AIDSCAP

HIV/AIDS Care and Support Projects

Using behavior change communication techniques to design and implement care and support projects

USAID

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GLOSSARY

AIDS	Acquired Immunodeficiency Syndrome
BCC	Behavior Change Communication
HIV	Human Immunodeficiency Virus
IEC	Information, Education, Communication
NGO	Nongovernmental Organization
PLWHIV	People/person living with HIV
STD	Sexually Transmitted Disease
TB	Tuberculosis
WHO	World Health Organization
UNAIDS	United Nations Agency for HIV/AIDS

INTRODUCTION

This is one in a series of practical "how-to" handbooks developed by AIDSCAP's Behavior Change Communication (BCC) Unit. Its objective is to help organizations implement HIV/AIDS care and support projects using behavior change communication techniques.

The handbook addresses these care and support topics:

▶ Choosing care and support interventions

▶ Selecting target audiences

▶ Planning and designing care and support interventions

▶ Using effective communication approaches

▶ Meeting the training and education needs of staff, volunteers and target audiences

▶ Developing systems for supervision, support and monitoring of activities

▶ Influencing social norms

▶ Other important care and support topics (e.g., confidentiality, referrals, family issues, supporting people living with HIV/AIDS)

In addition to this handbook, other AIDSCAP BCC handbooks may help guide the development of a care and support project. They are:

How to Create an Effective Communication Project

Behavior Change Through Mass Communication

How to Conduct Effective Pretests

Assessment and Monitoring of BCC Interventions

How to Create an Effective Peer Education Project

Partnership with the Media

BCC for STD Prevention

Policy and Advocacy Work on HIV/AIDS Prevention

Other useful resources are listed in the Appendix of this handbook.

HIV/AIDS CARE AND SUPPORT PROJECTS

A. What Are Care and Support?

Care and **support** mean different things to different people. To some, care means providing medical assistance. To others, it means meeting various needs of people living with HIV/AIDS and supporting their families and other caregivers.

This handbook defines the **care** and **support** of people living with HIV/AIDS in the broadest sense. This means meeting the overall **needs** of people living with HIV/AIDS, their families, caregivers and communities. **A person or people living with HIV/AIDS will be referred to as PLWHIV in this handbook.**

Care and **support** projects can address:

▶ **Health needs:** e.g., providing knowledgeable health workers, medicine, services, home care, medical supplies

▶ **Emotional needs:** e.g., encouraging a safe and supportive environment in the home and/or community; decreasing stigma; giving counseling; forming support groups

▶ **Spiritual needs:** e.g., encouraging a supportive environment in religious communities, organizing prayer groups, promoting home visits by religious leaders

▶ **Nutritional needs:** e.g., helping families improve their gardens, teaching about nutritional foods and preparation, ensuring safe drinking water, providing food

▶ **Social needs:** e.g., helping people overcome fear of visiting and supporting PLWHIV

▶ **Capacity needs:** e.g., helping PLWHIV and their families and caregivers make their own decisions and run their own programs

► **Day-to-day needs:** e.g., helping with child care, feeding and tending livestock, going to the market and other household chores

► **Financial needs:** e.g., helping families of PLWHIV by providing school uniforms or fees, seeds and fertilizers, house rent

The final goal of all care and support interventions is to help PLWHIV live positively.

B. What Does "Living Positively" Mean?

Living positively with HIV/AIDS means:

► Spending time with family and friends

► Planning for the future of loved ones

► Keeping busy and remaining productive

► Having hope

► Maintaining spiritual health

► Going for individual and/or group counseling

► Eating a balanced diet

► Learning about the virus

► Protecting others from HIV infection

► Self care

► Limiting the use of alcohol and tobacco

► Getting enough physical exercise

► Getting enough sleep and rest

► Seeking medical help whenever an illness arises

C. What are the Benefits of Care and Support Projects?

Care and **support** projects help PLWHIV live positively. They can also decrease the impact of HIV/AIDS on families and on society as a whole. Other benefits are:

Benefits of Care and Support	Explanation/Example
Care and support can improve the quality of life for PLWHIV and their caregivers.	Groups of people (support groups) affected by HIV/AIDS can come together in a safe place to discuss difficulties and share concerns. This helps to relieve stress, anxiety and depression.
Care and support can decrease the stigma of having HIV.	When community leaders respect, support and accept people affected by AIDS, others in the community may follow their lead.
Care and support can strengthen AIDS prevention activities by allowing target audiences to have contact with PLWHIV.	Meeting PLWHIV can put a human "face" on the epidemic and help people realize that anyone could be at risk of infection.
Care and support may help prevent the spread of AIDS-related illnesses that also infect other people.	Caregivers who learn basic care and prevention techniques can prevent the spread of diseases associated with HIV/AIDS such as tuberculosis (TB).
Care and support can keep PLWHIV and caregivers healthy and employed for as long as possible.	Businesses that modify the work load of employees with HIV/AIDS can keep them productive longer.

D. Who are Target Audiences for Care and Support Projects?

Meeting the needs of PLWHIV requires the cooperation of many people. For this reason, the target audience(s) for a care and support project could be:

► **Health workers** who counsel PLWHIV, teach caregivers how to care for their sick family members, and/or make home visits

► **Caregivers** who provide daily care and support for PLWHIV (often family and friends)

► **Community members** who provide a supportive and compassionate environment for PLWHIV and provide support to caregivers

► **PLWHIV** who may need to learn new ways of living positively

Important

This handbook does not cover HIV testing and counseling issues. Contact the World Health Organization and/or UNAIDS in your country for more information and direction.

CARE AND SUPPORT ACTIVITIES

This section provides a list of some care and support activities to help you start thinking about what you would like to do. In order to decide which type of activity would be best, consider your organization's past experience, funding, and trained staff and volunteers.

Mark the care and support activities that might be appropriate for your organization:

A. **Home Care**

❑ Train caregivers in the basic home health care of PLWHIV.

❑ Provide counseling services to PLWHIV and their caregivers at home.

❑ Train clinic or hospital medical staff to meet the medical needs of PLWHIV in their homes.

B. **Clinic- or Hospital-based Care**

❑ Update medical staff on the special medical needs of PLWHIV.

❑ Train medical staff in emotional issues related to HIV/AIDS.

❑ Train counselors to meet with PLWHIV to discuss their psychological needs.

C. Support Groups

❑ Organize support group meetings for PLWHIV.

❑ Organize support group meetings for caregivers/family of PLWHIV.

❑ Organize support group meetings for medical or nonmedical staff or volunteers making home visits.

❑ Conduct support group meetings for medical or nonmedical staff working with PLWHIV and/or their caregivers in clinic or hospital settings.

D. Education/Training

❑ Provide care and support sensitization for people in the workplace.

❑ Offer care and support training to community groups.

❑ Provide care and support sensitization to religious groups.

❑ Make care and support presentations in schools and universities.

❑ Train PLWHIV and/or caregivers in work that can be done from home.

❑ Provide job retraining so that PLWHIV can switch to less physically stressful work.

❑ Train PLWHIV and/or caregivers in how to provide safe drinking water, protect oneself from malaria, prepare nutritious meals, etc.

E. Peer Education

❑ Train PLWHIV to educate other PLWHIV on care and support issues.

❑ Train caregivers to educate other caregivers on care and support issues.

❑ Train community members (religious, business, etc.) to educate other community members on the needs of PLWHIV and their caregivers.

F. Family/Community Support

❑ Provide volunteers/staff to help PLWHIV and caregivers with day-to-day household needs (e.g., cooking, cleaning, shopping).

❑ Provide volunteers/staff to help PLWHIV and caregivers cultivate gardens and/or care for livestock.

❑ Provide volunteers/staff to help care for the young children of PLWHIV and caregivers.

❑ Provide volunteers/staff to help PLWHIV get to medical appointments.

❑ Provide volunteers/staff to help sell produce/products of PLWHIV and caregivers in the market.

❑ Provide volunteers/staff to help PLWHIV and caregivers organize their financial and/or legal affairs.

❑ Provide for the housing, food or other needs of AIDS orphans.

❑ Encourage home visits by religious leaders to PLWHIV and their caregivers to provide spiritual guidance.

❑ Organize fundraisers to help pay the school fees of children of PLWHIV.

❑ Organize fundraisers to help pay for the medical needs of PLWHIV.

❑ Organize fundraisers to help pay for your organization's support of PLWHIV.

G. Policy Initiatives

❑ Meet with business leaders to encourage policies on AIDS in the workplace.

❑ Meet with religious leaders to encourage supportive church/mosque policies related to PLWHIV.

❑ Meet with community leaders to encourage local policies and laws.

❑ Encourage political leaders to establish policies and laws supportive of PLWHIV and their caregivers.

❑ Organize meetings of community, religious and business leaders to deal with AIDS care and support issues in the community.

❑ Work with leaders in health care settings to enforce AIDS policies.

H. Public Opinion Activities

❑ Conduct mass media campaigns to influence public opinion about PLWHIV.

❑ Provide an opportunity for community, business, religious and/or political leaders to publicly support people affected by HIV/AIDS.

❑ Provide an opportunity for popular entertainment figures to publicly support people and communities affected by HIV/AIDS.

❑ Provide an opportunity and supportive environment for PLWHIV to publicly talk about their struggle with HIV/AIDS.

❑ Conduct publicity events for care and support activities.

❑ Place supportive stories about HIV/AIDS in newspapers, magazines and radio/television news sources.

The rest of this handbook will help you make decisions about the type of care and support project that will be best for your organization.

SHOULD YOUR ORGANIZATION WORK IN CARE AND SUPPORT?

A. Who Implements Care and Support Interventions?

Any organization (e.g., community, religious, development, educational, financial or health) can play an important role in the care and support of PLWHIV. Here are some examples of how organizations can add care and support activities to their interventions:

Organization	AIDS Care and Support Activity
A NGO that works to prevent water-borne diseases	The NGO can use its network of outreach educators to include an information campaign on the dangers of water-borne diseases to PLWHIV.
An agricultural extension project	The project can introduce and teach about crops and food preparation to meet the nutritional needs of PLWHIV.

Organization	AIDS Care and Support Activity
A women's service organization	The service organization can assist families affected by HIV/AIDS by helping them in the household with chores such as planting and weeding home gardens, taking care of small children, or cooking meals.
A human rights group	The human rights group can work to end discrimination against PLWHIV by including them in their mission statement and publicizing violations of their rights.

B. Questions to Help Guide Your Decision

Your organization's past experience will help determine how effectively it can incorporate care and support interventions into its current or new activities. Below are some questions to guide your thinking.

1. Check the areas in which your organization has experience:

   ❑ HIV/AIDS prevention

   ❑ Medical care

   ❑ Counseling

   ❑ Community health

   ❑ Child and maternal health

   ❑ Reproductive health

   ❑ Community mobilization

   ❑ Agricultural extension

   ❑ Workplace organization (e.g., unions)

   ❑ Church groups

   ❑ Religious outreach

   ❑ Media/journalism

❑ Spiritual healing

❑ Child care

❑ Housing assistance

❑ Small business development

❑ Income generating activities

❑ Water supply and sanitation

❑ Transportation

❑ Education

❑ Other _____

_____

2. For each item checked, how could this benefit an AIDS care or support project?

3. Do you have experience working with any of the following?

❑ People living with HIV/AIDS

❑ Health workers who care for PLWHIV

❑ Families caring for sick relatives at home

❑ Traditional healers

❑ Traditional birth attendants/midwives

❑ Traditional circumcisers

❑ Community groups (e.g., youth groups, women's groups)

❑ Religious organizations

❑ Business organizations

❑ Professional organizations (e.g., Rotary Club, Lions Club)

❑ Unions

❑ Clergy

❑ Politicians

❑ Teachers

❑ Business leaders

❑ Peer educators

❑ Medical personnel

❑ Students/youth

4. For each area checked, how could this experience benefit an HIV/AIDS care and support project?

5. In the space below, write down the activities you checked in SECTION III.

6. Could the care and support activities you listed for question 5 be added to your organization's ongoing activities? How?

7. Based on the activities you listed for question 5, do you want to start a new project specializing in care and support activities or add care and support activities to an on-going project?

8. What additional expertise do you need to implement these care and support activities?

9. Where can you find this expertise?

10. What resources do you need (human, material, financial, experience) to develop a new care and support project?

11. If you don't have these resources, how could you develop or find them?

Although you may not be able to answer all these questions now, your answers will help you decide whether a care and support project is possible or appropriate for your situation.

Important

The rest of this handbook will help you to think about the expertise, resources, training, etc., you will need to develop and implement successful care and support activities or interventions. At the end of each section return to the questions in this section to gain a fuller picture of your care and support activities.

IMPORTANT STEP: SELECTING THE TARGET GROUP

You have examined the expertise in your organization and thought about the activities or interventions you would like to implement. Now think about the target audience(s).

(For more guidance on selecting target audiences consult the AIDSCAP BCC handbook *How to Create an Effective Communication Project*.)

A. Choosing a Target Audience

The four target audiences for a care and support project are:

Target Audience	Definition
People Living with HIV and AIDS (PLWHIV)	People who have HIV and may or may not have some of the opportunistic infections associated with AIDS.
Health workers	1) **Clinic- or hospital-based health workers** and other trained health professionals who visit PLWHIV at home to assess and address their health status. 2) **Community-based health workers** at the local or village level who have received some health training. These can include traditional birth attendants and healers as well as community health workers.

Target Audience	Definition
Health workers (cont)	3) **Informal health workers** such as peer educators, who provide PLWHIV and their caregivers with information and services, and provide some health and psychological support. 4) **Social workers** who provide professional psychological support and make referrals to available services
Caregivers	Family members and/or close friends who provide daily care and support to PLWHIV. Some caregivers may also be PLWHIV.
Communities	Groups of influential individuals and/or the general population who help provide a supportive and compassionate environment for PLWHIV.

Remember:

The best target audience for your project may be groups you have worked with in the past.

Action

Select the target audience now!

IMPORTANT STEP: UNDERSTANDING YOUR TARGET GROUP

In order to develop successful care and support interventions and BCC/IEC materials, you need reliable information about your target audience(s).

Sometimes the information has already been collected by others. Call, visit or write some of the most promising places:

▶ National AIDS Control Program

▶ Nongovernmental organizations working in HIV/AIDS

▶ Community-based organizations

▶ Religious groups/associations

▶ United Nations agencies

▶ Community health facilities

▶ Universities

▶ Research institutes

Other times, you will need to collect the information yourself. Do this by developing a questionnaire and conducting individual interviews or focus groups with members of your target audience. For additional guidance on segmenting a target audience and conducting a situation analysis, refer to the BCC handbook, *How to Create an Effective Communication Project.*

A. Segmenting a Target Audience

Each target audience represents a diverse group of people. You can segment your target audience by determining specific information about their:

▶ Economic situation (e.g., How do they pay for health care? Will lack of salary limit their willingness to participate?)

▶ Demographic situation (e.g., Are they urban? Rural? Do they work in a specific place?)

▶ Socio-political situation (e.g., Do they face discrimination because of their occupation? Ethnic background? Primary language?)

B. Situation Analysis

When you have clearly identified and segmented your target audience(s), conduct a situational analysis to learn about their beliefs, physical needs, etc. A situation analysis gives you detailed information about the target audience so that you can effectively plan and design the project.

The situation analysis will help you clarify:

▶ The services and resources the target audience knows about and uses

▶ The services and resources that are available in the community

▶ The target audience's knowledge attitudes and beliefs about HIV/AIDS/STDs

▶ The target audience's health situation

▶ Community norms and misconceptions surrounding HIV/AIDS/STDs

▶ The solutions or improvements suggested by the community

A situation analysis can be conducted using one or more of the following methods:

▶ Focus group discussions

▶ Individual interviews

▶ Group interviews

▶ Self-administered questionnaires

1. For all ***target audiences***, ask:

   ❏ What do they know about HIV/AIDS (e.g., risk behaviors, modes of transmission, preventing transmission)?

   ❏ Is the information accurate?

   ❏ Where do they get this information?

   ❏ What myths or prejudices do they hold about PLWHIV (e.g., it is a punishment from God; false modes of transmission; only certain people are at risk)?

   ❏ What communication approaches are they likely to respond to (e.g., peer education, training, outreach, counseling, word of mouth [through family and friends, or by people in a similar situation])?

   ❏ Which media do they prefer for information (e.g., brochures, comics, video, radio)?

   ❏ Do they have access to important resources and services (e.g., transportation, medical supplies, referral sources)?

   ❏ What would make their work/lives easier?

2. If your target audience is ***PLWHIV***, also ask:

   ❏ Are there ways in which their activities affect their health (e.g., do they use mosquito nets? eat good food? drink a lot of alcohol? continue to have unprotected sex with an infected partner?)?

   ❏ Are there ways in which their activities put others at risk (e.g., do they have unprotected sex? are they sharing razors? planning to have children?)?

   ❏ How is HIV/AIDS affecting their children or family?

   ❏ To whom do they turn for emotional and spiritual support (e.g. family, friends, church, support group)?

   ❏ What health services are presently available to them?

   ❏ What types of support would they like to have (e.g. support groups, home visits, child care, assistance getting to health services, economic help)?

3. If your target audience is **trained health workers**, also ask:

❑ Are they able to discuss sexual issues using the correct vocabulary without embarrassment?

❑ Do they have any counseling skills (formal or informal training)?

❑ What types of services do they presently provide to PLWHIV?

❑ What types of additional services could they provide?

❑ (If they make home visits) What do they do during home visits (e.g., prescribe medication? make health assessments? counsel the caregivers?)?

❑ What type of emotional support do they have (e.g., support groups, access to counseling, supervision)?

❑ What type of emotional support would make their work easier?

4. If your target audience is **informal health workers** (e.g., peer educators) or **community-based health workers** (e.g., traditional healers) you will also want to ask:

❑ What is their level of health care knowledge?

❑ Are they knowledgeable about basic home health care techniques?

❑ How do they feel about illness and disease?

❑ Are they able to discuss sexual issues using the correct vocabulary without embarrassment?

❑ Do they have counseling skills (formal or informal training)?

❑ Are they aware of resources for referral in the community?

❑ What type of emotional support do they have (e.g., support groups, access to counseling, supervision)?

❑ What type of emotional support would make their work easier?

5. If your target audience is **home caregivers** such as family and friends, you will also want to know:

    ❏ What is their level of health care knowledge?

    ❏ Are they knowledgeable about basic home health care techniques?

    ❏ How do they feel about illness and disease?

    ❏ What is their relationship to the PLWHIV?

    ❏ What do they do as caregivers?

    ❏ Are there ways in which their caregiving puts their health at risk (e.g., cleaning bloody wounds without protection)?

    ❏ Do any of their activities put the people with HIV/AIDS in their household at risk (e.g., do they refuse to get proper treatment for TB?)?

    ❏ How and from whom do they like to get important information about their caregiving (e.g., peer education, training, outreach, counseling)?

    ❏ To whom do they turn for support (e.g., family, friends, religious groups, support group)?

    ❏ What types of support they would like to have (e.g. support groups, home visits, child care, gardening)?

    ❏ What important resources would make their caregiving easier?

    ❏ Are they aware of resources for referral in the community?

6. If your target audience is **community groups** you will also want to know:

    ❏ What myths or prejudices do they believe about the caregivers (e.g., they must be HIV positive too; their families should be shunned)?

    ❏ How has HIV/AIDS affected the community?

    ❏ What are their beliefs about how PLWHIV should be treated?

❑ What community support exists for PLWHIV and caregivers?

❑ How does the community usually cope with community problems?

For *religious groups*, also answer these questions:

❑ How has HIV/AIDS affected the religious organization?

❑ How has the religious organization supported PLWHIV and their caregivers?

❑ How might the religious organization improve their support of PLWHIV and their caregivers?

For *community leaders*, also get some of the following information:

❑ What can community leaders do to support people living with HIV/AIDS and their caregivers?

❑ What can the community do to support people living with HIV/AIDS?

❑ What are the particular problems surrounding HIV/AIDS that community leaders need to address?

Important

You will use the information collected during the situation analysis to make planning and design decisions in the next section of this handbook.

Use the space below to write the characteristics you have learned about your target audience.

IMPORTANT STEP: PLANNING AND DESIGNING CARE AND SUPPORT INTERVENTIONS

At this point you have:

- ▶ Thought about care and support activities or interventions you would like to implement

- ▶ Chosen one or more target audience

- ▶ Conducted a situation analysis for that/those target audience(s)

Now use this information to design the intervention.

A. Initial Planning

Planning begins with a clear statement of goals and objectives. Using the information you have, think about the goals and specific objectives of the project.

1. What are the care and support project goals? (Why do you want to do this?):

2. What are the objectives (description of specific results):

   a. What services will be provided?

   b. Who will provide the services?

   c. In what way? (For example, how will home care clients receive services; how will health care workers get support; how will community leaders be encouraged to act; how will peer educators be trained?)

Keep these goals and objectives in mind when you are developing a monitoring plan (Section XIV). They will determine how you monitor and evaluate the project. For more information on evaluation methods, consult the ***AIDSCAP Evaluation Module One, Introduction to Evaluation.***

B. Designing Care and Support Interventions

1. Design Decisions

Think about these design issues. (NOTE: Information to help you make these decisions is found in Sections VIII-XVI that follow).

Target Audience:

▶ How will you convince the target audience to participate in your project?

▶ How many people will you support?

▶ How will you find them?

▶ How will you determine their needs?

▶ How will you ensure client confidentiality?

▶ Is there a secondary target audience (people who can influence the primary target audience)? If so, will you target them too?

Project Activities:

▶ What will be your main project activities?

▶ Will there be other project activities? If yes, what will they be?

▶ How will these activities be carried out?

▶ How often will they happen?

▶ Who will undertake them?

▶ Where will they take place?

▶ Which services can be referred outside the project?

Media and Messages:

▶ Which media will you use to carry out these activities?

▶ Which messages will you deliver to the target audience?

Project Staff:

▶ Who do you need on your staff (e.g., people with health care experience, experienced peer educators, counselors, supervisors)?

▶ How many staff members do you need in order to serve your target audience?

▶ Will you have volunteer staff?

▶ What nonfinancial incentives can you provide to volunteer staff?

▶ What kind of training will you provide your staff and volunteers?

▶ Where will you find experts to provide the necessary training?

Community Support:

▶ How will you inform community leaders about the goals and objectives of your project?

▶ Which community leaders or gatekeepers need to "buy into" the project before your activities can begin?

▶ Should you appoint an advisory committee of important leaders?

▶ Who do you need on your advisory committee?

▶ How often should your advisory committee meet?

▶ Which community resources can you use to help implement your project?

▶ How will you disseminate information about your project to outside sources?

Networking and Linkages:

▶ Does your management believe in networking with other agencies?

▶ Does your management have skills or experience with networking?

▶ Which agencies will be contacted for possible program linkages?

▶ How will networking take place?

▶ Who will be responsible for networking?

Logistics:

▶ How much money is available annually for this project?

▶ How will your staff and clients get to where they need to be for activities (i.e., transportation)?

▶ Where will support materials (e.g., medicine, condoms, educational materials) come from?

Monitoring, Evaluation and Supervision:

▶ What type of monitoring is necessary for your activities (e.g., quantitative monitoring such as the number of home visits by health workers and/or qualitative monitoring such as self-reported improvements in positive living)?

▶ Who will do the monitoring?

▶ How often will monitoring activities take place?

▶ How will you know if your activities need revising?

▶ How will you know if your activities have been successful?

▶ What type of supervision is necessary for your activities?

▶ Who will provide the supervision?

▶ How often will supervision take place?

Some project managers like to meet with colleagues and members of their advisory group and target audience to discuss the project goals and objectives and how to achieve them. The purpose of this meeting is to:

▶ Ensure that your information is accurate.

▶ Talk about ways to proceed with design and implementation.

▶ Talk about selecting and training staff and volunteers, etc.

Important

Where possible, link with existing successful projects and organizations.

Important

These design decisions are discussed in the next few sections of this handbook. Read these sections before making a final decision.

IMPORTANT STEP: CHOOSING EFFECTIVE APPROACHES

A. Approaches

Common communication approaches used for care and support interventions are:

▶ Interpersonal approaches

▶ Media approaches

▶ Community participation approaches

The communication approaches you choose will depend upon your project goals. For example:

▶ If you are designing a project to make home care visits to PLWHIV, use an interpersonal approach.

▶ If your goal is to change community norms about PLWHIV, mass media might be a better approach.

▶ If your goal is to provide assistance (e.g., gardening, child care or financial assistance such as school fees) for families affected by HIV/AIDS, you would choose a community participation approach.

In each case, the communication approach should be supplemented by other communication approaches or different methods of using the communication approach. For example,

▶ The interpersonal home care project could also use a community participation approach to help meet the nutritional needs of a PLWHIV.

▶ The mass media project to change community norms could be supplemented by small media materials.

▶ The staff of the community participation gardening project could be motivated by sermons given by religious leaders.

Important

Other organizations may be using communication approaches that can complement your activities. Ask the Ministry of Health, National AIDS Control Program, and other NGOs for print materials that you can use or adapt.

1. Interpersonal approaches

Some of the most effective care and support projects use interpersonal approaches. Interpersonal methods include:

▶ Counseling

▶ Support groups

▶ Peer education

▶ Outreach

▶ Training

Each of these interpersonal approaches uses a different method to reach members of the target audience, on an individual or small group level.

a. **Counseling:** Counseling uses trained personnel to help others understand their problems, identify and develop solutions, and make their own decisions about what to do. Counseling involves listening to client's problems and fears, helping to increase client's self-esteem, and giving correct and useful information.

b. **Support groups:** Support groups can provide group support to families, caregivers or PLWHIV. They can be led by trained counselors, informal or professional health workers, peer caregivers, peer PLWHIV, or others involved with project activities.

c. **Peer education:** Peer education uses trained people to educate others in their peer group. It can take place in almost any setting.

d. **Outreach:** Outreach uses trained people to reach target audience members with information and/or products (e.g., education materials, condoms) in a specific geographic area.

e. **Training:** Training activities help people acquire new information or skills. Trainers are experts in specific topic areas (e.g., clinic nurse).

2. Media approaches

Media approaches are most effective when they are used to support interpersonal activities or to create awareness of specific issues. The most common media approaches are:

a. **Mass media:** Mass media includes radio, television, newspapers, magazines and billboards. It is particularly useful for creating awareness and influencing social norms (e.g., showing PLWHIV working productively with co-workers). Mass media is best used as part of a communication campaign which may also involve small media and community participation approaches.

b. **Folk media:** Folk media includes drama, puppetry, music, poetry and dance. It can disseminate important information in a community setting (e.g., illustrating ways to deal with orphans in the community). Folk media is an entertaining medium which can attract large groups of people.

c. **Small media:** Examples of small media are leaflets, posters and flip charts. Small media can provide detailed information about topics presented through the mass media (e.g., information about the nutritional needs of PLWHIV).

3. Community Participation Approach

The community participation approach encourages members of a community (individuals or groups) to contribute to care and support projects. It provides day-to-day assistance and important information to PLWHIV and caregivers through acts of kindness.

Choosing the right combination of approaches for your project is very important. Below is an example of how several approaches can be used to accomplish the same goal:

Goal: To inform PLWHIV and their caregivers that contaminated drinking water could harm their health.

Approach	Method	Activities
Interpersonal	Outreach	Trained outreach workers can visit homes of PLWHIV to dispense iodine pills and explain how to use them.
	Support groups	Caregivers can include discussion of safe water during support group sessions.
Media	Mass media campaign	A radio campaign can explain the dangers of contaminated water to everyone, but especially to PLWHIV.
Community participation		Village women can help collect water and boil or filter it for a villager with HIV/AIDS.

B. Educational Materials

Provide materials that can help your staff and volunteers give correct and appropriate information to the target audiences. To determine their usefulness, you will need to pretest them.

For guidance on pretesting and using educational materials and other media refer to the BCC handbooks, *How to Conduct Effective Pretests*, *How to Create an Effective Communication Project* and *Behavior Change Through Mass Communication.*

Remember:

The Ministry of Health, National AIDS Control Program, or other NGOs may have already developed educational materials that you can use. Take advantage of these to save your project time and money.

IMPORTANT STEP: MEETING TRAINING AND EDUCATION NEEDS

The staff and volunteers who conduct care and support activities will need training. Training needs should be identified during the situation analysis.

A. **General Training and Education Needs**

Staff and volunteers of projects that use **interpersonal and community participation** approaches require knowledge and skills in many HIV/AIDS-related areas.

Mark the training topics that are necessary for your interpersonal project:

❑ Basic facts about HIV and AIDS

❑ HIV transmission (including mother-to-child transmission)

❑ HIV prevention

❑ Problems and symptoms commonly associated with AIDS

❑ The importance of protecting the human rights of PLWHIV

❑ Maintaining the confidentiality of clients

❑ Issues surrounding mother-to-child transmission and pregnancy

❑ HIV testing and counseling

❑ Nutritional needs of PLWHIV

❑ Recognizing and meeting the needs of caregivers

❑ Recognizing and caring for common physical and emotional symptoms of HIV/AIDS

❑ Basic home care techniques (including universal precautions)

❑ Techniques for working with families and communities (including leading a support group)

❑ Seeking additional help

❑ Making referrals to other community resources

❑ Peer education/outreach/education techniques (as appropriate)

❑ Others? _____

_____

B. Training Needs of Counselors

If **counseling** is a part of your care and support intervention, counselors should be trained in additional topics.

Mark the training topics that would be appropriate for your staff and volunteers who provide counseling to clients:

❑ Effective communication skills

    ❑ Active listening

    ❑ Understanding what the person is feeling

    ❑ Asking appropriate questions

    ❑ Respecting people and their feelings

    ❑ Being nonjudgmental

    ❑ Providing correct information

❑ Being comfortable talking about the details of sexual practices

❑ Leading a support group

❑ Couples and families counseling

❑ Helping clients deal with personal loss, death and dying

❑ Helping clients disclose their status to selected others

❑ Coping with counseling (e.g., the emotions a counselor may experience)

❑ Coming to terms with feelings about different lifestyles, disability, pain, loss and death

❑ Understanding group dynamics

❑ Understanding local language used to describe HIV/AIDS, illness and relationships

❑ Understanding local customs surrounding illness

❑ Understanding legal issues (e.g., making wills, plans for children)

❑ Others? _____

_____

C. Training Needs of Hospital, Clinic, Community, and Informal Health Workers Who Make Home Visits

Both professional and nonprofessional health workers require specialized training to work with people with HIV.

Check the topics you would include in a training for health workers

❑ Basic facts about HIV or updated information about the virus (depending on the audience)

❑ Recognizing common symptoms and their possible causes

❑ Basic home care techniques

❑ Training caregivers to provide day-to-day home care

❑ Counseling techniques

❑ Communication skills

❑ Discussing "safer sex" with appropriate vocabulary and without embarrassment

❑ Managing pain

❑ Providing adequate nutrition

- ❑ HIV testing

- ❑ Mother-to-child transmission

- ❑ Breastfeeding

- ❑ Making referrals to health facilities

- ❑ Maintaining confidentiality

- ❑ Avoiding transmission through health care procedures (universal precautions)

- ❑ Identifying local support services available for PLWHIV

- ❑ Community mobilization

- ❑ Others? _____

  _____

D. Training Needs of Staff and Volunteers Responsible for Assistance in Other Development Areas

Staff and volunteers responsible for other types of development activities (e.g., agriculture, income-generating activities, adult education) will need additional training in their topic area. For example, agriculture extension project educators would need to learn about the special nutrition needs of PLWHIV.

IMPORTANT STEP: INFLUENCING SOCIAL NORMS

Project activities influence people's thoughts and actions (i.e., the social norms of a community). Care and support projects aim to:

▶ Provide an accepting and supportive social environment for PLWHIV.

▶ Motivate individuals in the community to act compassionately toward PLWHIV.

These goals can be accomplished by using influential leaders, institutions and the media.

A. The Role of Leaders and Institutions

Institutions and their leaders can help create an accepting environment for PLWHIV and their caregivers. For this reason, interventions can involve:

▶ Religious institutions and leaders

▶ Business institutions and leaders (unions, management, business coalitions, etc.)

▶ Educational institutions and leaders (teachers, school boards, parent organizations, university clubs)

▶ Community institutions and leaders (youth groups, local and regional government, Ministry of Health policy makers, Rotary Clubs, etc.)

▶ Public figures (athletes, musicians, film stars, popular politicians).

Mark some of the ways in which institutions and leaders in the community can have an effect on social norms:

❑ Developing and implementing policies that prohibit discrimination against PLWHIV (e.g., workplace protection)

❑ Giving speeches and public statements encouraging their congregations, employees, or students to volunteer time and expertise to support PLWHIV

❑ Leading by example (volunteering their own time and expertise)

❑ Including PLWHIV in regular community activities

❑ Organizing fund-raising events for the purchase of medicines or payment of school fees, etc.

❑ Organizing community events to offer household or agricultural help

❑ Other? _____

_____

B. The Role of Media

Mass media (including radio, television and print media) reach large groups of people. Using respected community, political or entertainment figures can increase the impact of your messages.

Below is a sample of media stories that may influence social norms.

❑ Human interest articles that profile one person or a family affected by HIV/AIDS

❑ Interviews with PLWHIV

❑ Stories about communities or businesses implementing nondiscrimination policies

❑ Public discussions about how the community is dealing with PLWHIV

❑ Soap operas or dramas that show the struggles faced by PLWHIV

❑ Soap operas or dramas that show PLWHIV living positive, productive lives

❑ Discussions that try to dispel common myths about HIV/AIDS/STDs

❑ Others? _____
_____

To learn more about using the media and how to get stories placed in the media see the BCC handbook *Behavior Change Through Mass Communication.*

IMPORTANT STEP: INVOLVING COMMUNITY LEADERS

People often follow the advice and actions of respected community leaders. These leaders (e.g., religious, business, education, health, political) should be involved and supportive of the project.

Below is a list of ways to involve community leaders in your project:

❑ Create an advisory group of community leaders to give advice on the needs of their communities.

❑ Invite community leaders to be guest speakers at meetings.

❑ Conduct in-service training for interested leaders so they begin to understand the technical aspects of your project.

❑ Ask interested community leaders to inform their peers about your project.

❑ Invite interested community leaders to make home visits with you (with the client's permission).

❑ Invite them to all ceremonial occasions.

❑ Ask them to write articles or letters to the editor about the project.

❑ Invite PLWHIV to form a special advisory group.

❑ Hold regular meetings with interested leaders to update them on project activities.

Consider consulting community leaders when:

► Selecting target audiences

► Determining target audience's needs

► Designing interventions

► Choosing appropriate communication approaches

► Pretesting materials

► Conducting public relations or using publicity

Remember:

Make sure that community leaders are publicly thanked and acknowledged for their support. This will help gain more support in the future.

IMPORTANT STEP: INVOLVING PEOPLE LIVING WITH HIV/AIDS

The goal of HIV/AIDS care and support projects is to improve the quality of life for PLWHIV. By achieving this goal in your own workplace, you may help PLWHIV feel comfortable sharing their HIV status with others. Sharing their stories can have a tremendous impact on the community and the success of the project.

A. Working with PLWHIV

It is rewarding to develop partnerships with PLWHIV on your staff, as volunteers or expert consultants. PLWHIV can also be members of your community advisory group. Even if you are not aware of PLWHIV participating in your project, you need to establish policies and rules that are "friendly" to PLWHIV.

Check the ways in which you can help PLWHIV feel comfortable in your workplace:

❑ Implementing a nondiscrimination policy

❑ Not pressuring people to make their HIV status public

❑ Offering support if a PLWHIV wants to make his or her HIV status known

❑ Encouraging an open, caring environment

❑ Maintaining strict confidentiality requirements

❑ Instituting policies with generous sick and family leave

❑ Others? _____
_____

Remember:

**People may regard this project as an example of
how PLWHIV should be treated in the workplace.**

B. Going Public with HIV/AIDS

Each person who has the courage to tell his/her story helps others to
see that HIV infection is like any other serious health problem. Sharing
their status can help PLWHIV feel they are:

▶ Fighting stigma and discrimination

▶ Teaching others

▶ Giving an example

▶ Sharing their experiences

There are also possible risks to PLWHIV who talk openly about their
status:

▶ Loss of family and friends

▶ Loss of housing

▶ Loss of employment

▶ Stigma or shunning by the community

▶ Expectation (by others) that the PLWHIV is too weak to work

Keep these risks and benefits in mind when designing the project.

C. Other Things to Keep in Mind when Working with PLWHIV

There are some health-related HIV issues that need to be addressed before project activities begin. These include:

▶ How can employees who are HIV positive avoid exposure to colds and other contagious diseases in your workplace?

▶ What can you do to make the work situation easier for PLWHIV?

▶ Is your sick leave policy adequate to meet the needs of PLWHIV?

▶ Are other employees comfortable working side-by-side with PLWHIV?

▶ What training does your staff need in order to understand and support their HIV positive colleagues?

IMPORTANT STEP: CONSIDERING FAMILY ISSUES

Many care and support projects will touch on family issues such as:

▶ If or when to have additional children

▶ How to care for existing children

▶ Whether to follow traditional burial or inheritance practices

▶ Whether and how to make a will

▶ How to care for the special needs of AIDS orphans, etc.

▶ Personal loss (e.g., loss of loved one, loss of income)

▶ Discrimination towards children of PLWHIV

Both caregivers and PLWHIV are affected by these issues.

Decide how the project will deal with these issues and train your staff to respond to them appropriately.

Here are some issues to consider:

▶ How can family members share the burdens of caring for a sick person?

▶ How can the family survive the loss of income or labor when a family member becomes sick and dies and/or when a family member can no longer work because they are caregiving?

▶ Who will care for the children when one or both parents are sick or the caregiver is busy?

► Who will care for the children if one or both parents die?

► How can children continue in school if one or both parents die?

► Are traditional practices risky?

► Should a PLWHIV take a new spouse who is unaware of his or her HIV status?

► Should you recommend HIV testing for the spouse or partner of a PLWHIV?

► How will you encourage safer sex practices with regular partners?

► Do funeral rituals place a burden on surviving family members?

► What advice should women with HIV/AIDS be given if they desire additional children?

► What advice should women whose partners have HIV/AIDS be given if they desire additional children?

► What advice about breastfeeding should be given to women?

► What legal documents can help clarify the rights and property of women when their husbands die?

► Other? _____
_____

IMPORTANT STEP: DEVELOPING A SYSTEM FOR SUPERVISION, SUPPORT, AND MONITORING

The amount of *supervision, support and monitoring* your staff or volunteers need will depend on:

▶ **The types of activities they undertake.** Health volunteers will probably need more supervision and support than professional health workers. Health care activities may require more monitoring than gardening or child care.

▶ **The amount of training they have had.** Project workers who have had only a day or two of training may have greater support, information and supervision needs than those who have had more thorough training.

A system for supervision, support and monitoring must be established before the project begins.

A. Supervision

Supervision helps ensure that project workers are doing a good job.

Check the supervision techniques you will use:

❑ Observation of project workers during their activities

❑ One-to-one meetings with project workers to answer their questions and observe them at work

❑ Group meetings to resolve common problems

❑ Evaluation of project workers' performance and feedback to them about the evaluation

❑ Monthly or oral reports with feedback from you

❑ Other _____

_____

B. Support

Providing support to staff and volunteers should be part of care and support projects. Project workers may become extremely sad when they work with people who are sick or dying.

If some of the project workers are PLWHIV they may have additional support requirements. The best way to determine how to provide support is to ask them what they need.

Important

Support can also involve keeping your project workers motivated, interested and proud to be working on your project.

Below are some suggested support activities:

❑ Incentives to your staff/volunteers (e.g., money for transportation or lunch)

❑ Regular discussion (or support) groups for all your staff/volunteers

❑ Regular training updates and in-service meetings

❑ Additional educational materials for staff/volunteers' personal use

❑ Certificates, badges, T-shirts, bags, hats or pins to acknowledge their contribution to the project

❑ Emotional help for staff dealing with discouraging or difficult experiences

❑ Reference materials that give answers to commonly asked questions

❑ Referral books that allow project workers to send clients to other available resources (read Section XV)

❑ Opportunities for established project workers to teach and mentor new staff/volunteers

❑ Other _____

_____

C. Monitoring

Monitoring can help you determine:

▶ If you are meeting the design goals and objectives you listed in Section VII

▶ If your staff/volunteers have enough support, supervision and training

▶ If your project activities need to be modified

▶ If the activities are succeeding

Monitoring examines performance in both a quantitative and a qualitative way.

Quantitative Monitoring

Quantitative monitoring measures things by numbers. Below are some examples.

Check those you will use and add others:

❑ Number of home visits by staff/volunteers

❑ Number of office visits by clients

❑ Number of gardens worked on

❑ Number of child care visits

❑ Number of clinic accompaniments

❑ Number of materials distributed

❑ Number of support group sessions held

- ❑ Number of supervisory visits held
- ❑ Number of people trained
- ❑ Number of clients reached
- ❑ Number of workplaces with a new anti-discrimination policy
- ❑ Number of community leaders reached
- ❑ Others? _____
  _____

Qualitative Monitoring

Qualitative monitoring measures changes in opinions or behavior change. Below are some examples.

Check the ones you will use and add others:

- ❑ Influencing community thought and action (e.g., community leaders embracing non-discrimination policies)
- ❑ Increased interest in volunteering to help PLWHIV with day-to-day activities
- ❑ Self-reported evidence of a decrease in discrimination against PLWHIV
- ❑ Self-reported increase in supportive activities for PLWHIV
- ❑ Self-reported improvements in client health
- ❑ More religious leaders and/or business leaders speaking in support of PLWHIV
- ❑ More PLWHIV speaking openly about their disease
- ❑ More media coverage of activities
- ❑ More favorable media coverage about PLWHIV
- ❑ More requests for your services
- ❑ Others? _____
  _____

Important

There are other things you can measure that will give you meaningful information. Brainstorm with your staff and community representatives in order to discover them.

For a more detailed look at the monitoring of care and support interventions read the BCC Handbook *Assessment and Monitoring of BCC Interventions.*

IMPORTANT STEP: IDENTIFYING REFERRAL SOURCES

A. What are Referral Sources?

Referral sources are community services that can benefit your clients and staff. Learn about these resources in order to provide clients with information about care and support services that your project does not provide.

Check the types of referral sources that your clients may need:

❑ Health and mental health services

❑ Economic assistance

❑ Legal assistance

❑ Workplace benefits

❑ Housing assistance

❑ Home visits by health care professionals

❑ Medicine

❑ Income generation activities

❑ Child support

❑ Educational fees

❑ Food

❑ Clothing

❑ Transportation

❑ Other _____

_____

B. How Referral Sources Can Be Identified

Some members of your target audience may already be using or aware of existing resources. Include questions about known and available resources during the initial situational analysis (see Section VI). Also, find out about other resources.

Check the places where you may be able to discover additional community resources:

❏ Community leaders (political, religious, business, etc.)

❏ Community-based organizations

❏ Religious agencies

❏ Hospital or clinic staff

❏ Ministry officials

❏ International donors

❏ NGOs

❏ Other _____

_____

C. Creating a Referral Book

An efficient way to ensure accurate referrals is to create a referral book and distribute it to your staff. They can take this referral book with them when they meet with project clients.

1. Referral Services

A referral book usually has two parts. The first part lists the different services available to clients and staff and gives contact and background information for these services.

The following is an example of how services can be listed in a referral book:

HIV TESTING SERVICES

NAME:	**St Mary's Clinic**
ADDRESS:	214 Flower Street
TOWN:	Tanga City
TELEPHONE:	46523
HOURS:	Monday, Wednesday and Friday 9:00 to 12:00
CONTACT:	Richard Mbuto
OTHER INFO:	Appointment necessary. Test results returned in 2 weeks.
NAME:	**Chopa AIDS Project**
ADDRESS:	Annamara 314, 2nd Floor
TOWN:	Tanga City
TELEPHONE:	46332
HOURS:	Tuesday 16:00 to 20:00.
CONTACT:	Dorothy Kamande or Carol Onengo
OTHER INFO:	No appointment necessary (but clients should arrive early since the clinic can be crowded after 18:00). Test results returned in 10 days.

Some referral services you might want to include in your referral book are:

▶ AIDS prevention organizations (i.e., places where clients can contact get information on prevention)

▶ Chemists/pharmacies/medical stores where clients will be treated with respect

▶ Counseling centers

▶ Medical clinics

▶ HIV testing services

▶ STD services

▶ Public hospitals

► Information hotlines

► Organizations providing agricultural assistance

► Organizations providing child care assistance

► Organizations providing spiritual guidance

► Organizations providing legal assistance

► Local women's/men's/youth groups

► Others? (There are many others) _____

_____

2. Referral Slips

The second part of a referral book may include slips of paper on which staff can write the name, address and other referral service information for a client.

Below is an example of a completed referral slip:

TANGA CITY CARE PROJECT REFERRAL SLIP

CLIENT NAME: *Betty Mousa*

REFERRAL MADE BY: *Olusina Makinwa*

REFERRAL: *St. Mary's Clinic*

ADDRESS: *214 Flower Street, Tanga City*

TELEPHONE: *46523*

HOURS: *Monday, Wednesday and Friday 9:00 to 12:00*

CONTACT: *Richard Mbuto (Tell him Olusina sent you)*

OTHER INFORMATION: *Call to make an appointment. Test results returned in 2 weeks.*

D. Formal and Informal Referrals

Referrals to existing community resources can be made **formally** or **informally**.

Formal referrals require direct contact between the staff of another resource (or agency) and your staff to discuss the needs of a client. This type of referral is commonly used for medical referrals.

Informal referrals involve providing a client with the address/contact information of a resource. With **informal** referrals your staff does not need to make direct contact with that resource. This is the most common type of referral.

E. Including Referral Information in BCC/IEC Materials

People who are not clients of your project may nevertheless read the BCC/IEC materials developed by your project. In order to help these people contact important resources, include the address of key referral sources in all BCC/IEC materials you develop.

IMPORTANT STEP: ENSURING CONFIDENTIALITY

The names and medical conditions of clients should be kept confidential unless they tell you otherwise.

In many places maintaining confidentiality can be difficult because people in the community may know your staff and/or may have already guessed that your client is HIV positive. Ask clients about their ideas for ensuring confidentiality before beginning to provide then with services. From the beginning of the project consider ways to protect confidentiality.

Check ways the confidentiality of the target audience/clients can be protected:

- ❑ Offer to let the client come to you rather than visiting the client at home or work (as long as the client is healthy enough to travel).

- ❑ Use unmarked vehicles and notebooks when visiting people at home or in the workplace.

- ❑ Find a private, quiet, out-of-the-way place to conduct support groups and other group activities.

- ❑ Hire staff that will respect your confidentiality rules.

- ❑ Provide detailed training in confidentiality for your staff.

- ❑ Inform your staff that if they meet a client on the street or in a social situation they should let the client speak to them first.

- ❑ Protect personal records.

- ❑ Create a "safe space" where client's cases can be discussed in confidential settings.

- ❑ Demand that clients' cases be discussed only for professional purposes (unless the client gives permission).

- ❑ Familiarize yourself and your staff with local and national laws/ policies concerning medical records, etc.

Important

There is a difference between respecting confidentiality and encouraging a client to hide. Discuss this and other issues with your staff.

Important

Your staff will need to be trained in respecting confidentiality.

APPENDIX

List of Useful Documents

From the World Health Organization:

AIDS Home Care Handbook (WHO/GPA/IDS/HCS/93.2)

Living with AIDS in the Community (WHO/GPA/IDS/HCS/92.1 Rev 1)

From the AIDSCAP Behavior Change Communication (BCC) Unit:

How to Create an Effective Communication Project

Behavior Change Through Mass Communication

How to Conduct Effective Pretests

Assessment and Monitoring of BCC Interventions

How to Create an Effective Peer Education Project

Partnership with the Media

From the AIDSCAP Evaluation Unit Evaluation Tools:

Module One - Introduction to AIDSCAP Evaluation

Module Two - Conducting Effective Focus Group Discussions

Module Three - A Framework for Incorporating Evaluation into Project Design

Module Five - Qualitative methods for Evaluation Research in HIV/AIDS Prevention Programming

From the AIDSCAP Policy Unit:

Private Sector AIDS Policy - Businesses Managing HIV/AIDS