Community mobilization and AIDS

UNAIDS

technical update

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At a Glance

UNAIDS understands a ''mobilized community'' to have most or all of the following characteristics:

- members are aware – in a detailed and realistic way – of their individual and collective vulnerability to HIV/AIDS
- members are motivated to do something about this vulnerability
- members have practical knowledge of the different options they can take to reduce their vulnerability
- members take action within their capability, applying their own strengths and investing their own resources – including money, labour, materials or whatever else they have to contribute
- members participate in decision-making on what actions to take, evaluate the results, and take responsibility for both success and failure
- the community seeks outside assistance and cooperation when needed.

UNAIDS will advocate for and help with the design of programmes which:

- uphold the rights and dignity of people infected with and affected by HIV/AIDS
- ensure active participation by as broad and representative a group of community members as possible
- provide for equal partnership and mutual respect between the community and external facilitators
- build capacity and ensure sustainability
- build on the realities of living with HIV and AIDS while maintaining hope based on community collective action
- maximize use of community resources while identifying and using additional external resources as needed.

UNAIDS *Best Practice* materials

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is preparing materials on subjects of relevance to HIV infection and AIDS, the causes and consequences of the epidemic, and best practices in AIDS prevention, care and support. A *Best Practice* Collection on any one subject typically includes a short publication for journalists and community leaders (Point of View); a technical summary of the issues, challenges and solutions (Technical Update); case studies from around the world (*Best Practice* Case Studies); a set of presentation graphics; and a listing of key materials (reports, articles, books, audiovisuals, etc.) on the subject. These documents are updated as necessary.

Technical Updates and Points of View are being published in English, French, Russian and Spanish. Single copies of *Best Practice* publications are available free from UNAIDS Information Centres. To find the closest one, visit UNAIDS on the Internet (http://www.unaids.org), contact UNAIDS by email (unaids@unaids.org) or telephone (+41 22 791 4661), or write to the UNAIDS Information Centre, 20 Avenue Appia, 1211 Geneva 27, Switzerland.

Journalists seeking more information about a UNAIDS Point of View are invited to contact the UNAIDS Geneva Press Information Office (+41 22 791 4577 or 791 3387).

Community mobilization and AIDS: UNAIDS Technical Update (UNAIDS *Best Practice* Collection: Technical Update). Geneva: UNAIDS, April 1997.

1. Acquired immunodeficiency syndrome – prevention and control
2. Acquired immunodeficiency syndrome – transmission
3. Community

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Background

Community-level action – much of it initiated by persons infected or affected by HIV – has always played a major role in the global response to AIDS. In many countries, community response came before the official national response. It has proved essential to many components of a successful national response – most notably awareness, prevention, policy and legal changes, impact alleviation, advocacy, and family or community care and support.

Starting a community effort is generally much easier than sustaining it. Many community organizations and programmes have been at work for years, and continue today with the same energy. Others have withered and lost energy; some have disappeared.

For national responses to be effective, existing community initiatives must be reinforced and new ones must be nurtured as they establish themselves. This will require flexible partnership arrangements with governments and other forces in the campaign against HIV/AIDS, particularly in developing countries.

Defining "community"

UNAIDS defines "community" in its widest and most inclusive sense: a community is a group of people who have something in common and will act together in their common interest. A community's ability to act together may have existed for centuries, or it may be triggered in a very short time by some urgent problem. Many people belong to a number of different communities – examples include the place they live, the people they work with, or their religious group.

In the past, community mobilization has usually meant initiatives at a neighbourhood, village or local district level. Today, however, the AIDS pandemic and modern communications technology have challenged traditional ideas of community. National and even global communities have emerged with shared concerns to prevent the spread of the virus, to care for those affected by HIV and AIDS, and to advocate for health and human rights.

While the *concept* of community has been widened, the need to design culturally and epidemiologically specific responses (i.e. to help specific groups of people) has created a corresponding need to define individual communities more closely. Such a definition includes the objective work of counting people, identifying their socio-economic status, and so on.

Equally critical, however, is understanding *who* defines the community. Outside definitions are useful but not complete: until people identify themselves as a community and share some sense of mutual belonging, there is no real community.

Nurturing and sustaining community mobilization

A community becomes mobilized when a particular group of people becomes aware of a shared concern or common need, and decides together to take action in order to create shared benefits. This action may be helped by the participation of an external facilitator – either a person or another organization. However, momentum for continued mobilization must come from within the concerned group or it will not be sustained over time.

