Engaging the Community in the Fight against HIV

Community Planning Methods and Approaches

April 2007
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Who is this module for?
This training module is designed for Caribbean National AIDS Coordinators (NAC).

What is this module for?
To give NACs various tools with which they can:
1) Mobilize community and promote ownership and responsibility for addressing the epidemic.
2) Engage community in participatory HIV planning processes.
3) Empower community to develop interventions to address service gaps, population specific and regional needs.

What is in this module?
The module describes concepts of community involvement and provides examples of the different ways in which community is involved in HIV planning and implementation. It is intended to raise issues that a NAC might want to consider as he/she moves forward with participatory programs.

Introduction: Addresses definitions of community and provides rationale for involving community in HIV prevention programs. It provides tips for establishing, supporting, and maintaining participatory and community planning groups.

Chapter One: Community Planning for Advocacy and Group Action. This chapter describes why community groups are an important mechanism for advocacy, and explains how such groups can advocate for changes in policy or improved services, as well as develop and implement plans of action.

Chapter Two: Community Planning for Service Inventory and Prioritization. This chapter describes why it is important for community to establish their own HIV program priorities, and explains how community groups can use their understanding of the HIV needs of the community and their knowledge of available HIV services to identify gaps and establish community priorities.

Chapter Three: Community Planning for Monitoring and Coordination: This chapter describes the role of community that community groups can play in coordinating HIV program activities, as well as the monitoring methods they can use to hold providers accountable to commitments they make in plans and actions.

What is “community”? It is very challenging to define “community”, and in general it is probably most helpful to agree that definitions can be fluid. Community can be defined
- Geographically (neighborhood, town),
- By affiliation (students attending a particular school may define themselves as a school community),
- By shared cultural or ethnic traits (e.g., the “Puerto Rican” community).
- In the field of HIV, communities are often defined by the behaviors that put them at risk for HIV (e.g., the MSM community, the IDU community, etc).
**Why should I try to involve the community?**

*Supports National AIDS Program activities*
Developing a formal structure through which to involve community helps you, the NAC to educate the public about what you are doing, what resources are available, and the limitations that you are confronting. With this understanding, the community is empowered to advocate on behalf of the National AIDS Program when you may be unable to do so.

A formal structure provides a supportive environment and platform for community and government to confer about HIV free from many of the usual political dynamics. In this setting, community and government can learn from each other, (which builds trust), and together begin to confront some of the social barriers (gender, race, behavior) that contribute to the HIV epidemic.

*Improves the impact and sustainability of HIV services*
Since the community is the recipient of HIV services, their early engagement in HIV service selection and design improves the responsiveness and effectiveness of the services, and promotes service buy-in and utilization.

*Is itself an HIV prevention intervention*
Involving community in the HIV response promotes awareness in the community of the epidemic, and builds community capacity and understanding of how to respond.

A community planning group helps members address stigma and denial by providing a supportive environment and a structured forum for consumers to learn how to speak out about the disease.

A community planning group builds its own norms and expectations which influence the individual behaviors of its members – therefore, community involvement can be an intervention for HIV risk reduction and behavior change.

*Builds community capacity.*
Community involvement builds community leadership and human resources: it places community advocates in positions where they can learn about the epidemic, how to work with others in the community, how to articulate a position, etc.

**How do I establish a community planning group?**

*Address Parity, Inclusion, Representation:*
Fundamentally, community planning is a consultative process, and must therefore reflect an open, candid, and participatory approach, in which differences in cultural and ethnic background, perspective, and experience are essential and valued. HIV community planning processes can be found across the world, including in the United States, Cambodia, Botswana, Ethiopia, Zambia, and elsewhere. The articulation and attempt to uphold the principles of parity, inclusion, and representation are a hallmark of all of these processes.
**Representation** is defined as the act of serving as an official member reflecting the perspective of a specific community. A representative should truly reflect that community’s values, norms, and behaviors. Members should have expertise in understanding and addressing the specific HIV prevention needs of the populations they represent.

**Inclusion** is defined as meaningful involvement of members in the process with an active voice in decision making. An inclusive process assures that the views, perspectives, and needs of all affected communities are actively included.

**Parity** is defined as the ability of members to equally participate and carry-out planning tasks/duties. To achieve parity, representatives should be provided with opportunities for orientation and skills building to participate in the planning process and to have equal voice in voting and other decision making activities.

Examples of methods that can be used to achieve Parity, Inclusion, and Representation include:

**Inclusion**
- Holding meetings after working hours or at weekends to accommodate working members and youth in school or college.
- Take the issue to the community through focus groups, interviews, or working with service providers.
- Providing child care, stipends, and bus tokens to support participation of members.

**Parity**
- Mentoring new members to introduce them to the work of the group.

- Ensuring clarity around process. Establishing goals and objectives, expected outcomes, and communicating these to participants.
- Providing orientation to new members.
- Establishing ground-rules for communication.
- Establishing a decision-making process and methods to resolve conflict.

**Representation**
- Clarifying roles and responsibilities; using the existing knowledge and skills of community members and not expecting them to do/be what they are not.

**Clarify the purpose and authority of the community planning group**
A community planning group is established by a NAC when the advice and direction of the community is critical for successfully addressing an AIDS program issue. It is important to begin with to be clear about the nature of the issue, and how exactly you wish the community to assist. The group must be accorded the authority necessary to perform the task it has been given. The following questions might be asked:

- What is the group to do? (For example, provide information, make decisions, and perform activities).
- How will authority be accorded to the group? (For example, through legislative mandate, through a MoU or development of bylaws, through a concurrence process – e.g., that funding applications developed by the NAC reflect the priorities identified by the community group).
- Who will lead the group? (For example, the NAC, a community member, or co-chairs with representation from both entities).
Community Planning Methods and Approaches

- Who will facilitate the group? (For example, an independent facilitator, the NAC, or the co-chairs?).
- How will decisions be made? (For example, the NAC will use the input of the group to make decisions, the group will make decisions through consensus, or the group will make decisions through majority vote).

**Clarify the size, length of existence, and number of group(s)**
Other factors to be considered when forming a group might include geography, population, and the political and environmental context. In general, a group should be established at the broadest level that makes sense to achieve its purpose. Establishing multiple groups can result in duplication of work, miscommunication, cost more in terms of time and resources, and set up false expectations.
- National groups should be established when national issues (e.g., national policy or multi-sectoral approaches) are being considered.
- Regional groups should be established only if regional contexts and/or the regional HIV epidemic vary significantly enough to suggest that the outcomes or decisions of the group would vary regionally.
- Long term groups are best suited to provide input to ongoing activities such as comprehensive planning, or repeated funding proposal development.
- Short term groups are best suited to provide input to one-time only or widely spaced recurring activities, such as to legislatures that might only develop policy bi-annually, or to a proposed one-time only revision to national counseling and testing policy.
- A short term group may be appropriate in areas where migration is extensive.

**Consider Composition**
The primary purpose of establishing a community planning group is to provide the NAC with a structured way to access the diversity of opinion and knowledge within the community – therefore, regardless of its ultimate purpose the community planning group must have representation from multiple stakeholders. It is of critical importance to include your consumers, or those populations most impacted by HIV in the community planning group, for example, people living with HIV and AIDS (PLWHA), injecting drug users (IDU), men who have sex with men (MSM), substance users, commercial sex workers (CSWs). Other stakeholders might include service providers, representatives of local government, representatives from the private sector, community advocates, non-governmental organizations, faith-based organizations, donor agencies, and the media.

**Start Up & Establishing Membership**
Ultimately, a community planning group is only effective if there a trusting relationship between members and all members “buy-in” to the process. This is usually best achieved when members feel that they have a “say” in the process used to establish the group, and that this process was fair and open. There are a variety of methods to appoint, select, or elect members to a community planning group, and we recommend that whichever approach is most likely to result in buy-in of both community and the NAC should be used. Some pointers / suggestions include:
- Since the group should include people (including consumers) who have knowledge and experience of the issues to be addressed, creating categories of representation may be helpful (e.g., MSM, IDU, PLWHA, government, law/police, service
provider, experts, etc.). Potential members can then be selected from these categories.

- Asking an existing community group or groups to define a list of candidates for membership which NAC then selects from.
- Creating an open application process, using a selection committee of both government and community representatives to select successful candidates.
- Once a community planning group is established, it can take on the task of recruiting and selecting its own members.

Since the community planning group is to engage community in a meaningful way, the process by which a planning group is established should be transparent, and communicated to the public. It is therefore helpful to create a written protocol that documents the process used to start up the community planning group, and which is used to promote and publicize the group to the community. This protocol should clarify:

- The goal or purpose of the group.
- The life expectancy of the group, and meeting schedule.
- The authority under which the group is being established.
- The proposed decision making process. For example, will decisions be made by the initiating agency with advice from the group, or will the group make decisions through majority vote, consensus, or some other decision making process?
- Proposed membership, and the process by which members will be recruited and selected.

**Recruitment**
Develop a plan for recruiting members to your group. Recruitment activities might include:

- Working with community leaders to promote the community group, and to help you identify appropriate outreach venues. However, the NAC also needs to be visible in this process to promote trust and relationship building.
- Presentations at public health events, churches, barber shops, bars, schools, and community centers. The presentations might provide an overview of the impact of the HIV epidemic on the community, a description of your planning process as outlined in your protocol, and distribution of membership applications if you choose to establish membership in that way.
- Distribution of written materials through service provider organizations, and to media organizations. Materials should include essential elements of why you are communicating these activities, and what you want the response to be, and should be linguistically and culturally appropriate (multi-modal).

**Retention**
Community members have many different reasons for volunteering their time to participate in a community planning group. To retain members it is important that the group be able to address these reasons. For example, members participate because they

- Want to help fellow community members
- Feel that their talents and skills are being put to good use
- Feel that the agency they are working for is trustworthy, and effective – well respected in the community
- Feel that they are making a difference
- Feel that they are learning something new
- Know exactly what is expected from them
- Experience camaraderie and fun, they like being with other members
- Appreciate community recognition and thanks

Actions that a community planning group can take to help retain its members might include:

- **Mentorship** – pair a new member with a more experienced member who can help explain what is to be expected, provide a personal link to the group, and provide the newer member with personal recognition and thanks.
- Developing a process that allows members to contribute in different ways that match their skills and needs
- Making sure that a decision or an action occurs at every meeting, not just discussions
- Being organized.

### Challenges to Recruitment & Retention

Recruiting individuals to participate in a HIV community planning group poses some special challenges.

**Stigma**: Fear and condemnation of people infected with HIV, or of people at risk for HIV inhibits members of at risk populations (such as injecting drug users, MSM, or commercial sex workers) from revealing who they are, while others may not want to work or communicate with infected or at risk people. There is no easy answer to the problem of stigma. Some of the following actions might help:

- Creating a formal space and process in which NAC is seen to value HIV positive and at-risk individuals, and treat them equally
- Articulating, discussing, and following principles of equality, parity, inclusion and representation
- Recruiting at-risk or HIV positive individuals to “tell their stories” during recruitment and orientation

**Access**: For many stakeholders for whom HIV is a critical issue, accessing a community planning group can be complicated. Working people, or youth in school may not be participate during the day; others may not have transport to a community planning group meeting, or be able to find child care so that they can attend. Some strategies to address this challenge include:

- going to the community to solicit input; e.g., holding an after-school pizza session for youth, visiting a prison to talk to inmates or a gay bar to talk to MSM. Even if community members cannot participate in a group, opportunities can still be created for them to have their say.
- holding meetings at evenings or weekends.
- providing stipends to working people to compensate for lost earnings.
- reimbursing for, or providing child care and transportation.
- and, always – providing snacks or a meal during the meeting!

**Knowledge**: While many community members can speak to their individual experience of being infected or affected by HIV, they may not know about the HIV epidemic, the topic at hand, or about group process and group decision-making. There are two important strategies to address this challenge:

- To call upon community members to provide the useful knowledge that they do have, and not require of them to provide knowledge that they do not. If additional knowledge is needed, recruit additional members to the group who can provide it (for example, epidemiologists, planners, policy makers, etc).
- Provide orientation and training to all members sufficient that they can participate effectively in the process.
Monitoring and Evaluating the Process.
It is valuable to set up a process from the outset that can collect information about the productivity, effectiveness, and performance of group. It is important to
- Share the information collected with the group (the group should be able to observe the impact of their work).
- Use the information collected to modify the composition/process of the group if it is indicated.

Implementation Challenges
There are multiple challenges associated with establishing and maintaining a community planning group including:
- Natural tension between government and community.
- Time constraints.
- Changes in the HIV epidemic changes.
- Lack of funding / resources.
- Undue influence of members.
- Creation of breakaway factions.
- Becoming distracted by false choices (e.g., that at-risk populations must compete for limited resources, rather than working together to leverage additional resources).

Such challenges are inevitable, and best addressed when anticipated and prepared for. Establishing a clear and simple process, maintaining transparency and good communication, ensuring skilled facilitation, and prioritizing issues of parity, inclusion, and representation are all appropriate ways in which to address these challenges.

Resources (Appendix A)
NASTAD (2006): HIV community planning for community ART treatment adherence. Session Seven: Mobilizing the Community and Implementing the Plan

NASTAD 2006: HIV community planning for community ART treatment adherence. Session Five: Involving people living with HIV/AIDS.


Chapter One: Community Planning for Advocacy and Group Action

Introduction
There are two ways in which the community can act: by taking an action or providing a service itself or by demanding that others do so (advocacy). When both these occur, we can say that the community is “mobilized”, or “empowered.” It is often in the best interest of a NAC to support community mobilization, since there are many factors that contribute to the HIV epidemic that cannot be addressed by government alone. Stigma, gender inequity, discrimination, and harmful traditional or cultural practices and beliefs can only be impacted by the community itself. Community planning can be a way to empower or mobilize community members, since it provides community members with access to information and skills, and since it creates and supports a structure through which community members can work together.

How can a Community Planning Group Become Advocates?

Identify a common interest. What is the problem the community wants to work on? What is urgent about this problem, and what is happening in the environment about this problem that presents an opportunity to the community to work on it now? For example, perhaps there is a piece of legislation that the community wishes to oppose or support; perhaps an incident in the community or media event has occurred resulting in heightened awareness of an issue.

