Monitoring and Evaluating Community Home-Based Care Programs

Monitoring HIV/AIDS Programs
A FACILITATOR'S TRAINING GUIDE
A USAID RESOURCE FOR PREVENTION, CARE AND TREATMENT

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Impact Implementing AIDS Prevention and Care Project

USAID

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Monitoring HIV/AIDS Programs: A Facilitator's Training Guide

A USAID Resource for Prevention, Care and Treatment

Module 4: Monitoring and Evaluating Community Home-Based Care Programs

September 2004

Family Health International

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This Monitoring and Evaluation series is based on the assumption that Core Module 1 (Introduction to Monitoring and Evaluation) is always the first module, that it is followed directly by Core Module 2 (Collecting, Analyzing, and Using Monitoring Data), which is followed by one or more of the optional technical area modules (Modules 4 through 10), and that in all cases the final module is Core Module 3 (Developing a Monitoring and Evaluation Plan). The specified sequence is shown below:

1. *Core Module 1: Introduction to Monitoring and Evaluation*
2. *Core Module 2: Collecting, Analyzing, and Using Monitoring Data*
3. *Optional Technical Area Modules 4 through 10*
4. *Core Module 3: Developing a Monitoring and Evaluation Plan*

Learning Objectives

The goal of the workshop is to build participants' skills in monitoring and planning evaluations of community home-based care programs.

At the end of this session, participants will be able to:

- Understand the components of community home-based care (CHBC) that need to be monitored.
- Develop home-based care (HBC)-specific process indicators.
- Identify appropriate monitoring and evaluation methodologies and tools.
- Appreciate better the different data uses and how they influence data collection and analysis.

Session Overview and Schedule

TIME		TOPIC	TRAINING METHOD
8:30-8:45	15 min	**A. Welcome and Review**	*Facilitator Presentation*
8:45-10:00	75 min	**B. Overview of Care and Support Framework**	*Facilitator Presentation, Group Exercise*
10:00-10:30	30 min	**C. HBC Experiences or Programs and Definition of HBC**	*Group Discussion*
10:30-10:45	15 min	**BREAK**	
10:45-11:15	30 min	**D. Models of Home-Based Care**	*Facilitator Presentation, Group Exercise*
11:15-11:45	30 min	**E. Components of Community Home-Based Care**	*Facilitator Presentation*
11:45-12:25	40 min	**F. Goals and Objectives for HBC Programs**	*Group Discussion*
12:25-1:00	35 min	**G. Monitoring and Evaluation Questions**	*Facilitator Presentation, Small Group Exercise*

Session Overview and Schedule

TIME		TOPIC	TRAINING METHOD
1:00-2:00	60 min	**LUNCH**	
2:00-2:15	15 min	**H. Special Considerations for Monitoring HBC Programs**	*Facilitator Presentation, Group Discussions*
2:15-2:45	30 min	**I. Developing Indicators**	*Small Group Activity, Facilitator Presentation*
2:45-3:15	30 min	**J. Data Collection Methods and Tools**	*Group Discussion, Small Group Exercise*
3:15-3:30	15 min	**BREAK**	
3:30-4:15	45 min	**K. Data Flow and Data Use**	*Small Group Exercise*
4:15-4:30	15 min	**L. Data Presentation and Dissemination**	*Small Group Exercise*
4:30-4:55	25 min	**M. Evaluating HBC Programs**	*Group Discussion*
4:55-5:00	5 min	**N. Wrap-Up**	*Q & A Session*

Materials

- Flipchart paper and stand
- Markers
- Pens or pencils
- Tape or Blue-Tac
- Evaluation Form

- Handout: The Continuum of Care
- Handout: Gaborone Declaration on Home-Based Care
- Handout: Care and Support Framework
- Handout: Comprehensive HIV/AIDS Care and Support
- Handout: Continuum of Care: Models of HBC
- Handout: Presentation Scenario/Case Study
- Handout: Checklist Tool for Monitoring Home-Based Care Visit
- Handout: Mock HBC Data
- Handout: Illustrative Indicators for HBC Programs
- Handout: Essential Components of Home-Based Care

Background materials

1. Connie M. Osborne, E. van Praag, and H. Jackson, "Models of Care for Patients with HIV/AIDS," *AIDS* 1997, 11 (supplement B):S135-S141.
2. World Health Organization, 2002. *Community Home-Based Care in Resource-Limited Settings, A Framework for Action*.

A.   Welcome and Review

8:30-8:45	15 min	A. Welcome and Review	*Facilitator Presentation*

Materials
- Objectives on flipchart

8:30-8:35   (5 min)

1. Introduction

Thank participants for arriving on time and remind them (in a humorous way) that anyone who arrives late will be subject to shame and humiliation from the whole group.

Because this module is being delivered after Core Module 1 (Introduction to Monitoring and Evaluation) and Core Module 2 (Collecting, Analyzing, and Using Monitoring Data), participants will be familiar with each other. Therefore, each morning during this time, the facilitator can take about 15 minutes to review with the participants the material they learned in the preceding modules. This provides an excellent opportunity to generate energy among the group by asking the participants to ask questions of each other, to quiz each other, and to see who has the answer. This review activity can be light, energetic, and even humorous. Encourage participants to stand up or do something else physical as they ask or answer their questions.

8:35-8:45   (10 min)

2. Overview of HBC Objectives and Agenda

The goal of this workshop is to build your skills in monitoring and planning an evaluation of your home-based care program.

At the end of this session, you will be able to:
- Understand the different components of HBC that need to be monitored.
- Develop HBC-specific process indicators.
- Identify appropriate monitoring and evaluation methodologies and tools.
- Appreciate better the different data uses and how they influence data collection and analysis.
- Identify possible evaluation questions and determine when and if an evaluation is necessary.

The facilitator now lists five objectives on a flipchart and reviews them with participants. Leave this flipchart up on the wall for the remainder of the workshop.

Review the Home-Based Care Module agenda topics. It is not necessary to specify the times, but do specify that there will be a 15-minute mid-morning break, 1 hour for lunch, and a 15-minute mid-afternoon break, and that the workshop will end by 5:00 p.m.

B.   Overview of Care and Support Framework

8:45-10:00	75 min	B. Overview of Care and Support Framework	*Facilitator Presentation, Group Activity*

Materials
- Flipchart paper and stand
- Markers
- Tape
- Cut out cardstock or flipchart paper with each piece of the care and support model, including individual effected by HIV/AIDS

- Handout: The Continuum of Care: Models of HBC
- Handout: Gaborone Declaration on HBC
- Handout: Care and Support Framework
- Handout: Comprehensive HIV/AIDS Care and Support

8:45-9:15   (30 min)

Group Activity
Each group needs markers, tape, flipchart paper, and 3-5 small sheets of paper.

