Section 2
Partnerships for HIV/AIDS: case presentations

BRIDGING THE GAP BETWEEN THE COMMUNITIES AND THE SERVICE PROVIDERS BY WAY OF LOCAL RESPONSES: THE DISTRICT RESPONSE INITIATIVE IN UGANDA

Dr Cyril Pervilhac

From district health systems to communities: local responses

The district has been at the centre of health interventions within the district health systems over the past two decades. In many countries, national AIDS programmes (NAPs) have been able to develop planning tools and to invest in human resources to this effect; for example, HIV/AIDS focal points in the district health teams.

At the local level, primary health care (PHC) approaches in the 1970s and 1980s had already bridged a substantial gap between the health services and the communities. However, in the 1990s, concomitant with the escalation of the HIV/AIDS epidemic, there was less emphasis on the PHC agenda. This situation created a vacuum in the HIV/AIDS responses in the districts. District programme managers often lack the approaches necessary to enable them to translate the priorities of national programmes, often outlined under national HIV/AIDS strategic plans, into district HIV/AIDS plans, based on community needs and priorities. This highlights the importance of local responses (LRs), which aim to place the communities and individuals in the districts, together with their various partners and stakeholders, as centre actors in the expansion of the responses to HIV/AIDS. In epidemics, LRs are particularly relevant at the community level.

Various options relevant to expanding the responses to HIV/AIDS justify LRs (UNAIDS, 1998). These might include expanding the geographical coverage of participation or interventions and focusing the actions to include the most vulnerable groups. These options also embrace the expansion of joint working and partnership efforts in the design, implementation and evaluation of HIV/AIDS policies and programmes. The aim is to involve all the relevant sectors and not only the health sector, hence increasing the resources that can be mobilized in support of HIV/AIDS prevention and care. But the logistics of implementing such an agenda at the local level remain a challenge. The experience of the Kabarole District in Uganda, is an innovative example of an LR approach for bridging the gap between the communities and the health systems in addressing the HIV/AIDS epidemic (Pervilhac, 1997).

Improving local responses: multi-country studies

Between 1996 and 1997, UNAIDS, WHO and GTZ launched a multi-country study under an initiative called the District Expanded Response Initiative (DRI). Five countries in the African region were selected. These were Burkina Faso, Ghana, Uganda, United Republic of Tanzania and Zambia. The aim was to learn how to strengthen local responses. A situation analysis for each country was the starting point for a 2–3-year case-study documenting changes over time. Box 6 lists the objectives of the situation analysis.

Box 6. Objectives of the situation analysis for LR initiatives

- Actions, stakeholders and networking: who is doing what and where at the local level (communities, districts and the link between the two)?
- Expertise and direction: how to take stock of the present skills and vision of the key players and partners at the local level, i.e. communities, non-governmental organizations, faith-based organizations, and local private and public sector agencies.
- Experiences and lessons: are we taking the best advantage of what we know does or does not work with the communities?
- Value and effectiveness: overall, is the local response initiative a worthwhile endeavour?
- Tools: which tools can be used at the local level to expand the local response in the districts? Which tools already exist, or can be adapted to answer these needs?
Partnerships for HIV/AIDS: case presentations

Local responses: application in Uganda
The Kabarole District in Uganda, which has a population of 860,000, reported a 17% rate of HIV infection in 1997, and had benefited over the years from a comprehensive range of prevention and care activities.

Methods
In situation analysis, the units of analysis are organizations. These were grouped into three categories: the public sector, the private sector and those organizations centred around the communities. A three-pronged approach was utilized.

- A community-level study with community leaders, youth representatives and lay people. This was undertaken in four different communities, using adapted participatory rapid appraisal (PRA) methods, mapping, Venn diagrams, focus group discussions and interviews.
- An institutional/organizational district level study. This employed group discussions and interviews with representatives of the public and private sectors as well as of NGOs and CBOs.
- A coordinating mechanisms study. This took the form of group discussions with various local councils and interviews with representatives from the public and private sectors.

Tools
The tools that were employed (Pervilhac, 2000; KIT, 2002) included WHO indicators to assess the capacity for performance of services, community participation assessment and qualitative methods, political mapping for political analysis and policy advocacy, and organizational analysis.

Findings
Coverage. Rural areas were not sufficiently covered, knowledge of HIV/AIDS in urban and semi-urban settings was much greater than in rural settings. Home-based care was lacking in many rural communities.

Entry points. Entry into the villages and communities with local responses was gained through the parishes and the local councils of the sub-counties instead of directly into villages from the district. This takes advantage of the decentralization policy which has enabled sub-counties to be the basis for successful programmes and for increased local independence (e.g. raising local taxes and budgeting). By using well rooted and powerful local structures that group several villages and communities, it also enables a unifying, catalysing, and multiplying (scaling-up) effect starting with the parishes and their communities within the district (Pervilhac, 1998). However, this requires at least one active CBO per sub-county and well-documented processes and outputs for the HIV/AIDS activities of that sub-county. Figure 3 depicts the coordinating mechanisms for the district response initiative in the Kabarole District of Uganda.

Figure 3. Local responses: the coordinating mechanisms for the district response initiative in Kabarole District, Uganda

Some of the coordination committees involved included district management committee, district technical committee, district population committee, hospital management committee and health unit management committees.
Recognition. The accomplishments of the departments of health should be recognized. However, their top-down approach has decreased community participation and the chances of sustainability. This is because communities may consider such programmes and activities as being external interventions over which they have no control. Once the funding stops, communities have been unable and unwilling to sustain efforts. Communities would like health to be considered as a development issue, and community planning and interventions should facilitate the integration of HIV/AIDS activities into the activities of the community.

Tailoring. Young girls were not targeted sufficiently by programmes for HIV prevention, and HIV testing was not actively promoted outside the District capital. Traditional birth attendants, midwives from the private sector and health centre staff should have been included in counselling programmes. The findings suggest that HIV/AIDS is still taboo in the health centres. Patients treated for TB and STI at health centres received education about the risks of HIV/AIDS if seen by the senior staff, but not if they were seen by the junior staff who were often in charge, and had not received any appropriate training.

Gatekeepers. Gatekeepers, i.e. community leaders, lack skills or a mandate (often resting with the health authorities) on how to handle HIV activities productively.

Sustainability. Trained community counsellors, such as trained traditional birth attendants, have a high turnover because their “volunteer” status is not accompanied by compensation from the health system or the communities.

In conclusion, LR can be instrumental in its early stages as a participatory diagnosis method serving to bridge the gap between the communities and the health services by determining roles and stimulating partnerships, using or adapting some relatively simple existing tools (Salla, 1998; M’Pele, 2000; UNAIDS, 2000; Rwomushana, 2002). On the basis of this positive experience there is a need for a better definition of WHO’s role in contributing to the local responses agenda and its documented benefits, and WHO should take the lead in relation to the “service providers” component.

Box 7. Local responses: summary of overall accomplishments

- The local response focuses on the communities, and brings consensus and common vision to the partners in the public and private sectors to feed into local planning activities.
- The local response uses existing tools applied in different contexts and with different partners. As it triangulates information collected through various channels and means, this adds value to the approach.
- The local response was well accepted and useful in all the five countries studied. Direct benefits to planning programmes and implementation, and numerous national schemes to scale up HIV/AIDS activities were noted. It was valuable in districts that had a low profile of activities.
- The tools that have been developed can be used or adapted to suit the situation in a particular country.
- The same mistakes are being made in working with communities as those that caused PHC to fail 20 years ago (e.g. top-down planning, lack of ownership in the communities, lack of supervision and motivation schemes).
- Local response is a worthwhile investment for a district wishing to focus, accelerate and expand the activities of partners sharing a common vision. The costs of the local response can be reduced by focusing only on the interface between the health systems and communities.
HEALTH SERVICES–COMMUNITY INTERFACE FOR HIV/AIDS: INITIATIVES IN CAMBODIA, CHINA AND VIET NAM

Dr Bernard Fabre-Teste and Dr Masami Fujita

Background

The pattern of HIV/AIDS in the Western Pacific region has been characterized by epidemics concentrated in populations with high-risk behaviours, notably among injecting drug users and sex workers, in countries such as China, Malaysia and Viet Nam. The region also has one country, Cambodia, where there is already a generalized epidemic with an estimated HIV prevalence rate in its adult population of 2.7%.

As the epidemic grows, the number of patients with AIDS increases. There is thus a growing need for more efforts to be directed towards caring for patients with HIV/AIDS. By the end of 2001, the WHO Regional Office for the Western Pacific (WPRO) estimated that almost 1.2 million people in the Region were living with HIV/AIDS. The number of AIDS cases is now increasing by an estimated 55 000 new cases per year and the number is projected to reach 120 000 by 2005.

In the priority countries in the region, discussions are currently taking place on developing models for the care of patients with HIV/AIDS. The WHO Regional Office is assisting these countries to develop national frameworks and guidelines, to initiate model development projects and to facilitate the exchange of experiences.