Identify who or what you are trying to influence. Legislators/elected officials should be the target group when a policy to be changed or develop. Funding issues might need to be addressed by donors, or by legislators.

Identify the players who you would like to work with you, as well as those who might oppose you. Gather information about these influential stakeholders, including their background and history.

Develop your position and your message. What arguments are you going to use to support your position? The best messages are simple ones. Use research, data, and experience to support your arguments (anecdotes are not sufficient).

Develop your strategy: Advocacy can happen through:
- Personal contact
- Group intervention (protests)
- Voting
- Developing legislation
- Hiring or working with professional or volunteer lobbyists
- Media
- Community education

Build advocacy skills of the community planning group
- Talking to legislators/politicians/media
- Understanding the political process
- Preparing talking points and counterarguments
- Manage the media/community events/site visits
- Supporting infected and affected persons to talk about their lives (mentorship, community support).
How can a Community Planning Group take Action?
A community planning group can take action to perform HIV prevention, provide services and promote access to care. The group members themselves can choose to take action, or they can use their collective focus and planning skills to work with community members outside of their group to take action.

If the community planning group is a local one, it can perform basic grassroots actions, including, for example, developing brochures, planning community awareness events, developing TV and radio spots, setting up buddy systems for individuals and families impacted by HIV, and providing home based care.

If the community planning group is a regional one, with an understanding of the range of available services in the region and connections to multiple service providers, it can perform more on-going activities, such as setting up community outreach programs, planning series of speakers or events, and promoting linkages and referrals between providers.

Recruiting Community Members to help with the Service Plan
Examine the composition/membership of the community planning group. Members who can help develop and implement an action plan include those who have

- Influence – people with extensive and active social networks (the ones who know all the gossip!)
- Respect – people who are respected in the community – religious leaders, teachers, midwives/traditional birth attendants, etc.
- Organizers – people who can get things done, and get other people to do them
- PLWHAs and their families and friends – people who know about HIV, and can tell others about it

Organizing the Community for Action
- Chapter Two of this module provides guidance to a community planning group on how to develop a plan for WHAT to do in the community
- Once the community planning group has developed a plan for WHAT to do, it must also develop a plan for HOW to do it (a work-plan).
- Plans ALWAYS use the same framework
  o What is the outcome (goal)?
  o What activities will be performed to achieve the outcome (objectives and activities)?
  o Who will conduct the activity, what resources will they use? How will they conduct the activity, When will they conduct the activity (work-plan)?
  o How will you know when the activity has been done and the outcome achieved (evaluation)?

Managing People and Assigning Tasks
Once a plan has been developed, it is important the community planning group agree on a process to implement it. The group should
- Choose a member or members to be in charge of organizing and implementing a work plan.
- Choose members to perform the activities identified in the work plan
- Consider whether training for community planning group members is needed in order to help them learn how to develop and conduct those activities
- Consider who will coordinate and deliver that training.

<table>
<thead>
<tr>
<th>How will the Community Planning Group choose a member to be in charge of organizing and implementing a work-plan?</th>
<th>Is the NAC co-chair or some other provider assigned to be in charge?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Should this person be selected by the rest of the Committee – perhaps on a rotating basis?</td>
</tr>
<tr>
<td></td>
<td>This person should have trust and support of the rest of the Community Planning Group.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How will the Community Planning Group choose members to work on developing and implementing a work-plan?</th>
<th>Community Planning Group develop tools and policies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Distribute a “skills and interest” survey to all Community Planning Group members</td>
</tr>
<tr>
<td></td>
<td>Match activities with skills and preferences of Community Planning Group members</td>
</tr>
<tr>
<td></td>
<td>Develop policies that clearly define expectations for performing activities – e.g., hours per month of volunteerism, participation on work-plan development committees, etc.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What kind of training do Community Planning Group members need to help them conduct the activities? Who will give it to them?</th>
<th>Does the NAC or some other provider have responsibility or capacity to train community members?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>What training manuals or tools already exist that can be accessed by the Community Planning Group?</td>
</tr>
</tbody>
</table>
Develop Work-Plan for Implementation of an Intervention.

**Intervention**  Develop and distribute brochure to address need lack of knowledge of resources of population Community Leaders

<table>
<thead>
<tr>
<th>Activities (What do you need to do to make the intervention happen?)</th>
<th>Resources Needed</th>
<th>Who is Responsible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seek funds for this effort: Kabele AIDS Committee chair and Health Extension worker submits request for funds as part of annual plan to HAPCO OR Support in kind is sought from local NGOs or churches.</td>
<td>Skills, time, access to computer to develop request for funds Skills, time to solicit support from NGOs/churches</td>
<td>Kabele AIDS Committee chair and Health Extension worker OR Member G – church leader.</td>
</tr>
<tr>
<td>Research and list available community resources, who they serve, locations, hours of opening, and cost of services</td>
<td>Skills, time, access to computer to develop resource list</td>
<td>Health Extension worker will coordinate. Kabele AIDS Committee members X, Y, Z will contribute</td>
</tr>
<tr>
<td>Develop a prototype brochure that lists primary resource – use pictures, lots of space. Keep brochure short.</td>
<td>Skills, time, access to computer, access to pictures.</td>
<td>Member F (works for Save the Children) will ask Save the Children social marketing director to assist in this effort.</td>
</tr>
<tr>
<td>Kabele AIDS Committee reviews prototype brochure, and makes any changes</td>
<td>Copier</td>
<td>Kabele AIDS Committee chair, with members F, X, Y, and Z</td>
</tr>
<tr>
<td>Brochure is finalized and printed</td>
<td>Money and access to printer.</td>
<td>Kabele AIDS Committee chair and Health Extension worker OR Member G – church leader.</td>
</tr>
<tr>
<td>Brochure is distributed throughout the community</td>
<td>Time to distribute by hand, or resources to distribute by mail.</td>
<td>Members A, B, C, D, and E agree to distribute the brochure to friends, families, churches, schools, etc</td>
</tr>
</tbody>
</table>
Introduction
Because resources for HIV prevention and control are limited in most settings, it is important that they are not diffused, but directed to those groups and activities where they can have most impact. To ensure that these resources reach those most in need, and that the decision-making process is perceived as fair and transparent, two critical components must be present: the first is use of data and evidence to make prioritization and allocation decisions; and the second is involvement of those communities for whom resources are to be allocated in the decision-making process. Prioritization and resource allocation should occur at any level where decisions are being made about HIV control activities. This could be at a village or community level, at a city or regional level, or at a specialized national level. Regardless of the level at which decisions are being made the same approach is taken:

1. Epidemiologic Profile: The community planning group examines the available information about the epidemic and learns about the impact of the epidemic at that level (i.e. who is being impacted by the disease, where, and why).

2. Needs Assessment: The community planning group identifies and collects any additional information they need to make decisions by performing needs assessment (learning why people are at risk, and what is needed to address the epidemic).

3. Service Inventory and Gap Analysis: The community planning group familiarizes itself with services that are already available, so that they can determine, based on the needs assessment, which services are still needed.

4. Prioritization: The community planning group determines which of all the services that are needed, are most important to do.

5. Documentation: The community planning group documents their decisions in a plan.

Epidemiologic Profile.
It is important that communities use whatever data is available to make their decisions. Using an evidence-based process helps to address the impact that stigma and political perspectives may have on the anecdotal evidence that is provided or shared by the community and/or by the government. One of the responsibilities of a National AIDS Coordinator is to ensure that there exists an epidemiologic profile for the country that includes local, regional and national data. This information may be sufficient for a community to make decisions – but special studies may also be needed to gather additional relevant information or to validate anecdotal evidence provided by the community.
**Needs Assessment**

Needs assessment can be performed by the NAC, or by the community itself. In either case, it is important that community members should be involved in the design and implementation of assessments of their own communities. Community members can be involved by:

- Identifying needs assessment priorities and questions.
- Identifying appropriate needs assessment methods.
- Participating in the collection of the information by engaging the identified community, by conducting focus groups, leading public meetings or hearings, performing door-to-door canvassing, or engaging in literature research.
- Helping to develop summary findings.

Needs assessment activities can have a broad focus, and be performed to learn more about disenfranchised or stigmatized risk populations for whom such information is often lacking.

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**RAR (Rapid Assessment and Response)**

Uses multiple tools (e.g., key informant interviews, focus groups, and surveys) to collect data on WHO, WHAT, WHERE, WHEN, AND WHY in the areas of context, risk/protective factors, and interventions.

- A Brief Introduction to Rapid Assessment. [The Centre for Research on Drugs and Health Behaviour](http://www.rararchives.org), Imperial College, University of London.
- Rapid Assessment, Response and Evaluation. [RARE.pdf](http://cbr.cbrc.net/files/1032733986/RARE.pdf)

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**PLACE (Priorities for Local AIDS Control Efforts)**

The PLACE Method uses available geographic and contextual data to identify “priority prevention areas” and then assess HIV prevention program coverage among persons socializing in these areas at venues most likely to attract people with high rates of new sexual or needle sharing partnerships. It offers the following strategy for assessing a local epidemic:

1. Convene a national level steering committee to identify Priority Prevention Areas (PPAs) in the country. These areas could include red-light areas, transportation corridors, border stations, etc; the steering committee also identifies key populations of interest, such as sex workers, injecting drug users, or youth relevant to each of these PPAs.
2. Develop a protocol based on these decisions for implementation in each PPA.
3. Identify places where people meet new sexual partners and/or injection drug users socialize in the PPA.
4. Visit, map, and characterize these venues.
5. Interview sample of persons socializing at the venue.

**MEASURE Evaluation Priorities for Local AIDS Control Efforts (PLACE)**

[https://www.cpc.unc.edu/measure/leadership/place.html](https://www.cpc.unc.edu/measure/leadership/place.html)

When the community examines the evidence presented to them in an epidemiologic profile, questions may arise that are too specific to be answered by a broad assessment such as a RAR. In this instance, it is
important for the group to be as clear as possible about the nature of their question - clarifying, for example:

- Whether they wish to learn more about a group at risk for HIV, or about what kinds of services are needed.
- The specific questions that must be asked in order to collect enough information to address the identified problem

- The methods by which the data will be collected.

The following table provides an example of a process that a community planning group can use to clarify their needs assessment activities.

<table>
<thead>
<tr>
<th>Target Group /Service</th>
<th>To learn what?</th>
<th>Because of which finding in Epi Profile?</th>
<th>Assessment questions (examples)</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Pregnant HIV+ women</td>
<td>What barriers prevent known HIV positive women from accessing PMTCT?</td>
<td>While 500 pregnant women test positive each year, only 250 women receive PMTCT</td>
<td>Do pregnant women know about PMTCT services? What would help them reach PMTCT services (child care, transportation, buddy system?) Do they find the services caring, competent? How do people in their community treat women who access PMTCT? What are the hours of PMTCT service? How easy is it to get an appointment? Are there waiting lists?</td>
<td>Focus group of HIV+ pregnant women</td>
</tr>
<tr>
<td>2. PMTCT services</td>
<td></td>
<td></td>
<td></td>
<td>Interviews of PMTCT service providers</td>
</tr>
</tbody>
</table>

Service Inventory and Gap Analysis

Once a community planning group understands which groups in their community are most at risk, and why, they must understand which services are already available to those groups, and which are still needed. A services inventory is usually performed and maintained by a government agency, and made widely available to the community for two reasons: first to promote networking and referral between existing services; and second, in order to know what is available and to identify gaps in services. A service inventory is most useful when it considers a wide range of resources, and might include curanderos or bush doctors (traditional healers), community leaders, churches/mosques, as well as clinics, CBOs, community centers, etc.

Gap analysis is a process that compares the content of the service inventory to the recommendations developed through the needs assessment to identify still needed services. The following steps can be followed.

- Needs assessment findings should be presented to the community, and the community should have an active participatory role in design, execution, and analysis, and formulation of findings, preliminary conclusions and recommendations.
- Look at the available services – do they address the recommendations included in the needs assessment?
Remember that in addition to lacking a service altogether, lack of information about services, barriers to accessing a service, and poor quality of a service are also gaps. 

- Describe in as much detail as possible the service that is still needed (including who it is for, where it needs to be located and what it needs to be doing).

The following table provides an example of a process that a community planning group can use to clarify their gap analysis.

<table>
<thead>
<tr>
<th>Groups that most need to be targeted</th>
<th>Activities that are already reaching this group</th>
<th>What activities are still needed by this group?</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV+ pregnant women in three regions</td>
<td>Voluntary Counseling and Testing</td>
<td>Provision of PMTCT services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- counseling</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- support groups</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- nevarapine at time of delivery</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Infant course of nevarapine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Integrate PMTCT program into existing VCT programs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 regional sites</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NAC</td>
</tr>
</tbody>
</table>

**Prioritization**

Prioritizing HIV interventions and activities and thereby providing guidance on resource allocation is a vital role for community in planning. It is appropriate for the community to participate in this way because

- They may implement or oversee the chosen activities.
- It promotes buy-in and support of the chosen activities.
- Since resources are limited, and usually provided by government, community prioritization provides an appropriate “check and balance” to government influence.

Prioritization is the critical stage in planning before engaging in action: it is when the community determines which interventions or activities to execute in a timely, viable manner.

All steps taken to this point have provided the community with the information they need to make the best possible decisions. Next steps are to:

1. Take the set of interventions identified in gap analysis
2. Agree on criteria by which prioritization will occur
3. Apply criteria in a decision making process
4. Discuss and come to consensus on outcomes of decision making process.

What are criteria? Criteria are simply pieces of information that can be considered when trying to make choices. When a group is trying to come to a decision together, it helps if every member in the groups thinks about the decision in the same way (applies the same criteria). Examples
Community Planning Methods and Approaches

of criteria that might be considered when choosing between HIV activities might include.

