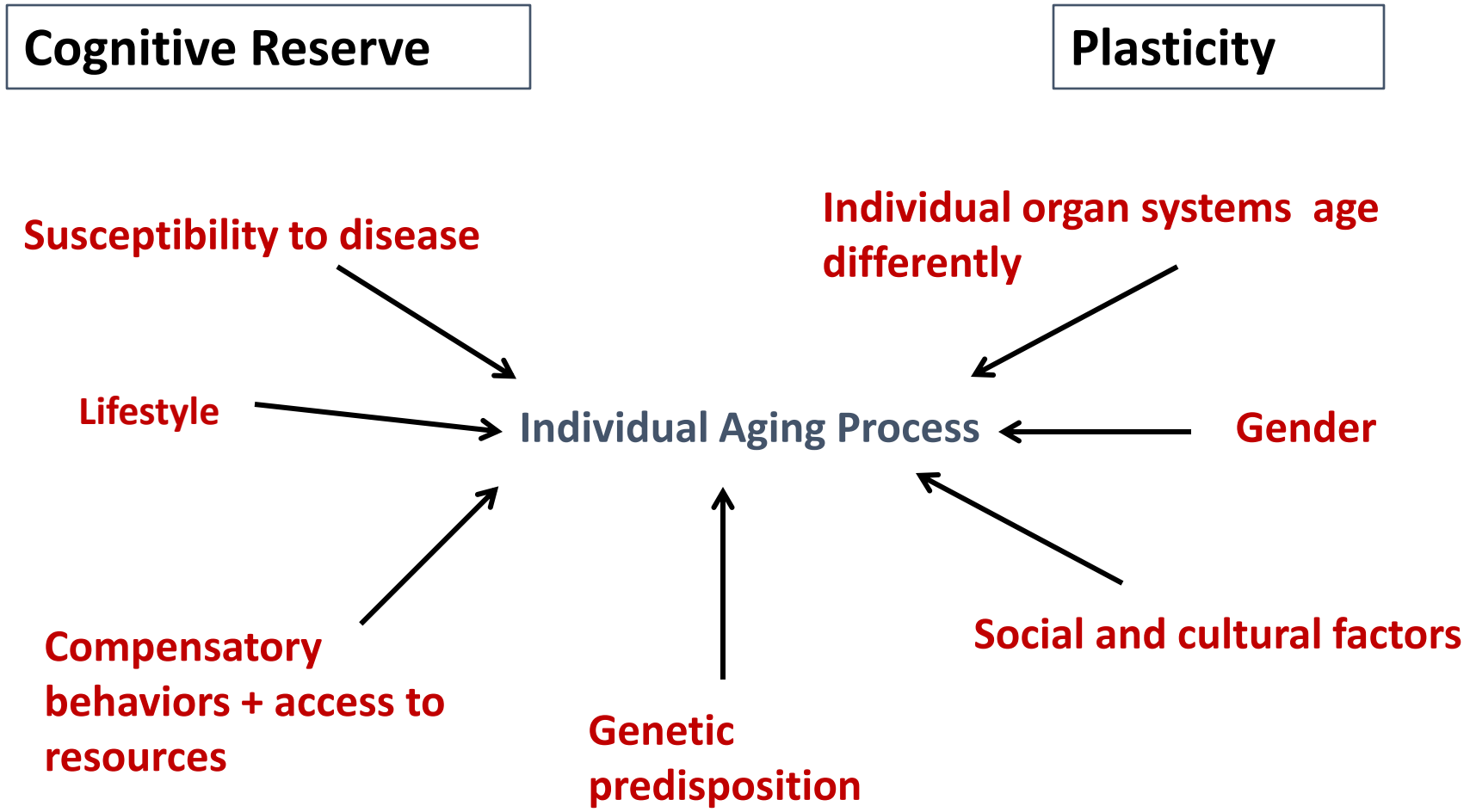
(Factor et al., 2012).

