

Monitoring HIV/AIDS Programs: Participant 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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MODULE 4:

Monitoring and Evaluating Community Home-Based Care Programs

Learning Objectives

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

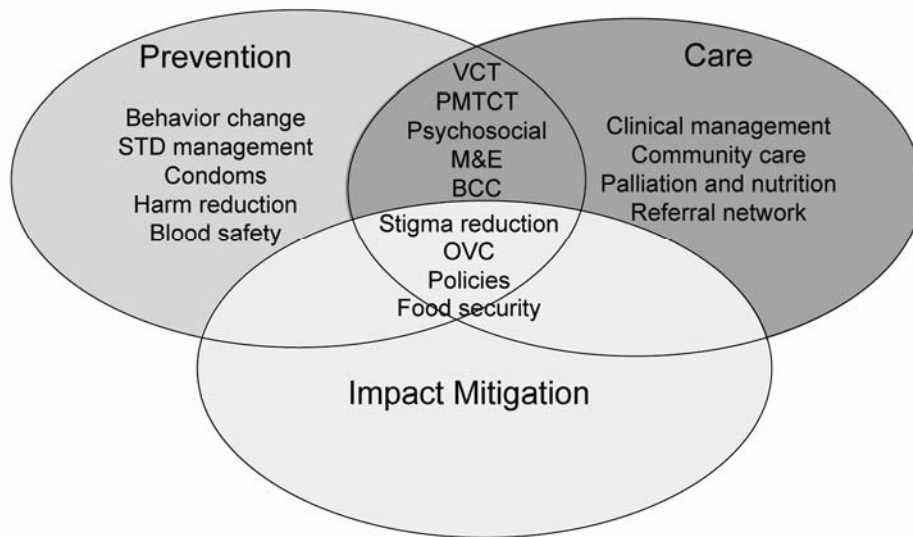
- Understand the components of community home-based care (CHBC) that need to be monitored.
- Develop home-based care (HBC)-specific process indicators.
- Identify appropriate monitoring and evaluation methodologies and tools.
- Appreciate better the different data uses and how they influence data collection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

Overview of Care and Support Framework

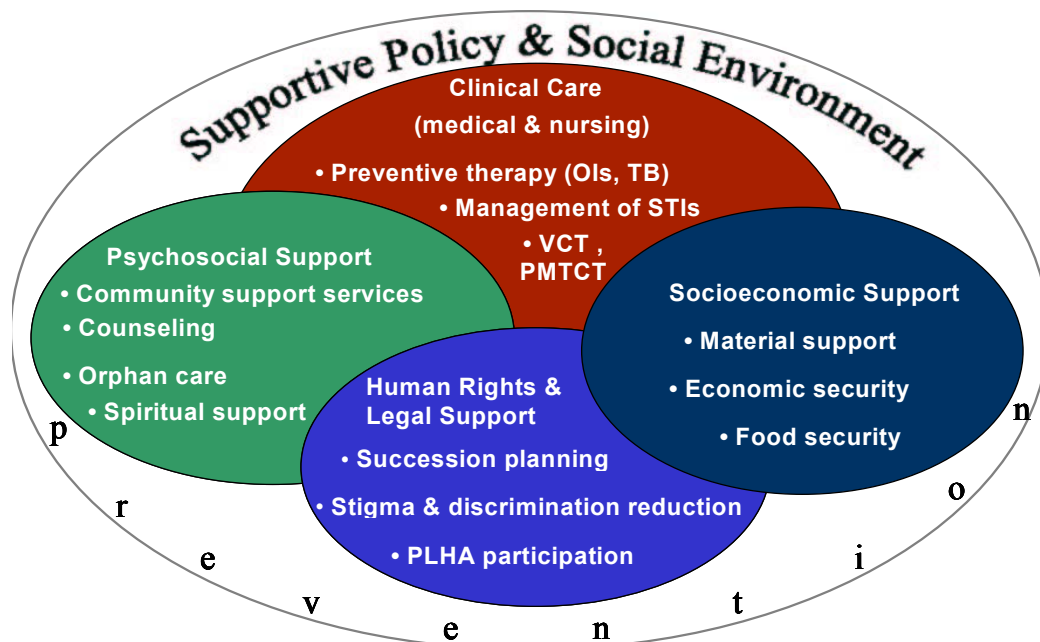
HIV/AIDS Care and Support

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.

