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Dementia and Intellectual and Developmental Disabilities

October 10, 2014
The Hotel Woodbridge at Metropark, Iselin

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Dementia and Intellectual & Developmental Disabilities

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Put away your cell phones, text messages, & worries of the day

Learn from Ms. Piggy

Developmental Disabilities (DD)

- Umbrella term for multiple disabilities including Intellectual Disabilities (ID)
- Expected to last a lifetime
- In New York State prior to birthdate of 22, varies in each state 18 - 22
- Affects independent functioning in 1 or more areas including activities of daily living, vocational, socialization, learning, communication, independent living thus requiring lifetime supports and services,
- Federal definition and state criteria for service eligibility

Intellectual Disabilities (ID)

- The international and now national term to replace the term mental retardation
- Significant intellectual challenge with IQ below 70
- Also meets the criteria on the previous slide
- Has undergone many changes and continuing to be debated at the national and state level, especially in terms of eligibility for services
Aging is aging...

- It is essential to always compare the adult to who she or he has been throughout a lifetime.
- Age-related changes occur in all persons regardless of pre-existing conditions:
  - Normal
  - May be interventions to reduce decline
- Age-associated changes in all persons:
  - Those associated with disease, mental illness, or poor environmental fit
  - May be higher risk factors based on pre-existing conditions.

Factors of aging

- Genetics, environment, lifestyle, and attitude interact with any pre-existing disability.
- Affected by severity of disability.
- Affected by age of onset.
- Create a unique group of risk factors in each individual within patterns of aging for all of us.

Life expectancy in general population

- Life expectancy: Males = 73
- Females = 78 in the United States at this point in time. For every decade of life our Life expectancy increases.
- Maximum Life potential appears to be = 120.
- For persons with Down syndrome shortened life expectancy.
- For all others with IDD dependent on severity of the disability interacting with aging factors & other diseases.
- Similar to general population if less severe.

Reserve or vitality concept of aging

- The higher reserves in each organ or system of the body the increased reserves or vitality to draw upon in later years.
- The more compromised each body system or organ is earlier in life the increased risks for disease and age-associated conditions:
  - Example of weight bearing for adults with cerebral palsy.
  - Epilepsy & steroidal based medications reducing absorption of vitamin C.
  - Cognitive impairment across the lifespan for adults with ID.

Known risk factors for adults with IDD

- Down Syndrome
  - Congenital heart disease
  - Earlier onset for risk factors than the general population
  - Medications
- Cerebral Palsy (CP)
  - Eating and swallowing disorder affecting nutritional intake
  - Scoliosis
  - Tuberous sclerosis
  - Medications
Myths and Stereotypes about Aging and IDD

- Lifetime accumulation of assumptions of lack of competency with double jeopardy
- Higher risk for mental illness which also increases the myths about aging with IDD
- Automatic assumption of dementia as normal aging for adults with IDD
- Dementia is disease process and not normal aging
- Assumption when functioning and cognitive decline occurs it is normal aging and not disease process

Health Care Disparities & IDD

- Lack of knowledge & research about aging in adults with IDD
- Lack of training & expertise for health care providers on IDD, even less known about aging
- Aging for everyone still one of the stereotypes and prejudice allowed to be voiced (watch late night talk shows for example)
- In a society in which material wealth is highly valued especially for quality of life in later years adults with IDD more likely to be in poverty, existing on minimal income, and less family supports

Importance of Health Care Advocacy

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

Staff and family are the experts about individuals with IDD.

Health care is an art, not a science!

4 Steps of Health Care Advocacy

#1. Observe

- Look for changes in the person such as:
  - Behavioral
  - Personality
  - Activity level
  - Unintended weight loss or gain (10%) or weight loss or gain of less than 10%
  - Changes in wake/sleep patterns
  - Diarrhea/constipation

#2. Report

- Document your observations
- Be accurate and specific
- To the right person
- Use correct forms and processes

#3. Prepare for the health care appointment

- Make a team meeting (residential/family/program/individual advocates)
- Meet with caregivers to bring together symptoms observed
- Prioritize symptoms and concerns to be addressed
- Checklist or form for the attending caregiver to bring to the appointment
- Gather all pertinent information in an organized format so that the information can be provided in a brief and concise manner if the person who goes with the individual is included in the meeting
- Order to communicate symptoms
- Use same health care advocacy skills

#4. Continue

- Discuss intervention strategies for individual advocate
- Ask what strategies work and what do not work
- Review what the person is experiencing
- Encourage family and program to keep intensive care planning

4 Steps of Health Care Advocacy (Continued)
4 Steps of Health Care Advocacy (Continued)

#4. Follow-up after the appointment

- Follow-up recommendations with all caregivers
- Make sure recommendations are understood.
- Are there any follow-up questions?
- Continue observing and reporting.
- Don’t give up!
- You may have to search out a new provider
- Be as prepared for the follow-up as for the first appointment

