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**SWAZILAND**

IMPROVING QUALITY LIFE AND HEALTH SERVICES FOR THE EPILEPTIC CHILDREN  
IN SWAZILAND

## A REPORT ON COMMUNITY AWARENESS CAMPAIGN ON EPILEPSY CARE CONDUCTED IN SWAZILAND IN THE PERIOD 3 NOVEMBER 2008 UNTIL 11 FEBRUARY 2009

PREPARED FOR;

NATIONAL CHILDREN'S COORDINATING UNIT-NCCU

AND



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## **Acronyms**

WHO

IBE

FODSWA

SEO

SWANNEPHA

SNYC

World Health Organisation

International Bearue for Epilepsy

Federation of the Disabled in

Swaziland

Swaziland Epilepsy Organisation

Swaziland National of People LIVING

With HIV/AIDS

Swaziland National Youth Council

## 1.0 INTRODUCTION



*Front: Victory Irwin Chairman Epilepsy Board Of Truseess Mr. Zwane(WHO) Mr. M. Mahlalela Epilepsy Director  
Back: Mbabane Schools SOS, St. Marchs, MDS, St. Francis and Ekwetsembeni Privet School.*

Epilepsy is a physical condition characterised by unusual electricity in the brain. It is a symptom of a neurological disorder and shows itself in the form of seizures. Epilepsy is the tendency to have recurrent, unprovoked seizures and seizures are caused by a temporal change in the way the brain cells (neurons) work. Epilepsy is neither a disorder, not a disease, illness, psychiatric disorder nor a mental illness; and it is not contagious. Epilepsy affects all people, sexes, all ages, all races, people of all levels of intelligence and of all social backgrounds. Most people with epilepsy are diagnosed before age 20, but the onset can be at any age. Many children with epilepsy do outgrow it and are able to live drug-free and seizure-free as adult.

As seizures are mostly unpredictable they may cause a disruption or interruption of the person's daily routines. Many people who have epilepsy however state that the actual seizures do not impact negatively on their lives, but that it is the ignorance, stigmatization, discrimination and lack of knowledge of society that impact very negatively on their lives. Due to the fact that society does not understand what epilepsy is and people often fear the condition, they discriminate against people with epilepsy, such as not allowing them to participate in social events, careers, etc. this entails people with epilepsy turn to be discriminated in the workplace, after having declared their status some may be demoted even though they are highly qualified for their jobs.

The same often happens to children who have epilepsy and they experience discrimination at schools, within sports or amongst their friends. This can severely affect a child's self esteem and should therefore be immediately addressed. Parents often find it very difficult to accept the diagnosis of epilepsy in a child. Parents tend to experience a grieving process and may need assistance and counselling during this time. It is important to know that persons with epilepsy, both adults and children, can live active and normal lives, as long as society is willing to accept and learn more about epilepsy. An alarming factor is the fact that the prevalence of epilepsy in the developing countries such as Swaziland is increasing steadily more especially in children.

Swaziland Epilepsy Organisation saw the above issues and the need to address them urgently and that is what prompted the organisation in choosing its targeted group or respondents.

## 2.0 OBJECTIVES

The objectives of the project were mainly to promote awareness on epilepsy issues mainly on literacy and epilepsy care. The project also seeks to strengthen the capability of community based volunteers (bagcugcuteli), teachers, and religious leaders on tackling epileptic issues.

Six (6) Tinkhundla centres termed constituencies were visited. Workshops were conducted, mainly for the benefit of epileptic groups, teachers and community caregivers and not forgetting the family care givers who live with the children who are epileptic. The project's focus was community based Epilepsy awareness campaigns whereby IEC materials were distributed and mass education workshop took place to effectively mobilise communities on epilepsy prevention, care and support.