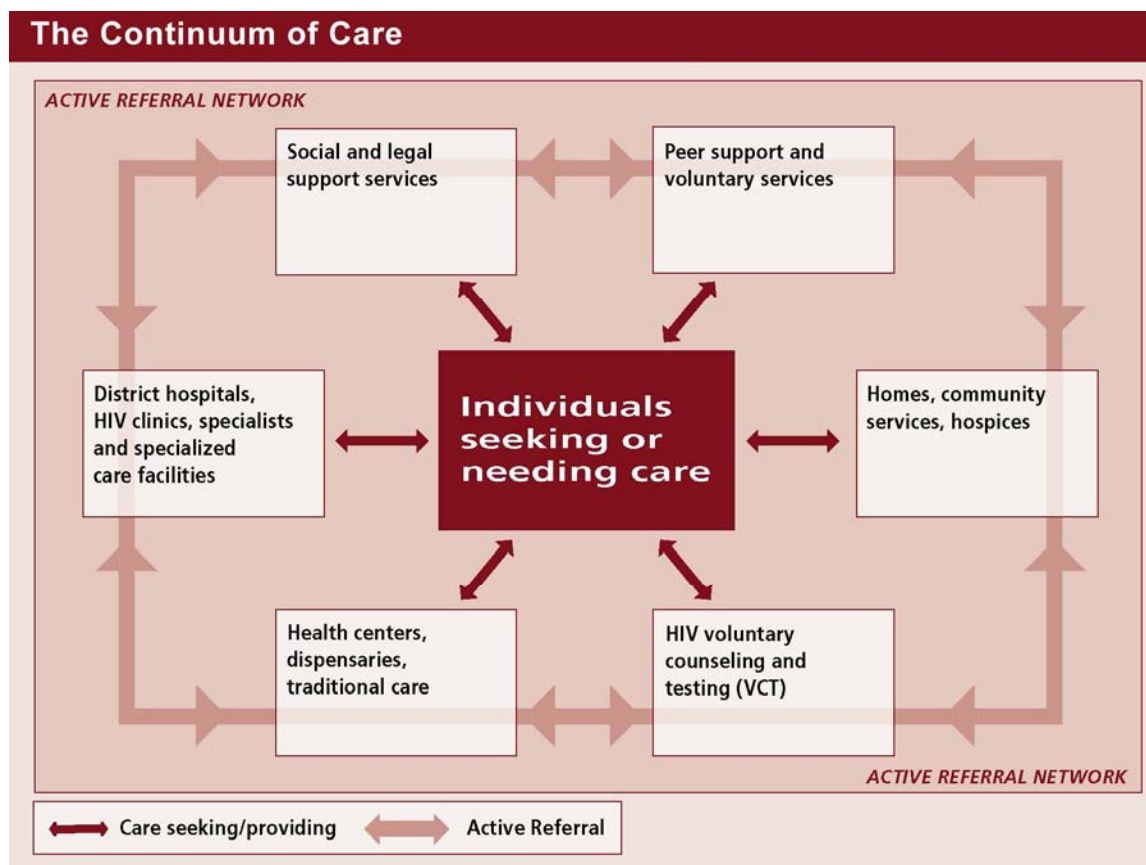
The Care/Prevention/Support Synergy



Comprehensive HIV/AIDS Care and Support



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.



Home-Based Care Experiences or Programs and Definition of HBC

Definition of Community Home-Based Care (CHBC)

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.”

Models of Home-Based 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	<ul style="list-style-type: none"> • Costly • Strong focus on medical care • No direct benefit to family • Stigmatized 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Eligibility may be biased or selective • Weak links with hospitals • Isolated from supplies and hospital back-up • Sustainability and coverage difficulties 	<ul style="list-style-type: none"> • 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		<ul style="list-style-type: none"> • 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		<ul style="list-style-type: none"> • Government and community structures linked • Hospital-referral possible • Reduce stigma

Components of Community Home-Based Care

Essential Components of Home-Based Care		Handout
Category	Subcategory	
Provision of Care	<ul style="list-style-type: none"> • Basic physical care • Palliative care • Prevention counseling • Nutrition counseling • Psychosocial support and counseling • Care of affected and infected children 	
Continuum of Care	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Curriculum development • Education management and curriculum delivery • Outreach • Education to reduce stigma • Mass media involvement • Evaluation of education 	

Essential Components of Home-Based Care		Handout
Category	Subcategory	
Supplies and Equipment	<ul style="list-style-type: none"> • Location of HBC team • Health center supplies • Management, monitoring, and record-keeping • Home-based care kits 	
Staffing	<ul style="list-style-type: none"> • Supervising and coordinating HBC • Recruitment • Retaining Staff 	
Financing and Sustainability	<ul style="list-style-type: none"> • Budget and finance management • Technical support • Community funding • Encouraging volunteers • Pooling resources • Out-of-pocket payments • Free services 	
Monitoring and Evaluation	<ul style="list-style-type: none"> • Quality assurance • Quality-of-care indicators • Monitoring and supervision • Informal evaluation • Formal evaluation • Flexibility 	

Special Considerations for Monitoring HBC Programs

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.

Evaluating HBC Programs

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.