Divide participants into small groups (number in each group will vary depending on the total number of participants) and give the following instructions to each group:

- **Part 1 Instructions***:* On the flipchart paper, draw a person living with HIV/AIDS. Draw what you imagine this person would look like if he/she were living in the best of circumstances. Emphasize that they should only draw the person and what they would look like, nothing else. Facilitators should walk around and see how the groups are doing and give them about five minutes to draw.
- **Part 2 Instructions:** Now we would like you to think about what that person needs to live in the best of circumstances. "What sort of support does that person need to live like that? Don't use any words; just draw pictures."
- **Part 3 Instructions:** Instruct each group to select a "reporter," and then find wall space to hang each group's pictures. The reporter from the group will explain the main drawing and the "needs" drawings. Other members of the group can help out with the description, too.
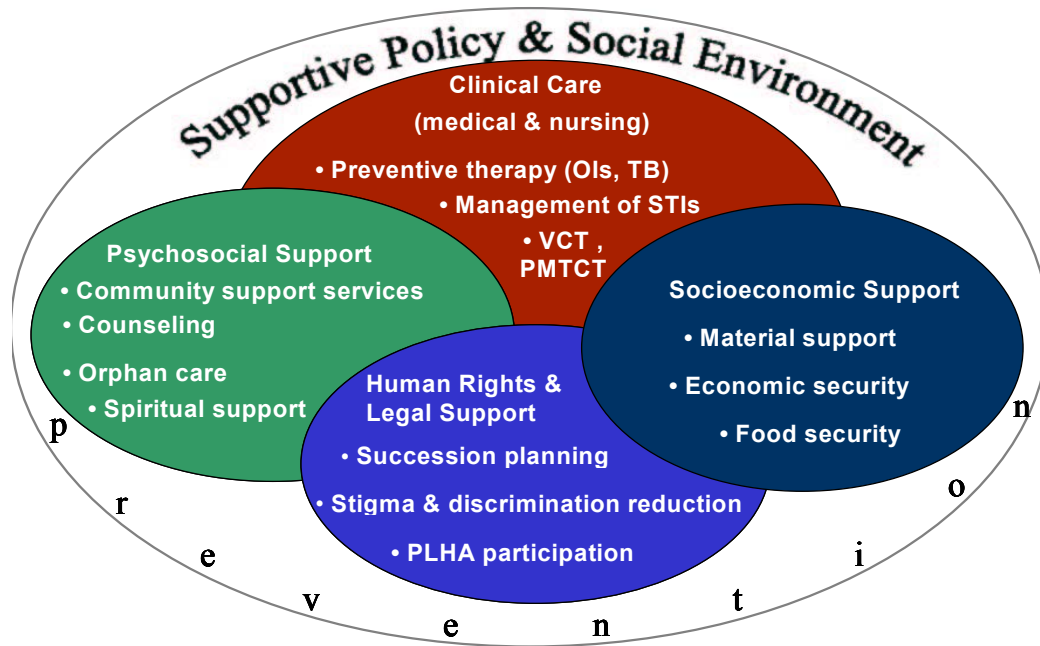
Process Activity
After all groups have reported, the facilitator leads a discussion to process the activity by saying, "What have we just done? By thinking of what someone needs in the best of circumstances you've come up with the basis for the standard of HIV Care and Support. You've created our gold standard (clarify gold standard, if necessary, as the ideal of what we strive for)." While discussing this, hang pre-made signs with elements of the care and support world written on them around one group's drawings. This illustrates how the needs they identified relate to the HIV/AIDS care and support design.
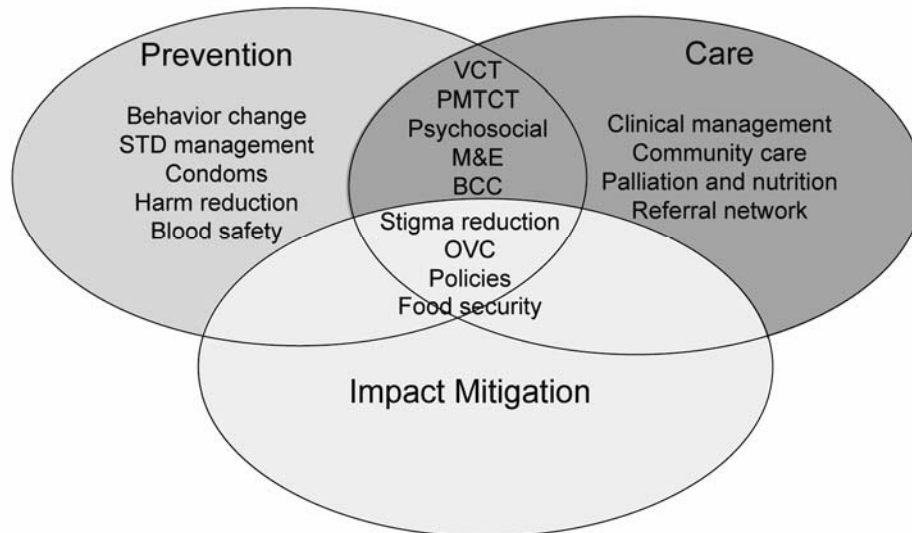
HIV/AIDS Care and Support
  A. **Comprehensive Care.** Providing HIV/AIDS care to PLHA and their families requires a broad range of services that include not only clinical care focusing on diagnosis and treatment, but also supportive and complementary services that address nutritional, psychosocial, and daily living needs and strengthen prevention wherever opportunities arise.

Refer participants to the Handout: Comprehensive HIV/AIDS Care and Support and discuss it with them.

Comprehensive HIV/AIDS Care and Support

Supportive Policy & Social Environment

Clinical Care (medical & nursing)
- Preventive therapy (OIs, TB)
- Management of STIs
- VCT, PMTCT

Psychosocial Support
- Community support services
- Counseling
- Orphan care
- Spiritual support

Human Rights & Legal Support
- Succession planning
- Stigma & discrimination reduction
- PLHA participation

Socioeconomic Support
- Material support
- Economic security
- Food security

prevention

The Care/Prevention/Support Synergy

Prevention
Behavior change
STD management
Condoms
Harm reduction
Blood safety

VCT
PMTCT
Psychosocial
M&E
BCC
Stigma reduction
OVC
Policies
Food security

Care
Clinical management
Community care
Palliation and nutrition
Referral network

Impact Mitigation

This comprehensive approach to HIV care is reflected in the current strategic plans of nearly every National AIDS Program and is being promoted by public and nongovernmental health programs and institutions. Each service in this comprehensive approach reinforces and is linked to the other services. For example, adherence to medications increases if patients are able to cope with their HIV status, do not feel stigmatised, and feel supported.

9:15-10:00   (45 min)

Group Activity
Transition from the care and support activity by saying something like, "Now that we have seen the pieces of the care and support world, we're going to look at a strategy for application."

