WE COUNT

Issue - 04
March 2007

INSIDE

BasicNeeds
BasicRights

Editorial

You are welcome to this edition of 'We Count' magazine. We hope you enjoyed reading the last edition, which explored how cultural perceptions of the possible cause(s) of mental illnesses influences the places people go to seek treatment for their mental illness. In this edition, we attempt to look into the relationship between poverty and mental illness and how this affects the family.

Mental illness holds back a person's ability to learn and engage productively in their communities. Poverty in turn increases the risk of developing mental illnesses, and reduces the ability to gain access to treatment and rehabilitation.

This two-way effect is visible on both the individual and the household, and may have repercussions for the wider community too. Sudden or prolonged mental illness can precipitate into an irretrievable loss of resources on affected families and even the breakdown of the household as an economic unit.

People who suffer mental illness often lose their source of livelihoods; this is also so with caregivers who often spend more time and resources caring for their mentally ill relatives to the neglect of their livelihood activities. This situation eventually impoverishes the entire family especially where the primary carer is the breadwinner. This negative economic effect also affects relatives outside the immediate family of the mentally ill person, especially where resources are usually mobilised from extended family relations to support treatment.

However, access to sustained livelihoods enhances recovery and brings about steady integration and increased recognition in society, as the stories in this edition reveal.

We hope this edition will increase your awareness of the economic impact of mental illness on the people who suffer the illness, their primary carers and family members and challenge you to support initiatives directed at improving the well-being of mentally ill people.

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

“This edition of We Count focuses on the relationship between poverty and mental illness and how it affects various individuals and family. Not long ago I was crossing the square of a large village on the way to sit with a self help group to discuss economic and social development, that I passed a gentleman who was obviously sitting alone and looking longingly at the group meeting on the other side of the square. When I reached the group I asked “Why don't you invite that gentleman?”. As you will have guessed the answer was because the person was deemed to be mentally ill and therefore unable to contribute to the life of the group that was being formed.

Self help groups are mentioned by a number of the writers in this very interesting edition as are others and different ways of people joining the mainstream in seeking to play a part in the social and economic activities of their community.

Why is this so important? All communities attach great importance to its members being able to make individual contributions to the well being of the whole. At BasicNeeds we have learned that nothing brings happiness to the faces of the person most affected, their family and the wider community than a contribution in income generation or productive work.”

THE STORY OF RICHARD AKANBOE ATIA

Story written by: Dokurugu Adam Yahaya, *Community Mental Health Officer,* BasicNeeds Northern Ghana Programme.

"IT'S NOT ALL OVER"

Growing Up Deprived
Richard lives in a compound house built of mud. It has three square-shaped rooms and two round huts. There is a smaller round room, which serves as a sheep's pen.

Richard did not grow up to meet his father, his father died when Richard was still just an infant. According to Richard, “I was told my father died in a motor accident when I was still young. I did not know my father had passed away. It was when I grew up that my uncle (my father's brother) disclosed to me that my father was deceased. I suspected this was so because at school my surname was different from those of my uncle's children. He used my father's name for me while his own children bore our grandfather's name. This difference in surnames made me wonder who my father really was, but until then, my uncle never told me my father was dead, and nobody else did. I only heard my relatives talking about him as 'my father.' My mother confirmed what my uncle had told me earlier about my father.”

Disowned and Let Down
“My uncle took care of me from my primary education to technical school level.” Richard was pursuing an intermediate course in Auto Mechanical Engineering when his education ended abruptly. His uncle suddenly stopped taking care of him. He said, “When I completed Bolgatanga Technical Institute in December 1998, I travelled to Tamale, capital of the Northern Region of Ghana to stay with my uncle's third wife. I later moved to stay with my elder brother at Kalpohin Estates, a suburb of Tamale.”

While in Tamale, I got a temporary job at the Survey Department as a labourer for six months. “After working a few months in the Survey Department, I was laid off. My elder brother also threw me out of his house because he could no longer look after me.”

Initial Symptoms
“I used to feel some movements in my brain whenever I was studying. This started when I was in form one of Junior Secondary School. I felt some itching sensation in my brain similar to what is experienced when a sore is healing, but this was considered an ordinary headache and treated as such. I easily got angry, especially whenever I was hungry. I actually got sick and became violent just after I completed technical school and was temporarily working at the Survey Department in Tamale. This was what terminated my temporary appointment there. I was hospitalised at the Tamale

Regional Hospital for two months and then sent back to Walewale."

Treatment and Interventions

Richard said his relatives sought treatment from medical doctors at the hospital and from traditional healers while he was confined at home but could not find the right treatment for him. "Whenever I was violent, my relatives used to tie me down and call Madam Salome Mensah, the Community Psychiatric Nurse in the Walewale hospital to come and give me injections that will calm down my violence." (Chaining mentally ill patients is quite a common practice in Ghana, especially if the person wanders around or is destructive.)

"My relatives sometimes beat me and made cuts on my body as a punishment for being destructive. I was sent to Accra Psychiatric Hospital in 2002 for treatment. My condition improved and I was discharged and brought home. I relapsed thereafter and my relatives decided to pursue traditional treatment. I was confined at home with chains whilst receiving treatment from a traditional healer. The local treatment somehow worked for me. However, this relief did not last long as I relapsed again. All this while, I did not know what I was being treated for. My relatives resumed taking me to the Psychiatric Unit at the Walewale hospital for drugs, until one day a psychiatrist visited the hospital and told me that I was suffering from a type of mental illness called schizophrenia."

In Many Ways Many Things Ended

"My illness affected my focus and my expectations of life. I am no longer living with my uncle's wife. Neither am I living with my brother. My educational pursuit has come to an abrupt end. I have also lost my respect among my relatives and friends, because during my sickness, I destroyed many domestic items including my personal belongings. In Tamale, I used a blade to cut the foam on my brother's sitting chairs into shreds. This made him throw me out. No relative is ready to accommodate me now.

The only person who is ready to assist me now is my auntie, Atampoka. She is my father's sister. The room I am presently living in belongs to my sister's friend who has also been kind to me. I take supper at my auntie's house."

Coping with Social Stigma

"Those who knew me before my illness no longer respect me. When I contribute in conversations, they perceive it as silly. I know this from the way

they respond to whatever I say. They read all sorts of meaning into everything I say. This is an indirect way of calling me 'a mad person.' Others openly call me 'mad,'" Richard said with emotion. He however added that some friends and relatives accept that his condition has stabilised and therefore treat him well others do not, "but that is not a matter for me to worry about" he quickly added.

Social stigma of mentally ill people in Ghana is strong. It usually takes the form of exclusion, mockery, and derogatory remarks. Richard has learnt to accept the situation in which he finds himself. He is simply hoping for the best, but he is not carefree. He does not want to dwell on his illness since that can trigger off his condition again.

Past Bruises

Richard remembers the past with such hatred and disgust that he almost wept as he narrated how he felt whenever his own relatives mistreated him. "Whenever they chained me, they starved me as punishment for being destructive and violent. Chaining me was the most unpleasant thing to me but they were always happy to do that because I realised they were always laughing while chaining

me. I was never happy about this because it hurts so much." He said this slowly, took a deep sigh, and looked away from me. I guess he was reflecting on the pain of being in shackles.

"At our family house in Walewale, my relatives locked up my room. In my frustration to find a place to sleep, I broke all the other doors in the house. My uncle vowed never to allow me to live with him, first because of the heavy medical bills he had to pay when I was hospitalised and secondly because he is not certain about my sanity and what destruction I can unleash on him and his family at anytime."

Contact with BasicNeeds

"Although I have been part of BasicNeeds' programme of Community Mental Health and Development by reason of the support it lends to the Psychiatric Unit, my first direct contact with BasicNeeds was during a Participatory Data Analysis[1] session held at the Walewale Secondary Technical School.

The meeting sought to find out whether BasicNeeds is delivering on issues raised during the initial field consultation[2] with mentally ill people and their families, and the impact of its programme on their lives.It also highlighted issues of advocacy and carers' responses to the challenges in the lives of their mentally ill relatives. I also attended an awareness creation programme at the chief's palace organised by Gub-Katimali, a partner organisation of BasicNeeds. It was a drama that portrayed how people with mental illness are treated in society and where mentally ill people could go for treatment."

"Where Will I Get This Support?"

Richard still has a strong desire to pursue his dream of becoming an automobile engineer. His intermediate examination results showed that he performed impressively in two out of the three subjects he sat for. He thinks that with some support he will be able to achieve this dream.

"My results indicate that with little support I can make it." Richard was not awarded a certificate because he is required to rewrite his Science and Calculation paper that he failed. "I am very confident that, given a second chance I can make amends, but where will I get this support?"

Better Than Nothing

"I had no idea how I could accomplish my aspirations in life. I explained my situation to Mr. Moses Kangbe, a cobbler at Walewale and expressed my desire to work with him. With the support of my friend Ibrahim, Mr. Moses accepted me. I have been

working with him for almost a year now. At least I get two thousand cedis (¢2,000.00) (£0.12) daily for porridge. That is better than doing nothing."

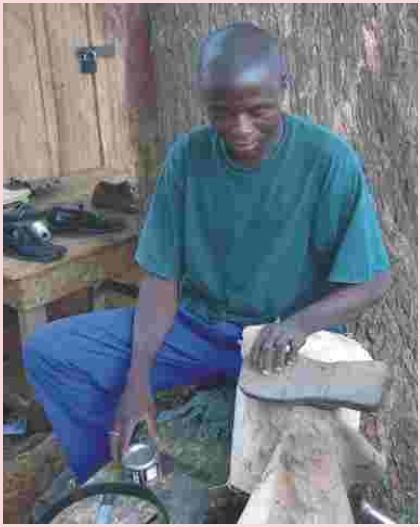
Richard wishes he could be working or doing an activity related to his studies in order to enhance his practical knowledge of what he studied in school. Now he has no alternative and just wants to do something that will earn him his daily bread, hence his concentration on repair of shoes.

A Good Person

Moses Kangbe explained that Richard is a good person. "He is an honest and obedient person. I can trust him with my goods even when I am travelling. I am comfortable working with him. I have no fears, even though I know he has ever been mentally ill."

"My Greatest Joy"

According to Madam Salome Mensah, "Earlier on Richard was not consistent with his treatment, because of this, he relapsed frequently. I almost got frustrated about his condition so I warned his family not to default treatment again or else I will stop attending to him. This threat made the family more involved in his treatment. Now Richard is able to come for the drugs himself. His condition is now stable enough for him to do any job he wants to do. I am simply happy to see him in this condition. I was very active in supporting his treatment, and he has recovered faster than I thought. This is my greatest joy."



Writer's Reflection

Richard is a young energetic man. He is physically strong and communicates very well. As any young man would have, Richard had dreams he wanted to realise. These came to an abrupt end with the sudden onset of mental illness. The illness made him aggressive and destructive and he does not feel proud about this. Although he was let down by loved ones, he never remained down. He has learned in all things to pay good for evil. Although he was physically abused by the frequent chaining and emotionally bruised by being

called all sorts of derogatory names, he is determined to face the future with courage because he thinks it is not all over for him, and, the best is yet to come.

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.

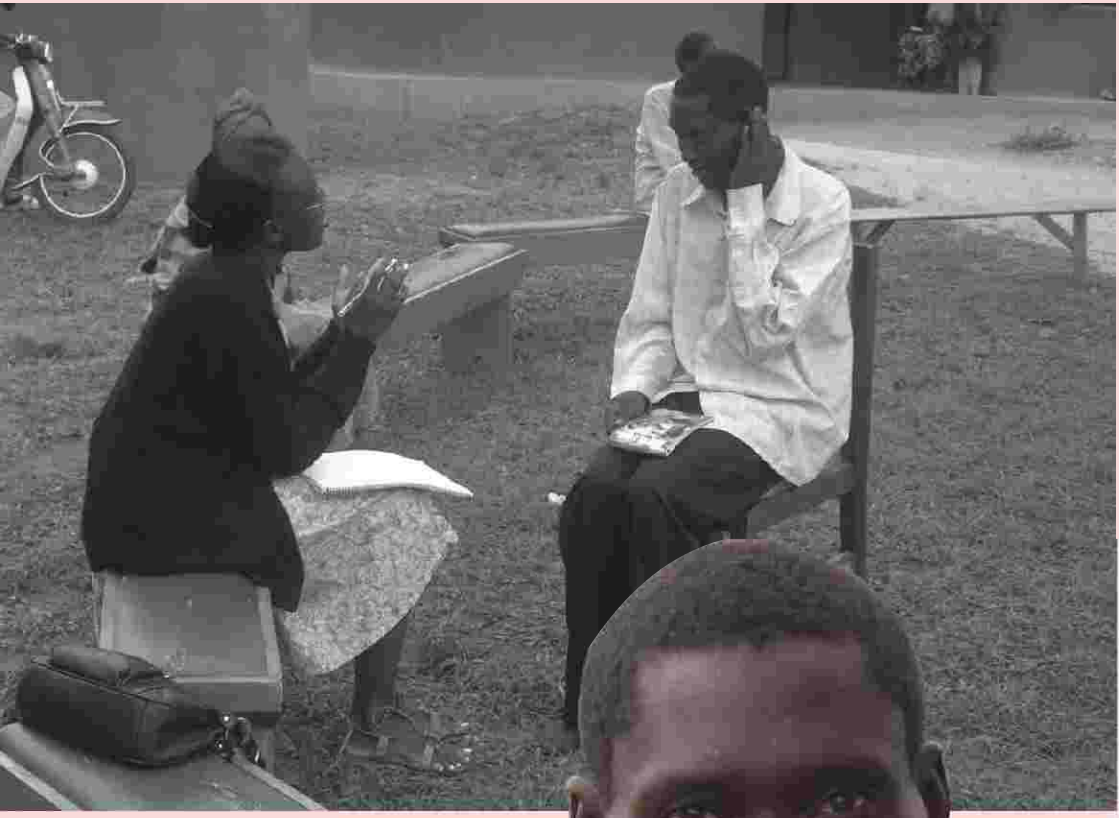
Schizophrenia is a serious mental disorder marked by irrational thinking, disturbed emotions and a breakdown in communications with others. Schizophrenia is the most common form of psychosis, a serious emotional or mental condition that makes a person unable to function in society. The cause of Schizophrenia 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 KABAGAMBE DAVID

Story written by: Irene Among, Programme Coordinator, BasicNeeds Uganda
from December 2005 to January 2007



A QUEST FOR HELP

It was the mental health outreach clinic[3] day at Ntete Clinic. Kabagambe's mother had accompanied him to the clinic. After getting his medication, we interacted with his mother and expressed our wish to visit them at home. This was such a welcome relief to her because, they would not have to walk back home, a distance we later discover to be four kilometres from the outreach clinic.

At Home

The family house is a one-room hut with walls made of mud and elephant grass reeds. The roof is thatched with grass. As we arrived in the house, Kabagambe's mother quickly brought a traditional straw mat for us to sit. She introduced the rest of her family as they came to greet us. Soon, we got to the purpose of our visit.

I explained to Kabagambe's mother that we were visiting her family in order to listen to them and understand what it means to grapple with mental illness in the family.

Kabagambe's mother says she agrees that people need to know what mental illness is all about. “Most people do not understand us; even in the village, they think we are a curse,” she explains. I obtained permission to write the story and to take photographs. Then the discussion began.

About Kabagambe

On this particular day, Kabagambe was not able to provide much information except for explaining that his medication makes him weak. Most of the conversation was therefore between his mother and us. Nnalongo Baziraki is a frail woman, who, in her late 50s, looks almost ten years older. She informed us that Kabagambe is one of the four children she has. Her first marriage was to Kabagambe's father who died about twenty years ago. They had two children, Kabagambe being the eldest. She remarried and had a pair of twins. Unfortunately, her husband abandoned her and the children and she has not heard from him since.

Kabagambe is twenty-five years of age and stands at about 5' 6”, with a slender stature. He does not have much formal education as he dropped out of school at an early age due to an unstable family income that could not pay his school fees.

The Illness

Kabagambe was a young petty trader for many years before he got ill in 1995. He used to trade in matchboxes, salt, sugar and other groceries. One day, when he returned from a business trip, his mother noticed that Kabagambe was speaking in an incoherent manner. When his

mother asked him what was happening, he just did not seem to notice her.`At the same time, Kabagambe started going around the neighbourhood uprooting people's crops in their gardens, which made them hate him and the family. He would light fires outside the house and sit there all night long talking to himself. He even attempted to set his house ablaze. Sometimes, he spent nights outside just walking up and down till morning. He did not like people and tried to avoid them every time they came by.

Forfeiting Property

Before BasicNeeds' intervention, Kabagambe had only been taken from one traditional healer to another. Nnalongo Baziraki gave us a tour of her property as she narrates what she had endured to find help for her son.

"My land used to stretch from that far end to there…" Nnalongo says, as she stretches her hands to point in two extreme directions. "I once had a big chunk of land, but twice now, I have sold bits of it."

Selling Land to Find Help

"The first time I sold a piece of land at 100,000 Uganda Shillings (£33) to pay a traditional healer at Mbirizi in Masaka, a neighbouring district," Nnalongo Baziraki said. "He also demanded poultry, goats, and alcohol. The traditional healer admitted Kabagambe to a shrine for three months where he was given herbs. During this time, we had to provide for our food and other necessities. It was a difficult time for the family as the rest of the children, both below ten years, were left at home at the mercy of the neighbours who were not on good terms with the family because of Kabagambe's destruction of their gardens." After three months of little progress, Nnalongo decided it was time to return home.

Stripped of More Land

"After months of despair, a friend told me about a powerful traditional healer at Kyazanga in Masaka, a neighbouring district. I sold another piece of land for 90,000 Uganda Shillings (£30). This witch doctor told me to stand at the crossroads and scatter the money so that whoever picked it up would pick away my problems. The witch doctor also performed a ceremony called 'okwambula' where Kabagambe was stripped, in the belief that his problems were being stripped away. The traditional healer's treatment could not improve Kabagambe's health condition."

No Improvement, Greater Impoverishment

"Later, village folk told me about a more powerful witch doctor from Tanzania. I told them that I had no

more land to sell, otherwise, my children and I would have nowhere to till. However, I had some eight-iron sheets with which I was planning to construct a decent house. I sold them off for 6,500 Uganda Shillings (£2) each. I also sold the sack of groundnuts I had harvested for 35,000 Uganda Shillings (£11) to raise money to pay the witch doctor. We stayed at the witch doctor's shrine for two months, but this too was to no avail. My son did not improve, and I became poorer…"

Back home, the family gardens were laid waste, as there was no one to tend them. Nnalongo ponders that this could be the reason for the food insecurity in their household to date.

Contact with BasicNeeds

BasicNeeds and the Masaka Regional Hospital at the Ntete Health Centre in Nakasenyi Parish started an outreach clinic in June 2004. By this time, Nnalongo had visited most of the witch doctors she could, to no avail. When she heard about the mental health outreach clinic from a Village Health Worker of her community, Nnalongo reluctantly decided to try it out. "I thought it

would end in nothing, like my earlier efforts; but I decided to try it because the Village Health Team members assured me that I didn't have to pay any money for the treatment," remarks Nnalongo.

For the first time, Kabagambe got a diagnosis for his condition, which according to the clinic's records is schizophrenia. Kabagambe continued to attend the outreach clinic every month and takes his drugs as well. His condition has now improved. He does not wander about and does not uproot crops of neighbours. Kabagambe now sleeps in the room.

Kabagambe is Helpful

"I am happy that now, instead of threatening to burn the house, my son has started helping me to make the home a comfortable place. He helps me in activities like fetching water, digging in the garden, and cooking," remarks a relieved mother.

Community Acceptance

As Kabagambe continued to take medication for his condition, his health started improving. His body personal hygiene and general behaviour improved and this became visible to people in his community.

"I am happy that the community now understands. People are not so hostile to my son any more Although they don't offer much help, people generally treat him well when he strays. He is calm and does not destroy people's property any more or abuse them. When he goes to the well, people are kind enough to let him draw water without letting him wait in a queue," remarks Nnalongo.

Greatly Impoverished

Despite the access to free medication, the family has still not been able to recover from the losses to traditional healers. The family does not have any food in the gardens, nor does it have anything stored for the long dry season.

"Drought makes our poverty even worse. We have experienced drought for three years now and it is really bad. I could not even migrate during the drought period because I am the mother and the father in this household. I fear that if I go away, people will grab the only piece of land I am left with," says Nnalongo.

"I had three goats, but I sold them last month for 10,000 Uganda shillings (£3) each, and I bought corn meal, which we fed on for two weeks. We have only one meal of corn porridge a day. Kabagambe has even started refusing to take his medication because he complains that it

makes him very hungry and there is no food for him. I am happy that he is getting treatment and getting better, but this drought is making his health deteriorate."

"For us, poverty is there even in the rainy season. I am old and too weak to cut grass for thatching the house. When it rains, we can't sleep. We sit in a corner of the hut, but we still get drenched. We don't have food, water or soap. Sometimes I go to the village and dig in people's gardens so that I can get money to buy soap. It's the dry season now, and I can't do much because there is practically no work. If I could get some drought-resistant banana suckers, I am sure we would not starve during the next dry season," laments Kabagambe's mother.

Kabagambe Speaks Out - "I Have Changed"

On the 14th of March 2006, Kabagambe came to the clinic premises to attend a Participatory Data Analysis (PDA) session with other village folk. He was clad in a white shirt and brown pants and was in the company of his twelve-year-old sister, Jackie. Kabagambe tells me, "Mother is not well, so she could not come, but we left her in the garden," Jackie added, "I did not go to school today because I had to escort my brother to the meeting." During the analysis, Kabagambe went on to say, "My mother has been accompanying me to the clinic to get me treatment. I used to suffer from severe headaches, but I am better now. Mother sent me to dig in the garden, and I can now dig."

"I have changed. I was so sick. I could not even come here by myself, but now I can come to the clinic without my mother accompanying me. I can now dig, clean the compound and go to the well to fetch water." The drought we have suffered of recent has been bad for us for I wish I could be fully engaged in producing food for our family.

Reflections

The story of Kabagambe is an affirmation of the truth that mental illness exacerbates poverty.

The fact that Kabagambe is not able to engage in livelihood activities such as agriculture is really worrying. It could lead to stress, thus worsening his mental condition. Kabagambe's home is one of the places that are severely affected by drought. Just like his fellow villagers, Kabagambe is willing to engage in agriculture so as to get something to eat but because of drought, this is not possible, and the desired outcome far from reach.

Interacting with Kabagambe's family re-emphasises the need

to mental health. This is the very essence of the Mental Health and Development model that BasicNeeds espouses. The different people and communities we work with experience different needs.

BasicNeeds' Mental Health And Development Programme

BasicNeeds is an international non-governmental organisation promoting inclusion and integration of mentally ill people and their needs and right in development programmes and policies. Its vision is “that the basic needs of mentally ill people throughout the world are satisfied and their basic rights are respected”. At the heart of the work of BasicNeeds, is a model uniquely developed with mentally ill people themselves and their carers to implement and sustain initiatives in mental health and development.

A series of extensive consultations with mentally ill people, their family members, carers and partner organizations led to a formation of the 'Mental Health and Development' model that BasicNeeds developed to address the needs and challenges (as) espoused by mentally ill people themselves. Within the model are five distinct yet mutually reinforcing modules to tackle the most important challenges and barriers as perceived by mentally ill people. They include: **Capacity Building**; to build the capacity of mentally ill people, their families and partner organisations in order to involve them in the development process. **Community Mental Health**; to provide appropriate mental health care and treatment to mentally ill people living in the community. The programmes have already demonstrated a capacity for economic regeneration. Thus, assisting recovery through going to work and earning **Sustainable Livelihoods;** leading to self-reliance and social integration. **Research and policy**; to research the situation of mentally ill people in the community, to begin to tackle the lack of awareness of mental health issues and policies within the wider community and institutions including the government. Underlying all work in this area so far has been the careful collection of life stories and ensuring that experiences of mentally ill people are central in the research process. **Administration**; to provide an efficient administrative service in support of BasicNeeds and its supporting partners.

THE STORY OF EUGENE DOE

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

"NOW I BELONG TO A GROUP"

An Emphatic Speaker

I first met Eugene Doe during a Participatory Data Analysis (PDA) with mentally ill people, carers, Community Psychiatric Nurses, volunteers[4], and animators[5] in Okai Koi Sub-Metro in Accra. His contribution to a discussion on the sources of treatment for people with mental illness attracted my attention. He was very emphatic in stating his position on traditional and herbal practitioners; "they are not the best of places for treating people with mental illness," he said. His observation was based on his experience with two traditional healers.

At the end of the programme, I interacted with Eugene and expressed my desire to document his experience, and share with others who are also suffering the same condition. It will also be used to inform the general public and influence them to support mentally ill people and people suffering epilepsy. Eugene was happy, and agreed that I could come to his house whenever I was ready.

The Life Story Begins

Eugene began his narration. "I am the first born of my mother, Sera Grant, a baker based in Kumasi, the Ashanti Regional capital of Ghana, and the third child of my father, Mr. Emmanuel Doe, a lotto agent[6]. I am currently living with my father and my half brothers and sisters as well as my stepmother and two other girls helping my stepmother. I work as a shopkeeper at Kaneshie market in Accra."

A Problem-Free Infancy

Eugene narrates about his childhood experience, "I was born in Accra. I was told my mother did not have any difficulty in giving birth to me. I was also told that she travelled with me to stay with my grandmother in Kumasi shortly after I was named." In Ghana most cultures require a woman upon delivering her first child, to go and stay with her mother until the child is strong enough before the woman can return to her husband's house. The reason is for the woman's mother to help take proper care of the child. "My mother stayed with me in my grandmother's house until I was eight years old. In all these years I was told I did not suffer any major illness."

The Beginning Of Illness

"I started experiencing symptoms of my illness when I attained eight years. I used to wake up in the night, talking, shouting, and making noise in the dark. My mother and my grandmother prepared herbal concoctions they bought from itinerant peddlers for me to drink. My symptoms stopped, but this was only temporary."

The Next Phase of my Illness
Eugene's stable condition did not last long. He relapsed, this time with very severe symptoms. “My mother decided to send me to my father in Accra. This time, I could not do anything on my own. I used to urinate and defecate on myself without any control. Deep in my sleep at night, I would suddenly wake up and find myself hitting my head and my feet on the ground. The black irises of my eyes would disappear and my eyes would only be white. My parents could not sleep because of me.”

Further Treatment
“I was taken to Accra Psychiatric Hospital. The doctor there examined me and referred me to Korle Bu Teaching Hospital for further examination. I underwent a scan of my brain and chest at the Korle Bu Teaching Hospital. The scan could not detect the cause of my illness. I was however still treated and given some drugs. The drugs improved my condition, but I still could not do things on my own.”

In Search of Complete Cure
“My father pursued several other avenues of treatment to find a complete cure for my sickness. We were told about a powerful traditional healer at Saviekofe Agokpo, a village in the Volta Region of Ghana, so my stepmother took me there for treatment. The healer gave me a bottle of Frytol cooking oil[7] to be drinking in the morning and evenings. I stopped taking the drugs I was given from the Accra Psychiatric Hospital, and concentrated on the frytol oil from the traditional healer. I developed diarrhoea and that even compounded my sickness

When I came back from Saviekofe Agokpo, I realised there was no potency in the frytol oil, so I stopped taking it. I went back to taking the drugs I was earlier given from the Accra Psychiatric Hospital. This stabilised my condition once again, but I still needed complete cure. My stepmother again heard about a pastor who is also a practising herbalist and took me there for healing. The pastor also gave me frytol cooking oil at one time as treatment, palm kernel oil at another time, and later with different medicines.

The sickness became much more severe than before, because I had stopped taking the hospital medications. The pastor's treatment brought me no improvement, so I stopped his treatment and continued with the medicine from the hospital. I was taken to other traditional healers but their prescriptions and medications were also of no help.”

Illness, a Depriving Condition
"My sickness used to affect me at night. Many people in the vicinity did not know I had such sickness. So, I did not face any stigma in the community. I could go anywhere during the day without being noticed. With my illness, I am still able to do everything for myself, cooking, bathing, and washing. I completed my technical school course in electronics. I am now a qualified electronic technician. In the shop where I am working, no one knows I am suffering from epilepsy. I relate very well with everyone there.

Financially, my illness drained the little resources my parents had. All the traditional healers I was taken to demanded various items ranging from cloths, animals to cash in place of items we could not provide and the cost of actual treatment itself."

Eugene's father corroborated that a lot of money has really been spent on going to and from the hospital, treatment from traditional healers' place and other expenses associated with treatment.

Disbelieving Myths
"I experience seizures whenever I do hard work. At Saviekofe Agokpo, the herbalist told me it was my maternal grandmother who caused my sickness. In the beginning, I believed him, because I had stayed with my grandmother for quite some time. Also, when I went for my grandfather's funeral, my grandmother received me very well, and I thought she was trying to pretend she loved me. However, I later disbelieved the herbalist because when I was not working my grandmother used to give me money every time she came to Accra. So what the herbalist told me could not be true."

"I Need Drugs All the Time"
"The hospital medicine has been helpful to me. I am now better, but I need to have the drugs all the time. Whenever I skip taking my drugs, my hands tremble and when I want to talk, I stammer. I need to have drugs all the time.

I realised some improvement in my condition when I started coming to the Kaneshie Polyclinic for drugs. I no longer tremble or stammer when I speak. My only problem is that, I have very little time to go to the polyclinic for the drugs. I work from 6am to 6pm from Monday to Saturday."

BasicNeeds Plays a Big Role
Eugene narrates how he got to know BasicNeeds, "I got to know BasicNeeds through Nathaniel Kotey's mother. Nathaniel is a beneficiary of BasicNeeds. His mother invited me to come with them to an outreach clinic where

I will not have to pay any money for drugs. I did and the doctor told me that I was suffering from nocturnal fits. He said it was a type of epilepsy. I was treated and given drugs and since then I have been attending outreach clinics and other meetings BasicNeeds organised for mentally ill people. I used to experience my condition several times at night, but now it only happens mildly I only now shiver a little when it occurs.

I am now a member of the Okai Koi South Self-Help-Group[8]. The Self-Help Group meetings are very helpful because during such meetings, we discuss issues of common interest to us. It is also an encouragement to me whenever we meet to share our problems and think together to find solutions to them. BasicNeeds has really transformed my life for the better."

Reflections

Eugene's condition is now stable and he works as a shopkeeper of an electrical shop at Kanashie market. He is hardworking, dedicated, and conscious of his work. He leaves his house for work very early in the morning and returns in the evening.

Despite his busy nature, Eugene is still able to make time to attend Self-Help Group meetings and go for his drugs without failing, because he appreciates the importance of being in an association of people who also share the same fate as him.

He is a brilliant person. His timings and work schedule are so rigorous and he tries to always be on time wherever he is going.

Epilepsy

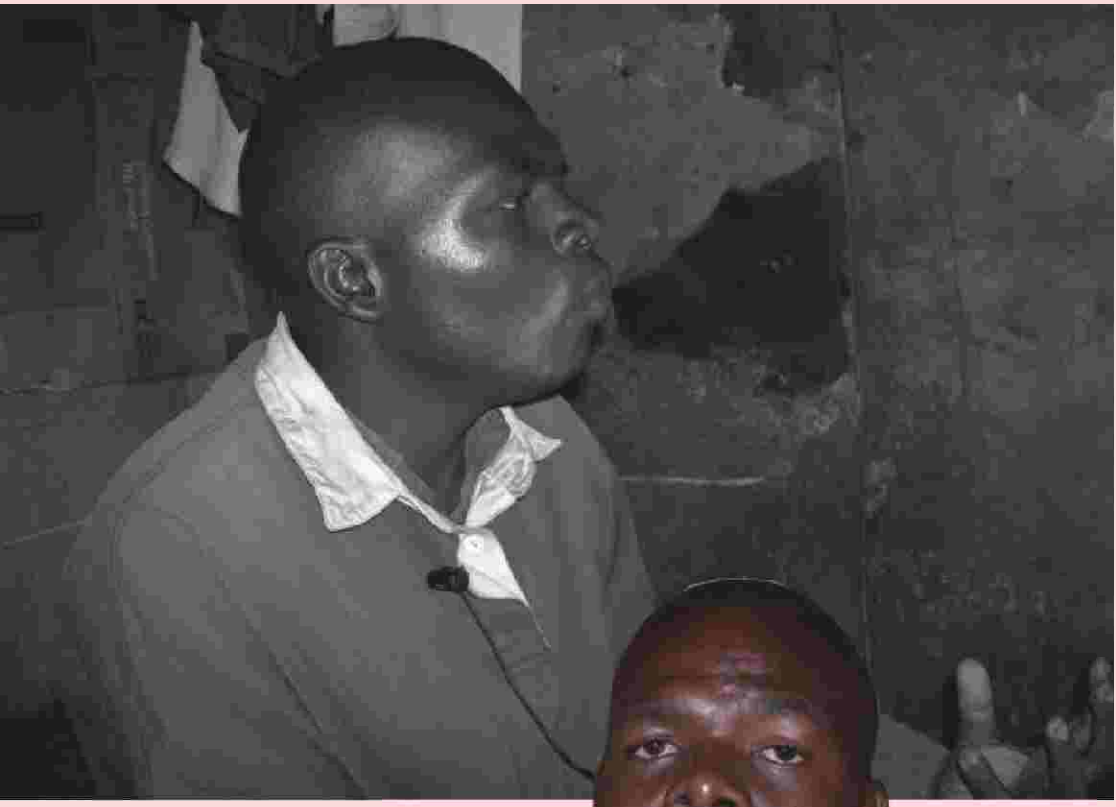
Epilepsy is the most common brain disorder in the general population. It is characterised by recurrence of seizures, caused by outbursts of excessive electrical activity in a part or the whole of the brain. The majority of individuals with epilepsy do not have any obvious or demonstrable abnormality 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
Essential Psychiatry Edited by Nicholas D.B. Rose
The World Health Report - 2001
Maximum work count = 200 wrds.

THE STORY OF MICHAEL NYANJE

Story written by: Allan Oginga, Research and Policy Officer, BasicNeeds Kenya



"I AM NOT WHAT YOU THINK"

A Calm, Quiet Young Man

Michael is among the first mentally ill people to attend a BasicNeeds' supported mental health outreach clinics at Kangemi Health Centre[9] in May 2006. It was while Michael was attending a follow-up and referral session at the clinic that Joel Kimata, a Community Health Volunteer[10] recommended him to me to construct his life story. We visited Michael three days later and he accorded us a very warm reception and assured us that he had no problem if his story was constructed and published.

Michael had earlier been noted at the clinic sessions as a rather quiet young man, about 28 years of age, always wearing clean clothes, and reserved. He is very respectful and calm. Michael stands about 5ft 11inches tall and has a dark brown complexion. Though a bit underweight, he looks physically fit. He does not look like someone suffering mental illness.

Those Early Happy Years

Michael was born in 1975 in Kangemi. His father was a junior sales assistant in a company that sold office supplies and stationery. His mother was a secretary, at a nearby local high school. His mother retired from her secretarial job in 2000 and his father retired in 2003. Things got very difficult for Michael at this time as he had to start living on his own.

He is the fourth child in a family of four boys and four girls. Michael attended St. Martin's Primary School and then proceeded to Kakamega High School, a boarding school in the western part of Kenya, and graduated in 1996. He remembers his childhood as generally happy and though they did not have much financially, as a family, he got along well with all his siblings, his neighbours and friends.

After his high school education in 1996, he studied basic computer operations at a small training room in Kangemi that had earlier been started by his mother. Michael also sat for the Pitman's test in typewriting and obtained a certificate. He could type thirty-five words per minute.

Trouble Looms

Michael managed to secure a teaching job at a kindergarten in his village for a few months in 1998. He did not like being in his rural home because he was constantly fighting with his uncle. “My uncle was a quarrelsome person, I could not cope with him,” Michael says.

In 1999, Michael gave up the teaching job and started helping his elder brother, Fred, in selling ice cream. Later in 2001, he

worked on part-time at the computer training school his mother had set up in Kangemi, teaching the youth basic computer skills. He had disagreement with the regular teacher of the training school and decided to leave for a part-time job of cleaning the Kenya Assembly of God (KAG) church at Kangemi for a fee of Kshs 100 (US$ 1.25) per day.

Something Wrong

Michael says he started feeling ill towards the end of his high school education in 1995. He was about twenty years old at the time. He feels that his illness started due to the stress of examinations and due to thoughts about qualifying for University. He heard voices, which he informed his schoolmates about, but they often responded that they were not hearing any voices. Michael says he knew there was something wrong and he informed his family but he thinks that his family just felt that he was going through a period of adjustment being away from home for sometime. So he just persevered and suffered alone so that he could sit for his examinations. He did not insist on seeking treatment till after school.

A Sense of Unfairness

Michael feels his father has been unfair to him during his illness. He said during the early days of his illness, he used to be quarrelsome and whenever there was a problem between him and any of his siblings, his father always supported them. “I felt neglected and isolated. I believe this intensified my illness.”

Michael thinks that his siblings felt he was “babied around” too much by his parents. At this point Fred, Michael's elder brother, interjects and admits that they did not appreciate that Michael was actually ill. They just felt that he was being spoilt by his parents. He says most of Michael's siblings, including some of his sisters, had moved out of the family home and were trying to fend for themselves, while Michael seemed to them not to want to pull his own weight. “My brother is predisposed to bouts of extreme violence.” He shows us a knife wound on his cheek, “this was a knife attack from Michael.” Fred said.

Michael quickly interrupts Fred at this point and explained that in 1998 he heard voices at night while coming back from a late night church service and in his confusion he fell down at the Mau Mau bridge in Kangemi. He did not know where he was and spent the night at this bridge. He was found by a Good Samaritan the next morning and taken to Mathari Hospital. He tried

explaining this to his siblings, but most of them just ignored him. Only Fred seemed to start taking interest in him. He also narrated that he was once a member of Mary Akatsa's church[11] in Kawangware, another informal settlement located close to Kangemi.

Unsavoury Experiences

Michael's first experience with mental health treatment was in 1997, about two years after he first complained of his problem. He was taken to Mathari Hospital where he was immediately hospitalised. He says he spent three months at the hospital. He was tied up with ropes by his family and taken to Mathari. He thinks that it is not good for neighbours to see him being tied up like a criminal. Some medicines were prescribed for him but he did not have the money to keep buying them, so he was not consistent with his medication regime. He also complains that the medication made him very hungry and tired and because most of his jobs were manual he found it difficult to take the medication.

Michael has been to Mathari Hospital thrice. His last visit was in December 2005 when he was there for a month. He says, “I hate being hospitalised. I want to always be with my family. They understand me better than the doctors and nurses.” He believes his mental health problems arise primarily from stress and taking him to Mathari Hospital does not help him. He also thinks that family feuds and quarrels also affect him.

The Community Reacts

Fred says that Michael has on several occasions stripped naked. Therefore, some community members in Kangemi are afraid to associate with him, “when Michael’s illness was very severe and we tried to take him to the hospital, our neighbours did not attempt to help us. They were afraid to come closer to him.” Michael does not want to be reminded about his past. He feels the present matters more than the past. He says, “I have been living in this current place in Kibagare for four months now and have not had any relapse, most of my immediate neighbours are not even aware that I am sick.” At this point, interestingly, Michael's next-door neighbour - a man in a checked red shirt - passes by, and noticing that Michael's door is open, peeps in and says “hallo” to us all and goes into his house.

Michael says that he is more comfortable in his new residence than his previous one, because there, most of the people knew him and his family often asked questions about his condition that reminded him of his past. “I

always felt that they were over sympathising with me. They would always say, 'What was wrong with you? Why are you still living with your mother in the same house?'" Michael narrates this in a rather angry tone.

BasicNeeds in Kangemi

BasicNeeds started operation in Kangemi In March 2006. Michael said he heard about BasicNeeds' programme from a lady called Judy, who in turn had heard about it from a lady who had attended a mental health sensitisation campaign in the community in Kangemi. Later he was taken to attend a mental health outreach clinic at the Kangemi Health Centre supported by the same organisation.

Wishing Things Would Change

Michael says the medicines that he gets at the clinic are really helping him because he has not experienced any relapse since he started taking them. However, they make him very hungry and since he earns very little from his weekly cleaning at the Kenya Assembly of God church, he cannot afford to buy enough food.

Michael says that he is constantly worried about his rent. His brother, Fred, has paid his rent for the last four months, Fred has his own family too, and his ice cream business cannot sustain his current expenditure.

Michael thinks that being alone is a problem for him; and since he is not living with his siblings any more, he needs a girlfriend or a wife to take care of him. He however says that there is some difficulty when the ladies get to know that he is (or was) mentally ill. He is however trying. “I have found a lady who says she will introduce me to her younger female relative once I get a job,” says Michael.

At this point Fred tells us that he has advised Michael that there are girls who may want to take advantage of him so he needs to find someone who really loves him. Fred narrates to us a story that happened in 2005 when a lady in Langata, a middle class suburb about 30 kilometres from Kangemi, played around with Michael's feelings and finally admitted that she was not really interested in Michael and that it was only a joke.

Michael appeals to BasicNeeds to support him to obtain a job. He feels his problem is compounded by the lack of activity to keep him busy so that he can stop thinking about being alone and worrying about rent. At the end of our conversation, Michael said a short prayer to God before we left. He prayed for all of us

individually and for BasicNeeds' programme.

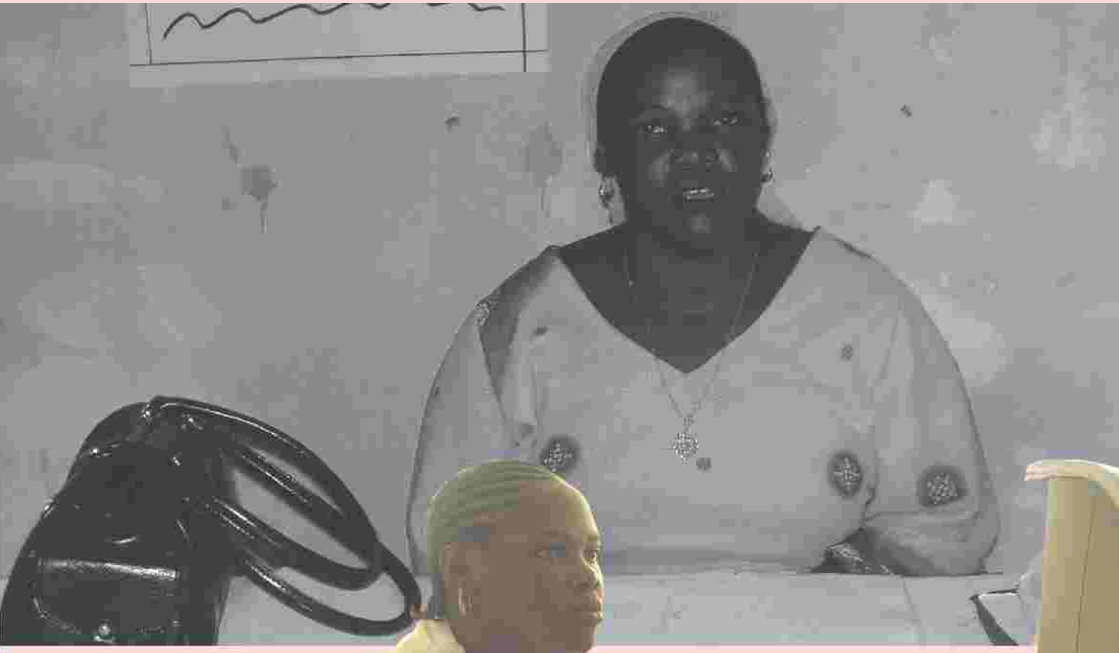
Reflections
Michael is very religious and positive about leading a normal life. His biggest concern is that he is misunderstood and thus mistreated. He however downplays his symptoms and does not want to discuss the occasional bouts of anger, violence, and irrational behaviour that he is occasionally prone to. He actually seems ashamed of it.

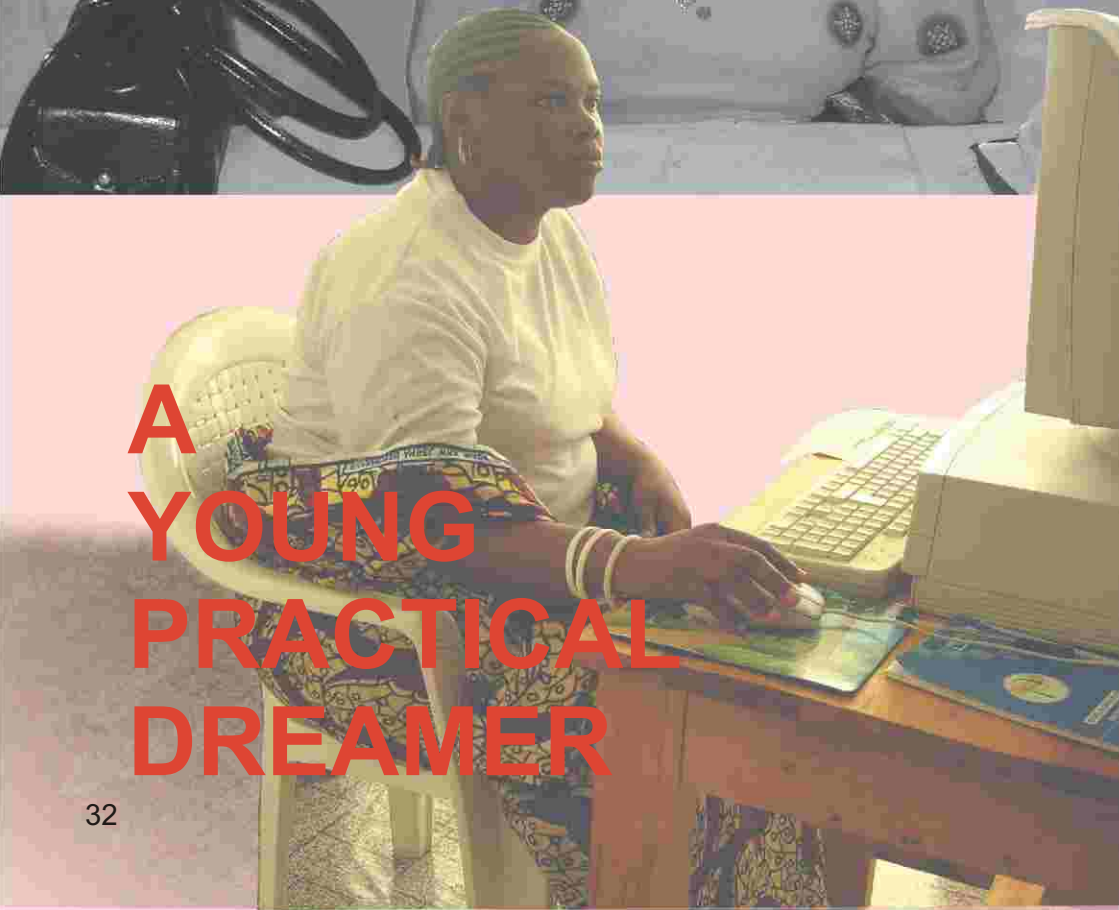
Michael is to some extent dependent on Fred and also seems ashamed of this. Michael is an example of how mentally ill people have aspirations and actually strive to be understood and live a normal life. He seems very talkative to people he is comfortable with, but appears to lose confidence in a crowd. Could this be because he feels we, the so-called normal people, fail completely to listen to him?
Michael realised long ago, even before the intervention of BasicNeeds' programme, that institutionalisation was not the answer to his illness.

BasicNeeds' mental health outreach clinic and its community-based programme are quite possibly one of the life-saving answers Michael and other mentally ill persons in Kangemi have recourse to. It is my personal hope that Michael will fully stabilise with treatment from the mental health outreach clinic and benefit from BasicNeeds' programme.

THE STORY OF ZAMDA SAID KUPWAJA

Story written by: Meckland S. Millanzi, Community Animator, BasicNeeds, Tanzania, Mtwara Programme





A YOUNG PRACTICAL DREAMER

Smiling And Charismatic
Smiling and charismatic these are prominent qualities you can notice about Zamda whenever you meet her. She is plump but full of energy. Zamda is the fourth in a family of seven children, three of whom are men and four, women. Her father, Said Kupwaja, was employed as a driver by a local transportation company called KAUMU. He was a truck driver and used to travel to various places in the country.

Zamda was born in 1981 in the town of Mtwara where she got her primary education. After doing well in her primary school examination, she was selected to join secondary school in Saba Saba Day Secondary School located in Mtwara town.

Chikongola Street
Zamda lives with her parents on Chikongola Street in Mtwara town. Chikongola Street is highly populated. Houses have been erratically built. Water shortage is the major problem of this street. It is common to meet women and children carrying buckets of water from one place to another. Hygiene standards are very poor due to overcrowding of the houses and the lack of proper sewage system. This has resulted in high incidence of malaria in the area.

The residents of the area are mostly petty traders who earn little from the businesses they do every day. Majority of them depend on seasonal businesses associated with the harvesting of cashew nuts, which is the main cash crop of the area. Work also revolves around the production of cereals like maize, rice and beans, which are the main food crops. Only a few residents are employed in government offices and private organisations.

Illness Strikes Unawares
Zamda narrates how her illness started, “My illness started in 1997 when I had just joined Saba Saba Day Secondary School for my secondary education. I liked my studies but it did not take long for me to discontinue it as my mind was steamed up with a strange illness, I was admitted to the Psychiatric Unit of the Ligula Regional Hospital[12], where my illness was diagnosed as schizo-affective disorder.”

Zamda's father explained how he first realised that his daughter was sick, “I first got information about her condition from her teachers at school. They narrated the various unusual things she did. They complained she was always laughing now and then and talking about unusual things to her colleagues. Sometimes, she would cry while at school. The situation persisted to such an extent that I was advised to stop her from schooling. I took her to hospital and she was admitted for one

month and discharged, but her condition did not get better. I then decided to send her to a traditional healer in another town for further treatment. She was so aggressive then, and never liked to see her mother. There were days she refused to speak and would communicate only through signs."

A Surprisingly Great Academic Performance

Zamda's condition improved and she returned to school. While at school, her colleagues used to call her all sorts of names and made jokes that were directed at teasing at her, this made her feel discriminated against. This triggered a relapse of her illness. Zamda's relapse was characterised by loitering about the school compound while classes were in session, "My daughter started to come back home from school in very dirty uniform although she would leave with clean clothes," said her father.

Zamda's condition worsened when she was preparing to sit for her form two National Examinations. She says, "I thought of the exams with fear since I had not prepared well, most of my time was consumed by my illness. My friend, Neema Kamwenda, helped me. She always came to study with me in the evenings. We used to study very hard during the last days to the examination. This helped us, because both of us passed the exams. I held the sixth position among 120 students."

An Unexpectedly Bad Turn

However, when school reopened Zamda could not return to her studies. She had relapsed, this time very severely. She says, "I remember one day I urinated inside our classroom because I felt shy to go to the toilet. My colleagues laughed at me so much that I felt very shy."

Zamda's father added his voice about how he sought treatment for Zamda, "Having seen her situation, I took my daughter to Ligula Regional Hospital in Mtwara, where she was again admitted for a month. Her condition improved and she was discharged. My friends then advised me to send her to another secondary school that is far from town where she could have the peace of mind to study without any stigma. I secured her transfer to Mtwara Girls' Secondary School."

No Money for Treatment

Zamda resumes her narration, "While I was at Mtwara Girls' Secondary School, I studied hard in order to cope with my new classmates who had already covered much of the syllabus. However, my efforts did not materialise because I started experiencing headaches whenever I studied a little longer. My teachers encouraged me to go to the hospital regularly for my medication."

The cost of medication at Ligula Regional Hospital was quite high for Zamda's father, “each dose of injection cost me Tsh 21,000 (about £8.75 pounds). There were times when I just did not have money to pay for it,” said Zamda's father.

Bitter Disappointments

Zamda completed her secondary school education in 2001 and gained admission to do a certificate course in Mtwara Teachers' Technical Training College (MTTTC) for one and half years. However, she relapsed after their field practical training and could not complete the course. She reapplied to another college in 2004 to pursue the same programme, but the illness struck again and she was taken to Muhimbili Hospital[13] in Dar es Salaam. She said some nurses in the Psychiatric Unit gave her some drugs and allowed her to go home. The drugs could not improve her situation, so she

was sent to an Islamic spiritual healer for treatment. “I stayed with the healer for two months and felt some improvement in my condition. We therefore decided to return to Mtwara because it was expensive staying at the traditional healer's compound in Dar.” Zamda said.

Medicines “A Part of My Life”
Zamda looked healthy despite her obesity. She gave out a bright smile and talked slowly, but surely. “I am doing very well with the medicines. My condition is now stabilised to a great extent. I am now able to go alone to the hospital for medication every month. Though I have become plump due to these drugs, I will never stop taking them since they are now part of my life. I don't want to relapse again.”

On The Road to Recovery
Zamda's father described how Zamda became part of BasicNeeds programme, “It was in mid 2004, after coming back from a traditional healer in Dar es Salaam without any relief that my younger brother, who lives in Tandahimba district visited my family and informed us about BasicNeeds' activities in the district. I had my doubts about the help they could give to my daughter. I thought this was another waste of time and money, but my brother assured me and took Zamda to Tandahimba to seek treatment. She was diagnosed with schizophrenia and was given treatment. Since then Zamda has been taking those medicines and her health has improved so much. Even though she has gained a lot of weight because of the medication, we are still grateful to God.

Expectations and Aspirations
Zamda has not given up hope of a better life. She has been interviewed for the post of sub-village executive officer. She has also enrolled for computer classes to learn computer skills.

Reflections
Zamda is in her early twenties. She is young, a young practical dreamer whose dreams of achieving academic excellence have been jeopardised by mental illness. But she has not despaired of her illness. She is carrying on her computer studies with the intention of doing better in her new expected job. She has been ill for so long, she and her family have spent a lot to get proper treatment for her illness, which has severely robbed them of a significant amount of their resources.

This also reveals that even though mental health services might be available in the area, proper diagnosis and treatment

is still lacking. This makes traditional healers seem to be a better option for many mentally ill people like Zamda.

Notes

1. Participatory data analysis is a group activity involving mentally ill people, their caregivers, and community health volunteers, in which with facilitation from BasicNeeds and its partners, help them to analyse information emerging from programme implementation, including life stories, and individual files of mentally ill persons. This process yields new insights into the programme from the point of view of community level.

2. A field consultation is a group consultation exercise, particularly for mentally ill people and their carers and family members, as well as health and development practitioners within the community. Field consultations are the starting point of BasicNeeds' Mental Health and Development Programme in an area. The first step towards composite health and development. Mentally ill people, their carers, and other stakeholders like medical staff and BasicNeeds' partner organisations participate in this initial exercise in a new area. Usually the facilitator/animator leads the group towards an open and candid discussion of issues that impinge on their lives. They are encouraged to sketch their world, spell out their needs, and mark a way forward

3. Outreach clinics are clinics, usually 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. Volunteers volunteers in the BasicNeeds Accra programme, are community members who support mentally ill people to access treatment within their communities. Volunteers mostly undertake home visits to homes of mentally ill people to monitor treatment progress.

5. Animators animators are focal persons within the various sub-metros where BasicNeeds operate in Accra. They act as intermediaries between volunteers and Community Psychiatric Nurses. They mostly supervise the activities of volunteers within a particular sub-metro.

6. A lotto agent is an intermediary between a lotto company and people who buy lotto tickets. An agent registers with the company and collects the tickets for sale on a commission basis.

7. Frytol oil is one of the vegetable cooking oils commonly sold in Ghana. It is a product of Unilever Ghana

8. Self-Help Group (SHG) A group of mentally ill people and/or their carers who come together with a common interest of drawing mutual support. They meet regularly to discuss issues of common concern

9. **Kangemi Health Centre** is a City Council (local authority) clinic in Nairobi, Kenya where BasicNeeds Kenya supports to provide mental health services. Specialists Psychiatrists outreach clinics are also held there. BasicNeeds' support to the health centre is in the form of supply of drugs, stationery, and filing folders.

10. Community Health Volunteers in Kenya, are mostly residents of the community who are attached to the local clinic. They help with support-jobs like filing, crowd control during clinic days and registration of patients. They also undertake home visits to homes of mentally ill people as part of their work in the community. They are trained in first aid, basic mental health, hygiene, and diagnosis.

11. Mary Akatsa's church also known as Christ Church of Bethlehem - gained prominence in the late 1980s through to the late 1990s in the Kawangware area. The church was quite popular, particularly with members of the Luhya community - the second largest ethnic group in Kenya - to which Mary and Michael Nyanje belong. The church has been variously accused of misleading people, especially young men, into having sexual relations and entering into marriage with older women, and of even engaging in ritualistic and cult like activities. Mary Akatsa conducted miracle prayers for her followers, praying for the sick, the blind, for crippled people, mentally ill people, barren women and others facing all sorts of personal problems. In Kawangware she was referred to as 'Mami' and revered for her healing powers. Mary later got married and is believed by some to be a wealthy woman with investments in Kangemi and in Western Kenya. The church compound is now a large unused field sealed off by a stone wall.

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