

# COMMUNITY HOME-BASED CARE IN RESOURCE-LIMITED SETTINGS

A FRAMEWORK FOR ACTION



PUBLISHED COLLABORATIVELY BY  
THE CROSS CLUSTER INITIATIVE ON HOME-BASED LONG-TERM CARE,  
NON-COMMUNICABLE DISEASES AND MENTAL HEALTH AND  
THE DEPARTMENT OF HIV/AIDS, FAMILY AND COMMUNITY HEALTH,  
WORLD HEALTH ORGANIZATION

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The named authors alone are responsible for the views expressed in this publication.

This document is founded on research, conceptual development, observations of practice and relevant community home-based care literature. The people who played an important role in informing this work and who were responsible for the development of this document include:

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## EXECUTIVE SUMMARY

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This document provides a systematic framework for establishing and maintaining community home-based care (CHBC) in resource-limited settings for people with HIV/AIDS and those with other chronic or disabling conditions. Most CHBC services so far have been established through unsystematic, needs-based efforts. As the HIV/AIDS epidemic continues to grow, many organizations and communities are now considering expanding in a more programmatic approach, and countries are looking for scaled-up responses and national strategies for CHBC. This document therefore provides an important framework to guide governments, national and international donor agencies and community-based organizations (including nongovernmental organizations, faith-based organizations and community groups) in developing or expanding CHBC programmes. The need for such a document has been clearly identified.

CHBC is defined as any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. The goal of CHBC is to provide hope through high-quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life.

This document targets three important audiences: policy-makers and senior administrators, middle managers and those who develop and run CHBC programmes. Although the roles and responsibilities of these target audiences differ somewhat, developing effective partnerships among the three is essential. Policy-makers and senior administrators must be involved in developing and monitoring CHBC programmes, and the people who manage and run the programmes must share information and feedback with senior administrators. In this sense, policy and action are interrelated as each partner learns from and guides the other. To this end, this document is divided into four interrelated sections: a policy framework for CHBC; the roles and responsibilities for CHBC at the national, district and local levels of administration; the essential elements of CHBC; and the strategies for action in establishing and maintaining CHBC in resource-limited settings. A brief overview of each of these sections follows.

### A policy framework for CHBC

This framework is a systematic approach for policy-makers, senior administrators and government decision-makers to follow in developing the overall policies and guidelines for CHBC. The framework is divided into eight discrete categories: the nature of the programme, eligibility criteria, eligibility assessment, benefits, programme operation, financing, coverage and cost. Each of these categories is described and questions are posed for senior administrators and policy-makers, in individual settings, to address as they develop the overall policy framework for CHBC.

### Roles and responsibilities for the administration of CHBC

This section addresses issues related to CHBC administration. Decisions must be made about which administrative level is responsible for the various aspects

of CHBC. For ease of description, three levels of administration have been identified: the national or central level, the district or provincial level and the local or community level of administration. An overview of each of these levels of responsibility is presented with questions to help guide decision-makers in determining how the responsibility for managing, administering and delivering CHBC should be organized.

## Essential elements of CHBC

The essential elements of CHBC have been developed from case studies, research, observations from practice, and CHBC evaluations in various regions of the world. These essential elements are divided into seven main categories: provision of care; continuum of care; education; supplies and equipment; staffing; financing and sustainability; and monitoring and evaluation. Each of these broad categories has many subcategories that provide details of the important elements of sustainable and effective CHBC. To provide clarity, each category and subcategory stands alone. In reality, all these elements come together for holistic CHBC. The essential elements of CHBC outlined here are the ideal. Implementing all these elements at once might not be possible in resource-limited settings. However, this section provides guidance on what is important in establishing and maintaining CHBC in resource-limited settings. Case examples are included within this section to highlight how various CHBC programmes throughout the world have addressed some of the essential elements of CHBC.

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## Strategies for action in establishing and maintaining CHBC

This action phase uses a development process at the community level for establishing and maintaining CHBC programmes. Establishing new CHBC projects or scaling up existing programmes requires a systematic process of development. This systematic process includes: the entry phase; community assessment; needs assessment; planning; implementation, and evaluation. The elements identified in the previous three sections are revisited and placed within this action framework.

All four sections of this document raise questions to stimulate thought and discussion. The first section poses questions to guide policy formation. The second section raises issues that reflect the overall management and administration of CHBC. The final section raises questions to guide community groups in planning, implementing and evaluating CHBC programmes. Responses to all the issues raised should reflect the differing CHBC needs within each country, programme or community setting.

CHBC programmes are continually evolving as they respond to the changing needs of families. For example, in the beginning, most CHBC programmes focused on the care of ill people and family caregivers. As the AIDS epidemic continues to grow, orphan care is becoming a critical concern. The stage of the HIV/AIDS epidemic and the ratio of people with HIV/AIDS to those with other chronic and terminal illnesses therefore dictates different priorities.

This document provides guidance and suggestions to governments, international and national donor agencies, nongovernmental organizations (NGOs), faith-based organizations, community-based organizations and community groups as they undertake the important challenge of developing or scaling up effective and responsive CHBC in resource-limited settings.



# INTRODUCTION

*“Home-based care is taking us back to the root of human coexistence. It reminds us that we all have the responsibility to one another. If we hold hands through this tragedy ... we will be able to retain our humanity and will come out of this epidemic as a stronger community.”*

*Joy Phumaphi, Minister of Health, Botswana*



A man helps his wife to stand.

UNAIDS/Michel Szulc-Kryzanowski

This document provides a systematic framework for the establishment and maintenance of community home-based care (CHBC) in resource-limited settings. Most CHBC services so far have been established through unsystematic, needs-based efforts. As the HIV/AIDS epidemic continues to grow, many organizations and communities are now considering expanding in a more programmatic approach, and countries are looking for scaled-up responses and national strategies for CHBC. This document therefore provides an important framework to guide governments, national and international donor agencies and community-based organizations (including NGOs), faith-based organizations and community groups) in expanding their CHBC programmes. The need for such a document has been clearly identified.

The overall purpose of this document is to provide a framework for the systematic development and maintenance of CHBC in resource-limited settings for people with HIV/AIDS and other chronic illnesses and disabilities. This document has three interrelated target audiences. First, governments, national and international donor agencies and larger NGOs will find this document useful in making decisions and policy for CHBC programmes. Second, middle (or district) management can follow this framework as they implement policies for developing CHBC. Finally, community groups will find the framework helpful for establishing, monitoring and maintaining CHBC projects.

CHBC is defined as any form of care given to sick people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities.<sup>1</sup> Home care draws on two strengths that exist throughout the world: families and communities. Families are the central focus of care and form the basis of the CHBC team. Communities are places where people live and a source of support and care to individuals and families in need. The goal of CHBC is to provide hope through high-quality and appropriate care that helps family caregivers and sick family members to maintain their independence and achieve the best possible quality of life.<sup>2</sup>

1 WHO. *AIDS home care handbook*. Geneva, World Health Organization, 1993 (document WHO/GPA/IDS/HSC/93.2).

2 WHO. *Home-based and long-term care: home care issues at the approach of the 21st century from a World Health Organization perspective: annotated bibliography*. Geneva, World Health Organization, 1999 (document WHO/HSC/LTH 99/1).

Between 70% and 90% of illness care takes place within the home.<sup>3</sup> Research evidence clearly demonstrates that most people would rather be cared for at home and that effective home care improves the quality of life for ill people and their family caregivers. CHBC is the best way for most people to be cared for and to die. Throughout the world, most caregivers are family members (usually women and young girls), and these caregivers are valued as the main source of care for ill people.

Implementing CHBC in a team ensures that all the essential elements in CHBC are included. The CHBC team consists of ill people, family caregivers, health and social welfare personnel, community health workers and community volunteers. Other key stakeholders that may be included in the team are community and spiritual leaders, traditional healers, pharmacists, community health committees, neighbours, other community agencies or organizations and community groups (including groups of people with HIV/AIDS, orphans, youth and women). A number of significant individuals may support CHBC, such as business and union leaders and journalists and other mass media personalities.

Governments and many different organizations and community agencies develop and run CHBC programmes. For example, national, provincial and local governments and national and international donor agencies have been involved in developing and administering CHBC programmes. In addition, faith-based organizations, NGOs and other forms of community-based organizations have been major players in developing CHBC.

The first requirement for care is to ensure the basic needs of shelter, food, safe water, sanitation, cooking utensils and clothing. Providing effective CHBC is difficult if these basic needs are not being met. In addition, people in many resource-limited countries, and especially poor people, have to pay for health care out of their own pockets at the very time they are sick and least able to pay. As a result, poor people often avoid attending health facilities. Strategies must therefore be developed to make CHBC available and accessible to everyone who needs it. Such strategies will require creativity in financing and a commitment to providing sufficient funds.

This document targets three important audiences: policy-makers and senior administrators, middle managers and those who develop and run CHBC programmes. Although the roles and responsibilities for these target audiences are somewhat different, developing effective partnerships among the three is essential. Policy-makers and senior administrators must be involved in developing and monitoring CHBC programmes, and the people who manage and run the programmes must share information and feedback with senior administrators. In this sense, policy and action are interrelated as each partner learns from and guides the other. To this end, this document is divided into four interrelated sections: a policy framework for CHBC; the roles and responsibilities for CHBC at the national, provincial and local levels of administration; the essentials of CHBC; and the strategies for action in establishing and maintaining CHBC in resource-limited settings.

CHBC programmes are continually evolving as they respond to the changing needs of families. For example, in the beginning, most CHBC programmes focused on the care of ill people and family caregivers. As the AIDS epidemic continues

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3 WHO. *Fact sheets on HIV/AIDS for nurses and midwives* [www-nt.who.int/whosis/statistics/factsheets\_hiv\_nurses]. Geneva, World Health Organization, 2000 (document WHO/EIP/OSD/2000.5; accessed 9 June 2002).

to grow, orphan care is becoming a critical concern. The stage of the HIV/AIDS epidemic and the ratio of people with HIV/AIDS to those with other chronic and terminal illnesses therefore dictates different priorities. Policy formation must reflect these changing priorities.

All four sections of this document raise questions to stimulate thought and discussion. The first section poses questions to guide policy formation. The second section raises issues that reflect the overall management and administration of CHBC. The final section raises questions to guide community groups in planning, implementing and evaluating CHBC programmes. Responses to all the issues raised should reflect the differing CHBC needs within each country, programme or community setting.

Although this document provides a framework for the establishment and maintenance of CHBC in resource-limited settings, some community agencies will be able to implement more of these strategies than others. Smaller NGOs, faith-based organizations and poorer communities may not be able to implement the entire complement of services described in this document. Communities should therefore start by setting priorities among their needs and actions. The fourth section of this document provides a framework for this priority-setting.

## A POLICY FRAMEWORK FOR CHBC

This development framework is a systematic approach for policy-makers, senior administrators and government decision-makers to follow in developing the overall policies and guidelines for CHBC. This conceptual framework presented here has been adapted from two WHO documents: *Long-term care laws in five developed countries*<sup>1</sup> and *Home-based long-term care: report of a WHO Study Group*.<sup>2</sup> The framework is divided into eight discrete categories: the nature of the programme; eligibility criteria; eligibility assessment; benefits; programme operation; financing; coverage; and cost<sup>1</sup>. Each of these categories is described and questions posed for senior administrators and policy-makers to address as they develop the overall framework for CHBC. Responses to the issues raised in this section should reflect the differing CHBC needs within each country, programme or community setting. Not all governments and donor agencies in resource-limited settings can address all of the issues and questions raised in this framework. However, each country has to decide what can be included (or not). Table 1 provides an overview of this CHBC planning and policy framework.

1 WHO. Long-term care laws in five developed countries: a review. Geneva, World Health Organization, 2000 (document WHO/NMH/CCL/00.2).

2 WHO. Home-based long-term care: report of a WHO study group. Geneva, World Health Organization, 2000 (WHO Technical Report Series, No. 898).

**Table 1. Planning and policy framework for CHBC**

<b>Category</b>	<b>Items to be addressed</b>
Nature of the programme	Purpose, goals and objectives of CHBC Target population Location Time frame
Eligibility criteria	Age Disease category Degree of disability Relationship of caregivers Knowledge of diagnosis Number of CHBC hours Ability to pay Degree of family support Provision of physical and emotional care Provision of housekeeping duties General state of family and home
Eligibility assessment	Assessment tool (universal or contextual) Who will be the assessor? Measurement of the level and type of care
Benefits	Cash allowance, service provision or combination Maximum and minimum benefits Waiver system Medicines and supplies Food provision Transport Respite and day care services Counselling Basic nursing care Assistance with housework
Programme operation	Government-run or joint operation Responsibility for service delivery Care planning Education Quality assurance
Financing	Funded through general taxation Cost sharing Funding by other organizations Cost containment
Coverage	Percentage of the population covered Locations Disease categories and target populations Levels of disability
Cost	Cost of services Hourly cost Ratio of paid to unpaid workers Education Medicines and supplies Transport Food supplements

## Nature of the programme

The exact purpose of the CHBC programme must be identified first. This purpose has to be clearly identified to develop policies, guidelines and implementation strategies that match this precise purpose. The overall purpose statement must include a description of the service, the target population, the locations for CHBC and a time line. Deriving this clear statement of purpose requires considering the following questions.

- Who is the target population? Only people with HIV/AIDS? People with HIV/AIDS and/or other chronic illnesses and disabilities? Will specific chronic illnesses be targeted, or will all chronic illnesses and disabilities be covered? Will the definition of chronic illness include communicable and noncommunicable diseases, or only one of these?
- Will orphans be included in the target population?
- Will people with mental disorders be included in the target population?
- Will people with substance abuse problems be included?
- Will people suffering from common “acute” illnesses such as malaria and dysentery be included?
- Will the CHBC services directly assist family caregivers and ill people or indirectly by assisting community organizations and their existing care programmes? Is the focus on assisting one of these target groups over another?
- Are there existing policies and guidelines for CHBC?
- If existing policies and guidelines have been used, how useful were they? Can they be adapted or revised to the present circumstances?
- How will CHBC become integrated into the overall health and social welfare system, especially into the local community health and welfare systems?
- Are the CHBC services to be delivered throughout the country from the onset, to selected sites or through a pilot project initially?
- When will specific services be initiated? What is the time frame for implementation?
- Based on the answers to these questions: what will be the precise nature of the CHBC services? Can the purpose, goals and objectives for CHBC be clearly identified?

It is very important that senior administrators and policy-makers decide on a clear statement of purpose for CHBC. The exact nature of the programme should be stated briefly and clearly. Then the goals and objectives for CHBC must be identified to address measurable and achievable outcomes.

Decisions also have to be made about who will benefit from the CHBC services. This means that the target population must be clearly identified. Ideally, all ill people or orphans needing care within the home should be included, whether directly or

indirectly through assistance to community organizations and grassroots initiatives. However, such an inclusive policy is unlikely to be possible. Policy-makers must therefore decide who will (and who will not) receive CHBC services.

The locations for CHBC support must also be determined. Again, ideally, CHBC services would be implemented throughout the country, but this might not be possible for a number of reasons. Policy-makers might decide to start with a few pilot projects so that lessons can be learned and adaptations made to better provide more efficient and effective services (see the final section of this document). In addition, funding might only be available to start CHBC in some parts of the country. For example, decisions might be made to start CHBC in large urban settings and to leave rural areas for later development. Another option might be to develop CHBC where a functioning community health system exists. Some countries have poorly developed local health systems, whereas others have systems that are well integrated into the overall health care system. Finally, decisions might be made to implement CHBC only where active community-based organizations, NGOs, faith-based organizations and others involved in home-based care exist. In this way, the services can strengthen existing nongovernmental CHBC services. Nevertheless, underserved or unserved areas are the very ones that often most need professional assistance in CHBC. These are therefore just a few examples of the decisions that have to be made about the location of the CHBC programme.

Finally, clearly setting a time frame for programme development is important: a time frame for starting CHBC and one for expanding the programme.

## Eligibility criteria

All people in need cannot be included into proposed CHBC services. Such a strategy would overwhelm the resources of the funding agency. Developing criteria for eligibility is therefore essential. Making decisions about eligibility requires addressing the following questions.

- Should CHBC be available for sick people being cared for at home, regardless of their illness or disability? If restrictions on diagnosis are to be made, how would these restrictions be assessed and applied?
- Will transient families be eligible?
- Will CHBC be available for people with acute illness or only for those with chronic illness and disability or terminal illness?
- Should CHBC be available to people of all ages? Should there be an age restriction on eligibility? If there is an age restriction, what will it be and how will it be applied?
- Does the caregiver have to be a family member, or are other caregivers (such as friends and neighbours) eligible for assistance in CHBC?
- How will the degree of disability be assessed? How will assessment take into account the degree of reduction in the activities of daily living such as washing, dressing, eating and mobility and instrumental activities of daily



living such as cleaning, cooking, doing laundry and errands? How will this degree of disability be factored into the assessment of eligibility for CHBC?

- Is it important for the ill person's diagnosis to be confirmed before CHBC is made available, or is a clinical diagnosis sufficient? (For example, stigma might affect people's willingness to state the diagnosis of HIV/AIDS.) Will reluctance to disclose the diagnosis preclude access to CHBC?
- Will there be a maximum and minimum number of hours available for CHBC assistance?
- Should the family's income level be taken into consideration in assessment for eligibility? That is, should a means test be applied? Should families that can afford to pay towards CHBC be required to do so? Or should CHBC be available free of charge to everyone who qualifies for assistance?
- Should the amount of family assistance be taken into account? That is, should families that have an adequate number of family members involved in caring for the sick family member be included in the CHBC or not?
- Will people needing psychological support be eligible for CHBC or only people who need physical support and care? That is, will people who predominantly require emotional and psychological support and care be assessed for eligibility differently (or similarly) to those who require mostly physical care and support?
- Will the state of the home and the general condition of the family be taken into account for CHBC eligibility? That is, will those in greatest need be given priority?

It is generally agreed that assessment should be performed by either professionals in a single field such as physicians, nurses and social workers or by a multidisciplinary team. A single professional is usually sufficient if the assessment criteria are narrow in focus and if the assessment tools and guidelines are clearly structured. However, if the assessment is multidimensional and leaves room for flexibility and professional judgement, then a team of assessors from different professional groups might be necessary. This decision should be based on: the type of assessment done, the availability of the professionals and the ability of the funding agencies to afford a team rather than a single assessor.

## Eligibility assessment

After the eligibility criteria have been determined, tools should be developed for evaluating and assessing eligibility. To that end, the following questions should be addressed:

- Will a structured assessment tool be established? If so, will this tool be used nationally, or will different tools be used for each district?
- Who will be responsible for developing the assessment tool?
- How will this assessment tool be used?

- How will the objectivity of the assessment tool be assured? That is, how will the process of assessment be transparent, egalitarian and consistent?
- Who will be responsible for administering this assessment tool? That is, will a community health or social service professional do the assessment or will a person or team from an outside agency be charged with this responsibility?
- How will the level of care and support be measured? That is, how will the assessor identify the number of hours required for the CHBC service? Will the number of hours depend on the severity of the illness or on the needs of the caregiver and ill person?
- How will the type of care and support be assessed? That is, who will identify the type of care and support required?

Assessment should be uniform and consistent. That is, the process of assessment should be transparent, objective, fair and consistently applied. Although the assessment tool could be adapted to reflect local differences, the main focus of assessment should therefore be consistent across CHBC programmes.

## Benefits

CHBC may provide benefits to families through the CHBC programme itself or by developing relationships with programmes in other sectors, such as emergency food programmes. When benefits are to be made available through other sectors or agencies, relationships and referral mechanisms must be in place to ensure that families have easy access to those benefits.

Providing benefits for CHBC might not be possible in some resource-limited settings. In countries where benefits can be provided, the amount of benefits available will still be limited. Decisions therefore have to be made about what benefits will be available to the family. The following questions address the decisions to be made:

- Will CHBC include the provision of medication? If so, which medicines will be available through the CHBC programme and which will be restricted?
- Will the CHBC programme include the provision of medical supplies? If supplies are part of the service, what supplies will be included?
- Will CHBC include physical and emotional care, or will the care and support provided be restricted? That is, will CHBC incorporate both emotional and physical care and support?
- Will counselling be part of the services provided by CHBC?
- Will the provision of food or food supplements be included in CHBC?
- Will the provision of material items such as bedding and soap be included in CHBC?
- Will the cost of transport for the ill person and caregiver be included in the CHBC programme?



- Will help with housework and other instrumental activities of daily living be included in the provision of CHBC?
- Will families be given cash allowances so that they can access CHBC services as they see fit?
- If so, will the families be provided with a mix of benefits? That is, will families be provided with cash allowances to access specific services necessary for their particular situation as well as being provided with some general CHBC services?
- If cash benefits are provided, will some restrictions apply or will the family be given the responsibility of deciding how the cash allowance should be spent?
- If the use of the cash allowance is to be restricted, how will these restrictions be monitored?
- What will be the maximum and the minimum limit to benefits?
- Will the family caregiver be compensated? Will there be a salary attached to this service? Will there be any other form of honorarium?
- Will a waiver system be applied to people in absolute poverty? If a waiver system is applied, how will it be administered and monitored to ensure equal access to the system with a transparent process for assessment?
- Will respite care be part of the CHBC programme? That is, will day care or other forms of respite be available for caregivers?

