WE COUNT

Issue - 03
October 2006

INSIDE

BasicNeeds
BasicRights

Editorial

This edition of **We Count** presents you with five stories of people suffering from various mental conditions. These are stories of people from five BasicNeeds programmes in four African countries.

In this edition, you will read about how mental illness limits people's ability to be fully involved in the development of their communities. This limitation, as the stories would reveal, worsens the situation of mentally ill people and makes it even harder for them to manage their own recovery. The absence of community rehabilitation activities also compounds their suffering and makes their reintegration more difficult.

Thankfully, however, BasicNeeds' programmes and activities have attempted to fill the gap, and successfully too, demonstrating the value of community level support to mentally ill people to their recovery and integration. Upon gaining stability of their conditions these people who have freely given their stories have proven their usefulness and resourcefulness. All they ask of us all is as echoed by Mary Monali from Kenya, *"Don't turn your back on me just because I don't fit into your world, my torment is real and I would change it if I could. If you take the time to understand me you will make my world a less painful place."* There could not be better words to express this than those Mary has spoken!

All that is asked of each one of us is the least we can do for mentally ill people themselves primarily, as well as their carers and families, most of who are poor. As the name of this magazine goes we all owe it a duty and responsibility in helping mentally ill people say *"We Count"* too, so include us in your planning, and involve us in activities that can help our recovery and participation.

Peter Yaro
Chair of Panel

Bernard Alando
Coordinator - Africa Life Story Project

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.

Privacy

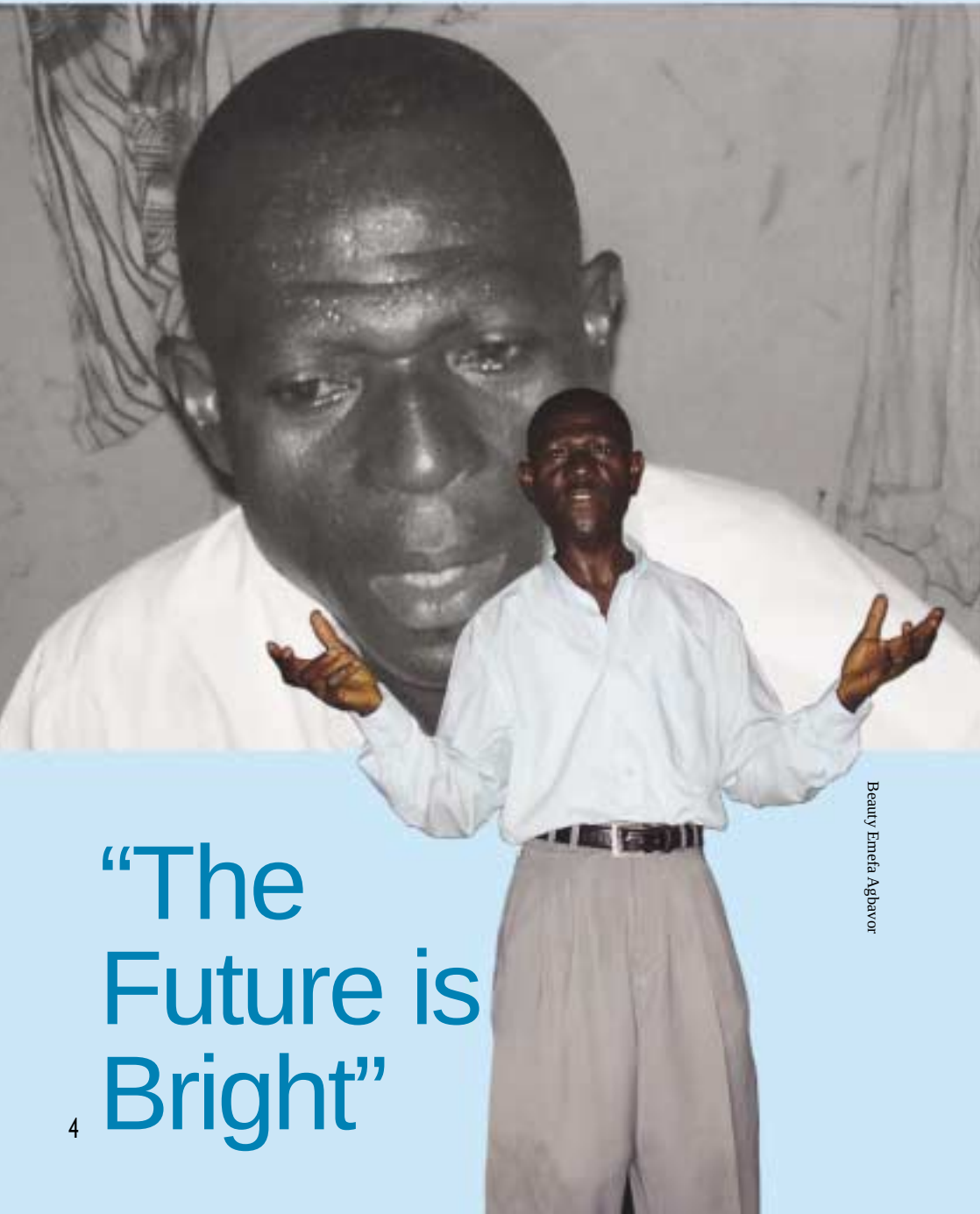
All the stories and photos featured in this issue were freely and willingly constructed with the expressed permission of the mentally ill people and their families. This publication is purely to educate the wider society about mental illness and challenge them to treat mentally ill people with dignity.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

Message from Founder Director

Our life story project continues to develop, both in terms of the quality of the effort made by our editorial team in Northern Ghana and the writing by colleagues, past and present, from Tanzania, Uganda and several places in Ghana. One of the hallmarks of the life story work that we do within the context of the Model for Mental Health and Development is to support mentally ill people and those with epilepsy to think through, or analyse, the situation for themselves. As the sophistication of our own writing teams increases so they are able to portray with ever increasing subtlety the activities of analysing that our participants are undertaking. We are, as it were, in the privileged position of being present with Consolata (Life Story, Uganda) as she describes her life and thinks through the decisions that she has to take. All in all, this is a deepening of the process that we started some time back now and I have derived great pleasure in reading all of the articles and hope that you do too.

