MAINTAINING THE ESSENCE OF A LOVED ONE: ADVOCATING FOR PROPER CARE OF AN INDIVIDUAL WITH AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY AND DEMENTIA

WI Board for People with Developmental Disabilities

Jeremy Gundlach

MIND & MEMORY MATTERS PROJECT

- Alzheimer's Disease Initiative – Specialized Supportive Services Grant (Administration for Community Living)
  - Greater WI Agency on Aging Resources (GWAAR)
  - Alzheimer's Association – Greater WI Chapter
  - Wisconsin Alzheimer's Institute (WAI)
  - UW-Oshkosh Center for Career Development and Training
  - WI Board for People with Developmental Disabilities(BPDD)

- Partnership between WBPDD and WI Department of Health Services (DHS) to inform families and care providers on the prevalence of Alzheimer's/dementia in the Intellectual/Developmental Disabilities community

- Provide outreach, screening, training, and support for professionals, families and individuals with I/DD

- Overall outcome is to increase the quality of life for people with dementia and their caregivers

MIND & MEMORY MATTERS

A PROJECT OF Wisconsin BPDD
WISCONSIN BOARD FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

HEALTHY AGING AND I/DD

Health Disparities and Challenges

Factors Impacting Healthy Aging

Healthy aging is impacted by the following factors:

- Poor lifespan health practices
- Long-term consequences of early-life therapeutic interventions
  - Ex. Post polio syndrome
- Prolonged usage of medications adding to chronic conditions in older age (adverse drug reactions & polypharmacy)
  - Ex. Thorazine

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Factors Impacting Healthy Aging (cont.)

- Problems with accessing health services
  - Not having medical personnel familiar with ID
  - Not tracking risk conditions
- Age-associated pathologies
  - Dementia, cardiovascular disease, etc.
- Lack of exercise
- Poor nutrition and bad eating habits
  - Ex. Chewing, swallowing problems in Cerebral Palsy

Challenges to Healthy Aging in Adults with I/DD

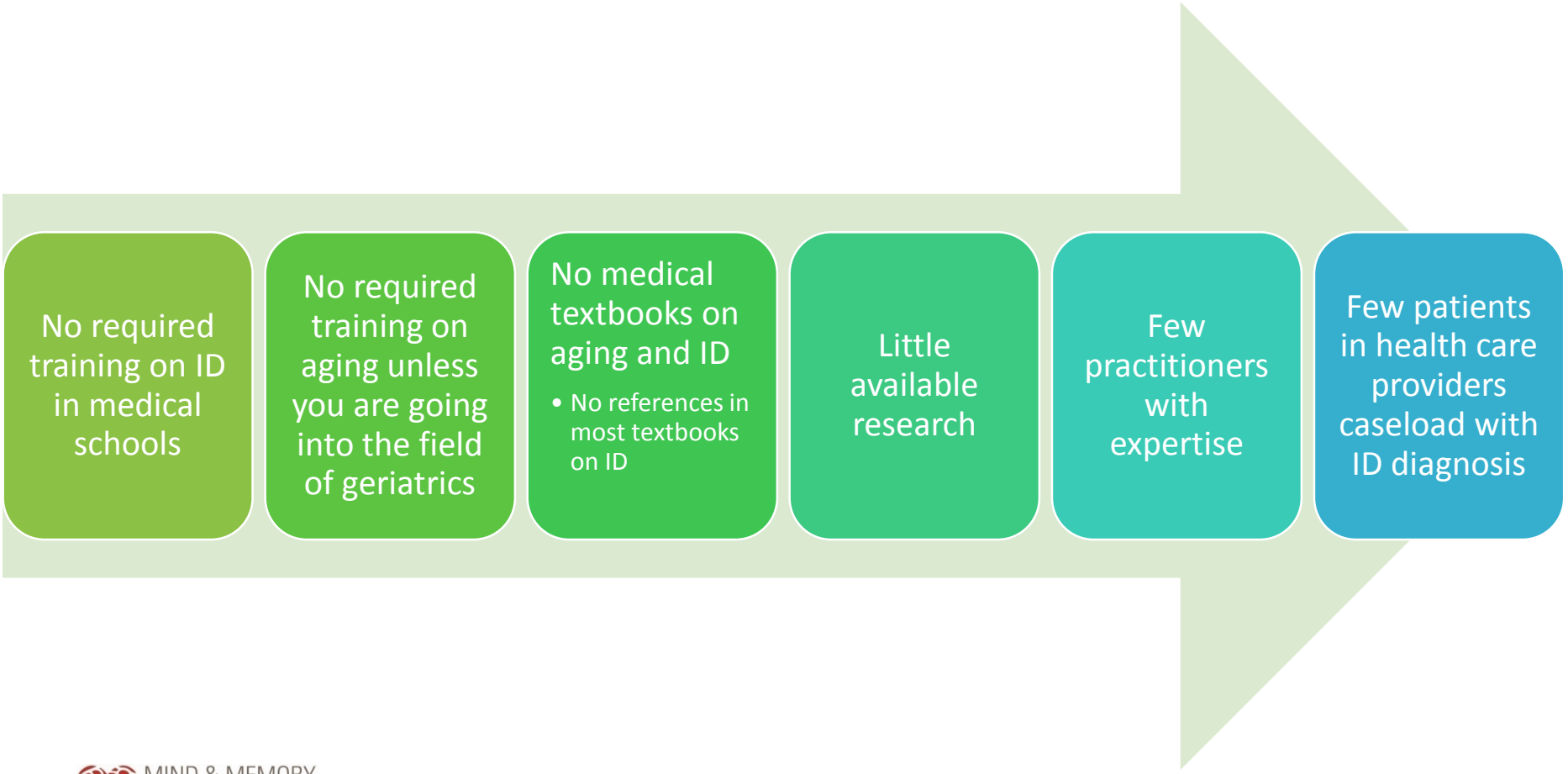
Medical history is often incomplete or unknown.

- Staff turnover
- Family not available for information, historical documentation unavailable
- Health care provider turn over
- Providers not understanding baseline functioning of the presenting older adult with I/DD
  - IDEA: Video can provide a visual of the person over their lifespan.

Diagnostic Overshadowing

The tendency for clinicians to attribute symptoms or a change in behaviors of a person with I/DD to their underlying cognitive deficits and therefore under-diagnose the presence of co-occurring disease such as dementia.

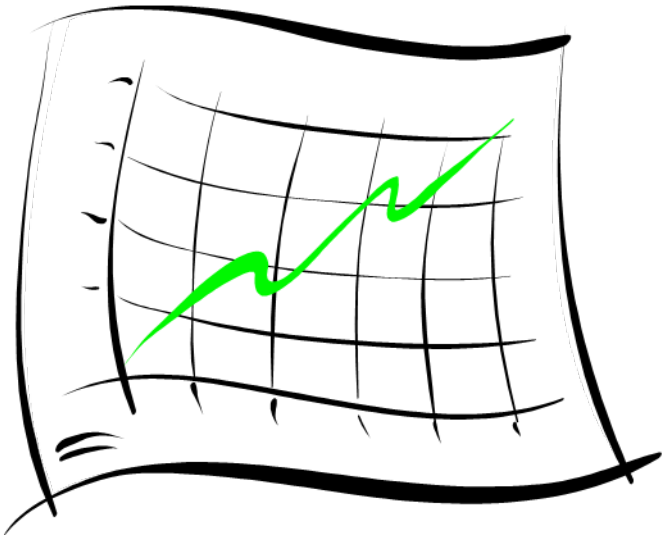
Health Care Disparities for Adults with I/DD



Dementia and I/DD

Risk of Dementia in I/DD

Most adults with I/DD are typically at no more risk than the general population.



Exception: Adults with Down syndrome are at increased risk!

- Younger (40's and '50's)
- More rapid progression.

Dementia Prevalence: I/DD vs. DS

Intellectual/Developmental Disability

Age	Percentage
40+	3%
60+	6%
80+	12%

Down Syndrome

Age	Percentage
40+	22%
60+	56%

Matthew P. Janicki and Arthur J. Dalton (2000) Prevalence of Dementia and Impact on Intellectual Disability Services. Mental Retardation: June 2000, Vol. 38, No. 3, pp. 276-288.

Irreversible Dementias

The symptoms we call "dementia" can have many different causes.

Alzheimer's disease is the most common.

