

COMMONWEALTH of VIRGINIA

Nelson Smith Commissioner DEPARTMENT OF BEHAVIORAL HEALTH AND DEVELOPMENTAL SERVICES Post Office Box 1797 Richmond, Virginia 23218-1797

Telephone (804) 786-3921 Fax (804) 371-6638 www.dbhds.virginia.gov

# Office of Integrated Health – Health Supports Network Health & Safety Alert/Information Intellectual and Developmental Disabilities (IDD) Health & Safety Alert

## 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 covers 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 can change or worsen with age. Numerous other secondary health conditions can 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 may 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).

Original Date: 06/2022 Last Updated: 08/2023 RL13.3 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).

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

- 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).

<u>Virginia Code § 37.2-100</u> 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".

#### DEPARTMENT OF BEHAVIORAL HEALTH AND DEVELOPMENTAL SERVICES Post Office Box 1797 Richmond, Virginia 23218-1797

**Disability Impacts** 

Telephone (804) 786-3921 Fax (804) 371-6638 www.dbhds.virginia.gov

## Prevalence

The Disability Data Digest, published by MediSked 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, 40% of people, with any type of disability, experienced some form of financial hardship, such as not enough food, unmet healthcare needs, difficulty paying regular household bills, and 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). Individuals with disabilities also experience many different types of accessibility barriers which can make life extremely difficult for them to live normal lives. Accessibility barriers may include a physical environment which is difficult to navigate, lack of assistive technology to communicate or adapt to their surroundings, negative attitudes towards disabilities from others, and policies, systems or services which block involvement of people with disabilities in the community (13).



There are known gaps in healthcare equity for individuals with IDD compared to those in the general population. Lack of medical professional's knowledge regarding all aspects of the disorder, difficulties accessing proper healthcare in the community and delays in diagnosing illnesses and other chronic conditions, which often occur as a result of the diagnosis, are all barriers for individuals with IDD when attempting to receive healthcare (42) (25).

Individual's with IDD often experience medical discrimination through diagnostic overshadowing, which is when healthcare professional attribute an individual's symptoms to their disability without considering that the symptoms may be due to a co-occurring illness or condition, which is unrelated to their IDD diagnosis. Physicians typically don't perform the same assessments, testing or procedures they would for an individual without IDD, before discharging them back into the community (42).

The Lurie Institute at Brandeis University conducted a survey which measured health outcomes of individual's with IDD in 2018, found 23% reported fair or poor health, 29% reported having at least one chronic health condition such as diabetes, hypertension, or high cholesterol, 20% did not get regular physical exercise, and 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).

Nelson Smith	
Commissioner	

# **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).



#### DEPARTMENT OF BEHAVIORAL HEALTH AND DEVELOPMENTAL SERVICES Post Office Box 1797 Richmond, Virginia 23218-1797

Telephone (804) 786-3921 Fax (804) 371-6638 www.dbhds.virginia.gov

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 diagnosis IDD (30).

#### DEPARTMENT OF BEHAVIORAL HEALTH AND DEVELOPMENTAL SERVICES Post Office Box 1797 Richmond, Virginia 23218-1797

Telephone (804) 786-3921 Fax (804) 371-6638 www.dbhds.virginia.gov

## **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 <i>and</i> 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).

Physical causes for 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 of the most common 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, behavior problems, emotional issues, and physical growth difficulties (21).
- Some other chromosomal syndromes which lead to IDD are:

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 as 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 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 nervous system 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 nervous system disorder affecting the development of the brain and is considered a developmental disability. It is believed multiple causes act together to affect the developing brain, but much more research is required to state 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 mental health disorders (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 have shown more disruptive tendencies and aggression actions such as 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 behavior 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 affective (40).



# **Secondary Physical Health Conditions**

On average 5 or more co-occurring health conditions have been reported in adults with IDD, with approximately 61.5% have at least one secondary health condition (19) (40).

