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Office of Integrated Health – Health Supports Network
Health & Safety Alert/Information

Intellectual and Developmental Disabilities (IDD) Health & Safety Alert

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Introduction

Intellectual Disabilities (ID) and Developmental Disabilities (DD) are recognized differences in individuals which are typically present at birth. Both ID and DD are large umbrella terms which cover many other disabilities. Both terms encompass differences in multiple body parts or systems, which may impact the individual's physical, intellectual, and/or emotional development.

ID and DD are both chronic conditions which will affect the individual's life forever. The level of disability may remain stable as the individual grows, or it may change or worsen with age. Numerous other secondary health conditions can also impact the progression of an individual's disability (8).

When both intellectual disabilities (ID) and developmental disabilities (DD) are present the term "IDD" is used (27). The exact definition of IDD can vary depending on the source of the information (21).

Intellectual Disability (ID)

Intellectual disability (ID) affects 1–3% of the world's population (23). An intellectual disability must start before a child turns 18, and individuals must meet specific conditions in three separate categories of functioning (intellectual, adaptive, and developmental) in order to meet criteria for the diagnosis. A clinical assessment and a standardized intelligence quotient (IQ) test are both required when diagnosing any type of intellectual or developmental disability (42) (5) (21).

Intellectual/cognitive abilities are measured by an IQ test. A score of approximately two standard deviations below average represents a significant cognitive deficit. The test used to measure IQ must be standardized and culturally appropriate. This is typically an IQ score of 70 or below. An individual's intelligence or IQ indicates their ability to

(CDC, 2022a).

communicate, problem solve, use reasoning skills, think abstractly and overall learning aptitude (4) (40).

Typically, delays in the development of the nervous system during the growth period between birth and adulthood, affects numerous body systems, their intelligence level, and emotional development, making it difficult for a child to meet expected developmental milestones (42) (4).

Adaptive functioning demonstrates an individual’s capacity to use different concepts, social skills, and practical skills such as self-care ability, coping with activities of daily living, developing relationships, making friends, and using concepts like words, numbers, and time (40).

The American Psychiatric Association's (APA) diagnostic criteria for intellectual disability (ID) is found in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (1). A summary of the diagnostic criteria in the DSM-5 are as follows:

- **Intellectual functioning deficits.**
    - Reasoning.
    - Problem solving.
    - Planning.
    - Abstract thinking.
    - Judgment.
    - Academic learning (ability to learn in school via traditional teaching methods).
    - Experiential learning (the ability to learn through experience, trial and error, and observation).
- **Adaptive functioning deficits**.
    - Communication.
    - Social skills.
    - Personal independence at home or in community settings.
    - School or work functioning.
- **Developmental deficits** (must occur during the period from birth through adolescence, or up to the start of adulthood).

Virginia Code § 37.2-100 defines intellectual disability as the following: "Intellectual disability means a disability, originating before the age of 18 years, characterized concurrently by:

(i) significant subaverage intellectual functioning as demonstrated by performance on a standardized measure of intellectual functioning, administered in conformity with accepted professional practice, that is at least two standard deviations below the mean.
(ii) significant limitations in adaptive behavior as expressed in conceptual, social, and practical adaptive skills."

Developmental Disability

Developmental disability (DD) is a broader category. DD is considered to be a significant chronic mental or physical health impairment which occurs before age 22 and will likely continue indefinitely throughout an individual's life (4) (2).

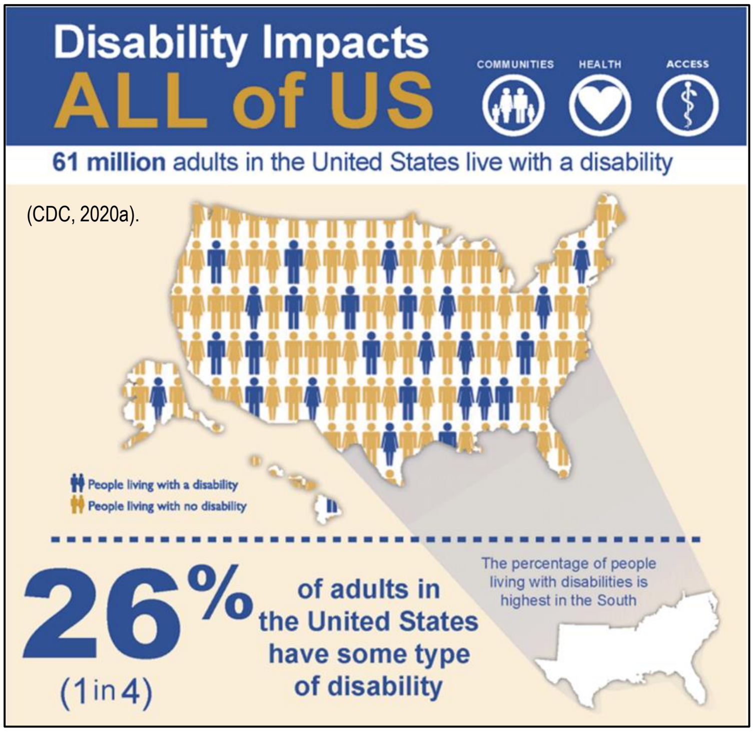
Severe functional limitations most be present in three or more areas of an individual's life to qualify them as DD, such as a decline in self-care abilities, communication and learning difficulties, mobility limitations, decreased ability to live independently, and or be financially self-sufficient (39) (4) (12) (2).

