

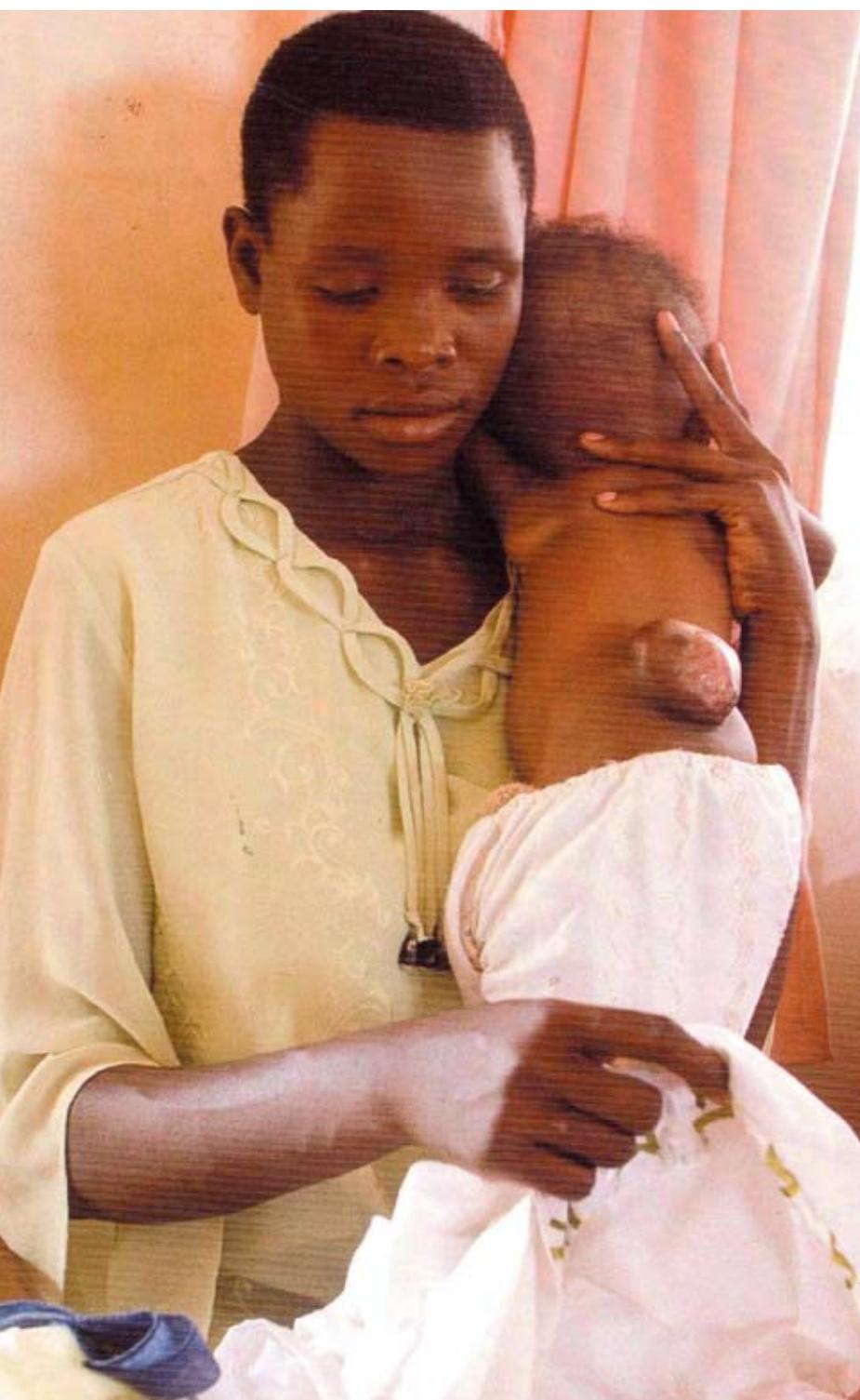
UPDATE

UNAPD

A bi-monthly newsletter for Uganda National Action on Physical Disability

SEICAL EDITION

ISSUE 1, 2013



A mother of a child born with spina bifida. She needs a lot of financial and medical support in addition to intensive rehabilitation for her kid to grow and live a fulfilling life.

PHOTO BY BRETT MORTON AND ZJUULDEVENS

INSIDE THIS EDITION

Spina Bifida

IT is one of the most common congenital birth defects, globally affecting one in every 1000 live births. This condition is common in low income countries

Prevention better than Cure?

THE cheap and easy ways of preventing the two bizarre disabling conditions; spina bifida and hydrocephalus

Supporting the 'rejects'

THEY were denied admission in many schools or discontinued from where they had been admitted. A good Samaritan comes to the rescue of these bright, beautiful but unfortunate children

Not limited by the sky

TO many people the sky is the limit but to Ephrance, it is the inaccessible to her school and other buildings

Bothered

but not shattered

SHE has met many great challenges in her few years at school but is beating all the odds to become a doctor

Horrible and tormenting

A mother's tale about giving birth to a child with spina bifida



George W. Koyingi
Executive Director

Our esteemed readers, I wish you a Happy New Year. I also welcome you to our first edition of UNAPD update in the year 2013. I wish to thank you all for supporting our programs the previous year and for the constructive advice you gave us which has continuously helped us to improve our newsletter. We look forward to the same in this year.