References


The situation of HIV/AIDS care in countries in the region

The care of patients with HIV/AIDS in countries in the Western Pacific Region is modulated by the following constraints and strengths.

Constraints

Countries have very limited experience and low coverage of care that is specific to HIV/AIDS (e.g. VCT, treatment for opportunistic infections, antiretroviral therapy, palliative care and home-based care).

The medical services are user charge-oriented (except in Papua New Guinea) and there are no incentives for hospitals (or medical services) to provide any form of educational or psychosocial support.

There is considerable discrimination against PLWA in the health facilities and in society in general. The individual PLWA and their families have limited opportunities to meet and interact with others in the same position and to support one another.

There is a lack of functional links between the health facilities, homes and the community. For example, home-visit services are not utilized for early detection of TB cases, or for involvement of the community in care. Neither household nor community members are involved in supporting adherence to prophylaxis against opportunistic infections or to antiretroviral therapy. Limited collaboration and communication takes place between the health services and camps for the rehabilitation of injecting drug users and sex workers.

Strengths and opportunities

The governments of the countries of the Western Pacific Region have shown their commitment to care of patients with HIV/AIDS. This has been supported with considerable funding including the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM).

There is wide coverage of primary health care, TB and other programmes by the public health service structures (e.g. preventive medicine and control of communicable diseases).

Technical institutions, academic bodies, bilateral agencies, NGOs and WHO are strongly committed to the care of people with HIV/AIDS (e.g. with the International HIV Treatment Access Coalition).

There are already a variety of peer support group activities and mechanisms to support them (see Box 8).

Box 8. Examples of peer support activities and potential mechanisms of support

Cambodia

Regular meetings of people living with or affected by AIDS are organized in top referral hospitals that provide antiretroviral treatment.

Marginalized women (abandoned by their families, victims of domestic violence, etc.), including those who are infected with HIV, have formed groups for peer support and occupational training/promotion supported by NGOs.

Establishment of nationwide networks of people living with or affected by AIDS (24 groups, 4000 members) partly based on home-visit services to AIDS patients.

China

Top referral hospitals have established care sites called “Home of Red Ribbon” and “Home of Loving Care” for providing various services. Similar sites are attached to health facilities at the local level. These could promote peer support activities.

Viet Nam

“Friend-to-friend club”: officers in charge of HIV/AIDS at the local level have supported people living with or affected by AIDS in forming groups in Ho Chi Minh City and other provinces.

Coffee shops for HIV/AIDS: a local government authority, with support from international NGOs, has established coffee shops for promoting HIV/AIDS prevention activities in an urban setting. These could also be used for group activities for people living with or affected by AIDS.

An urban health centre supported by an international NGO has established a care centre for homeless people, including those infected with HIV, mobilizing peer support and education.
Partnerships for HIV/AIDS: case presentations

Key lessons learned from other regions
The experiences in countries where major progress has been made (e.g. Brazil, Thailand and Uganda) suggest that PLWA can play various critical roles in HIV/AIDS prevention and care. These experiences, particularly those of northern Thailand (see Box 9), have pointed the countries in the Western Pacific Region in the direction of exploring and applying approaches and developing models of care that may facilitate the greater involvement of PLWA and reinforce the continuum of care in resource-poor settings.

Box 9: The hub of the continuum of care: the day-care centre for people living with or affected by HIV/AIDS

What is a day-care centre (DCC)? It is a place where people living with AIDS (PLWA) can meet freely and participate in a wide range of activities, facilitated and supported by health workers. Many DCCs are attached to district hospitals, whereas others are in health centres (e.g. those in northern Thailand).

Activities and actions: The DCC is a place where PLWA support one another (peer support), and receive and share health education on self-care, home care and prevention. DCCs also offer socio-economic support (e.g. in responding to discrimination in daily life, occupational training/promotion). The DCC also promotes the early detection of opportunistic infections including TB, and could be used to ensure adherence to antiretroviral therapy and to prophylaxis against opportunistic infections. Hence the DCC offers comprehensive peer support (physical, psychosocial, spiritual, educational and economic).

Links and connections: The DCC refers patients with HIV/AIDS to the appropriate health facilities. The DCC also serves as a base for home visits for PLWA by PLWA with technical backup from health workers, and as a base for work with the community to raise awareness about HIV/AIDS in society.

Resources and requirements: The DCC can be launched with minimum resources (a room and staff), and without any major capital investment. It can be viewed as a user-friendly one-stop service with no waiting time and friendly staff.

Strategies in countries in the region
Based on the situation analysis in the priority countries of the Western Pacific Region and the lessons learned from other regions, the Western Pacific Region drafted the following strategies.

Core strategies
The strategies below could be applied to most areas of the region in which HIV is prevalent.

1. Creating a partnership mechanism between public health services, medical services and PLWA groups at the intermediate levels. This is the so-called “day-care centre” approach.
   - **Aim:** provision of care, management, capacity building and coordination. Linking of the medical and public health services with the community-based and home-based care. This requires an HIV care team and/or coordinator.
   - **Level:** to be identified on the basis of the number of PLWA in the area, the capacity of the health facilities and their physical accessibility to the PLWA.
   - **Format:** the experiences of the day-care centre are to be applied flexibly according to local context and should build on existing initiatives, e.g. Warm House, coffee shops, etc. NGOs and community organizations are also expected to play crucial roles.

2. Developing an essential care package, including antiretroviral therapy, and involving PLWA groups and other stakeholders.
   - **Aim:** ensuring that quality care is provided in an efficient and sustainable manner, and involving PLWA groups, other sectors and civil society in the provision of care.
   - **Mode:** gradual and incremental, stepwise development.
   - **Voluntary counselling and testing** should be offered as part of care.
   - **Collaboration:** the management of TB and HIV requires the systematic identification of common potential areas and themes for possible partnerships and team efforts.

3. Ensuring multisectoral political commitment to comprehensive care.
   This should include ministries and/or the agencies responsible for welfare, education, labour, women’s affairs,
public security, etc. Comprehensive care and support require services that address a broad range of needs. These cannot be provided by the health sector alone, and therefore a range of providers need to be committed to the collaborative, multisectoral efforts.

4. Promoting approaches for reducing discrimination and raising awareness about care. Such approaches include:
   ◗ establishing PLWA-friendly environments in the health facilities;
   ◗ formulating locally appropriate information suitable for the context in which it will be given and received, and developing education and communication packages employing a range of participatory approaches; and
   ◗ promoting constructive dialogues and discussions, for example, through community forums and other collective channels.

5. Generating responsiveness to a range of diverse and changing situations that may include:
   ◗ setting up relevant monitoring and evaluation systems; and
   ◗ promotion of mutual learning and action, for example, through a joint proposal-based funding mechanism.

Complementary strategies
Depending on the country or local context, stage of HIV epidemic, mode of HIV transmission, availability of existing services, progress of responses, etc., the following complementary strategies could be considered:
   ◗ prevention of mother-to-child transmission as a major entry point for care;
   ◗ extensive home-visit services;
   ◗ extensive involvement of community organizations (China and Viet Nam);
   ◗ expanding peer support at community level;
   ◗ link to rehabilitation camps for injecting drug users and sex workers (China and Viet Nam); and
   ◗ Expanding outreach activities to increase access for and utilization by marginalized PLWA.

Progress made
Cambodia, China and Viet Nam have drafted national frameworks or plans for HIV/AIDS care, with support from WHO/WPRO, incorporating most of the strategies listed above.

In order to test these national frameworks or plans, pilot projects are starting in all three countries. In Cambodia, for instance, day-care centres will be set up in the health centres at the operational district level in several provinces in parallel with the introduction of antiretroviral therapy in rural areas. In Viet Nam, similar schemes are being established in Ho Chi Minh City where the pilot projects are being conducted as part of the national project funded by GFATM.

Because the building of capacities and the fostering of partnerships between health workers, PLWA group members and NGOs are vital, a series of workshops and field-visits have been conducted. These have included visits to the day-care centres, followed by a planning workshop in Northern Thailand, which involved government officials at the central and local levels, representatives of PLWA groups and NGOs involved with the pilot projects in Cambodia, China and Viet Nam. These cross-regional learning experiences have contributed considerably to the development and implementation of national plans for care that incorporate strategies for collaborative interaction with support for PLWA.