Resource-limited settings are likely to have limited benefits for CHBC. These benefits will therefore have to be determined by setting priorities among the needs.

Countries that can provide some form of cash benefits have considerable debate about how benefits should be provided. Unrestricted cash benefits are thought to empower families to develop their own plan of care. They may choose services and service providers and directly contact and schedule personal assistance to suit their needs. Those who oppose cash benefits argue that, without supervision, costs will be high and the quality of care may be poor. That is, with cash benefits, it is not clear whether the cash will provide needed services or supplement general family income.

Providing services in kind helps families to receive services selected by the CHBC programme. However, families cannot access services outside the programme. A combination of cash allowances and service provision would allow for flexibility. Families could access services within CHBC, while also accessing necessary services outside the programme. For example, families might need cash allowances for food and school uniforms as well as needing CHBC services.

## Programme operation

Decisions must be made about CHBC administration. The following questions should therefore be considered.

- How can the government or international or national donor agencies share responsibility for the CHBC services, or will the government involve other agencies and organizations in providing CHBC? That is, how will NGOs, faith-based organizations and the private sector be involved in developing, implementing and managing CHBC?
- How will national AIDS councils and primary health care committees be involved in programme development?
- How will NGOs, faith-based organizations and the private sector be supported or contracted and/or subcontracted?
- How will guidelines and procedures be developed that outline the responsibilities of the government, NGOs, faith-based organizations and the private sector in providing CHBC?<sup>1</sup>
- How will the services of these organizations be monitored?
- Who will be responsible for delivering services? Will there be a CHBC team, or will people be drawn from the existing pool of community health workers?
- How will responsibilities be determined to avoid duplication or gaps in services to CHBC?
- Who will be responsible for planning care? Who will assist the ill person and family in planning care: health workers, a health team or a case manager?
- Where will the focal point for coordinating CHBC be?
- Will there be a case manager to supervise the provision of care?
- Will traditional healers be considered part of the CHBC team?
- How will care providers be educated, supervised and possibly licensed for specific CHBC services?
- Will family caregivers be provided with education? If so, how will this education be managed, and who will educate the caregivers?
- What will be the defined criteria for assessing the establishment and regulation of quality standards?

<sup>1</sup> All possible partners need to be made aware of the opportunity to develop contractual relations within the context of the national health policy. Such contracting requires a legal framework, coherent contractual policies and evaluation mechanisms that will monitor equitable access and the quality of care. To avoid fragmentation and to ensure the coherence of all health and home-based care within the health system, collaboration should be based on trust, responsiveness and openness and clearly indicate the objectives sought, the commitment of each party and how these commitments are to be respected (WHO. The role of contractual arrangements in improving health systems' performance ([www.who.int/gb/EB\\_WHA/PDF/EB109/aeb1095.pdf](http://www.who.int/gb/EB_WHA/PDF/EB109/aeb1095.pdf)). Geneva, World Health Organization, 2002 (document EB109/5; accessed 13 June 2002).

- How can consumer (or community) input be incorporated into quality assurance criteria and regulations?
- How will quality assurance be managed?
- How will CHBC be evaluated? Will informal and formal outcomes of CHBC be evaluated? When or at what intervals will this evaluation be undertaken?
- Who will conduct formal CHBC evaluation?
- What CHBC information systems (such as record-keeping) will be established?
- Who will monitor these systems?
- Who will monitor the costs of CHBC?
- Who will monitor material benefits (such as food and bedding) or cash allocation to families in CHBC (where feasible)?
- If day-care centres or other respite care provisions are part of CHBC, how will these services be monitored, supervised and evaluated?
- Based on the evaluation of services, how will the necessary changes to the CHBC programme be made?
- Who will be responsible for making the necessary changes to the CHBC programme?

The roles and responsibilities of government and other complementary organizations should be decided at the planning stage. These complementary organizations include NGOs, faith-based organizations, community-based organizations and others. General agreements should also be made on how they will partner and communicate with one another. Thus, the roles, responsibilities and types of communication should be determined and partnership agreements made at the onset of planning a CHBC programme. Establishing and maintaining relationships between organizations (especially public and private) as well as between sectors can be challenging and staff-intensive, requiring diplomacy and frequent communication.

Quality assurance and evaluation are generally agreed to be difficult activities. However, without these standards, programmes might continue unchecked and, over time, cease to meet the needs of the target population. Quality assurance standards and methods of evaluation should therefore be developed at the planning stage. Nevertheless, quality assurance standards might change as the programme evolves. Any changes should be made based on sound evidence.

Managing information systems, supervision and technical support are important components in CHBC. Collecting data and recording information are important for policy-making, planning and managing care. In addition, determining the type and level of supervision required for CHBC and the type of technical support required is important.

## Financing

One of the most important challenges facing any CHBC programme is how to fund and sustain the programme over the long term. In some countries, the government is responsible for funding most CHBC. In others countries, the primary sources of funding may be international or national donor agencies, NGOs and faith-based organizations. Funding partnerships might also be developed between the government and nongovernmental donor agencies. In light of these issues, the following questions should be addressed.

- Will CHBC funds be provided through general taxation from the national government?
- Will a form of prepaid financing for CHBC be established? For example, will a social insurance scheme or other forms of community-based insurance mechanisms be put in place?
- Will a special premium be applied to employers and employees to contribute to the CHBC programme?
- If the national government provides funds for CHBC, will there be a line item for CHBC or will these funds come from revenue provided for general health care?
- Will the costs of CHBC be shared between the national, district and the local governments? If so, what proportion of funds will be available from the national government and what proportion will have to be raised at the district and local levels?
- What percentage of CHBC funds will be invested in developing and maintaining services, and what percentage of funds will be allocated to running the CHBC programme?
- If NGOs, faith-based organizations and the private sector are involved in delivering CHBC, will government funds be allocated to these various organizations? Will donor agencies be encouraged to assist these organizations with funding? Will the programme be responsible for funding its own CHBC programme?
- If NGOs, faith-based organizations and the private sector have taken responsibility for obtaining their own funding, what mechanisms can be put in place to ensure that funding sources can be sustained over the long term?
- If the local community is expected to be responsible for a proportion of the funds, how is the community expected to raise these funds?
- Will community-based insurance schemes be introduced and, if so, how will they be managed and maintained?
- Will there be a user fee for CHBC? If so, will provision be made for people who are unable to pay?
- What cost-containment measures will be put in place?

There is abundant evidence throughout the world of programmes that were evaluated as being successful and necessary but were discontinued. This usually came about because funding either stopped or was inadequate to sustain the programme. Every eventuality cannot be considered in budgeting and allocating funds. However, checks and balances should be in place that address funding sustainability from planning through implementation and evaluation.

## Coverage

The percentage of the population to be covered within the CHBC programme must be decided. In countries where HIV/AIDS is endemic, these calculations might be difficult, since the numbers are hard to predict. However, calculating the predicted numbers is necessary to forecast the cost of the service. This does not mean that certain disease categories or groups of people might not be eligible for this service but that service eligibility should be determined at the onset of the programme. For example, in some parts of the world, CHBC is provided only to people with HIV/AIDS. In contrast, other countries have very few people with HIV/AIDS and chronic or terminal care is the norm. In many of the resource-limited countries of the world, however, HIV/AIDS care is the most pressing CHBC need. The section on programme eligibility criteria provided detailed questions about who should be included in the CHBC programme. This section raises questions related to the general coverage for CHBC.

- Will the provision of CHBC depend on population density? That is, will urban areas be served before rural areas? How will these decisions be made?
- To what percentage of the population will CHBC services be provided?
- Will CHBC be delivered to every community in the country? If not, how will decisions be made about which communities will be served?
- Will preference be given to certain disease categories or target populations (see eligibility criteria)?
- Will certain age categories be given priority for CHBC, or will the service be open to all age groups?
- Will the level of disability determine the coverage?

Decisions on CHBC coverage depend on the availability of funding and on the specific needs of the country's population. There is no agreed list of minimum or core services in CHBC. However, the decisions about coverage must be made carefully and be well known to key stakeholders.

## Cost

The cost of the CHBC programme depends on the composition of CHBC workers and the cost of salaries, supplies, transport and other miscellaneous items. In addition, the availability of funding will determine what costs are possible. The following questions should be addressed to determine the cost of a programme.

- What services will be provided in CHBC?
- How much do these services cost?

- What is the ratio of volunteer workers to paid workers?
- How are volunteer workers compensated for their work: for example, in-kind contributions, honoraria or other means?
- What is the ratio of semiskilled employees to professional employees?
- What are the salary scales of paid employees?
- How much does educating health and social welfare professionals cost?
- How much does educating community workers and volunteers cost?
- How much does educating family caregivers cost?
- What is the maximum number of hours of service to which a family is entitled?
- How do CHBC workers travel to people's homes? Are there transport costs involved? If so, what are these costs?
- Does CHBC reimburse ill people and caregivers for the cost of visiting health care facilities? If so, what is that cost?
- How much do home-care kits and supplies cost?
- How much do essential medicines for CHBC cost?
- Does demand warrant local production of supplies and equipment?
- What can be done to encourage local production?
- How can priorities be set among supplies?
- How much do food supplements cost?
- Is money provided for destitute people?
- Is the family given a cash allowance, or are services paid within CHBC?
- How can health facilities be encouraged to share material resources?
- How can community agencies be encouraged to share material resources?
- What other miscellaneous costs must be factored into the CHBC programme?

Resource-limited settings have a very limited amount of money to spend on CHBC. Decisions must therefore be made about what services are affordable and priorities set among services. In addition, governments should consider how they might cut costs, such as bulk buying, reducing import tariffs, sharing supplies with other health care agencies and manufacturing medicines and supplies within the country.

The questions posed within the policy framework set the stage for planning and sustaining CHBC. These policy decisions should reflect the essential elements of CHBC found in the third section of this document. The next section builds on this policy framework by providing an overview of the roles and responsibilities for CHBC at the national, district and local levels of administration. In this sense, each section is closely interrelated with the others. Although these sections are presented separately, the questions raised and information contained within each section should therefore reflect the issues raised in the other sections.



UNAIDS/B. Neeleman

A doctor from the Central Hospital of Maputo in Mozambique examines a young child for possible HIV infection during his home care visit to a village on the outskirts of Maputo, the capital.



# ROLES AND RESPONSIBILITIES FOR CHBC AT THE NATIONAL, DISTRICT AND LOCAL LEVELS

This section addresses issues related to administering the roles and responsibilities for CHBC at the national, district and local levels.<sup>1</sup> These roles and responsibilities might involve different levels of government and the activities of international, national or local nongovernmental agencies. Whatever the case, decisions must be made about which level of administration should be responsible for different aspects of CHBC. Although this might sound simple, the challenges in making these decisions can be complex. For example, all three levels of administration must undertake some roles and responsibilities (such as financing and sustainability). In addition, the levels of administration taking responsibility for different aspects of CHBC may vary in different jurisdictions. Despite this complexity, decisions should be made about these roles and responsibilities for CHBC and who should act upon them.

For ease of description, three levels of administration have been identified: the national (or central) level, the district or provincial level and the local or community level. An overview of each level is presented with questions to help to guide decision-makers in determining how to organize the responsibility for managing, administering and delivering CHBC. The responses should reflect the varying CHBC needs within each country, programme or community setting. As with the previous section, not all the issues and questions raised are relevant in all settings. In addition, different jurisdictions might divide these roles and responsibilities differently. The purpose of providing this framework is to draw attention to the need for determining the roles and responsibilities of different levels of CHBC administration within a particular country or setting.

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## National-level responsibilities

At the national level, policies are needed to guide the planning, legislation and regulation of CHBC. Central administration should be responsible for allocating resources, financing and supervising organization and management (including monitoring and evaluation). In addition, central administration should be responsible for developing human and material resources and allocating them based on clearly defined priorities. The first policy framework presented here raises many of these issues. The following questions are intended to help decision-makers in allocating the roles and responsibilities of central administration.

- What can be done to place CHBC visibly on the political agenda and ensure political will for implementation?
- How will CHBC be financed and how will the funds be allocated?

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<sup>1</sup> WHO. Community home-based care: action research in Kenya. Geneva, World Health Organization, 2001 (document WHO/NMH/CCL/01.01).

WHO. Long-term care laws in five developed countries: a review. Geneva, World Health Organization, 2000 (document WHO/NMH/CCL/00.2).

WHO. Home-based long-term care: report of a WHO study group. Geneva, World Health Organization, 2000 (WHO Technical Report Series, No. 898).

WHO. Lessons for long-term care policy. Geneva, World Health Organization, 2000 (document WHO/NMH/CCL/02.1).



- How can CHBC be integrated into the continuum of care framework and managed as part of the overall health care system?
- How can intersectoral cooperation be encouraged? How can the various national ministries such as health, welfare, finance, labour, agriculture and education cooperate in the overall planning and delivery of CHBC?
- Who will be responsible for developing CHBC policies and guidelines, including monitoring and evaluation?
- What national policies and guidelines should be developed to address orphan care?
- How will contractual relations be firmly placed within the country's national health policy?
- How will the legal framework for contracting and coherent contractual policies be developed?
- How will these contracts be evaluated to ensure that they are in accordance with the policies and contractual arrangements?
- What can be done to ensure the provision of basic needs to destitute families, including food programmes, adequate shelter, water, sanitation, cooking supplies, soap and education?
- What national strategies can be undertaken to combat the stigma of HIV/AIDS?
- Who will be responsible for determining the education and training requirements for CHBC?
- Who will develop CHBC education and training programmes?
- Who will be responsible for determining the staffing mix for CHBC?
- What can be done to ensure a consistent and adequate source of supplies and equipment to local health facilities and CHBC?
- What can be done to develop and maintain information systems, including record-keeping and referral?
- What strategies can be put in place to ensure that CHBC is sustainable, effective, accessible and affordable?
- How can the national government cooperate with the governing bodies of important organizations such as NGOs, donors, faith-based organizations and the private sector in developing and implementing CHBC?
- How can communication between the national, district and local levels of administration be established and effectively maintained?

The national administration might not need to undertake all these initiatives. However, senior administration is responsible for addressing each of these issues and making sound judgements about the allocation of responsibilities to the district or local levels. One of the most important factors for the national government is the need for various ministries to harmonize their policies in relation to CHBC. Most ministries have their own financing, organizational structure, culture and areas of responsibility. They are not used to working across ministries, sharing financial resources and supporting each other's work. Strong leadership is therefore required to establish a culture of cooperation and collaboration in the overall development of CHBC. Box 1 provides an overview of the national roles and responsibilities for CHBC.

## Box 1. National-level roles and responsibilities for CHBC

Securing political commitment for CHBC  
Financing and securing funds for CHBC  
Promoting intersectoral collaboration  
Integrating CHBC into a continuum of care framework  
Planning ongoing financing and sustainability  
Developing policies, guidelines and regulations for CHBC (including orphan care)  
Developing a legal framework for contracting and subcontracting  
Providing basic needs to destitute families  
Developing national strategies to reduce stigma  
Developing CHBC education programmes  
Developing strategies for organizing and managing CHBC  
Developing strategies and time frames for monitoring and evaluation  
Developing effective referral mechanisms  
Developing human resources  
Providing material resources  
Allocating resources and funds  
Sustaining partnerships with NGOs and private organizations  
Communicating between levels of administration

## District-level responsibilities

District or middle management is responsible for allocating resources based on clearly defined priorities set by the national administration. The district-level management team should also monitor standards of quality for CHBC. National standards should be adapted to meet district and local needs, and district guidelines for CHBC should be established. In addition, the rewards and incentives for community volunteer workers should be determined. Finally, district or middle management may become responsible for allocation of resources and for quality assurance mechanisms for orphan care. Although local authorities usually implement CHBC, middle management will have overall responsibility. In this sense, middle management is the interface between the policies and guidelines outlined by the national administration (see the first section on a policy framework) and the actual planning, implementation and evaluation of CHBC programmes at the local or community level (see the final section on establishing and maintaining CHBC). The following questions should be considered in determining the responsibilities of the district or middle management team.

- How can the capacity of the district level be strengthened to effectively administer and monitor CHBC, including an effective referral system?
- How can district-level leadership encourage innovation and creativity in developing and managing CHBC?

- How can orphan care be managed?
- How can the national funds for CHBC be managed in a transparent and equitable manner, and who will be responsible for allocating these funds to local authorities?
- How can accessibility to CHBC be ensured?
- How will a waiver system (or free service for those who cannot afford to pay) be equitably and transparently managed?
- What stigma-reducing strategies can be managed at the district level?
- What partnerships can be established between various government agencies, health programmes, NGOs, faith-based organizations and other community-based organizations?
- How will these partnerships be firmly placed within the contractual policies? And how will continuity and quality of care be monitored and assured?
- How many managers with which qualifications are required to administer CHBC at the district level?
- How can these managers be recruited and educated in CHBC?
- What strategies for educational management in CHBC have been established? Will curricula for educating different members of the CHBC team be developed or will educational materials from other areas be used and adapted?
- How can an adequate and consistent source of supplies and equipment be monitored and equitably distributed to local health units?
- Which mechanisms for monitoring and evaluating CHBC should be developed at the district level?
- Who should be responsible for monitoring and evaluation at the district level?
- How can communication between the district, national and community (local) level be established and effectively maintained?

The level of administration at the district level and the responsibility decentralized to the community or local level must be decided. These decisions must be made in the planning stage of CHBC and guidelines developed so that each level of administration realizes its responsibility for CHBC. Such guidelines should help to avoid the problems of duplication or gaps in service. Box 2 provides an overview of district or middle management roles and responsibilities for CHBC, and case study 1 provides an example of how Tanzania located the primary responsibility for CHBC at the district level.

## Box 2. District-level roles and responsibilities for CHBC

Promoting capacity-building  
Defining priorities  
Administering funds  
Ensuring accessibility  
Establishing a waiver system or free service for those who cannot afford to pay  
Monitoring standards, including a system of referral  
Planning and monitoring orphan care  
Reducing stigma  
Developing partnerships with complementary organizations within established contractual policies  
Allocating resources  
Recruiting and training CHBC managers  
Planning the administration of CHBC education  
Planning the administration of monitoring and evaluation  
Communicating between levels of government

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## Local-level responsibilities

CHBC is applied in practice at the community level. The culture of the community organization and its norms, standards and leadership play an important role in the CHBC programme. Strategies must therefore be developed that promote effective leadership and mobilize community action in planning and implementing CHBC. This community involvement includes the participation of caregivers, ill people, health and social service workers, community volunteers, community members and influential leaders. This means that all community members associated with CHBC should be involved in the initiation, responsiveness and sustainability of the programme. In addition, this programme should be integrated into existing community services and agencies. In most settings, this integration will be with local health facilities.

Since the four sections of this document are designed to interrelate with one another, the final section highlights a community development framework together with checklists for the establishment and maintenance of CHBC. This community development framework complements the issues raised in this section. In addition, the following questions for local-level responsibilities are organized to reflect the essential elements of CHBC identified in the third section of this document.

### Planning care

- Have strategies been developed to attend to the physical care of ill people?
- Have strategies been developed to attend to the emotional and spiritual needs of ill people, caregivers and members of the CHBC team?

- Have strategies been developed to promote effective palliative care?
- Have strategies been developed to support effective orphan care?

### **Continuum of care**

- How can cooperation and collaboration be encouraged between NGOs, faith-based organizations, other community-based organizations and members of the CHBC team?
- Have strategies been developed to ensure equal access to CHBC?
- How can the waiver system (or free services for poor and destitute people) be administered equitably and transparently?
- Have mechanisms been developed for record-keeping and referral?
- How can CHBC be integrated into the local health care system?
- Have other resources for referring ill people and family members been identified?
- Have mechanisms been developed so that members of the CHBC can communicate with other community resources?

### **Education**

- Have educational strategies and materials been developed or adapted for training ill people, family caregivers and members of the CHBC team?
- Who should administer and monitor these educational programmes?
- Have community education projects been established?

### **Supplies and equipment**

- Has a list of essential drugs for CHBC been developed?
- Has a list of equipment and supplies for CHBC been developed?
- Has a list for CHBC kits been developed?
- Has the ordering system been developed to ensure a continuous supply of the necessary equipment and supplies?
- Who will manage supplies, equipment and CHBC kits?
- Has a location been found for CHBC management and for storage?

### **Staffing**

- Who will manage and supervise CHBC? How will these supervisors be recruited, educated and supported?
- Has an effective staff mix been developed for CHBC?

## CASE STUDY 1

### Collaboration, partnerships and referral: a district-focused multisectoral approach to CHBC in Tanzania

The national government organizes CHBC in Tanzania. However, the government has developed a multisectoral approach to ensure that ill people and families have access to a continuum of care. To that end, the government has formed a ministerial department in which all ministries associated with care, prevention and support for people with HIV/AIDS and other chronic illnesses and their families are represented. Moreover, NGOs, faith-based organizations and other community groups are also represented at this ministerial level. However, collaboration, partnerships and referrals have become a district-level responsibility to ensure holistic care for ill people and their families. This is done by developing district management teams, assessing and listing community resources, providing education for effective coordination and referral and hiring a CHBC coordinator to oversee comprehensive care for ill people and their families and support while respecting the confidentiality of ill people and their families.

