

Dementia Capable Care

For Individuals with IDD

What is Aging?

- ▶ Active Process that occurs over an individuals lifespan, from birth to death.
- ▶ Aging is unique to each person.
 - ▶ Marked by gains and losses within common patterns of aging.
- ▶ Conditions that impact aging:
 - ▶ Genetics
 - ▶ Lifestyle
 - ▶ Environment
 - ▶ Attitude

Adopt a Lifespan Approach

- ▶ Based on the premise that what happens in childhood and young adulthood affects the quality of life in old age.
- ▶ It's never too late to make a difference, but the earlier we start the larger difference we can make.
- ▶ Dementia is NOT a normal process of aging.
- ▶ Healthy aging is impacted by the following practices:
 - ▶ Poor lifespan health choices
 - ▶ Long term consequences of early life therapeutic interventions.
 - ▶ Prolonged usage of medications adding to chronic conditions in old age.
 - ▶ Lack of systems of care for health advocacy. (different staff at appts, . Etc)

Continued

- ▶ Problems with accessing health services:
 - ▶ Not having medical personnel familiar with IDD
 - ▶ Not tracking risk conditions
- ▶ Age associated pathologies such as dementia and cardiovascular disease
- ▶ Lack of exercise
- ▶ Poor nutrition and bad eating habits.

Challenges to Health Aging in adults with IDD

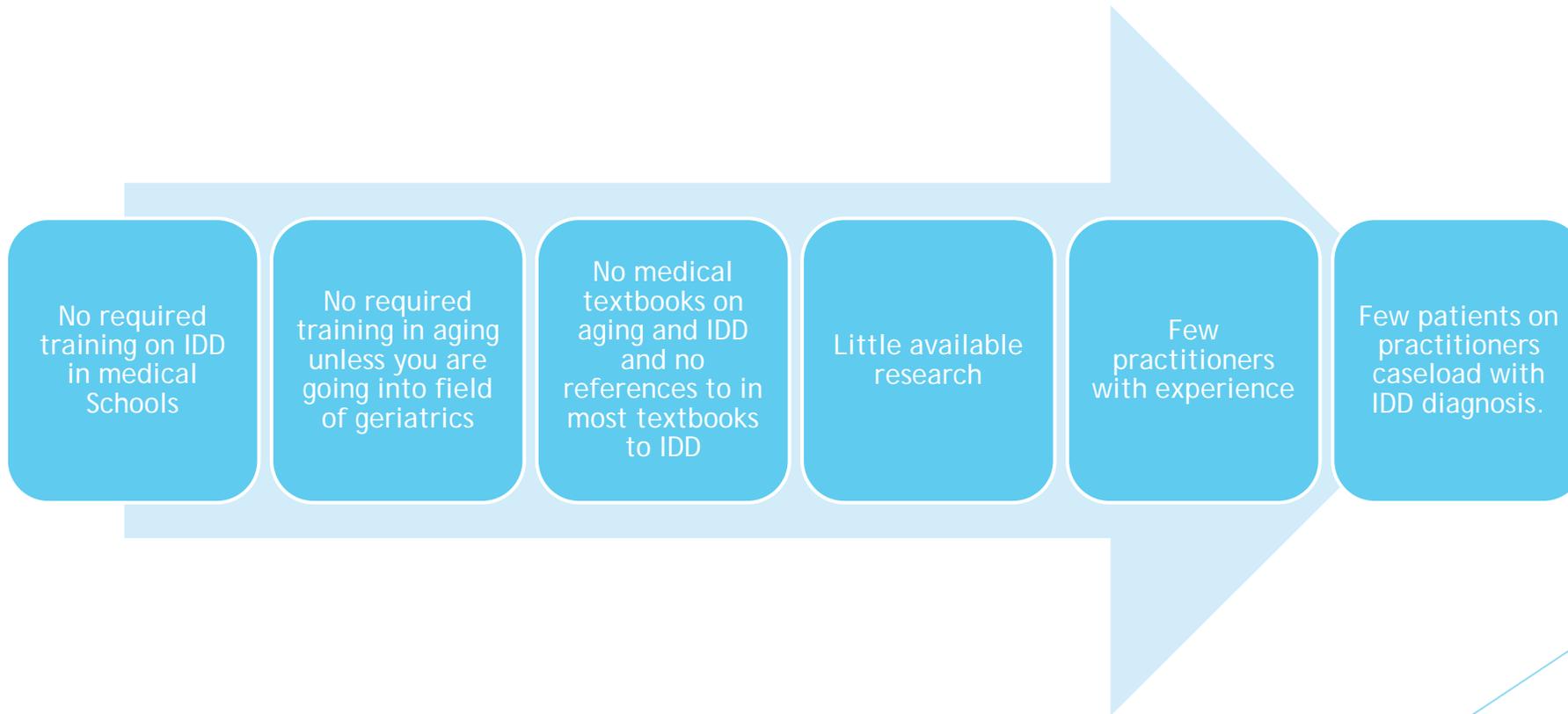
Medical history is often incomplete or unknown.

