May 2002

Republic of Kenya
Ministry of Health
In collaboration with
National AIDS Control Council

National Home-Based Care Policy Guidelines

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Home Based-Care for People Living with HIV/AIDS

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List of Abbreviations

ACC	AIDS Control Committee
ACU	AIDS Control Unit
AIDS	Acquired immune deficiency syndrome
CACC	Constituency AIDS Control Committee
CBO	Community-based organization
CHW	Community health worker
DACC	District AIDS Control Committee
DHMT	District Health Management Team
DOT	Directly observed therapy
HBC	Home-based care
HIV	Human immuno-deficiency virus
IEC	Information, education, and communication
KEMRI	Kenya Medical Research Institute
MTCT	Mother-to-child transmission
MCH	Maternal/child health
MOH	Ministry of Health
NACC	National AIDS Control Council
NASCOP	National AIDS/STD Control Programme
NGO	Non-government organization
PACC	Provincial AIDS Control Committee
PHC	Primary health care
PLWHA	Person living with HIV/AIDS
STD	Sexually transmitted disease
TB	Tuberculosis
TOT	Training of trainers
VCT	Voluntary counselling and testing
WHO	World Health Organization

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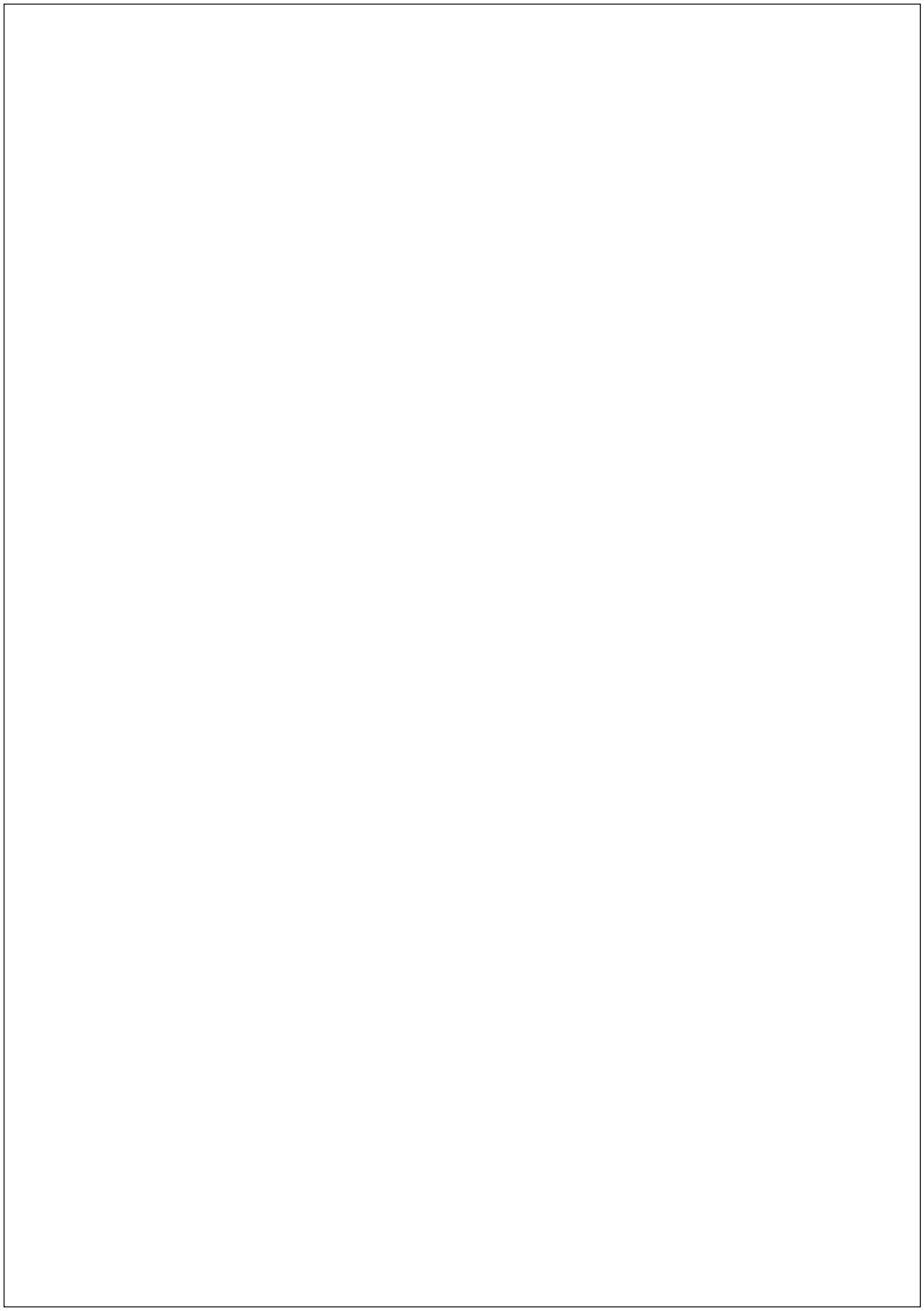
List of Abbreviations



Foreword

The small emblem that appears above and on the cover of this booklet carries a big message about the commitment of the Government of Kenya to reduce the impact of the HIV/AIDS epidemic. The separate elements of the emblem will be familiar to most of us, yet they are combined in a new and significant way.

Today almost everyone will know that the red ribbon represents AIDS. And the family is just that – a family, but with the red AIDS ribbon superimposed to indicate that HIV/AIDS is not an affliction of individuals only, it affects everyone. The heart is widely recognized as a symbol of love and caring. The green, too, is significant: Green is regarded by many as the colour of hope. Thus the small emblem portrays an AIDS-stricken family surrounded by a heart full of hope and caring. That is the message of home-based care.

Home-based care is an approach to care provision that combines clinical services, nursing care, counselling and psycho-spiritual care, and social support. It represents a continuum of care, from the health facility to the community to the family to the individual infected with HIV/AIDS, and back again. The Government regards home-based care as a viable mechanism for delivering services because it has important benefits for everyone on that continuum.

The purpose of this policy guideline, then, is to ensure the integration of home-based care into Kenya's existing health care system. The guide first summarizes the existing policy framework defining and supporting home-based care. With that foundation, it then presents the preferred approach to programme design and service delivery. The need is urgent, as individuals and organizations throughout the country are striving to improve

the quality of life of persons living with HIV/AIDS and their families. There are hundreds of thousands of such Kenyans, struggling to come to terms with their HIV-positive status and to cope with the illness and disability that come with AIDS. They need all our care and compassion, and the Government is committed to looking beyond prevention to the quality of life of persons living with HIV/AIDS.

Home-based care will help us do just that, as it helps us change attitudes towards persons living with HIV/AIDS and towards the disease itself. Home-based care recognizes that a diagnosis of HIV does not necessarily mean death is at hand, and it helps reduce the stigma attached to the disease. Home-based care can provide the support that will enable HIV-positive persons to extend their productive lives for many years, "living positively" in the fullest sense of the word.