*Developing district management teams.* A CHBC management team has been formed in each district throughout Tanzania. This team is headed by the district medical officer and involves partnerships with local health centres, NGOs, faith-based organizations, traditional healers and other community organizations and groups. This team is responsible for developing a district resource list that includes a description and the location of community resources and the services they provide. In addition, the district management team is responsible for developing an action plan to ensure holistic management and home care for people with HIV/AIDS and other chronic illnesses.

*Avoiding duplications and gaps in service.* As the district management team develops a resource list, they can assess whether there are any gaps in comprehensive care across a continuum and identify duplication. For example, if an ill person and family require psychosocial support and counselling, a member of

the district management team can refer this family to the appropriate resource. However, ill people requiring medical attention are referred to a medical centre or hospital. Should gaps in service be identified, the district management team is responsible for developing services to meet that need.

*Developing coordination.* Providing comprehensive care across a continuum of services requires effective coordination. The Tanzanian government realized that such coordination would require further training of health and social service personnel. Training sessions were therefore provided to train trainers at the district level health centres. These trainers, in turn, train community health workers, volunteers, ill people and family members. This establishes the knowledge and skills of how to coordinate comprehensive care across a continuum. To ensure effective coordination, each district hospital has a CHBC coordinator. The role of the coordinator is to facilitate and support this coordination and referral process.

*Respecting confidentiality.* Referral forms for ill people have been developed and are now being used by the resources and services within the district management coordination system. However, although this system of referral and coordination is comprehensive, confidentiality is still respected and maintained. This is accomplished by ensuring a confidential record-keeping system and by promoting the confidentiality of ill people and their families throughout the system of care.

This comprehensive continuum of care was established recently in Tanzania to meet the growing needs of people with HIV/AIDS and other chronic illnesses living at home and their families. Such an approach has helped to provide a system of referral and coordination in which CHBC is an integral component within a continuum of care framework.

- Who will recruit and train paid and voluntary health and social service workers?
- Have strategies been developed to promote staff retention?

### **Financing and sustainability**

- How can effective community leadership be encouraged and promoted?
- How can innovation and creativity be encouraged through community mobilization, including creative sources of local CHBC funding?
- How can people associated with CHBC become active participants in developing and managing local CHBC programmes?
- How can available resources and accumulated experience be identified and used as a starting-point for further development?
- Who will manage CHBC funds? Who will be responsible for preparing and monitoring the budget?
- How will these funds be equitably and transparently allocated?

### **Monitoring and evaluation**

- What strategies have been developed for quality assurance?
- Have the criteria for informal evaluation been developed?
- Who is responsible for informal evaluation?
- Who is responsible for formal evaluation? Have plans for formal evaluation been made?
- How will the necessary change be monitored?

### **Communication across different levels**

- How can communication between the local, district and national levels of administration be established and effectively maintained?

The impact of CHBC will be experienced at the local level, especially in the homes of ill people and caregivers. However, the national (central) and district (middle management) levels will probably decide regulations, policy guidelines, administration and overall management. Using the four interrelating sections of this document as a whole is therefore essential. In addition, effective communication between all levels of administration and within different government agencies is important in establishing and maintaining effective and responsive CHBC. Box 3 provides an overview of the important features of local- or community-level roles and responsibilities for CHBC.



**Box 3. Local-level roles and responsibilities for CHBC**

Providing physical, emotional and spiritual care and support

Establishing a continuum of care

Developing mechanisms for educating the ill people, caregivers and CHBC teams

Ensuring adequate supplies and equipment for the CHBC programme

Recruiting and retaining an adequate and appropriate mix of staff

Developing effective methods for monitoring and evaluating CHBC

Addressing the financing and sustainability of CHBC

Creating intersectoral communication between various levels of administration

In conclusion, this second section provides a framework to determine the administration and management issues for CHBC programmes. As such, this section should be viewed in relation to the first section on policy formation and the next two sections on the essential elements of CHBC and community action to establish and maintain CHBC programmes. The purpose of presenting this framework is to provide decision-makers with tools to determine the division of the roles and responsibilities for CHBC between national, district and local administration.



WHO/L.Gubbb

These two young Tanzanian orphans are being cared for by their grandparents. In some communities, whole families are dying and elderly people are increasingly left without support and with the responsibility for bringing up their grandchildren.





UNAIDS/Berno Neeleman

Doctors and nurses from the Central Hospital of Maputo in Mozambique make weekly home care visits to AIDS patients who are too weak to go to hospital, like this 25-year-old woman.

# ESSENTIAL ELEMENTS OF CHBC

## Introduction

The essential elements of CHBC have been developed using case examples, research, observations from practice and CHBC evaluations in different regions of the world. These essential elements are divided into seven main categories: provision of care; continuum of care; education; supplies and equipment, staffing, financing and sustainability; and monitoring and evaluation. Each of these broad categories contains many subcategories that provide details of the elements that are important in ensuring sustainable and effective CHBC. To provide clarity, each category and subcategory stands alone. However, in reality, all these elements are integrated in holistic CHBC. For example, the first category, provision of care, has the subcategories of basic physical care, palliative care, psychosocial support and counselling and care of affected and infected children. However, the health care team needs to be educated to provide these elements of care, and education is a different category.

The essential elements of CHBC outlined here are the ideal. Implementing all these elements at once might not be possible in resource-limited settings. However, this section provides guidance on the factors that are important in establishing and maintaining CHBC in resource-limited settings. Some communities might have to start by setting priorities among these elements and then work toward achieving the full complement of services over the long-term. In other communities, “piggybacking” some of these elements with other community resources might be possible. CHBC might already be well established in some settings. In this case, this document will be useful as communities begin to coordinate and scale up their CHBC efforts.

This section includes several case studies to highlight how different CHBC programmes have developed and implemented a variety of strategies for effective and sustainable CHBC in resource-limited settings.

As with other sections of this document, this section should be viewed in relation to the other three sections. Policy-makers (see the first section) should understand these elements as they develop overall policies for CHBC. In addition, the roles and responsibilities of national, district and local administration (see the second section) should reflect these essential elements. The final section provides a framework for action, placing the essential elements of CHBC within a framework for establishing and maintaining CHBC in resource-limited settings. Thus, the information in this section should be applied to issues related to policy formation, administration and management and to establishing CHBC at the community level.

Needs change and issues evolve in all effective programmes. For example, the need for CHBC was first established as increasing numbers of people became sick and died from HIV/AIDS. Unfortunately, this problem is now escalating, and other relevant issues are gaining importance. Orphan care is now an increasing challenge, with some communities reporting 5–10 children becoming orphaned each month. In addition, antiretroviral treatments are now more common, especially for preventing mother-to-child transmission. These new challenges require additional resources and education for the CHBC team. Therefore, although this section

addresses the essential elements of CHBC in resource-limited settings, these priority needs will change as the epidemic evolves. The final section on the action required to establish and maintain CHBC addresses this evolutionary process.

Table 2 provides an overview of the essential elements of CHBC together with the relevant categories and subcategories.

**Table 2. Essential elements of CHBC**

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

## Provision of care

### Basic physical care

Physical care at home involves providing basic nursing care and comfort measures. Such care includes recognizing symptoms, diagnosis, treatment, symptom management, referral and follow-up. In addition, issues related to prevention and protecting the ill person and caregiver through the use of universal precautions are included. Identifying situations in which the basic needs of shelter, food, bedding and clothing and adequate caregiving are not being provided may require identifying other resources to enable physical care to be provided at home.

### Basic nursing care

Basic nursing care<sup>1</sup> includes positioning and mobility, bathing, wound cleansing, skin care, oral hygiene, adequate ventilation and guidance and support for adequate nutrition.

### Symptom management

Symptom management depends on the ill person's condition. However, basic symptom management includes:

- reducing fever;
- relieving pain;
- treating diarrhoea, vomiting and cough; skin, mouth, throat and genital problems; and general tiredness and weakness; and
- treating neurophysiological symptoms.

These treatments might include pharmaceutical preparations or the use of traditional remedies and herbal treatments. The CHBC team should have basic home care kits that contain the basic medicines and supplies for home care (see the subsection on supplies and equipment). For people with HIV/AIDS, various treatments may be given for opportunistic infections, the most common being tuberculosis. Tuberculosis medication is usually administered through a directly observed therapy, short course (DOTS) programme. However, these medicines might be given as part of the CHBC programme or through a separate community service.

Treatment for preventing opportunistic infections as well as antiretroviral therapy may be available in some countries. For example, some settings are now providing antiretroviral treatment and alternative breastfeeding options to HIV-infected mothers to prevent transmission from mother to child. In addition, tuberculosis medicine is sometimes given as a prevention strategy. These treatments might be provided at a local health facility or, in some circumstances, members of the CHBC team may administer these medicines at home. Finally, the CHBC team often distributes condoms.

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<sup>1</sup> This overview of basic nursing care does not refer to the role of the nurse but to the dictionary definition “to nurse”, which is “to tend or minister to in sickness” (Random House Webster’s College Dictionary, 1991).

## Universal precautions

The use of universal precautions should follow national guidelines. Universal precautions include hand-washing, cleaning linen with soap and water, using disinfectants and detergents and burning or safely disposing of rubbish. These precautions should be taken regardless of the ill person's condition. Avoiding contact with blood or body fluids is especially important, and protective devices such as gloves and diapers should be used. In resource-limited settings, affording protective devices can be difficult, and creativity (such as using plastic bags) is needed.

In most countries, national guidelines and local manuals have been developed on providing basic comfort measures, managing symptoms, prevention strategies and the use of universal precautions. These manuals should be consulted, as the information provided here is far too brief for effective safety and care of ill people. Further information can be found in the bibliography under provision of care.

## Palliative care

Palliative care is the combination of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life-threatening illness. Such care strives to meet the physical, psychological, social and spiritual needs of ill people and caregivers. It requires a team approach including the ill person, family, health and social welfare workers and community volunteers.

Palliative care emphasizes living, personal choice, helping people to make the most of each day and maintaining a sense of hope. Terminal care aims to improve the quality of daily life at the end of life by relieving symptoms (especially pain) and enabling people to die in peace, with dignity and in keeping with their wishes.

The previous category provided a brief overview of physical care. Such comfort, treatment and prevention measures, as well as the use of universal precautions, are also necessary in palliative care. In addition, caring for the psychosocial and spiritual needs of ill people, families and members of the CHBC team is covered in the next category.

## Pain relief

Pain relief is an essential element of palliative care. In resource-limited settings, medicine can be scarce. Aspirin and paracetamol are often available but not given in adequate doses to relieve pain. This often results from inadequate education on effective pain relief (see the education category). Trained health workers can administer Class A controlled drugs. Such Class A drugs include morphine injection, tablets, oral mixture and other narcotics. These drugs must be provided in accordance with the national laws on dangerous drugs and with the national drug policy. People involved in CHBC should provide these treatments in accordance with the regulations and lists of essential drugs for their respective settings. Members of the CHBC team should be familiar with these policies and guidelines. A physician should prescribe these analgesics, and at least one member of the CHBC should be qualified to

## CASE STUDY 2

### A hospice and herbs at home: Moretele Sunrise Hospice, Temba, South Africa

“We must create our own history. Make our own very good footprint.”

Temba is a rural community outside Pretoria, South African with a population of 4400. This community has 27 health clinics spread over 78 villages within 120 km<sup>2</sup>. The Moretele Sunrise Hospice home-based care programme began in 1998 through the hard work and determination of one nurse. This nurse had previously worked in a local hospital, where she witnessed terminally ill people being discharged home. She visited one of these people at home and saw the desperate need for palliative care and support. From this experience she decided to make the home-based care programme her life work. She left her paid employment and visited people at home and supported and trained family caregivers for 3 months. Gradually the community and donors began to see the importance of her work and external funding began.

*Community sensitization and mobilization.* This nurse realized that the community must become involved to provide effective palliative care within the home. The project therefore started with a needs assessment questionnaire distributed to 72 of the 78 villages within the greater Temba community. Through this process, the community became aware of families' needs for palliative care at home and became mobilized to volunteer to work with the programme.

*Care across the continuum.* Holistic care is provided for people with HIV/AIDS and other chronic and terminal illnesses. Care starts with pre-test counselling and continues through post-test counselling and support. Fifteen support groups meet weekly at which prevention education, counselling and support for disclosure are provided. When people become ill they are referred for treatment, but counselling and support continues during this period. During the terminal stages, the ill person and family are supported through the hospice home-based care programme. Food parcels are provided where necessary.

*Developing an interdisciplinary team.* Moretele Sunrise Hospice has an interdisciplinary team including a palliative care

nurse, social worker, physician, pastor and psychologist. There are also 4 home-based care programme supervisors, 4 trainers and 40 trained volunteer health workers. The nurse, social worker, supervisors and trainers are paid employees, and the other team members volunteer their time and services.

*Support for children.* There are 79 orphans in the community and 4 child-headed households. Fourteen of the children are HIV-infected. A support group for affected and infected children meets every Saturday. Activities include recreation, education on prevention and abuse, life skills, nutrition, individual and group bereavement counselling and income-generating activities.

*Community education.* The home-based care programme educates ill people and family members about basic nursing care, universal precautions, nutrition and how to grow a vegetable and herb garden. Education is also provided for income-generating activities: making and selling crafts and soft furnishings.

*Homegrown medicinal herbs and natural medicines.* One of the most important aspects of the home-based care programme is growing and using natural herbs and medicines. A local pastor has been trained in the use of traditional remedies by the Doctors for Life programme in Durban. This pastor provides community education on how to prepare natural medicines and how to treat and prevent illnesses through natural methods. These natural remedies are prepared as teas, oils, ointments, poultices, inhalants, soaps etc. For example, garlic, neem and paw paw are used to boost the immune system and treat common symptoms such as sore throat, gum disease, dysentery, cough, skin lesions, allergies and sinus infections.

The Moretele Sunrise Hospice programme is based on identified needs and on the principles of community mobilization and empowerment. The overall philosophy of the programme is to instil hope and to provide motivation and support. As the nurse explained: “By motivation and instilling hope, we help them rise up. We use our mouths to talk health.”

administer Class A drugs (usually a qualified nurse).<sup>2</sup> Herbal remedies and traditional therapies can also be effective in relieving pain. Case study 2 provides an example of how one community group combined terminal care and the use of herbal remedies.

### **Spiritual and emotional support and promoting death with dignity**

Caring for a person in the terminal stages of an illness greatly strains everyone involved. Families, children, friends, communities, health and social service workers, community volunteers and other people are all affected. Emotional and spiritual support and guidance (where appropriate) should therefore be available for the ill person and family and caregivers.

People with HIV/AIDS sometimes suffer from confusion and dementia and often die at a young age. Several family members may also be infected. In addition, many health and social service workers and community volunteers are either infected themselves or have family members who are. Such experiences put an added strain on care providers. People dying from other chronic illnesses might be elderly and may have been ill and/or disabled for a long time. However, family members will likely experience the same emotional strain and bereavement. Encouraging community support and enlisting the help and support of friends, neighbours and other people can be an important long-term care strategy.

### **Anticipatory guidance**

In many communities and cultures, people fear open discussion of illness and death. As a result, adequate preparations for death are not made. Ill people and family members often need help in discussing death and making plans for the future. Such plans might include where to place orphans, memory projects for surviving children, funeral plans and making a will.

### **Inheritance rights**

Dying without a will often denies children and other family members (especially women) their right to inheritance. In some countries, cultural practices often deny women and children their right to succession. It is therefore important to help the dying person and family members to adequately prepare for death, including orphan placement and inheritance rights.

### **Bereavement counselling**

Providing support and counselling is very important for the family and members of the CHBC team as they provide care to a person who is dying and to the family following death. Bereavement counselling should be continued for as long as necessary. In addition, the bereavement issues of children must be attended to, especially those who are orphaned. The basic elements of effective interpersonal communication can be used to address issues related to death and dying for both individual and group bereavement counselling.

<sup>2</sup> Pain & Policy Studies Group. WHO annual report: improving cancer pain relief in the world, 2000 ([www.medsch.wisc.edu/painpolicy/publicat/annrepts.htm](http://www.medsch.wisc.edu/painpolicy/publicat/annrepts.htm)). Madison, WI, Pain & Policy Studies Group (accessed 9 June 2002).

Rajagopal MR, Joranson DE, Gilson AM. Medical use, misuse, and diversion of opioids in India ([www.medsch.wisc.edu/painpolicy/publicat/01lancet/contents.htm](http://www.medsch.wisc.edu/painpolicy/publicat/01lancet/contents.htm)). The lancet, 358:139–143 (accessed 9 June 2002).



## CASE STUDY 3

### Linking home, hospice and orphan care: Tumelong Hospice and Lekegema Orphan Haven, Mabopane, South Africa

“This came out of a direct need. We kept hearing very poor stories about people dying at home, patients left alone and partners leaving...”

Tumelong Hospice and Lekegema Orphan Haven were established in 1997 in a rural South African township. These centres are part of a larger Anglican mission providing care and relief, nutrition centres, a primary school, a primary health clinic, rape relief, rehabilitation for disabled adults and children, life centres for youth groups, income-generating activities and home-based care. This Anglican mission works in collaboration with government ministries and with other donor agencies and religious missions.

*The Hospice.* Tumelong Hospice is rare in that it is run by lay community health workers. The overall philosophy is to provide terminal care for people to die in peace and with dignity. Hospice care includes basic palliative care and treatment for opportunistic infections. Bereavement counselling is also available for family members for up to 1 year following death. The hospice cares for people with HIV/AIDS, cancer and advanced tuberculosis, although almost all have HIV/AIDS. It began with 7 beds that quickly expanded to 11, and now there are 21. Further expansion is necessary, especially a children’s wing. Most of the ill people are 15–25 years old.

*Team approach.* The Hospice team consists of 22 staff members with 19 lay community health workers, a social worker, physician and nursing sister. The daily operation of Tumelong Hospice is carried out by the lay community health workers in consultation with the health and social welfare professionals. A team meeting is held every Thursday to discuss difficult cases, provide mutual support and have in-service training sessions. Every 3 months the staff has a team-building break. This is a time for members to have fun and to support and care for one another. Families are also considered to be part of the team, and family visits are encouraged. If the family has a problem with transport, the staff arrange for them to be collected from the community.

*Linking memories to building a future.* Staff members help ill people and family members with memory projects (“this is who I am and what I am like”) for their orphaned chil-

dren. In addition, the social worker helps the family in obtaining a death certificate and helps with the burial preparations if nothing has been arranged. This social worker also helps the family in understanding the bureaucratic process for inheritance rights and orphan grants.

*Comprehensive care.* Ill people are referred to Tumelong Hospice from NGOs, health facilities, neighbours, churches and the home-based care team. This referral is done when the family can no longer cope (even with the support of the home-based care team), or if the person is very ill and lives alone. Each community health worker is responsible for 4–5 ill people, and they are required to know the ill people and their family members well. These community health workers build supportive, caring relationships in which HIV/AIDS disclosure is encouraged.

*Lekegema Orphan Haven.* The Haven is linked to Tumelong Hospice, and the home-based care programme and provides day care to 64 preschool children each day and 86 children on Saturdays and school holidays. These numbers are growing rapidly, with 5–10 new referrals each month. Referrals come from the home-based care team, Hospice or other community referrals. The children are collected daily and brought to the Haven where they get medical and dental care, food and clothing. These children also receive early childhood education, participate in recreational activities and, where necessary, receive bereavement counselling. The focus is to provide support and respite for the extended family, who continue to be the primary caregivers for these orphaned and vulnerable children. Many of these family caregivers also volunteer in the Haven. There are two new satellite orphan projects, one in Maboloka with 47 children and one in Stinkwater with 52 children. These projects operate 2 days a week as more caregivers need to be trained before full operations can be provided.

Linking home-based care, hospice and orphan care has helped the Mabopane community to contribute to the care and support for people infected and affected by HIV/AIDS and other terminal illnesses. As one community health worker explained, Tumelong Hospice and Lekegema Orphan Haven “are creative ways to care for our community”.



## Hospice

In some communities, the ill person and family might have a choice about where the person would like to die. This choice might include a hospice, terminal care facility or tertiary care hospital. These centres usually have staff trained in palliative care who can care for the dying person and their loved ones. Hospice centres can be residential or day care and are usually run by NGOs and faith-based organizations. In addition, some communities have a hospice home-based care team. The focus is on palliative and terminal care and on long-term psychosocial support and counselling for the ill person and family members. Orphan care is often started as an outreach of the hospice programme. Case study 3 provides an example of how one community linked home, hospice and orphan care in Mabopone, South Africa.



UNAIDS/Shehzad Noorani

A volunteer comforts a woman dying of AIDS at a remote temple in central Thailand, where a Buddhist monk has established a hospice for AIDS patients so that they can die with dignity. During his stay at the monastery, this young man has devoted his time to visiting patients. He also gives them herbal massages.

## Psychosocial support and counselling

The mental health of ill people, family members and members of the CHBC team is vitally important. Psychosocial support and counselling is known to improve the quality of life. Emotional support and sometimes individual or group counselling are therefore important for everyone involved in care within the home. However, providing emotional support is very difficult for caregivers (both family and the CHBC team) if they do not feel supported themselves. This often leads to caregiver burnout.

