Pediatric Intellectual & Developmental Disabilities

Definitions & Diagnosis

Historically, cognitive disabilities were medically & socially identified as "mental retardation," but were renamed intellectual & developmental disabilities (IDD) to reduce the associated stigma. This fact sheet delineates complex medical, educational, & interpersonal issues faced by pediatric patients with IDD. Additionally, this document highlights some of the most frequently diagnosed IDDs in the U.S.

Developmental disability describes a broad 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

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

Medical Concerns

In the past several decades, childhood mortality has declined, while the prevalence of childhood chronic diseases has increased. Today, approximately 12.6 million noninstitutionalized children & youth experience a special health care need. In the past, premature, low birthweight, or otherwise unhealthy infants often did not live long enough to manifest symptoms of chronic conditions. Because medical technology has advanced, many unhealthy infants can achieve an average life expectancy, but they may experience long term issues such as epilepsy, learning disabilities, psychological maladjustment, & physical disabilities.

Because of their dependence on others, children with IDD are particularly vulnerable to mistreatment, including harassment & sexual abuse. Recent studies indicate that up to 83% of women with developmental disabilities experience sexual assault. So, it is imperative that youth with IDD receive adequate information about bodies, sexual intercourse, & appropriate sexual behaviors. Physicians can help facilitate sexual education by engaging the patient in frequent discussions about the topic, & by encouraging caregivers to help disseminate similar information.

Children who are diagnosed with IDD are often eligible to receive Medicaid benefits. However, in spite of assistance to pay for medical care, there are few health care providers who specialize in working with children who have IDD. A lack of specialized health care providers increases the risk that children with IDD will suffer from less than adequate medical care.

Sources: Boyle et al. 2011; Grunau et al. 2002; Liptak et al. 2011; Lodygensky et al. 2008; Murphy et al. 2006; Putnam 2003; Sola et al. 2005; van Dyck et al. 2004; Witt et al. 2003

Common 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 trauma that triggers a condition.

Common causes are:

- Genetic mutations, additions, or deletions
- Chromosomal abnormalities
- In utero chemical or drug/alcohol 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

- Developmental disabilities are common & were reported in 1 in 6 children in the U.S. between 2006–2008
- Down syndrome (DS) is the most common chromosomal disorder, with approximately 5,400 infants with DS born in the U.S. each year
- Children with disabilities are sexually abused at a rate that is 2.2 times higher than children without disabilities
- Given IDD-related chronic conditions, children with IDD account for a disproportionate amount of U.S. health care expenditures
- Psychological maladjustment is more common among children with IDD, compared to children in general
- Children with developmental disorders are reported to need or receive special education services at significantly higher rates than children with no identified disabilities
- African-American youth are undertreated for chronic conditions such as IDD, compared with their white peers

Sources: Boulet et al. 2009; Boyle et al. 2011; Murphy et al. 2006; Shin et al. 2009; Simon et al. 2010; Witt et al. 2003

Educational Needs

Developmental disabilities are associated with learning challenges. Children diagnosed with IDD frequently experience difficulties in academic achievement, attention, & fine motor skills. Many children with IDD need specialized educational interventions. In 2009, about 35% of children with neurodevelopmental disorders needed or received special education services, compared to 2.4% of children with no medical disabilities. Children with IDD would benefit from educational programs that allow them to learn social, behavioral, & academic topics through direct observation & guided firsthand activities.

Social coaching should be a critical component in educational programs for children with IDD, because many symptoms of IDD result in barriers to achieving social integration. Although students with IDD represent a very small portion of school enrollment, the difficulties they often encounter may result in more behavioral infractions. Developing an understanding of social cues & behavioral expectations can help to ease misunderstandings encountered by youth with IDD as they transition into educational or occupational situations.

Sources: Boulet et al. 2009; Grunau et al. 2002; Lodygensky et al. 2008; Shipley-Benamou et al. 2002; Sugai et al. 2000

Attention-Deficit/Hyperactivity Disorder

Attention-deficit/hyperactivity disorder (ADHD) is a common neurobehavioral disorder, affecting up to 8% of children & 5% of adults. Causes for ADHD appear to be genetic & environmental, but males are more likely to be diagnosed than females. Symptoms include an inability to focus on tasks, forgetfulness, & erratic or impulsive behaviors. ADHD can seriously affect the academic achievement, well-being, & social interactions of children. Physicians should carefully analyze the patient's personal & academic history, while excluding other disorders, before concluding a diagnosis of ADHD. After an accurate diagnosis of ADHD, a number of pharmacological & psychosocial interventions can help to minimize the negative effects of the disorder. Without early interventions, children diagnosed with ADHD may continue to experience negative outcomes, such as academic & career problems, throughout adulthood.

Sources: NIMH 2015; CDC 2015; CHADD 2015; Weiss et al. 2005. Wilens et al. 2008; Wolraich et al. 2011

Autism Spectrum Disorders

Autism spectrum disorders (ASD) affect about 1 in 68 children in the U.S., & encompass a range of symptoms that manifest as social & behavioral impairments. Males are more likely to be diagnosed with ASD than females. ASD is a lifelong diagnosis that can result in serious deficits of social relatedness, language, & behavior. Children with ASD may be high functioning or severely disabled, & those with ASD have an increased risk of epilepsy. Many patients with ASD have difficulty adjusting to changes in routine, forming relationships, & communicating emotions. Early detection is key to helping children develop critical social skills. Transitionary phases may trigger behavior problems in children with ASD, including increased aggressiveness, anxiety, & distress. To ease transitions, social coaching can assist those with ASD in planning reactions to impending changes to routine, including adapting dynamics in social relationships.

Sources: The ARC 2015; CDC 2015; Cihak et al. 2010; Mandell et al. 2002; NIH 2015; Spence et al. 2009

Cerebral Palsy

Cerebral palsy (CP) has a prevalence of 3.6 per 1,000 people, & more than 100,000 children in the U.S. are affected. CP is the result of abnormal brain development in utero or shortly after birth. Symptoms of CP can range in severity & may manifest as mild spasticity (impairment) in the legs to full quadriplegia. CP is associated with a spectrum of health issues, including cognitive impairments, gastrointestinal difficulties, seizures, & complete functional dependency. Children with CP are more likely than children without CP to have co-occurring conditions like learning disabilities, attention deficit/hyperactivity disorder, & other developmental disorders. Early detection allows caregivers & physicians to develop treatment plans that can include medications, occupational or speech therapy, & leg braces.

Source: Boulet et al. 2009; CDC 2015; Liptak et al. 2011; NINDS 2015

Down Syndrome

Down syndrome (DS) is the most common chromosomal disorder, occurring in about 1 out of 800 live births. Research indicates the current prevalence of DS among children & adolescents is approximately 8.3 per 10,000. Although the specific causes of DS are still under investigation, women who conceive later in life have a greater risk of having a child with DS. Increased rates of DS have been observed among Latinos & males. Due to improved medical interventions, 90% of children with DS survive beyond 5 years of age. General life expectancy for those with DS has improved from 25 years in 1983 to 60 years in 2014. DS is associated with an increased risk of medical & psychosocial problems, but among all IDDs, DS is associated with more sociability & fewer maladaptive behaviors. Some medical issues associated with DS include sleep disturbance, poor muscle tone, heart defects, obesity, gastrointestinal difficulties, & auditory or vision deficiencies.

Sources: Besser et al. 2007; CDC 2015; Cotton et al. 2010; NADS 2015; NDSS 2012; NICHD 2014; Shin et al. 2009; Stoneman 2007

Interpersonal Dynamics

When a child is diagnosed with IDD, there are often significant shifts in family dynamics. Today, the primary caregivers for children with IDD are typically the child's parents, & caregiving responsibilities may contribute to marital strife, financial strain, & deterioration of social relationships. To reduce the consequences of family strain, it is important to connect caregivers of children with IDD to appropriate support groups & IDD specialized physicians. Parents of children who are profoundly disabled (non-ambulatory) can benefit greatly from a network of respite caregivers.

Additionally, at the time of diagnosis, youth with IDD should begin to receive preparation for their transition into adulthood. Careful attention should be given to teaching patients with IDD self care, such as hygiene, meal prep, & sexual health, as many patients with IDD will eventually live in group homes or semi-independent living situations. To alleviate loneliness, it is also important to encourage children with IDD to develop social connections with peers.

Sources: Gunther et al. 2006; Hogan et al. 2007; Liptak et al. 2011; Murphy et al. 2006

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Web Resources

- **American Association on IDD: www.aaidd.org**
- **Autism Spectrum Disorders Foundation www.asdf.org**
- **Centers for Disease Control: www.cdc.gov/ncbddd**
- **CHADD: National resource on ADHD www.chadd.org**
- **DETECT Mississippi: www.detectms.com**
- **National Down Syndrome Society www.ndss.org**
- **National Association for Down Syndrome www.nads.org**
- **National Institutes of Health: www.nlm.nih.gov**
- **The Arc. For people with IDD: www.thearc.org**