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Social Mobilisation For AIDS

By

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SOCIAL MOBILISATION FOR AIDS

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The assessments and views expressed in this paper are entirely the author's own.
Introduction

A discussion on social mobilization for AIDS would range from the mobilization of the individual at the micro level, to the mobilization of organizations, governments and international agencies at the macro level. However, this paper will focus on social mobilization in the context of AIDS-specific NGOs, non-AIDS-specific NGOs and the Malaysian Council of NGOs on AIDS and their respective programs and activities.

Therefore, the paper will be divided into five sub-sections. The first sub-section will look at the reasons which mobilized non AIDS-specific NGOs to incorporate AIDS-related projects into their organizations’ program structure and the factors leading to the establishment of AIDS-specific NGOs. The second sub-section will focus on the activities conducted by NGOs to create awareness and to enlist the support of citizens in AIDS-related work. The third sub-section will examine/overview the role of the AIDS Council in social mobilisation and the dynamics and collaboration between Council and members. Fourthly, this sub-section looks at the networking carried out inter-NGOS and between NGOs and various agencies, government or otherwise. The last sub-section will examine mass media coverage of the AIDS issue in general and of the AIDS programmes conducted by NGOs, in particular.

Mobilization of NGOs

In Malaysia, the approximate number of NGOs involved in AIDS-
related work is twenty to twenty-five. A few NGOs became involved in AIDS-related work from the late eighties while others started in the early nineties. The relative late start is largely due to Malaysia only experiencing the early stages of the epidemic, concurrently, AIDS-related work is also in its early stages. The NGOs involved range from nationwide bodies such as the Red Crescent Society, Malaysian Medical Association and the National Council of Women's Organizations, to small, community-based organizations such as Tenaganita (works with migrant workers, sex workers and estate workers) and CASP (works with sex workers and IDUs). The groups reached by the NGOs vary from race, culture, age group, religion, sexual preference, gender, sero-status and socio-economic status. Most of the NGOs are situated in the capital, Kuala Lumpur, thus, AIDS-related work is concentrated in that part of the country. Outside of Kuala Lumpur, in the larger towns, only a few NGOs conduct AIDS-related work. The clustering of AIDS-related work in cities causes concern as the outlying areas, ie rural areas, have little access to the education and facilities found in cities.

The initial organised non-government response to the AIDS epidemic was initiated by an NGO called Pink Triangle in the late eighties. **Pink Triangle** was initially established with the objective of providing support services for people working on the issue of sexuality. Concurrently, with the advent of AIDS in the country and the inextricable connection between sexuality and AIDS, this NGO undertook AIDS-related work which has since been the primary focus.
of its programs which include outreach work, counselling and IEC. Therefore, \textit{Pink Triangle} falls into the category of AIDS-specific NGO. \textit{Pink Triangle} is selected as a case study as it highlights the elements of social responsibility and personal motivation, two important factors in the social mobilization for AIDS.

The group of individuals responsible for the establishment of \textit{Pink Triangle} shared one or more of the following considerations:

\begin{itemize}
\item[a)] they had lived and/or were educated abroad and thus, were sensitized to the AIDS issue and had knowledge of AIDS-related work being conducted;
\item[b)] it was noticed that non-governmental local support for the AIDS issue did not exist; and
\item[c)] the AIDS issue was personalized, i.e., they were personally affected, as they all had HIV positive friends or relatives who were either alive or had died.
\end{itemize}

It should be emphasized that the personalization of the AIDS issue has played a key role in mobilizing individuals to rally around the issue. Unlike other issues such as the environment, animal rights, etc., which are considered rare and even stigmatically in some instances, there is much controversy and negative associations surrounding AIDS and thus, usually those committed and involved in AIDS work whether as a volunteer or paid staff are motivated by personal reasons.
Unlike *Pink Triangle*, most other NGOs involved in AIDS-related work are non-specific-AIDS NGOs. NGOs in this category are involved in non-AIDS-related areas, eg family planning, but have incorporated the AIDS agenda into their existing program structure. For example, the *Malaysian Consultative Council of Buddhism, Christianity, Hinduism and Sikhism* has undertaken AIDS education and awareness work with its constituents, mainly through seminars, talks and forums. For most NGOs, the incorporation of the AIDS agenda is due to their realizing the extent of the AIDS threat and to the urging of the AIDS Council and/or the government. Although these non-AIDS-specific NGOs have organizational priorities, at least there is a concerted effort to address the AIDS issue within the context of individual NGO's programs. There are other non-AIDS-specific NGOs which have identified AIDS as a "direct" threat to their members, communities and clients, eg women, sex workers and IDUs, and thus, developed programs to deal with the AIDS issue within these communities. For example, the NGO Tenaganita which works with sex workers implemented priority AIDS programs for the sex worker community when HIV/AIDS appeared within this community.

**NGO Activities**

The activities organised by NGOs range from public forums to the empowerment of sex workers and can be classified under three broad categories: IEC, Direct Services and Skills Building/Enhancement. IEC activities concentrate on educating and raising the awareness of the public through talks, forums, seminars, etc. Direct services
would include support groups for PWA/HIV, counselling, outreach programs and half-way house facilities. Skills Building/Enhancement is for AIDS workers, members of organizations, communities and clients. Skills building/enhancement would include the training of trainers, counsellors for Hotlines and face-to-face counselling, peer educators and outreach workers, assisting AIDS workers to organize and manage projects more efficiently, ie implementing proper and consistent procedures and follow-up measures, and revision workshops to brush-up on skills, eg counselling skills. To date, NGO initiatives include two Drop-In Centers which provide support services, such as basic medical assistance for IDUs and sex-workers; a Half-way House for HIV positive women, particularly sex workers -- included in its program is health recovery and family support and reunification; and outreach work with marginalised communities such as sex workers, IDUs, transsexuals and homosexuals. The target groups NGOs choose to work with are usually communities which they have ready and easy access to, such as the Malaysian Dental Health Association working with the practitioners of the dental health profession.

While a few NGOs are capable of conducting activities under the three categories, others are only involved in activities under one or two of the categories according to the capacity of and resources available to the organization. The bulk of of the programs NGOs undertake concentrates on IEC targeted at different groups. IEC activities include talks, seminars and exhibitions and relevant
resource materials are produced to support these activities. The
groups reached include factory workers, school-going adolescents,
women, medical and dental personnel, private sector corporations,
migrant workers, estate workers and religious communities.

IEC programs and direct services have had a measure of success in
complimenting the government's efforts to raise awareness amongst
the public and in serving to educate specific communities. As most
of the IEC programs cater to larger groups of people, not only is
the public educated but it also serves as an avenue to recruit
volunteers. Participants of such projects have volunteered
themselves to assist in existing NGO programs, e.g. on project basis,
and/or inquired on assistance to conduct echo programs within their
respective communities. High profile activities such as World AIDS
Day provide recruitment opportunities and are utilized to recruit
assistance from the public. The mass media is also employed
directly and indirectly for recruitment purposes. Direct employment
such as advertising and publicizing recruitment exercises for the
training of counselors has been effected. Indirectly, publicity
generated on work conducted by NGOs through interviews or feature
articles have mobilized individuals to be involved in AIDS-related
work. Thus, through these activities the volunteer base can expand
outside of NGOs as well as within organizations as members too are
recruited to support and maintain programs.

1. Awareness of AIDS, per se, is high amongst the public, both
in the rural and urban areas, whether awareness has translated into
behavioural change has not been established.
Outreach projects provide another source of recruitment as included in these projects is a component to identify and enlist volunteers and workers. An example would be work with the sex worker and IDU communities as NGOs actively source members within the community to take on the role of peer educators and also to empower such marginalised populations to contribute towards "having their voices heard", i.e. highlighting their particular needs and predicaments.

Although the enlistment of members of the public is an important aspect of the social mobilization for AIDS, it must be emphasized that to conduct effective and efficient work on AIDS there is a need to remunerate AIDS workers for their capability and skills, accordingly.

Independent of NGOs conducting AIDS-related work, the AIDS issue is highlighted through TV dramas and documentaries, radio broadcasts, movies and even local theater productions have staged plays with the AIDS theme.

Malaysian Council of NGOs on AIDS

In 1991, the Ministry of Health mooted the idea of forming the Malaysian Council of NGOs on AIDS, also known as the AIDS Council, which was registered by the Malaysian Registrar of Societies in 1992. The AIDS Council, aware of the need for a multi-sectoral approach, has consciously sought to invite various NGOs to affiliate themselves with the Council to work towards a multi-prong
strategy in AIDS programs. The AIDS Council is an umbrella organization whose affiliates are AIDS-specific NGOs and non-AIDS-specific NGOs. The Malaysian Ministry of Health and the AIDS Council maintains close cooperations and work towards complimenting each other’s programs.

How does the AIDS Council operate to realize its aims and objectives? And what is the basis of networking and collaboration between the AIDS Council and affiliate NGOs?

Currently, around 20 NGOs are affiliated to the AIDS Council. These affiliates were either invited or applied for membership to the Council; all affiliates have to meet the requirement of being involved in AIDS-related work. Although affiliates run programs independent of the Council, under the Council’s umbrella, affiliates collaborate on projects, provide input to the development of the Council and its programs and raise issues which need the attention and deliberation of the Council and affiliates.

Often, the Council takes on the facilitator and coordinator roles, reflected in its projects and activities during its two year life span to date. At the outset, the Council in furthering its objective of coordinating activities and complimenting governmental efforts, decided to formulate an NGO Action Plan for AIDS Prevention and Control. The Action Plan was formulated according to specific community groups and priority activities to meet their needs. As
important was the process of formulation, itself, where members of
different NGOs become acquainted with one another and hence forged
closer linkages and networking; this comradeship is a necessary
feature of the work of the Council. In addition, the exercise
brought into sharp focus the areas of strengths and the
deficiencies in AIDS prevention activities, thus enabling better
planning of future activities. Recently, a follow-up workshop was
held to evaluate the Action Plan. The assessment brought forth
recommendations to implement the Action Plan more effectively,
raised the latest concerns/issues on AIDS and witnessed the
restructuring of the Council's Executive Committee in order to
develop a comprehensive, proactive and dynamic Council.

The nature of cooperation between Council and affiliates is
reflected in projects such as World AIDS Day and International AIDS
Candlelight Memorial and Mobilization. The Council coordinates the
activities of members and/or members volunteer to assist in the
organization and execution of Council events.

The most major task undertaken by the Council to date is the
setting-up of a Half-way House for PWHIV/AIDS. Individual members
were enlisted for their expertise and skills by the Council to
perform the tasks of planning, organization, management, budgeting,
etc. The establishment of the Half-way House is an example of how
the Council mobilizes members by tapping their expertise/skills for
input into a Council project, thus, ensuring the involvement of
members and making it a community project. The Council also facilitates the transfer of skills, in this case, as the more experienced affiliates train the less skilled members, therefore assisting in capacity building. Another spill-over effect is the fostering of better working relations and complimentary work.

The Malaysian AIDS Foundation (MAF) established in 1992 by the AIDS Council, is the fund-raising arm of the latter. Although fund-raising remains the primary activity of the MAF, it collaborates closely with the Council and its affiliates on projects such as World AIDS Day. In addition to the funds generated by MAF, the Council forwards project proposals by its members to the Ministry of Health who then provides funding on approval basis. Thus, Council affiliates are provided with another source of funds to compliment the funds allocated by their primary funders.

The relationship between the Council and affiliates is akin to a two-way system, where the Council sources out members with specific skills to oversee its projects and provides funding, while members utilize the resources of the Council, eg training facilities and uses it as a platform on matters arising. The agenda of the Council is kept flexible to allow for input from affiliates which help shape its direction and growth.

For the future, the Council will embark upon implementing programs identified as priority areas by its members, such as training and
education of affiliates, developing IEC materials, support services and lobbying for HIV policies. The programs will be run by committees comprising of the affiliates. There is also a move towards decentralizing AIDS-related work in an effort to reach out to peripheral communities in the less developed and rural areas. One possible means is to create "mini" state AIDS Councils, calling upon affiliates with nationwide membership to impress upon their members to initiate "mini" Councils in each state.

**Networking Inter-NGO**

The small number of NGOs working on AIDS and limited resources have inadvertently caused a positive outcome -- closer cooperation amongst NGOs that has created close-knit ties. NGOs working on specific issues/agendas or with particular communities have come together and collectively shared resources and complimented one another's programs. For example, Ikhlas and Pengasih, both working with IDUs, have shared experiences and expertise on outreach work and identified mutual problems which they resolve together or have highlighted. The Federation of Family Planning and the National Council of Women's Organizations are concerned with educating women on AIDS, particularly in rural communities, and are working to develop a module on women and AIDS which will be disseminated nationally utilizing their nationwide network of affiliate organizations and members. In addition, by planning to disseminate the module to their affiliates, these two NGOs are in effect mobilizing affiliates within their respective organizations to
undertake AIDS work.

AIDS-related NGOs have also mobilized other non-AIDS NGOs to be involved in AIDS-related work. An example is the Names Project where the Rotaract Club collaborated with Pink Triangle to exhibit a portion of the AIDS Quilt to the public. The project took months to plan and organize and succeeded in highlighting the AIDS issue, particularly in remembering the people who have died of AIDS. As important was the opportunity to raise the awareness of and sensitize Rotaract Club members on the AIDS issue. Another example of one NGO mobilizing another would be the provision of support, by the experienced NGO, in the form of assistance during the setting-up stage and the training of staff of the new NGO’s programme.