THE ROLE OF THE COMMUNITY IN THE CONTROL OF TUBERCULOSIS

Dr Dermot Maher

Introduction
WHO has recently estimated the global burden of tuberculosis and reviewed its global trends and interactions with HIV (Corbett et al, 2003). The estimated global incidence of tuberculosis in 2000 was 8.2 million, with an incidence rate of 136.1 000 000. Ten percent of all new cases of tuberculosis recorded in adults aged between 15 and 49 years were attributable to HIV infection. There were 1.82 million deaths from tuberculosis in 2000, of which 226 000 (12%) were attributable to HIV. Table 2 shows the breakdown of these global estimates by WHO region.
Table 2. Summary of tuberculosis estimates by WHO Region

<table>
<thead>
<tr>
<th>Region</th>
<th>AFR</th>
<th>AMR</th>
<th>EMR</th>
<th>EUR</th>
<th>SEAR</th>
<th>WPR</th>
<th>Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population (millions)</td>
<td>640</td>
<td>832</td>
<td>485</td>
<td>874</td>
<td>1536</td>
<td>1688</td>
<td>6053</td>
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<tr>
<td>New cases of TB</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of cases (thousands)</td>
<td>1857</td>
<td>382</td>
<td>587</td>
<td>468</td>
<td>2986</td>
<td>1960</td>
<td>8240</td>
</tr>
<tr>
<td>Incidence rate (per 100,000)</td>
<td>290</td>
<td>46</td>
<td>121</td>
<td>54</td>
<td>194</td>
<td>116</td>
<td>136</td>
</tr>
<tr>
<td>Change in incidence rate 1997–2000 (%/year)</td>
<td>4.3</td>
<td>4.1</td>
<td>1.4</td>
<td>2.8</td>
<td>1.3</td>
<td>0.0</td>
<td>0.5</td>
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<tr>
<td>HIV-related tuberculosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV prevalence in new adult cases of tuberculosis (%)</td>
<td>38</td>
<td>5.9</td>
<td>1.8</td>
<td>2.8</td>
<td>3.2</td>
<td>1.3</td>
<td>11</td>
</tr>
<tr>
<td>Incidence rate of cases attributable to HIV (per 100,000)</td>
<td>65.8</td>
<td>1.4</td>
<td>1.1</td>
<td>0.9</td>
<td>3.5</td>
<td>0.8</td>
<td>8.4</td>
</tr>
<tr>
<td>Deaths</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deaths from tuberculosis (per 100,000)</td>
<td>75</td>
<td>6.6</td>
<td>28</td>
<td>8.3</td>
<td>47</td>
<td>21</td>
<td>30</td>
</tr>
<tr>
<td>Tuberculosis deaths attributable to HIV (%)</td>
<td>39</td>
<td>6.5</td>
<td>2.0</td>
<td>2.1</td>
<td>3.7</td>
<td>1.5</td>
<td>12</td>
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</table>

Of all the regions in the world, sub-Saharan Africa carries the biggest burden of tuberculosis both in terms of the overall incidence and mortality rates, and in terms of the absolute numbers and rates of cases and deaths attributable to HIV. Sub-Saharan Africa has also seen the largest increase in incidence rate between 1997 and 2000 (6% per year). With the worst indicators of health and economic development of all regions of the world, sub-Saharan Africa is the least well-equipped to deal with the biggest burden of tuberculosis, and therefore deserves particular emphasis in mobilizing efforts for tuberculosis control.

Globally, the regional distribution of incidence of HIV infections shows wide variation; about 4 million incident infections were reported in 1999 in sub-Saharan Africa. This incidence was about four times that reported in southern and eastern Asia (estimated at less than 1 million new cases) and was more than the total number of incident HIV infections in the rest of the world.

In sub-Saharan Africa, national TB programmes (NTPs) need to ensure widespread access to effective tuberculosis care in the face of the mounting TB epidemic, which is increasingly fuelled by HIV infection. Widespread access requires collaboration between NTPs and a range of health service providers. These include government health facilities, NGOs, employer health services, private practitioners and the general community.

The main thrust of the efforts by WHO to promote community contribution to tuberculosis care has its geographical focus on sub-Saharan Africa. In the face of severe constraints on resources, NTPs are struggling to cope with the increasing numbers of TB cases related to infection with HIV. The internationally recommended strategy for TB control (DOTS) depends on TB case-finding and cure. NTPs need to improve case-holding if they are to obtain high rates of successful treatment. It is important to expand case-finding only where NTPs achieve high rates of successful treatment. Otherwise the result of NTP activities is to find TB cases without curing them, thus increasing the prevalence of drug-resistant TB.
**Project implementation**

The WHO-coordinated project, Community TB Care in Africa, is a collaborative initiative between six agencies: WHO, UNAIDS, CDC, USAID, IUATLD and the Royal Netherlands TB Association (KNCV). The collaborative project was started in 1995 by a WHO-led mission for the assessment of TB care in community care projects. Between 1998 and 2000, this initiative implemented eight district-based community projects for TB care in six countries with a high prevalence of HIV, namely, Botswana, Kenya, Malawi, South Africa, Uganda and Zambia. The goal of the project was to harness the community contribution to TB care and improve case-holding and treatment success. The additional expected benefits included improved equity (through extended access to TB care), mobilization of community resources against TB (which is a disease of the poor), and improved community oversight of health care provision.

Within the six countries, the project capitalized on different forms of already established community organizations and networks. Such networks included guardians and community workers, primary health care volunteers, community-based distributors of contraceptives, other NGOs working on HIV such as the AIDS Support Organization (TASO) in Uganda, faith-based NGOs, home care programmes for patients with HIV/AIDS, NGOs working on tuberculosis and traditional healers, as well as civic structures (such as the parish development committees in Uganda).

The projects aimed to establish and strengthen the links between the health services providers, the district medical and TB officers, and a range of community organizations. It was necessary to train the district level health workers, health centre workers, community project supervisors and volunteers. This required the development of a variety of training tools and educational materials. Figure 4 depicts a general model of integrated community TB care tested by the participating projects.

### Figure 4. A model of integrated community care for TB

The examples of community responses to HIV provide an opportunity for collaboration with NTPs in detecting cases of TB and improving case-holding. The projects sought to answer the following question: “Can communities contribute to TB care in ways that are effective, affordable, cost-effective and acceptable?”
**Partnerships for HIV/AIDS:**
case presentations

**Project results**

**Acceptability.** The results of focus group discussions and questionnaires indicated positive attitudes towards community care for TB patients. However, the barriers to community acceptance of such an approach to TB care included fear of TB, poverty and HIV-related stigma.

**Effectiveness.** Figure 5 illustrates the performance of the district TB programme before and after the introduction of a decentralized/community approach between 1997 and 2000. The performance of district TB programmes that incorporated a decentralized/community approach was better than that of district TB programmes that used the traditional approach.

**Cost-effectiveness.** For new, smear-positive patients with pulmonary TB, Figure 6 shows the comparative cost-effectiveness (cost per patient successfully treated) for conventional and decentralized/community approaches between 1997 and 2000.

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**Figure 5. Success rate of tuberculosis treatment: comparison of conventional and decentralized/community approaches**

<table>
<thead>
<tr>
<th>District TB programmes sites</th>
<th>Conventional approach</th>
<th>Decentralized/community approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Machakos, Kenya</td>
<td>85</td>
<td>88</td>
</tr>
<tr>
<td>Lilongwe, Malawi</td>
<td>58</td>
<td>68</td>
</tr>
<tr>
<td>Kiboga, Uganda</td>
<td>58</td>
<td>74</td>
</tr>
<tr>
<td>Ndola, Zambia</td>
<td>48</td>
<td>60</td>
</tr>
<tr>
<td>Cape Town, South Africa</td>
<td>62</td>
<td>67</td>
</tr>
</tbody>
</table>

**Figure 6. Cost-effectiveness of tuberculosis treatment: comparison of conventional and decentralized/community approaches**

<table>
<thead>
<tr>
<th>District TB programmes sites</th>
<th>Conventional approach</th>
<th>Decentralized/community approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Machakos, Kenya</td>
<td>696</td>
<td>239</td>
</tr>
<tr>
<td>Lilongwe, Malawi</td>
<td>786</td>
<td>296</td>
</tr>
<tr>
<td>Kiboga, Uganda</td>
<td>911</td>
<td>391</td>
</tr>
<tr>
<td>Ndola, Zambia</td>
<td>1209</td>
<td>726</td>
</tr>
<tr>
<td>Cape Town, South Africa</td>
<td>1400</td>
<td>1200</td>
</tr>
</tbody>
</table>
Conclusions

Communities can contribute effectively to TB care where the health services, the NTPs and the community organizations collaborate successfully to establish mechanisms for referral, logistics, training and patient education on TB care in the community.

The CBOs working on HIV/AIDS have a potential role in TB control. Such organizations have the following advantages:

- increasing awareness of the links between HIV and TB and therefore the willingness to contribute to TB care;
- the potential for providing means of access to at-risk and target groups; and
- the possibility of extending the treatment of common HIV-related diseases beyond health facilities, which could help to abolish the mystery and stigma surrounding HIV/AIDS.

Nevertheless, CBOs working with HIV/AIDS also have certain disadvantages.

- They are often small-scale organizations with limited population coverage.
- The stigma attached to HIV/AIDS may deter TB patients.
- The emphasis is often on care rather than treatment.

Recommendations

**Links.** Establishing links with NTPs and health service providers, and maintaining the motivation of community members involved in TB control are important. Connections between the community on the one hand and the health professionals and the formal health service providers on the other are essential for good-quality care.

**Community.** NTPs should harness community contributions to TB care where there is a need to improve the access to and quality of care. NTPs need to ensure the effectiveness of community members as supporters of TB treatment by identifying the right group(s), providing training in supporting TB treatment (including directly observing treatment) and ensuring sustainability.

