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WHAT ARE DEVELOPMENTAL DISABILITIES



Iowans with developmental disabilities are children and adults who are handicapped by mental retardation, cerebral palsy, epilepsy, autism and some forms of dyslexia. Persons who are developmentally disabled live in all parts of Iowa, from the rural areas to the large metropolitan centers. They are people with the same needs and rights as all other citizens. The opportunity to live as full, happy and normal a life as possible should be available to them.

Yet developmentally handicapped people throughout the country have not had adequate opportunities to develop to their fullest potential and integrate into the community where they live. The Federal Developmental Disabilities Act of 1970 was passed to assist states in planning, providing services and constructing facilities to meet the current and future needs of citizens who are developmentally disabled. Iowa and other states now have special funding which is essential in implementing a broad-based and professional program to help educate, train and habilitate these citizens.

What are the handicaps that the Iowa Developmental Disabilities Program addresses?

MENTAL RETARDATION

Mental retardation refers to below average general intellectual functioning with deficits in adaptive behavior originating during early childhood. Persons who are mentally retarded experience difficulty in learning, social adjustment and economic productivity. Mental retardation is a condition, not a disease.

Who is affected?

Over 6 million Americans or 3 per cent of the population of the United States is mentally retarded, including 84,000 Iowans. Some 120,000 children are born or will become mentally retarded every year. Persons in every social and economic class are affected. Although poverty is not a cause, many factors contributing to retardation are found among the poor.

What causes mental retardation?

For 75 to 85 per cent of the persons who are mentally retarded, no clear reason for retardation can be found, although over 200 specific causes have been identified. Conditions interfering with development before birth, during birth and in the early childhood years can be the cause of mental retardation.

An unborn child can suffer irreparable damage if his mother experiences German measles, venereal disease or suffers from malnutrition. Chromosome abnormalities, RH factor incompatibility and x-ray damage have also been identified as damaging to a fetus.

Meningitis, lead poisoning, malnutrition and common measles contracted by a child can cause him to become mentally retarded. Detrimental factors in the living conditions of the poor, such as health hazards and disease producing surroundings, can contribute to incidence of retardation. Poor home conditions, resulting in the child being neglected or abused during the early critical years of his development, can produce retardation. Mental development, like physical development, is promoted by the right kind of activity. It grows when nourished with human warmth and stimulation, no matter how severe the handicap.

What can be done to prevent mental retardation?

A mother's health before and during pregnancy is of prime importance in the prevention of mental retardation; good nutrition and health care of the mother are vital to the development of a baby from embryonic stage through delivery.

From birth, a child should receive proper medical care, diet and the opportunity to learn and to experience sensory and cultural stimulation to develop properly.

Because little more is known about the actual prevention of mental retardation, research and scientific efforts are ongoing to better our knowledge of this handicapping condition.

What are the different levels of retardation?

Approximately 89 per cent of all persons who are mentally retarded are MILDLY RETARDED. These persons are also referred to as "educable" and the great majority of them can become self-sufficient adults unless exposed to marked social or economic stress. They are capable of employment and at least semi-independent living within the community. Persons who are mildly retarded have an IQ of 52 to 67.

The rate of development of a person who is MODERATELY RETARDED is less than half of that expected of a normal individual. This classification is given to six per cent of our nation's citizens who are mentally retarded. Persons who are moderately retarded can learn to take care of their personal needs and perform useful tasks in the home or in a sheltered working situation. They are sometimes referred to as "trainable." The IQ for this group is 36 to 51.

Those who are SEVERELY RETARDED are 3.5 per cent of all persons who are mentally retarded. These people can learn self care, but their potential economic productivity is limited. An individual who is severely retarded has an IQ between 20 and 35.

Only 1.5 per cent of all persons who are mentally retarded are PROFOUNDLY RETARDED. This group requires special training to master the basic self help skills such as feeding and dressing. They profit additionally from special training in such areas as behavioral control, self protection, language development and physical mobility. The IQ of a profoundly retarded person is less than 20.

How can we help those who are already retarded?

Early diagnosis and intervention should reach handicapped children during the most important growing period of their lives, between birth and five years of age. The proper treatment program at an early age will help develop the potential of each individual. Preschool and special education programs appropriate to the child's level of retardation need to be available to all handicapped youngsters during the critical years of their development. Even the most profoundly retarded person can benefit from early training, good medical care and a nutritional diet.

As persons who are mentally retarded grow and develop, their educational activities and treatment program will need to be altered and expanded. Periodic evaluation and review will insure that each person is always receiving the program most appropriate to his individual needs and capabilities.

