

WE COUNT

Issue - 05

November 2007

INSIDE

Editorial

1

Vision / Mission

2

Message from Founder Director

2

"I have left them all to God" The Story of Rashida Hamidu

3



A struggle with stigma
The story of Fatuma Mohammed Kaisi

9



"Far Better Now than before" The story of Florence Amoo

15



Unwavering Hope
The story of Namara Agnes

21



The Challenge of Destitution
The Story of Martha Njoki Wanjiru

27



Notes

31

Editorial

Once again, we welcome you to the fifth and latest edition of We Count magazine. This edition attempts to look at involvement of the individuals whose life stories are recounted here in community level user groups commonly called Self-Help Groups (SHGs) in the operational areas of BasicNeeds. The work of BasicNeeds and extensive partnership with mentally ill people and people with epilepsy and their primary carers themselves and with the national health services and local organisations has brought in its wake the ever-increasing desire for mentally ill people and people with epilepsy and their carers to represent themselves.

Although this has gained momentum over the last two years SHGs are in their infant formative stages. Nonetheless, their impact on mentally ill people, people with epilepsy and primary carers individually and collective has been tremendous.

Mental illness leads to isolation and discrimination in all facets of the lives of people who suffer it. They mostly lose their affiliation to groups and organisations that they belonged to prior to their illness. People who get mental illness during their childhood never get to belong to a group or even associate with their peers

because of their condition. This social ostracism marginalises mentally ill people, and so does not give them the opportunity to play a part in the development of their communities. This trend has resulted in the exclusion of mentally ill people as well as mental health issues from the policies and plans of the larger society.

It is in this light that BasicNeeds associates with and facilitates these SHGs as they are the surerest of broad-based grassroots and empowered national movement of mentally ill people and people with epilepsy and primary carers articulating their own needs and advocating for change that will recognise them as full members of society.



Peter Yaro
Chair of Panel

We hope you enjoy this issue just as you must have of the previous ones. We are interested in getting feedback on anything about this edition. Send us a letter, drop us an e-mail, or just call us and we will find space to feature your views and opinions about this magazine or even our work.



Alando Bernard
**Project
Coordinator**

Vision

Our vision is “that the basic needs of all mentally ill people, throughout the world are satisfied and their basic rights are respected.”

Mission

“To initiate programmes in developing countries which actively involve mentally ill people and their carers/families and enable them to satisfy their needs and exercise their basic rights. In so doing stimulate supporting activities by other organisations and influence public opinion.”

Disclaimer

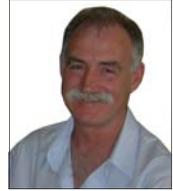
All the stories and photos featured in this issue were freely and willingly constructed with the expressed permission of the mentally ill people and their families. This publication is purely to educate the wider society about mental illness and challenge them to treat mentally ill people with dignity. These stories have been edited even though their originality have been maintained throughout.

Message from Founder Director

All the people in this edition of We Count are girl children or women. The relations between children, age groups, and above all the gender as it affects the five people in this magazine are powerful and very evocative. What a difference in life a good mum and dad make for Rashida and how tough still is her life as the children around

beat her up and victimise her. If Rashida at aged nine is at one end of the age spectrum then Martha Njoki is at the other end living as she does alone, in a great slum in Nairobi.

Each life story is precious in its own right, yet in this edition of We Count we see all the difficulties faced by people as the five grap- **Chris Underhill** ple before our eyes with conditions that were initially not known to them, that were not diagnosed for a long time, and whereby treatment is often very late in coming. Alongside this fact we see a revitalising of life itself as work and contribution to family life is entered into once again.



Those of us who work for Basic-Needs know that not all life stories can end well. Fatuma, despite the evidence that her condition is now stable, is yet to be accepted in school. Martha Njoki is often lonely and ekes out a living and a life in one of Africa's great slums.

In common with these two cases and also those stories that seem more optimistic we are stuck by the tenacity and will power of these women. As if to say “It is my life and I will live it to the full”. Gender, poverty, mental health all compete to make this edition an engrossing read.

THE STORY OF RASHIDA HAMIDU

Story written by: Dokurugu Adam Yahaya, Community Mental Health Officer, and Truelove Antwi-Bekoe, Research and Policy Officer, both are staff of BasicNeeds Northern Ghana Programme



**“I Have
Left them
all to God”**



A True Picture of Suffering

At a field consultation¹ in Salaga, a town in Northern Ghana, people with mental illness and epilepsy shared their experiences about how mental illness and epilepsy had changed the course of their lives. Rashida, the youngest of the group also used the opportunity to share her experience. In a small shrill voice, she passionately described her situation, giving a powerful picture of what people suffering from epilepsy endure in their communities however young they might be.

Rashida said, “whenever I am about to fall I feel as if I want to urinate”. On her relationship with her peers and children in the community, she added that “I was once playing with my friends and one of them hit me with a stick. When I hit him back, they insulted me that I should fight my epilepsy before fighting them.”

Upon hearing this, we became interested in hearing more about her story. So we immediately sought permission from her mother, who sat next to her, to allow Rashida to share her story in detail with us later. She willingly agreed and added, “I will also have something to contrib-

ute on that day. I look forward to meeting you again”.

The Family of Rashida

Rashida’s family is made up of her father, Fuseini Hamidu, mother Aisha Hamidu, Rashida herself and her two younger siblings (a girl and a boy). She is nine years old. Her father descends from a family of blacksmiths but he is currently a farmer. He and his wife are Dagombas by tribe and Moslem by religion. Aisha Hamidu engages in the extraction of sheabutter² for sale, an important source of income for the family.

When we went to construct this story, Rashida’s mother and father were present. We were warmly welcomed.