- Donor/political mandates which may require specific activities to be performed.
- Available resources/capacity to perform the activity.
- Whether the activity addresses the short term impact of HIV (i.e., provides care and treatment) or the long term impact (i.e., provides prevention). Clearly both kinds of activities are needed.
- Geographic location of the activity.
- Numbers reached by the activity.
- Acceptability of activity to the targeted group.
- Effectiveness of intervention in changing behaviors, preventing transmission or delivering care/treatment.
- Cost (including thinking about start-up costs vs. expansion/continuation costs)

There are many ways in which a community planning group can apply these criteria in a decision making process. Whatever method is chosen, it is important that:

- The method reflects parity, inclusion, and representation; i.e., that all participants in the group have an equal voice in the decisions being made.
- All members of the community planning group understand the method, and agree that it should be used.
- The group has the opportunity to discuss and review the outcome of the method used.

**Nominal group process**

The benefit of this method is that it results both in a selection of a slate of options, and differentiates between them (results in a ranking of options). In this method, choices are listed on newsprint around the room, and individuals in the group are each given a certain number of “votes” (a checkmark, or a sticky dot). This number varies according to the number of choices to be made – usually each person should receive votes in the amount of one quarter to one third of the available choices. For example, if there are 40 options to choose among, voters receive about 10 votes each. Each person then can apply their votes to the available options in whatever quantity they choose: they can place all 10 votes against one option, or distribute their votes across up to 10 different options.

**Consensus**

In this method, the group together strives to come to agreement about a choice. Unlike the nominal group process, it allows for members of the group to discuss the issue at hand, and influence each others’ opinions. It is best used when trying to come to agreement about a single proposal, being quite cumbersome and time-consuming for use in ranking many options. The method is as follows:

- Discussion of the item: The item is discussed with the goal of identifying opinions and information on the topic at hand.
- Formation of a proposal: Based on the discussion, a formal decision proposal on the issue is presented to the group.
- Call for consensus: The facilitator of the decision-making body calls for consensus on the proposal. Each member of the group usually must actively state their agreement with the proposal, often by using a hand gesture or raising a colored card, to avoid the group...
from interpreting silence or inaction as agreement.

- Identification and addressing of concerns: If consensus is not achieved, each dissenter presents his or her concerns on the proposal, potentially starting another round of discussion to address or clarify the concern.

- Modification of the proposal: The proposal is amended, or re-phrased in an attempt to address the concerns of the decision-makers. The process then returns to the call for consensus and the cycle is repeated until a satisfactory decision is made.

- When consensus cannot be reached a dissenting participant can:
  1. Declare reservations: Group members who are willing to let a motion pass but desire to register their concerns with the group may choose "declare reservations." If there are significant reservations about a motion, the decision-making body may choose to modify or re-word the proposal.
  2. Stand aside: A "stand aside" may be registered by a group member who has a "serious personal disagreement" with a proposal, but is willing to let the motion pass. Stand asides may also be registered by users who feel they are incapable of adequately understanding or participating in the proposal.
  3. Block: Any group member may "block" a proposal. Blocks are generally considered to be an extreme measure, only used when a member feels a proposal "endanger[s] the organization or its participants, or violate[s] the mission of the organization" (i.e., a principled objection). In some consensus models, a group member opposing a proposal must work with its proponents to find a solution that will work for everyone. Another method of addressing a block is to move to a majority vote.

**Majority Vote:**
As with consensus, a majority vote is best used when trying to come to agreement about a proposal. In a majority vote, each member registers their approval or disapproval, and the approach agreed upon by the most members is taken.

**Documentation**
Your community planning group should have documented how they carried out each step in their planning process and what their decisions were at each step. Creating a plan is a matter of summarizing processes and decisions. Once completed, the plan will serve as a guide to the community and to funders to help them decide what activities to support. The plan will also serve as a guide to non-governmental organizations, clubs, organizations, and others to help them develop proposals for funding.

The following chart provides guidelines for putting the plan together. It is not intended to show you how your plan should look. Instead, use it as a guide to help ensure that you include important information in your plan.
<table>
<thead>
<tr>
<th>Step</th>
<th>Describe Process</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop an epidemiologic profile</td>
<td>What data do we have? What populations are infected/affected? What populations are most at risk? What are the risk factors in our community? How reliable are the data? What data were collected?</td>
<td>Conclusions drawn from the data</td>
</tr>
<tr>
<td>Needs Assessment</td>
<td>What do we know about at risk groups in our community? Are there specific questions that arise from the available data? What methods were used to collect additional data?</td>
<td>Needs assessment findings. Recommendations developed as a result.</td>
</tr>
<tr>
<td>Community Services Inventory</td>
<td>Document available resources</td>
<td>Results of information collected</td>
</tr>
<tr>
<td>Gap Analysis</td>
<td>Compare needs identified with available resources. What, where, and how big are unmet needs (gaps)? What activities need to be performed? Who will conduct the activities? How will the activities be performed? What is the expected outcome?</td>
<td>Interventions—what, who, when, and how they will be done—identified based on unmet needs</td>
</tr>
<tr>
<td>Prioritize Interventions</td>
<td>Develop criteria that the group has agreed upon to prioritize interventions. What decision making process was used for prioritization?</td>
<td>Prioritized interventions</td>
</tr>
</tbody>
</table>

Note that the plan outlined here is a strategic or comprehensive plan. It makes recommendations about WHAT should be done, based on evidence collected by the community. The community planning group can then take this plan and develop an action plan – that is, decide HOW these activities should be done, that they can then implement. This action planning process is described in Chapter One of this module.

### Resources and References

**Appendix C**

- CCNAPC (Draft) *NAC Toolkit: Surveillance*
- NASTAD (2005): *Guidance on conducting a needs assessment*
- NASTAD (2005): *Instructions for performing community services inventory and services gap analysis*
Chapter Three:
Community Planning for Monitoring and Coordination.

Introduction
Once the community understands and uses mechanisms to determine what HIV control activities are happening and how effective they are, the community is better able to:

- Understand how well their plans are meeting the needs of the community (they can use data collected to justify refinements and mid-course corrections, as well as to contribute to the development of future plans).
- Hold government and providers accountable to commitments they have made. Monitoring of HIV control activities in their community is therefore a natural and vital role for community planning groups. Monitoring of local HIV control activities is therefore a natural and vital role for a community planning group.

Monitoring and Evaluation
There are many ways to define Monitoring and Evaluation. The two concepts are intricately related, since monitoring is the first step to be taken in a process to ultimately evaluate the effectiveness of an activity. For the purposes of this module we are defining monitoring as “the process of systematically observing what is happening and documenting those observations”. Evaluation is “the process of analyzing the monitoring data so it can be used to help refine and improve the activities observed”.

Monitoring of HIV activities occurs at different administrative levels, including at the level of the National AIDS Program, at regional and district levels, as well as at the most local level. Usually larger administrative structures are dependent on data collected at the more local administrative levels, and aggregate this data to measure broad indicators of the progress and success of national level programs. Such indicators may include: numbers of people receiving ART, or numbers of pregnant women accessing PMTCT, etc.

At this level, the community can participate in national committees to coordinate monitoring efforts, provide input on selection of indicators, review reports, and provide recommendations or advocate based on the information provided.

While understanding progress at the national level is of value at the local level, communities often need additional, more specific information to assess the progress of the individual programs they are monitoring. At the community level, data must be collected both to contribute to national monitoring and evaluation goals AND to understand progress of local activities. In particular, the community planning group should be interested in monitoring and evaluating the activities that it has planned for, advocated for, or implemented itself. Data collected about these activities
feeds back into the planning process, refining the groups’ understanding of what activities are needed in the future.

Often local level activities are accountable to more than one stakeholder (e.g., for multiple donors, as well as for different administrative entities), and are engaged in collecting different kinds of data for different kinds of purposes. Different entities therefore develop different indicators of success depending on their priorities. Examples of such indicators may include numbers of people served; money spent; services provided; behaviors changed; distribution of medication, etc. Another role of the community at this level, therefore, can be to coordinate and standardize data being collected in the community, thereby

- Making sure that the community planning group receives the full complement of information it needs to assure effective planning and actions.
- Helping providers meet multiple stakeholder (including national level) data needs while minimizing their data collection burden.
- Enabling the community planning group to make the evidence-based comparisons between programs necessary to perform effective prioritization and resource allocation.

**Coordination**

In many countries, HIV/AIDS has such a significant impact on multiple areas of social and economic life it becomes necessary to develop a coordinated and multi-sectoral response. In such a response the community, multiple government ministries, and the private sector collaborate together to achieve a common goal. Clearly a community planning group is an appropriate way to coordinate a multi-sectoral response, since such a group consists of representation from all of these players. When asking a community planning group to take on a coordination/collaboration role it is vital that there is clarity regarding the roles and responsibilities both of participant members, and of the group as a whole, and this clarity is best articulated through the development of clear Terms of Reference. It helps to identify very discrete areas of attention for the group, and be knowledgeable about the spheres of influence as well as the limitations of each partner at the table.

Activities that a community planning group devoted to coordination might take include:

- Advise each other about HIV prevention and control activities.
- Jointly developing referral networks
- Providing a forum for correcting action in different areas
- Providing a mechanism to segregate activities to avoid duplication
- Merge and simplifying surveillance, monitoring, and data collection.

Since more than one entity may be engaged in collecting different kinds of data for different kinds of purposes from a single agency or community, there may be differences in the end results, and conflicts regarding interpretation. Thus conflict resolution between the monitoring entities may be part of the process.

Challenges associated with multi-sectoral coordination include:
- Clarifying goals and products of the group
- Ensuring that every member brings something meaningful to the table. convincing partners of the value of coordination,
- Varying expectations that different partners bring to the table regarding the process
- Recognizing that meaningful collaboration on the ground (for example, establishing referral systems), requires specific resources.

Examples of Community Planning Groups focused on Monitoring and Coordination.

**Country Coordinating Mechanisms**
The Global Fund to Fight AIDS, Tuberculosis and Malaria requires all recipient countries to develop Country Coordinating Mechanisms (CCMs). The Global Fund is committed to local ownership and participatory decision making; and CCMs develop and submit grant proposals to the Global Fund based on priority needs at the national level. After grant approval, they oversee progress during implementation. Country Coordinating Mechanisms include representatives from both the public and private sectors, including governments, multilateral or bilateral agencies, non-governmental organizations, academic institutions, private businesses and people living with the diseases. For more information on CCMs, see [http://www.theglobalfund.org/en/appl y/mechanisms/](http://www.theglobalfund.org/en/appl y/mechanisms/)

**District Multi-Sectoral AIDS Committees (DMSACS), Botswana**
The following description of District Multi-Sectoral AIDS Committees is contained within Botswana’s National Strategic Framework (2003-2009), and is an example of how terms of reference have been articulated for the roles and responsibilities of the group:

“The DMSAC, with its multi-sectoral representation, manages and coordinates the district-level response to HIV/AIDS that has been designed to meet its own unique needs. It also maintains the elevated profile of HIV/AIDS at the district level ensuring that related issues receive the attention they warrant” ..........

“The DMSAC’s core functions include managing inputs, facilitating the development of a multisectoral annual HIV/AIDS Action Plan, supporting local level capacity building for implementation, mobilising resources, coordinating strategic implementation partnerships across sectors, and monitoring and documenting the district response. The DMSAC must avoid undertaking both management and implementation functions” .......

“In addition to these, the DMSAC also functions as the voice of the district level response to HIV/ AIDS. In partnership with other districts, it uses this authority to advocate for the greater primacy of district-led responses and for meeting the diverse needs and contexts that the districts represent. In addition, having oversight of the district’s response, the DMSAC acts as the communication channel through which that information must be shared and disseminated”.

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**Provincial and District AIDS Task Forces, Zambia**

Provincial and District AIDS Task Forces (PATFs and DATFs) were formed by an act of Parliament in 2002 as an effort to mobilize, coordinate, supervise and monitor Zambia’s multi-sectoral response to AIDS. The AIDS Task Forces are subcommittees of the Provincial/District Development Coordinating Committees (DDCC), and consist of volunteer representatives from multiple sectors, and include PLWHA. At the district level, all new HIV/AIDS providers are required to report to the DATF and participate in the DATF process.

The specific functions of the DATF are to develop an annual plan that describes ideal and comprehensive AIDS response activities for the district. DATF members (stakeholders/sectors) then take responsibility for implementation of the plan according to their comparative advantage. The DATF is also responsible for monitoring progress on achievement of these activities, and reports data to the DDCC and to the PATF using National AIDS Committee Activity Reporting Forms. The DATF is also responsible for mobilizing Community AIDS Task Forces (CATFs), and for providing them with assistance as they develop funding proposals for access to Community Response to AIDS funds (CRAIDS). DATFs have a role in the review of these proposals.

**Resources and References Appendix D**

- NEW YORK LINKING INFORMATION NETWORKING KNOWLEDGE (NY LINK) is an example of a cross border capacity building project that relies on coordination and collaboration between multiple partners.
- COMMUNITY PLANNING IN ST. LUCIA (Presentation to CCNAPC AGM, September 2006) provides examples of multi-sectoral planning, as well as action planning.
Appendix A

NASTAD (2006): *HIV community planning for community ART treatment adherence. Session Seven: Mobilizing the Community and Implementing the Plan*

From “HIV Community Planning for Community ART Treatment Adherence”, a training of trainers (TOT) developed by NASTAD in collaboration with Centers for Disease Control and Prevention (CDC/Ethiopia, and the National HIV/AIDS Prevention Control Office (HAPCO) of Ethiopia.

