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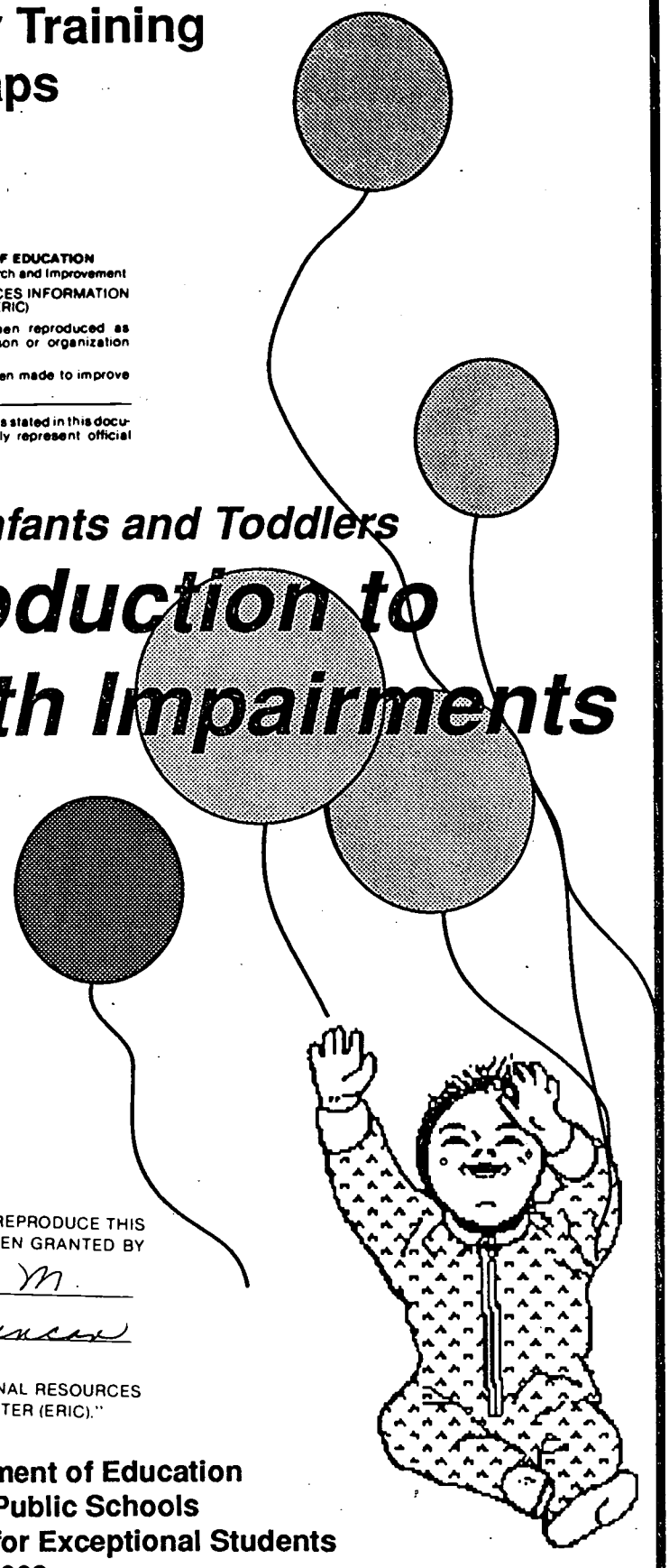
ABSTRACT

Intended for use in Florida training programs for caregivers of infants and toddlers with disabilities, this booklet describes some of the more common physical and health impairments that can affect young children. For each disability, the description generally stresses typical characteristics and special requirements. Addresses and telephone numbers of relevant organizations as well as one or more references are also provided for each condition. Conditions described are: cerebral palsy, cystic fibrosis, Down Syndrome, infantile autism, juvenile diabetes mellitus, muscular dystrophy - Duchenne type, prematurity, scoliosis, seizure disorders, and spina bifida. An additional section defines terms used with children having disabilities. Also included are a list of local Florida diagnostic and learning resource system centers, a glossary, and an index. (DB)

Model of Interdisciplinary Training for Children with Handicaps



A Series for Caregivers of Infants and Toddlers

A Simple Introduction to Physical Health Impairments

Florida Department of Education
Division of Public Schools
Bureau of Education for Exceptional Students
1990

This training series is one of many publications available through the Bureau of Education for Exceptional Students, Florida Department of Education, designed to assist school districts, state agencies which operate or support educational programs, and parents in the provision of special programs for exceptional students. For additional information on this training series, or for a list of available publications, contact the Clearinghouse/Information Center, Bureau of Education for Exceptional Students, Division of Public Schools, Florida Department of Education, Florida Education Center, Tallahassee, Florida 32399-0400 (telephone: 904/488-1879; Suncom: 278-1879; SpecialNet: BEESPS).

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Model of Interdisciplinary Training
for Children with Handicaps

A Series for Caregivers of Infants and Toddlers

A Simple Introduction to Physical Health Impairments

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Introduction

A child with cerebral palsy wishes to enroll in your daycare setting. You are told this child has special needs. You may ask the following questions:

- What does the term special needs mean?
- Will this child have to be taught in a different way?
- Will the child need additional help in order to learn and function in the school setting?
- What is cerebral palsy?

Questions like these are usually asked when a person must deal with a new or unknown situation. This booklet will attempt to explain and provide some answers to these questions.

Children with special needs have a physical, mental, or emotional condition which interferes with their learning and development. Such children may require something special in order that their needs be met. In many cases, with proper stimulation or equipment, these children can learn and function in the same educational setting as other children.

For example, a young child with a physical impairment who is unable to walk independently may need a wheelchair, walker, or other equipment for mobility. Mentally, the child may be as alert and capable of learning as any other child. Providing appropriate equipment may allow the child to attend a regular childcare program. If additional services, such as physical or speech therapies, are needed, trained personnnel can provide these services within the home or the childcare setting. Often these services are provided by the public school system.