Individuals with genetically acquired IDD are known to have several additional secondary health conditions as a result of their accompanying syndrome (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, or have the ability to respond accurately when asked questions about how they are feeling, such as "Are you in pain?" or "Are you feeling dizzy?" (25).
  - Non-verbal individuals with IDD are unable to verbalize how they are feeling physically and emotionally but may be capable of expressing themselves through sounds and behavior (30).
  - Undiagnosed hearing problem affect an individual's ability to communicate (25).
- Seizure disorders.
  - Individuals with IDD due to chromosomal syndromes or congenital issues are more likely to be diagnosed with a seizure disorder or epilepsy (17).
  - Seizure activity in individual with IDD have been connected to challenging behaviors to include aggression and irritability (7).
- Obesity and poor nutrition.
  - The rates of being overweight and obese are 2-3 times higher in individuals with IDD than the general population (32).
  - Obesity starts at an earlier age for individuals with IDD which may be due associated syndromes and psychotic medication side-effects (41).
  - Being overweight and obese 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 longterm pain issues (43).
  - Communication difficulties are a barrier for individual with IDD to be treated appropriately for their pain issues (43).



- Often times pain issues for individuals with IDD might be displayed as challenging behavioral issues and or self-injurious behaviors (29).
- Cancer.
  - Less cancer screenings and preventative testing are done on the IDD population compared to the general population resulting in a higher rate of fatalities (35).
  - Individuals with IDD don't communicate discomfort or pain in the same way as someone without IDD, making it more difficult to diagnose cancer, as a result most cancers in the IDD population are diagnosed at a late 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-Willis 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).
  - Down syndrome individuals have a higher likely hood 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 do permanent physical damage even leading to death, if not managed 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 the IDD population 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 the possibility pica (eating non-food items) are all common causes of constipation and bowel obstructions for individuals with IDD (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 assistant are at risk for acquiring pressure injuries (24).
- Swallowing difficulties and choking issues.
  - Swallowing issues increase the chances of a choking death for individual with IDD (39).
  - Aspiration is a serious problem for individuals with IDD who also have swallowing difficulty, GERD, dysphagia, constipation and take medications with sedative side-effects (39).
  - Aspiration pneumonia can be a life-threatening issue for individuals with IDD which can quickly turn into sepsis if not caught in time (39).

# Care and Management of IDD

Every individual diagnosed with IDD requires a person-centered approach to care and treatment to assist them in living their best possible life. Each stage of life presents it's on challenges for the individual with IDD, their families, and caregivers, this is especially true if the individual has several secondary conditions (8).

The individual's primary care physician (PCP) is considered the lead healthcare professional who provides regular preventive medical care as well as coordinates referrals to other needed specialty healthcare professionals to assist in accessing needed support services (42) (30).

Certain generalized treatment and care should be built into the management of an individual's overall physical and mental health outcomes to include:

- Treatment of medical complications.
- General preventive medical care and testing.
- General dental care.
- Treatment of secondary medical and mental health conditions.
- Treatment of challenging behaviors.
- Rehabilitation services such as physical, occupational and behavioral therapy.
- Educational and academic support.
- Vocational and employment training.
- Social supports and assistances with building meaningful relationships.
- Support for community-based living.
- Support for appropriate level of employment.
- Transition to services from child focused to those more appropriate for adults.
- Guardianship, financial, legal considerations, and assistance (30).

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 funding for numerous services for individuals with IDD (30).

Early intervention services at the local community level 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).

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. Once the individual graduates from the educational system an Individualized Habilitation Plan (IHP) is done 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

### Subscribe to DBHDS Licensing Updates Here:

https://visitor.r20.constantcontact.com/manage/optin?v=001fonDe7OLpVle31MpMgDtiZ 79Er3SHdqf-

<u>1DeB56fXjNwWEy5aOunPTxAP3CPPwBRsxmSGA0mZXI5RtSgKfoUTGwjBIeN5pe4L</u> <u>K3w3alx4q2u1IrZaN1LSkvLY1IR2LjHOb0wndBcqifqKYzZkckzXtcuNwYIzCJZ</u>

DBHDS Office of Licensing Regional Contacts: <u>https://dbhds.virginia.gov/clinical-and-guality-management/office-of-licensing/ol-contact-info/</u>

#### **DBHDS Human Rights Department:**

For more information on individuals' human rights in relation to psychotropic medications.

https://dbhds.virginia.gov/library/human%20rights/ohr%20decision%20making%20cons ent.pdf

The My Care Passport Health and Safety Alert can be downloaded from the OIH-HSN website at <u>https://dbhds.virginia.gov/office-of-integrated-health/</u>. 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 <u>https://dbhds.virginia.gov/assets/Housing/DBHDS-External-Entities-Domain-GuideCOVLC.pdf</u>, 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.

#### References

- 1) American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders: DSM-5, Fifth Ed. *Am Psychiatric Assoc*, *21*(21), 591-643.
- 2) American Psychological Association (APA) (2022). Developmental disability. <u>https://dictionary.apa.org/developmental-disability</u>
- 3) Avades, T., Doulton, F., Fajerman, M., Huovinen, K., Ito, A., Martinho, M., Meloche, J., Pewitt,

J., Venne, R., Zhang, G., & Zonderland, M. (2015). Global status report on disability and development - Prototype 2015. *UN Department of Economic and Social Affairs (DESA)*. 1-230. <u>https://ininet.org/global-status-report-on-disability-and-development-prototype-2.html</u>

- 4) Barth, S., Lewis, S., & Simmons, T. (2020, October). Medicaid services for people with intellectual or developmental disabilities – Evolution of addressing service needs and preferences. *The Medicaid And Chip Payment and Access Commission*, 1-61. <u>https://www.macpac.gov/wp-content/uploads/2021/01/Medicaid-Services-for-People-with-Intellectual-or-Developmental-Disabilities-%E2%80%93-Evolution-of-Addressing-Service-Needs-and-Preferences.pdf</u>
- 5) Bathje, M., Conrad, S., Medick, M., Ross, M., & Fogg, L. (2021, June). Differences in hospitalbased care for patients with intellectual and developmental disabilities. *American Journal of Occupational Therapy*, 75(3), 1-10. 7503180080. <u>https://doi.org/10.5014/ajot.2021.046508</u>
- 6) Bhambhani, V., & Muenke, M. (2014). [Image] Noonan syndrome. American Family Physician, 89(1), 37-43. <u>https://www.aafp.org/pubs/afp/issues/2014/0101/p37.html</u>
- 7) Blickwedel, J., Vickerstaff, V., Walkerd, M., & Hassiotis, A. (2019) Challenging behavior, epilepsy and intellectual disability: A secondary analysis of findings from a randomized controlled trial. *Journal of Intellectual & Developmental Disability*, 44(4), 457–463. https://www.tandfonline.com/doi/abs/10.3109/13668250.2019.1587594
- 8) Boat, T.F., & Wu, J.T. (2015, October). Clinical Characteristics of Intellectual Disabilities. Mental Disorders and Disabilities Among Low-Income Children. The *National Academies of Sciences, Engineering, and Medicine*, Chapter 9, 1-8. <u>https://www.ncbi.nlm.nih.gov/books/NBK332877/</u>
- 9) Bowers, B., Webber, R. & Bigby, C. (2014). Health issues of older people with intellectual disability in group homes. *Journal of Intellectual & Developmental Disability*, 39(3), 261–269. http://dx.doi.org/10.3109/13668250.2014.936083
- 10) Centers for Disease Control and Prevention (CDC). (2017, November). Estimated prevalence of children with diagnosed developmental disabilities in the United States, 2014–2016. https://www.cdc.gov/nchs/products/databriefs/db291.htm#:~:text=boys%20than%20girls.-,During%202014%E2%80%932016%2C%20the%20prevalence%20of%20children%20ever%2 0diagnosed%20with,among%20girls%20(Figure%203)
- 11) Centers for Disease Control and Prevention (CDC). (2019, October). [Image] CDC's environmental public health tracking: Developmental disabilities and the environment. https://www.cdc.gov/nceh/multimedia/infographics/developmental\_disabilities.html
- 12) Centers for Disease Control and Prevention (CDC). (2020a, September). Disability and health related conditions. <u>https://www.cdc.gov/ncbddd/disabilityandhealth/relatedconditions.html</u>
- 13) Centers for Disease Control and Prevention (CDC). (2020b, September). Common barriers to participation experienced by people with disabilities. https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html
- 14) Centers for Disease Control and Prevention (CDC). (2022a, May). Facts about developmental disabilities. [Image]. https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html#:~:text=Developmental%20di sabilities%20are%20a%20group.last%20throughout%20a%20person's%20lifetime
- 15) Centers for Disease Control and Prevention (CDC). (2022b, April). What is cerebral palsy? <u>https://www.cdc.gov/ncbddd/cp/facts.html#:~:text=Cerebral%20palsy%20(CP)%20is%20a,prob</u> <u>lems%20with%20using%20the%20muscles</u>
- 16) Centers for Disease Control and Prevention (CDC). (2022c, March). What is Autism Spectrum Disorder? <u>https://www.cdc.gov/ncbddd/autism/facts.html</u>
- 17) Devinsky, O., Asato, M., Camfield, P., Geller, E., Kanner, A. M., Keller, S., & Singh, B. K. (2015). Delivery of epilepsy care to adults with intellectual and developmental disabilities. *American Academy of Neurology*, 85(17), 1512-1521.