Virginia Code § 37.2-100 defines "Developmental disability means a severe, chronic disability of an individual that:

(i) is attributable to a mental or physical impairment, or a combination of mental and physical impairments, other than a sole diagnosis of mental illness.
(ii) is manifested before the individual reaches 22 years of age.
(iii) is likely to continue indefinitely.
(iv) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency; and
(v) reflects the individual's need for a combination and sequence of special interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the criteria described in clauses (i) through (v) if the individual, without services and supports, has a high probability of meeting those criteria later in life".

Prevalence



(CDC, 2020a).

The Disability Data Digest, published by Medi Sked and the Arc of the United States, estimates between 39.9 million and 61 million people with disabilities lived in the U. S. during 2018. The majority of disabled individuals live in the southern states (18).

As of 2016, approximately 7.37 million individuals had some form of IDD in the U.S. The largest majority of the IDD population at that time where African Americans, American Indians, Alaskan natives, and Whites (5).

There are approximately 2 males to every 1 female globally with IDD. Worldwide 1% to 3% of the population has some form of IDD, percentages vary per country and region (8) (30).

During the period between 2014 – 2016, the prevalence of children diagnosed with any type of developmental disability increased from 5.76% in 2014 to 6.99% in 2016 (10).

Disparities and Inequities

In 2017, nearly half (40%) of people with any type of disability, experienced some form of financial hardship, which included some, or all of the following: not having enough food; unmet healthcare needs; difficulty paying regular household bills; or not being able to find affordable accessible housing (18).

Individuals with IDD often experience the highest rates of discrimination and human rights violations compared to the general population (3). They also experience many different types of accessibility barriers which can make life extremely difficult. Accessibility barriers may include: a physical environment which is difficult to navigate; lack of assistive technology to communicate or adapt to surroundings; negative attitudes towards disabilities (in general); and policies, systems or services which block involvement of people with disabilities within their community (13).

There are known gaps in healthcare equity for individuals with IDD compared to those in the general population. Lack of medical professionals who have knowledge of IDD; difficulties accessing appropriate healthcare in the community; and delays in diagnosing illnesses and other chronic conditions, are all barriers for individuals with IDD when attempting to receive healthcare (42) (25).

In addition, individuals with IDD often experience medical discrimination through diagnostic overshadowing. This occurs when healthcare professionals attribute an individual's symptoms to their disability without considering that their symptoms may be due to a co-occurring illness or condition totally unrelated to their IDD diagnosis. Due to this, healthcare professionals may not perform the same assessments, testing or procedures they would for an individual without IDD. This may result in individuals being prematurely discharged, undiagnosed, misdiagnosed and oftentimes left untreated (42).

In 2018, the Lurie Institute at Brandeis University conducted a survey among individuals with IDD which measured health outcomes. Twenty-three percent (23%) reported fair or poor health; Twenty-nine percent (29%) reported having at least one chronic health condition such as diabetes, hypertension, or high cholesterol; Twenty percent (20%) did not get regular physical exercise; and sixty percent (60%) were obese or severely overweight (18) (31).

Over the past ten years, individuals with IDD have been living longer, which means they are being diagnosed with more age-related illnesses resulting in an increased complexity of their overall care (42) (5). Annual vision and hearing screenings are often overlooked, resulting in undiagnosed problems affecting their quality of life as they age (42).

Individuals with IDD are twice as likely to experience violent victimization and seven times more likely to experience sexual violence than their peers without disabilities (18) (38) (12).

(Population Reference Bureau (PRB), 2022).