Nevertheless, the disease remains without cure and without a vaccine, and is ultimately fatal. We must continue our prevention efforts with utmost diligence. Here, too, home-based care has an important role. When community members provide care to their family members, neighbours, and colleagues, they not only increase access to care, but become involved in prevention activities. Everyone benefits.

We hope that the use of this policy guide will go a long way toward realizing the Government's commitment to ensure that those infected and affected by HIV receive quality care, in their homes and in their communities.

Prof. Julius S. Meme, EBS, FAAP
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Ministry of Health
Republic of Kenya
May 2002

1 Background

The HIV/AIDS epidemic in Kenya has moved beyond public health crisis to a personal, community, and national development catastrophe. Because the epidemic acts at all these levels, efforts to contain it must also act at individual, community, and national levels. One important way of addressing the epidemic at these points is by developing systems, strategies, and capacities to provide care for people living with HIV/AIDS (PLWHAs) within their own homes and communities.

Home-based care represents a partnership in care that has many advantages for the PLWHA, for the PLWHA's family, for the community, and for the health-care system. Home-based care is not only an important mechanism for extending the continuum of care by providing at home the basic nursing care and treatment necessary for many of the afflictions that strike PLWHAs. It also promotes community awareness of HIV/AIDS, provides powerful examples to motivate behaviour change and decrease the stigma attached to the disease, and enables PLWHAs to maintain their family and community roles. Home-based care is cost effective as well. It frees up hospital beds and medical personnel for the acutely ill and thus relieves the burden on the health care system.

1.1 Policy Goal

Clearly, home-based care for PLWHAs has an important place in Kenya's health care system and in the strategy for combating the AIDS epidemic. These policy guidelines therefore intend to ensure that home-based care is thoroughly integrated into existing health services. The policy guide summarizes the existing policy framework supporting home-based care and sets out the Government of Kenya's approach to this care modality. It defines home-based care and presents the rationale and guiding principles, spells out the components that home-based care programmes are expected to comprise, and outlines the programmatic standards and the requirements for service delivery.

The policy also describes the players, activities, training, referral mechanisms and support services, resources, and monitoring and evaluation. And it reminds us of the rights and responsibilities of persons living with HIV/AIDS and the roles of the family, the community, and the government in the home care system. The policy is intended to be explicit enough to provide a workable framework, but flexible enough to permit a synergetic variety of home care approaches.

The audience for the policy is multifaceted: policy makers, health care professionals, community health committees, and AIDS Control Committees at all levels. The policy should also be an important resource to programme planners, coordinators, and evaluators.

1.2 Definition of Home-Based Care

The Kenya National HIV/AIDS Strategic Plan 2000–2005 defines home-based care in the following way: "Home-based care includes the care given to the sick and affected in their own homes and care extended from the hospital or health facility to their homes through family participation and community involvement. This is a collaborative effort between hospital, family and community. It includes components such as physical, psychological and spiritual support".

1.3 Rationale for Home-Based Care

The rationale for emphasizing home-based care rests in its benefits to PLWHAs, the families of PLWHAs, the community, and the healthcare system:

- Home-based care allows ***persons living with HIV/AIDS*** to take responsibility for their own welfare and well-being; receive care in a familiar environment; continue participating in family affairs; retain a sense of belonging to social groups; and accept their condition more easily.
- Home-based care contributes to ***family*** solidarity; helps the family accept the infected person's condition; makes it easier to provide care/support; can reduce health care costs; and makes it easier for family members who provide care to attend to other responsibilities.

- At the ***community*** level, home-based care helps reduce health care costs; affords opportunities for community members to confront stigma and provide support to persons living with HIV/AIDS; contributes to community cohesiveness; and raises awareness about the causes and impact of HIV/AIDS.
- The ***health care system*** benefits because home-based care helps ease the demand on health care facilities; does not require the creation of extra services where none exist; and extends responsibility to individuals, families, and communities.

1.4 Foundational Principles of Home-Based Care

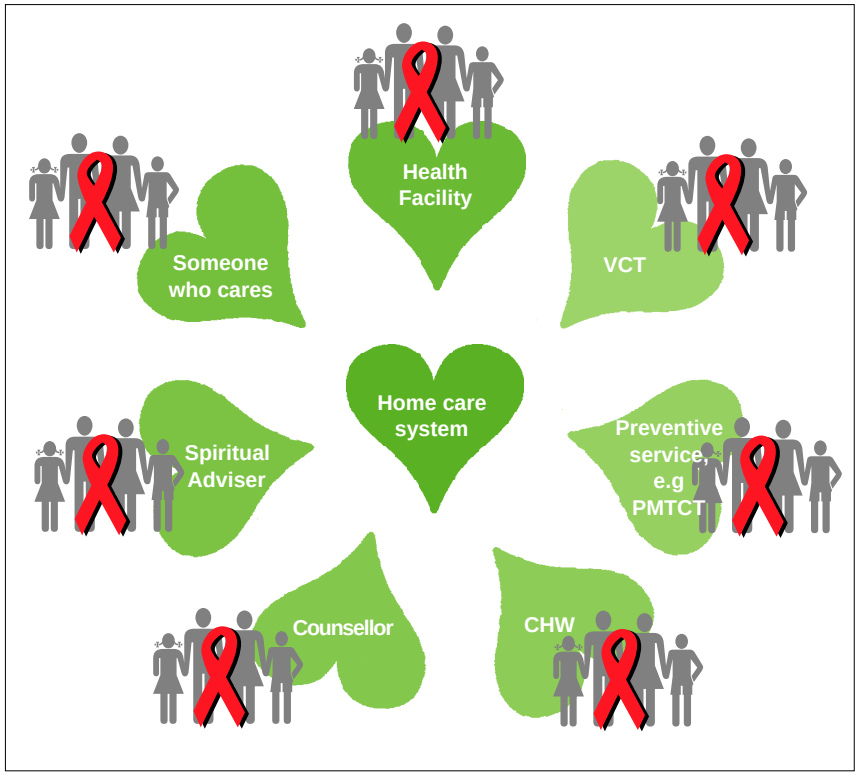
To ensure that the foregoing benefits are realized, home-based care should be regarded as a holistic system of care with provisions for:

- Ensuring appropriate, cost-effective access to quality health care and support to enable persons living with HIV/AIDS to retain their self-sufficiency and maintain quality of life.
- Encouraging the active participation and involvement of those most affected – the persons living with HIV/AIDS.
- Fostering the active participation and involvement of those most able to provide support – the community at all levels.
- Targeting social assistance to all affected families, especially children.
- Caring for caregivers, in order to minimize the physical and spiritual exhaustion that can come with the prolonged care of the terminally ill.
- Ensuring respect for the basic human rights of PLWHAs.
- Developing the vital role of home-based care as the link between prevention and care.
- Taking a multi-sector approach to care and support.
- Addressing the reproductive health and family planning needs of persons living with HIV/AIDS.
- Instituting measures to ensure the economic sustainability of home care support.