For people with HIV/AIDS and family members, the stigma, fear and discrimination often associated with the illness (or mere suspicion) can create a barrier to effective care. However, there are many examples throughout the world of effective psychosocial support breaking the silence surrounding HIV/AIDS. This can lead to acceptance and caring by family members and the larger community. Case study 4 provides an example of how psychosocial support and counselling became an important strategy in HIV/AIDS prevention and care in Papua New Guinea.

## Interpersonal communication and counselling

The important elements of effective interpersonal communication include respect and dignity, a nonjudgemental attitude and empathy. This includes cultural sensitivity and respect for traditional practices. Empathy involves listening to the other person's concerns. The simple act of listening can make an enormous difference to the quality of life of the ill person, family and CHBC team. Such care can be provided in individual communication or through group support.

## Spiritual support and guidance

In many parts of the world, spiritual support and guidance is a vital component of care. For some, this will include following a traditional faith; for others, it might be finding their own spiritual path. Spiritual leaders can play a vital role in this aspect of care. In addition, many community health workers and volunteers provide spiritual support and guidance to ill people and family caregivers.

## CASE STUDY 4

### Psychosocial support and counselling: Papua New Guinea

“We send them home to live, not die. We try to help them with their living.”

In the rugged highlands of Papua New Guinea, a network of volunteers is providing community home-based counselling and support for people with HIV/AIDS. At any given time between 50 and 60 volunteers are visiting people with HIV/AIDS in their home villages and providing counselling as well as practical care and support. Volunteers come from many walks of life. They include teachers, pastors, nurses and church workers. They are trained as counsellors in a two-week course and then attend periodic follow-up meetings and workshops. The network was started 10 years ago and is coordinated by a religious sister and a physician. They have operated throughout these years without outside donor funding. However, some of the volunteers are religious sisters who are supported by their communities to work full time.

*Accessing care.* When the person with HIV/AIDS needs health care, the volunteer helps to arrange this. Volunteers also work in the clinics where HIV tests are done, especially in conjunction with sexually transmitted infection clinics. When a person is found to be HIV positive, the volunteer visits them in their homes and provides counselling and support to the affected person as well as to the family. These volunteers also advise the people with HIV/AIDS and family members how to stay healthy.

*Providing psychosocial support.* Volunteers say that when people first learn that they are HIV positive, they often feel numb and in shock. They describe themselves as

“feeling blank” and all they can think of is dying. Volunteers help the families in understanding what the people with HIV/AIDS are going through. They explain their need for support and care. Volunteers also provide reassurance to family members that they will not become infected by caring for their HIV-infected relative. Where appropriate, the volunteers also help to establish informal support groups, so that people with AIDS can help one another.

*Promoting shared confidentiality.* Volunteers discuss the importance of informing other sexual partners that they may have been exposed to the virus. Some people with HIV/AIDS ask for help in informing their contacts. In addition, in some cases the volunteer may be asked to help the person in telling family members about their HIV status. With permission, the volunteers help in tracing contacts and in encouraging them to be tested.

*Positive living.* Follow-up activities support positive living within the family and community. Vegetable gardening, personal hygiene and care and safer sexual practices are explained and encouraged. As a volunteer explained: “We try to help them with their living.”

Providing support for people with HIV/AIDS is not easy in the highlands. The terrain is rugged and many of the villages are in hard-to-reach areas. But this committed group of volunteers is doing it and has been doing it for 10 years. Their lives are a testimony to what can happen when dedicated people come together to make a difference for the people in their communities.

### **Mobilizing community support**

Community members are helping and supporting each other. In many countries, community volunteers provide emotional and spiritual support within the home. In addition, peer groups have been formed to promote mutual support. Many examples throughout the world show how community support can increase people's quality of life and ability to cope. This kind of community support can be actively stimulated, encouraged and supported.

### **Care for the caregiver**

Family caregivers and members of the CHBC team frequently experience burnout. Burnout is a result of excessive emotional and physical strain without the necessary care to support the caregiver. This leads to excessive fatigue, poor motivation, anxiety and depression. Building in support sessions, ensuring recreational breaks and rotating staff help to reduce burnout. In addition, friends, spiritual leaders, neighbours and community volunteers can provide support to help ill people and family caregivers.

### **Confidentiality and autonomy**

One of the many challenges facing the CHBC team is to respect confidentiality while providing effective team care. Confidentiality is especially challenging in caring for people with HIV/AIDS. Some ill people do not want family members or members of the CHBC team to know their diagnosis. Some ill people present symptoms of opportunistic infections but refuse to be tested for HIV. These problems make it difficult to provide access to treatment, prevention, care and effective case management. CHBC team members should encourage and support shared confidentiality. However, the rights of the ill person must be respected. This often leads to ethical dilemmas for the CHBC team.

### **Voluntary counselling and testing**

Many communities now have access to voluntary counselling and testing through clinics or at the local hospital. Ill people can be encouraged to be tested through effective interpersonal communication and support. Knowledge of HIV diagnosis can lead to effective prevention, treatment and care.

The bibliography lists sources of information on effective psychosocial support and counselling, voluntary counselling and testing and care for the caregivers under the heading of psychosocial support. In addition, many manuals and reference materials have been developed for programmes in different settings.

## **Care of affected and infected children**

HIV/AIDS and other terminal illnesses greatly affect children's lives. Economic hardship often leads to malnutrition, prostitution, becoming street children or entering into early marriage. Children often have to leave school to care for the sick family member or orphaned siblings. In addition, emotional suffering can lead to depression, aggression, drug abuse, insomnia and failure to thrive.

Children affected by HIV/AIDS suffer from poverty, stigma, discrimination and multiple losses, including the deaths of family members and friends. Such suffering results in profound grief. Psychosocial support is therefore an essential component of care (Masiye Camp, 2001).<sup>3</sup> Psychosocial support is an ongoing

## CASE STUDY 5

### Home-based care responds to growing orphan needs: Hope Worldwide Siyawela community child care, Soweto, South Africa

“Siyawela, we are crossing over”

The Siyawela programme for community child care began in November 1999 as a response to the growing need of orphans and vulnerable children affected by HIV/AIDS. The main beneficiaries are children affected and infected by HIV/AIDS and their immediate caregivers and family. At this time, Siyawela has been implemented in three townships in Greater Soweto. A fourth township will soon be included. Eventually, it is hoped that Siyawela will be established in other South African cities where Hope Worldwide has projects.

*Support for children.* Research evidence suggests that children of parents who die from AIDS ultimately become very susceptible to infection themselves. The overall purpose of Siyawela was therefore to break this tragic cycle. To that end, the programme provides support groups for children that include counselling and psychosocial support, recreational activities, nutrition support and food parcels, home-based care, referral for treatment, life skills training and basic education. To ensure comprehensive care, Siyawela tracks children from institutional care (such as perinatal care) to the home and community and vice versa.

*Participatory action research.* The organizers of Siyawela realized that a broad community-based initiative would be necessary to ensure that orphans and vulnerable children have access to care and support. To achieve this broad support, members of Hope Worldwide, Soweto engaged in a participatory action research project. This research included community resource mapping, developing and strengthening a collaborative community network, training child care and home-based care coordinators and develop-

ing a referral and tracking network between all stakeholders and service providers. Through this participatory research, the community identified the following concerns: disclosure to their immediate family and friends, future planning for their children, access and referral to health care, basic needs such as food, clothing and medicine, care for caregivers, HIV testing for their immediate family and support and care for their surviving children.

*Community mobilization.* In keeping with a participatory research approach, Siyawela’s operational strategy is to act as a catalyst for community mobilization. To that end, NGOs from social welfare, health and HIV/AIDS programmes are beginning to respond to the growing community concerns identified in the research. In addition, Siyawela focuses on community mobilization and capacity-building to address psychosocial support for orphans and vulnerable children as well as home-based care and succession planning for parents with HIV/AIDS. There are also plans to continue to create links and alliances in areas not being addressed yet. Such links include partnerships with: microfinance institutions, microenterprise development organizations, victim support groups, voluntary counselling and testing, mother-to-child transmission specialists and preschools.

The challenges of caring and supporting people with HIV/AIDS and family members continue to evolve. Hope Worldwide in Soweto began by providing care and support to ill people and family members at home and in the community. Now the challenges of providing care and support for orphans and vulnerable children have emerged. In this sense, Hope Worldwide in Soweto has crossed over to providing much-needed care and support for orphans and vulnerable children affected and infected by HIV/AIDS.

process of meeting physical, emotional, social and spiritual needs. Such support is considered essential for meaningful and positive human development.

### **Role of CHBC**

Children affected by HIV/AIDS and other terminal illnesses may first be encountered through CHBC or hospice care. As family members are cared for and die, the bereaved children will become a significant part of care. CHBC services can become involved in the care of affected and infected children in two important ways: by promoting an enabling environment for psychosocial support for vulnerable children and by helping to create an expanded response by families, communities, governments, faith-based organizations and other organizations for promoting psychosocial support for children. To that end, CHBC services can become part of a larger response to orphan care. In particular, this larger response can help affected children by:

- promoting programmes that support orphans and vulnerable children psychologically, economically and socially;
- acknowledging children's changing roles: children quickly have to act like adults;
- ensuring children's rights;
- creating an enabling environment by building on children's own resources and peer support;
- involving youth in solutions;
- talking about death and dying;
- providing access to education, health and social services;
- setting clear firm targets to improve the lives and prospects of orphaned and vulnerable children; and
- making a long-term commitment to community and human development.

Case study 5 provides an example of how a CHBC programme in Soweto, South Africa expanded its mandate to include the care of affected and infected children. The Siyawela programme is part of Hope Worldwide.

### **Planning for the future**

CHBC team members should be actively involved in planning for the future of bereaved children. Such planning should begin before the parents die. It is important to help the family to openly discuss death and provide anticipatory guidance (see the subsection on palliative care). This guidance should include making plans for the children's future and making wills (see the subsection on palliative care). Older children might also be involved in this planning process. Access to bereavement counselling (see psychosocial support and counselling) is also very important for the affected children.

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3 *Masiye Camp*. First Eastern and Southern Africa regional "think tank" on psychosocial support for children affected by AIDS. *Masiye Camp, Zimbabwe, 20–23 August 2001*.

## Challenges to communities

Communities are facing mounting challenges in caring for orphans. As the HIV/AIDS epidemic continues its devastation, more children are being orphaned and many extended families are being stretched to the breaking-point. Although caring for orphans involves the whole community, the CHBC team is often the first contact in identifying orphans and providing care. The CHBC team (including the extended family) is therefore often responsible for beginning the process of planning continuing orphan care. Members of the CHBC services should work in partnership with various community groups to find the best solution for orphan care.

## Orphan care options



UNAIDS/Louise Gubb

A caregiver at the Cotiands baby sanctuary and hospice for HIV-positive orphans in Johannesburg, South Africa, kisses an abandoned nine-month-old orphan who is HIV positive.

The following is a list of orphan care options in order of preference.

- Extended family. Tracing relatives and encouraging them to take on the care of the orphaned children is important.
- Substitute or foster care families. After careful caregiver selection, orphans can be placed with non-relative family units within the community. Foster care should recognize the cultural and traditional norms and values of the deceased parents.
- *Family-type grouping*. Paid foster mothers live with small groups of orphans within the same community.
- Child-headed households. Adolescents care for young siblings with the support of the community.
- Orphanages. In most circumstances, orphanages should be considered as a last resort, although there are exceptions to this rule. Other viable options should therefore be explored first. If these options are not available, then orphanages have been found to provide a very necessary home for orphaned children.

## Grants and bursary funds

Communities should promote the establishment of orphan grants or other community orphan funds. These funds are necessary to help orphans to survive without wage earners in the family and to continue their schooling or job training. The CHBC team social worker might be required to help to secure these funds for orphan survival and to support future opportunities.

## Community support programmes

Community after-school programmes that provide time for homework, and sometimes a meal, will help children to remain in school. These after-school programmes might also include care at weekends and during school holidays. Preschool day care programmes provide an opportunity for the head of child-headed households to attend school or job training. Where such community services exist, CHBC team members should be responsible for referring children to these programmes.

Most communities have their own manuals and materials on orphan care. The bibliography provides further information under the heading of orphan care. Case study 6 describes the range of experiences of one orphan in Namibia.



## Continuum of care

A continuum of care involves a network of resources and services that provide holistic and comprehensive support for the ill person and family caregivers. The goal is an affordable range of services in various settings, from home to community agencies and clinics, to hospitals and vice versa. Comprehensive care involves the provision of care, treatment, support and preventive services. Holistic care involves referral, follow-up, monitoring and case management.

### Accessibility

Ill people and family members often experience difficulty in accessing care. The reasons for this include family poverty, lack of knowledge about CHBC and other community resources, lack of transport and the stigma associated with HIV/AIDS.

#### Poverty

In many resource-limited settings, ill people and their families have to pay for health care, including medicines and supplies. As a result, poor families become increasingly poor. Eventually, some families can no longer access care. The CHBC team can therefore play an important role in ensuring that ill people and family members (including orphans) have access to health and social welfare, regardless of their ability to pay. This might include having emergency rations (such as food and money) in CHBC kits, providing a payment waiver system or hardship fund or helping to develop a community fund for CHBC. These strategies can be very challenging when poverty is extreme and needs are great. Policies have to be established and followed consistently to ensure that people in extreme poverty have access to care.

#### Lack of knowledge

Health and social welfare professionals working in hospitals and clinics are sometimes unaware of CHBC programmes. As a result, CHBC is missing in hospital discharge planning. In addition, other community resources and agencies might be unaware of the CHBC services. CHBC team members should therefore help in raising awareness of these services to the broader community involved in caring for ill people and families.

#### Transport

Comprehensive care involves ill people and family members being able to travel to and from health facilities and other community resources and members of the CHBC team being able to travel to ill people's homes. Transport is expensive; in resource-limited settings, access to care (both in health facilities and the home) can be difficult. However, adequate transport is required for ill people and families to access care. Such transport might include bicycles, scooters, vehicles, and if close to health facilities, by foot. Access to comprehensive CHBC can only be provided when there is an adequate means of transport.

#### Stigma of HIV/AIDS

Stigma associated with HIV/AIDS has caused people with HIV/AIDS and family members to avoid accessing care. Even if the diagnosis is not HIV/AIDS, some



## CASE STUDY 6

### The contribution of one child: the experience of an orphan in Namibia

“But most importantly, we share a lot on how we should bring about a change in our society when we grow up.”

Zebedeus Nou-gawaseb, a 13-year-old orphan, is being supported by Catholic AIDS Action in Namibia. Zebedeus was orphaned last year when his mother died. His father died when he was very young. Zebedeus, who looks younger than 13 years, talks of difficult times. He was born in Windhoek, but within the first 4 years of schooling, he moved to three different communities with his mother in search of work. “She did not have a good job and used most of her income to buy alcohol. That is why I chose to stay with my aunt.” Zebedeus is aware of the hardship facing his aunt, who has four children of her own to care for. As a result, his aunt sought help from Catholic AIDS Action. This NGO has its headquarters in Windhoek, with satellite services in other parts of Namibia.

*A day in the life of Zebedeus.* Zebedeus gets up at 5:00 every day to walk the long distance to his primary school. He is neatly dressed in a school uniform. After school he goes to the Catholic Centre in Katutura where he eats something and has time to talk with other orphans. He then walks home in one and a half hours. He says: “These people are very good to us. They pay for my school fees and buy my uniform. Each day after school I come there (to the Catholic Centre) to eat something. ... We talk about HIV and how it affects us, and how to avoid it.”

*Facing discrimination.* Zebedeus, like hundreds of other orphans, has been left to struggle not only with his personal losses but with the stigma and discrimination that often accompanies AIDS. “Other learners at my school often talk badly about me when I approach them for a piece of bread during the break. Some know that my mom died of AIDS but still ask why I can’t bring my bread to school,” he explains, with tears rolling down his cheeks.

*Communities struggle to cope.* So far, this community, like others in Namibia, is managing to absorb orphan care into extended families with the support of various NGOs such as Catholic AIDS Action. However, there is great concern that, as the numbers of orphans increase, the additional losses and pressures experienced by the surviving relatives may well become too much for some to bear. As one worker comments: “We don’t want to take the kids out of households because we want them to feel that they are welcome among family members and grow up in such an environment.” However, as this aid worker comments, “Food is the biggest problem children face.” Catholic AIDS Action takes care of 160 of the poorest orphans most in need of care and support within this one community.

*Commitment to others.* On several occasions, Zebedeus has accompanied members of Catholic AIDS Action on their home-based care trips to more than 300 people they care for in Katutura. He helps by giving ill people food, washing them and cleaning their homes. He knows a lot about AIDS and how it is affecting so many in his community. He says he wants to stay with the organization until he finishes school and “will help them further their work.” He and other orphans meet as a group after school each day and talk about their problems and concerns. But mostly Zebedeus explains, “We share a lot on how we should bring about a change in the society when we grow up.”

Zebedeus is one orphan among millions that need care, support and love as they grow and mature. However, as this one example shows, such care can lead to a sincere commitment to help others in the future. With such a commitment, there is hope for this generation of “lost” children.



WHO/L. Gubb

In the areas of the world hardest hit by the AIDS epidemic, grandmothers are increasingly left to care for their grandchildren orphaned by AIDS. Tanzania.



UNAIDS/Shehzad Noorani

A boy sits on his grandfather's lap in their home in northern Thailand. The boy's father died, and his mother left home after learning that she, too, was ill. His grandparents now care for him.

people do not access CHBC because they fear that people will assume they are HIV-infected. Combating stigma is a complex issue. Increasing community sensitivity and acceptance is very important. Education (see this category), community involvement, effective communication and psychosocial support (see this category) are some of the strategies that help to reduce stigma. Case study 7 presents the results of a research study in Thailand that identified stigma-reducing strategies for people with HIV/AIDS.

## Continuity of care

### Discharge planning

Without effective discharge planning, the CHBC team may be unaware of the needs of the ill people and their families for CHBC. Such planning usually starts at the hospital. Hospital and other health facility staff should therefore be encouraged to complete discharge planning forms and inform the CHBC staff.

### Referrals

The CHBC team is part of the overall referral system within a continuum of care. Effective referrals should be made from health facilities to the home and vice versa. Members of the CHBC team must encourage effective referral from health facilities. This should include a written referral on the ill person's condition and their treatment and care needs. This referral document can either be given to the ill person or family or mailed to the CHBC team. If the ill person is given the referral, it is important to remember that they may not access CHBC (see the category on accessibility). Notifying the CHBC team is therefore also important.

Problems often arise when the ill person, members of the family or the CHBC team refer the person to a health facility. Professionals in health facilities do not always respect the referral from the home. Respecting referral from home to health facility is important. Members of the CHBC team might accompany the ill person or family to the health facility or raise the awareness of health facility staff to this problem.

When appropriate, referrals should also be made to other resources within the community. Again, written documentation to accompany this referral is helpful in promoting the continuity of care and tracking of ill people. Note that some community health workers and volunteers might be unable to read or write. In some cases, CHBC professionals (such as the supervisor or coordinator) must therefore be responsible for writing referrals or reading and recording incoming referrals. Sensitivity and respect for the literacy level of CHBC members is essential.

## Knowledge of community resources

Everyone involved in CHBC should know the available community agencies and resources that provide holistic care to the ill person and family (including affected and infected children). Local and district health facilities, NGOs, community-based organizations, faith-based organizations, respected traditional healers, spiritual counsellors and others might all contribute to the overall care of the ill person and family.

## CASE STUDY 7

### Strategies to reduce stigma: people with HIV/AIDS in Bangkok, Thailand

The Thai Red Cross conducted research to identify strategies and behaviour to reduce stigma for people with HIV/AIDS. The study respondents included people with HIV/AIDS, family members and health care providers. The following are some of the types of behaviour and strategies that were found to reduce stigma.

*Role modelling.* When a person with HIV/AIDS was first diagnosed, they tended to deny the diagnosis. They isolated themselves and became self-stigmatizing. This period of denial and isolation usually lasted until they found someone who was open about his or her HIV status. This person would support the newly diagnosed people with HIV/AIDS and encourage them to disclose this to close family and/or friends. In this way, other people with HIV/AIDS role modelled shared confidentiality and being open to the diagnosis. Such role modelling promoted openness and an ability to seek necessary health care and psychosocial support.

*Turning to religion.* Most people in Thailand are Buddhist, and karma is a central concept of Buddhism. An important element of karma is accepting that acts, deeds and misdemeanours in the past may affect present and/or future lives. The diagnosis of HIV/AIDS is seen as a consequence of some past misdeed. As such, the religion supports the people with HIV/AIDS and family members in accepting their fate. Karma helps the people with HIV/AIDS and family members in coming to terms with the diagnosis and promotes effective coping.

*Seeking support.* The first response to the diagnosis is often to remain silent and isolated. However, many health care facilities advertise support groups for people with HIV/AIDS and family members. As ill people and families visit these health and social service agencies, they begin to open up to the idea of seeking support. They often take down a telephone number or talk to an AIDS volunteer. Such actions open the ill person and family to accessing emotional and financial support and seeking information and support.

