Caring for Adults with Intellectual Disabilities
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University of Massachusetts Medical School Population Health Clerkship

Adults with Intellectual Disabilities: Definition & Epidemiology

Intellectual disability (ID): refers to a mental capacity that is below normal, and can be related to any condition that impairs brain development before birth, during birth, or during childhood.

Common Etiologies:
- Genetic abnormality: over 500 identified, most commonly Down syndrome and Fragile X
- Brain injury (i.e. cerebral palsy)
- Trauma, metabolic abnormalities, toxin exposure, or infections
- Fetal alcohol syndrome
- No cause determined (about 33% cases)

Epidemiology & Trends:
- Affects up to 2.5% of US population
- Prevalence of ID: 6.6 per 1000 in adults
- In MA, 1 out of 5 adults served by DDS is over the age of 55
- Adults with ID are living longer and in the community rather than in institutional settings

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Commonly Associated Health Conditions
- GI Problems: dysphagia, constipation, GERD
- Vision and hearing problems, poor oral hygiene
- Dementia: by age 60, 1 in 16 adults with ID will be affected; Down syndrome associated with increased Alzheimer’s risk
- Musculoskeletal conditions: joint disease, osteoporosis
- Mental health: behavioral disorders, depression and anxiety
- Diabetes & obesity
- Seizure disorders
- Cardiovascular disease, congenital cardiac abnormalities

What are some of the health care access challenges?
- Communication barriers
- Clinicians often wrongly attribute mental health symptoms to a person’s disability rather than a separate health condition
- Legal issues regarding guardianship and paperwork
- High need for various specialists
- Lack of training for physicians and shortages of health care professionals willing to accept adults with ID

Interprofessional Network

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Clerkship Important Lessons & Next Steps
- Important for physicians to recognize some medical conditions may present as behavioral changes in patients with ID
- Individuals with ID are living to older ages
- Greater prevalence of chronic aging conditions such as Alzheimer’s disease and dementia, heart disease, diabetes, etc.
- Below is a checklist for physicians working with aging adults with ID:
  - Obtain a comprehensive medical, family, and social history
  - Assess baseline memory using the Test for Severe Impairment
  - Consider medications, sensory deficits, metabolic disturbances, sleep disorders, seizures, falls, and mental illness as causes of memory dysfunction
  - Educate caregivers and family members to observe any behavioral or memory changes
  - For future visits, obtain a description of current function and compare to baseline
  - Synthesize information and communicate with the patient’s other physicians and healthcare workers
- Future goals include creating a systematic electronic model with all of an individual’s healthcare information to ensure quality care at every medical appointment or encounter

Service Learning Projects

Healthy Athletes FUNfitness
- Conducted at the Special Olympics in collaboration with the American Physical Therapy Association
- Goals
  - Assess balance, flexibility, strength, and aerobic fitness
  - Teach exercises to help improve these areas if needed
  - Educate athletes and caregivers on importance of overall fitness
- Progress and Outcomes
  - Many athletes at the Special Olympics Massachusetts Senior Sports Classic participated
  - Information was collected from each participant
  - Each participant received education in areas that needed improvement

Preventative Screening
- Preventative Health Recommendations for Adults with Intellectual Disability Brochure
- A resource to assist healthcare providers in assuring quality preventative healthcare to adults with ID
- Well Chart
- A checklist for caregivers to fill out before medical appointments to detect any unmet or appropriate preventative screenings
- Goals, progress, and outcomes
  - Both updated to include the 2014 MHQP Adults Preventative Screening Guidelines
  - Additional information added on screening certain populations of patients such as Down syndrome individuals that often have multiple common co-existing medical conditions
  - Both will be used in clinical settings to improve preventative care in the ID population

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References