

# Disabilities in Kenya

Disability is not Inability



Kupenda<sub>for the</sub>  
children



Kupenda for the Children would like to thank the following people for all of their time and effort into making this book a success.

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## Introduction to the Guidebook

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Many people, including parents of children without disabilities in Kenyan society, still hold negative attitudes towards children with disabilities. Beliefs and lack of knowledge about disabilities are among the causes of such attitudes. One of the ways of changing these negative attitudes is by educating the community about disabilities. For most Kenyans getting access to literature on the subject of disability is difficult and if one happens to get access, usually books carrying such information are expensive and written in a language understood only by professionals in disability issues. Kupenda for the children has therefore come up with this guide covering most of the common disabilities, their characteristics, causes and treatment. Language used has been made simple for easy understanding. Our goal is that the guide should provide a useful resource for learning about children with disabilities.

This guide is only a summary and anyone who believes they know a child with a disability that needs assistance should take them to the Kupenda for the children office in Gede or to any of the following institutions in your locality:

- Malindi Educational Assessment and Resource Centre.
- Kuhenza for the children's Foundation
- Malindi district hospital or the nearest public health facility.
- Malindi district children's department
- Culture and Social services

Special schools and units in the district:

- Gede special school
- Sir Ali special school
- Kakoneni unit for Mentally challenged
- Kakuyuni unit for Mentally challenged
- Mambrui unit for Mentally challenged
- Takaye unit for children with hearing impairments
- Marereni unit for children with hearing impairments
- Shomela unit for children with hearing impairments
- Mijomboni unit for the mentally challenged
- Marafa units for children with cerebral palsy and hearing impairments

*Leonard Mbonani*

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## About Disabilities in Kenya

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The World Health Organization conservatively estimates that 10% of the Kenyan population has a disability of some sort. A thorough research study is still needed to determine the exact statistics and to discover the common causes. It is likely that the higher numbers of people with disabilities in developing countries is due to the lack of adequate health care, diseases such as malaria and meningitis, malnutrition and other issues related to poverty.

People with disabilities in the developing world are sometimes viewed as having received a curse from God, or as subhuman, and are often neglected, abandoned, abused, raped or even killed. Disabilities occur through no fault of the person with the special need or anyone else. Disabilities are the result of many factors unrelated to anything of a spiritual nature.

It is very important for any one who comes in contact with people with disabilities to realize that they are people first and foremost, who have simply come upon challenges. They want to be loved, accepted, and successful just like everyone else. Therefore it is important to remember that children with disabilities are still just children. One way to encourage this is to always refer to their disability after referring to them as a person first. Examples of this include:

- The little boy with cerebral palsy instead of referring to him as a "cerebral palsied child"
- The girl who has autism instead of the "autistic girl"

## Autism



### Description:

In general, children with autism have problems in three areas of development: social skills, language and behavior. It is a condition which exists on a spectrum, known as the Autism Spectrum Disorders (ASD): this means that the abilities and behaviors of affected children vary widely, so that two individuals diagnosed with it may act differently and have very different skills. The most severe (or profound) cases are marked by a complete inability to communicate or interact with other people. If a child has autism, he or she may develop normally for the first few months or years of life, but then later stop interacting with familiar people and places in a way that most children without autism would.

The following are examples of common problems and behavior for a child with Autism:<sup>1</sup>

1. Little or limited use of eye contact
2. Use of pointing to people or things rather than calling them by name (not speaking)
3. Does not play with other children near to their age
4. Problems with friendship and playing with others, preferring to play alone, and using children/adults as “tools” which means only using them to get the object they want (for example, placing an adult’s hand on a door knob to open the door)
5. Delay or lack of using words and sentences to communicate
6. Repetitive speaking, saying the same words again and again
7. Strong need for consistent routines and habits, being very inflexible with changes to a daily routine/schedule
8. Repetitive body movements such as flapping arms or jumping up and down over and over or chewing on a string
9. Can’t use their imagination
10. Does not like bright lights or loud noises
11. Does not like to be touched and often may refuse to be hugged<sup>2</sup>

### Cause:

There is no single cause of autism. It is known that the brain of an autistic child differs in many ways from a child without autism, and that genetics may have a partial role. Other than that, the reasons for it remain a mystery. It is neither the result of anything the mother did before or during pregnancy, nor the fault of the child.