Divide participants into small groups. Give one or two groups (depending on the number of participants) several of the elements detailed in the Comprehensive HIV/AIDS Care and Support Framework shown above and in the handout. Each group should answer the following two questions:

1. What does "element name" (e.g., ARV or socioeconomic support) provide to a person living with HIV/AIDS?
2. How does "element name" (e.g., ARV or socioeconomic support) relate to each of the other elements under the framework's components?
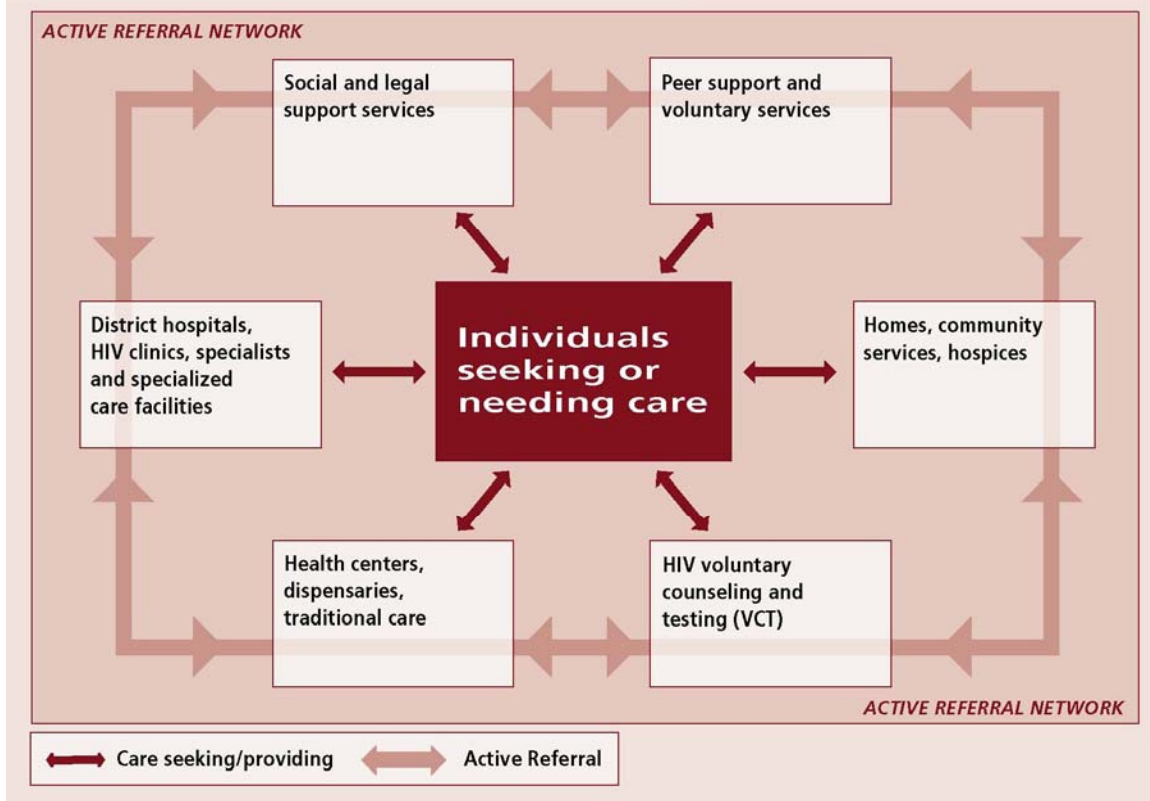
Instructions:
- The facilitator should ask for a volunteer to role-play an individual with HIV/AIDS.
- Volunteer(s) from each group will tape the element(s) to their chests (number of volunteers equals number of elements given to each group).
- All six elements will stand in front of the larger group. Each of the smaller groups will share their answers to the two questions with the rest of the group. As the answers for the first question are shared, the volunteer "element" walks over to the HIV-positive person and puts one hand on his/her shoulder. As the answer for the second question is given the volunteer "element" calls over the next volunteer "element" in line, who then puts his/her hand on the HIV-positive person's shoulder as they join the circle. Repeat this until all elements have joined the circle.
- Wrap up the activity by saying something like, "What does this activity show us? How does this relate to HBC?" Facilitator response could include, "HBC is a **network of services** offered **at the community level** and is **more** than **counseling** and **home visits.**"

B. **Continuum of Care/Referral Network.** The range of HIV care, treatment, and support services may be offered by multiple providers or programs. Partnership and collaboration among all of these providers is essential to provide patients with a continuum of care and support.

Facilitator should refer participants to the Handout: The Continuum of Care, and discuss it with the group.

The Continuum of Care

ACTIVE REFERRAL NETWORK

- Social and legal support services
- Peer support and voluntary services
- District hospitals, HIV clinics, specialists and specialized care facilities
- **Individuals seeking or needing care**
- Homes, community services, hospices
- Health centers, dispensaries, traditional care
- HIV voluntary counseling and testing (VCT)

ACTIVE REFERRAL NETWORK

◆━━▶ Care seeking/providing　　◀▬▶ Active Referral

C.　Home-Based Care Experiences or Programs and Definition of HBC

10:00-10:30	30 min	**C. Home-Based Care Experiences or Programs and Definition of HBC**	*Group Discussion*

10:00-10:20　　(20 minutes)

1. **HBC experience and existing programs** (participants sharing ideas)
   This session gives participants an opportunity to share and tell their stories. Ask participants if they have HBC programs or plan to have them.

   Group Discussion
   Ask participants who do have HBC programs to describe them to the group, explaining what the program looks like, how it is designed, what services it provides, who the target population is, and so on. What are their experiences so far? Also ask those planning to start HBC for their experiences.

   Because some HBC programs may still be in the planning phase or initial implementation phase, it is useful to allow participants time to share their thoughts, ideas, and experiences.

10:20-10:30   (10 min)

2. Definition of Community Home-Based Care (CHBC)

Group Discussion
Write the Gaborone definition on a flipchart and review it with the participants. Ask if they have heard **any other definitions or if there is something they would like to add to this one.**

The Gaborone Declaration on Community Home-Based Care (March 2001) defines community home-based care as "care given to an individual in his/her own natural environment by his/her family and supported by skilled social welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs."

10:30-10:45	15 min	**BREAK**

D.   Models of Home-Based Care

10:45-11:15	30 min	**D. Models of Home-Based Care**	*Facilitator Presentation, Group Exercise*

Materials
- Handout: Continuum of Care: Models of HBC

Group Activity
Write the name of each HBC model type on separate sheets of flipchart paper, and make two columns below the name: "Weaknesses" and "Strengths."

Divide the participants into small groups and distribute one Handout: Continuum of Care: Models of HBC to each group.

Give each group 10 minutes to discuss and record the strengths and weaknesses of their model. Each group should select a presenter who will present the information to the larger group for comment and discussion.

Models of Care
When discussing the continuum of care and how community and home-based care programs fit into this continuum, it is important to be aware of what the various models of care are and to identify their strengths and weaknesses. The HBC programs will need to address some of these weaknesses while building on and incorporating their work into the strengths.