THE STORY OF GYESI NIMAKO

Story written by Winfred Darko, BasicNeeds' Contact Person, Ayawaso sub metro and Beauty Emefa Agbavor, Communications and Fundraising Officer, BasicNeeds Accra from 9th June 2005 to 30th June 2006 now at Ford Foundation for further studies in the United States.



Beauty Emefa Agbavor

"The Future is Bright"

Down Memory Lane

"I was born in 1961 in New Adjuampong in the Ashanti Region of Ghana. I started my primary education in the same village at the age of six and completed middle school in 1977.

I remember, as a young boy schooling in the village, I joined the local football team where I played most of the time. One day while playing football, I headed a ball which resulted in blood oozing from my nose. This had no effect on me, so my parents ignored it because the blood stopped flowing without any medication."

Epilepsy Became a Normal Occurrence

"After completing school, I went to live with my aunt, Yaa Anom, in the Brong-Ahafo Region of Ghana. While living with her for about three months, I woke up one night between 12:30am and 1:00am and realised a crowd around me pouring water on me. I felt embarrassed, not knowing what was happening to me. To my surprise, I had bitten my lips and tongue. I asked my aunt what was wrong, and she told me I was screaming, shouting and barking like a dog in my sleep. They tried to wake me up by pouring water on me.

"After this first incident it became a normal occurrence, happening every three days. I began to feel resentment towards my aunt, believing I was bewitched by her, especially when everyone acknowledged that this type of sickness is caused by witchcraft. I then started entertaining thoughts of killing my aunt so that I would be freed from her attacks. But I never had the opportunity to do so. My mother came and took me back to our home-town which was about three hours' drive from New Adjuampong."

An Endless Search

"My parents took me to several places in search of a cure. We visited a fetish priest[1] who gave me herbal concoctions to drink. Somehow my illness got better and I had less frequent attacks. Later, I decided to learn welding as a trade. After apprenticeship, I started my own shop and married my first wife. A year after I got married, the sickness occurred again. I had a number of attacks which scared my wife and she

packed her things and left me. My relatives again took me to a spiritual healer for treatment. My condition improved and I got back to my welding job. I married another woman and we had two children; a boy and a girl. My condition started again and my second wife also left with the children."

Change Brings Relief

"I travelled down to stay in Accra, where I joined a Pentecostal Church called Ever Green International Church. I later joined another church called Gospel Power Centre also in Accra. The church sponsored me to study a Diploma course in Theology. I was ordained pastor in the church afterwards. While in the Bible School, I travelled to my home-town, in the Ashanti Region of Ghana, and married for the third time even though I still had symptoms of the sickness."

Anguish and Misery

"I became a lay preacher in the church, until my senior pastor helped me to start a new branch of the church elsewhere in Accra. After four years of working as a pastor of the new branch, I was sacked by the senior pastor for no apparent reason. This hurt me very badly. I did not want to quarrel with him because he had sponsored my training and supported me to start that branch."

No, Not Again

"My third wife and I lived happily and were blessed with three children. Unfortunately, I started experiencing attacks again. I was not earning anything to support my family. My wife was a seamstress and had to look for an additional source of income since she was now the breadwinner. She started selling "Aboboi[2]" alongside the sewing. One day my wife, who was then pregnant, fell down while carrying "Aboboi", the steaming hot beans poured over her. My wife's parents visited us and advised her to leave because I could no longer take care of her.

My landlord also evicted me from the house because I could not pay the rent. I moved to sleep in a kiosk by the road side with my two children. I had to send my children to their

mother in Kumasi because it was dangerous for them to stay with me in the kiosk. I became very frustrated. I wanted to end my life and be free from this frustration."

It Did Not Matter Where…

"The attacks became very frequent and I visited about five different pastors for help. Some of them prescribed between one to two weeks of fasting for me. This I did religiously with the hope that I would be delivered from this demonic attacks. At one point, I became so frustrated that I even visited a shrine called Tongo in the Upper East Region of Ghana where I was told I could be treated. It did not matter anymore where I sought treatment. After all, my prayers and fasting could not save me."

BasicNeeds Brings Hope

"On the 5th of October 2004, I was encouraged by my sister, Victoria Nimako, BasicNeeds' Animator, to

attend a field consultation organised by BasicNeeds. I was happy to attend this meeting. I came in contact with people who also suffer similar conditions as mine and I was encouraged that my condition could be managed. I was also asked to be attending the regular Outreach Clinics[3] in my community, which I have been attending till now. Since I started the treatment, the attacks have stopped. I no longer feel like ending my life. Now I have hope for a bright future."

The Future Is Bright

"I am currently not working, but I am happy because my third wife who left me has agreed to come back as soon as I secure accommodation. I hope to secure a job soon. I currently depend on my sister, Victoria for financial support. I wish I could get accommodation so that I can have my family back with me. I see a bright future for myself, since the attacks are no longer frequent. I have joined another church and I hope to soon start preaching again. I thank God for all he is doing in my life."

Reflections

"Gyesi Nimako is calm and collected, but can be aggressive sometimes," says Victoria. Beauty Amefa, BasicNeeds Communication and Fundraising Officer, observed that he appears decently dressed. A visit to his place revealed a well-organised environment. "I am not sure whether this was a show for me to see, since he knew I was coming over."

The story of Gyesi Nimako was first started by Mr. Winfred Darko, a Community Psychiatric Nurse and BasicNeeds contact person for the Ayawaso sub metro, which I had to follow up to complete. I heard Gyesi Nimako confess about the suicidal tendencies he used to have, which, according to him, have stopped completely after he started receiving treatment. According to him it was all about love, care and acceptance. Because he does not wish people to know about his situation, he has tried to keep his life away from public knowledge.

Gyesi Nimako is once again looking hopeful about the future and believes that he will soon have his family together.

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

THE STORY OF TUMUSIME CONSOLATA

Story written by Ssekyanzi Robert, Research Assistant, BasicNeeds UK in Uganda

"Braving Life"

John Birungi

A Caring Organisation

It is a hot afternoon in Kampala. Elsewhere, people are preparing to have their midday meal, but Consolata waits patiently for me in the premises of the Kamwokya Christian Caring Community's[10] (KCCC) mental health clinic in the Kamwokya slum. This is actually the place where patients receive treatment.