Health Care advocacy

- Dementia-related health advocacy is
- Speaking for the adult affected by dementia
- Looking after their interests during health interviews and visits
- Ensuring that concurrent conditions are diagnosed and treated
- Tracking the rate and course of dementia and helping the health practitioner better understand the changes occurring
- Coordinating care when various providers are involved
- Arranging for appropriate care and supports

Dementia & IDD

- Same risks and rate as in the general population
- The one exception adults with Down syndrome
- The more severe the disability the increased likelihood of co-morbidities that increase the risk for disease and age-associated conditions with earlier onset
- Co-morbidities misdiagnosed or undiagnosed
- Diagnostic overshadowing – blaming on the pre-existing condition or diagnosis

Differential Diagnosis and IDD

- Differential Diagnosis is essential for everyone to rule out causes for decline
- It is essential to rule out possible causes for decline by assessing and providing intervention when possible
- Need to determine if there are reversible causes for decline in cognition and functioning
- Often in older adults there are many causes for decline that can be treated
- In older adults with IDD even more likely there is increased risk for age-related and associated diseases, conditions

Differentiating normal aging changes from disease process

- Determines types of interventions to best match needs
- Inappropriate interventions or services could result in:
  - Activities not appropriate with cognitive/physical changes related to aging
  - Poorer quality of health as not aware that changes related to aging may mask or mimic diseases
  - Misdiagnoses or missed diagnosis of dementia, especially Alzheimer’s disease
  - Reduced quality of life for the adult with ID & their caregiver(s)
Diagnostic Overshadowing

Definition: Blaming loss, decline, and changes on the pre-existing diagnosis

- Example - Decline assumed to be a result of intellectual disability rather than disease process
- Example - Reported chest pain ignored because of the pre-existing diagnosis of ID
- Assumption of lack of cognitive capacity due to diagnosis of ID in combination with aging
- Lack of experience or verbal capacity for the adult with ID to report symptoms

Age-associated changes that may be misdiagnosed as Dementia

- Stroke/Cardiovascular
- Seizures - approximately 15% of adults with DS
- Dehydration
- Nutritional deficits or imbalances
  - Vitamin B series/B-12
  - Sleep deprivation/Sleep apnea
  - Spinal cord abnormalities especially C spine
- Sensory impairments

Age-associated changes that may be misdiagnosed as Dementia

- Adjustment reaction
  - Result of loss of parent or elderly caregiver
  - Depression
  - Behavioral change (a form of communication)
  - “Non-compliant behavior”
  - Increased “obsessive compulsive” behavior

Age-related changes that may be misdiagnosed: Visual impairment

- Significant impairment will affect functioning
- May appear as acute dementia
- Sensory overload
- Cataracts, early onset, 15 - 20% between ages 45 - 65
- Increased visual impairments, likely earlier onset

Age-associated changes that may be misdiagnosed as Dementia

- Side effects of medications
- Respiratory/Pneumonia
- Infections
  - Urinary Tract
- Constipation
- 100s of other conditions & diseases
  - Urinary tract

Behavioral Challenges

Some symptoms may present as behavioral problems:
- Reduced sensory perception:
  - Hearing - refuse to participate in activities, inappropriate response to questions, confusion in noisy situations
  - Vision - unable to recognize familiar people, disorientation
- Menopause - memory impairment
- Multiple medications - confusion
- Delirium - sudden behavioral change which may fluctuate as the day progresses.
- Depression - lethargy, change in appetite or sleep, unnecessary worry over trivial issues.
Diagnosing adults with ID

Rule out underlying causes for decline or changes through the process of elimination of possible causes. (Differential Diagnosis)

- Depression
- Metabolic Changes
- Nutritional Problems
- Endocrine Imbalance
- Other forms of Dementia
- Cat Scan or MRI
- Lab Studies
- Family History

Sensory processing and differential diagnosis

Rule out sensory impairments and challenges.

Seven senses: Responsible for our interaction with the external world.

1. Auditory (hearing)
2. Visual (sight)
3. Olfactory (smell)
4. Gustatory (taste)
5. Tactile (touch)
6. Proprioceptor (position) - the sensory feedback that informs us where the parts of our body are and how they are moving. Integrates input from the 5 senses.
7. Vestibular (balance) - related to and dependent on the proprioceptive system. The vestibular system is what gives us balance, allows us to stand and move through space without falling over.