*Sensitizing health professionals.* Health care professionals are often criticized for acting in ways that stigmatize people with HIV/AIDS and family members. This study found that

such behaviour mostly resulted from fear and ignorance. In particular, health professionals were afraid of HIV transmission. It was not enough to teach the health workers about universal precautions; they needed to express their emotions and have open discussion about how to care for people with HIV/AIDS. This open discussion involved expressing their fears and ignorance about HIV while also listening to the experiences and problems faced by ill people and family members as they try to negotiate the health and social service systems. This sensitizing process helped health professionals to learn about safe health care practices while alleviating their unfounded fears of HIV transmission. Moreover, learning about the problems faced by people with HIV/AIDS and family members helped health care workers to become more sensitive and supportive.

*Normalizing HIV/AIDS.* Stigma associated with HIV/AIDS is often caused by fear, ignorance and social taboos related to sexuality. The respondents in this research study believed that normalizing HIV/AIDS, so that it was thought of as another chronic condition, led to social acceptance and to better care and support. Health professionals described how they learned to treat a person with HIV/AIDS as any other ill person and how they role modelled this behaviour to others. In this way, HIV/AIDS was normalized within the health care setting.

This study revealed some common themes related to HIV/AIDS stigma such as fear, isolation and discrimination. However, the study also provided some important strategies that helped to alleviate the negative effects of HIV/AIDS. In particular, teaching health and social service personnel about universal precautions was not enough to reduce stigmatizing behaviour. Providing opportunities for these workers to express their fears, uncertainties and prejudices was equally important. In this way, they could overcome these negative emotions and learn more about the experiences and challenges facing people with HIV/AIDS and their family members. In addition, as people with HIV/AIDS and family members accessed care and support, they began to open up to others. In doing so, they learned to cope more effectively and to gain strength and wisdom through the support of other people.

## Accessing other forms of community care

Many ill people and families need to access other forms of community care. For example, an ill person may access hospice care (see palliative care), or caregivers may need access to respite care. Respite care might include a caregiver coming into the home to give the family caregiver a break, or day care or overnight facilities might be available to ill people, thus providing a respite from family caregiving in the home. Affected children may also be able to access after-school care or day care. In addition, access to support groups, voluntary counselling and testing services, spiritual support and guidance services, educational campaigns and other forms of community care might also be helpful. Accessing these forms of community support helps to build community capacity within a continuum of care framework.

## Community coordination

### Networking

Community network meetings should be encouraged between the different practitioners, organizations and agencies involved in caring for ill people and families at home. This networking can raise different issues and discuss solutions to problems. Case study 8 provides a good example of community partnerships and coordination.

### Communication

All agencies and community resources involved in caring for ill people and families at home should communicate with one another. However, such communication should respect client confidentiality. Effective forms of community communication include written and oral communication, face-to-face meetings and, where possible, the use of telephones (including mobile phones) and e-mail.

## Record-keeping for ill people

Up-to-date records on the ill person's condition, treatment regimens and referrals should be kept with the person, at the CHBC centre or at the local health facility. Each CHBC visit should be recorded together with the care provided. If any members of the CHBC team are illiterate, the CHBC team can discuss the visits during team meetings. The CHBC supervisor or coordinator (or other designated person) can then complete the person's records.

## Case-finding

Ill people and family members who require CHBC may be unaware of the service or how to access home care. It is therefore important for members of the CHBC to find cases in the community and to encourage other community members to refer ill people and families needing the service. Such case-finding is often performed through word of mouth and through CHBC community volunteers. These volunteers usually live in the community and know a great deal about what is going on. They can therefore mediate and communicate with the larger community. In addition, volunteers are often the first to know when a family needs help. Case-finding also promotes early detection, treatment and access to other community resources.

### Working in partnership: the Khutsong Centre, Carletonville, South Africa

“We work with trust, and that trust develops into confidence, which means we take responsibility for our tasks. There is also commitment.”

The Khutsong Centre was established in 1998 in a gold-mining community west of Johannesburg, South Africa. The Centre was built on the trust already developed by the Carletonville AIDS Action Committee. As the nurse coordinator explained, “this committee allowed us to do what we do”. From this early partnership, the Khutsong Centre and Heartbeat orphan programme began. The Centre has four main project areas: home-based care; orphan care; poverty alleviation and income-generating activities; and support group work.

*Team partnership.* Members of the project team explain that the most important partnership is the relationship that is constantly developing between the team members. The nurse coordinator, social worker, orphan care workers, nurses and caregivers have developed a sense of trust and respect for each other and the work they do.

*Partnerships with ill people and families.* The home-based care team is very conscious that they need to be invited into people’s homes. This partnership began by educating caregivers and providing care to one family. When the ill person died, the family gave permission to speak out about AIDS and to describe the home-based care service. Since then, ill people and families have welcomed the home-based care team into their homes.

*Partnerships with the community.* Within Carletonville, six groups work in partnership with the Centre. These partners include schools, churches, support groups for people with HIV/AIDS, women’s groups, youth groups and traditional healers.

*Partnerships with other agencies.* The Khutsong Centre is a member of a community forum that coordinates local agencies and services. Through this partnership, the Centre benefits from services provided by other local NGOs. For example, members of the Centre have received education and support on legal matters, on how to grow market gardens and on life skills.

*Partnerships with industry.* Other partnerships were formed to sustain the Centre. A local bank and a mining company provide financial assistance as well as technical support. For example, staff of the bank and mining company help with project accounting, and the bank is providing marketing outlets for crafts made by the project.

*Partnerships with government ministries.* It soon became clear that working on poverty alleviation and orphan care was inseparable from home-based care. However, it was also evident that comprehensive care would require the support of many different government ministries. To that end, government representatives from the Departments of Health, Social Development, Justice, Education and Agriculture have come together to provide support for the Centre. A local member of parliament sits on the project committee to help in coordinating and facilitating these important partnerships. The community learns from these government representatives and they, in turn, learn from the community.

Coordinating all these partnerships and developing and maintaining relationships with the various stakeholders is challenging. As the social worker explained: “If I didn’t attend to that, there would be a serious problem.” In this sense, the partners working together for the Khutsong Centre project are integral to its success. However, maintaining these relationships takes time and effort. This effort has been worthwhile.

## Case management

Sometimes ill people require more than one agency to be involved in their care. For example, people with HIV/AIDS may access the directly observed therapy, short course (DOTS) for tuberculosis, antenatal care, family planning, sexually transmitted infection clinics, pharmacists and traditional healers. Other services might include Integrated Management of Childhood Illnesses and paediatric care. People with chronic illnesses will most likely also access different services. These services are usually organized through vertical programmes, and coordination between these services is rare. As a result, ill people and family members often go from one service to another, and the records of these visits stay within the service. Although the CHBC team cannot be responsible for the overall coordination of services, a member of the CHBC team may be able to take the role of managing cases and coordinating care of ill people. This would help to avoid gaps or duplication in the care of ill people and families.

Case study 9 examines the opportunities for people with HIV/AIDS to become case managers in CHBC. This study in Thailand suggests that having people with HIV/AIDS as case managers improves the quality of care provided to ill people and families while increasing the confidence of the family caregivers. In addition, the relationship between the case manager and the ill person and family provided continuity of care that sometimes continued after the person died.



## CASE STUDY 9

### People with HIV/AIDS as case managers in home-based care in eastern Thailand

The Faculty of Nursing at Chulalongkorn University became involved with community groups in eastern Thailand to provide a holistic capacity-building approach to families caring for people with HIV/AIDS at home. This was project was undertaken by recruiting, training and supporting people with HIV/AIDS as case managers in CHBC.

*Starting the programme.* People with HIV/AIDS were recruited as case managers by accessing networks of people with HIV/AIDS and asking for volunteers. One criterion for recruitment was that the people with HIV/AIDS already were involved in and well connected with the community. These volunteers first participated in focus group meetings. They were asked to consider what their roles and responsibilities should be and what knowledge and skills they would need to work effectively as case managers. Based on the results of these focus group interviews, a manual was developed for volunteer training and monitoring.

*People with HIV/AIDS as case managers.* Each case manager is responsible for five to ten families. They conduct weekly visits to assess the family's need, provide direct care and support and, where necessary, make referrals to other community resources. Continuity of care is established through a care plan for the ill person and family. In this way, each visit builds on previous visits and overall care is monitored. These case managers also help to educate family members on effective care. One of the most important roles the case managers perform is to provide psychosocial support to the ill person and the family. In addition, case managers provide traditional remedies and therapies or refer ill people to traditional healers in the

community. In summary, these case managers are responsible for providing physical, psychological, social and spiritual support to the ill person and the family and to refer to other community resources when necessary. Family support often continues after the ill person dies.

*Outcomes.* The Faculty of Nursing at Chulalongkorn University evaluated the efficacy of this programme. This evaluation concluded that the quality of care improved, the continuity of care was well established and psychosocial support was one of the most important aspects of the case manager's role. These case managers built close relationships with families, who felt they had someone to whom they could turn in times of need. In addition, experiences of stigma were reduced as families became educated about HIV/AIDS care and prevention, including the use of universal precautions. Family caregivers also benefited from their relationship with the case managers. They reported increased satisfaction in their caregiving role, with an improved quality of life. They also reported feeling more confident in providing care for ill people as their knowledge and skills improved. Moreover, families were more likely to join support networks and reach out to support one another. Finally, the ill people and families became more aware of community agencies and resources that could provide them with additional care and support. Two problems emerged as a result of this evaluation. First, some case managers became ill and had to discontinue their case manager role. In addition, transport to family homes was often problematic. However, having people with HIV/AIDS as case managers for other people with HIV/AIDS living at home and their families was considered to be very successful.



## Education

Ill people, family members, health and social welfare professionals, community health workers and community volunteers all require adequate education and training in prevention, treatment and care. Since many people are illiterate, creative strategies should be developed to provide training to ill people, families and community workers who cannot read or write.

### Curriculum development

The CHBC team requires adequate education and training. The content of the CHBC curriculum should include:

- basic information on HIV/AIDS transmission and how to prevent it;
- basic comfort measures and nursing care for adults and children;
- managing symptoms and administering medication;
- use of traditional remedies;
- universal precautions;
- palliative care, including counselling terminally ill people, bereavement counselling and pain relief;
- nutrition;
- psychosocial support and counselling for ill people, caregivers, orphans, health and social welfare workers and volunteers;
- training the trainers for continued in-service education;
- supervising and managing CHBC, including motivating staff;
- stress management and care for caregivers; and
- managing referrals and resources.

Some education can be provided in combined sessions with all members of the CHBC team (including the ill person and family). Such multidisciplinary teaching helps team-building. Separate sessions should be given for education focusing on specific disciplines. Most education can take place in groups; however, members of the CHBC team might educate ill people and families in the home.

### Educational management and curriculum delivery

Educational sessions should be well managed. In some communities, higher administrative levels manage education. However, in other communities a CHBC supervisor or coordinator is responsible for this management. Such management includes assessing needs, planning periodic training sessions, training the trainers, on-site training and offering different educational formats.

**Needs assessment**

People have different learning needs and levels of literacy. Assessing learning needs and determining the literacy level of the learners therefore ensures that sessions are relevant and appropriate to the learners.

**Planning periodic training sessions**

Education needs to be reinforced. Health and social welfare personnel, community health workers, volunteers, ill people and family caregivers should therefore receive continued education.

**Training the trainers**

Training the trainers is important so that education can be an ongoing part of CHBC. Follow-up training sessions are required for education to be effective. Follow-up sessions can introduce new information and help to consolidate previous learning.

**On-site training**

Learning is often more relevant when it is delivered on site or within the home.

**Offering different educational formats**

People learn in different ways. Different teaching and learning methods should therefore be used. These methods might include lectures, group discussion and participation in various activities, role play and simulation, repeat demonstrations, visual learning aids, story-telling, drama, song, games and play and the use of information pamphlets, posters and leaflets. These educational materials must be in the local language and at the literacy level of the learners. Case study 10 demonstrates how SERVANTS, an NGO in Phnom Penh, Cambodia, developed a training programme and continuing education opportunities for its volunteer CHBC team.

**Outreach**

People in the larger community should be educated about the transmission, prevention and care of illnesses prevalent within their area. Education sessions can be provided at schools, community gatherings, faith-based meetings, community celebrations, the marketplace, the workplace and in any area or at any occasion at which community members will be present. Members of the CHBC team may be asked to present information at these meetings. CHBC team members should therefore be trained and supported in providing public education.

**Education to reduce stigma**

In various parts of the world, there are people who believe that HIV/AIDS is caused by witchcraft, karma or other spiritually based causes. In addition, examples of HIV/AIDS stigma, discrimination and rejection have been noted throughout the world. One of the most effective ways of reducing this stigma is through education. Such education can be provided through individual, group or community outreach sessions (see previous component on outreach).

## Mass media involvement

The mass media comprise a powerful mechanism in educating the public. However, before the mass media are capable of providing public education, they must first be educated. The CHBC team might not be responsible for planning mass media education. However, they might be called upon to help to educate the mass media about home care and how to support ill people and families at home. In particular, CHBC team members might be called upon to provide examples of HIV/AIDS stigma and discrimination. They may also wish to highlight the problems of children affected by and infected with HIV. CHBC team members can suggest strategies to reduce these negative experiences.

## Evaluation of education

Education sessions should be evaluated. Evaluation should include: the content of learning, the degree of student learning, the credit given to learners, the frequency of education sessions and teacher performance. Each district is likely to develop its own curricula, learning outcomes and methods of evaluation. However, some communities might use educational materials from other settings. In this case, the learning needs of the community should be assessed, the learning outcomes determined and the level of student learning evaluated.

Having educational materials that reflect the needs of each community and country is important. In this way, educational strategies are tailored to different areas of the world. However, some international sources might also be helpful. The bibliography provides some of these materials under the heading of education.



WHO/Miriam-Hirschfeld

A young Cambodian man with his parents. The home care team arranged for housing and is providing care.

## CASE STUDY 10

### Educating volunteer caregivers: SERVANTS, Phnom Penh, Cambodia

“We wanted to train a network of community caregivers.”

SERVANTS is an international NGO involved in an outreach programme in the Mean Chey district of Phnom Penh. This NGO consists of a network of teams living and working in Asia’s urban slums. They participate with poor people in community development projects to seek to relieve suffering and bring hope and justice. Mean Chey district has a population of 160 000 with a number of poor urban and squatter communities. There is also a large migrant population, with people arriving from rural areas in search of work and a better life. SERVANTS started CHBC for people with HIV/AIDS in 1996 and began to train and support a network of community caregivers.

*The training programme.* A periodic 12-week caregiver training programme is provided. This training includes: general knowledge about AIDS, trust and confidentiality, HIV testing, responses to HIV/AIDS and counselling and care for dying people. Symptom management, such as diarrhoea, cough, skin problems, thrush and general hygiene, is also covered.

*Educational options.* There are three different options for caregiver education. First, there is the formal 12-week programme run by SERVANTS (see above). Second, SERVANTS provides on-site education and support. As new volunteers get involved with SERVANTS (and before there are enough to run a training course), they attend afternoon training sessions twice a month. This continuing education programme provides caregivers opportunities to talk about issues related to HIV/AIDS care and to discuss difficult cases. This

is also a time when volunteers experience support in their work. Finally, the AIDS coordinating network (KHANA) in Phnom Penh runs refresher courses for AIDS home care workers, and some volunteers attend this programme.

*Flexibility in education and care delivery.* SERVANTS has found that younger and older caregivers focus on different aspects of learning. Young caregivers request information on giving injections and on specific treatments and medicines. Older caregivers are more interested in the practical aspects of care such as helping with washing, cooking and cleaning. Differences in location also require different forms of care. Areas that have a high proportion of abandoned people need more basic care such as money, food, shelter and clothing. In other areas, although the community is very poor, they tend to be in a caring family network. In these circumstances, counselling and advice on treatments and medication and where to seek help in times of need are required.

*Responsiveness to changing demographics.* The number of ill people needing care is rapidly increasing. This places considerable strain on SERVANTS staff. They have recently hired a second nurse and a half-time volunteer to computerize records and recruit, coordinate and train staff.

The educational programmes offered by SERVANTS and other network organizations provide volunteer caregivers with flexible learning opportunities to meet a variety of learning needs. Formal training, continuing on-site education and refresher courses all provide educational support for volunteer caregivers in the Mean Chey district of Phnom Penh.

## Supplies and equipment

Supplies and equipment for CHBC should be kept at a central location. This location might be a local health centre or the offices of community nongovernmental agencies. Basic CHBC kits must also be available for CHBC team members to take to the home. Whenever possible, imported goods and supplies should be avoided to reduce costs. Some supplies and equipment can be made locally.

### Location of the CHBC team

The CHBC team should be located in a local health facility or NGO where meetings can be held, records kept and supplies and equipment stored. In addition, there should be periodic team meetings between health centre staff and CHBC team members. These joint meetings help to promote continuity of care, referral, diagnosis, care for affected and infected children and prevention and treatment options (including palliative care).

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### Health centre supplies

Decisions about basic supplies and equipment should be based on priority needs. The priorities depend on the availability of funds and on the health care needs of ill people. Most countries have a national list of essential drugs. In addition, there is usually a list of necessary drugs to treat illnesses most prevalent in the community. For example, health centres may have pain medication, basic treatments for opportunistic infections, tuberculosis medication and some treatments for prevention (such as tuberculosis and HIV). Other basic drugs might include:

- calamine lotion;
- oral rehydration salts;
- nystatin;
- paracetamol;
- aspirin;
- ferrous sulfate and folic acid;
- vitamins A, B and C;
- oral, rectal and topical antibiotics and antifungal agents; and
- traditional herbs and remedies.

This list is not exhaustive. Many countries and districts have developed their own lists of essential drugs. In addition, pain-relieving Class A drugs should be available. These drugs must be provided in accordance with the national laws on dangerous drugs and with the national drug policy (or adapted where necessary). Such Class A drugs include morphine injection, tablets, oral mixture and other narcotics. People involved in CHBC should provide these treatments in accordance with the ill person's need considering the regulations controlling

the use of narcotics in their particular settings. A list of essential drugs, their use and the national and local regulations for administration should be available in CHBC settings.

The health supplies and equipment necessary for providing effective CHBC may include:

- basic dressings;
- basic instruments;
- laboratory equipment (or access to a laboratory);
- disinfectant, soap, gloves, incontinence pads, diapers, mackintoshes, bedding, etc. (priorities set based on CHBC funding);
- condoms;
- a refrigerator;
- dry storage facilities; and
- food or food supplements.

Again, each setting has different priority needs. This list should therefore only be used as a complement or checklist to the equipment and supplies necessary for CHBC within a particular setting.

## Management, monitoring and record-keeping

### **Record-keeping**

Consistent records must be kept for ordering and delivery of supplies and equipment. This will help to avoid excessive or insufficient supplies of goods.

### **Sharing resources**

Sharing supplies and equipment among various community agencies and services will help to cut costs in CHBC. Organization, management and protocols for cost-sharing will probably be decided by higher administrative levels. However, members of the CHBC team can implement cost-sharing measures (including sharing resources).

### **Equitable distribution of supplies and equipment**

Ill people often avoid local health facilities and go to more central agencies because the local community does not have supplies and equipment. Ensuring that equipment and supplies are available locally is therefore important. Members of the CHBC team might not be responsible for stocking local health facilities but can draw attention to the need for local supplies. Providing ill people with the necessary supplies, medicines and equipment, regardless of their ability to pay, is also important (see continuum of care).

## Home-based care kits

Kits taken by members of the CHBC team to the home must be tailored to the needs of the ill person. Essential drugs (based on the essential drug list) and basic equipment (such as dressings, soap, disinfectant, gloves and other protective materials) should be available in these kits. Traditional remedies and herbal treatments might also be included. In some parts of the world, these home-based care kits also include emergency food supplies, bedding or money. These emergency supplies are provided to help destitute people in need of CHBC. The CHBC kits must be systematically restocked from supplies at a local health unit.

People involved in CHBC must follow national and local guidelines on essential drugs, supplies and equipment. A document on the community home-based care kit developed by the WHO Regional Office for Africa is included in the bibliography. This is an example of the work that has been undertaken in one region. Case study 11 also provides an example of an innovative CHBC kit programme that provides supplies and equipment to be left in the home. In most cases, this kit is provided free of charge, and adequate information (in local languages and with diagrams) is included.

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## Staffing

Staffing for CHBC includes making decisions about the entire complement of staff for the CHBC team. In particular, decisions have to be made about supervising and coordinating the CHBC programme, recruiting and retaining staff and having a workable and financially manageable mix of staff.

### Supervising and coordinating CHBC

A nurse or social welfare professional is usually responsible for supervising and coordinating CHBC. The CHBC team should have adequate supervision and support from a person with the authority to make and carry out decisions. Such a person has to gain the respect of the CHBC team and the local community. In addition, this supervisor has to access available resources and advocate for CHBC funding. Education for CHBC supervision and management is therefore important (see education).

### Recruitment

#### Hiring

Members of the CHBC team should be recruited based on established hiring criteria. For example, staff may be recruited based on their professional qualifications, knowledge and skill level. Demonstrating qualities such as empathy, sensitivity, nonjudgemental attitude, confidentiality and motivation are also important considerations. Most CHBC programmes contain the following paid and unpaid staff members.

#### Paid CHBC employees

- The team includes at least one nurse and social worker. One of these professionals usually serves as the CHBC supervisor or coordinator.



## CASE STUDY 11

### Home-based care kits – changing the face of care

The Centre for the Study of AIDS at the University of Pretoria has developed a home-based care kit in an attempt to transform how care is administered in the homes of people with HIV/AIDS. This kit was developed through a joint project with the South African National Department of Health, University faculties and various community groups involved in community and home-based care. These kits are provided free of charge, although a means test is sometimes applied.