Global Trends in Life Expectancy

Bittles et al. 2004, Developmental Medicine and Child Neurology



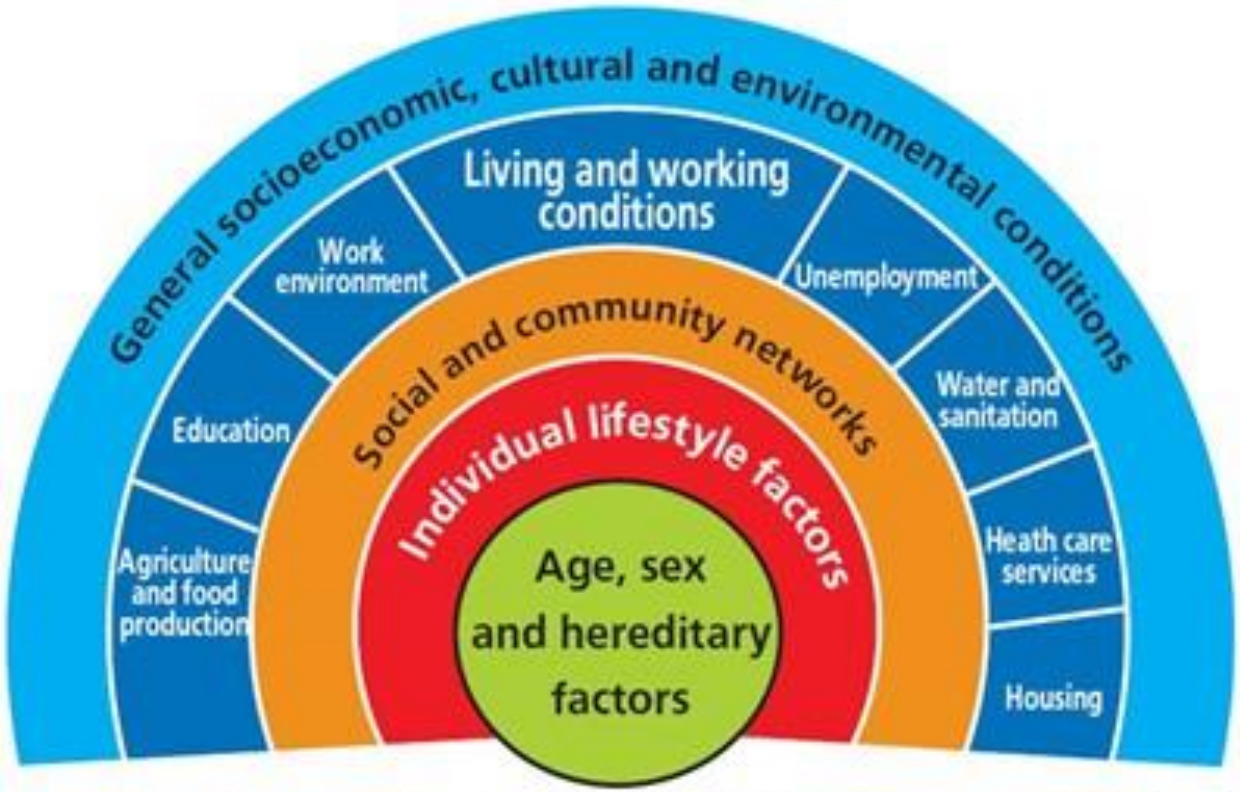
Diversity of the Aging Process



Source: Keller & Service, 2017

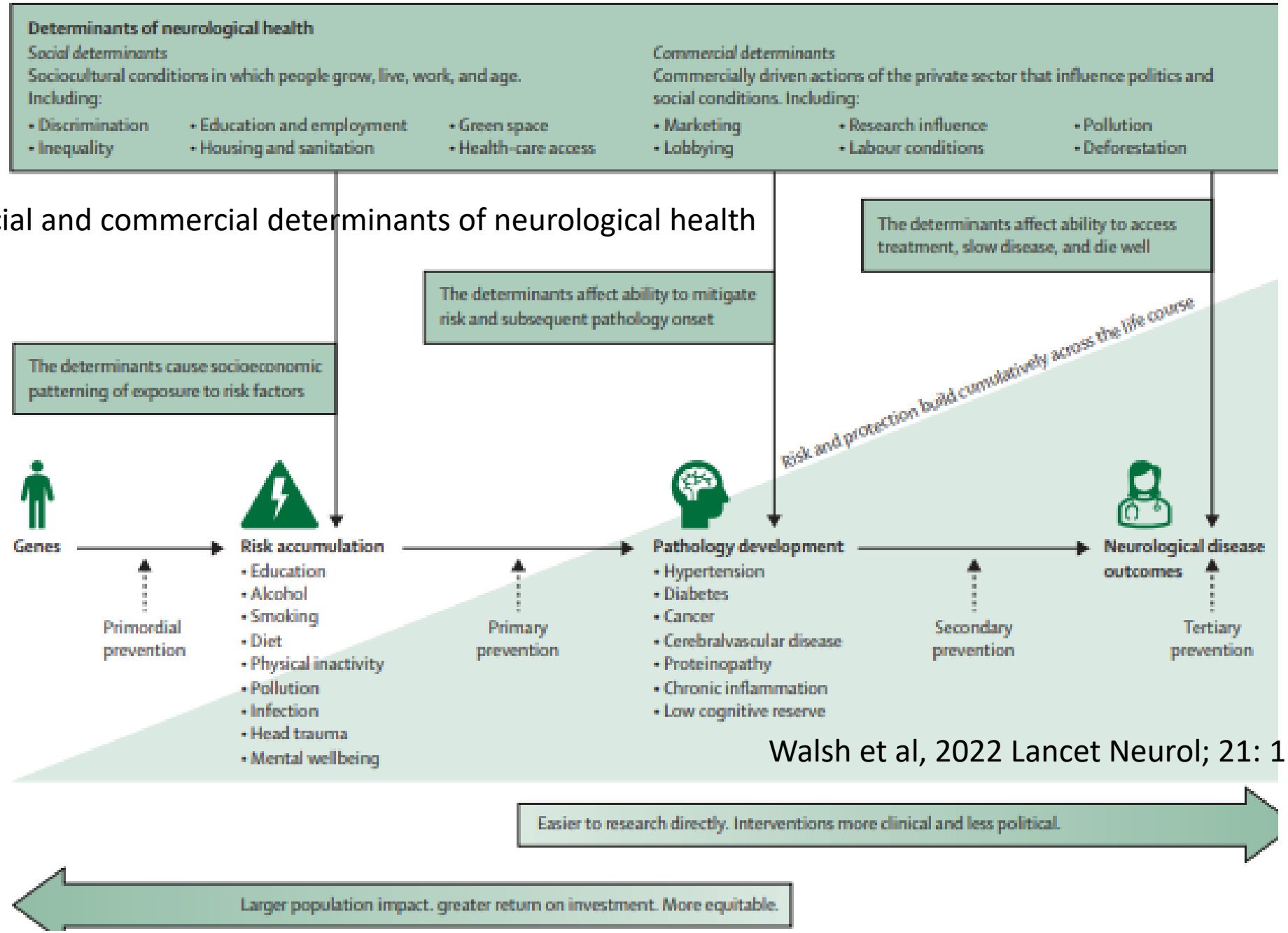
The “Rainbow Model” of Social Determinants of Health

Source: adapted from Dahlgren & Whitehead (1991)



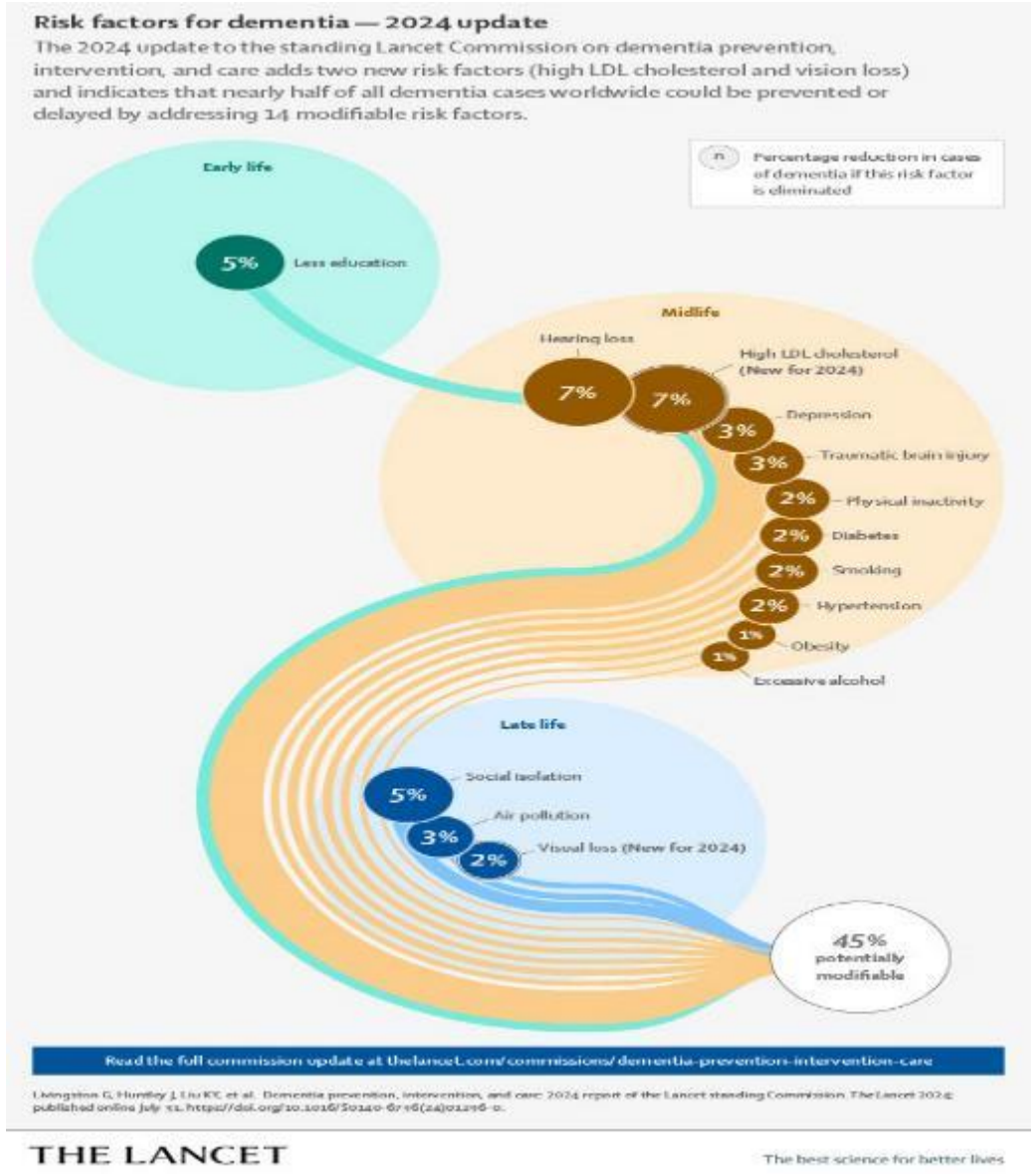
The Determinants of Health (1992) Dahlgren and Whitehead

The social and commercial determinants of neurological health



Walsh et al, 2022 Lancet Neurol; 21: 1151–60, pg 1157.

BRAIN HEALTH



- **Lives in rural area , inner city, geographic isolation**
- **Geopolitical uncertainties**
- **Lack of transportation**
- **Environmental and physical barriers**
- **Poor or wealthy**
- **Lives with aging parent**
- **Lives in group home, high staff turn over, other challenging clients**
- **Lack of access to wellness and health promotion activities**
- **Poor prescription coverage for medications, testing and associated aides**
- **Lack of access to medical, social, behavioral IDD/DS AD experts**
- **Language and communication barriers**
- **Minority, refugees**

Risk Factors for People with IDD

- Hypertension
- Obesity
- Physical Activity
- Smoking
- Depression
- Hearing & Visual Loss