Continuum of Care: Models of HBC			Handout
Model Type	Description	Weaknesses	Strengths
Hospital-initiated	Hospital staff provide outreach care services	• Costly • Strong focus on medical care • No direct benefit to family • Stigmatized	• Easy monitoring and supervision • Good link with supplies • Access to professional staff • Hospital-referral possible
NGO-initiated (e.g., faith-based, PLHA associations)	Support groups established by NGO provide counseling, medical care, and home care	• Eligibility may be biased or selective • Weak links with hospitals • Isolated from supplies and hospital back-up • Sustainability and coverage difficulties	• May provide comprehensive care • Accessible, innovative, and flexible
NGO-coordinated	NGO trains community members and/or family members to provide CHBC services; NGO provides follow up		• Sustainability, innovative, and considers specific community needs
Integrated	Patient support units established at hospitals where patients are counseled during their stay and discharge plans are made, which include follow-up care that is closer to home and/or home care		• Government and community structures linked • Hospital-referral possible • Reduce stigma

E.   Components of Community Home-Based Care

11:15-11:45	30 min	E. Components of Community Home-Based Care	*Facilitator Presentation*

Materials
- Handout: Essential Components of Home-Based Care

Group Work
This activity focuses on the essential components and subcategories for monitoring HBC program activities.

- Write each component on flipchart paper with a symbol (e.g., tree, house, shoe, or other item) next to it. Hand out symbols to participants so they can match to an element and find others in their group. (Make enough of each symbol so that small groups can be formed for each of the seven elements. For example, for each of the seven elements make a symbol. If you have 21 participants, then you will need to make three additional trees, three additional houses, three additional shoes, and so on.)
- Participants in each small group should discuss the component and identify two or three subcategories. (The handout with suggested subcategories will be given out **after** the activity.)
- Give the groups five minutes to discuss and list on the flipchart. Then have each group present to the larger group.
- The report titled, *Community Home-Based Care in Resource-Limited Settings* (WHO) identifies the following seven essential components of home-based care: (1) provision of care, (2) continuum of care, (3) education, (4) supplies and equipment, (5) staffing, (6) financing and sustainability, and (7) monitoring and evaluation.

Essential Components of Home-Based Care	Handout
Category	**Subcategory**
Provision of Care	• Basic physical care • Palliative care • Prevention counseling • Nutrition counseling • Psychosocial support and counseling • Care of affected and infected children
Continuum of Care	• Accessibility • Continuity of care • Referral to care and support services • Knowledge of community care • Community coordination • Record-keeping for ill people • Case-finding • Case management
Education	• Curriculum development • Education management and curriculum delivery • Outreach • Education to reduce stigma • Mass media involvement • Evaluation of education
Supplies and Equipment	• Location of HBC team • Health center supplies • Management, monitoring, and record-keeping • Home-based care kits
Staffing	• Supervising and coordinating HBC • Recruitment • Retaining Staff
Financing and Sustainability	• Budget and finance management • Technical support • Community funding • Encouraging volunteers • Pooling resources • Out-of-pocket payments • Free services
Monitoring and Evaluation	• Quality assurance • Quality-of-care indicators • Monitoring and supervision • Informal evaluation • Formal evaluation • Flexibility

F.   Goals and Objectives for Home-Based Care Programs

11:45-12:25	40 min	F. Goals and Objectives for Home-Based Care Programs	*Group Discussion*

Materials
- Flipchart paper
- Handout: Presentation Scenario/Case Study
- Memory Sheet: Types and Objectives of Monitoring and Evaluation

Goals and Objectives

Tell participants to refer back to the first day of training when goals and objectives were discussed (refer to the Memory Sheet from Core Module 1). Ask participants to identify possible goals for their home-based care program.

Group Discussion

Brainstorming session around the following questions:
- What is a goal?
- What are some examples of goals?

The facilitator will record all goals mentioned and try to get group consensus on one main goal. (This list of goals will be helpful during the discussion of SMART objectives.)

Ask participants to identify possible objectives for a home-based care program, keeping in mind the concept of SMART objectives. Review the characteristics of SMART objectives. Facilitate a brainstorming session to create SMART objectives.

Group Activity

Divide participants into small groups and give each group a Presentation Scenario/Case Study handout and flipchart paper. Each group should come up with a goal and two or three objectives. Give them 10 minutes to work and then have each group **briefly** present to the larger group.

G.   Monitoring and Evaluation Questions

12:25-1:00	35 min	G. Monitoring and Evaluation Questions	*Facilitator Presentation, Small Group Exercise*

Materials
- Handout: Essential Components of Home-Based Care

Group Exercise

Refer to components of HBC and ask participants to create three to five monitoring questions for each component. Each group will record its questions on a half sheet of paper that has one HBC component written across the top. Remind them to think about their program **goals** and **objectives**, as these will drive most of their questions. Give the groups about 10 minutes for this section of the exercise. Then have each group present its questions to the larger group.

1:00-2:00	60 min	**LUNCH**

H.   Special Considerations for Monitoring HBC Programs

2:00-2:15	15 min	H. Special Considerations for Monitoring HBC Programs	*Facilitator Presentation, Group Discussion*

Special Considerations When Monitoring HBC Programs:
- The client's and his/her family's **care and support needs will change over time** as the disease progresses. The services offered by the provider must therefore be adjusted over time. Regular monitoring and evaluation of the efficiency and effectiveness of the comprehensive care continuum is thus crucial to ensure that the client is able to maintain some level of quality of life.
- Monitoring and evaluating community home-based care programs requires that data be collected from households affected by HIV/AIDS and regular household visits. This can be a problem in the context of **stigma, whereby the person or household affected by HIV/AIDS may either refuse to provide information or a visit from a provider may result in the individual and/or household becoming ostracized by the community**. Data collection from such households should, therefore, be kept to a minimum and be conducted in a sensitive, discreet, and confidential manner.

Ask participants to describe some of the other challenges they can think of and offer ideas for addressing these challenges.

I.   Developing Indicators

2:15-2:45	30 min	I. Developing Indicators	*Small Group Activity, Facilitator Presentation*

Materials
- Flipchart with characteristics of ideal indicators

Group Discussion/Activity
Ask the group to summarize what indicators are and identify the main characteristics of indicators. Remind them of the discussions and activities from the first day of the workshop. (Refer to the flipchart with the list of ideal indicators.)

Activity Instructions:
- Assemble the same groups that were used in the previous session's exercise and refer to the half sheets of paper with the monitoring questions written on them.
- Ask each group to convert questions into indicators.
- Call time after 10 minutes and reconvene the full group. Ask each small group to present its exercise to the rest of the class.

Facilitator Presentation
Some organizations have developed HBC indicators. We have a list of those that are used by USAID. These indicators are required by USAID for HBC programs and data must be collected. A program can select additional indicators, but these are required by USAID.

Facilitator will prepare the following on a flipchart and/or handout:
- # households served
- # individuals reached by community theme-based care programs
- # USAID-assisted community- and home-based care programs
- # individuals reached by community-based and home-based care programs in past 12 months

J.   Data Collection Methods and Tools

2:45-3:15	30 min	J. Data Collection Methods and Tools	*Group Discussion, Small Group Exercise*

Materials
- Handout: Checklist Tool for Monitoring Home-Based Care Visit

Group Discussion
Facilitator leads brainstorming questions. Use the following questions to guide the discussion. List responses on flipchart.
- **What do you think might be some methods for monitoring a home-based care program**? (Facilitator should probe for the following: verbal method of data collection from low-literacy audiences, supervisory observations, CHBC caregiver weekly documentation of activities, client [e.g., PLHA and their families] interviews, external monitor observation of provision of services, periodic NGO assessment of supplies and medications stock-outs, and in-depth interviews with community leaders.)
- **What are some tools that you have used? What has been your experience using HBC-specific tools?** (Facilitator should probe for the following: supervisory reports, caregiver/volunteer reports, inventory record of commodities and drugs, observation checklists to be used to observe client-staff interaction, and pictorial tools used by low-literacy outreach workers).
- **What tools might you use to assess the quality of the services being provided?**
- **What are some special considerations when coming up with HBC tools? What are some special issues when considering what to monitor and which tool to use?**

Allow participants to share some of their own experiences and to describe some of the tools and instruments they use in their own programs.