*The kit remains in the home.* The essential aspect of this kit is that it stays in the home where the person is receiving care and support. In most home-based care programmes, teams visit the homes and dispense small amounts of supplies and basic medicines. Although these team visits remain crucially important, the ill people and family caregivers need basic supplies throughout the period of care. Many families are too poor to be able to provide the essential materials for care, and the ill person becomes a burden to the family and receives substandard care.

*Components of the kit.* The home-based care kit has the essential components for 6 weeks of care and support within the home. The kits are made from reinforced, lightweight cardboard and are flame and water retardant, transportable, compact and painted in bright colours. They can be stored in cupboards, under the bed or in the corner of a room. They can be locked, and all containers have childproof caps. Everything in the kit is packed in a waterproof container that fits into a slot for easy access. The kits come with two sets of instructions. One set is for quick use; the second has more detailed information. The quick reference set is presented on flat reinforced paper sheets and has

simple instructions and diagrams for home care. The other set is a full manual on small flip charts that cover care and support, nutrition, legal and social service information, bereavement support and information about the available services from the Departments of Health, Social Development and Justice. All the information is a mix of text and pictures and is colour coded with text and pictures on the containers within the kit. Thus, people who cannot read can locate the appropriate container to help with a particular problem. This information has been translated into the four most common languages in South Africa.

*What the kit contains.* The kits have basic medicines including painkillers, antivomiting and diarrhoea medication, vitamin supplements, salt and sugar solution, calamine lotion, cough syrup and mouthwash. It also contains the essentials for personal hygiene such as a toothbrush, toothpaste, face and body cloths, body cream, shampoo, powder and materials for supporting ill people such as bleach and antiseptic, linen savers, gloves, plastic containers, cups, straws and washcloths.

*Evaluation.* The testing of the kits has shown that they provide families and caregivers with essential means to give quality care. The relationship between the caregiver and the ill person also improved, and the ill people said they felt and looked better. In addition, the families were freed from much of the anxiety about their ability to provide quality and sustained care at home.

The kits are being extensively piloted through national programmes in early 2002.

- Community health workers provide care within the home and supervise and complement the work of community volunteers. The number of community health workers depends on: the size of the community, access to transport and the distances to be travelled, the number of ill people and family members enrolled in CHBC and the financial resources of the CHBC programme. Countries give community health workers different titles, but they are paid members of the CHBC team. They usually live within the community and have received CHBC training (see education).

### **Unpaid CHBC team members**

- Community volunteer team members are recruited from within the community and have received some CHBC training (see education). Honouring these valued community volunteers is important. Some form of incentive (such as honorarium, in-kind payment, uniform, badges or T-shirts) is therefore important. The choice of incentives depends on the wishes of the community and the financial status of the CHBC programme.
- Ill people and family caregivers are rarely paid in resource-limited settings. However, they do receive education on basic physical care from members of the CHBC team.

### **Staff mix**

Establishing an effective mix of CHBC staff is important. The ratio of professionals, community health workers and community volunteers should be determined. This staff mix should depend on: the roles and responsibilities of various team members, the knowledge and skills of the CHBC team, the health care needs of ill people and the financial status of the CHBC programme. However, this staff mix should include at least a nurse and social worker (sometimes shared with other community services), several paid community health workers and as many community volunteers as necessary to provide effective care within the home. This mix should also attend to the gender balance within the team. Most CHBC team members are women. Encouraging men to become members of the CHBC team is therefore important. This gender balance is sometimes important in providing physical care to men who are ill.

### **Other potential CHBC practitioners**

People who also provide care to ill people and family members at community level and sometimes at home include the following.

- Physicians (usually located at the community health facility) are also responsible for care. Physicians may act as consultants to CHBC team members and diagnose and treat ill people.
- Respected traditional healers might also provide care. Herbal treatments and other traditional remedies can often effectively relieve symptoms.
- Pharmacists also provide an important complementary service. Ill people and family members often consult pharmacists for symptom relief, medical supplies and for preventive therapy.

## Skills and other competencies

Each community will develop its own recruitment and hiring criteria. However, the following list of skills and other competencies for CHBC team members might be helpful.

**Physicians.** Physicians are qualified professional medical practitioners. Their overall skills and competencies are accurately diagnosing and effectively treating diseases.

**Nurses.** A qualified nurse is one who has undertaken a standard training programme and passed the examinations set by the national (or sometimes district) government. Specific CHBC skills and other competencies of the nurse include: supervising, monitoring and managing the CHBC services, diagnosing and treating common conditions in collaboration with a physician, case management, serving as a case coordinator and referral agent, educating other CHBC team members and as a support person and counsellor for the ill person, family and CHBC team.<sup>1</sup>

**Social workers.** Social workers are qualified practitioners that provide assistance with financial, legal and social support. They may be part of the CHBC team or may act as complementary practitioners supporting the team, ill person and family. The skills and other competencies of social workers include: helping families in accessing grants, providing financial support, supporting affected children and providing assistance and advocacy with legal matters. Social workers also refer families to other resources and agencies and provide psychosocial counselling to ill people and family members.

**Community health workers.** Community health workers are usually trained by nurses and other health and social service personnel to care for people in local health centres and within the home. This training can vary from about 3 weeks to 3 months, depending on the setting. These workers are usually paid employees of the CHBC team. The skills and other competencies of the community health workers may include: the use of universal precautions, providing basic nursing care, providing palliative care, administering DOTS treatment for tuberculosis, administering other treatments (under the supervision of the nurse), providing psychosocial support and counselling within the home and local health centre, referring the ill person and family and educating the ill person and family on basic nutrition, nursing care and treatment regimens.

**Community volunteers.** Community volunteers usually form the backbone of the CHBC team. They live in the communities and know the population well. These workers are usually provided with training that can last between 3 days and several weeks. Volunteers usually have clearly defined responsibilities that include visiting ill people and families regularly, providing basic nursing and palliative care, finding cases, providing emotional and spiritual support, providing nutritional advice, referring ill people and families, educating ill people and families and arranging for ill people and families to receive welfare support such as food, blankets, clothing, transport and assistance with funerals. These volunteers also carry out practical jobs such as cooking, cleaning, washing and fetching water and firewood. Case study 12 gives an example of how one NGO in Cambodia recruited and trained its CHBC volunteers.

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<sup>1</sup> The role of the nurse described here does not include the entire scope of nursing practice. This role is confined to the most usual roles practiced by nurses in CHBC in resource-limited settings.

*Traditional healers.* Traditional healers are often educated from wisdom passed down from generation to generation. However, in some parts of the world, traditional healers are now receiving more standardized education and qualifications. The skills and other competencies of respected and effective traditional healers are to diagnose common ailments and to provide traditional herbs and other remedies to alleviate symptoms. Traditional healers may or may not be formal members of the CHBC team. In any case, they play an important complementary role in care.

*Pharmacists.* Pharmacists are professionals who have met the standardized pharmaceutical qualifications for the country in which they practise. The skills and other competencies of pharmacists include: dispensing medicines and treatments prescribed by a physician (and sometimes a nurse), providing treatment advice to ill people and family members and acting as a consultant to ill people and family members on the treatment of common ailments. Pharmacists play a complementary role to the CHBC team.

Frequent on-site training and support should be provided to keep the skills and other competencies of all members of the CHBC team current (see education).

## Retaining staff

Caring for ill people and family members at home presents many challenges. The CHBC team visits families that are destitute with no food, water, adequate shelter or access to necessary treatments. In addition, HIV/AIDS stigma is very problematic among communities, families and health and social welfare workers. As the HIV/AIDS epidemic continues to grow, CHBC teams often feel overwhelmed and exhausted as they try to care for increasing numbers of ill people and families with few resources. Some of the CHBC team members are also HIV-infected or have family members who are. Under such difficult circumstances, retaining CHBC team members and supporting, motivating and encouraging them to provide effective care comprise a challenge. Strategies to help to support, motivate and encourage CHBC team members include providing support group sessions, addressing stigma, staff rotation, respite care and honouring CHBC team members.

### Providing support group sessions

Members of the CHBC team require ongoing psychosocial support and counselling. This care can be provided in periodic support group meetings or through individual counselling sessions (see care for the caregiver). When workers feel supported, they are more motivated to provide effective care.

### Addressing stigma

Some communities, families and health and social welfare workers have stigmatizing attitudes towards people with HIV/AIDS. Within CHBC, people with chronic illnesses have also experienced stigma. The reasons for stigma and discrimination are varied and extremely complex. However, stigma must be reduced to provide access to health care and to provide effective CHBC. To that end, CHBC team meetings should address stigma among staff members and the general community. As the effects of stigma and discrimination are explored, strategies should also be developed that reduce stigmatizing attitudes and promote the effective care of ill people and their families.

## CASE STUDY 12

### Recruiting and retaining volunteers: Phnom Penh, Cambodia

“One difficulty is that the people we most want to be involved – those poor and able to get alongside those ill and in difficult circumstances – tend to have difficult lives of their own, and at times, these can be overwhelming.”

The necessity of recruiting and retaining volunteers was the first challenge facing SERVANTS in their CHBC programme. SERVANTS, an international NGO, consists of a network of teams living and working in Asia’s urban slums. They participate with the poor in community development projects to seek to relieve suffering and bring hope and justice. The CHBC project in the Mean Chey district of Phnom Penh started in 1996 to care for people with HIV/AIDS and their family members. The population of Mean Chey is 160 000, with a number of poor urban and squatter communities and a large migrant population.

*In the beginning.* The first community caregivers were recruited from those already known to be involved in care. Village leaders, local women’s associations and local churches were approached to suggest people who might be interested in working in this new CHBC programme for people with HIV/AIDS. The original volunteer caregivers included a mother whose son had recently died, a traditional village midwife with extensive community activities and networks and a local woman caring for neighbours dying of AIDS.

*Growing and developing.* The first 12 volunteers were trained in 1998 and a further 32 followed. Of these original members, 27 are currently active, with 15 remaining very enthusiastic and committed to the project. In addition, SERVANTS has trained five volunteers for other organizations or church groups. These volunteers work outside the Mean Chey district.

*Recruiting for diversity.* SERVANTS makes every effort to recruit people from different villages and from a range of ethnic and religious groups. For example, there are Khmer and Vietnamese volunteers who follow the Cham Muslim and Christian faiths as well as the majority religion, Bud-

dhism. Particular difficulties have been found in locating volunteers for the Vietnamese community, as they need to have a basic knowledge of Khmer to work with the staff. Currently a good compromise has been reached in that a pair of women working together have, between them, a good grasp of both languages and extensive community networks. Many of the people that SERVANTS would like to recruit are poor and tend to have difficult lives of their own. However, every effort is made to recruit people living in these poor and disadvantaged communities and to retain their commitment and support.

*Retaining volunteers.* Retaining volunteers is a constant challenge. All volunteers are poor and have to work to eat and feed their family each day. These volunteers therefore receive a small stipend. However, visiting the homes of people dying of AIDS is emotionally and physically demanding. To help in compensating for this, various strategies have been put in place. Recreational activities, such as a picnic for volunteers, are considered great morale boosters. SERVANTS staff also help volunteers and their families with personal and health problems. In addition, although the CHBC programme is only for people with AIDS, medical consultations and a small compassionate budget are available for those with other terminal or serious conditions. Volunteers can assist families in accessing these services. These activities allow volunteers to help in curing some community members of serious illnesses, and they thus see some positive outcomes. Such strategies provide support and encouragement for the volunteers.

Providing volunteer support and care have proved to be essential elements of recruitment and retention in the SERVANTS CHBC programme. Volunteers are paid a stipend and receive psychosocial support and health care from SERVANTS staff for themselves and their family. The opportunity to have fun and recreation has been another important element in retaining volunteers. In addition, the volunteers have experienced they can make a difference in people’s lives. Such strategies have helped volunteers in staying committed and enthusiastic about the programme.

### Staff rotation

CHBC team members may become exhausted and unable to provide effective care within the home. Some CHBC programmes have found that rotating staff between CHBC and community clinic work helps to alleviate such exhaustion. This change of job often provides necessary respite.

### Respite care



WHO/Miriam Hirschfeld

A member of the home care team visits a Cambodian woman and her children.

The daily challenges of trying to provide care in the home often exhaust family caregivers. These caregivers are often poor, malnourished and overwhelmed with their caregiving responsibilities. Some form of community respite day-care facility is very helpful. In addition, neighbours or friends can be encouraged to provide the caregiver with respite from their caregiving responsibilities. CHBC team members might also require periods of respite from their work. Staff education, vacation periods and recreational outings can provide some respite from the daily challenges of providing care within the home.

### Honouring CHBC team members

A system of rewards and incentives should be established to help in retaining CHBC team members. Although health and social welfare personnel and some community health workers are paid, they still need to feel valued within the community and by the health and social systems to which they belong. Recognizing the importance of the work of CHBC team members within the health care system is essential. In addition, community volunteers require recognition and support for their work. Incentives might include further education, honouring CHBC team members at community gatherings, providing awards for outstanding service, honoraria and in-kind payments to volunteers. In addition, CHBC team members might be supplied with T-shirts, uniforms, bags, umbrellas, badges etc. and need to hear from health officials at higher ranks that their work is recognized and valued. The important element in retention is that members of the CHBC team feel valued for their work and supported by the community and by other units and levels of the health care system.

## Financing and sustainability

Financing and supporting CHBC is very challenging for communities. These programmes are often vulnerable to inconsistent and sporadic sources of revenue. The following strategies can help to promote the sustainability of the CHBC programme. These are only some suggestions, and community agencies might have found other financial strategies that help to promote sustainability.

### Budget and financial management

In many resource-limited settings, governments, national or international donor agencies and NGOs fund CHBC. These funds often come from a central pool. However, a CHBC supervisor is usually responsible for preparing, managing and recording the CHBC budget. In addition, managers are required to provide periodic financial statements to the funding source.



## Technical support

Obtaining funding for CHBC from NGOs, faith-based organizations and other sources usually requires writing proposals and preparing a budget. Members of the CHBC team might be required to write these proposals. However, such skills are usually beyond the scope of most members of the CHBC team. Technical support and assistance from other community agencies and local government programmes are therefore necessary.

## Community funding

Creativity and innovation are important strategies in contributing to CHBC funding. Members of the CHBC team cannot be expected to undertake all the following strategies to raise funds; however, they may be able to stimulate some of the activities and take part in others. Such strategies include promoting CHBC ownership, promoting partnerships, promoting community mobilization, generating community income and establishing revolving community funds.

### **Promoting CHBC ownership**

It is important that community members view CHBC as being part of the overall care and well-being of the community. Members of the CHBC team can help to promote this community ownership by consistently involving community members and organizations in the planning and by raising community awareness of CHBC.

### **Promoting partnerships**

In many instances, CHBC programmes come about through partnership and joint sponsorship of the programme: government and NGOs develop partnerships to fund CHBC. In addition, community-based organizations and the private sector can join forces to help in supporting CHBC. Members of the CHBC team are likely to be actively involved in establishing and maintaining these partnerships. These team members may require technical support (see previously) to assist in writing proposals and negotiating contracts.

### **Promoting community mobilization**

Community and spiritual leaders and other respected leaders within the community can be asked to play a role in mobilizing community resources. Such activities can help to build community capacity to sustain CHBC.

### **Generating community income**

Many communities are very poor, and contributing to CHBC funding is difficult to imagine. However, there are examples of how communities have managed to help in funding CHBC. Such strategies might include income-generating activities such as community gardens and farms, craft markets, community fairs, recreational, sport and artistic activities, contributions from local businesses, faith-based organizations and others able to provide funds (however modest) for CHBC.

### **Establishing revolving community funds**

Systems of revolving community funds have been established in some resource-limited settings. Money is provided to buy the drugs, supplies and equipment



necessary for CHBC. Ill people and family members then pay a small fee (if possible) for these services. These fees go into a revolving fund to help in sustaining the programme. Case study 13 provides information on the benefits and challenges of encouraging income-generating activities by providing microcredit in the Philippines.

## Encouraging volunteers

Throughout the world, CHBC could not be sustained without the enormous contribution of volunteers. Over 90% of these volunteers are women. Their educational backgrounds and life situations differ. However, volunteers have one thing in common – a desire and ability to help others. Many volunteers respond to a call for help through their places of worship. Others offer to help when they see how CHBC volunteers have helped their own family, neighbours or friends. Volunteers are mostly poor and struggle to feed, clothe and pay for schooling for their own children.

Given the physical, economic and emotional demands volunteers face, it is impressive how many volunteers persist with their caregiving activities. What motivates many volunteers is a sense of spirituality and religious conviction. In addition, volunteers often feel a sense of group solidarity and pride in what they achieve. The issues related to retention such as group support, education, honouring volunteers and providing awards, honoraria and payment in kind are important sources of encouragement for volunteers. In addition, considering group celebrations, badges, uniforms, T-shirts, umbrellas and other forms of volunteer recognition is also important. To encourage and support the vital role that volunteers play, it is important that they feel valued for their work and supported by the community. Case example 14 is a speech given by a volunteer describing her experience in providing care in Namibia.

## Pooling resources

Developing networks between other community agencies and services associated with CHBC can help to contain costs. Networking, partnerships and effective budgetary administration may enable sharing supplies and equipment across sites. Pooling resources such as supplies, equipment, information and education with other health-related NGOs, community-based organizations, faith-based organizations and community health facilities can help to reduce the costs of CHBC.

## Out-of-pocket payments

Most CHBC programmes rely on some payment by the ill person and family. However, this payment should be kept within people's ability to pay, and out-of-pocket payments should not contribute to increasing the poverty of ill people and families. CHBC team members may be asked to assess whether ill people and family members can afford this payment.

## Free services

Poverty cannot become a barrier to accessing CHBC. A waiver system or some form of free care that can be equitably applied to destitute families must therefore be developed. In some countries, funds for financial support come from some form of community taxation. In addition, CHBC programmes run by NGOs and faith-based organizations usually have a source of funding from

## CASE STUDY 13

### **Kapit Kamay Sa Bagong Pag-Asa: promoting financial independence for people with HIV/AIDS in the Philippines**

The Philippine National AIDS Council in partnership with the Centre for Community Transformation and the Pinoy Plus Association, Inc. have established a livelihood assistance project through microfinance for people with HIV/AIDS and their family members. The overall aims of the project are: to assist people with HIV/AIDS in achieving financial stability by helping them to generate savings and to manage or own microenterprises; to assist them in regaining their self-worth and dignity by becoming productive and augmenting family income; and to reintegrate isolated people with HIV/AIDS back into their respective families and communities.

*Qualifying for microfinance.* Applicants for microfinancial assistance must first participate in an orientation and training session. Included in this session are discussions on loan policies, the responsibilities for programme partners, the development of business proposals and business management strategies. The applicant's proposal must include information on the project to be undertaken together with a short feasibility study including a statement on the return on investment. A budget must be prepared that includes the items to be purchased and the income expected to be derived from the business. In addition, applicants are expected to begin saving for 4 weeks during their training and orientation period to demonstrate their responsibility in financial management. Based on the project proposal and on the applicant's ability to demonstrate financial responsibility, microfinance funds are provided to the applicant with a clearly agreed repayment schedule.

*Projects funded.* Nineteen projects were funded throughout the Philippines. These projects included variety and general merchandise stores, a piggery, tricycle and motorcycle hire, a video rental shop, a vegetable market stall, an eatery and a bar. Nine of the project managers were men and ten women. Five people with HIV/AIDS died during the project, but family members took over their businesses.

*Problems encountered.* The microfinancing project was housed in the same location as the social welfare office. As a result, there was some confusion as to the difference between a business loan and a welfare grant. Thus, some borrowers did not understand the importance of repaying

their loans. In addition, despite the orientation and training sessions, many participants experienced difficulty in managing their businesses. Problems were also encountered when participants used their loans for family expenditure. Finally, great distances between project locations resulted in poor monitoring. Only in Metro Manila was it possible to visit the business locations, whereas other projects were monitored by telephone.

*Lessons learned.* Based on the problems encountered by the project, the following lessons and recommendations were made. The organization responsible for managing the project should have had previous experience working with people with HIV/AIDS and family members. Such families pose unique problems related to illness, family disintegration and profound poverty. Rigorous standards must be established for reviewing proposals and disbursing and monitoring funds, and criteria must be established for loan defaults. Microfinance and social development programmes should not be attempted within the same organization.

*Beneficial outcomes.* Despite the challenges experienced in this microfinancing project, the programme monitors also found considerable benefits to people with HIV/AIDS and their families. This livelihood opportunity enhanced the self-worth of people with HIV/AIDS by restoring their confidence and dignity. They were able to help in supporting their family and to be productive members of the community.

The Kapit Kamay Sa Bagong Pag-Asa project provides one example of the challenges and benefits of supporting people with HIV/AIDS and family members to become financially independent and productive members of the community. The lessons learned from this project can help future programmes in developing more effective orientation and training sessions and setting clearer policies, guidelines and standards for granting microcredit while also monitoring and supporting project participants. Programmes that are well organized, managed and monitored will contribute to alleviating poverty among people with HIV/AIDS and family members while also increasing their sense of self-worth and self-efficacy. Such strategies help in contributing to an improved quality of life for the people with HIV/AIDS and their family members.