- Building and supporting referral networks/linkages and collaboration among participating entities.
- Building capacity at all levels – household, community, institution.
- Addressing the differential gender impact of the HIV/AIDS epidemic and care for persons living with HIV/AIDS.
- Monitoring and documenting activities to form the basis for sharing lessons learned.

Because home-based care represents a continuum of care, entry into the system can be at many points along the way (Figure 1).

Figure 1: Entry into the home-based care system



2

The Policy Framework

The Government of Kenya has long recognized the importance of a national policy response to the AIDS epidemic. The AIDS Programme Secretariat was established in 1985 to control the spread of HIV. Subsequent steps included the establishment of the Kenya National AIDS Control Programme in 1987 and the development of successive medium-term five-year strategic plans (1987–1991 and 1992–1996) for containing the epidemic and its impact. The first of these strategic plans focused, among others, on awareness creation, a safe blood supply, and management of opportunistic infections. The second plan built on these, and added emphasis on mobilizing a broader national response and the need to provide care and social support to persons with HIV/AIDS and their families and communities.

2.1 National Development Plans

The Seventh National Development Plan and the Fifth District Development Plan both included chapters on HIV/AIDS. Subsequently, the recognition of the link between sexually transmitted diseases and HIV transmission led to the broadening of the mandate of the AIDS Control Programme and the establishment of the National AIDS/STD Control Programme (NASCOP) in 1992. An early activity of NASCOP was the development of the first draft guidelines for home- and community-based care of HIV infected persons, including resource and training requirements.

2.2 Sessional Paper No. 4 of 1997

During this period, as well, the Government sought additional assistance from international donors to provide the resources for financing HIV prevention and care. To ensure the most effective use of these resources the Government, through a highly participatory process, developed Sessional Paper No. 4 of 1997 on AIDS in Kenya,

which provides a comprehensive policy framework for combating the AIDS scourge on a national level. Among other important measures the Sessional Paper called for the establishment of a National AIDS Council to expedite HIV prevention and control activities at national, provincial, district, and community levels, and to coordinate all inter-ministerial AIDS functions and other actors from non-government and community-based organizations to religious groups, the private sector, and donors.

The Sessional Paper has many provisions that lay the groundwork for home-based and community care for persons living with HIV/AIDS. Chapter 3 refers to "care and support for the infected and affected [that] facilitates their integration into society thus reducing discrimination, stigmatisation and isolation" and emphasizes "community specific interventions coupled with advocacy on social-cultural issues". Related to home-based care, Chapter 3 also calls for:

- Support to communities to prevent the spread of AIDS and STDs (3.1).
- Establishment of infection control procedures in health care settings and the informal traditional medical sector (3.4).
- Education and training for health care providers, especially traditional practitioners, to enhance sterile practices (3.4).
- District level strategies (3.5) to
  - Mobilize societal will to recognize their strengths and weaknesses in handling AIDS related concerns.
  - Stimulate communities to identify and participate in community-based programmes.
  - Encourage establishment of community-based programmes.
- Support community programmes including support groups.
- Community level strategies (3.5) to:
  - Mobilize community resources.
  - Integrate AIDS into ongoing programmes such as family planning, Bamako initiative, etc.
  - Promote community awareness and counselling.
  - Provide care and support for people infected and affected.

Chapter 4 of the Sessional Paper pledges Government support to "create an environment where AIDS related strategies will be translated into meaningful action to reduce the magnitude of the epidemic". Regarding potential application to home-based care, Chapter 4 proposes the following steps, among others:

- Collaborate with other agencies to extend and intensify counselling services at community level to address family problems, enhance behaviour change, and provide psychological support for people infected and affected communities (4.3).
- Develop codes for counselling that have the force of law, and take into account the requirements for voluntary testing and confidentiality as they relate to home/community-based care of HIV infected persons and people living with AIDS (4.4).
- Ensure protection of children orphaned by AIDS and people infected with HIV (4.4).
- Enhance collaboration with the traditional health systems through organization and provision of a regulatory framework to enhance the capacity to provide health care (4.8).
- Strengthen community-based health care systems through involvement of individuals, families, communities, and support groups (4.8).
- Support such initiatives as community home-based care, counselling, care of the terminally ill, and social support (4.9)
- Ensure care providers' safety in the health care setting and at home (4.9).

2.3 National HIV/AIDS Strategic Plan 2000–2005

The Kenya National HIV/AIDS Strategic Plan 2000–2005, defining home-based care as noted above, explicitly calls for home-based care as an integral part of the "continuum of care of the infected and affected" (Section 3.5). The Strategic Plan recognizes that "communities and NGOs have generated innovative responses to help people infected and affected to cope with HIV and improve their quality of life. PLWHAs have a big role to play in care and support, and their visibility ensures that planning for care programmes is based on reality rather than speculation".

The Strategic Plan also establishes a national framework for combating the AIDS epidemic in the country, consisting of national, provincial, district, and constituency AIDS Control Committees, and articulates the important role these committees will play in AIDS prevention, control, and mitigation activities (Section 3.9.1). At the apex of the framework is the National AIDS Control Council (NACC), which has overall responsibility for monitoring and supervising HIV/AIDS related activities. Among other functions, NACC mobilizes resources, formulates policy and strategy, develops information systems, and collaborates with international and local agencies (Section 4.3). Also at national level, each ministry has an AIDS Control Unit (ACU) to coordinate the implementation of the Strategic Plan within and across sectors (Section 4.3.2). The National AIDS/STD Control Programme (NASCOP), which is the ACU in the Ministry of Health, is the technical arm of the fight against the epidemic.

Three levels of AIDS Control Committees bring the framework right down to the local community. Provincial AIDS Control Committees (PACCs), the coordinating bodies at provincial level, include people from various government departments, the civil society, and the private sector, as well as persons living with or affected by AIDS (Section 4.3.3). District-level implementation and monitoring will be coordinated by District AIDS Control Committees (DACCs), with similar memberships to the provincial committees at their respective levels, which will function as the interface between national/provincial levels and the communities (Section 4.3.4).