NGOs such as DKT Consultants and Pink Triangle have mobilized private sectors corporations in highlighting the AIDS issue in the workplace. DKT Consultants approach is to increase the understanding of AIDS and STDs and to facilitate and motivate a change in sexual behavior to reduce the spread of HIV and STDs in the workplace and institutional settings. Project activities include training peer leaders, providing referrals for counselling and holding talks. Similar projects are conducted by Pink Triangle but it has managed to secure a business partnership with the corporation, the Body Shop, in selling "safer sex" packages, which contains safer sex messages in 3 languages, 2 condoms and 1 pack of lubricant. The income generated from this project is channelled
back into AIDS projects.

Mass Media Coverage

The AIDS issue has received increasing coverage from the mass media over the past few years as the rates of HIV infection rise. The most coverage has come from the print media, particularly the press, and as such an examination of this sector will be discussed over the other forms of media. It is observed that there are 3 main categories of reporting, the first is coverage of information released and the issues raised by the Ministry of Health and government agencies. The second is coverage of programmes/activities conducted by NGOs, while the third are general feature articles on AIDS.

How does the press know what and when to report? When an NGO embarks on a programme or an activity, the press, which consists of the English, Malay, Chinese and to a lesser extent Tamil language press, are informed to cover the event. It is also more likely for editors to assign a reporter if in attendance are VIPs or experts (local and international) on AIDS. Thus, the onus is usually on the NGO to ensure coverage of their activities. A "standard" article would be a "straight-forward" report on who is the organiser, what is the event about, where it was held, followed by the latest statistics and breakdown (eg. according to groups such as IDUs and sex workers) of HIV/AIDS cases.
Press coverage of government actions or operations are usually literal reports of statements made by ministers or officials. These reports are monitored by NGOs and occasionally when a controversial issue arises such as the government's plan to rehabilitate HIV positive sex workers, NGOs will issue statements in response or reporters will elicit comments from NGOs. As a result of these public statement, on a few occasions, dialogue has commenced between government and NGOs or representation from NGOs has been invited to be part of planning committees.

However, press coverage is intensified, ie in quantity, over events such as World AIDS Day. Preceding World AIDS Day, newspapers, especially the English papers, will carry special pull-out features in Sunday editions, followed by daily coverage of events. The features would include global trends and responses, interviews with NGOs and experts, and more recently, in-depth accounts of the effect of AIDS on local, marginalised communities and its members. Thus, at least once a year there is comprehensive coverage and the coverage has so far been positive and insightful. The quality of articles reflect much research and analysis by the journalists. It is observed that sound journalistic pieces can be produced if journalists are familiar with and have followed the course of the AIDS epidemic. This contrasts sharply with general reporting of the AIDS issue. Perhaps this can explained by the fact that there is a

2. Government in this context encompasses all sectors, from Cabinet level to the law enforcement agencies, eg the police force.
high turnover of reporters and, therefore, reporters have less opportunity to keep abreast of the issues and latest developments.

The AIDS Foundation, in addition to its fund-raising portfolio, also acts as a public relations (PR) arm. Although, most of the PR focuses on fund-raising projects, concurrently, press coverage provides an opportunity for responding to latest developments, usually in response to the government's proposed plans on AIDS.

Conclusion

The mobilization of NGOs and their programs have placed NGOs in the forefront of the fight against AIDS. While NGOs work independently within their communities and according to their capabilities, they have also taken the initiative to work collectively amongst themselves in sharing resources, to collaborate on problem-solving and to compliment one another's programs. With improved coordination of NGOs' programs, the likelihood of a more focused and lucid approach to the fight against AIDS increases and would lead to further social mobilization for AIDS.

The mass media's coverage of the AIDS issue ranges from "straight-forward" reporting to in-depth articles, the latter appearing much less. As the mass media is a conveyor of information (at its most basic of functions) from which opinions and viewpoints are constructed, it has the social responsibility of bringing to the public factual and balanced information. Therefore, the following
are three basic suggestions for the producers of mass media to consider:

a) usage of appropriate language, ie high-risk behaviour instead of high-risk groups. (See Appendix B);

b) eradicate sensationalization of HIV/AIDS related issues which lead to misconstrued perceptions and unnecessary blaming, ie by-lines such as "6 Call-Girls HIV Positive; and

c) sensitise all sectors of the mass media, eg reporters, editors and management, to the AIDS issue by organising workshops which could be conducted by NGOs.
APPENDIX 1