This is a special edition dedicated to spina bifida and hydrocephalus – some of the two greatly disabling conditions. It is in line with one of UNAPD's key objectives of implementing programmes to prevent disabling conditions and reduce physical disabilities.

Spina bifida and hydrocephalus have become so rampant in Uganda today. Statistics indicate that out of all the children born in Mulago national referral hospital per week, seven-10 are born with spina bifida. The situation in other hospitals countrywide could even be worse.

I therefore appeal to the Government of Uganda to fight the occurrence of these conditions through mandatory food fortification. Fortified foods are enriched with folic acid that when taken by women before pregnancy and during pregnancy highly prevents mothers from producing children with such conditions. This should be coupled with improving maternal and child health care as well improving immunization coverage.

The public needs to be continuously sensitized on these conditions in regard to the causes, prevention and handling of children born with these conditions. Nutritional education on the type food to be consumed which has high folic acid content should be provided to the public as well as emphasis on family planning.

Children born with these conditions face a lot of challenges as they grow up - ranging from stigmatization, inaccessible physical environment, unhygienic latrines, inaccessible schools - to expensive and regular health care and treatment.

We appreciate stakeholders like Child Help Uganda, CURE Hospital in Uganda, Katalamwa Cheshire Home and OURs for providing treatment, care, and support to children with spina bifida hydrocephalus as well as creating awareness on these conditions.

I appeal to government to improve the health care system because many children acquire hydrocephalus because of infections due to poor health service delivery. Government should also enact a law on compulsory food fortification as well as including Accessibility Standards in the Building Control Act. This will make buildings accessible to persons with disability including those with spina bifida and hydrocephalus.

EDITORIAL

Take action on these disabling conditions

THIS is a special edition of our newsletter only focusing on some two of the most vulnerable categories of physical disability. That is persons with spina bifida and hydrocephalus. There are increasing cases of children born with spina bifida, a congenital disability, but many people even doctors and health workers are not aware of it.

Here we bring you testimonies of parents and children and you will read about how some health workers runaway at the sight of babies produced with spina bifida. Such people are not even equipped with the necessary information to make referrals for these cases. If professionals in the health sector could behave like this, you know what to expect from the communities: denial of paternity, stigmatization, discrimination, and superstition, among others. This publication therefore comes in handy to create awareness about these conditions.

Hydrocephalus in most cases develops after birth or at any time in somebody's life but is common in children where its impact is also great. In some cases, a child can have both conditions in addition to others such as brain injury, epilepsy, learning and cognitive disability.

Spina bifida is a birth defect that occurs when the bones of the spine (vertebrae) do not form properly around part of the baby's spinal cord. It can be like a sac of water at any point on the back of the baby or an open sore. In severe cases, it can make walking or daily activities hard to do without help. Many people with it depend on assistive devices such as wheel chairs, walking sticks and calipers.

Hydrocephalus, also called Water on the Brain, is a condition in which there is an abnormal build up of fluids in the cavities of the brain. The buildup is often caused by an obstruction which prevents proper fluid drainage. The fluid buildup raises pressure inside the skull which compresses surrounding brain tissue, causing progressive enlargement and softening of the head, convulsions, and brain damage. Hydrocephalus can be fatal if left untreated.

Spina bifida and hydrocephalus are very expensive conditions to manage as they require much labour and money. However, both of these conditions can be prevented but the government is silent on these conditions as it has so far no definite interventions in regard to sensitization, prevention and management of the conditions. It is the civil society organizations that are doing great work in this field but they are also limited with financial and technical resources.

We wish you nice reading.

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Spina bifida should be prevented



By Arthur Blick Sn.
Chairman UNAPD

THERE is no doubt that Uganda for sometime has been steadily registering high level of economic growth and development especially for the last 27 years of NRM's governance. This economic growth and development is characterized by improvement in provision of social services such as health and education, reduction in poverty levels, improvement in infrastructure, and reduction in illiteracy levels, among others.

As a result of improved health services and literacy among Ugandans, disability as a result of polio which was hitherto the traditional cause of disability was contained. This would be a great cause to celebrate. However, for us in the disability fraternity, we are concerned that there are increasing cases of disability in spite of "kicking out of polio from Uganda" and great improvements in the citizen's knowledge and health.

The focus of my article and this edition of the newsletter is on spina bifida and hydrocephalus, conditions which cause physical disability. This newsletter comes in the wake of revelations by Dr Michael Muhumuza, the Acting Head of the Neurosurgical Unit at Mulago Hospital and Uganda's hosting, late last year, of an international conference on spina bifida and hydrocephalus. Dr Muhumuza said in a press report that seven-ten children with spina bifida are produced in Mulago alone every week. This translates to about 480 children produced with this condition in just one year and in Mulago hospital alone. This is a very big number which cannot be ignored.

A person can have both spina bifida and hydrocephalus, or either of the two conditions. Most people with these conditions normally have severe and multiple disability. You could find many of them confined in wheel chairs, having epilepsy, slow learners and brain injury. Such a person and the family finds the life very challenging as they are mostly likely to live in a life of great poverty and miserly. We are all aware that disability cause poverty and poverty also causes disability.

The good thing is that these conditions can be managed and preventable to some extent. However, managing the conditions is so expensive as the child may need surgery and services of many specialists such as physiotherapist, occupational therapists and close supervision and review of doctors and nurses. We are aware that these specialists are not available in our communities and where they are available, their services are so expensive. The children also need assistive devices, rehabilitation and clean intermittent catheterization and bowel management as they cannot control urine and bowel movement.

The government and the communities therefore should highly concentrate on the preventive measures because it is cheaper to prevent the cause than managing the effects of spina bifida and hydrocephalus. The two basic preventive measures are mandatory fortification of foods (adding folic acid to foods) because spina bifida is caused by lack of folic acid by pregnant mothers. The other one is improvement of the health service delivery more especially maternal health, avoiding of infections and cerebral malaria. These are highly responsible for causing hydrocephalus.

Spina bifida and hydrocephalus are some of the types of physical disability and UNAPD had done some limited countrywide sensitization on these two conditions. That is why we are now so grateful to the International Federation for Spina Bifida and Hydrocephalus that is working in Uganda through IF Child Help Uganda. IF Child Help Uganda has worked so hard to identify children with hydrocephalus and spina bifida and also to sensitize parents and caregivers about managing patients. They have gone ahead to support hospitals especially CURE Children's Hospital in Mbale to carry out surgery for the patients and have also supported some other organizations to establish follow-up systems of clinics where children receive medical review, rehabilitation and social support.

The patients need multidisciplinary support to be able to live a meaningful life. That is, medication and rehabilitation are not enough; the children also need a conducive social and physical environment to realize their full potential. A social environment free of discrimination and stigma and a physical environment free of accessibility barriers in schools, hospitals, places of work, among others. That is why IF Child Help Uganda and the International Federation for Spina Bifida and Hydrocephalus have to continue to work together to create better living conditions to all people with physical disability.

Spina bifida and hydrocephalus

Some of the two bizzare disabling conditions whose cases are on the rise in Uganda today

What is spina bifida?

Spina bifida is one of the most common congenital birth defects, affecting one in every 1000 live births globally. This condition is common in low income countries due to limited or lack of consumption of foods with folic acid by pregnant women. The spina bifida is caused by a fault in the development of the central nervous system in the first 25 days of a pregnancy.

The spinal cord and vertebrae do not form completely and the neural tube fails to develop normally. Because of these defects, people born with spina bifida usually have some degree of paralysis, which affects their mobility as well as their bowel and bladder control. Infants born with spina bifida need surgical closure of the spine, and rehabilitation services of physiotherapists, continence nurses, and occupational therapists to manage the effects of the paralysis such as difficulties in walking and incontinence.

How to manage spina bifida?

Prevention of further damage to bladder and kidneys can be achieved through routine catheterization to fully empty the patient's bladder. This procedure called Clean intermittent Catheterization [CIC] can be taught to children from four or five years of age and to parents. A tube is inserted through the patient's vagina or penis up to the bladder to draw out the urine. With the CIC knowledge and equipments, patients can become dry and infection free, thus allowing for greater inclusion in everyday life.

In addition, patients with paralysis need special care to prevent secondary impairments and complications such as pressure sores. They need to regularly change their sitting positions, use good seat cushions and braces and shoes that fit properly and are checked on a regular basis.



Children with spina bifida and or hydrocephalus like these can live a fulfilling life if they are rehabilitated and looked after very well

Prevention of spina bifida

Having adequate levels of folic acid before and during pregnancy is the most crucial preventative measure of spina bifida. There are three recommended ways to increase folic acid uptake in women of child bearing age.

1. Intake of one folic acid tablet daily for women in reproductive age. While daily supplements are a simple method of decreasing the likelihood of an infant contracting spina bifida, supplements are still not readily available to the entire female population of child-bearing age or are only taken after the first trimester, when the spine has already formed. Health workers and policy makers have a role to advocate for the use of folic acid tablets in women of child bearing age and not only after the first antenatal visit.
2. Folic acid is found in local foods in Uganda, and women in child bearing age are encouraged to eat foods rich in folic acid such as greens, liver, ground nuts, fresh maize and fresh mangoes to prevent spina bifida in their unborn infants.
3. Folic acid can be added to food through fortification of staple foods more especially maize flour, wheat flour and corn flour.

WHAT IS HYDROCEPHALUS?

A child can have both spina bifida and hydrocephalus. Approximately two third of children with spina bifida in Uganda also develop progressive hydrocephalus. Ventricles or cavities of the brain in all persons produce cerebral-spinal fluids and it is absorbed in the brain and spinal cord. However, hydrocephalus develops if there is no balance between the cerebral-spinal fluids produced and that that which is absorbed. This can also occur with people without spina bifida. If the natural circulation of CSF is obstructed, fluid accumulates in the brain and hydro-

cephalus results.

The excess fluid presses on the brain causing damage to the surrounding tissue. In babies and infants where the skull is still soft, the head enlarges. This obstruction of the normal CSF pathways can be caused by abnormal brain anatomy as is the case with spina bifida. It can also be the result of meningitis (cerebral malaria), trauma or intracranial bleeding which occurs more frequently following premature birth.



Hydrocephalus can be treated

Hydrocephalus is treated surgically either by draining the excessive fluids into the abdomen by placing a special tube called a drain or a shunt. It is also possible to create a natural by-pass, without using a shunt using a process called endoscopic surgery. These procedures are done in CURE Hospital in Mbale district.

Both spina bifida and hydrocephalus require life long care and surgical intervention is only the first step. Adequate surgery is the start of a broader package of total multidisciplinary care, engaging other professionals, parents and the child itself. With proper support, most children and adults can learn to overcome problems, gain confidence in themselves and go on to live full and independent lives.

Prevention of hydrocephalus

Prevention of hydrocephalus is a more complex matter, as there are more possible causes. They include congenital disorder, post-infections, and cerebral hemorrhages or tumors. However improving maternal and child health care and improving immunization coverage is believed to prevent some of the post-infectious cases. Adequate and timely referral for treatment of hydrocephalus prevents secondary disabilities such as blindness and brain damage.

Where to get services

In Uganda there is an organization called IF Child Help Uganda. It is a branch office of the International Federation for Spina Bifida and Hydrocephalus. IFChild Uganda works together with hospitals and rehabilitation centers to provide interdisciplinary care for persons with spina bifida and hydrocephalus.

Specialized neurosurgical care for children with spina bifida and hydrocephalus in Uganda is offered by CURE children's hospital in Mbale. Since its opening in 2000, CURE has become a center of excellence for neurosurgery and has developed a multidisciplinary approach for the care of children with spina bifida and for prevention efforts.

After neurosurgery, children receive medical review, rehabilitation and social support services through a follow-up system of clinics in Gulu (AVSI Foundation/ Gulu Regional Rehabilitation Center), Regional Referral Hospitals, Katakemwa Cheshire Home (Kampala), Lira Regional Referral Hospital, and Our Useful Rehabilitation Services for Persons with Disabilities (OURS-in Mbarara).

Rehabilitation activities include physiotherapy, occupational therapy, provision of appliances, clean intermittent catheterization and bowel management, and community based rehabilitation.

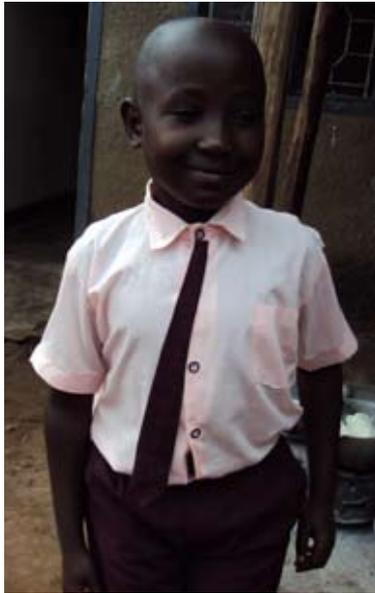
Social support is provided through parent support groups, self-help groups of parent with children with spina bifida and hydrocephalus, counseling, and lobbying at schools to promote inclusive education.

How to improve the lives of persons with spina bifida and hydrocephalus

In order to reduce cases of children with spina bifida and/ with hydrocephalus, the following interventions are recommended:

1. More sensitization is necessary to improve accessibility and inclusion of persons with spina bifida and hydrocephalus in society at national and local level. The celebration of world spina Bifida and Hydrocephalus Day is one way to increase awareness in the wider public.
2. Public health facilities need to be equipped to the surgical and rehabilitation needs of children with spina bifida and hydrocephalus.
3. Constructions of new buildings should follow the accessibility standards as developed by the Uganda National Action for Persons with Physical Disabilities, while existing buildings can be adapted using these standards.
4. More attention to inclusive education in teachers's education, and provision of education materials fit for children with special needs will assist in creation of a more enabling environment in schools
5. Health workers need to be informed about the specific needs of children with spina bifida and hydrocephalus, and the importance of promoting folic acid use in women of child bearing age. In addition, there should be mandatory food fortification and this would be supported by enacting a law to enforce it.

To understand the magnitude of the problem and success of intervention, birth defects such as spina bifida and hydrocephalus need to be registered at a national level.



Supporting the 'rejects'

These children were rejected in many schools because of their disability; spina bifida. A good Samaritan Miriam Ongom has come to their rescue but she is over stretched

BY HAMAD LUBWAMA

Why are these children not going to the same schools like others?

These children are not going to the same schools with other children because they have been rejected. They have been sent away from the normal schools. The teachers claim that these children smell because of the urine incontinence. Their mums were told to find other schools for them.

What special things do they need?

They have special needs. They need a toilet where they can sit. They cannot use toilets where they squat because they cannot manage that. They need a private place with chairs to use for their bowl management to remove the stool daily because they cannot control it. They also need to remove their urine after every two-three hours because of their disability.

What inspired you to start a school...

The burden came from the mothers. I work with CURE Mbale hospital and I do counseling. I heard the outcries from their mothers that their children had been rejected from the usual schools. The head teachers could not keep the children in these schools. I thought that if I had brought these children together, I could lobby for support from the districts and other people but I have not yet been successful. The Government is encouraging inclusive education and this is okay but the fact is that the schools are not accessible for these children.

Are the parents able to support their children at school?

I could say that spina bifida is a disease for the needy or for the poor. I have one parent who has managed to pay out of six and he has not paid a significant amount. The rest zero; not even

one thousand shillings. I even asked them to buy only one litre of jik but they failed. It is not because they don't want to pay but because they are so poor. Some of them I have even visited their homes.

What would be the ideal school fees per child?

I calculated the fees for the second term (2012) and the cost came to 600,000 per child each term. That can make each child stay here comfortably.

What is your appeal to the children, parents and the community?

For the children I want to encourage them that they are normal. Their disability doesn't mean that they are not useful. They should have hope that in future they will be great people in the community and the world at large. For the parents I encourage them not to give up. Continue supporting your children physically, emotionally and all other ways because these are our future leaders. These children are really very bright children because they compete with other children.

For the communities I encourage them to accept these children and motivate them because no one really asked for their kids to have a disability like this. And no one would wish their children to be treated like this. You should support them materially and financially so that they can feel loved like their friends.

Any last words

I encourage all the people to advocate for children with disability and to support them in all ways. The children here are not financially okay. I don't think that next year I may be able to financially support them. Everybody who has seen these children want to bring theirs in and I know what their finances are. I call upon every individual, government, NGO and well wishers to support us in this noble cause.

Please contact Miriam Ongom for support on Tel: 0772778810



1

1. Miriam Angom (R) with the children, teacher and two other employees who look after them

2. Teacher doing her work in class

3. The children are intelligent and very active in class

4. The pupils in relaxing in the compound

5. The disability cannot stop the children from playing football.



2



3



4



5

“I have learnt to deal with some challenge
but there are those I have really failed”

Limited by inaccessibility

The children are tired of missing out on opportunities because of inaccessibility to the buildings. Led by Ephrance Nadunga, the children presented a petition to the Deputy Speaker of Parliament Jacob Oulanya asking the MPs to intervene. In picture Ephrance Nadunga reading the petition



BY EPHRANCE NADONGO

MY NAME is Ephrance Nadongo, a student in Senior Two. I was born with spina bifida and later developed hydrocephalus. Almost all people have some level of disability or develop it later in their life. A child with spina bifida, a person with a broken leg, and an elderly person, among others, are all disabled in one way or the other. Those who remain healthy and able-bodied all their lives are the minority.

I remember when I had just joined my primary school every pupil would stare at me. They would ask so many questions in one day, while others would feel pity for me. This would make me feel uncomfortable and at times end in tears.

Dealing with challenges

For some of these challenges I have learnt to deal with. However, there are those which I really cannot deal with or get used to. For example, from the time I leave home to the time I get back home from school, there are a number of challenges more so the physical ones that I encounter.

First of all, travelling a distance of more than three kilometers in the morning makes my body tired even before attending the first lesson in class. My parents have tried to sort this out by hiring me a motorcycle. However, at times I feel they are incurring a lot of expenses by getting me a boda-boda to take

me to and from school. I always feel sorry because they are spending a lot on me compared to my fellow children. Besides that, even before I climb the stairs to my class on the second floor, I feel as if I am beginning another long journey to get to class.

Climbing up and down the stairs several times in a day makes me really tired, so I try to reduce my movements. For example, I do not attend assemblies; I stay and listen to teachers' speeches while in class. I also limit the number of times I go to library since it also requires climbing stairs. Sometimes I skip having eats during break time as I have to double the burden of stairs and the rough way to the canteen.

When it comes to clean intermittent catheterization, I share the same latrines with others and this poses a great health risk to me because of the unhygienic schools latrines.

For sports, I only watch other students play for fear that if I played, students may push me down and this may further hurt me.

I believe that if my accessibility challenges were not as many as they are, my academic performance would also have been far better than it is now.

As far as the built up environment is concerned, it is important that it should be barrier free and adapted to meet the needs of all people equally. As a matter of fact, the needs of

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When the sky is not the limit

“I would like to thank UN-APD for the Accessibility Standard guidelines. ..We are limited to a certain way of life because our movements are limited. We cannot access most places. Our roads are not accessible neither accessible transport system for chair users, to mention but a few. Most of the banks, schools and hospitals around us don't have ramps or signage.”



The Deputy Speaker Jacob Oulanya after receiving a petition from the Ephrance Nadunga

From Page 8

youth with disabilities coincides with the needs of the majority of people with varying abilities and disabilities.

Vote of thanks

On behalf of all persons with spina bifida and hydrocephalus conditions, I thank IF Child Help Uganda for the great help extended to us in the provision of medical materials necessary to keep us dry and able to fit in the society.

Growing with spina bifida has been a great challenge. I have grown up struggling to access health centers, schools and other places. This is because while constructing such places, no one had my physical condition in mind.

I would like to thank UNAPD for the Accessibility Standard guidelines. They are to guide architects, engineers and property developers on how to construct places like schools, hospitals, churches as accessible as possible. This is a big step towards accessibility in our nation.

However, these standards like most of the good laws in our country have remained on paper because there is poor implementation. We are limited to a certain way of life because our movements are limited. We cannot access most places. Our roads are not accessible neither accessible transport system for chair users, to mention but a few. Most of the banks, schools and hospitals around us don't have ramps or signage.

Parliament's task

We too have a right to access schools, banks and health cen-

ters. We are thus making a humble appeal to the Members of Parliament present, the Speaker of Parliament and all those in charge of making laws and implementing them to think about us and ensure that accessibility is very high on the agenda while planning for our country especially when it comes to construction.

We shall contribute much more to country's development once given the opportunity through easing accessibility. No matter the challenges as a result of spina bifida, we are typically developing individuals not different from those without spina bifida and hydrocephalus. We can live meaningful lives and also contribute to the communities we live in provided we are always put in mind and included in societal issues.

We have a right towards use of roads, accessing healthcare centers, banks and above all we are growing into adults who would like to contribute towards the growth and development of the nation but without accessibility, we are limited which makes it impossible.

We request the government to enforce already existing laws towards accessibility and the Accessibility Standards as developed by UNAPD be enforced so that all buildings are accessible to everyone. With accessibility the sky is the limit.

Editor: This is a slightly edited testimony that Ephrance Nadunga presented at the International Day of Spina Bifida and Hydrocephalus.

Ten babies born with spina bifida every week at Mulago

BY FLAVIA LANYERO

THIRTY-FIVE-YEAR-OLD, Pascal Nabakooza, calmly sits by her three weeks old baby, Angelina's bed awaiting news of when her operation will be done.

Baby Angelina was born at Mulago Hospital with a cranium bifidum defect, a condition where a child is born with sac-like protrusions usually on the back of the head.

"If you knock the swelling by mistake she cries, I think it hurts," Nabakooza says.

She keeps on caressing the baby and when I tell her that her baby is cute, she is quick to say that I am only saying that out of sympathy.

"I saw the defect for the first time when she was born. I was surprised I didn't expect to see anything like that," she says.

According to Dr Michael Muhumuza, the Acting Head of the Neurosurgical unit at Mulago Hospital, these conditions called congenital anomalies are increasingly becoming common, with neural tube defects (NTDs) the commonest at Mulago Hospital.

When and how it occurs

NTDs are birth defects of the brain and spinal cord which occur during the first one month of fertilisation or conception just like the other congenital anomalies. "When the process of forming the neural tube goes wrong (when the structure that develops into the brain and spinal cord, fails to close completely) it results into defects in the brain, skull, spinal cord and vertebrae," says Dr Muhumuza.

Data from the neurosurgical unit of Mulago Hospital shows that about seven to 10 babies are born every week with this condition at this hospital alone. The commonest NTDs occurring, Dr Muhumuza says, include; spina bifida which presents with a sac-like protrusion on the lower back of the baby, cranium bifidum which is a sac-like protrusions usually on the back of the head, and hydrocephalus which is a big head among others.

Caesarean- the only alternative

Babies with these defects can only be born by caesarean and although surgeries are done to close off these defects, Dr Muhumuza says, depending on the location and severity of the abnormality, babies usually suffer life-long irreversible disability like paralysis of the legs, inability to control urine or stool, intellectual disability, vision problems and seizures.

"The most unfortunate thing is that most people know that they are pregnant after one month when they miss their peri-



Baby Angelina born with spina bifida at Mulago hospital

ods and if any problem has happened, it is too late to reverse it," says Dr Muhumuza.

Family Planning

"So it important to plan for a pregnancy so that one can start taking foods rich in folic acid or tablets at least one month before pregnancy and during pregnancy," he says. "Also important is to educate the masses to plan for their pregnancies. Folic acid is quite a cheap vitamin but you might find that the people do not know that they need to feed on them."

Folic acid is a vitamin abundant in green vegetables. It is also found in liver and fruits. Although many women do take these vital vitamins during pregnancy, it may not be of great help if these foods were not taken within the first 28 days of pregnancy. Dr Muhumuza also advises pregnant mothers to have three dimensional scans which can clearly show how a foetus looks. This, he says, can help doctors advise couples accordingly as at times, the foetus is severely deformed and the babies may not be able to survive.

The issue of planning families however remains a big challenge in Uganda, a society where people still prefer to have many children and women are not empowered to negotiate for the number of children to have and when.

Nabakooza, for instance, says she got pregnant while still breastfeeding the baby before Angelina, as her husband would not allow her to use any family planning methods. Dr Muhumuza says there is urgent need to educate women in the child bearing age about planning pregnancies to avert these cases.

Editor: This article and picture were published in Daily Monitor, January 23, 2013

Bothered but not shattered

BY BEAUTIFUL KAMUKAMA

I **AM** Beautiful Kamukama, 12 years old and studying in Primary Five. I am glad that despite all the challenges I have gone through since birth, I am able to go to school.

I was born with spina bifida and because of nerve damage; I have a problem of controlling urine and difficulty in walking. At school, I need a separate room or a very clean accessible toilet, where I can use a catheter to remove urine so that I can be clean in the society and at school.

However, it has been really a big struggle for me to get a school where I can learn with others. Today public schools are still built when they are not accessible to children with special needs. Every day I walk with difficulty for over five kilometers to a private school because I was not accepted to study in the nearby public schools.

The government of Uganda advocates for inclusive education as compared to special education. However in reality, inclusive education remains very good on papers but not practiced in our areas. Schools are not prepared to meet the needs of the children with special needs.

This can only be possible when the school is accessible for me and I can fit with the other pupils in the school. Teachers should also accept us children with spina bifida and or hydrocephalus who have big heads, difficulty with walking and controlling urine.

They should know that we are not stupid but we can learn and even perform better than the 'normal' children in class. Studying from a class where I feel loved by teachers and fellow pupils helps me fit in the school environment and this helps me study well and get good grades.

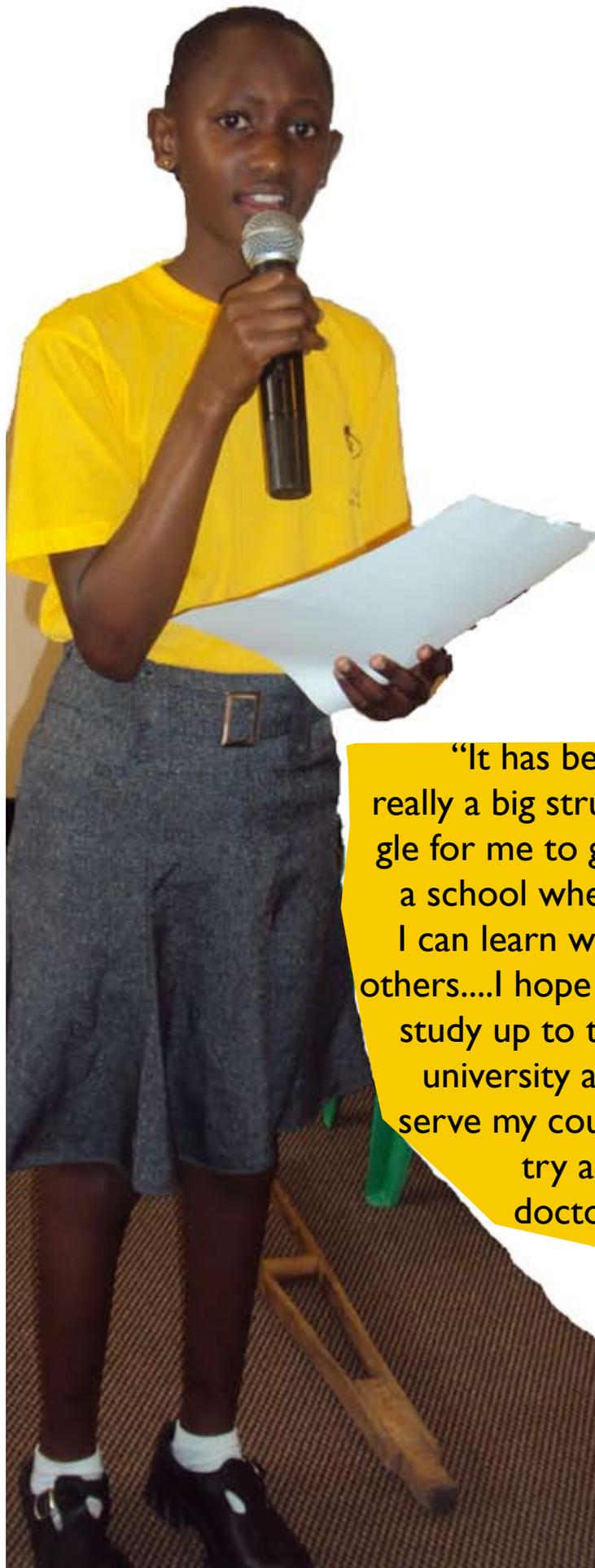
Most of the children with challenges like me are not allowed in schools by head teachers. Parents have struggled to have their children enrolled in schools. Our parents have been empowered through trainings to sensitize the school teachers and administration about our conditions but the teachers need to change their attitude towards us. This will also make fellow pupils change their attitude towards us. The school environment including class rooms, latrines, offices and the compound also need to be accessible so that we can move about and around freely.

I humbly request that inclusive education should be made practical by adjusting the school facilities to meet the needs of all children including us.

Thank you for listening to me and I hope to study up to the university and serve my country as a doctor.

Editor: Kamukama made this presentation at the World Spina Bifida and Hydrocephalus Day held in Kampala on October 25, 2012.

“It has been really a big struggle for me to get a school where I can learn with others....I hope to study up to the university and serve my country as a doctor”



“My horrible experience of giving birth to a child with spina bifida”

BY CONCEPTA N. KATENDE

MY NAME is Naluyima Concepta Katende, the mother of William Darlington Mayinja. He was born with spina bifida and later developed hydrocephalus. Like any mother, I prepared to have a healthy baby. I produced by caesarian section and after regaining my consciousness, I asked for my baby. Nobody was ready to tell me what had happened. The baby was hidden from me for two days and kept in a nursery until I became rough to the nurses. They later told me that the baby had a wound on the back. I asked whether the baby had been cut during the operation. They eventually told me that the baby had a natural wound from God.

I kept wondering what wound could that be but my attendants, the nurses and the doctors could not tell what it was not until another doctor called Dr Nakaketo from Mulago Hospital came and explained to me what it was. She explained to me and referred me to CURE children's hospital in Mbale District.

Just imagine the pain I went through because this was my first time to see such a baby and with less information about my child's condition. Everybody feared my baby including nurses.

Spina bifida and hydrocephalus are not new in Uganda, but not much has been done to make the people aware of the conditions, how the patients can be handled, where they can be treated, or even how it can be prevented. When you produce such a child, stigma is all around you, people come to stare at the funny baby: some think you're bewitched; some medical personnel fear to touch; relatives disown you. If you're not lucky enough, the husband runs away and you remain all alone with your baby in dilemma.

I appreciate the efforts of IFSBH International, IF Child Help-Uganda, CURE children's Hospital, Katalamwa Cheshire Home, CoRSU, OURS, Lilliana Foundation, AVSI and most importantly parents who take care of spina bifida and hydrocephalus children in their respective capacities.

Helping hands

As parents of children with spina bifida and hydrocephalus, we appreciate the work done by the stakeholders in the care of our children with spina bifida and hydrocephalus. Surely they have struggled to give us the right information regarding the care of our children. If it was not them, these children would have fewer chances to survive.

Some of us learnt about the conditions of our children when we gave birth to them. At the time very little was known about these conditions but now with IF, CURE, Katalamwa and OURS, we have received sensitisation through radio programs and sports, workshops and trainings, TV programs, during clinic days, brochures and posters.

Prevention

Many mothers all over Uganda, however, continue to give birth to children with spina bifida and hydrocephalus. Research has shown that 70% of these impairments can be prevented by increased



Concepta Katende with her son Darlington Mayinja

intake of folic acid supplementation, eating food rich in folic acid like fruits, vegetables, mushrooms, meat, and liver, among others and eating foods that have been fortified with folic acid. We as women know it very well that 95% of pregnancies are not planned for and this brings in the importance of taking a folic acid tablet a day to prevent some of these birth defects.

We parents through our stakeholders have tried to raise awareness and urge mothers to eat food rich in folic acid and swallow a folic acid tablet every day. However, the issues of fortification requires a law to be passed on mandatory food fortification so that it becomes a law that can be implemented by all the industries. This will make the majority of the population enjoy foods rich in folic acid and other preventive methods can compliment it. This will help to greatly reduce the prevalence rate like the case has been in South Africa and many other countries that have mandatory food fortification.

We would also request for the improvement in the health care system because many children acquire hydrocephalus at birth because of poor health service delivery. If more attention is paid to children and mothers at birth, then we shall register fewer cases of hydrocephalus,

The cost of treatment is far greater than the cost of prevention. Spina bifida and hydrocephalus patients require long life care which is very expensive compared to the preventive methods.

It is our appeal that we all join hands to reduce the increase in number of children born with spina bifida and hydrocephalus through massive sensitization in the media and enacting a law on compulsory food fortification like other countries have done.