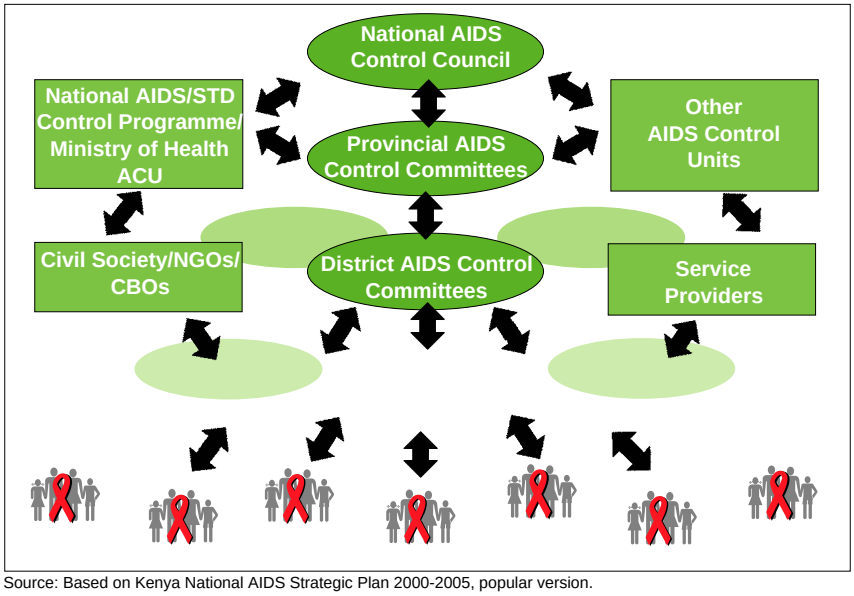
Perhaps most relevant to the immediate needs of home-based care programmes are the Constituency AIDS Control Committees (CACCs), whose members will be drawn from the same sectors as the district and provincial committees. According to the Strategic Plan (Section 4.3.5), these committees have the following mandate:

- Mobilize communities to play an active role.
- Operate as agents of change.
- Promote positive health-seeking behaviours.
- Ensure that committees of elders discuss local cultural influences on the spread of HIV/AIDS.
- Facilitate the participation of youth in activities aimed at behaviour change.

- Develop sustainable community-owned care and support systems for the affected and infected, including widows, widowers, and orphans.
- Mobilize and ensure proper use of local resources.
- Promote and strengthen income-generating activities among vulnerable groups.
- Network, collaborate, and coordinate with other AIDS service organizations.
- Establish and implement monitoring and evaluation systems and submit quarterly and annual reports to NACC.

This system is illustrated in Figure 2. The figure shows the various levels of AIDS control units and committees, which reach from the national oversight and coordinating level through to the communities and thence to the individual families affected by HIV/AIDS. These committees, at all levels, work with the civil society, non-government and community organizations, and service providers. NASCOP, as the ACU in the Ministry of Health, has the primary oversight role for home-based care activities.

Figure 2: The national public sector framework for fighting HIV/AIDS



Source: Based on Kenya National AIDS Strategic Plan 2000-2005, popular version.

2.4 Other Policy Guides

This ***National Home-Based Care Policy Guidelines*** is thus a logical extension of the Government's long commitment to mobilize the necessary will and resources to fight the HIV/AIDS pandemic. In addition to this policy guide, the Ministry of Health, through the National AIDS/STD Control Programme, is publishing and making available the ***National Home-Based Care Programme and Service Guidelines***, a curriculum for training community health workers, a ***Home Care Handbook*** to serve as a ready reference for primary care providers, and an orientation module for home-based care programme managers and health practitioners. Also available are national voluntary counselling and testing guidelines and a training curriculum for voluntary counselling and testing.

3 Elements of Home-Based Care Programming

Home-based care is a collaborative venture by the nation, the health care system, the community, the family, and the PLWHA to meet the crisis of HIV/AIDS. At every level it will be necessary to define specific programme objectives, roles, and responsibilities. Where necessary, the effective implementation of home-based care programmes will be supported by appropriate legislation.

3.1 Objectives of Home-Based Care

The overall goal of home-based care is to ensure a high standard of humane, holistic care that meets the physical and social needs of persons living with HIV/AIDS. Within that broad goal, home-based care has the following specific objectives:

1. To facilitate the continuity of care of the PLWHA from the health facility to the home and community.
2. To promote family and community awareness of HIV/AIDS prevention and care.
3. To empower the PLWHA, the family, and the community with the knowledge needed to ensure long-term care and support.
4. To empower the PLWHA in self-care and positive living.
5. To facilitate quality community care for the infected and affected.
6. To raise the acceptability levels of PLWHAs by the family/community in order to reduce the stigma associated with AIDS.
7. To streamline the patient/client referral from the institutions into the community and from the community to appropriate health and social facilities.
8. To mobilize the resources necessary for sustainability of the service.

3.2 Key Players and Roles

There are five key players in home-based care, with each one having a particular role:

- ***The health facility:*** Making the initial diagnosis and delivering clinical care, recruiting the PLWHA into the programme, identifying needs at various levels, preparing the PLWHA for discharge home, preparing the family caregiver for the caring responsibility at home, supplying simple drugs and basic home nursing supplies, facilitating training and supervision of community health workers in home care and the use of simple drugs and supplies, caring for terminally ill PLWHAs depending on their wish. Some non-clinical aspects of these functions may be filled by non-government/community-based organizations or other responsible entity.

- ***The family and other caregivers:*** Caring for the PLWHA at home, collaborating with other care providers, e.g., religious institutions, support groups, and health and social institutions, consulting and involving the PLWHA on matters concerning them, accepting the reality of the situation, and helping the PLWHA to prepare for death.

- ***The community:*** Accepting the situation of the PLWHA, collaborating with existing agencies to meet the needs of those infected, forming support groups, advocating for the rights of PLWHAs.

- ***The PLWHA:*** Identifying the primary or alternative caregiver, participating in the care process, writing a will, identifying own spiritual/pastoral needs, resolving to take personal responsibility to stop the further transmission of HIV, advocating for behaviour change.

- ***The government:*** Creating a supportive policy environment, developing policies and guidelines, developing and maintaining standards, providing/coordinating training, providing drugs and commodities.

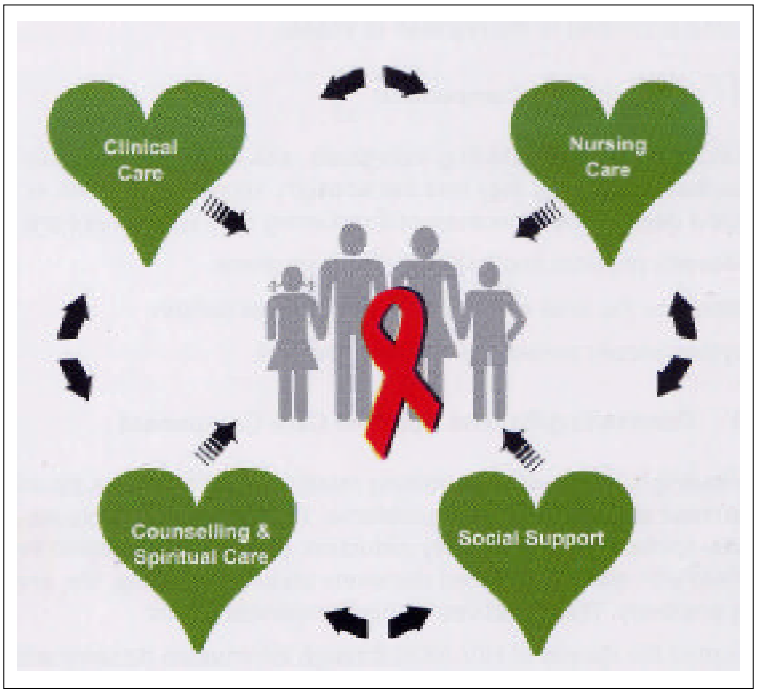
3.3 Components of Home-Based Care

Home-based care is a holistic, integrated system of care that incorporates the following components (see Figure 3):

- Clinical care
- Nursing care
- Counselling/psycho-spiritual care
- Social support

All home-based care programmes must contain some combination of these four components, with the proportion of each component to be determined by local realities and needs.

