

PROMOTING BRAIN HEALTH EQUITY FOR ALL! | WWW.HEALTHMATTERSPROGRAM.ORG

- Approximately 6.5 million people in the United States have an intellectual disability (IDD). Approximately 1 - 3 percent of the global population has an intellectual disability—as many as 200 million people.
- Number of adults with IDD age 60 years and older may double from 641,860 in 2000 to 1.2 million by 2030 resulting in a need for more services.
- About 11,000 (6%) of the 180,000 older people with IDD will experience a form of Alzheimer's disease and related dementias (ADRDs) after age 60 (increases with age).
- People with Down syndrome have a higher risk, with about 2 in 3 people over the age of 60 developing dementia, usually Alzheimer's disease (AD), with a mean age of onset or diagnosis of AD at 53.



CHANGING THE MYTH

- People with intellectual and developmental disability (IDD) have healthy brains.
- ADRDs are NOT a natural course of aging for people with IDD.
- People with IDD like their nondisabled peers can optimize cognitive, emotional, psychological and behavioral functioning with or without dementia to cope with life situations.
- Healthy lifestyles among people with IDD can be supported by considering the impact of structural and social determinants on healthcare and health outcomes.



Know the Signs & Symptoms

- Loss of daily living skills (difficulty with usual abilities, changes in daily routine, sleeping, or eating habits, inability to choose clothing)
- Changes in personality (withdrawal, frustration, increased aggression, unjustified fears, inability to focus, periods of inactivity, disinterest in activities previously enjoyed)
- Increase in stereotyped behavioral traits (most often stubbornness)
- Difficulties remembering names of people previously known
- Loss of language and other communication and social skills
- Changes in coordination (increased difficulty with visual/motor coordination or accidents and falls, difficulty learning new tasks)
- Development of seizures not previously seen
- Disorientation to time and place or getting lost in familiar environments
- Repeated choking incidents
- Changes in hearing and vision
- Hyperactive reflexes



SCAN ME

WHAT IS THE IMPACT OF STRUCTURAL/SOCIAL DETERMINANTS OF HEALTH (S/SDOH) FOR PEOPLE WITH IDD

Equitable healthcare and health outcomes can only be achieved for people with IDD when S/SDOHs are assessed

1. **Socioeconomic Factors:** Unemployed, under-educated, low income, limited social support, lifelong interdependency with care provider (compound caregiving, caregiver stress), high prevalence of abuse, neglect and exploitation
2. **Physical Environment:** Limited community disability-friendly policies and accessible housing and transportation
3. **Health Behaviors:** Low physical activity, poor nutrition
4. **Healthcare Access:** Inaccessible healthcare facilities and lack of cultural humility among healthcare providers

"On Our Own"	Hidden Majority	
<ul style="list-style-type: none"> • People with IDD and their supports must navigate a fragmented system of professional health and social care throughout their lifetime. • Point of Entry for possible services is complex: <ul style="list-style-type: none"> ◦ System varies by different states. ◦ Preadmission Screening (PAS) Agency ◦ Independent Service Coordination (ISC) Agency • Coordinate and negotiate among the multiple people and institutions who span a variety of licensed healthcare professionals. 	<ul style="list-style-type: none"> • 76% of people with IDD live with their family, foster family, or on their own. • 22% of people with IDD are known to their state developmental disabilities agency. • 9% of people with IDD received at least one long-term support or service in addition to case management. • Healthcare providers need training on how to provide inclusive and accessible healthcare. 	
Modifiable Risk Factors	Diagnostic Overshadowing	Caregiving
<p>Nearly 40% of all ADRDs may be prevented or delayed</p> <ul style="list-style-type: none"> • Physical inactivity • Social isolation • Depression • Sleep problems • Hypertension • Obesity • Diabetes • Polypharmacy • Oral health • Hearing and vision • Gait and balance • Sensory challenges • Poverty 	<p>Treating comorbidities</p> <ol style="list-style-type: none"> 1. Diagnostic overshadowing assumes an individual's symptoms are due to their disability. 2. People with IDD may be overdiagnosed or underdiagnosed with ADRDs with delays in treatment. 3. Diagnostic overshadowing may be more common with poorly managed multiple chronic conditions (e.g., high cholesterol, hypertension, cardiovascular disease, obesity, mental health concerns). 	<p>Customized supports for caregivers</p> <ol style="list-style-type: none"> 1. Tailored messages to people with IDD, caregivers, and healthcare providers can reduce risk of cardiovascular disease, diabetes, hypertension, and obesity and improve quality of care. 2. Caregivers are challenged to provide effective and financially viable daily supports and long-term care. 3. 'Double jeopardy' may occur with lifelong caregiving from aging parent of aging adults with IDD.