There is a large body of literature on how communities mobilize themselves, and on how outside facilitators can help them do so. Most books and articles describe a sequence of assessing needs, developing plans, mobilizing resources, and finally implementing and monitoring activities – ideally involving the community at every stage.

In reality, few successful examples of community mobilization have followed a clear pattern from start to finish. Much solid work is often accomplished long before formal assessment has been done, or before anyone has a clear idea of what resources are available.

The Challenges

The most frequently cited challenges to local HIV/AIDS mobilization are cultural and religious sensitivities about sexual behaviour. It can be argued, however, that these should not be regarded as special challenges; rather, they are simply part of the very specific conditions that any initiative has to take into account.

The same is true of competing political agendas and power structures. No initiative should be undertaken without a realistic assessment of who the influential people (often referred to as ''gatekeepers'' and ''power brokers'') are within a community.

However, experience in various parts of the world indicates that several barriers do, in fact, pose common challenges to community mobilization. These barriers appear at different times and in different guises according to local conditions, but most community organizations or movements have to confront them at one time or another.

Time and energy expected from community members

In traditional examples of communities working together on a common problem – responding to a flood, for example, or harvesting communal fields – no one has to be asked to participate. The urgency of a flood, or the age-old rituals of village life are enough to motivate everyone to put the necessary effort into the work.

Although there exist a few examples of such spontaneous mobilization against HIV/AIDS, most community initiatives against the virus do not have such visible urgency or tradition as motivating factors. They generally depend heavily on the participation of unpaid volunteers who have many other priorities, and who have to be recruited, trained and motivated.

In developing countries these volunteers are often peasants or labourers who must balance the time they spend volunteering with the time they need to spend working in order to feed themselves and their families. Sometimes volunteers are unemployed persons whose first priority is to find a job.

Paid facilitators sometimes do not understand the priorities and needs of their volunteers. This often leads to unrealistic expectations about what volunteers will do with no other incentive than their awareness of the problem.

Motivation cannot be taken for granted, even with a serious threat like the AIDS pandemic. Most community initiatives at some time or another are forced to find new ways of keeping volunteers' enthusiasm high and helping them continue to identify with the problem.

But HIV/AIDS initiatives have an additional vulnerability: it is especially hard to maintain motivation when highly valued colleagues who are infected with the virus eventually succumb to it.

Rigid pre-set expectations

When mobilization is triggered entirely from within the community, the leadership understands the community's customary priorities and ways of organizing itself. In contrast, facilitators hired to work with HIV/AIDS programmes are often primarily motivated by their strong sense of urgency about the pandemic. Unless they understand the community's natural rhythms of everyday life, they are likely to be frustrated by what they perceive to be a lack of progress. At the same time, community members can be irritated, offended or simply confused by the expectations of the facilitators.

It has been said that generals are always fighting the previous war – meaning that they use the same strategies as before, even if the new battleground is very different. It is sometimes true that facilitators are still ''working on the previous project,'' trying to apply to a new community all the techniques that they judged successful somewhere else.

Pre-determined lifespans of initiatives

Many community initiatives – both with and without external facilitation – have a pre-planned project design imposed on them without the wide participation of community members. Typically, such a design has a specific schedule, including a fixed end-date and rigid reporting requirements. This builds inflexibility into the project from the start and frequently imposes

an unrealistic pace on it. Inflexible planning often cannot adapt to events that are highly important to community members.

In a village setting, for example, a tightly planned series of community training workshops can be thrown off schedule by funerals or marriages, or even an unexpected rainfall. This may eventually result in the initiative not achieving its goals by the official ending date.

Incomplete participation or representation

In any initiative, there is always a risk that community leaders or spokespersons – whether traditional or newly arisen – will not represent the whole community, but instead will focus on their own concerns or agendas. At the same time, certain groups within the larger community – whose participation can be highly important to HIV/AIDS prevention or care – may be marginalized or ignored.

Depending on the local society, these groups may include ethnic minorities, people in stigmatized professions such as sex workers, or people excluded from power because they are too young, too old, or because they are women. Often they are reluctant to speak publicly for fear of reprisals or discrimination, or have no experience in doing so.

Coping with success: from mobilization to management

Charisma and enthusiasm are usually needed by individuals working to raise awareness about AIDS in a community. Once that awareness has been achieved, however, and a community is ready to move on to prevention measures and care-giving, the ability to manage (i.e. create procedures, operate systems and monitor budgets) becomes more important.

Unfortunately, people who can lead the awareness-raising phase do not always have good management skills. Ideally, they must either learn the necessary skills, hire people who already have them, or make way for more qualified leaders. If the latter occurs, the new managers must remember that the original leaders of a community mobilization effort can still make a contribution if included in decision-making; conversely, they may retain considerable power to disrupt a project if they are ''left out in the cold''.

Spontaneous beginnings: TASO, Uganda

Now one of the biggest HIV/AIDS service organizations in Africa, The AIDS Support Organization (TASO) started informally in 1987. People infected by HIV, or affected by HIV in their family, began to meet in one another's homes. They met to comfort each other, to escape the stigma and rejection many were experiencing, to share information and to give practical help like transport to medical appointments. Word spread, and more and more people joined.

The numbers and needs of members soon exceeded the group's technical capacity. Recognizing they needed help, they approached ACTIONAID *for financial and logistical support to train counsellors and organize a home-based prevention and care programme.*

Although TASO now has a staff of 150 and almost 2,000 volunteers, it retains its founding principle: involvement and full participation of the infected and affected person in formulating policy and programmes as well as in delivering services.

The Responses

Ensuring that community members "take ownership" of the initiative

It is generally accepted that a true community-based initiative is one in which local people will say, "We did it ourselves." This basic principle of community mobilization is frequently forgotten in the haste of many community health initiatives. Facilitators and sponsors may rush the mobilization process in order to meet planned goals, and in doing so jeopardize its long-term success.

The assessment and planning phases of an initiative must take into account the need for community feelings of ownership to be created. This may require more resources or simply more time than is necessary to meet the *technical* requirements of the initiative; it may also require better communications with community opinion-makers or informal leaders.

One of the most effective ways of encouraging ownership is to work on some short-term and easily achievable objectives that involve as many people as possible. Small-scale but visible achievements are valuable ways to keep people's interest, spark more participation, and show people that their collective action can actually lead to success. For example the Ugandan group TASO (see box) worked hard in their early days to get a physician to join their group; once this was accomplished, TASO's HIV-infected members were finally able to get treatment in hospital for opportunistic infections.

Creating strong links to outside resources

Communities are not closed, self-sustaining systems. The ability of communities – no matter how well organized and motivated – to meet all of their needs is limited. These limits must be recognized and then planned for. For example, a community may successfully distribute information about the use of condoms for HIV prevention to most of its families, but that is not helpful if there is no consistent source of condoms. Similarly, an awareness campaign can quickly lose the confidence of community members if there is no place to refer

Mobilizing a professional community: The Lawyers' Collective, Bombay, India

Bombay-based lawyer Anand Grover was hesitant when the Indian Health Organization asked him to take the case of Dominic D'Souza in February, 1989. D'Souza was found to be HIV-positive after he donated blood in a local hospital. Under the Goa Public Health Act he had been arrested as a "public threat" and put in solitary confinement.

Grover knew almost nothing about HIV at the time, but as a member of the Lawyers' Collective (a small group of lawyers doing public interest litigation) he knew a great deal about human rights. He fought the case all the way to the High Court, was able to get D'Souza released, and also caused amendments to be made to the Public Health Act.

*The Lawyers' Collective soon began to devote a great deal of energy to the legal needs of people with HIV/AIDS. Largely self-financed, it fought many individual cases in court, lobbied politicians, and worked hard to change laws that discriminate against people with HIV/AIDS. And, by recruiting and training a nation-wide network of lawyers, it has set an example of how a professional community can mobilize against the pandemic. (*See *Broadening the Front: NGO Responses to HIV and AIDS in India* in the Key Materials.*)*

people who want to test for HIV or who need counselling or care for AIDS-related problems.

Community-level initiatives should identify and create linkages to other sources of information or support. This may include negotiating formal agreements or simply cultivating contacts with a range of other organizations, including any government agencies that can aid (or block) the community's efforts. For example, the Bangkok-based support group ''Wednesday Friends' Club'' has for many years worked with a monk from a local Buddhist temple, enabling the club to offer much-appreciated spiritual and emotional support to members.

Securing long-term support

Maintaining the momentum of a community response needs regular replenishment of energy, skills and resources. Some communities are able to do much of this from within through such methods as local fund raising (for more financial resources) or rotating leadership posts (to avoid ''burning out'' existing leaders or entrenching a clique). Other communities with fewer internal options must make arrangements with outside sources.

Non-financial support, such as skill-building workshops and advice from experienced leaders in another community, can be very helpful in maintaining momentum.

Optimal leadership and optimal representation

Energy must be invested not only in supporting good leadership but in ensuring optimal representation. The participation of marginalized groups such as refugees, or people in stigmatized professions, is an important part of this, particularly when they are among the most affected by the problem.

Whenever possible, widening the established discussion or decision-making mechanisms of the community (e.g. the village council or community hall meeting) to accommodate these groups should be tried first. In some cases, reserving seats for them at these meetings or on the governing bodies of community organizations may be all they need to participate fully.

In other cases, special efforts such as focus groups (small, facilitated discussion groups) may be necessary to help people to voice their concerns in a setting that feels safe and supportive. The opinions and information brought out by these discussions can then be communicated to the larger community. (For more on focus groups in HIV initiatives, see *Manual of Group Interview Techniques to Assess the Needs of People with AIDS* in the Key Materials.)

Taking action: Duang Prateep Foundation, Thailand

The Duang Prateep Foundation has provided a wide range of educational and social services in the poor Bangkok neighborhood of Klong Toey since 1979. All decision-makers and fieldworkers of the foundation are community members themselves. Gradually, the foundation became aware of the rapid spread of HIV among people such as injecting drug users, sex workers, and Bangkok's ubiquitous motorcycle taxi drivers.

At first, Duang Prateep viewed HIV/AIDS as too complex an issue for a community-based organization to deal with. But as they recognized the growing impact on their community, the foundation took action. By 1992, five full-time staff and over 200 volunteers were working directly with vulnerable groups, and promoting general public awareness. One of their most notable successes, they feel, has been the increased acceptance of people with HIV/AIDS by relatives, friends and neighbours. (See *Community Responses to HIV and AIDS: Experiences from India and Thailand* in the Key Materials.)

Key Materials

Aboagye-Kwarteng T, Moodie R, editors. *Community action on HIV: a resource manual for HIV prevention and care.* Fairfield VIC, Australia: Macfarlane Burnet Centre for Medical Research for AusAID, 1995. 224-page manual aimed to assist communities and organizations to respond to HIV/AIDS. Includes information on community participation, project planning, community care and prevention strategies.

Academy for Educational Development. *Handbook for HIV prevention community planning.* Washington, DC: The Academy, 1994. Comprehensive manual aimed at helping HIV prevention community groups in US who are receiving funding from the US Centers for Disease Control.

United Nations Development Programme. *Community responses to HIV and AIDS: Experiences from India and Thailand*. New Delhi: UNDP, 1992. 44-page booklet with photos and examples detailing the efforts of the South India AIDS Action Programme (Madras), the Gujarat AIDS Prevention Unit (Ahmedabad) and the Duang Prateep Foundation (Bangkok).

Welbourn, A. *Stepping Stones.* London: ACTIONAID, 1995. 240-page training manual and 70-minute workshop video on HIV/AIDS, gender issues, communication and relationship skills. Designed for use in sub-Saharan Africa.

Manual of group interview techniques to assess the needs of people with AIDS. Geneva: World Health Organization, 1995 (GPA/TCO/HCS/95.2). A reader-friendly training manual with examples and group exercises. Includes in-depth discussion of focus groups.

The orphan generation. [videocassette]. St. Albans, UK, TALC, 1992. A 50-minute video about community-based care and support for children orphaned by AIDS in one village. Includes a 10-minute video called "These are our children".

Strategies for Hope is an 11-volume series of booklets published jointly by ACTIONAID, the United Nations Development Programme and a variety of publishers from developing countries. The series is available from TALC, P.O. Box 49, St. Albans, Herts, AL1 5TX, UK. All booklets, some of which are available in French, describe community HIV initiatives in developing countries. The following are particularly useful regarding community mobilization:

No. 1. *From fear to hope: AIDS care and prevention at Chikankata Hospital, Zambia*. A rural hospital's home-based care programme for people with HIV/AIDS.

No. 2. *Living positively with AIDS: The AIDS Support Organization (TASO) Uganda*. Describes how TASO, one of the earliest grassroots HIV initiatives in Uganda, provides care and support for people with HIV/AIDS and their families.

No. 4. *Meeting AIDS with compassion: AIDS care and prevention in Agomanya, Ghana*. The work of a maternity clinic in AIDS prevention and home-based care.

No. 5. *AIDS orphans: A community perspective from Tanzania*. Community responses to the impact of AIDS on families in rural Tanzania.

No. 7. *All against AIDS: The Copperbelt Health Education Project, Zambia*. The early years of an HIV/AIDS prevention initiative.

No. 9. *Candles of hope: The AIDS programme of the Thai Red Cross.* Includes description of the development of the Wednesday Friends' Club.

No. 11. *Broadening the front: NGO responses to HIV and AIDS in India.* Includes description of the HIV-related legal and human rights work of the Lawyers' Collective in Bombay.