Figure 3: Components of home-based care



3.3.1 Clinical Care Component

Clinical care in the context of home-based care is the continuation of medical care in the home. The goal is to ensure the continuity of the care and treatment the PLWHA was receiving from the health facility. Clinical care intends to:

- Ensure early detection and treatment of opportunistic infections and other complications that occur as a result of HIV/AIDS.
- Reduce the suffering from conditions associated with the HIV/AIDS infection.
- Protect the patient against further infections especially during a long hospital stay.
- Prevent transmission of HIV or other opportunistic infections from PLWHAs to health workers, relatives, and friends.
- Ensure that drugs prescribed by the clinician are administered at home according to the regimen of intake.

3.3.2 Nursing Care Component

Nursing is "The art of assisting individuals, sick or well, to do those things they would do if they had the strength, knowledge, or will, or to a peaceful death". The objectives of the nursing care component are to:

- Alleviate physical and psychological symptoms.
- Maximize the level of function of the affected person.
- Systematically assess the needs of the sick.

3.3.3 Counselling/Psycho-Spiritual Care Component

Counselling is a professional helping relationship that assists people to understand and deal with their problems. This component includes psycho-spiritual support, anxiety reduction, promotion of positive living, and help with making informed decisions about HIV testing, life, and living positively. The objectives of this component are to:

- Control the spread of HIV/AIDS through information dissemination, promotion of safer sex, advocacy for behaviour change, and encouragement of better health seeking behaviour.

- Help the PLWHA to come to terms with the infection and to adopt a positive living attitude.
- Help the PLWHA make well informed decisions about sex and sexuality.
- Offer psychological/spiritual support to PLWHAs and their families.
- Help PLWHAs accept the need to talk to family members about their condition and future plans.
- Strengthen the spiritual, physical, mental, and social well-being of the PLWHA and the family.
- Help the community to avoid condemnation of the infected and affected and hence be challenged to help when needs arise.

3.3.4 Social Support Component

Social support, for HIV infected people, is the creation of an enabling environment for the PLWHA by all involved in providing care. It incorporates information dissemination and referral to support groups and welfare, economic, and legal services. The objectives of this component are to:

- Contribute to the social and material well-being of the PLWHA.
- Involve the community in the care of the PLWHA and support for the affected family.
- Provide relief for family caregivers from the burden of care.
- Raise awareness among community members of issues related to the transmission of HIV.
- Develop social safety nets for affected children.

4

Programme Guidelines

Details of programme guidelines are spelled out in the ***National Home-Based Care Programme and Service Guidelines*** published by the Ministry of Health through the National AIDS/STD Control Programme. The guiding principles are summarized below.

4.1 Rights and Responsibilities of Persons Living with HIV/AIDS

Planners of home-based care programmes must ensure that their programming takes account of the basic human rights of people living with HIV/AIDS. Sessional Paper No. 4 of 1997 makes it clear that persons infected with the AIDS virus remain Kenyan citizens in every respect, with all rights and responsibilities afforded by the Constitution of Kenya, and must not be victimized because of their HIV status. Home-based care programming is expected to reinforce those rights and reduce the stigma attached to HIV infection.

HIV-positive persons have the right to the following, among others:

- To be treated with respect.
- Access to appropriate health care.
- Confidentiality regarding their condition by all who know about it (within limits pertaining to the safety of their sexual partners, family members, and caregivers).
- A source of income/income-generating activity.
- To own, inherit, and bequeath property.
- Freedom of worship according to their faith, which should be respected by the health worker and the care providers.
- To participate in community activities and school.

PLWHAs also have some basic responsibilities:

- To preserve human life by not infecting others deliberately.
- To inform their sexual partners of their HIV status.
- To take steps while able to provide for their families' future.

4.2 Planning and Setting up a Home-Based Care Programme

Because home-based care emphasizes community participation, community members and representatives of community institutions should come together to discuss these issues, compile background information, and develop objectives and strategies that are appropriate to their community. This process will be facilitated by District and Constituency AIDS Control Committees in collaboration with District Health Management Teams. Among the issues that should be taken into consideration when setting up a home-based care programme are the HIV/AIDS prevalence in the community, the services that are already available, the recognized need for home-based care services, and mechanisms for determining the eligibility of those to be served. Clear objectives, a management plan, and a strategy for mobilizing required resources are also necessary.

4.3 The Home Care Team

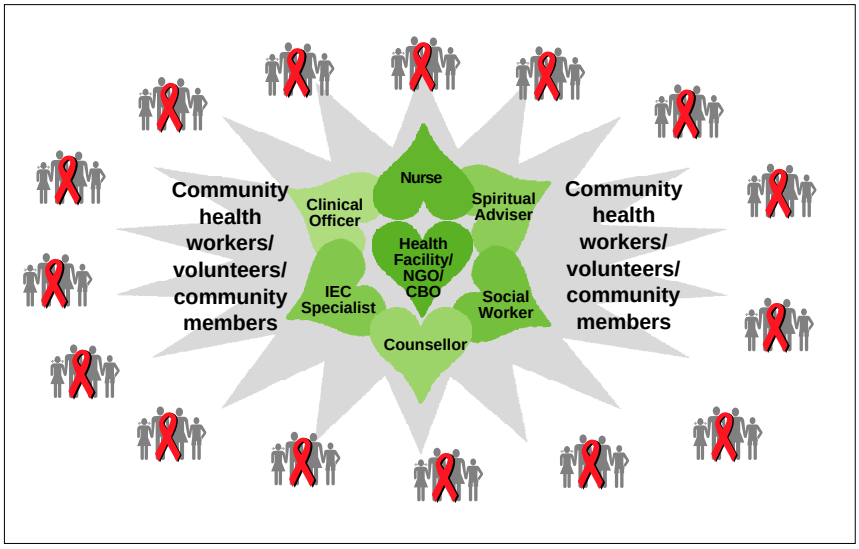
The home care team should be multi-disciplinary in order to handle the physical, social, psychological, and spiritual needs of care recipients. Responsibilities of the team members will include records management and monitoring and evaluation functions as well as professional services. The team leader should be a care professional – a doctor, nurse, counsellor, social worker, etc. Ideally, core team members should include a clinician or nurse, a counsellor, community health worker, and spiritual leader, with a home care supervisor on each team appointed by the relevant health facility or responsible non-government or community-based organization. They should have access to information, education, and communication expertise within the programme. Other members of the team may be volunteers on full or part time basis, drawn from the community and trained by the core team to handle various responsibilities (Figure 4).

The core team members should have requisite professional expertise and relevant experience. The volunteers should have commitment, motivation, and preferably some personal experience with family or friends who are PLWHAs or who have died of AIDS-related complications. To be effective, those selected for the home care team must be convincing educators who will facilitate change in attitude and behaviour. Local community members must be given priority in the recruitment of team members,

In addition to these qualifications, all team members must have the following personal characteristics:

- Commitment to the fight against HIV/AIDS.
- A caring attitude toward the afflicted.
- A lifestyle consistent with HIV prevention messages.

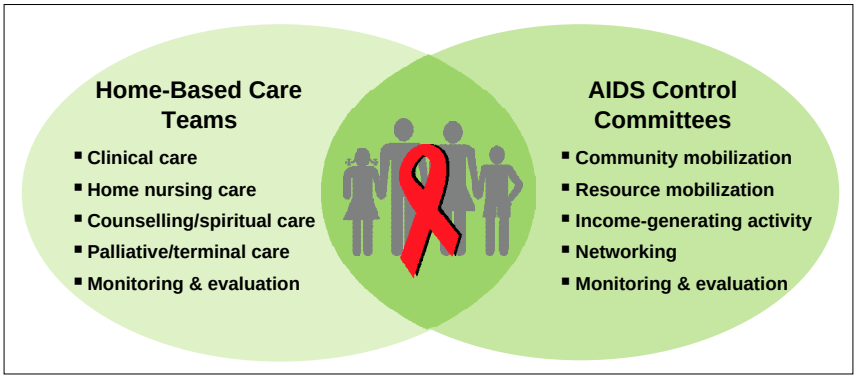
Figure 4: Typical home care team



4.4 Liaison with Public Sector Systems

Private and non-government programmes for home-based care will be expected to conform to national standards and guidelines and to collaborate with the local/district public sector health teams and AIDS Control Committees. Figure 5 illustrates the links.

Figure 5: Public–private sector linkage



4.5 Resource Mobilization

Resource mobilization entails identifying and using all available services or goods required to meet the identified needs of the PLWHA, the family, and the community. Resource mobilization is essential to ensure that the goals at various levels of home-based care are achieved.

4.5.1 Identifying the Required Resources

Necessary resources for effective and sustainable care can be considered in the following three categories:

- ***Manpower:*** The people who assist the PLWHA or the PLWHA's children, including health workers at all levels, family members, relatives/friends, community leaders, spiritual, political, and administrative leaders, and community volunteers.
- ***Materials:*** The material resources required to assist, including food, cooking fuel (e.g., firewood), water, transport, or money for drugs, children's education needs, or other expenses.

- ***Moments:*** The time required for providing care and support for persons infected and affected by HIV/AIDS.

4.5.2 Mobilizing the Required Resources

Resources are required at every level of the home-based care continuum. And, the players at every level – the individual, the family, the community, and the nation – should be expected to contribute to the extent possible. The CACCs are mandated to take the lead in identifying and mobilizing resources at the local level. They should work closely with government agencies, the private sector, and non-government organizations in the area. The Government will to the extent possible provide the following support:

- Political commitment and advocacy.
- Adequate financial resources for national oversight of home-based care programmes.
- Essential drugs for opportunistic infections at the primary health care level.
- Coordination of training and supply of drugs to strengthen the capacity of primary health care providers to care properly for people with HIV/AIDS.
- A support structure for mobilizing resources at the community level, e.g., through AIDS Control Committees, health centre management boards, community health committees, barazas, etc.
- The multi-sector involvement of all government ministries to improve land use and increase food production.
- Monitoring and evaluation of HBC activities to ensure that programme objectives are met.

4.6 Support Services

Depending on the stage of the illness and the needs of the PLWHA, any or all of the following support services may be necessary:

- Recognized health institutions.
- Social support groups.
- Spiritual leaders.

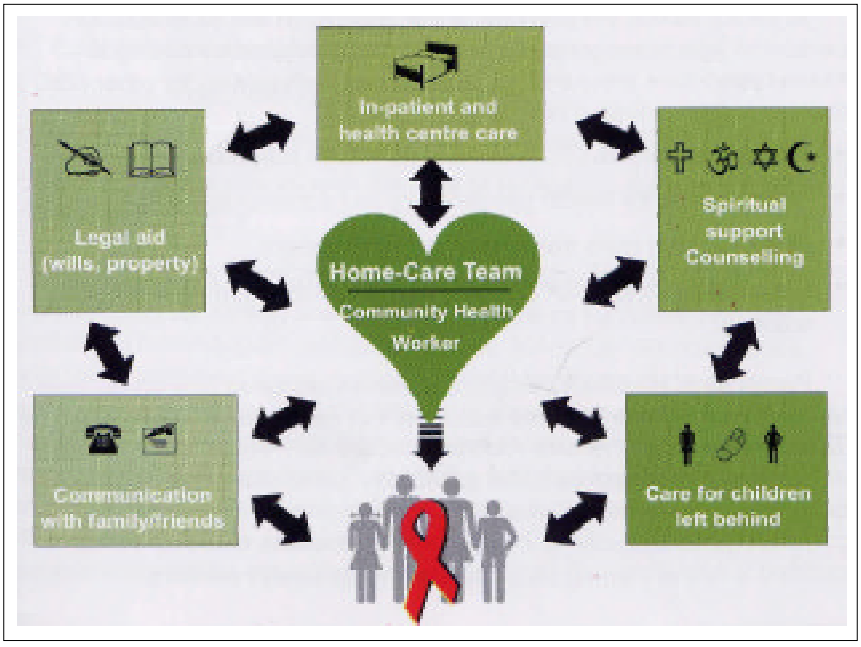
- Legal agencies/local administration, e.g., for writing wills, settling property disputes, addressing burial disputes/arrangements.
- Any other relevant agencies according to the PLWHA's needs.

4.7 Referral Mechanisms

Referral is an effective and efficient two-way process of linking the PLWHA from one caring service to another or to other needed services (Figure 6). Referral and networking are essential to ensure continuity of quality care for the PLWHA at all times. Referring a PLWHA will be deemed necessary:

- When services or resources within reach are not able to meet the PLWHA's immediate needs.
- For better, more competent management in the next stage of required care.
- For specialized care in a hospital setting, especially if the PLWHA is deteriorating.

Figure 6: A simple referral network



- In cases where the acute phase of the PLWHA's care has been dealt with and it is deemed safe to transfer care to other caring services/organizations within the community.
- When the care provider experiences burnout and has no access to counselling services for personal growth.
- When the caregiver has limitations in meeting certain needs of the PLWHA, e.g., based on cultural or religious beliefs.
- For continuity of care from the health facility to the family or from family level back to the health facility.