Peripheral health units and community TB treatment supporters should record and report the outcomes of TB treatment.

**NTPs.** An effective NTP is necessary to handle the extra management responsibilities resulting from decentralizing the provision of TB care beyond the health facilities into the community. NTPs need to ensure an effective, secure and safe system of supplying drugs to TB patients and community treatment supporters. NTPs should monitor the community contribution to TB care using standard NTP performance indicators (i.e. percentage of patients choosing different DOT options, and quality-of-care indicators).

**Ministries.** Ministries of health need to ensure adequate financing to cover the new costs involved, while recognizing the cost-effectiveness of this approach.

**Sustainability and expansion.** Sustainability and expansion require the commitment of ministries of health, NTPs, donors and NGOs. Expansion involves developing costed plans and clear criteria for choosing those districts targeted for expansion.

References


Partnerships for HIV/AIDS: case presentations

NURSE FACILITATORS WORKING TOGETHER WITH THE COMMUNITY IN HIV/AIDS PREVENTION AND CARE: EXPERIENCES FROM THAILAND

Dr Arphorn Chuaprapaisilp

Background
HIV/AIDS is a serious health problem in Thailand. There are no social boundaries for the disease, and it has affected people from all groups and social strata in Thai society. Currently, there are about one million people living with HIV/AIDS in Thailand. A range of programmes and projects have been formulated and implemented to help solve the problems that are being encountered, and to plan for the prevention of infection and the care of those already infected. This chapter describes the projects undertaken by the Faculty of Nursing at the Prince of Songkla University in Thailand. It addresses the issue and roles of nurse facilitators in HIV/AIDS prevention and care. The projects were implemented in southern Thailand between 1991 and 2001.

The starting point: nurse and participatory action research
The project is an illustration of the potential inherent in international collaboration in nursing. The collaboration described here was between Thailand (Faculty of Nursing, Prince of Songkla University) and Australia (School of Nursing, LaTrobe University). The two institutions worked jointly on a variety of issues including the research design, data collection, interim and final analysis of the data, as well as providing training for researchers and community workers on community assessment and development, epidemiology, social anthropology, action research methodology, nursing therapeutics and capacity building. The initial focus of the collaboration between the two institutions was a project that addressed a case study of the family-based nursing care programme. Its aim was to prepare communities to live with HIV/AIDS without stigmatizing the families and individuals affected. This project had four specific objectives:

- to enable family caregivers to develop family-based nursing skills for the management of infectious diseases including HIV/AIDS;
- to develop strategies to assist caregivers in treating and caring for people living with AIDS;
- to develop nursing kits and a Thai “train-the-trainer” manual to enable public health nurses to train caregivers in HIV/AIDS prevention and care; and
- to develop an HIV prevention programme.

From this initial partnership between the two institutions, an array of mutually beneficial programmes was generated. Over the following 10 years, this collaborative endeavour was expanded to include three further working projects and about 12 formal research programmes. Almost all of these projects were implemented on the basis of qualitative research methods and participatory action research principles, where nurses played a range of facilitating roles in community empowerment. For example, developing rapport and raising awareness, enhancing understanding through study visits to observe real-life situations and through group reflections, stimulating mutual participation in every step of the project and providing opportunities for self-development. Tactics were sought that would provide the resolution that was best fitted to the society and the culture of the individual communities. The nurse facilitators also undertook tasks that included training of trainers workshops for village health volunteers and public health nurses; training of housewives; training of researchers and community workers; study visits; friends-helping-friends project; campaigning; a slogan competition (and production of stickers carrying the winning slogan); a story-writing competition, and shadow-puppet theatre on AIDS prevention. All these activities are related to enhancing the interaction between health practitioners on the one hand and individuals, families and communities on the other, within the wider perspective of improving community and home care for people living with HIV/AIDS. Figure 7 illustrates the range of stakeholders involved in this international networking initiative for HIV/AIDS prevention and care and Box 10 outlines the progression and historical overview of 10 years of work in community and home care.
Figure 7. Mobilizing nurses: international networking for HIV/AIDS prevention and care

Australian nurses
Funding agency

Buddhist monks
Postgraduate students

Universuty-Based
Network of
Nurses

Schools
Muslim leaders

NGOs
PLWA

Factories
Volunteers

Local communities (Family-Based Care)
Ministry of Public Health (MOPH) nurses
# Partnerships for HIV/AIDS: case presentations

## Box 10: Community and home care in Thailand: A 10-year overview

<table>
<thead>
<tr>
<th>Year</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1991</td>
<td>The design phase of a feasibility study addressing &quot;Women and AIDS prevention&quot; — a collaboration between World Vision Australia/Thailand, School of Nursing, LaTrobe University, Australia and the Faculty of Nursing, Prince of Songkla University, Thailand.</td>
</tr>
<tr>
<td>1993</td>
<td>Emergence of the south Thailand family-based nursing care projects: HIV/AIDS prevention and care, in collaboration with AusAID.</td>
</tr>
<tr>
<td>1994</td>
<td>HIV/AIDS prevention and care project in Muslim communities, in collaboration with United Nations Development Programme. This project was similar to the family-based nursing care projects: HIV/AIDS prevention and care, but with a focus on Muslim communities. Human caring project, with support from the Prince of Songkla University Fund. This project provided caring support for HIV/AIDS patients living in a Thai Buddhist temple, as well as training for volunteers in the temple and caregivers in the home.</td>
</tr>
<tr>
<td>1997</td>
<td>Self-care of people living with HIV/AIDS in a Thai cultural context at a Buddhist temple in south Thailand (supported by the Prince of Songkla University Fund).</td>
</tr>
<tr>
<td>1998</td>
<td>The &quot;experiences of death and dying&quot; of AIDS patients living in a Buddhist temple in south Thailand. This was a phenomenological study to describe and explain the perceptions of people living with AIDS regarding near-death experiences. AIDS prevention for teenagers in south Thailand: conducted in conjunction with the Thai Research Fund. This project aimed to develop a model for preventing HIV/AIDS in teenagers in southern Thailand, and to enable them to develop sustainable preventive activities.</td>
</tr>
<tr>
<td>1998</td>
<td>Development of networking model for HIV/AIDS prevention and care: utilizing a Buddhist as a network centre. White Bridge Project (PLWAs support group). This project established the first PLWAs' support group in Songkla Province. It aimed to establish &quot;friends-helping-friends&quot; for PLWAs. White Bridge refers to the bridge for increasing true understanding, knowledge and caring skills, and reducing discrimination against and misunderstanding of PLWAs. Health perception and self-care of long-term surviving PLWAs. This project described and explained the experiences of PLWAs who had survived for more than 7 years. It described the phenomena of inability to adjust, seeking for survival, and self-care as a means of survival and harmonious life, at which stage informants became able to accept HIV/AIDS and death. Songkla family-based nursing care projects (Ministry of Public Health).</td>
</tr>
<tr>
<td>2000</td>
<td>Study on perceptions of health and self-care in AIDS patients with TB. This study reflected the perception that TB is a double stigma for PLWAs.</td>
</tr>
<tr>
<td>2001</td>
<td>Qualitative study on AIDS patients and care as perceived by public health volunteers. This study described and explained the public health volunteers’ perceptions of care for PLWAs. The findings suggested that some informants were frightened and dared not get close to PLWAs and some even hated them. Empowering and networking for home and community care. This project aimed at developing innovative strategies to empower communities, health teams and PLWAs to provide holistic and continuous care. It commenced with social mobilization using local wisdom. Social mobilization led to mutual collaboration between PLWAs, their relatives, and the communities. The strategies included having an understanding of the community; strengthening the community-owned financing scheme to increase cooperation among members; involving the community in developing holistic health practices; working in collaboration with the existing AIDS networks; building up teams to sustain care; and, mobilizing resources for care and support.</td>
</tr>
</tbody>
</table>
Holistic approaches: mobilization, empowerment and networking

All the projects were based on key humanitarian principles. The respect and dignity of PLWA was a central and ongoing concern. A range of (traditional eastern spiritual) holistic approaches were employed by both the PLWA and the researchers. These approaches focused on the harmony of the triad of the body–mind–spirit and resulted in activities that addressed the spiritual, psychosocial, economic and physical needs of the PLWA. All the activities were rooted in the communities, and villagers learnt new skills from the process of implementing actions. They were then able to apply what they had learned to other activities, reflecting the sustainability of the projects. The actions involved in the prevention of HIV and the care for PLWA were all based on a true understanding of the local culture. Furthermore, the activities were completely integrated with traditional care, and multidisciplinary networks of volunteers to help and support PLWA built upon and worked in collaboration with existing AIDS networks. The result was the gradual development of a community–health services interaction model for mobilizing, empowering and networking. It was sustained through fund-raising, seeking support, setting up a community-owned saving fund for health (Sud-Ja Aom-Suub), and mobilizing resources for care and support. The model simultaneously addressed a combination of holistic approaches, as well as the continuity of home and community care. Volunteers and villagers demonstrated the effectiveness of their knowledge of and skills in HIV/AIDS prevention and care.