Alzheimer’s Disease (AD) and IDD

- The same risk factor as the general population
- With the exception of adults with Down syndrome
- The same issues as in the general population only magnified with health care providers assuming cognitive and functioning loss is the result of AD
- The most common form of irreversible dementia in old age is Alzheimer’s Disease
- Persistent memory loss of new and recent information/learned skills
- Must be compared to individual’s previous level of functioning

Alzheimer’s Disease

- Most common form of dementia.
- Gradual onset.
- Unable to remember new information.
- Impaired daily activities.
- Generalized brain atrophy.
- Amyloid plaques and neurofibrillary tangles.

By the final stage of Alzheimer’s, damage is widespread, and brain tissue has shrunk.
Normal Brain vs. Late Stage Alzheimer's

Cause for Alzheimer’s dementia
- Exact cause is still unknown.
- We do know that a complex series of events takes place in the brain over a long period of time.
- Likely that the cause includes some mix of genetic, environmental, and lifestyle factors.
- Because people differ in their genetic makeup and lifestyle, the importance of any one of these factors in increasing or decreasing the risk of developing Alzheimer’s may differ from person to person.
- Most people with Alzheimer’s disease have “late-onset” Alzheimer’s, which usually develops after age 65.
- Early-onset Alzheimer’s is a rare form of the disease. It occurs in people age 30 to 60 and represents less than 5 percent of all people who have Alzheimer’s disease.
- Individuals with Down syndrome develop Alzheimer’s at a younger age than the general population.

How Dementia Progresses

Known effect from the disease
- Proprioception system integrates the input from the five senses to create meaning of the environment and your place in it.
- Individual with AD literally “lost in space and time.”
- Think of AD as a problem of location in space.
- Can not perform functions of daily living if can not locate in space.
  - Ex. Could you solve a complex math word problem while free falling on a roller coaster?

Vestibular
- Includes the parts of the inner ear and brain that controls balance.
- Vestibular sensory information is well represented in the medial temporal lobe and these brain regions deteriorate first in AD.
- Studies indicate likely controlled by the hippocampus.
- Humans develop a cognitive map for movement using landmarks that may now be forgotten or misinterpreted.
- Location and directional movement is disrupted if visual stimuli are removed (such as in the dark). Can be restored but not easily within AD even within familiar surroundings.
  - Connecting of movement to other events and locations (episodic memory) likely impaired.

Alzheimer’s disease and Down syndrome
- At higher risk for Alzheimer’s dementia
- At higher risk for other age-related diseases and conditions with earlier onset than the general population
- At higher risk for misdiagnosis of Alzheimer’s dementia
- Through advocacy and understanding can make a difference
Down syndrome and Alzheimer’s Dementia

MYTH: All adults with Down syndrome will be diagnosed with Alzheimer’s

- It is not 100% of all adults with Down syndrome!!!
- Differences in rates with persons with Down syndrome
  - Much higher prevalence of neuropathology
  - Earlier onset and shorter duration
  - Clinical changes in brain appear to be the same 100%
  - Approximately 60% will be diagnosed with AD by 60 years of age

Interaction of Aging and DS?

- Complex interaction of factors with Down syndrome
- Known as a disability of premature aging
- Life expectancy has continued to increase.
- Adults with DS are at risk for diseases and changes about 20 years earlier than the general population

By age 60, only 60% diagnosed with AD
APOE-4 to late-onset Alzheimer’s disease and believed that people with 2 copies would show symptoms by age 90

Down syndrome: What is it?

- One of the developmental disabilities, usually associated with Intellectual Disability (ID)
- 1 in 750 live births, genetic, older parent correlation,
- Trisomy 21 (Chromosomal defect)
  - All cells of the body (99%)
  - Some of the chromosomes in all cells (2 – 3%)
  - All chromosomes in some cells of body, mosaicism, (2 – 3%)

Down syndrome: What is it?

- In approximately 25% of the time Fathers appear to be the source of the extra chromosome. Association with fathers 55+ increased incidence.
- In approximately 5% of children born with DS, the extra chromosome is attached to another chromosome, “translocation.”
Differences in longevity for persons with Down syndrome

- Longevity is shorter, in one Australian study men live longer than women
- Experience early aging changes which has an impact on cognitive and/or physical function
- May lead to behavior problems
- Early changes may result in loss of functioning, go unnoticed, or a behavioral change

Possible Risks for adults with DS

- Health: Assuming changes related to aging or the disability without recommended interventions
- Illness: Behaviors may mask or mimic diseases reducing chances for appropriate assessments and interventions
- Dementia: Misdiagnosis or missed diagnosis, especially Alzheimer’s dementia

APP and Early-onset Alzheimer’s

- APP (beta amyloid precursor protein)
- Early onset Alzheimer’s:
  - strikes before age 65
  - spreads more predictably through families than late-onset
  - accounts for 5-10% of Alzheimer’s cases
  - afflicts people with Down syndrome