**SESSION SEVEN: Mobilizing the Community and Implementing the Plan**

**Objectives**
- List ways to encourage community participation in community planning
- Practice developing an activity work plan
- Learn simple methods for monitoring an activity work plan
- Learn simple methods for evaluating an activity work plan

**Time**
Three Hours

**Teaching Aids**
- Completed “Interventions” Handouts from Session Six
- Newsprint
- Newsprint stand
- Markers – at least 2 colors
- Tape
- Lap top and light box OR Overhead projector
- Extension cord

**Presentation**
- Mobilizing the Community and Implementing the Plan

**Handouts**
- Work-plan Handout
- Evaluation Handout

**A. Introduction**

- Explain that in this session, the group will be learning how best to engage the community in implementing some of the interventions that they identified in Session Six.
B. Recruiting Community Members to help with the ART Service Plan (45 minutes)

- Explain that the group has already developed some strategies and ideas for recruitment and making the AIDS Committee a welcoming place in the section on PLWHA involvement.
- Now, we will spend some time talking about how to recruit additional members, and motivate and train them to develop and implement a Community ART Service Plan.
- Conduct a brainstorm session by asking the following question: “What kinds of people in the community does the Kabele AIDS Committee need to help develop and implement the ART Service Plan?”
  - HIV, and Influence – people with extensive and active social networks (the ones who know all the gossip!)
  - Respect – people who are respected in the community – religious leaders, teachers, midwives/TBAs, etc.
  - Organizers – people who can get things done, and get other people to do them
  - PLWHAs and their families and friends – people who know about can tell others about it
- Remind the group that the Ethiopian Strategic Plan describes the kinds of people who should be involved in Kabele AIDS Committees. “Kabele AIDS Committees consist of PLWHAs, representatives from CBOs, community leaders, community health workers, traditional birth attendants and the health center provider or team leader.”
- Divide the group into three small groups. Assign one of the following questions to each group, and ask them to record their answers on newsprint. After 10 minutes, ask each group to present their answers to the larger group, and encourage questions and comments:
  - Group One: “What can the Kabele AIDS Committee do to learn more about people in the community who may be of help?”
  - Group Two: “What can the Kabele AIDS Committee do to help the community learn about the KAC and the proposed ART Service Plan?”
  - Group Three: “What can the Kabele AIDS Committee do to motivate community members to help with the ART Service Plan?”

C. Retaining Kabele AIDS Committee Members (45 minutes)

- Point out to the participants that the Kabele AIDS Committee consists of volunteers. People volunteer to be part of an effort for different reasons, and if a group is to be successful in retaining volunteers, it must be able to address at least some of those reasons.
- Conduct another brainstorm session asking, “Why do you think community members would want to participate in the Kebele AIDS Committee?” Place answers on newsprint. Make sure that the following examples are included in the discussion:
  - compassion, wanting to help fellow community members
Mobilizing the community and implementing the plan

- feeling that your talents and skills are being put to good use (that you are productive)
- feeling that the agency you are working for is trustworthy, and effective – well respected in the community
- feeling that you are making a difference
- feeling that you are learning something new
- knowing exactly what is expected from you
- camaraderie, it’s fun, you like being with other members
- community recognition and thanks
- someone you know and respect has asked you to participate

- Conduct a small group exercise. Divide participants into small groups, and ask each group to take three of the reasons why volunteers might want to participate in an AIDS Committee. For each of those reasons, ask the small group to develop answers to the question: “What actions can a Kabele AIDS Committee take to help retain its members?”

- After 10 minutes, have each group share its volunteer retention strategies with the larger group. Examples of some answers might be:
  - Mentorship – pair a new member with a more experienced member who can help explain what is to be expected, provide a personal link to the group, and provide the newer member with personal recognition and thanks
  - Developing a process that allows members to contribute in different ways – perhaps some members do not like to plan, but like to be given a task to do in the community to help implement the plan
  - Making sure that a decision or an action occurs at every meeting, not just discussions
  - Being organized

D. Organizing the Community for Action (45 minutes)

- Remind the group that once the Kabele AIDS Committee is convened, the community planning process described in Session Six will help the group develop a plan for WHAT to do in the community to address stigma, disclosure, and treatment adherence.
- Once the Kabele AIDS Committee has developed a plan for WHAT to do, it must also develop a plan for HOW to do it (a work-plan).
- Plans ALWAYS use the same framework (See Slide Two):
  - What is the outcome (goal)?
  - What activities will be performed to achieve the outcome (objectives and activities)?
  - Who will conduct the activity, What resources will they use? How will they conduct the activity, When will they conduct the activity (work-plan)?
  - How will you know when the activity has been done and the outcome achieved (evaluation)?
- Divide the group into the same small groups that identified needs and interventions in Session Six. Explain that the assignment is to develop a partial work-plan for an intervention. Walk through the assignment with the group
Appendix A
Mobilizing the community and implementing the plan

using the Work-plan Presentation/overhead (Slide Three), which uses the example of developing a brochure.

- Distribute the “Work-plan” handout. Each small group should take one intervention they identified on the Interventions handouts from Session Six, identify what need the intervention addresses and for whom, and develop a plan for its implementation. They should answer the questions listed on (Slide Four):
  - What is the intervention?
  - What activities need to be done to implement the interventions?
  - What resources are needed to do those activities?
  - Who will do those activities?

- Have each small group present its work-plan to the larger group. Encourage the large group to provide constructive criticism to the smaller groups, in particular to make sure that no needed activities are missing from the plan.

E. Managing People and Assigning Tasks (30 minutes)

- Ask the group “How well did you work together in the small groups to come up with your work plan? What made it easy for you to work together? What made it difficult to work together? List the answers under two headings on the newsprint: “Things that made it easy;” “Things that made it hard.”
- Summarize the discussion by ensuring that the following points are made:
  - Working in a group to develop (and implement) a plan is much easier when someone is in charge.
  - Working in a group to develop (and implement) activities for a plan is much easier when there are people in it who are knowledgeable about those activities (e.g., knowledgeable about how to find funds, how to develop brochures, how to distribute brochures).
- Ask “how would you organize the group/assign tasks in the future to make this group planning process more productive?” and list the answers on the newsprint.
- Ask the group to develop ideas for each of the following, and write them down on newsprint:
  - How will the Kabele AIDS Committee choose a member to be in charge of organizing and implementing a workplan?
  - How will the Kabele AIDS Committee choose members to work on developing and implementing a workplan?
  - What kind of training do Kabele AIDS Committee members need in order to help them learn how to develop and conduct those activities?
  - Who will coordinate and deliver that training?
- During summary of this brainstorm session, make sure that the points and information included in the table below are discussed.

| How will the Kabele AIDS Committee choose a member to be in charge of organizing and implementing a workplan? | ▪ Is the extension worker the person assigned to be in charge?  
▪ Should this person be selected by the rest of the Committee – perhaps on a rotating basis?  
▪ This person should have trust and support of the rest of the Kabele AIDS Committee. |
Mobilizing the community and implementing the plan

How will the Kabele AIDS Committee choose members to work on developing and implementing a work-plan?

- Kabele AIDS Committees develop tools and policies
- Distribute a “skills and interest” survey to all Kabele AIDS Committee members
- Match activities with skills and preferences of Kabele AIDS Committee members
- Develop policies that clearly define expectations for performing activities – e.g., hours per month of volunteerism, participation on work-plan development committees, etc.

What kind of training do Kabele AIDS Committee members need to help them conduct the activities? Who will give it to them?

- The District AIDS Desk is charged in the Ethiopia Strategic Plan with “linking facilities, kabeles, and the community” and “supporting ART activities at the community level and encouraging community mobilization among NGOs, CBOs and FBOs”.
- Distribute copies or references to training manuals (see Handout: “Toolkits”)

D. Monitoring the Activity (15 minutes)

- Explain that monitoring means “tracking what you are doing”. Explain that the implementation of the work-plan needs to be monitored. Ask participants what reasons they can think of for monitoring their work-plan, and list these on the newsprint. Answers may include:
  - To make sure that the work gets done in the way that it was planned
  - To see what is left to be done
  - To understand if members of the Kabele AIDS Committee need help in doing their pieces of the plan
- Explain that if you use the example of developing a brochure, you will want to know if the members of the Kabele AIDS Committee did the work they said they would do, so to help you decide how best to work with them in the future. You will want to know if the brochure was distributed to the people that needed it most, and whether they found it helpful. You will want to know if you need to print more brochures in the future. And undoubtedly, HAPCO and Save the Children will want to know whether their financial and in-kind contributions were of value.
- Explain that to monitor an activity involves just one additional step in the work-plan process – documentation. Using the Monitoring Overhead (Slide Five), explain how to document each of the activities described in the work-plan. If documentation is considered during the work-plan process, it will inform implementers of the information they need to keep or collect.

E. Evaluating the Activity (45 minutes)

- Explain that evaluating means “assessing the impact of what you are doing.” Ask participants what reasons they can think of for evaluating their work-plan, and list these on the newsprint. Answers may include:
o To see if the activity/intervention achieved what you thought it was going to. Did it meet the need you identified?
o To see if you need to do more or less of the same activity another time
o To provide information to funders about what you have done with their money

- Explain that evaluation of the activity is more complicated than monitoring. To answer evaluation questions such as those listed above usually involves a specific evaluation activity.

- Divide the large group into the same small groups as before. Explain that the assignment is to develop a brief evaluation plan for the intervention work-plan they developed in Section D of this session. Use the Evaluation Presentation/Overhead (Slide Six) to walk through an example for the small groups.

- Distribute the Evaluation Handout, and ask the small groups to answer the questions on (Slide Seven):
  - Identify their evaluation questions --- what do they want to know about the impact of this activity.
  - Recommend a way to answer those questions
  - Suggest who will collect the information and when
  - Suggest how that data will be used.

- Have each small group present its work-plan to the larger group. Encourage the large group to provide constructive criticism to the smaller groups, in particular to make sure that no needed activities are missing from the plan.
NASTAD 2006: *HIV community planning for community ART treatment adherence. Session Five: Involving people living with HIV/AIDS.*

From “HIV Community Planning for Community ART Treatment Adherence”, a training of trainers (TOT) developed by NASTAD in collaboration with Centers for Disease Control and Prevention (CDC/Ethiopia, and the National HIV/AIDS Prevention Control Office (HAPCO) of Ethiopia.

**SESSION FIVE: Involving People Living with HIV/AIDS**

**Objectives:**
Participants will be able to articulate:
- Benefits of involving PLWHA in a community planning process of which the goal is to increase uptake of ARV
- Barriers and challenges to involving PLWHA
- Strategies for successfully involving PLWHA in community planning

**Time:**
One hour and 45 minutes to two and one-half hours

**Teaching Aids:**
- Newsprint
- Newsprint stand
- Markers – at least 2 colors
- Tape
- Completed newsprint from large or small group
- Laptop that can play DVD (if using DVD)
- Overhead projector
- Screen for projecting overhead
- Extension cord

- For testimonials, any of 3 options:
  - DVD: Beating the Drum Loudly, or
  - PLWHA willing to speak to the group, or
  - Case studies (hand-outs): description of 2 PLWHA for interview

**Handouts:**
- Role Play descriptions for AIDS Committee members

**A. Benefits of Involving PLWHA in HIV Community Planning for Community Mobilization (20 minutes)**

- Ask the group to participate in a brainstorming exercise to identify why it is important to involve PLWHA in a community planning process that has a
Appendix A
Involving People Living with HIV/AIDS

purpose of increasing uptake of ARV. Explain that this is not the time to identify barriers and challenges; there will be an opportunity for that later.

- In the large group, brainstorm responses to 2 questions and record responses on newsprint:
  - What are the benefits to the Kebele AIDS Committee of involving PLWHA?
  - What are the benefits to PLWHA to participating in a Kebele AIDS Committee?

<table>
<thead>
<tr>
<th>B. Testimonials (30 to 45 minutes)</th>
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- Introduce the testimonials: for example “Let’s hear in the words of PLWHA how being public with their HIV status and becoming involved in HIV works has been important for them.”

**Testimonials:**

*Option One (15 minutes): DVD “Beating the Drum Loudly” (show selections from the 28-minute DVD about PLWHA in Uganda who staff a clinic)*

*Option Two (30-40 minutes): Guest speakers 2 PLWHA and 1 other AIDS Committee member speak about the importance of involving PLWHA, the challenges and strategies for increasing involvement*

*Option Three (20 minutes): Role Play. At a break prior to this session, ask 2 participants who have served on or led AIDS Committees to role play the part of a PLWHA. The person may either create a role (based on people they have known, but not sharing identifying information), or he/she can play the role of the person described on a handout. The facilitator interviews the person playing the PLWHA role and asks questions such as:
  - Please describe how you are involved in HIV work (AIDS Committee, other volunteering or employment)?
  - How did you get involved?
  - If I may ask, when did you learn of your HIV status?
  - How did you come to be willing to disclose?
  - In what ways was that difficult?
  - In what ways was it rewarding?
  - How has being involved in HIV work and in the AIDS Committee been beneficial to you?

If the role player feels comfortable, members of the group may also ask questions.

- Facilitate a discussion about the themes that came up in the testimonial. Add some of the following items if they were not brought up by the group.

**Benefits to the AIDS committee:**

- Consumer perspective
- Provide a reality check and consumer perspective to the KAC on HIV issues
- Help in assessing consumer needs and priorities
• Identifying service barriers
• Provides options to the KAC for outreach and community involvement
• Quality control
• Community liaison
• Reduce stigma (PLWHA are just like everyone else)
• Influence Community Norms

Benefits to the PLWHA:
• Serve as role model for other PLWHA to promote testing, disclosure and treatment
• Helps motivate PLWHA to continue to care self and protect their partners
• Opportunity to represent the PLWHA community
• Opportunity to improve services and access
• Representation of an underserved community
• Access to new information and knowledge
• Increased awareness of treatments and service
• Opportunity for personal advancement/achievement
• Sense of empowerment, pride, and accomplishment at being part of the process

C. Barriers to involving PLWHA in AIDS Committees (30 minutes)

• Divide participants into small groups of 5 or 6 to brainstorm the barriers to gaining and sustaining involvement of PLWHA in AIDS Committees. Barriers can be from the perspective of the PLWHA or the committee. Each group should write these on newsprint.
• Using a different colored marker, each small group should cluster the barriers they identified under headings. Some items may not fall under a major cluster heading.
• One representative from each group should present their headings to the larger group. Each group has a 5 minute limit to present. There is no need to repeat items that other groups have identified so the second and subsequent groups may need less time. Each group should share the name of the heading and the kinds of items included. For example:
  Heading: Transportation
  o Cost of the bus
  o Bus running before meetings end
  o Health care is far from where the meetings are held, so too much time for transportation

  Heading: Stigma
  o People fear being ridiculed if they disclose
  o People fear losing their job
  o People fear that their children may be discriminated against at school
• Note overlap and themes among the groups’ reports, and summarize the discussion.
D. Strategies for Gaining and Sustaining Involvement of PLWHA in AIDS Committees (30 minutes)

- Reconvene the small groups from the previous activity.
- The same small groups will take their headings (they may add to the list after hearing from other groups), and list strategies for gaining and sustaining involvement of PLWHA on newsprint. For example:

  Transportation
  o Hold meetings at or near medical clinic or food pantry
  o Provide bus tickets
  o Make sure meetings end before bus stops running

- One representative from each group should present their strategies (Each group has a 5 minute limit to present). There is no need to repeat items that other groups have identified so the second and subsequent groups may need less time.
- Facilitator notes similarities and overlap. Facilitator may want to make sure that the following major topics are addressed.

  o Support to PLWHA to participate, including orientation, ongoing training and mentoring to PLWHA to minimize discomfort with the process
  o Policies outline how the group operates, and addresses conflict resolution, value of PLWHA input, gender equity
  o Incentives for participation such as bus tickets and food vouchers where possible; provision of child care
  o Develop a non judgmental attitude and reputation
  o Work on reducing stigma
  o Provide economic generating support (job training etc.)
  o Pathway to ART treatment and support
  o Peer support and advocacy
  o Involvement in planning, implementation and evaluation
  o Provide spiritual support

<table>
<thead>
<tr>
<th>Additional Strategies for Involving PLWHAs in AIDS Committees</th>
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<tbody>
<tr>
<td><strong>Maintaining Effective PLWHA Involvement</strong></td>
</tr>
<tr>
<td>• Provide training, orientation and mentoring</td>
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<tr>
<td>• Minimize the financial costs of participation</td>
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<tr>
<td>• Reduce the psychical and psychological costs</td>
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<td>• Provide needed supports</td>
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<tr>
<td>• Demonstrate that they are respected partners</td>
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<tr>
<td>• Provide continuing communication and information access</td>
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<tr>
<td>• Provide training and develop materials to sensitize members to cultural and gender differences and to respect those differences</td>
</tr>
<tr>
<td>• Demonstrate a shared and ongoing commitment to recognize and overcome obstacles to PLWHA participation</td>
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| **Activities that Enhance**                                   |
| • Policies, guidance and processes                           |
| • Establish a PLWHA committee                                |

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Appendix A
Involving People Living with HIV/AIDS

<table>
<thead>
<tr>
<th>Consumer Involvement</th>
<th>Recruitment of PLWHA</th>
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<tbody>
<tr>
<td>Consultation and communication with PLWHA</td>
<td>Defined structure and process to recruit</td>
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<tr>
<td>Research and reports</td>
<td>Defined roles for PLWHA</td>
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<td>Training and technical assistance</td>
<td>Identify and recruit existing PLWHA</td>
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<td>Targeted advertising</td>
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<td></td>
<td>PLWHA recommendations</td>
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<td></td>
<td>Community Linkages</td>
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<td></td>
<td>Provider input</td>
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<td></td>
<td>Individualized outreach</td>
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<td></td>
<td>Targeted outreach</td>
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<td>Public meetings</td>
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<tr>
<td>Involving and Sustaining Members</td>
<td>Provide initial orientation</td>
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<td></td>
<td>Establish positive relationships and manage conflict</td>
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<td></td>
<td>Debrief after first meeting</td>
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<td></td>
<td>Provide ongoing training</td>
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<td></td>
<td>Take action to address burnout and grief/loss and separation</td>
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<td></td>
<td>Establish a mentoring system</td>
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<td>Provide a safe environment</td>
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<td>Develop and sustain peer groups</td>
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<td></td>
<td>Conduct exit interviews to determine the reasons for discontinuing participation</td>
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Appendix: Role Play (Kabele AIDS Committee Meeting) (30 minutes)

- The role play should include 7-8 people. In a small training, all participants might play roles. In a larger training, only some members will play roles.
- Give each participant their role and a name plate with their role. They have a few minutes to get into their role and flesh out some details (age, family status, job, living situation, etc.)
- Distribute the role play descriptions to each role player describing their role and their perspective, and provide them with a few minutes to get into their role.
- The trainer should take the role of the facilitator of the Kabele AIDS Committee Meeting. Introduce the role play by saying:
  - Let’s go around the circle and introduce ourselves. Tell us your name and what perspectives you bring to the Committee. In particular, I want to welcome anyone who is new today. [Members introduce themselves – 5 minutes]
  - At our last meeting, we agreed that it is very important for the Committee to have a number of members who are living with HIV/AIDS. For a variety of reasons, it has been difficult to sustain the membership of PLWHA. We decided that we would spend the first part of today’s meeting talking about how the Committee can get more PLWHA to attend meetings, and if there are other ways to get input from PLWHA. As always, we want to
make sure that everyone has a chance to talk and that we have a good exchange of ideas. [15 minutes; facilitated as needed]

- Provide about 15 minutes to perform the role play
- Debrief the role play. Ask role players how they felt playing the role they did and if they learned anything as a result. Then open up the discussion to observers to identify what they noted about major factors affecting PLWHA participation.

### Meeting process

<table>
<thead>
<tr>
<th>Circle one number or N/A for each row.</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>N/A or missing</th>
</tr>
</thead>
<tbody>
<tr>
<td>The desired outcomes for today’s meeting were clearly communicated by the co-chairs.</td>
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<tr>
<td>There was an adequate amount of time available to cover each agenda topic.</td>
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<tr>
<td>We spent too much time on topics unrelated to the desired meeting outcomes.</td>
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<tr>
<td>I felt comfortable raising questions and participating in today’s discussion.</td>
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<tr>
<td>The desired meeting outcomes were met.</td>
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### Presentations and discussion

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<tr>
<th>Circle one number or N/A for each row.</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>N/A or missing</th>
</tr>
</thead>
<tbody>
<tr>
<td>The information presented today was easy to understand.</td>
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<tr>
<td>The gap analysis process conducted today (discussion followed by the dot exercise) was effective.</td>
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</table>

### Decision making

<table>
<thead>
<tr>
<th>Circle one number or N/A for each row.</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
<th>N/A or missing</th>
</tr>
</thead>
<tbody>
<tr>
<td>I had the information I needed to make informed decisions.</td>
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<tr>
<td>I had enough time to use the information presented to make informed decisions.</td>
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<tr>
<td>I felt that my opinions were taken into consideration during today’s prioritization process.</td>
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</table>

### What was the best thing about today’s meeting? What was most valuable or helpful to you?

### What was the worst thing about today’s meeting? What was not valuable or helpful to you? What could we change to improve future meetings?

### Provide any additional comments you have about today’s meeting.
MEDIA ENCOUNTER FORM

DATE: __________________________
NAME OF MEDIA CONTACT: _______
CONTACT INITIATED BY: _________
CONTACT INFO: ________________

FORMAT:

☑ NEWSPAPER
☑ RADIO
☑ TV
☑ OTHER

PURPOSE OF CONTACT:

SINGLE OVERRIDING COMMUNICATION OBJECTIVE(S):

ACTION TAKEN:

DATE OF BROADCAST/PUBLICATION:
MAKING THE MOST OF THE INTERVIEW

Before the Interview

- Pick the SOCOs/Focus
- Note deadline
- Get facts on who is interviewing you/what station or newspaper/what audience
- Set your agenda
- Anticipate questions and rehearse them
- Be informed about local and national events that could impact this story
- Be prepared and have brief information for the reporter: e.g., a fact sheet from the Epidemiologic Report in your district, rather than the entire report
- Look in the mirror/be and dress professionally

During the Interview

- Lead the reporter with your conclusions, try not to be led
- Talk conversationally, not as a reporter
- Bring the message home/short answers work best
- Turn the negatives into positives
- Be human, honest and sincere: Tell the truth
- Repeat the message as much as you can
- DO NOT GO OFF RECORD
- Avoid saying NO COMMENT
- Remember you are the expert
THE TEN COMMANDMENTS OF WORKING WITH THE MEDIA

1. **BE PROACTIVE**
   When an interview moves in a direction you don’t like, always remember to transition back to your main message. Answer the question quickly, then spend time talking about what you want to say.

2. **BE UP FRONT**
   Gone are the days of releasing bad news on Friday afternoon. There is no news cycle, it’s a 24/7 business.

3. **TELL THE TRUTH**
   Bending the facts gets you nowhere but in more hot water.

4. **BE SYMPATHETIC**
   Always remember to acknowledge the challenges and struggles of a group affected by you, your company, or the news you are delivering.

5. **NEVER SPECULATE**
   You don’t need to have ALL of the facts, tell them what you do know, and stick to it.

6. **TAKE THE HIGH ROAD**
   Explain your decision. Don’t trash your opponents.

7. **ALL NEWS IS LOCAL**
   Take care of the local media, no matter how much national attention comes. When the nationwide hype is over, national media will leave. The local media will still be there to cover the end of the story.

8. **REMAIN CALM**
   Don’t return the reporter’s aggression. Remember, you rarely see them ask the question, just your answer.

9. **PREPARE! PREPARE! PREPARE!**
   The key to winning the game of journalism is preparation. Know the facts, and find a few supporting examples.

10. **OWN YOUR CORE MESSAGE!**
    Live it, breathe it and express it with conviction.
Planning Your Advocacy Message
“Hook, Line, Sinker”

Funding For AIDS Drug Assistance: Example

**Hook**  
*Your ID:* Your name, where you live, the organization you are with (volunteer or staff), or the why and who you represent

**Line**  
*Your Message:* A personal story, facts about the program or persons living with HIV/AIDS who need drugs etc.

**Sinker**  
*The Ask:*  
“Currently we receive no government funding for AIDS Drugs. We are one of only X countries in the Caribbean that do not provide government appropriations for the program. If given the opportunity, **Will you vote to provide funding for AIDS drugs?**

“The Governor included $10,000 in his budget recommendations this year for the AIDS drugs Program. This is only a portion of the funds needed to assist those in need. “If given the opportunity, **Will you vote for increased funding for AIDS drugs?**”
Funding for PMTCT Program: Example

**Hook**

*Your ID:* Your name, where you live, the organization you are with (volunteer or staff), or the why and who you represent.

**Line**

*Your Message:* A personal story, facts about the program or persons living with HIV/AIDS who need drugs etc.

Brenda, a 25-year-old mother, attended her first antenatal visit for her second pregnancy. During the group counseling, the health visitor discussed HIV/AIDS transmission from a mother to her child and ways to reduce this transmission. Brenda, who was about twelve weeks pregnant, underwent individual pre-test counseling on HIV and agreed to take the HIV test.

During her second visit, the nurse shared the HIV test results which were stamped in red on the form "HIV antibodies detected." Upon learning of her HIV test, Brenda experienced a range of emotions from disbelief to hurt.

It is possible for Brenda to live a healthy life with HIV, and to prevent transmission of the virus to her baby. All Brenda needs is a short course of antiretroviral prophylaxis two hours before her baby’s delivery; the baby itself needs a pediatric course of nevirapine. Prevention of Mother to Child Transmission Programs (PMTCT) provide these medications to infected mothers and their children, as well as counseling on infant feeding, safe sex practices, and family planning.

**Sinker**

*The Ask*

"7% of pregnant women in our country are HIV positive, and in need of PMTCT services. **Will you vote to support PMTCT services in our country?**"

This module was developed to provide a brief overview on HIV/AIDS surveillance for state AIDS directors, and is designed to be a component of a larger toolkit that is still under development. (March 2007).

1. INTRODUCTION

As the National AIDS Coordinator, you are the person who oversees HIV program planning and development for prevention, care, and treatment services in your state. This oversight includes making fiscal decisions related to support of these services. To make these important and sometimes difficult decisions, you will need to obtain and understand information, or data, that will allow you to estimate the number of people with disease, identify trends in disease, and characterize populations at risk of contracting disease. These data will give you a better understanding of the epidemic so you can predict resource needs and plan for them, as well as information about whether the programs that you are providing resources for are reaching the populations most in need. The collection of these data is called “public health surveillance” and surveillance activities are conducted by staff you oversee who are specifically trained to do so.

In your role as National AIDS Coordinator, you do not need to understand all of the technical details of public health surveillance activities. However, you do need to understand that surveillance data are an essential tool for guiding decision making on the allocation of limited resources, the strengths and limitations of different data sources, and the methods by which surveillance data are collected and protected.

“Public health surveillance is the ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with timely dissemination of these data to those who need to know. The final link in the surveillance chain is the application of these data to prevention and control. A surveillance system includes a functional capacity for collection, analysis and dissemination linked to Public Health programs.” (Thacker, S.B. and Berkman, R.L. Public Health Surveillance in the United States, Epidemiology Reviews 10 (1988): 164-190.)

2. PURPOSE OF SURVEILLANCE

HIV/AIDS surveillance should be used as a means to ensure that national response to the epidemic is well-focused. HIV/AIDS surveillance activities are carried out for a number of reasons:

- To allow for assessment of the status of HIV/AIDS within a country and to clarify the factors driving the epidemic;
- To facilitate the design, assessment, and adjustment of the response to the epidemic; and
- To estimate the number of people living with HIV/AIDS in a state or country.
3. BENEFITS OF HIV/AIDS SURVEILLANCE

The immediate, direct benefit of collecting data about or from those with or at risk for HIV infection is that you can achieve better-designed, more relevant programs with implementation based on knowledge gained from the collected data. Indirect benefits might include:

- Greater collaboration among the various agencies participating in the response to HIV/AIDS, including government agencies and NGOs;
- More information about the needs of vulnerable populations that results in provision of additional services;
- Increased trust of vulnerable and often stigmatized populations, resulting in demand for HIV/AIDS-related health services and other services.

4. POPULATIONS OF INTEREST FOR SURVEILLANCE

Understanding HIV prevention and care needs means understanding the needs of several different but not always exclusive populations. These include:

- High risk populations, such as sex workers, injection drug users, and men who have sex with men;
- Bridge populations, such as men who have sex with sex workers and also have sex with their wives, so interact both with the high risk population and the general population;
- The general population.

5. SURVEILLANCE METHODS

There are several approaches to HIV surveillance:

- Routine surveillance based on case reporting;
- Sentinel surveillance. This allows the adequate collection of HIV, STD, and behavioral data concerning specific vulnerable subpopulations, such as injecting drug users, sex workers, and prisoners.

Surveillance activities can either be active or passive. The following describes the two systems:

- In an active surveillance system, public health officials seek out cases and collect data on each case. They may do this by routinely visiting clinics and/or by re-examining records for new cases.
- In a passive system, health officials rely on physicians or other healthcare workers to collect and report cases.

In addition to the ongoing routine and sentinel surveillance activities conducted by state and local health departments, a number of other studies can be carried out in a region. These studies can identify specific risk factors for HIV infection within the study area. Some of these studies include:

- Community-based cross-sectional sero-surveys among commercial sex workers, and behavioral studies among men who have sex with men.
- Population-based cross-sectional sero-surveys representative of the general population.
Conducting behavioral surveys and sero-surveys requires resources in terms of staff time and money, so it is important to understand what the data will be able to tell you and how you will use them before you make an investment in collecting them. You will want to understand:

- The population that you’re trying to get more information about and, in the case of vulnerable subpopulations, how they will be approached and recruited for the study;
- The number of people needed for the study;
- Methods by which the study can obtain a sample that is representative of the population (for instance, if you study only sex workers who work in brothels, you may not be able to describe the needs of sex workers who work on the street). Sampling methods include:
  - Simple random samples;
  - Convenience samples;
  - Respondent-driven samples.

Mapping exercises can be used to identify community-based entry points for accessing vulnerable populations and estimating the size of vulnerable populations. These exercises include ethnographic assessments and are often conducted in collaboration with NGOs who serve the populations.

6. FOCUS ON VULNERABLE POPULATIONS

- Vulnerable populations should be the cornerstone of the surveillance system in most countries.
- In general, the sentinel surveillance system is focused on vulnerable subpopulations, particularly IDUs, sex workers, MSM, and prisoners.
- However, a surveillance system also includes STI patients and pregnant women, who are often considered as proxies for the general adult population.
- The surveillance scope needs to be expanded to include other vulnerable people, such as youths, immediate family and friends of IDUs, military recruits, Tuberculosis patients, and patients with hepatitis.

7. FREQUENTLY ASKED QUESTIONS ABOUT SURVEILLANCE

Following are some questions that you may have or receive from others as you try to plan and evaluate HIV prevention, care, and treatment services and the sources of surveillance data that may help to provide answers to these questions.

a. How many people in my country have HIV?

Obtaining an exact number of people who have HIV is difficult for a number of reasons. Many people who are infected have never been tested so do not know that they are infected. When someone is tested for HIV and is positive, there is no consistent mechanism that exists for reporting the newly diagnosed case. Several sources of information about the number of people who have HIV are:

- **AIDS case reporting or AIDS case surveillance** – is the regular identification and reporting of persons who meet the AIDS case definition. The number of reported AIDS cases will be an underestimate of people who are HIV infected because not all individuals with HIV have advanced to AIDS and reporting is not consistent across providers.
**Sentinel surveillance and estimates** – Every year, anonymous blood samples can be collected from specific populations to see how many of these individuals are infected with HIV. These populations include those who may be at higher risk for infection, such as attendees of STD clinics or drug de-addiction centers, or at low risk, such as mothers attending antenatal clinics. HIV prevalence (% of people from these populations who have HIV) is estimated using these studies and the results are used to make estimates of the number of all people living with HIV.

b. **What are the sizes of the vulnerable populations in my region?**
This is not a systematic part of the surveillance system. Usually, there is very little information on the number of members of vulnerable populations. A rapid assessment using ethnographic methods and mapping can be carried out to estimate the number of injecting drug users, sex workers, and prisoners. NGOs can be very helpful in estimating the sizes of these vulnerable populations.

c. **Is the number of people becoming infected with HIV every year getting bigger or smaller?**
Since data are collected at the sentinel surveillance sites (see above) every year, it is possible to look at whether a higher or lower proportion of those getting tested are HIV positive compared to the previous year. Over time, the direction of the change in these proportions will help to estimate whether infections are increasing or decreasing.

d. **Who are the people who have HIV in my country?**
It is important to understand the characteristics of those who have HIV or are at high risk for acquiring HIV in order to most effectively target prevention and care programs. Are they primarily male or female? How old are they? Where do they live? What types of employment are they involved in? What is their education level? What is their marital status? It is important to focus on the characteristics of groups of people, not individuals, in trying to understand the epidemic in your state. Protecting the confidentiality of individuals with HIV and being careful not to inadvertently identify them through presentations of data is a responsibility that should be taken very seriously.

e. **Who are the high-risk populations in my country?**
High-risk populations have a higher prevalence of HIV infection in comparison to the general population and high-risk individuals are at greater risk for contracting HIV. For these reasons it is important to determine the HIV prevalence in high-risk groups. High-risk populations play a central role in the spread of HIV infection. They may also serve as bridges to other populations including the general population since they can introduce HIV into these groups. An example of this is male clients of female sex workers, who become infected and bring the infection home to their wives.

f. **How were people who have HIV exposed to the virus?**
The predominant route of HIV transmission in the Caribbean is heterosexual transmission. However, it is important to monitor exposure risks over time in order to better target prevention programs.
g. Are there ways to describe/identify people who are at higher risk for HIV infection?
In addition to understanding the characteristics of those who are HIV infected, it is also important to understand the characteristics of those who are at higher risk for infection. As an example, it is important to understand the characteristics of people who are attending clinics for treatment of sexually transmitted infections (STIs); they are people who may have multiple casual sex partners and/or are engaging in unprotected sexual activity and are at higher risk. They may also be at higher risk because some STIs facilitate the transmission of HIV infection. People at high-risk for HIV infection may be highly vulnerable to social and economic conditions that increase their risk of HIV infection. These same conditions may also hinder their involvement in regular surveillance activities. Examples of these conditions include: extreme poverty, reduced opportunities for education, increased risk of violence, or discrimination.

h. Are there ways to learn more about peoples’ risk behaviors?
Most of the time, very little information is collected about the behaviors that put people at risk for HIV. While it is useful to know that the majority of individuals who have HIV in the Caribbean were infected through heterosexual transmission, it would be useful to know more in-depth information such as whether these people had multiple casual sexual partners, if they ever used condoms, or if they didn’t use condoms, why not? While it is impractical to collect such extensive information on all individuals with HIV studies in which these data are collected from a sample of individuals can be very useful for guiding program planning.

i. How do I know that my state’s HIV prevention and care programs are reaching the right people?
As described above, it is important to understand both the demographic and behavioral characteristics of people with HIV infection in your state. You can then look at information about the people who are being reached with your HIV prevention and care program services to see if they have the same characteristics or if there are gaps in who is being served.

7. DATA ANALYSIS, PRESENTATION, AND DISSEMINATION

- Data can be used positively to design and modify programs. For example, if data show that 50% of prisoners inject drugs, it may lead to piloting harm-reduction programs in a prison.
- Data can be used at the national, regional, and local levels. Data can be shared with Public Health Departments, local authorities, and other ministries through roundtable meetings, and presented at national meetings.
- Since data are used for program planning, it is important that study data get analyzed and disseminated in a timely way.
- Data feedback is critical to NGOs and vulnerable people, especially those who participate in studies, and should be done in appropriate, understandable ways.
- Different audiences will have different needs in regards to how they will be use data, and presentations should be tailored to meet these specific needs.
- AIDS Programs need to hire or have access to individuals with strong analytic skills in order to process and present data accurately.

8. SURVEILLANCE CAPACITY DEVELOPMENT
• **Human Capacity**: Ability to train government specialists through various means, including workshops, study tours, peer professional training, and on-the-job training (include example).
• **Laboratory Capacity**: Ability to provide laboratories with training, quality assurance, and technical support (include example).
• **Information Systems Capacity**: Ability to collect data in electronic formats in sustainable ways (include example).
• **Transportation Capacity**: Ability to provide vehicles for surveillance activities.

### 9. ENVIRONMENTAL ISSUES IN CONDUCTING SURVEILLANCE

- Policies regarding needle-exchange.
- Attitudes toward persons living with HIV or AIDS and members of vulnerable populations.
- Use of identifying information and weak controls for protecting confidentiality.
- Segregation of HIV positive prisoners.
- Mandatory HIV testing.
- Medical scientific ethics.
- Social norms, values, and culture; and how these values are affected by the attitudes of people in authority.
- Centralized decision making framework.
- Vertical, fragmented, health systems.
- Political context.

### 10. HIV/AIDS TESTING AND SURVEILLANCE

- Effective surveillance for HIV depends on availability and reliable HIV testing.
- Testing purpose
- Sensitivity and specificity of HIV tests
- HIV prevalence

### 11. COLLECTING SURVEILLANCE DATA TO MEET DONOR REPORTING REQUIREMENTS

Requirements to collect data about certain populations are often made by donors’ organizations. Since a surveillance system is based on “ongoing, systematic” collection of data, relying on these data can lead to limitations in surveillance activities:

- Often, data are collected for a short period of time and there’s an absence of baseline data.
- Many organizations receiving donor funds do not have staff with the technical abilities to analyze data.
- Coordination of surveillance efforts becomes fragmented.
- There may limited focus on certain high risk, vulnerable populations and over-reliance on other methods of data collection, such as case reporting or data from HIV testing sites, that are biased.
- It can divert from the government taking responsibility for ongoing, systematic surveillance as an important part of the core public health infrastructure (may want to note all the efforts that have been made in India to put systematic systems into place).
NASTAD (2005): *Guidance on conducting a needs assessment*

From the District Multi-Sectoral AIDS Committee Evidence-Based Planning Toolkit developed in collaboration with the Republic of Botswana Ministry of Local Government AIDS Coordinating Unit by the National Alliance of State and Territorial AIDS Directors (NASTAD), with the support of BOTUSA.

**Decide on the types of questions to ask**

As you set out to collect information from clients it is important first to understand WHICH gaps you are asking clients about, and WHAT you will DO with the information that you collect.

Questions about **AWARENESS** will help the DMSAC know if people in your district are aware of the current prevention and treatment programmes. The DMSAC will then be able to decide if it needs to prioritize IEC programmes (workshops, advertising, community events, etc) so that more of these services are offered in the district.

Questions about **BARRIERS TO CURRENT SERVICES** will help the DMSAC know if the current prevention programmes are helpful in reducing HIV transmission in your district. The DMSAC will then be able to decide if it should recommend changes to existing services or prioritize outreach or transportation to help people access existing services.

Questions about **NEEDS FOR SERVICES** will help the DMSAC know people’s needs for new services in your district. The DMSAC will then know what additional prevention activities are needed in your district. In developing the annual plan, the DMSAC can prioritize new services and encourage sectors and NGOs/CBOs to develop them.

Questions about **SATISFACTION WITH SERVICES** will help the DMSAC know whether the current services are being delivered in the best way possible.

**Decide on a methodology (survey, focus group, interview)**

Sometimes, because of stigma, clients are reluctant to answer questions about HIV programmes. Often you will get better information from client if an assessment is as short and simple as possible, if you do not ask unnecessary questions, and if you can clearly explain to a client how collecting the information will benefit them or their community.

A needs assessment must be conducted in a way that is appropriate to the target group’s culture and language. It is important to translate a survey or interpret an interview carefully and sensitively. Use experts (elders, traditional leaders) to help you design your assessment. Test the assessment on a few people first and ask them if it was understandable and appropriate.

Select from this list of three simple ways to collect information from your target group. The list of benefits and disadvantages will help you decide.
A. Survey - *Written questions are given to a client to read and answer.*

**Benefits:**
- confidentiality – it is easier for a client to answer sensitive questions
- it is cost efficient, since it does not need anyone to administer it
- it can be mailed or distributed widely – it does not depend on a client being in one place to complete
- the client can answer the survey in a time and place convenient to him/her

**Disadvantages:**
- Not appropriate for clients who cannot read or write
- There is no one available to answer questions as the client answers the survey, so the survey needs to be short, simple, and easy to follow. It is best to pilot such a survey with one or two people before you give it to everyone
- It can be hard to make sure that completed surveys are returned

B. Interview - *An interviewer asks the client questions*

**Benefits:**
- Good for getting information from someone who cannot read or write
- The interviewer can explain if the questions are not clear

**Disadvantages:**
- People are less likely to give personal or sensitive information
- People may be more likely to give an answer they think the interviewer wants to hear, rather than the answer they really think
- The interviewer needs to go to the client, or the client needs to come to the interviewer to answer the questions.

C. Focus groups - *An interviewer asks a group of people the questions*

**Benefits:**
- People are often more creative in a group – they get ideas from listening to each other
- The interviewer can probe – ask more questions about a topic that interests them
- Good for getting opinions or ideas from people
- Good for getting a sense of what a community as a whole might think
- Sometimes a focus group can be used to help explain or explore a finding you have made in a survey or interview activity (e.g., “we found that 50% of the people we interviewed are afraid to get an HIV test ... tell us more about that – why do you think people in this community are afraid of getting a test?”)

**Disadvantages:**
- *It is difficult to get the same kinds of information from each individual in the group*
In any approach it is best to try out the instrument first, as a pilot, and then adjust it based on what you learn.

## Sample Questions for Focus Groups

### If you want to ask about AWARENESS of services:
Questions you might ask to find out how a client became aware of the services (or how well your service has been marketed). You would use answers to make more people who needed the service aware of the service.

**Examples of Focus Group questions**
- Where do you think the best places are to put brochures/posters about the new PMTCT programme?
- Name all the places in our district where you could go to get an HIV test. At each of these places, how much does it cost? When are they open? Will other people learn your results, or are the results confidential?
- If you have an HIV test and learn you are HIV-positive, what are some of the things you should do once you learn your status?

### If you want to ask about BARRIERS TO CURRENT SERVICES:
Questions you might ask to find out what prevents a client from accessing a service that already exists in the community. You would use the answers to improve the utilisation of a programme.

**Examples of Focus Group Questions**
- What do you think makes it difficult for PLWHA to get ARVs at the hospital?
- What are your fears about getting tested?

### If you want to ask about NEEDS FOR SERVICES:
Questions you might ask to find out what needs of a client are not currently being met. Use answers to decide whether a new or expanded programme is needed.

**Examples of focus group questions**
- What kinds of education would you find most helpful to you as you try to change your high-risk sexual behaviors?
- Learning whether or not you have HIV is one of the most important ways to keep other people from getting infected AND to help improve your health. What do you think is the best way to encourage people to get an HIV test?

### If you want to ask about SATISFACTION with services:
Questions you might ask to find out if clients are satisfied with the quality of the services they receive. Use the answers to these questions to improve the quality of a programme.

**Examples of focus group questions**
- Please tell me about your visit to the VCT. What was good about the visit? What was bad about it?

Because you want to get a variety of opinions and ideas from a focus group you should use open-ended questions – that is, questions that cannot be answered with a Yes or No. For example, instead of asking “Was your experience at the VCT site good?” say “Tell me about your experience at the VCT site.”

## Conduct the needs assessment

The number of people to include in the assessment depends on the size of your target group and the community where you are conducting the assessment. Obtain **15-25 responses** as a rough guide.

Please note that a needs assessment is not formal research. It is okay to do an assessment without the rigor of scientifically calculated sample sizes and statistical
analyses. The purpose is to collect useful information to help the planning process. You can do this even if you are not a scientist!

Some Technical Advisory Committees may have access to resources that will allow them to outsource the needs assessment to a consulting group. In most cases, however, a Technical Advisory Committee will be able to conduct the assessment within its existing capacity. Some large Technical Advisory Committees have created smaller Planning Subcommittees to guide the assessment process. Assistance is available from the AIDS Coordinating Unit to help provide additional capacity building as needed.

**Analyze and use the results**

After getting the data, the District AIDS Coordinator should **summarize the most useful information on Worksheet 3-C**. The summary should be written in a way that helps the DMSAC set priorities for next year. Because you cannot assess all the target populations each year, the Technical Advisory Committee should also review the summaries of assessments completed in previous years.
A community services inventory describes the programmes currently in place in your district. It is useful for two purposes:

1. As a community resource to make it easier for programmes to refer clients to another programme
2. To help DMSAC members and others in the district know what services exist, and identify what services are missing, or, gaps.

Begin by developing the inventory as a community resource.

The inventory format should include the following:

- Name of organisation
- HIV/AIDS contact person/title
- Phone number
- Fax number
- Email address (if available)
- Postal address
- Physical address
- Type of organisation
- Target group
- Category of service
- Days and hours of service

Print and copy the inventory in a format that can be shared with all members of the DMSAC and other interested stakeholders in the district. It is essential that organisations that make referrals to other organisations have a copy to help with the referrals.

**Important:** For each organisation, list the target groups on separate rows. Do not group them together. Notice in the example (Attachment 2) how the different services are shown separately for each target group. Listing groups and services on separate rows makes it easier to see which services are targeted to which groups. See Attachment 2 for the format of the community services inventory. See Attachment 3 for an optional questionnaire you may wish to use to collect the information.

Information for the inventory may be collected two ways:

1. A District AIDS Coordinator can collect the information on a face-to-face basis by visiting each organisation you are aware of, meeting the HIV/AIDS contact person, and building a relationship with them. This approach helps people get to know you
and understand your role. It builds a spirit of collaboration between the District AIDS Coordinator office and the rest of the community.

2. Alternatively, a District AIDS Coordinator can mail out an inventory questionnaire and compile the information as it is returned to the District AIDS Coordinator office. An example of such a questionnaire is included as Attachment 3. A questionnaire allows the District AIDS Coordinator to compile more information that may be useful for analysing the district situation. People you already have a good relationship with are more likely to respond to a written questionnaire.

**Once the community inventory is complete, you can use it to identify gaps.**

Organize the inventory by type of service. This way, all the organizations that provide similar services can be found together. If an organization provides several different services, it may appear several times on your form.

A gap can be:
1. There is no service at all for this population
2. There is a service, but not enough people know about it
3. There is a service, but there are barriers to access (hours are inconvenient, it is not easy to get to, it is too expensive; it is overcrowded)
4. There is a service, but people do not like to use it because of stigma, or poor service
Attachment 2: Community Services Inventory Example

This is the first page of a community services inventory from Lobatse. The inventory listed approximately 50 organizations and sector programs in Lobatse. This information was compiled by the District AIDS Coordinator office based on information received from each separate sector and organization.

<table>
<thead>
<tr>
<th>Name of Sector/Organization</th>
<th>Contact Person &amp; Phone Number</th>
<th>Address Postal/Physical</th>
<th>Type of organization</th>
<th>Target Group</th>
<th>Activities and Services</th>
<th>Days and Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Athlone Hospital</td>
<td>Dr. Monga, 5330333 Mr. R.S. Majula, 5330333</td>
<td>PO Box 20 Lobatse</td>
<td>Health sector</td>
<td>General Public</td>
<td>*VCT</td>
<td>Mon-Fri 730-1630</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>PLWHAs</td>
<td>*Condom Dist.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>*ARV Therapy</td>
<td></td>
</tr>
<tr>
<td>District Council (DHT) (*Clinic information)</td>
<td>Ms. M. Mopedi, 5330392 Ms. E. Tsae, 5330392 Ms. M. Mmopi, 5330392 Ms. B. Tshenyego, 5330392</td>
<td>Private Bag 28 Lobatse Civic Centre</td>
<td>Health sector</td>
<td>General Public</td>
<td>*IEC</td>
<td>Mon-Fri 730-1630</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>*VTC</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>*Condom Dist.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Expectant Mothers</td>
<td>*PMTCT</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>HBC Patients</td>
<td>*CHBC</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>PLWHAs</td>
<td>*IPT</td>
<td></td>
</tr>
<tr>
<td>District Council (S&amp;CD)</td>
<td>Ms. E.G. Malete 5330392</td>
<td>Private Bag 28 Lobatse Civic Centre</td>
<td>Local authority program</td>
<td>CHBC patients</td>
<td>*Food</td>
<td>Mon-Fri 730-1630</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Orphans</td>
<td>*Basic Needs</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>*Counseling</td>
<td></td>
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<tr>
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<td></td>
<td></td>
<td></td>
<td>*Food</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>*Basic Needs</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>*Counseling</td>
<td></td>
</tr>
<tr>
<td>Botswana Harvard Partnership</td>
<td>Ms. L. Tsalaile, 5334442</td>
<td>PO Box 126 Lobatse</td>
<td>Health sector</td>
<td>Expectant mothers enrolled in PMTCT</td>
<td>*Study on PMTCT</td>
<td>Mon-Fri 730-1630</td>
</tr>
<tr>
<td>Lobatse Mental Hospital</td>
<td>Dr. P. Sidandi, 5330267</td>
<td>PO Box 126 Lobatse</td>
<td>Health sector</td>
<td>Mental Patients</td>
<td>*IEC</td>
<td>Mon-Fri 730-1630</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>General Public</td>
<td>*IEC</td>
<td></td>
</tr>
<tr>
<td>Stigma Reduction Project (UNV)</td>
<td>Mr. M. Mahupu</td>
<td>Private Bag 20 Lobatse Civic Centre</td>
<td>Local authority program</td>
<td>Health Professionals</td>
<td>*Research</td>
<td>Mon-Fri 730-1630</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>PLWHAs</td>
<td>*Research</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>General Public</td>
<td>*IEC</td>
<td></td>
</tr>
</tbody>
</table>
Sample Questionnaire for Collecting Information for HIV/AIDS Community Services Inventory

Below is an example of the questionnaire to be used in gathering data for the inventory. It is a self-administered type of questionnaire. Use of this questionnaire is optional. District AIDS Coordinators may prefer to get the information in other ways.

Introduction Letter for Questionnaire

The ___ (enter name of district here) ___ District Multisectoral AIDS Committee (DMSAC) is developing a district HIV/AIDS profile for the year 2004. The DMSAC is asking for your help in developing an inventory of all HIV/AIDS related activities in ___ (enter name of district here).

A District Inventory of HIV/AIDS services can help the DMSAC

- To identify organisations with or without HIV/AIDS prevention, care and mitigation strategies in place.
- To carry out co-ordination, monitoring and evaluation of HIV/AIDS activities in the district in an more informed manner.
- To help organisations and sectors refer clients to other organisations and sectors
- To identify the level of HIV/AIDS mainstreaming into the organisation's primary activities.

Please complete this questionnaire in as much detail as possible.

Thank you in advance.

District AIDS Coordinator, ___ (enter name of district here) ___.
Appendix C
Instructions for performing community services inventory and services gap analysis

Sample Questionnaire (Optional)

Date the questionnaire is completed: ________________________________

Section 1: Information for the Community Services Inventory

1. Name of organisation: ___________________________________________

2. HIV/AIDS contact person: _______________________________________
   Title: ___________________________________________________________

3. Phone number: _________________________________________________

4. Fax number: __________________________________________________

5. Email address (if available): _____________________________________

6. Postal address: _________________________________________________

7. Physical address: ______________________________________________

1. Type of organization (tick one):
   □ Health sector
   □ Nongovernmental organisation
   □ Community-based organisation
   □ Faith-based organisation
   □ Other central gov't programme
   □ Other local authority prog.
   □ Parastatal
   □ Private sector programme
   □ Other: _______________________________________________________

9. Target groups (tick all that apply):
   □ Women (adults)
   □ Men (adults)
   □ Youth
   □ Children
   □ Orphans
   □ Pregnant women
   □ Employees/workers
   □ Community as a whole
   □ Persons living with HIV/AIDS
   □ Family of PLWHA
   □ Other: _______________________________________________________

10. Categories of service: (tick all that apply)
    □ Information and education communication (IEC)
    □ Behavior change intervention (BCI)
    □ Condoms
    □ Voluntary counseling and testing and/or routine testing (VCT/RT)
    □ Prevention of mother-to-child transmission (PMTCT)
    □ Antiretroviral treatment (ARV)
    □ General medical care/health services
    □ Screening and treatment for sexually transmitted infections (STI)
    □ Prophylaxis to prevent tuberculosis (IPT)
    □ Treatment for tuberculosis (TB)
    □ Home-based care
    □ Orphan care
Appendix C

Instructions for performing community services inventory and services gap analysis

- Counseling and support
- Income generation/employment programme
- Research
- Stigma reduction
- Other: ________________________________________________

11. Days of service: _______________ Hours of service: _______________

Section 2: Other information for the District AIDS Coordinator and DMSAC

12: Which National Strategic Framework goals are you addressing (tick all that apply)?
   - Goal 1: Prevention of HIV Infection
   - Goal 2: Provision of Treatment, Care and Support
   - Goal 3: Strengthened Management of the National Response to HIV/AIDS
   - Goal 4: Psycho-social and Economic Impact Mitigation
   - Goal 5: Provide a Strengthened Legal and Ethical Environment

13. When did your organisation/sector first provide services or programmes for HIV/AIDS (year): ____

14. Does your organisation/sector have an HIV/AIDS action plan?
   - Yes  □ No  □ Do not know

15. Does your organisation/sector have an HIV/AIDS mission statement?
   - Yes  □ No  □ Do not know

16. If you are a NGO, CBO, or FBO, is your organisation registered?
   - Yes  □ No  □ Does not apply

17. To whom do you provide reports about your services/programmes?
   - Branch/village/local office
   - District/subdistrict office
   - District Health Team
   - DMSAC/District AIDS Coordinator
   - National office (such as ministerial headquarters, Ministry of Health, Central Statistics Office, BOTUSA)
   - Other (specify): __________________________________________
   - Do not provide any reports to anyone

18. How often do you provide these reports?
   - Monthly  □ Twice a year
   - Quarterly  □ Annually

19. Who funds your organisations HIV/AIDS activities (tick all that apply)?
   - My organisation  □ DMSAC
   - Other local authority  □ Central government
Appendix C

Instructions for performing community services inventory and services gap analysis

☐ Local donors ☐ International Donors (specify: ___________)  
☐ Others (specify: ___________) ☐ No funding

20. Approximately how much money do you spend on HIV/AIDS related activities annually (tick one)?

☐ under P 25,000 ☐ P 75,000 – P 100,000  
☐ P 25,000 – P 50,000 ☐ Over P 100,000  
☐ P 50,000 – P 75,000 ☐ Do not spend any money  
☐ Do not know

21. Are the resources – financial, physical, time, human – allocated to your organisation adequate to carry out the HIV/AIDS activities in your organisation? (tick one)

☐ Yes ☐ No If “No”, explain: ____________________________________________

22. What more do you want to see your organisation doing in terms of HIV/AIDS prevention, care, and support?

23. Are you aware of the District Multisectoral AIDS Committee in this district? (tick one)  
☐ Yes ☐ No

24. Does your organisation have a representative on the DMSAC? (tick one)

☐ Yes ☐ No

25. Please list the organisations you work or network with in the struggle against HIV/AIDS?

26. Please make any other additional comments in relation to enhancing HIV/AIDS related activities in this district:

Thank you for completing the questionnaire. Please return the questionnaire to the District AIDS Coordinator.

From “HIV Community Planning for Community ART Treatment Adherence”, a training of trainers (TOT) developed by NASTAD in collaboration with Centers for Disease Control and Prevention (CDC/Ethiopia, and the National HIV/AIDS Prevention Control Office (HAPCO) of Ethiopia.

D. Monitoring the Activity (15 minutes)

- Explain that monitoring means “tracking what you are doing”. Explain that the implementation of the work-plan needs to be monitored. Ask participants what reasons they can think of for monitoring their work-plan, and list these on the newsprint. Answers may include:
  - To make sure that the work gets done in the way that it was planned
  - To see what is left to be done
  - To understand if members of the Kabele AIDS Committee need help in doing their pieces of the plan
- Explain that if you use the example of developing a brochure, you will want to know if the members of the Kabele AIDS Committee did the work they said they would do, so to help you decide how best to work with them in the future. You will want to know if the brochure was distributed to the people that needed it most, and whether they found it helpful. You will want to know if you need to print more brochures in the future. And undoubtedly, HAPCO and Save the Children will want to know whether their financial and in-kind contributions were of value.
- Explain that to monitor an activity involves just one additional step in the work-plan process – documentation. Using the Monitoring Overhead (Slide Five), explain how to document each of the activities described in the work-plan. If documentation is considered during the work-plan process, it will inform implementers of the information they need to keep or collect.
## Develop Work-Plan for Implementation of an Intervention.