- ▶ Staff turnover
- ▶ Family not available for information, historical documentation unavailable
- ▶ Health Care provider turn over
- ▶ Providers not understanding the baseline functioning of the presenting older adult with IDD.

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- ▶ Lack of systems for health advocacy
- ▶ Information provided for the appointment may not include all necessary information.
- ▶ Staff/family attending the appointments might not be knowledgeable about the symptoms.

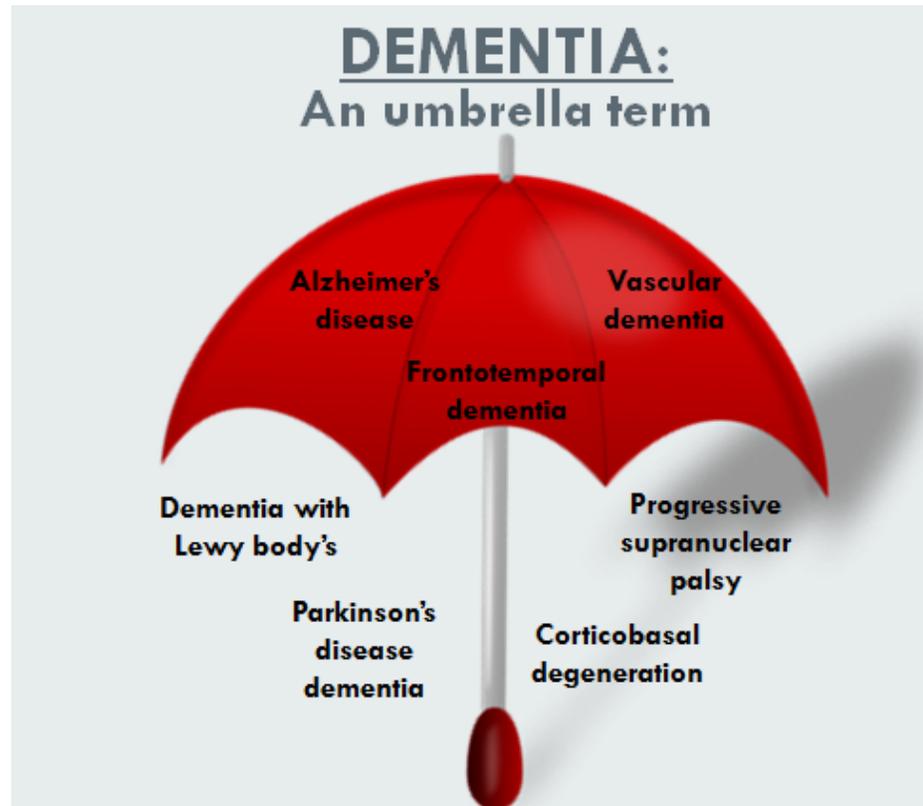
Health Care Disparities for Adults with IDD



Dementia 101

- ▶ Dementia is “A loss of cognitive function severe enough to interfere with daily functioning.
- ▶ The term “dementia” describes a group of symptoms, it is not a specific disease.
- ▶ The condition we refer to as dementia may be caused by many things
 - ▶ Some may be treatable, ie dehydration or B12 deficiency
 - ▶ Others are irreversible, such as Alzheimer's, vascular, or Lewy Body.
- ▶ Dementia is NOT a normal part of aging.

There are over 100 conditions that cause dementia.



Risk of Dementia in IDD

- ▶ Most adults with IDD are typically at no more risk than the general population, although studies proving this are few.
- ▶ The exception to this is individual with Down's syndrome, who are at increased risk. They typically begin to exhibit symptoms young, and have more rapid progression.
 - ▶ 22% of individuals with Downs syndrome over age 40 will present with Alzheimer
 - ▶ 56% of individuals with Downs syndrome over age 60 will present with Alzheimer.

Prevalence of dementia and impact on IDD Services.

- ▶ Increased lifespan=increase in dementia
- ▶ What this means for programs:
 - ▶ Need to raise the index of suspicion among staff and families
 - ▶ Programs and services need to become dementia capable.
 - ▶ Need to improve:
 - ▶ Diagnostic and technical resources,
 - ▶ Care management supports to promote aging in place.

Warning Signs



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 people with DS age prematurely (in their 50s)
- ▶ Adults with DS are at risk for diseases and changes about 20 years earlier than the general population.
- ▶ DS is one of the most significant risk factors for Alzheimer's disease.
 - ▶ Specific risk factors such as hearing and visual impairment, vitamin B12 deficiency, seizures, depression, dehydration and side effects of medication.