1992: Amyloid Cascade Hypothesis

- The gene for amyloid is found on chromosome 21 and codes for APP
- Enzymes improperly cut the APP
- The resulting amyloid becomes sticky and clumps together forming plaques which:
  - are toxic to neurons in the brain
  - stimulate the immune system and create an inflammatory response further damaging the brain
- A chemical reaction causes “tangles” inside the neurons

Caregiving, IDD, & dementia

Caregiving tips

- It is the disease not the person
- It is essential each caregiver takes care of their own health & emotional needs
- Work as a team in families & organizations
  - Do not be reluctant to ask for help
  - Discuss the issues and responsibilities
- Preserving the essence of each person is the major goal and responsibility of each caregiver
Stage Based Care Considerations

- **Early Stage**
  - Observation & reporting of functional changes to the team.
  - Support, functionality, and maintain quality of life.

- **Mid-Stage**
  - Identify stage consistently to support, functionality, and maintain quality of life.

- **Late Stage**
  - Specialized training of staff including mobility, eating, comfort care.
  - Increased use of adaptive equipment and procedures.

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.

Helpful Hints for Redirecting

- **Body Language**: People with dementia are very adept at picking up on your body language. Smile, try to relax, and be warm and open when redirecting someone with AD to reduce their agitation.
- **Ask questions**: A good all-purpose phrase is “…tell me about it.”

Example:

**Betty:** “I want to go home!”
**You:** “Tell me about your home. Is it a big house?” The gently redirect the conversation away from what is bothering Betty… “I’m hungry, Betty, would you like some ice cream?”

Reorientation Tips

- Whose reality is it?
  - A person with dementia can no longer make sense of the present and as recent memories are lost memories of years past will become their new reality and they even may re-live past events. To avoid frustration and increasing agitation you must enter their reality. Don’t argue. This is not lying, it is respecting their reality.

Key Concepts in Dementia Care:

- **Reorientation**
  - Do not correct the person or try to reorient them.
  - Example: “What time is my mother coming?” (You know Ken’s mother died 20 years ago.)
  - Which response is better:
    - a. “Your mother is dead, Ken. Your sister will pick you up at 4:00.”
    - b. “She’ll be here in a little while. Let’s get a dish of ice cream while we wait.”

- **Life Story**
  - Validation

- **Rehabilitation**
  - Redirection
  - Reorientation
Key Concept in Dementia Care: Validation Approach

- An approach that focuses on empathy and understanding.
- Based on the general principle of validation—the acceptance of the reality and personal truth of another's experience no matter how confused.
- All behavior has meaning and is an attempt to communicate.
- 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 than the logic that leads to them.

Environmental adaptations

- Change the environment & the approach to care, not the person with ID & dementia
- Concrete versus abstract
- Eliminate fall hazards
- Create safe pathways
- Reduce unnecessary and disturbing background noises, glare, visual stimuli
- Create an environment for peace, calm, and moments of joy within the disease

What other reasons (besides dementia) may cause someone to be unable to find his or her bedroom?

Would you have trouble finding your bedroom?

Can you suggest adaptations or modifications that might make it easier to navigate?

Systems Issues

- Our networks are still not working together to share our resources as much as we could be, “silos of resources”
- Historical experiences of segregation
- Language and funding differences
- IDD network has traditionally focused on youth and childhood development

Systems Issues

- Interventions are often the opposite from what is needed when an older adult with IDD has AD
- Health care providers do not have the experience or expertise to diagnose and treat adults with dual diagnosis
- Staff turnover and staffing patterns
- What does Age in place mean?
- We need to ask some tough questions and find the solutions together
Summary

- Aging is normal aging.
- Dementias and significant decline are not normal aging.
- Always try to determine underlying cause.
- Assist caregivers to find knowledgeable healthcare providers.
- Rule out underlying causes and provide interventions through services as appropriate.

Resources

- National Task Group on Dementia and IDD, www.aadmd.org/ntg
  - Webinar
  - Screening tool
  - Thinker Document

National Task Group on Intellectual Disabilities and Dementia Practices

What are we?

The NTG is a coalition of interested persons and organizations working toward ensuring that the needs and interests of adults with intellectual and developmental disabilities who are affected to Alzheimer's disease and its related dementias are recognized and addressed in a timely and appropriate manner - as well as those who care for them.

We are part of the national plan to Address Alzheimer's Disease

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 DSQID, 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

We can all make a difference together!
Reading list for October 10, 2014
Aging, IDD, and Dementia
Prepared by Kathleen M. Bishop, PhD

Websites for training information and resources:
For National Task Group on ID and Dementia website: http://aadmd.org/ntg

The training information page and online registration has been published here http://aadmd.org/ntg/training/nhs-allegheny-valley-school for the next NTG training on dementia & IDD

Suggested Readings:


