

Brain Health Across the Lifespan for People with Intellectual and Developmental Disabilities

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Disclaimer

- The views expressed in this presentation are strictly those of the presenter and do not reflect any official positions of the California Department of Developmental Services
- Review of the **NTG-EDSD (National Task Group-Early Detection Screen for Dementia)** represents work done through the National Task Group for Intellectual Disabilities and Dementia Practices

Objectives for Presentation

- ❖ Consider strategies that support brain health for people with intellectual and developmental disabilities across the lifespan
- ❖ Consider the six pillars of health
- ❖ Introduce the **National Task Group-Early Detection Screen for Dementia (NTG-EDSD)** and make the case for its use for adults age 35+ as a tool for health promotion, advocacy and shared decision-making



The Good News...

- Although we do not have a cure for aging related cognitive and adaptive decline, there is a great deal that we can do to reduce risk of that decline
- Many of the health conditions and lifestyle choices that put us most at risk for poor health, cognitive and functional decline as we age, are modifiable
- Healthy aging = cognitive health
- The same things we can do for persons without disability, we can do for persons with disabilities



Aging is a Lifelong Process

- Aging begins at birth...
- The quality of older adulthood for individuals with disabilities will be influenced by the quality of their childhood, early and middle adulthood
- Begin healthy lifestyle choices as early as possible
- Regular and routine healthcare
- Attention to exercise, nutrition, stress level, relationships, meaningful activity
- Attention to chronic medical conditions which will impact the overall health of the older adults with disabilities
- Attention to sensory processing issues (i.e., hearing, vision and movement) that are important to adaptive functioning and often overlooked

Expected Physical Changes of Aging

- Age-related bone loss
- Progressive loss of muscle mass
- The lens of the eye becomes stiffer and less flexible – affecting the ability to focus on close objects (accommodation)
- Age related change in the ability to detect higher pitches – more noticeable in those age 50+
- Changes in the sense of taste 60+
- Olfaction (i.e., the sense of smell), decrements become more noticeable after age 70+
- Reduction in sensitivity to pain, touch, temperature, proprioception
- Reduction in balance and coordination
- Reduction in short term memory, changes in attention and tracking, change in effort needed to retrieve learned information, changes in processing speed (we all slow down!)

What do we know about aging with IDD

- Given the higher incidence of medical and mental health disorders among persons with IDD, we are more likely to see the cumulative effects of chronic health conditions and decades of therapeutics as individuals age
- Individuals with IDD are more likely to experience aspiration, dehydration, constipation, sensory processing issues that go undetected and untreated at onset and contribute to declines in cognitive and overall functional status
- Higher risk for falls than same aged peers with heightened risks attributable to seizure disorder, taking four or more medications, using mobility assistive devices or having other physical limitations (Scaife, Lape, and Woods 2019)
- Life expectancy for persons with IDD generally lower than for non-disabled population
- Individuals with IDD may not be diagnosed or treated for medical or mental health conditions by virtue of lack of access to medical and psychiatric services and disparity in care experienced by individuals with IDD

Attention to the aging trajectory for neurodevelopmental disorders

- Down syndrome is associated with early onset dementia because of the genetic tendency for accumulation of beta amyloids with trisomy 21; individuals with DS may also experience cardiac, thyroid and sleep apnea which have implications for brain health
- Cerebral palsy can be associated with changes in muscle tone, swallowing and pain that impact overall functioning with age
- Prader Willi can be associated with higher rates of cardiovascular disease and diabetes
- Adults with Fragile X may have more issues with heart problems, musculoskeletal problems
- Sensory processing issues may go unrecognized or untreated contributing to decreases in adaptive behavior or cognitive functioning
- Individuals with IDD are thought to carry a higher risk for mental health conditions (that require medication management) than their non-disabled peers

COVID-19 has taken a toll on the brain health of aging individuals with IDD

- We have heard about an increase in reported loneliness connected with such COVID restrictions as quarantine and social distancing
- We are still learning about the brain health effects of COVID on the overall cognitive functioning for long-haulers; might there be distal effects for those recovering from COVID?
- Individuals have been at risk for heightened stress due to loss of loved ones, disruptions in care routines, reduction in community access and disruption of social networks

Loneliness is a health risk

- Loneliness is a physical and mental health risk.
- Social isolation is viewed as a risk factor for premature death on the order of cigarette smoking, physical inactivity and obesity
- Without social connection and meaningful activity cognitive and functional status may decline
- Loneliness and isolation can have serious health consequences.
- Research has shown that people who feel lonely or isolated are at increased risk for developing coronary artery disease, stroke, depression, high blood pressure, declining thinking skills, an inability to perform daily living tasks, or an early death.