**Intervention**  Develop and distribute brochure to address need lack of knowledge of resources of population Community Leaders

<table>
<thead>
<tr>
<th>Activities</th>
<th>Documentation</th>
<th>By When</th>
<th>Who is Responsible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seek funds for this effort: Kabele AIDS Committee chair and Health Extension worker submits request for funds as part of annual plan to HAPCO OR Support in kind is sought from local NGOs or churches.</td>
<td>Proposal Submitted to HAPCO / contract with HAPC Proposal submitted to local NGO or Church/ written promise of funds</td>
<td>Month One</td>
<td>Kabele AIDS Committee chair and Health Extension worker OR Member G – church leader.</td>
</tr>
<tr>
<td>Research and list available community resources, who they serve, locations, hours of opening, and cost of services</td>
<td>List of resources completed</td>
<td>Month Two</td>
<td>Health Extension worker will coordinate. Kebele AIDS Committee members X, Y, Z will contribute</td>
</tr>
<tr>
<td>Develop a prototype brochure that lists primary resource – use pictures, lots of space. Keep brochure short</td>
<td>Prototype brochure</td>
<td>Month Three</td>
<td>Member F (works for Save the Children) will ask Save the Children social marketing director to assist in this effort.</td>
</tr>
<tr>
<td>Kabele AIDS Committee reviews prototype brochure, and makes any changes</td>
<td>Kabele AIDS Committee meeting minutes and revised brochure</td>
<td>Month Four</td>
<td>Kabele AIDS Committee chair, with members F, X, Y, and Z</td>
</tr>
<tr>
<td>Brochure is finalized and printed</td>
<td># of brochures printed</td>
<td>Month Five</td>
<td>Kabele AIDS Committee chair and Health Extension worker ORMember G – church leader.</td>
</tr>
<tr>
<td>Brochure is distributed throughout the community</td>
<td># of brochures distributed to members # of brochures and locations at which brochures distributed</td>
<td>Month Six</td>
<td>Members A, B, C, D, and E agree to distribute the brochure to friends, families, churches, schools, etc</td>
</tr>
</tbody>
</table>
E. Evaluating the Activity (45 minutes)

- Explain that evaluating means “assessing the impact of what you are doing.” Ask participants what reasons they can think of for evaluating their work-plan, and list these on the newsprint. Answers may include:
  - To see if the activity/intervention achieved what you thought it was going to. Did it meet the need you identified?
  - To see if you need to do more or less of the same activity another time
  - To provide information to funders about what you have done with their money
- Explain that evaluation of the activity is more complicated than monitoring. To answer evaluation questions such as those listed above usually involves a specific evaluation activity.
- Divide the large group into the same small groups as before. Explain that the assignment is to develop a brief evaluation plan for the intervention work-plan they developed in Section D of this session. Use the Evaluation Presentation/Overhead (Slide Six) to walk through an example for the small groups.
- Distribute the Evaluation Handout, and ask the small groups to answer the questions on (Slide Seven):
  - Identify their evaluation questions --- what do they want to know about the impact of this activity.
  - Recommend a way to answer those questions
  - Suggest who will collect the information and when
  - Suggest how that data will be used.
- Have each small group present its work-plan to the larger group. Encourage the large group to provide constructive criticism to the smaller groups, in particular to make sure that no needed activities are missing from the plan.
## Slide Seven: Developing an Evaluation Plan

- Identify evaluation questions --- what do you want to know about the impact of this activity.
- Recommend a way to answer those questions
- Suggest who will collect the information and when
- Suggest how that data will be used.

### Develop Evaluation Plan for Implementation of an Intervention.

**Intervention**  
*Develop and distribute brochure* to address need *lack of knowledge of resources* of population *Community Leaders*

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Data Collection Method(s)</th>
<th>Data Collection Timeline</th>
<th>Using the data</th>
</tr>
</thead>
</table>
| Did the brochures get distributed to those who needed them? Did those who received a brochure read it, understand it, and use it? | Return to sites where brochures were distributed at a later date. Ideally ask those who received a copy of the brochure, or those who distributed the brochures (e.g. schools/teachers) through interview or survey. Did you take a brochure? Did you read it, understand it? Did you act on the information in it? How would you improve it? Did people take the brochure? Did they read it, understand it? Did they ask you questions about it? Did you run out of brochures? | 3 months after distribution of the brochures. | Results from the interviews / surveys should be summarized and reported to the Kabele AIDS Committee to  
- determine if distribution of brochures is useful in getting information out to the community  
- if so, how to improve brochures for the future |
NEW YORK LINKING INFORMATION NETWORKING KNOWLEDGE (NY LINK) is an example of a cross border capacity building project that relies on coordination and collaboration between multiple partners.

**Introduction**

The NY LINK is a technology transfer and resource exchange project between New York City (NYC) HIV/AIDS service providers, people living with HIV/AIDS (PLWHAs), community-based organizations (CBOs) working with immigrants from the Caribbean, Central America and Mexico, and their counterparts doing similar work in the Caribbean, Central America and Mexico. The project is comprised of two components: a two-week capacity building program including; Train-the-Trainer (TOT) and Twinning activities and follow-up technical assistance (TA). The NY LINK brings together multidisciplinary teams composed of at least one physician, a nurse and two PLWHAs from the Caribbean, Central America, Mexico, to New York City for the two-week capacity building program. The NY LINK develops strategic alliances among agencies and individuals, leading to more effective HIV prevention efforts and care service delivery in NYC and partner countries. The NY LINK was originated by CAI (a non-profit educational organization), in partnership with New York State Department of Health AIDS Institute, New York Community Trust, UNAIDS, and international donors in several Caribbean and Central American countries.

**Scope of Work**

The NY LINK began in 1999, both in response to the growing AIDS epidemic in the Caribbean, Central America and Mexico and the need to improve services to immigrant populations throughout NYC. Multidisciplinary teams composed of people living with HIV/AIDS (PWHA) and health care providers from different Central American and Caribbean countries, come to NYC for the NY LINK. During the first week of the program, international participants receive a 5-day training held on HIV/AIDS related topics identified in pre-training needs assessment and in consultation with key partners. As part of the second week of the program, international participants are matched with NY-based CBOs to visit a community clinic or CBO program for a mutually beneficial professional exchange, which may include orientation to, and observation of specific programs or activities, and structured dialogue on programmatic issues of greatest concern to both parties. At the completion of the two-week capacity building program, CAI provides in-country training and/or technical assistance upon request from individual participating countries. CAI has delivered TA on a variety of HIV/AIDS related topics, working closely with National AIDS Programs (NAP) and the Global Fund to prevent HIV/AIDS, TB and Malaria (GFATM) of several Caribbean and Central American countries. In addition to the two-week capacity building program and in-country technical assistance follow-up visits, CAI continually provides technical assistance to NY LINK participants through virtual classrooms, on-line discussion boards, an annual newsletter, emails and conference calls.
The NY LINK seeks to develop leadership and empower PLWHAs and health professionals working with vulnerable populations both in the United States (US) and internationally by accomplishing the following:

- Coordinate and manage sustainable “linkages” between health care providers, PWHA networks and non-governmental organizations (NGOs)/ community-based organizations (CBOs) in the Caribbean, Central America, and Mexico, with New York City health care providers, PWHA groups, and NGOs/CBOs serving these immigrant populations.
- Develop and/or strengthen multidisciplinary teams to facilitate the process of integrating HIV prevention and care to improve the quality of health services.
- Develop and deliver culturally and linguistically appropriate, training-of-trainers (TOT) programs on HIV/AIDS prevention and treatment related issues targeting Caribbean, Central American, and Mexican populations.
- Facilitate the development of concrete plans for technology transfer on key issues with culturally appropriate strategies for improving HIV services between health care providers, PWHA groups and NGOs/CBOs in the Caribbean, Central America and Mexico with NYC health care providers, NGOs/CBOs and PWHA groups.
- Evaluate the effectiveness of these interactions including tracking of networking, resource and strategy exchanges, as a potential “model” for replication in other regions of the world.

Lessons Learned
The NY LINK is a highly significant project that demonstrates innovative HIV/AIDS strategies. It is an excellent demonstration of resource and technology transfer between New York City and State and the Caribbean, Central America, and Mexico, regions highly affected by HIV/AIDS. As a result of this program we have seen the development of multidisciplinary teams where they did not exist before. At the beginning of this project many participating country teams consisting of physicians and PLWHA had never sat face to face to discuss HIV care strategies and policies. Through the NY LINK program, CAI was able to facilitate many of these first encounters. Also, unique to the NY LINK program is through twinning participants from participating countries are able to receive hands on information from NYC health care providers who have been working in HIV/AIDS for over 20 years. In contrast, NYC service providers are given the opportunity to learn about how best to serve the immigrant communities in NYC and NYS from the visiting physicians, nurses and PLWHAs. This exchange relating to immigrant populations has been successful especially in NYC where foreign born persons have the highest new infection rates. ¹ Persons born in the Caribbean comprise the largest percentage followed by those from Central (16.6%) and South America (13.3).

Performance Outcomes
As result of this project CAI has developed a cadre of highly skilled trainers on related HIV/AIDS topic who can in turn train other in order to strengthen in-country capacity. Over the past five years, CAI has conducted two NY LINK programs each year, for a total of 10 programs delivered so far. Over 200 representatives from 18 countries have participated in the two-week training program, working together with U.S.-based counterparts to share and develop HIV/AIDS programmatic strategies on such issues as risk reduction and behavior change, HIV counseling and testing,

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¹ NYCDOMH: Foreign-born Person Newly Diagnosed with HIV, New York City 2004. Vol.4, No.1
leadership development of PLWHA, prevention for positives, treatment and adherence, and the development and maintenance of multidisciplinary teams to implement developed strategies. Over 330 health and social service personnel have been trained on multidisciplinary team building, treatment adherence, pre and post-test counseling, and rapid testing. The NY LINK program employs a multi-sectoral strategy involving a large number of institutions and individuals for resource development and project implementation. Through this process, CAI has developed and strengthened institutional relationships at the country level by working with Ministries of Health, National AIDS Programs, UNAIDS offices and PWHA networks. In 2003, the NAP of the Dominican Republic requested that CAI provide in-country training and TA in an effort to expand the cadre of trainers throughout the country available to assist organizations and health care institutions with the implementation and delivery of ARV and HIV care services. Since 2004, CAI has been working in close collaboration with El Salvador’s GFATM project and NAP to build in-country training and TA capacity, and to strengthen prevention and treatment services offered by MOH facilities, and NGO’s, and other service providers funded by public-private ventures or international collaborative agreements.
COMMUNITY PLANNING IN ST. LUCIA (Presentation to CCNAPC AGM, September 2006) provides examples of multi-sectoral planning, as well as action planning.
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AED</td>
<td>Academy of Educational Development</td>
</tr>
<tr>
<td>AGM</td>
<td>Annual general meeting</td>
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<tr>
<td>AIDS</td>
<td>Acquired immune deficiency syndrome</td>
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<tr>
<td>ARV</td>
<td>Antiretroviral</td>
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<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
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<tr>
<td>BCI</td>
<td>Behavior change communication</td>
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<tr>
<td>BOTUSA</td>
<td>Botswana/USA</td>
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<tr>
<td>CBO</td>
<td>Community based organization</td>
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<tr>
<td>CCM</td>
<td>Country coordinating mechanism</td>
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<tr>
<td>CCNAPC</td>
<td>Coalition of Caribbean National AIDS Program Coordinators</td>
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<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
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<tr>
<td>CSW</td>
<td>Commercial sex worker</td>
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<tr>
<td>DATF</td>
<td>District AIDS task force (Zambia)</td>
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<tr>
<td>DDCC</td>
<td>District development coordinating committee (Zambia)</td>
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<tr>
<td>DMSAC</td>
<td>District multi-sectoral AIDS committee (Botswana)</td>
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<tr>
<td>FBO</td>
<td>Faith based organization</td>
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<tr>
<td>GFATM</td>
<td>Global Fund for AIDS, Tuberculosis, and Malaria</td>
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<tr>
<td>HAPCO</td>
<td>HIV/AIDS prevention control organization (Ethiopia)</td>
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<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<tr>
<td>IDU</td>
<td>Injecting drug user</td>
</tr>
<tr>
<td>IEC</td>
<td>Information education communication</td>
</tr>
<tr>
<td>Kabele</td>
<td>Neighborhood (Amharic)</td>
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<tr>
<td>KAC</td>
<td>Kabele AIDS committee</td>
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<tr>
<td>MOU</td>
<td>Memorandum of Understanding</td>
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<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
</tr>
<tr>
<td>N/A</td>
<td>Not applicable</td>
</tr>
<tr>
<td>NAC</td>
<td>National AIDS Coordinator</td>
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<tr>
<td>NASTAD</td>
<td>National Alliance of State and Territorial AIDS Directors</td>
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<tr>
<td>NYC</td>
<td>New York City</td>
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<tr>
<td>NGO</td>
<td>Non governmental organization</td>
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<tr>
<td>PATF</td>
<td>Provincial AIDS task force (Zambia)</td>
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<tr>
<td>PLWHA</td>
<td>Person living with HIV/AIDS</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of mother to child transmission</td>
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<tr>
<td>PPA</td>
<td>Priority prevention area</td>
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<tr>
<td>RAR</td>
<td>Rapid assessment response</td>
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<tr>
<td>SOCO</td>
<td>Single overriding communication objective</td>
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<tr>
<td>STD</td>
<td>Sexually transmitted disease</td>
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<tr>
<td>STI</td>
<td>Sexually transmitted infection</td>
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<tr>
<td>TA</td>
<td>Technical assistance</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>TBA</td>
<td>Traditional birth attendant</td>
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<tr>
<td>TOT</td>
<td>Training of trainers</td>
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<tr>
<td>VCT</td>
<td>Voluntary counseling and testing</td>
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