4.8 Training and Certification

The government of Kenya will conduct, or collaborate with others to conduct, training and orientation in home-based care. All such training and orientation must be conducted using the materials developed by NASCOP: ***National Home-Based Care Programme and Service Guidelines***, the ***Curriculum for Training Community Health Workers to Care for People with HIV/AIDS at Home***, and the ***Home-Based Care Orientation Module for Health Service Personnel and Programme Managers***.

At senior levels, the purpose of the orientation will be to acquaint personnel with management and implementation issues arising in home-based care programmes. Training and orientation for other HBC team members will also include the following:

- Training of trainers (TOT) training for health practitioners.
- Skills training for health practitioners and community health workers.
- Home nursing skills training for family members.
- Counselling training for health practitioners and community health workers.

Participants in skills training programmes will be examined on their ability to perform the required activities. For example, the ***Curriculum for Training Community Health Workers to Care for People with HIV/AIDS at Home*** includes standards for passing required skill tests. Testing will be by observed demonstration of skills for health practitioners and community health workers. Having passed the test, trainees will be certified in home nursing skills for community health workers.

4.9 Motivation and Incentives

Home-based care functions will be incorporated into the standing duties of MOH health care practitioners. The community health workers who volunteer to assist the home care teams will be motivated through training and supportive supervision. Communities are encouraged to devise incentive mechanisms for their local home-based care volunteers.

4.10 Monitoring and Evaluation

All home-based care programmes will be expected to put in place a comprehensive monitoring and evaluation system to:

- Ensure that guidelines in the provision of home-based care are being adhered to.
- Assess the impact of the home-based care programme on the affected and the infected.
- Assess the viability of the programme in order to make alterations and substitutions for the success of the programme.
- Help identify constraints and possible solutions.
- Establish proper organizational and supervisory structures.
- Enhance accountability and transparency.
- Document programme activities and progress.
- Identify best practices with the idea of replicating them to the extent possible.

The National AIDS/STD Control Programme will have overall responsibility for setting and enforcing standards for monitoring and evaluating home-based care programmes. NASCOP will collaborate with the private sector and non-government agencies to develop appropriate guidelines and indicators for monitoring and evaluating home-based care services. These will be based on the provisions of the ***National Home-Based Care Programme and Service Guidelines.*** They will be widely circulated and will be revised and updated as necessary. All public and private sector and NGO/CBO home-based care programmes will be expected to use these guidelines.

5

Service Guidelines

Details of service guidelines are spelled out in the ***National Home-Based Care Programme and Service Guidelines***. The guiding principles are summarized below.

5.1 AIDS Case Definition

Until proven otherwise, Kenya acknowledges the link between HIV and AIDS, and accepts the World Health Organization (WHO) case definition of HIV/AIDS, as set out in the ***National Home-Based Care Programme and Service Guidelines.*** This case definition has implications for the care and treatment of PLWHAs and for the protection of both PLWHAs and their caregivers.

5.2 Links between HIV/AIDS and TB and Other STDs

HIV/AIDS has demonstrated links with tuberculosis and sexually transmitted diseases. TB is one of the first opportunistic infections to appear in PLWHAs. It is highly infectious and can be readily passed from them to their caregivers and others, or vice-versa. The presence of STDs greatly increases the chance of transmitting HIV, and it increases the level of the virus in those who are already infected. The weakened immune system caused by HIV infection renders the body more susceptible to both types of infection.

Screening for and prompt treatment of both TB and STDs are critical to efforts to contain the HIV epidemic.

5.3 Safety Precautions and Infection Prevention

Safety precautions and infection prevention must work in both directions: to protect the PLWHA and to protect the caregiver. Home-based care programmes must provide information and training on infection prevention for PLWHAs and caregivers alike.

5.3.1 Protecting the PLWHA

Persons infected with HIV have lowered immunity and even relatively common or "simple" infections such as cold and flu can be dangerous. Caregivers must be informed about the need to take care to avoid situations where they may pass infections to the PLWHA. Both PLWHAs and caregivers should be screened for TB, and vaccinated or treated as appropriate.

5.3.2 Protecting the Caregiver

There is presently no cure for AIDS, and all persons involved in the direct care of people with HIV/AIDS, whether professionals or volunteers, must be informed of the possibility of contracting the virus through contact with contaminated body fluids. All caregivers must be trained in basic procedures for handling body fluids and practising infection prevention procedures such as wearing gloves or other protective gear or using disinfectants. Caregivers who are accidentally exposed should follow guidelines for anti-retroviral post-exposure prophylaxis.

5.3.4 Protecting the Community

PLWHAs who are sexually active may infect others with the disease. Thus their right to privacy and confidentiality ends when they behave in a way that threatens other members of the community. The home care team leader, in consultation with relevant health authorities, will determine the best course of action in such a case. Persons found to be deliberately attempting to infect others may be liable for criminal prosecution.

5.4 Requirements for Various Aspects of Home-Based Care

The Government recognizes the following minimum requirements for effective home-based care services, and resources permitting will strive to either make them available or facilitate community processes that do so.

5.4.1 Clinical Management Requirements

- Trained clinical personnel: Doctors, nurses, clinical officers, and other paramedical staff involved in patient management, e.g., physiotherapists, laboratory technologists, social workers, etc.
- Drugs for opportunistic infections: anti-fungals, antibiotics, anti-diarrhoeals, analgesics, anti TB drugs, rehydration solutions, herbs, effective local remedies.
- Anti-retrovirals: These have known benefits and will be made available as far as possible. There is need here for close clinical and laboratory monitoring of the PLWHA.
- Supplies of various types: Gloves, waterproof sheeting, draw sheets, bed sheets, etc.
- Dressing materials: Cotton wool, gauze, strapping, cleansing lotions, etc.

5.4.2 Nursing Care Requirements

- Nurses and health care workers trained in HBC.
- Community health workers and family members trained to provide care.
- Home care kits containing gloves, cotton wool, disinfectants, and basic medicines.
- Equipment and supplies for general nursing procedures.
- Time and transport.

5.4.3 Counselling/Psycho-Spiritual Care Requirements

- Professional ethics: Observance of confidentiality, backed by legislation as necessary.
- Training: Integration of counselling into all training curricula for health workers, social workers, teachers, community health workers, trainers of trainers, and PLWHAs.
- Monitoring and supervision: Follow up of all those offering counselling services to provide technical support and to ensure quality control.

- Hotline service and counselling support services for PLWHAs and their families.
- Establishment of voluntary counselling and HIV testing centres.
- Political will and support.

5.4.4 Social Support Requirements

- An understanding of the social side of health.
- Recognition of the primary issues in social support.
- Effective community leadership.
- Involvement of community members at all levels.
- Mechanisms to provide sustainable programme support.

5.5 Home Care Kit and Allowable Drugs and Supplies

Home-based care programmes must include provision for access to appropriate nursing supplies and necessary medications. Where programmes are not health facility based, the responsible entity will be expected to cooperate with the local hospital or health unit to ensure access.