The Tinkhundla centres that were visited are; Zombodze emuva, Nkhaba, Mbabane East, MpolonjeniSteki, Mkhiweni, , Mafutseni, A one of its kind session was done with the boys (regiments) who had gone to attend the Lusekwane which is a well known culture in Swaziland. This was well attended by the boys with their Tindvuna's as this was just before the annually celebrated Incwala ceremony (popularly known as the Prayer for the Swazi's)

The targeted groups to receive training on awareness of epilepsy were, community members, children afflicted with epilepsy who are in school and those who are out of school, and the teachers of schools surrounding those Tinkhundla centres. The topics which were discussed with the targeted audience included *inter alia*;

- What is epilepsy
- What causes epilepsy
- Can any one have epilepsy
- Does epilepsy strike at a particular age
- Types of seizures and what can bring on a seizure
- Treatment of epilepsy
- What to do during a seizure
- How epilepsy affects a person's life

- The role of the teacher
- Epilepsy and learning
- Possible seizure triggers at school
- Memory and concentration which are essentials for school
- Is Epilepsy contagious
- Teaching strategies for teachers
- Emergency and First Aid Action
- Rights of people with epilepsy

Teaching was conducted in an interactive manner whereby the audience was lectured and following the lectures were discussions which included questions and answers. The last workshop which was attended by students and teachers from different schools in Mbabane ended up by an interesting competition and prizes amounting to E2000 were set to be won on the drawing date. Students were asked to write a summary on what they have learnt about Epilepsy and the best essay will appear on the daily newspaper. This was set in order to ascertain whether the project's goal was reached with students.



*Mkhiweni Constituency Community and Kutsim'leni Primary School*



Providing the lectures was;

- ❖ Dr. Delsile Pearl Maseko-Magongo... MMED-NEUROSURGERY stationed in South Africa
- ❖ Two(2) qualified nurses working for The Government Hospital Swaziland
- ❖ Mr Mbusomuni Mahlalela ..... National Director for SEO
- ❖ Six (6) people from the administration office
- ❖ Thobile Dlamini..... Legal officer for SEO.
- ❖ Mr. Khanyakwezwe Dlamini.....SEO associate
- ❖ Michael Hlophe (qualified nurses )Mbabane Government Hospital
- ❖ Mrs. Dluldu Nhlango(qualified nurses ) Government Hospital
- ❖ Mrs.Nomsa Mnisa (qualified nurses ) Program Manager Epilepsy
- ❖ Balindzile Hlophe from SEO administration
- ❖ John Paris – a journalist and SEO associate

The number of people who received lectures from the different stipulated workshops totalled----- . This includes -----community members, -----students, and ----- teachers respectively.

### **3.0 About Swaziland Epilepsy Organisation**

His Royal Highness Prince Bandzile is the Patron of the organisation. The Swaziland Epilepsy Organisation was formed in 2003 and formally registered in 2004 by the Company Act 1912 under Section 21 as a non profit making organisation. Mr Mbusomuni E. Mahlalela who is the co. founder was declared epileptic when he was 14 years and had no access to proper medication and information about the issues surrounding epilepsy. After a long time suffering from the extenuating circumstances surrounding epilepsy he subscribed to membership with the South African Epilepsy Organisation and this prompted him to establish the organisation as his brain child.

Since the NGO's establishment Mr Mahlalela had been dedicating his life, assets, and other resources for the betterment of the organisation with no financial assistance which made the administration of the office difficult. Things began to ease a bit as the organisation affiliated to Government of Swaziland under the Ministry of Health and Social Welfare, NCCU, IBE, FODSWA, etc. A Board of Directors was formed and the organisation hopes one of the good days the government of Swaziland will see the seriousness of the epilepsy issues and give out a subvention towards the conditions surrounding epilepsy.

To date the national director Mr. Mahlalela is still a volunteer as he has no salary. The organisation has other volunteers who include the secretary, legal officer, associates, and the board of directors.

The organisation needs financial assistance to cater for the administration expenses, and a car or any means of transportation for the running of the day to day errands of the office and providing assistance to the affected population in the rural and urban areas of Swaziland.

## 4.0 ACTIVITIES



Mbabane East Inkhudla, different schools participated.

Even though workshops were the main activities through out the project, other activities did ensure which made the project a huge success, this includes among others;

- ❖ Awareness through the television
- ❖ Awareness through radio
- ❖ Awareness through the printing of T-Shirts
- ❖ Awareness through the playing games
- ❖ Awareness through indulging in cultural activities

#### 4.1 Television



*John Peres at Kusile Breakfast Show (Swazi TV) Dr. Makongo*

Swaziland has 2 powerful television stations which have a wide national coverage and these were the ones utilized by the Swaziland Epilepsy Organisation to enhance the project in being the huge success that it has been. Swazi TV and Channel Swazi are the TV stations that ensured that the Awareness campaign turned a huge success. The organisation was featured in the news bulletin in both Siswati and English in both stations were they were covered at some of the different Tinkhundla centres advocating on epilepsy issues. The organization's national director together with Dr Delsile Maseko-Magongo was featured in the morning breakfast show termed Kusile Breakfast Show in Swazi TV.

#### 4.2 RADIO

Awareness was raised through radio programmes where people were even allowed to ask questions on pertinent issues and get answers live on air after having heard the lectures from the Dr. such programmes include among

others; Letisematseni( The latest broadcast) Letishisako (Today's Hottest News), Nawe unaDokotela (you also have an opportunity to a doctor).

A special programme was also transmitted at V.O.C (Voice Of the Church) a Christian broadcasting unit in Swaziland. It can also be added that the organisation has its own facility of recording the events which includes a video camera and a tape recorder; this ensured the smooth transfer of information coverage of all the events that ensured during the workshops.



*Radio live Program Nawe UnaDokodela Mr. Mbusomuni Mahlalela and Dr. Magongo (SBIS)*

### **4.3 T-SHIRTS**

The printing of T-Shirts with messages on epilepsy were presented to some of the staff working for the television station and radio broadcasting unit. This includes among others the CEO's of the different stations and the news covering crew. It can be highlighted that each time the organisation went to facilitate the project they would be wearing this similar branding T-Shirts.

The T-Shirts afforded to the CEO's was an expensive brand as the financial report will show. The reasoning behind this was a strategy to create a lasting

relationship with the different media houses since the organisation does not have money or any means of tokens of appreciation. So this was our way of ensuring the CEO's will do business with the organisation at the same time passing epilepsy news.

#### **4.4 GAMES**

His Royal Highness Prince Bandzile who is a patron to the organisation donated games he came with from school which have information on epilepsy. This games by frequent use improves one's knowledge on epilepsy facts and they were used mainly to draw attention to students and mainly the boys (regiments) found taking part in Lusekwane in the Royal Residents. Schools were donated with boxes of these games to keep and use under the teacher's guidance.

#### **4.5 CULTURE**

This was not included in the proposal but the organization saw a once off opportunity and grabbed it. The boys (regiments) came from all spheres of Swaziland even though a section was picked randomly and attendance was good and with an interpretation of questions found in the games information as passed successfully. This cultural event turned to be an indicator to the organisation and the people taking part that no information is passed around on epilepsy awareness. Information picked up from the regiments entailed that epilepsy is understood to be a witchcraft practice or a bad omen that befalls the homestead where such child is born reasons being the ancestors are not happy about a certain issue so they let this befall the family. They were assured such stories are not even close to the causes of epilepsy.

## 5.0 CHARECTERISTICS OF THE GROUPS

The groups demonstrated a high interest in learning about epilepsy in the workshops. It was apparent they had not had the chance to be taught specifically on epilepsy issues and it seemed this was a new topic to them altogether.

### 5.1 The importance of having teachers as a targeted group .How it impacts on the child?



*Teachers for Schools under Nkhaba Constituency*

It was important to have teachers as a targeted group so that teachers can recognise seizures and respond appropriately to seizure types, and to encourage educators to be more accepting and understanding of the child or adult with epilepsy.