Risk Factors

Social and economic risk factors which negatively affect individuals with IDD and increase their risk for inequity throughout their lives, include the following:

- Poor nutrition of the mother during pregnancy.
- Reduced access to healthcare during pregnancy.
- Low financial income of parents, and/or living at, or below the poverty level.
- A minimal educational level of the parents (30).

Early intervention can improve outcomes, increase academic achievement and overall functioning for children with mild to moderate IDD (44).

Risk factors for severe and profound intellectual disabilities, include the following:

- Parents who are carriers of genetically-linked chromosomal abnormalities.
- Spontaneous congenital brain abnormalities which occur during the growth of the fetus.
- Degenerative diseases.
- Congenital central nervous system infections.
- Errors of metabolism (usually genetically-linked).
- Accidental in utero exposure to toxins.
- Injuries and accidents involving the newborn infant (30).

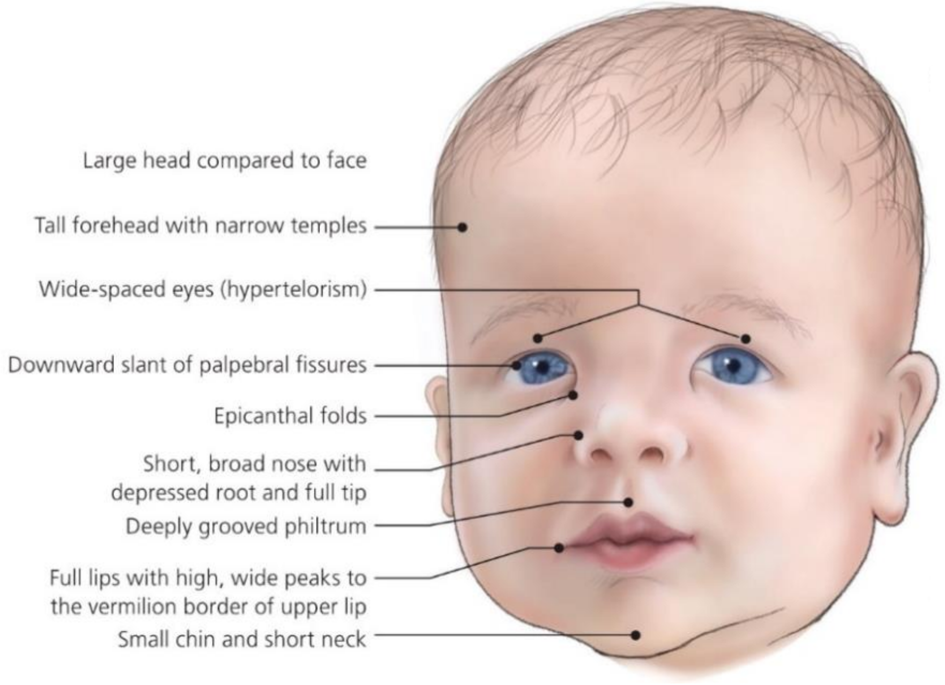
If there is a history of IDD within a family, new parents should consider consultation with a geneticist prior to conceiving. There is a 3 to 9% chance of having a second child with IDD when the first child has been diagnosed with severe or profound intellectual disability (30).

Signs and Symptoms

The first signs of IDD are typically noticed during infancy or as a very young child. Signs and symptoms of IDD can vary widely in severity. Symptoms of mild or moderate IDD may not be identified in a child until they are in school, and may be first noticed due to academic difficulties, communication difficulties, or behavioral concerns (30).

The signs and symptoms of severe or profound IDD are easier to recognize in an infant or young child when the underlying genetic condition is known, and/or if there are physical characteristics present at birth (30).

Some physical signs indicating there might be an intellectual disability present at birth would be an unusually large head compared to the face, an unusually small head compared to body size, a broad nasal bridge, low set ears, slanting eyes, downward slanting eyebrows, epicanthal eye folds (occurs when the upper eyelid covers the inner corner of the eye), delayed muscle tone, strength or movement, or difficulties during feeding (22) (30).



(Bhambhani and Muenke, 2014).

Classifications of Intellectual and Developmental Disabilities

The American Association of Intellectual and Developmental Disabilities (AAIDD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR), published by the American Psychiatric Association, are the two standard testing systems used in the U.S. to classify and identify IDD (8).

Both systems categorize severity of IDD according to the level of supports needed for an individual to reach their best possible life and achieve independence in the least restrictive environment. Both systems break down their classifications into four groups to include mild, moderate, severe, and profound IDD (8) (29).

