Risk Reduction, Brain Health, and Intellectual and Developmental Disabilities

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Background

Research Associate Professor, Department of Disability and Human Development, University of Illinois at Chicago

Co-President, National Task Group on Intellectual Disabilities and Dementia Practices

Member, Federal Advisory Council on Alzheimer's Research, Care, and Services

Principal investigator, Longitudinal study of specialized dementia-related care group homes designed for adults with intellectual disability

Formerly, Director for Aging and Special Populations for the New York State Office for People with Developmental Disabilities, and member of NYS DDPC

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NATIONAL ALZHEIMER’S PROJECT ACT

THE 'NAPA'

The **National Alzheimer's Project Act** required the creation of a national strategic plan to address the rapidly escalating Alzheimer's disease crisis and calls for coordination of Alzheimer's disease research and caregiver support efforts by the federal government

- **National Alzheimer's Project Act** *(became law in early 2011)*
  - Requires DHHS to submit an annual Alzheimer's plan to Congress – from 2012 to 2025
- Administered by federal **Department on Health Human Services** (DHHS)
- **Advisory Council on Alzheimer's Research, Care, and Services**
  - Council composed of Presidential appointees and federal agency staff
  - Creates the **National Plan to Address Alzheimer's Disease** with annual updates

National Plan called for -- among other things….

☑ Issuance of practice guidelines for care and supports and expanded public education

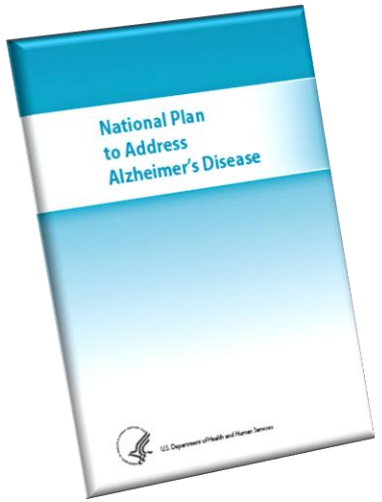
☑ Promotion of assessment tool for detection of cognitive impairment as part of the annual wellness visit

☑ Enhanced supports for caregivers

☑ Expanded research

☑ Special population focus - I/DD

First released on May 15, 2012
Will be updated annually until 2025!



IMPLICATIONS OF NAPA FOR PROVIDERS & COUNCILS

- **Tie-in to State Alzheimer's Plans' objectives**
  - *https://aspe.hhs.gov/pdf-document/national-plan-address-alzheimers-disease*
- **GWEPs* – enhancing the capacity of the workforce (working in dementia-related areas)**
  - *http://bhw.hrsa.gov/grants/geriatricsalliedhealth/index.html*
- **Potential implications of CMS' Setting Rule – Dementia housing**
  - *https://www.medicaid.gov/medicaid/hcbs/index.html*
- **CDC's Healthy Brain Initiative**
  - *http://www.cdc.gov/aging/healthybrain/index.htm*
- **Alzheimer's Disease Program Initiative – Annual funding call-out**
  - *http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/*
  - ID-oriented grant projects funded in various states

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*Geriatrics Workforce Enhancement Program

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BOLD INFRASTRUCTURE FOR ALZHEIMER’S ACT

BOLD Infrastructure for Alzheimer's Act

BOLD Infrastructure for Alzheimer's Act (P.L. 115-406)

Became law on Dec. 31, 2018

- Amended Public Health Service Act
- Created uniform national public health infrastructure with BOLD activities to increase:
  - early detection and diagnosis
  - risk reduction
  - prevention of avoidable hospitalizations
  - support for dementia caregiving
- Promoted implementation of CDC's
  - *Healthy Brain Initiative State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map*
  - *Healthy Brain Initiative Road Map for Indian Country*
- Updated of *Road Map* for 2023-2028 underway

Source: CDC. https://www.cdc.gov/aging/bold/index.html

Definition of Brain Health

'*Brain health*' encompasses neural development, plasticity, functioning, and recovery across the life course

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

World Health Organization

Source: WHO (2021) www.who.int/health-topics/brain-health#tab=tab_1

BOLD *Public Health Centers of Excellence (CoE)* and Public Health Programs

- Funding for state health departments to promote a strong public health approach to Alzheimer's disease and related dementias
- Public Health Centers of Excellence
  - Alzheimer's Association (*Dementia Risk Reduction*)
  - NYU School of Medicine (*Early Detection of Dementia*)
  - University of Minnesota (*Dementia Caregiving*)
- Public Health Programs
  - Core Capacity (18 programs)
  - Enhanced Program (5 programs)

The Healthy Brain Initiative (HBI) is a partnership of organizations across the country working collaboratively to improve the understanding of brain health as a central part of public health

HEALTHYBRAIN INITIATIVE

Source: https://www.cdc.gov/aging/funding/php/index.html

HEALTHY BRAIN INITIATIVE

National Healthy Brain Initiative activities promote brain health, address cognitive impairment including ADRD, and support the needs of caregivers (unpaid persons providing care or assistance to someone with ADRD)

HBI members are involved with

- creating informational resources for the public
- engaging state and local partners to adopt Road Map action items
- developing training materials for current and future professionals about ADRD
- disseminating effective messages related to brain health

https://www.alz.org/hbi-collaborative

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Healthy Brain Initiative Component B Grantees

- International Association for Indigenous Aging
  Native Americans and Alaska Natives

- UIC/HealthMatters™ Program
  Adults with Intellectual and Developmental Disabilities

- UsAgainstAlzheimer's
  Communities of Color and language diversity

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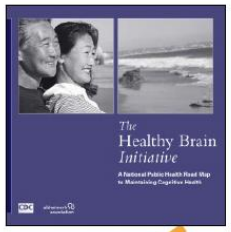
Source: https://www.cdc.gov/aging/funding/php/index.html

History: Healthy Brain Initiative (HBI)

State and Local Public Health Partnerships to Address Dementia

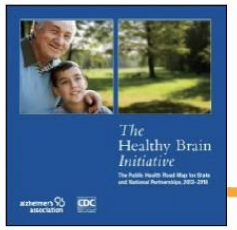
2005
Healthy Brain Initiative
Established with Congressional Support



2007
A National Public Health Road Map to Maintaining Cognitive Health
Published

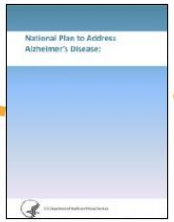
2010
Healthy People 2020
Includes "Dementia" Objectives

2011
National Alzheimer's Project Act (NAPA)
Signed in to Law
(Public Law 111-375)



2013
The Public Health Road Map for State and National Partnerships, 2013-2018
Published

2012
National Plan to Address Alzheimer's Disease
Published



2018
State and Local Public Health Partnerships to Address Dementia, the 2018-2023 Road Map

2019

Healthy Brain Initiative Road Map for Indian Country

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6 Pillars of Brain Health

- Physical Exercise
- Food & Nutrition
- Health Checks
- Sleep & Relaxation
- Mental Fitness
- Social Interaction