5.5.1 Home Care Kits

A simple kit containing basic home nursing supplies will be made available to community health workers, PLWHAs, and PLWHAs' families. The primary caregiver will be trained on the use of the supplies and advised on replenishing supplies as needed. The PLWHA and family will be expected to meet all or part of the cost of the kit, but in no case will a person be denied appropriate supplies because they cannot afford to contribute to the cost. Communities are encouraged to develop income-generating activities to support the provision and replenishment of home care kits for needy PLWHAs and families.

The supplies included will be those identified by the health facility/ hospital/health unit to meet the specific needs of the PLWHA and may change over time as the needs change. Basic supplies will be those

stipulated in the ***National Home-Based Care Programme and Service Guidelines,*** or as revised from time to time.

5.5.2 Allowable Drugs

Drugs for treating the opportunistic infections associated with HIV/AIDS will in general be the same as those for treating similar infections in the absence of HIV, as provided in the national essential drugs lists. As a general rule, drugs will be administered by qualified medical personnel, but in appropriate circumstances the family/primary caregiver of the PLWHA may be trained to administer the drugs.

Special provisions will be established for the following, among others, and will be updated as necessary:

- Antibiotics: These drugs will be made available according to the essential drug lists and guidelines for treating sexually transmitted infections, opportunistic infections, and other conditions.
- TB: Kenya uses the directly observed therapy (DOT) system for administration of tuberculosis drugs. Community health workers will be trained to administer these drugs under this system.
- Anti-retrovirals: Guidelines for the administration of anti-retrovirals generally and those for prevention of mother-to-child transmission are available from NASCOP.
- Analgesics: Guidelines for the administration of pain medication are based on the WHO 3-step analgesic ladder (1: acetaminophen, ibuprofen, paracetamol, aspirin; 2: codeine phosphate; 3: morphine sulphate).

5.6 Home and Alternative Therapies

The use of traditional home remedies for relieving pain and treating simple ailments is encouraged, provided that these do not make conditions worse or threaten the health and welfare of the PLWHA and family. The Kenya Medical Research Institute (KEMRI) is currently studying the efficacy of various traditional therapies. As the research results become available, appropriate information about effective home and traditional remedies will be circulated to the extent possible. PLWHAs and care providers are advised to seek their health worker's opinion before using traditional home remedies alongside prescribed drugs.

5.7 Quality Assurance

The benefits of the home-based care approach will be lost if systems are not put in place to ensure the maintenance of quality of care at all levels. The National AIDS/STD Control Programme will have overall responsibility for quality control of home-based care programming and implementation and will provide appropriate guidance, regulation, and training to local programmes. Quality control systems will be sufficiently standardized to ensure quality clinical, nursing, and social support, and yet flexible enough to permit effective community participation and enforcement.

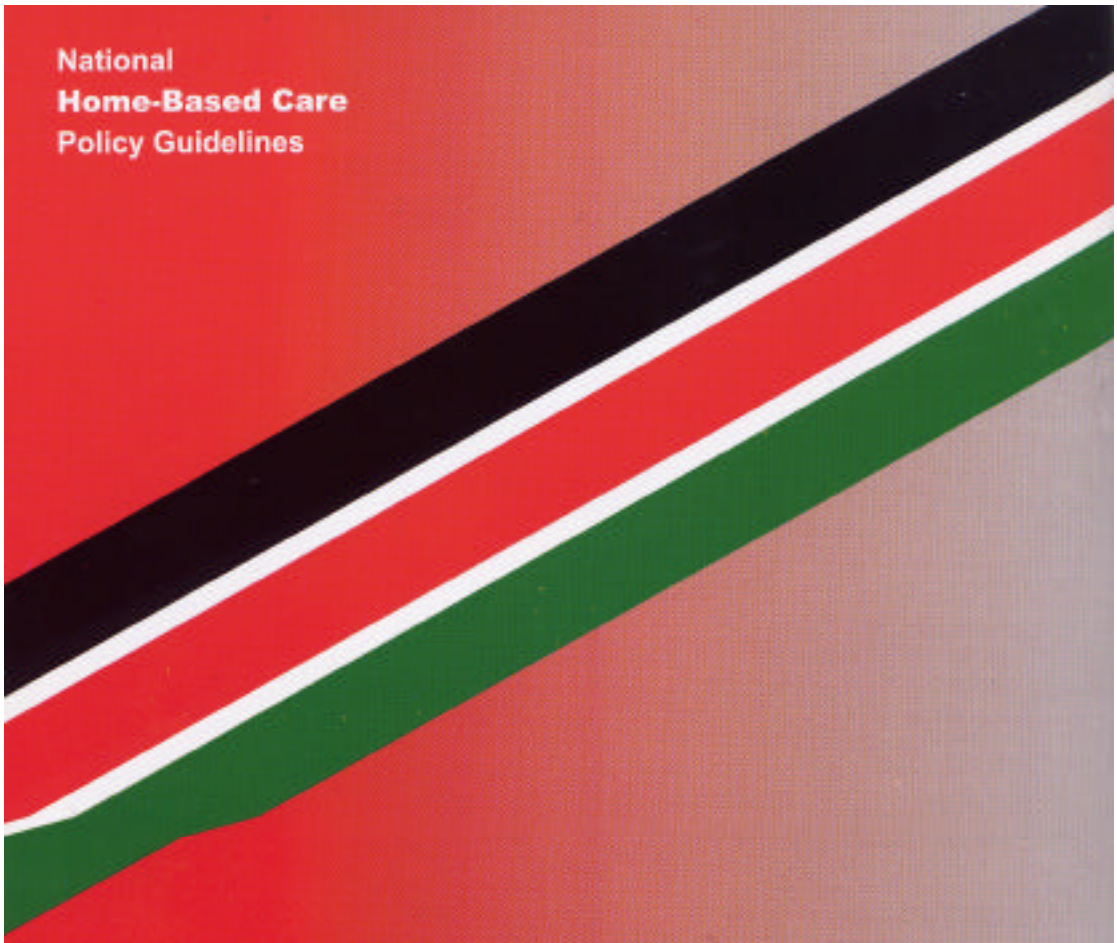
5.7.1 Supervision by District Health Coordinators

District Health Management Teams (DHMTs) will be responsible for the continuity and effectiveness of the home-based care system within their area. The DHMTs will liase with local AIDS Control Committees and other community-based programmes to ensure that community mobilization and support activities are mounted to complement medical care and meet the social support needs of PLWHAs and families. The home-care supervisors appointed by the local hospital/health care facility will be responsible for ensuring the day-to-day quality of care within their specific areas of jurisdiction.

5.7.2 Development and Use of Supervision Checklists

The National AIDS/STD Control Programme will collaborate with the private sector and non-government agencies to develop appropriate checklists for monitoring and supervising home-based care services. These lists will be based on the provisions of the ***National Home-Based Care Programme and Service Guidelines.*** They will be widely circulated and will be revised and updated as necessary. All public and private sector and NGO/CBO home-based care programmes will be expected to use these checklists.

National
Home-Based Care
Policy Guidelines



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