Shelters and temples were available for PLWA to live in if they were rejected by their families. PLWA could gain confidence as well as an income by becoming counsellors and consultants for patients newly diagnosed with PLWA, and for governmental organizations and NGOs working in HIV/AIDS projects.

The centre for network development in HIV/AIDS prevention and care is based at the Prince of Songkla University, and works collaboratively with other organizations aiming at helping PLWA in developing AIDS networks in south Thailand; raising awareness on living in acceptance with PLWA, and providing materials, resources, medication and herbs for PLWA. The centre was developed in order to mobilize resources and support networks in the communities. Nursing kits were produced and volunteers were trained in the care of PLWA.

However, professionally trained nurses were central to these projects. The activities of these nurses resulted in the development of networking among the health teams, PLWA, families and relatives, NGOs, villagers, religious leaders and traditional healers. Both the PLWA and the volunteers praised the effective knowledge, skills and expertise that the nurses brought to the projects. The key issues in developing home and community care are listed in Box 11.

<table>
<thead>
<tr>
<th>Box 11: Key issues in developing home and community care</th>
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</thead>
<tbody>
<tr>
<td>➤ Working together as friends with communities and PLWA</td>
</tr>
<tr>
<td>➤ Multidisciplinary networking</td>
</tr>
<tr>
<td>➤ Involvement of PLWA and traditional healers</td>
</tr>
<tr>
<td>➤ Understanding the local culture</td>
</tr>
<tr>
<td>➤ True community involvement</td>
</tr>
</tbody>
</table>

Lessons: difficulties to be addressed

➤ Collaborative work is very time-consuming and requires committed team members from both the community and the health services.
➤ Involving PLWA in participating in activities for HIV/AIDS prevention and care is not always feasible, because of health and income constraints.
➤ It is not necessarily easy to apply ideal, holistic approaches rather than ad hoc single interventions.
➤ A continuum of care between the hospital, family and community, needs to be established to meet the needs of both the communities and the PLWA.
➤ Networking between governmental organizations, NGOs and local communities can be difficult, and acceptance by the various organizations and communities of each other’s roles is not easy. Mutual understanding, is crucial for networking.
➤ Communities prefer one-stop information centres. Local health care systems should therefore be
Partnerships for HIV/AIDS: case presentations

strengthened to enable them to provide a variety of services and to integrate information and education on HIV/AIDS with existing services so that PLWA do not have to go to many different organizations for support or information.

- A consideration of the politics of the situation and continuous lobbying for the resources required to achieve success is involved in such work.

Key factors in success

The various projects that have been implemented over the past 10 years show that the following factors are key to success in assisting communities to empower themselves for HIV/AIDS prevention and care. A model for community empowerment for HIV/AIDS care is illustrated in Box 12.

- Focusing on the development of skills as regards community development, working with communities, participating in cultural activities, and in caring within a specific cultural context for patients with infectious diseases (including HIV/AIDS) benefits the whole community and is a successful strategy for home and community care.

- Providing space for truly participative/community involvement is a necessity.

- Working in collaboration with existing AIDS networks, and the availability of an information centre where guidelines and handbooks can be consulted, strengthens the impact of the projects.

- Flexibility in management and open-mindedness in team members are vital.

- Using the expertise and experiences of PLWA and volunteers (in the roles of counsellors, speakers and caregivers) contributes substantially to the success of the projects.

- Long-term survival of PLWA through self-care and harmonizing the balance between mind, body and spirit inspires others.

- An understanding of self, others and the nature of life contributes to self-care, self-healing and positive caregiving.

- Traditional healers, complementary therapies, and an understanding of the culture play major roles in developing appropriate interventions for home and community care.

- Working together as friends with community members and with PLWA, in a multidisciplinary network of volunteers, is a basis for success.

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Box 12: A model for community empowerment for the care of patients with HIV/AIDS

<table>
<thead>
<tr>
<th>Dynamic structure</th>
<th>Group Emancipation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flexible management</td>
<td>Gaining insight</td>
</tr>
<tr>
<td>Understanding concepts &amp; principles</td>
<td>Learning from experience</td>
</tr>
<tr>
<td>Participation &amp; emancipation</td>
<td>Self-esteem</td>
</tr>
<tr>
<td>Self-development</td>
<td>Recognition</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Collective Emancipation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collective Collaboration</td>
</tr>
<tr>
<td>Group selection</td>
</tr>
<tr>
<td>Training</td>
</tr>
<tr>
<td>Participating in every step</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Understanding</th>
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<tbody>
<tr>
<td>Awareness-Raising</td>
</tr>
<tr>
<td>Networking</td>
</tr>
<tr>
<td>Developing rapport</td>
</tr>
<tr>
<td>Training researches</td>
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<tr>
<td>Baseline survey</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Getting Started</th>
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</thead>
<tbody>
<tr>
<td>Faith &amp; trust</td>
</tr>
<tr>
<td>Gaining insight</td>
</tr>
<tr>
<td>Learning from experience</td>
</tr>
<tr>
<td>Self-esteem</td>
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<tr>
<td>Recognition</td>
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<table>
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<tr>
<th>Continuous consciousness</th>
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<tbody>
<tr>
<td>Reflection process</td>
</tr>
<tr>
<td>Sincerity &amp; commitment</td>
</tr>
<tr>
<td>Continuity</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Collective Collaboration</th>
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<tbody>
<tr>
<td>Understanding</td>
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<tr>
<td>Awareness-Raising</td>
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<tr>
<td>Getting Started</td>
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<tbody>
<tr>
<td>Group Emancipation</td>
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<tr>
<td>Awareness-Raising</td>
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<tr>
<td>Getting Started</td>
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</tbody>
</table>
PARTNERSHIPS BETWEEN SEX WORKERS AND GOVERNMENT HEALTH SERVICES FOR HIV PREVENTION: MARGINALIZED WOMEN IN BANGLADESH

Dr Mausumi Amin

CARE Bangladesh initiated the work with brothel-based sex workers in Tangail in 1995. The overall goal of CARE was to develop and implement effective national strategies and programmes to fulfil its mission of reducing the spread of HIV/AIDS in Bangladesh. Since then, CARE has gradually expanded its work with vulnerable populations. Programmes have been implemented in different communities. Examples of these communities include the street-based sex workers, transgender sex workers, male-to-male sex workers, hotel-based sex workers, PLWA, injecting drug users, transport workers, people who frequently cross international borders, dock labourers, factory workers and tea gardeners. The geographical area of coverage now includes 27 districts of Bangladesh, out of a total of 64.

To maximize the accessibility and availability of intervention activities the HIV programme is using the drop-in centre, peer-based model whereby clinical and outreach services are delivered through peers. This unique model is the basis for the practice in 94 drop-in centres throughout the country.

Programme approaches
The overall approaches employed for all the interventions in the HIV programme incorporated the following principles:

- a basic humane approach: working on restoring the respect and dignity of the marginalized community;
- creating an enabling environment for the effective implementation of intervention activities;
- involvement of the target communities in all the decision-making processes of the project (i.e. planning, implementation and monitoring of project activities); and
- empowering the vulnerable population.

Brothel-based interventions
In Tangail, two categories of brothel-based activities were in place to address the issues of vulnerability. These were:

- clinical and outreach service delivery; and
- social mobilization and capacity building.

The clinical services provided include treatment of sexually transmitted infections, promotion of condom use, education about HIV/AIDS, counselling, patient referral and follow-up.

The social mobilization and capacity building involves several aspects, namely:

- formation of self-help groups and organizations and strengthening their skills for building capacity;
- networking and alliance-building between self-help groups, the Government of Bangladesh, NGOs and other stakeholders;
- education and income-generating activities that facilitate empowerment;
- advocacy to create an enabling environment at the national level;
- building partnerships with NGOs, self-help groups and government departments;
- strengthening the community capacity for implementation of HIV programmes; and
- mainstreaming of the vulnerable population.

Programme approaches
The process employed for the brothel-based intervention comprised two stages, the preparatory stage and the action stage, both of which were based primarily on a peer approach.
Partnerships for HIV/AIDS: case presentations

Preparatory stage. The preparatory stage started with assessing the social structure that operated within the brothel e.g. “Samaj” to gain an understanding of the context (in terms of values, beliefs, norms, customs and culture) so that the programme could be designed accordingly. Secondly, a set of enabling activities was initiated with the collaboration of the key actors and stakeholders. These activities included acts of advocacy and lobbying, building linkages and creating connections, and establishing the sharing of opinions. Thirdly, other activities, employed simultaneously, were directed to the sensitization of government officials, NGOs, local government and opinion-leaders to the various issues and concerns, with the aim of involving them in the various decision-making processes related to the project. The community capacity was also assessed and enhanced. The activities were undertaken side by side, reinforcing each other, because the issues were interconnected.

