Chapter 2

Causes, Risk Factors and Prevention of Disability

By the end of this chapter the PHC physician should be able to:

- Recognize and describe causes and risk factors of the major disabling conditions of children.
- Demonstrate the most common risk factors and causes of disabilities during the early childhood period.
- Describe the role of social and environmental barriers in the disability process.
- Recognize important preventive measures of important disabling conditions.
- Early recognition and intervention for prevention of disability and its complications.
- Recognize and describe the role of parents and care takers as primary actors and communities in the rehabilitation process.

Causes, Risk Factors and Prevention of Disability

Causes of disabilities

There are two main reasons that professionals strive to find the causes of disabilities: first, the identification of a specific cause can help in treating the condition, and second identification of the cause of a disability may help prevent the occurrence of such disabilities in future generations.

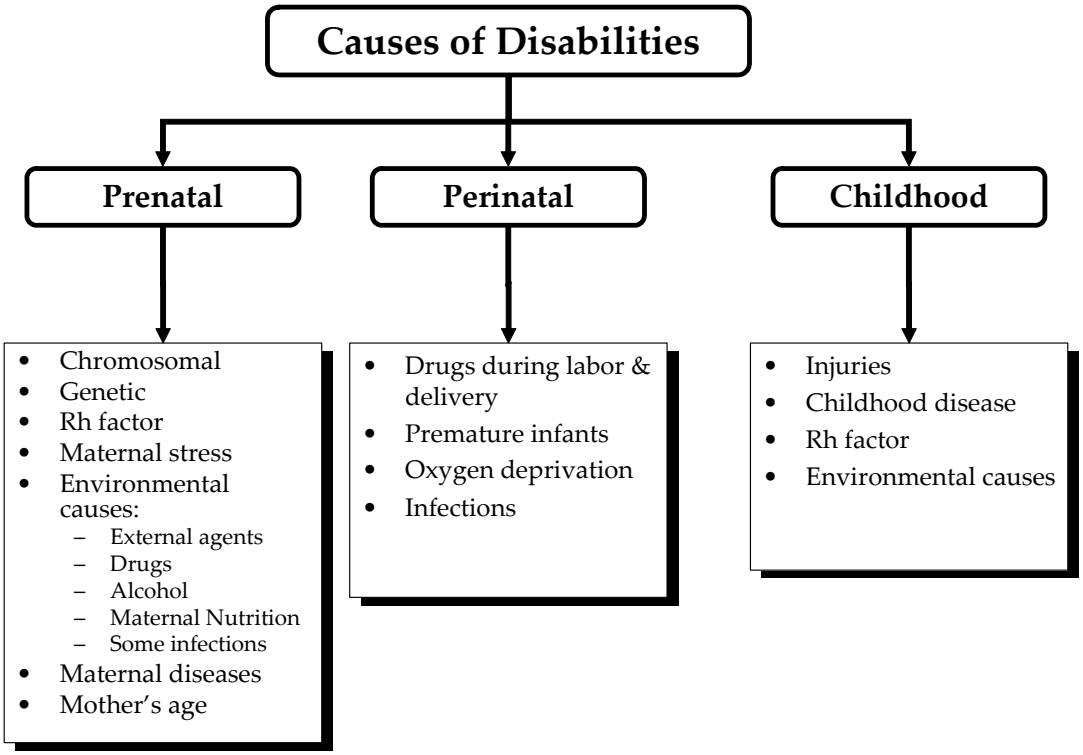


Figure (2-1): Causes of disability

There are thousands of known causes of disabilities, but in a great number of cases the exact cause of the impairment is never known. Several factors may combine to create a disability, but for the purpose of this discussion two major categories to classify the known causes of disabilities: biomedical or constitutional, and socio-cultural/environmental.

Biomedical or constitutional causes have a basis in the body of the individual; there is a biological aspect to the condition. Most severe and multiple handicaps include conditions which fall into this category. Congenital disabilities, those present at birth, are constitutional conditions.

Socio-cultural and environmental causes of disabilities are those which originate outside the individual's body. This includes not only those causes which stem from the social, cultural,

and physical environments, but also those causes which result from the individual's life-style and behavior. These factors are hard to isolate for two reasons. First, they are very complex, and second, they do not inevitably result in impairment. For example, risks among people of low socio-economic class can run through generations because the cycle of poverty creates conditions which contribute to the incidence of disabilities. In spite of these conditions, the majority of poor children do not develop disabilities. Since there is no direct cause and effect correlation between the associated socio-cultural and environmental conditions and disabilities, the conditions are generally called "risk factors". Those exposed to them are considered "at risk" for developing a disability.

Disability may be developmental or acquired and may arise from prenatal damage, perinatal factors, acquired neonatal factors and early childhood factors. These may include genetic factors, infections, traumatic or toxic exposure or nutritional factors, which result in perinatal or postnatal damage.

1. Prenatal causes of disabilities

The prenatal period extends from conception to the time of birth. Disabling conditions can occur at any point in the developmental process between those two events. Prenatal development can be divided into several periods. First, there is conception. Then, the time from conception to birth is usually divided into three phases. The first phase, the germinal stage, lasts from conception until implantation, when the developing organism becomes firmly attached to the wall of the uterus. This period is about 10 to 14 days long. The second phase, which extends from the second to the eighth week, is the embryonic stage. It is characterized by cell differentiation as the major organs begin to develop. The last phase, from 8 weeks until delivery, is the fetal stage. It is characterized mainly by growth. During this time the various body systems, which were led down in rudimentary form earlier, become quite well developed and begin to function.

Some prenatal biomedical causes of disability involve the basic building blocks of life: the genes and chromosomes which the person inherits. Other handicaps result from the prenatal environment within the womb. These causes can be considered separately, but it should be realized that heredity and prenatal environment work together to produce the infant.

Chromosomal causes of disability

Chromosomal abnormalities can involve the loss, gain, or exchange of genetic material from a chromosome pair. Such abnormalities often cause miscarriages, but may occasionally result in a baby with some kind of disability.

Down Syndrome, a congenital condition which usually includes health problems and mental retardation, is caused by an abnormality of the chromosomes. The twenty-first chromosome set is a triplet instead of a pair, hence the other name of this syndrome, Trisomy 21. Down Syndrome is associated with the mother's age. The incidence rate is high when mothers are extremely young, low for mothers in early adulthood, and increases with the mother's age after 35.

