

BasicNeeds

BasicRights



Lessons from the African User Movement: The Case of Ghana

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Introduction

Beyond the momentum of individual leaders, there are two main drivers for the growth of the user movement in Africa: the human rights movement and scarce resources. The seminal World Health Report 2001: *Mental Health: New Understanding, New Hope*, calls for increased user involvement for practical reasons. 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, 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 (the remainder are private sector or retired). 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 mental health user participation to come to the forefront of the global 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.

1. Community level groups

The formation of community level user groups in Ghana grew spontaneously from consultations BasicNeeds organised with communities 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 districts¹ 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.

a. 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.

b. 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

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

¹ District also refers to sub-metropolitan, municipal and metropolitan authorities of the local government.

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 SHG 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.

c. 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.

c. 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.

d. Funding

SHGs are mainly funded from monthly membership contributions and grants from BasicNeeds and other bodies. Membership registration fee is fifty Ghanaian Pesewas (GBP 20p) with a monthly levy of one Cedi (GBP 50p), which some groups charge. On some occasions, members make special contributions in response to specific needs, such as child-naming ceremonies, wedding 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 GHS 4,000 (£1,700) in seed capital to support livelihoods ventures for the members of one group. Livelihood ventures are mainly petty trading and small scale agro-processing for which costs include support for tools and equipment as well as training fees.

2. 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.

a. 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 Associations 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.

b. 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.

c. 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 feedback 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.

d. 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.

3. National Assembly

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. 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. 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.

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 key 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.

a. 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.

b. 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.

c. 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's 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 this user involvement work.

d. 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 GBP £1,000,000 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 grant applications independently of BasicNeeds.

4. 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 fulfil the human rights of mental health service users. In particular, PANUSP promotes its members' disability rights, as per the UN Convention on Disability, and rights to dignity, participation and self-determination. PANUSP was founded in 2006, with headquarters in Uganda, and now has membership from nine African countries: Uganda Kenya, Tanzania, Rwanda, South Africa, Ghana, Guinea, Zambia and Malawi. 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 by close of 2009. As its name implies, PANUSP is also affiliated with the World Network of Users and Survivors of Psychiatry (WNUSP). The Pan-African group held their first members forum in February 2009 at a regional conference of WNUSP in Uganda. Lack of funds

and a strategic plan currently hinder the progress of PANUSP, however, there are efforts underway to strengthen activities by developing regional sub-groups, starting in East-Africa.

- **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.

Conclusion: Ten Lessons for Starting Your Own User Movement

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

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 promote human rights.** 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.** Developing grassroots user-led groups requires time and money. In Ghana, it has taken four years from when the first self-help group was put into place in a suburb of Tamale, and it has cost over £500,000 together with countless man-hours to create a national user-association with broad-based membership.
3. **Battling poverty is one role of a 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 in Africa is to secure livelihoods.
4. **Interest in advocacy develops with learning.** Advocacy initially takes second place to income-earning; but the incentive to advocate develops when participants realise 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. It is therefore at 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. As new membership associations, groups will grow from mistakes of commission and omission. Those facilitating the groups must resist the temptation to take over and do things for them.
6. **Illiteracy 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. **Size matters.** 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 key to the sustainability of community mental health.** Groups are essential in order 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 government practice.
9. **Mental health service users can learn from other 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 national government accountable.

Annex: Template group constitution

THE CONSTITUTION OF

NAME: SELF-HELP GROUP

PREAMBLE

We, the members of the Self-Help Group, realizing that we share a common vision, realizing 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:

- a) This Constitution
- b) The Constitution of the Republic of Ghana
- c) 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:

- a) To support and assist members in their treatment-help them take their drugs regularly.
- b) To create and provide a forum for addressing the needs and concerns of the members.
- c) To promote activities and schemes that would make the members have a sense of belonging and acceptance into the larger society.
- d) To improve upon the social, moral and economic conditions of mentally ill people and deal with the stigma they suffer.
- e) To develop and embark upon educational activities meant to avert various conditions that precipitate mental illness.
- f) To facilitate the integration of mentally ill people into their communities.
- g) To advocate their return to their previous places of work
- h) 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

- a) Friends / Well wishers
- b) 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, Organizer 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

1. The Chair shall preside over all meetings and shall be the spokesperson for the group
2. He/She shall ensure that the group achieves its aims and objectives
3. He/She shall be required to sign documents of the group

VICE-CHAIR

1. He/She shall assist the Chair in the execution of duties
2. He/She shall act in the absence of the chair

SECRETARY

1. The Secretary shall keep record of all minutes
2. He/She shall write and sign all letters upon the approval of the Chair or the Executive Committee
3. He/She shall take custody of all documents, files of the group
4. He/She shall prepare quarterly and annual accounts for presentation to the group.
5. He/She shall perform secretarial duties as are necessary for the advancement of the Group

ASSISTANT SECRETARY

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

TREASURER

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

ORGANIZER

1. He/She shall arrange for meetings and for meeting places
2. He/She shall act as the Public Relations Officer
3. 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 organization 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 organization 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	NAME	NAME
(CHAIR)	(SECRETARY)	(TREASURER)

.....