Cleveland Clinic Healthy Brain https://healthybrains.org/pillars/

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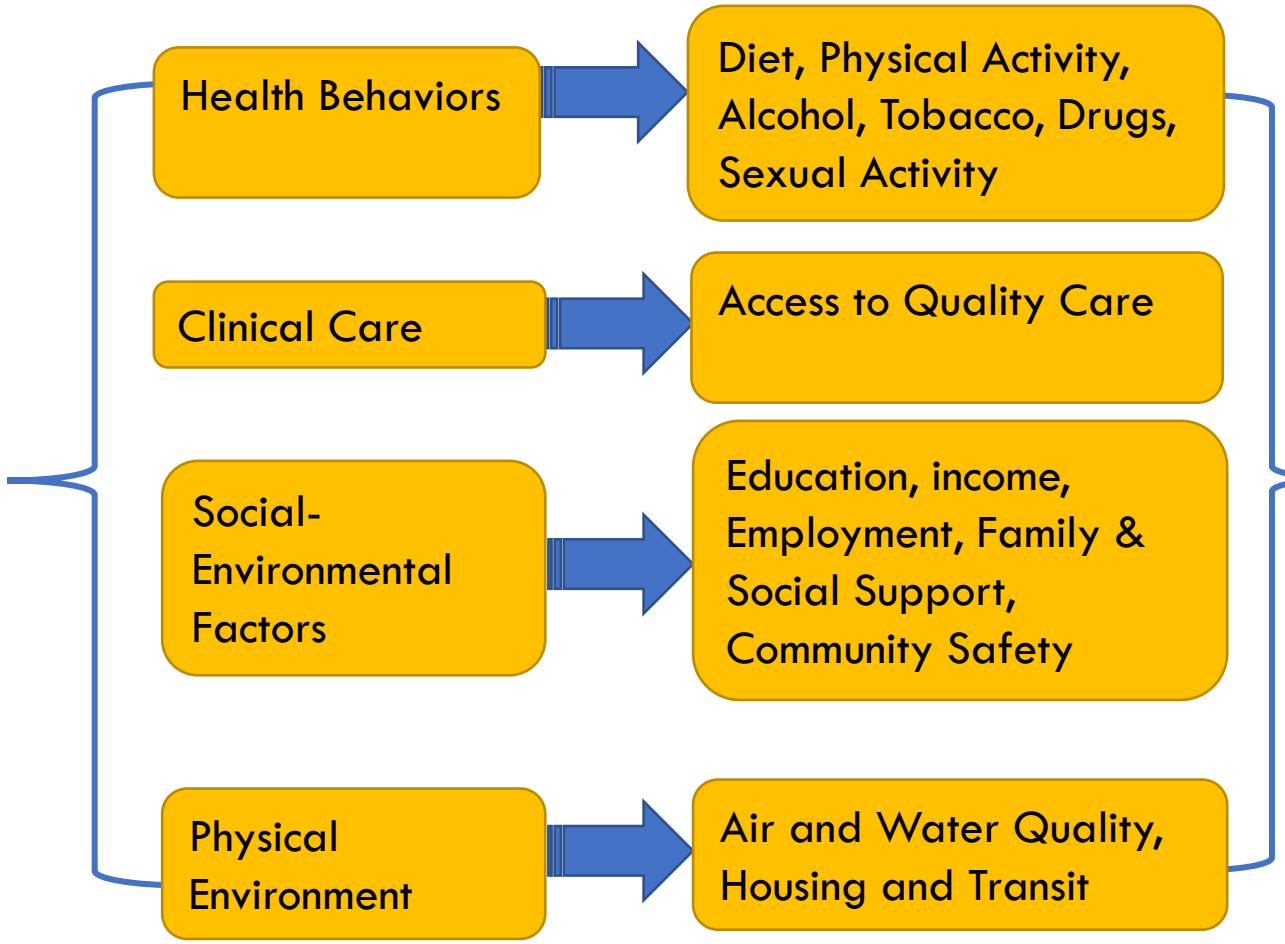
Healthy Brain Initiative for Persons with Intellectual and Developmental Disabilities

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[1]

Promote brain health for persons with IDD and their supports:

1. realize their abilities
2. manage life situations
3. optimize cognitive, emotional, psychological, and behavioral functioning

Social Determinants of Health



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Educate and Empower, Policies and Partnerships, and Workforce Development[2]

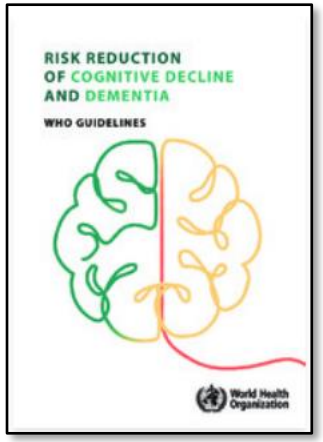
Increased engagement in:

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

[1]WHO [2]Cleveland Clinic Healthy Brain

WHO recommendations

- Physical activity interventions
  - Evidence is strong that physical activities helps reduce risk of cognitive decline
- Nutritional interventions
  - Evidence is strong that a healthy, balanced diet can reduce risk of cognitive decline (Mediterranean-like diet is recommended)
- Cognitive interventions
  - Evidence is low the cognitive exercises work to reduce risk, but any cognitive stimulation helps strengthen brain function
- Social activities
  - Social participation and social support are strongly connected to good health and well-being and thus can mitigate mental health issues



Also, reduction or cessation of alcohol and tobacco use

Source: WHO – Risk reduction of cognitive decline and dementia guidelines. https://www.who.int/publications/i/item/9789241550543

'NAPA', BOLD, & NTG

National Task Group on Intellectual Disabilities and Dementia Practices

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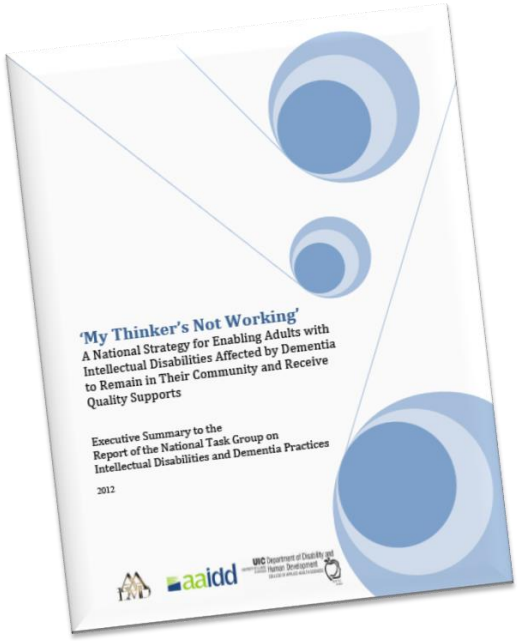
'My Thinker's Not Working'

National Task Group on Intellectual Disabilities and Dementia Practices



- ✓ To define best practices that can be used by agencies in delivering supports and services to adults with intellectual disabilities affected the various dementias
- ✓ To identify a workable national a 'first-instance' early detection / screening instrument
- ✓ To produce educational materials of use to families, people with ID, and providers of services
- ✓ To further public policy with respect to dementia as it affects adults with intellectual disabilities

The **National Task Group** is a not-for-profit corporation charged to advocate, educate, provide technical assistance and program protocols, and guide public policy. Its members are composed of provider agency personnel, clinicians, academics, government officials, family members, and others.