The AIDS Council was formed with the premise of achieving the following aims and objectives:

a) to work towards attainment of better health and health care system for all Malaysians, especially in terms of prevention and control of AIDS;

b) to educate Malaysian and NGOs on AIDS and AIDS prevention program and services;

c) to coordinate programs and actions of various NGOs and AIDS prevention and patient care;

d) to develop and formulate policies for AIDS prevention and intervention by NGOs in Malaysia;

e) to strengthen and generate services and programs on AIDS by NGOs

f) to strengthen support services for AIDS and HIV infected patients and affected persons;

g) to conduct and coordinate and support research on AIDS;

h) to develop and disseminate resource materials for AIDS awareness programs;

i) to promote and protect the rights of HIV infected people and people with AIDS;

j) to protect HIV infected persons and people with AIDS against discrimination; and

k) to establish and manage a Foundation known as the Malaysian AIDS Foundation.
HIV and Development Workshop

UNDP HIV-RELATED LANGUAGE POLICY

General

Language should be inclusive and not create and reinforce a Them/Us mentality or approach.

For example, a term like "intervention" places the speaker outside of the group of people for/with whom one is working.

It is better if the vocabulary used is drawn from the vocabulary of peace and human development and not from the vocabulary of war.

For example, synonyms should be found for words like "campaign", "control", "surveillance", etc.

Descriptive terms used should be those preferred or chosen by persons described.

For example, "sex workers" is often the term preferred by those concerned rather than "prostitutes"; "people living with HIV" or "people living with AIDS" are preferred by many infected persons rather than "victims".

All language should be gender sensitive. In the same way, the terms used should be those preferred by the disempowered.

Terms used need to be strictly accurate.

For example, "AIDS" should only be used to describe the diagnosed condition. Otherwise, the terms used include "the HIV infection", "HIV epidemic", "HIV-related illnesses or conditions", etc.

The terms used need to be adequate to inform accurately.

For example, the modes of HIV transmission and the options for protective behaviour change must be explicitly stated.
HIV Language Policy

The choice and use of words carries with it messages in addition to the literal meaning of the words themselves. Discussion of HIV and related issues is often fraught with tension because of the taboos and prejudices which lie beneath the surface of cultures. Careful use of language helps to avoid reinforcing prejudice and to clarify essential issues of human rights and dignity which are so often early casualties of the epidemic.

It is the UNDP HIV language policy to use:

- "Person with HIV", not "person with AIDS" unless it is used to describe the medical conditions which conform to the current case definition of clinical disease. A person either has a diagnosis of AIDS or they haven't. Terms such as full-blown AIDS and pre-AIDS condition are inaccurate.

- "People living with HIV infection", not "HIV-infected" or "HIV or virus carriers" because the emphasis should be on the people and not the virus or the infection.

- "People living with AIDS", not "AIDS victims" or "AIDS sufferers" because the emphasis should be on the people and not the medical condition. Furthermore, the terms victim and sufferer suggest powerlessness.

- "Living with AIDS", not "dying of AIDS" as it stresses the fact that a person is continues to participate in life's activities.

- "Men who have sex with men", not "homosexual", "bisexual" or "gay" because many men who have sex with men do not identify themselves as homosexual, etc. It is also inappropriate to label people by virtue of their sexual orientation.

- "Women who have sex with women", not "lesbians" because many women who have sex with women do not identify themselves as lesbians. It is also inappropriate to label people by virtue of their sexual orientation.
• "Commercial sex worker", not "prostitute" as this is the term used by women who do this work. The nature of "prostitution" differs from country to country and from culture to culture. The term "sex worker" is inadequate because some sex workers operate for money and some "non-commercial sex workers" operate for security.

• "Person with haemophilia", not "haemophiliac" because a person should not be identified by his/her disease.

• "Us" not "them" as all of us are living within the epidemic.

• "Living in poverty", not "poverty stricken". "Poverty stricken" implies powerlessness and an inability to be anything else.

• "The population", not "the general population", "the heterosexual majority", "normal people", etc., because everyone is part of the population and no one should be excluded or isolated because of sexual orientation or behaviour.

• "Risk behaviours", not "risk groups". In the context of the HIV epidemic it is the behaviour that places one at risk of HIV infection rather than their affiliation with a group.

• "Children living in families affected by HIV", not "orphans", "AIDS orphans" or "children orphaned by AIDS". "Orphan means different things in different countries (in African countries it often means a child who has lost one parent). "Orphan" also implies helplessness and can be demeaning. An association with AIDS may bring discrimination.

• "Working for life", not "fighting against AIDS" because the use of combative or military language does not encourage an attitude of caring.

• "Person", not "AIDS patient". "AIDS patient" describes the person by his/her medical condition and a patient is not a person but someone reliant on a doctor.

• "Babies with HIV infection", not "innocent babies", because this suggests that someone else is guilty or has got the infection deliberately.