



HUMBLE BEGINNINGS: GREGOIRE AHONGBONON AND THE ST CAMILLE ASSOCIATION



Grégoire Ahongbonon talking to a homeless man.

"In certain countries in Africa and elsewhere, mental illnesses are considered to be a magical, supernatural event, caused by spirits that take over the body. People who are mentally challenged are considered dangerous or contagious and are abandoned by their families, left to wander the streets with no food and no home. Or they are chained to tree trunks, left alone, hidden from the rest of the society. Some are beaten and left with little food to 'purge the evil spirits' through physical suffering."

"I was born in 1953 to a farming family in a small village in Western Africa. I immigrated to Côte d'Ivoire. By 1994, I had been caring for people excluded from society such as prison inmates and people with HIV/AIDS for 10 years. At this time, I learned about the fate of people with intellectual disabilities and mental health problems. I decided to get actively involved in their care and founded the St Camille Association for people challenged with Mental Health in Western Africa."

"The first challenge was to get these people off the streets, liberate them from their chains, care for them, and rehabilitate and reintegrate them. In almost every village, there is a person chained up, but it is so shameful to the family that it is hidden. Sometimes I find patients in the most deplorable state. I see mistreatment almost everywhere I go.

"My mission is to give dignity back to people with mental disorders, through care, support, and help to reintegrate them back into society. The St Camille Association provides shelter, medical treatment and follow up for ex-patients and their families and supports their social reintegration and rehabilitation through skill training and education. Several farms and centres have been created where ex-patients can cultivate manioc and other local products, as well as breed chicken, pigs and rabbits. We also try to facilitate the reintegration of these people into their village of origin.

The Fondazione Saint Camille de Lellis supports the activities of the Association St. Camille de Lellis, founded in West Africa by Gregoire Ahongbonon in 1983. The St. Camille has 10 centres, which are located in the cities of Bouake, Korogo, Boudoukou, in the conflict zone of the Ivory Coast and in Avrankou and Bohicon in Benin.

The 10 sites provide assistance in mental health, integrated in a broader range of health and social services, including rehabilitation, housing and vocational skill training for reintegrating patients into their native villages.



VOICES FOR MENTAL HEALTH - Service user groups and other NGOs

In 1998, following the increasing needs of the local population, the Association improved its services inaugurating in Bouake the Saint Camille Hospital which provides comprehensive health care in general medicine, an eye clinic and dentistry.

The Hospital with the centres of Bouake provided medical treatment, shelter, water and nutritional services for over 70,000 people daily at the height of the Ivorian crisis. Today, the Hospital treats 25,000 patients each year. Recently, it began to make available antiretroviral treatment to HIV+ patients.

With more than two decades of experience in the health and social sectors, the St. Camille commitment in West Africa, aims to improve assistance and provide additional resources in scaling up an organic response to the mental health and furthermore general health crisis in the region.

The Association St. Camille together with the Fondation in Lugano is working with international organizations such as, Catholic Relief Services, The World Food Program and the Red Cross. Recently they have secured a grant from the Elizabeth Glaser Pediatrics Aids Foundation for a HIV/AIDS unit in the Saint Camille Hospital, in Bouake.

The Fondation St. Camille is a member of the Clinton Global Initiative in New York and is partnering with the Clinton Foundation, the Ivorian Government and PEFAR to secure free antiretroviral treatment to patients at the St. Camille Hospital.

For more information about the work of Grégoire Ahongbonon and The Fondazione and Association St. Camille de Lellis visit: www.fondazione-st-camille.org

AMIT, KRISHAN AND THE WORK OF KOSISH

KOSISH is a mental health self help organization which works to improve conditions for people with mental disabilities in Nepal. Here are two stories illustrating the key role of service user organizations in promoting and protecting the rights of people with mental disabilities.

TAGGED TO BE UNCURED: AMIT'S STORY

Amit is a very innocent, honest and loyal boy, 20 years old. Unfortunately, he suffered from severe mental illness for three years. Amit has five younger brothers and two younger sisters and the family entirely depends on the father's income on painting traditional pictures named THANKA.