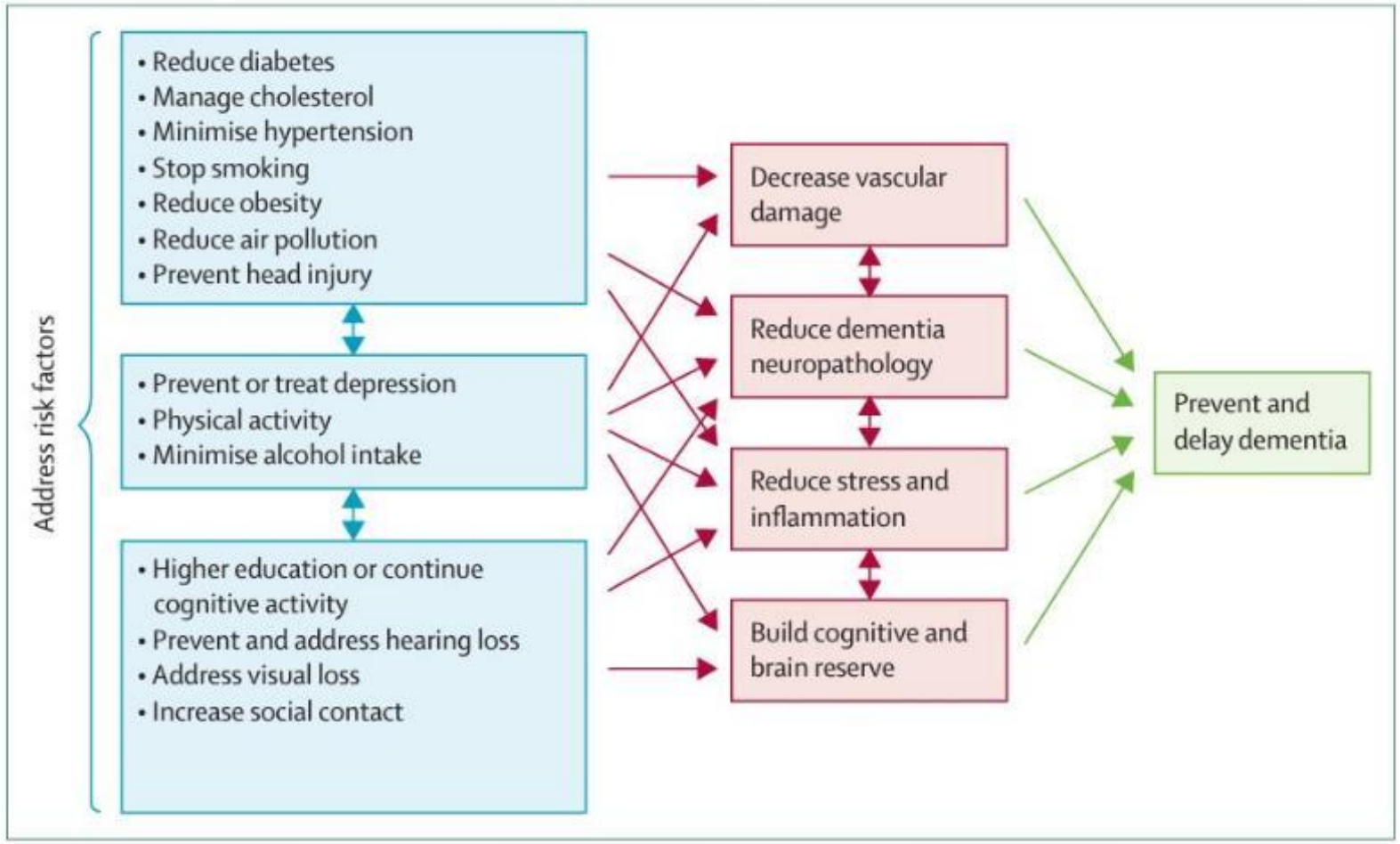


Figure 2: **Possible brain mechanisms for enhancing or maintaining cognitive reserve and risk reduction of potentially modifiable risk factors in dementia**

UPDATE: Lancet. 2024 Aug 10;404(10452):572-628. https:// doi: 10.1016/S0140-6736(24)01296-0. **Vision & Cholesterol** Lancet 2020; 396: 413–46 Published Online July 30, 2020 https://doi.org/10.1016/ S0140-6736(20)30367-6

General Body Changes

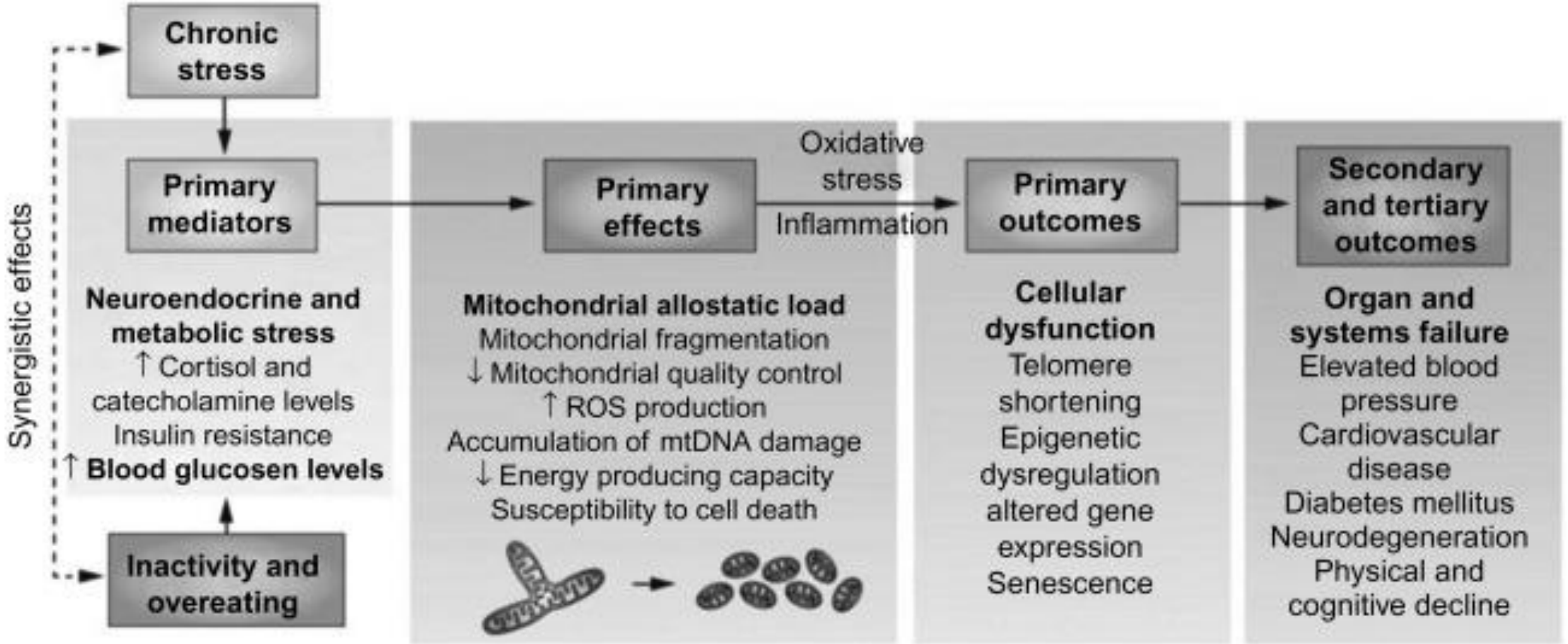
- **Our Bones** - normal aging-related bone loss
- **Our Muscles** - progressive loss of muscle mass
- **Our Eyes-** the lens of the eye becomes stiffer and less flexible – affecting the ability to focus on close objects (accommodation)
- **Our Ears**– aging related change in the ability to detect higher pitches – more noticeable in those age 50+
- **Our Taste**- decrements become more noticeable >60+
- **Our Smell**- decrements become more noticeable after 70+
- **Other Senses -** Reduction in sensitivity to pain, touch, temperature, proprioception, reduced reaction time
- **Our Vestibular System** – Reduction in balance and coordination
- **Our Minds** – Reduction in short term memory loss, attention, and retrieval
- **Our Ability to Bounce-Back Homeostenosis** – narrowing of reserve capacity; decline to maintain homeostasis (depressed immune response)

Age related health conditions

- Seizures
- Osteoarthritis, osteoporosis> PAIN
- Falls and fractures
- Behavioral and mental health issues
- Visual and hearing deficits
- Dementia
- Gait dysfunction
- Altered metabolism>obesity
- Cardiopulmonary disease
- Sleep disorders

- Strokes
- Cancer
- Spinal disease
- Liver & Kidney disease
- GI disturbances (Dental,GERD, constipation)
- Altered Medication Metabolism
- Geriatric Syndromes- common clinical conditions that don't fit into specific disease categories
- **Secondary Conditions (IOM)**
- **Allostatic Load (McEwen et al, 1999)**

Taken Directly from Juster RP, McEwen BS, Lupien S. **Allostatic load biomarkers of chronic stress and impact on health and cognition.** Neurosci Biobehav Rev 2009;35(1):5. Copyright 2009. Elsevier. Accessed 3/28/2023: https://www.sciencedirect.com/topics/neuroscience/allostatic-load



LIFE EXPECTANCY

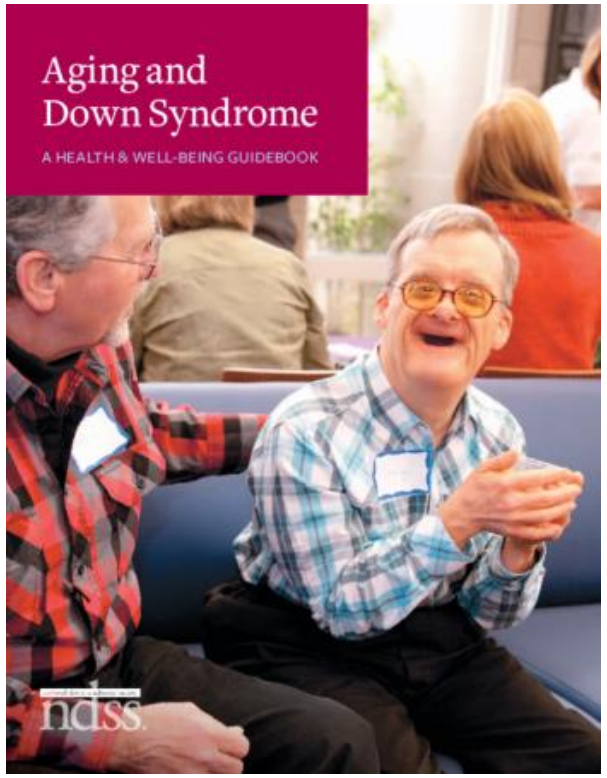
Syndrome	40-50	50-60	60-70	70-80	80-90
Angelman				72	
Cerebral Palsy			55???		
Cornelia de Lange				71	
Down syndrome					82
Fragile X					87
Phenylketonuria				70	
Prader-Willi				72	
Rett			55		
Sanfilippo				69	
Tuberous Sclerosis			50		
Williams			55		

with Maximum Age (years) Coppus, 2013

DOWN SYNDROME

- Sensory-Eyes-Ears
- Skin
- Hypothyroid
- Sleep Apnea
- Osteoarthritis
- Atlantoaxial Instability/C-Spine
- Celiac Disease
- Mental Health Issues (Affective disorders, Regression in younger) ** BRAIN CHEMISTRY
- Orthostatic Hypotension
- Alzheimer's Disease BIOMARKERS (mAbs? Use w/CAA)

https://ndss.org/

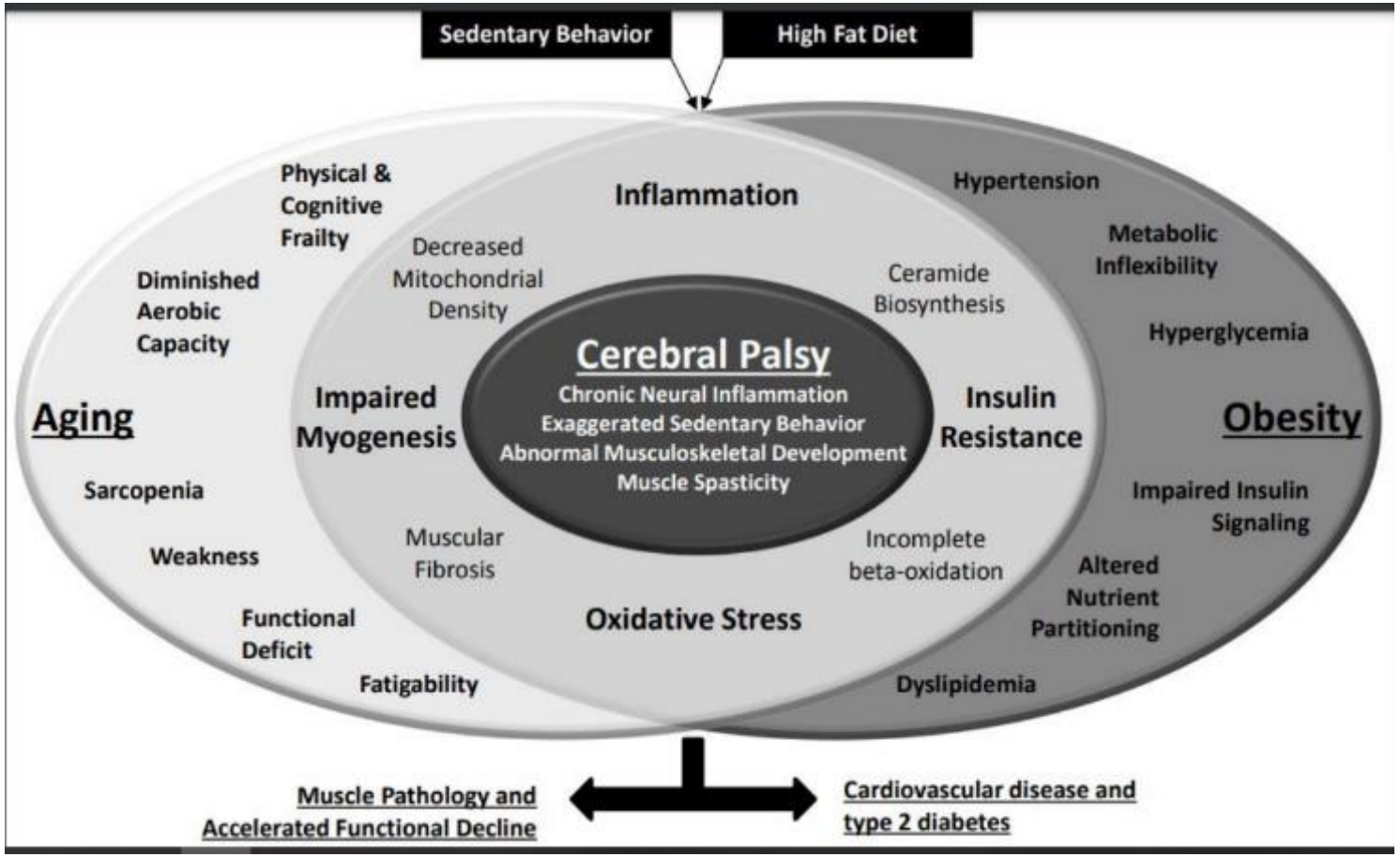


https://www.globaldownsyndrome.org/medical-care-guidelines-for-adults/

Adults with Intellectual Disabilities: Aging (Coppus, 2013)

- **CEREBRAL PALSY-** Accelerated aging – PAIN, musculoskeletal dysfunction, degenerative arthritis fatigue and weakness, scoliosis, arthropathies, and contractures overweight/obesity, gastroesophageal reflux, urinary tract infections and dysphagia, asp pna, seizures, 'post impairment' syndrome. Higher rate of chronic conditions such as diabetes, asthma, hypertension, other heart conditions, stroke, cervical myelopathy, emphysema (Mahran 2021). Risk of early and late onset **ADRD in adults with cerebral palsy (Mahmoudi,et al, 2021) (Smith , 2020) ??**
- **FRAGILE X -**Connective tissue anomalies, (prolapsed mitral valve), scoliosis, joint laxity and postpubertal testicular enlargement The behavioral phenotype comprehend social anxiety, attention deficit hyperactivity disorder (ADHD), and hyperarousal to sensory stimuli, autism, vulnerable to development of the neurodegenerative fragile X tremor/ataxia syndrome (FXTAS)-tremor and ataxia Variable: parkinsonism, executive defects, dementia, other psychiatric problems, neuropathy, and autonomic issues, Berry-Kravis (2007)
- **PRADER-WILLI -** obesity, hypotonia, and hypothalamic dysfunction. Adverse reactions to medications, high pain tolerance, gastrointestinal and respiratory issues, lack of vomiting, and unstable temperature. Adrenal insufficiency obesity, hypotonia, and adrenal insufficiency. Dementia case- Sinnema et al (2010)

Aging in Adults with 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

Heterogeneous population

Peterson MD, Gordon PM, Hurvitz EA, Burant CF. Secondary muscle pathology and metabolic dysregulation in adults with cerebral palsy. Am J Physiol Endocrinol Metab. 2012 Nov 1;303(9):E1085-93.