Teachers also showed appreciation on information they received as they even shared light on their various experiences that they have encountered with epileptic children. It is an unmistakable fact that children turn to spend most of their precious time at school with teachers than their parents. This entails that

the teacher plays a central role in acceptance and self –development of the child who has seizures in the classroom.

Sufficient knowledge and understanding of what epilepsy is will allow the teacher to educate the other students and influence the way in which children respond to this disorder. The teachers confirmed that children who are affected by epilepsy often feel isolated and 'different' from the rest of the class. They then turn to live in fear that will have a seizure in front of their peers.

Aside from seizures themselves, there are no outward physical signs that make children with epilepsy identifiable. Teachers were informed that epilepsy should not impact on the children's normal growth and development. They are as active and interested in the same experience as their peers.

Early recognition and treatment is important because children with epilepsy can face problems in school. This includes;

- Learning disabilities
- Safety risks
- Behaviour problems
- Chronic absenteeism

As epilepsy is a chronic disorder, the occurrence and frequency of seizures are unpredictable. The child, the family, and the teacher must learn to live with this uncertainty, and not let fear of a seizure interrupt a normal life.

Children with epilepsy exhibit the same wide range of intelligence and ability as other children. This means children do not require special education simply because they have epilepsy. Frequent seizures can affect the learning process, causing cognitive delays and the same happens with absenteeism which can impact the learning process by causing the child to miss socialization opportunities and class instruction. It is important to note that negative reactions from peer groups and teachers to epilepsy can adversely affect the child with a seizure disorder.



## 6.0 OVERVIEW OF THE EXERCISE



*Mkhiweni Inkhundla Children's From Different Schools to get Epilepsy Awareness, 100 loafs of Bread and 7 bags of Rise*

### 6.1 Sampling method

On our sample, most of the areas turned out to be rural based than urban. This is because most people in urban areas have an advantage of being closer to libraries, this entails they have access to information as and when they need it. The only urban area in the sample is Mbabane East. This is because there lots of schools in Mbabane and those who participated are those who were available on the stipulated date as afforded permission by their respective school principals and the Ministry of Education. The organisation made an application to the Ministry Of Education to convene the workshop and permission was afforded respectively.

Each Inkhundla centre was visited three (3) times, each day was set to teach; the community as a whole, teachers, and last but not least the children. When

we start the workshop we tried to make sure that we circulate a register so we keep the data of the people who actually attended the workshop. Normally we would break for tea at 10:00Hrs and for lunch 1300Hrs and we would end the session at 1600Hrs. Questioners were also used to determine the knowledge of epilepsy in the community, and they were handed randomly.

Our first assignment where the workshop was to be conducted was Mpholonjeni Siteki, unfortunately our visit proved to be in vain because the Bucopho benkhundla had an urgent meeting which had to be called on that specific date. This meant resources utilised in preparation for that specific day were wasted as the financial report will point clearly. Attempts to do a return job proved impossible because the same excuse kept ensuring as this meant we had to wait for the meetings to be concluded before we start the workshop which limited our time with the community.

### **NKABA INKHUNDLA**

Our second assignment was at Nkaba which was visited between the dates 13-30 November 2008. The groups demonstrated a high interest in the epilepsy lectures. It transpired that they were happy to understand even the signs and symptoms because in the past they shied away from such children mistaking their symptoms for diseases associated with witchcraft. The teachers even confessed that if they had been taught earlier they would have been able to keep more children in school as opposed to the high dropout rate attributed to epilepsy in the area, which could have been prevented.



St. Paul's Primary at Nkhaba Inkhundla

## **MAFUTSENI INKHUNDLA**

Mafutseni Inkhundla was visited between the dates 10-15 December 2009. There seemed to be nothing particular about this Inkhundla. The attendance was good compared to that of Nkhaba and people were so fascinated by the issues of epilepsy. They even pointed figures to the organisation that since its establishment they haven't heard anything about epilepsy that means we don't know how serious this issues are in the rural communities. The organisation pointed it out that it is because of the financial constraints that the communities were delayed with information. The time spent proved to be little as people were starving for more information about epilepsy. They confirmed that they saw the high rate of HIV infections in the area as caused by the fact that people took advantage of people even children who are epileptic or even those with disabilities. They confessed that in the community they have children who are epileptic and now disabled because they were not treated in their early stages of epilepsy, this children have been treated for STI's and no one has ever came out in the open to claim having had intercourse with them. This issue is serious a matter since the two girls come from the same household and the mother explained that initially she had three children who were epileptic the other one, a son is in a controllable situation. She even pointed out that she suspects witchcraft. Asked what steps she has taken for the safety of her children since they rely on her, she said she has

since enrolled them on taking contraceptives. Clearly this is dangerous and can not stop the spread of STI's and HIV infections.

From such a story the Organisation was convinced that counselling is very important to people who are affected by epilepsy one way or another mainly the caretakers of those who are epileptic. This includes among others the parents, close relatives who may stay with them e.g. grand parents and the whole community, so they keep an eye on such children.

### **MKHIWENI INKHUNDLA (LUBE)**

The third place to be visited was Mkiweni inkhundla at Lube in the period between 19-23 January 2009. There were fourteen(14) community members and in this community most of the attendants seemed to know something about epilepsy as they confessed to have seen some form of epilepsy. About five (5) residents confirmed that they have had a member of the family who was epileptic due to the lack of early treatment now the attacks are heavy and uncontrollable by medication, in the same household a son has had to repeat a class four (4) times and this is caused by epilepsy.

Another person testified that her daughter had since passed away because of epilepsy caused by HIV related sicknesses including TB. The epilepsy had been on an advanced stage such that her daughter had to go to the psychiatric centre.

In the same community a woman testified that he has a violent son who is an adult who is epileptic and does not want to get treatment, in fact he does not want to discuss this issue with any one.

This is one community who showed to be free and non discriminative on residents who are epileptic and did not have a problem in sharing ideas and discussion their experience on any health issues.

## **ZOMBODZE EMUVA INKHUDLA**

In this community twenty (20) people attended the workshop on the period between 6 and 8 January 2009. In this community the main problem was finding means to medication for the children because the drugs are not available in health facilities especially those at community level. Due to the unavailability of drugs at the health facilities children suffering from epilepsy are forced to get such drugs from pharmacies which are expensive and unobtainable because most families live under poverty. The worse scenario is the fact that even the clinics in the community lacked health personnel who can attend to epileptic patients.

According to the Organisation this is not a true reflection since normally a qualified nurse can see an epileptic patient then the issue which may need attention may be the drugs being transported to the community clinics as this is one of the poverty stricken areas in Swaziland.



*Zombodze Emuva School*

## **MBABANE EAST**

This was the last Inkhundla to be visited and it was the only one where monitoring was done. The assignment was done from 11-14 February 2009. This constituency is the only one which is in the urban area. The children mainly consisted of high school students and a total five (5) schools in Mbabane were in attendance, namely; St Marks, St Francis, Mbabane Central, Herman Gmermiar S.O.S and Mater Dolorosa. The total number of attendants was fifty (50) made up by twenty five (25) teachers and twenty five (25) students. Nearly the same response was attained from the workshop except that the students posed different sets of questions than the general ones we had been used to and would have been able to answer which entailed they study science subjects, especially biology. It was like the schools were competing among themselves in turns of asking questions. Fortunately a neurologist from South Africa was facilitating so they had all their curiosity filled.

The lecture proved to be different and successful. This is because a competition was launched the same day where all the attending students were allowed entry into the competition. They had to write an essay about epilepsy in five hundred (500) words and they had to do this in 5 days. An amount of two thousand Emalangeni E2000.00 was set aside to be won by the best essay writer and the school the student attends. St Marks took the first price and Mbabane Central got the second price, while St Frances High School came third. These three winners got trophies which they won on behalf of their school.



*Siyabonga Menon first Price St. Marks High School*



*Third Price was St. Frances High School*



*second price was at Mbabane Central High*

## **7.0 ISSUES WHICH AROSE**

On the whole project of awareness campaign on epilepsy there were many issues which arose in the field. This include inter alia the fact that;

- the period for the workshop was too short –since all the sample groups demonstrated a high interest in the epilepsy lectures, they were disappointed on the minimal time they were afforded. They requested more training for longer periods of time, so that more information can be availed and ensuring that there is still time for discussions of any emerging issues.
- There are many misconceptions surrounding epilepsy- a percentage of the Swaziland population still belong to the old school of thought who presumes epilepsy has everything to do with being bewitched.
- Access to treatment by children who are epileptic is difficult- most health facilities in the communities which include clinics do not have epilepsy drugs. In poverty stricken communities children with epilepsy are left unattended because family can never affording buying the drugs in pharmacists.
- Stigmatisation- there is a lot of stigmatisation associated with the condition of epilepsy. This is further influenced by that services for people with epilepsy is only available at psychiatric centres, this creates the perception that epilepsy is a mental condition. The same is a problem in the Mbabane Government hospital were people with

epilepsy are attended to near the VCT. The discrimination associated with HIV and Aids lead the people with epilepsy to be afraid to get the monthly supply of drugs because they will be mistaken for visiting the VCT.

- Diagnosis and treatment-skilled health professionals are needed for working with people with epilepsy in Swaziland since it is difficult to obtain proper diagnosis for epilepsy. The mere fact that there is no one specialist around the health centres in Swaziland; entails people with epilepsy are denied maximum opportunity to health care. This plainly means there is an infringement to their human right which is stipulated under the Bill of Rights and in accordance to The Constitution Of Swaziland 2005.
- Support groups need strengthening in terms of current information and teaching aids.
- Income generating projects are requested by the support groups so that they are able to conquer poverty and any other socio-economic factors thus turning life to be worth living.

## **8.0 CHALLENGES FACED**

- Transportation is a problematic issue as the organisation does not have its own transport. This has a negative effect on the financials as reflected because most of the facilitators had to be given a substantial sum for travelling to the different venues.
- Unavailability of sufficient teaching aids is an impediment to the organisation reaching its goal such as booklets, overhead projector. This is because the organisation has no funding to purchase such.



## 9.0 RECOMMENDATIONS

- The people in the communities felt that the sessions were too short yet they needed more time to learn about epilepsy, where more content would be available. They recommended the organisation find more time and visit them and teach the traditional healers on how to see and then confirm symptoms of epilepsy. This will enable those who have faith in traditional healers to take their children for treatment all in good time.
- At the end of the lecture, one-on-one interviews should be conducted since that will benefit some of the affected but still shy to talk about issues of epilepsy in fear of stigmatisation.
- Brochures and other communication materials should be translated to our local language (siSwati) for easy access to information to all.
- Some people turn to be less interested on information but turn up only when it is time to eat. This meant in some areas less people were registered but more people turned up at the dining halls to eat. Most of the people would be the high ranking officials in government or in the community such that it would turn up to be difficult to turn them down merely for food.
- Education session should be controlled so that they are short and kept in line with the agenda failing which the life experiences confessed by individuals turn to use up more time than the initial lectures.
- The organisation should conduct a (five) 5 day training for teachers at schools during school holidays which should be residential
- Conduct weekend camps for children where they can learn about epilepsy and also learn each other's positive living when one is living with epilepsy.
- Capacitate community support groups by impacting them with sufficient information on the management of epilepsy.
- Initiate income generating activities for support groups by liaising these community groups with organisations which can capacitate them with the know how on income generating activities and funding.

**10.0 Attached is ;**

- **calendar for all the activities conducted**
- **statement of accounts**
- **workshop programmes**