### Treatment:

There is no known cure for Autism. The earlier it is discovered that a child has it, the better it is for learning ways for communicating and socializing. There is some research that certain diets, vitamins, and other medications may help to reduce some symptoms in some children.

A daily plan or schedule of a child’s day will help to calm him or her and to become less frustrated when there is a change in routine. For example, you can have pictures on a board of what the child is to do during the day, and then always remind them when they are moving to the next part. Warnings and reminders help in a big way.

It is important to find a way that affected children can communicate, such as by using pictures. It is helpful to put common things on a picture board, so that a child can point to the picture to tell you what he/she wants/needs. Examples include:

- Yes
- No
- I'm hungry
- I'm tired
- I'm hurt
- I need to use the toilet

If the child is unable to point, the adult can take their hand and point it to the picture. This will hopefully begin to teach them the skills of basic communication. You can also “talk” for them and say “I am hungry”, and then give them something to eat. This can also begin to teach them to “speak” of their wants/needs. You can also teach the child how to appropriately act in social situations with other people.

Treatment should be varied according to need, because no two children have the same symptoms. A child won't “outgrow” autism, but he or she can learn to live according to their abilities, especially if treatment begins early. Children under the age of 5 who receive special learning to correct behavior show good progress.

When working with autism, it is not always about fixing problems, it is also about finding out what the child is good at, and encouraging them. Autism can be a gift: some people who have it call non-autistic people “neurotypicals”, meaning they see their unique brains as something special, an advantage over “normal” people.

### **Prevention:**

There is no known method of prevention.



### **Children with Autism CAN:**

Have something in their daily routine that brings them joy and happiness and can bring joy and happiness into the lives of others!

As they get older, some children with autism will find ways to turn their disability into an advantage. Because their brains are set up to see things differently, they tend to focus their attention on a single interest. This single-minded dedication and passion have led some autistic people to accomplish great things in their lives, and some have even become famous for it.

## Blindness or Vision Loss



### Description:

Blindness is a lack of vision. **Partial blindness** means you have very limited vision. **Complete blindness** means you cannot see anything and do not see light.<sup>3</sup>

### Cause:

The major causes for blindness in sub Saharan Africa are:

1. Vitamin A deficiency -- A lack of needed nutrition from food such as: carrots, peppers, green vegetables, liver.
2. Measles – A disease from a virus, causing fever and a rash.
3. Cataracts – A condition causing clouding of the eye and obstructing vision. Surgery can sometimes help.

Some other possible causes for blindness are:

1. Trachoma -- A disease of the eye caused by bacteria, common in developing countries.
2. Glaucoma – A disease of the eye that limits vision.
3. Macular degeneration – thinning of the inner eye in elderly people.
4. Trauma or Corneal scars damage to eye from an injury.
5. Tuberculosis – A disease caused by bacteria, spread through coughing.
6. Staphyloma – protrusion of any part of the globe of the eye.

Some blindness is inherited genetically.<sup>4,5</sup>

### Treatment:

In many cases in Kenya, poor vision can be treated simply with proper eyeglasses. Cataracts may be removed surgically resulting in restoration of sight.

### Blindness or Vision Loss Prevention:

Good health and nutrition during childhood are important in preventing blindness. Make sure children with sickness and diseases are looked at by healthcare services.

### Children with vision loss CAN:

Think, feel, express themselves and be understood just like any other child! A child with vision loss can contribute to their family and community and lead very meaningful lives.

## Cerebral Palsy



### Description:

Cerebral Palsy (CP), which means 'brain paralysis', is a problem with the brain that causes problems with movement of the arms, legs and/or body.

This is not a problem with the body, but is due to damage to a part of the brain that controls movement and body position.<sup>6</sup> The severity of CP can vary greatly: some children with it have only a mild disability and appear like children without CP at first; other cases are so severe that the child has loss of sensation (sense of touch) and cannot control either the upper or lower body. Such children need almost constant care and help.

A child with CP may often appear to be unable to control arms, legs, and neck, and may sit or crawl in a different or abnormal way. They may frequently cry, appear to be bad tempered and be slow to react; some may even have seizures. They may also have other disorders such as epilepsy, mental retardation, growth problems, and impaired hearing and/or vision. The child may lack the ability to communicate or walk but also be completely normal mentally and be just as smart as a child without the condition.<sup>7</sup>

### Cause:

The damage to the brain can happen before the baby is born, at birth, or as a young child. Once damaged, the parts of the brain do not recover, but they do not get worse either.