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Source: Philippines National AIDS Council, Centre for Community Transformation and Pinoy Plus Association, Inc., Manila, the Philippines.

the donor agency. The CHBC team is unlikely to be responsible for developing this free service. This will probably fall to government officials or administrators of NGOs, faith-based organizations or community-based organizations. However, CHBC team members may be asked to assess the needs of the ill person and family for free services and to provide the necessary resources. These resources might include transport, medicines, CHBC supplies and sometimes food, blankets, clothing and money.

## Monitoring and evaluation

The CHBC team as well as outside members will be responsible for monitoring and evaluating the CHBC programme. The CHBC team will be responsible for day-to-day quality assurance, monitoring and informal evaluations, and outside evaluators will probably carry out formal evaluation. The following issues are important to attend to in effective monitoring and evaluation.

### Quality assurance

The national government or funding agencies will probably establish the standards, policies and regulations that govern CHBC (see the first section). However, the CHBC supervisor or coordinator and the team will be responsible for ensuring that these policies, standards and regulations are upheld. Thus, members of the CHBC team will be responsible for ensuring that their practice conforms to CHBC standards, policies and regulations. In addition, CHBC team members (including ill people and family members) should be asked to participate in developing the overall goals, objectives (short, medium and long-term) and sub-objectives of the CHBC programme. In summary, the important elements for an effective CHBC quality assurance framework include:

- developing the standards, policies and regulations for CHBC;
- determining CHBC goals, objectives and sub-objectives;
- determining CHBC practice guidelines based on these standards, policies and regulations;
- determining the roles and responsibilities of CHBC team members;
- developing standards for monitoring performance;
- developing outcome measures for CHBC; and
- ensuring adequate resources: staff, supplies and equipment, education and financing.

The CHBC team is unlikely to be responsible for determining the criteria for quality assurance. However, they will be asked to suggest the criteria and may judge whether the CHBC programme meets these standards.

### Quality of care indicators

Developing indicators for assessing the quality of care in a CHBC programme is important. These indicators will be assessed by ill people, families and

## CASE STUDY 14

### Protecting our candle so it won't burn out: a letter from a volunteer in Namibia

"I think of our work like holding up a candle of hope to other people. But unless we also protect that candle, it will burn out."

My name is Jane Wachila and I live in Katima Mulilo in the Caprivi region of Namibia. Since last July I have been providing home-based family care for Catholic AIDS Action as a volunteer. I am one of the 86 trained volunteers for Catholic AIDS Action in three different areas of the Caprivi region.

I would like to talk about my region, Caprivi. As you all know from the statistics, each single day in Caprivi, we lose our beloved ones: a brother, sister, mother, father, husband, wife, son, daughter or neighbour. It is very hard to face this day after day.

As volunteers, many times our bodies do not want to respond to our volunteer work, but the situation forces us to do it. Many times, before you wake up in the morning, somebody knocks at your door telling you that one of your clients or an orphan you take care of needs your attention. You rush there, but before you get back home, you meet another person who tells you that your other client is admitted to the hospital. Then, when you quickly rush to the hospital, before you reach the ward, you get the message that he or she is dead. You feel down and turn back dragging your feet, your neck bent down into thoughts.

At the end of the day you feel down, tired, lonely, empty. Then you ask yourself, WHAT IS NEXT? This is truly what happened to me last month when my client and her son died on the same day. At the end of this day, I could not eat or drink anything. I found myself staring at nothing with tears running down my cheeks. I asked myself: will this ever end? Do I make any difference? What should we do and how shall we do it?

When I go to Church, I even start to wonder: where is God? How could this be happening to our people? There are days when you feel so bad, you just want to give up. But

then I feel Him, and I can keep going. I know this is what He wants. This is what I must do.

Even with these difficult situations, you do not stop taking care of patients and orphans because you know about the big need for our work. At the end of May I had five clients; four of them passed away in the beginning of June. The remaining one is seriously sick now.

To help my clients, I try to support the whole family by nursing the sick person while teaching the relatives how they can help, too. Sometimes I also clean their homes, cook for them if necessary, and accompany them to the hospital. But I think one of the most important things I do is to listen to their problems and fears and give support to them by counselling them and their families. For the orphans, I visit every week. Now I have 13 orphans, but some of them are sisters and brothers who live in the same household. Whenever we meet, they tell me of their feelings, and we talk and play together. Through this, I can find out whether they are safe and well taken care of and whether there is something else I need to do.

Because of the many losses we go through, we recognize the importance of caring for ourselves in order to care for others. We appreciate the chance to meet other people at this Conference and to get new ideas about how to cope with grief and loss. We want to feel stronger inside so that we can keep going with our work in caring for the sick and the orphans and in reaching out with new awareness and prevention programmes. Our beliefs need to be strengthened, too, so that we can help our fellow countrymen see the danger of HIV/AIDS, in order that they will change their behaviour to live as long as possible.

I think of our work like holding up a candle of hope to other people. But unless we also protect that candle, it will burn out. And with that, our whole nation may fall into darkness and ruin. We must make sure that won't happen because our work, and our nation, are too important. Thank you for caring.

members of the CHBC team. In addition, external evaluators will assess the quality of care during outcome evaluation. Quality of care indicators include the following.

### **Ill person**

- Educating the ill person on provision of care (see provision of care)
- Access to health care (free or affordable)
- Access to transport (free or affordable)
- Access to medicines, including herbal remedies (affordable or free)
- Access to medical supplies and equipment (affordable or free)
- Adequate symptom relief
- Use of universal precautions
- Adequate nutrition
- Provision of basic nursing care and comfort measures such as cleanliness of the ill person, general house cleanliness, adequate clothes and bedding
- Mobility of the ill person (where appropriate)
- Adequate heat and ventilation
- Access to psychosocial support and counselling, including voluntary counselling and testing
- Promoting shared confidentiality
- Reducing the family and community stigma associated with illness and care
- Adequate referral and access to community resources
- Satisfaction with the quality of care
- Improving the ill person's quality of life
- Improving the coping and empowerment of ill people

### **Family members**

- Adequate family education on the provision of care (see provision of care)
- Access to affordable or free health care, including medication, treatment, transport, supplies and equipment
- Access to community funds for destitute people or participation in income-generating activities
- Access and referral to community resources

- Access to psychosocial support and counselling, including voluntary counselling and testing
- Promoting shared confidentiality
- Reducing the family and community stigma associated with illness and care
- Respite from caregiving
- Satisfaction of family members with the quality of care and family support
- Improved quality of life for family members
- Improved family coping and empowerment

### **CHBC team members**

- Satisfaction of CHBC team members with providing high-quality care for ill people and family members (see indicators above)
- Adequate educational preparation of nurses, social workers, community health workers, community volunteers, physicians and other complementary health and social service personnel involved in CHBC
- Continuing education of CHBC team members
- Psychosocial support and counselling for CHBC team members (care for the caregivers)
- Acceptable quality of life for CHBC team members
- Adequate supervision and monitoring for effective care of ill people and their families
- Adequate and effective case management for care of ill people and their families
- Adequate and effective referral to other needed resources
- Access to transport to visit homes
- Access to adequate drugs, supplies and equipment for care in the home
- Access to community funds to support destitute families

### **Monitoring and supervision**

Monitoring the CHBC programme involves supervision (usually by a nurse) to ensure adequate and effective care delivery. Monitoring care activities might include conducting site visits to assess care and promoting peer supervision. In addition, access to essential drugs, supplies and equipment must be monitored and adequate staffing and continuing CHBC education must be provided. Statistics on the number of ill people accessing CHBC and their diagnosis and treatment regimens should also be monitored. Finally, financial accountability and budget management is also part of monitoring

responsibilities. In summary, CHBC monitoring includes:

- supervising care delivery;
- on-site visits and peer supervision;
- monitoring essential drugs, supplies and equipment;
- monitoring an adequate staff mix;
- monitoring CHBC education;
- recording statistics on the CHBC programme, such as the number of ill people, diagnoses, number of referrals and treatment regimens; and
- monitoring the CHBC budget.

### Informal evaluation

The CHBC supervisor (or another team member) is usually responsible for periodic informal evaluation. This evaluation often takes place about every 3–6 months. Measurement tools for informal evaluation should reflect the quality of care indicators outlined above. Members of the CHBC team should collaborate with members of the relevant funding agencies in developing these methods of informal evaluation.

### Formal evaluation

The time for formally evaluating the CHBC programme is often decided at the onset of the programme. This time-line is usually 3–5 years. Qualitative and quantitative research methods might be used. Formal evaluation is usually carried out by an external evaluator. The quality of care indicators will likely be covered in formal evaluation. However, indicators for formal evaluation should be decided upon by the evaluator in partnership with the CHBC team (including the ill person and family members). In addition, formal evaluation will attend to whether the CHBC programme met the overall goals and objectives developed for CHBC.

### Flexibility

Based on the informal and formal evaluation results, the CHBC programme should be flexible enough to make the necessary changes. However, these changes should be made in collaboration with the CHBC team and only after careful consideration. Once these changes have been made, they should be carefully monitored to ensure that they have the desired outcome.

In conclusion, this section has provided an overview of the essential elements of CHBC in resource-limited settings together with case studies to highlight important issues. However, establishing effective and sustainable CHBC requires viewing this section in relation to the other sections. The essential elements of CHBC must also reflect policy formation (see the first section), management and administrative issues (see the second section) as well as determining community action in establishing and maintaining CHBC in resource-limited settings (see the final section).





UNAIDS/B. Needelman

Doctors and nurses from the Central Hospital of Maputo in Mozambique make weekly home care visits to AIDS patients who are too weak to go to hospital, like this 25 year-old woman.

## ESTABLISHING AND MAINTAINING CHBC

This final section provides an overview of the action necessary to establish and maintain a CHBC programme. The essential elements of CHBC (from the previous section) are incorporated into this model for action at the community level.

Establishing new CHBC projects or scaling up existing programmes requires a systematic process of development. This systematic process includes: the entry phase, community assessment, needs assessment, planning, implementation and evaluation. The initial development of the CHBC programme should follow the phases in this order. However, as the programme becomes a reality, this process will become more circular and the step-by-step approach will no longer be necessary. Once the programme is up and running, maintaining community commitment and responding to the changing needs of ill people, families and the CHBC team are still important. Gathering resources and monitoring and evaluating the programme are also necessary. However, this will be more of an evolving process of continuing development at the community level.

Each phase in the framework is described, and the action to be taken is highlighted. Questions are posed within each phase to aid this movement to action. The responses to these questions should reflect the differing needs for CHBC within each programme or community setting. The “community” here refers to NGOs, faith-based organizations, community-based organizations and other community agencies. In addition, in times of crisis or where a community is not well established, implementing a small pilot project and then slowly building on success might be the best option. If implementing a small pilot project is considered to be the first step, then as the programme is scaled up, this process should be undertaken. In this way, community mobilization and monitoring will be established as resources unfold. Table 3 provides an overview of this framework for action at the community level.

### The entry phase: community assessment

To begin, a community team must be developed. This team will consist of people interested in improving CHBC in their community: developing a new CHBC programme or scaling up an existing one. The most important task in this phase is to learn as much about the community as possible. Many people assume they know their community (or agency). However, presenting new ideas can create resistance or disinterest. Therefore, having as much knowledge about the community or agency as possible can help in gaining acceptance of a scaled-up or new programme. This community assessment involves knowing about the structure of the health and social welfare system, existing agencies and organizations and the past history of the community and its physical characteristics, population, economy and power structures.

Table 3. Framework for community action

Phase of the process	Focus of attention	Major tasks of each phase
Entry phase: community assessment	The existing situation	<p>Create a community team</p> <p>Learn about the community</p> <p>Assess with the community team what is already being done and available in the community</p> <p>Discuss and plan for improving CHBC or new services</p>
Needs assessment phase	<p>The needs of family caregivers, ill people and paid and voluntary community workers</p> <p>Community acceptance</p>	<p>Gather information on the needs of ill people, caregivers and potential members of the CHBC team</p> <p>Learn what skills and resources already exist</p> <p>Involve key stakeholders and local community members in accepting and promoting CHBC</p> <p>Promote community mobilization</p>
Planning phase	How to respond to health and support needs	<p>Explore and choose methods to respond to the health and support needs and plan CHBC</p> <p>Obtain necessary resources</p>
Action phase	Community action	<p>Implement CHBC plans</p> <p>Evaluate what works well and what does not</p>
Renewal phase	Evaluation and responsiveness	<p>Determine what has been learned</p> <p>Make changes to programme as necessary</p> <p>Re-examine the evolving CHBC programme</p>

## The structure of the health and social welfare system

Learning about the health and social welfare system within the community and at the district level is important. Existing health and social welfare personnel (both paid and voluntary) working in the community hospital and local health centres are one of the most important stakeholder groups. As much information as possible should be collected about the roles and responsibilities of these health and social welfare personnel. Once this information is obtained, considering how CHBC will fit into these existing programmes will then be possible. The following checklist will help in guiding this assessment.

- What community health and social welfare services exist?
- Who is responsible for which service?
- Who has the authority for policy, programme, finance, personnel and evaluation?
- How does each service fit into the larger health and social welfare framework?
- What is the mix of health and social welfare personnel within each agency?
- What is the full complement of paid and volunteer health and social welfare workers?
- What CHBC services are already provided?
- How can CHBC be integrated into the mix of services?

## Community agencies and organizations

NGOs, faith-based organizations, community-based organizations and other community groups usually run numerous community-based programmes. It is important to know about these various agencies and services, to determine whether CHBC activities are included in their programmes and to consider how to collaborate with and complement these services. The following checklist can guide this assessment.

- List the NGOs, community-based organizations, faith-based organizations and other community groups.
- What are the roles and responsibilities of the service agencies?
- What is the complement of workers within each agency?
- Do these existing services coordinate and collaborate with one another?
- How do these existing services fit into the larger health and social welfare framework?
- How could CHBC fit into these existing structures and programmes?

## Past history

The past often affects the present. What has happened in the past in relation to community services might affect the start-up of a new CHBC programme. In addition, the history of previous programme successes and failures and past conflicts and alliances might affect the development of CHBC. Finally, people's perceptions and opinions of CHBC will determine how the CHBC programme accomplishes its goals. To learn about this history, the following issues should be addressed.

- How have previous community programmes been accepted?
- Which community programmes have been successful? What accounts for their success?
- Which community programmes failed? What accounted for this failure?
- What conflicts exist within the community? How can these conflicts be managed?
- What alliances are there in this community? How can these alliances be helpful in introducing a CHBC programme?
- What do people think about CHBC? Have they heard of this before? What is their opinion on how CHBC should be developed in the community?
- How can knowledge of this past history be used to support a CHBC programme?

## Physical characteristics of the community

The physical characteristics of a community can influence how CHBC is introduced and managed. Rural and urban areas differ, especially in relation to the availability of roads, transport and accessibility for ill people, family caregivers and CHBC personnel. In addition, slum areas require special consideration in planning and implementing CHBC.

Consideration also has to be given to whether the homes are dispersed or close to one another. Obtaining information about where people gather (such as community meeting places, schools and places of worship) is also important so that community meetings can be held to support CHBC. To obtain this information, the following issues should be assessed.

- Is this community rural, urban or a slum district?
- How far do people have to travel to collect water, cooking supplies and food?
- How far do people have to travel to collect medical supplies and equipment and visit the local health centre, pharmacies, community centre and other facilities?
- What is the typical house like? Are houses single-family dwellings or multi-family complexes?

- Are most of the homes overcrowded or not?
- What are the roads like?
- What is the transport system like?
- What kinds of businesses are there in this community? Will these businesses support or negatively affect CHBC?
- Where do people gather? For example, where are the schools, places of worship, bars, parks and community centres?
- How might these factors affect the health of the community as well as planning and implementing CHBC?

## Population

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Knowing the demographic characteristics of the community can help in assessing basic health needs and in determining how to effectively plan and implement CHBC. Many urban populations are predominantly younger than rural populations. However, this has been shifting as people return to rural areas when they become sick with HIV/AIDS.

HIV/AIDS orphans sometimes have to return to different communities to join their extended family. In addition, orphan-headed households might be either urban or rural. However, street children are usually found in urban areas.

Knowing whether the size of the population is stable, expanding or decreasing is also important. For example, many people have to leave an area to find work and either return periodically or send money to family members. This work migration can profoundly affect the community, especially the number of female-headed households.

The religious, ethnic and racial mix of the population is important to consider. Are there common languages and what are they? Are some minority groups included or excluded from the general community? Are some subcommunities marginalized, such as very poor and destitute people, commercial sex workers, drug traffickers or criminals? Again, these marginalized communities might greatly need CHBC, but their access to community resources might be limited. The following questions can be used to assess the overall population.

- What is the population mix of the community? Does the community consist of mostly older, middle-aged or young people?
- How many orphans are there in this community? Are these orphans mostly cared for by family members, foster care, orphan-headed households or orphanages or are they street children?
- Is the population increasing, decreasing or stable? If the population is changing, what is accounting for this change?
- Is this a stable population or is it mobile? Do community members tend to stay within the community or do they leave for work or for other reasons? If the community is mobile, what is the reason for this mobility?

- Are there subcommunities within this community? For example, are there different racial and ethnic mixes, languages, religious groups or marginalized communities such as commercial sex workers, drug traffickers and criminals?
- Are these subcommunities integrated into the community or marginalized? If they are marginalized, what effect does this have on these subcommunities?

## Economy

The overall economy of the community will greatly affect the health of the population and their ability to access CHBC (see the essential elements of CHBC in the third section). Knowing whether the average family income is adequate to meet the basic needs of the family is important. One of the most important issues is whether the community can help in supporting the sustainability of the CHBC programme. The following questions will guide this assessment.

- Is this community mostly poor or middle class?
- What is the major source of income in this community? Is the economy based on agriculture, industry or a mixed economy?
- Has the overall economy of the community changed recently? Has the overall community economy increased or decreased? How has this change affected the community?
- Does the community have enough people to support the local economy? Can the population support agriculture, industry or businesses within the community? If not, what is happening as a result?
- Are community structures and practices in place to help in supporting the overall economy of the community? Are there revolving funds, community income-generating activities, taxes or other sources of income to help in supporting the economy of the community?
- If the overall economy of the community is poor, are any outside funding sources available? Do these outside sources contribute to the overall economy of the community?
- If people are destitute within the community, are there community resources to help them? How are these resources assessed?
- How do these issues affect the planning and implementation of CHBC?

## Power structures

Knowing who the most powerful and influential people are in the community is important. These people are often known as the gatekeepers to the community and can be either formal or informal. Formal gatekeepers might include community leaders, spiritual leaders, members of faith-based organizations, members of NGOs and community-based organizations and mass media personalities. There are also informal gatekeepers who can exert enormous influence on a community. This influence is more hidden and difficult to determine.



Both formal and informal gatekeepers can either make or break a community initiative. Determining who these people are and where their interests lie is therefore important. It is also important to discover how they can be brought on board. The following questions will help in assessing the power structures within a community.

- Who are the most powerful and influential people (both formal and informal) within this community?
- How do these powerful people respond to the health and social welfare needs of the community?
- How do these gatekeepers respond to change?
- What is the best way to approach these powerful and influential gatekeepers?
- What are the channels of communication (both formal and informal) within the community? Who talks to whom about what?
- How might these formal and informal gatekeepers help or hinder the planning and implementation of CHBC?
- How can these gatekeepers be brought on board to assist in developing CHBC?

While the community is being assessed, the community is also assessing the planners of CHBC. People who enter the community with no prior relationship can take nothing for granted. Norms, values, customs have to be learned, as a new person can unwittingly offend. However, new people have no prior history to overcome. People who already live in the community have to re-establish themselves in this new role. In this instance, past history plays an important role. Was the person valued in his or her former roles and responsibilities? If this is the case, this reputation can be helpful in supporting a new CHBC programme. If, based on past experience, the person is uncertain about how the community will perceive her or him, then making a fresh start might be difficult and some relationship-building will be important.

Note that programme planners often exclude community members from participating in the assessment and sometimes even miss this community assessment phase, as it seems to be a waste of time. However, experience shows that doing this preliminary groundwork makes a critical difference between programmes that succeed and those that fail.

## The needs assessment phase

The needs assessment phase consists of several important steps. First, the health needs of ill people, families and the CHBC team must be assessed. Next, it is important to gain community acceptance for the CHBC programme and to assess the needs of the larger community. It is also important to choose priorities for the CHBC programme: implementing all the issues related to CHBC at once is unlikely. Finally, the CHBC team and the broader community must commit to action.

## Assessing the needs of the target group

The specific needs of ill people, families and paid and volunteer health and social welfare personnel must be assessed. This assessment can then become part of the action plan.

The needs assessment phase is also a time to continue gaining community acceptance and to determine priority needs. For example, CHBC planners might consider a constant source of home-based care kits to be a priority need. However, others might identify access to affordable transport as a priority need. The overall needs of the target group must be taken into account and then priorities set. To aid in this needs assessment process, the following issues should be addressed.

- What are the home-care needs of ill people? Can they set priorities among these needs?
- What are the needs of orphans? Can they set priorities among these needs?
- What are the home-care needs of family members? How would they set priorities among these needs?
- What are the needs of paid health and social welfare personnel for the development of a CHBC programme? How would they set priorities among these needs?
- What are the needs of community volunteers for the development of a CHBC programme? How would they set priorities among these needs?