Job training situations in activity centers and sheltered workshops make it possible for mentally retarded people to have the opportunity to experience some form of employment. The productivity of some persons will require their continuation of sheltered employment situations throughout their lives; others will move into competitive job situations in the community.

Three million mentally retarded persons are capable of full-time employment. In many ways, the mentally retarded employe differs little from any other employe — he merely needs more specific instructions and a little patience on the part of his employer.

A wide variety of residential living opportunities and services must be available to enable all mentally retarded persons to function in the most normal and suitable way of life they can enjoy. Children may need living situations which are in direct coordination with their educational programs to best develop their potential. Adults may need a group home to live in with other handicapped persons to learn daily living skills and possibly progress to a more independent living environment. Allowing the person who is mentally retarded to function in the least restrictive situation possible, thus developing and using his fullest capabilities, is always the end goal.

CEREBRAL PALSY

Cerebral palsy is a group of medical conditions characterized by nerve and muscle dysfunction caused by damage to the human brain. Since cerebral palsy affects the muscle control centers of the brain, its most common effects are awkwardness, shambling gait, lack of balance, tremors, guttural speech and grimacing. For some persons, cerebral palsy will present difficulty only in walking. Others will experience seizures and spasms in varying degrees, plus defects in vision, hearing and speech. Some persons with cerebral palsy also are mentally retarded.

Who is affected?

Some 750,000 persons in the United States are affected by cerebral palsy and nearly 10,000 of them live in Iowa. One third are teenagers and young adults.

As the nation's number one childcrippler, 25,000 babies are born with this condition each year; that's one in every 200.

What causes cerebral palsy?

Brain damage or injury at anytime in life can affect control and coordination of muscle action and cause cerebral palsy. It is usually, however, caused by damage to the infant brain during pregnancy, at birth or soon after birth.

Poor maternal health, viral infections in early pregnancy, Rh factor or A-B-O blood type incompatibility and lack of oxygen to the developing brain have been identified as conditions that cause cerebral palsy. Premature birth can also contribute to brain damage, with poor nutrition, drug abuse and smoking identified as leading to premature delivery. Lead poisoning and rubella or German measles also have been linked with brain damage.

The search for additional causes goes on. However, cerebral palsy is neither hereditary nor contagious.

Can cerebral palsy be detected?

Early detection and diagnosis of cerebral palsy is vitally important as treatment and training can reduce the extent of the disability and prevent severe deformity. A physician should be told if a child is

unusually tense or irritable, feeds poorly, has difficulty in sucking, appears listless to people around him, or is slow to develop muscular control and coordination.

What can be done to prevent cerebral palsy?

Although there is no cure for cerebral palsy, preventative measures can be taken to reduce birth injuries. Healthy mothers before conception, good every day health practices during pregnancy and neo-natal medical care are necessary.

The rubella vaccine is helping to reduce the number of cerebral palsied births each year. Routine tests on pregnant women for blood compatibility with their husbands are now done. Protection is also found in the control of diabetes, anemia, high blood pressure and general good health habits in mothers.

Research is being done on such causes as lead poisoning, viruses, malnutrition, bilirubinemia (excess bile in the blood causing jaundice) and prematurity in an effort to better understand the prevention of cerebral palsy.

What are the different forms of cerebral palsy?

Three classifications of cerebral palsy have been identified, depending upon the area of the brain that is affected. The spastic individual moves stiffly and with difficulty; the athetoid individual will have involuntary and uncontrolled movements, and the ataxic person will have a disturbed sense of balance and depth perception.

How can we help those already affected?

A child who has cerebral palsy should be helped through the day to day teaching of small skills that will assist the child in normal growth and development. His potential for development should be established and an individual course of treatment begun to meet his needs. The goal should be for the person with cerebral palsy to use what he has to the maximum. Hopefully, this will eventually prepare him for independent living.

Important features of the treatment program are physical, occupational, speech and hearing therapy. Orthopedic surgery improves muscle coordination in some cases. Braces can reinforce a muscle group and prevent or correct deformity. Doctors have pre-

scribed drugs for some persons with cerebral palsy to reduce tension, muscle spasms and convulsions, and limit problems connected with nerve damage. It is important to teach a person with cerebral palsy to relax his muscles so that the muscles will respond to his needs.

For the person who has cerebral palsy, detection, treatment, care, education and psychological counseling are valuable. Job training and guidance for sheltered workshop experience and competitive employment need to be provided, as well as recreational opportunities and residential facilities for independent living.

EPILEPSY

Epilepsy is a disorder of the central nervous system in which the nerve cells of the brain become temporarily overloaded with electrical charges. When the brain cells discharge too much electrical (nervous) energy, some type of seizure occurs. Seizures range from a momentary lapse of consciousness to several minutes of convulsive movements.

Who is affected?

One in fifty people is likely to have some form of epilepsy. There is a reluctance of those with epilepsy to disclose their condition because of the stigma and prejudices still attached to the disorder, but it's estimated that 4 million Americans are affected. People with epilepsy have the same general range of intelligence and mentality as other people. Epilepsy is in no way contagious.

What causes epilepsy?

At some time, part of the brain has been injured by a blow, a trauma, an infection, a clogged blood vessel, lack of oxygen or impaired circulation. Epilepsy can be caused by prenatal or birth injuries, tumors, body disorders and still unknown other causes. Although it strikes most often in childhood, epilepsy can occur at any time in life.

What is a seizure?

Seizures often differ in what may be experienced by the individual. This is related to the area of the brain from which the neurons discharge excessively.

A Petit Mal seizure is sometimes not recognized by either the person with epilepsy or those around him. For 5 to 25 seconds, an absence or lapse in consciousness will occur in which the individual appears to be day dreaming or staring and is not aware of his surroundings. This may happen up to 100 times per day in young persons, but such frequency is usually not present in adults. After a Petit Mal seizure, the individual's activity will continue as if nothing had happened.

During a Grand Mal seizure, the individual will lose consciousness, his body will stiffen and his muscle movements will be jerky and irregular. His face, fingernails or lips may appear to be a dusky blue or pale color and his respiration will be noisy and irregular. After a Grand Mal seizure, the individual may be drowsy, confused or experience fatigue. This is the type of seizure the general public associates with epilepsy. It may last one to twenty minutes, but is usually less than five. It can occur one or more times daily, weekly, monthly or yearly.

Psychomotor seizures, which can occur at any age, present the most complex behavior of a person with epilepsy and are often difficult to identify. Such activities as chewing and lip-smacking, staring and confusion, abdominal pains and headaches, changes in color perception, spots before the eyes, buzzing and ringing in the ears, dizziness, fear, rage and anger may occur. The length of a psychomotor seizure is about 15 to 20 minutes, but they can last several hours. The individual is in a confused mental state, but is usually amenable to suggestions and comments made in a pleasant and friendly manner. The person should not be restrained and during a psychomotor seizure, he may react violently although he will not be aware of his actions.

Many persons who have epilepsy experience an aura prior to a seizure. This is a type of warning or signal to them that a seizure is coming on. This warning has shown itself as a feeling of fear, impending doom, unpleasant odors, funny sounds, tingling of the skin and spots before the eyes.

How is epilepsy medically detected?

An electroencephalogram or EEG is a painless electrical test that measures, locates and records electrical discharge patterns of the brain cells. Small disks or electrodes are applied to various places on the scalp to detect the areas of increased nerve cell activity. The written record of the brain's electrical activity is in the form of a wavy line on a moving strip of paper. During the actual recording of the brain waves, the patient usually rests, although he may be asked to breathe deeply or perform some other special tasks. The entire examination usually takes less than 45 minutes and can aid the physician in determining proper medication should epilepsy be detected.

What can be done for those who have epilepsy?

Through careful selection and follow-up of the right combination of drugs, 80 per cent of the persons with epilepsy can live normal, useful and productive lives; 50 per cent becoming seizure free with medically supervised drugs, and 30 per cent having seizures significantly reduced with drugs, enabling them to take their rightful place in society.

It has been found that persons who have epilepsy have fewer seizures and a better response to medical treatment if they lead active and normal lives. While certain limitations are advisable, overprotection is discouraged. Full activities and a busy schedule act as a deterrent to convulsions.

Epilepsy is comparable to such disorders as diabetes, heart disease or a fracture of the arm or leg. Yet, thousands of years of superstition and social rejection in which the individual was considered bewitched, insane or feeble-minded still force persons to try to hide epilepsy from their friends and employers. Epilepsy is not an emotional, psychological or social disturbance.

Persons with epilepsy, like everyone else, react to their problems and try to cope with them. Living under the threat of seizures is naturally a strain. The person with epilepsy can be caused great personal hardship because of the ignorance and prejudice of his fellow man. Thus, the difficulties faced by the individual with epilepsy can be as much emotional as physical.

What can be done for a person who is having a seizure?

1. Keep calm. Once the seizure has begun, there is nothing you can do to stop it.
2. Do not restrain the person who is having the seizure. Clear the area around him and do not interfere with his movements.
3. Don't force anything between his teeth. If his mouth is already open, fold a soft cloth and place it between his side teeth.
4. Loosen tight clothing, necktie and belt, if possible.
5. If you can, turn him on his side so that saliva can flow from his mouth, and place something soft under his head, a pillow or folded coat.
6. Do not call a doctor unless the seizure lasts more than 10 minutes or is followed immediately by another major seizure.
7. After a seizure, treat the person in a calm matter-of-fact manner and do not add to his embarrassment. Allow him to rest if he wants to do so.

AUTISM

Autism is a severe disturbance of mental and emotional development in young children. It is characterized by great problems in communication and behavior with an inability to relate to people in a normal manner. This rare condition ranks as one of the most puzzling and distressing handicaps of childhood.

Who is affected?

Due to the lack of a standardized definition or diagnostic criteria for autism, there is a variation in the actual number of those affected. Incidence figures have been given at 4 in every 10,000 children. The typical parents of autistic children tend to be above average in intelligence and it is estimated that the condition occurs two to four times more often in boys than in girls. In the United States, there are roughly 60,000 autistic children under the age of eighteen.

What causes autism?

Because of its rarity, little is known about possible factors causing autism or conditions preceding

or accompanying it. An early theory stated that lack of parental affection and pleasant experiences caused a child's disturbance. There is little or no support of this theory today. At this time, many researchers feel that disturbances in the central nervous system or in the body's chemical balance may be at the root of the problem. Roughly one-third to one-half of all autistic children also have some other severe condition affecting the central nervous system, such as spasticity or epilepsy.

What are the characteristics of autism?

Autism can be suspected as early as a few weeks or months after birth or not until the child is two to 2½ years old.

From birth to eighteen months of age, symptoms of autism may appear. The child will have feeding problems and difficulty in sucking; he will be unresponsive to his parents and show no desire to be held or cuddled; he will exhibit a constant cry, or hardly ever cry, even when hungry; he will react strongly if his physical environment is changed, and he will have sleeping problems.

The toddler who is autistic will continue to be extremely self-isolated and will not begin to talk when expected. He will have an obsessive interest in certain toys or mechanical appliances, not for their function but for the feel of their surface and the way they look when twisted and turned. He may be withdrawn and quiet, or hyperactive with odd spasmodic movements. His eating habits and preferences will be strange and he will be difficult to toilet train.

Behavioral symptoms vary from child to child. Some autistic children never learn to talk and others will acquire speech but lose it again. They may repeat phrases, long lists and television commercials but not understand them. They are basically uninterested in speech because it has no meaning for them. They may be able to understand simple familiar sentences, but will just stop listening when a conversation gets complicated because their handicap makes it frustrating to try to understand.

The autistic child typically does not understand the pronoun "I" and will refer to himself as "you" or by his name. When copying other persons' phrases, autistic children may speak very clearly, but have poor pronunciation when they produce their own words.

The child who is autistic responds to sounds in unpredictable ways. He may sometimes ignore a very loud noise, but cower in a corner with ears covered at another time the noise is made. He may be fascinated by a special noise made by a toy, but will show no interest when spoken to, not even when his own name is called.

Because they have as much trouble in comprehending unspoken language as they do with the spoken word, gestures are not helpful in communicating with autistic children. With their problems in understanding any kind of language, young autistic children are as handicapped as children who are born both deaf and blind. In older mute autistic children, however, sign language appears to be a great help.

It is not surprising that autistic children because of their handicap, have many behavioral problems. Because they cling to the few things they understand, a slight change from the same routine produces screams and tantrums.

An autistic child is likely to be frightened by quite harmless things and this lack of understanding also allows the child to ignore real dangers.

What can be done for autistic children?

Some autistic children will make no progress at all, remaining mute and withdrawn throughout life. But the majority show improvement as they grow older and the world becomes more understandable to them. With the development of suitable educational programs and training specifically for the child who is autistic, many more children with autism will progress.

As adolescents, they still need teaching but also vocational training, so they can learn work skills. Adults who have been autistic may be able to earn their living at an ordinary job, but most will need sheltered employment. Group homes and apartments are also needed so autistic adults can live the most normal lives their capabilities will allow.

DYSLEXIA

Dyslexia is a language disorder that affects a person's perception of letters and sounds. As one of approximately 100 varieties of learning disabilities, dyslexia is believed to be a physical condition caused by damage to the portion of the brain involved in reading skills.

Characteristics of a person with dyslexia include an inability to distinguish letters that appear similar, such as "b" and "d." Letters may also appear upside down, reversed and even whole words will be transposed: "on" becomes "no," "saw" appears to be "was" and "stop" reads "spot" to some persons with dyslexia.

For purposes of inclusion in the Developmental Disabilities Program, the disorder is limited to those persons with dyslexia who also have mental retardation, cerebral palsy, epilepsy or autism.

Prepared for:
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