Genetic causes of disability

Chromosomes are made up of genes which, alone or in combination, govern all our inherited characteristics. Some disabilities are caused by specific genes that create damaging biomedical conditions. There are over 3,000 different genetic causes of disability.
There are definite patterns of inheritance which govern whether or not various traits affect us. An example of a genetic defect is Sickle Cell Disease, a blood disorder caused by recessive genes. Children only have the disorder if they receive the gene from both parents. If the gene is paired with a normal one, the individual does not have the condition, but can pass it on to his or her descendants. These individuals are called "carriers".

Rh factor

When an Rh-positive man and an Rh-negative woman have children together, there can sometimes be adverse consequences for their offspring. If their baby has Rh-positive blood, the mother's blood may begin to form antibodies against the "foreign" positive Rh factor. During the next pregnancy the antibodies in the mother's blood may attach the Rh-positive blood of the unborn infant. The resulting destruction may be limited, causing only mild anemia, or excessive, causing cerebral palsy, deafness, mental retardation, or even death. Fortunately, a way of preventing these consequences has been developed. The blood of the newborn infant is tested immediately after birth, using a blood sample from the umbilical cord. If an Rh-positive child has been born to an Rh-negative mother, the mother is given a vaccine that will seek out and destroy the baby's Rh-positive blood cells before the mother's body begins producing many antibodies. The red cells of later children will not be attached because the blood of the mother was never allowed to develop the antibodies.

Maternal stress

Even though there are no direct connections between the maternal and fetal nervous systems, the mother's emotional state can influence the fetus's reactions and development. This is true because emotions like rage, fear, and anxiety bring the mother's autonomic nervous system into action, liberating certain chemicals (e.g., acetylcholine and epinephrine) into the bloodstream. In addition, under certain conditions the endocrine glands, particularly the adrenals, secrete different kinds and amounts of hormones. As the composition of the blood changes, new substances are transmitted through the placenta, producing changes in the fetus's circulatory system. These changes may be irritating to the fetus. Bodily movements of the fetuses increase by several hundreds while their mothers are undergoing emotional stress. If the mother's emotional upset last several weeks, fetal activity continue at an exaggerated level throughout the entire period. When the upset is brief, heightened irritability usually last several hours. Prolonged emotional stress during pregnancy may have lasting consequences for the child. Infants born to upset, unhappy mothers are more likely to be premature or have low birth weights; to be hyperactive and irritable; and to manifest difficulties such as irregular eating, excessive bowel movements, gas pains, sleep disturbances, excessive crying, and excessive need to be held.

Prenatal environmental causes of disability

The prenatal environment is almost always a safe and nourishing one for a developing baby, but there are some environmental influences, which can damage a fetus. These influences include external agents, infections, toxins, and maternal health.

• External agents

External agents which can cause prenatal damage include injury and radiation. Seatbelts done up across the mother's abdomen can injure the baby in an accident. Any violent blow to the mother's abdomen can also hurt her child. Radiation such as X-rays can affect the fetus. This can result from treatment of pelvic cancer, from diagnostic testing, or from exposure to atomic energy sources, occupational hazards, or fallout. Although the hazards of radiation are not fully understood, it is clear that radiation can have a wide range of effects on unborn children, including death, malformation, brain damage, increased susceptibility to certain forms of cancer, shortened life span, and various mutations. Radiation that occurs between the time of fertilization and the time when the ovum becomes implanted in the uterus is thought to destroy the fertilized ovum in almost every case. The greatest danger of malformations comes between the second and sixth weeks after conception. Although the effects of X rays may be less dramatic later in pregnancy, there is still some risk of damage, particularly to the brain and other body systems.

• Many prescription and non-prescription drugs

These drugs can cross the placenta and adversely affect the developing child. Physicians and parents have become increasingly concerned about the potentially harmful effects of drugs on the developing embryo and fetus. One of the most dramatic reasons for this concern was the discovery around 1960 of the gross anatomical defects caused by a drug, thalidomide, that many women had taken during pregnancy. Thalidomide was introduced as a medication to control nausea in pregnant women, but it turned out to cause severe malformations in the legs and/or arms of the developing child. Many other drugs are suspected of producing birth defects when taken during pregnancy; substances that produce such effects are called teratogens. There is a long list of substances known or suspected to be teratogens, including legal drugs (alcohol, nicotine, caffeine), prescription drugs (some antibiotics, hormones, steroids, anticoagulants, anticonvulsants, tranquilizers, methadone), illegal drugs (cocaine, heroin, marijuana), and environmental pollutants (including lead, methylmercury, and polychlorinated biphenyls, or PCBs).

• Alcohol

Alcohol crosses the placenta easily and stays in the baby's system longer than it does in the mother's (FAS Symposium, 1993). Alcohol can create a spectrum of effects on the baby. These may include any or all of the following: various degrees of mental retardation, physical abnormalities, hyperactivity, autistic tendencies, and failure to thrive. There are many identified variables that influence the degree to which a mother's alcohol consumption affects the fetus. Some of these variables are: the amount of alcohol consumed, the stage of development of the fetus, whether the mother had been "binge drinking" or drinking on a regular basis, and the mother's general health, nutrition level, and metabolism.

• Maternal nutrition

Maternal nutrition affects the developing child. Deficiencies in iron, vitamins, and calorie intake can place the baby at risk. Some aspects of diet are especially important in the first few weeks of pregnancy, before many women know they are pregnant at all. For instance, not having adequate levels of folic acid is a risk factor for having a baby with spina bifida. Adequate levels are vital in the first weeks after conception and are difficult to get from diet alone. Babies born to mothers with nutritionally deficient diets are more likely to have low birth weights, to suffer from impaired brain development, to be less resistant to illnesses such as pneumonia, and bronchitis, and to have a higher risk of mortality in the first year of life. Severe maternal malnutrition may impair the child's intellectual development in addition to having adverse effects on physical development.

• Infections

Some infections that the mother suffers can damage the infant when the disease organisms cross the placental barrier. Viral diseases such as cytomegalovirus (which affects 5 to 6 percent of pregnant women), rubella (German measles), chicken pox, and hepatitis are particularly dangerous during the embryonic and early fetal periods. One of the most serious viral diseases during the first three months of pregnancy is rubella, which may produce heart malformations, deafness, blindness, or mental retardation. About 50 percent of babies whose mothers had German measles in the first month of pregnancy suffer birth defects; this figure falls to 22 percent in the second month, 6 percent in the third month, and only a small number thereafter. A pregnant woman can be tested to see whether she has already had rubella, but if she has not, she cannot be given vaccine for rubella because it contains the live virus. Thus, it is best for a woman who is considering pregnancy to ascertain whether she has had rubella before she becomes pregnant, and to receive vaccine at that time if she has not had it.