Health Maintenance

- Wellness check-up
- Immunizations
- Monitor health issues unique to neurodevelopmental conditions
- Age and gender relevant health screenings:
 - ❖ diabetes
 - ❖ cholesterol,
 - ❖ Cervical and breast cancer screening for females; prostate exams for males
 - ❖ Colorectal cancer
 - ❖ osteoporosis
 - ❖ depression and suicide risk
 - ❖ cognitive screening for adults 50+

Ten Health Risks That Impact Wellness

- Tobacco usage
- High Blood Pressure
- Stressful living
- Lack of physical activity
- Overweight/ obesity
- Poor diet
- Home safety
- Lack of personal care
- Lack of social connection
- Lack of mental stimulation



SIX PILLARS FOR HEALTHY BRAIN HEALTH

Exercise, nutrition, sleep, mental
stimulation, social connection



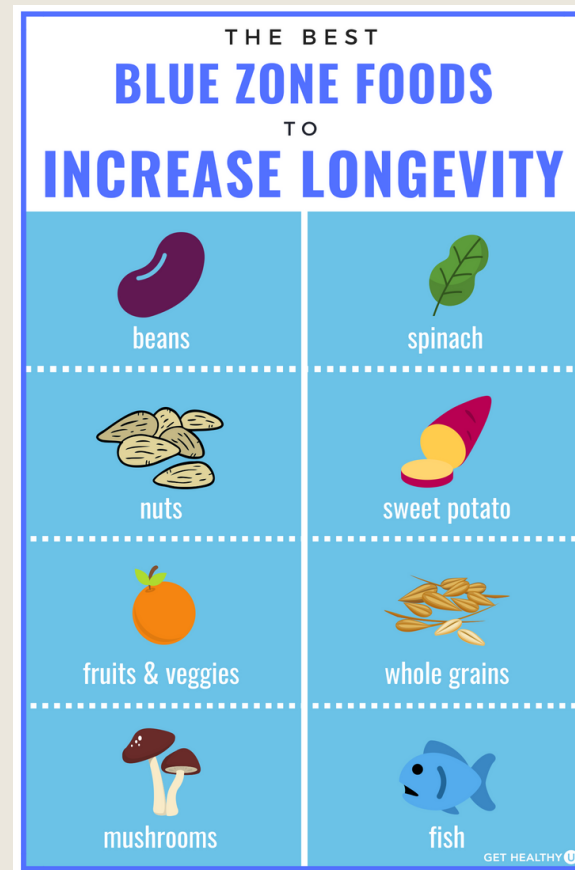
Never Too Late to Start Exercising!

Exercise is a great way to improve health, physical functioning and well-being. Among the reported benefits:

- improved strength and mobility
- improved balance which can help prevent falls
- improved mood, decreased fatigue, lowered blood pressure and cholesterol
- improved self-esteem
- increased clarity of thinking
- Physical Activity can improve sleep, prevent weight gain and improve bowel and bladder function

Food Eaten in the “Blue Zones”

- Follow the 95:5 rule—eat mostly plants
- Eat small portions of meat
- Moderate fish because of pesticides
- Avoid cow’s milk
- Eat a cup of beans daily
- Limit sugar; use honey
- Eat a handful of nuts daily
- Eat only 100% whole-grain breads
- Eat whole foods or ones with fewer than five ingredients
- Drink mostly water



Common Denominators within the “Blue Zone” (places known for healthy brain aging)

- Move naturally, such as walking, gardening
- Purpose for waking up each day
- Routines to deal with stress
- Stop eating when 80% full and eat smallest meal at end of day
- Diet includes beans (fava, black, soy and lentil)
- Drink wine moderately
- Belong to a faith-based community
- Put families first
- Belong to social circles that support healthy behaviors

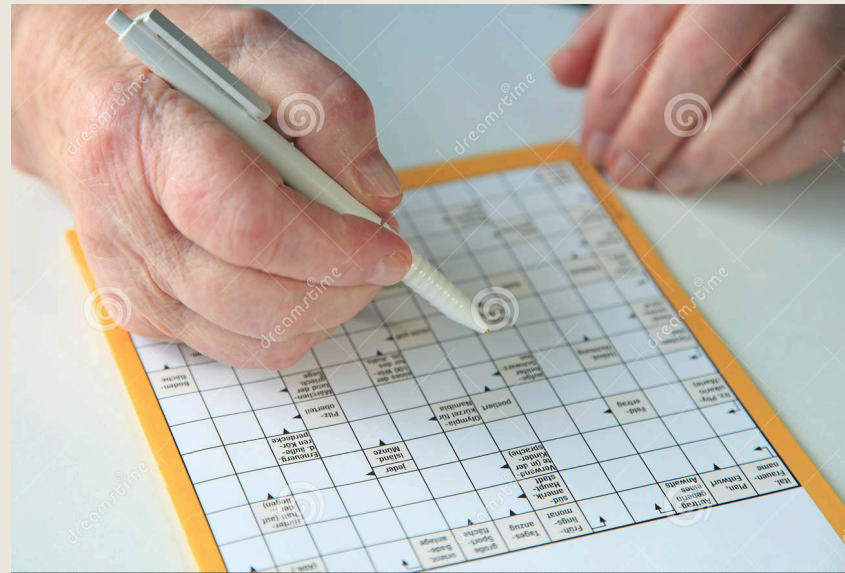
Sleep

- Sleep changes occur naturally after age 60. Shifts in hormone and melatonin levels may cause us to take longer to fall asleep, sleep more lightly, and wake up more often during the night
- Lack of sleep is not to be taken lightly: It depresses our immune systems, affects our daily activities, increases confusion, affects our mood and concentration, and may lead to falls. It's vital to good health as good nutrition, regular exercise, and a positive attitude. So, if someone is not sleeping soundly, that person should consult his/her doctor.
- Develop a more consistent sleep routine:
 - Go to bed at the same time every night; awake at the same time every morning
 - Fall asleep in the same position
 - Have a cup of warm milk or herbal tea before bedtime
 - Try a warm soak in the tub
- Address snoring issues



Mental Stimulation

- **Mental activity and lifelong learning.** Staying mentally active can enrich your life, reduce boredom, and confer a sense of purpose and accomplishment—all good for cognitive health.
- Mental stimulation does not have to be in a classroom/academic setting. You can learn a new hobby, do puzzles, watch an educational television show, learn to play an instrument, learn to sing a new song, learn how to cook a new recipe



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Learn ways of handling stress

- Hormones secreted when you're under stress have a stronger effect on older brains, challenging your ability to recover from emotional upset. So, take change slowly and learn ways to cope with anxiety or tension.





Social Connection

- **Staying socially active.** Social activity, and interpersonal exchanges can help counter depression and help people maintain cognitive abilities
- Connect with family, friends and communities

Need for an administrative tool

- Clinicians reported that Persons with IDD (PwIDD) are not brought to the attention of health care providers until well advanced into a change process (cognitive, behavioral and/or adaptive skills)
- Need to capture information about change that could be used by the IDT to consider relevant health care, service and support options
- For those eligible, the **NTG-EDSD** could be used as part of the Annual Wellness Visit paralleling screening done for individuals without disabilities after the age of 65

Practical Utility of the NTG-EDSD

- Provides family and professional caregivers with a tool to capture information about changes in cognition, behavior and function
- Provides caregivers with a format to share important information and begin a dialogue with the consumer's health care practitioner
- The categories on the tool promote attention to areas of significant change thereby helping family and professional caregivers become better observers and reporters of relevant signs and symptoms of functional change

NTG -EDSD

Early Detection Screen for Dementia

- adapted from *the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities* (Deb et al., 2007) and *the Dementia Screening Tool* (adapted by Philadelphia Coordinated Health Care Group from the *DSQIID*, 2010)
- Down Syndrome: begin as early as age 35 but not later than age 40, then annually; non-DS: begin when changes noted or ≥ 50
- Piloted in 2012; now used internationally

ntg
National Training & Technical Assistance Center
for the Aging

NTG-EDSD

v1/2013.2

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 functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with action 2.8 of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aamd.org/ntg/screening).

(1) File #: _____ (2) Date: _____

Name of person: (3) First _____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

(7) Sex:

<input type="checkbox"/> Female
<input type="checkbox"/> Male

(8) Best description of level of intellectual disability

<input type="checkbox"/> No discernible intellectual disability
<input type="checkbox"/> Borderline (IQ 70-75)
<input type="checkbox"/> Mild ID (IQ 55-69)
<input type="checkbox"/> Moderate ID (IQ 40-54)
<input type="checkbox"/> Severe ID (IQ 25-39)
<input type="checkbox"/> Profound ID (IQ 24 and below)
<input type="checkbox"/> Unknown

(9) Diagnosed condition (check all that apply)

<input type="checkbox"/> Autism
<input type="checkbox"/> Cerebral palsy
<input type="checkbox"/> Down syndrome
<input type="checkbox"/> Fragile X syndrome
<input type="checkbox"/> Intellectual disability
<input type="checkbox"/> Prader-Willi syndrome
<input type="checkbox"/> Other: _____

Instructions:
For each question block, check the item that best applies to the individual or situation.