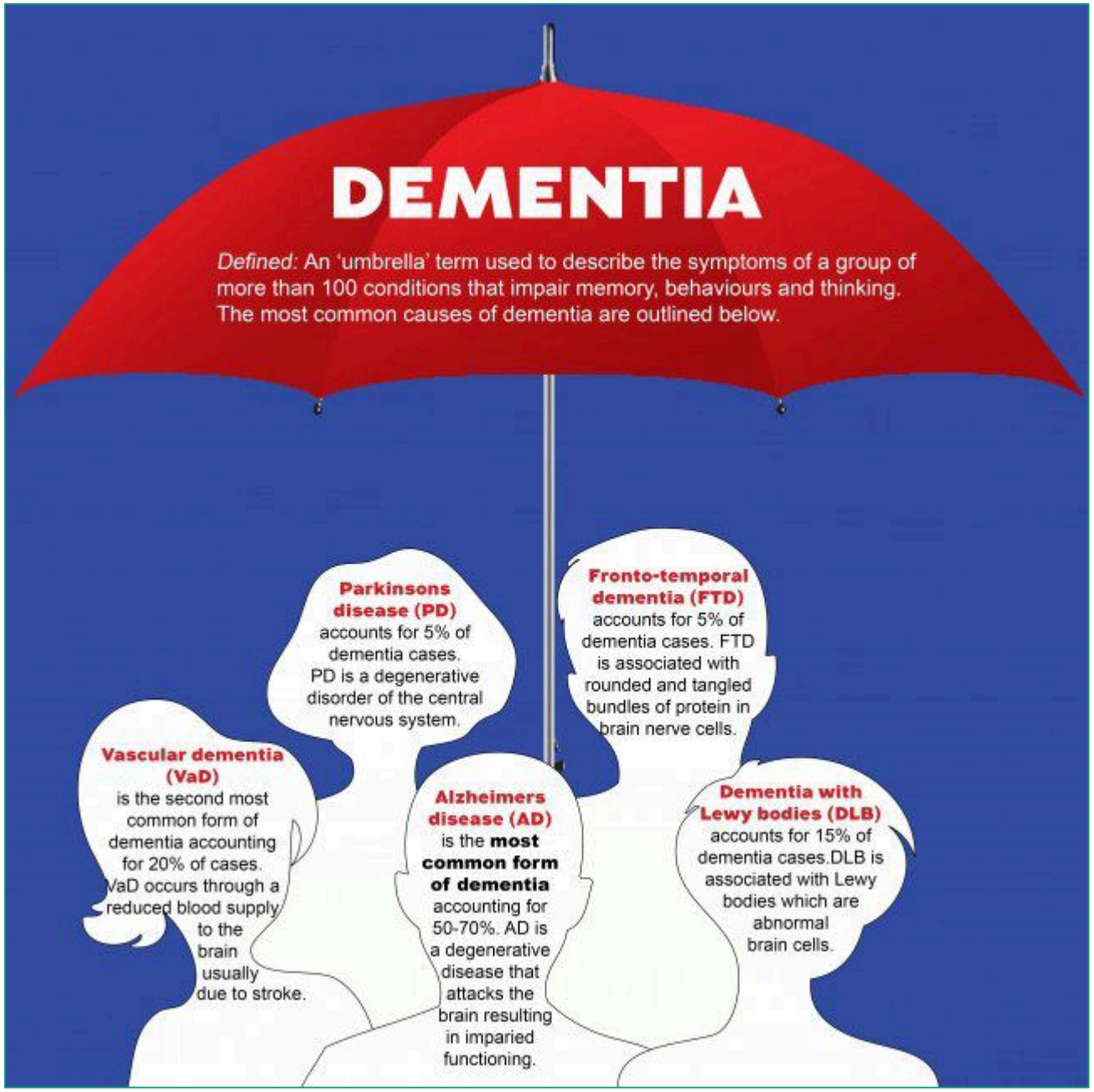


Image: Dementia Forward

MIND & MEMORY MATTERS

Alzheimer's Disease

- Damage begins 10 – 20 years before symptoms begin to show!
- Most people with Alzheimer's disease have "late-onset" Alzheimer's. (After age 65)
- Early-onset Alzheimer's is a rare form of the disease. (Age 30-60)
- Individuals with Down syndrome develop Alzheimer's at a younger age than the general population.

Down Syndrome & Alzheimer's Disease

Why a Focus on DS?

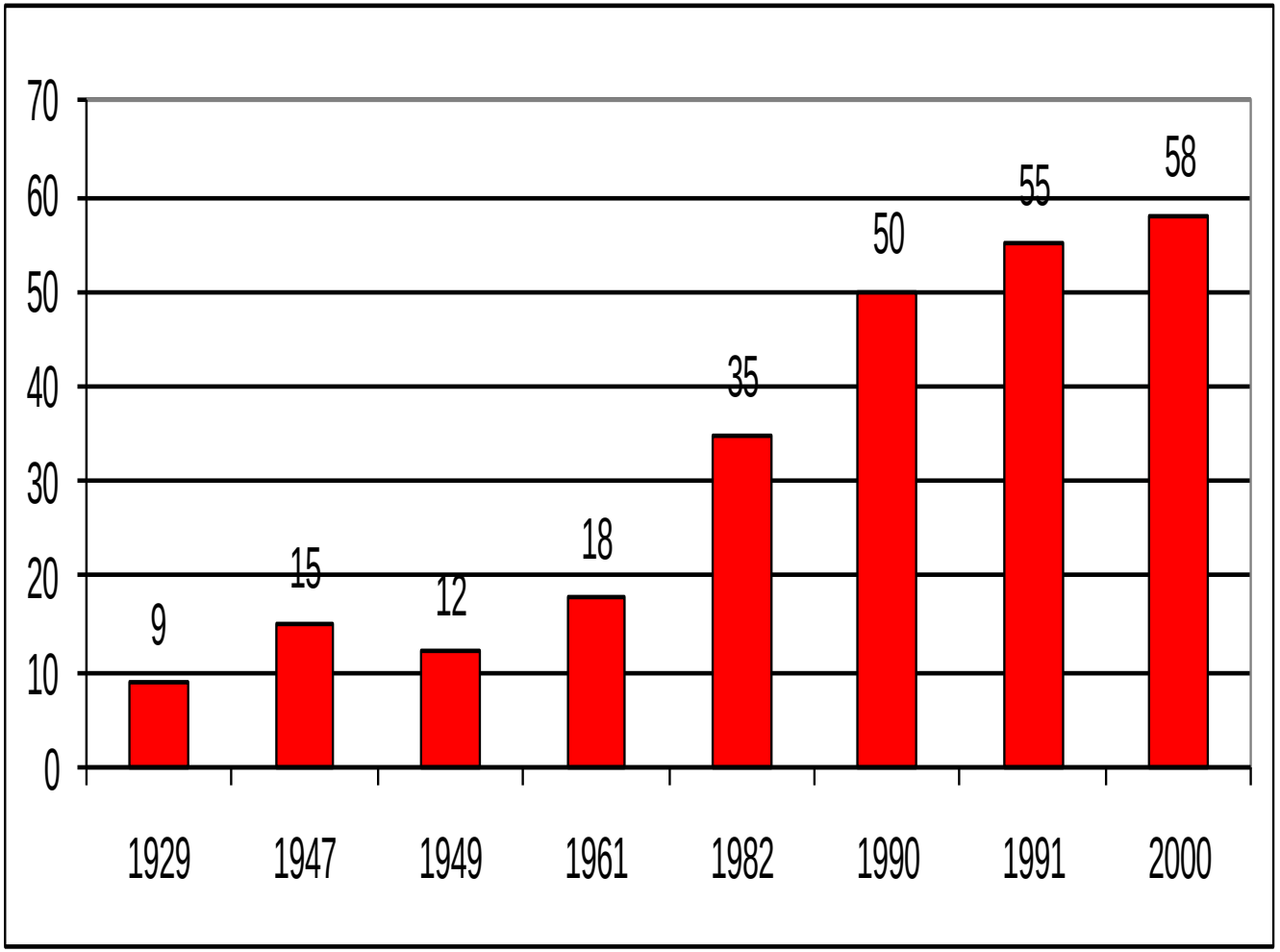
Down syndrome is one of the most significant risk factors for Alzheimer's disease.