## Gaining acceptance and assessing community needs

Three sets of people within the broader community are very important in gaining acceptance and assessing needs: the initiators of the programme, the legitimizers and the community action group.

The initiators of the programme are people who decide there is a problem and decide that something needs to be done. The second group are the legitimizers who have a reputation for acting on various community needs. Legitimizers are opinion leaders who can either make or break a new project. The initiators should take the need for a CHBC programme to the legitimizers. These legitimizers can then support the proposed programme. This stamp of approval should be obtained from formal legitimizers before the project is taken to the community as a whole.

The people who introduce the programme to the larger community should be respected members of the community. These people become the community action group, involving the overall community in identifying needs and suggesting possible solutions. As these people gather this information, they and other community members become more committed to doing something about the situation. Gaining community acceptance requires addressing the following questions.

- Who are the initiators of the CHBC programme? What role have they played?

- Who are the legitimizers or opinion leaders in the community? Who in the community has the reputation of getting things done?
- How can these legitimizers be brought on board to support the CHBC programme?
- Who are respected community members who could form the action group?
- What are the identified needs of the broader community in relation to CHBC?
- What solutions are suggested to these broad community needs?
- How can the community be mobilized?

### Choosing priorities

Setting priorities for CHBC depends on several important factors. First, the priorities should reflect the needs assessments done with the target group and the overall community. However, priorities also depend on whether staff (both paid and voluntary) are available for the programme and whether funding is in place to allow the programme to be implemented. These priorities will also depend on whether this is a new programme or the scaling up of an existing programme.

Some elements of CHBC may take longer to implement than others. Decisions therefore have to be made about which aspects of CHBC can be implemented immediately and which aspects might be implemented over an agreed time frame. In addition, some resources might already be available within the community to support CHBC, whereas other resources might need to be developed. Tapping into available resources would therefore take priority over developing new resources. For example, medicines and supplies might be provided to the home through the resources of the local health facility, whereas providing adequate education for the target group could take more time to plan and implement.

The philosophy of starting easy is useful. Start with resources that are available, affordable and accessible for CHBC. Then, based on the needs assessment, set priorities among the needs and develop a plan to implement these resources. The following questions will help in setting priorities among needs.

- What are the priority needs of the target population?
- What are the priority needs of the broader community?
- Can the CHBC programme address these priority needs?
- Is the staffing mix adequate for CHBC?
- Are sustainable funds and mechanisms in place to support the CHBC programme?
- Are there other community resources to help in supporting CHBC?
- What is a manageable time line for planning and implementing CHBC?
- Can these priorities begin by starting easy and building on success?

## Gaining commitment to action

People are not necessarily willing to act just because they agree with a programme. Gaining a commitment to action is therefore important. This action might include deciding on a time frame, recruiting people for certain activities, inviting people to participate in other aspects of the programme, developing a CHBC committee, planning community meetings and creating funding opportunities. Thus, mobilizing the community is an important step in developing a CHBC programme. The following questions will help to promote this movement towards action.

- Who should be recruited to act on the CHBC programme?
- Who from the larger community should be invited to participate in developing CHBC?
- Who should sit on the CHBC committee?
- How can meetings be well attended? Who should be recruited to mobilize community meetings?
- Who should be involved in creating funding opportunities?
- What funding programmes should be considered?
- What is a manageable time frame for planning and implementing CHBC?

Do not proceed further until enough information has been gathered and there is general agreement on and commitment to the CHBC programme. Without adequate information and the beginning of community commitment, the chances of success are slim. If a programme is started and then becomes blocked, not only will this waste time and effort but people might begin to feel discouraged. This could actually damage plans for the future of the CHBC programme.

## The planning phase

There are four aspects to planning a new or scaled-up CHBC programme: deciding who should be involved in the planning process; identifying and assigning the tasks to be undertaken; developing goals and objectives for the programme; and working out the details of implementation.

### Who should be involved in the planning process?

Involving the target group in planning CHBC is very important. Ill people, families and paid and voluntary health and social welfare personnel should be involved in this planning process. Not all these people can be involved. Decisions must therefore be made about who should represent each of these different target groups.

Next, people active within the community should be involved. People who can influence the development of CHBC and its eventual outcome should also be involved in this planning process. The following questions will help in deciding who should be involved in planning.

- How will health and social service professionals be recruited to work on planning CHBC?
- How will community volunteers be recruited?
- How will ill people and families be recruited to work on planning CHBC?
- How will orphans be recruited to this planning process?
- How many people in the target groups are necessary to adequately represent this population?
- Who are the community activists? Are these people respected by the community and known for their ability to get things done?
- How can these community activists be recruited to work on planning CHBC?
- Who are the influential people within this community that could help to promote the programme?
- How can these influential people be recruited to help with planning CHBC?
- What other community members should be invited to work on planning the CHBC programme?

### Identifying and assigning tasks

The initial plan should include a statement of need with background information about the priority needs for CHBC. Including a values statement about how the programme should be run is also important. The overall goals and objectives for CHBC should then be developed. In addition, the roles, tasks and time frames for the programme should be identified. At this stage, an evaluation plan for CHBC should be developed. Finally, a budget should be presented. This budget should also contain a list of resources required to effectively implement or scale up the programme. Plans on how to obtain these necessary resources should also be included.

As these tasks are identified, relevant individuals and groups should start planning how these tasks will be accomplished and who will take action. To aid this process, the following questions should be addressed.

- Has a CHBC planning committee been established?
- Has the CHBC committee identified the tasks to be accomplished?
- Have the roles, tasks and responsibilities for scaling up or developing a new programme been established?
- Have the time frames been set?
- Has a CHBC evaluation plan been established?
- Has a budget been planned?

- Have plans been made to address the need for sustained funding, including community income-generating projects?
- Has a list of community resources been developed to help in supporting CHBC?
- Have people working in these different community resources been contacted and asked to be involved in overall collaboration for CHBC?
- Have gaps in services related to CHBC been identified? Have plans been made to address these gaps in services?

### Developing goals and objectives for the programme

The goals and objectives for the CHBC programme should be based on the identified priority needs of the target group and the broader community. The goal for CHBC should reflect the norms, values and philosophy identified by community and agency representatives in the planning phase. Once the overall goal or mission statement has been created, then specific objectives for CHBC can be developed. These objectives should include the priority needs of the target group as well as those of the broader community. To that end, the following questions should be addressed.

- Has the planning committee established the norms, values and philosophy on which the CHBC programme will be established or scaled up?
- Have the goals for CHBC been developed from the priority needs of the target group and the broader community?
- Have the objectives and sub-objectives been developed from these identified goals?

### Working out the details for implementation

Once the goals and objectives have been identified, plans should be made for how they can be put into action. Tasks and time schedules should be identified and decisions made about who will undertake the action. A resource plan must also be developed. This plan should address adequate funding, collaboration with other community services and resources and how to develop or obtain resources that are not available within the community.

Developing needed resources usually requires considerable creativity, as additional resources cost money and take time to develop. For example, educational materials might be found that other communities have used to teach ill people, caregivers and health and social welfare personnel. These materials can then be adapted for teaching in this community. However, finding community resources for a school bursary fund for orphans might not be possible. If outside resources are not available, this resource will have to be planned for and budgeted within the CHBC programme.

Finally, plans for evaluation should be made at the same time that the plans for CHBC are developed. Both formal and informal evaluation (see the essential elements in CHBC in the previous section) should be developed at the onset of the CHBC programme. To attend to these details, the following questions should be considered.

- Who will be responsible for working on each objective?
- What is the time frame for each objective?
- Who will be responsible for communicating and collaborating with other resources and services within the community?
- Who will be responsible for identifying gaps in services?
- Who will be responsible for creating ways to fill these service gaps?
- How will creative funding for CHBC be promoted? Who will be responsible for working on creative funding issues?
- Who will work on an evaluation plan?
- How will informal evaluation be undertaken? How often will these informal evaluations take place?
- How will formal evaluations be established? How often will these formal evaluations be undertaken?

## The implementation phase

Implementation means putting into action all the plans that have been developed in the previous phase. This phase also includes the essential elements of CHBC outlined in the previous section. To that end, implementation should address issues related to the provision of care, continuum of care, staffing, education, supplies and equipment and funding of the programme. The questions to be addressed in the action phase therefore include the following.

### Provision of care

- Has a list of the physical care needs of ill people been developed?
- Has palliative care been included in CHBC?
- Has attention been paid to the psychosocial and counselling needs of ill people, families and members of the health care team?
- Have strategies been put in place to help in reducing caregiver burnout?
- Have strategies been put in place to help in reducing HIV/AIDS stigma?
- How is orphan care to be established in CHBC?

### Continuum of care

- Have strategies been developed to help people in accessing CHBC?
- Has a system of transport been developed? Who will monitor this system and how?
- How will the transport system be serviced and maintained?



- What is the record-keeping process for CHBC? How are records kept and monitored?
- Has a referral system been developed? Is the referral and tracking of ill people monitored?

### Staffing

- Have key coordinators for CHBC been identified and recruited?
- Have health and social welfare staff been recruited to CHBC?
- Have community volunteers been recruited to CHBC?
- Have methods of staff retention been established (such as honoraria or in-kind payments)?
- Have CHBC teams been developed? What is the staff mix for these teams?
- Have CHBC supervisors been recruited and trained?

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### Education

- Has the content of the CHBC training curriculum been developed? Have curricula from other communities been adopted and adapted for use in this community?
- Are members of the CHBC team being trained?
- Have educators been hired?
- Has a process for managing CHBC team education been developed?
- Have community education projects been established?
- Have criteria for evaluation of education been established?

### Supplies and equipment

- Has a location for CHBC management been found?
- Has a list of essential drugs for CHBC been developed?
- Has a list of equipment and supplies for CHBC been developed?
- Have lists for CHBC kits been developed?
- Has the ordering system been developed to ensure a constant supply of necessary equipment, supplies and CHBC kits?
- Have adequate storage facilities for supplies and equipment been found?

## Funding

- Have partnership agreements between governments, NGOs, faith-based organizations and community-based organizations been established to fund CHBC?
- Has a budget for CHBC been established? Who will monitor this budget?
- What fundraising activities have taken place? Have they been successful?
- Have collaboration and partnership been established with other agencies and organizations?

## Evaluating the process and outcome of CHBC

Between each of the action steps in the community development process, it is important to stop and evaluate what has been done, how well it was achieved and whether changes should be made. However, as the programme becomes a reality, this evaluation process will become more circular and this step-by-step approach will no longer be necessary. Once the programme is up and running, maintaining community and agency commitment and responding to the changing needs of ill people, families and the CHBC team are still important. In addition, gathering the necessary resources and monitoring and evaluating the programme will still be important. However, this will now become an evolving process of continued community development. Evaluation has two important aspects: informal evaluation occurs regularly and is usually undertaken by the CHBC team, and formal evaluation is usually undertaken by an outside evaluator. In addition, supporting necessary change, celebrating success and continuing the processes of evaluation are important elements to consider as the CHBC programme evolves.

### Informal evaluation

Informal evaluation monitors the programme on a regular basis. This form of evaluation is usually done by checking with the target group members (ill people, family members and members of the CHBC team) about how the CHBC programme is working and whether it is meeting the needs of the target group. Such informal evaluations can take place during home visits and at team meetings. Even though this evaluation is done on a regular, somewhat informal basis, it should become part of the overall work of CHBC. The results of these evaluations should be monitored and recorded and plans established to improve services and care where necessary.

The quality of care indicators presented in the previous section (the essential elements of CHBC) should be used for informal evaluation. In addition, the following issues should be addressed in planning and implementing informal evaluation.

- Who is responsible for developing the criteria for informal evaluation?
- How often is informal evaluation done?
- Who is responsible for making sure that informal evaluation is undertaken?

- Who is responsible for making necessary changes to the CHBC programme?
- Are ill people, family members and members of the CHBC team involved in these informal evaluations?
- How are these informal evaluations recorded?
- Have the results of informal evaluations been shared with the target group (ill people, orphans, family caregivers and members of the CHBC team)?
- How are the necessary changes implemented?

### Formal or outcome evaluation

The second form of evaluation is more formal and often involves outside evaluators. The purpose of formal evaluation is to evaluate the outcomes of the CHBC programme. Outcome evaluation addresses the overall goals and objectives of the programme and assesses whether the programme met these overall goals. In addition, the quality of care indicators identified for use in formal evaluation should also be used (or adapted) for outcome evaluation. The following issues should be addressed to guide the development of outcome evaluation.

- Were plans for a formal or outcome evaluation of the CHBC programme planned at the onset of the programme? That is, are plans in place to conduct an outcome evaluation of the CHBC programme within a given time frame?
- Who is responsible for developing the criteria for formal evaluation?
- Who will be responsible for ensuring that outcome evaluation is performed?
- How will outcome evaluation be funded? Who will be responsible for obtaining funds? Where might these funds be found?
- Who will conduct formal evaluation? Will outsiders be asked to conduct this evaluation?
- Are the goals, objectives and sub-objectives of the CHBC programme clearly identified so that the outcome evaluator can evaluate the programme based on these stated purposes and objectives?
- Have the results of informal evaluation (including the actions taken) been incorporated into the formal evaluation process?
- Have plans been established to share the results of formal evaluations with the target group (ill people, family members, orphans and members of the CHBC team) and with members of the broader community?

### Support and reinforcement as changes are made

The results of both the informal and formal evaluations should be shared with the people involved in CHBC. The target group should be intimately involved in assessing what changes are necessary and how these changes should be implemented and later evaluated. In addition, members of the target group should be supported if changes are to be made. Change, even when it is

considered necessary, can be disruptive and stressful. Support and reinforcement for the change are therefore probably necessary. To that end, the following questions should be considered.

- Based on the results of both formal and informal evaluation, are the target group and members of the broader community involved in CHBC participating in determining what changes are necessary and how these changes will be made?
- Have the target group and the broader community been supported as the results are identified and the recommended changes to the programme are undertaken? Has the process of change been acknowledged as a sometimes stressful and disrupting experience?
- Have necessary changes to the CHBC programme been made?

### Celebrating success and the people involved

Presenting evaluation results often provides an opportunity for celebration. This important element in programme development is too often forgotten. Successes should be celebrated and people should be honoured for their contributions. These celebrations can take place at the same time that decisions are being made on how to respond to the changing needs of the target group and the broader community. In this way, both celebration and change are essential components of effective evaluation. To that end, the following issues should be considered.

- Have the results of the evaluation been celebrated? Has the broader community acknowledged the successes of the CHBC programme? Have community celebrations taken place?
- Were the people involved in CHBC (both the target group and the broader community) acknowledged for their contributions to CHBC? How were these acknowledgements made?

### Continuing the evaluation process

Evaluation is a continual part of the CHBC programme. Informal evaluation should continue on a regular basis and changes should be made to the programme where necessary. In addition, a time frame should be set for the next formal evaluation. Thus, effective and sustainable CHBC should evolve and change based on the needs of the target group and the broader community. Without this continual feedback loop, the CHBC programme could become obsolete and no longer meet the changing needs of the community.

In conclusion, this framework for community level action identifies five phases, including community assessment, needs assessment, planning, implementation and evaluation. Not all the phases of the community action framework will be visible. The implementation phase might be the only activity that is obvious to the broader community. However, the fact that nothing is visible does not indicate that nothing is happening. The invisible parts of the process are crucial. Establishing rapport with the community, learning about priority needs and gaining acceptance for the CHBC programme comprise the groundwork that generates successful community programmes.

## CASE STUDY 15

### Participation of people with HIV/AIDS: New Life Friend Centre, northern Thailand

“So long as I breathe ... I shall dream.”

The New Life Friends Centre was founded 12 years ago by people with HIV/AIDS. The overall goal of the Centre is to act as a central meeting place for people with HIV/AIDS and to provide support and care for people affected or infected by HIV/AIDS in northern Thailand. The Centre is governed and run by administrative and advisory committees that are responsible for planning and conducting the work of the Centre and for supporting a large network of members throughout northern Thailand. The main activities of the Centre include promoting effective coping, gaining acceptance, sharing information, advocacy and CHBC.

*Promoting effective coping.* Group meetings are held at which the Centre members provide advice, help to solve problems and exchange ideas on coping strategies in daily life. One of the most important elements is the care members provide to one another. They make sure that people eat well, rest and take their medication. People with HIV/AIDS sometimes live in the Centre for a week or two until they either return to their families or find a place to live.

*Gaining acceptance.* A team from the Centre holds outreach sessions in the community where issues related to HIV/AIDS are discussed. These sessions focus on promoting greater acceptance of HIV/AIDS in the broader community and on helping to build good relationships between people with HIV/AIDS and their family members.

*Sharing information.* A newsletter is published periodically on AIDS-related information and Centre activities. Pamphlets and leaflets related to HIV/AIDS treatment and care are also distributed. Members also act as advisers to visiting groups of people with HIV/AIDS to help in strengthening and supporting new organizations. The

Centre provides training sessions on HIV counselling and care for volunteers with HIV/AIDS. Attrition rates can reach 50% as the volunteers die, which necessitates frequent training sessions.

*Advocacy.* Members of the Centre accept invitations to speak and participate in conferences and seminars. They also act as coordinators between people with HIV/AIDS and related government organizations and NGOs. The Centre members attempt to develop good relationships with health care personnel and to help the people with HIV/AIDS in negotiating the health care system. They also act as advocates for appropriate treatment and care. This includes advocating appropriate pharmaceutical treatments and the use of traditional herbal remedies.

*CHBC.* Every member of the Centre participates in CHBC. Families often experience considerable stress in caring for people with HIV/AIDS at home. Centre members therefore provide emotional support and education to family members. This education includes information on how the disease might progress and how to provide treatment and care for the people with HIV/AIDS. With additional education and support, the family members are able to cope with the illness and help in improving the quality of life of the people with HIV/AIDS. The Centre also provides support and caring to the bereaved family.

The New Life Friend Centre was founded and continues to be run by people with HIV/AIDS in northern Thailand. As such, this Centre is responsive to the needs of people with HIV/AIDS and their family members. The Centre supports, educates and advocates better care for people with HIV/AIDS and their families. In particular, the Centre provides group support to people infected and affected by HIV/AIDS. It also provides education to the broader community and advocates access to appropriate treatment and provides support and care for people at home.

This community process is rarely smooth. Sometimes it is necessary to back up and do something again, a little differently. This process may appear slow and frustrating at times. However, trying to skip a step can lead to much greater problems in the future. The real value of this process is in how it helps in empowering individuals and communities to identify their own needs and decide what to do about them. The process gives communities control over their own issues. Because the process builds on the strengths of individuals, groups and communities, the talents and resources of the community can be developed and built on. This leads to building community capacity with less reliance on outside government funding. This does not mean that government or donor funding should not be provided but that the strengths and capacity of the community can help to sustain the CHBC programme over the long term.



UNAIDS/G. Prozzi

Wherever they live, HIV infected people can participate in caring for themselves.

## CONCLUSION



WHO/Miriam Hirschfeld

Home care can help this woman and her child in many ways.

CHBC has been defined as any form of care given to sick people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities.<sup>1</sup> This document has provided a systematic framework for establishing or scaling up CHBC programmes in resource-limited settings for people with HIV/AIDS and other chronic illnesses. To that end, this document is divided into four interrelated sections. First, a policy framework for CHBC was presented. This was followed by the roles and responsibilities for CHBC at the national, district and local levels of administration. The essential elements of CHBC were then presented together with strategies for action to establish and maintain CHBC in resource-limited settings. As such, this document provides a comprehensive overview of the issues and challenges of developing and sustaining CHBC.

CHBC is an evolving process whereby policy-makers and community groups adapt to the changing needs of ill people and families. The stage of the HIV/AIDS epidemic and the ratio of people with HIV/AIDS to those with other chronic and terminal illnesses dictate different priority needs. Throughout this document, questions were posed to stimulate thought and discussion and to aid in developing policy and in effectively planning and managing CHBC.

1 WHO. AIDS home care handbook. Geneva, World Health Organization, 1993 (document WHO/GPA/IDS/HSC/93.2).



Answers to these questions should reflect the evolving needs for CHBC that can only be found within individual countries, taking into account the economic, political, social and cultural norms and values of the country and/or community. In addition, some questions are more relevant to policy-makers and senior administrators, whereas others are more relevant to CHBC programmes.

Although this document provides a framework for establishing or scaling up CHBC in resource-limited settings, some countries and community agencies can implement more of these strategies than others. Smaller NGOs, faith-based organizations and poorer communities may not be able to implement the entire complement of services described here. Community programmes therefore need to start by setting priorities among their needs and activities.

Greater involvement of people with HIV/AIDS and their family members has been advocated. Sufficient evidence is now available to highlight the necessity of their full participation in developing, implementing and evaluating CHBC programmes. Case study 15 provides an example of how people with HIV/AIDS in Chiang Mai, Thailand developed, managed and advocated for ill people and families in community projects and in home-based care.

In conclusion, it is hoped that this document will provide a guidance framework and suggestions to governments, international and national donor agencies, NGOs, faith-based organizations, community-based organizations and community groups as they undertake the important challenge of establishing and maintaining effective and responsive CHBC in resource-limited settings.

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