Amit chained in bed.



Amit chained in his wrist.

Amit was at first admitted in local private hospital in Kathmandu named Temple of health hospital. During our usual visit to that hospital we encountered him in vulnerable and heart wrenching situation, chained to a bed. However, we could not raise our voices for him because we were not an authorized person there. Psychiatrist prescribed him 33 tablets of mental health drug for him per day. We consulted with other psychiatrists and they were surprised to hear about the amount of drugs being prescribed to him. Luckily, we found out from our confidential sources that Amit's consultant psychiatrist forced his parents to take him away from the hospital and suggested to them that they make a criminal case for him and have him locked in jail. After this information we decided that it is high time that we acted. We decided to find out Amit's family contact address with the help of the staff of the hospital. After that we rung his parents and called them, offering them our help.

After few discussions with the family members and making them understand that the illness suffered by Amit can be cured, we took him to a Community Mental Health Center located in the northern part of Kathmandu.

Amit was kept in that center for one and a half months. His consultant and medication was also changed. After continuous care and medication he has now recovered and is going on with his normal lifestyle. Amit studies humanities at intermediate level and aspires to become a writer and a poet in future. He has already written and compiled his poems and writings.

Initially, Amit's brothers and the family members including the relatives were scared that after losing his mental balance he would be a threat to them. In fact he would attack whoever was near to him. Hence, he was excluded by his relatives and family members. However, his father did not lose hope and did everything in order to cure him, whether it be with hospital care, medication or consulting a *Jhakri* (a traditional healer). Even when Amit was kept in the hospital, he was tagged to be uncured. The psychiatrist himself started pushing for him to be locked up in jail.

Since the attitude of society has always been negative towards mentally ill people, Amit was socially feared, excluded and stigmatized. His illness was thought to be incurable. Nevertheless, this attitude has been challenged by his recovery and his present ability to lead a normal life. His recovery has also build up new and fresh hopes not only in himself but his family members as well.

FROM THE STREETS OF KATHMANDU TO REHABILITATION: A FIFTEEN YEARS JOURNEY FOR KRISHAN

Krishan is a schizophrenic man. He is 40 years old and has suffered from the debilitating symptoms of his disease for fifteen years. He lived on the street surrounded by many, many bags of rotten food, knives, spoons, and waste paper. Because he is well educated and has many friends, people came to give him money for food and to check to see if he was alright frequently.



Krishan in the streets of Kathmandu.



Krishan now.

But, only recently has he received help for his mental disorder. KOSHISH workers have rescued him from the streets and placed him in a rehabilitation facility where he is receiving medication and treatment for his illness. He is doing much better. The symptoms of his mood disorder, violent anger, are gone. He loves music and plays the guitar and other instruments. After rehabilitation he looks forward to a career in music, as a singer or as the head of a music school.

Had KOSHISH not been there to get him off the streets and into treatment he would still be sitting in the dirt, surrounded by bags, sometimes shouting with anger at people passing by.

He needed what KOSHISH provided, understanding, a correct diagnosis, treatment and rehabilitation. He is no longer a man of the streets but is on the road to living a productive life, despite his illness. If the public had a better understanding of mental illness many like Krishan could be helped. If you have read this story, make a point of telling someone else. Be part of the solution of the stigma of mental illness!

ABOUT KOSISH, MENTAL HEALTH SELF-HELP ORGANIZATION

KOSISH is non profit, National, Non- governmental, Mental Health Self- Help Organization registered in 2008. However, it has been working informally and voluntarily on mental health since 2004. It's successful rehabilitation of dozens of people encouraged the organization to register with the District Administrative Office in Kathmandu, with the approval of Nepal Social Welfare Council. The existence of KOSISH self help organization evolved from the experience of people suffering from mental illness and their families. The organization also collaborates with people engaged in mental health service activities including mental health professionals.

The mental health service users; are proud of who they are, how productive they have become, and they would like to be accepted with dignity rather than discrimination and stigma to have their rights respected and be included in society. . Without the participation of the mental health service users, the whole health delivery system is imperfect.

KOSISH's Vision:

To facilitate in the development of a society: where mental health is a priority and mainstream issue in the country, which receives a priority emphasis and resources proportional with other health services; and where those suffering from mental illness receive respect, and are able to live in an inclusive social environment both within the family and in the community.

KOSISH's Mission:

- a. To empower mental health service users and their families to advocate for better treatment as this is their right.
- b. To facilitate the building of a national mental health rights based advocacy network.
- c. To formulate plans, programmes and execute a strong rights based awareness and advocacy to target grass roots community, top level government, bi-lateral and multi-lateral agencies
- d. To monitor and evaluate treatment services for quality and accessibility for users and their families.

KOSISH's strategic objectives:

- a. To create awareness and advocate for mental health policies, plans and inclusiveness of mental health services in the general health system in Nepal.
- b. To establish a strong mechanism in national and global collaborative networking to raise our voice.
- c. To explore policies for comprehensive community based rehabilitation strategy in Nepal.
- d. To organize, develop and empower self help mental health groups
- e. To participate in developing human resource for mental health.

KOSISH's determinative value:

We will never give up challenging discrimination and campaigning for better mental health. Our independence ensures our integrity - we are never compromised.

COMMUNITY INTEGRATION IN SRI LANKA

The Sri Lanka programme is built on the principle that all members of the community should be included and that no-one, particularly mentally ill people, should be excluded.

It was this principle that resulted in BasicNeeds Sri Lanka developing the BasicNeeds Mental Health and Development Model to work out collaborative interventions on a pilot basis to demonstrate that mentally ill people can participate actively in the process of development.

The pilot project started in February 2003 with thirty four mentally ill people. We now have 1,283 registered mentally ill people in just a small part of the Southern Province.

As a result, the mechanism called "Mental Health Care through Community Partnership" was developed, which complements the local government service delivery structure. Crucially perhaps, the most outstanding feature of the partnership are the community volunteers in which community volunteers run a number of very important community based activities including:

- Monthly mental health camps run in collaboration with a specialist mental health hospital, Angoda and the teaching hospital at Ratnapura;
- Outreach clinics by medical officers providing local service in collaboration with general hospitals at places such as Hambantota and Kahawatte;
- Out patient clinics for drug administration in collaboration with primary level hospitals such as the District Hospital of Katuwana.

Piyasena was treated as mentally ill person when BasicNeeds first came into his village. However, now he has joined the volunteer committee which plays an active role in organizing communities in the programme. Equipped with a three wheeler and a loudspeaker, Piyasena is responsible for announcing in the neighbouring villages when we have events such as mental health camps. About 30% of the membership of our volunteer committees are mentally ill people. The balance comprises carers and community members free from mental illness.

The programme has started to get everyone thinking. For example, when BasicNeeds and the Southern Provincial Directorate of Health Services invited five mentally ill persons to share their experiences about mental illness. This was to help the Southern Province Mental Health Forum propose recommendations to the government for the effective replication for the "Mental Health Care through Community Partnership" pilot for other parts of Southern Province.

Recommendations were also made to the government so that its medical scheme includes A-typical drugs into the essential drug list from January 2005.

Chintha Munasinghe, our Programme Manager, also sees herself as a user of mental health services. She is sitting with a group of mentally ill people and notes:

"I am sitting with my friends here to talk about our personal experiences in mental illness. We feel that this is our duty so as to motivate other mentally ill persons to come forward, talk, discuss and get rid of their pain. We see ourselves as "live" case studies who want to share their experiences so as to educate primary health care officers. This is all part of the training that our Consultant, Dr. Neil Fernando, would like to see happen."

Chintha reflects:

"We still have much to do but I am pleased with "Ape Viththi" - Our News. I was once a journalist and take particular pleasure with this newsletter, which offers an opening to consult mentally ill people and their families for a wider sharing of the model. Stabilized mentally ill people are our main contributors and we also have news from community leaders. Contributions from practitioners are particularly welcome!" chuckles Chintha.

Here are some of the milestones that Chintha and her team have achieved:

- Community mental health model of BasicNeeds Sri Lanka recognized nationally and internationally as an effective way of providing service
- Sri Lanka's largest enterprise development organization, Sarvodaya's Economic Enterprise Development Services (SEEDS) Guarantee Ltd. Is involved in developing an enterprise oriented sustainable livelihoods package for mentally ill people and their families.
- A training programme with project participants to record and analyses family expenditure which is now being used in many households, was developed.
- A participatory home management training programme with 10 families of the mentally ill people experiencing family conflicts, was developed.
- Home gardening systems and horticulture therapy programmes to suit the needs and interests of mentally ill people continues with high participation from mentally ill people. As a result nine discharged mentally ill people labeled as destitute, have reunited with their families and have been employed as gardeners.
- Seventy six members of volunteer committees have taken the responsibility of working with victims of the tsunami disaster in immediately providing emotional support and designing development interventions.

VOICES FOR MENTAL HEALTH - Service user groups and other NGOs

Piyasena, who alerts the community about the mental health camp from his tree wheeler comments:

"Even during my schooldays I was scared even to sing a song at a social gathering. It is true that the programme has covered all our medical needs, but more than that, it has helped us to come forward and develop our talents. I was really surprised to find how well I could do the announcing part at the mental health camp. Now I can address even a huge gathering."

Chintha smiles appreciatively and observes:

"The Basic Needs family is proud of mentally ill people in Sri Lanka for taking the lead in sharpening the mental health services in our country -- slowly but surely!"

-- from: *The Basic Needs Review. Community, My Community*, p. 32 to 35; url: http://www.basicneeds.org/download/community_my_community.pdf (last accessed 12 September 2007).



The following statements are taken from ***Mental health and development: targeting people with mental health conditions as a vulnerable group***. Funk M, Drew N, Freeman M, Faydi E. 2010. World Health Organization. Geneva, Switzerland. available at http://www.who.int/mental_health/policy/mhtargeting/en/index.html

Elena Chávez, President, ALAMO (Mental health service user organization), Lima, Peru

We, ALAMO, a group of mental health service users in Peru, want to highlight the importance of [...] the social vulnerability of persons with mental disorders and the actions that could be taken by development stakeholders *to improve their lives*.

Although we are persons who have some mental health problems we are able to develop our capacities. The prevailing social situation in which we find ourselves, in particular poverty, is the real cause of our vulnerability and the major obstacle to overcoming our vulnerability.

In my country, Peru, some people with mental health conditions who have a high economic status do not suffer exclusion. They are called "rayados" or "chiflados". They are accepted because they have access to medicines, they look fine, they have expensive houses and cars. The rest, 98 per cent of us, are excluded: we are called "locos" and considered to be dangerous persons.

Dr Francesco Colizzi, President, Italian Association Amici di Raoul Follereau (AIFO), Italy

Persons with mental health problems are among the most marginalized and excluded groups of persons in different societies. Their increased vulnerability coupled with social stigma and discrimination, often means poverty and violation of human rights.

Our Association has chosen to work with the most marginalized and excluded groups of persons and our experience of the past twenty years in community-based programmes in different parts of the world underlines the importance of mainstreaming, that means networking with all existing institutions and services involved in development work, to ensure that persons with mental illness can have access to all the right opportunities.

Matrika Devkota, Chairperson, Koshish, A Mental Health Self Help Organization, Nepal

We, persons with mental health problems, are lacking access to treatment. We, persons with mental health problems, are seeking medical, psychological and social support. We believe that medical and social support should go together.

We, persons with mental health problems, are facing high levels of stigma and discrimination. When tagged as having a mental health problem, we experience social deprivation - losing our jobs, losing social prestige and becoming isolated from family and society. Women are particularly affected. If you are a woman, you are more likely to be divorced as a result of having a mental health problem and less likely to receive treatment and social support. For almost all other diseases like cancer and heart problems, society recognizes the value of treatment. Unfortunately for mental health problems, there are many misconceptions which means that if someone suffers from a mental health problem, the family and society give up as the problem is considered untreatable and unmanageable. It is a great tragedy that many beloved people with mental problems are chained, locked in dark rooms, as well as imprisoned. Persons with mental health problems are excluded from social life.

Professor Dr Allen Foster, President, Christoffel Blindenmission (CBM), Germany

Many mental health conditions can be prevented or treated, but lack of health services at the community level results in unnecessary illness and disability. Persons with mental health conditions not only face problems from their illness, but also from disability resulting from the attitudes and practices of society which exclude them from participation. Stigma, loss of dignity, discrimination and the lack of basic human rights towards persons with mental health conditions remain common, and in low-income countries this is further exaggerated by poverty and reduced opportunity to earn a livelihood for themselves and their families.

CBM, as a development agency, has been working in low income countries to improve the quality of life of persons with disabilities for over 100 years. CBM is pleased to partner the World Health Organization and other stakeholders in promoting the rights of persons with mental health conditions and in improving the provision of good community health services, as part of the wider development agenda.

Clemens Huitink, Policy Employee, International Affairs, Dutch Association for Mental Health and Addiction Care (GGZ Nederland)

From our practice, we know that thus far people with mental health conditions are often overlooked when it comes to developmental aid. Mental health is not a very “sexy” issue for policy-makers and governments and thus often neglected.

[The case is convincing] that developmental aid, without paying attention to the mental health needs of the population, is often counterproductive. In a similar way it is also counterproductive when people who are directly affected by mental health conditions and their families are left out of the policy-making processes.

GGZ Nederland is convinced that solidarity among countries and systems in bringing mental health policies more to a “state of the art” level will bring us forwards on the complicated road to development.

Sylvester Katontoka, President, Mental Health Users Network of Zambia

Evidence proves that mental health problems are both a cause and a consequence of poverty. Eliminating world poverty and human rights violations is unlikely to be achieved unless the human rights and needs of persons with mental disabilities are taken into account. An estimated 450 million people globally are suffering from mental disabilities and many are affected by widespread stigma and discrimination making them vulnerable to violence, exploitation, physical and sexual abuse, malnutrition, illnesses and even death.

In recent years, there is a growing conviction globally that unless the rights of persons with mental disabilities are mainstreamed in development sectors, people will remain caught up in a vicious cycle of poverty and mental ill health.

Targeting persons with mental disabilities within development programmes will undoubtedly reduce the levels of poverty and accelerate the pace of economic, social and human development. Global cooperation accompanied by action is needed to ensure that persons with mental disability are supported in their efforts to develop their full potential, and to lead productive and fulfilling lives. Direct support to country policies and programmes should incorporate mental health to help reduce and respond to the needs of persons with mental disabilities.

Tomás López Corominas, President HIERBABUENA, Asociación Para La Salud Mental”, Asturias, España (Mental health service user organization)

We are tens of millions, but nevertheless there is a substantial lack of knowledge about mental suffering and its consequences on the lives of all those affected. Ignorance leads to misunderstanding which in turn leads to fear, and this fear results in stigma that distorts reality and transforms our sufferings into many forms of discrimination, which multiply our problems, the likelihood of relapse and the personal, social and financial costs to our lives. If this happens in developed countries it is not difficult to imagine the extremes of suffering that can be reached in places with fewer resources, where people with mental problems are even more neglected.

We all have a responsibility for the mental health of others. In addition, all organizations have the duty to assist its most disadvantaged citizens. Greater political attention will bring the social and health resources needed to provide a sufficient response to mental health problems. Advocacy that brings visibility to mental health issues will help combat stigma and discrimination. Both political attention and advocacy can reverse the amount of suffering that we experience.

Professor Wilfred Mlay, Ambassador for World Vision Africa

In my previous role as leader of World Vision's development, relief and advocacy work for over 10 years, with operations in 26 African countries, especially in the context of our HIV related work, I have seen first hand that mental health issues, such as depression, are significantly limiting development efforts if not addressed. As a result World Vision Africa pioneered large scale field implementation of the approach of Interpersonal Psychotherapy for Groups (IPT-G). A clinical trial study in 2002 by Columbia University and John Hopkins* showed a highly significant fall in the overall severity of depression symptoms and number of people diagnosable with depression among those who received IPT-G compared with the control group. In programmatic terms this study has also demonstrated the feasibility of this intervention with facilitators, unskilled in mental health, but trained in IPT-G, run by NGOs such as World Vision. [...] We must include people with mental health conditions in our programs. This a human rights issue as well as a program quality issue. World Vision's experience with IPT-G shows that development agencies can make a significant contribution towards positive mental health outcomes at community level.

Nydia Rengifo, President, Foundation "I have my space", Panama

Our Foundation reaffirms the importance of [...] the vulnerability of people with mental health problems. Our Foundation, created in Panama in 2005, is a non-profit entity that has as its primary aim the support of people with chronic mental disability. In order to serve their needs, we are carrying out a programme known as the "Center of teaching and job training for persons with chronic mental disability." [...] Our foundation works with people with mental health problems to provide education, employment and housing opportunities as well as addressing their overall health needs. Our overarching aims are to promote the human rights of people with mental health problems and their social inclusion. To make this happen on a larger scale, the commitment of all development actors is required. Governments, donors and civil society, in particular, service-user and family associations, need to work in close partnership to provide better opportunities for development for people with mental health problems.

Charlene Sunkel, Coordinator: Gauteng Consumer Advocacy Movement (GCAM); Chairperson: South African Mental Health Advocacy Movement (SAMHAM)

In this statement I am not only representing myself as a mental health care user (diagnosed with schizophrenia in 1991), but also representing the Gauteng Consumer Advocacy Movement (GCAM) - a project of Central Gauteng Mental Health Society (CGMHS), and the South African Mental Health Advocacy Movement (SAMHAM) - a project facilitated by the South African Federation for Mental Health (SAFMH). Both movements focus on: empowering persons with mental disability to advocate for themselves; promoting the rights of persons with mental disability, and fighting the stigma and discrimination attached to having mental health conditions.

We must recognize people with mental health conditions as a vulnerable group that should be prioritized in development. In doing so we must fight the stigma and discrimination which acts as a barrier to accessing services, to obtaining equal recognition of basic human rights, and to inclusion and reintegration into society. It is also vital that advocacy movements, like GCAM and SAMHAM, nurture a strong bond with national and international movements, mental health NGOs, Government and other stakeholders, so that together we can identify and address the needs and rights of persons with mental health conditions, and ensure that we are included in all decision-making and provided opportunities to influence legislation and policies that would be most beneficial to persons with mental health conditions.

Chris Underhill, MBE, Founder Director, BasicNeeds, United Kingdom

In the ten years since I founded BasicNeeds, an NGO implementing the Model for Mental Health and Development, I have observed that getting a person back to work, be it driving a tractor, growing vegetables, or selling textiles, is one of the most powerful ways to overcome not only poverty but also stigma.

“Integration is a process, not an event,” and as such requires sustained commitment. I am reminded of my own view which is that development itself is a process and not an event. The sustainability of this work will be best ensured when we follow the advice herein and build the capacity of service users and their carers to participate fully in public life and the decisions affecting them. Self-help groups of mental health service users are springing into being across Africa and Asia as we speak. [...] we must stand shoulder to shoulder with their members in promoting the development process.

Anil Vartak, Secretary, Schizophrenia Awareness Association (SAA), Pune, India

The Schizophrenia Awareness Association is glad that in the last ten years even with modest financial/manpower, it has enabled several persons with disabilities to enjoy better quality of life at various levels - economic, social, cultural - and as a human being. We are glad that these efforts will be multiplied and institutionalized if development stakeholders incorporate mental health issues in their agenda. Our association is always happy to share its experiences of the last several years.