- Disability Data Digest. (2018, October). Population and demographics. MediSked and The Arc of the United States, 1-34. <u>https://thearc.org/blog/medisked-arc-release-2018-disability-datadigest/</u>
- 19) Dunham, A., Kinnear, D., Allan, L., Smiley, E. & Cooper, S. A. (2018, May). The relationship between physical ill-health and mental ill-health in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 62(5), 444–453. DOI: 10.1111/jir.12483
- 20) Durbin, A., Sirotich, F., Lunsky, Y. & Durbin, J. (2015, October). Unmet needs of adults in community mental health care with and without intellectual and developmental disabilities: A cross-sectional study. *Community Mental Health Journal*, 53,15–26. DOI: 10.1007/s10597-015-9961-6
- 21) Eunice Kennedy Shiver National Institute of Child Health and Human Development. (2021, November). About intellectual and developmental disabilities (IDDs). *National Institute of Health (NIH)*. <u>https://www.nichd.nih.gov/health/topics/idds/conditioninfo</u>
- 22) Gunduz, M. and Unal, O. (2016, September). Dysmorphic facial features and other clinical characteristics in two patients with PEX1 gene mutations. *Case Reports in Pediatrics*, 1-5. http://dx.doi.org/10.1155/2016/5175709
- 23) Ilyas, M., Mir, A., Efthymiou, S., & Houlden, H. (2020). The genetics of intellectual disability: advancing technology and gene editing. *F1000Research*, *9*, F1000 Faculty Rev-22. https://doi.org/10.12688/f1000research.16315.1
- 24) Jaul, E., Barron, J., Rosenzweig, J. P., & Menczel, J. (2018). An overview of co-morbidities and the development of pressure ulcers among older adults. *BMC Geriatrics*, 18(305), 1-11. https://doi.org/10.1186/s12877-018-0997-7
- 25) Jennings, A. M., Mery, J. N., Quiroz, L. S., & Vladescu, J. C. (2022, February). A scoping review of the healthcare and hygiene literature for individuals with intellectual and developmental disabilities. *Advances in Neurodevelopmental Disorders*, 1-16. https://doi.org/10.1007/s41252-022-00249-7
- 26) Maia, N., Nabais, M. J., Melo-Pires, M., de Brouwer, A. P. M., & Jorge, P. (2021). Intellectual disability genomics: current state, pitfalls and future challenges. *BMC Genomics*, 22:909, 1-17. DOI.org/10.1186/s12864-021-08227-4 https://bmcgenomics.biomedcentral.com/articles/10.1186/s12864-021-08227-4
- 27) National Institutes of Health (NIH) (2021). About Intellectual and Developmental Disabilities (IDDs): What are IDDs? <u>https://www.nichd.nih.gov/health/topics/idds/conditioninfo</u>
- 28) National Library of Medicine (NIH) (2021). What is the cost of genetic testing, and how long does it take to get the results? https://medlineplus.gov/genetics/understanding/testing/costresults/
- Patel, D. R., Apple, R., Kanungo, S., & Akkal, A. (2018, December). Intellectual disability: definitions, evaluation and principles of treatment. *Pediatr Med*, 1(11), 1-10. http://dx.doi.org/10.21037/pm.2018.12.02
- 30) Patel, D. R., Cabral, M. D., Ho, A., & Merrick, J. (2020, February). A clinical primer on intellectual disability. *Translation Pediatric*, 9(1), 23-35. http://dx.doi.org/10.21037/tp.2020.02.02
- 31) Phillips, K. G., Houtenville, A. J., & Reichard, A. (2019, April). Using all-payer claims data for health surveillance of people with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 63(4), 327–337. DOI: 10.1111/jir.12578
- 32) Ptomey, L., Goetz, J., Lee, J., Donnelly, J. & Sullivan, D. (2013, December). Diet quality of overweight and obese adults with intellectual and developmental disabilities as measured by the healthy eating index-2005. *Journal of Developmental Physical Disabilities*, 25(6), 1-12. DOI:10.1007/s10882-013-9339-z.
- 33) Population Reference Bureau (PRB). (2022, April). [Image] U.S. adults with intellectual and