The rapid spread of the genital herpes virus among young adults poses another danger. Infection of the fetus with this virus usually occurs late in pregnancy, probably during delivery, and can result in severe neurological damage. When infection occurs several weeks prior to birth, a variety of congenital abnormalities can result. Prompt medical intervention is necessary if the presence of herpes during pregnancy is suspected.

Acquired Immune Deficiency Syndrome (AIDS) currently threatens the lives of a growing number of unborn and newborn babies. The percentage of women, who have developed AIDS or ARC (AIDS-related complex), principally through intravenous drug use or from a bisexual or drug-using partner, is rising rapidly. Mothers with AIDS can pass the virus to their babies, either across the placental barrier during pregnancy, during birth, or by breast feeding. Not all HIV-infected women infect their children, however. Estimates of transmission vary from 10 to 40 percent. Ongoing work is being done to determine if there are risk factors that influence the likelihood of transmission. It was found that mothers who transmitted HIV to their children had lower levels of vitamin A (low enough to constitute a deficiency) than mothers who did not. If this findings holds up, or other risk factors are identified, over which mothers have some control, it might be possible to reduce the number of babies born infected.

Infection of the fetus with syphilis is not infrequent. Fortunately, however, the placental barrier does not permit passage of the spirochetes that cause syphilis until after the fourth or fifth month of pregnancy. Consequently, transmission of the spirochetes (which otherwise

would take place in about 24 % of cases) may be prevented if treatment of a mother with syphilis begins early in pregnancy. When infection does occur, the spirochetes may produce miscarriage or a weak, deformed, or mentally deficient newborn. In some cases the child may not manifest symptoms of syphilis for several years.

• **Maternal diseases and disorders during pregnancy**

Some general disturbances of the mother during pregnancy may also affect the fetus. One of the most common of these is toxemia. Children whose mothers had severe toxemia during pregnancy run a risk of lowered intelligence. Illness of the mother, especially long-term illness, can also affect the child. Good prenatal medical care reduces these risks and increases the likelihood of having a healthy infant.

• **The age of the mother**

It is another factor associated with an increased risk of impairment. Teen-age mothers, especially those under 15 years of age, have a greater risk of having babies with low birth weight as well as neurological defects and childhood illnesses. Babies who are full term, but unusually small, are more likely to have a disability than are larger, more robust infants. Women with over 30 have a lower fertility rate than those in their twenties, and fertility continues to decline with age. They are also more likely than younger women to experience illnesses during pregnancy and to have longer and more difficult labor. Mothers over 40 run a sharply increased risk of having a child with a chromosomal abnormality, particularly Down syndrome. The average incidence of this disorder increases from less than 1 per 1000 through age 29 to 1.5 at ages 30 to 34, 6 at ages 35 to 39, 20 at ages 40 to 44, and 30 at ages over 45. Women over 35 are also more likely to have miscarriages and to give birth to underweight or stillborn babies. The older the woman, the greater the likelihood that these problems will arise; nevertheless, the absolute incidence of serious complications remains relatively small, especially for women who engage in good health practices and receive appropriate medical care. In cases in which there is reason to suspect the presence of a chromosomal or other abnormalities, procedures such as chronic villus sampling, ultrasound scans, and amniocentesis may be recommended.

• **Parental effects**

The risk of genetic disorders appears to increase with parental as well as maternal age. For instance, it has been found that older fathers have an increased risk of having children who suffer from genetic disorders caused by dominant genes, but where there is no history of the disease in the family. Such deviant genes may arise in the process of cell division leading to spermatogenesis. The overall genetic mutation rate in sperm cells may be six times higher than it is in eggs. As man's age increases, the number of times his sperm cells have gone through cell division also rises.

Fathers can cause problems in infants in non-genetic ways as well. They may transmit viruses to mothers along with semen, including sexually transmitted diseases such herpes, gonorrhea, syphilis, chlamydia, and AIDS. Furthermore, fathers' exposures to alcohol, nicotine, radiation, and pollutants such as lead have all been associated with risks to offspring.

2. Perinatal causes of disability

The perinatal period is the time immediately before and after birth. Disabilities originating from this time period are primarily biomedical ones. They may result from drugs taken during labor and delivery, prematurity, injury, oxygen deprivation, or infections acquired during the trip through the birth canal.

Drugs taken during labor and delivery

Because birth can be a painful process for women, various approaches have been devised to help deal with the pain. Perhaps the safest methods for both mothers and babies are methods for controlling pain through breathing, meditation, showers, appropriate movement, and support from a partner. Giving birth in this way is sometimes termed natural childbirth. However, other women feel they benefit from the use of medical intervention for pain control during delivery. Drugs such as pentobarbital or meperidine (Demerol) are one method of pain control. If taken just prior to delivery of a baby, however, they may make the infant less attentive, at least temporarily. Another medical method of pain control is anesthesia through epidural injection of painkillers into the mother's spinal cord. If administrated too close to delivery, however, such anesthesia can make it difficult for birthing mothers to push effectively in the second stage of labor.

One study of the effects of anesthetic drugs on sensorimotor functions in newborns found lags in muscular, visual, and neural functioning. While most such effects were greatest in the first few days of life, longer-term effects on cognitive functioning and gross motor abilities, particularly with heavy drug dosages, have been found at 1 year of age.

Premature infants

They are babies who were born too soon. Infants born earlier than the 38th week of gestation and weighing less than 2 Kg. Are referred to as premature. Prematurity is more frequent among economically disadvantaged mothers than among the affluent. In addition, smoking, alcohol,, and various drugs increase the likelihood that a baby will be born prematurely. Genetic factors play a role in determining birth weight.
The long-term effects of prematurity on development depend on how early the infant is born (gestational age), its birth weight, the type of postnatal care it receives, and the quality of its environment during early and middle childhood. Infants with gestation periods of less than 28 weeks (extreme prematurity) or weights of less than 1.5 Kg. Have a reduced chance of survival. In contrast, those who are only slightly premature (34 to 38 weeks) and whose weight is appropriate for their gestational age resemble full-term babies in many ways. They are generally healthy, though they are less mature, more vulnerable to illness, and slower to gain weight, and they must be monitored carefully. Recently, considerable progress has been made in caring for extremely premature infants and for "intermediate-term" infants, those that fall in the middle range of prematurity. These babies' gestational ages between 30 and 33 weeks, and their birth weights are at least average for their age, around 1500 grams or more at 30 weeks and 2000 grams or more at 33 weeks. Premature babies that have received intensive, highly specialized care have not only survived but gone on to develop normally.