Spotting the Danger Signs

Rashida narrated how she felt whenever she was about to experience a fit. “Whenever I am about to experience a fit, I feel a bitter taste in my mouth, then I start shaking and fall down. Other times, I feel like I am being whipped with a cane and then I fall to the ground.” she explained that though she falls, she is usually conscious of whatever happens around her.

Reality of Epilepsy Sets

Rashida's mother, Aisha, narrated how Rashida came to be epileptic. "Rashida's condition started while she was living with her grandmother. She used to exhibit signs of dizziness and this later developed into convulsive episodes.

We sent her to a traditional healer for treatment and the healer confirmed that Rashida's illness was convulsion. He requested ten Ghana Cedis (GH¢ 10, GBP£ 5.20) and a red cock to make herbal preparations for Rashida, but this did not stop the illness. We went to another traditional healer called Afa Rahimu. He requested twenty Ghana Cedis, twenty Ghana Pesewas (GH¢20.20Gp, that is about GBP£ 10.07) and a bottle of perfume in order to treat our child. After his treatment, Rashida was still experiencing fits, so we sent her to another healer a neighbour recommended to us. This healer also asked for ten Ghana Cedis (GH¢10, about GBP£5.20) and a white goat.

The last traditional healer we went to requested for an amount of ten Ghana Cedis, fifty Ghana Pesewas (GH¢10.50Gp, that is about GBP£ 5.46) and a black

hen, but there was still no change in Rashida's condition. So we decided to stop visiting healers and to wait on God."

Rashida's medical file revealed that she was diagnosed with epilepsy at an outreach clinic³ sponsored by BasicNeeds in March 2005.

Living with Stigma

Mentally ill people and people suffering epilepsy suffer a lot of stigma and discrimination in this community. Epilepsy is perceived by most people in Rashida's community as a contagious disease and so invokes fear. This belief is so entrenched that most of Rashida's friends shun her company.

Rashida said, "They say if I fart and they smell the flatulence, they will be infected with my sickness. So they do not come near me. They even mock me, saying I am possessed by evil spirits. Even when children who are younger than me pass provocative comments about me, I dare not touch them because they will always call in their elder siblings to beat me up."

Aisha, Rashida's mother also recounted the humiliation she



went through at the hands of her friends and neighbours. “I faced a lot of stigma in the neighbourhood. I even quarrelled with some neighbours and friends because of derogatory remarks they made about me. Some of my friends do not want their children to play with Rashida. Some people even think that Rashida should be taken away from the community.”

“I Have Never Been to School”

Rashida is a pretty child, with enthusiasm to achieve something in life. It is her parents’ hope that she will become a useful person to herself and the family in future. Rashida should have been in school; unfortunately, she has not been enrolled because of her illness. Rashida emphasises with some bitterness “I have never been to school. My father says he will send me to

school when I am well.”

Rashida’s father confirmed that he has never enrolled her in school. “Considering how people behave towards her at home, she is likely to suffer the same rejection at school. It is best for her to stay outside school till she gets stabilised.”

Thankful to God and Basic-Needs

Rashida's father recounted that, “One day, I heard an announcement at the mosque that a doctor was coming to Salaga to attend to people with mental illness and epilepsy. We sent Rashida to meet the doctor for the first time to examine her.”

Mr. Hamidu also revealed that, in November 2005, he and Rashida participated in a field consultation

in Salaga. “At the meeting, we shared our experiences as carers about the situation we find ourselves in and our needs and concerns. We also explored ways we could better help ourselves and let others, government and non-government agencies, know about us.”

Rashida’s mother remarked that, “as a result of the drugs we have been receiving from the psychiatric nurse, Rashida’s condition has significantly improved. My daughter and I are now members of a Self-Help Group⁴ in Salaga here. We meet once every month to discuss our problems and share ideas about how to improve our lives and cope with its challenges.”

Still Hoping

Rashida’s condition that used to occur very often has reduced significantly to just once in a month, and in some months she does not experience the fit at all. Her mother says this is a great relief to them. “Now that I do not suffer from fits frequently, I am happy because I can now go to school”, Rashida said.

Reflections

This story typically reveals how epilepsy, which can be perfectly

described as ‘the silent tormenter,’ afflicts Rashida and several hundreds of children (and even adults) in Ghana and elsewhere. Epilepsy brings a lot of stigma, discrimination, isolation, and rejection to those who suffer it and their families. Rashida’s parents want to see her completely free from fits before she is enrolled in school, but the illness lingers on.

Epilepsy brings many setbacks, especially to children. They are denied access to education because of the belief that it is contagious. Even when they are in school, they usually withdraw as a result of discrimination. They also tend to disrupt lessons whenever they get an attack in class. Many parents do not want to see their children playing with a child suffering from epilepsy, leaving that child totally isolated. Neighbours attach stigma to both the patient and her/his parents. The embarrassment it brings to the family is enormous.

Rashida’s courage and the determination of her parents are evidence of their struggle to win over her illness.

Self-Help Groups (SHGs)

These are community-based groups of mentally ill people, people with epilepsy and their primary carers mainly found around operational areas of BasicNeeds programme area. They are formed with the aim of providing members peer support, including discussions about the progress of their illnesses, the general quality of treatment provided, and to educate them on the need to take advantage of livelihood opportunities in the communities.

As user groups, SHGs provide rallying points for all people affected directly and indirectly by mental illness to form a critical mass to challenge the social stigma against them and advocate for change, inclusion and better treatment at the community and wider society levels. They are the main points of contact for other organisations wishing to work with poor people with mental illness and epilepsy and their carers, as well as conduits for micro-credit and other sustainable livelihood initiatives for them.

Community groups formed, usually by vulnerable groups like women, disabled people and in the case of BasicNeeds' programme mentally ill people and their carers, to articulate and share ideas on issues that affect them and to find possible solutions. Membership in many cases is the conduit for micro-credit. Group members have a common purpose - to discuss their situations and find possible solutions to them. They also do invite Psychiatric Nurses and other resource persons to educate them on their conditions. Self-help groups are supported by BasicNeeds to start-up and undertake activities as a group. This is an opportunity for mentally ill people and their families, who have been excluded from association for so long, to meet and draw emotional and peer support from one another. These groups come together to form District User Group Movements to advocate for their rights and address their needs.

THE STORY OF FATUMA MOHAMED KAISI

Story Written by: Kalista Higini, Research Coordinator, BasicNeeds Tanzania



A Struggle with Stigma

“I wish to go to school like my fellow children, but I’m afraid of being called awful names. I feel very bad; it pains me to hear such names.” These are the words of Fatuma Mohamed Kais, a ten-year old epileptic girl.

Unschooling and Unlettered

Fatuma is the first born in a family of three children. She has two younger sisters, Jamila and Salama. Unlike her sisters, Fatuma is unable to read and write because she was taken out of school due to her illness. Fatuma’s parents are peasant farmers. They also sell wood, which is an additional source of income.

Discrimination and Stigma

Fatuma’s father lamented during the discussion, “I am always unhappy when I see my first born, Fatuma, walking around the village while her colleagues are in school.”

He explained that Fatuma stopped schooling due to the stigma attached to her condition, “I plan to take her to her grandmother in another village very far away from here where she can start schooling afresh without stigma, because her new friends will not know

about her condition. However, I am afraid about her age; she is 10 years old and the age for standard one is eight years.”

The Beginning Of Fatuma’s Illness

Fatuma’s mother recounted the story of her daughter’s sickness. “Fatuma’s illness started when she was one year old. Prior to her epileptic symptoms, she suffered several fevers which often came with high body temperature. On one occasion, she suffered severe fever and was taken to Dar-es-Salaam where, without any treatment, her fever improved. I believed the suggestion of a friend that she was allergic to the weather at Mahuta. However, six months later while she was still in Dar-es-Salaam, she suffered a strange sickness which caused her mouth to twist to her left jaw and she appeared restless.”

This was Epilepsy

Fatuma’s mother continued, “Two years later when we had almost forgotten everything that had happened to Fatuma in the past, she started experiencing epileptic symptoms, so we pursued traditional treatment. We visited several traditional healers in many different locations. We

even travelled to the Tanga region³ but could not find proper treatment for Fatuma's condition. All the traditional healers we visited demanded items ranging from fowls to lump sums of money."

Fatuma Talks of Her Condition

"I often feel nausea whenever I am about to experience a fit. I also see images of people coming from nowhere to blindfold me. This is usually followed by darkness that covers my face to the extent that I can not see anything. Now, when I am about to experience a fit, I talk to myself unknowingly. This is followed by rumbling in my stomach and eventually I will fall asleep."

Effective Treatment

Previously, Fatuma's parents never knew that there was treatment for epilepsy in the hospitals. "I never went to a hospital for treatment for Fatuma's illness, because it is believed in this area that epilepsy is associated with witchcraft. I spent a lot of time searching for traditional treatment. We spent almost six years moving from one traditional healer to another," Fatuma's mother added.

In April 2004, Fatuma experienced an epileptic fit while sitting under a tree behind their house. A visitor from a neighbouring village who had come to do business with Fatuma's parents, was shocked to see Fatuma's condition and asked her parents to take her to the hospital. The visitor explained to them that treatment for epilepsy was available and that an organisation called BasicNeeds was making this possible. Apparently, this visitor had attended a field consultation organised by BasicNeeds where they discussed the situation of mentally ill people and their needs. The next day Fatuma's mother took her to Mahuta Dispensary⁶, where they had a long discussion with the psychiatric nurse about Fatuma's illness. She was diagnosed with epilepsy and given medications to last for a month. They were advised to come back for a review after the one month. Fatuma began to register remarkable improvement in her condition after the first three weeks. The number of times she experienced fits reduced drastically from 2 times a day to once a week. Fatuma's condition continued to improve as she took her drugs.



Greater Improvement

Although Fatuma no longer experiences fits, she still takes her drugs. Dr. Samora, the Mental Health Coordinator in the Tandahimba District, confirmed that Fatuma's condition was stable. "Fatuma's condition has improved a lot. She had very serious epilepsy, so serious that the frequent fits affected her left leg and hand. However, her condition is now improving and her affected leg and hand have returned to their normal state. We are also thinking of stopping her medication since her condition has improved very much and she has not suffered fits since November 2005."

A Sad Ordeal

Fatuma loves to go to school, but the teachers are not ready to accept her at home in Mahuta. She suffered discrimination and stigma at the hands of her colleagues and the teachers. They feared that they would contract epilepsy by associating with her. The teachers also believed that children who suffer epilepsy or mental illness are not intelligent enough to attend school. They claim that they are also concerned about the patient experiencing a fit during school sessions.

Fatuma's mother went to enrol her in a pre-primary school but was denied admission because

she suffers epilepsy. Her mother reported the matter to the District Education Officer before Fatuma was granted admission.

“Despite the fact that my mother went through great pains to get me admitted in school, I am unable to go to school again because my colleagues always laugh at me. They also call me many names like ‘evil spirit,’ ‘crazy girl,’ ‘empty box,’ ‘mentally retarded person,’ and many other unpleasant names. I was not happy in school, so I stopped going in 2005, when I was nine years old.” Fatuma said.

A Relief from Burden of Care

Fatuma’s mother is now greatly relieved from the burden of caring for Fatuma. Fatuma’s condition has greatly improved and she no longer experiences fits. Her mother now only ensures that she reminds her to always go for her drugs. “I hope Fatuma will soon be discharged of taking drugs, because she is okay now. I am just waiting for the psychiatric doctor’s advice about it,” Fatuma’s mother said.

“I Wish to go to School...”

Fatuma said, “I wish to go to school like my colleagues in this

area, but I am afraid of being called awful names. I feel very humiliated when I hear them calling me such names.” A recent update on Fatuma’s story revealed that her parents have decided to transfer her to another school quite distant from her current school, Mahuta Ward Primary School. She was considered by the Headmaster and registered to start in January 2008 even though she has passed the admission age of eight.

Her mother said, “I am happy that my daughter has been accepted at Mahuta Ward Primary School. She will join standard one next year.”

Reflections

It is evident that Fatuma wishes to continue her primary school education, but the prejudice of her friends has driven her to despair. This underscores the need for mental health education to be incorporated in primary and secondary education to educate students to appreciate that mental illness is like any other physical disorder. Structured education as suggested will help reduce stigma and discrimination against students who suffer mental illness and epilepsy.

Epilepsy

Epilepsy is the most common brain disorder in the general population. It is characterised by recurrence of seizures, caused by outbursts of excessive electrical activity in a part or the whole of the brain. The majority of individuals with epilepsy do not have any obvious or demonstrable abnormality in the brain, besides the electrical changes. However, a proportion of individuals with this disorder may have accompanying brain damage, which may cause other physical dysfunctions such as spasticity or mental retardation.

The causes of epilepsy include genetic predisposition, brain damage caused by birth complications, infections and parasitic diseases, brain injuries, intoxication and tumours. Cysticercosis (tapeworm), schistosomiasis, toxoplasmosis, malaria and tubercular and viral encephalitis are some of the common infectious causes of epilepsy in developing countries. Epileptic seizures vary greatly in frequency, from several a day to once every few months. The manifestation of the epilepsy depends on the brain areas involved. Usually the individual undergoes sudden loss of consciousness and may experience spasmodic movements of the body. Injuries can result from a fall during the seizure.

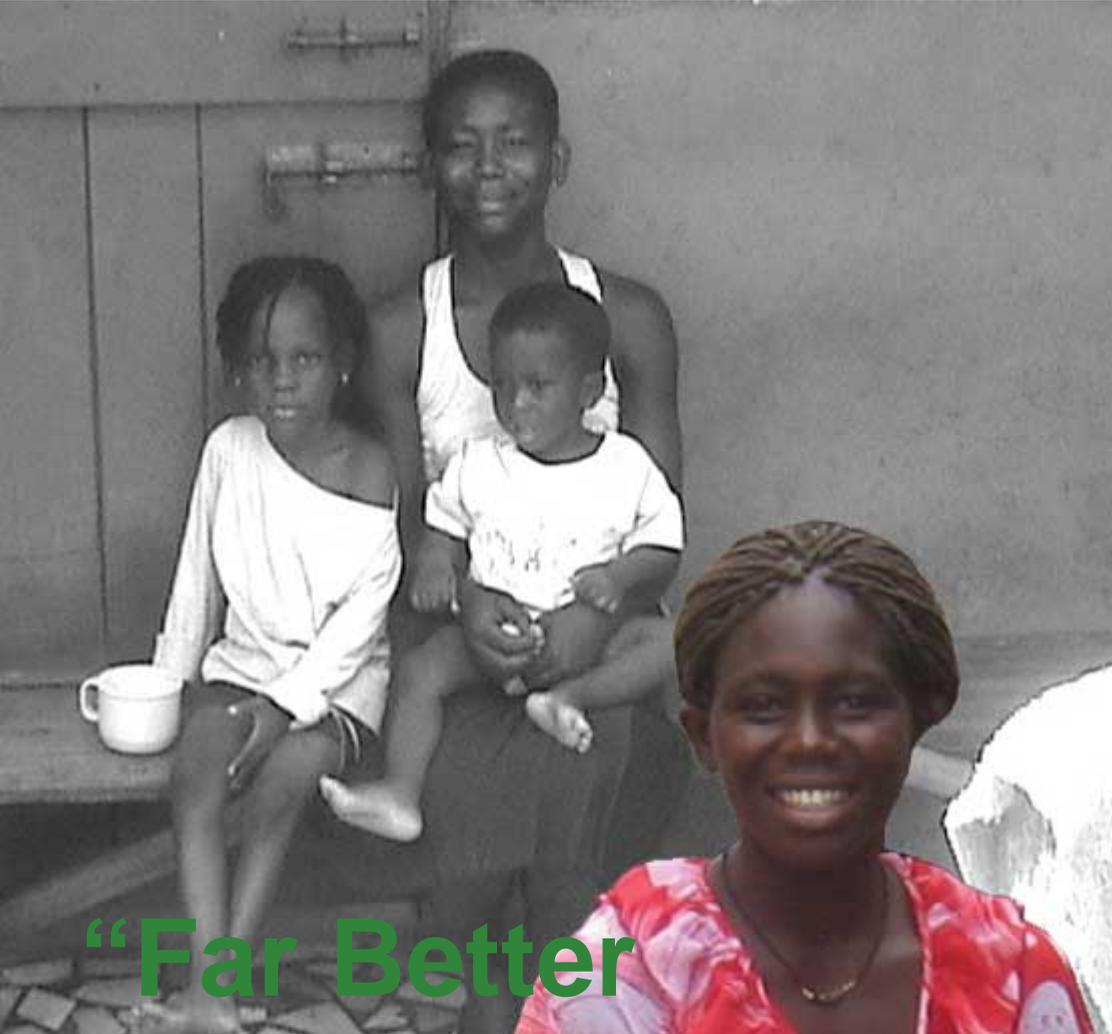
Sources:

Foundation and Techniques in Psychiatric Rehabilitation – NIMHANS, Bangalore India.

Essential Psychiatry – Edited by Nicholas D.B. Rose
The World Health Report – 2001

THE STORY OF FLORENCE AMOO

Story written by: Dominic Deme-Der, Research Officer, BasicNeeds Ghana, Accra



**“Far Better
Now than
Before”**

A Mentally Ill Person in Crisis

Florence is a nineteen-year-old lady diagnosed with organic psychosis. She and her grandmother (her carer) are members of the Ashiedu Keteke Self-Help Group. Florence is the elder child of her parent's two children. She herself has two children, (a 3-year-old girl, and an 8-month-old boy). The two children have different fathers, but none of them is Florence's husband. Her maternal grandmother, Comfort Yeboah, helps in caring for Florence and her children.

During a Participatory Data Analysis⁷ in December 2006 at the St. Mary's Anglican Church hall, Florence Amoo had a plaster on her head. The Community Psychiatric Nurse (CPN) in-charge of the Ashiedu Keteke sub-metro found out that Florence's father had beaten her the previous day, which resulted in the wound on her head. The CPN therefore booked an appointment with Florence and her carer, Comfort to visit their family and talk to them on how to relate with Florence.

A Bright Early Life

Florence was normal like other children in her neighbourhood

when she was young, with greater ambitions of becoming a responsible person. She even attended Teacher Akwetey Nursery School when she was five. Nobody expected that she would one day be a mentally ill person.

Early Symptoms

Comfort says, "Florence's illness started when she was about 5 years old. She went out to play one day, but we suddenly saw her running back to us very fast. When she got to us, she stopped, bent down and twisted her neck unusually. One could feel her heart beating unusually fast but she claimed she was fine. She spoke different languages that no one understood."

A search for spiritual treatment

Comfort continues, "some people told us that Florence's problem was caused by evil spirits. So we took her to Odiffo Akwa Church at Anyan in the Amasaman District of the Greater Accra Region of Ghana. The pastor prayed for her and requested that we continue to pray for her too. This confirmed our belief that the problem was spiritual. However, when there was no improvement after a while, we decided to take her to New Light Church at

Adabraka, an area in Accra. There, the pastor said someone had poisoned Florence's spiritually, and that it was the cause of her illness. He also prayed for her, but Florence still needed treatment. So we took her to yet another church, Pastor One Touch Church in Kwashieman, a suburb of Accra. While there, the sickness manifested itself and the pastor told us there was a fetish⁸ in our family that was worrying her."

Traditional Healing

Comfort again narrated that "following the diagnosis of the pastor at Pastor One Touch Church, we took Florence to our ancestral home at Korle Worko to perform some rituals to appease the fetish. We were asked to provide one bottle of Schnapps for libation⁹. After that, we were directed to the fetish priestess¹⁰ to make another libation. We were told that if it was a fetish that was worrying Florence, her condition will manifest immediately after the libation was made. While the ritual was going on, the priestess pronounced that if Florence was also a priestess, she should get possessed, but nothing happened to her."

Trying a New Method

Having failed to find a remedy from spiritual sources for Florence's condition, Madam Comfort said "we took her to the Korle Bu Teaching Hospital in Accra. Here, several tests were conducted on her. Her brain was scanned and blood samples taken, but nothing was found. She was referred to the Accra Psychiatry Hospital. She was treated with psychotropic drugs and Vitamin B Complex."

Education Disrupted

According to Comfort, Florence's carer, despite her illness, Florence continued her education up to Junior Secondary School. She became pregnant in 2001 and had to stop going to school for a while. The man she mentioned as being responsible for the pregnancy denied responsibility. The matter was reported to the Police, but it was not pursued further.

Florence resumed schooling after her delivery but became pregnant again in 2003 when she was in her final year in Junior Secondary School. The young-man who claimed responsibility was a school dropout who used to bathe in the commercial bathhouse of Florence's mother.



Illness Has a Price

When Florence's illness started, Comfort explained that they used to do everything for her - bathing, washing, and even supervising her to take her drugs "I used to trade in the Makola Market, in central Accra but due to Florence's sickness, I stopped trading in order to take care of her." But now, Florence bathes herself, takes her medicines herself, cooks occasionally, and even sells iced water. She carries the drugs in her waist bag wherever she goes.

Free Treatment for Mentally Ill People

Says Comfort, "We continued going to the Accra Psychiatry

Hospital until we heard in a dawn radio broadcast one day that people with mental illness and epilepsy could access treatment at the Usher Polyclinic. We took Florence there the next day and she was given the same drugs and Vitamin B Complex that we have been receiving from the Mental Hospital. To date we continue to go there because some of the drugs we used to buy are now given us free of charge. We have been invited to join a Self-Help Group of mentally ill people in the area, and we have since been attending meetings every month."

A Favourable Response

Florence is responding well to

treatment now. Her sickness used to manifest three times a day, but now it only happens once a week. She, however, still talks a lot, especially when she does not take her drugs.

Reflections

The story of Florence reveals how mental illness affect people's ambitions in life. As a young girl growing up, Florence had greater ambitions, but these were thwarted by her sudden illness, leaving her as a school dropout. It also reveals how people take advantage of the conditions of mentally ill people to perpetrate all sorts of vices against them, including having sex with them. Florence has two children with different men neither of whom is her husband. Apart from the burden of caring for these children, the sexual encounters exposes her to a risk of contracting HIV/AIDS¹¹ and other sexually transmitted diseases.

Psychosis

An acute or brief psychosis appears similar to schizophrenia, which is a more severe form of mental illness, but is different in that it usually starts suddenly and is brief in duration. Thus, most sufferers recover completely within a month and do not need long-term treatment. Brief psychosis is typically caused by a sudden severe stressful event such as the death of a loved person.

The typical symptoms of acute or brief psychosis are

- Severe behavioural disturbance such as restlessness and aggression
- Hearing voices or seeing things others cannot
- Bizarre beliefs
- Talking nonsense, confusion, indecent exposure in public
- Fearful emotional state or rapidly changing emotions, from tears to laughter.

Sometimes, a severe medical illness in the brain can cause acute psychosis. This condition is also called delirium. Delirium often needs urgent medical treatment.

The typical symptoms of delirium are

- Disorientation, the patient not knowing where he is or what time it is
- Fever, excessive sweating, raised pulse rate and other physical signs
- Poor memory
- Disturbed sleep pattern
- Visual hallucinations, seeing things others cannot
- Symptoms that vary from hour to hour, with periods of apparent recovery alternating with periods of severe symptoms.

Sources:

Foundation and Techniques in Psychiatric Rehabilitation – NIMHANS, Bangalore India.

Essential Psychiatry – Edited by Nicholas D.B. Rose
The World Health Report – 2001

THE STORY OF NAMARA AGNES

Story written by: Ssekyanzi Robert, Research Officer, BasicNeeds Uganda, now left BasicNeeds to become a priest.



**Unwavering
Hope**



Opting for God's Way

Agnes was born in 1980 in a small village called Kikondeka in the Lwebitakuli Sub-county in Sembabule District. She has eight siblings (two boys and six girls) but the two boys both died. Three of her sisters are married and living with their husbands while the other three including Agnes, are still living with their mother. Agnes's father died when she was still young, so she did not grow up to enjoy her father's love.

Agnes is a devout Catholic and therefore opted to end her primary education when she was in 3rd standard for study of Catholic doctrine. Agnes's mother said, "No one forced her to study Catholic doctrine. She suddenly refused to continue her primary education". "I wanted to learn more about my faith. So I decided to study how to live my life in the way God wants us to live", Agnes said.

Marriage and Children

"After my religious education, I stayed at home for about two years. I got married in 1994 and I had four children, two boys and two girls, but two of them died."

"The Illness Got Me"

"My illness started after I got married. I remember one day I went to dig some tubers of yam¹² from the farm, and on my way, I felt like an insect had fallen into my eye. I suddenly felt dizzy, so I decided to lie down for a while. I only regained consciousness at the Kagadi Hospital (in western Uganda) where I got some treatment." Agnes said.

But there was a Reason

According to Agnes' mother, Agnes' illness was the result of continues annoyance and anger she suffered from her husband. Agnes received a loan from a women traders group she belonged to. Her husband took the money away from her including two bags of groundnuts they had harvested from their farm. Her husband never showed any interest in any work that Agnes did. He does not even buy her clothes, so Agnes does not have the privilege of changing clothes like her colleagues."

Agnes continued with her story: "when my condition became worse, my husband decided to bring me back to my mother. That is why I am here."

Her mother again confirmed that



Agnes became sick while living with her husband in Kibaale district in the western part of Uganda. “One day I had a call from her husband that I should come for my daughter because she was possessed by evil spirits. So I went for her. The man has never showed up here to find out how his wife is feeling. Maybe he thinks Agnes is dead.”

BasicNeeds’ Intervention

Before BasicNeeds’ intervention, Agnes’ mother said she had tried several treatment sources for Agnes, but did not see any much

improvement. “I took her to Fr. Bill and Fr. Bushobora, two famous Catholic priests who were well-known for preaching and healing. They prayed for her and her condition improved for a while, but reoccurred again.”

One day, I went to visit a relative of mine at Kikondeka Primary School. It was there I heard about BasicNeeds and the work they were doing to facilitate treatment for mentally ill people at the Ntete Health Centre II. The next day I took Agnes there for treatment.

The Health Officer there attended to us and gave her some drugs to be taking daily. Her condition has improved so tremendously since she started taking those drugs. Agnes has now started helping in a hair dressing saloon, just to assuage her boredom.”

A Hope for the Future

“Agnes is interested in running a business. I am hoping that her condition will stop completely so that I would start a small business for her to be selling food stuff”, her mother said.

Life now

An update on Agnes’ story on 14th May 2007 showed that Agnes now attends the mental health clinic and other programmes of BasicNeeds regularly. Her mental condition has improved. However, Agnes now appears very slim and sick. She also coughs very badly. Her mother reported that she has encouraged her to be attending HIV/AIDS clinics even though she is not sure of Agnes’ HIV status yet.

Her mother reported that Agnes had changed her priority from wanting to run a business to learning dressmaking. She is

therefore, saving towards supporting her to acquire a sewing machine and to enrol with a master artisan.

Reflections

Mental illness always presents great challenges to the households that experience it. However, one needs to have courage and hope to triumph over it. Much as accessing treatment is good for patients, there is a lot more that needs to be done for mentally ill people and it is the responsibility of carers to provide the nurture and support they need. It is a carer’s responsibility to encourage and renew the hopes of mentally ill people that they will be treated. Therefore, counselling is very necessary for mentally ill people and carers. Agnes now lives with her mother where she helps with domestic chores like any other family member.

Schizophrenia

Globally, 24 million people have schizophrenia. Mental and behavioural disorders are common, affecting more than 25% of all people at some time during their lives.

Schizophrenia is a serious mental disorder marked by irrational thinking, disturbed emotions and a breakdown in communications with others. Schizophrenia is the most common form of psychosis, a serious emotional or mental condition that makes a person unable to function in society. The cause of Schizophrenia is unknown, and scientists currently relate it to a metabolism disorder thought to be hereditary. Others add that, the environment also has an influence. Biochemical imbalances in the brain, which influence how we think and feel, are also known to be a cause.

People who develop schizophrenia often have a history of unhappiness and emotional stress in early childhood. Later, frustration and disappointment may contribute to the development of schizophrenia in a person who is predisposed to it. The condition can, however, arise in people from a stable family background too.

Sources:

Foundation and Techniques in Psychiatric Rehabilitation – NIMHANS, Bangalore India.

Essential Psychiatry – Edited by Nicholas D.B. Rose
The World Health Report – 2001

THE STORY OF MARTHA NJOKI WANJIRU

Story written by: Ruth Walioli, Assistant Research Officer, Africa Mental Health Foundation; **Edited by:** Allan Oginga, Research and Policy Officer, BasicNeeds Kenya



The Challenge Of Destitution

A Hard Life

Martha Njoki is an old woman in her late eighties. She suffers from schizo-affective psychotic disorder, a severe mental disorder. Martha is a frail, old woman living alone in a single-room house in the Kibagare slum in Nairobi. The walls of her house were constructed with wooden planks and plastic and carton papers. The house is roofed with corrugated iron sheets, but the roofing was poorly done such that the room leaks badly when it rains.

The Kangemi slum is one of the worst slums in Nairobi, Kenya. The houses are highly congested, leaving very little space for human traffic. The drainage system is very poor and so is sanitation. During the rainy season, the area looks very filthy.

Njoki's Early Life

Njoki said she was born during the "Italian war," in Kenya "mbaraya italiani" in Kikuyu. This was between 1914-1918. She recalled that she was born in Githumu Mission in Murang'a, a district in the central province of Kenya. She is the second child in a family of six children. She said "when I was young, I attended school for only two years. At the

time, schooling was not taken seriously. Educated girls were not popular because they were believed to be rude. This was the reason why I dropped out of school."

Njoki explained that she got married and had children. "I got married to a man in Murang'a, and we had three children. However, the marriage broke up about thirty years ago. It was then that I moved to stay in Kangemi. I had two more children with another man, but we were not married."

The Tragedy of HIV/AIDS

All five of Njoki's children are females. Unfortunately, four died of HIV/AIDS about 20 years ago. Her only surviving daughter, Miriam Waithera is married and lives in Thika, a town in Kenya's central province. "She does not want to come to see me because she believes the death of her other sisters was the result of a curse in the family. Miriam thinks the curse is here with me so when she comes to see me she will also die"

An Evil Blew Over Me

Njoki's current mental illness started six years ago when she was also suffering from tuberculosis (TB). "The doctors thought I



had HIV/AIDS and made me to take a test, which showed negative”, said Njoki.

Njoki remembers that about six years ago, she felt a very strong wind blow over her head while she was working on her farm. Njoki said ever since she had that experience, she has not been the same again. “I started getting strange feelings of dizziness in my head. My thoughts were always racing with ideas in my head and I never had good sleep at night. Some of my racing thoughts suggested to me to

kill myself”

A Thing of the Past

A Health Worker who was treating Njoki for TB introduced her to the community mental health clinic at Kangemi. She is currently on treatment for her mental illness with the community mental health clinic in Kangemi. “When I was not on treatment, I used to feel very restless and worthless, but now that is a thing of the past.

Once A Business Woman

Before her illness, Njoki said she

used to buy vegetables from 'marikiti', a large vegetable wholesale market, to retail. However, she started feeling weakness in her body about four years ago and could no longer continue the business. One of her late daughters, Wanjiru, was by then down with HIV/AIDS, so they used to get food support from 'Lea Toto'¹³ Programme, who used to provide medications and food for Wanjiru. Even though Njoki was no longer working, the food they got was enough for both of them, but when her daughter died they stopped, so Njoki now fend for herself.

Providence Plays a Part

A Good Samaritan whose name Njoki does not remember, started providing food and clothing for elderly people once a month. "The Good Samaritan usually leaves a word with one of the beneficiaries about when he will be coming and then we will gather on that day. Also, a neighbour comes to help me wash my clothes and fetch firewood and water. My next door neighbour also tends my garden and brings me the harvest."

Since Njoki's sitting room is spacious and empty, she hopes that,

a Good Samaritan will help her renovate it. She says she can then rent it for 500 Kenyan Shillings (about £3.6) per month and that such a constant source of income would go a long way in helping her meet her needs.

Reflections

The story of Njoki is a call for all to do something about the mental health and well-being of our aged in the community, especially those suffering mental illness. Miriam Waithera, Njoki's only surviving daughter, may represent many who are doing fairly well, but have forgotten all about their aged, dying parents. Njoki's life also speaks of the devastation that HIV/AIDS can cause in families, and how the elderly, traumatized and bereft, are far more susceptible to its damaging effects.

Finally, BasicNeeds community mental health services seem to have given Njoki some sense of belonging and have, to some extent, dealt with her loneliness.

End Notes

1. **Field Consultations** – Community meetings usually held before the start of active programme implementation. These consultations are generally coordinated by a local community based organisation, potential partner or ally, and initially, animated by BasicNeeds' staff. At the consultations people with mental illness, their carers/other family members, discuss their needs, suggest solutions and the way forward.
2. **Sheabutter** – it is butter extracted from fruits of the shea tree, an African tropical tree whose seeds yield sheabutter used as a food and in soap manufacture.
3. **Outreach Clinic** – are the same as health outreach camps as they seem to be referred to in other countries where BasicNeeds works, for instance, in India. BasicNeeds supports the camp financially by paying for the cost of transport and fuel and the allowances for the psychiatrist, other health workers, and volunteers. The Community Mental Health Unit, under BasicNeeds'

Mental Health and Development Programme, organises outreach clinics every quarter. Outreach clinics are organised in hospitals and health centres and at other more central locations within communities where psychiatric diagnosis, treatment and counselling are provided to mentally ill people, especially those living in remote rural communities without access to psychiatric facilities.