Aging in Adults with Autism

- A heterogenous population (TSC, Rett, genetic anomalies even DS-16%)
- Significantly increased rates of all major psychiatric disorders including depression, anxiety, bipolar disorder, obsessive–compulsive disorder, schizophrenia, and suicide attempts
- Nearly all medical conditions were significantly more common , **immune conditions, gastrointestinal and sleep disorders, seizure, obesity, dyslipidemia, hypertension, and diabetes**. Higher associated risk of developing diabetes, dyslipidemia, and heart disease, but not hypertension or stroke (Dhanasekara, 2023)
- Rarer conditions, such as **stroke and Parkinson's disease** [Starkstein, 2015] were also significantly more common among adults with autism
-

Concepts of Change
"Something's Different"

FUNCTION
- Independent in self care tasks

SKILLS
- Changes in ability to do routine tasks

MEMORY
- Increased forgetfulness, confusion

BEHAVIORS
- New behaviors, changes in behavior

PERSONALITY
- Any changes to personality

MOOD
- Increased mood swings

Source: Moran et al (2017)

~~Dementia~~ CHANGE Assessment

Thorough, comprehensive interview

- Include family or staff members who know the pt well (at least one year)

Clinical History

- General overview
- Cognitive symptoms
- Neuropsychiatric symptoms
- Functional changes/activities of daily living
- Physical symptoms

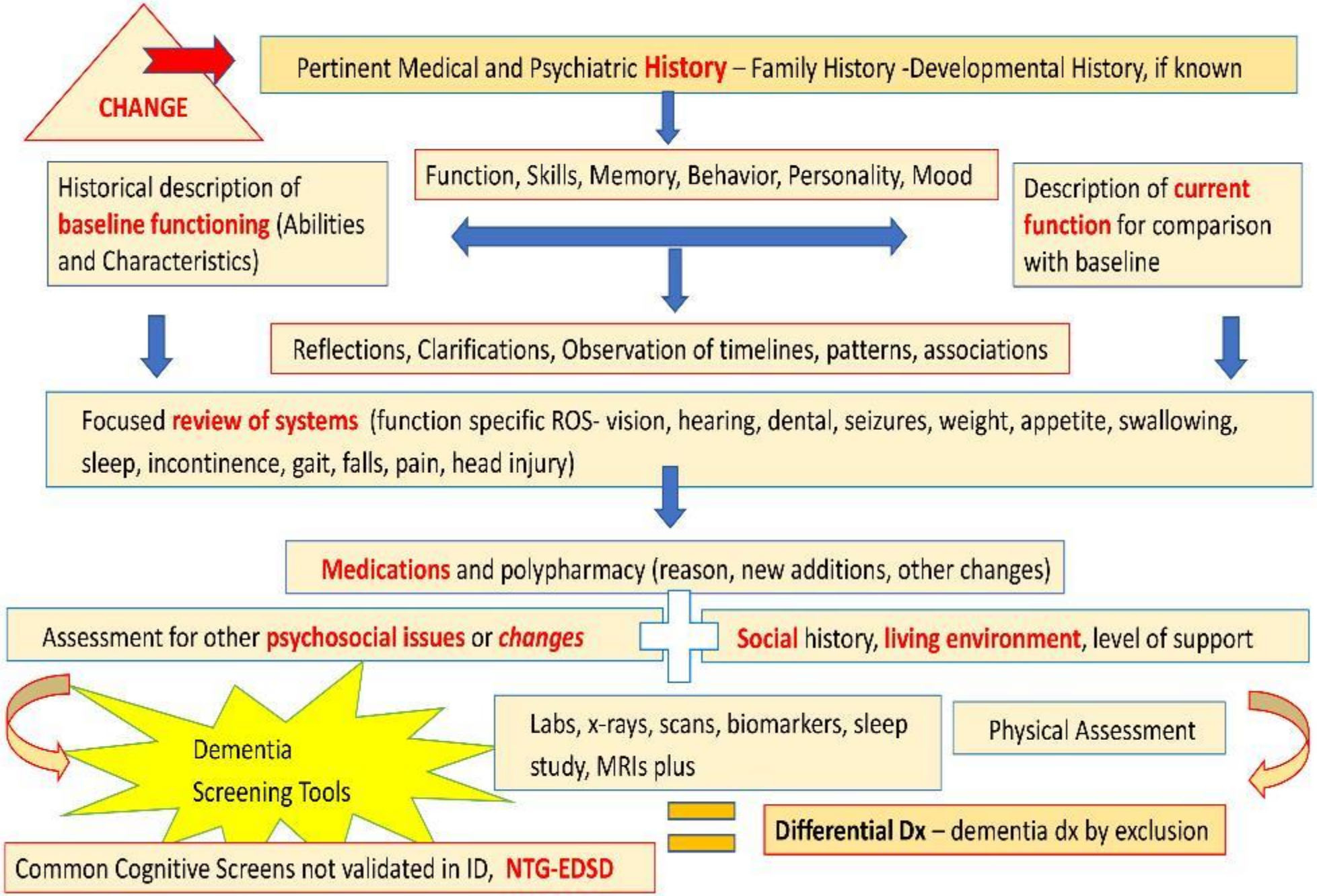
Medications

- Includes OTC-CAM
- Reason
- History

Other Tests * Vax status

- Bloodwork, Brain Imaging, EEG, special studies such as PET, LP, cognitive testing and other biomarkers (From: Moran et al, 2017) –(e.g. CBC, electrolytes, BUN, Cr, Mg, Phos, Ca, AST, ALT, TSH, free T4, B12 and folate; others such as ESR,CRP, Lyme, Vitamin D level, homocysteine level, COVID, TTG-IgA & total IgA, etc dependent upon the above assessments) NOTE: https://www.the-ntg.org/screening-assessment

Examining Adults with Neuroatypical Conditions for MCI/Dementia During Cognitive Impairment Assessments – Report of the Neuroatypical Conditions Expert Consultative Panel (2022)


CHANGE
Pertinent Medical and Psychiatric History – Family History -Developmental History, if known
Historical description of baseline functioning (Abilities and Characteristics)
Function, Skills, Memory, Behavior, Personality, Mood
Description of current function for comparison with baseline
Reflections, Clarifications, Observation of timelines, patterns, associations
Focused review of systems (function specific ROS- vision, hearing, dental, seizures, weight, appetite, swallowing, sleep, incontinence, gait, falls, pain, head injury)
Medications and polypharmacy (reason, new additions, other changes)
Assessment for other psychosocial issues or changes
Social history, living environment, level of support
Dementia Screening Tools
Labs, x-rays, scans, biomarkers, sleep study, MRIs plus
Physical Assessment
Differential Dx – dementia dx by exclusion
Common Cognitive Screens not validated in ID, NTG-EDSD

Differential Diagnosis of Memory/Functional Decline in Adults with IDD

- Sensory impairments
- Thyroid disorder
- Sleep disorder
- Depression
- Life events
- Physical illness
- Medication effects**
- Dementia
- Any combination of above

- ***Mental Wellness in Adults with Down Syndrome, 2nd edition by Dennis McGuire & Brian Chicoine* (2021)** formerly through Woodbine Press.
- FREE Now: Here is the direct link, but check out all the other incredible resources at their website! : https://adscresources.advocatehealth.com/mental-wellness-in-adults-with-down-syndrome-2nd-edition/
- ****SEE NTG's Over-Medication and Older Adults with Intellectual Disability: Risks for Brain Health (Statement). https://www.the-ntg.org/publications-1

Common Medication Classes Associated With Possible Worsening of Cognitive Function in Pts w &w/o Dementia

(Moran et al, 2013)

Medication class	Examples	Comments
Antihistamines, * first generation	Diphenhydramine Hydroxyzine, Promethazine	Anticholinergic adverse effects, urine retention, confusion, sedation
Bladder agents	Oxybutynin, Tolterodine	Anticholinergic adverse effects, urine retention, confusion, sedation
Certain pain medications	Meperidine Propoxyphene	Increased risk of seizures with renal impairment
Tricyclic anti -depressants	Amitriptyline, Clomipramine Doxepin	Risks and benefits of this medication class should be guided by a psychiatrist with familiarity with patients with I/DD
Some Antipsychotics	Chlorpromazine, Clozapine Pimozide	Sedation, mental sluggishness. Atypical antipsychotics associated with increased mortality when used to treat behavioral problems in elderly pts w/dementia, but no such studies have been conducted in Down syndrome or I/DD in general
Long-acting benzodiazepines	Clonazepam, Temazepam Diazepam	Very sedating; caution for gait impairment, dizziness For anxiety, consider short-acting agents (appropriately dosed): alprazolam, lorazepam

Overmedication & Older Adults with ID (see previous slide) Health In Aging https://www.healthinaging.org/ Beers List

Challenges to Diagnosis

- Individuals with ID 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 ID
- Difficulty of measuring change from previous level of functioning
- Conditions associated with ID maybe mistaken for symptoms of dementia
- Diagnostic overshadowing
- Aging parents and siblings
- Lack of research, education, and training