Group Exercise
Facilitator opens discussion with, "Let's take a look at an example of a HBC program monitoring tool."

Give a tool to each table/group. Hand out copies of the Checklist Tool for Monitoring Home-Based Care Visit and ask each group to discuss the following issues:
1. What information can be collected from this tool?
2. What things can be improved, added, or deleted to enhance the usefulness of the tool?
3. Are there any implications for adding new things to this tool (for example, sensitivity, difficulty and cost of collecting the additional information)?

Give participants 10 minutes for this section of the exercise. Then call time and reconvene the entire group. Ask each small group to present its findings to the entire group.

3:15-3:30	15 min	**BREAK**

K. Data Flow and Data Use

3:30-4:15	45 min	**K. Data Flow and Data Use**	Small Group Exercise

Materials
- Handout: Mock HBC Data and Graphs
- Handout: Checklist Tool for Monitoring Home-Based Care Visit

Data Flow for HBC Program

Group Discussion
Now we're going to talk about analyzing and using data. Ask participants to review key points from the second day of training (Core Module 2: Collecting, Analyzing, and Using Monitoring Data). The facilitator should facilitate a group discussion using the following questions:
- Who is responsible for analysis?
- How do you describe data flow for HBC programs?
- What are some ways that the data can be "housed" or managed? What programs do you use? (Facilitator, here we want people to identify different databases that they can use to store the data and to run basic analysis [e.g., Excel, Access]. List the examples from the participants.)

Use of HBC Data
The facilitator should make the transition from data flow to data use by introducing the following questions and facilitating a group discussion:
- What are some uses for data? How can you improve program/reporting to funders?
- How have you used HBC monitoring data?
- Who have you shared these data with and why?

Group Activity
The facilitator will divide the participants into small groups to discuss the questions below and then report to larger group. Each group will select one person to report on the small group's work. Then give each group a mock data table and ask them to answer the following questions:

> The facilitator should list the questions on flipchart paper before the class convenes.

1. What do these data tell you about the strengths and weaknesses of the program in the two districts described in the Mock HBC Data handout?
2. What additional information would you need to confirm and/or supplement the conclusions you reached in answering question 1?
3. What would you do to improve the program?

L.   Data Presentation and Dissemination

4:15-4:30	15 min	L. Data Presentation and Dissemination	*Small Group Exercise*

Materials
- Flipchart paper
- Markers
- Handout: Presentation Scenario/Case Study

Ask participants to remember Core Module 2: Collecting, Analyzing and Using Monitoring Data and the different ways of presenting data.

Group Exercise

Have the participants break into the same groups as in the previous session.

Facilitator distributes the Handout: Presentation Scenario/Case Study and assigns one Data Use Scenario (see appendix) to each group.

1. Scenario 1: Presentation to HBC Volunteers in Districts A and B
   (You are the volunteer coordinator.)
2. Scenario 2: Presentation to Community-Based Organizations in Districts A and B
   (You are NGO director for the area; communicate the program's achievements to the community.)
3. Scenario 3: Presentation to Regional Hospital
   (You are meeting with heads of regional hospital to persuade them to expand into two more districts.)
4. Scenario 4: Psychosocial Support Systems
   Your preliminary needs assessment has identified a group of elders in the community who are HIV positive and who are suffering greatly from problems that include outliving their children, caring for too many grandchildren, and worrying about living long enough to continue to see their grandchildren grow. You want to establish a program that will support their emotional and psychological needs.
5. Scenario 5: Government Involvement
   Discussions with your counterparts in the provincial government tell you that they do not understand what HBC is for and why it is necessary. They believe that HIV-positive people should just use the government clinics for health care. You need to get the government involved and supportive of your program.
6. Scenario 6: Funding Agencies
   You want to be able to expand your HBC program to other communities in the region. To do this, you will need to work with organizations that fund the healthcare system to support this expansion.
7. Scenario 7: Buddy System
   Your highly trained "buddies" have reported to their supervisors that their clients are being blocked from clinics by the staff members of other care services because these staff members do not know who the "buddies" are, do not know if this "Buddy Project" is reputable, and are not sure if buddies really know what they are doing. So the referrals being made are being ignored.
8. Scenario 8: Setting Up the First HBC Program
   Your preliminary data show that a large number of HIV-positive people are too ill to come into the clinical setting and are in need of HBC. The community leaders have approached your organization to establish the first HBC program in the region.

M.   Evaluating HBC Programs

4:30-4:55	20 min	M. Evaluating HBC Programs	*Group Discussion*

Group Discussion
Ask participants to discuss if an evaluation of their program is recommended. If they decide that it should be evaluated, what evaluation questions should be asked, what kind of methodology should be used, and when, where, and by whom will the evaluation be conducted?

Review distinction between outcome evaluation and impact evaluation
Outcome evaluation (short-term and intermediate-term effects):
- Measures the effects of the program on the recipients
- Not able to show that the program activities have been the source of the effects observed (i.e., there is no attribution)
- Conducted at the beginning and then again at the mid-point or end of project
- Conducted by program staff or evaluation specialists

Impact evaluation (long-term effects):
- Demonstrates program impact on health status and social conditions (But what is attributable?)
- Requires using a rigorous scientific method (notes changes in program areas and compares them with changes observed in non-program areas)
- Rarely performed for NGO programs because of confounding factors (e.g., other service providers working in the same area)
- More appropriate for national-level programs to look at the synergistic impact of all care and support programs

Why outcome evaluations are not always conducted:
- To conduct an outcome or impact evaluation, rigorous research methodologies must be applied. Typically, a combination of quantitative and qualitative methods must be used, all of which require staff who are skilled in selecting and designing the right kind of methodology and data collection tools (e.g., a questionnaire for in-depth interviews that does not lead the respondent to provide certain kinds of answers), in administering the tools, and in data analysis.
- If a causal relationship between the program and the outcome is to be made, a comparison or control group (i.e., groups of people who have not been exposed to the program yet whose characteristics are similar to those of the people who have been exposed to the program) must be used.
- Because few NGOs have the necessary skilled staff and resources to conduct an outcome evaluation, FHI usually does not require its implementing partners to conduct such exercises. This is especially true if it is a small-scale project and it has a limited duration. Instead, the FHI country office may conduct an evaluation that includes several or all of its projects in the area.

Possible HBC evaluation questions about outcome and impact:
Outcome:
- What has the effect been on the quality of life (social, economic, psychological well-being) of the clients, their caregivers, and their families?
- What has the impact been on surrounding health facilities?

- What has the impact been on the community (passive vs. active involvement in delivery of HBC services, community capacity to provide care and support, awareness and attitudes towards PLWHA, etc.)
- What has the impact been on HIV/STI-related risk behaviors among clients, their caregivers, their families, and the community?

Impact:

Impacts are often impossible to measure and attribute to CHBC programs because defining the cause of illness or death is complicated; it is often impossible to link the illness or death to HIV. Thus, linking the following to a CHBC program would be nearly impossible:
- Mortality rates
- Morbidity rates

Methods for Evaluating HBC programs
- Observational studies:
  - Cohort studies with concurrent controls
  - Cohort studies with historical controls
    - Surveys of PLHA
    - Interviews with key informants
    - Facility assessments
    - Household surveys
    - Community assessments
- Controlled trials with no randomization
- Mortality and morbidity registries

Non-experimental observational methods without control groups are used routinely in behavioral outcome evaluations. Before-and-after evaluation designs without comparison groups may help to assess a program's success in delivering services, but is not useful for measuring program effectiveness. Inferring "cause and effect" from such a design is problematic because one cannot rule out other explanations for changes over time.

N.   Wrap-Up

4:55-5:00	5 min	**N. Wrap-Up**	*Q & A Session*

Materials
- Markers
- Evaluation Form

Ask participants to think of two major lessons they learned during the workshop, and then (if time permits) ask them to draw a picture of a few key things they learned today and describe it to group.

Thank participants for their participation.

Distribute the Evaluation Forms and ask participants to fill them out and submit them before leaving the classroom.

Appendix

Module 4:
Monitoring and Evaluating
Community Home-Based Care Programs

Care and Support Framework

1. Clinical Care

- Voluntary counseling and testing

- Prevention of mother-to-child transmission

- Antiretroviral treatment

2. Socioeconomic Support

- Stigma and discrimination reduction
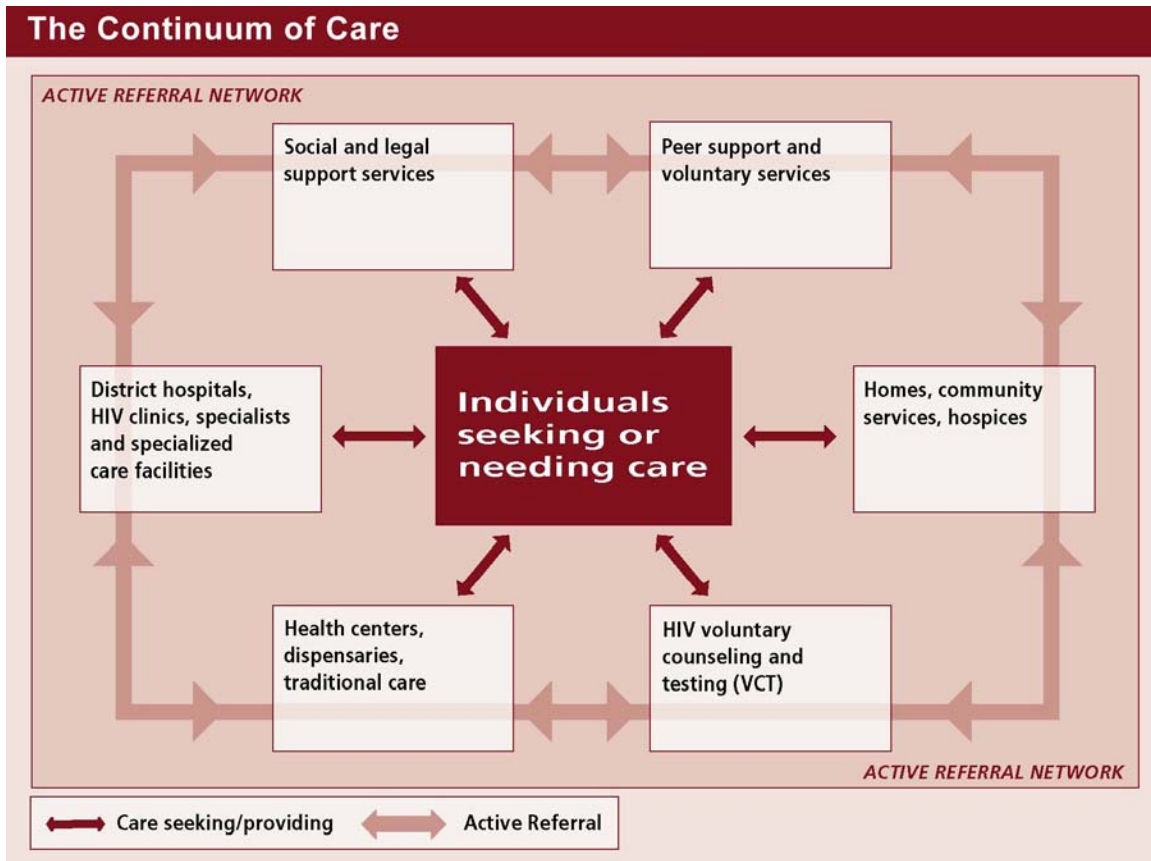
- Succession planning

- PLHA participation

3. Psychosocial Support

- Counseling

- Orphan care

- Community support services

- Spiritual support

Illustrative Indicators for HBC Programs

trainings
individuals trained in home-based care
clients visited in the last quarter that are less then 15 years old
% all clients who are less then 15 years old
# clients visited in the last quarter who are between 15 and 19 years old
% all clients who are between 15 and 19 years old
# clients visited in the last quarter who are between 20 and 24 years old
% all clients who are between 20 and 24 years old
# clients visited in the last quarter who are 25 years old or older
% all clients who are 25 years old or older
# individuals reached by community- and home-based care programs
# clients provided with medical support
# clients provided with psychosocial support
# clients referred to clinic or health facility
# family members trained in caring for PLHA
# households served
# USAID-assisted community- and home-based care programs

The Continuum of Care

The Continuum of Care

ACTIVE REFERRAL NETWORK

Social and legal support services

Peer support and voluntary services

District hospitals, HIV clinics, specialists and specialized care facilities

Individuals seeking or needing care

Homes, community services, hospices

Health centers, dispensaries, traditional care

HIV voluntary counseling and testing (VCT)

ACTIVE REFERRAL NETWORK

◆──◆ Care seeking/providing   ◆──◆ Active Referral

Continuum of Care: Models of HBC

Model Type	Description	Weakness	Strength
Hospital-initiated	Hospital staff provide outreach care services	• Costly • Strong focus on medical care • No direct benefit to family • Stigmatized	• Easy monitoring and supervision • Good link with supplies • Access to professional staff • Hospital-referral possible
NGO-initiated (e.g., faith-based, PLWHA associations)	Support groups established by NGO provide counseling, medical care, and home care	• Eligibility may be biased or selective • Weak links with hospitals • Isolated from supplies and hospital back-up • Sustainability and coverage difficulties	• May provide comprehensive care • Accessible, innovative, and flexible
NGO-coordinated	NGO trains community members and/or family members to provide CHBC services; NGO provides follow-up		• Sustainable • Innovative • Considers specific community needs
Integrated	Patient-support units established at hospitals where patients are counseled during their stay and discharge plans are made, which include follow-up closer to home and/or home care		• Government and community structures linked • Hospital-referral possible • Reduce stigma

Essential Components of Home-Based Care

Category	Subcategory
Provision of Care	• Basic physical care • Palliative care • Psychosocial support and counseling • Care of affected and infected children
Continuum of Care	• Accessibility • Continuity of care • Knowledge of community care • Community coordination • Record-keeping for ill people • Case-finding • Case management
Education	• Curriculum development • Education management and curriculum delivery • Outreach • Education to reduce stigma • Mass media involvement • Evaluation of education
Supplies and Equipment	• Location of HBC team • Health center supplies • Management, monitoring, and record-keeping • Home-based care kits
Staffing	• Supervising and coordinating HBC • Recruitment • Retaining staff
Financing and Sustainability	• Budget and finance management • Technical support • Community funding • Encouraging volunteers • Pooling resources • Out-of-pocket payments • Free services
Monitoring and Evaluation	• Quality assurance • Quality-of-care indicators • Monitoring and supervision • Informal evaluation • Formal evaluation • Flexibility

Presentation Scenario/Case Study

Data Use Scenario 1:
Presentation to HBC Volunteers in Districts A and B

You are the volunteer coordinator in charge of all the HBC volunteers working in Districts A and B and are meeting with the HBC volunteers in Districts A and B. You are happy with their work and want to share these data with them to give them encouragement and support for their efforts. Think of how to present these data in a way that will motivate them and maintain their support. Unfortunately, you need to tell the volunteers that the funding from the donor may be cut and there may not be funds to continue providing compensation to the volunteers. You are working with the coordinating NGO to investigate the possibility of getting government support to cover this cost, but this is a long process and nothing is definite yet. You need to persuade the volunteers to continue working even with this change. This is a challenging task.

Data Use Scenario 2:
Presentation to Community-Based Organizations in Districts A and B

You are the director of the NGO that coordinates HBC activities in Districts A and B and are meeting with CBOs in Districts A and B, some of which are involved with the HBC program. You need to convince those not involved to participate and to become active linkages and members of the HBC program referral network within these two districts. You do not have any funds to supplement any additional costs the CBOs may incur (e.g., increased staff or expanded hours of operation). You are also asking that CBOs track information related to HBC activities such as referrals or services provided. Your job is to present the data and convince them to participate in the community HBC program. You'll have to promote the benefits of HBC and persuade them that this is the right thing to do.

Data Use Scenario 3:
Presentation to Regional Hospital

You are a member of the NGO that coordinates HBC activities in Districts A and B are meeting with the executives of the Community Union to persuade them to expand the HBC program into Districts C and D. The NGO wants the Community Union to fund this expansion. You need to present the data to the Community Union executives and create a strong case for HBC, persuading them that funding the expansion is the right thing to do.

Data Use Scenario 4:
Psychosocial Support Systems

Your preliminary needs assessment has identified a group of HIV-positive elders in the community who are suffering greatly from problems that include outliving their children, caring for too many grandchildren, and worrying about living long enough to continue to see their grandchildren grow. You want to establish a program that will support their emotional and psychological needs.

Data Use Scenario 5:
Government Involvement

Discussions with your counterparts in the provincial government tell you that they do not understand what HBC is for and why it is necessary. They believe that HIV-positive people should just use the government clinics for health care. You need to get the government involved and supportive of your program.

Data Use Scenario 6:
Funding Agencies

You want to be able to expand your HBC program to other communities in the region. To do this, you will need to work with organizations that provide financial support in the healthcare system to support this expansion.

Data Use Scenario 7:
Buddy System

Your highly trained "buddies" have reported to their supervisors that their clients are being blocked from clinics by the staff members of other care services because these staff members do not know who the "buddies" are, do not know if this "Buddy Project" is reputable, and are not sure if buddies really know what they are doing. So the referrals being made are being ignored.

Data Use Scenario 8:
Setting Up the First HBC Program

Your preliminary data show that a large number of HIV-positive people are too ill to come into the clinical setting and are in need of HBC. The community leaders have approached your organization to establish the first HBC program in the region.

Checklist Tool for Monitoring Home-Based Care Visit

Home care program: _____ **Compound:** _____
Volunteer: _____ **Date:** _____
Type of visit: initial assessment____ regular visit____ TB DOTS visit____
Length of visit: _____

Type of Support Offered (as observed):

Basic nursing care:
Provision of basic drugs	Yes/No/Not applicable
Provision of TB DOTS	Yes/No/Not applicable
Turning bedridden patients	Yes/No/Not applicable
Bathing/toileting	Yes/No/Not applicable
Provision of prescribed drugs	Yes/No/Not applicable

Emotional support   Yes/No/Not applicable

Counseling   Yes/No/Not applicable

Spiritual support   Yes/No/Not applicable

Referral   Yes/No/Not applicable _____

Housekeeping:
Cooking	Yes/No/Not applicable
Sweeping	Yes/No/Not applicable
Fetching water	Yes/No/Not applicable
Fetching firewood	Yes/No/Not applicable
Washing	Yes/No/Not applicable
Health education	Yes/No/Not applicable
IEC materials	Yes/No/Not applicable
Provision of condoms	Yes/No/Not applicable

Provision of welfare:
Blanket	Yes/No/Not applicable
Bedsheets	Yes/No/Not applicable
Soap	Yes/No/Not applicable
Mealie Meal	Yes/No/Not applicable
Microcredit	Yes/No/Not applicable

Support for family members:
Emotional support	Yes/No/Not applicable
Basic care	Yes/No/Not applicable
Health education	Yes/No/Not applicable
Referral _____	Yes/No/Not applicable
Support for children _____	Yes/No/Not applicable

Record-keeping: satisfactory/unsatisfactory _____

Follow-up date of visit made: Yes/No

Comments:
_____
_____
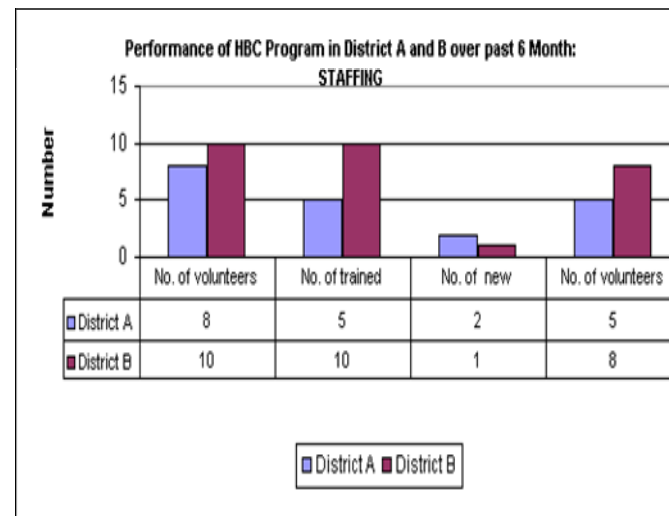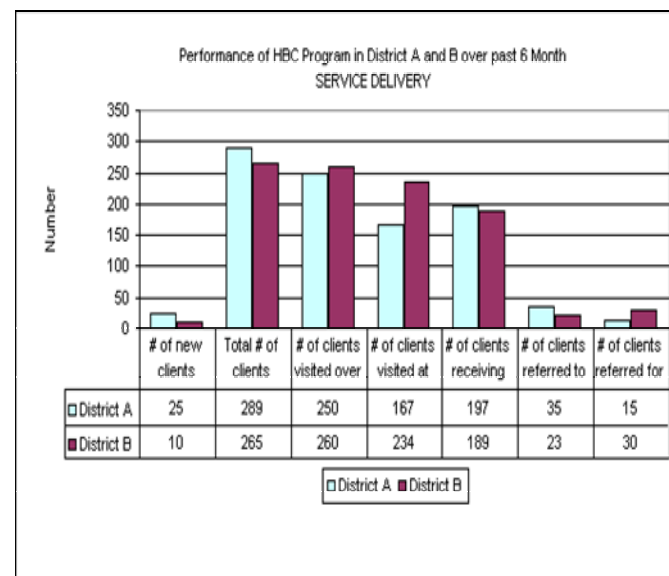_____

Mock HBC Data and Graphs
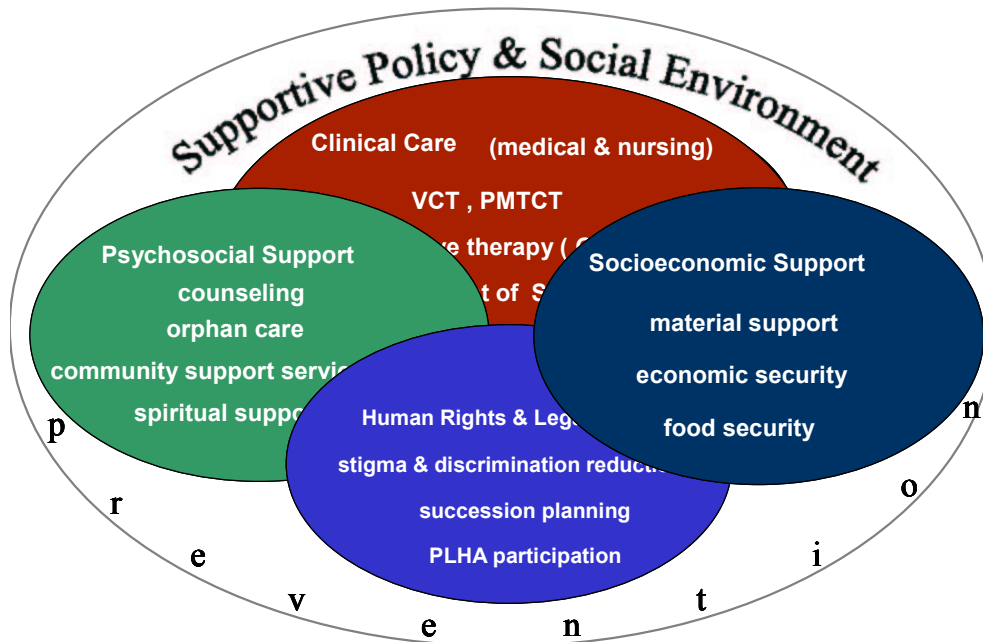
Performance over past 6 month

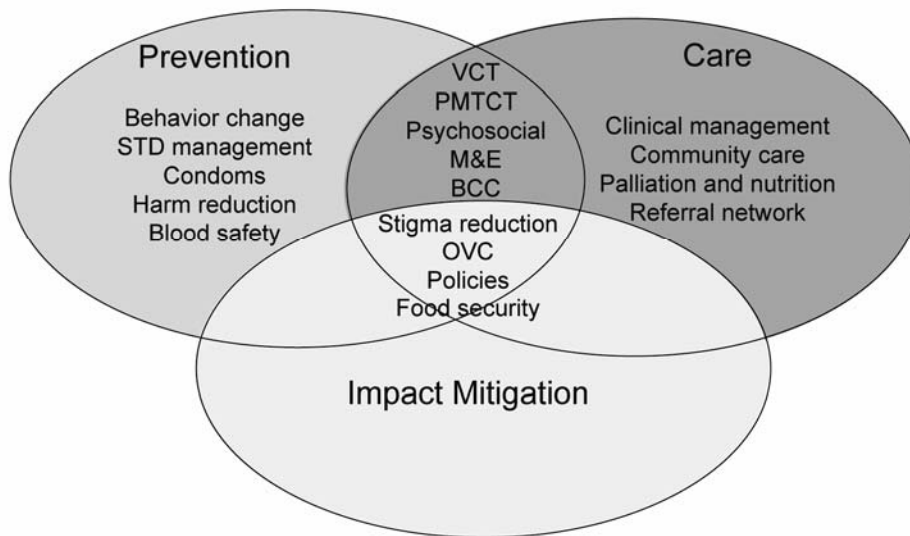| Service Delivery	District A	District B
# new clients registered	25	10
Total # clients registered	289	265
# clients visited over past 6 month	250	260
# clients visited at least every 2 weeks	167	234
# clients receiving food aid	197	189
# clients referred to clinic	35	23
# clients referred for psychosocial counseling	15	30

Staffing	District A	District B
# volunteers	8	10
# trained volunteers	5	10
# new volunteers	2	1
# volunteers submitting report on time	5	8

Performance of HBC Program in District A and B over past 6 Month
SERVICE DELIVERY

	# of new clients	Total # of clients	# of clients visited over	# of clients visited at	# of clients receiving	# of clients referred to	# of clients referred for
District A	25	289	250	167	197	35	15
District B	10	265	260	234	189	23	30

□ District A ■ District B

Performance of HBC Program in District A and B over past 6 Month:
STAFFING

	No. of volunteers	No. of trained	No. of new	No. of volunteers
District A	8	5	2	5
District B	10	10	1	8

□ District A ■ District B

Comprehensive HIV/AIDS Care and Support

Supportive Policy & Social Environment

Clinical Care (medical & nursing)

VCT , PMTCT

e therapy (

t of S

Psychosocial Support
counseling
orphan care
community support servi
spiritual suppo

Socioeconomic Support

material support

economic security

food security

Human Rights & Leg

stigma & discrimination reduct

succession planning

PLHA participation

p r e v e n t i o n

The Care/Prevention/Support Synergy

Prevention

Behavior change
STD management
Condoms
Harm reduction
Blood safety

VCT
PMTCT
Psychosocial
M&E
BCC

Stigma reduction
OVC
Policies
Food security

Care

Clinical management
Community care
Palliation and nutrition
Referral network

Impact Mitigation

The Gaborone Declaration on Community Home-Based Care (March 2001)

Defines community home-based care as:

> "Care given to an individual in his or her own natural environment by his or her family and supported by skilled social welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs."