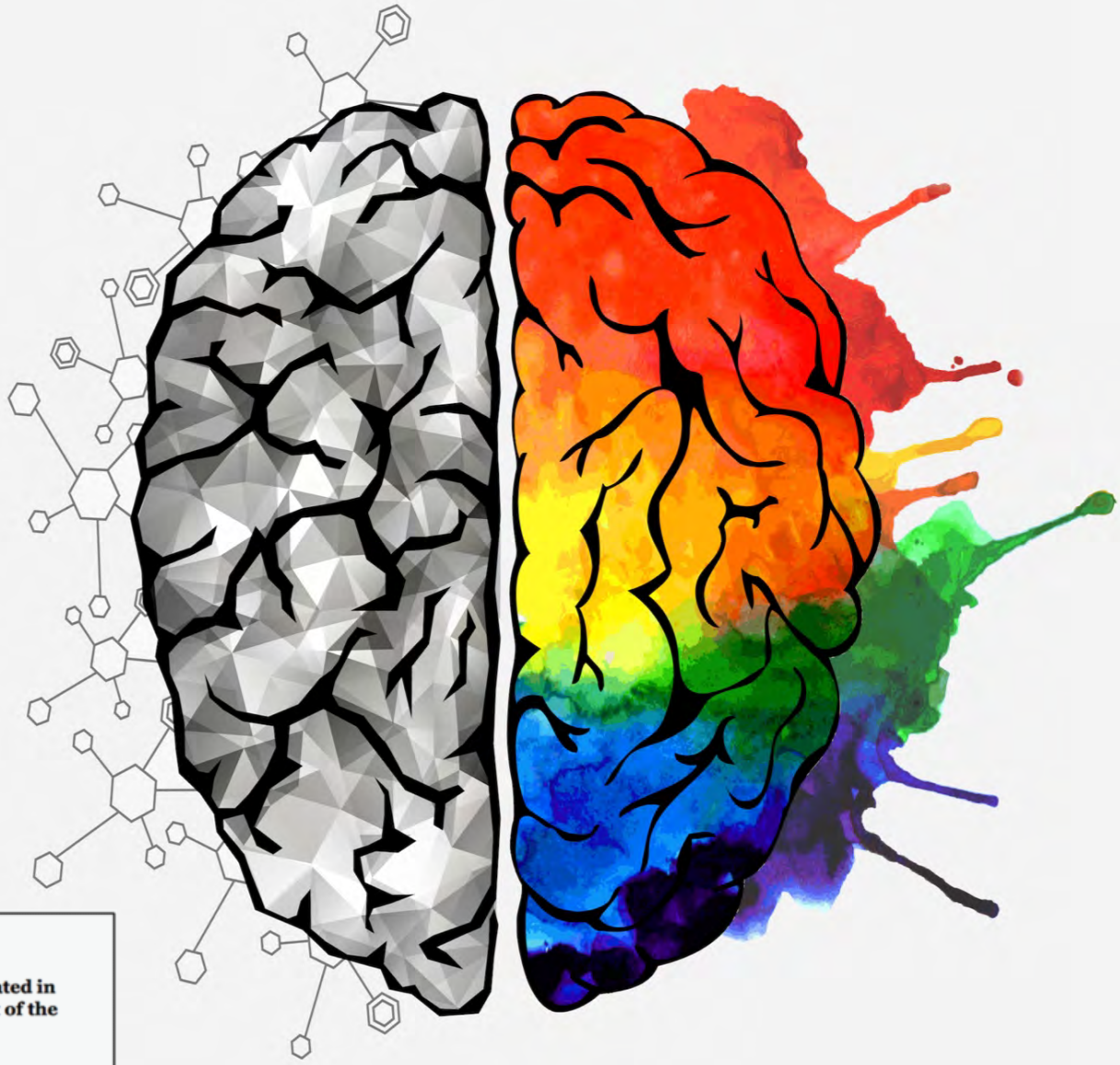
Creating Dementia Capable Environments

Dr. Matthew Mason

Licensed Psychologist
Board Certified Behavior Analyst
Director, DDA Health Initiative



Forward

University Center for Excellence in Developmental Disabilities
GEORGETOWN UNIVERSITY CENTER FOR CHILD AND HUMAN DEVELOPMENT

The following training was produced by Georgetown University's Center for Child & Human Development as part of the the DDA Health Initiative project. This project supports the mission of the District of Columbia's Developmental Disabilities Administration, and focuses on improving the physical, behavioral and mental health supports that affect the quality of living for people with intellectual and other disabilities.

