

Health Conditions Guide

New York State Children and Youth with Special Health Care Needs

Sponsored by New York State Regional Support Centers

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Children and Youth with Special Health Care Needs (CYSHCN) in New York State

According to the Health Resources and Service Administration's Maternal and Child Health Bureau, Children and Youth with Special Health Care Needs (CYSHCN) are defined as those children and youth who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. A priority of the New York State (NYS) Department of Health (DOH) Title V Maternal and Child Health Services Block Grant program (Title V) is to increase supports to address the special health care needs of children and youth, and to improve health outcomes and the system of care for CYSHCN and their families. Please refer to the NYS CYSHCN website for additional information.

https://www.health.ny.gov/community/special_needs/

The National Survey of Children's Health (NSCH) analyzes annual data for NYS to identify the frequency of conditions reported by families. The identified health conditions are listed in this document. The eligibility for local health department (LHD) CYSHCN programs is not limited to these conditions.

In NYS, the CYSHCN program aims to provide information and referral services to families. The Title V program established CYSHCN Regional Support Centers (RSCs) to increase the capacity of LHDs to support families and caregivers of CYSHCN, as well as individuals with special healthcare needs.

This guide is intended to provide technical assistance and resources for local health departments to serve families of CYSHCN.

"Funded by the New York State Department of Health using federal Health Resources and Services Administration Title V funding. The opinions, results, findings and/or interpretations of content contained therein are the responsibility of the Contractor and do not necessarily represent the opinions, interpretations or policy of the State or Federal funding agency."

October 2022

Table of Contents

Allergies	3
Anxiety Disorders.....	4
Arthritis	5
Asthma	6
Attention-Deficit/Hyperactivity Disorder (ADHD)	7
Autism Spectrum Disorder (ASD).....	8
Behavior Disorders.....	9
Blood Disorders.....	10
Cerebral Palsy (CP).....	11
Cystic Fibrosis.....	12
Depression	13
Developmental Delay.....	14
Diabetes	15
Down Syndrome	16
Epilepsy/Seizure Disorder	17
Genetic Disorder	18
Hearing Problems	19
Heart Problems	20
Intellectual Disability (ID).....	21
Learning Disability.....	22
Mental Health Condition	23
Migraines	24
Seizures	25
Sickle Cell Disease	26
Speech and Language Disorders.....	27
Substance Use Disorder	28
Tourette Syndrome.....	29
Traumatic Brain Injury (TBI).....	30
Vision Problems	31

Allergies

What are Allergies?

Allergies are problems with the body's immune system. Allergies are the reactions that happen when the immune system "thinks" a normally harmless substance is harming the body. Substances that cause allergies (called allergens) can be breathed, swallowed, or enter through contact with skin.

Key Points

- Allergens can include foods, substances carried in the air (like dust and plant pollen), medicines, chemicals, and insect bites.
- Allergies can affect people of any age. Allergies are often hereditary (run in families).
- Allergy symptoms can include itchy eyes, stuffy nose, sneezing, throat tightness, difficulty breathing, rashes, and headaches. The kind and severity of symptoms will be different for different people. Symptoms also will be different based on the type and amount of the substance the person comes in contact with.
- Allergens can cause an extreme reaction (called anaphylactic shock) in some people. This can be life-threatening. Call 911 immediately for help if this happens.
- An important way to manage allergies is to avoid the substances that are causing the allergy. That may not be possible, or that may not help. Health care providers can recommend other ways to manage allergies, such as medications, injections, or special therapies.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Asthma and Allergy Foundation of America](#)
- [MedlinePlus](#)
- [KidsHealth](#)

* Use the Search function for the specific information you want to find.



Sources

1. KidsHealth (Nemours)
2. MedlinePlus

Anxiety Disorders

What are Anxiety Disorders?

Anxiety is a feeling of fear or worry as a response to actual, anticipated, or imagined danger. Occasional anxiety is a part of life and a natural response to a possible threat. An anxiety disorder is when the feeling is extreme or does not go away.

Key Points

- There are different types of anxiety disorders. These can include *panic disorder* (recurring attacks of panic), *phobia* (excessive fear of an object or situation), *social phobia* (fear of being judged by others), *separation anxiety* (fear of being away from home or a loved one), *post-traumatic stress disorder* (anxiety that occurs after an extreme stress or trauma), and others.
- Anxiety may make an individual seem tense, irritable or angry. Other symptoms may include difficulty sleeping, headaches, tiredness, frequent crying, stomach aches, and shortness of breath.
- A person who is having anxiety symptoms should get a general health checkup. It is important to make sure that no other health problem is causing these symptoms.
- Anxiety disorders can affect people of any age. Several things can be involved in causing anxiety disorders, including family genes, brain activity, and life events and situations.
- Treatment can include psychological/behavioral therapy and medications.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Centers for Disease Control and Prevention](#)
- [Healthy Children](#)
- [KidsHealth](#)
- [National Alliance on Mental Illness](#)
- [National Alliance on Mental Illness in New York State](#)
- [Families Together NYS](#)
- [Mental Health Association in New York State, Inc.](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. Healthy Children (American Academy of Pediatrics)
3. KidsHealth (Nemours)
4. National Alliance on Mental Illness
5. Mental Health Association in New York State, Inc.

Arthritis

What is Arthritis?

Arthritis is the swelling of a person's joints, causing stiffness, pain, and limitations in movement. Arthritis can prevent joints from working correctly. Joints are where two bones meet, making it possible for a person to move. They include knees, ankles, wrists, elbows, knuckles, and others.