A child with special needs is entitled to receive the same educational privileges guaranteed to all children. This is a right mandated by federal and state laws. Children with special needs are children first, just like all other children. Instruction often can be the same for all the children. Often, children with special needs can learn and develop from the same program and curriculum that is provided for all children. All children learn from imitation and from stimulation in the learning environment. If program modifications do have to be made, they may be very minor. To assist the childcare worker in providing appropriate programming, many different curricula have been published for use with children both with and without special needs (see MITCH publication entitled *Curricula for Use with High Risk and*

Handicapped Infants and Toddlers).

The caregiver and service related personnel, such as therapists and doctors, can work together to provide the child with a well rounded educational environment. The relationship between the caregivers and related service personnel must be open and positive. Understanding the problems that affect a child can be an important first step in providing that child with a good and positive educational atmosphere.

This booklet uses basic terminology to describe some of the more common disorders that can affect infants and toddlers. The booklet also lists organizations that can provide more detailed information about these problems. Reference materials are also listed for anyone who would like to read more about a particular disorder.

Additionally, personnel at the local Florida Diagnostic and Learning Resources System (FDLRS) Associate Center may be able to provide the needed information. Persons seeking information may call their local FDLRS Associate Center. A complete listing of all FDLRS Associate Centers can be found at the end of this booklet.

Local March of Dimes Foundation offices also provide valuable information. Information can also be obtained from the national chapter:

March of Dimes Birth Defects Foundation
303 S. Broadway
Tarrytown, NY 10591
(914) 428-7100

An addition to any childcare professional or resource library is a book entitled, *Physically handicapped children: A medical atlas for teachers*, by Drs. E. E. Bleck and D. A. Nagel. This volume describes in detail several handicapping conditions that can affect infants and young children. The cost is approximately $46.00. It is available through:

Psychological Corporation
P.O. Box 83995
San Antonio, TX 78283-9955
(800) 228-0752

Cerebral Palsy

A child with cerebral palsy (CP) is unable to properly control some body movement. Cerebral palsy is not a disease. It is a group of symptoms. CP results when one or more areas of the brain do not receive enough oxygen. It frequently involves the part of the brain that controls muscle movement. The damage can happen before, during, or after birth. Accidents, such as being hit by a car, near-drowning, or head injury in early childhood may cause CP. Although there is no cure, education, therapies (physical, occupational, speech), and medication can be very helpful in alleviating some of the symptoms. Cerebral palsy is not a degenerative condition. It is usually not a life threatening condition, and it is not inherited.

Children with CP usually exhibit a variety of symptoms depending on the area of the brain which is affected. These symptoms can vary from severe to very mild. Sometimes children with CP are unable to walk, write, or speak clearly, while other children exhibit symptoms so mild that only a trained professional can detect them. Symptoms may include motor disorders, such as paralysis, extreme weakness, lack of coordination, and involuntary body movement. (Heward & Orlansky, 1980, p. 246) In addition to lack of motor control, the CP child may display:

- delayed mental development
- a learning disability
- a language or speech delay
- feeding problems
- difficulty with self-help skills
- tremors or shaking
- visual problems
- hearing problems.

Many CP children are sensitive to light, loud music, and temperature. They are frequently congested, and may drool constantly. The five types of CP that affect children include spastic, athetoid, hypotonic, ataxic, and rigid.

Spastic CP - A child with spastic CP is unable to stretch muscles. When stretching is attempted, the child's muscles get tight. These children tend to have very stiff motor movements in their affected limbs. They often assume abnormal and/or unnatural postures and require help for proper positioning in the classroom.

Athetoid CP - Children with athetoid CP make large, irregular, twisting uncontrollable movements when they try to move. As they move, they tend to overeach. When not moving, they tend to look very normal.

Hypotonic CP - Babies who are born hypotonic are "floppy." Their muscles are very weak. These babies need much physical support. Children can also exhibit hypotonia due to medication.

Ataxic CP - Children with ataxic CP appear very uncoordinated. They have little sense of balance and body position.

Rigid CP - Babies born with this condition have very tight muscle tone, are very stiff, and are hypersensitive to touch.

For additional information about CP contact your local FDLRS Associate Center, local United Cerebral Palsy Association, or

United Cerebral Palsy Association
66 E. 34th Street
New York, NY 10016
(212) 481-6300
(800) USA-1UCP

Reference:

Heward, W. L., & Orlansky, M. D. (1980). Exceptional children: An introductory survey to special education. Columbus, OH: Merrill.

Cystic Fibrosis

Cystic Fibrosis (CF) is a disease that affects the lungs, pancreas, and intestines. It is a hereditary disease. Both parents must be carriers in order for the disease to appear in the child. Persons with CF usually have an average life span of 20 years. Symptoms include persistent coughing, wheezing, and pneumonia. These symptoms can occur right after birth or develop as the child grows. There is a thick buildup of mucus in the lungs which clogs the breathing passage, thereby trapping air. The mucus buildup in the lungs causes children to contract many serious infections. These infections must be aggressively treated with antibiotics and occasionally may be fatal.

The gene causing CF has just been identified. It affects a particular chemical that, in turn, affects the water balance across cell membranes. This results in thicker body secretions which cause the problems seen in the lungs, intestines, and other organs of persons with CF. It can be recognized in infancy and early childhood through tests performed by doctors.

The children usually require daily medication to keep their airways clear and to properly digest their food. Some of these may need to be given during the time the child is in the caregiving setting. Children with CF may also need chest physiotherapy during the day to keep their airways clear of mucus. It will be important to discuss the child's specific therapeutic needs with the parents.

These children may also spend considerable time in clinics and hospitals due to the progression of the disease. This often results in many absences from the caregiving setting which interfere with learning even though children with CF can be expected to have normal intelligence.