When standardized testing is found to be invalid or ineffective due to other barriers such as motor or sensory impairments and or other physical or mental health disorders only a clinical functioning assessment is used to diagnose IDD (30).

Classifications of Intellectual Disability Severity

Severity Category	Approximate Percent Distribution of Cases by Severity	DSM-IV Criteria (severity levels were based only on IQ categories)	DSM-5 Criteria (severity classified on the basis of daily skills)	AAIDD Criteria (severity classified on the basis of intensity of support needed)	SSI Listings Criteria (The SSI listings do not specify severity levels but indicate different standards for meeting or equaling listing level severity.)
Mild	85%	Approximate IQ range 50–69	Can live independently with minimum levels of support.	Intermittent support needed during transitions or periods of uncertainty.	IQ of 60 through 70 *and* a physical or other mental impairment imposing an additional and significant limitation of function
Moderate	10%	Approximate IQ range 36–49	Independent living may be achieved with moderate levels of support, such as those available in group homes.	Limited support needed in daily situations.	A valid verbal, performance, or full-scale IQ of 59 or less
Severe	3.5%	Approximate IQ range 20–35	Requires daily assistance with self-care activities and safety supervision.	Extensive support needed for daily activities.	A valid verbal, performance, or full-scale IQ of 59 or less
Profound	1.5%	IQ <20	Requires 24-hour care.	Pervasive support needed for every aspect of daily routines.	A valid verbal, performance, or full-scale IQ of 59 or less

(Clinical Characteristics of Intellectual Disabilities, Boat and Wu, 2015).

Individuals with Mild IDD:

- Make up the largest majority of the IDD population at 85% (8) (30) (26).
- Have an IQ range between 50 - 69 with some physical or mental health impairment which affects their functioning ability (26).
- Function at age 9 - 11 years, in adulthood (30).
- Are slower at conceptual development of language and academic skills but can typically write and do simple math (30).
- Can learn practical life skills with regular review and practice.
- Can live independently with a minimum level of support, they can be easily manipulated by others (30).
- Can do basic self-care and home activities.
- May display awkward immature and or inappropriate social skills (30).
- Need support with money management, making medical decisions and during periods of uncertainty, such as severe weather events, the pandemic, or upsetting news situations (8) (30).
- Can perform independent job skills such as arriving on time, staying on task, and interacting with co-workers (30).
- Can be taught to drive and or use public transportation independently (30).

Individuals with Moderate IDD:

- Make up approximately 10% of the IDD population (8) (26).
- Have an IQ range between 35 to 49 (26).
- Function at about age 6 – 8 years, in adulthood (30).
- Require consistent support in order to achieve some level of independence living in the community, and with being employed.
- Have difficulty with social interactions and common behavioral norms which can affect their ability to adjust or participate in some settings (30).
- Can have widely varied language and academic skills, and most do have some ability to recognize sight words, copy their address from a card, and match written numbers to numbered items (29).
- Can perform their own self-care with regular cueing and assistance from caregivers with a moderate level of support (30).
- Can help with meal preparation.
- Can learn basic job skills through repetition.
- Can use public transportation with assistance.
- Can learn basic safety skills (8) (29).

Individuals with Severe IDD:

- Make up a smaller percentage of the IDD population at approximately 3.5% (8) (26).
- Have an IQ range between 20 to 35 (26).
- Function at about age 3 – 5 years as adults (30).
- Typically have major delays in development but can be taught simple self-care skills with intensive training.
- Often have limited communication skills with the ability to understand speech, but may not be able to respond, and or will use one-word phrases or gestures to reply (30).
- May have impaired motor skills and/or decreased mobility.
- Require extensive assistance with self-care activities.
- Have very limited abilities for social interaction with others.
- Require supervised supports for safety.
- Need regular consistent lifelong support, often living with family for direct care, or residing in a supervised group home (8) (29) (30).

Individuals with Profound IDD:

- Individuals with profound IDD often have congenital syndromes (8) (26).
- Have an IQ below 20 (26).
- Function at about age 3 years, in adulthood (30).
- Are completely dependent on their caregivers for all their needs.
- Require around the clock support.
- Cannot live independently.
- Have very limited ability to communicate using words, yet with intensive training they can learn to use adaptive communications tools.
- May communicate with caregivers through facial expression of emotions, physical gestures, and or by making audible sounds.
- Have very little capacity for academic learning.
- Often have extensive physical limitations, and mobility issues.
- Are most likely to have secondary medical conditions, including incontinence in addition to their IDD, requiring high intensity supports (8) (30).

