

Intellectual & Developmental Disabilities Among Adults



Definitions & Diagnosis

Developmental disability is a broad term describing a range of syndromes that inhibit cognitive or intelligence capabilities. Intelligence refers to the cognitive ability to learn quickly from experience, plan for the future, solve problems, & comprehend complex or abstract concepts. *Intellectual disability* is a developmental disability that manifests a below average cognitive ability with the following characteristics:

- ◆ Onset of cognitive disability occurs before age 18
- ◆ Intelligence quotient (I.Q.) of 75 or below
- ◆ Significant limitations in adaptive behaviors, such as ability to manage daily life activities like meal preparation, personal hygiene, socializing, & communicating

Historically, cognitive disabilities were medically & socially identified as “mental retardation,” but have been renamed to reduce the associated stigma. Now collectively called intellectual & developmental disabilities (IDD), these conditions may differ in age of onset, severity of symptoms, & I.Q. levels.

Common IDD-related conditions include:

- ◆ Autism spectrum disorders (ASD)
- ◆ Down syndrome
- ◆ Fragile X syndrome
- ◆ Fetal alcohol spectrum disorders
- ◆ Cerebral palsy
- ◆ Epilepsy
- ◆ Other developmental delays

Sources: AAIDD 2015; Arc 2015; Seewooruttun et al. 2014; Ward et al. 2010

Common Causes

Intellectual & development disabilities have a variety of causes. Some manifestations of IDD are preventable or foreseeable due to their cause, but other conditions are less predictable. Many patients with IDD are born with a disorder, while others experience traumatic events that trigger a condition. Common causes are:

- ◆ Genetic mutations, additions, or deletions
- ◆ Chromosomal abnormalities
- ◆ In utero chemical/substance exposure
- ◆ In utero infections
- ◆ Childbirth complications
- ◆ Traumatic injury or illness in developmental years

Sources: del Rosario et al. 2012; Krahn et al. 2015; NIH 2015; SAMHSA 2015

Facts & Figures

- ◆ Recent research indicates that approximately 1.5-3.0% of the population have an IDD-related condition
- ◆ Down syndrome is the most common chromosomal IDD
- ◆ In 1990, the Americans with Disabilities Act recognized people with disabilities, including IDD, as meriting federal civil rights protections
- ◆ From 1977 to 2000, the number of large state institutions for individuals with intellectual disabilities decreased by almost 70%
- ◆ In 2002, over \$34 billion in public expenditures was spent on long-term care for patients with IDD, of which 65% was committed to community living arrangements
- ◆ People with disabilities have a high likelihood of being violently victimized, & people with IDD have the highest rates of violent victimization

Sources: Courtenay et al. 2015; Iezzoni 2011; Krahn et al. 2015; NIH 2012; Powers et al. 2011; Seewooruttun et al. 2014

Social Stigma

Prior to the late 1970s, it was common to permanently institutionalize patients diagnosed with an IDD. Due to policy changes that called for the deinstitutionalization of care, it is now typical for minor patients with IDD to live with their families, while adult or elderly people with IDD are frequently housed in assisted living group homes in their communities. In spite of the often conspicuous local presence of people with IDD, research demonstrates that specialized medical, behavioral, educational, & social resources continue to be limited, especially in rural & inner city areas.

Both public misunderstanding & social stigma hinder the ability of people with IDD to participate socially & seek services within their communities. People with IDD are often excluded from “normal” social activities because of their limited ability to conform to social

beliefs about “normal” functioning. Furthermore, people with IDD are frequently mislabeled as abnormal, less fortunate, & incapable as a partner, parent, peer, or employee. The lack of necessary support services, such as specialized health providers, educational & social services, & job or housing placement agencies can cause people with developmental disabilities to become overly dependent on family members for social & economic resources. Recent research indicates that young adults with IDD are less likely to enroll in college, to find employment, & to procure independent housing after high school.

To combat the social stigma of IDD, & to repair the damage of discrimination against those with developmental disorders, it is important that communities promote the following:

- ◆ Community awareness about the local presence of people with IDD, along with suggestions for strategies that encourage inclusiveness in schools & workplaces
- ◆ Physicians, dentists, optometrists, behavioral therapists, & other health care providers with experience & comfort treating patients with IDD
- ◆ Patient services such as transportation programs, educational support, group socials, employment agencies, & assisted living housing options
- ◆ Support services available to families & caregivers of patients diagnosed with IDD, such as counseling services, respite care, & social support groups
- ◆ Intervention/de-escalation tactics for employers & law enforcement who may be first-responders to behavioral or physical health emergencies of people with IDD

Sources: Brock et al. 2014; Buljevac et al. 2012; Chowdhury et al. 2011; Henninger et al. 2014; Holwerda et al. 2013; Krahn et al. 2015; Lewis et al. 2010; Oullette-Kuntz et al. 2010; Ryan et al. 2015; Scior et al. 2013; Seewooruttun et al. 2014; Starke 2011; Waldman et al. 2010; Ward et al. 2010

Common Health Disparities & Co-occurring Conditions

Patients diagnosed with IDD face significant barriers to quality physical, mental, & dental medical care, resulting in poorer health outcomes. Many health professionals lack specialized training and/or feel uncomfortable addressing the needs of patients with IDD. Health providers' reluctance to treat people with IDD likely stems from a general lack of knowledge or firsthand experience interacting with & caring for patients with IDD.