For questions or additional information on this training and the DDA Health Initiative, or to obtain permission to reproduce this presentation, please visit our website at https://ucedd.georgetown.edu/DDA/ or email the Project Director, Dr. Matt Mason, at mam711@georgetown.edu

Objectives

At the completion of this training, participants will be able to:

1. **Define** dementia and it's general impact.
2. **Identify** challenges in identifying dementia among people with disabilities.
3. **Describe** strategies to diagnose dementia.
4. **Describe** strategies for creating "dementia capable" environments.

What is Dementia?

Dementia is not actually a diagnosis, but rather a catch-all phrase that refers to a variety of symptoms.

- Alzheimer's Disease is the most common and most commonly recognized dementia-like diagnosis.
- Other less known types – but quite commonly occurring – include Vascular Dementia, Dementia with Lewy Body, and Frontotemporal Dementia.

Domains Affected

Prevalence

- The global prevalence of dementia is estimated to be between 5% and 7% of adults age 60+
- An estimated 5.7 million Americans of all ages are living with Alzheimer's dementia in 2018.
- One in 10 people age 65 and older has Alzheimer's.
- Almost two-thirds of Americans dementia are women.
- African-Americans are about 2 times more likely to be diagnosed with a dementia.
- Hispanics are about 1.5 times more likely to be diagnosed with a dementia.

People with Disabilities

- Prevalence rate among people with disabilities is about the **same** compared to non-disabled peers **except** ...
- People diagnosed with **Down Syndrome** are at higher risk for early onset and at faster progression.
- About 22% of people aged about 40 diagnosed with Down Syndrome are also diagnosed with dementia.
- This number **leaps** to 65% at about age of 60+
- People with disabilities are living longer … so the **rate** of a diagnosis of dementia is **rising.**

Cost of Care

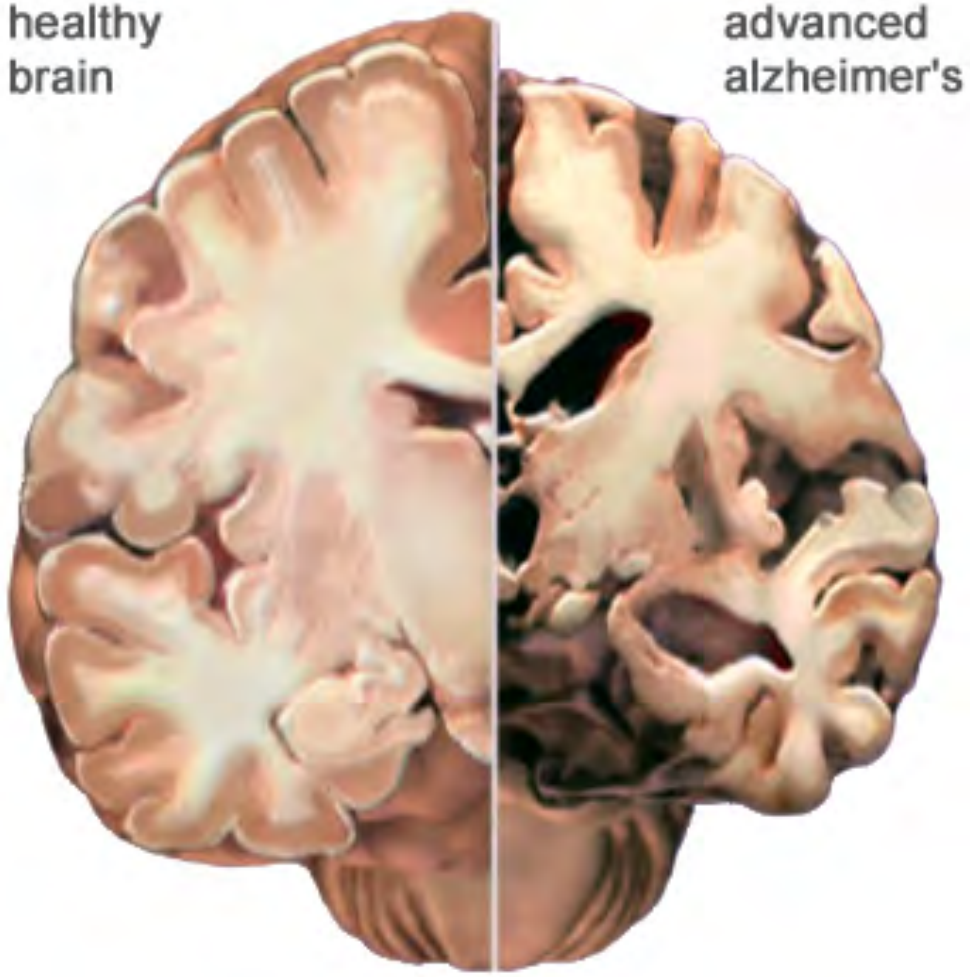
- Average cost of care is about $287,000 per person. Compare this to the cost of heart disease or cancer (about $175,000 per person).
- For seniors with dementia, the cost of care is about 23 times higher than seniors without dementia.
- Annual cost exceeds $215 billion.