Causes of Intellectual and Developmental Disabilities

It is often difficult to determine the exact cause of intellectual disability. A specific cause is cited in 30% to 50% of all diagnosed cases of IDD (26). Often the cause is unspecific, or there may be a variety of causes which remain unknown (14).

Currently, specific genetic disorders are diagnosed in only 25% - 50% of all cases, but recent advances in genetic testing, may lead to a significant increase in the percentage of explained intellectual disability, from 50% in the past, to 80% (26).

However, it is important to note that DNA testing is not covered under many health insurance policies. The cost of genetic testing varies but can range from under $100 to more than $2,000, depending on the complexity of the test. The cost also increases if more than one test is necessary, and/or if multiple family members must be tested to obtain a meaningful result (28).

Causes of IDD can be divided into three groups: before birth (prenatal), occurring at birth (perinatal), and or, after birth (postnatal) (37) (40) (14).

Some prenatal causes of IDD include the following:

- Chromosomal abnormality.
  - Down syndrome is the most commonly known genetic cause of IDD, resulting in distinct physical features, and typically mild to moderate IDD (8) (37) (26).

  - Fragile X is the leading causes of inherited IDD which mostly affects males (8) (37).
  - Prader-Willi Syndrome (PWS) is a genetic disorder leading to life-threatening obesity, challenging behaviors, emotional issues, and physical growth difficulties (21).
  - Some other chromosomal syndromes which lead to IDD are:

    Aarskog.
    Allan-Herndon.
    Angelman.
    Christianson.
    Coffin-Lowry.
    De-George.
    Duchenne Muscular Dystrophy.
    Edwards.
    Klinefelter.
    Lesch-Nyhan.
    Lowe.
    Menkes.
    Patau.
    Palizaeus-Merzbacher.
    Phelan-McDermid.
    Renpenning.
    Rett.
    Smith-Magennis.
    Turner.
    Williams (30).

- Metabolic disorders.
  - Phenylketonuria (PKU) is an error in metabolism, a recessive gene trait, IDD can possibly be prevented if dietary intervention begins right after birth (37).
  - Other metabolic disorders which lead to IDD are congenital hypothyroidism, neurofibromatosis, tuberous sclerosis, and Spina bifida (37).
- Maternal infections.
  - Rubella (German measles) is a leading cause of IDD, with severe consequences as a result of exposure in the first trimester of pregnancy (37).
- Environmental conditions.
  - Fetal alcohol syndrome can result in mild to moderate IDD with associated physical deformities; is a leading cause of ID (37).

Some perinatal causes of IDD include the following:

- Gestational disorders.
  - Low birth weight and or premature birth are common in mothers living in poverty, women engaged in substance abuse, and teenage mothers which puts the infant at increased risk for serious problems at birth with potential for learning and sensory difficulties (37).

- Neonatal complications.
  - Anoxia (oxygen deprivation) of a baby during delivery.
  - Birth trauma.
  - Breech presentation is when the baby's feet or buttocks are turned to deliver first.
  - A prolonged delivery can put an infant at increased risk for developing IDD (37).

Some postnatal causes of IDD include the following:

- Infections and drug intoxicants.
  - Meningitis is a viral infection which can cause damage to the covering of an infant's brain (the meninges).
  - Lead poisoning from ingestion of lead-based paint chips by infants or toddlers living in older homes have the potential to cause seizures, central nervous system damage and ultimately brain damage (37).
- Environmental factors.
  - Malnutrition has been connected to mild cases of IDD.
  - Child abuse and or neglect can increase risk factors for some children to experience learning difficulties (37).

Cerebral Palsy (CP) is a neurological disorder causing abnormal brain development or damage to the developing brain which affects an infant's ability to control their muscles and posture which could possibly lead to a diagnosis of IDD. CP can occur due to complications before birth, during birth (due to lack of oxygen), within a month after birth, or during the first years of life while the brain is developing (15).

Autism spectrum disorder (ASD) is also a neurological disorder affecting the development of the brain and is considered a developmental disability. It is believed multiple issues may act together affecting the developing brain, but much more research is required to conclude the specific cause of ASD. Some diagnoses of ASD have been connected to genetic conditions, while other causes are still unknown (16).

Individuals with ASD may have sensory issues which can make daily life difficult for them, they may have difficulty developing and maintaining friendships, communicating with peers and adults, and adjusting to expected social norms (16).

Secondary Mental Health Conditions

Approximately 32 to 40% of children diagnosed with IDD are also dually diagnosed with a serious mental health condition. Research suggests as many as one half of the IDD population are affected by some form of mental health disorder (20) (40).