Key Points

- There are more than 100 types of arthritis and related conditions. The two most common types are osteoarthritis and rheumatoid arthritis. Osteoarthritis results when cartilage (the flexible tissue at the ends of bones that helps protect them) wears down. Rheumatoid arthritis is an autoimmune condition. This results when a body's immune system—a system that helps fight off illnesses—makes an error and attacks healthy tissues.
- Arthritis in children is called juvenile arthritis or childhood arthritis. The most common type is called Juvenile Idiopathic Arthritis (JIA) or Juvenile Rheumatoid Arthritis (JRA). JIA/JRA is an autoimmune condition.
- Treatments of arthritis in adults and children depend on the type of arthritis and the symptoms or effects that the person experiences. Treatments can include physical therapy, medications, special drugs to block the immune system from attacking joints, injections of steroids into affected joints, and sometimes surgery.
- JIA/JRA sometimes goes away for some children and teens. This is called remission. Remission can last for months, years, or even permanently. It is very difficult to know who will go into permanent remission and who will continue to need treatment as an adult.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [The Arthritis Foundation](#)
- [Centers for Disease Control and Prevention](#)
- [Mayo Clinic](#)
- [Healthy Children](#)
- [NY Connects](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. Healthy Children (American Academy of Pediatrics)
3. KidsHealth (Nemours)
4. Mayo Clinic
5. NY Connects

Asthma

What is Asthma?

Asthma is a chronic (long-term) disease that causes breathing problems. It affects how air is carried in and out of the lungs. The airways of the lungs start to swell, muscles around the airways start to tighten, and mucus starts to build up and plug the airways. Symptoms of asthma can include shortness of breath, chest tightness, coughing, whistling sound while breathing (wheezing), and fast heartbeat. Not all people who have asthma have all the symptoms listed here.

Key Points

- The exact cause of asthma is not known. Experts believe that it can run in the family.
- Things that bring on a reaction in airways and make it hard to breath are called triggers. Triggers can include allergies to things in the environment, chemicals in the air, infections, changes in weather, and exercise.
- An asthma attack is when a person's asthma symptoms become worse than usual. Emergency care may be needed. Severe asthma attacks can be life threatening.
- There is no cure for asthma. It can often be controlled by staying away from triggers and by medications prescribed by a health care provider.
- It is important for a person who has asthma to make a care plan with their health care provider. The plan should give directions on how to manage their asthma. This should include the medicines needed and when to take them, the person's triggers and how to avoid them, what to do when symptoms start, and when emergency care is needed.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Asthma and Allergy Foundation of America](#)
- [Centers for Disease Control and Prevention](#)
- [MedlinePlus](#)
- [KidsHealth](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. KidsHealth (Nemours)
3. MedlinePlus

Attention-Deficit/Hyperactivity Disorder (ADHD)

What is Attention-Deficit/Hyperactivity Disorder (ADHD)?

Attention-Deficit/Hyperactivity Disorder is a behavior disorder that involves one or more of these behaviors: inability to focus attention, being overactive, or being unable to control behavior. Individuals with ADHD have differences in brain development and brain activity that affect their behavior.

Key Points

- It is not clear what causes ADHD. It tends to run in families. It is more common in boys.
- There are three major types of ADHD:
 - Inattentive – The individual has difficulty paying attention and is easily distracted but is not overactive. This type is often called ADD, attention deficit disorder.
 - Hyperactive/impulsive – The individual is overactive and impulsive (acts before thinking) but does not have difficulty with attention.
 - Combined – The person has difficulty paying attention and is overactive and impulsive.
- A health care provider diagnoses ADHD.
- There is no cure for ADHD, but it can be managed. Treatment may include behavior therapy, medication, and behavior management training for parents and caregivers.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Centers for Disease Control and Prevention](#)
- [Children and Adults with ADHD \(CHADD\)](#)
- [KidsHealth](#)
- [MedlinePlus](#)
- [NY Connects](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. KidsHealth (Nemours)
3. MedlinePlus
4. NY Connects

Autism Spectrum Disorder (ASD)

What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder is a developmental condition that affects communication and social interaction, and involves restricted (limited) or repetitive behaviors, interests, and activities. Autism (ASD) is known as a spectrum disorder because there is a wide range in the types and severity levels of the symptoms that people experience. Some individuals with ASD may have only mild symptoms, and others may have more severe symptoms.

Key Points

- The exact cause of ASD is not known. Research suggests that a combination of a person's genes, biological factors, and influences from the environment affect the individual's development in ways that can cause ASD.
- People with ASD have differences in the way their brains develop and process information.
- ASD is one of the most common developmental disabilities. ASD symptoms/signs generally appear in the first two years of life, but it can be diagnosed at any age, including adulthood. Treatment of ASD is helpful at any age.

Early identification and treatment/intervention is **most** helpful and can increase skills and language development, as well as improve behavior.

- There is no medical test (like a blood test) to diagnose ASD. Doctors and other health care providers diagnose ASD based on an individual's behaviors and general development.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Autism Speaks](#)
- [Autism Speaks OPWDD](#)
- [Centers for Disease Control and Prevention](#)
- [KidsHealth](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Autism Speaks
2. Centers for Disease Control and Prevention
3. Kids Health (Nemours)

Behavior Disorders

What are Behavior Disorders?

A behavior disorder involves a **pattern** of disruptive or unwanted behavior (for example, aggression, anger, lack of control) that causes problems at home, school, and social situations. A behavior disorder may be diagnosed if the behavior is not common for the individual's age, the behavior continues over a period of time, or the behavior is severe.