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, thyroid disease and UTIs common in DS and can mimic dementia.
- ▶ Normal age associate deficits are common.
- ▶ Often present with behavioral symptoms instead of memory loss.
- ▶ Don't forget: there are treatable causes of dementia-like behaviors, such as medication interactions, depression, dehydration, UTIs, Lyme disease, B12 deficiency.

Diagnostic Overshadowing

- ▶ The tendency for clinicians to attribute symptoms or a change in behaviors of a person with IDD to their underlying cognitive deficits and therefore underdiagnose the presence of co-occurring disease such as dementia.
- ▶ Traditional screening instruments for detecting dementia in the general population are designed for people with average baseline intelligence and not useful for cognitive impairment in adults with DS.
- ▶ NTG-EDSD is specific to resident, and what is used here at SLC.

Essentials of a diagnostic workup

- ▶ History and physical including psychiatric, personal, past medical and family histories and mental state assessment.
- ▶ Lab tests
 - ▶ Evidence supports the following tests
 - ▶ Complete blood cell count
 - ▶ Serum electrolytes
 - ▶ Glucose
 - ▶ BUN/creatinine
 - ▶ Serum B12 levels
 - ▶ Thyroid and Liver function tests
 - ▶ Celiac screening if DS
- ▶ MRI and/or CT scan to detect lesions.

Common Conditions to Rule Out through Differential Diagnosis

- ▶ Stroke
- ▶ Side effects of Medications
- ▶ Nutritional deficits and imbalances
- ▶ Hypothyroidism
- ▶ Dehydration, Malnutrition
- ▶ Cardiovascular Disease
- ▶ Environmental Changes
- ▶ Sensory impairments
- ▶ Depression
- ▶ Lyme Disease
- ▶ Normal Pressure Hydrocephalus
- ▶ Sleep apnea

The Three “D’s”

- ▶ Dementia: Gradual over months to years.
- ▶ Delirium: Sudden onsets, hours to days. This is a medical emergency. UTIs are present in 95% of people admitted to hospitals in a psychotic state. Constipation is the #2 reason, and pneumonia is #3.
- ▶ Depression: Recent unexplained change in mood that lasts for over 2 weeks.

Why a focus on Alzheimer's?

Often presents differently in people with DS.

- ▶ Abrupt onset of seizure activity where there has been none in the past.
- ▶ Incontinence when an individual has been independent in toileting.
- ▶ Short term memory loss may depend on level of memory in past.
- ▶ Most common first symptom is changes in perceptions: May be afraid to walk on carpets, or outside.
- ▶ Changes start happening in brain 10-12 years before first symptom.

Key Concepts in Dementia Care

Caring for a person with dementia means we must understand that

- ▶ He/She does not see the world the same way we do.
- ▶ That we see as normal can be very confusing and threatening.
- ▶ We must enter their reality as they cannot conform to ours.
- ▶ Need to be patient, supportive and understanding
- ▶ We must change, because they cannot.

Key concept #1: Maintenance Support

Generally accepted as the best practice in dementia care.

- ▶ Proactive approach
- ▶ Focus is on support of remaining abilities
 - ▶ Respect 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.

Key Concept in Dementia #2: Lifestories

- ▶ Everyone has a lifestory that needs to be honored and respected.
- ▶ The story is the essence of the 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.

Key concept #3: Validate

- ▶ Focuses on empathy and understanding.
- ▶ Based on the general principle of validation..the acceptance of the reality and personal truth of a persons experience, no matter how confused.
- ▶ Can reduce stress, agitation and need of medication to manage behavioral challenges
- ▶ Forcing a person with dementia to accept aspect of reality that he or she cannot comprehend is cruel.
- ▶ Emotions have more validity than logic—at least to them.

Key Concept #4: To Reorient or not to reorient.

- ▶ Best practice in dementia care: Do not correct or try to “reorient “ the person.
- ▶ Ask “What does it achieve?” You have permission to do what makes sense in the moment.
- ▶ To avoid frustration and increasing agitation you must enter their reality. Don’t argue. This is not lying, it is respecting their reality.
- ▶ Memory regression occurs, which no longer makes sense of the present. Memories of years past become the new reality.

Key Concept #5: Redirection

Distract and Divert

- ▶ Distract and divert to minimize or avoid outbursts and challenging behaviors.
- ▶ Redirect with gentle distractions or by suggesting a desired activity.
- ▶ Smile and use assuring tone. Body language is very important.
- ▶ Ask questions. A good all purpose one is "Tell me about it."

Be flexible..What works today may not work tomorrow.

- ▶ The Key to managing difficult behaviors is being creative and flexible in your strategies to address a given issue.

Supporting Derek



Thank you.