Home to the Poor

The Kamwokya slum, which has become home to Consolata, is characterized by unplanned settlements, poor drainage and poor sanitary conditions. The estimated population of the slum is 45,000 people, many of whom are migrants from rural or war-torn areas of Uganda and neighbouring countries. The main activities carried out in the slum include petty trading, prostitution and brewing of the local alcoholic drink. Most of the people living in the slum are unemployed, with a few engaged in manual work.

First Impressions

When I arrived at KCCC, I found Consolata waiting for me. She was dressed in a red skirt and a white blouse and she looked a bit stressed. I later learnt that the difficulties in her poultry business were the major source of her stress. We exchanged greetings; then I explained to Consolata that I am writing her Life Story to publish for the purpose of spreading the message about mental health so that people who read it would understand that mental illness is manageable. People would also understand that mentally ill people deserve to be treated with dignity. Consolata granted me permission to document her story.

Braving Life

Consolata is a strong woman who has braved the storms and challenges of life. This forty-five- year old widow, looks younger than her age and demonstrates a sense of perseverance when talking to me. She is a resident of the Kamwokya urban slum where she lives with her two children, and a niece. They live in a two-bedroom house made of burnt bricks and cement and old corrugated iron roof; by any means a fairly decent shelter, compared to most households in her neighbourhood. Consolata's house also has a store where she

is able to run a poultry business on a small scale. She has lived in this slum since 1990, when she emigrated here with her husband from Mulago, which is about two kilometres from Kampala's city centre. Consolata is a practising Catholic and has benefited a lot from the Kamwokya Christian Caring Community.

Education, an Aspiration

"I was born in August 1960 in Kabale District in Western Uganda. My parents are both dead but I have two surviving sisters and three brothers who live in different parts of Kampala. I am forty-five years old. My parents were not able to look after me in Kabale because they did not have enough money. They owned a small plot of land there. This is why I came to live with my brother in Kampala so that I could have education. My brother was a trader at the time, running a small shop in town. I came to Kampala for my studies in my early teens; I could only go home for special occasions like Christmas and New Year celebrations."

The Day Illness Started

Consolata was first diagnosed with bipolar affective disorder in 1979. She says, "I remember very well the day my illness started. It was the 3rd of June, 1979. We had gone to Namugongo, a community about sixteen kilometres from Kampala's city centre, to celebrate Martyrs' Day[11]. During the ceremony I could hear the voices of people talking to me and I thought they were the martyrs. When I reached home that evening I could not sleep. I had nightmares of people throwing me in deep pits, crocodiles eating me and lions and leopards chasing me."

Before BasicNeeds

Consolata explains "My relatives took me to the Mental Health Unit at the Mulago hospital, the national referral hospital." Referring to ECT[12] treatment, Consolata explains, "While there, the doctor put a machine on my head saying that she was 'gathering' my brain. I felt pain in the beginning, but later I passed out. I received this kind of treatment for some months but it did not work."

Death Lurked Close

"My relatives raised funds and took me to a traditional healer in Busunju, which is located about 40 kilometres from Kampala, on the way to Hoima district. I was taken to the traditional healer because it had become difficult to access Mulago Hospital due to the insecurity in Uganda at the time. I sometimes paid for my treatment from my earnings at a restaurant in town where I was working as a waitress. Because I had become a regular customer, the traditional healer sometimes gave me medicine free of charge."

"I was at the point of death. I didn't know what was going on in the world around me; I didn't even know which road had brought us to the traditional healer's place. The healer's medicine saved me from death."

A Relapse after a Long Time

"I went back to school and continued my studies, and in 1982, I got married and had two children, a girl and a boy. We used to live in Mulago but we eventually settled here in Kamwokya in 1990. After some time in the marriage my husband started beating me; he would hit me at night claiming that I was disturbing him, so the illness resurfaced."

Consolata said nothing much about the deterioration of her marriage, except for the problems of being beaten by her husband.

"The Worst Experience of My Life"

"This time, my husband took me to Butabika Hospital, the national mental referral hospital, and this was the worst experience of my life. I do not even want to talk about those unpleasant moments. In Butabika, nobody monitors you. They give you medicine, especially injections, which leave you drowsy. In this drowsy state, other patients can hit you and when it is meal-time, no one gets food for you. If you are in this state, it means you do not have food and no nurse will come to monitor the distribution of food.

One day while I was in Butabika, my husband came to take me home. I remember being so excited. Again my relatives raised funds among themselves and took

me to the Traditional Healer who earlier on treated me. The healer gave me incense and other herbs, which really helped me."

A Bitter Revelation

"I got back to my children and my husband and life was good until my husband started getting a kind of prolonged illness. I was worried, but he kept telling me that he had tuberculosis and that it was being treated at the KCCC clinic. In early 2001, my husband's illness worsened and I took him to the clinic. We were asked to go to the Joint Clinical Research Centre[13] where we could get subsided price for treatment. This is the time I found out that my husband was HIV positive."

About this complex web of illness, she says, "I don't know with clarity the kind of sickness I am suffering from. But with the kind of education that has been given to us by KCCC and Mental Health Uganda[14], I think it is HIV related."

Consolata quickly clarifies that she had a mental problem before she acquired HIV/AIDS. Consolata seems to have come to terms with the fact that she has HIV/AIDS. She is not ashamed of saying it.

The Struggle with HIV/AIDS

"Before joining the BasicNeeds programme, I continued visiting Butabika Hospital whenever I was ill. The people in the community, i.e. Kamwokya, knew that I was mentally ill. They used to see me in moments when I had relapsed. Besides, most of them used to bring their clothes to me for mending since I am one of the best tailors in the Kamwokya slum.

"When BasicNeeds and the Kamwokya Christian Caring Community started the Mental Health and Development Programme, community members told me about the new development and I joined it. I used to get HIV/AIDS drugs at the subsidized rate of Ugandan Shillings 1500 (less than a dollar) from KCCC. This was before the mental health programme. But sometimes I was given drugs free of charge by KCCC. I used to do some businesses like tailoring and poultry to meet my drug expenses

but it was extremely difficult to carry on with them in times when I relapsed. At that time, that is 2003, my HIV/AIDS status became worse and this worsened my mental illness." Consolata had high fever and other opportunistic infections like cough and diahorrea.

"My relatives however helped by giving me some money for drugs. My relatives, especially those who cared for me, now feel relieved because I am fine. I now get free drugs for my mental health problem from KCCC, which is supported by BasicNeeds."

It is confirmed that Consolata has HIV/AIDS. She was tested at KCCC

where voluntary testing and counselling are done.

The Community Approach

Consolata appreciates the community-based mental health services run by KCCC with the support of BasicNeeds. She says, "If it were not for the community-based volunteers, I would never have known about the Mental Health and Development Programme at KCCC. I also thank the other people in the community for not shunning me."

Life 'On a Small Scale'

When asked about what she does for a living, Consolata responded thus;

"I am a tailor and I also engage in poultry farming on a small scale. Of late, I have started selling cold drinks, which I make from millet. I feel much better now, but I think I relapse because of financial problems, especially when I have to pay school fees for my children. I have inadequate money now and my poultry business is not doing well, yet my children need school fees. Poultry feeds are very expensive and the business is not very profitable. I made a loss in the previous sale of my fowls. This stresses me a lot. Sometimes I get sleepless nights and the drugs do not work in such a situation. I can get help or loans from fellow community members but I hate loans because they bring me depression and I get very worried. I am also a tailor but people no longer contract me to do work for them. I only benefit from tailoring during the Christmas and Easter seasons. At the moment I am not benefiting from tailoring."

Consolata is not benefiting from tailoring because people do not have the money to bring their clothes for mending. It is something to do with the general poverty situation of the area. Normally people actively visit tailors only in the event of special occasions like weddings and festive seasons.

But Life has Purpose

Kamwokya is a place that comprises of people from various backgrounds. This explains why there is no strong sense of community spirit. Consolata says, "There are some areas here in Kamwokya I can't go to. People in

such places are thieves. However, the community-based volunteers are nice people. They come to my aid in case of any problem related to my mental illness. I can live a normal life provided I take my drugs as instructed by the health worker. I once asked a lady friend what people think about me and she told me that people regard me like a normal person though they fear I may harm them if I relapse. But I think people no longer fear me because they invite me to their functions. I am now a leader in a support group, which has been formed by Mental Health Uganda. I advise fellow patients and carers on issues ranging from mental health and general health to livelihoods.

If There is Life

"If God blesses me with life I will look for a better business than poultry or tailoring because these two occupations are seasonal."

Reflections

Consolata is one among many experiencing mental health problems. She is unfortunate that she is a victim of both mental illness and HIV/AIDS. She is HIV positive and her husband died in 2001. Having said that, it would be very difficult, if not impossible, for Consolata to have a decent livelihood were it not for the community-based mental health services that KCCC is running with the support of BasicNeeds. This emphasises the value of the community based approach to mental health services as opposed to institutional care. With the support of the community volunteers Consolata is reminded of clinic days by community-based volunteers. Consolata is a member of a support group where she meets other people with similar problems, and they share, learn and support each other. The bigger challenge remains with government to ensure that people are not only provided with health services but are also empowered to meet their basic daily needs.

THE STORY OF MARY MONARI

Story written by Faith Wanjiru, Project Officer, Schizophrenia Foundation of Kenya, attached to the BasicNeeds Kenya Programme.

"My torment is real"

Meeting Mary

When Mrs. Lillian Kanaiya, Director, Schizophrenia Foundation of Kenya, and I called on Mary for the interview, she requested us to meet her at a shop where she was delivering juice. "I have just got a market for my home-made juice. This is my first customer," Mary said gladly when we met her.

Mary is a middle-aged woman in her early forties, who will be admired by anyone once they start engaging with her. She is cheerful, full of smiles and has a very positive attitude despite her illness. She is determined to go against the odds caused by her mental illness and is very willing to help other people with mental illness.

Mary holds a BA in Agriculture from Baraton University, located in the Rift Valley Province in Kenya. She fell sick in 1995 when she was attending a workshop near the coastal town of Mombasa. She was then nursing her first and only child, Solomon.

A Mood Swing

Mary explains "We had just come from Kilindini harbour and had bought a lot of gifts for my family. On coming back I locked myself in a hotel room and did not want to associate with anyone. This went on for a while and the hotel management had to use the master key to open the door. The next day during the discussions at the workshop, I did not want to talk to anyone. I was really scared."

Mary remembers that when she returned to her home in Malindi, she experienced breathing problems and could "only see a mirage." She remembers telling her deceased niece, "Nikikufa, msitese mtoto wangu." "When I die please do not torture my baby," but of course her sister had already died.

A Search for Treatment

Mary was taken to hospital and her husband had to be called from Nairobi, the capital of Kenya. She does not recall what happened at the hospital but she later gathered what was happening to her from her friends and relatives.

According to them, she wanted to beat people at Galana Hospital and at times she pulled at the hospital beds. Also, when arrangements were being made for her return flight from Mombasa to Nairobi, she at one point suggested that she was going to jump off the plane. In fact she had to miss the flight since the airline staff insisted that without an immediate letter of assurance from a doctor that it was safe for her to travel, they would not allow her on the plane.

Mary was transferred to Masaba Hospital on arrival in Nairobi and later to the Nairobi Hospital. In Nairobi, she was mostly cheerful and even spoke well to members of her family and friends. However, she could not remember the exact nature of the conversations. Two weeks after her arrival from Mombasa, she was discharged from the Nairobi Hospital under heavy medication that she says made her drowsy and increased her appetite; the latter led to her weight gain. She later went back to work in 1996 doing light duties with the same employer and worked till 1997 in Malindi, when she resigned, due to her need to be close to her family in Nairobi. "I resigned with the hope of getting a new job in Nairobi. However, finding a job as a person with mental illness is not easy."

However, Mary was not about to give up and she kept searching for a job till she eventually found a "light job" at Hundreds of Original Projects for Employment (HOPE), an Austrian non-governmental organization, where she was put in-charge of supervising and report writing for HOPE projects in western Kenya.

Mary's mental illness is usually accompanied by cold feet and breathing problems. She vividly remembers seeing the "streets of gold in heaven." At times, she sees close images on television as "making faces" at her.

Mary feels that most people do not understand her situation and therefore she needs to meet people with the same conditions and in particular, mothers and wives like herself. During one of her hospital visits at Menelik Hospital in Nairobi she came across a brochure from the Schizophrenia

Foundation of Kenya. She contacted the Director and attended its first meeting at the All Saints Cathedral Church. She was warmly welcomed and enjoyed sharing with people their experiences with schizophrenia and allied disorders. Nyawira, also a person with mental illness, sang a nice welcome song for Mary and since then, she has learnt a lot from her and other members. Mary's family members occasionally attend the monthly group meetings.

While at home, Mary is vibrant and independent, and has taken up a hobby, knitting. She currently spends a lot of time taking care of her ten-year-old son as well as her nephew. In addition, she spends

some of her time reading, and the most inspiring book she has read is 'How To Stop Worrying And Start Living' by Dale Carnegie.

Challenges

"Life as a mentally ill person is not easy, people do not understand you and when you recover they don't trust you. Some want to manage your life and think you can't do anything for yourself. Many are not involved in making decisions that revolve around their lives. People with mental illness feel like they are burdens to their families and carers. At times your priorities do not seem as their priorities and you get tired of asking for money for everything."

Mary complains about the high cost of medicine. According to her, marketing goods made by people with mental illness has not been easy. The sweaters she makes face a lot of competition from second-hand clothes. At some point her machine broke down and she was idle for quite a while.

Mary has lost contact with many of her close friends since she fell sick. Some of her relatives no longer visit her. She is however lucky to have a supportive family. Some people have advised her to visit an 'mganga', a native doctor. She says that such people believe that she is bewitched. For a long time she did not know what she was suffering from. At one point she was diagnosed with cerebral malaria. It is only very recently - she does not explain when - that she insisted on finding out her condition and she was properly diagnosed. She now knows her condition - bipolar disorder or mood swings.

Mary's Last Words

"Don't turn your back on me just because I don't fit into your world," she says. "My torment is real and I would change it if I could. If you take the time to understand me you will make my world a less painful place."

Bipolar Affective Disorder

Bipolar disorder is one of the affective disorders, or disorders of mood, a type of mental illness. The affective disorders include a wide range of abnormalities, from mild states to severe and even life-threatening conditions. Mild forms are relatively common and usually self-limiting, but the more severe forms, while less common, are very important, first, because of the associated risks like suicide, and second, because of the existence of very effective treatments.

Bipolar disorder affects two people in every hundred. Men and women have an equal chance of developing it. It is most common in people in their twenties. It is believed that bipolar mood disorder is caused by a combination of factors including genetics, biochemistry and stress.

Characterised by episodes of extreme mood swings, from depression and sadness to elation and excitement, bipolar affective disorder and other affective disorders place an enormous burden on society and are ranked as the fourth leading cause of burden among all diseases, accounting for 4.4% of the total Disability Adjusted Life Years (DALYs) and 11.9% of total Years Living with Disability (YLDs).

Sources: Foundation and Techniques in Psychiatric Rehabilitation - NIMHANS
Essential Psychiatry - Edited by Nicholas D.B. Rose
The World Health Report - 2001

THE STORY OF AHMED ABDULAI (SENIOR)

Story written by: Alando Bernard, Documentation and Learning Associate, BasicNeeds Northern Ghana.

Alando Bernard

"I Shall Overcome"

Back From Nowhere

Ahmed Abdulai, popularly known as 'Senior,' is a forty-five year-old-man who was diagnosed with manic psychosis, but he personally believes his condition is caused by evil spirits. Ahmed said, "I was born in 1961 in Yendi[4] in the Northern Region of Ghana. I have five brothers and two sisters who are all married and living happily with their families. I am the third born among my siblings. Our family occupation is farming but my elder brother who currently takes care of me is a tailor."

Ahmed has been through rough times as a mentally ill person. Falling from grace as a promising student and hitting rock-bottom as a destitute mentally ill patient living in a cemetery, he is now gradually making his way back to a normal life. Ahmed Abdulai said he was the Senior Prefect of Yendi Secondary School where he studied. 'Senior' became his nickname and to date even after he left school. He is one of ten mentally ill people currently engaged in a horticultural project[5] established by BasicNeeds for training of mentally ill people on gardening skills at Datoyili near Tamale. Ahmed said when his condition was severe he used to see images. "I used to see very short people giving me instructions to carry out certain things. They used to threaten me when I refused to carry out their orders. Sometimes they even whipped me."

"It All Started One Morning"

Ahmed explained that his illness started in 1982. He was then a final year Agricultural Science student at Yendi Secondary School.

He narrates, "It all started one morning, when I was preparing to go to school. I greeted my father, 'Good morning', but my father did not respond. Instead, he said I was sick and asked me to go and call my friends from school so he could ask them a few questions. When I got to school my colleagues were already assembled for the usual Monday morning assembly. I greeted them saying 'asalamu alekum,' meaning, 'peace be unto you', but no one responded to my greetings. So I became furious and insulted them saying they were all

pagans who did not know how to respond to my greetings. They broke into laughter.

"At this point one of our teachers said I was not saying anything sensible and ordered some students to carry me to hospital. I did not know what was happening around me. I was hospitalised for three days. I cannot remember what I was diagnosed with, but I do know that I was given a number of injections on my buttocks and some tablets to take. On the third day of my stay in the hospital, my condition had still not improved. I was still speaking incoherently and staring fiercely at people. I also felt some pains in my head. I was discharged from hospital and taken to a traditional healer called Afa Alidu who happens to be my uncle too."

A crucial revelation

"Afa Alidu told me to confess to him all that I had done in the past before he commences treatment, because he had a revelation that I contacted a 'Mallam[6]' for spiritual powers. I confessed to him that I did approach a Mallam for spiritual powers to enable me pass my exams. He then asked for the head of a ram to perform rites and pacify the gods to forgive me for my past deeds. After performing the rites the healer told me that my sins were forgiven. He added that a lady called Rafatu who was my girlfriend then, was destined to become my future wife." Ironically, Senior is still single. He says he wants to get fully cured of his condition, start earning an income before he will look for a woman to marry.

But Destiny Sours

Senior continues, "Afa Alidu encouraged me to continue my friendship with my girlfriend and ensure I maintain a serious, committed relationship with her until I was well enough to marry her. However, a few months later, I overheard people discussing that Rafatu was getting married to another man. I contacted my closest friend, Iddrisu Mohammed, about the news I had heard and he confirmed it. I had also overheard some people discussing that Rafatu could not marry me because I was mad. I became so worried about Rafatu that I fell sick again.

"I was taken to the psychiatric unit at the Yendi hospital, newly opened then. I was treated and put on medication - some tiny tablets. After six months of treatment from the psychiatric unit, my condition improved. So I decided to go and live with my uncle who was a farmer at Berekum, a town in the Brong-Ahafo Region of Ghana. The illness occurred there again and I was brought back home, this time to Tamale, since my elder brother had moved from Yendi to settle in Tamale."

Mocked and Sidelined

Ahmed resumes the narration by noting, "people used to mock at me, they say I am mad and that whatever I say does not make sense. Some of my friends avoided me. People still discriminate

against me but I am no longer bothered because a traditional healer ever told me that it is the work of an evil spirit inhabiting in me that makes people discriminate against me."

Mistaken for a Thief

"One Friday I went for prayers in a mosque around the Tamale Regional Hospital, after which I decided to share a word with the congregation. They were so touched by my preaching that they contributed some money for me." Ahmed says he does not remember exactly what he said to his audience but it is his belief he spoke about the love of God and God's special favour for humankind. "On my way home I lost my way and emerged at Russian Bungalows[9], a very lonely part of town. It was dark and I was still trying to make my way home. A security guard mistook me for a thief and raised an alarm. People gathered around me and beat me mercilessly and broke my leg. I was left in the bush until the next day when I saw one of my uncles passing and I called out to him. I don't know if he was looking for me but he came to my rescue."

Hopes and Aspirations

"My hopes about the future are still bright, but I think for now I want to gain complete recovery first, before doing anything else. I hope to set up a garden of my own in the future." Ahmed says he would like to do mixed cropping in his future garden so that he could generate enough income to marry and settle down.

"My Carer Shoulders a Burden and Explores Options"

Abdulai Iddrisu, Senior's elder brother and carer, says, "When Senior was brought to me in Tamale he was always roaming aimlessly. Sometimes we did not see him for weeks. Someone told me that he usually sat near the cemetery and that people from Shekhinah Clinic[7] usually came to give him food and water in the afternoon. Upon hearing this, I decided to follow up with them and find out how best they could help to treat Ahmed (that is 'Senior').

"My intention was that Shekhinah Clinic would keep him at the clinic to be working for them, while he receives treatment, but the doctor in charge of the clinic, and

a well known philanthropist, told me that this would not be possible. He treated Ahmed and gave him some drugs. He also prescribed some drugs for us to buy since he did not have them. While Ahmed was confined home to be taking his drugs, I heard of a traditional healer at Guo-Naayili, a village near Tamale and decided to combine the drugs with the traditional medicine. The healer gave us herbs to boil for him to bath. He also forbade Ahmed from eating certain kinds of food, but because he roams a lot, I could not monitor the food he eats. For this reason, we abandoned the traditional treatment and concentrated on the drugs we received from Shekhinah Clinic. Now as you can see, his condition has improved a lot."

Serving the Community

Kwame Lambong, a Community Psychiatric Nurse who is a volunteer[8] at Shekhinah Clinic, and who is a link person between Shekhinah Clinic and BasicNeeds Northern Ghana Programme also shared some bit about his contact with Ahmed. He said, "I first saw Ahmed at the Tamale public cemetery four years ago when we went to bury a deceased friend. I interacted with him briefly and later informed our food distribution team about him and they were serving him food. They were two of them but the other person later disappeared. The food distribution team complained that there were times they went and did not meet Ahmed but I encouraged them to keep serving him food. This went on until his elder brother showed up and brought him to the clinic for treatment. I diagnosed him with manic psychosis and put him on treatment (haloperidol tablets)."

Ahmed's Last Words

Ahmed sums his story in the following words, "I believe I am being haunted by evil spirits but I shall overcome them."

Mohammed Alhassan, Ahmed's supervisor at the Datoyili horticultural project, observed "the experience of Ahmed is indeed a rough one. He presents himself as a very respectable and obedient person. He is also a very hardworking person, who never

complains about the kind of work you assign to him. He is very serious about whatever he does."

Reflections

The story of Ahmed reveals an issue of perseverance in the face of reality. Ahmed is introduced as a young energetic student who hopes for the highest point of success in life but is struck down by mental illness, which forced him out of his home to live in a cemetery. But this does not prevent him from pursuing his dreams. He still aspires to set up his own garden, raise money and settle down with a family. This is very typical of people who have lost some time to mental illness. They always strive to catch up with events and be part of the real world.

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

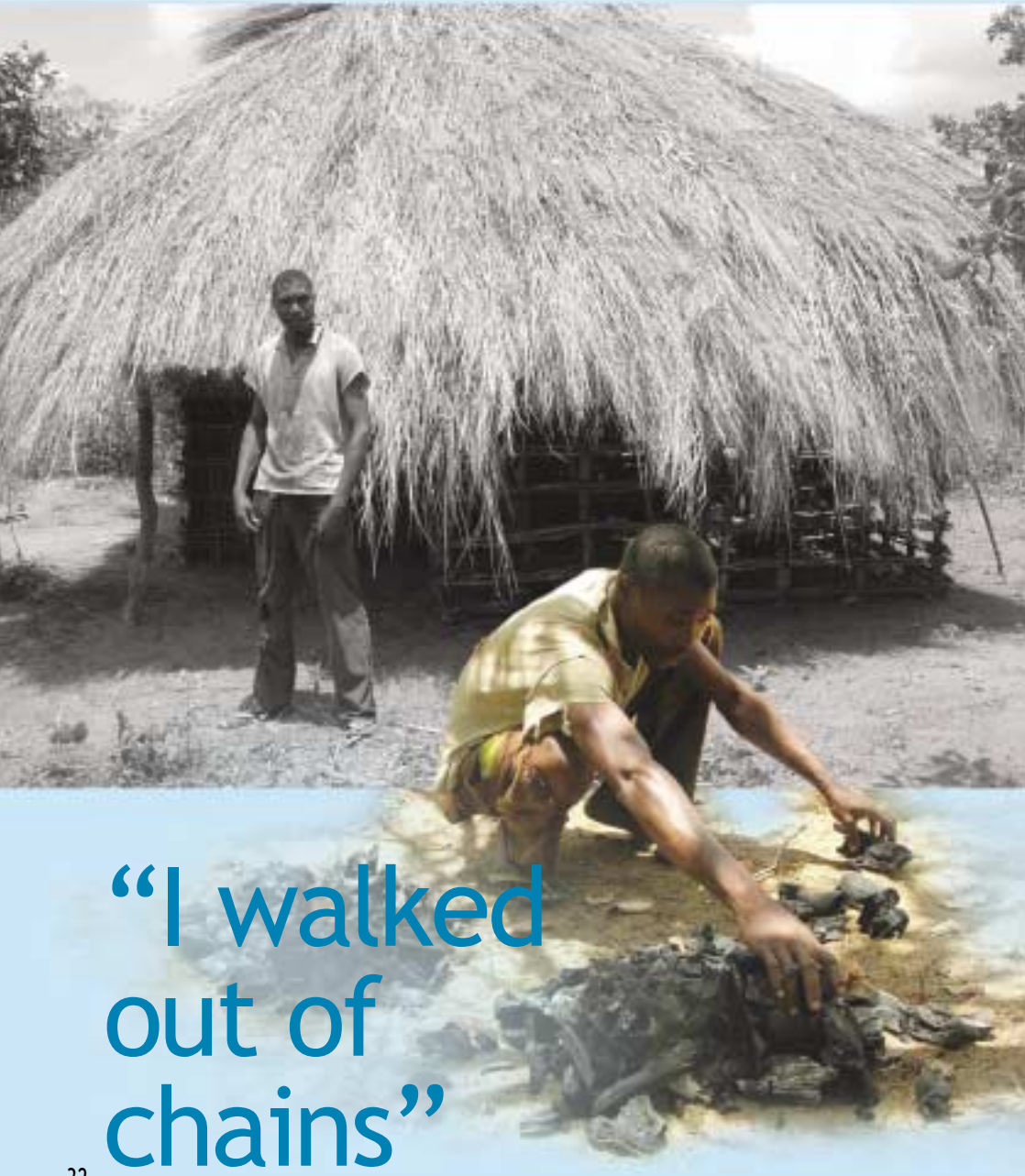
- Severe behavioural disturbance such as restlessness and aggression
- Hearing voices or seeing things others cannot
- Bizarre beliefs
- Talking nonsense, confusion, indecent exposure in public
- Fearful emotional state or rapidly changing emotions, from tears to laughter.

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

Source: Foundation and Techniques in Psychiatric Rehabilitation - NIMHANS, Bangalore, India

THE STORY OF MUSA LIVINDA

***Story written by:** African Mlay, Research and Policy Officer, BasicNeeds Tanzania, from 1st October 2003 to 31st December 2005, now moved to Canadian Cooperation Office, Dar Es Salaam, as Governance Advisor.*



"I walked out of chains"

A Quiet Appeal

No one could easily believe that Musa Livinda could ever recover from eight years of mental illness. We first met Musa at a field consultation BasicNeeds organised with mentally ill people at Nanyamba ward located in Mtwara rural district. Musa was brought to the meeting by his brother, Ally. Musa had shackles binding his hands and legs. During this field consultation in April 2004 he was calm and pleading for the removal of the shackles from his legs and hands.

His brother, Ally, said that, it was impossible to remove the shackles because Musa was very aggressive. Ally looked so disturbed by his brother's illness. Musa sat among his colleagues with his shackles and joined in the group discussion. They were discussing issues about their world and their needs. But Musa kept his head down and when he was asked to describe what constitutes his world, he said, "my world is full of shackles and I want to be free."

"Please Feel at Home"

Eight months later we visited Musa in his village to document his life story. He was out of his chains and shackles and showed us the scars which were left on his legs and feet by the chains and shackles.

As we arrived in Musa's compound, he was seen relaxing on a mat with a small radio set. Upon seeing us, Musa quickly woke up and welcomed us. We exchanged greetings and sought his permission to construct his life story and publish to the general public. "I know it is you, the BasicNeeds people, you are very welcome. Please feel at home and go ahead." With permission granted, Musa starts to narrate his life story.

"Now I am out of my chains as you can see, I can now work on my cashew farm." This farm he said was given to him by his family. "I am building my own house and I am even thinking of getting married soon."

"I Lost my Sense of Reasoning"

"For some years my mind has been clouded with a strange illness. For

quite sometime, I couldn't discern anything. I lost insight into everything and I didn't know anything about myself. Loneliness possessed my life. I could hear voices which kept me walking outside at midnight." Musa was very aggressive towards people. His relatives took him to several traditional healers but all these efforts were in vain.

Ally, Musa's brother added, "When Musa's situation worsened, we used to put him in shackles in order to calm down his aggressiveness. We took him to several traditional healers but his condition remained the same. When we heard of the field consultation organised for mentally ill people by BasicNeeds, we came to the meeting hoping to receive some medicine. Some months after the consultation we went to Nanyamba Health Centre, run by missionaries and supported by BasicNeeds. Musa was diagnosed with schizophrenia. The doctor prescribed some drugs for him which completely calmed his aggressiveness. That was when we removed the chains and shackles from his legs and hands."

Musa is Now Well

Wearing a bright smile on his face, Musa looks healthier than the first time we saw him at the consultation meeting.

"I am doing very well with the medicine. My condition has improved a lot. I keep the drugs myself and I take them daily without missing a single dose. The drugs make me feel so hungry and dizzy such that I am unable to work in the day time so I take it at bedtime."

Socio-economic Context

Musa is the fourth born in a family of eight. He is now thirty-eight years old. He explains, "I never got married. In my community, parents would not agree to their daughters marrying a mad person. I hope to get married now that I am recovering." Generally Musa thinks positively about himself. He knows that the medicine has helped him to walk out of the chains and shackles. He also feels that he has recovered enough and can work hard to earn an income to build his personal house and get married.