Common causes include:

1. Cerebral infection caused by meningitis
2. Seizures from rapid increase in body temperature often caused by malaria
3. Lack of good diet and nutrition
4. Exposure to infectious diseases such as encephalitis, tetanus, measles, syphilis, etc.
5. Malnutrition in the mother during pregnancy or the child at infancy
6. Mother's exposure to mind altering toxins or other drugs during pregnancy
7. Premature birth
8. Seizures in the mother during pregnancy
9. Alcohol and/or cigarette smoking by the mother during pregnancy
10. Exposure to Methyl mercury (mercury poisoning)
11. Loss of oxygen to the infant immediately before or during birth (umbilical cord complications, rupture of the uterus, hemorrhage, etc.).

### Treatment:

Cerebral Palsy cannot be cured. However, it will not get worse over time and early treatment can often improve the child's capabilities. No two people with it are exactly the same, because the brain of each has been affected in a different way. Therefore there are various treatment options, depending on how the child is affected. Medicines usually do not help, except for drugs to control seizures. Surgery is sometimes useful for correcting resistant contractures (constant shortening of a muscle due to abnormal tone and weakness associated with CP).

A variety of therapies and assistive equipment are the best "treatments" for this condition. Again this is dependent on how the brain has been affected.

Certain equipment may benefit a child with Cerebral Palsy depending on their level of ability. The therapist working with the child may recommend such equipment as: Leg braces, Abduction pillows, Wheelchair, Special seats, Crutches or Walkers.

### **Prevention:**

The chances of having a child with Cerebral Palsy can be reduced by:

1. Mosquito netting to keep malaria away
2. Vaccinations against infection diseases
3. Good nutrition for the pregnant mother and child
4. Pregnant mothers staying away from alcohol, cigarettes or drugs
5. Giving birth in a hospital equipped to deal with difficult births



### **Children with Cerebral Palsy CAN:**

Have emotions and feel things just like anyone else! Children with Cerebral Palsy can find joy and happiness in their life and can bring joy and happiness into the lives of others! Take the time to help a child with CP develop a system of communication, and you will be surprised to find out how much they already know and understand.

## Clubfoot



### Description:

**Clubfoot is a deformity of the foot: instead of pointing straight out, a clubfoot is curved in toward the body and the toes point down.**

Clubfoot can be found in newborn babies, and is easily identified. If an infant has two clubfeet, the soles of the feet face each other. It can be associated with other disorders such as Spina Bifida and Hip Dysplasia (this guide also has descriptions of these disorders).

Having a clubfoot does not cause any pain to the infant but if untreated it will lead to difficulties in walking normally. Many children with it appear to be walking on their ankles but are actually walking on the outside part of their foot. They may develop skin infections because they are walking

on a part of the foot that was not meant to be walked on.<sup>8</sup>

### Cause:

The cause of clubfoot is unknown. It appears to be more common in families where another family member has one, suggesting that the origin may be genetic. It is the most common birth defect, occurring in one in 1000 births. Being born with clubfoot is not the fault of the child or the family.<sup>9</sup>

### Treatment:

A clubfoot may be treated by moving the foot into the correct position and using a cast to keep it there. This is often done by an orthopedic specialist (a doctor who specializes in treatment of problems with bones and muscles).

The treatment should be started as early as possible: it's best if it can be done right after birth when reshaping the foot is easiest. Gentle stretching and recasting occurs every week to improve the position of the foot. Generally, 5 to 10 casts are needed. The final cast remains in place for 3 weeks. After the foot is in the correct position, a special brace is worn for 3 months. After 3 months of consistent use, the brace is used while the child is sleeping for an additional 3 years.<sup>9</sup> Some severe cases of clubfoot will require surgery if other treatments do not work or if the problem returns. The child should be monitored by a doctor until the foot is fully grown. With the described treatment, a child will eventually be able to walk normally on the flat surface of their foot.

### Prevention:

There is no way to prevent this genetic condition.

### Children born with clubfoot CAN:

Communicate, think, feel and be understood just like anyone else. Children born with a clubfoot can succeed in school and accomplish many great things in their lives!

## Deafness or Hearing Loss



### Description:

**Hearing loss is a full or partial decrease in the ability to detect or understand sounds.**

Hearing loss has a wide variety of biological or environmental causes.<sup>8</sup> Total deafness is actually very rare: most people identified as deaf actually do have some hearing, but it is generally not useful.<sup>9</sup>

### Causes:

There are many causes of loss of hearing and they can be genetic, present at birth, or environmental. A study conducted by the International Deaf Children's Society found that 80% of those that are deaf in Kenya acquired it in a way that could have been prevented.

Preventable causes of deafness include:

1. Impacted wax as a result of untreated acute ear infections
2. Inflammation of the ear canal and perforated ear drums

3. Measles, whooping cough, poliomyelitis, meningitis, rubella, tuberculosis, pneumonia and malaria
4. Misuse of certain drugs that affect the ear
5. Birth difficulties.

### Treatment:

Possible treatments include hearing aids, special training, certain medicines and surgery.<sup>10</sup> A high-tech option is a cochlear implant, which is a small electronic device that helps people hear. It is not the same thing as a hearing aid because it is surgically implanted and works in a different way.<sup>11</sup>

### Prevention:

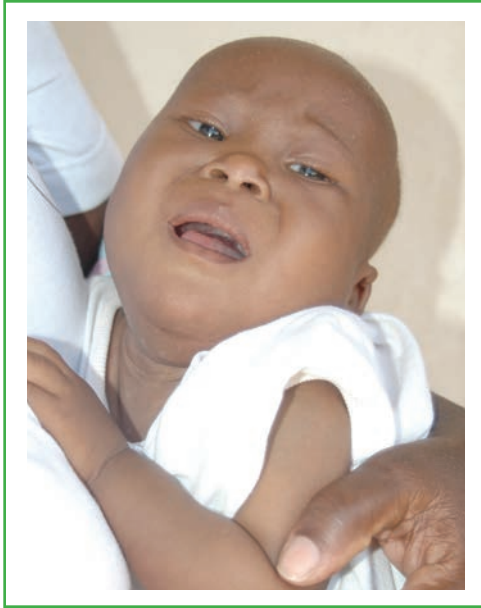
Deafness that is genetically inherited cannot be prevented. However the likelihood of acquiring hearing loss in other ways can be avoided through immediate treatment of ear infections, proper vaccinations against diseases that contribute to deafness, and giving birth in proper health facilities. For women who are pregnant, getting vaccinations before pregnancy will also assist in avoiding their child acquiring deafness.

### Children with Deafness or Hearing Loss CAN:

Learn to communicate and be understood just like any other child. A child with hearing loss can receive an education and contribute in wonderful ways to their family and community.

Being born with hearing loss does not mean that a child will be unable to communicate and be understood. Many countries around the world with deaf populations have a signed language used for communication. Sign languages are unrelated to spoken languages and have different grammatical structures.<sup>12</sup>

## Down Syndrome



### Description:

**Down syndrome is a genetic disorder that results in varying degrees of physical and mental abnormalities.**

Some of the common physical characteristics are:

1. Slanting eyes
2. Poor or low muscle tone
3. White dots on the iris of the eyes
4. Large space between the “big toe” and the “second toe”
5. Difficulty controlling the tongue (trouble speaking)
6. Short neck

A child born with Down syndrome may also have learning disabilities, often in the mild to moderate range. They may be able to be educated at a normal school. Some may have more severe difficulty in learning, and may need more specialized schooling. It is not possible at birth to predict the extent of a child's learning capabilities.<sup>15</sup>

### Cause:

Down syndrome is a genetic defect from having an extra chromosome. Older mothers have a higher chance of giving birth to a child with Down Syndrome. It is not believed to be the result of anything the mother did during pregnancy and it is not the fault of the child.<sup>16</sup>

### Treatment:

The most important thing to remember when working with a child with Down syndrome is that they are more like other children than otherwise.<sup>14</sup> They often benefit from occupational, speech and physical therapy. They often have poor muscle tone, so a physical therapist may work with young children to help them learn to roll over, sit independently and walk. Speech therapists may work on skills for language and communication, and an occupational therapist may work on other daily living skills, like learning to button and unbutton a shirt.<sup>16</sup>

### Prevention:

There is no known method of prevention, but again, the earlier it is discovered in a child the better. Early treatment, such as listed above, can greatly benefit young children with it.<sup>15</sup>

### Children with Down Syndrome CAN:

Feel, communicate, socialize and be understood in many of the same ways as other children! Children with Down Syndrome can bring joy and cheerfulness to all those around them.

# Epilepsy

(Sometimes referred to as Seizure Disorder)



## Description:

**Epilepsy is a disorder caused by cells in the brain sending out wrong signals, which cause the child to have a seizure.**

When this happens the child loses control of arms and legs and the body shakes. Often, the child will first go limp, and then go into convulsions (uncontrolled jerking and shaking). Sometimes there is no shaking and the body stiffens for a period of time; alternatively shaking may occur in only one part of the body. The child may also pass out. Having seizures is not painful, but a child may have sore muscles afterwards.<sup>17</sup>

It is common for a young child to have a seizure as the result of a high fever during an illness. Medical tests indicate that 1 out of every 10 people may have a seizure in their lifetime.<sup>18</sup> Therefore, having one seizure does not mean that a child has epilepsy; it cannot be diagnosed until a person is reported to have had at least two. A doctor must take a medical history. Brain scan machines called EEGs are also used to learn about the child's brain.

The condition can affect both males and females of any age, so it is seen both in young children and adults over the age of 60.<sup>19</sup> Most seizures do

not cause brain damage and in some cases, it is possible for seizures to go away on their own.<sup>18</sup>

## Cause:

In most cases, the cause of epilepsy is not known, other than that seizures occur because there is a problem with brain activity. This happens without blame to the child or the family. Sometimes there is a reason for the seizures, such as brain injury, an infection such as meningitis or malaria, or tumors.

## Treatment:

There is currently no cure for epilepsy. Medication or small surgical procedures to mimic electrical signals in the brain remain the best method for controlling seizures.<sup>19</sup>

It is important to try to keep children with epilepsy in safe environments – for example, not in very high places where they may hurt themselves if they have a seizure and fall to the floor.

## Prevention:

There is no known method of preventing the development of epilepsy.

Meningitis and malaria can be prevented by the use of mosquito netting and having clean water available. If they are prevented or treated early with the use of medication, the likelihood that a child may develop epilepsy may be reduced.

## Children with Epilepsy CAN:

Lead very normal lives that include: succeeding in school, making friends, having their own family when they are grown up and accomplish many great things throughout their lives!

## Hip Dysplasia

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### Description:

**Hip dysplasia is a condition that affects the joint where the hip bone meets the pelvis.** This condition is usually apparent at birth. The hip is made up of a ball and socket joint. The ball is at the top part of the thigh bone and the socket is in the pelvis. Hip dysplasia is when the hip may be all the way out of the joint or the socket may be a little shallow. It is possible for a child to be born with one or both hips dislocated.<sup>21</sup>

### Cause:

Some risk factors for children who may be born with hip dysplasia include:

1. Being the first child
2. Being female
3. Breech delivery
4. Family history of the disorder

Hip dysplasia occurs in about 1 out of 1,000 births.<sup>21</sup>

### Treatment:

There are two types of treatment for hip dysplasia.

1. A pelvic harness, which a child can wear throughout the first year of life, which will keep them from moving too much and will allow the hip sockets to form more tightly on their own.
2. Corrective surgeries which can be performed to create a tighter socket. More than one surgery may be required, because a child's bones continue to grow and the sockets may become loose over time. Generally, once a child has become an adult, there is little need for surgery for correction.<sup>23</sup>

Though treatment for hip dysplasia is possible, arthritis may develop as a result of damage to the joint. Arthritis can cause pain, and further treatment may be needed to treat this.<sup>24</sup>

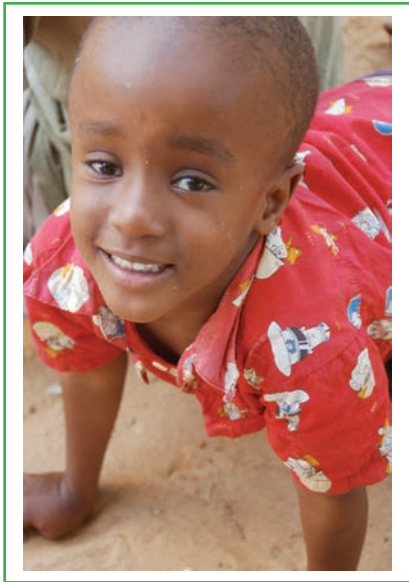
### Prevention:

There is no way to prevent a child from being born with hip dysplasia. If it occurs, it is not believed to be the fault of anything the mother did while pregnant and it is not the fault of the child.

### Children with Hip Dysplasia CAN:

Think, feel, and express themselves and be understood just like any child! With treatment, many children will learn to walk, run or dance and live a life like a child without the condition.