Action stage. After these three preparatory stages, the actions were implemented. Viable income-generating schemes were initiated to enhance the empowerment of the community. Initially, several slogans were coined to proclaim the sex workers’ demands and vision; for example, “right to wear shoes first, not condoms”, “living with dignity” and “recognition as humans”. Wearing shoes had an important symbolic meaning for the sex workers’ dignity and CARE needed to address this need first. Over time, the priorities expanded to “ensure safer sex by using condoms” and “access to STI treatment”.

Service users were involved in the management of the health services provided within the brothel with a view to ensuring the quality of care for patient’s with sexually transmitted infections and to exercising the user’s right in service delivery. The community selected individuals from within the community to become members of the Clinical Governance Committee and the members were involved in planning, implementation and all the decision-making processes relating to clinic management.

Actions to meet the health needs of the sex workers were linked to other existing services such as family planning, and the health centres were jointly operated by the government and the NGOs.

A need for partnership and collaboration
An important strategy was to build partnerships aimed at fostering collaboration between a wide range of government bodies and NGOs and institutions. This was undertaken for a number of reasons:

- to address a broad range of perceived needs of the community that could not be provided by a single agency;
- to contribute to and aid in sustainability;
- to maintain the activities in the future; and
- to widen the coverage and maximize the impact of the intervention.

The Nari Mukti Sangha
The Nari Mukti Sangha (NMS) is an officially registered sex workers organization based in the Kandapara Brothel, Tangail. NMS was formed in the hope of creating unity among sex workers, establishing their social and legal rights and implementing sustainable programmes aimed at combating HIV/AIDS, especially among vulnerable populations. For NMS, collaborative partnerships with a range of other stakeholders are considered to be both essential and important for the reasons given above. Through partnerships with other NGOs, the programme offered includes income-generation projects (e.g. sewing), adult literacy schemes and the sale and distribution of condoms.

Building the partnership with government health services
This section focuses on the partnership with the government health services. In building partnerships with government health services, the areas of interest of these health services were identified, and an assessment made of where CARE and NMS could contribute to and complement the government programmes that were already established. CARE/NMS became involved in the Extended Programme on Immunization (EPI), in the national immunization day and in the maternal and neonatal tetanus campaign. The government considered that CARE could contribute to their priority programmes by gaining access to the brothel, which is an area to which access for the government services is prevented by social constraints.
As a result of being involved in the national immunization day, the demand from the community (i.e. the sex workers) for immunizations for their children was raised. Because the brothel was situated within the municipal area, the local government needed to include it in their actions to obtain a wider immunization coverage. This was accomplished by establishing the immunization centre in the brothel. With a view to ensuring both maximum coverage and sustainability, the community members were involved in establishing the immunization centre and several of them were trained by government officials to enhance their technical capability of running the immunization centre.

As a part of the mainstreaming activities, the NMS was also involved in a variety of “activity days” where they made their voice heard, disseminated their messages, presented various organizational activities, explored the barriers to their work and the ways in which these could be overcome, and created space to articulate their views and rights. Gradually, the community members became more aware of the different services available and started bargaining with the numerous service providers to make those services more accessible to their members through partnerships with their organization.

Partnership activities were not confined to the location of the brothel, but also took place at the level of the government health facility. Sex workers visited the government health centres to receive training in administering immunizations and visited the Thana health complex for meetings with the family planning and health programme staff. Through NMS, the sex workers discussed with the government issues related to the improvement of the referral system from the brothel-based clinic to the government hospital. Together, the government and NGOs, with the support of WHO, organized meetings to sensitize the politically influential and religious leaders to the subject of HIV prevention and to reduce the stigma attached to sex working.

The partnership that was established had many other advantages. This was demonstrated when a large fire broke out and 46 homes in the brothel area were burnt down. An ad hoc disaster committee was formed with the participation of the community members and the NGOs. A disaster relief programme was also implemented by a consortium of the GO, local government, NGOs and allies of the sex workers’ network.

### Barriers and opportunities

Various barriers were encountered. These included:

- the stigma attached to the vulnerable population;
- government limitations in recognizing the vulnerability of the sex workers to HIV/AIDS;
- social barriers (the reluctance of members of mainstream society to use the same hospital premises as the sex workers);
- condom promotion was seen as having a negative impact (i.e. to be encouraging premarital and extramarital sex); and
- low self-esteem among the sex workers affected their negotiation and decision-making skills.

However, several opportunities, strategies and activities contributed to overcoming these barriers. These included:

- working closely with the government health officials and identifying their interest in the work of the community members on the programme;
- organizing opportunities for social interaction between members of the vulnerable community and the mainstream society;
- making cross-visits to the government health centres;
- organizing sessions to sensitize and influence the civil societies, as well as different social and religious groups; and
- general advocacy to create enabling environments and to influence policy.

We recommend the reinforcement of the movement for the protection of the rights of vulnerable populations through advocacy at the national and international levels. For this, policies will need to be developed and their implementation in the field needs to be ensured. Various needs and priorities must be addressed (see Box 13).
Partnerships for HIV/AIDS: case presentations

<table>
<thead>
<tr>
<th>Box 13: Addressing country needs and priorities: shoes for sex workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>CARE Bangladesh had a mission to fulfil through its HIV programme, namely, the reduction of the spread of HIV/AIDS in Bangladesh.</td>
</tr>
<tr>
<td>An innovative brothel-based intervention was employed to address the situation of the vulnerable sex workers; it consisted of two strands.</td>
</tr>
<tr>
<td>The first strand was clinical service delivery. This included treatment of sexually transmitted infections, promotion of condom use, education about HIV, referral and follow-up and a counselling service.</td>
</tr>
<tr>
<td>The second strand comprised social mobilization and capacity building by means of self-help groups, networking and advocacy, income generation and mainstreaming of the vulnerable population of sex workers.</td>
</tr>
<tr>
<td>However, in the preparatory stage of this innovative intervention, the concerns of the sex workers were not directly related to HIV/AIDS, but rather to a more basic need. They were forbidden to wear shoes, a measure taken to stigmatize them socially and to distinguish them from members of mainstream society. This discrimination had many repercussions. For example, sex workers were being charged more than other women for goods such as clothes and medicine. Wearing shoes had a symbolic meaning for the dignity and identity of these sex workers.</td>
</tr>
<tr>
<td>Hence they coined the slogan: “rights to wear shoes first, not condoms”.</td>
</tr>
<tr>
<td>When this basic need had been met, the sex workers turned their attention towards HIV interventions and gradually strengthened their partnerships with the government health services. Although there is still a long way to go, this partnership has already led to many opportunities for collaboration. This is an example of working on many fronts to the degree that the national sentinel surveillance is now being undertaken inside the brothel, in collaboration with the sex workers.</td>
</tr>
</tbody>
</table>
COMMUNITY CAPACITY FOR TREATMENT: THE “SOLIDARITY IN TREATMENT” PROJECT

Mr Donald De Gagné

Background

PLWA and their community groups play a crucial role in both the fight against AIDS and in AIDS care. Actions Traitements, an NGO based in France, has links with various community organizations and agencies in the southern hemisphere. It was recognized that within those organizations, the activists (who are HIV-positive themselves), who have considerable experience in addressing the problems of HIV/AIDS and have received extensive training, were dying because of a lack of access to treatment as a result of the limited resources available within their countries. We were facing the problem of losing human capital. Thus, three organizations in France, Solidarité Sida, L’UNALS and Actions Traitements, decided to initiate a new project for solidarity in therapy. The project is meant to help these community leaders and activists to continue to live, to have an acceptable quality of life and to continue to contribute to the work.

The project: “solidarity in treatment”

The project was implemented in partnership with two of the organizations involved in the struggle against AIDS in Burkina Faso (Associations REVS+ and Association African Solidarité (AAS)) and one organization in the Philippines (Positive Action Foundation Philippines Inc. (PAFPI)). These organizations were selected because they already had the level of capacity that was required for the care and treatment of patients with AIDS. Some of the three community organizations had already developed small-scale projects for treatment by collecting antiretroviral drugs from countries in the northern hemisphere to be used by members in the south. Similarly, these community agencies were already interacting with the community doctor(s) regarding treatment. One group had, among its activists, health workers living with HIV.

From each of these organizations, 16 persons started the treatment, most of whom were women. The patients to be treated were selected by these organizations using the following criteria:

- symptomatic and CD4 counts;
- involvement in a community-based organization (CBO);
- length of involvement in the CBO (including members who are ill and no longer capable of being present regularly); and
- whether a partner, child or close relative is living with the person already on the treatment protocol.

The treatment package consisted of:

- antiretroviral medicines;
- physical examinations and laboratory tests (including CD4 cell count four times per year);
- medicines for treating a range of opportunistic infections; and
- complementary nutrition.