- Some MH disorders which commonly accompany a diagnosis of IDD are:
  - Attention-deficit/hyperactivity disorder (ADHD).
  - Major depressive disorder.
  - Autism spectrum disorder (ASD).
  - Schizophrenia.
  - Bipolar disorder.
  - Anxiety disorder.
  - Conduct disorder.
  - Eating disorders (20) (40).

Clinical assessment can be extremely difficult when making a diagnosis of MH due to barriers with communication, physical deficits, and cognitive delays for an individual with IDD (8) (40).

Individuals diagnosed with severe IDD and MH are more likely to be disruptive or aggressive, which may include self-injurious behaviors, violence toward self and others, and property damage (40).

Hospital emergency room visits and or hospital admissions are more frequent for individuals who are dually diagnosed with IDD and MH requiring them to have a higher level of support and care needs (20).

Management and care for individuals with IDD and MH may include behavioral interventions such as a positive behavioral support plan, psychotropic medications to treat the co-occurring MH and challenging behaviors, along with early interventions of developmental and educational services. For individuals with mild to moderate IDD, who can participate, some group therapies or one-on-one verbal psychotherapy can be effective (40).

Secondary Health Conditions

Many adults with IDD have 5 or more co-occurring health conditions. Approximately 61.5% have at least one secondary health condition (19) (40).

Individuals with IDD-related genetic syndromes typically have many additional secondary health-related conditions (9) (19).

Some common co-occurring conditions are:

- Communication issues.
  - Many individuals with IDD have limited language skills and may not be able to understand abstract concepts. Due to this, they may be unable to respond accurately when asked questions such as “Are you in pain?” or “Are you feeling dizzy?” (25).
  - Non-verbal individuals may be unable to verbalize how they are feeling physically and emotionally but may be capable of expressing themselves through sounds and behavior (30).
  - Undiagnosed hearing problems may also affect an individual’s ability to communicate (25).
- Seizure disorders.
  - Individuals with IDD are more likely to be diagnosed with a seizure disorder or epilepsy (17).
  - Seizure activity has been connected to challenging behaviors including aggression and irritability (7).
- Obesity.
  - Obesity rates are 2-3 times higher among individuals with IDD than the general population (32).
  - Obesity starts at an earlier age for individuals with IDD which may be due to associated syndromes and psychotropic medication side-effects (41).
  - Obesity increases the individual’s risk for coronary heart disease, osteoarthritis, type 2 diabetes, and some cancers (32).
- Chronic pain issues.
  - Individual with IDD have been found to suffer from unrecognized chronic long-term pain issues (43).
  - Communication difficulties often result in untreated or under-treated pain (43).

  - Often, the source of their pain goes undiagnosed and their response to pain (which often includes self-injurious behaviors) is misinterpreted as a behavioral issue (29).
- Cancer.
  - Less cancer screenings and preventative testing are done on individuals with IDD, when compared to the general population, resulting in a higher rate of cancer-related fatalities (35).
  - Individuals with IDD may not communicate pain or other symptoms in the same way as someone without IDD, making cancer more difficult to diagnose when it is still in an early stage (35).
- Diabetes. Diabetes has been reported to be 3 – 4 times higher in the IDD population partly due to unhealthy diets, low activity levels, dependence on caregivers, and the inability to understand the consequences of daily choices (41) (12).
  - Individual’s with Prader-Willi and Williams syndrome are more likely to be diagnosed with type 2 diabetes, possibly due to issues surrounding food (41).
  - Insulin resistance and hypertension are common in individuals with Klinefelter syndrome, making diabetes more prevalent for these individuals (41).
  - Individuals with Down syndrome have a higher likelihood of a type 1 diabetes diagnosis (41).

Common Health Conditions Which Can Lead to Serious Decline for Individuals With IDD

Individuals with IDD are at increased risk for serious health decline due to common health conditions compared to their peers without IDD. Many of these common conditions, if not addressed in a timely manner, can result in permanent physical damage or death, if not managed well on a regular daily basis (39).

One-third of all deaths in the IDD population have been connected to avoidable causes compared to less than one-quarter of the deaths which occur in the general population (25).

Some common health conditions which have been found to seriously affect individuals with IDD are:

- Poor oral health.
  - Is the second most common health condition affecting individuals with IDD (36).