Current living arrangement of person:

<input type="checkbox"/> Lives alone
<input type="checkbox"/> Lives with spouse or friends
<input type="checkbox"/> Lives with parents or other family members
<input type="checkbox"/> Lives with paid caregiver
<input type="checkbox"/> Lives in community group home, apartment, supervised housing, etc.
<input type="checkbox"/> Lives in senior housing
<input type="checkbox"/> Lives in congregate residential setting
<input type="checkbox"/> Lives in long term care facility
<input type="checkbox"/> Lives in other: _____

<https://www.the-ntg.org>

Role of Family and Staff

- Family and Staff are raters for the **NTG-EDSD**
- Staff need to have worked with the individual for at least 6 months in order to serve as a rater on this instrument
- Staff are more likely to be aware of subtle changes in behavior and functioning that may signal important information for health care providers



How is Early Detection of Change linked to Health Promotion?

- By identifying areas of early change, the IDT can refer for further targeted evaluation
- By identifying areas of early change, the IDT can plan targeted supports and services, accommodation of existing services and equip the client, family and staff with training and relevant resources
- By identifying areas of early change, the IDT can obtain valuable information about contributions to change in cognition, behavior or adaptive functioning relevant to:
 - ❖ Sensory status
 - ❖ Mental health needs
 - ❖ Management of chronic illness
 - ❖ Pain management

NTG-EDSD as a Tool for Shared Decision-making

- The NTG-EDSD is an administrative rating tool
- It is not used as a way of diagnosing dementia
- It is used to capture observations of change
- The tool is used to promote discussion within the IDT regarding possible ways of addressing observed change
- The tool is used to promote discussion among DSPs, family members and health care providers which can aid in decision-making about the care of individuals with suspected dementia

How Does the EDSD help capture information about change?

- Domains correspond to areas in which you may see a decline in functioning (from baseline) related to dementia:
- *Behavior*
- *Personality*
- *Memory*
- *Activities of Daily Living*
- *Sleep*

What do you do with the Ratings from the EDSD?

- Look for patterns
- What are areas in which change has been noted?
- What is the extent of change?
- Is something being done to currently address identified issues?
- Share with members of the IDT



Sharing Findings with Members of the IDT

- Discuss observations captured through **EDSD** ratings
- Reconcile any discrepancies across settings
- Request additional information, if necessary
- Brainstorm possible approaches
- Operationalize a plan of action
- Develop criteria to determine effectiveness of plans of care



Types of Decisions that May Follow from Use of the EDSD

Modification of residence

Change in residence

Changing staffing support

Changing programming

Developing a positive daily routine

Identifying items and activities for stimulation

Promote time-sensitive interventions and support

- If a consumer has declined in ADLs ...
- This may affect level of care supports, deployment of staff, staffing arrangements, physical setting in which the individual is supported, supplies and equipment the person may need



Share findings from NTG-EDSD with the healthcare provider

- Provide information to healthcare provider about the consumer's daily functioning
- Advance the conversation leading to possible further assessment or diagnosis
- Get the most out of visits with the healthcare provider



Utilize to identify, advocate and promote the health needs of the PwIDD

- What types of visual and verbal cuing, role modeling or other supports help the individual remain as independent as possible?
- What does the person need in order to be safe?
- What areas may need follow up for optimal health (sensory, pain management, mental and social stimulation)?
- What does the person need in order to be comfortable?
- What does the person need in order to have the best Quality of Life (QoL)



NTG-EDSD use considerations...

- This tool is not used for the diagnosis of dementia; the EDSD is an *administrative* and not a clinical rating instrument
- The diagnosis of a neurocognitive disorder involves medical exam and direct cognitive and adaptive testing of the individuals in question
- If the consumer is already known to have dementia, use the rating form to baseline observation of functioning
- Since this is an early screening tool, it is not necessary to continue using if the person is diagnosed with dementia





Health Promotion and Advocacy for Persons with IDD

- Advocate for parity of medical and mental health services for persons aging with IDD (diagnostic assessment, treatment, rehabilitation and health monitoring)
- Reconsider service and programmatic designs and environments that will promote independence within capability
- Educate all stakeholders about the relevant issues and local resources for individuals aging with disabilities
- Encourage cross training to build capacity and maximize resources for both the aging and the disability communities
- Recognize that aging is a highly diverse process which may begin early for persons with IDD, and that chronological age may not be the best indicator of health status
- Individuals with IDD age with disability but may also age into disability (i.e., dementia, physical limitations, sensory processing problems)
- Place a greater emphasis on health promotion and maintenance
- Build upon what we have learned about hybrid models of health provision that can benefit older adults with IDD?
- When do we begin to pay attention to aging with IDD? **NOW!**

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