Underlying Cause

Dementia is caused by damage to brain cells.

- This interferes with the ability of brain cells to communicate with each other. Cognition, behavior and feelings can be affected.
- The brain has many distinct regions, each responsible for different functions. When cells in a particular region are damaged, that region cannot function normally.
- Damage to brain tissue can vary tremendously in location, progression and severity.

For Example



alzheimer's association

Neural Cell Changes

We know some forms of cell changes in the brain are associated with dementia:

- There might be **fewer** cells
- **Plaques,** abnormal clusters of protein fragments, can build up between nerve cells
- Protein pieces called **beta-amyloids** can clump together and builds up into plaques.
- Dead or dying nerve cells contain **tangles,** which are made up of twisted strands of other proteins

Neural Cell Changes

- We don’t understand why these cell changes occur.
- We don’t understand how these cell changes cause specific symptoms.
- We cannot directly observe these changes among living people.

Diagnosing

- There isn't a single test to determine whether dementia is present.
- We use **differential diagnosis** to identify dementia, including the medical history, physical exams, laboratory tests, and observing changes in thinking, day-to-day function and behaviors.
- It is hard to determine the exact type of dementia because the symptoms and brain changes of different dementias can overlap.
- Development of dementia is not a normal process of aging.

May Look Like Dementia …

- Depression
- Medication side effects
- Excess use of alcohol or drugs
- Thyroid problems
- Vitamin deficiencies
- Hearing loss or other sensory changes
- Dehydration
- Stroke
- Malnutrition
- Sleep apnea

Cultural & Linguistic Issues

- Cultural bias play a limiting role in identifying symptoms and impact of dementia.
- Why are people of color and women more likely to be diagnosed, but less likely to be identified early?
- People with a disability are at an **even greater disadvantage** due to how how they may be valued in their communities … tendency to discount the relative impact, less likely to detect due to language ability, less likely to believe accounts.
- Presence of **pre-existing** behavioral, cognitive and ability limitations among people with disabilities.

Dementia Capable Environments

1. **Requires** a stronger focus on screening.
2. **Broader** use of preventative strategies.
3. **Emphasis** on advance planning form in-home supports and community programs that addresses loss of independence.
4. **Multi-element** cross-disciplinary basis of community treatment including family support, counseling, medical, behavioral, cognitive care.

Words of Caution

There is no cure for dementia. Our focus must be on prevention if possible, and then on quality of life.

The greatest difficulty is accepting that their reality is changing, that we can have a limited impact on that reality, and that we must join with their reality in order to find ways to support them.

Early Detection Screen for Dementia

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	Always been the case	Always but worse	New symptom in past year	Does not apply
[19] **Activities of Daily Living**				
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)				
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)				
[20] **Language & Communication**				
Does not initiate conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
[21] **Sleep-Wake Change Patterns**				
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night				
Wakes earlier than usual				
Sleeps later than usual				
[22] **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				

Differential Diagnosis

Dementia Differential Diagnosis Checklist

Person		DOB		Agency	

Check All That Apply. Key Informants should include people who have a thorough knowledge (at least 6 months) of the person.