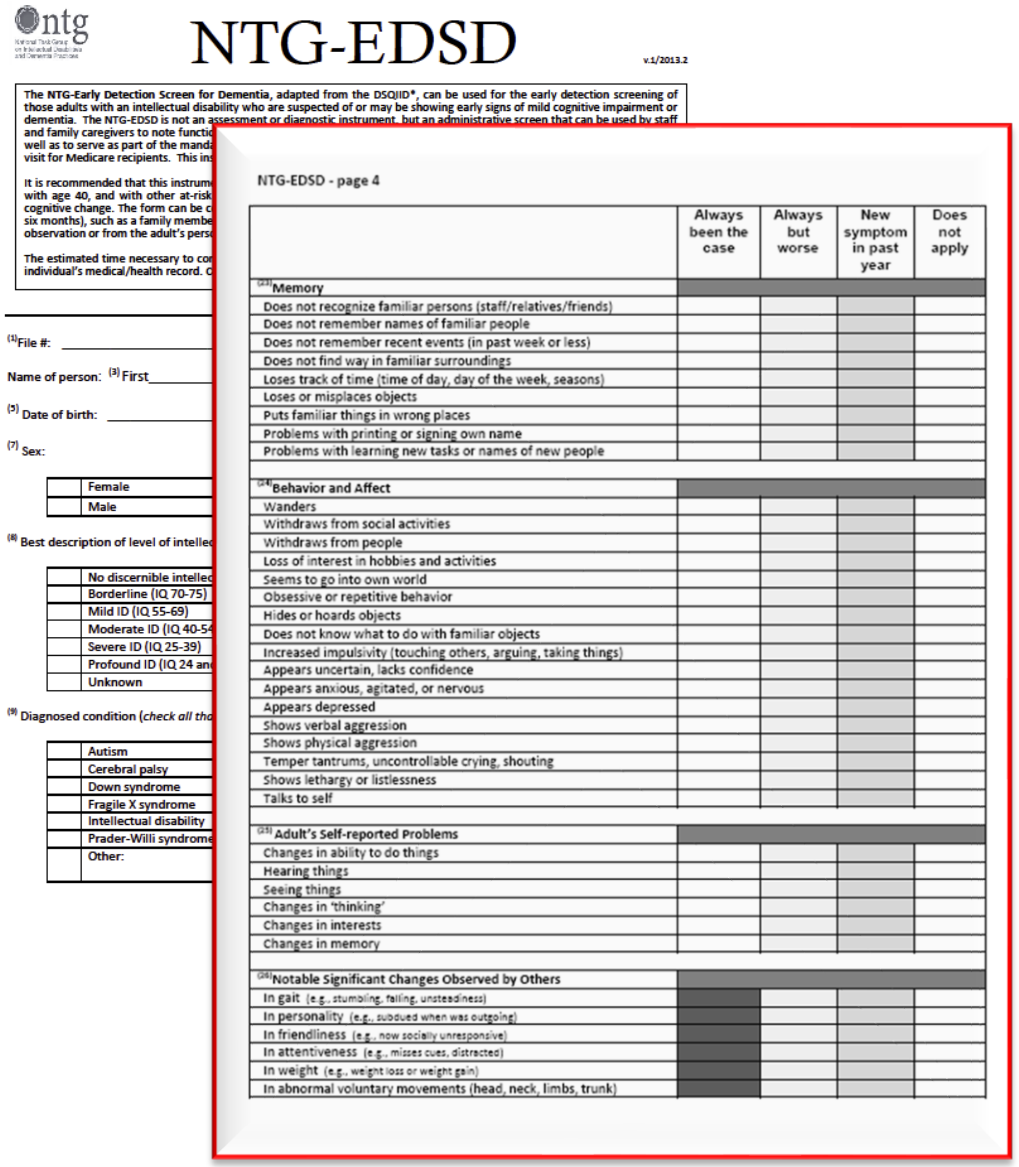
Early detection/screening

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

- Issued in December 2012
- 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

Use: to provide information to physician or diagnostician on function and begin the conversation leading to possible assessment/diagnosis

https://www.the-ntg.org/ntg-edsd



ntg

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 suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functi... well as to serve as part of the manda... visit for Medicare recipients. This ins...

It is recommended that this instrum... with age 40, and with other at-risk... cognitive change. The form can be c... six months), such as a family membe... observation or from the adult's pers...

The estimated time necessary to co... individual's medical/health record. C...

[1] File #: _____

Name of person: [3] First_____

[5] Date of birth: _____

[7] Sex:

	Female
	Male

[8] Best description of level of intelle...

	No discernible intelle...
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-5...
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 an...
	Unknown

[9] Diagnosed condition (*check all tha...*

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

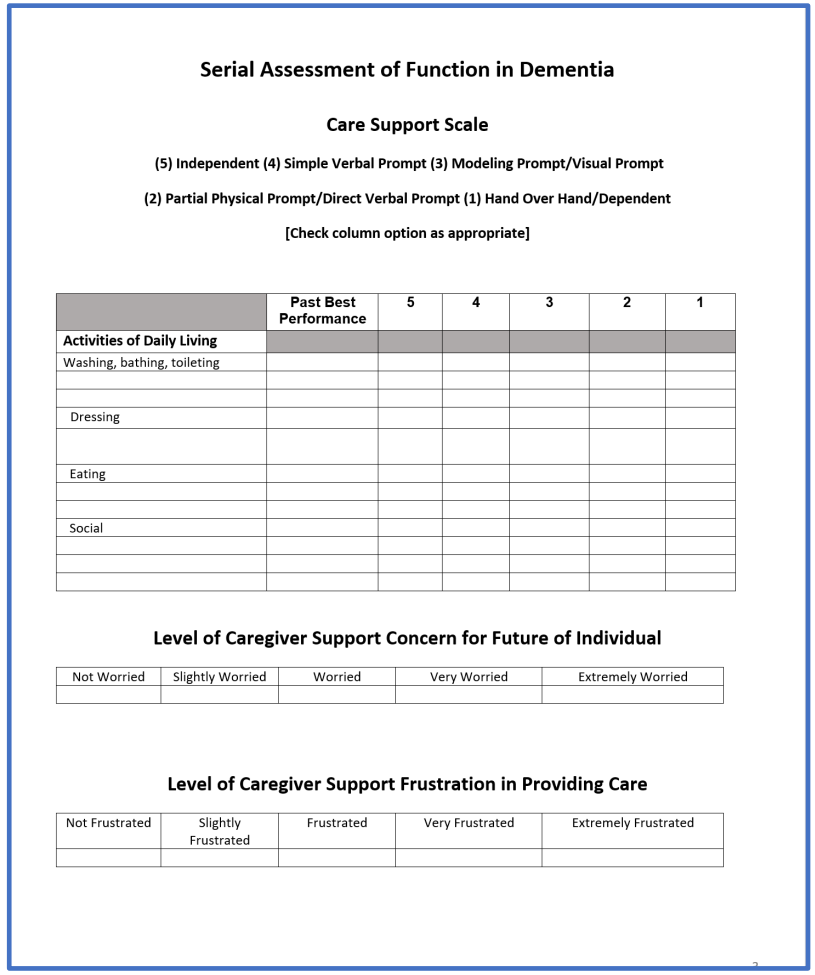
NTG-EDSD - page 4

	Always been the case	Always but worse	New symptom in past year	Does not apply
[23] 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				
[24] 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				
[25] Adult's Self-reported Problems				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
[26] 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)				

Serial Assessment of Function in Dementia

https://www.the-ntg.org/safd

- Informant based
- Likert
- Care Support Scale
- Addresses caregiver concerns
- Severity of dementia symptoms/signs
- Quick overview
- Future; EMR/Digital



Serial Assessment of Function in Dementia

Care Support Scale

(5) Independent (4) Simple Verbal Prompt (3) Modeling Prompt/Visual Prompt

(2) Partial Physical Prompt/Direct Verbal Prompt (1) Hand Over Hand/Dependent

[Check column option as appropriate]

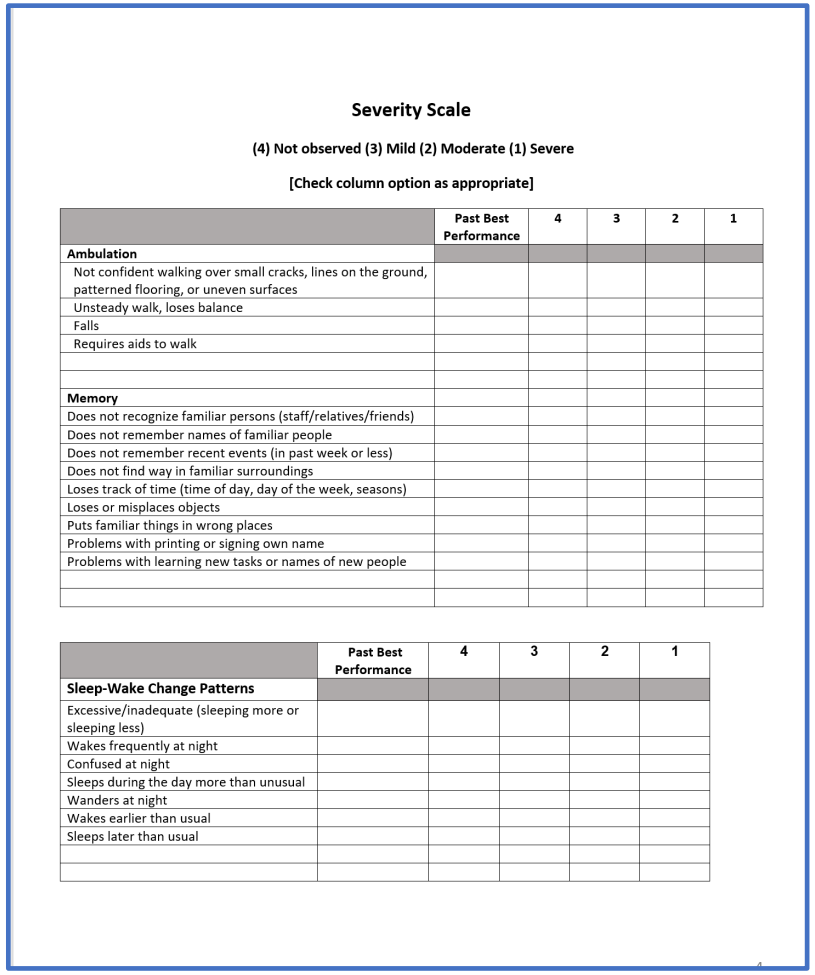
	Past Best Performance	5	4	3	2	1
Activities of Daily Living						
Washing, bathing, toileting						
Dressing						
Eating						
Social						

Level of Caregiver Support Concern for Future of Individual

Not Worried	Slightly Worried	Worried	Very Worried	Extremely Worried

Level of Caregiver Support Frustration in Providing Care

Not Frustrated	Slightly Frustrated	Frustrated	Very Frustrated	Extremely Frustrated



Severity Scale

(4) Not observed (3) Mild (2) Moderate (1) Severe

[Check column option as appropriate]

	Past Best Performance	4	3	2	1
Ambulation					
Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces					
Unsteady walk, loses balance					
Falls					
Requires aids to walk					
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					

	Past Best Performance	4	3	2	1
Sleep-Wake Change Patterns					
Excessive/inadequate (sleeping more or sleeping less)					
Wakes frequently at night					
Confused at night					
Sleeps during the day more than unusual					
Wanders at night					
Wakes earlier than usual					
Sleeps later than usual					

Specialized clinical practice challenges in dementia assessment among adults with intellectual disability. SM Keller, Poster, Alzheimer Europe, Berlin, GE 10/2017.

Changing Focus in I/DD Care

Before the diagnosis of dementia

- Learning new skills
- Independence and autonomy are valued and encouraged
- Behavior modification
- Providing choices, stimulation, and community outings –the more and varied, the better, Community membership !!!!
- Focus on “doing”

After the diagnosis of dementia

- Maintaining function and social interactions as much as possible
- “Hands-on” personal care
- Providing support and failure free activities, timing of activities
- Predictable, consistent routine, stabilizing environment
- Limiting choices
- Focusing on “feeling or being”

- Source: Service, 2017

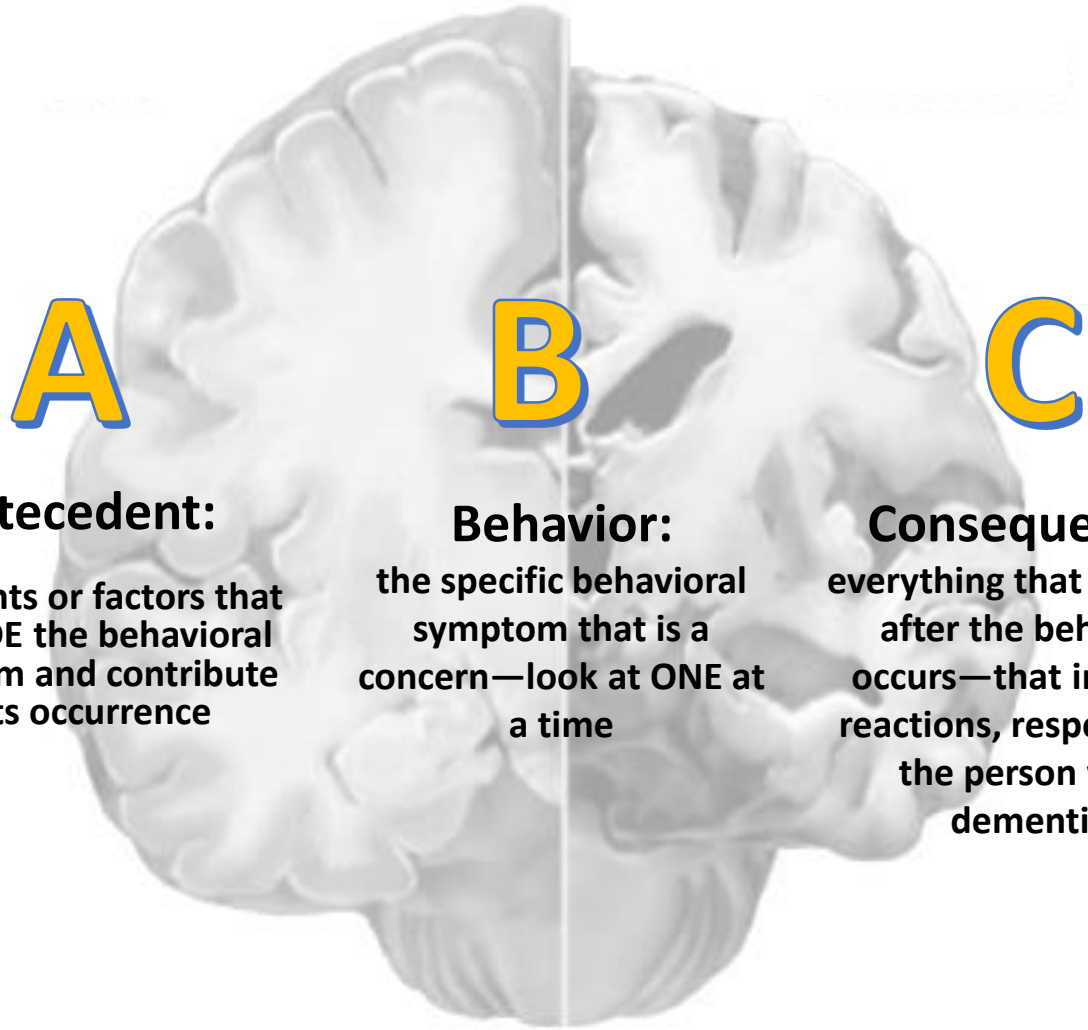
Possible causes of disruptive behaviors

Triggers

- Too hot/cold, thirst / hunger, fright, pain/discomfort (and inability to express such), adverse drug reactions
- Activities: Asked to think of more than one thing at a time, making choices. Being asked questions. ”Why” questions are the hardest
- Changes or interruptions in routines

Internal and External Environments

- **The External Environment-**
  - lighting , glare, shadows, clutter, unfamiliar objects, sounds or people, unpredictable & loud
- Noise level –Conflicting sounds –TV (frightening or rapidly changing scenes), phone, radio, multiple conversations
- Misjudgment or misinterpretation of people and/or events (N.B. Sensory impairments, Vocal accents)



A

Antecedent:

the events or factors that PRECEDE the behavioral symptom and contribute to its occurrence

B

Behavior:

the specific behavioral symptom that is a concern—look at ONE at a time

C

Consequence:

everything that happens after the behavior occurs—that includes reactions, responses to the person with dementia

Healthy Brain Initiative for People with Intellectual and Developmental Disabilities – Healthy Aging Model

Promote brain health for persons with intellectual and developmental disabilities (IDD) and their supports to realize their abilities and cope with life situations by optimizing their cognitive, emotional, psychological and behavioral functioning.
Source: www.healthmattersprogram.org/hbi-pwidd/

Good brain health is a state in which every individual can realize his or her own abilities and optimize their cognitive, emotional, psychological and behavioral functioning to cope with life situations.

WHO

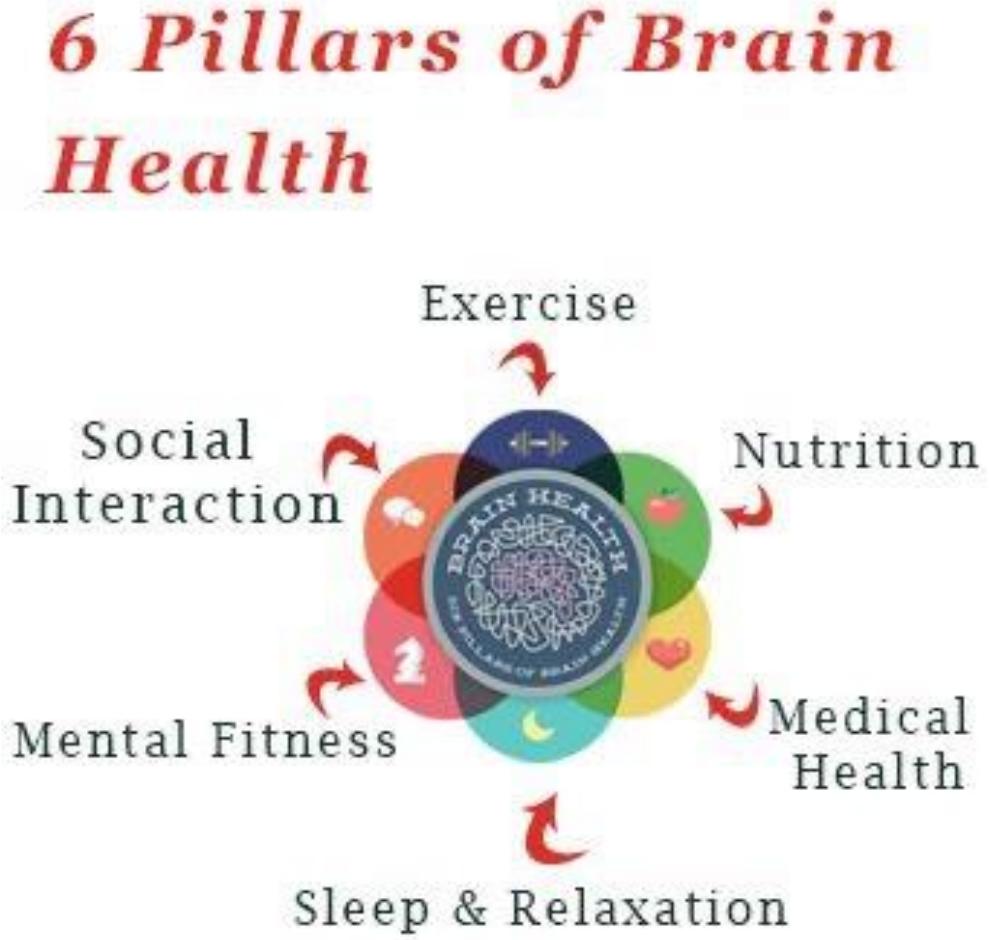
Health Behaviors	Diet and Physical Activity
Clinical Care	Access to Quality Care
Social-Environmental Factors	Education, Employment, Income, Family & Social Support, Community Safety
Physical Environment	Air and Water Quality Housing & Transit

Impact

Increased engagement in:

1. Physical Exercise
2. Food & Nutrition
3. Medical Health
4. Sleep & Relaxation
5. Mental Fitness
6. Social Interaction

Factors for Well-Being across the lifespan –



[Cleveland Clinic Healthy Brains](https://healthybrains.org/pillars)
https://healthybrains.org/pillars

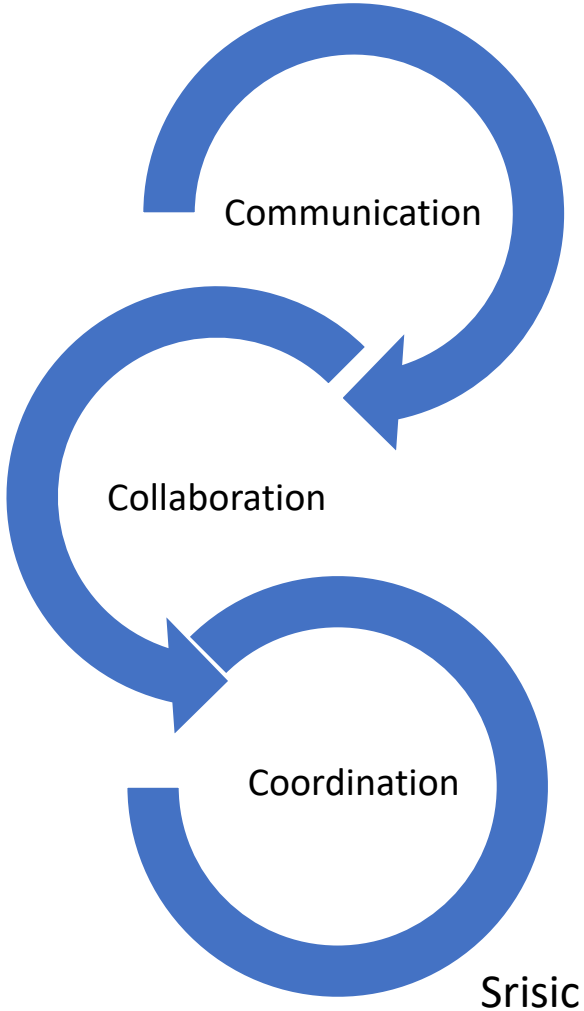
Planning

Goals- Well Being

Life Story & Lifespan- (Baseline)

Dynamic

Person AND Relationship-centered



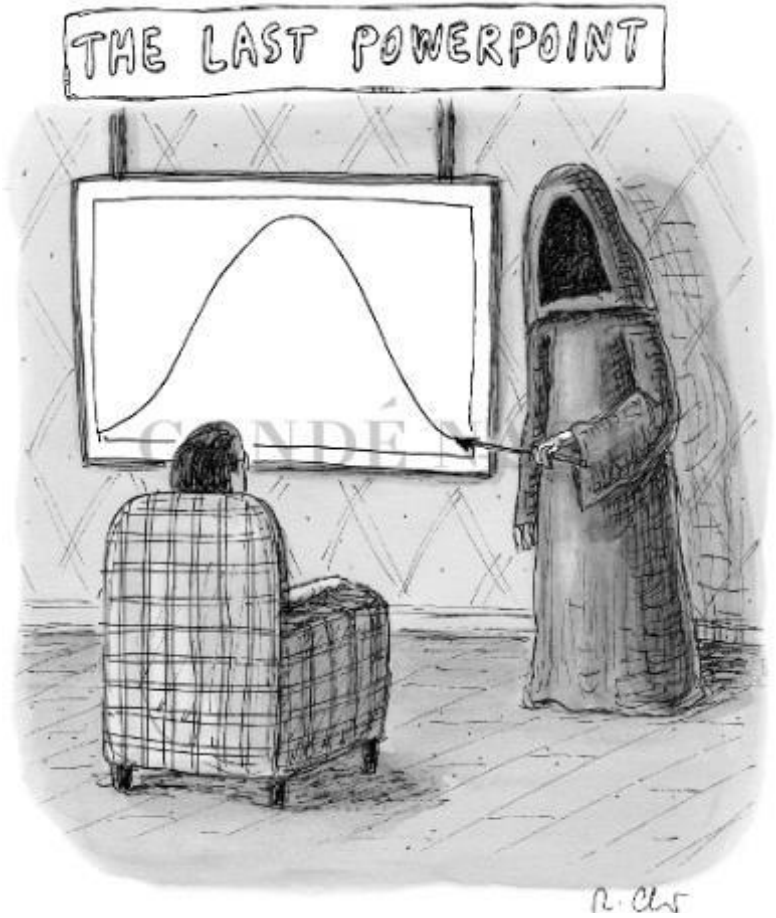
Srisic –Stoehr, 2013

Discovery consists in seeing what everyone else has seen but understanding it for the first time.
Albert Szent-Gyorgyi, Nobel Laureate in physiology & medicine

People First Wisconsin

Dementia Friends Massachusetts

The senses. . .



- With warm appreciation to Robin, John, Bobby, Fred, Tony, Bobbi, Kathleen, Nancy, Kirk, Ellen, Tony, + so many more and their families and staff~

My Greatest Teachers~
What the heart has known, it will never forget

- Kathy Service: kathyservice@gmail.com