For additional information about cystic fibrosis contact your local FDLRS Associate Center, local Cystic Fibrosis Foundation, or

Cystic Fibrosis Foundation
6931 Arlington Road, Second Floor
Bethesda, MD 20814-5205
(301) 951-4422
(800) FIGHT CF

References:

Blackman, J. A. (1984). Medical aspects of developmental disabilities in children birth to three. Rockville, MD: Aspen System Corp.

Carlin, M. E. (1989, October 31). Personal communication. Miami: Mailman Center for Child Development.

Down Syndrome (Trisomy 21)

Down Syndrome is a condition resulting from a chromosomal abnormality. Down Syndrome causes a child to have physical, mental, and developmental problems.

The presence of an extra chromosome in each cell of the body causes Down Syndrome. Normal cells, except for the sperm and egg cells, contain 46 chromosomes. The cells of a child with Down Syndrome contain 47 chromosomes, the extra one being a #21 chromosome. Down Syndrome can be identified at birth.

The common physical characteristics of the syndrome may include:

- slanted eye appearance
- defective heart
- protruding tongue
- depressed nasal bridge ("flat face")
- shortened feet and hands
- short height
- low muscle tone
- tendency toward obesity. (Hallahan & Kauffman, 1982, p. 48)

Down Syndrome children demonstrate various degrees of mental retardation. Most children display mild to moderate range of retardation. (Hallahan & Kauffman, 1982, p. 48) Babies with Down Syndrome may be quiet and sometimes slow to respond. These infants benefit from various forms of stimulation. They need to be talked to, played with, and handled. (Blackman, 1984, p. 94) Stimulation through the use of music, colorful materials to look at and reach for, exercise, and so on, can help promote physical and mental development. Self help skills may be difficult for children with Down Syndrome to learn. Special help in the learning and practice of these skills is recommended.

Some Down Syndrome children tend towards overweight. Therefore, foods high in calories should generally be avoided. They also may have trouble having bowel movements. This is because they lack muscle tone and tend to be inactive. Eating high fiber foods and drinking a lot of water can help alleviate the problem of constipation. Regular exercise will help with both the weight and constipation

problems. (Blackman, 1984, p. 95)

Health problems such as frequent colds and ear infections can cause many absences from the caregiving setting. Children with Down Syndrome also have increased fluid in their middle ears which can cause periodic hearing loss. These situations may interfere with the education of the child.

For additional information about Down Syndrome contact your local FDLRS Associate Center, your regional genetics center, or

Association for Children with Down Syndrome
2616 Martin Avenue
Bellmore, NY 11710
(516) 221-4700

National Down Syndrome Society
141 Fifth Avenue, Seventh Floor
New York, NY 10010
(212) 460-9330
(800) 221-4602

References:

Blackman, J. A. (1984). Medical aspects of developmental disabilities in children birth to three. Rockville, MD: Aspen System Corp.

Hallahan, D. P., & Kauffman, J. A. (1982). Exceptional children: Introduction to special education (2nd ed.). Englewood Cliff, NJ: Prentice-Hall.

Infantile Autism

Infantile autism is a developmental disorder that starts during early childhood. Children with autism may display the following characteristics, which appear before 30 months of age:

- Abnormal response to people (e.g., avoidance of eye contact, mutual conversation, game-playing).
- Language severely delayed or impaired.
- Occurence of unusual speech patterns, such as,
  - repeating the speech of others in a meaningless way (echolalia)
  - pronoun confusion (e.g., "you" instead of "I")
  - repeating unclear words or sounds
- Uncommon attraction to objects (e.g., wanting to play only with paper, or a specific toy or object).
- Difficulty accepting even minor changes in routine or environment.
- Performance of repetitive or ritualistic self-stimulation behavior (e.g., rocking back and forth, hand flapping, light gazing, and becoming greatly disturbed when this is interrupted).
- Fascination with objects, especially those that are spinning (e.g., wheels and pinwheels).
- Inappropriate use of toys and objects (e.g., turning a toy car upside down to spin the wheels rather than "driving" the car).

The term infantile autism is used to describe the disorder because of the age at which the characteristics begin. The disorder is often referred to only as "autism."

At the present time, no one really knows the specific cause of autism. One theory suggests that autism is caused by a brain dysfunction that arises before or at the time of birth. However, most autistic children do not have a brain injury that can be identified medically. The disorder is more often seen in boys than girls. About one in two thousand children have autism.

Autism cannot be detected through any specific medical laboratory test. It can only be identified through observation. The child must exhibit several of the characteristics listed earlier. It is a disorder that starts at birth or soon after. The symptoms continue throughout the child's life. After intensive therapy, some persons with autism are able to lead independent adult lives. However, most must continue to live in some form of supervised or custodial care. One writer suggests that independence and the ability to live a normal life can be predicted if useful speech is produced by age five (Blackman, 1984, p. 12).

Some children who are autistic may have normal or above average intelligence, however, most have mental handicaps. Children with autism may show a very high ability in one or two specific areas, for example, an ability to remember or work with numbers, but may have very low abilities in others.

Children with autism require instruction that focuses on learning language, and self-help skills. The educational program must also include therapy and instruction to lessen inappropriate behaviors and improve socializing skills. When communicating with a child with autism, be direct, use simple directions, have the child ask for things by name, and encourage interaction with children with a higher level of language development. Tangible reinforcers such as tokens, food, or small toys, to control behavior is often successful (Blackman, 1984, p. 13).

Close interaction and communication between the parents, caregivers, and other related personnel can help the child with autism. Working together not only encourages the child's learning, but it also helps to control or eliminate any behavior problems.

For additional information about autism, contact your local FDLRS Associate Center, local Society for Children and Adults with Autism, or

National Autism Hotline
Autism Services Center
Douglas Education Building
10th Avenue & Bruce
Huntington, WV 25701
(304) 525-8014

National Society for Children and Adults with Autism
1234 Mass. Avenue, N.W., Suite 1017
Washington, DC 20005
(202) 783-0125

Reference:

Blackman, J. A. (1984). Medical aspects of developmental disabilities in children birth to three. Rockville, MD: Aspen Systems Corp.