4. **Self-Help Group** – groups formed by mentally ill people, people suffering epilepsy and their carers to provide peer support to one another and lobby authorities for better appreciation of their interest.
5. **Tanga region** – This is a region along the coast of the Republic of Tanzania known for its congregation of traditional healers who practise a variety of healing methods and treat different illnesses. People repose faith in them, believing that they are more powerful than their counterparts in other parts of Tanzania.
6. **Mahuta Dispensary** – This is one of the health facilities in the Kangemi slum. BasicNeeds supports this dispen-

sary to provide appropriate diagnosis and treatment for mentally ill people and people with epilepsy in the BasicNeeds programme area.

7. **Participatory Data Analysis**

– It is a process of engaging people with mental illness, and people with epilepsy and their primary carers to examine and analyse sets of data (facts and figures) collated from previous filed consultations and from other activities of BasicNeeds so that they can draw their own conclusions and make recommendations for improvement of mental health development services. Similar analyses are done by various other stakeholders to get a more representative and holistic picture of conclusions and recommendations for policy influencing and advocacy. Data analysis done in groups at different levels starting at the community level by primary stakeholders i.e. people with mental illness, their carers and other community members, at other locations by health staff, BasicNeeds' partners etc.

8. **Fetish** –It is an object of worship believed to possess

magical or spiritual powers and procures for its owner/ worshipper the services/ powers of a spirit lodged within it. The object could be a physical object that can be seen, or an invisible object.

9. **Libation** – In the context used here, it refers to pouring of water or non/alcoholic drink to ones ancestors with a sense/intention of seeking appeasement, divine intervention/support from those ancestors. Families with fetishes usually pour wine or other liquid as libation on them regularly, or use it for sacrifice. When certain spiritual/practical obligations of a family are violated or taboo broken, the ancestors can become angry and make an evil spirit to possess a member of the family to show their displeasure about such commissions and/or omissions. This can only be reversed if libations and sacrifices are performed to appease the ancestors for their divine intervention and also to the fetish to abate the spell/curse of the fetish. It is believed that any time the libation or the obligations are being fulfilled; the affected person will get possessed.

10. **Fetish Priest/Priestess** – The person who officiates at the worship of the fetish is a fetish priest or priestess, who is appointed by the manifestation of a spirit in them in several ways, through sickness, or a dream.

11. **HIV/AIDS – Acquired immune deficiency syndrome or acquired Immunodeficiency syndrome (AIDS or Aids?)** is a collection of symptoms and infections resulting from the specific damage to the immune system caused by the human immunodeficiency virus (HIV) in humans, and similar viruses in other species. The late stage of the condition leaves individuals susceptible to opportunistic infections and tumors. Although treatments for AIDS and HIV exist to decelerate the virus' progression, there is currently no known cure.

12. **Yam** – a tuber crop cultivated for the consumption of its starchy tubers. It is mostly cultivated in Africa, Asia, Latin America and Oceania. It is used in a fashion similar to potatoes and sweet potatoes.

13. **Lea Toto** – A programme in Uganda that runs outreach services to support HIV positive children at the community level. They provide food and Anti-Retroviral Drugs to people living with HIV/AIDS

Feedback form

Please kindly help us improve on the quality of the magazine. Just complete this sheet and send to us through the address below.

2. How did you get this magazine?

Was sent to me personally by BasicNeeds Was sent to my organisation

Through a friend

Others (please specify

2. Did you enjoy reading it?

Yes No

If Yes/No please explain

2. What do you think about the situation of mentally ill people?

2. Please give us your candid opinion about the quality of this magazine.

If you are interested in supporting the work of BasicNeeds please contact:

Yaro, Badimak Peter
Country Programme Manager
BasicNeeds Ghana
P. O. Box TL 1140
Tamale, NR
Tel: +233 71 23566
Fax: +233 71 24245

Jane Cox
Director or Corporate Services
BasicNeeds 158A Parade
Leamington Spa, Warwickshire
UK Cv32 4AE
Tel: +44 1926 330101

Contacts

Jane Cox

BasicNeeds

158A Parade, Leamington Spa,
Warwickshire, UK
CV32 4AE

Tel: +44 1926 330101

E-mail: Jane.cox @basicneeds.org

Tina Ntulo

BasicNeeds UK in Uganda

Town House, 1 Plot 1744, Kisugu Gabba Road,
Kansanga Trading Centre, Kampala
Uganda

Tel: +256 41 269558

E-mail: tina.ntulo@basicneeds.org

Yaro, Badimak Peter

BasicNeeds Ghana

P. O. Box TL1140
Kalpohin Estates , Tamale
Ghana

Tel: +233 71 23566

E-mail: peter.yaro@basicneeds.org

Tobias Chelechele

BasicNeeds Dar Es Salaam,

P. O. Box 8149, Dar Es Salaam
Tanzania

Tel: +255 22 2127048

E-mail: tobias.chelechele@basicneeds.org

Joyce Kingori

BasicNeeds UK in Kenya

Elgeyo Marakwet Road, Kilimani
P. O. Box 14590-00100, Nairobi
Kenya

Tel: +254 20 3862155

E-mail: joyce.kingori@basicneeds.org

Malembo Makene

BasicNeeds Tanzania

P. O. Box 358, Tingatinga Plot No. 118,
Shangani East Area, Mtwara,
Tanzania

36 **Tel:** +255 22 2333848

E-mail: malembo.makene@basicneeds.org

Editing: Editorial Board/Chris Underhill - **Design & Layout:** Alando Bernard - **Print:** Unik Image