Key Points

- The cause of behavior disorders is not known. Some things that can increase the risk for a behavior or conduct disorder include a family history of these disorders, a traumatic life experience, brain injury, or abuse and neglect.
- Children and teens may **occasionally** misbehave and show unwanted behaviors. They may act defiant, argumentative, or disruptive in other ways. Disruptive behaviors that happen only occasionally are not considered disorders.
- Behavior disorders are diagnosed by a mental health professional or other qualified health care provider. A comprehensive evaluation may be needed to make a diagnosis.
- Common behavior disorders include conduct disorder and oppositional defiant disorder (ODD).
- Treatment is based on the diagnosis and specific needs of the individual. It may include behavior therapy, behavior management training for parents and caregivers, medication, or a combination of these therapies.

Want to learn more?

Please visit the websites* of **these** organizations for more info and supports:

- [Centers for Disease Control and Prevention](#)
- [MentalHealth.gov](#)
- [MedlinePlus](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. MedlinePlus
3. MentalHealth.gov

Blood Disorders

What are Blood Disorders?

A blood disorder involves a problem with red blood cells, white blood cells, or blood platelets (tiny cells in blood that help stop bleeding). A blood disorder prevents blood from working correctly in the body.

Key Points

- Many blood disorders are inherited (passed down through parents' genes). Causes of other blood disorders include some diseases, side effects of certain medications, and a lack of certain nutrients (vitamins and minerals) in a person's diet.
- There are different kinds of blood cells. Red blood cells carry oxygen from the lungs to the other parts of the body. White blood cells help the body fight infections and substances that could harm a person's health. Platelets collect at the site of an injury (for example, a cut) and form a plug to stop the loss of blood.
- A health care provider uses information from a complete blood count (CBC) test to help diagnose a blood disorder. The test reports how many of each type of blood cell a person has.
- The most common blood disorders in young people include anemia (a lack of red blood cells or red blood cells that are not working correctly), bleeding disorders (for example, hemophilia), sickle cell disease, and blood cancers (for example, leukemia).
- Treatment for a blood disorder depends on the cause of the disorder. Common treatment may include medications, dietary supplements, and changes in a person's diet. More serious cases may involve blood transfusions and/or possible surgery (bone marrow transplant).

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Centers for Disease Control and Prevention](#)
- [Healthline](#)
- [KidsHealth](#)
- [MedlinePlus](#)
- [NYSBD Coalition](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. Healthline
3. KidsHealth (Nemours)
4. MedlinePlus
5. New York State Bleeding Disorders Coalition

Cerebral Palsy (CP)

What is Cerebral Palsy (CP)?

Cerebral Palsy is a disorder in the area of the brain that controls movement and muscle tone. CP affects body movements, reflexes, muscle control, coordination, posture, and balance. CP symptoms can vary from person to person and can range from mild to severe.

Key Points

- Most CP is related to brain damage that happened before or during a child's birth. CP can occur after birth, usually from infection or head injury.
- CP does not get worse over time, but the ways it affects a person's body can change as a person grows and ages.
- Many individuals with CP are likely to have other medical or learning needs in addition to their mobility concerns which can include communication, growth delays, seizures, and vision.
- CP is a lifelong condition.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Cerebral Palsy Foundation](#)
- [Centers for Disease Control and Prevention – Cerebral Palsy](#)
- [Healthy Children](#)
- [KidsHealth](#)
- [Cerebral Palsy Associations of New York](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. Healthy Children (American Academy of Pediatrics)
3. KidsHealth (Nemours)
4. Cerebral Palsy Associations of New York

Cystic Fibrosis

What is Cystic Fibrosis?

Cystic fibrosis is a genetic (inherited) disorder of the body's mucus glands. The disease causes the body to build up too much mucus. It affects the lungs, airways, digestive tract, and other organs of the body.

Key Points

- A person who has cystic fibrosis has a faulty gene that causes their mucus to become sticky and thick. The mucus most often plugs up the lungs. This makes breathing difficult and can cause a person to get frequent respiratory infections.
- The mucus build-up often affects the pancreas and intestines, too. It blocks some of the enzymes (substances that cause important chemical reactions in the body) that help break down food in the intestines. This prevents a person from getting some of the necessary nutrition (health benefit) from food. It can slow a person's growth.
- Some people show symptoms of cystic fibrosis early in their lives. Other people have symptoms at the time of puberty or later. Symptoms are different from person to person.
- There are a variety of treatments for cystic fibrosis, but at this time there is no cure. The goals of treatments are to lessen symptoms and reduce the risk of serious problems. Treatments include various medications, physical therapy, and devices to help clear mucus in a person's chest, enzymes to help digest food, and surgery for serious conditions.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Cystic Fibrosis Foundation](#)
- [Centers for Disease Control and Prevention](#)
- [KidsHealth](#)
- [MedlinePlus](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Cystic Fibrosis Foundation
2. Centers for Disease Control and Prevention
3. KidsHealth (Nemours)
4. MedlinePlus

Depression

What is Depression?

Depression is a mood disorder and medical illness that involves brain chemicals. It causes feelings of sadness and loss of interest in activities the person usually enjoyed. The symptoms continue for an extended period of time and affect how a person feels, thinks, and acts.

