

**AIDS TECHNICAL SUPPORT PROJECT (ATSP)
LESSONS LEARNED: COMMUNITY
PARTICIPATION, NONGOVERNMENTAL
ORGANIZATION DEVELOPMENT,
AND NETWORKING**

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Acronyms

AIDS	Acquired immunodeficiency syndrome
AIDSCAP	AIDS Control and Prevention Project
ATSP	AIDS Technical Support Project
ASO	AIDS supporting organization
CBO	Community-based organization
GIPA	Greater involvement of people with HIV/AIDS
HIV	Human immunodeficiency virus
NCIH	National Council for International Health
NGO	Nongovernmental organization
PACA	Participatory Analysis for Community Action
PLA	Participatory Learning Action
PLWHA	People living with HIV/AIDS
PRA	Participatory Rural Appraisal
PSKP	Progoti Samaj Salyan Srotisthan (a Bangladeshi STD/HIV/AIDS community organization)
PVO	Private voluntary organization
PWA	People with HIV/AIDS
STD	Sexually transmitted disease
STI	Sexually transmitted infection
TAP	Tanzania AIDS Project (USAID)
UNAIDS	Joint U.N Programme on HIV/AIDS
USAID	U S Agency for International Development
USPVO	U S –based and U S –registered private voluntary organization
WHO	World Health Organization

Introduction

For over a decade, countries around the world have been working to prevent the further spread of HIV infection. In the earliest days, the global response benefitted from international leadership by the World Health Organization (WHO) and bilateral donor agencies working through member governments. Despite the strong commitment and vigorous planning of these groups, however, it soon became apparent that the spread of HIV would not be stopped by centrally directed plans carried out exclusively or primarily through national ministries of health.

Over the last several years, there has been an expanded response. Governmental dominance of HIV/AIDS programming has given way to increasing involvement by nongovernmental organizations (NGOs), including not-for-profit groups and, more recently, for-profit institutions. With this expanded response has come a greater appreciation that communities themselves need to be fundamentally involved in the design and implementation of programs and that sharing experiences and combining voices can help improve the results of such programs.

This paper provides an overview of the lessons learned over the past decade in community participation in HIV/AIDS programming, working with NGOs, and networking among NGOs.

I. Community Participation

Community participation, at all levels, is essential for effective HIV/AIDS care and prevention programs. Community involvement puts the focus on the *process* of designing and implementing such programs, not on the end product. Involving the community institutionalizes capacity-building. In addition, interventions and solutions are more relevant and meaningful to the communities in which they will be implemented when they are designed by members of those communities.

“Community” can be defined in various ways. In this paper, the term refers not to a particular geographic area, but to a single institution, a group of related institutions, and/or one or more affinity groups whose members may live in a number of geographic areas.

In this paper, the counterpart to the community is the donor or development organization that is instigating the change or the program. One objective of this paper is to explore how the process of change can be defined and managed by the community in partnership with these donors and development organizations.

Why is community participation important? When communities participate in designing and implementing HIV/AIDS programs, the issues and solutions are more clearly defined and relevant and the programs are more successful. Allowing them to participate helps communities become full partners in the programs.

Communities need to be involved in defining the issues to be addressed by the program and in identifying the assets they bring to the table. Program interventions that are imposed on communities by outsiders, without their participation, often meet with little success — or, they enjoy success only in the short term and dissolve when the donor or development organization moves on.

A. LESSONS LEARNED

- **Context matters when organizations are designing HIV/AIDS interventions.** If the cultural, social, economic, and gender context is not taken into account, the interventions are neither relevant nor sustainable. When this context is understood, the underlying issues that propagate the spread of the epidemic can be more effectively addressed and the programs are more likely to be sustained. For example, if an underlying factor in the spread of HIV is the nature of relations among genders, these must be explored and targeted by the community in order to effect a change in the course of the epidemic over the long term.
- **Capacity-building through community involvement can increase the sustainability of the programs.** Communities can learn how to identify and address their own issues, how to recognize the assets at their disposal, and, hopefully, how to identify and obtain the outside resources needed to address the issues. These assessment and planning skills can help community members address other issues they face.
- **The fact that the community and the donor or development organization may have different and, perhaps, competing agendas needs to be recognized and addressed.** The donor may not be able to meet all of the community's needs or objectives, but these cannot be ignored. Both parties may be able to meet their objectives when they are willing to negotiate and make compromises.
- **The mechanisms and procedures for decision-making must be understood and accepted as legitimate by participants at all levels if the process is to be effective.** Community members often are encouraged to participate and to voice their needs and opinions even when decisions will be made by people at different levels who may not take into account the community's input. Such instances jeopardize future efforts to elicit community participation.
- **Involving the community can help prevention efforts move beyond just raising awareness.** Tools and methodologies such as Participatory Rural Appraisal (PRA), Participatory Learning Action (PLA), and Participatory Analysis for Community Action (PACA) allow communities to describe and analyze the issues of concern to them and to explore how

these issues link to sexual vulnerability, HIV/AIDS, and obstacles to behavior change

- **Building community participation is an ongoing process that does not stop after a needs assessment is completed.** Effective responses to HIV/AIDS require the active involvement of community members at all stages of program design and implementation
- **Participatory methodologies are not ends in themselves.** They must be complemented by high-quality information and skills if programs dealing with HIV/AIDS, gender, sexuality, and development are to be effective
- **Effective community action requires not only participatory methodologies and processes, but also participatory attitudes and behaviors on the part of others involved, including donors' facilitators and NGO staff members.** In practice, adopting such attitudes and acting on them can be very challenging, it involves a learning process that must be consistently nurtured over time
- **Building community participation into NGO programs is likely to shift the balance of power or the dynamics between NGOs and the communities they serve.** This may be threatening to some people on both sides, but they should be encouraged to embrace this as an opportunity to build more positive relationships and programs
- **Relying on local technical support decreases dependence on international resources and enhances the sustainability and "institutionalization" of the effort.** Where appropriate, it is advisable to build the capacity of local people by having them work alongside experienced regional or international practitioners

B. CASE STUDIES

1. Progoti Samaj Sallyan Srotisthan (PSKP) and the International AIDS Alliance

Bangladesh PSKP is an established community organization that integrates issues relating to sexually transmitted diseases (STDs) and HIV/AIDS into maternal and child health services provided to garment factory workers in Dhaka. PSKP initiated a program development process using a community needs assessment targeting young men and women, with the support of the linking organization HASAB (supported by International AIDS Alliance). The participatory process strengthened the relationship between PSKP and the community. The key findings of the needs assessment were.

- The factory workers included large numbers of young, single migrant workers who worked long hours for low pay and lived in cramped accommodations
- There was a low awareness of personal hygiene and STDs among both men and women, and workers feared losing their jobs for taking time off to seek treatment.
- Literacy was low, particularly among women

Subsequently, PSKP used these and other findings from the assessment to develop a broad prevention program, based on a participatory approach, that goes beyond providing information and actually seeks to address the factors that may promote the spread of HIV. The program includes health education sessions that are held in the factory during working hours and which use pictorial flip charts and card games to highlight personal hygiene and sexual health. A night clinic provides STD treatment and condom provision. PSKP trains peer educators and sponsors peer education among employees as well as ongoing liaison and awareness-raising with factory management.

2. Peace Corps Volunteers Working with Community Groups in Malawi

Since 1992, Peace Corps has assigned volunteers to work with District AIDS Coordinators in the Health Education and Counseling for HIV/AIDS Prevention and Support Project in Malawi. The volunteers have worked on HIV/AIDS prevention and care in the communities where they live, focusing their efforts on health care workers, young people, and other members of the general community.

Volunteers in two of the districts were instrumental in establishing community centers that provide HIV/AIDS education and counseling, STD management, training for home-based care, orphan care, and youth activities. The Peace Corps volunteers facilitated a process through which the communities assessed their needs, identified the resources needed to establish the centers, and trained community volunteers to run the centers. The Peace Corps volunteers used participatory tools such as PACA (see references below) to help the communities identify their needs and take action to address them, and they were available to the community during the transition of the centers to community ownership. The program was sustained after the Peace Corps volunteers moved on, with the centers continuing to provide and even to expand their services — evidence that the process fostered capacity-building.

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II. NGO Development

Nongovernmental organizations provide unique and essential services in support of HIV prevention and AIDS care. Their ability to mobilize and support community efforts are increasingly viewed as the foundation for building a sustainable response to HIV/AIDS.

NGOs take the lead in providing community-based care and support for the most stigmatized and vulnerable groups as well as in addressing contextual factors that help facilitate the transmission of HIV, including low female literacy, poverty, and poor access to services. The NGO sector is in touch with the communities they serve. NGOs are frequently more responsive to the changing needs for HIV/AIDS programming at the community level than their government partners. NGOs are well-placed to mobilize a larger, more integrated group of community-based volunteers in support of HIV/AIDS programs and to forge alliances between government and the for-profit private sector in creative ways to improve services delivery and sustainability.

Despite their strengths, however, NGOs also face some common challenges. These include the limited reach of their community-based efforts, fragile managerial and technical capacities, and, often, a narrow base of donors and supporters.

At its broadest, the term “nongovernmental organization” can be defined to encompass all entities outside the formal public sector. In this paper, however, we distinguish among the following types of private sector agencies:

- Nongovernmental organizations (NGOs) include indigenous, developing country not-for-profit organizations that have formal and legal charters and are organized to provide a social or institutional service. NGOs also

include large grassroots organizations such as women's unions and trade unions

- Community-based organizations (CBOs) are smaller, grassroots-focused not-for-profit groups which are generally comprised of individuals from the communities they serve. These include, for example, Mothers' leagues that are part of church organizations, parent-teacher associations (PTAs), or women's market groups
- Commercial private sector organizations are local, independent business entities or locally managed subsidiaries of national or multinational companies.
- Private voluntary organizations (PVOs) represent U S –based and U S –registered not-for-profit organizations that implement or support development efforts in developing countries. In this paper, these are also referred to as USPVOs

Although USPVOs and the commercial private sector clearly have an essential contribution to make to HIV/AIDS programming in developing countries, this paper focuses primarily on lessons learned from donor collaboration with and support of NGOs and CBOs

A. LESSONS LEARNED

1. Working with NGOs and CBOs

- **Working with existing organizations is generally more effective and sustainable than encouraging the establishment of new ones.** Established organizations with strong links to their communities are generally better able to respond to changing community needs regarding HIV/AIDS even if they previously have had little or no HIV or health experience. NGOs can successfully integrate HIV/AIDS into their ongoing mandates, and such integration generally results in stronger, more cost-effective, and more sustainable programs

- **Organizations have their own “carrying capacities” to provide services to their constituents.** Successful NGOs can become vulnerable to over-commitment if there is no concurrent expansion of their management systems to absorb additional work. A comprehensive assessment of an NGO’s or CBO’s organizational skills and carrying capacities is a useful early step for a donor and the organization to take jointly before they enter into a collaborative partnership.
- **Working with CBOs presents unique and sometimes intensive management challenges for donor organizations.** The use of intermediary organizations can provide a supportive mechanism for encouraging wider participation of CBOs (e.g., through umbrella or linking configurations or through cluster groups as described in the case study below). The role of intermediary organizations is a delicate one, however, since power imbalances between the lead and the partner organizations can threaten the essential element of collaboration that is essential for making these arrangements work.

2. Donor Relations

- **Establishing balanced, equitable relationships with NGO implementing organizations requires an open and ongoing commitment by all parties.** The participation of all parties in every phase of assessment, planning, and implementation is essential to achieving an ambiance of mutual learning in which shared goals can be articulated and achieved.
- **When capacity-building is an objective, it is critical for both parties to arrive at a shared understanding of goals and processes.**
- **Opportunities for program review and revision need to be built into agreements between donor organizations and NGOs.** This encourages adaptation and responsiveness to new opportunities, which can improve program outcomes. Budget revision must be a part of this review process.
- **Donors must carefully examine their programmatic and financial reporting requirements with an eye to reducing the administrative burden on NGOs.**

3. Capacity-Building

Capacity-building is defined here as “enhancing the ability of organizations to design, implement, manage, and evaluate HIV prevention and AIDS care and support programs ” Capacity can be strengthened by enhancing technical skills, organizational and management skills, and organizational systems and by networking.

- **Ongoing strategic planning is essential for NGOs if they are to ensure consistency with their mandate and best use of their organizational resources.**
- **Capacity-building efforts are more sustainable if they focus on building systems rather than individual skills.** Improving systems can help ensure that the knowledge to operate is found in written procedures and guidelines and/or in acknowledged structures and operations
- **There is an inherent tension between efforts to immediately improve program results and measures to strengthen organizational capacity.** Donors, contractors, implementing agencies, and beneficiaries should agree on time frames and reasonable benchmarks for measuring improvements in program results over the short term and increases in the overall capacity of the organization over the longer term
- **NGOs generally require significant assistance in developing their financial management systems.** They need assistance not only to meet the needs for donor reporting but to ensure adequate program budgeting

B. CASE STUDY: NGO CLUSTERS IN TANZANIA

USAID/Tanzania supported an in-depth and progressive assessment of CBOs, NGOs, private sector companies, and parastatals in Tanzania during the design of their Tanzania AIDS Project (TAP) The mission found that Tanzania has a rich, diverse, and expansive assemblage of CBOs and NGOs.

Specifically, USAID directed a broad-based assessment of this sector across much of the country over several months Once TAP’s geographic coverage was further defined, a second analysis was undertaken of the strengths, interests, and

capabilities of NGOs and CBOs in conducting HIV/AIDS programming in TAP-specific regions

Based on this assessment, USAID and AIDSCAP completed TAP's design, including the framework of an NGO cluster. Under this framework, geographically proximate NGOs and CBOs were to be encouraged to form networks, to jointly identify the needs of the community in HIV/AIDS programming, and to develop a unified but comprehensive proposal to USAID that built on the unique strengths and interests of each cluster partner. A cluster management committee with representation of each partner was to be created to facilitate joint planning and coordinated implementation. To allow flow of funding and meet donor reporting requirements, each cluster was to elect an "anchor NGO" that would receive funding and allocate it according to the joint cluster work plan.

One of AIDSCAP's first implementation steps was to provide technical and facilitation support to the clusters for strategic planning, undertaking community needs assessments, and articulating potential program ideas. Following the cluster-specific field work, a 3-5 person team from each cluster met in Dar-es-Salaam to participate in a combined two-week proposal design workshop.

During the first week, participants were introduced to the broader TAP design, including the STD service upgrading and condom social marketing components. They received training that allowed them to formulate their project ideas into comprehensive proposals.

During the second week, the clusters received intensive one-on-one technical support from AIDSCAP staff members in finalizing their proposals. These proposals were incorporated into subproject agreements between Family Health International (FHI) and the anchor NGO of each cluster, approved by USAID/Tanzania. Initial funding was requested. At the same time, common technical support needs expressed by the cluster representatives were identified, and a project training plan was developed.

Over the two years of cluster project implementation, over 180 NGOs and CBOs have provided comprehensive community-based services in prevention, care, and orphan support. These NGOs and CBOs come from nine geographic regions of Tanzania that represent half the country's total population.

A number of innovations and augmentations have taken place as these programs have evolved. For example, the NGO clusters formalized their earlier, informal linkages with local governments to encourage closer planning and coordination. A number of the clusters view closer links with local governments as essential if

they are to ensure access to commodities, complimentary services, and sustainability over the longer term

Some of the clusters expanded, from their initial 9–11 organizations to over 20 groups, in response to the perceived success of the clusters. Nonetheless, this growth has required the cluster's management to delicately balance the value of inclusiveness and the risks that the cluster will lose its focus and its ability to coordinate effectively.

A number of clusters have begun to re-examine the role of the anchor NGO. Specifically, they are moving toward a less hierarchical but more formalized coalition approach to cluster management. The clusters have initiated an inter-cluster management review process in which managers from 3–4 clusters visit and collaboratively review the program of another cluster with a view to sharing lessons and best practices.

Finally, the cluster model is being decentralized to the district level.

From AIDSCAP's perspective, the NGO cluster approach continues to be an exciting, promising strategy for encouraging the contribution of numerous, diverse organizations in a less competitive, potentially more sustainable environment for effective community-based programming. In Tanzania, the nine clusters were launched simultaneously, which was difficult in terms of program management and seriously stretched the capacity of the AIDSCAP country office to provide adequate support and monitoring to these vibrant groups. This intensity could be reduced by staggering the launch of a large number of clusters.

III. Networking

The need to share information is crucial for those involved in HIV/AIDS education and prevention programs. Increased collaboration among these organizations and acknowledgment of the critical role of NGOs and networks responding effectively to HIV/AIDS are among the positive outcomes from the global crisis.

Networking, for our purposes, is the unique collaboration among PVOs, NGOs, governmental representatives, and community members who are infected and affected by HIV/AIDS that helps to create a social cohesion around the issue. These collaborations primarily evolve from personal contacts built around trust and commonality. Theoretically, the basic principles of networking are partnership, information-sharing, transferring knowledge and skills, and sharing resources.

Although the quantitative benefits of networking have not been extensively documented, there are numerous examples of how collaborating with colleagues — domestic and international — can help increase AIDS awareness and save lives. PVOs, NGOs, and other institutions of civil society play a growing role in a number of countries throughout the world, increasingly taking direct action to resolve local problems and successfully encouraging policy change at the national and international levels.

At the same time, national governments in many parts of the world have fewer resources and diminished capacity to address HIV/AIDS and other humanitarian problems. Networking is a proven intermediary for NGOs to form alliances and work collaboratively, sharing resources and skills.

When they act collectively as part of these alliances, individual organizations can more effectively advocate for increasing spending, avoid duplicating services.

provided to people living with HIV/AIDS (PLWHA), and share innovative approaches to AIDS prevention. Networking also provides individuals and organizations a greater sense of empowerment and support.

A. LESSON LEARNED

- **Differences in the political agendas of certain NGOs, AIDS supporting organizations (ASOs), and governmental groups can create competition and misunderstandings.** NGOs working toward the common goal of the prevention and care of HIV/AIDS may approach their tasks in extremely different manners. Moral beliefs and prejudices often create deep schisms between organizations and individuals.
- **Geographic distance and communication problems are barriers to successful networking.** Networking is often stymied by problems in communication, particularly in the developing world where e-mail, fax, and telephone services may be unavailable. A lack of resources can prohibit some organizations from participating in meetings that involve travel or may limit their ability to become involved in or equal partners in a network.
- **Professional translation services and efforts to clearly understand cultural differences are needed to prevent misunderstandings and misperceptions among members of networks comprised of individuals from different cultures and languages.**
- **Collaboration among NGOs and PVOs can be difficult when there are inequities in their resources and experience.** Organizations with more experience often are treated as “experts” in the field, creating an imbalance that hampers the sharing of knowledge and ideas. Inequities are not always avoidable, nor are they necessarily negative as long as the other partners are recognized to bring something valuable to the table.
- **NGOs and PVOs with overlapping areas of expertise often compete with each other for scarce funding, creating “turf wars” and distrust that may hamper collaborative partnerships with other organizations.** Fear of losing innovative ideas to other organizations inhibits organizations from sharing knowledge and expertise.

- **The process of networking is difficult and requires practice.** NGOs and PVOs that have never experienced the benefits of networking may be wary of entering into collaborative partnerships. Communities themselves may overestimate their capacities to work collaboratively and may avoid networking when conflicts arise. Also, a lack of experience with democratic-style networking may create conflicts within some organizations in developing countries if they lead individuals to position for greater power.
- **Sufficient time and resources must be allotted to networking.** Networking is not static or an end to itself. Networks are generally built upon a series of meetings where representatives from NGOs and PVOs have a chance to meet and exchange ideas. Trusting relationships formed on the basis of these meetings are the foundation of effective networks.
- **NGO and PVO representatives to networks are primarily directors or program coordinators who may have insufficient time to devote to the networks.** One solution is to use rotating representatives and responsibilities, but this may face opposition among some representatives who want to remain key players and seek to avoid the inclusion of others. Using rotating representatives (as long as they are viewed equally as collaborators) has an added benefit: ensuring that “valuables” attached to networking do not become identified with one person.
- **Networking provides opportunities for smaller, more marginalized organizations to gain access to information and to be introduced as “players” in the national and/or international AIDS arena.** Networks can bring these organizations instant recognition among international donors and governmental representatives.
- **NGOs and PVOs gain valuable knowledge about specific projects through the process of project development.** By agreeing on the distribution of responsibilities, organizations can avoid duplicating services.
- **NGOs and PVOs can develop alliances to apply for funding collectively.** Networking provides an opportunity for a wide range of organizations to outline their specific needs to donors, governmental representatives, and international communities. Valuable information about donors and fundraising techniques can also be shared.

- **Networking provides an arena for sharing lessons on what has worked and what has not worked.** This information encourages organizations to improve on existing projects and discourages them from “reinventing the wheel ”
- **Networking encourages NGOs, PVOs, and government representatives to develop a broader view of HIV/AIDS.** They may become less issue-specific and may orient themselves to the larger picture, which may help generate interest in and focus creativity on more cutting-edge programs
- **Networking can be an advocacy tool, uniting a wide array of institutions and organizations to advocate on a specific theme or issue related to HIV/AIDS.**

B. CASE STUDY: NCIH GLOBAL AIDS PROGRAM

The National Council for International Health’s (NCIH’s) Global AIDS Program has successfully utilized networking as an advocacy tool, uniting various organizations on a specific theme. One outcome of their efforts was the success of the Paris AIDS Summit in December 1994, when delegations from 42 countries gathered in Paris to mark World AIDS Day and attend a summit organized at the initiative of the French government and the World Health Organization. The event marked the first time that world leaders gathered to discuss a specific health issue. NCIH’s Global AIDS program and its vast network of AIDS-related PVOs worked in collaboration with La Cellule, a group of French NGOs and international networks, to carry out advocacy activities around the summit. Their efforts began when the French minister of state announced plans for the meeting at the Marrakech AIDS Conference in December 1993. Members of La Cellule included Act UP-Paris, AIDES, APARTS, the Global Network of People Living with HIV/AIDS (GNP+), and the Pan-African Organization to Fight AIDS.

The December 1994 Paris AIDS Summit issued an official declaration that contained four sections recognizing the wide-ranging aspects of the HIV/AIDS pandemic and pledging the signatory countries to pursue certain policies and initiatives at the national and international levels. In response to the declaration, NCIH Global AIDS Program, La Cellule, and other NGOs in Paris during the

Summit developed a parallel NGO appeal. This document helped to form the basis of the GIPA Initiative ("Greater Involvement of People with HIV/AIDS")

The GIPA Initiative focused on the greater participation of people living with HIV/AIDS (PLWHA) in policy and project formulation, implementation, and evaluation. The goal of the initiative was "to ensure that people living with HIV/AIDS and community based/non-governmental organizations are recognized and accepted in full partnership with all governmental, multilateral institutions and agencies, and the private sector to effectively confront the AIDS pandemic." More specifically, GIPA called for the inclusion of representatives of NGOs and PLWHA in international policymaking bodies. The GIPA Initiative was successful in helping NGOs and PLWHAs participate as members of the UNAIDS Programming Control Board and as board members of other multilateral institutions.

The networks and relationships formed during this effort have been strengthened and continue to support and advocate for the inclusion of PWAs and NGO representatives in all policymaking institutions and planning committees.

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