

## Report on National PLWA/AIDS Support Group Surveys

### An Overview

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#### **Introduction**

A nation-wide survey of people living with HIV/AIDS and other AIDS related support groups or structures was conducted between 20<sup>th</sup> and 29<sup>th</sup> June, 1998 by Malawi Network of People Living with HIV/AIDS (MANET+). These support groups are basically community based organisations (CBOs), largely owned and run on voluntary basis by the communities themselves in response to the HIV/AIDS epidemic.

#### **Purpose**

The purpose of the survey was threefold; to formally enlist membership for the network, to establish baseline information of support groups and to update on information collected by Southern African AIDS Training Programme (SAT) in April, 1997 at a PLWA conference.

#### **Size**

A sample total of thirty-three (33) support groups were earmarked in this first survey by MANET+. Out of this sample figure the interviewers succeeded to establish information on twenty-eight (28) groups. The fundamental criterion of selection of the groups surveyed was based on the fact that the groups were either of people living with HIV/AIDS (PLWAs) or those that directly work with PLWAs and indeed all those groups previously interviewed.

#### **Methodology**

Various places were visited in all the three administrative regions of the country. Interviewers (one for each region) from MANET+ Secretariat conducted the surveys using questionnaires, two from MANET+ and one from SAT. Responsible officers of the various groups were interviewed to complete two questionnaires to establish information on the group as entities. Individual members of the groups were also requested to fill in details of personal identity to establish the composition and capacities of their groups.

#### **Findings**

##### *Strengths*

There is active participation in communities at grassroots levels in response to the AIDS epidemic. This has been clearly demonstrated by the self-help spirit

with which people have responded in their efforts to alleviate the impact of AIDS. Communities see the onslaught of AIDS and their need to act collectively, hence the formation of CBOs.

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## Malawi Network of People Living with HIV/AIDS

In addition to establishing community based support groups people have gone further to erecting infrastructures, on self-help basis, to provide the necessary administrative supports.

These CBOs enjoy considerable support of existing institutions in their localities in terms of administration and communication facilities (postal contact addresses, telephone, and space for meetings).

Out of the 28 support groups 18 were closely linked with AIDS co-ordinators of the Ministry of Health & Population in various rural health centres across the country. Seven (7) of these were basically operating on their own supported from various other sources. The remaining three (3) enjoy the support of mission hospitals.

### *Gaps*

There is need for most support groups to emphasise on clearly knowing their goals and objectives. There were several instances where responsible officers would not readily and comprehensibly come up with the goals and objectives of their organisations. Clarity on goals and objectives of groups would assist people set activities that will help them in working towards realistic ends.

Need was also felt regarding definition of catchment areas by support groups in terms of population sizes and size of the areas the groups were targeting to serve. There was a general tendency identified during the surveys that showed that most groups were labouring to over-stretch their existing resources and capacities. Out of the 28 groups reached only five (5) had some figures to define their catchment areas.

Another conspicuous existing gap was lack of records systems. Most groups do not have monitoring and evaluation bases for assessments. In several cases groups had difficulties to make available information on their group membership let alone on their activities. In brief there is need for capacity building in terms of record management.

Much as the support groups play an important role in their communities, there is evidence suggesting that little or no marketing is done about the services offered.

Most of the promotion is done through word of mouth. Good as this could be, it is not adequate. There is need for support groups to explore more ways of reaching out to their targeted communities.

### *Way Forward*

A participatory review is envisaged by MANET+ in due course to discuss and establish the existing needs. This review will help map out the way forward.

The major and common activities of support groups in response to the HIV/AIDS epidemic (based on the aim to promote awareness and reduce the impact of HIV/AIDS) comprise Counselling, Public AIDS/Health Education Talks (Outreach), Home Based Care, Orphan Care and Income Generating Activities (IGAs).