Key Points

- It is normal for a person to **sometimes** feel sad, helpless, or even hopeless. This is different from depression. A person who is depressed has these kinds of feelings every day, throughout the day, for two weeks or more.
- The exact cause of depression is not known, but some research shows that it may be caused by a combination of genes and a stressful environment or life situation.
- Different people are affected differently. Symptoms vary and can include crying, anger, avoiding social situations, physical pain, sleeping too much or difficulty sleeping, feeling tired all the time, changes in appetite, changes in weight, difficulty paying attention, having thoughts of death or suicide, and others.
- Mental health professionals diagnose depression. There are different forms of depression, and they can range from mild to severe and from short term to long term.
- Treatment for depression can include medications, psychotherapy (talk therapy), or a combination of both. Depression can get worse without treatment. It is best to start treatment as soon as possible.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Centers for Disease Control and Prevention](#)
- [KidsHealth](#)
- [MedlinePlus](#)
- [National Institute of Mental Health](#)
- [Mental Health Association in New York State, Inc.](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. Kids Health (Nemours)
3. MedlinePlus
4. National Institute of Mental Health
5. Mental Health Association in New York State, Inc.

Developmental Delay

What is a Developmental Delay?

A developmental delay is when a child is behind in achieving one or more typical growth milestones. A *milestone* is an ability that most children reach at a certain age. The delay may be in achieving skills in one or more developmental areas: physical, cognitive (thinking), emotional and social, communication, and skills used in daily life.

Key Points

- Most children can have some small and temporary delay in their skills. The delay is a concern when a child's skill is very much behind children of the same age and when the delay continues for a long time.
- It is important to know what skills are typical for certain ages. A developmental delay can include a delay in the normal age range for skills such as rolling over, sitting up, making sounds, talking, walking, recognizing familiar sounds, and many others.
- Parents and caregivers need to talk with their child's doctor or health care provider when they have any concerns with their child's development of typical skills. The child needs a medical evaluation because they may have a health condition that is causing the delay.
- The New York State Department of Health has a specific definition for *Developmental Delay*. Children aged birth through 2 who fit the definition can receive special services, called Early Intervention Services, to help overcome or manage the delay.
https://www.health.ny.gov/community/infants_children/early_intervention/memoranda/2005-02/eligibility_criteria.htm

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Centers for Disease Control and Prevention](#)
- [Center for Parent Information and Resources](#)
- [KidsHealth](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. KidsHealth (Nemours)
3. MedlinePlus

Diabetes

What is Diabetes?

Diabetes is a long-term medical condition that causes problems with how a person's body uses glucose, a type of sugar in blood. Glucose comes from food and is the main source of fuel for the body. A person needs insulin, a special hormone (a chemical in the blood), to use glucose and to turn food that they eat into energy.

Key Points

- There are two main types of diabetes:
 - Type 1 – A person with type 1 diabetes cannot make insulin.
 - Type 2 – A person with type 2 diabetes cannot use insulin that the body makes, and later may have problems making insulin. (More people have type 2 than type 1.)
- A health care provider can diagnosis diabetes. It is very important for a person to start treatment as early as possible to manage the condition and reduce long-term problems due to having too much glucose in their blood. Long-term problems can include damage to the heart, kidneys, eyes, and nervous system.
- A health care provider may also diagnose a person as having *prediabetes*. This means that a person's blood sugar levels are higher than normal, but the levels are not high enough to be diabetes. A person with prediabetes needs to follow the recommendations of their health care provider to help prevent the condition from becoming diabetes.
- There is no cure yet for diabetes, but a person with the condition can stay healthy and lead a normal life by keeping the condition under control. This means keeping blood sugars within a normal range.
- Treatment for diabetes often includes taking a form of insulin, eating a healthy diet, and exercising daily. It also helps to lose weight if a person is overweight.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [American Diabetes Association](#)
- [Centers for Disease Control and Prevention](#)
- [Healthy Children](#)
- [MedlinePlus](#)
- [NY Connects](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. American Diabetes Association
2. Centers for Disease Control and Prevention
3. Healthy Children (American Academy of Pediatrics)
4. MedlinePlus
5. NY Connects

Down Syndrome

What is Down Syndrome?

Down syndrome is a lifelong, genetic condition in which a person is born with extra genetic material in their cells. Down syndrome causes physical and intellectual developmental delays and disabilities. It also increases a person's risk for certain medical issues.

Key Points

- Down syndrome is sometimes called Trisomy 21 because a person with Down syndrome has extra material of that chromosome in the cells in their body. (Humans usually have 23 pairs of chromosomes, for a total of 46.)
- There are actually three types of Down syndrome: Trisomy 21, Mosaic Down syndrome, and Translocation Down syndrome. Most people with Down syndrome have Trisomy 21 Down syndrome.
- Individuals with Down syndrome often have some common physical features, grow at a slower rate, and have low muscle tone.
- Individuals with Down syndrome have a higher risk than most people for various health issues, such as heart defects, hearing loss, vision problems, ear infections, thyroid problems, skin infections, digestive problems, breathing problems, and others.
- The physical and intellectual effects of Down syndrome can range from mild to more severe. Every person born with Down syndrome is different.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [National Down Syndrome Society](#)
- [Centers for Disease Control and Prevention](#)
- [KidsHealth](#)
- [MedlinePlus](#)
- [NYS Office of People with Developmental Disabilities](#)
- [Global Down Syndrome Association](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. KidsHealth (Nemours)
3. MedlinePlus
4. National Down Syndrome Society
5. Global Down Syndrome Association

Epilepsy/Seizure Disorder

What is Epilepsy? / What is Seizure Disorder? *

* (Please see the sheet *What is a Seizure?* for more information about seizures.)

Epilepsy (sometimes called *Seizure Disorder*) is a complex and chronic disorder of the nervous system. The activity of nerve cells in the brain becomes disrupted and causes seizures. Recurring seizures is the main characteristic of the disorder. Having a single seizure does not mean that a person has epilepsy.

Key Points

- A person who has a single seizure does not always have epilepsy. A person may be diagnosed with epilepsy, if they (1) have two provoked, or (2) one unprovoked seizure and a medical condition that makes it likely that they will have more. Provoked means that the cause can be identified and is fixable, such as fever, infection, or other known causes. Unprovoked means that there is not an immediate cause for the seizure.
- Seizures cause changes in how the brain functions. A person who has seizures may experience temporary changes in muscle tone, uncontrollable jerking movements, unusual emotions or feelings, loss of awareness, and other symptoms.
- Many people with epilepsy do not have an identified cause for the disorder. Some of the common causes include genes, head injury or other trauma, certain diseases, brain tumors, brain damage that occurred before birth, stroke, and some developmental conditions.
- There are two situations that are medical emergencies and are times to call 911: 1) when a seizure lasts longer than 5 minutes, and 2) when a person has many seizures and has difficulty breathing or waking up.
- Treatment for epilepsy usually starts with the use of medications. When medications are not effective for the individual, treatment may include surgery or other therapies, including a special diet. Some children and adults are able to stop using medications under certain conditions without experiencing seizures.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Epilepsy Foundation](#)
- [Healthline](#)
- [Mayo Clinic](#)

* Use the *Search* function for the specific information you want to find.



Sources

- Epilepsy Foundation
- Healthline
- Mayo Clinic

Genetic Disorder

What is a Genetic Disorder?

A genetic disorder is any disease or health problem caused by change or different arrangement of the structure within an individual's cells. The difference can range from minor to major or serious.

Key Points

- Genes have an important role in determining the features or traits (appearance, talents, mental abilities, health) that an individual inherits from their parents. These can be passed from one generation to another in a family.
- Many genetic disorders are caused by gene changes in every cell of the body and affect every system of the body (for example, the circulatory (blood) system, the muscular system, the immune (disease defense) system, nervous system, and others).
- Some of the most common genetic disorders include Down syndrome, cystic fibrosis, Tay-Sachs disease, celiac disease, and sickle cell anemia.
- Many genetic disorders cannot be cured, but some of their effects can be treated or managed by medication, surgery, diet changes, and other therapies. The type of treatment depends on the type of disorder.
- A new and developing treatment for some genetic disorders is gene therapy. It involves changing genes in the body's cells. This treatment is still being researched.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Centers for Disease Control and Prevention](#)
- [KidsHealth](#)
- [MedlinePlus](#)
- [National Institutes of Health Human Genome Research Institute](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. KidsHealth (Nemours)
3. MedlinePlus
4. National Institutes of Health

Hearing Problems

What are Hearing Problems?

Hearing problems involve having trouble hearing or understanding some or all sounds. A person's hearing (auditory) system includes parts of the ears, nerves that send sound signals from the ears to the brain, and the part of the brain that processes and interprets the sound signals. Hearing problems result when there are problems with one or more parts of the hearing (auditory) system.

Key Points

- The four major types of hearing loss: conductive (something blocks sound from going to the inner ear), sensorineural (the inner ear or nerves are damaged), mixed (includes both conductive and sensorineural losses), and central (the part of the brain that controls hearing is damaged).
- Hearing losses can range from mild to severe. A hearing loss (including a mild hearing loss) can cause problems with communication, learning, and social skills development.
- Auditory processing disorder (APD) is another brain-based hearing condition. People with APD have normal hearing but their brains have difficulties recognizing and understanding the meaning of sounds. They may have problems understanding speech.
- New York State has a law that all hospital and birthing centers in New York have to test the hearing of all newborn babies. Babies who do not pass the test will have more hearing tests and may receive additional services, including Early Intervention services from a hearing specialist.
- Treatments for hearing problems can include special instruction (special education, speech therapy, sign language instruction), hearing aids, medical treatments, hearing assistive technology systems, cochlear implants, and surgeries. Environmental modifications also can be very helpful.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [American Speech-Language-Hearing Association](#)
- [Centers for Disease Control and Prevention](#)
- [KidsHealth](#)
- [MedlinePlus](#)
- [Hearing Loss Association of America](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. American Speech-Language-Hearing Association
2. Centers for Disease Control and Prevention
3. Kids Health (Nemours)
4. Hearing Loss Association of America

Heart Problems

What are Heart Problems?

Heart problems include problems with the structure of the heart, problems with how the heart functions, or a combination of both conditions. There are two major types: congenital and acquired.

Key Points

- *Congenital* means that the problem develops before a baby is born when the heart is forming. Some congenital heart problems are mild and do not need treatment. Moderate and severe problems do require treatment, such as medications, surgeries, or other medical procedures.
 - Common heart defects involve abnormal connections in the heart or blood vessels. These cause blood to flow to incorrect parts of the heart. Another common defect involves the valves in the heart. Blood cannot flow smoothly when the valves do not open and close correctly.
 - Congenital heart problems can cause health difficulties throughout a person's lifetime.
- *Acquired* means that the problem develops at a time after birth. Certain diseases, viruses, and bacteria can cause damage to the heart.
 - Common acquired heart problems include a reduced supply of blood to the heart due to small or blocked blood vessels; an abnormal pumping rate due to a weak or sick heart muscle and problems with the valves in the heart; and a bad heart rhythm, too fast or too slow, so that the heart and the rest of the body do not get the blood needed.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Healthy Children](#)
- [Healthline](#)
- [KidsHealth](#)
- [MedlinePlus](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Healthy Children (American Academy of Pediatrics)
2. Healthline
3. KidsHealth (Nemours)
4. MedlinePlus

Intellectual Disability (ID)

What is an Intellectual Disability (ID)?