Six months after starting the treatment, out of a total of 48 persons, three had died of gastroenteritis and one of TB, two had discontinued the treatment because of pulmonary infections and had later restarted the treatment, and three had developed hepatic intolerance and needed to change treatment. However, most of the persons are doing well on the medication. Dramatic visible improvements such as gaining weight, feeling better and being able to go back to work every day have given people hope and created a sense of solidarity. For instance, those people in the Philippines who are now able to work again and are earning money, want to pay at least part of the cost of their medication in order to create opportunities for the treatment of others who were not selected initially. The groups in Burkina Faso are having discussions with their government on the acceptance of generic drugs. These
developments are important as the project is not just about putting a few people on medication. The project is aimed at broadening the capacity in the groups in order to widen access to treatment. Other aims include learning skills that are useful in lobbying for treatment, and searching for and finding resources in the country for providing treatment. The goal is to have a broader and ongoing community impact.

Interactions between community groups and health care professionals
People living with AIDS and their community groups are unable to undertake all aspects of treatment on their own. They require technical support. The community groups involved in the treatment project have a trained health worker in a health institution to act as their partner and medical adviser. Good relationships and interactions between the community groups and patients receiving treatment on the one hand and the doctor on the other are of the utmost importance in avoiding treatment failure.

The community groups involved in the project select the doctor with whom they wish to work not only on the basis of his or her medical skills but, more importantly, on the commitment to the community movement that he or she shows. Doctors need to be willing to relate to, to interact with and to communicate with the community group as well. The doctors selected are open to the NGOs and to the work that they undertake, and, in many instances, they are already involved at the government level in making improvements in care.

The level of knowledge in community groups is surprisingly high. For instance, they may use the Internet to collect information on treatment side-effects and to follow the new developments in treatment. People have a desire for information and will approach different persons and institutions to collect the information that they and their organizations require. These patients need a doctor who does not feel threatened by a patient who already has considerable information and awareness and who, at times, may know more than the medically trained personnel.

It is also necessary for the doctor to have sufficient time for the patient. Often patients experience conflicting feelings about their treatment regime because of its side-effects. In such a case a doctor is needed who will take time and who has the consideration, patience and motivation to explain the benefits of the treatment; otherwise the patient might discontinue the treatment.

Positive interactions between the doctors and the communities are also necessary, because the doctors need the community groups as well. Doctors in developing countries are faced with an overwhelming burden of work and community groups undertake a great deal of work with families and communities. They play an important role in helping the patient with adherence, with nutrition and with checking the side-effects of the medication. Considerable capacity exists within the communities in both developed and developing countries. In every community organization that we work with someone collects and manages the data; for example to ensure that the CD4 cell counts are done. The members of the groups meet regularly to provide each other with emotional support. The low level of education in certain countries does not present a barrier. The people running the community programmes are well informed.

Community groups play a vital role in managing the treatment programme and in the follow-up, mobilization and support for people receiving treatment. A good relationship with health professionals who understand and accept this role of the community is crucial. In the absence of such a relationship between doctors and communities, there is a risk of treatment failure.
The presentation of the cases-studies at the WHO Consultation on the Enhancement of the Health Services–Community Interface was an important way to share lessons of good practice. The case-studies represented a range of positive approaches to collaborative interactions between health services and communities. They also demonstrated a variety of ways of responding to the many challenges that arise. The important lessons to be learned from the case-studies are summarized below.

1. Any gaps between the communities and the service providers will require bridging. The experiences from the Local Response Initiative in Uganda suggested that partnerships between a variety of stakeholders result in wide coverage of, and targeted tailoring for, marginalized groups. The experience also highlighted the appropriate entry points into the villages and communities, as well as the importance of functional coordinating mechanisms and structures that link the districts to the local health committees to the hospitals and to the communities. However, for success to be achieved, the support of facilitators is needed to bridge the gap between communities and service providers.

2. Within the formal health care system, national frameworks and innovative models of care can be developed that facilitate partnerships aimed at increasing the involvement of PLWA in HIV/AIDS care. In the WHO Western Pacific Region, national frameworks and plans for HIV/AIDS care have been drafted, and several approaches aimed at constructive dialogues and discussions between the community and the health services are being promoted. However, there are certain prerequisites for success, namely, political commitment to comprehensive care and the provision of opportunities for the involvement of PLWA.

3. There are lessons for efforts in HIV/AIDS prevention and care to be learned from the TB programmes that are based on community contributions to treatment. Decentralized community approaches from sub-Saharan Africa and Asia are reported to be more cost-effective and to have a better rate of treatment success than the conventional TB programmes. However, there are certain prerequisites for success: good links between health professionals and the community members involved in TB treatment are essential for quality care.

4. Nursing institutions have the potential to facilitate partnerships between nursing institutions and other health service providers on the one hand and communities on the other hand. Experiences from Thailand suggest that family-based nursing care programmes for patients with HIV/AIDS are both feasible and effective when founded on a strong community base. It is possible to prepare communities to live with HIV/AIDS without stigmatizing families and individuals and to enable family caregivers to develop family-based skills for caring for patients with AIDS. However, there are certain prerequisites for success: projects must be based on respect for human dignity, use holistic approaches that address the spiritual, psychosocial, economic and physical needs of the PLWA, and be rooted in the communities through mobilization, empowerment and networking.

5. Collaboration between the mainstream government health services and marginalized groups is both achievable and necessary. Evidence from Bangladesh indicates that partnerships between government health workers and disadvantaged groups such as sex workers are both possible and functional. However, there are certain prerequisites for success: there must be a willingness to address the priorities of each group of stakeholders, unlimited by the boundaries of any single issue. Effective partnerships might need to go beyond HIV/AIDS or even beyond health to a broader focus on societal justice and development. The lessons from Bangladesh also show that non-professionals have the potential to run their own clinics and, after training, to be able to carry out various administrative and clinical tasks traditionally performed by professionals.

6. Community groups can implement their own HIV/AIDS care and treatment programmes in association with the health professionals. Experiences from Burkina Faso and the Philippines show that PLWA community groups are able to organize and implement comprehensive care and treatment programmes. However,
there are certain prerequisites for success: health workers who are open, encouraging and sympathetic to community-driven initiatives and committed to linking with and supporting the community movement are essential for effective treatment programmes. In communities where many people are affected by HIV/AIDS, community groups are an important source of support for the efforts of health workers who have heavy workloads and are constrained by limited resources.
Section 3
Conclusions and recommendations

OUTCOMES OF THE MEETING

The meeting was chaired by Mr Tesfamicael Ghebrehiwet, Nursing and Health Policy Consultant of the International Council of Nurses (ICN) and Mr Stuart Flavell, International Coordinator of the Global Network of People Living with HIV/AIDS (GNP+). Through the meeting’s plenary sessions and discussions, presentations and small-group work, the participants of the meeting were collectively able to formulate several outcomes. These outcomes were related to identifying strategies and mechanisms for the enhancement of the health services–community interface, identifying ways in which WHO could contribute to strengthening the collaboration between health services and communities, and providing suggestions of avenues that WHO could explore.

The meeting’s participants were in consensus regarding several issues:

- The potential of the concept of the interface offers a great opportunity to move forward with the prevention, care and treatment of HIV/AIDS.
- There were serious constraints on working in partnership with the communities. Most of these constraints were at the level of the health care system, and needed to be addressed.
- There were strategies (based on various successful experiences in the field) that could enhance the interaction between the health services and the community.
- There was a leading role for WHO in putting the strategies into action.
- The next important step is developing a plan of action.

STRATEGIES AND MECHANISMS

Strengthening the capacity of health care systems to interact with the communities

The participants at the Consultation identified several strategies for strengthening the capacity of the health systems to interact with the communities. They considered that further progress would require the triad of reducing the interpersonal barriers between the health workers and the community members, changing the attitudes of the health workers towards the communities, and building capacity to work in partnership with the communities and families. The participants presented several mechanisms that would contribute towards accomplishing these goals. The means of applying the proposed mechanisms would require the development of a true understanding of the community by health workers and application of the concept of “we” rather than “them and us”. Hence “people-centred” approaches will be needed to facilitate mutual and joint learning and to emphasize the necessity for listening to and learning from the local responses of communities and PLWA. The recruitment of PLWA with the necessary skills for all levels of service provision (planning, implementation and evaluation) is also necessary.

The participants also perceived a need for creating enabling environments in which the health services can interface with the communities. Such work would have to involve all the stakeholders and all the levels of the health system in the process of building an enabling environment and bringing about change (towards collective vision, shared values, respect, trust and dignity). The accomplishment of such goals would require a review of the existing human resource frameworks in health to explore how these relate to the interface and how they can provide a foundation for developing human resources for collaborative interaction.

Another direction would entail making effective use of the existing professional bodies and organizations to bring about changes in the practice of professionals in their interactions with communities. These mechanisms will also require improvements to the resources and integration of the local health services, while creating and employing incentive systems for increasing self-esteem, setting a higher value on work done and offering better remuneration to health workers.
Conclusions and recommendations

Strengthening the capacity of the community for interacting with the health services

The participants at the Consultation indicated that the application of a variety of approaches that collectively contribute to community empowerment would be necessary. The mechanisms for these approaches would need to focus on community strengths and assets rather than on weaknesses and deficiencies. They would also build on respect and trust between individuals, while mobilizing the communities and promoting community ownership of projects and programmes. A pertinent point raised was the creation of enabling environments for the community to interface with health services. Such mechanisms would need to alter the balance of power between the health workers and the community by recognizing the expertise and responses of the communities. There is also a necessity to support the work of effective activists, advocates, champions and “boundary-spanners” from the existing community structures. In addition to these mechanisms the creation and employment of incentive systems for increasing self-esteem, setting a higher value on work done, and providing opportunities to increase the financial remuneration for the community is needed. The working groups also called for strengthening of the HIV/AIDS-specific capacity and knowledge within communities where a good understanding of HIV/AIDS prevention, care and treatment issues is required.

Strengthening the processes and methodologies for change

The participants felt that it was essential to acknowledge and mainstream a range of participatory methodologies. The mechanisms for this goal could make use of, and give recognition to, the role and potential of participatory methodologies in the prevention, care and treatment of HIV/AIDS. They could also expose stakeholders at the central and global levels to experiences and lessons from community action initiatives with the aim of influencing policies. There is certainly a place for documenting and analysing the processes and methods that work effectively and produce good results. The working groups also noted that the promotion, exploration and use of participatory methods and tools is essential. Mechanisms to establish participatory methods were suggested such as providing opportunities for PLWA to take leading roles in the participatory processes, the use of bottom-up planning, and the inclusion of civil society members and PLWA. It was also suggested that policies that build on positive community experiences, and methods and channels to feed back knowledge and experiences to the communities should be developed.

WHO ROLES

In general, the role of WHO is seen as being in the area of supporting the institutionalization and replication of the small-scale successes that have been achieved in the health services–community interface. For this to happen, WHO should take a leading role in enhancing the collaborative interaction by reinforcing messages, facilitating the removal of barriers in the health care system and providing global visibility of the achievements possible at the local level.

The participants agreed that WHO should formulate, endorse and advocate a clear policy on the interface. WHO can bring about a process of change in the practice of local health service provision that will move towards collaborative interaction with communities. WHO should network and tap into the resources of a broad variety of organizations and sectors.

Normative role

The participants felt that the normative role of WHO should focus on the development of concepts and frameworks. This would include the development of a viable framework for the concept of the interface and advancement of the interface as a workable public health strategy. The normative role of WHO could also include the facilitation of the development of principles of good practice for the interface and guidelines for countries. Through such activities, WHO will be validating the participatory approaches and partnership building. A further point was the role of WHO in directing the change in policy to make it more conducive to interactions between communities and health services and in expanding the successful but small-scale experiences to a larger scale.

Advocacy role

The participants at the Consultation agreed on the role of WHO as regards advocacy. This would include promoting the concept of the interface and persuading governments to adopt approaches that have been shown to work and to allocate resources for enhancing the concept of the interface between the health services and the communities. WHO will have to advocate partnerships using the evidence on the benefits of partnerships in health, give recognition to the value of civil society and provide visibility of cases in which civil society has been successfully included in health planning and HIV/AIDS service provision.
Research role
The working groups considered the research role of WHO to be a multi-pronged one that embraces three aspects: the building of the evidence base, operational and action research, and monitoring and evaluation.

The evidence base. It was agreed that WHO will need to contribute to building the evidence for the necessity for the interface and local partnerships in health in order to develop evidence-based policies and to justify approaches.

Operational and action research. WHO could document and analyse methodologies that work for partnerships to enable identification of the critical factors that bring about change and lead to success. A further role identified was the demystification of research and the promotion of participatory research methods that will allow NGOs and communities to document the experiences themselves and will maximize the dissemination of lessons learned by the communities.

Monitoring and evaluation. WHO could promote and provide guidelines for the monitoring and evaluation of partnership processes and of the performance of local health services in partnerships with communities.

Capacity-building role
The participants suggested that WHO has a role in capacity building that embraces both the health services and the community. As regards the health services, WHO’s role was seen as facilitating the development of an enabling environment for building capacity and expertise in participatory methods and partnerships, and the development of appropriate guidelines and manuals. Participants considered that WHO will need to provide support to countries in building capacity, in resource allocation and formulation of incentives for forming partnerships with communities. The role would also include networking and making use of the existing professional organizations and training institutions in capacity building and supporting countries to develop strategies for the involvement of the next generation of health workers in partnership work.

In connection with community capacity, the working groups indicated that the role of WHO would be to recognize and build on existing community responses and actions, while networking with NGOs and CBOs that can help with community capacity building. It would also embrace the provision of support to community organizations in building the necessary capacity for the interface and for HIV/AIDS prevention, care and support and develop appropriate manuals.

Role in facilitating and supporting implementation
As regards role-modelling, the working groups felt that the WHO role would be to demonstrate its commitment to enhancing the interface. This would include a position statement or declaration about the interface and the value of partnerships, as well as the implementation of the necessary activities and the allocation of resources to this area of work. A further point was the bringing about of internal institutional changes within WHO that could contribute to the credibility of partnerships (e.g. WHO’s own relationship and partnership dialogue with NGOs, and the position on PLWA who are employed by WHO).

Suggestions to WHO for follow up
The participants made the following suggestions:

◗ That WHO Headquarters take a leading role in advocating the development and enhancement of the notions of the interface and partnerships. WHO will need to recommend ways of enhancing and promoting the collaborative interactions movement and of facilitating the global exchange of information on collaborative partnerships at the interface between the health services and the community. A centralized role will be required, as this work goes beyond the capacities of the regional offices.

◗ That WHO bring together an ad hoc group to carry forward the agenda and recommendations arising from this international meeting.

◗ That there be an exploration into whether donors with related agendas are willing to fund this WHO initiative.

◗ To pose the interface as a prominent feature of the International Treatment Access Coalition (ITAC).

◗ That WHO form links with other agencies with similar concerns and explore the possibilities for complementary roles.
Conclusions and recommendations

◗ That there be joint development with relevant partners of a framework for partnership between health services and communities. Such a framework will need to incorporate the principles of good practice learnt from experiences in various countries that have promising strategies for strengthening the capacity of health systems to interface with communities and, similarly, to strengthen the ability of communities to interact with health systems.

◗ Different parts/sections of WHO have different relationships with countries based on global, regional or country connections. Such relationships need to be utilized and could contribute to the playing of different and harmonizing roles in taking the agenda forward and making progress.
# Annex
## List of abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
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<tr>
<td>CBO(s)</td>
<td>Community based organization(s)</td>
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<tr>
<td>CHW</td>
<td>Community health workers</td>
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<tr>
<td>CSO(s)</td>
<td>Civil society organization(s)</td>
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<tr>
<td>DRI</td>
<td>District Expanded Response Initiative</td>
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<tr>
<td>GFATM</td>
<td>Global Fund to Fight AIDS, Tuberculosis and Malaria</td>
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<tr>
<td>GIPA</td>
<td>Greater involvement of people living with HIV/AIDS</td>
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<tr>
<td>GTZ</td>
<td>Deutsche Gesellschaft für technische Zusammenarbeit (the German bilateral technical cooperation agency)</td>
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<tr>
<td>HBC</td>
<td>Home-based care</td>
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<td>HCD</td>
<td>Human capacity development</td>
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<tr>
<td>ICASO</td>
<td>International Council of AIDS Service Organizations</td>
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<tr>
<td>IEC</td>
<td>Information, education and communication</td>
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<tr>
<td>ILO</td>
<td>International Labour Organization</td>
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<tr>
<td>LC(s)</td>
<td>Local council(s)</td>
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<tr>
<td>LR</td>
<td>Local response</td>
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<tr>
<td>MTCT</td>
<td>Mother-to-child transmission</td>
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<td>NAP(s)</td>
<td>National AIDS programme(s)</td>
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<tr>
<td>NGO(s)</td>
<td>Non governmental organization(s)</td>
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<tr>
<td>PAHO</td>
<td>Pan American Health Organization</td>
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<tr>
<td>PAR</td>
<td>Participatory action research</td>
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<tr>
<td>PHC</td>
<td>Primary health care</td>
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<tr>
<td>PLWA</td>
<td>People living with or affected by HIV/AIDS</td>
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<tr>
<td>PRA</td>
<td>Participatory rapid appraisal</td>
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<tr>
<td>SEARO</td>
<td>South-East Asia Regional Office</td>
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<tr>
<td>STI(s)</td>
<td>Sexually transmitted infection(s)</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>TDR</td>
<td>UNDP/World Bank/WHO Special Programme</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<tr>
<td>UNDP</td>
<td>United Nations Development Programme</td>
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<tr>
<td>UNGASS</td>
<td>United Nations General Assembly Special Session on AIDS</td>
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<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
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<tr>
<td>VCT</td>
<td>Voluntary counselling and testing</td>
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<tr>
<td>WHA</td>
<td>World Health Assembly</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>WPR</td>
<td>Western Pacific Region</td>
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<td>WHA</td>
<td>World Health Assembly</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Recommended citation

In citing it is recommended to use the title and author name of the original article.

For example: