

2.AFRICA

2.1 Psychiatric users and caregivers unite to contribute to mental health and own development in Uganda: mental health Uganda (mhu)

Julius Lutaakome

Mental Health Uganda (MHU)

Wandegeya, Kampala

Uganda

kayiiral@yahoo.co.uk

MHU is a national NGO in Uganda of People with and Survivors of Mental Illness (PWSMI) and their caregivers which started in 1997. MHU is a registered membership organisation and a member of the National Union of People with Disabilities in Uganda (NUDIPU). Currently, MHU has 18 district Associations spread in all parts of the country. With a vision that “People with and survivors of mental illness in society are embraced with respect and enjoy their human rights as other citizens”, it aims to create a unified voice that influences the provision of required services and opportunities in favor of people with and survivors of mental illness in Uganda through capacity building, networking, advocacy and partnership.

MHU has in the last twelve years made efforts to mobilise People with Mental illnesses (PWMI) to form a national organisation and grass root associations for their own identity and collective action. This has resulted in increased numbers of user leaders and activists emerging. They have played a key role in local, national and even international mental health, disability and rights activism. The mobilised members in Uganda have now reached 8,057, spread in associations in the country with an estimated 2 million people benefitting from our services (Impact Assessment Study; Mental Health Uganda, 2009).

Through MHU, users and care givers address policy gaps at both local and national levels and in the last ten years have contributed to all relevant policy debates and legislative processes.

Currently users and care givers are working with the Government to review the outdated 1964 Mental Health Treatment Act. Through community and national level advocacy and user and caregiver-led support, Mental Health Uganda has raised community awareness about mental health promotion, care and support. With the users in the front seat, efforts have been made to educate the masses on the potential of people with mental illnesses. Efforts have focused on highlighting the challenges faced by people with mental illnesses, and there have been several good cases of favorable responses from the community.

The primary challenges faced by our membership include poor and limited mental health services located at great distance; inconsistent supplies of drugs even in the biggest national psychiatric referral hospital; poverty with many members losing their employment and other sources of livelihood on developing mental health conditions due to stigma, little knowledge about mental health, and poor mental health services.



Gabudiel Omiyo (Mbale), a user who has returned to selling in his shop after seeking medical treatment. After an advocacy campaign, mental health services were brought closer to him but he was also encouraged to seek medical services after joining the MHU association in his district - Mbale. He also now qualifies for a loan from the association-run revolving loans scheme.

Our community support programmes mostly target our members' families and households, immediate community members, community leaders, health administrators at both district and national level (sometimes at international levels in collaboration with our international partners), traditional and conventional mental health service providers, church and administrative leaders, developmental service providers and even security forces. This is based on the fact that although the security agencies often take charge of the security of homeless people with mental illnesses, there are still many cases of people with a mental illness that end up in prison at the hands of the security agencies instead of starting their rehabilitation process.

Educating security agencies has been one of our key aims. This is based on lessons learnt, keeping in mind the security of the populace including those with mental illness, where, if not adequately understood, could lead to human rights abuse. This is evidenced by summary incarceration of those suffering a mental illness instead of undertaking their rehabilitation, or referring them for psychosocial support and medical treatment.

Lessons learnt from our work include the need to comprehend and make use of the potential of people living with mental illness, not only for them, but also for the good it brings to the community. "If you enable one father to access mental health services, you will have done a lot for the family; his children will have food and be educated, and have shelter. If you neglect a father with mental illness, you risk having him a dependant member of your community, the family will collapse, have uneducated children that finally become a social problem to the community, maybe even lose a would-be resourceful future leader of the community". We can never do all that needs to be done, so part of our efforts have focused on building good networks, coalitions and collaborations with both government and civil society agencies to ensure the integration of mental health in their main stream programmes. There are many issues related to poverty and rights at both individual and community level. Poverty can cause mental illness, can become a barrier in the recovery process and can also cause relapse in a person who was otherwise recovering.

Thus poverty can't be ignored in good psychiatric user programmes.

One of our partners, Basic Needs, shared a very good concept with MHU that we have continued with our members, namely, 'Meaningful and sustainable livelihoods'. Another lesson is enabling PWMIs to be independent economically and this has been a tool of advocacy and attitude change in the communities.



Claudia, an MHU staff member, is shown with members of their livelihoods project: Brick laying in Kabale South Western Uganda

In future we look forward to building more partnerships to have more agencies contribute to the efforts of addressing the needs of our members. We look forward to intensifying our work and even spread to more parts of the country. We will also continue to contribute to the start and strengthening of similar efforts in other parts of Africa. We need to strengthen the human rights component in our work especially, using the Convention on the rights and dignity of persons with disabilities. With more education, communities can change attitudes and reduce stigmatisation, which fosters good practice and less discrimination. Finally we also look forward to further strengthening our individual members, the local associations and the national organisation.

2.2 User/Survivor initiatives: Non-professional, peer-based, community support services in Mental Health; successes and challenges to date.

Achmat Moosa Salie

World Network of Users and Survivors of Psychiatry (WNUSP)

Ubuntu Centre South Africa

Cape Town, South Africa

moosa_salie@absamail.co.za

Historical Context

The user/survivor movement emerged simultaneously in many places in Europe and North America in the early 1970s. Linda Morrison (2003) explains the American consumer/survivor/ex-user movement's characteristics and goals as follows:

“The c/s/x movement is not a centralised national movement with well-defined leadership, membership, goals and objectives. It has no official leaders, no official hierarchy, and no ongoing organisational structure. Rather, it exists as a loose coalition of advocacy and activist groups whose members engage in numerous activities designed to promote mutual support, rights protection, alternatives, advocacy, and information flow that will enhance empowerment and choice for people whose lives have been affected by psychiatry“.

The above characterisation of the user/survivor movement had been the experience everywhere until the formation of the World Network of Users and Survivors of Psychiatry (WNUSP) in 1991 as the World Federation of Psychiatric Users. The WNUSP grew out of user and survivor demands for recognition and representation.

The following is a brief chronology of the WNUSP:

1991: Network began as World Federation of Psychiatric Users (WFPU) at the World Federation of Mental Health conference in Mexico

1997: Name changed to WNUSP

2000: Secretariat established in Odense, Denmark

2001: First General Assembly in Vancouver, Canada

2004: Second General Assembly in Vejle, Denmark

2009: Third General Assembly in Kampala, Uganda

Prior to the formation of the WNUSP, a rich tapestry of groups had arisen globally, particularly in North America and Western Europe.

These groups started organising in the early 1970s with the Mental Patients Liberation Movement in New York and also the formation of Support Coalition International which later became MindFreedom International, later in the same decade. Many countries in Europe as early as the 1960s and 70s had already set up national user/survivor bodies and today we find national and local groups in all continents, including Africa, South America and Asia. In fact at the General Assembly of the WNUSP in Kampala in March 2009, participants from more than 50 countries attended.

One individual did much to formalise and capture the ethos of this movement. This was Judi Chamberlin who in 1978 wrote the seminal piece on user/survivor writing, called *On Our Own: Patient Controlled Alternatives to the Mental Health System*. In the initial chapters Chamberlin talks about her experiences in the mental health system, but most importantly in later chapters she elaborates in depth on her experiences in user-run projects in the US and Canada. She also dedicates a chapter in the book to an ideal project, which basically is a “how to” guideline for users considering establishing what essentially would be self-help and self-empowerment projects. It would be too ambitious for this paper to write an exhaustive report on user-run approaches.

This needs to be done, and the writer imagines that it would be the basis of many dissertations to be written in years to come. What are the predominate characteristics of user/survivor-run projects over these last four decades?

It is hard to identify the common threads, but mostly these groups and self-help projects arose out of people's desire to counteract the negative and very often stigmatising impact of the treatments they had received in mainstream mental health facilities and institutions. In other words people with similar experiences drew together in order to gain strength in the solidarity they experienced from fellow members in the groups. There was also an exploration of non-medical and grassroots approaches, which would foster the experience of better mental health through peer-support. Rights advocacy alongside the development of peer-run and self-help approaches became the two tiers of the work of many of the groups.

At the launch of the Global Forum for Community Mental Health in Geneva in May 2007, the writer personally heard Dr Benedetto Saraceno speaking the following words on the meaning of Community Mental Health Services.:

“What we are talking about is not about moving psychiatry into the community, but what can be done in the community to foster better mental health”.

In fact Saraceno here captures what had been the experience of all the user/survivor run projects since the beginning, and this was to find new (maybe rediscover old) grassroots, self-help and peer-support approaches which would improve the lived experience of persons who had experienced burn-out, breakdown, and who were living with experiences of altered states and various kinds of madnnesses. The key ingredient which many found missing in the mainstream was the attention given to maintaining the dignity and the social acceptance experienced by individuals who joined these groups.

The above paragraphs form the background to the successful projects run by users all over the world of which a few will be discussed now in more detail. The agenda of these groups had never been solely liberatory or even anti-psychiatry in its objectives. Mostly, the feeling of the writer has been that self-organizing

and mutual support restored people's humanity to them, whereas going through the services had for many people often been dehumanising and traumatic.

So it is no surprise that much of the advocacy activity coming out of this movement had been around rights and restitution for harm done to individuals.

The writer will in the rest of this paper talk about some of these projects and for the purpose of brevity only use one example from each of the following continents; North America, Europe, Africa and South America.

Freedom Center and The Icarus Project¹

"Freedom Center is a support and activism community run by and for people labeled with severe 'mental disorders.' We call for compassion, human rights, self-determination, and holistic options. We create alternatives to the mental health system's widespread despair, abuse, fraudulent science and dangerous treatments. We are based in pro-choice harm reduction philosophy regarding medical treatments, and include people taking or not taking medications" (Freedom Center website²).

"The Freedom Center is one of a collection of grassroots organisations springing up across the country in reaction to the prevalence of medication in America. It alerts people to the downside of psychiatric drugs but does not try to force people off them: it seeks instead to help sufferers find the best methods of coping, even if their solution is unconventional by the standards of the medical establishment"

(Forbes Magazine, 2004).

The Freedom Center was started in 2001 by a group of users/ex-users/survivors which included Will Hall and Oryx Cohen in Northampton Massachusetts. One of the first activities set up was a weekly support group, where "people gather to

¹ **The Icarus Project** is a website community, support network of local groups, and media project created by and for people struggling with bipolar disorder and other dangerous gifts commonly labeled as "mental illnesses." The Icarus Project is creating a new culture and language that resonates with our actual experiences of madness rather than trying to fit our lives into a conventional framework (<http://theicarusproject.net>)

² <http://www.freedom-center.org>

share stories of frustration and hope, recommend resources and recovery strategies, and plan our educational and advocacy campaigns for change”. (Freedom Center website). Since its beginnings in 2001 the Freedom Center has had many achievements, which include:

- a free weekly yoga class
- regular writing group
- free weekly acupuncture clinic
- Madness Radio, a weekly radio show hosted by Will Hall; since its launch in 2005 more than 100 shows have been aired.
- the Freedom Center along with the Icarus Project³ published a 40 page guide called, the Harm Reduction Guide to Coming Off Psychiatric Drugs (2007).
- drafted Peer Educator Guidelines (2007)

The Berlin Runaway-house (*Weglaufhaus*)⁴

The Berlin Runaway-house was opened on January 1, 1996. It “is a place for people who want to get out of revolving-door psychiatry and have decided that they want to live without psychiatric diagnoses and psychiatric drugs. It opens up a space outside or beyond the (social) psychiatric net that keeps people dependent, a space in which the residents can try to regain control over their lives. Here they can recover, regain their strength, talk about their experiences and develop plans for the future without psychiatric views of illness blocking access to their feelings and their personal and social difficulties” (Hölling, 2006). The Runaway House is a project of the Association for Protection against Psychiatric Violence (Verein zum Schutz vor Psychiatrischer Gewalt e.V.) which was founded in 1989. The Runaway house is based at Villa Stöckle in a quiet suburb on the northern edge of Berlin. It is named after Tina Stöckle, one of the co-founders of the association, and it was donated to the association in 1990. The following comes from an English article on the website of the runaway house, called, *The Runaway House at a Glance*:

⁴ <http://www.weglaufhaus.de>

Who lives in the Runaway House?

The house accommodates homeless (ex-) users and survivors of psychiatry who escaped from the psychiatric network and who are determined to manage their lives on their own again. Not accepted are alcoholics and drug addicts as well as those whose accommodation could not be cancelled prematurely and/or those who are detained in forensic institutions because of criminal offences.

Who works in the Runaway House?

The house employs qualified staff who have had their own experiences with diagnosed craziness, psychiatric institutions or other hardship in life and have gotten over it. They are in 24/7 service for the residents.

What happens at the Runaway House?

Needless to say, there are no psychiatrists, no psychiatric diagnoses and no therapies. But there is quite a lot to do, both in personal areas of life (such as housing, work, education, „office works“, doctor and lawyer appointments, interaction with relatives, friends and colleagues) and regarding common household issues (such as grocery purchases, cooking, washing, repairing things, gardening etc.)

The runaway house has been in operation since 1996.

Mental Health Uganda (MHU), experiences with self- help groups.

MHU founded in 1997 is an indigenous National NGO and it is a membership based organization for users/survivors of psychiatry. The mission of MHU is to create a unified voice of people who influence the provision of requisite services and opportunities for people with mental health problems.

MHU core activities are: group formation, self- advocacy, livelihood promotion, raising awareness, membership formation, family and community education, influencing policy, advocacy and lobbying and legislation in favor of users and survivors of psychiatry.

MHU operates in 18 districts of Uganda; West (6 districts) Central (6 districts), East (4 districts), North (2 districts).

Mental Health programmes are needed most in the North because of the effects

and trauma caused by a rebel group, the Lords Resistance Army (LRA) and the ensuing displacement of people.

MHU's advocacy involves; lobbying for Mental Health service provision, inclusion into other development programmes, policy advocacy and legislation, community Mental Health education, and research and documentation on Mental Health. User-directed interventions include: addressing psychosocial needs, support for Income Generating Activities (IGA), savings and credit schemes support (through establishing revolving funds), support to community MH volunteers and support to delivery of MH services. Capacity building encompasses: skills training according to identified needs, entrepreneurship skills, group formation, leadership and group management, resource mobilisation and advocacy skills.

MHU, along with an international conference organising committee, hosted the WNUSP's third General Assembly and world conference in Kampala in March 2009.

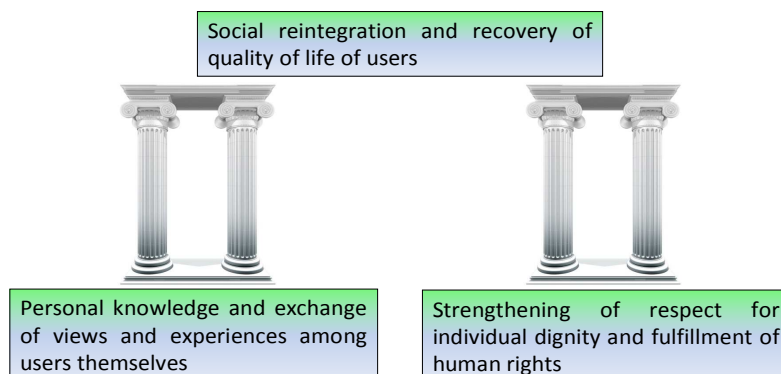
Alamo Peru

Alamo Peru was started by Elena Chavez in 1991. It remains the only user-run association, supported by their families, in Peru to date. Barrionuevo (2009) writes about the goals of Alamo:

“Alamo arises from the need to provide a proper service to users of psychiatry and their family's environment. Alamo's main objectives are the users' personal knowledge and exchange of views and experiences among themselves in order to strengthen the respect for individual dignity and the observance of Human Rights; pillars of social reintegration and recovery of the quality of life of users involved in this project.”

The following diagram illustrates Alamo's 3 tiered/pillared approaches:

Alamo Peru – WNUSP:



Barrionuevo further states regarding the importance of Alamo:

“Initiatives such as Alamo are indispensable in our country due to the lack of work plans in mental health, the non existing enforcement of the ones already created as well as lack of budget provided by the government. In Peru there is no psychological therapy or counselling, and no training for users and their families through conferences or other means. That is why it becomes a priority to create organised civilian groups”.

Alamo has to date worked with more than 400 users and their families. It continues to struggle with capacity problems, being under-funded and under-resourced. Four of Alamo's youth leaders attended the General Assembly and World Conference of the WNUSP in Kampala Uganda in March 2009. Alamo is at present busy planning to host a meeting of young users from South America early in November 2009.

2.3 Lessons from the African User Movement: The Case of Ghana

Peter Yaro

BasicNeeds Ghana

Tamale

Ghana

peter.yaro@basicneeds.org

Victoria de Menil

BasicNeeds

Leamington Spa

United Kingdom

Victoria.demenil@basicneeds.org

Introduction

There are two main drivers for the growth of the user movement in Africa: human rights and the scarcity of resources. The seminal World Health Report 2001: *Mental Health: New Understanding, New Hope*, articulates the need to increase user involvement globally. One of its ten recommendations is to “involve communities, families and consumers” (recommendation 5), which it argues “should lead to services being better tailored to people’s needs and better used.” Indeed, the primary argument offered by the World Health Report in support of user involvement is practical: users are a valuable human resource in a context of scarcity.

This point cannot be over-stated, and is certainly true in Ghana, where only three psychiatrists work in the public sector, serving a population of 22 million. Most care is provided by psychiatric nurses, but these too are in short supply with only 500 operating throughout the country.

Recently, thanks to a push from the *Convention on the Rights of Persons with Disabilities*, user involvement has been increasingly justified by a human rights argument. Until now, the human rights agenda in global mental health has been largely dominated by deinstitutionalisation (MDRI, GIP, MDAC). Rights abuses in large-scale residential institutions for people with mental illness are indeed deeply problematic and deserve wide attention. In Africa, much of the bio-medical care offered for mental health is centralised in mental hospitals. However, most African countries lack the resources to maintain people institutionalised over long periods. Moreover, with the advent of international NGOs, such as BasicNeeds, CBM and International Medical Corps, there have been increasing efforts to put mental health into the community. The timing is therefore ripe for user participation to come to the forefront of the global mental health human rights agenda. Indeed, the Movement for Global Mental Health, launched in 2007 following a call for action by the Lancet journal, embraces human rights as one of its two core principals, along with evidence-based practice. Indeed, user-led advocacy is an effective means of fulfilling the rights not only to participation but also to non-discrimination and autonomy.

In Ghana, mental health service user involvement has grown dramatically over the past five years with support from the international NGO BasicNeeds (for which both authors work).

BasicNeeds has built an innovative approach, called the model for Mental Health and Development, that enables people with mental illness or epilepsy to live and work in their community by tackling their poverty as well as their illness. BasicNeeds has been working in Ghana for eight years and is currently supporting 17,462 Ghanaian service users, 47% of whom are female. Over the past several years, BasicNeeds has helped form 239 user-led groups in Ghana at community district and national levels. Financial support for this initiative has come from the UK Department for International Development (DFID), the European Commission Development Fund and Comic Relief.

Thanks to the sustained commitment of many, Ghana now has a registered national user association with a secretariat that is actively representing their

needs and rights at national and international levels.

In order for Ghana's mental health user movement to become an example rather than an anomaly, it must be replicated elsewhere in Africa. To that end, this paper seeks to share the journey of creating a national user movement of people with mental illness and epilepsy and their carers, and to convey the lessons learned along the way. Ghana's user movement was developed in three stages, starting at the community level, and moving up to the district and finally national levels, so the paper is structured according to those levels of activity. The body of the paper describes the current user group set-up – its purpose, membership, activities, and financing – while the conclusion reflects on lessons learned.

COMMUNITY LEVEL GROUPS

The formation of community level user groups in Ghana grew spontaneously from the community consultations BasicNeeds organised so as to understand the needs of people with mental illness and their families. These groups are referred to as self-help groups (SHGs), as distinct from the associations at district and national levels. As of June 2009, 233 SHGs were active in 35 districts⁵ from four regions of Ghana, mainly from BasicNeeds programme areas. There is an average of 8 SHGs in a district (range: 7 - 10).

Sixty percent (60%) of the SHGs have been in operation for four years or more.

The Impact of Community Self Help Groups

“It is good we have met and I hope we continue this meeting after these people have left. I have never felt so wanted as to be listened to. I would like us to continue with this meeting, and I am happy to ask my brother, who has come with me, to go round and invite you [to another meeting], as I may not be very welcome in your homes.” - Service user, community self-help group, Ghana

“Being part of this self-help group has been one of the greatest things to have happened to me. Through this group, I have come to be respected. And through the group, my needs were assessed and I was provided with a sewing machine to perfect my sewing that I stopped doing because of my illness.” - Mahamadu Seidu of the Wa Town Group

“I didn't believe that mentally ill people could be so calm as even to sit together and hold discussions to take decisions affecting them. But for the past months now I see them hold a meeting every week on market day, and I am impressed about their calmness and sense of purpose.” - Community member, Northern Ghana

⁵ District also refers to sub-metropolitan, municipal and metropolitan authorities of the local government.

▪ **Purpose**

Community self-help groups have a number of functions. One purpose of the groups is to offer peer support for members. Sometimes people who meet regularly at outreach clinics decide to constitute a group to remind one another of the next clinic date and collectively go for their medical reviews and pick up their medicines.

Another crucial function of community level groups is to establish cooperatives for engaging in livelihoods activities. To this end, groups establish a bank account into which they put membership fees and seed grants from BasicNeeds or their local government. Group members collectively decide how to allocate the money, and they receive training in book-keeping, which is carried out by the group Treasurer.

In addition, SHGs raise awareness of mental and neurological disorders and seek to reduce their associated stigma. The groups serve as examples to disabuse community members of erroneous perceptions about mental illness and epilepsy, for example the perception that they cannot “sit together and hold discussions” (see text box). Generally SHGs serve as a social medium that gives meaningful identity to mentally ill people and people with epilepsy and their primary care-givers.

▪ **Membership**

Membership of self-help groups in Ghana is open to all people with mental illness or epilepsy and their primary care-givers, regardless of age. As much as possible, membership is encouraged for people with mental illness or epilepsy alone or with their primary care-givers. But in cases where the person with mental illness or epilepsy cannot effectively follow the meetings, sometimes the carers join alone. This is done with the understanding that as soon as the person with illness shows signs of recovery, he or she will be encouraged to join the meetings. Service users form just over half (53%) of community group membership, and women come in slightly higher numbers (59%) than men.

User group membership is voluntary, and one in three users in the BasicNeeds

programme in Ghana has chosen to join a self-help group (5,708 people out of 17,462). The core of the groups are people who have participated in a community consultation organised by BasicNeeds or one of its local implementing partners. Most people come from poor families and have just basic education (primary level) or none at all – as is the case with most people from the rural and northern parts of Ghana.

As a result of the low levels of education, many of the groups rely on more literate volunteers to serve as volunteer Secretaries, supporting them in activities such as writing letters or interpreting between English and the local language during meetings with external agencies. Most of the volunteers are young adults in their thirties and forties, who have had some secondary education but with no steady employment. They usually expect a small stipend for their upkeep as they go about their duties. In Ghana many of volunteers are young males and fewer are women. More information on the role of volunteers, also called community workers, can be found in a separate chapter of this book.

▪ **Activities**

Outside of group meetings, one of the key activities of community self-help groups is to provide emotional and moral support to members through home visits. SHGs also take up cases of abuse of people with mental illness or epilepsy to the community leaders for resolution and they seek support for protection from verbal and physical abuse.

Self-help group activities also include accessing resources – financial and material – for individual and group livelihoods activities through writing small grant applications. They sometimes instruct their District Associations to submit applications on their behalf on areas of common interest to most of the SHGs.

Finally, SHGs conduct education outreach and membership mobilisation drives. They do this by requesting time to speak at gatherings, such as in churches or mosques, where they talk about their groups, what they stand for and what they do. They will mostly use their own experiences as testimonies, which they share with the audience.

Based on their own experiences, they encourage people with mental health problems to come forward for treatment and join their groups.

- **Structure**

All self-help groups have a constitution (see appendix) and elect an Executive Board. The group executive typically consists of six people: chair, vice-chair, secretary, assistant secretary, treasurer and organiser. Once they have voted their constitution, groups are able to open a collective bank account and register with their local District Assembly. Registration takes place either through the Assembly's NGO desks office or through the Department of Social Welfare and Community Development. Part of the registration includes providing a list of current members and their Executive Board.

- **Funding**

SHGs are mainly funded from monthly membership contributions and grants from BasicNeeds and other bodies. Membership registration fee is fifty Ghana Pesewas (GBP 20p) with a monthly levy of one Ghana Cedi (GBP 50p), which some groups charge. On some occasions, people make special contributions in response to specific needs, such as child-naming ceremonies, weddings and funerals. Groups access grants to cover the costs of basic logistics, including stationery and benches or chairs, so they can hold and document proceedings of their meetings. They also access seed-capital for individual and group income-earning ventures. It costs about GHS1,200 (£515) to support the operations of a group of about 40 members for a year and another GHS4,000 (£1,700) in seed capital to support livelihoods ventures for the members of one group. Livelihoods ventures are mainly petty trading and small scale agro-processing for which costs include support for tools and equipment as well as training fees.

DISTRICT ASSOCIATIONS

As Ghana's community SHGs have grown in number and solidified in organisation, they have begun to engage with their District Assemblies and other local authorities for attention. To strengthen their advocacy, a unified stance on issues of concern needed to be presented to the district level authorities. As a result, the community groups agreed to form district-level groups to present their positions to district authorities and appropriately feedback to them. The district groups have blossomed to become a permanent structure referred to as the District Association of SHGs. The District Association is an assembly of representatives of SHGs serving as an intermediary between SHGs and their local government. All members of District Associations are also members of community SHGs.

▪ Purpose

The purpose of the District Associations is to influence decision-making of local government authorities so that the rights of mentally ill people are effectively addressed by their District Assemblies. District Associations seek audience with District Assembly authorities and other decentralised ministries, departments and agencies of government. They also engage with non-governmental agencies, such as NGOs and corporations. District Associations perform a two-way function, conveying the needs and interests of users and carers to their local authorities and feeding back to the community SHGs the response from those authorities. Since they assemble some of the strongest members of the community SHGs, the District Association have also evolved to serve as advisory and supervisory entities to their constituent community groups. There are currently 35 active District Associations across Ghana, mainly in the four regions where BasicNeeds Ghana operates.

▪ Membership

Members of the District Associations are elected representatives of the community SHGs.

They are usually elected from the Executive Board of the SHG, but other active members can also be included. By dint of having more education or more perceived wisdom, District Association members are chosen on the basis of having the necessary clout to influence decision-makers. As much as possible, there is equitable representation of users and carers, women and men.

- **Activities**

As an intermediary entity, the District Associations mainly serve as a mouth-piece of SHGs of a certain district. They hold meetings with District Assemblies and other influential government and non-government agencies to present their concerns and make appeals. The District Associations liaise with the Departments of Community Development and Social Welfare to register the SHGs as CBOs in the district. They also support some of the SHGs in their meetings and funding applications. Finally, District Associations also hold meetings with their constituent SHGs and feed back results of their meetings, including communicating opportunities that have arisen. Similar to the community groups, District Associations undertake outreach to educate communities about mental health. In some instances, they invite community psychiatric nurses to participate in their outreach and talk to people about the facts of mental illness.

- **Funding**

The District Associations are funded through membership fees of their constituent SHGs and also through grant-based funding they may secure from BasicNeeds, District Assemblies and other sources. They also develop and submit applications for financial and in-kind support on behalf of their community SHGs. The District Associations are the main body to fundraise for and supervise community SHGs.

NATIONAL ASSEMBLY

The national user association, known as Mental Health Society of Ghana (MEHSOG), is the umbrella organisation for all mental health user groups in Ghana. The Mental Health Society represents the needs and interests of its constituent groups at the national level.

Forming a national user group is the last stage in the evolution of a broad-based representative body to champion the rights of people with mental illness or epilepsy. The need for a national body grew organically from the SHGs and District Associations with support from BasicNeeds. Members wanted an organisation that could make them known at the national level and make their issues become part of national discourse and debates. Most of the groups that called for the national association made reference to Ghana's disabled people's groups, which have gained national prominence thanks to a national Disability Movement. It was the view of mental health service users in Ghana that their voices could only be heard and their issues effectively addressed when there was a representative body keeping mental health in the headlines and the 'in-trays' of health and development policy authorities. In response to this demand, BasicNeeds facilitated a meeting of delegates from all over the districts to discuss forming a national group. This initial discussion was followed by three keys meetings where a national steering committee was constituted to preside over the drawing and adoption of a constitution and the election of an executive secretariat. The Mental Health Society of Ghana (MEHSOG) completed its registration in March 2009 and plans are for a formal inauguration in October 2009.

▪ **Purpose**

The purpose of the Mental Health Society of Ghana is to promote human rights, disability rights and socio-economic development of people with mental illness or epilepsy at the national level. It seeks to engage national authorities to ensure the needs and rights of mentally ill people are effectively addressed in national policy initiatives.

MEHSOG is the national mouth-piece of all people with mental illness or epilepsy in Ghana and it gives an identity to poor mental health service users who have previously been invisible.

▪ **Membership**

MEHSOG is made up of representatives from the District Associations and some community SHGs. To serve in the national association, one must have been elected from his or her district. Most of the members are recovered users and carers.

They are also usually literate and active members in their district groups. An equal number of users and carers, women and men serve in the national association.

▪ **Activities**

The main activities of *MEHSOG* are to engage national policy authorities, network with like-minded civil society entities, create awareness with national media, fundraise and promote the socio-economic wellbeing of users and carers. They also organise and preside over Annual General Meetings (AGMs) and other meetings of the user groups. Much as they draw their power from the SHGs and their District Associations, *MEHSOG* also has supervisory responsibility over the SHGs and their District Associations, especially with regards to reporting. The Mental Health Society has already built links with several like-minded civil society organisations, such as the Ghana federation of the Physically Disabled and the Network for Women Rights in Ghana. In addition, *MEHSOG* has developed good relations with the media such as television stations (Ghana Television, Metropolitan Television, TV3, Africa TV) newspapers (the Daily Graphic, Ghanaian Times, the Chronicle and Public Agenda) and radio stations (GBC Radio, Choice FM, Radio Gold, and Joy FM). The media have been supportive of their work.

- **Funding**

Funding for the Mental Health Society of Ghana comes through contributions from the SHGs and grants provided by BasicNeeds via DFID and Comic Relief. DFID provided GBP£486,810 for building community SHGs and their District Associations and strengthening region-based alliances in Northern Ghana; and Comic Relief are providing a GBP£1,000,000 grant over five years to support the emergence of the national user association and their advocacy engagement. Although the initial cost of set-up is considerable, the user association should be self-sustaining over time. Indeed, sustainability is one of the main arguments for creating a movement of user-led advocacy. MEHSOG has already submitted a number of grants applications independently of BasicNeeds.

REGIONAL ALLIANCES

As Ghana's national user movement grows in importance, it is looking increasingly to the international stage to increase its influence. Two important players stand out as potential regional allies in the near future.

- **PANUSP**

At regional level, the Pan-African Network of Users and Survivors of Psychiatry (PANUSP) is a continental network of users and ex-users of psychiatric services which seeks to protect and develop the human rights of mental health service users, including disability rights, dignity and self-determination. PANUSP was founded in 2006, with headquarters in Uganda, and now has membership from Ghana, Kenya, Uganda and Tanzania. They are a membership organisation bringing together national user associations in each of their affiliated countries. PANUSP recently signed a memorandum of understanding with BasicNeeds, and The Mental Health Society of Ghana plans to affiliate with PANUSP by close of 2009.

- **WNUSP**

The World Network of Users and Survivors of Psychiatry (WNUSP) is an international organisation representing and led by mental health service users. WNUSP is a network of individuals and organisations from over 50 countries

with a strong human-rights approach to mental health.

The network was closely involved in developing the Convention on Disability, particularly as regards psycho-social disability, and they are now instrumental in promoting that document. WNUSP is part of the larger International Disability Alliance together with major advocacy groups for the deaf, blind and motor disabled. WNUSP has collaborated with PANUSP, particularly at its historic first African conference in February 2009, held in Kampala.

Overview of Ghana's Mental Health User Movement

(June 2009 data)	Community Self-help groups	District Associations	National Association
Purpose	Livelihoods, peer-support and awareness	District level advocacy and fundraising	National and regional advocacy
Number of groups	233	35	1
Size of groups	20-30	20-30	10,730 members 7 executives
Total members	10730		
% Female	59% (N= 6,339)		57% executives (N=4)
% Users (vs carers)	53% (N=5,708)		57% executives (N=4)
Membership fee	GHS 0.50/month (GBP £0.21)	No membership fee needed as they are drawn from SHGs	A fee is yet to be determined for SHGs to pay to the national body
Operational cost	GHS 5,200/yr (GBP £2,450)	GHS 2,800/yr (GBP £1,400)	Up to GHS 8,520/yr (GBP £4,260)
Funding source	SHG membership fees and BasicNeeds with grants from DFID and Comic Relief	SHG membership fees, BasicNeeds, District Assemblies	SHG membership fees, Comic Relief, DFID, and possibly in the future the Disability Rights Fund

Conclusion: Ten Lessons for Starting Your Own User Movement

A number of lessons have emerged from this process of user-group development, for which we will highlight a few in the interest of making this work replicable.

1. User groups are an essential component of human rights for people with mental health problems.

User-led groups are essential in enabling poor and marginalised people with mental illness or epilepsy to demand services. Group action ensures the sustained recognition of individual needs as rights, rather than as charity. Collective action enables people to move beyond tokenism and little “mercies” to achieve real impact on a large scale.

2. Creating a user movement costs time and money.

Supporting the development of grassroots user-led groups requires time and money. The birth of the Ghana user association bears testimony to this. It has taken four years from when the first self-help group was in place in a suburb of Tamale, and it has cost over £500,000, together with countless man-hours, to create and register a national user-association with a broad-based membership.

3. Battling poverty is one of the functions of a mental health user group.

Groups have different purposes at different levels. One of the main motivations of people with mental illness and epilepsy and their carers in forming community-level groups is to secure livelihoods.

4. Interest in advocacy develops over time and through example.

Engagement in rights-based advocacy initially takes a secondary priority to efforts concentrated on income-earning. The incentive to do advocacy comes when participants realise that they are entitled to claim resources they thought were provided as a favour. Achieving these entitlements requires group members to engage with existing power structures through organised advocacy. It is at the district and national levels that advocacy work is strongest and most effective.

5.Groups require facilitation in the early stages.

Groups do not always consistently abide by their own rules and conventions, including documentation and accountability of important processes.

Those facilitating the groups must resist the temptation to take over and do things for them. As new membership associations, these groups will grow from these mistakes of commission and omission.

6.Problems of literacy can be overcome.

Some literacy is necessary within a group to ensure effective documentation and reporting of activities. As a result of the low literacy levels among most of the members of the community SHGs, support is usually needed from more literate members of their community who serve as volunteer secretaries.

7.The size of a group influences its effectiveness.

BasicNeeds have found that in Ghana a size of 15 to 25 members, with a maximum of 30 members is the most effective for maintaining a balance of group activity and individual engagement. Initially, the groups we supported had upwards of 100 members; but we gradually reduced the size to the current level, which has been a key component of smooth operation.

8.User groups are a key component to the sustainability of community mental health.

Groups are essential in order to go beyond provision of services to build the capacity of people to demand services. Encouraging a vocal demand for quality services – including, for example consistent drug supply – is the only way to ensure lasting service provision through changing governments and health providers.

9.The African user movement is learning lessons from other user movements.

The Mental Health Society of Ghana is in the process of allying itself with the Ghana Federation of the Disabled (GFD), the Network for Women's Right's in Ghana (NETRIGHT), and NAP+, a network for people living with HIV/AIDS.

Mental health users can gain much by associating with these broader and more-established user movements in their countries.

10. User involvement is a means of promoting democracy and accountability.

The structure of Ghana's national user movement is a model of democratic governance.

Community self-help group members elect district members who elect national members, and each has its own elected executive board.

This structure creates an excellent mechanism for holding Ghana's government accountable to its citizens.

Annex: Template group constitution

THE CONSTITUTION OF _____

NAME: _____ (SELF-HELP GROUP)

PREAMBLE

We, the members of the Self-Help Group, realising that we share a common vision, realising that by coming together we shall afford ourselves an opportunity to know ourselves and to help solve each other problems, and having the firm belief that such grouping will contribute to an improvement in our welfare in various ways, have come together to have this Constitution as a working document to guide our operational activities. We do hereby in the name God adopt, enact and give unto ourselves this Constitution.

ARTICLE 1: SUPREMACY

The organization shall be subject to:

This Constitution

The Constitution of the Republic of Ghana

Any other rules and regulations of the Republic of Ghana concerning the work of non-governmental and community based organizations.

ARTICLE 2: NAME

The association shall be known as and calledSelf-Help Group hereinafter referred to as

ARTICLE 3: SLOGAN:

ARTICLE 4: AIMS AND OBJECTIVES

The aims and objectives of the Association shall be:

To support and assist members in their treatment, help them take their drugs regularly

To create and provide a forum for addressing the needs and concerns of the members

To promote activities and schemes that would make the members have a sense of belonging and acceptance into the larger society

To improve upon the social, moral and economic conditions of mentally ill people and deal with the stigma they suffer

To develop and embark upon educational activities meant to avert various conditions that precipitate mental illness

To facilitate the integration of mentally ill people into their communities.

To advocate their return to their previous places of work

To undertake joint projects so as to be self-supporting and capable of assisting the work of the group.

ARTICLE 5: POLICIES

The association shall be non-political, non-sectarian and non-profit.

ARTICLE 6: MEMBERSHIP

Membership of the Association shall be open to mentally ill people and carers of all ages, sexes and from all walks of life who are living in and around who agree absolutely with the aims, objectives and aspirations of the Association.

Members shall be committed to the aims and objectives of the Association.

AFFILIATE MEMBERSHIP

Friends / Well wishers

Other Associations—national and/or international –with similar objectives

ARTICLE 7: EXECUTIVE BOARD

The Association shall have an Executive, which shall be the highest supervisory and policy making body of the Group. It shall consist of five or seven members, including the Chair, Vice Chair, Secretary, Assistant Secretary, Treasurer, Organiser and Welfare Officer.

The Association shall have the power to appoint its Chair and Secretary whose tenure shall be annual.

Duties of the Executive

CHAIR

The Chair shall preside over all meetings and shall be the spokesperson for the group

He/She shall ensure that the group achieves its aims and objectives

He/She shall be required to sign documents of the group

VICE-CHAIR

He/She shall assist the Chair in the execution of duties

He/She shall act in the absence of the chair

SECRETARY

The Secretary shall keep record of all minutes

He/She shall write and sign all letters upon the approval of the Chair or the Executive Committee

He/She shall take custody of all documents, files of the group

He/She shall prepare quarterly and annual accounts for presentation to the group.

He/She shall perform secretarial duties as are necessary for the advancement of the Group

ASSISTANT SECRETARY

He/She shall act in the absence of the secretary and assist him/her in the execution of his duties.

TREASURER

The Treasurer shall receive all monies and issue receipts and keep proper records for the monies collected. He/She shall keep records of all monies disbursed.

ORGANISER

He/She shall arrange for meetings and for meeting places

He/She shall act as the Public Relations Officer

He/She shall collect relevant information and also deliver information to the appropriate constituents.

ARTICLE 8: MANAGEMENT BOARD

There shall be a management board, which shall be responsible for the day to day running of the Association. The Management Board shall comprise the Chair, the Financial Secretary and the Secretary.

The Management Board shall hold meetings once every month. The administration of the association shall be vested in the management board, which shall be responsible to the Executives.

ARTICLE 9: MEETINGS

There shall be general meetings once every month. The general meeting shall be the highest legislative body of the Association. The number of meetings may be increased as and when there is the need. For the avoidance of doubt, an emergency general meeting shall be convened to discuss serious and important matters affecting the association

ARTICLE 10: VOTING

All members have equal rights of voting

ARTICLE 11: FINANCE AND BANKING

Income for the organisation shall be derived from the following:

- a) Donations
- b) Dues and contributions from members
- c) Grants from donor agencies/other NGOs/individuals

The books of accounts shall be kept by the Chair and/or Secretary of the Association. The Management Board shall determine where all funds shall be deposited and how the funds should be expended.

The organisation shall open and operate an account with any commercial bank appointed by the Management Board. Cheques shall be signed by the Chair, the Secretary and/or Treasurer

ARTICLE 12: AMENDMENT

This Constitution shall be subject to amendment by a two third majority of members present at a meeting specifically scheduled for that purpose.

ARTICLE 13: EFFECTIVE DATE OF THE CONSTITUTION

The effective date of this constitution shall be the date on which it is accepted by majority of two-thirds of the members present at the meeting.

ARTICLE 14: PROMULGATION OF THE CONSTITUTION

The Constitution is promulgated on the (DATE)

.....
.....

NAME
(CHAIR)

NAME
(SECRETARY)

NAME
(TREASURER)

2.4 Scaling up community mental health care in Africa. Exciting times

Julian Eaton

Christian Blind Mission (cbm)

Abuja

Nigeria

julian_eaton@cbm-westafrica.org

Introduction

It is easy to list the desperate statistics relating to the lack of services for people with mental health problems in Africa, and to find harrowing tales of the neglect and outright human rights abuse experienced by some people. In fact, Africa is often cited as a case study for failed health systems, with mental health services amongst the most dysfunctional of all. Despite the challenges, there are several examples of exemplary services being provided, and places across the continent where people with psychosocial disabilities are making their voices heard in their communities. Though they are currently the exception rather than the rule, these examples show how basic, accessible, good quality services can transform the lives of the people who use them.

Exciting times

It is over a hundred years since colonial authorities started establishing institutions in African countries that reflected their own policies.

In West Africa for example, a string of asylums was established between 1903 and 1908 in Calabar, Lagos and Accra (Sadowsky, 1999). Of course Africa has many ancient traditional systems, with healers and functional ways of dealing with social consequences of mental disorder prior to this.

Fifty years ago, Chlorpromazine, the first marketed anti-psychotic medication

was released, and this set the stage for a major revolution in being able to provide effective treatment for severe mental disorders. This was followed by development of pharmaceutical agents that could effectively alleviate symptoms of a wide range of disorders, paving the way for the majority of people to be able to remain in their communities while receiving mental health care.

Following independence, many African countries carried over the policies of colonial times, including those related to mental health. However, in most cases, even these inadequate services were not developed, and legislation quickly got out of date. Only 30% of African countries have legislation that was developed since 1990 (WHO, 2005). The reality now is that in most Africa countries, services are limited to a few big hospitals, with few community-based services. This is despite the fact that basing mental health care at the primary health care level has been accepted as a founding principle of service delivery for many years (WHO,1990).

The Global Burden of Disease study, published in 1996 (Murray, 1990) used new ways of measuring health needs that incorporated measures of disability rather than just mortality. As a consequence, it became clear that mental health issues were vastly under-resourced in relation to the burden they caused to communities. The 2001 WHO World Health Report; 'New Understanding, New Hope' (WHO, 2001) also highlighted the degree to which mental health needs were unmet globally, but more importantly made the point that we now had good tools with which to address the needs. The failure to meet these needs now became an issue of organising resources effectively to deliver care rather than a lack of knowledge about what works. It became a moral issue, not just a technical one.

Since the WHO report, there has been a growing call for action to galvanise resources towards addressing the lack of access to services that is faced by people with mental health problems in low and middle income (LAMI) countries around the world. The WHO launched the mhGAP programme, recently re-launched in 2008.

In 2007, The Lancet medical journal published a series on Global Mental Health.

This landmark set of six original papers was commissioned from leaders in the global mental health field.

They reviewed the current situation, argued that paying attention to mental health was essential to succeed in global (physical) health initiatives, gathered the evidence for effective treatment, looked at barriers and resources needed to improving care, and finally ended with a call to action. The call to action was a demand that services must be scaled up. It was argued strongly that without action, nothing would change. One of the consequences of this was the launch of the Movement for Global Mental Health, an initiative to build a strong movement to advocate for greater resources to be allocated to scaling up service, and to pay more attention to the abuse of human rights that is too often a feature of the lives of people with mental illness in many parts of the world.

Lack of implementation

Given the length of time (at least 20 years) that the message about improving services has essentially been the same, we need to understand what the reasons are for the lack of progress made. One of the papers in the Lancet Series (Saxena, 2007) explored this, and the themes that emerged were:

- Availability of resources was scarce
- Distribution of resources was unequal
- Utilisation of resources was inefficient
- Many stakeholders reported a common experience of...
 - Lack of resources (human and financial)
 - Lack of political will and poor governance
 - Lack of public awareness about mental health issues

Successful interventions and examples of good practice

Despite this overall lack of progress, there are many examples of good practice to learn from. There are two levels of activities, which must be done in unison to achieve sustained change.

At the international and national level, a consensus should be reached about universal principles that should be applied in design and implementation of services. Research must be carried out that is practical and be disseminated in accessible ways (for example as ‘packages of care’ or guidelines) to those who need the answers to key questions. Policy and programmes must be put in place based on these principles and the evidence base generated by research.

It is at the local level that there is often a failure to implement these policies and programmes. Sometimes the problem is that they are not sufficiently sensitive to local needs and the local environment to succeed in practice. Often the problems of insufficient, inequitably distributed and inefficiently used resources described above prevent effective implementation in communities. The problems of human resources are particularly acute, with a high proportion of those trained in mental health leaving their home countries for greater opportunities abroad.

The Global Forum for Community Mental Health ⁶is unique in trying to work at an international level by forming a coalition for real change in LAMI countries, while at the same time focusing strongly on the experience of service users and local practitioners.

Examples of good practice

There are many examples of good practice in Africa. Groups in many countries, including Ethiopia, Nigeria, Tanzania, Kenya and Uganda are working to integrate mental health into the Primary Health Care system.

Thousand of people receive broad, holistic care through Community-Based Rehabilitation (CBR) in Burkina Faso, Cote d’Ivoire, Ghana, Niger, Nigeria, Tanzania etc often in the most rural and challenging terrains.

In Nigeria, a successful project has dramatically improved the lives of people with mental health problems who find themselves incarcerated in prisons, often with no formal charge.

⁶ The Movement for Global Mental Health (www.globalmentalhealth.org)

Persons with mental health problems in Uganda, Zimbabwe, South Africa and Ghana are forming alliances to advocate effectively for their own needs to be met, on their own terms. The Pan-Africa Network of Users and Survivors of Psychiatry was represented in the Global Forum meeting held in Uganda.

Self-help groups in Ghana are now providing peer support, and accessing resources to develop sustainable livelihoods.

Some lessons learnt from these experiences

Mental health is a human rights issue

The 2008 United Nations Convention on the Rights of People with Disabilities was the most quickly endorsed convention in UN history, and has been ratified by many African countries. The international mental health service users' movement was consulted in the process of its development, including those, such as Mental Health Uganda, from Africa. In fact it was a major shift in recognising that there were many shared issues, and that the disability movement had a lot to teach campaigners in mental health. Importantly, signing and ratifying the convention puts a responsibility on countries to put into place mechanisms to implement the principles laid out in the convention. This needs to be capitalised on by those in the mental health advocacy movement.

"Nothing about us without us"

"He who is reluctant to recognise me opposes me."

Frantz Fanon. Revolutionary, psychiatrist, and adoptive African.

Nothing about us without us is a motto of the international disability movement which underlines the fact that users of services are central to transforming the services they are able to access.

Apart from the moral sense in self-advocacy, it is also a highly effective form of advocacy. Those with personal experience speak with the most authority.

"Together we can do more..."

“‘Go in that direction’ does not mean that you send someone. To go means, ‘let’s go together!’”

Sena Proverb, Mozambique

It is only by including all relevant players that services can truly meet the needs of all who interact with them. These people include users of services, the wider community, non-governmental and faith-based organisations, traditional healers, government agencies and professionals. Stakeholders working together become a powerful force for change, and in some countries, united stakeholder groups are already having an impact.

Know the context

“The hand that dips into the bottom of the pot will eat the biggest snail.”

Wole Soyinka. Nigerian playwright

It is only in really understanding the contexts where we work that we can be effective in changing it for the better. It is one of the unique challenges of global health work, and in particular mental health activities. While ‘packages of care’ and use of relevant evidence from other areas is an important starting point, we need to ensure that they always meet local needs.

The Twin Track Approach

“The heap of yams you will reap depends upon the number of mounds you have ploughed”

Igbo proverb, Nigeria

It is an important principle to ensure that persons with psychosocial disabilities

are included in mainstream services, but at the same time we must keep working to provide quality specialised mental health services.

While aspiring to effect profound systemic change (‘a world turned up-side down’), we need to ensure that people are not neglected while mainstream services continue to fail them.