- Over age 40 - approximately 25% will show clinical signs of dementia.
- Over age 60 - approximately 60% will show clinical signs of dementia

Premature Aging in Down Syndrome

- Life expectancy has continued to increase for people with Down syndrome.
- Aging increases risk for physical and cognitive changes for people with DS.
- Many individuals with DS age prematurely (age in their 50s).
- Adults with DS are at risk for diseases and changes about 20 years earlier than the general population.

Down Syndrome: Life Expectancy



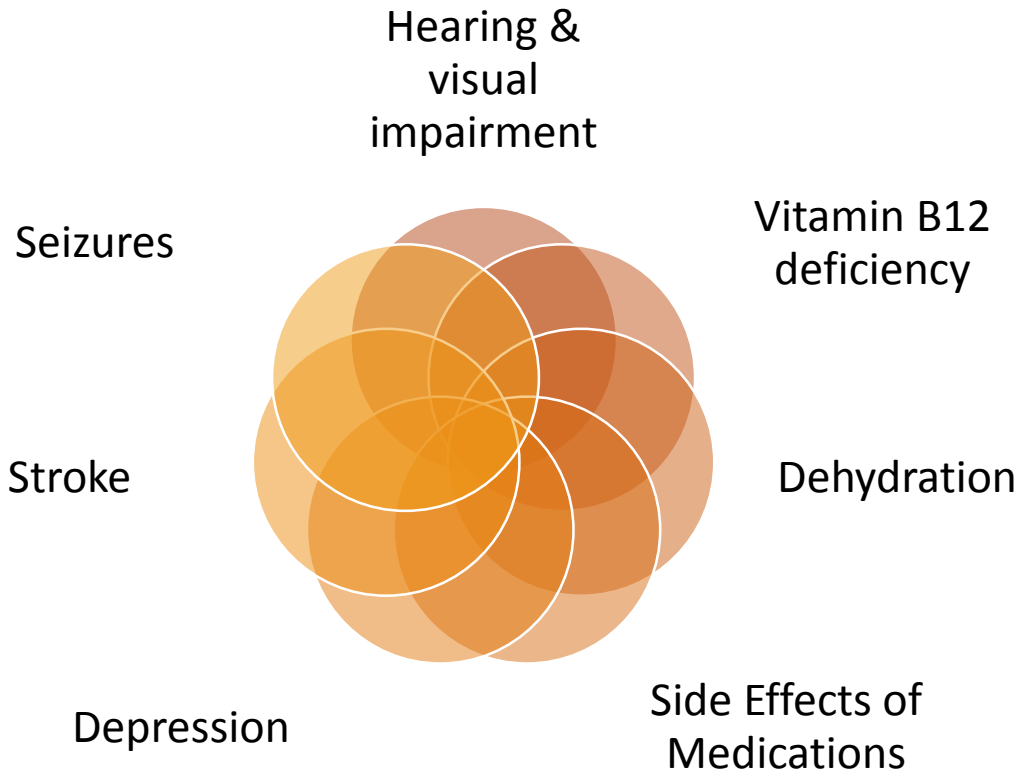
Why a Focus on Alzheimer's?

Alzheimer's often presents differently in people with Down syndrome.

- Abrupt onset of seizure activity when there had been none in the past.
- Incontinence when an individual has always been independent in toileting.
- Short- term memory loss may depend upon the previous level of memory demands and reliance on memory in everyday life.
- Sleep/wake cycle disruptions.

**Just as in the general population, the course and symptom presentation is unpredictable and unique to the individual.*

Adults with DS have Specific Risk Factors for Developing "Dementia."



Atypical Presentation of Alzheimer's in DS

- Earlier onset than general population (> 40).
- Management similar to general population.
- No strong evidence that Alzheimer's drugs benefit.
- Depression and thyroid disease common in DS and can mimic dementia.
- Normal age-associated deficits are common.
- Often present with behavioral symptoms instead of memory loss.
- Seizures, myoclonus (sudden, involuntary muscle contractions or relaxation)

Supporting Derek

- https://www.youtube.com/watch?v=O3ekO4QdKXU

Early Screening for Dementia

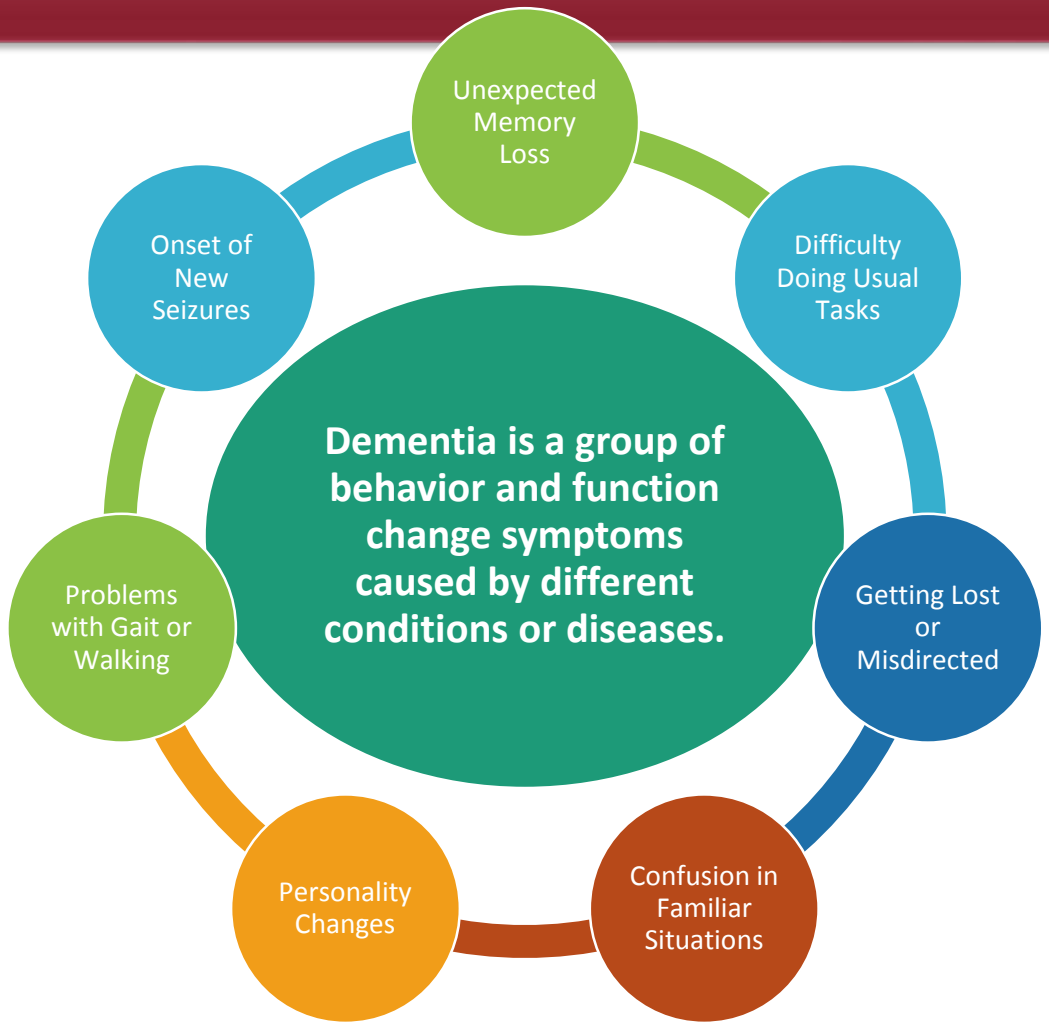
NTG-EDSD Assessment Tool

What is Early Detection/Screening?

- It is **looking for and recognizing** symptoms that if untreated may become more serious.
  - It is an important first step in managing a disease or disorder
  - Can alert to any more changes or symptoms
- Family and staff caregivers can **work together** with the person's health care provider to share information about observed changes
- Use of a **screening tool** to note changes in adaptive skills, behavior, and cognition is recommended.
  - National Task Group Early Detection Screen for Dementia (NTG-EDSD)

Warning Signs

These problems must be notable and usually occur in a cluster



What to Do When Dementia is Suspected?

- Benefits of a screening instrument - can help to identify early signs of dementia.
- If screening instrument results are positive, refer for assessment.
  - Refer to Agency MD, local MD , psychologist, nurse, other person who may do formal assessment to validate suspicions
- If assessment confirms screening results, refer for diagnostic work-up.
  - Ideally: neurologist, geriatrician, geriatric psychologist

Remember…
Early Detection is Important

- Dementia presents many **problems and challenges** for the adult affected by it and their care partners.
- When dementia can be identified early, there is potential to **proactively** address signs and delay symptoms.
- **Interventions, services or supports** may be more effective if offered prior to significant cognitive and/or functional change.
- Early detection can lead to greater opportunities to **impact quality of life and quality of care.**

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Early Detection is Important (cont.)

- Can **confirm suspicions** that behavior is changing.
- Can lead to **earlier referral** for assessment.
- Early assessments can help in **identifying potentially treatable conditions** that are causing symptoms.
- Makes **persons feel better** because what they are experiencing is being recognized and treated.
- Can help **prevent or minimize** more serious problems by initiating supportive interventions early in the disease process.

NTG Early Detection Screen for Dementia (EDSD)

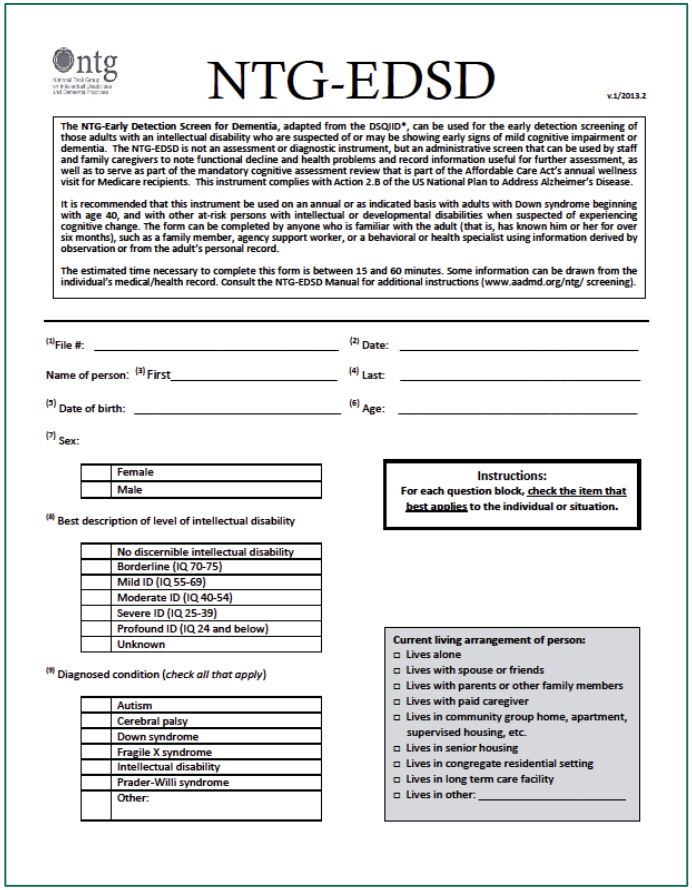
Adapted from:

- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (Deb et al., 2007), and
- Dementia Screening Tool (adapted by Philadelphia Coordinated Health Care Group from the DSQIID, 2010)

Down syndrome begin age 40 then annually.

Non-DS begin at age 50.

Tool & manual available online in multiple languages: www.aadmd.org/ntg/screening



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 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.B 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.aadmd.org/ntg/ screening).

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

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

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

(7) Sex:

	Female
	Male

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

(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:

Current living arrangement of person:
- ☐ Lives alone
- ☐ Lives with spouse or friends
- ☐ Lives with parents or other family members
- ☐ Lives with paid caregiver
- ☐ Lives in community group home, apartment, supervised housing, etc.
- ☐ Lives in senior housing
- ☐ Lives in congregate residential setting
- ☐ Lives in long term care facility
- ☐ Lives in other: _____

A Screening Tool is Not a Diagnostic Instrument.

- **Screen -** an instrument that permits the recording of select data that is associated with a condition or disease.
  - EDSD
- **Diagnostic instrument -** is one that is based on valid measures that are associated with agreement on the presence of a condition.
  - For example, a MRI will show an image of the brain that may show shrinkage and validate suspicions of the presence of Alzheimer's disease

Who Can Complete the NTG-EDSD?

- Any caregiver, either family or staff who is familiar with the person can complete the NTG-EDSD if they:
  - Have known person for a minimum of 6 months
  - Have access to information in the person's record

How to best complete the form?

- Combine perceptions of function offered by several staff or family members.
- Use best judgment when responding to questions asking for impressions (e.g., health, function).
- Be truthful – don't 'hide' problems to make a good impression

NTG-EDSD: 4 Key Sections

Demographics

Ratings of health, mental health and life stressors

Review of multiple domains including

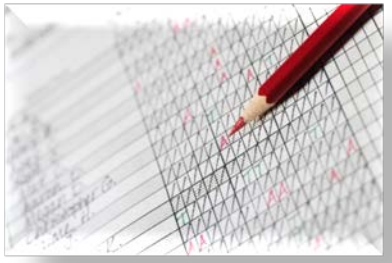
- Activities of Daily Living
- Language & Communication
- Sleep – Wake Patterns
- Ambulation
- Memory
- Behavior & Affect

Chronic Health Conditions

Why is All This Information Needed?

Can help with the physician's visit or for an assessment by a clinician.

- Collects basic information about the adult so it is all in one place.
- Focuses on behaviors that are usually associated with cognitive decline or functional changes.
- Looks at other diseases or conditions that may be present and may impact the adult's functioning.



I've completed the EDSD… now what?

- **Review** the form and see if there are any changes noted that are potentially of concern.
- **Talk it over** with the individual's key workers to ensure agreement with the findings.
- **Discuss** findings with the team and supervisor.
- If there are concerns, **make an appointment** to have the person further assessed.
  - Collate all of the information into useful packet
  - Assemble a list of medications being taken
  - Bring any digital video evidence of function or functional problems

From Screening to Diagnosis

Screening

Administrative [NTG-EDSD]

Clinical (DSDS, DLD, AADS]

Assessment

Dementia Assessment Scale

Neuro-psych evaluation

CT - MRI

Diagnosis

Possible

Probable

Definitive

Diagnosing Dementia

The Differential Diagnosis

The Importance of Differential Diagnosis

1. Rule out treatable conditions.
2. Receive appropriate treatment and support services.
3. Maintain the highest possible quality of life and functioning.

Conditions Common to Aging That Can Mimic Dementia

Dehydration, Malnutrition

Metabolic Disorders

Vitamin & Mineral Deficiencies

Sensory Impairments

Common Conditions to Rule Out through Differential Diagnosis

- Stroke
- Side effects of medications ★
- Nutritional deficits and imbalances
- Alcohol and drug abuse
- Hypothyroidism
- Dehydration, malnutrition
- Cardiovascular disease
- Environmental challenges
- Sensory impairments
- Depression
- Lyme disease
- Normal pressure hydrocephalus
- Sleep apnea

The Three D's

Dementia

Gradual over months to years

Delirium

Sudden onset, hours to days

Depression

Recent unexplained change in mood that lasts for over 2 weeks

Health Care Advocacy

What it is and Why it's Important

Health Care Advocacy

Health care advocate - a person who is not a health care professional, but can assist a patient in obtaining high-quality health care.

An advocate may be a counselor at a service organization, a relative, or a friend of the patient.

www.communityhealthadvocates.org/advocates-guide/appendix/glossary

Importance of Health Care Advocacy

There are often interventions that make a difference in quality of life and health.

Staff and family are the experts about individuals with ID.

- To recognize current changes and symptoms knowing the person across the lifespan is the best resource.

Health care is an art, not a science!

Why is Dementia Health Care Advocacy Needed?

- Unable to “self-advocate.”
- ‘Ageism’ (prejudice or discrimination on the basis of a person's age) by health care providers.
  - Providers may assume that there will be automatic losses and declines in functioning as part of aging.
- “Diagnostic overshadowing.”
  - Providers may assume that the diagnosis is dementia, when another issue may be the cause of behavioral changes.

Staff and family are often times the EXPERTS!

Mimi & Donna

http://www.mimianddonamovie.com/

Caregiving Needs

Dementia Capable care in I/DD

Caring for Someone with Dementia Requires a Shift in Thinking

Behavior is Communication

Common "Behaviors"

Wandering
Repetitive questions
Rummaging, hoarding
Verbal outbursts – yelling, excessive vocalizations, cursing
Physical – hitting, spitting, kicking
Paranoia
Hallucinations
Sleep-wake disorders
Sundowning
Resistance to personal care
Inappropriate sexual expression

General Tips

- Do not try to reason or argue.
- Stay calm.
- Make sure you have their attention.
- Short sentences with yes/no answers.
- Loud voice can be interpreted as angry.
- Allow time.
- Respond to emotion.
- Distract and redirect.
- Step away and try again in a few minutes.

Communication: 4 Key Strategies

1) Difficult behaviors cannot be changed with words

Technique: Change your approach to the person, reaction to the behavior, the environment. Individuals with dementia have impairments in short term memory as well as an inability to learn new information. They cannot be told to do, or not do something and be expected to remember

2) Don't say "No" and never argue

You cannot reason with a person who has lost the intellectual ability to process thoughts in a logical and rational manner. Arguing will encourage frustration, fear, and anger. Your goal is not to be "correct" or "right". The person is experiencing a decline in their reasoning skills at the same time they are experiencing an increase in their emotional reactions. Feelings are more important than facts.

Communication: 4 Key Strategies

3) It's their reality and you must enter it

Technique: Validation – builds empathy and creates a sense of trust and security that reduces anxiety. Enter their reality and reminisce with them. Match their emotions.

4) Reduce fear by acknowledging underlying emotions

As the disease progresses the person loses their ability to express and cope with their fears. A person with dementia cannot "self soothe" if their fears become overwhelming. Reassure the person and respond to their emotion

> "Amygdala" – Fight or Flight – Responsible for managing basic emotions such as rear and anger. Alzheimer's disease can severely damage – the result is emotional instability (paranoia, temper outbursts, anxiety, etc.)

Dementia-Capable Environments

Dementia alters visual perception – can't shut out other stimuli

- Adults with I/DD may already have been compromised
- "lost in space" – help with cues like placemats on the table
- Bathrooms often white on white – need contrasting colors
- Keep landmarks the same – arrows to the bathroom
- Colors may appear differently, glare sensitivity, black & white tiles or "busy" carpet
- Visual field about 3' from floor
- Food – one food at a time – don't load plate with all and use contrasting colors and easy to use utensils

Stage Based Care Considerations

Early Stage

- Screen with NTG-EDSD
- Observation & reporting of functional changes to and team.
- Support functioning and maintain quality of life

Mid-Stage

- Modify/adapt environment to support functioning and safety
- Increase staff supervision and supports
- Maintain routine and structure as much as possible

Late Stage

- Specialized re-training of staff including mobility, eating, and comfort care
- Increased use of adaptive equipment and procedures
- Grief support – family, staff, friends

Promoting Quality of Life

- Stage-based support strategies help maintain independence, function, and community participation for as long as is possible and reflect genuine community living.

- A goal of care is to provide and maintain a quality care environment that recognizes the affected adult's dignity and personhood.

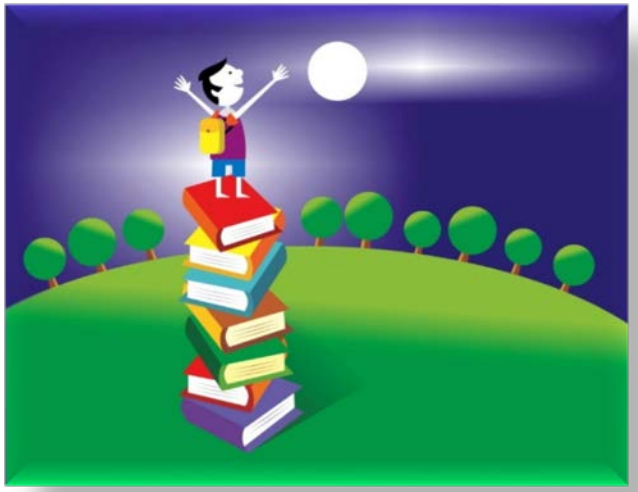
Take-Away Points

- Maintain the ESSENCE of the person – be present
- At 40 look at them as age 60 (accelerated aging)
- Structure & routine is important
- Document success and what works
- Dementia is different in every individual
- Protect the person from physical injury
- Maintain independence as long as possible
- Focus on what they can still do
- Provide physical and mental activities the person can do
- Support person's dignity and self-esteem at all times

Key Concept in Dementia Care:
Life Stories

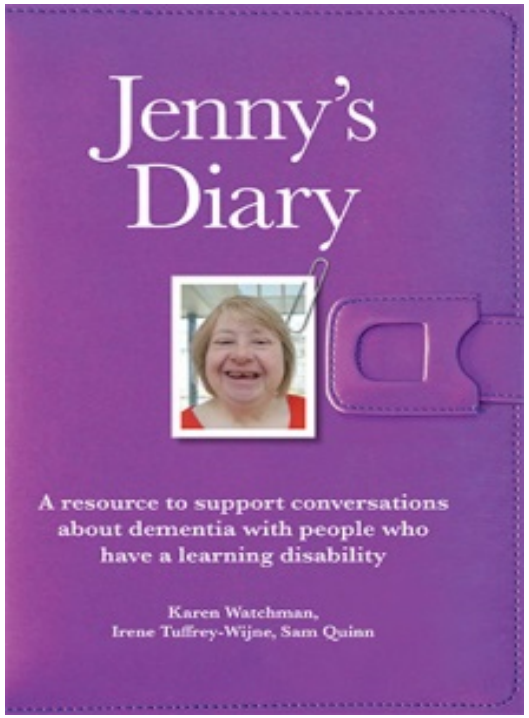
Everyone has a life story that needs to be honored and respected.

- The story is the *essence* of each person and should be documented over the lifespan.
- When they can no longer tell their own story, it can still be used to inform caregiving and plan activities.
- Scrapbooks, videos, interests, hobbies, personal likes/dislikes/routines.



For Guidance…

Jenny's Diary



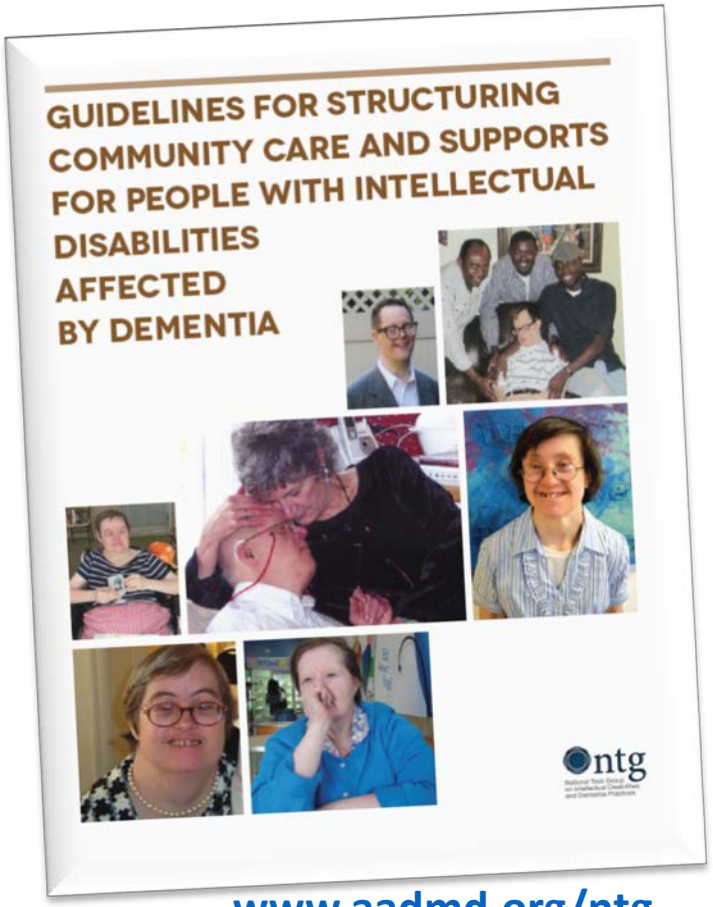
- Part 1 Opens dialogue about why Jenny is behaving differently, and how she can be supported to live as well as possible with dementia.

- Part 2 Suggests how to have a conversation with Jenny about her diagnosis of dementia

- Part 3 Contains guidance to talk about dementia with George, Jenny's partner

www.uws.ac.uk/jennysdiary

For Guidance…



www.aadmd.org/ntg

- This NTG document provides a guide to what actions should be undertaken within the *staging model* generally accepted for practice among generic dementia services.

- The staging model flows from a pre-diagnosis stage when early recognition of symptoms associated with cognitive decline are recognized through to early, mid, and late stages of dementia, and characterizes the expected changes in behavior and function.

- The NTG document also provides information on nonpharmacological options for providing community care for persons affected by dementia as well as comments on abuse, financial, managing choice and liability, medication and nutritional issues.

Helpful Resources

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M&MM Website:

www.MindandMemory.org

NTG Tool & Guidelines :

www.aadmd.org/ntg

National Down Syndrome Society:

www.ndss.org