The NTG is associated with the National Down Syndrome Society, is part of the LEAD Coalition in Washington, and has connections with university aging programs and community organizations.

www.the-ntg.org

THE FUNCTIONS OF THE 'NTG'

- Advocacy
- Education & training
- Family aids
- Policy
- Information dissemination
- Diagnostics and assessment
- National and international connections

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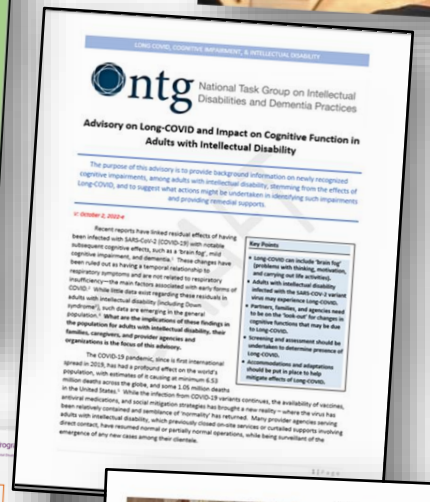
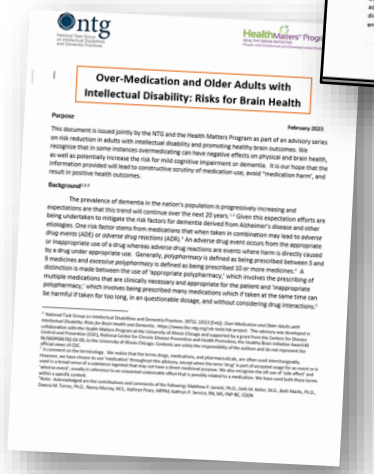
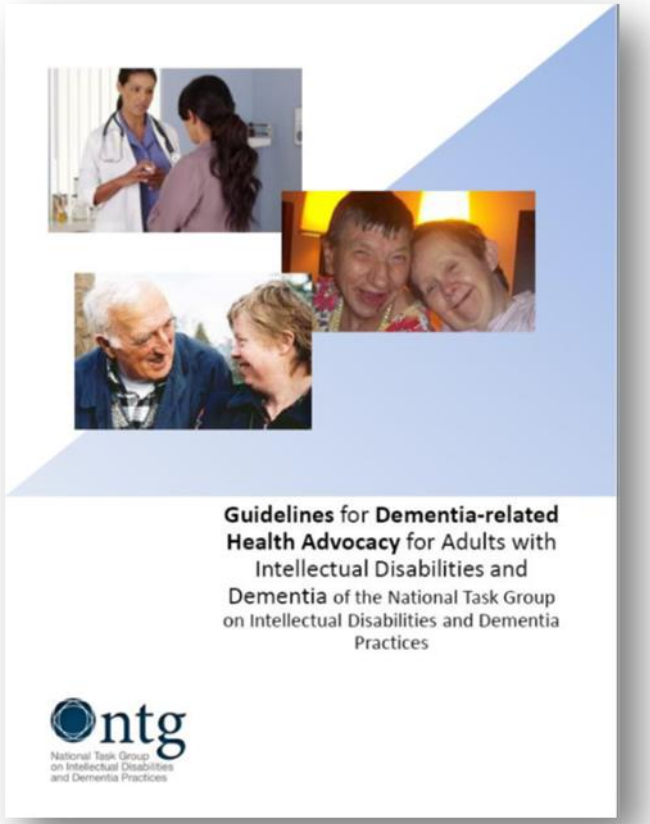
www.the-ntg.org

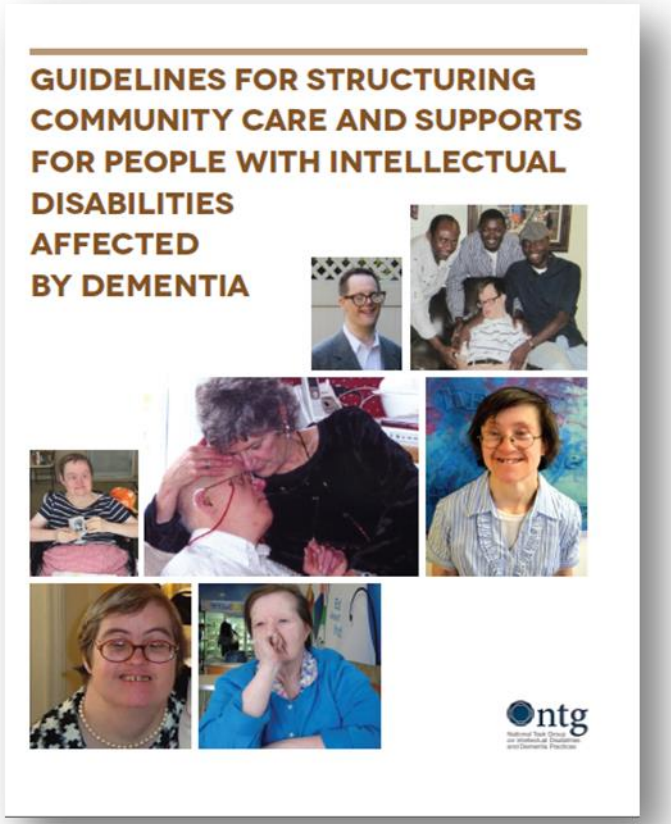




NTG GUIDELINES

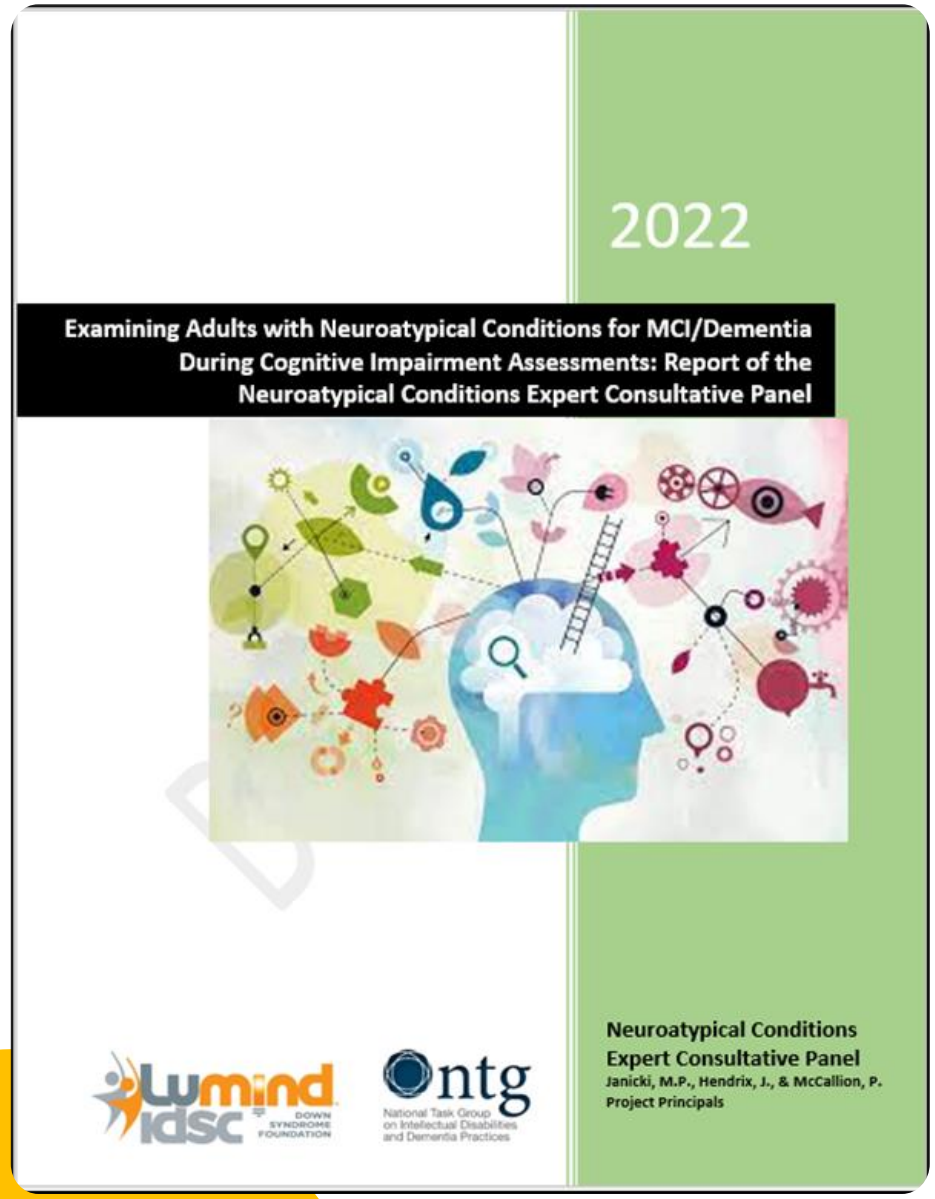


JANICKI (2023) **Health advocacy**



Community living & supports

Diagnostics and medical care



The Neuroatypical Conditions Expert Consultative Panel

Assembled by the Lumind IDSC Foundation and the National Task Group on Intellectual Disabilities and Dementia Practices

- Composed of academic and clinical experts familiar with each of the neuroatypical conditions included

Charged with:

- **examining** what **barriers** existed to effective screening, detection, and assessment of adults with neuroatypical conditions and with…
- **identifying** the special **adaptations** that may be employed when examining adults with these conditions

www.the-ntg-org

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Risk reduction, Brain health, and Dementia

Intellectual Disabilities and Dementia

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Adult life factors contributing to brain risk

- Social deprivation
- Malnutrition
- Obesity
- Adverse drug reactions/polypharmacy
- Inadequate stimulation or remediation
- Toxic element exposure (e.g., lead, mercury)
- Head injuries
- Mental distress
- Tobacco, alcohol, and drug abuse

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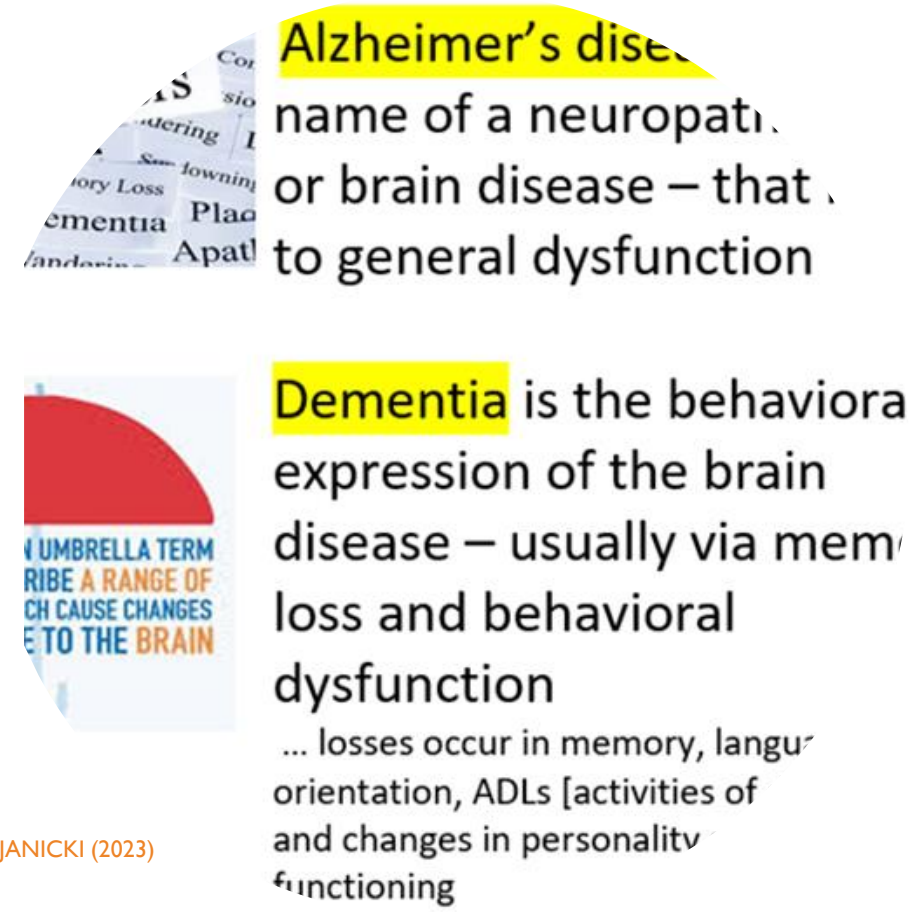
THINGS TO KNOW ABOUT DEMENTIA



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- **Dementia an umbrella term** for a range of changes in behavior and function affecting aging adults and usually linked to brain disease (e.g., Alzheimer's) or injury (e.g., stroke)
  - Alzheimer's is **a disease of the brain** – dementia describes the resulting behavior
  - Most adults with Down syndrome (DS) are at high **risk of Alzheimer's disease** and consequently dementia; same risk as general population for adults with other ID
  - **Average age of 'onset'** in Down syndrome is about **53** and +60s/-70s for ID; Alzheimer's begins some 20 years before 'onset'
  - **Changes in memory** often signal dementia in ID; changes in personality often signal dementia in DS
  - After diagnosis **progressive decline in DS** can last for from 1 to 7+ years; up to 20 years in other ID
  - Care after the early stage can become more challenging as memory, self-care, communication, and walking become more difficult… eventually leads to **advanced dementia**

WHY SOMETHING TO THINK ABOUT?

- Dementia is the result of a brain disease or injury, such as Alzheimer's disease, Lewy body disease, or a brain injury or trauma
- With progression an adult with dementia is increasingly less able to take care of him or herself … and requires supervision and someone to help him or her with necessities
- Main dementia care options for most agencies are to support the person in place (whether at home or in their residential accommodation), refer to a long-term care facility, or admit to a specialty dementia-capable group home
- Dealing with dementia calls upon agencies to make some critical decisions about dementia care and developing support resources

KEY DIFFERENCES IN ADULTS WITH INTELLECTUAL DISABILITY

Some adults have early onset and shorter duration

- Younger-age (or early) onset is found in adults with Down syndrome and head injury
- Most adults with Down syndrome survive less than 7 years after the onset of dementia

Some differences in symptom presentation

- Most early symptoms are the same, except in Down syndrome where there are more notable early personality changes

Assessments are conducted differently

- Standard tests used with typical adults with dementia are not useful – With adults with intellectual disability need to use comparisons of the same individual over time

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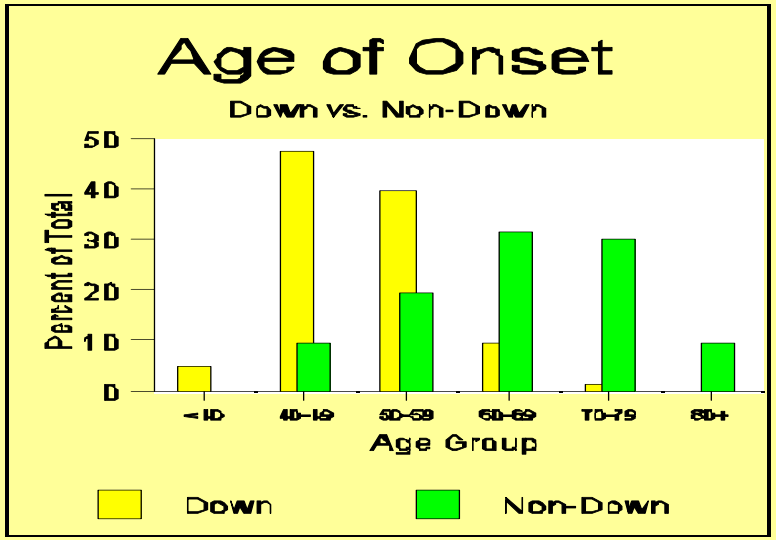
WHY IS RECOGNITION OF 'ONSET' IMPORTANT?

- **Knowing expected onset gives a 'heads-up' for initiating surveillance**
  - Look for changes
  - Introduce periodic screening
  - Alert staff to be watchful
  - Provides for an 'index of suspicion'
- **Helps us to begin to reformulate services and care practices**
  - Creating safer environments
  - Introducing cues for movement and way-finding
  - Engaging in planning ahead for eventualities
  - Setting goals for terms of service – adapting personal program plans
  - Helping to anticipate parental/kin caregiver needs with aging



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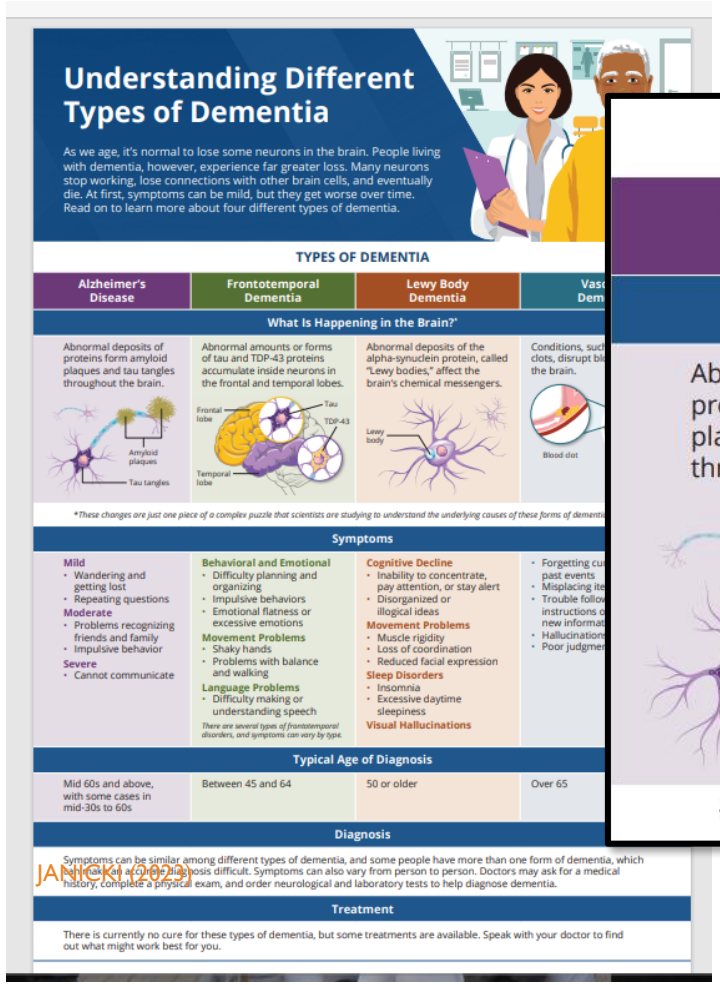
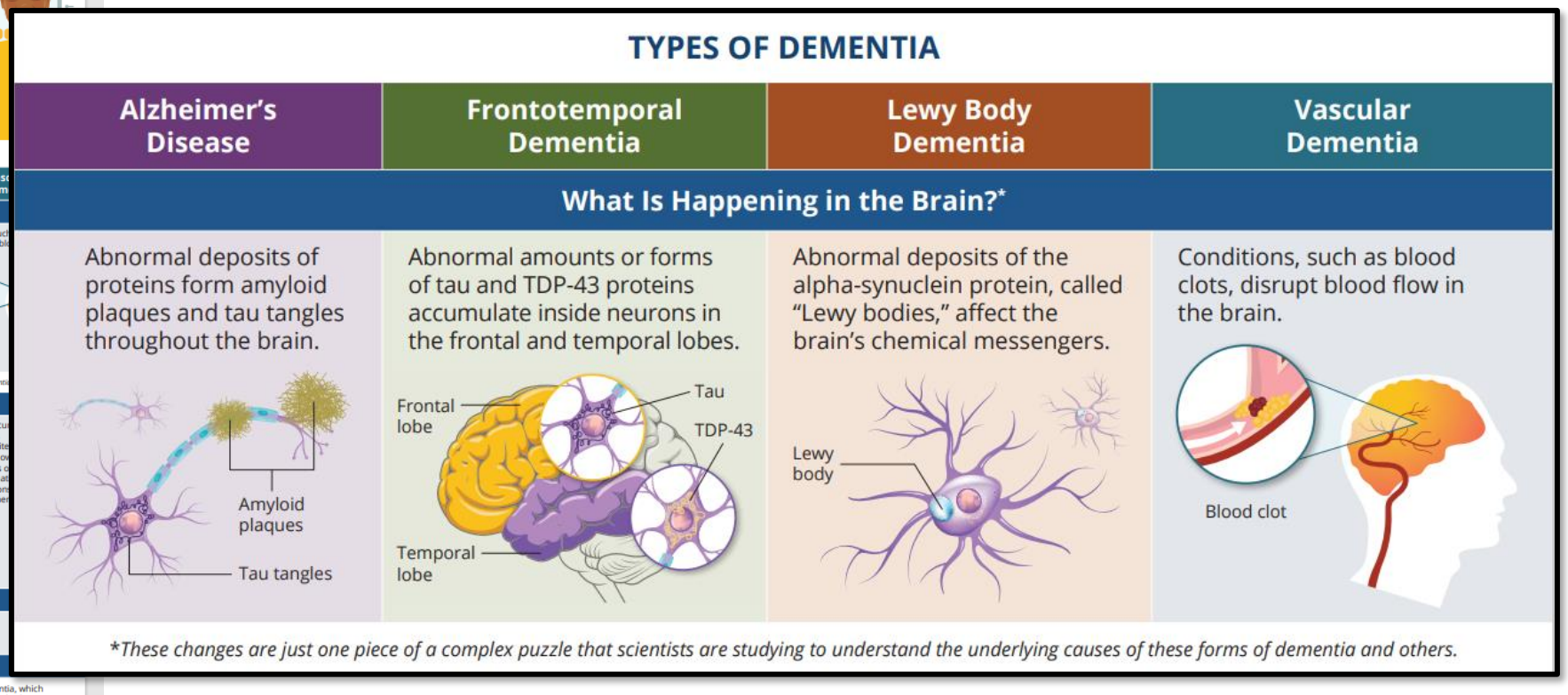
TYPES OF DEMENTIA





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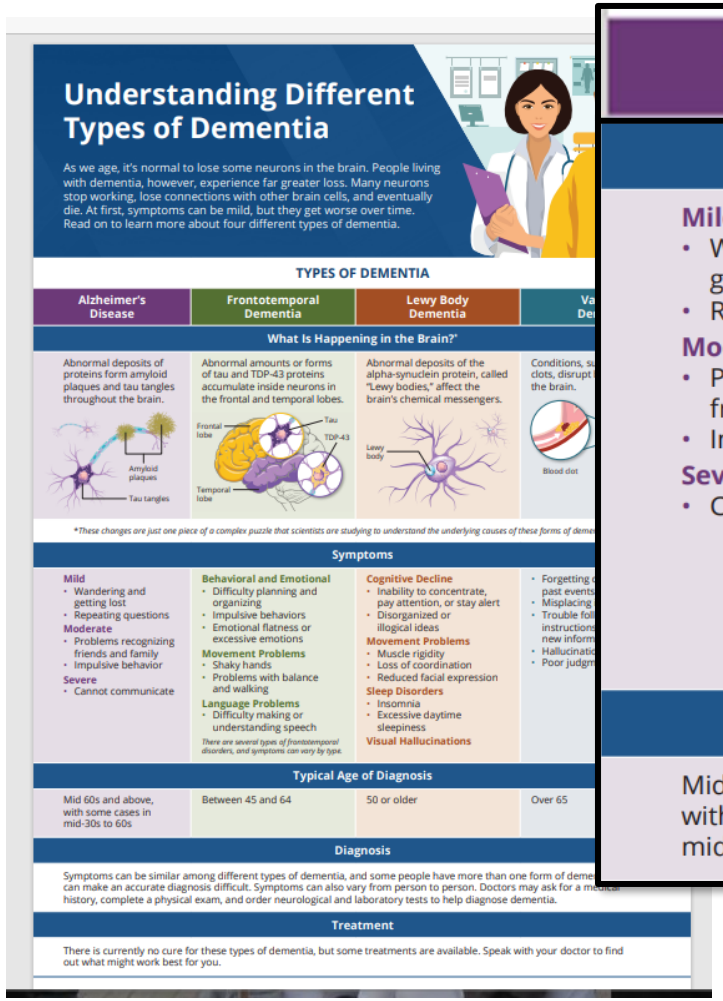
SYMPTOMS BY TYPE OF DEMENTIA



Alzheimer's Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
Symptoms			
Mild • Wandering and getting lost • Repeating questions **Moderate** • Problems recognizing friends and family • Impulsive behavior **Severe** • Cannot communicate	**Behavioral and Emotional** • Difficulty planning and organizing • Impulsive behaviors • Emotional flatness or excessive emotions **Movement Problems** • Shaky hands • Problems with balance and walking **Language Problems** • Difficulty making or understanding speech *There are several types of frontotemporal disorders, and symptoms can vary by type.*	**Cognitive Decline** • Inability to concentrate, pay attention, or stay alert • Disorganized or illogical ideas **Movement Problems** • Muscle rigidity • Loss of coordination • Reduced facial expression **Sleep Disorders** • Insomnia • Excessive daytime sleepiness **Visual Hallucinations**	• Forgetting current or past events • Misplacing items • Trouble following instructions or learning new information • Hallucinations or delusions • Poor judgment
Typical Age of Diagnosis			
Mid 60s and above, with some cases in mid-30s to 60s	Between 45 and 64	50 or older	Over 65

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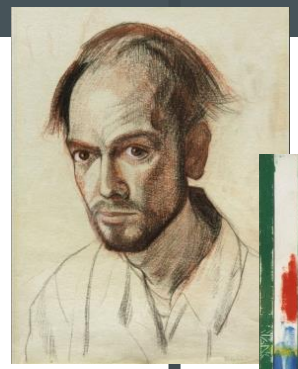
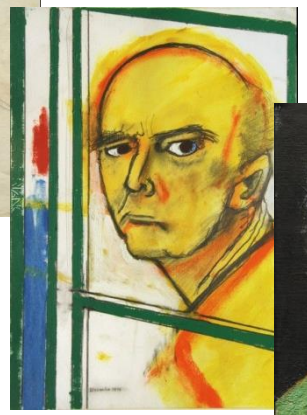
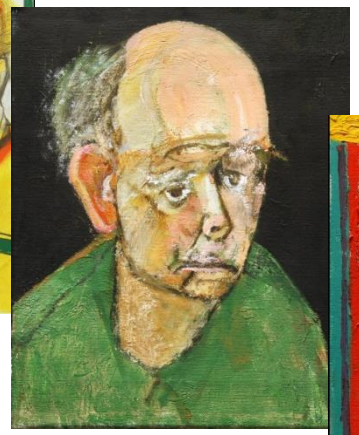
PROGRESSIVE COGNITIVE DETERIORATION DUE TO ALZHEIMER'S DISEASE



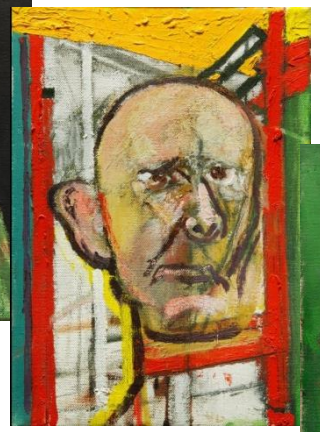
1967



1996



1997



1998

1999

2000

Functional capacity

Time

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Source: http://www.huffingtonpost.com/2012/02/09/william-utermohlens-self-portraits_n_1265712.html

IMPLICATIONS OF TRAJECTORIES AND DURATION

- Knowing something about variations in trajectories
  - Anchors around potential duration of 'stay' at same level of functioning
  - Provides ideas about potential changes and their nature
  - Creates a schedule for timing changes in service orientation – planning care, evaluating patterns of care, and organizing staffing and environmental modification
  - Provides an empirical basis for expectations of co-morbidities
  - Gives staff information about anticipating changes
  - Helps with introducing ameliorative interventions or aids for day-to-day functioning
  - Eases long-term planning for care financing (budgeting for shifts in staff and housing)

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UNDERSTANDING DEMENTIA

Knowns…

- People with ID have same rate of dementia as general population (some exceptions)
- Some people with ID have higher rates (e.g., Down syndrome, head injury)
- Some % of any adult client pool will be affected
- Early interventions can aid in adapting to changes and prolonging lucid periods
- Effects of dementia will be progressive and eventually lead to death

Unknowns…

- Who will be affected?
- How pronounced will be early changes?
- How dramatic will be the changes in function?
- How long will person live after diagnosis?
- What other diseases or medical conditions may be co-incident?
- Which particular dementia-related behaviors will be more evident?

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EXPECTATION OF CHANGE AND FACTORS IN ID AND DEMENTIA UNDERLYING HOUSING AND CARE PRACTICES

Expectations of change

- Cognitive skills will decline
- Support needs will increase
- Increase risks of falls, injuries
- Swallowing dysfunction, clots, pneumonia, bladder infections, nutritional deficiencies, seizures

Care factors

- Watch for signs of abuse and neglect (including self-neglect)
- Watch for signs of caregiver burn-out and stress at home … effects adult's behaviors
- Watch for advanced dementia and needs for end-of-life care (palliative care and hospice)

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ID associated issues that extenuate these factors:

- Co-incident conditions that may affect gait, sensory faculties, and cognition
- Co-morbidities or diseases that may affect physiological functions
- Previously identified 'mental health' issue
- Late-onset seizures
- Precocious (early) aging effects
- Expressive language difficulties
- Nutritional deficiencies & diet inadequacies
- Presence of polypharmacy

ntg
National Task Group on Intellectual Disabilities and Dementia Practices

WHAT SERVICES ARE NEEDED FOR AGING PEOPLE WITH ID AND DEMENTIA?

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- **Pre-clinical symptom phase**
  - Periodic screening
- **Assessment & diagnostic phase**
  - Referrals for assessment and diagnosis
- **Post-diagnostic support phase**
  - Supports for continued living with families - when available and appropriate
  - Interventions to help with *Behavioral and Psychological Symptoms of Dementia*
  - Health reviews and surveillance
  - Appropriate screening and assessments for co-incident aging-related conditions
  - Health maintenance – nutrition and exercise
  - Supports for 'dementia-capable' care in community care settings that can change as the disease progresses; including education and training
  - Supports for caregivers

WHAT CAN BE DONE?

- Improve understanding of aging and dementia
- Be alert to risk and early signs decline
- Adapt living environments to minimize risk
- Help with futures planning (health and social care)
- Aid families who are carers
- Enhance staff skills – training with respect to dementia
- Quality checks on services
- Provide stage-related services
- Plan for future growth of aging segment of population

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RISK REDUCTION, BRAIN HEALTH, AND DEMENTIA

SOME THOUGHTS

Taking on a 'lifespan' perspective

What happens in younger age influences what occurs in older age

What can help?

Reduce stressors – improve mental health and consequently brain health

Consider nutrition and weight – avoid overweight – leads to disease

Promote social inclusion and involvement – stimulate cognitive capacities

Look at total life situation – who is involved, who helps, who influences

Stimulate planning – get systems involved to aid lifespan health and later age outcomes

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Targeting Risk Reduction

Possible activities…

- Request that state **public health healthy brain measures** include activities targeting adults with intellectual disability
- Engage state developmental disabilities authorities to **improve healthy life situations and practices** among adults with intellectual disability
- Provide materials that **enhance education** and information uptake among adults with intellectual disability
- Enhance **medical training and continuing education** curricula so that practitioners are more surveillant of compromising co-incident health conditions and employ beneficial prophylactic interventions for brain health

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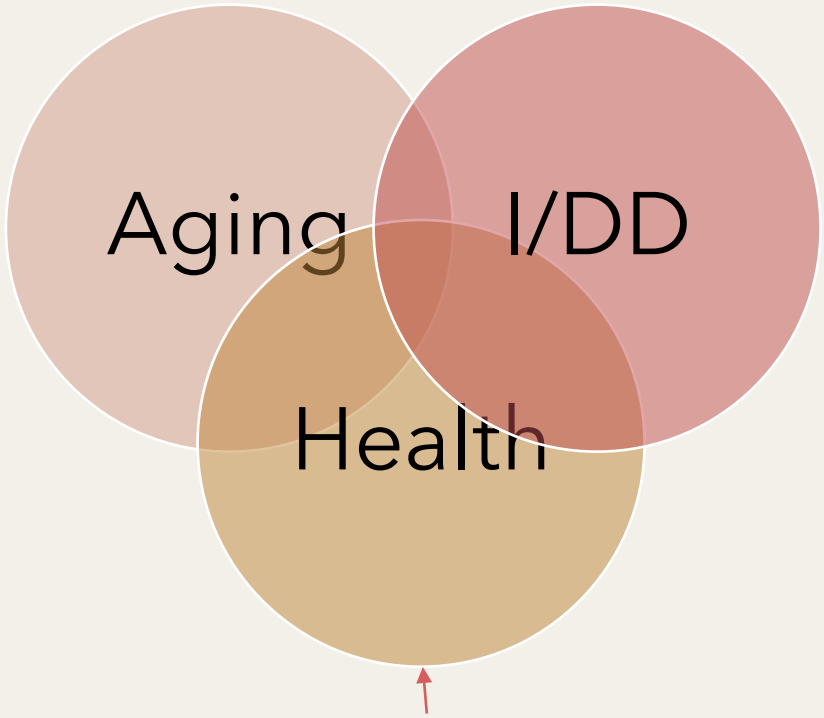
Bridging Silos/Networks

Older adults in general



Adults with intellectual and developmental disabilities

Senior centers
Nutrition sites
Adult day
Supports

Support services
Residential support
Advocacy
Day/vocational

Health services sector

Diagnostics, Health care, Treatment

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Scope of Aging

- Recognition that as people with developmental disabilities age, the focus of services changes
  - transitions to 'retirement'
  - variations in aging trajectories
  - refocusing medical concerns
  - non-vocational activities
- Needs for variability in housing and daily supports
- Health considerations provide critical focus – both physical and mental health
- Adults over 60 are a heterogenous group, ranging in capabilities, health status, and needs …*no "one size fits all" approach*
- Older Americans Act services – access and bridging

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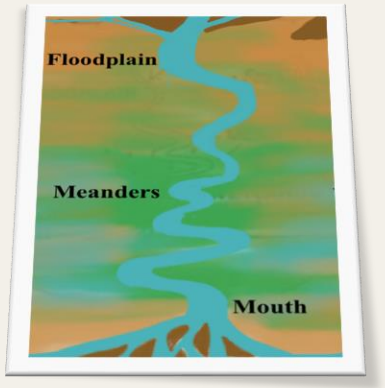
Activities at all levels



UPSTREAM INTERVENTIONS

- Structural determinants such as social status, income, racism, and exclusion (meaning having resources, not experiencing daily "triggers" with racism, sexism, ageism, ableism, and having to advocate for living essentially)…. changes that generally happen at the macro policy level: state, national, and transnational. *These are about diminishing the causes-of-the-causes*.

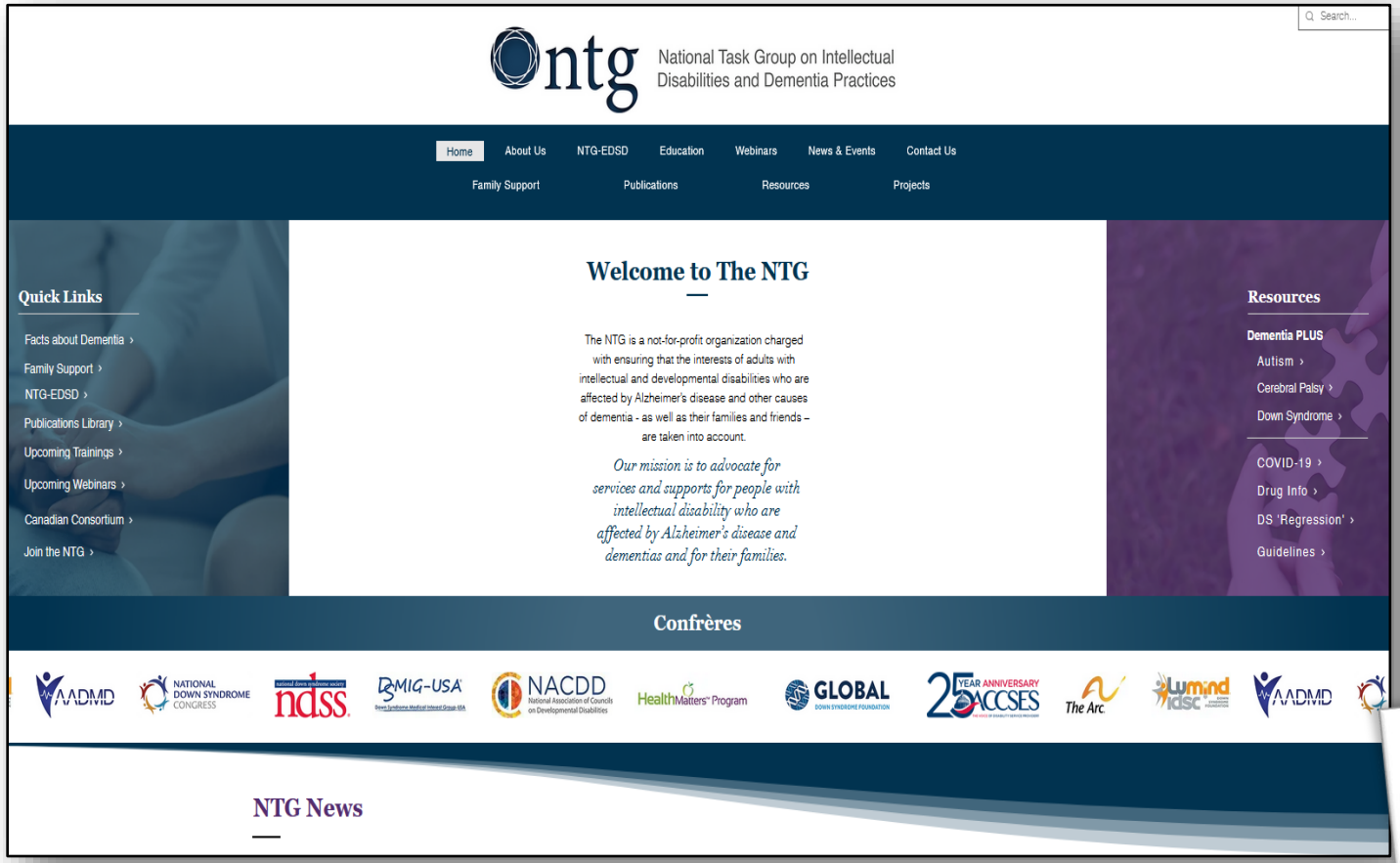
MIDSTREAM INTERVENTIONS

- Intermediary determinants, or material circumstances such as housing conditions, social and emotional supports, health and food security … these changes generally occur at the micro policy level: regional, local, community or organizational. *These are about changing the causes*.

DOWNSTREAM INTERVENTIONS

- Immediate needs of populations that are marginalized,. *These are about changing the effects of the causes*.

Source: National Collaborating Centre for Determinants of Health. (2014). Let's talk: Moving upstream. Antigonish, NS: National Collaborating Centre for Determinants of Health, St. Francis Xavier University.



The NTG website – *everything you need to know* about adults with intellectual and developmental disabilities and dementia

www.the-ntg.org

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National Task Group on Intellectual Disabilities and Dementia Practices