Intellectual disability is a developmental disability (meaning it is identified before age 18) that limits general mental abilities, such as learning, problem solving, and reasoning. Intellectual disability also affects adaptive skills, such as daily activities, independent self-care, social skills, and language.

Key Points

- The cause of intellectual disability for the majority of children is not known. It can be caused by any condition that interrupts normal brain development. These can include genetic conditions (like Down syndrome), problems during pregnancy or childbirth, illnesses, injuries, and factors in the environment.
- Intellectual disability can range from mild to profound (mild, moderate, severe, profound). The majority of people with ID have a mild form. Individuals with mild and some moderate forms of ID are able to live independently as adults, with the right supports.
- IQ tests (IQ = intellectual quotient) are specific tests used to measure a person's ability to learn. Adaptive behavior tests are used to measure a person's ability to do daily living skills without help. An intellectual disability is a term that describes a person who has a significantly below average IQ and who lacks some skills needed for day-to-day activities of life.
- Children who have intellectual disabilities often have additional disabilities or disorders. The disabilities or disorders can be physical, sensory, and/or behavioral.
- Children with ID can benefit from an appropriate education that may include services from a team of specialists, such as special education teachers, speech therapists, physical therapists, occupational therapists, psychologists, counselors, and others. Treatment can also include specific skills training and environmental adaptations.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Healthy Children](#)
- [Centers for Disease Control and Prevention](#)
- [MedlinePlus](#)
- [WebMD](#)
- [NY State Office of People with Developmental Disabilities](#)
- [New York Alliance for Inclusion and Innovation](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Healthy Children (American Academy of Pediatrics)
2. Centers for Disease Control and Prevention
3. MedlinePlus
4. WebMD
5. New York Alliance for Inclusion and Innovation

Learning Disability

What is a Learning Disability?

A learning disability is a disorder in one or more of the ways that the brain works to get information, use information, keep information, and send out information. A learning disability may cause difficulties in reading, writing, spelling, math and remembering and organizing information.

Key Points

- Individuals with learning disabilities can be successful by developing different ways of instruction and learning. The most common treatment for learning disabilities is special education services.
- The causes of learning disabilities are not always known. Learning disabilities often run-in families. Other causes may include prematurity and low birth weight, a childhood injury (such as a head injury), environmental effects (such as lead poisoning), or a serious childhood illness.
- Other disabilities, such as intellectual disability, deafness, blindness, autism, attention-deficit/hyperactivity disorder, or behavior disorders, can cause learning **challenges**. These are different and are not considered learning disabilities.
- Talk with your child's health care provider if your child is having learning difficulties. The health care provider may want to check your child's hearing and vision or do other tests to help find the cause.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Healthy Children](#)
- [KidsHealth](#)
- [LD Online](#)
- [MedlinePlus](#)
- [Learning Disabilities Association of New York](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Healthy Children (American Academy of Pediatrics)
2. LD Online
3. MedlinePlus
4. KidsHealth
5. Learning Disabilities Association of New York

Mental Health Condition

What is a Mental Health Condition?

A mental health condition or mental illness is a medical condition (emotional, social, psychological) that affects how a person thinks, feels, or behaves. The condition can interfere with daily life activities and relationships with other people.

Key Points

- Some mental health conditions are mild, and some are more serious. Some last for a short period of time, and some can last throughout a person's life.
- Some of the mental health disorders that children and teens may have include anxiety disorders, attention-deficit/hyperactivity disorders (ADHD), depression, behavior disorders, eating disorders, and substance use disorders (drugs and alcohol).
- There is no single cause for mental illness. Many different factors can affect mental health: life experiences (for example, trauma or abuse), a family history of mental illness, genes or brain chemistry, and long-term physical illness.
- There are treatments to help a person who has a mental health condition and recovery is possible. Mental health conditions that are severe, long lasting, or interfere with daily life activities need to be treated.
- It is important to first talk with a health care provider for information about what to do if a person may have a mental illness.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Centers for Disease Control and Prevention](#)
- [KidsHealth](#)
- [MedlinePlus](#)
- [National Institute of Mental Health](#)
- [NY State Office of Mental Health](#)
- [Mental Health Association in New York State, Inc.](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. MedlinePlus
3. National Institute of Mental Health
4. KidsHealth
5. Mental Health Association in New York State, Inc.

Migraines

What are Migraines?

Migraines are recurring headaches that cause moderate to severe pain that is throbbing or pulsing. Other symptoms can occur with migraines, including nausea; vomiting; dizziness; sensitivity to light, sound, or odors; and general weakness.

Key Points

- A migraine headache can last from 4 to 72 hours. The pain can range from moderate to severe.
- Experts are not sure what causes a migraine headache. Migraines may run in families and could have a genetic cause. Many experts think migraines are caused by an imbalance in brain chemicals.
- Individuals who get migraine headaches may have certain experiences that can bring on the headaches. These are sometimes called triggers. Different people can have different triggers. Some common triggers include stress, strong smells, bright or flashing lights, loud noise, certain foods, and ingredients, too much or not enough sleep, tobacco, alcohol, and caffeine.
- Migraines are diagnosed by a health care provider. The health care provider will also check to make sure that there are no other medical conditions that are causing the symptoms.
- There is no cure for migraines. The treatment includes medications and therapies to relieve the symptoms and to prevent more migraine headaches.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Healthy Children](#)
- [KidsHealth](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Kids Health (Nemours)
2. MedlinePlus

Seizures

What is a seizure? *

*(Please see the sheet *What is Epilepsy? /What is Seizure Disorder?* for more information.)

A seizure is a sudden interruption in the normal electrical activity between brain cells. It causes changes in how the brain functions, which can result in temporary differences in muscle tone, movements, behaviors, sensations, and states of awareness.

Key Points

- A seizure is a “one time” event. Having a single seizure does not mean that a person has epilepsy. If a person has more than one seizure, there may be a more complex health condition, such as epilepsy.
- A one time or single seizure can occur because of a direct or immediate result from a head injury, drugs, infection, fever, chemical imbalance in the blood, or when stopping a medication. These are called provoked seizures because the cause can be identified.
- A seizure caused by high fevers is a special type of *provoked* seizure in young children. The seizure causes muscle contractions (tightening) and stiffening and jerking of arms and legs and can last for several minutes. Some children have more than one febrile (fever-related) seizure, but it is rare to have more than three. Most children outgrow febrile seizures by age 5.
- Seizures are grouped into two major types: *Generalized* (affecting both sides of the brain) and *Focal* (located in just one area of the brain). Several other terms within these two groups describe the way a seizure looks (the symptoms and parts of the body that are involved). Most seizures last from 30 seconds to 2 minutes and do not cause lasting harm.
- Two situations are medical emergencies and require a call to 911: 1) A seizure lasts longer than 5 minutes, and 2) A person has many seizures and has difficulty breathing or waking up.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Centers for Disease Control and Prevention](#)
- [Healthline](#)
- [Mayo Clinic](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. Kids Health (Nemours)
3. MedLine
4. Mayo Clinic

Sickle Cell Disease

What is Sickle Cell Disease?

Sickle cell disease is a group of genetic disorders of red blood cells. The red blood cells become hard and sticky and look C-shaped (like a sickle tool) or the shape of a crescent moon. This shape makes it difficult for the cells to move easily and carry oxygen to all parts of a person's body. Sickle cells also die early and result in a reduced supply of red blood cells (called anemia).

Key Points

- The cause of sickle cell disease is a defective gene that is called a sickle cell gene. A person who has sickle cell disease was born with two sickle cell genes. A child's mother and father (both) must pass the defective gene to their child for that child to have sickle cell disease.
- A person who has born with only one sickle cell gene has **sickle cell trait**. That person does not have sickle cell disease. It means that the person received the sickle cell from one of their parents.
- Sickle cell disease is diagnosed with a simple blood test. The disease is usually found by the general health screening (health tests) done for newborn babies in the hospital. Some babies can be diagnosed before they are born.
- People with sickle cell disease start to have signs of the disease (including symptoms such as growth delays, pain, infections, swelling of hands and feet) during their first year of life. The symptoms and effects are different for each person and can range from mild to severe.
- Treatments for sickle cell disease are different for each person and depend on the type of symptoms the person has. A new and developing treatment for Sickle Cell Disease is gene therapy. It involves changing genes in the body's cells. This treatment is still being researched.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Sickle Cell Disease Association of America](#)
- [Centers for Disease Control and Prevention](#)
- [KidsHealth](#)
- [MedlinePlus](#)
- [NYS Sickle Cell Advocacy Network Inc.](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. KidsHealth (Nemours)
3. MedlinePlus
4. NYS Sickle Cell Advocacy Network Inc.

Speech and Language Disorders

What are Speech and Language Disorders?

Speech and language disorders are difficulties with the ways a person can communicate. Speech involves the way sounds and words are formed. Language involves the way people receive and express information.

Key Points

- *Speech difficulties* can include issues forming specific word or sounds correctly (articulation), making words or phrases flow smoothly (fluency), and voice.
- *Language difficulties* can include issues understanding language (spoken or read) and expressing information (when speaking or writing).
- Speech or language disorders can occur with other disabilities, such as autism spectrum disorder, intellectual and developmental disabilities, attention-deficit/hyperactivity disorder, and others.
- Some causes of speech and language disorders include hearing loss, brain injury and disorders, illnesses, and physical disorders.
- Speech-language pathologists (SLPs) diagnose and treat speech and language disorders in children and adults.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [American Speech-Language-Hearing Association](#)
- [Centers for Disease Control use the search and Prevention](#)
- [KidsHealth](#)

* Use the *Search* function for the specific information you want to find.

Sources

1. American Speech-Language-Hearing Association
2. Centers for Disease Control and Prevention
3. KidsHealth (Nemours)

Substance Use Disorder

What is Substance Use Disorder?

Substance use disorder is a condition that affects a person's brain and behavior. It involves using an illegal substance or using a legal substance in a wrong and/or unhealthy way. This can include addiction (meaning that the person has no control over the use of the substance). Some individuals can abuse a substance but not have an addiction.

Key Points

- Health care providers can diagnose substance use disorder in children and adolescents. An individual receives this medical diagnosis when their use of the substance causes problems in school or at work, problems in social relationships, and/or dangerous behavior.
- There are two main types of addiction: 1) Physical addiction - this means that a person's body becomes dependent on a particular substance; and 2) Psychological addiction – this means that the person has strong cravings for the substance that are too strong to overcome.
- Individuals with substance use disorder often have other conditions like depression, anxiety, and attention-deficit/hyperactivity disorder (ADHD). A person may have started the use of a substance to try to reduce or overcome the symptoms of the other condition(s). The condition(s) should be treated by a health care provider at the same time the substance use disorder is treated.
- Treatment for substance use disorder depends on the specific needs and situation of an individual. The treatment plan will be based on several factors, including the age of the person, the substance(s) being used, the severity of their disorder, and how long the individual has had the disorder.
- Treatment for substance use disorder may include behavior therapy and medications. Treatment often involves several steps.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Child Mind Institute](#)
- [KidsHealth](#)
- [Healthy Children](#)
- [National Institute of Mental Health](#)
- [NYS Office of Addiction Services and Supports](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Child Mind Institute
2. Healthy Children (American Academy of Pediatrics)
3. KidsHealth (Nemours)
4. MedlinePlus
5. National institute of Mental Health

Tourette Syndrome

What is Tourette Syndrome?

Tourette syndrome is a condition that affects a person's brain and nervous system and causes the person to have tics. Tics are sudden, repeated movements or sounds that a person makes automatically; that means the person makes the movements or sounds without planning to make them. A person who has Tourette syndrome has several motor (movement) tics and at least one vocal (sound) tic.

Key Points

- Motor tics may include twitching, frequent eye blinking, head jerking, foot stomping, and other movements. Vocal tics may include making clicking sounds, shouting, frequent throat clearing or sniffing, and other sounds.
- The specific cause of Tourette syndrome is not known. Some researchers report that it is caused by an imbalance of chemicals in the brain. This imbalance results in a problem with how certain nerves in the brain communicate.
- A person with Tourette syndrome may have other conditions, such as attention-deficit/hyperactivity disorder (ADHD), learning disabilities, anxiety, and obsessive-compulsive disorder (OCD).
- Symptoms of Tourette syndrome usually start when a child is 5 to 10 years old. Tics often decrease during adolescence and early adulthood. Some individuals with Tourette syndrome may continue to have tics as adults, and the tics can become worse.
- There is no cure for Tourette syndrome, but there are medications and behavioral treatments to help manage the tics. Some people with Tourette syndrome do not need any treatment, because the tics do not disrupt or interfere with their daily life activities.

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Tourette Association of America](#)
- [Centers for Disease Control and Prevention](#)
- [KidsHealth](#)
- [MedlinePlus](#)
- [NY Connects](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. Kids Health (Nemours)
3. MedLine
4. Tourette Association of America
5. NY Connects

Traumatic Brain Injury (TBI)

What is Traumatic Brain Injury (TBI)?

Traumatic brain injury is a sudden injury that causes damage to the brain and changes the way the brain normally works. It can happen when there is a strong hit or severe shake to a person's head. A TBI can range from mild to severe.

Key Points

- A TBI can result in impairments of thinking, memory, movement, communication, senses (hearing, vision, smell, touch, and taste) and emotions (including depression, aggression, anxiety, and post-traumatic stress) and changes in personality.
- A concussion is a type of mild TBI and usually has a temporary effect on the brain.
- Severe TBI can cause serious physical and psychological difficulties that are longer lasting. Some people with severe TBI may have permanent impairments.
- The healing process is different for every TBI. Health care providers cannot predict the **exact** amount of time it will take to heal from a TBI or the **exact** number of skills a person will gain back at the beginning of treatment.
- Treatment of severe TBI can include:
 - Surgery to help prevent more damage to a person's brain
 - Medications to treat the symptoms of TBI
 - Rehabilitation therapies to treat physical, emotional, and thinking difficulties

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [Centers for Disease Control and Prevention](#)
- [KidsHealth](#)
- [MedlinePlus](#)
- [Brain Injury Association of New York State](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. Centers for Disease Control and Prevention
2. Kids Health (Nemours)
3. MedlinePlus
4. Brain Injury Association of New York State

Vision Problems

What are vision problems?

Vision involves a complex system. The major parts of the system include the eye, special nerves, and the brain. Vision problems can be due to damage or disorders of one or more of these major parts.

There are many different types of vision problems. They include problems related to visual distance, range, clarity, stability, and perception. Some people have more than one type of vision problem.

Key Points

- It is very important for young children to have an examination by a vision specialist. Not all vision problems are easily recognized. A child may think their vision is satisfactory because they have always seen that way. They may not be aware that they have a problem that could be corrected.
- The general meaning of the word “blind” is that a person has no sight at all, but there also is a legal definition of “blindness” based on national standards. A person who is “legally blind” often has limited usable vision.
- Cortical visual impairment (CVI) is a severe form of brain-based visual impairment. The person seems to be blind but can have healthy eyes that see. Their brain cannot make use of visual information correctly.
- There are other less severe brain-based problems. Some people can see but have difficulties in processing and interpreting what they see. A visual processing disorder can significantly interfere with learning.
- Treatments for vision problems can include special instruction, corrective lenses, medications and medical therapies, and surgeries. Environmental adaptations and adaptive equipment also can be very helpful. (Corrective lenses do not help all vision problems.)

Want to learn more?

Please visit the websites* of these organizations for more info and supports:

- [American Foundation for the Blind](#)
- [Healthy Children](#)
- [KidsHealth](#)
- [MedlinePlus](#)
- [New York Vision Rehabilitation Association](#)

* Use the *Search* function for the specific information you want to find.



Sources

1. American Foundation for the Blind
2. Healthy Children (American Academy of Pediatrics)
3. KidsHealth (Nemours)
4. MedlinePlus
5. New York Vision Rehabilitation Association