developmental disabilities are living longer, but COVID threatens to erase recent gains. <u>https://www.prb.org/articles/u-s-adults-with-intellectual-and-developmental-disabilities-are-living-longer-but-covid-threatens-to-erase-recent-gains/</u>

- 34) Roll, A. E. (2018, March). Health promotion for people with intellectual disabilities A concept analysis. *Nordic College of Caring Science*, 32(1), 422–429. DOI: 10.1111/scs.12448.
- 35) Satgé, D., Axmon, A., Trétarre, B., Sandberg, M. & Ahlström, G. (2020, August). Cancer diagnoses among older people with intellectual disability compared with the general population: a national register study. *Journal of Intellectual Disability* Research, 64(8), 579–588. DOI: 10.1111/jir.12734
- 36) Selbera, L. M., Boyd, L. D., Vineyard, J., & Smallidge, D. L. (2021, April). Impact of oral health education on the knowledge, behaviors, attitudes, and self-efficacy of caregivers for individuals with intellectual and developmental disabilities. *The Journal of Dental Hygiene*, 95(2), 21-27. https://pubmed.ncbi.nlm.nih.gov/33875526/
- 37) Shree, A. & Shukla, P. C. (2016, April). Intellectual disability: Definition, classification, causes and characteristics. *Learning Community*, 7(1), 9-20. DOI: 10.5958/2231-458X.2016.00002.6
- 38) Smit, M. J., Scheffersa, M., Emckb, C., van Busschbacha, J. T., & Beek, P. J. (2019, October). Clinical characteristics of individuals with intellectual disability who have experienced sexual abuse. An overview of the literature. *Research in Developmental Disabilities*, 95, 1-11. doi.org/10.1016/j.ridd.2019.103513
- 39) Smith, M. A. (2015, February). Intellectual and developmental disabilities. Haymarket Medical Education, 49-59. <u>https://www.clinicaladvisor.com/home/cme-ce-features/intellectual-and-%E2%80%A8developmental-disabilities/</u>
- 40) Virginia Commission on Youth. (2021). Neurodevelopmental disorders: Intellectual disability. http://vcoy.virginia.gov/007%20ID-1.pdf
- 41) Wallén, F. E, Ljunggren, G., Carlsson, A. C., Pettersson, D. & Wändell, P. (2018, April). High prevalence of diabetes mellitus, hypertension and obesity among persons with a recorded diagnosis of intellectual disability or autism spectrum disorder. *Journal of Intellectual Disability Research*, 62(4), 269–280. DOI: 10.1111/jir.12462
- 42) Weatherford, E. (2019, May). A good doctor is hard to find: a grounded theory study of the health care of people with intellectual disabilities in the United States. *Baylor University Thesis*. <u>https://baylor-</u>

ir.tdl.org/bitstream/handle/2104/10545/emma\_weatherford\_honorsthesis.pdf?sequence=4

- 43) Weissman-Fogel, I., Roth, A., Natan-Raav, K., & Lotan, M. (2015, October). Pain experience of adults with intellectual disabilities – caregiver reports. *Journal of Intellectual Disability Research*, 59(10), 914–924. DOI: 10.1111/jir.12194
- 44) Zuckerman, K. E., Chavez, A. E., Murillo, C. R., Lindly, O. J., & Reeder, J. A. (2018, November). Disparities in familiarity with developmental disabilities among low-income parents. *Academic Pediatric Association*, 18(8), 944-951. https://www.sciencedirect.com/science/article/abs/pii/S1876285918304224

To the best of the OIHSN Nursing Team's knowledge the information contained within this alert is current and accurate. If the reader discovers any broken or inactive hyperlinks, typographical errors, or out-of-date content please send email to <u>communitynursing@dbhds.virginia.gov</u> to include the title of the Health & Safety alert with specifics details of concern.