A special problem for premature babies is respiratory distress syndrome, or breathing problems. This syndrome is typically caused by a lack of a substance called surfactant, a foamy lining the inside of the lungs that helps the lungs to expand and draw in air. Some progress is currently being reported in manufacturing substitute surfactant. Another difficult problem for premature babies is the occurrence of intracranial hemorrhage, which can cause permanent damage.

Premature infants need more than just medical care. Psychologists have worked on various kinds of programs to provide sensory and tactile stimulation and encourage parents to participate in the child's care while the child is hospitalized. Some investigators have thought that children would benefit from rocking (as on water beds) and gentile tactile stimulation (as from lying on sheep skins), interventions aimed at stimulating the conditions in the uterus. Others have provided visual, tactile, and auditory stimuli (such as mobiles, message, and music) that are thought to facilitate short-term benefits for premature children, including greater weight gain, less irritability and more quiet sleep, and better sensory responsiveness. The differences that can be attributed to the interventions typically decrease with age, as time since the interventions increases.

Like children who experience anoxia or complications during birth, premature children are particularly vulnerable to the effects of their environment. Premature children who are born into loving, nurturing homes where they receive competent physical and psychological care are usually show little long-range impairment unless they were very premature and did not receive appropriate neonatal or postnatal care. In homes with poor parental care and living conditions, premature babies are far more likely than full-term children to have both physical and psychological difficulties. Because prematurity and perinatal complications are more frequent among economically disadvantaged families than among middle-class families, poor children are more likely than richer ones to have to deal both with impairment at birth and a less favorable environment.

Oxygen deprivation

It may occur during a prolonged or difficult birth, and, because the brain suffers damage very quickly without a fresh and adequate supply of oxygen, brain damage can result. One major danger associated with birth is hemorrhaging, which is caused when very strong pressure on the head of the fetus breaks blood vessels in the brain. Another danger is failure of the infant to begin breathing soon after being separated from the maternal source of oxygen. Both hemorrhaging and failure to breathe affect the supply of oxygen to the nerve cells of the brain and produce a state called anoxia. The neurons of the central nervous system require oxygen; if they are deprived of it, some cells may die, and this can cause physical and psychological defects. If too many neurons die, the infant may suffer serious brain damage or, in extreme cases, may die.

Anoxia in a newborn is more likely to damage the cells of the brain stem than those of the cortex, and to result in motor defects. The child may experience paralysis of the legs or arms, a tremor of the face or fingers, or inability to use the vocal muscles. In this last case, the child may have difficulty learning to speak. The term cerebral palsy describes a variety of motor defects associated with damage to the brain cells, possibly as a result of lack of oxygen

during birth process. It is estimated that about 30% of cerebral palsy cases involve problems that occurred during birth or immediately afterward.

Anoxic infants are more irritable and show more muscular tension and rigidity than normal infants do during the first week. Infants with mild anoxia score lower on tests of motor development and attention during the first year and are more distractible. At age 3, they perform less well on tests of conceptualization. By age 7 or 8, behavioral differences between normal and mildly anoxic children are generally small, and their IQ scores are equal. In brief, the differences between mildly anoxic and normal children become smaller with age, and there is at present no firm evidence of serious and permanent intellectual damage.

Infections

Several sexually transmitted diseases can be contracted by a baby during the trip through the vagina. These infections include syphilis, AIDS, gonorrhea and herpes. Gonorrhea only affects the eyes of the infant, but herpes can result in severe disabilities due to nervous system damage. AIDS can also infect a baby through breast feeding.

3. Childhood causes of disability

Disabilities originating during childhood may be caused by biomedical and environmental factors.

Injury as a cause of disability

The types of injuries children are most likely to experience change with the age of the child. Tiny babies are rather floppy and slippery, and they have a tendency to put things in their mouths. These characteristics place them at risk for two types of accidents. First, they can fall when they slip out of restraints intended to care for and protect them, such as people's hands, cribs, high chairs, and playpens. The resultant injuries can produce motor or intellectual impairments as well as temporary damage such as bruises and broken limbs. Second, they can choke on small objects such as tiny toys, or pieces of toys. This type of accident can result in suffocation, anoxia, and brain damage.

Curiosity, lack of experience, and improved mobility combine to increase the toddler's chance of injury. Toddlers often fall when trying to get something they want, or see something that interests them. They may be injured when they investigate tools, pots on the stove, or electrical outlets. Cleaning products seem to hold a fascination for toddlers; according to the Saskatchewan Institute on the Prevention of Handicaps, thousands of poisonings involving household chemicals and children under four years old are reported each year (1991). Many of these accidents result in disabilities.

Spinal cord and brain injuries are of special concern due to the serious consequences of damage to the central nervous system. Such injuries often occur as a result of inadequate protection when children are riding in motor vehicles, or as passengers on bicycles.

Childhood disease as a cause of disability

Childhood diseases can retard a victim's future development. One of the most severe cases of disability is the result of meningitis suffered by the child in early infancy. It will develop sensory and motor limitations, and may have intellectual ones as well. It is impossible to assess the child's intelligence at present, because there is no appropriate method of evaluation for a youngster so severely handicapped.

Disabling conditions can sometimes result from common infectious diseases. Encephalitis, an inflammation of the brain which can cause mental retardation, is a possible complication of such childhood illnesses as mumps, chicken pox, and measles. Measles sometimes cause visual impairment. Ear infections which often accompany children's colds, can result in conductive hearing loss. Because of the tragic results of possible complications, even mild childhood diseases should be carefully monitored.

Environmental causes of disability during childhood

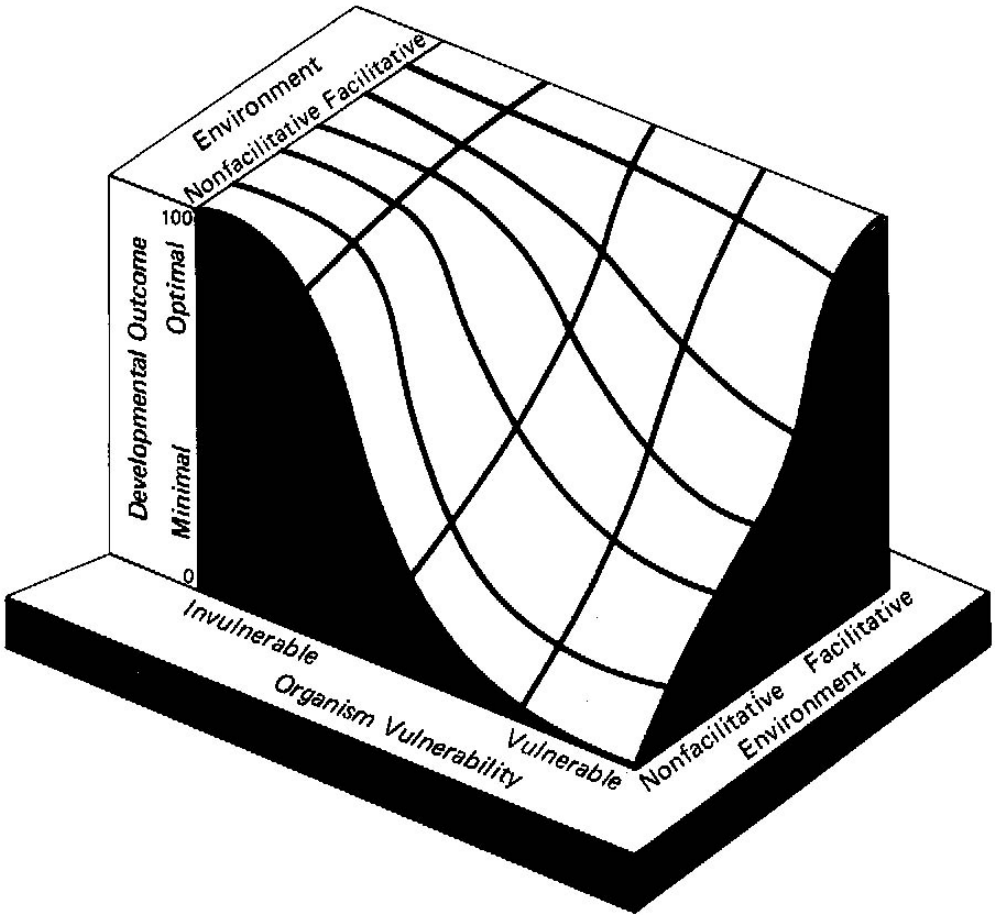


Figure (2-2): Horowitz's model of the interaction between the vulnerability of the child and the quality of the environment. The height of the surface is the "goodness" of the developmental outcome (like later IQ scores or language skills or social skills). The higher the surface, the better the outcome. As you can see, Horowitz proposes that a vulnerable infant in a non-facilitative environment will have by far the worst outcome – worse than the simple summing of the effects would predict. (Source: Adapted from Horowitz, 1982, Figure 2.1, p. 28.)

The child's constitution (genetic and biological attributes) and the environment are the two major influences on intellectual development. Most psychologists agree that both are important. Each contributes to a child's intellectual skills and academic accomplishments. A model for understanding one type of interaction between organism and environment is demonstrated by Horowitz (1987). In this model, organisms are placed on a continuum from constitutionally invulnerable to vulnerable and environment are classified on a continuum from facilitative to non-facilitative. Children with relatively invulnerable constitutions are expected to develop normally even in environments that are not highly stimulating or facilitating. Children in facilitative environments are expected to develop normally even when they have vulnerable constitutional attributes. The model is not intended to suggest that any child is completely invulnerable; a sufficiently bad environment can affect even a constitutionally strong child. Instead, it is intended to show that the greatest risk occurs for children who are biologically vulnerable and experience non-facilitative environments.

Though many children are resilient enough to grow up normally in spite of socio-environmental conditions such as neglect, poverty, famine, and even war, some do not. For some children environmental deprivation has a debilitating effect on the development of abilities such as language use, adaptive behavior, and cognition. Deprivation can include poor nutrition, poor housing, lack of social interaction and limited opportunity for varied experiences. These conditions are frequently associated with poverty, but can occur in any environment. They may sometimes be a symptom of child neglect or abuse.

Poor nutrition and starvation have been proven to have an effect on many areas of development. Hunger produces nervousness, irritability and a decreased ability to learn, thus it can have a negative effect on all aspects of a child's development. Negative effects increase with the degree of malnutrition. A severe vitamin A deficiency can cause blindness in children after they are weaned. A protein-calorie deficit during the first six months of life affects mental development and may damage the developing nervous system. Malnourishment is also associated with an increased susceptibility to infections.

Poor housing can be associated with a variety of disabling conditions. Chances of accidental injury increase when buildings are in poor condition. Cheap housing often consists of older buildings which may still have lead paint on walls and woodwork. Children often ingest this paint and get lead poisoning which affects the nervous system. Old buildings are often cold and drafty, and have substandard (or non-existent) plumbing and heating which increases the risk of disease and infection.

Limited social interaction and reduced opportunity for a variety of experiences are social-environmental factors which affect linguistic, emotional, and cognitive development. This type of environmental deprivation can occur in any home where language use is limited and life experiences lack variety.

Environmental deprivation can interfere with educational potential. Lack of exposure to reading and writing can adversely affect children's chances of academic success because this form of communication is unfamiliar. Reading and writing are less important when basic survival is in question; this can interfere with a child's motivation to learn academic skills.

Cultural differences can be risk factors for two reasons: discrimination and lack of understanding. Discrimination based on cultural differences may affect a family

economically and socially. Economic discrimination affects job opportunities, parental employment, and family income. It can result in hardship and poverty, which produce the risks described above. Social discrimination may add to the isolation of the family as a group and family members as individuals. Isolation can limit social interaction and experiences and have a harmful effect on the development of children in the culturally different family. Lack of understanding of cultural differences can result in a "mismatch" between what children experience at home and what is expected of them at school. This mismatch can lead to inappropriate schooling, which may result in intellectual impairments and functional limitations.

Deprivation during the developmental period is a contributing cause for many disabilities. Malnutrition, and increased risk of injury and infection, contribute to the number and severity of existing impairments. Limited opportunities for social interaction, lack of richly varied experiences, and low exposure to all forms of language, increase the risk for impairment of intellectual and linguistic development. Schools which do not consider the cultural and linguistic differences of students can deprive children of an adequate education.

Environmental risk factors, whether they are economic, social, cultural, or physical, intensify the effects of biological impairments and increase the likelihood of disability. Since deprivation is often associated with poverty, low socio-economic status itself becomes a risk factor.

Conclusion

There are many causes of disability, both biomedical and socio-environmental. Causal factors may operate independently, or combine to produce a disability. It is important to know the causes of a disability in order to prevent further occurrences. However, despite all that is known about the causes of various disabilities, there are many conditions for which no cause has been identified.

Prevention of disability

Every human society requires that its future generation be healthy. This depends on the birth and rearing of healthy children. To this end, preventive screening for genetic disorders, including developmental disabilities, is an essential component in uncovering possible disorders early, thus enabling timely medical intervention.

Such efforts are also required in order to reduce the expression and severity of disability. The ability of a physically or mentally disabled child to cope with and adapt to everyday life may be minimal compared to that of a normal child, and the disabled child may continuously suffer from trying to perform the functions so normal to others. This can have a major influence on the personality of the child which in turn can affect normal growth and development. Of particular distress is the fact that some disabled children never reach adulthood and some are at risk of developing other associated complications which may further disrupt their social and emotional development. These children and their families are under continuous mental and physical stress and require comprehensive services in order to help the children have a near normal life.

In addition, many disabled people require a continuous health care system, home help and other supportive services, which makes care programmes very costly. The management of childhood disabilities requires substantial medical, educational, social and rehabilitative care. The cost of preventive efforts is substantially lower and thus cost-effectiveness favors the prevention approach.

Stages of prevention

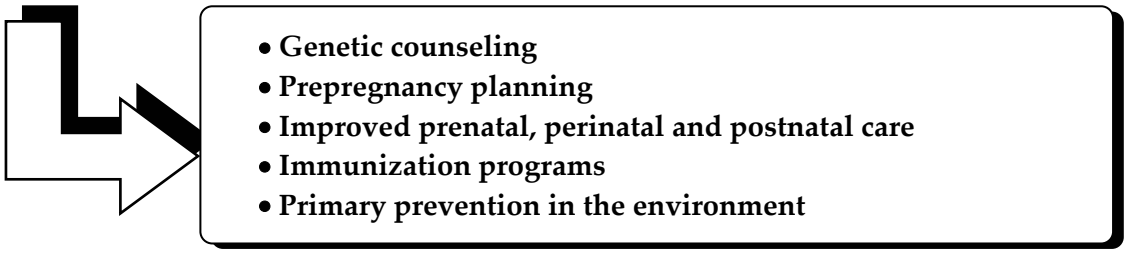
Endeavors for controlling disability can be categorized as primary, secondary and tertiary prevention.

1. Primary prevention

This involves the prevention of the manifestation of the disability. It may be universal (i.e. prevention desirable for everyone), or be restricted to a selected population (i.e. prevention recommended for high-risk groups) or to an indicated population (i.e. prevention in individuals with an identified risk).

Primary efforts are directed toward reducing the actual occurrence of disabilities and they employ measures that prevent the conception of a disabled individual or delay the disabling process.

Primary prevention efforts include:



Genetic counseling

Genetic counseling is an essential part of primary prevention strategies. It is the process of providing information on genetic (recurrence) risk, the nature and consequence of genetic disorders and the means available for the prevention of transmission of defective genes. Within this framework, there are three major aspects essential to effective counseling which are:

- Diagnostic aspects, where an accurate diagnosis is required for a secure foundation for advice
- Estimation of risk
- Preventive or ameliorative measures to ensure that those who are advised will benefit

One of the prime requirements of an effective genetic counseling program is to ascertain which individuals are at risk of having an affected child so that they can be offered advice. People who should consider genetic counseling include: those who are concerned that they might have, or "carry", an inherited disorder; couples who have a child with a disability that

may have been inherited; women who have had two or more miscarriages; and people who are concerned that their jobs or life-styles may pose a risk to pregnancy. Genetic screening and counseling prior to conception is important for the control of genetically determined disabilities. Many studies have shown that genetic counseling produces better understanding of the issues involved and hence has an impact on the subsequent reproductive decision. Several studies have shown that the number of children born with a serious genetic disorder leading to disability decreases significantly following genetic counseling.

Some inheritable genetic conditions can be identified through medical procedures such as blood analysis. Some "high risk" groups have been subjected to mass screening to try to reduce the incidence of genetic conditions common within those segments of the population.

"Pedigree analysis" is a form of genetic counseling which is done if there is a known abnormality in the family of either potential parent. This procedure takes the family histories, or pedigrees, of both partners, and analyzes them using the patterns of inheritance to determine the risk of this particular couple having a child with an inherited birth defect. Prenatal examinations check for another genetic cause of impairment, Rh blood factor incompatibility.

The best example of the successful application of this prevention strategy to prevent the birth of homozygotes for a certain disorder is the thalassaemia control program in Cyprus. Through health education, together with population screening and genetic counseling of carriers and prevention of carrier marriages, it was possible to reduce the homozygous affected births from 53 per 8594 births in 1974 to 0 per 10 752 in 1988 and 2 per 10 830 in 1990. The percentage of prevention achieved was 1.8% in 1974, 100% in 1988 and 97% in 1990. A similar approach when applied to other disorders could be equally successful.

Prepregnancy planning

Ideally, all babies are planned for and wanted by both parents; prepregnancy planning helps people achieve this goal.

People have many reasons for not wanting to have children at a particular time in their lives; impermanent relationships, educational or professional priorities, financial problems, or age and health concerns are only a few of the possibilities. Part of prepregnancy planning is to postpone pregnancy until both partners feel that they are ready to be parents. This requires the use of some form of birth control.

Once a couple decides to have a baby, they can increase their chances of having a healthy, normal child. Prepregnancy planning gives the parents-to-be time to establish good nutritional and exercise habits and to "kick" bad habits such as smoking or alcohol abuse. They should see a doctor at least three months before conception. At that time the doctor checks for medical conditions such as the: health problems in the mother, e.g., thyroid disease or diabetes; infections such as venereal disease; RH factor incompatibility; and the mother's immunization for rubella. All of these preconception efforts are primary prevention intended to reduce as much as possible the chances of having a child with an impairment.
Improved prenatal, perinatal and postnatal health care

This aspect of prevention concentrates on the management of maternal risk, factors at the time of delivery and support for the premature or compromised neonate.

Prenatal care helps insure that both mother and baby are as healthy as possible, and that any problems are addressed immediately. Prenatal clinics provide a combination of primary and secondary prevention. They not only try to prevent conditions that might put a fetus at risk, but also strive to reverse, reduce, or minimize risks that already exist.

Obstetricians attempt to ensure that all births are safe and that the infants are healthy. Medical procedures at the time of birth can prevent disabilities. Visual impairment is prevented by the use of medication to protect the eyes of the neonate from infections which may be picked up on the way through the birth canal. Careful monitoring of newborn babies and rapid treatment of anoxia can prevent mental disabilities.

After a baby is born, the public health nurses visit mother and child at home as soon as possible to give support and help. Later, at the Baby Clinics, nurses monitor babies' growth and screen them for sensory, physical, or developmental problems. Immunizations are started at the age of two months.

Immunization programs

Programs of general immunization during infancy have led to a remarkable decrease in, or in a few cases a complete absence of, several infectious diseases that used to be a major cause of disability. These include poliomyelitis, tuberculosis, meningitis and encephalitis.

Two good examples are rubella (German measles) and poliomyelitis. In the past, rubella epidemics occurred every three to ten years, leaving a legacy of babies with impairments such as blindness, hearing impairment, and mental retardation. Polio is leaving many people with physical impairments. The occurrence of such epidemics has been drastically reduced because immunization program reaches almost all of the population.

Primary prevention in the environment

The goal of primary prevention in the environment is to remove those causes of disability that reside in the social, cultural, and physical aspects of our lives. These risks include injuries associated with our daily activities, life-style and behavior patterns such as alcohol and drug abuse, lack of parenting skills, and the many characteristics of poverty which place people at risk. All of these socio-cultural/environmental areas should be addressed through primary prevention methods such as education, social and economic programs, and legislation.

2. Secondary prevention

Secondary prevention strategies aim at reducing the duration or severity of disability. These activities provide early identification of the disabling condition followed by prompt treatment and intervention to minimize the development of disability. These strategies can

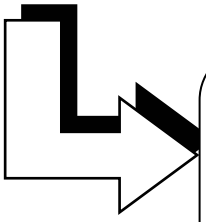
be applied either at the prenatal or neonatal level. Some of the conditions can be diagnosed during the prenatal and neonatal stages.

A history of certain risk factors indicates the need for careful evaluation. Prenatal insults such as maternal illness, infections, and teratogens (e.g., cigarettes, some anticonvulsants, and alcohol) increase the risk of DD in the child. Very low birth weight infants (under 1500 gm) have a 10% risk based on weight alone. This risk increases to 30-50% if there were associated problems such as hypoxia, infection, seizures, cerebral bleeding or being small for gestational age. Children in 1501-2500 gm birth weight group with a history of bronchopulmonary dysplasia, posthypoxic seizures, or meningitis have a 10% risk of a DD occurring. Larger babies who are appropriate weight for gestational age are at increased risk if there is a history of congenital malformation, birth trauma, perinatal hypoxia and seizures, meningitis, or adverse psychosocial factors. Low Apgar scores, especially at 10 or more minutes, may also suggest an increased risk for cerebral palsy.

Neonatal screening (organized examination of all neonates in order to diagnose specific disorders so that they can be treated) is a well established preventive approach and includes both clinical and biochemical screening. General developmental screening should include assessment of motor (gross and fine), social-personal, language, adaptive, and for older children, school-related abilities. Studies and experience have demonstrated that standardized, validated, and reliable screening systems are more successful in identifying developmental problems (especially mild ones) than the less accurate method of obtaining a developmental history from the parents and noting only major milestones on examination. In some countries, such information is available but in others, there is no information on detection frequency at birth of genetic disorders.

Follow-up of high-risk infants may use similar guidelines for developmental screening, with emphasis on testing at 6 and 12 months and 2 and 3 years of age. The preschool exam at 4-6 years should include vision and hearing screening. A few evaluation tools have been developed to measure school readiness, cognitive areas, speech and language skills, and emotional and behavioral problems that may interfere with school performance especially in children with very low birth weights.

Early intervention methods vary widely depending on the nature of the disability and its etiology but include the following:



- Genetic counseling to prevent further cases
- Specific treatment of underlying conditions, as in congenital hypothyroidism
- Treatment of specific contributory disabilities, e.g., hearing, vision
- Optimizing the functioning of the disabled individual and his or her family by:
  - Identifying and addressing the child's strengths and weaknesses, which will allow achievement of his or her full potential during the most crucial early years.
  - Preventing a single handicap from leading to secondary defects on other areas of development.
  - Preventing deterioration in development due to inappropriate physical and emotional handling by parents, peers, and society.
  - Improving interaction with siblings, between child and parents, and between parents, by lessening parental emotional reactions and promoting greater understanding the child's needs. This supportive relationship contributes to more successful developmental patterns later.
  - Helping families focus on the broad needs of the child.
  - Improving interaction and coordination among health and developmental providers.
  - Teaching parents how to utilize community resources more effectively and efficiently.
  - Providing direct supportive service to families in lower socioeconomic levels whose children are at increased risk for continuing developmental problems.

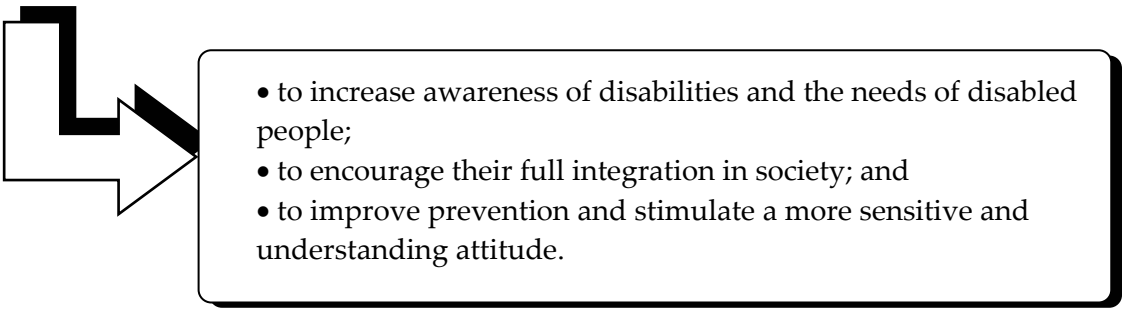
At the neonatal level, screening of neonates and proper intervention in those affected have been successful in reducing disability. The best known example of secondary intervention is that of neonatal screening for phenylketonuria (PKU), other aminoacidurias, hypothyroidism, the thalassaemias and other haemoglobinopathies. In PKU and other aminoacidurias, once the baby is diagnosed as having an abnormality, proper measures are taken by providing special diets.

Biochemical screening was first introduced for PKU in 1966 when it was shown that a low phenylalanine diet started in the first week of life prevents severe mental retardation. To screen for PKU, blood samples are usually taken by heel prick between 5 and 10 days after birth, when the body's metabolism has stabilized sufficiently for the results to be reliable. Screening for PKU is now established in several countries and screening for other abnormalities is also carried out, particularly since the advent of recombinant DNA technology. Hypothyroidism diagnosed during the neonatal period is treated by hormone replacement therapy, which encourages normal development and prevents complications such as mental retardation. In sickle-cell disease and thalassaemia patients, early detection enables better development and growth.

New forms of secondary prevention, such as genetic or surgical manipulation of an affected fetus to eradicate the biochemical or anatomical abnormality are being tried, some with a high degree of success. This is true for congenital heart disease, cleft lip and cleft palate, congenital dislocation of the hip and others.

3. Tertiary prevention

Tertiary prevention aims at limiting or reducing the effects of a disorder or disability that is already present. It involves long-term care and management of a chronic condition, e.g. rehabilitation or correction of the disability by surgical measures or by adopting strategies by which the disabled person can lead a normal or near normal life. **The main aims of rehabilitation of the disabled are**:



These measures also include special education programs. Only 50 years ago, the majority of disabled people were left illiterate. However, during the past three or four decades, considerable efforts have been made to develop special education programs to educate blind-deaf-mute, deaf-mute, blind and mentally retarded patients. Special schools with specially trained teachers have provided excellent education programs which have helped disabled people achieve goals that, in many ways, are similar to those of normal individuals.

Early recognition of disability

To apply any of the previously mentioned preventive measures successfully, the first step is an accurate and early recognition of the disability. Some impairment features are physical and obvious during clinical examination. These include skeletal abnormalities, blindness, hearing and speech disorders, some mental disorders and the chromosomal anomalies such as trisomy 18 or 21, Klinefelter syndrome and Turner syndrome. However, several other disorders do not become evident until later in life, although diagnosis may be made prior to the appearance of the disability or its complications. This has been possible using biochemical tests and, more recently, by applying recombinant DNA technology to the identification of the molecular basis of genetic disability.

The family in general and the mother in particular play a significant role in the early detection of disability. Abnormalities in development, both physical and others, and in learning ability may become obvious to the diligent eyes of the mother much earlier than a clinical diagnosis can be made. Early detection and early intervention can avoid the precipitation of several of the disabilities and can reduce the impact the disability may have on the family.

Once a diagnosis of genetic disorder is made in the carrier parents, proper counseling and premarital testing can prevent the pregnancy of a child with an abnormality. If conception has taken place, then prenatal diagnosis can be used; if the fetus is found to be abnormal, appropriate measures can be adopted and the parents can prepare themselves to look after a disabled child. If the child is diagnosed as having a disease that may lead to a disability, then proper intervention programs can be started at an early stage and can help ameliorate the effect of the disabling condition.

Medical and/or surgical approaches to preventive intervention provide whatever is necessary to overcome or correct disabilities and strengthen the family unit in order to enhance the abilities of disabled children and their families to cope.

Social and community efforts at tertiary prevention

Efforts to increase the accessibility of services in a community can be classified as tertiary prevention. As businesses and organizations provide better access, people with physical impairments are able to carry on their lives more normally. This reduces the effect of their limitations on their quality of life.

Social limitations caused by discrimination decrease as people become more accustomed to seeing and interacting with people with disabilities. Movies and television programs which emphasize the similarities between disabled and non-disabled individuals help encourage a positive attitude. School inclusion exposes students to individual differences and encourages social interaction between all types of people. Hopefully, the next generation of adults will accept people with disabilities as "just people" and grant them the equality they now lack.

Conclusion

Some disabilities can be prevented, others cannot. By the application of known techniques, a large number of disabilities can be prevented, or their severity reduced. Primary prevention is extremely effective because it targets the whole population, and, if it is successful, the disability addressed never occurs. Secondary and tertiary prevention efforts are also extremely valuable as they focus on specific groups with definite needs, and deal with their immediate situations. Some methods of disability prevention are controversial, but others involve the development of good health habits, good parenting skills, and adequate social supports.

Chapter Summary

Causes, Risk Factors and Prevention of Disability

Two major categories to classify the known causes of disabilities: biomedical or constitutional, and socio-cultural/environmental.

Prenatal causes of disabilities

Chromosomal abnormalities often cause miscarriages, but may occasionally result in a baby with some kind of disability; Down Syndrome. Some disabilities are caused by specific genes that create damaging biomedical conditions. The resulting destruction from Rh factor as a cause of disability may be limited, causing only mild anemia, or excessive, causing cerebral palsy, deafness, mental retardation, or even death. Moreover, the mother's emotional state can influence the fetus's reactions and development. The prenatal environment is almost always a safe and nourishing one for a developing baby, but there are some environmental influences, which can damage a fetus. These influences include external agents, infections, toxins, and maternal health.

Perinatal causes of disability

Drugs such as pentobarbital or meperidine (Demerol) are one method of pain control. If taken just prior to delivery of a baby, however, they may make the infant less attentive, at least temporarily. Infants born earlier than the 38th week of gestation and weighing less than 2 Kg. Are referred to as premature. The long-term effects of prematurity on development depend on how early the infant is born (gestational age), its birth weight, the type of postnatal care it receives, and the quality of its environment during early and middle childhood. Oxygen deprivation may occur during a prolonged or difficult birth, and, because the brain suffers damage very quickly without a fresh and adequate supply of oxygen, brain damage can result. Several sexually transmitted diseases can be contracted by a baby during the trip through the vagina.

Childhood causes of disability

The types of injuries children are most likely to experience change with the age of the child. Childhood diseases can retard a victim's future development; like Meningitis, Encephalitis, Mumps, Chicken pox, and Measles. Children are placed on a continuum from constitutionally invulnerable to vulnerable and environment are classified on a continuum from facilitative to non-facilitative; socio-environmental conditions, poor nutrition and starvation, poor housing, limited social interaction, lack of exposure to reading and writing, and cultural differences.

Prevention

Activities for controlling disability can be categorized as primary, secondary and tertiary prevention. Primary efforts are directed toward reducing the actual occurrence of disabilities and they employ measures that prevent the conception of a disabled individual or delay the disabling process. It includes genetic counseling, prepregnancy planning, improved prenatal, perinatal and postnatal care, immunization programs, and primary prevention in the environment. Secondary prevention strategies aim at reducing the duration or severity of disability. These activities provide early identification of the disabling condition followed by prompt treatment and intervention to minimize the development of disability. Tertiary prevention aims at limiting or reducing the effects of a disorder or disability that is already present. It involves long-term care and management of a chronic condition, e.g. rehabilitation or correction of the disability.

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