## Hydrocephalus



### Description:

**Hydrocephalus is a collection of fluid in the brain.** This cerebrospinal fluid (CSF) surrounds the brain and spinal cord and is absorbed into the blood. Too much CSF causes the spaces in the brain to grow which increases the pressure on the brain, which can be harmful.<sup>24</sup>

This condition is believed to affect 1 in 500 children and is most often diagnosed at the time of birth or in very early childhood. However, because some of the causes relate to the outside environment (such as meningitis, tumors, head injury), the disease can affect older children as well as adults.<sup>25</sup>

The symptoms can vary because of age and individual differences in tolerance for CSF. For example, infants are able to tolerate a greater amount of CSF because the joints that connect the bones of the skull are not completely closed and are therefore able to contain a greater amount of fluid. As a result, the most noticeable symptom in infancy is a large head.<sup>24</sup>

Other symptoms can include:

1. Vomiting
2. Sleepiness
3. Irritability
4. Seizures
5. Limited ability to think and comprehend
6. Other physical impairments

Because the brain of an older child or adult is fully formed and therefore unable to expand to include excess CSF, they may experience other symptoms related to the disease.

Older children and adults may have problems with:

1. Movement
2. Coordination
3. Blurry vision
4. Double vision
5. Swelling of a part of the nerves that help us see
6. Memory loss
7. Changes in personality
8. Limited ability to think and comprehend
9. Sleepiness
10. Irritability
11. Seizures and downward casting of the eyes.<sup>24, 25</sup>

### Cause:

There can be many causes of hydrocephalus, which include genetic inheritance, or complications from being born early, or as the result of other developmental disorders such as Spina Bifida. As with epilepsy, hydrocephalus may also be caused by meningitis, traumatic head injury or tumors. It is not believed to be the result of anything the mother did while pregnant, and it is not the fault of the child or the family.

### Treatment:

The most common treatment of the disease is for a doctor to insert a tube that will allow fluid to be moved from one part of the body to another, so that it can be moved away from the brain and be less harmful. This process is called shunting and can only be done by a doctor. It will need to be monitored by a healthcare professional to make sure that it is working

well and that it doesn't become infected. In many cases it may need to be replaced after a while.<sup>25</sup>

Children with Hydrocephalus may benefit from rehabilitative therapy (occupational and physical therapy) and educational interventions to accommodate their learning abilities. Early diagnosis and regular treatment are very important. If it is not treated it can result in death.<sup>24</sup>

**Prevention:**

Meningitis and malaria can be prevented by the use of mosquito netting and having clean water available. If these diseases are prevented or treated early, it can reduce the chances that a child may develop Hydrocephalus.



**Children with Hydrocephalus CAN:**

Participate and contribute in their families and their schools in very meaningful ways!

## Microcephalus (Microcephaly)



### Description:

**Microcephalus is a disease in which the brain grows too slowly, so the child's head is smaller than normal.** The child may therefore develop problems with speech and language and coordinating their body, but it will affect children in different ways with various results.<sup>26</sup> The child's muscle control may be affected as well as other developmental concerns such as short attention span and limited ability to understand things.<sup>27</sup> As the child grows, the size of the head may become more noticeable even though the body may be smaller and underweight.<sup>27</sup>

Children with Microcephalus may have:

1. Mental retardation
2. Delayed motor functions and speech
3. facial distortions
4. dwarfism or short stature

5. Hyperactivity

6. Seizures

7. Difficulties with coordination and balance, and other brain abnormalities.

Minor forms of the condition are also possible: such children will have normal intelligence and a head that will grow bigger, but will still be slightly smaller than normal.<sup>28</sup>

Microcephalus is very rare with only 1 in 40,000 children being born with it. Secondary Microcephalus, because of all of the other possible conditions that can cause the disorder, occurs at a higher rate.<sup>29</sup>

### Cause:

There are two types of Microcephalus:

1. Primary, which is genetically inherited
2. Secondary, when other conditions probably caused the decreased head size. Some of these conditions are: Down syndrome, bacterial meningitis, lack of oxygen after birth, or being exposed to drugs or alcohol during pregnancy.<sup>29</sup>

### Treatment:

There is no treatment for Microcephaly that will return the baby's head to a normal size or shape. It is a life-long condition that cannot be fixed. However, treatment can work to prevent or minimize deformities and maximize the child's capabilities at home and in the community. It is important for affected children to be encouraged to learn and to be rewarded for good behavior. Consistent positive feedback will encourage the child to strengthen his or her self-esteem and promote as much independence as possible.<sup>28</sup>

### Children with Microcephalus CAN:

Participate and contribute in their families and their schools in very meaningful ways!

## Spina Bifida



### Description:

**Spina Bifida (SB) is a problem with the spine (the bones in the center of the back).** It is sometimes thought of as a “split spine.” It means that the spinal column of a baby did not completely close when it was being formed in the first month of pregnancy, and the bones or vertebrae that normally form over the spinal column do not close so that part of the spinal column sticks out through the opening of the vertebrae.<sup>30</sup>

Children born with SB may have an exposed or open part of the spine where bone can be seen. There is usually nerve damage that causes at least some paralysis of the legs (meaning the child will have trouble standing or walking). Many people with the condition will need braces, crutches or wheelchairs. They may also have learning difficulties, urinary and bowel problems or a buildup of fluid in the brain.<sup>31</sup>

Complications can range from minor physical problems to severe physical and mental disabilities. It is important to note, however, that most people with SB are of normal intelligence. The disease could be minor or it could be severe, depending on the size and location of the malformation of the spine, whether or not skin covers it, whether or not nerves

protrude from it, and which nerves are involved. Generally all nerves located below the malformation are affected: therefore, the higher it occurs on the back, the greater the amount of nerve damage and loss of muscle function and sensation.<sup>32</sup>

Spina Bifida can also result in:

1. Varying levels of paralysis
2. Not being able to feel all touches to the skin because of affected nerves
3. Problems controlling the bladder
4. Spine and limb problems depending on the severity and location of the lesion on the spine.<sup>30, 32</sup>

### Cause:

There is no single cause of SB but lack of folic acid has been found to be a contributing factor of SB. Folic acid is found in many foods such as: dark green vegetables, whole wheat bread, nuts and seeds, oranges and grapefruits, liver, chicken, etc.<sup>33</sup> Spina Bifida is not believed to be the result of anything the mother did before or during pregnancy.

### Treatment:

There is no cure for SB because the nerve tissue cannot be replaced or repaired. Despite this, there are possible treatments to help some of the effects, such as surgery, medication, and therapy.<sup>31</sup>

Many children with SB can become more independent by using braces, crutches or wheelchairs to help them get around. Also, it is likely that a child with SB will need to have ongoing therapy, medical care, and/or surgical treatments to maintain their overall health.

### Prevention:

Current research indicates that eating foods with folic acid such as, leaf vegetables, whole grain bread, many fruits, breakfast cereals, and dried beans, can help to reduce the chances that a child will be born with Spina Bifida.<sup>30</sup>

### Children with Spina Bifida CAN:

Contribute to their families and communities in very meaningful ways. Most children with SB can think, feel, react and communicate in the same ways as other children!

**Here you will read brief descriptions of more rare disabilities experienced by children in Kenya.**

### **Brittle Bone Disease:**

Brittle bone disease is a genetic disorder in which children are born without, or with very little, of the proper protein needed for healthy bones. Without this important protein, a child's bones can be very weak or fragile. There are treatments available for the disease which increase overall bone strength to prevent bones from breaking.

### **Deformed or Missing Limbs at Birth:**

There are multiple causes for deformed or missing arms and legs present at birth. Sometimes it is genetic and other family members also have some kind of deformity or missing limb. It can also happen while the child is developing in the mother's womb: fibers may wrap around a limb causing it to be severed before birth, through no fault of the mother. A drug called Thalidomide, which was used to treat sickness associated with pregnancy, has also been known to cause missing or deformed limbs at birth.

### **Juvenile Arthritis:**

Arthritis is a disease of the tissue lining a joint (where bones are connected). The connection swells or becomes inflamed making movement difficult or painful. Normally older people are more likely to get arthritis, but juvenile arthritis can occur in childhood. Some symptoms are: suppressed appetite or not eating, decreased desire for physical activity and lethargy or constant tiredness. There is a wide range of possible treatments.

### **Knock Knees:**

Knock knees is when the lower legs of a child are at an outward angle, such that when the knees are touching, the ankles are separated. It can be a normal part of development for many children and are corrected on their own by age 5 or 6. In some cases, the child does not outgrow the condition. Sometimes assistive devices, like braces, may be used for the legs.

### **Muscular Dystrophy:**

The muscular dystrophies (MD) are a group of more than 30 genetic diseases characterized by increasing weakness and degeneration of the

muscles that control movement. Some forms are seen in infancy or childhood, while others may not appear until middle age or later.

There is no specific treatment to stop or reverse any form of MD. Treatment may include physical therapy, respiratory therapy, speech therapy and corrective orthopedic surgery. Some cases may be mild and progress very slowly over a normal lifespan, while others produce severe muscle weakness, functional disability, and loss of the ability to walk.

### **Phocomelia:**

Phocomelia is a condition in which the long bones of the body, often the arms and legs, are shortened or completely missing. The hands and feet may be attached to the shortened limbs, giving a "flipper-like" appearance. This is a rare condition which is present at birth.<sup>1</sup>

### **Spinal Cord injuries:**

Spinal cord injuries usually occur when something happens to cause the vertebrae, or bone disks that make up the spine, to tear into tissue which presses into the nerves that carry signals to the body. (This may not necessarily be caused by an external injury.) With immediate treatment, it may be possible to reduce the long term effects. Some symptoms may include problems with the bowel and bladder, arms and legs stiffening, loss of calcium in the bones, and trouble regulating heart rate, blood pressure and body temperature.



## Glossary

**Able:** having necessary power, skill, resources, or qualifications

**Abnormal:** not normal

**Ability:** the quality or state of being able

**Associated:** connected

**Capabilities:** the natural abilities or skills that allows you to be able to do something

**Chromosome:** a part of every living cell that is shaped like a thread which has contains genes

**Consciousness:** the condition of being awake and able to understand what is happening around you

**Convulsion:** an act of shaking violently and uncontrollably

**Coordination:** the way in which your muscles move together when you perform a movement.

**Crucial:** extremely important

**Deformity:** body or limbs that have a shape that is not normal

**Desire:** hope for something very much

**Diagnosis:** a determining or analysis of the cause or nature of a problem or situation

**Deficiency:** A lack something that is necessary

**Disability:** a physical or mental impairment that substantially limits one or more major life activities

**Disabilities:** plural of disability (more than one disability)

**Disorder:** A disturbance in normal functioning (mental, physical or psychological).

**Disruption:** a situation in which something is prevented from continuing in its normal way because of problems and difficulties

**Distortion:** change in the appearance, sound or shape of something so that it is strange or unclear

**Embarrassed:** ashamed, nervous or uncomfortable in a social situation

**Encephalitis:** inflammation of the brain caused by a virus

**Evaluation:** the act of considering something to decide how useful or valuable it is.

**Frustrated:** the feeling of being annoyed, upset, or impatient because you cannot control or change a situation or achieve something

**Gene:** the basic physical unit of heredity

**Genetic:** produced by genes

**Hemorrhage:** a large amount of bleeding

**Heredity:** the transmission of characters from parents to children

**Hyperactivity:** impaired ability to sit or concentrate for long periods of time

**Inability:** lack of ability

**Inflammation:** swelling and soreness on or in part of the body which is often red and hot to touch

**Intelligence:** the ability to learn, understand and think about things.

**Intervention:** to prevent harm or improve functioning

**Jerky:** rough movements with many starts and stops

**Meningitis:** a serious illness in which the outer part of the brain becomes swollen

**Mimic:** to behave or operate exactly the same way as something or someone else

**Normal:** similar to the standard or the common type

**Peers:** people of the same age

**Profound:** severe

**Reinforcement:** the act of making something stronger

**Retardation:** slowed development

**Rubella:** German measles

**Schedule:** a series of things to be done or of events to occur at or during a particular time or period

**Seizure:** uncontrolled electrical activity in the brain resulting in a fit or sudden attack

**Shun:** to avoid someone or something deliberately

**Socialize:** to spend time with other people in a friendly way

**Surgery:** an operation

**Symptom:** a sign or an indication of disorder or disease

**Tease:** to make jokes and laugh at someone in order to have fun by embarrassing them either in a friendly way or in an unkind way

**Thalidomide:** a drug given to people to make them calm, until it was discovered that it harmed the development of the arms and legs of unborn babies

**Therapy:** The treatment of an illness, disability or injury over a fairly long period of time especially without using drugs or operations

**Tremendous:** very great

**Tumors:** an abnormal growth resulting from diseased cells in the body that have divided and increased too quickly

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