  - They experience higher rates of periodontal disease, caries (cavities), and negative outcomes from tooth decay, and missing teeth (36).
- Dehydration.
  - Individuals with IDD are prone to dehydration due to poor appetite, deficient oral healthcare, difficulty with swallowing and or an inability to express when they are thirsty, or they just cannot get a glass of water on their own (39).
- Constipation and bowel obstructions.
  - Reduced physical activity levels, decreased movement of the gut, lack of sensation, poor diet, certain medication side-effects, and PICA (eating non-food items) are all common causes of constipation which can result in a bowel obstruction (39).
- Risk for pressure injuries.
  - Individuals with IDD who spend more than 4 hours a day in a wheelchair and those with mobility issues, who cannot reposition themselves without assistance, are at high risk for acquiring a pressure injury (24).
- Swallowing difficulties and choking issues.
  - Swallowing difficulties greatly increase the risk of a choking death for individuals with IDD (39).
  - Aspiration is a serious risk for individuals with IDD who also have dysphagia (swallowing difficulties), GERD (gastrointestinal reflux disease), PICA, and those who take medications with sedative side-effects which depress the central nervous system (i.e. narcotics, psychotropics, etc.) (39).
  - Aspiration pneumonia can be a life-threatening issue which can quickly turn into sepsis if not caught in time (39).

Healthcare and Case Management of IDD

Every individual diagnosed with IDD requires a collaborative, person-centered approach to care, treatment, and case management to assist them in living their best possible life. Each stage of life presents its own challenges for individuals, their families, and caregivers, especially if the individual has several co-occurring conditions (8).

The individual's primary care provider (PCP) should lead and guide preventive healthcare and coordinate referrals to medical and therapeutic specialists who can assist in accessing and obtaining needed supportive health services (42) (30).

The following services and supports should be included in the healthcare and case management of individuals with IDD for the best physical and mental health outcomes:

- Treatment of medical complications.
- General preventive healthcare and diagnostic testing.
- Preventive and general dental care.
- Treatment of secondary medical and mental health conditions.
- Management of challenging behaviors.
- Therapeutic and rehabilitative supports (physical, occupational, behavioral, and speech/language therapy, etc.)
- Educational and academic support.
- Vocational and employment training.
- Social supports and assistance.
- Community-based supports.
- Employment supports.
- Transition services from school-based services (during childhood) to adult services.
- Guardianship, insurance considerations, legal considerations, and assistance (30).

Disability Laws and Protections

There are various federal and state laws, regulations, and acts in the U.S., which have been put into place to provide for the development, implementation, and protection of education, rights and other services for individuals with IDD (30).

- The Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities in several areas, including employment, transportation, public accommodations, communications and access to state and local government' programs and services. As it relates to employment, Title I of the ADA protects the rights of both employees and job seekers. The ADA also establishes requirements for telecommunications relay services. Title IV, which is regulated by the Federal Communications Commission (FCC), also requires closed captioning of federally funded public service announcements.

- While the U.S. Department of Labor's (DOL) Office of Disability Employment Policy (ODEP) does not enforce the ADA, it does offer publications and other technical assistance on the basic requirements of the law, including covered employers' obligation to provide reasonable accommodations to qualified job applicants and employees with disabilities. For a quick overview of the ADA read "The Americans with Disabilities Act: A Brief Overview."

- In addition to the U.S. Department of Labor, several other federal agencies have a role in enforcing, or investigating claims involving, the ADA:
  - The U.S Equal Employment Opportunity Commission (EEOC) enforces Title I of the ADA. Title I prohibits private employers, state and local governments, employment agencies and labor unions from discriminating against qualified individuals with disabilities in applying for jobs, hiring, firing and job training.
  - The U.S. Department of Transportation enforces regulations governing transit, which includes ensuring recipients of federal aid and state and local entities responsible for roadways and pedestrian facilities do not discriminate on the basis of disability in highway transportation programs or activities. The department also issues guidance to transit agencies on how to comply with the ADA to ensure that public transit vehicles and facilities are accessible.
  - The Federal Communications Commission (FCC) enforces regulations covering telecommunication services. Title IV of the ADA covers telephone and television access for people with hearing and speech disabilities. It requires telephone and Internet companies to provide a nationwide system of telecommunications relay services that allow people with hearing and speech disabilities to communicate over the telephone.
  - The U.S. Department of Justice enforces ADA regulations governing state and local government services (Title II) and public accommodations (Title III).
  - The U.S. Department of Education, like many other federal agencies, enforces Title II of the ADA, which prohibit discrimination in programs or activities that receive federal financial assistance from the department.
  - The U.S. Department of Health and Human Services (HHS) also enforces Title II of the ADA relating to access to programs, services and activities receiving HHS federal financial assistance. This includes ensuring people who are deaf or hard-of-hearing have access to sign language interpreters and other auxiliary aids in hospitals and clinics when needed for effective communication.
  - Another federal agency, the Architectural and Transportation Barriers Compliance Board (ATBCB), also known as the Access Board, issues

guidelines to ensure that buildings, facilities and transit vehicles are accessible to people with disabilities. The Guidelines & Standards issued under the ADA and other laws establish design requirements for the construction and alteration of facilities. These standards apply to places of public accommodation, commercial facilities, and state and local government facilities.