Section I

Date	Completed by Key Informants	Notes
	NTG Early Detection Screen for Dementia (EDSD)	
	EDSD results reviewed by clinical staff	
	EDSD results included in annual wellness report	
	EDSD scheduled for follow-up screening	
	Referred to primary care physician for assessment	
	Referred to specialist(s) for assessment	

Possible Protective Strategies

1. **Diet:** Foods with higher levels of anti-oxidants, polyunsaturated fats, and lower calories beneficial.
2. **Exercise**: The universal cure. Obesity is a correlate to increased risk, along with diabetes.
3. **Cardiovascular**: Hypertension and high blood pressure are added risks, as are high cholesterol.
4. **Cognitive**: Active learning, reading and playing games associated with cognitive "longevity."
5. **Social:** Although unclear, social networks appear to have a protective effect against onset of dementia.

Medication … Not a Cure

- Cholinesterase inhibitors are prescribed to treat symptoms related to memory, thinking, language, judgment.
- Prescribed for early to moderate Alzheimer's Disease.
- May delay worsening of symptoms for 6 to 12 months.
- Examples include Aricept, Namenda, Exelon, Razadyne, Namzaric.
- Antidepressants may also be useful as a preventative technique.

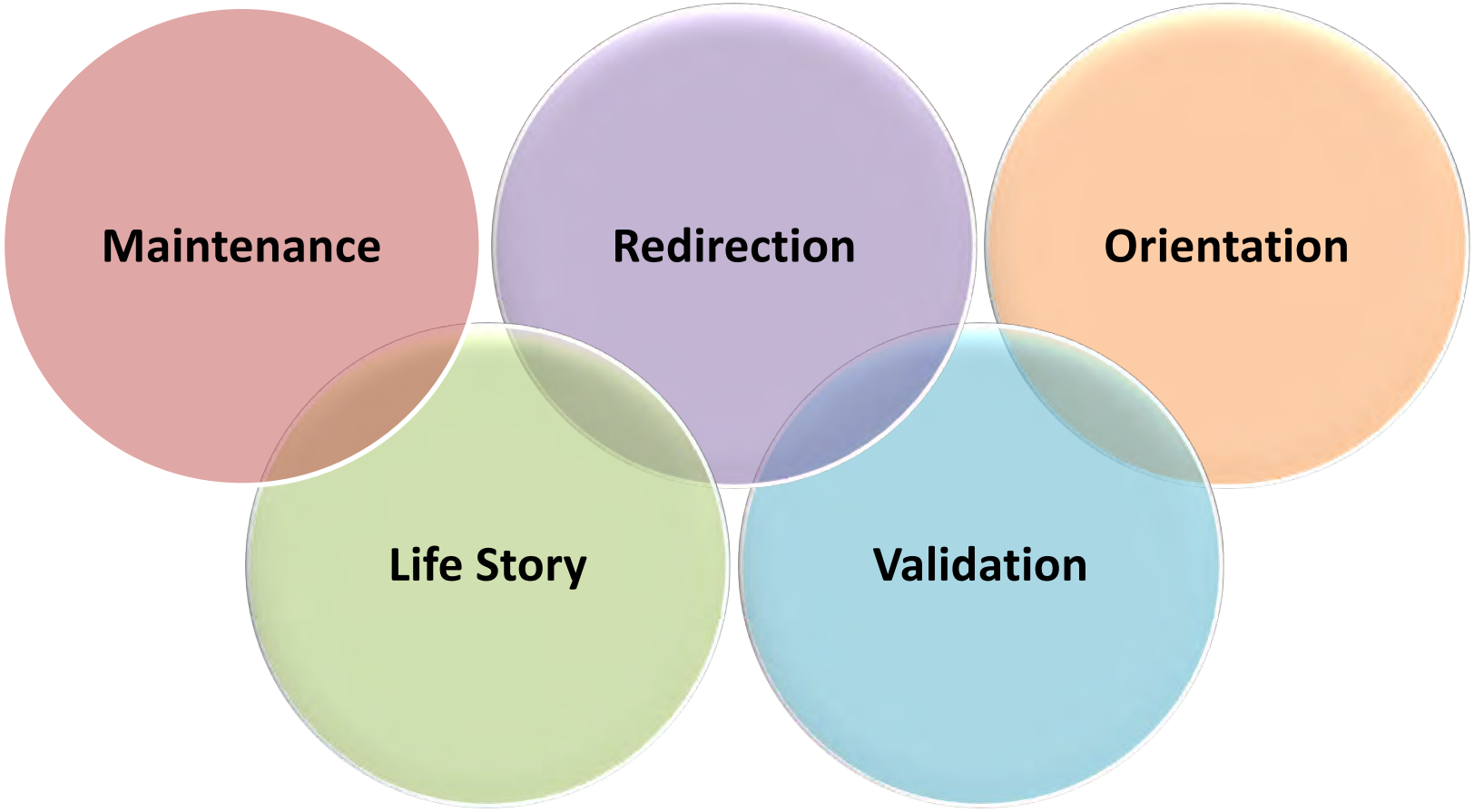
Family & Social Supports

- People with limited social/family networks and low social engagement may be more likely to develop dementia
- Social engagement combined with activities such as movies, clubs, centers, and volunteering may protect against cognitive impairment.
- However, low low social engagement may also be an early symptom of cognitive impairment.

Complex Social Engagement

- The interaction between social activity, cognitive activity, and physical activity may also be important.
- Leisure activities that include cognitive, social, and physical components might be the best strategy to reduce the risk of cognitive impairment or reduce the rate of decline.
- For people with Intellectual Disability, understanding their baseline cognitive and adaptive skills is especially important. “Diagnostic overshadowing” is a constant concern.

Key Support Strategies



Adapted from *Habilitation Therapy in Dementia Care*. Paul Raia, PhD. 2011.

Maintenance Supports

- Considered **best practice** in dementia care.
- **Proactive** approach can eliminate hours of reaction.
- Focus is on **support of remaining abilities**.
  - Respect the changing needs of the person
  - Provide meaningful, failure-free activity.
  - Allow the person to do as much as they can for themselves but…be aware that as the disease progresses the need for assistance will increase.
- Can **reduce or eliminate difficult behaviors** at all stages by reducing frustration, boredom, anxiety, fear, etc.
- Can be done in **all settings by all staff**.

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Redirection

- Distract and redirect to minimize or avoid outbursts and challenging behaviors.
- Redirected with gentle distraction or by suggesting a desired activity.
- Providing food, drink, or rest can be a redirection.
- Smile, use a reassuring tone. Body language is important.

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Orientation

- Do not correct or try to **reorient** the person.
- The person with dementia may no longer be able to make sense of the present. Lost memories of years past will become their new reality and they even may re-live past events.
- To avoid frustration and agitation, you must enter their reality. **Don't argue.** This is not lying, it is respecting their reality.

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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 a person can no longer tell their own story, activities related to storytelling can still be used to inform caregiving and plan activities.

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Validation

Focuses on **empathy and understanding**.

- Based on the general principle the **acceptance** of the reality and personal truth of a person's experience… no matter how confused.
- Can **reduce stress, agitation, and need for medication** to manage behavioral challenges.
- Forcing a person with dementia to accept aspects of reality that he or she cannot comprehend is cruel.
- Emotions have more validity then the logic that leads to them.

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Challenges

- Behavioral and emotional outbursts tend to increase over time, and may not respond to standard behavioral treatments.
- Language skills tend to decrease over time. Staff must be creative in using non-verbal skills.
- Sensory and perceptual skills will decline. Environmental modifications will be needed.
- Memory loss leads to confusion and repetition, with an underlying emotional base of fear, anxiety.

And More Challenges …

- Wandering
- Sundowning
- Hoarding
- Delusions
- Paranoia
- Hallucinations
- Sleep disruption
- Sexual disinhibition
- Resistance to care
- Sensory sensitivity
- Inability to communicate pain
- Tactile defensiveness

Big Picture

- The rate of decline and types of changes are highly variable … we must be responsive to nuanced changes of each person we support.
- Our behavior and environment must be the focus of change and adaptation … rather than focusing on changing the person.
- It can be a sad experience for staff. Celebrating the person and the staff must become a focal point or risk losing valued caregivers.

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