Juvenile Diabetes Mellitus

Diabetes is a disorder in which the pancreas produces little or no insulin to be used in the body. Often it is inherited. When this disorder is identified in infants and young children, it is called juvenile diabetes.

Juvenile diabetes may be detected when the child is a few months old, or several years old. Diabetes may appear in children whose close relatives have the disease. However, other factors, in addition to heredity, are believed to contribute to the onset of juvenile diabetes. Diabetes has been thought to occur after certain viral infections.

The symptoms of juvenile diabetes include:

- frequency in emptying the bladder
- increased thirst
- weight loss
- unsatisfied hunger
- slow physical growth
- irritability
- drowsiness or coma. Coma (when a child cannot be awakened) is a medical emergency and a doctor must see the child.

Once a child is properly diagnosed as having diabetes, the doctor will prescribe the proper dosage of insulin. Sometimes the child or infant can receive too much insulin. When this happens, an insulin reaction keeps glucose from reaching the brain. The symptoms of an insulin reaction include:

- headache
- dizziness
- irritability
- blurred vision
- nausea
- vomiting
- sweating

- if not treated in time, convulsions and/or coma.

(Bleck & Nagel, 1982, p. 274)

The symptoms of the reaction must be recognized and treated quickly. Usually giving the child sweetened fruit juice or hard candies will alleviate or lessen the symptoms. This will bring the insulin level down and the glucose level up. The parent should be notified of any reactions.

A child with diabetes can lead a normal and active life. The child should be exposed to the same learning and social activities as other children.

Close communication between parents, caregivers, and doctors can help in proper management of insulin and diet to avoid a possible insulin reaction.

For additional information about juvenile diabetes, contact your local FDLRS Associate Center, local Diabetes Association, or

American Diabetes Association
National Service Center
P.O. Box 25757
1660 Duke Street
Alexandria, VA 22314
(703) 549-1500
(800) 223-1138

Juvenile Diabetes Foundation International
423 Park Avenue S.
New York, NY 10016
(212) 889-7575
(800) 223-1138

References:

Anderson, J. W. (1981). A practical new guide to healthy living. New York: ARCO.

Bleck, E. E., & Nagel, D. A. (1982). Physically handicapped children: A medical atlas for teachers. New York: Grune & Stratton.

Muscular Dystrophy - Duchenne Type

Muscular Dystrophy (MD) is a group of diseases that may cause gradual weakness of the skeletal muscles. The Muscular Dystrophies are caused by a change in the genes that are needed to produce healthy muscles. In the United States, two-thirds of all MD cases involve children. A child with MD looks normal at birth but symptoms become apparent after birth within the first few weeks of life. Some of the symptoms include:

- stomach which protrudes or sticks out
- hollow or curved back
- difficulty with gross motor or large muscle movement, such as standing up.

The most common form, called Duchenne Muscular Dystrophy (DMD), is a degenerative, progressive disease. It results in death, usually in the late teens or early 20's. An older child with Duchenne dystrophy wil lose the ability to walk as the disease progresses. The small muscles of the hands and fingers are the last to be affected by the disease. Physical therapy and exercise have proven to be good methods to improve the child's health and slow the progression of the disease.

There are a few types of MD that appear in infancy and early childhood. They include:

Duchenne dystrophy - This affects the large muscles of the lower trunk and upper legs. The average life span of persons with Duchene dystrophy is 20 years.

Facioscapulohumeral dystrophy - This affects the muscles of the face, shoulders, and upper arms. Those affected have normal life spans.

Congenital dystrophy - This is the only type which is obvious at birth. The baby is floppy. The muscles are weak and small.

For additional information about muscular dystrophy, contact your local FDLRS Associate Center, local Muscular Dystrophy Association, or

Muscular Dystrophy Association (MDA)
810 Seventh Avenue
New York, NY 10019
(212) 586-0808

References:

Heward, W. L., & Orlansky, M. D. (1980). Exceptional children: An introductory survey to special education. Columbus, OH: Merrill.

Muscular Dystrophy Association. (1988). What everyone should know about muscular dystrophy. South Deerfield, MS: Channing L. Bete.

Prematurity (Preterm baby)

NOTE: Prematurity does not necessarily lead to handicapping conditions.

A baby born prematurely may be normal both physically and mentally. However, in other preterm children, problems can develop before, during, or after birth. These problems can damage the baby's brain and/or other parts of the body. Complications can result which interfere with normal health and growth development.

A baby is considered premature when it is born with a gestational age of less than 37 weeks. (Gestational age refers to "the length of time the fetus is carried in the uterus," Blackman, 1984, p. 143). Normal gestational age ranges from 37 to 42 weeks (Blackman, 1984, p. 143).

The complications associated with premature or preterm infants are referred to as neonatal problems or complications. When these problems happen, the infant is placed in a special area in the hospital. This area is called the neonatal intensive care unit (NICU).

Some of the neonatal problems include:

Hyperbilirubinemia - A condition in which bilirubin, a blood by-product or waste, is in the blood. This makes the infant appear yellowish in color. This is called jaundice. Low levels of bilirubin are common in all babies and are usually excreted normally. However, high levels can be found in preterm babies and can permanently damage the brain. This is treated with phototherapy.

Bronchopulmonarydyplasia - A condition in which there are abnormal changes in lung tissue. This may result from long periods on a respirator, a machine which supplies oxygen to the baby.

Apnea - Absence of voluntary breathing.

Respiratory Distress Syndrome (RDS) - An inability to breathe adequately. It is caused by immaturity in the lungs of a preterm infant. These babies may need to be on a respirator for a period of time.