In spite of clear health disparities, progressive medical care & technology has improved the quality & duration of life for people with IDD. Increased life spans pose new challenges to health providers, as aging patients with IDD may be more vulnerable to age-related conditions such as cardiovascular & respiratory disease, dementia, & obesity. For people with IDD to thrive, communities must provide better access to basic health services, such as medicine, dentistry, & psychiatry, from health professionals with experience treating the unique needs of patients with IDD.

Co-occurring conditions are experienced simultaneously with another illness. Patients with IDD are at a higher risk of experiencing co-occurring condi-

tions, which complicates daily care, medical diagnoses, & treatments. The following ailments are common among patients with IDD, & referred to as the "fatal five" by health providers who specialize in IDD conditions:

- ◆ Bowel obstruction: Constipation sometimes caused by polypharmacy, minimal fiber in diet, & dehydration
- ◆ Gastroesophageal reflux disease (GERD): Back up of stomach contents can be caused by poor diet, constipation medications, immobility, & obesity
- ◆ Aspiration: Accumulation of fluid into lungs can be caused by GERD, feeding tubes, swallowing difficulties, poor positioning, & eating habits
- ◆ Dehydration: Can be caused by patients' difficulty swallowing or fear of liquid, or limitations on fluid to reduce incontinence, which can lead to constipation, seizures, & accumulated toxins
- ◆ Seizures: Can be caused by accumulated toxins or by epileptic disorders; can lead to shortened life spans

In addition to the fatal five, health providers & caregivers should be prepared to address the following:

- ◆ Serious mental illness (SMI): Can cause or exacerbate behavioral issues among patients with IDD, such as emotional outbursts, self-injurious behaviors, communication difficulties, & social anxiety

- ◆ Social integration: Some IDD's lead to difficulties with academic performance, relationships, communication, & achieving independence, often stemming from repetitive behavior, single-mindedness, & trouble interpreting social cues
- ◆ Regurgitation: May lead to serious health conditions, such as malnutrition, tooth decay, & severe indigestion. Excessive salivation is associated with regurgitation & pouching (accumulation of food between cheeks/lips & gums)
- ◆ Altered salivary function: Medications can cause dry mouth, leading to tooth decay & mouth sores
- ◆ Dental deterioration: Due to limited mobility & ability to communicate, dental issues may become very advanced before they receive treatment
- ◆ Foot disorders: Poor foot health is more common in people with IDD, especially Down Syndrome, & can lead to infection & limited mobility
- ◆ Obesity: Elevated weight gain risk due to sedentary lifestyle, medications causing weight gain, & limited mobility
- ◆ Masked conditions: Medical conditions may present as behavioral conditions; medical causes of behavioral issues should be ruled out before prescribing treatments for behavioral issues

Sources: Courtney et al. 2015; Detect 2015; Friedman et al. 2012; Havercamp et al. 2004; Levy et al. 2006; Lewis et al. 2010; Mantry et al. 2007; Robertson et al. 2015; Ryan et al. 2015; Turgyn et al. 2014; Viron et al. 2012; Waldman et al. 2010; Ward et al. 2010; Wark et al. 2014

Medical Care

In addition to the Americans with Disabilities Act (ADA), other policies have been developed to ensure that patients with IDD have continuous access to health care. Medicaid is a major source of health coverage for people with IDD. In addition to subsidizing the cost of health care, Medicaid provides long-term coverage for other services needed by many people with IDD, such as intermediate care facilities, home & community-based care, physical therapy, & prescription drugs. Recently, the Affordable Care Act (ACA) included special provisions to bar caps on lifetime insurance benefits & expand the availability of Medicaid benefits to people with IDD who did not previously qualify for coverage.

While government programs substantially address the economic costs of care for patients with IDD, health disparities remain. There is a dearth of IDD specialized training available to medical professionals. Without appropriate training, health providers will be unable to work with some patients with IDD. When health professionals are unprepared to provide medical attention or advice on daily care, people with IDD & their caregivers struggle without adequate support.

Sources: Brock et al. 2014; Burkett et al. 2015; Carbaugh et al., 2006; Grinker et al. 2015; Henninger et al. 2014; Krahn et al., 2015; Robertson et al. 2015; Ryan et al. 2015

Author Info

Fact sheet created by:

John P. Bartkowski, Courtney K. Barrie, & Chelsea C. Belanger — 2015

Contact: John.Bartkowski@utsa.edu ~~~ (210) 508-2530

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Web Resources

- ◆ American Association on Intellectual IDD: www.aaidid.org
- ◆ Centers for Disease Control: www.cdc.gov/nchs/ddid
- ◆ DETECT Mississippi: www.detectms.com
- ◆ National Institutes of Health: www.nlm.nih.gov
- ◆ The Arc. For people with IDD: www.thearc.org
- ◆ The National Association for the Dually Diagnosed: www.thenadd.org