- The Individuals with Disabilities Education Act (IDEA) is a federal law which ensures a free and appropriate public education for students ages 2-21 who fall within 14 disability categories and who require specialized services and supports. IDEA provides for individualized services and supports to ensure the student can access and benefit from the general curriculum. It also provides for related services such as counseling, speech, transportation, physical therapy and more.
- Section 504 of the Rehabilitation Act of 1973, is a broader civil rights law with the purpose of protecting people with disabilities from discrimination and to ensure regardless of age, people with disabilities have equal opportunities and access to facilities, programs and services. In school settings this means removing barriers which prevent full participation by students.
  - The purpose of both Section 504 Plans and IEPs are to help students succeed in school by providing needed services and supports/accommodations. If a student doesn’t qualify for an IEP, he/she may qualify for a Section 504 Plan.
  - Both laws require the student have a documented disability. IDEA requires the student meet one of the 14 federal disability categories. Section 504 requires the student to have any mental or physical disability affecting a major life function.
  - Both laws are designed to ensure students are educated in the least restrictive environment and can access the general curriculum.
  - Evaluations (tests) are required under Section 504 and IDEA, and services are provided at no cost to the family under both laws.
  - Both laws also ensure a student cannot be removed from school for discipline reasons which are a manifestation or the direct result of his disability. The protections in IDEA are greater than those under Section 504.
  - A student with an eligible disability who needs specialized services and supports, including related services, accommodations or instructional changes will likely benefit from an IEP. A student whose disability affects their learning

and who needs classroom or accommodations, such as extra time to take tests (but not specialized instruction), may benefit from a Section 504 plan.

  - IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 8 million (as of school year 2022-23) eligible infants, toddlers, children, and youth with disabilities.
  - Infants and toddlers, birth through age 2, with disabilities and their families receive early intervention services under IDEA Part C. Children and youth ages 3 through 21 receive special education and related services under IDEA Part B.

- The Infant & Toddler Connection of Virginia (ITCVA) is Virginia's early intervention system for infants and toddlers (age 0-36 months) with disabilities and their families. Early intervention services along with an Individualized Family Service Plan (FSP) are used to help families of young children under the age of 3 years. When a child enters the school system an Individualized Education Plan (IEP) is developed to assist with their support needs (30).
- In Virginia, once a child reaches 14 to 16 years of age an Individualized Transition Plan (ITP) is created to review what possible supports might be needed as an adult. Similarly, once the individual graduates from the educational system an Individualized Support Plan (IHP) is developed to identify their continued support needs in the community and for their futures (30).

Resources

The Office of Integrated Health at DBHDS: If you have any questions about the information contained in this Health & Safety Alert, or need additional resources or support, please email your questions to the Office of Integrated Health's nursing team at: communitynursing@dbhds.virginia.gov

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For more information on individuals' human rights in relation to psychotropic medications.
https://dbhds.virginia.gov/library/human%20rights/ohr%20decision%20making%20consent.pdf

The My Care Passport Health and Safety Alert can be downloaded from the OIH-HSN website at https://dbhds.virginia.gov/office-of-integrated-health/. You can also download additional information about the My Care Passport on the OIH website. Once there, click on the Educational Resources button and the My Care Passport (and all of its resources) will be listed there. All documents can be downloaded.

For a more in-depth, narrated, educational experience, please check out The My Care Passport Training on the Commonwealth of Virginia Learning Center (COVLC). To learn how to sign up for trainings on the COVLC https://dbhds.virginia.gov/assets/Housing/DBHDS-External-Entities-Domain-GuideCOVLC.pdf, please read this instruction sheet for DBHDS outside entities (providers, etc.).

Tip Sheets and Resources from the Vanderbilt - Kennedy website:

Each Tip Sheet is a single page, easy-to-hand-out flyer that can be downloaded at no cost. The front provides facts and information on the specific topic and the back is a summary of Vanderbilt Kennedy Center and local, state, national, international resources that relate to the topic and point people to places where they can find more information.

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