Retinopathy of Prematurity (formerly, Retrolental Fibroplasia) - An abnormal increase of fibrous tissue behind the lens of the eye. It can cause problems with vision. This is caused by many factors working together. One

important factor is the level of blood oxygen.

For additional information, contact your local FDLRS Associate Center.

References:

Blackman, J. A. (1984). Medical aspects of developmental disabilities of children birth to three. Rockville, MD: Aspen Systems Corp.

Goldberg, S., & Dizitto, B. A. (1983). Born too soon: Preterm birth and early development. New York: W. H. Freeman.

Scoliosis
(Spinal Curvature)

Scoliosis is a side to side curving of the spine in the shape of the letter S. (The normal spine is curved in a front to back position.) It often exists along with other disorders or diseases. There are three main types of scoliosis found in infants and young children.

Infantile scoliosis - The cause of infantile scoliosis is not known. It is very rare in the United States. It is most common among girls and children with low birth weight and muscle disorders. In most cases, about 85%, the scoliosis stabilizes or, occasionally, gradually improves. In the other 15%, it may continue to progress. The curve may become worse and the deformity will get more severe (Blackman, 1984, p. 184). It is often partially corrected and/or arrested with surgery.

Congenital scoliosis - This type of scoliosis is present at birth. It occurs when the bony part of the spinal column develops abnormally. The defect can only be identified by an X-ray. If the defect gets worse, surgery may be needed to correct the curvature or to slow down the progression (Blackman, 1984, p. 184).

Neuromuscular scoliosis - This form of scoliosis comes about due to the effects of a neuromuscular disease, such as cerebral palsy. Abnormal muscle tone associated with the neuromuscular disease leads to scoliosis. Sitting and standing can cause curving of the spine because of an imbalance in muscle tone (Blackman, 1984, p. 185).

Treatment of the neuromuscular disease can alleviate the scoliosis. Proper orthopedic procedures and/or surgery can also become part of the treatment.

Children with mild forms of scoliosis can participate in most activities in the caregiving setting. Children who wear braces should be encouraged to participate whenever possible. When a child requires surgery, the child may miss several weeks or months of attending daycare (Bleck & Nagel, 1982, p. 443). Physical therapy may be required.

For additional information about scoliosis, contact your local FDLRS Associate Center, local Scoliosis Foundation, or

National Scoliosis Foundation
P.O. Box 547
93 Concord Avenue
Belmont, MA 02178

(617) 489-0888/0880

References:

Blackman, J. A. (1984). Medical aspects of developmental disabilities in children birth to three. Rockville, MD: Aspen Systems Corp.

Bleck, E. E., & Nagel, D. A. (1982). Physically handicapped children: A medical atlas for teachers. New York: Grune & Stratton.

Seizure Disorders (Epilepsy)

NOTE: Seizure disorders do not necessarily lead to handicapping conditions

A seizure is the result of abnormal, or unusual firing of nerve cells in the brain. A seizure can last for a few, brief seconds or for several minutes. The visible signs of the seizure may be mild, such as a momentary stare, an unusual movement of the body, or a change in awareness. Or, they can be much more severe, resulting in convulsions. (Convulsions are abnormal or unusual muscle contractions. Convulsions are often sudden and violent.)

The term epilepsy is used to describe reoccurring seizures. Therefore, a person with a seizure disorder is said to have epilepsy.

There are several types of seizure disorders that affect young children:

Generalized seizures (grand mal) - These last a few minutes. They involve all parts of the body. The child loses consciousness, falls, and has shaking movements of arms and/or legs.

Absence seizures (petit mal) - These cause a short period of unconsciousness. "The child may suddenly stop in mid-sentence, stare for a moment or two, then continue talking without knowing that any break in attention took place." (Epilepsy Foundation of America [EFA], 1985, p. 7).

Focal seizures - These cause involuntary, repeated movement of one part of the body. Usually the left hand and arm are involved. A loss of consciousness can occur.

Infantile spasms - These are usually seen for the first time between three to nine months of age and in general have a poor prognosis. Symptoms include drooping of the head and stiffening of the arms. Spasms may stop after a few years and be replaced with other types of seizures.

Myoclonic seizures (minor motor seizures) - These seizures consist of sudden contractions of muscle groups. They are very difficult to control and may be associated with decreased intellectual fuctioning. A small subgroup have onset of these seizures after four years of age. These children have no other neurological problem and have a good prognosis.

Psychomotor seizures (temporal lobe seizures) - These cause no observable convulsions. Instead the child seems to be sleepwalking. For example, you can ask the child to pick up clothes, sit down, and get up. The child will do as asked, but will not remember the incident later.

Simple febrile seizures - These are caused by a fever. They most commonly occur in children under the age of five. They can last up to ten minutes. Symptoms are similar to those of generalized seizures.

Treatment

Medication is used in controlling some seizure disorders. Most medications cause some side effects which include difficulty in concentration, learning, or controlling behavior. Close supervision and consultation should be done by the child's physician.

If a child has a seizure, remain calm. Your main concern should be trying to prevent the child from falling or inflicting self-injury. Convulsions can be quite frightening to watch, even for persons who are used to seeing them. When a child has a known seizure disorder, those who work and live with the child will want to be familiar with seizure management techniques and may wish to consult a nurse or medical doctor about specific treatment or management of the child's seizures.

For additional information about seizure disorders or epilepsy, contact your local FDLRS Associate Center, local Epilepsy Foundation, or

Epilepsy Foundation of America (EFA)
4351 Garden City Drive
Landover, MD 20785
(301) 459-3700 or (800) EFA-1000

The following are generally accepted guidelines for what to do when a child has a seizure:

- Remain calm. Do not try to stop a seizure once it has started. Let it run its course. Do not try to revive the child.
- If the child is in an upright position, carefully ease the child to the floor and loosen clothing.
- Attempt to prevent the child from striking the body against any hard or sharp object. Otherwise, do not interfere with the child's movement.
- Turn the child's face to the side so that the saliva can flow from the mouth.

- Do not insert anything into the child's mouth.
- Do not be alarmed if the child appears to stop breathing for a moment.
- Allow the child to sleep or rest following the seizure.
- Notify the nurse (if one is available), the center director, and the child's parents or guardians that a seizure has occurred.
- After a seizure, most children can carry on as before. However, if the child appears groggy, confused, or weak, the child may need to be taken home.
- Contact the Epilepsy Foundation of America for assistance in setting up standard procedures that all education center staff can be advised to follow.

These instructions have been directly taken from:

Cook, R. E., Tessier, A., & Armbruster, V. B. (1987). Adopting early childhood curricula for children with special needs (2nd ed.). Columbus, OH: Merrill Publishing, p. 361.

References:

Blackman, J. A. (1984). Medical aspects of developmental disabilities in children birth to three. Rockville, MD: Aspen Systems Corp.

Epilepsy Foundation of America. (1985). Epilepsy: You and your child (A guide for parents). Landover, MD.

List of Recommended Books for Further Reading on Epilepsy

Your public library may have one or more of these books. If not, they may be able to acquire them for you. Many book stores will order titles upon request.

For young people:

Girion, B. (1981). A handful of stars. New York: Charles Scribner's & Sons. (a novel for young people)

Kornfield, E. J. (1982). Dreams come true. Boise, ID: Rocky Mountain Press. 1520 Shaw Mountain Rd., Boise, ID 83712. To order send $5.95 plus $1.00 shipping (Idaho residents add 5% sales tax.) Profits from the book go to EFA.

Silverstein, A., & Silverstein, V. B. (1975). Epilepsy. Philadelphia: J.B. Lippincott. (for ages 10-15)

Young, H. (1980). What difference does it make, Danny? London: Andre Deutsch. To order send $12.50 to British Epilepsy Association, Anstey Housee, 40 Hanover Square, Leeds LS3 1BE, West Yorkshire, United Kingdom.

Adult reading:

Dickman, I. (1985). One miracle at a time, how to get help for your disabled child -- From the experience of other parents. New York: Simon & Schuster. To order send $15.00 to PACER Center, Inc., 4826 Chicago Avenue, Minneapolis, MN 55417. (use of these same techniques will get help for the child with epilepsy)

Jan, J. E., Ziegler, R. G., & Erba, G. (1983). Does your child have epilepsy? Austin: PRO-ED Press. To order send $17.00 to PRO-ED, 5341 Industrial Oaks Blvd., Austin, TX 78735. (comprehensive, thoughtful guide for parents)

Lechtenberg, R. (1984). Epilepsy and the family. Cambridge: Harvard University Press. To order send $7.95 for the paperback or $16.50 for the hardcopy to Harvard University Press, 79 Garden Avenue, Cambridge, MA 02138-1311. (all aspects of family relationships of persons with epilepsy)

Pollak, R. (1986). The episode. New York: New American Library. To order send $15.50 to New American Library, 1633 Broadway, New York, NY 10019-6708. (fiction)

Schneider, J. W., & Conrad, P. (1983). Having epilepsy, the experience and control of illness. Philadelphia: Temple University Press. To order send $24.95 to Temple University, Temple University Press, Broad & Oxford Streets, Philadelphia, PA 19122. (first hand account from interviews of coping with epilepsy)

List of Recommended Books for Further Reading on Epilepsy (continued)

Sullivan, M. W. (1981). Living with epilepsy. Danville, CA: Bubba Press. (autobiography) To order send $7.95; make check payable to the Epilepsy Foundation of San Francisco, 1728 Union Street, Ste.211, San Francisco, CA 94123. Enclose a note with your request.

Volle, F. O., & Heron, P. A. (1977). Epilepsy and you. Springfield, IL: Charles C. Thomas. (day to day living)

Whitman, S., & Hermann, B. P. (Eds.). (1986). Psychopathology in epilepsy, social dimensions. New York: Oxford Press. To order send $39.95 to Oxford University Press, 16-00 Politt Drive, Fair Lawn, NJ 07419- 2799. (discusses scientific research of social aspects of epilepsy with mental illness)

Spina Bifida

Spina bifida is a defect present at birth. It affects the spinal column and often the underlying tissue. It results from failure of the bony spinal column to close completely during the baby's development (Hallahan & Kauffman, 1982, p. 334). The defect may be found anywhere between the head and lower end of the spine. The spinal cord may stick out causing a cyst or lump under the skin. This is corrected surgically during infancy. In mild cases the defect may not be discovered until later in life. Severe forms of the defect may cause paralysis of the lower body because of damage to the nerves.

Spina bifida is one of the most common birth defects causing physical disability among young children and adults in the United States (Hallahan & Kauffman, 1982, p. 334). About one in two thousand babies are born every year with spina bifida (Lauersen, 1987, p. 229).

The specific cause of spina bifida is not known. Some researchers believe there may be a genetic component. A woman who has one spina bifida child has an increased risk of having another; about a one in 20 chance (Gillham, 1986, p. 93). Since spina bifida tends to occur more commonly in children of lower socioeconomic conditions, it is felt that poor diet before and after conception could be a contributing factor.

There are three common forms of spina bifida. They include:

Spina bifida occulta - In this defect parts of the bony spinal cord fail to form. The spinal cord does not stick out and there is no lump found on the back. The only visible sign may be a cluster of hair growing in the area of the spine that is involved. Because the spinal cord does not protrude or stick out, the child does not suffer neurological damage or disability.

Meningocele - This form of spina bifida can be identified by a lump or sac found along the spinal column. The sac contains only the cover of the spinal cord. Since the lump does not contain nerve tissue, there is often minimal neurological disability.

Myelomeningocele - This form is similar to meningocele. It can be identified by a lump or sac found on the spinal column. Unlike meningocele, the sac contains part of the spinal cord. Since nerve tissues are involved, there is neurological damage.

Children with myelomeningocele may have accompanying health problems. These problems could include:

- hydrocephalus - an enlargement of the head caused by excessive spinal fluid accumulation and pressure
- mental retardation - usually associated with hydrocephalus
- lack of control of leg muscles - paralysis or little function
- lack of bladder and bowel control
- lack of sensation in the skin which can lead to pressure sores
- curvature of the spine
- language and speech problems.

(Blackman, 1984, p. 160)

Surgery and/or treatments can be performed in early infancy to correct some forms of spina bifida and accompanying health problems.

A child with spina bifida often can attend a regular childcare program. Most children have intelligence within the normal range but may have some learning problems. Some children may miss many days in the caregiving setting because of frequent medical treatments.

The child may need to work with a physical therapist to learn how to use orthopedic equipment. A speech therapist may be needed to develop adequate speech and language. The therapists along with the caregiver and any health-related personnel can work together to develop a productive educational setting.

For additional information about spina bifida, contact your local FDLRS Associate Center, local Spina Bifida Association, or

Spina Bifida Association of America
1700 Rockville Pike #540
Rockville, MD 20852-1631
(301) 770-7222
(800) 621-3141

References:

Blackman, J. A. (1984). Medical aspects of developmental disabilities in children birth to three. Rockville, MD: Aspen Systems Corp.

Gellham, B. (1986). Handicapping conditions in children. London, England: Croom Helm.

Hallahan, D. P., & Kauffman, J. A. (1982). Exceptional children: Introduction to special education (2nd ed.). Englewood Cliffs, NJ: Prentice-Hall.

Lauersen, N. (1987). It's your pregnancy: An obstetrician answers your most intimate questions about pregnancy and childbirth. New York: Simon & Schuster.

Terms to Identify Children with Handicaps

The following terms are commonly used in referring to children with special needs in the elementary and secondary grades.

Deaf - This term pertains to a loss of most hearing sensitivity. The loss can occur either from birth (congentially) or be acquired later. Deaf means a severe or profound hearing impairment.

Emotionally Handicapped (EH) - This term refers to a child who, after receiving supportive assistance or counseling, still has severe behavioral disabilities that disrupt the child's own learning process.

Hearing Impaired (HI) - This term refers to a mild to severe hearing impairment. Persons with this condition are sometimes referred to as hard of hearing.

Mentally Handicapped (MH) - This term refers to mental or intellectual functioning that is significantly below average, along with deficits in adaptive behavior such as self-help skills. It shows itself during the early developmental period. A child's educational performance is negatively affected. Various degrees of intellectual functioning are suggested by the terms mildly, moderately, severely, or profoundly mentally handicapped. Sometimes children with this condition are referred to as mentally retarded.

Multihandicapped - This term refers to more than one impairment (such as mentally handicapped-blind, or mentally handicapped-physically impaired). This causes severe educational problems that cannot be successfully addressed in special education programs designed only for one impairment.

Physically Impaired (PI) - This term refers to a severe orthopedic (bones and joints) impairment, including an impairment caused by a birth defect (e.g., clubfoot), an impairment caused by disease (e.g., poliomyelitis), or impairment from any other cause (e.g., cerebral palsy, amputation).

Specific learning disabilities (SLD) - This term refers to a disorder in one or more of the basic psychological processes involved in understanding or using language, spoken or written. Problems in listening, thinking, speaking, reading, writing, spelling, or minimal brain dysfunction, dyslexia, and developmental aphasia. This term does not include problems which are a result of visual, hearing, or motor handicaps, of mental retardation or of cultural, environmental, or

economic disadvantage.

Visually Impaired (VI) - This term refers to a visual impairment that adversely affects educational performance, even with correction. Partially-sighted children have some usable vision. Blind children do not have any usable vision.

Note: Terms were adapted from:

- Exceptional student terms: A glossary by R. Charles, A. Diaz, and M. Gavelo. Available: Dade County Public Schools - Exceptional Student Education/Florida Diagnostic and Learning Resources System/South.
- Fact Sheet "General Information About Handicaps and People with Handicaps." National Information Center for Children and Youth with Handicaps (NICHCY).

Florida Diagnostic and Learning Resources System

Your local FDLRS Center can provide specific information regarding handicapping conditions and local community resources. They also may provide support services, screening and diagnostic services, resource materials, training, and other forms of assistance regarding the education and care of infants/toddlers with special needs. If they do not have a ready answer or solution for you, they may refer you to a resource that does.

There are 18 FDLRS Associate Centers throughout Florida. They are listed below according to the counties they serve.

Counties	FDLRS Center	Local Phone
Escambia, Santa Rosa, Okaloosa	FDLRS/Westgate Associate Center 30 E. Texar Dr. Pensacola, FL 32503	904/433-7563 904/434-3732
Washington, Bay, Calhoun, Franklin, Gulf, Holmes, Liberty, Walton, Jackson	FDLRS/PAEC Associate Center 411 W. Boulevard, Chipley, FL 32428	904/638-4131
Leon, Gadsden, Jefferson, Taylor, Wakulla	FDLRS/Miccosukee Associate Center 1940 N. Monroe St., Suite 50, Northwood Mall Tallahasse, FL 32303	904/487-2630 904/488-4150
Hamilton, Columbia, Lafayette, Madison, Suwannee	FDLRS/Gateway Associate Center P.O. Box 1387, Jasper, FL 32052	904/792-2877
Putnam, Baker, Bradford, Flagler, St. Johns, Union	FDLRS/NEFEC Associate Center N.E. Florida Educational Consortium Rt. 1, Box 8500, 3841 Ride St., Palatka, FL 32177	904/329-3800
Duval, Clay, Nassau	FDLRS/Crown Associate Center 1450 Flagler Ave. Room 15, Jacksonville, FL 32207	904/390-2075 904/390-2154
Marion, Alachua, Citrus Dixie, Gilchrist, Levy	FDLRS/Springs Associate Center Collier Elementary School 3881 NW 155th Street, Reddick, FL 32686	904/591-4300
Orange, Lake, Osceola, Seminole, Sumter	FDLRS/Action Associate Center 1600 Silver Star Rd., Orlando, FL 32804	407/293-5841 407/295-4020
Brevard, Volusia	FDLRS/East Associate Center 1450 Martin Blvd., Merritt Island, FL 32952	407/631-1911
St. Lucie, Indian River, Martin, Okeechobee	FDLRS/Galaxie Associate Center 1901 S. 11th St., Ft. Pierce, FL 34950	407/468-5385 407/468-5389
Pinellas, Hernando, Pasco	FDLRS/Gulfcoast Associate Center 1895 Gulf-to-Bay Blvd. Clearwater, FL 34625	813/442-1171 813/462-9687
Hillsborough	FDLRS/Hillsborough Associate Center Department of Education for Exceptional Students 411 E. Henderson Ave., Tampa, FL 33602	813/272-4555 813/272-4537
Polk, Hardee, Highlands	FDLRS/III Associate Center 1062 N. Broadway Ave. Bartow, FL 33830	813/534-2877

Counties	FDLRS Center	Local Phone
Sarasota, Charlotte, De Soto, Manatee	FDLRS/Suncoast Associate Center 1135 Gun Club Rd., Sarasota, FL 34232	813/373-4283
Collier, Glades, Hendry, Lee	FDLRS/Big Cypress Associate Center Collier County Public Schools, Administration Center 3706 Estey Ave., Naples, FL 33942	813/643-2700
Palm Beach	FDLRS/Alpha Associate Center, Cedar Square 2112 S. Congress Ave., West Palm Beach, FL 33406	407/433-3500
Broward	FDLRS/Reach Associate Center 1400 N.E. 6th St., Pompano Beach, FL 33060	305/786-7704 305/786-7699
Dade, Monroe	FDLRS/South Associate Center 9220 S.W. 52nd Terrace, Miami, FL 33165	305/274-3501

The following FDLRS Specialized Centers may also be helpful.

Center Contact	
Clearinghouse/Information Center Florida Department of Education Bureau of Education for Exceptional Students Florida Education Center, Tallahassee, FL 32399 904/488-1879	FDLRS/USF - Multidisciplinary Diagnostic and Evaluation Services University of South Florida, Psychiatry Center 3500 East Fletcher Ave., Suite 225, Tampa FL 33612 813/974-5001
Communication Systems Evaluation Center (CSEC) 434 N. Tampa Ave., Sta. 702 Orlando, FL 32802 407/423-9212 407/422-3200	FDLRS/UF - Multidisciplinary Diagnostic and Training Program Box J-282 JHM Health Center University of Florida Gainesville, FL 32610 904/392-6442 904/392-5874
Florida Instructional Materials Center for the Visually Handicapped (FIMC) 5002 N. Lois Ave., Tampa, FL 33614 813/876-5016 800/282-9193	FDLRS/JU - First coast Interdisciplinary Center Jacksonville University P.O. Box 17607, University Blvd., N. Jacksonville, FL 32245 904/725-4646
Educational Television and Captioning Center for the Hearing Impaired 207 N. San Marco Ave., St. Augustine, FL 32084 904/824-1654	FDLRS/Mailman - Multidisciplinary Evaluation Services Mailman Center for Child Development University of Miami P.O. Box 016820 Miami, FL 33101 305/547-6624
FSDB Outreach/Parent Education Services Florida School for the Deaf and the Blind 207 N. San Marco Ave., St. Augustine, FL 32084 904/824-1654	FDLRS/TECH - Instructional Technology Training Resource Unit 1450 Martin Blvd. Merrit Island, FL 32952 407/631-1911
FDLRS/FSU - Regional Evaluation and Consulting Center 312 Regional Rehabilitation Center Florida State University Tallahassee, FL 32306 904/644-2222	

GLOSSARY

alleviate - to make simple or to relieve.

catherization - the process of inserting a hollow tube in an organ, or a space, in order to withdraw fluids, e.g., insertion into the bladder through the urethra to withdraw urine.

congenital - present at birth.

degeneration - a gradual decrease in function, such as going from strong to weak.

dysfunction - the lack or cessation of normal function.

fatal - to bring about death.

fibrosis tissue - an excessive growth of tissue in an organ or part of the body.

gene - a small part of a chromosome that determines the inherited characteristics of a living thing; piece of DNA, the hereditary material.

inoculate - to place part or all of an organism inside a person's body in order to prevent or cure a disease.

neonatal - of or having to do with newborn babies.

neuromuscular - of or having to do with the relationship between nerves and muscles.

orthopedic - having to do with a branch of surgery that deals with deformities and diseases of bones and joints.

pancreas - a large gland found in the liver that produces insulin.

physical therapy - treatment that tries to improve and/or normalize the movement, coordination, and strength of the body. Such treatment may include massages and exercises.

preterm (premature) babies (infants) - babies born prior to or before full term (e.g., before 37 weeks of gestation).

psychosocial - of or having to do with the relation between psychological and social processes, disciplines, and services.

respirator - a device used to help a person breathe.

shunt - an artificial connection or pathway used to change the direction of fluid from its normal channels; often composed of plastic tubing.

spasm - a sudden unusual involuntary contraction of a muscle or muscles.

syndrome - a group of symptoms which occur together and are thought to be due to a single cause.

vaccination - the act, practice, or process of inoculating with a vaccine as a protection against a disease.

vaccine - any preparation used to inoculate a person in order to prevent or lessen the effects of a disease.

References:

Bleck, E. E., & Nagel, D. A. (1982). Physically handicapped children: A medical atlas for teachers. New York: Grune & Sutton.

The Merriam-Webster Dictionary. (1974). New York: Pocket Books.

The World Book Dictionary. (1989). Chicago: World Book.

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