Musa has a farm with sixty cashew trees. Cashew nut is the cash crop in Mtwara Region. Harvesting season starts in October and lasts till the end of January. In this season business people, mainly from the north, flock to the region to buy cashew nuts and sell them overseas. In most cases during the cashew season life is very good, especially for men, and sometimes very bad for some women, as most of the men look for new girls to marry and abandon old relationships. Thus, this is a time when marriages are unstable compared to the periods of the year, leading up to the harvests when men are poor and, ironically, relationships are relatively stable. Musa prepares his farm by ensuring regular weeding. He also plants other cereal crops such as millet and also grows cassava. For his cashew nut farm to do well, Musa says he needs two bags of the pesticide called sulphur. Each bag costs about Tanzania Shillings 11,000 (about US$11).

Expectations and Aspirations

Musa aspires to do a small business in the village market alongside his cashew farm. He would like to own a small kiosk to retail matchboxes, salt, biscuits and other provisions and small household items. He is also looking forward to improving his farm and getting married. Musa keeps a close watch over his drugs, taking them regularly to ensure his complete recovery. Generally, under Tanzania's health policy, mentally ill people are exempted from cost sharing in mental health services. So in general terms Musa does not have to pay for his drugs.

Update on Musa's live now

A visit to Musa's home recently reveals that, Musa's condition is now greatly improved and he has stopped taking his drugs. This relief was granted by Dr. Hauli, a psychiatrist who is associated with the work of BasicNeeds in the programme. During the visit to Musa, he had already harvested 40kg of cashew nuts and envisages harvesting more.

Musah still lives alone in his modest home. He explains that, he has plans to marry soon, because of this he is producing charcoal in addition to his cashew nut plantation in order to raise enough money to fulfil this dream.

Reflections

Access to treatment has released Musa from chains and shackles. The release from chains has restored Musa's freedom and determination to succeed. Adherence to the drugs as prescribed by the psychiatrist has hastened the recovery of a mentally ill person as is the case of Musa. He has taken personal initiative to take the drugs daily as prescribed by the doctor, which is a very important aspect that each mentally ill person and his/her family must strive to maintain to assure stability and complete recovery.

The available option of care for carers of aggressive mentally ill people like Musa is chaining and restraining the mentally ill person. In one perspective, it might be seen to contravene human rights, and indeed, it is so. But it is also true that in a rural context with no mental health services chaining seems to be the only available option for desperate carers.

Schizophrenia

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. Schizophrenia's cause is not known, but it may be related to a hereditary disorder in metabolism. 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.

Schizophrenia is found approximately equally in men and women, though the onset tends to be later in women, who also tend to have a better course and outcome of this disorder. Schizophrenia causes a high degree of disability. Globally, schizophrenic illness reduces an affected individual's lifespan by an average of 10 years.

sources: Foundation and Techniques in Psychiatric Rehabilitation NIMHANS Essential Psychiatry Edited by Nicholas D.B. Rose The World Health Report - 2001)

Notes

1. **Fetish Priest** is an individual of a community said to possess powers to communicate with the spirit-world, gaining such powers either by inheritance/ succession or just having been called to service by the spirits of a shrine, a god or deity. Fetish priests become the mouthpiece of a god or a deity and are said to be able to inflict calamity, a curse on an individual and destroy the evil spirit that has taken possession of a person and seeking to destroy the person. They can bring about healing, cause favours riches, good luck, fertility to the barren or take away a spell on someone.

2. **'Aboboi'** is a beans meal eaten with fried ripe plantation and or with 'gari', which is prepared from cassava.

3. **Outreach Clinics** are clinics held at community health facility level where psychiatrists make themselves available to treat mentally ill people, providing consultations and diagnosis as well as treatment for people with mental illnesses and epilepsy. BasicNeeds facilitates outreach clinics at the levels of health posts in inaccessible communities and district hospitals where psychiatric services are unavailable. These have gone a long way to improve access to treatment, by distance, costs and to a good degree quality of the services as well as to minimise travels to mental hospitals.

4. **Yendi** is the traditional capital of the Dagomba people. It is also the administrative capital of the Yendi district.

5. **Datoyili Horticultural Project** this is also known as the "tin laayigsi" project, which means, "We shall rise again." The project was initiated by BasicNeeds Northern Ghana in response to increasing calls by stabilised mentally ill people wanting to learn gardening skills as an alternative to mainstream farming, as most felt they were not too strong enough to walk the long distances to the bush to work on their farms. It also reduces idleness and boredom of

mentally ill people under treatment.

6. **Mallam** is an educated Islamic cleric who has powers to foretell future events.

7. **Shekhinah Clinic** is a private clinic run by a philanthropist. The clinic provides free medical care for poor and needy people in Tamale. The clinic also provides one hot meal everyday for destitute mentally ill people roaming the streets of Tamale. BasicNeeds supports this initiative.

8. **Volunteers** are people who are well known in their communities and serve as links to the activities of BasicNeeds and its implementation partners. Many of them are members of the Community Based Disease Surveillance teams of the Ghana Health Service responsible for health education and reporting disease outbreaks. They also have appreciable knowledge of community development issues.

9. **Russian Bungalows** is a Residential Area in Tamale that was first inhabited by Russian Expatriates who were working for the first post-independent government and who left after the overthrow of the government, now residential quarters of senior civil and public servants.

10. **Kamwokya Christian Caring Community** is a church-founded community-based organisation with which BasicNeeds in Uganda has entered into partnership to alleviate the suffering of people with mental illness in the Kamwokya slum.

11. **Martyrs Day** is a day set aside by Anglicans and Catholics who believe that fellow human beings were killed in Namugongo in Uganda for the sake of their Christian faith. People who die for their faith are called martyrs. Christians therefore usually make a pilgrimage to Namugongo to commemorate the faith of the martyrs.

12. **ETC** is Electro Convulsive Therapy or shock treatment as it is commonly known. It is prescribed for severe forms of mental illness.

13. **Joint Clinical Research Centre** is an institute where scientific research in diseases, especially HIV/AIDS is being carried out in Kampala.

14. **Mental Health Uganda** is a user organisation for people with mental illness, helping them to form user groups through which they can get the help of the government and other forms of assistance. Mental Health Uganda is also a partner organisation of BasicNeeds in Uganda.

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Editing: Editorial Board / Chris Underhill - Design & Layout: Dharshana Karunathilake - Printing: Dezine Focus, Ring Road Central, Accra, Ghana

BasicNeeds UK Reg. Charity No: 1079599