# SOUTH AFRICAN NATIONAL POLICY FRAMEWORK FOR HOME AND COMMUNITY BASED CARE AND SUPPORT PROGRAMME





Health Social Development

# **ACKNOWELDEMENTS**

The Department of Health and Social Development would like to acknowledge the valuable contribution of relevant stakeholders in the revision of the National Policy for Home and Community Based Care and Support Programme. The Departments would in particular, wish to thank the Coordinators from all the provinces, partners in National Action Committee for Children Affected by HIV and AIDS (NACCA) forum for the continued support, sharing of expertise and knowledge. Finally, the Departments sincerely appreciate the inputs and commitments of all individuals who were involved in finalising the revision of this Policy Framework.

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# **TABLE OF CONTENTS**

FOREWORD					
EXECUTIVE SUMMARY					
1 1.1 1.2 1.3	INTRODUCTION Background Vision Mission	13 14			
2 2.1 2.2 2.3	PURPOSE OF THE FRAMEWORK.  Goals and objectives.  Approaches.  Guidingprinciples.	15 16			
3	SERVICES	.18			
4	BENEFICIARIES	.21			
5 5.1 5.2 5.3	COORDINATION AND IMPLEMENTATION OF HCBC PROGRAMME Supporting strategies and legislative framework International and national obligations agreements Coordination, partnerships and institutional arrangements	24 27			
6 6.1 6.2 6.2.1 6.2.2 6.3 6.4 6.4.1	HCBC PROGRAMME SUSTAINABILITY AND RESOURCES	.30 .31 .31 .31			
7	RESEARCH, MONITORING AND EVALUATION				

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# **FOREWORD**

Home and Community Based Care (HCBC) is a key intervention by the South African Government in the fight against HIV and AIDS and the many other social challenges that confront our society. We applaude the tireless efforts of community caregivers who continue to provide services to vulnerable households despite the difficult challenges they face on a daily basis. Many of our achievements in home and community-based care resulted directly from our cooperation with non-governmental organisations. Their support continues to strengthen the foundation of the HCBC programme and add value to the services we deliver.

The revision of the National Policy Framework for the HCBC and its support programme coincides with a number of new developments. One of these is the National Strategic Plan (2007-2011) on HIV and AIDS and sexually transmitted infections which will guide the establishment and implementation of an integrated care and support programme for organisations involved in addressing the developmental and socio-economic challenges of HIV and AIDS and other chronic conditions. This collaborative effort will contribute to strengthening the traditional coping mechanisms of families and communities.

We are grateful for the contributions from individuals and organisations to the revision of this fundamental policy document. It is the product of a remarkable partnership between government and civil society and we look forward to a continuation of that partnership at all levels, including at community level, in its effective implementation.

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# **ACRONYMS**

ABC Abstain, be faithful and condomise
AIDS Acquired immune deficiency syndrome

ART Anti-retroviral Treatment

CBO Community Based Organisation CHH Child Headed Households

DIHS District Information Health System

DoH Department of Health

DSD Department of Social Development EPWP Expanded Public Works Programme

FBO Faith Based Organisation

HCBC Home and Community Based Care
HIV Human Immunodeficiency Virus

HWSETA Health and Welfare Sector Education and Training Authority

M&E Monitoring and Evaluation
NDOH National Department of Health
NGO Non-governmental Organisation
NPO Not for Profit Organisations
NOE National Qualifications Framewoo

NQF National Qualifications Framework NSP National Strategic Plan 2007-2011

OVC Orphans and other children made vulnerable by HIV and AIDS

PFMA Public Finance Management Act
PLHIV People living with HIV and AIDS
RPL Recognition of Prior Learning

SASSA South African Social Security Agency
SAQA South African Qualifications Authority
SPWP Special Public Works Programme

TB Tuberculosis

UNAIDS Joint United Nations Programme on HIV and AIDS

UNGASS United Nations General Assembly Special Session on HIV and AIDS

6

WHO World Health Organisation

# **DEFINITIONS**

# Capacity building

Capacity building is the creation of an enabling environment through skills transfer and the training and empowering of individuals and institutions.

#### **Child Care Forums**

A Child Care Forum is a collective of capacitated community members who identify orphans and other vulnerable children and their families and ensures their access to essential services (*Revised Child Care Forum Guidelines*, 2010).

#### Child-headed households

A child-headed household refers to a household where the parent, guardian or caregiver of the household is terminally ill, has died or abandoned the children in the household, or when no adult family member is available to care for the children in the household, or where a child over the age of 16 years has assumed the role of caregiver in respect of those children, and it is in the best interest of the children. (*Children's Act. No 38 of 2005, as amended*).

#### **Chronic conditions**

A chronic condition is any condition that has lasted or is virtually certain to last for longer than one year and requires comprehensive and coordinated long-term health care.

# **Civil society**

Civil societies are institutions and organisations outside government. In the context of welfare, this includes the formal and informal welfare sectors, trade unions, consumer organisations, non-governmental organisations (NGOs), community-based organisations (CBOs), religious organisations delivering welfare services, corporate social investment, employee assistance programmes, occupational social work and social workers in private practice (White Paper on Social Welfare, 1997).

#### Community

Community refers to all people living in a specific place, such as a group of people found within a particular geographic area who see themselves as belonging to that place and relate to one another in some respect (Learning about Community Development, 2006).

#### **Community Care Centres**

A community care centre is a community-based facility that provides a comprehensive basket of basic services to meet the physical, psychosocial and developmental needs of vulnerable groups. Such a facility usually has an outreach programme.

# Community caregiver

The community caregiver is the first line of support between the community and various health and social development services. He/she plays a vital role in supporting and empowering community members to make informed choices about their health and psychosocial wellbeing and provides ongoing care and support to individuals and families who are vulnerable due to chronic illness and indigent living circumstances (*Learning about Social Care*, 2006).

#### Continuum of care

A continuum of care refers to a network of resources and services that provide holistic and comprehensive support, as well as an holistic approach to treatment, care and support.

#### Communicable disease

A communicable disease is a disease that results from the pathogenic agents or toxins of an infection that are directly or indirectly transmitted from the source to the host (*Learning about Primary Health Care*, 2006).

#### **Evaluation**

Evaluation is the use of social research methods to systematically investigate the effectiveness of programmes (Learning about Social Care, 2006).

# Home and community based care and support programme

Home and community based care is the provision of comprehensive and quality health and social services in the home and community to promote, restore and maintain a person's optimum level of comfort, social functioning and health.

# Memory work

Memory work is a deliberate process of engaging with the past and the present by setting up a safe space to offer the opportunity to assist people with the preparation for loss, bereavement and future, it opens opportunities for communication with the family, breaking the culture of silence relating to death and dying.

#### Mental health

Mental health is a state of wellbeing with no psychological barriers that prevent individuals from realising their potential. Mental health enables individuals to cope with the normal stresses of life, work productively and fruitfully, and contribute to their communities.

#### Monitoring

Monitoring is the routine process of data collection and measurement to determine progress against programme objectives. Information is collected continuously throughout the implementation of the project (*Learning about Social Care, 2006*).

#### Non-communicable disease

A non-communicable disease (NCD) is a disease without infectious agents, which does not spread from one person to another. The cluster of non-communicable diseases identified by the WHO's (World Health Organisation) include cardiovascular diseases, cancer, diabetes, chronic obstructive pulmonary disorder (COPD) or chronic respiratory diseases, mental illness and injury.

#### Non-governmental organisation (NGO)

NGOs refer to all non-governmental, non-profit organisations which are concerned with the betterment of society or the individual. NGOs are private, self-governing, voluntary organisations that operate in the public interest and not for commercial gain, to promote the welfare and development of society, religion, charity, education and research (White Paper on Social Welfare, 1997).

8

# Non-profit organisation (NPO)

A non-profit organisation is a trust, company or other association of persons established for a public purpose, of which the income and property are not distributable to its members or office-bearers except as reasonable compensation for services rendered (NPO Act, No 71 of 1997).

#### Palliative care

Palliative care is an approach that improves the quality of life of patients and their families faced with life-threatening illness, through the prevention and relief of suffering by means of the early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems (World Health Organisation, 1998).

# **Psychosocial support**

Psychosocial refers to the dynamic relationship between psychological and social effects, where the one continually interacts with and influences the other. Psychosocial support services provide support and counselling to restore the normal functioning of individuals and families by enhancing their mental, social, spiritual and emotional wellbeing (Mainstreaming Psychosocial Care and Support into Home Based Care Programmes - REPSSI. 2009).

# Sustainability

Sustainability is the continued effectiveness of a programme or project over the medium- to long-term (*Reducing 'Human Cost' of Caring - South African Red Cross Society, 2007*).

#### **Unit standard**

A unit standard is a registered statement of desired education and training outcomes and the associated assessment criteria, as well as administrative and other information as specified in the National Standards Body (NSB) Regulations (SAQA website).

#### Vulnerable children

A vulnerable child is a child whose survival, care, protection or development may be compromised due to a particular condition, situation or circumstance, which prevents the fulfillment of his or her rights (*Policy Framework on Orphans and other Children made Vulnerable by HIV and AIDS in South Africa, Department of Social Development, 2005*).

# Vulnerable groups

Vulnerable groups are groups in the community that are at risk of not having their needs met due to inadequate or inaccessible resources and, as a result, are susceptible to deprivation or relative deprivation (New Dictionary of Social Work, 1995).

#### Vulnerable households

Vulnerable households are households that are at risk of not having their needs met due to inadequate or inaccessible resources and, as a result, are susceptible to deprivation or relative deprivation (New Dictionary of Social Work, 1989).



# **EXECUTIVE SUMMARY**

The South African Cabinet mandated the national Departments of Health and Social Development (DoH and DSD) to jointly take responsibility for the implementation of the country's Home and Community Based Care (HCBC) and support programme.

The revised National Policy Framework for HCBC outlines the approach and philosophy of the programme and guides policy makers and implementers in addressing the critical issues that affect the services and resources required for the effective implementation of the HCBC programme.

The policy is aligned with the National Strategic Plan (2007-2011) on HIV and AIDS and sexually transmitted infections, and integrates the HCBC programmes of the two departments. The policy also:

- promotes sustainable quality care and support to individuals, families and communities
  in a standardised, unified and collaborative manner to address the needs of the
  most vulnerable groups and create an enabling environment for care and support
  (beneficiaries of the HCBC programme include those infected with and affected by HIV
  and AIDS, as well as persons with other chronic conditions)
- emphasises the importance of an integrated programme, which requires additional institutional arrangements and coordination to, where necessary, pool resources among HCBC organisations
- · advocates a more coordinated, concerted effort from all role players, and
- recommends the creation of HCBC Consultative Forums at national, provincial and district levels to serve as platforms from which to organise the interaction between government and stakeholders about HCBC matters.

The introduction of a HIV and AIDS treatment programme for adults and children posed enormous challenges. These challenges included a lack of capacity and resources, as well as other critical measures, which limits government's ability to respond efficiently.

Capacity building within the HCBC programme needs a four-pronged approach that is underpinned by the relevant legislation, namely:

- profiling and screening prospective trainers and learners to determine and assess training needs and levels
- taking older and low-skilled trainees through the Recognition of Prior Learning process
- providing advanced learners with additional skills to steer career paths into more specialist areas of training, and
- implementing a retention and exit strategy for community caregivers.

The DoH and DSD have developed a monitoring and evaluation system to facilitate a clear sequence of monitoring activities, based on the national service delivery indicators of the HCBC programme. The purpose of the system is to provide an encompassing framework for monitoring and evaluation practices and standards for implementation of HCBC programme throughout South Africa.

It is envisaged that this policy framework will create an environment that is conducive to the national standardisation and monitoring of the coverage, service quality and impact of the HCBC programme.





# 1. INTRODUCTION

The Home and Community Based Care (HCBC) programme responds to the needs of people - individuals, families and communities - to access holistic and comprehensive services nearest home. This encourages participation and a return to the tradition of caregiving in community life, which strengthens mutual aid opportunities and social responsibility.

Home based care services focus on the family as a whole and can be classified into preventative, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories.

Research has shown that terminally ill people prefer to pass on in familiar environments. Parks and Weiss (1983, as quoted in Walker, 1991:242) reported that the family members of those who died at home or in a hospice felt less guilty than relatives of patients who died in hospital. Hospitals may provide good medical care and hygienic conditions, but often isolate patients from their families.

By its very nature, the HCBC programme provides psychosocial care and support to those infected with and affected by HIV and AIDS and other chronic conditions, and enables individuals, communities and families to access services closest to their homes. It can also be an entry point to other services.

The focus of social development interventions in the HCBC programme is on the social impact of HIV and AIDS, namely the burden of chronic diseases that hamper the normal functioning and development of individuals, families and communities. These interventions also involve:

- strengthening the capacity of families and communities to deal with the consequences of HIV and ADS and other chronic conditions
- tackling poverty
- creating an environment conducive to the provision of care and support, and
- a safe environment for the care and support of orphans and older persons, as well as the youth (those who are vulnerable) and people with disabilities.

The services offered by the HCBC programme primarily focuses on sustaining quality of life. This requires a concerted effort by government and civil society alike.

# 1.1 Background

The revised HCBC Policy Framework provides a common point of departure for both the Departments of Health and Social Development (DoH and DSD) in the establishment and implementation of the HCBC programme. The integrated approach, mandated by Cabinet

during the 1999-2000 financial year, entrusts the two departments with the responsibility to jointly implement the national HCBC programme by pooling resources and reducing duplication.

HIV and AIDS and all chronic conditions, such as Tuberculosis (TB), are major challenges facing South Africa. According to the UNGASS report of March 2008, the number of HIV-positive people in Sub-saharan Africa constituted 64, 5% of the global total of 39, 5 million people living with the condition. In South Africa, 5, 7 million people are HIV-positive, of which a total of 294 000 are children aged between 0-14 years (UNAIDS and Department of Health, 2006).

The emergence of HIV and AIDS increased the prevalence of opportunistic diseases, overcrowded and understaffed hospitals, public and private health care costs and deaths that contribute to the escalating number of orphans, vulnerable children and households headed by children. The resultant increase in indigent individuals and communities has also seen a return to traditional home and community based care initiatives.

In South Africa, the HIV and AIDS epidemic progressed at an astonishing pace and has taken a devastating toll on human lives. The condition has escalated to levels similar to other chronic conditions such as hypertension and diabetes. Treatment poses challenges, such as a lack of capacity and the required measures for Government to respond efficiently to the needs of HIV-positive adults and children, as well as those living with other chronic conditions. While medication is a priority, other challenges, such as access to treatment, are compounded by the neglect of psychosocial-related issues and sustained care.

The stigma attached to and discrimination against people living with HIV and AIDS (PLHIV) hampers the effective implementation of preventative care and support programmes. Consequently, indulgence in risky social behaviour continues to fuel the high rate of HIV infections, while it deters PLHIV from adhering to prescribed treatment. This, in turn, often results in a resistance to prescribed drugs and a high mortality rate.

It has become evident that HIV and AIDS erode traditional family and community support structures and systems, disintegrate families and lead to dysfunctional communities. In addition, the burden on the welfare system to cope with disability grants to PLHIV and other chronic conditions, albeit on a temporary basis, is significant. Initially, organisations established to care for and support people affected by and infected with HIV and AIDS were mostly based on the hospice and community-driven care models. Since 2001, however, appraisals of HCBC projects by the DoH and DSD show that most of these organisations have shifted from the community-driven to the NGO model.

At the beginning of the 2001-2002 financial year, the number of HCBC organisations came to 466. A year later, this figure had doubled to 892 organisations. In 2005, a 'rapid study' of the geographical distribution of these organisations found that most of them were concentrated along main roads in towns and cities and used different models to provide care. Four years

later, in 2009, an audit found that 1 824 HCBC organisations (91% of the total number) were active and functional.

An HCBC programme remains one of the best alternative ways of caring for and supporting people infected with and affected by HIV and AIDS and other conditions. This includes orphans and vulnerable children, child-headed households, the youth, older persons and people with disabilities. Generally, however, HCBC services are provided by organisations funded mainly by Government, and therefore have a limited source of funding. And while NGOs have access to other sources of funding, such as national and international donor organisations, as well as the private sector and religious bodies, the availability of these funds is often not sustainable.

# 1.2 Vision

Communities that are able to support and care for individuals and families and competently manage the health, social and economic consequences of all chronic conditions.

# 1.3 Mission

Provide comprehensive, appropriate and quality home and community based care and support programmes for individuals, families and communities in South Africa.

# 2. PURPOSE OF THE NATIONAL POLICY FRAMEWORK FOR THE HCBC PROGRAMME

The main purpose of this policy framework is to set parameters of practice for the establishment and implementation of a comprehensive and integrated home and community based care and support programme for South Africa. The policy is also the basis for the development of all policies related to the implementation of the HCBC programme.

# Goals and strategic objectives

# GOAL 1

To build the capacity of individuals, families and communities to enable them to deal effectively with the consequences of HIV and AIDS and other chronic conditions

# Strategic objective 1.1

To minimise the risk of HIV transmission within communities by maintaining sustained levels of care and support.

# Strategic objective 1.2

To increase awareness about the prevention of infection and re-infection through the promotion of a holistic approach to a healthy lifestyle.

# Strategic objective 1.3

To empower communities to care for their own health, emotional and social wellbeing by strengthening the capacity of community caregivers and the management of HCBC organisations.

# GOAL 2

To address the needs of the most vulnerable groups infected with and affected by HIV and AIDS and other chronic conditions in communities

# Strategic objective 2.1

To cater for the special needs of children, and especially women, through a comprehensive package of care and support services.

# Strategic objective 2.2

To facilitate the development of sustainable programmes to address issues of poverty and their impact on the special and basic needs of vulnerable groups.

#### Strategic objective 2.3

To address the vulnerability of youth who are in and out of school, older persons and people with disabilities.

# GOAL 3

To improve service delivery by creating an enabling environment for care and support

# Strategic objective 3.1

To strengthen the implementation of care and support policies through the HCBC programme.

#### Strategic objective 3.2

To support the delivery of and facilitate access to quality care through a functional, integrated system.

# Strategic objective 3.3

To mobilise communities to use available, comprehensive and quality services

# GOAL 4

To assess the impact of the HCBC programme through a functional monitoring and evaluation framework

# Strategic objective 4.1

To implement a functional monitoring and evaluation (M&E) framework to assess the care and support services of the HCBC programme.

#### Strategic objective 4.2

To support and conduct research to develop best practice models for home and community based care.

# 2. 2 Approaches

The policy framework adopts a developmental approach, which includes the following elements:

# · Person/individual-centred

The HCBC programme recognises individuality and the strength and ability of individuals to develop and achieve their potential.

#### Family-centred

The family is the foundation of society, the family unit is integral to the care and support of its members. The HCBC programme recognises the importance of preserving the family unit as a support structure for its members.

# · Rights-based

The HCBC programme recognises the right of individuals, families and communities to have equal access to services, protection and social justice.

#### Collaborative partnership

The programme does not negate Government's responsibility to families and communities, but rather recognises the value of partnerships between Government, communities and the private sector.

# Participatory democracy

Stakeholder involvement is important and active participation is encouraged, such as involving service recipients in decisions that affect their lives.

#### Integrating social and economic policies and programmes

The programme adopts a holistic and multi-disciplinary approach to addressing the social and economic needs of individuals, families and communities, especially those affected by the high levels of poverty in South Africa.

# Strength-based

All individuals, families and communities have potential of growth and development. They have the ability to care, support and provide services to people infected and affected by HIV and AIDS and other related vulnerabilities, provided that they are empowered and their capacity to do so is strengthened.

# · Community-based

The HCBC programme partners with the community and builds on its resilience, capacities, skills and resources to deliver sustainable solutions.

#### Social cohesion

Social cohesion is 'glue' that keeps people together in society, particularly in the context of cultural diversity and describes social connectedness, including family and community well-being.

# 2.3 Guiding principles

# 2.3.1 Principles of a home and community based care programme

- *Participation:* All community stakeholders are identified, invited and involved in the establishment and implementation of the programme to ensure full ownership.
- Non-partisan: The programme cuts across political, ethnic, religious, gender and racial lines.
- Empowerment: Individuals, families and communities are capacitated, strengthened and supported to care and support for vulnerable groups.
- Accessibility: No test or any form of selection is used to determine access to the services
  of the HCBC programme. All members of the community where the programme is
  established will have equal access to the services offered.

# 3. SERVICES IN THE HCBC PROGRAMME

The HCBC programme provides comprehensive and integrated services. As such, HCBC organisations should render at least four or more of the service categories listed below:

# 3.1 Categories of HCBC services

#### Home visits

- » Assessment of needs.
- » Early identification of those in need of care.
- » Basic nursing care.
- » Assistance with house chores where necessary.
- » Information, education and communication (IEC).
- » Basic/lay counselling.
- » Homework supervision.

# Psychosocial support

- » Counselling to address the psychosocial needs of children, individuals and families, including emotional and spiritual wellbeing, trauma debriefing and bereavement support.
- » Succession planning with regard to inheritance, writing of wills and memory work.

# Support groups

- » Support groups for those affected with and infected by HIV and AIDS and other chronic conditions.
- » Youth programmes to provide, among others, life skills training.

# Material support

- » Meals.
- » Food supplements.
- » School uniforms/clothing and blankets.

# Poverty alleviation projects

- » Income generating activities, such as fundraising
- » Home and community food gardens.
- » Families and caregivers linked to other poverty alleviation programmes.

# Facility based services (Community Care Centres)

- » Homework supervision.
- » Laundry services for children.
- » Recreational activities assistance.
- » Domestic work training for children.

- » Referrals for appropriate services.
- » Youth programmes, such as providing life skills training
- » Holiday programme planning, such as camps/Scouts.

# • Referrals for appropriate services

- » Stakeholders liaison/networking, such as with NGOs, government departments and traditional leaders.
- » Social grants facilitation through referrals to SASSA.
- » Referrals system to/for:
  - · legal, vital or other documents
  - · writing of wills and health care services
  - social workers for alternative care, such as transferring children to places of safety, into foster care or for adoption, and
  - specialised services from social workers, doctors, psychologists and priests.
- » Directory of available community services.

#### Treatment support

- » TB directly observed therapies (DOTS) supervision.
- » Anti-retroviral medication treatment adherence.
- » Chronic illness treatment and management, such as TB, HIV and AIDS, etc.
- » Defaulter tracing assistance.

# · Prevention and awareness education

- » Community mobilisation through:
  - · awareness campaigns
  - door-to-door campaigns
  - human rights promotion, and
  - addressing discrimination, stigmatisation and disclosure.

#### Social mobilisation

- » Community involvement.
- » Community sensitisation.
- » Advocacy.
- » Community dialogue.







# · Capacity building

- » Capacity needs of families, including life skills, parenting skills, child discipline, budgeting and domestic work.
- » Capacity needs of community caregivers, such as career path planning and skills development.
- » Organisational capacity training needs.

# 4. BENEFICIARIES

HCBC organisations provide services to a variety of beneficiaries infected with and affected by HIV and AIDS and other chronic conditions, including:

# · Vulnerable households

Poverty is unevenly distributed throughout South Africa's nine provinces and manifests itself as food insecurity, very low income levels, unemployment, social crime, HIV and AIDS and other chronic conditions. Poverty-stricken households need to be supported to reduce their vulnerability.

# · Persons living with HIV and AIDS and other chronic conditions

HIV and AIDS and other chronic conditions affect individuals as well as their families, friends and the wider community. People living with HIV and AIDS and other chronic conditions should be given opportunities to develop their capabilities, skills and support networks.

#### Orphans and vulnerable children (OVC)

The increase in the prevalence of HIV and AIDS is reducing the pool of traditional caregivers and breadwinners and increasing the number of OVC. The majority of these children live with a surviving parent or family member within their extended family unit (often a grandparent) or in institutions of care.

HCBC services should be provided to children living alone or with their extended family members. In their changed environments, many are neglected or abused and have no lifeline or means or seeking help. In addition, preventing children from becoming orphaned should be pivotal in HCBC programmes for children and parents, especially for women who are HIV-positive.

#### Child and youth headed households

These are households where a parent or primary caregiver is terminally ill or has died and no other adult family member is available to care for and support the children. As such, HIV and AIDS exacerbate poverty and affect the traditional way children are cared for. Instead, children are increasingly becoming young caregivers themselves by providing siblings with food, clothing and psychosocial support.

#### Older persons

Older persons are vulnerable to infection, both as caregivers and as sexually active people. It is essential to develop programmes that recognise the needs of older persons living with HIV and AIDS for treatment and support.

Those who are house-bound and living alone or with family members should receive home based care. Many of them who are diagnosed as being HIV-positive are left alone, neglected or even abused and have no life-line or means or seeking help.

The extension of HCBC services to individuals and families infected by HIV and AIDS and other chronic conditions also create opportunities for older people to work as caregivers by caring for frail older persons living at home.



# · Youth infected with and affected by HIV and AIDS

It is mostly teenagers and young adults between the ages of 15 and 25 years who are affected by HIV and AIDS, especially when they become economically active. The HCBC programme should consciously address their needs to mitigate the spread of the pandemic within this important group of beneficiaries.

HIV and AIDS awareness and support should become a primary focus of all services aimed at the youth, such as entertainment, schools and health services. They should be encouraged to talk openly among themselves about the condition and the realities of living with HIV and AIDS, without prejudice or discrimination. Government and all stakeholders need to ensure that the existing services are user-friendly and accessible to the youth.

While most of the HIV and AIDS education programmes in South Africa emphasise the "ABC" of AIDS prevention, research has shown that young people are still less likely than adults to adopt and maintain safe sexual behaviour. Therefore, social behaviour change programmes are critical when designing an effective response to AIDS.

# · People with disabilities

The impact of HIV and AIDS on people with disabilities is always under-estimated, especially in the context of how society regards them and their sexual practices.

The services provided to people with disabilities must be relevant and respond to the specific needs of those infected with and affected by HIV and AIDS. HCBC services should eliminate negative attitudes and the marginalisation of people with disabilities from mainstream society, as these lead to a general impression that they are not sexually active and therefore not at risk of contracting HIV and AIDS. People with disabilities should not be excluded from a caregiver's programme.

# 5. COORDINATION AND IMPLEMENTATION OF THE HCBC PROGRAMME

# 5.1 Supporting strategies and the legislative framework

The HCBC Policy Framework is aligned with a number of legal and policy frameworks, including the following important instruments:

Instrument	Précis of legal/policy framework	
Constitution of the Republic of South Africa, 1996	Government derives its core mandate from the Constitution, which asserts in its founding provisions that the Republic of South Africa, as a democratic state, is founded on the values of human dignity, equality and the advancement of human rights, freedom, non-racism and non-sexism.	
Non-profit Organisations Act, No 71 of 1997	This Act establishes an administrative and regulatory framework within which non-profit organisations can conduct their affairs and provides an environment in which they can flourish.	
Expanded Public Works Programme (EPWP)	A national programme that covers all spheres of government and state-owned enterprise programmes, with HCBC and ECD (early childhood development) selected as the lead pilot programmes for the social sector.	
Special Public Works Programme (SPWP)	A short-term, non-permanent, labour-intensive programme to create community skills, initiated by Government and fully or partially funded from public resources.	
Cabinet mandate for the joint implement-ation of HCBC, 1999	Cabinet identified home and community based care as a priority and mandated the DoH and DSD to take the lead in jointly implementing the HCBC programme.	
Social Assistance Act, No 59 of 1992	The Act provides those unable to support themselves and their dependants with a right of access to appropriate social assistance.	
Children's Act, No 38 of 2005	The Act gives effect to the rights of children as contained in the Constitution and sets out principles for the care and protection of children that define parental responsibility and rights.	



Qualifications

and Related

Substances Act, No 59 of 2002

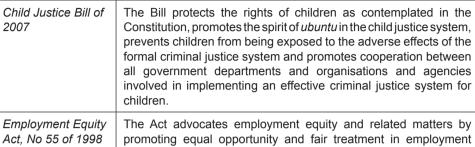
Regulations Act,

No 28 of 1974

International Health

Framework (NQF)

Instrument



Précis of legal/policy framework

	7101, 110 00 01 1330	through the elimination of unfair discrimination.
	Skills Development Act, No 97 of 1998	The Act provides an institutional framework and strategies to develop and improve skills within the South African workforce.
	South African Qualifications Authority (SAQA)	The entity oversees the development of the National Qualifications Framework (NQF) by formulating and publishing policies and criteria for the registration of bodies responsible for establishing education and training standards or qualifications.
	National	Sets out the principles and guidelines by which to register learner

achievement records and enables the recognition nationally of acquired skills, knowledge and qualifications in an integrated

of 1965 requires the registration of role players, and provides the

The purpose and scope of these regulations are to prevent,

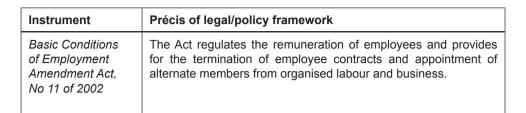
protect against, control and provide a public health response to

the international spread of diseases and health risks.

		system that encourages life-long learning.
	Patient's Rights Charter	The Department of Health is committed to uphold, promote and protect a patient's right to access health care services and proclaimed this Charter as the common standard for realising this right.
	National Strategic Plan (2007-2011) for HIV/AIDS and STIs	Provides strategic direction, guidance and strategies to prevent the spread of HIV and AIDS and other sexually transmitted diseases (STIs) and mitigate the impact thereof.
	Medicines	The amendment of the Medicines and Related Substances Act

related clarifications and definitions,

Instrument	Précis of legal/policy framework
Health Professions Act, No 56 of 1974	The Act regulates health professions, and partially medical practitioners, dentists, psychologists and other health-related professions, including community services rendered by the health professions.
Allied Health Professions Act, No 63 of 1982	The Act controls the practice of chiropractors, homeopaths and allied health professions and provides for the establishment of a chiropractor's practice.
Academic Health Centres Act, No 86 of 1993	The Act provides for the establishment, management and operation of academic health centres. This Act will be repealed by the National Health Act.
Nursing Act, No 50 of 1978	The Act consolidates and amends the laws relating to the professions of registered or enrolled nurses, nursing auxiliaries and midwives and provides for related matters.
National Health Act, No 61 of 2003	The Act creates a framework for a structured, uniform health system within the Republic of South Africa.
International Labour Organisation (Social Security) Convention, 102 of 1952	The International Labour Organisation defines social security as the protection which society provides for its members through a series of public measures. This is done to offset the absence or substantial reduction of income from work resulting from various contingencies to provide people with health care and provide benefits for families with children.
Older Persons Act, No13 0f 2006	The Act was promulgated to deal effectively with the plight of older persons through a framework aimed at empowering, protecting, promoting and maintaining their status, rights, wellbeing, safety and security.
Mental Health Care Act, No 17 of 2002	The Act provides for the care and treatment of persons who are mentally ill and sets out different procedures to be followed in the admission of such persons.
Occupational Health and Safety Act, No 181, 1993	The Act provides for the health and safety of persons at work and requires the establishment of an advisory council for occupational health and safety and related matters



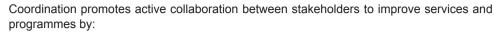
# 5.2 International and national obligations/agreements

Obligation/ agreement	Précis	
UNGASS report	Recognising that there was no more time for half measures in the global fight against HIV and AIDS, UN Secretary General Kofi Anan called on Ministers to join a global alliance against the virus after the Millennium Development Summit in 2000. A year later, in June 2001, Ministers from 189 nations met for the first special session of the United Nations General Assembly on HIV/AIDS (UNGASS).	
Millennium Development Goals (MDGs)	The Millennium Development Goals (MDGs), endorsed governments at the United Nations in September 2000, aim improve human wellbeing by reducing poverty, hunger, and chand maternal mortality, ensuring education for all, controlli and managing diseases, tackling gender disparity, ensuring sustainable development and pursuing global partnerships.	
World Health Organisation (WHO)	South Africa is one of the World Health Organisation (WHO) signatories. WHO is an agency of the United Nations, established in 1948, to further international cooperation in improving health conditions.	
Batho Pele principles	Eight <i>Batho Pele</i> (putting people first) principles were developed as an acceptable policy and legislative framework to guide service delivery in the public service.	
United Convention on the Rights of Persons with Disabilities	The Convention determines that all people with disabilities have an equal right of respect for their physical and mental integrity as able-bodied people, as well as full inclusion and participation in the community, including opportunities to choose their place of residence without obligation to accept a prescribed living arrangement.	

# 5.3 Coordination, partnerships and institutional arrangements

An integrated programme requires institutional arrangements and coordination to support the pooling of resources.

Partnerships with those committed to building a caring society should be based on enabling the poor and vulnerable to secure a better life for them in their own communities.



- creating a platform for advocacy
- · reducing duplication and unhealthy competition
- · mobilising resources, and
- maximising the impact of interventions and promoting networking.

The structure and partners indicated below play a pivotal role in HCBC programmes.

# 5.3.1 National Consultative Forum

A clear gap within the HCBC programme is the lack of a formal platform of engagement with all relevant stakeholders. A National Consultative Forum is proposed to address this gap and ensure effective public-private planning and co-ordination on all issues related to the HCBC programme in South Africa.

The Forum should, among others, ensure that:

- issues linked to the HCBC programme are addressed with all relevant sectors and stakeholders, including older persons and people with disabilities
- a networking platform is created to deal pro-actively with issues, share information and experiences and bridge the existing knowledge gap
- active collaboration between stakeholders is promoted to improve services and maximise the impact of interventions
- · healthy competition is promoted while avoiding unnecessary duplication, and
- a channel is provided for the DoH and DSD to jointly implement, monitor and obtain grassroots feedback on policy issues.
- The Forum can be formalised as a recognised structure with a functional Committee mandated to perform specified duties.

# 5.3.2 National departments

Develop policies to guide the implementation, monitoring and evaluation of the HCBC programme, by:

- coordinating structures across all levels within and between the DoH and DSD and with other relevant stakeholders
- planning jointly to avoid the duplication of activities and encourage the sharing of resources
- facilitating the development of and compliance with norms and standards for uniformity and to set a benchmark for HCBC organisations

28

- facilitating the development of HCBC guidelines to implement the programme effectively
- aligning the allocation of resources with national priorities
- facilitating the establishment of a consultative forum at national and provincial levels,
   and
- monitoring and evaluating the HCBC programme.

# 5.3.3 Provincial departments

Facilitate the implementation of the HCBC programme by:

- · appointing dedicated HIV and AIDS staff in the DoH and DSD
- · allocating resources aligned with the national priorities set for the HCBC programme
- facilitating the implementation of and monitoring compliance with the norms and standards in the province
- · facilitating the establishment of a consultative forum at provincial level, and
- monitoring and evaluating the quality standard of services provided.

# 5.3.4 District and sub-district offices

Implement the HCBC programme by:

- · monitoring, reporting and evaluating the services rendered
- implementing the norms and standards in the district, and
- · facilitating the establishment of the local Consultative Forum at district level.





# 6. HCBC PROGRAMME SUSTAINABILITY AND RESOURCES

# 6.1 Human resources

In 2006, DoH and DSD commissioned an audit to identify community caregivers involved in home and community based care programmes as well as the training programmes they have undergone. The study found that most of the caregivers were female with less than 10% male. Greater involvement of men should be encouraged at all levels in the programme to dispel the myth that caring is for and by women only.

Forty-one percent (41%) of those who became community caregivers did so because they saw a need to help their communities or the sick in their communities, while others indicated that their experiences with relatives and community members who were HIV-positive and had full-blown AIDS motivated them to provide care. Approximately sixteen percent (16%) identified their passion for caring for the sick as their reason for becoming caregivers, while others were motivated or influenced by community members and other caregivers.

All HCBC organisations must ensures that all community caregivers who work with children are screened and registered according to the Children's Act. No 38 of 2005 as amended.

# 6.2 Capacity building within the HCBC programme

The HCBC programme requires a four-pronged approach to build capacity, underpinned by the relevant legislatives frameworks, including the Basic Conditions of Service, Skills Development Act, Labour Relations Act and National Qualifications Framework. Guided by this approach, capacity building should include:

- profiling and screening prospective learners to determine and assess their training needs
- · exposing older and low-skilled learners to the Recognition of Prior Learning process
- providing advanced learners with additional skills to prepare them for specialist levels
  of training, and
- implementing a retention and exit strategy for community caregivers.

# 6.1.1 Building management capacity in HCBC organisations

DoH and DSD are jointly responsible for developing management capacity in HCBC organisations. This includes the:

- · sustainable development and management of HCBC organisations
- · identification of skills and capacity needs
- · alignment with general human resource and development policies, particularly the

Skills Development Act, and

a mentorship programme.

# 6.1.2 Training of community caregivers

HCBC organisations need to attend to the capacity needs of community caregivers. This should entail the development of an overall Staff Capacity Plan, which, among others, should include:

- training based on registered unit standards and aligned with a minimum skills set that includes the Recognition of Prior Learning process
- regular supervision of community caregivers
- · a database of accredited service providers and courses offered, and

# 6.3 Caring for community caregivers

Caring for individuals, families or anyone with a serious chronic illness is a physical and emotional challenge for even the most dedicated caregivers. This is particularly true for nurses, counsellors, volunteers and community caregivers in the home who provide most of the care for PLHIV and other chronic conditions.

Community caregivers work under stressful conditions which may lead to disillusionment and burnout. They need support to do their jobs well, remain infection-free and avoid burnout to ensure that the sustainability and quality of their services are not compromised.

The HCBC policy framework is based on a holistic care and support model that also addresses the diverse needs of community caregivers to promote their overall wellbeing. The framework identifies the following five independent but inter-related components:

- Social support, which includes peer support.
- Emotional and psychological support, which includes general counselling.
- · Bereavement counselling, as well as related debriefing.
- Supervision and mentorship.
- Debriefing sessions to relieve stressful situations.

Each HCBC organisation therefore needs a comprehensive strategy with:

- an organisation-specific plan
- support groups for community caregivers
- · a peer support programme
- · a performance recognition plan, and
- a self-care plan.

# 6.4 Remuneration of community caregivers

Government recognises the valuable contribution by community caregivers and the need to regulate the payment of their stipends, the efforts are underway to address this issue.

# 6.5 Funding of HCBC organisations

Public and private donors demand accountability from those who implement the programmes they fund, which includes efficiency measures to ensure that the funds are effectively utilised. This places pressure on Government to evaluate the cost and benefits of its activities and account to society as a whole, especially tax payers, how public funds and resources are allocated and distributed for the wellbeing of society.

The aim of the HCBC policy framework, therefore, is to ensure that funders perceive and receive value for money and that their priorities are met. This requires that Government, as well as the non-governmental sectors involved, accept accountability.

It is important that this policy framework is used in conjunction with all the national policies and legislation related to financial, procurement and service delivery partnerships, particularly the following:

- · Policy on financial awards.
- Public Finance Management Act, No 1 of 1999.
- · National Treasury Public Private Partnership Regulations, Section 16.
- Supply chain management.

The funding objectives of HCBC organisations are to:

- establish a funding relationship between the two departments (DoH and DSD) and the service providers who render services to the HCBC programme
- determine the requirements and mechanisms for remunerating those service providers, and
- create an enabling environment for emerging HCBC organisations previously excluded from government funding.

The DoH and DSD are not the sole funders of services to the poor and vulnerable sectors of community. Well-established HCBC organisations have the capacity and infrastructure to raise funds and should develop sustainable programmes to meet the needs of the poor and vulnerable groups they serve. Government should also encourage them to raise funds from other sources, such as donor organisations, private sector corporate social responsibility programmes and foundations.

# 6.5.1 Eligibility for funding

HCBC organisations are only eligible for financial assistance from the DoH and DSD when they meet the following requirements:

- Classification as a non-profit organisation in terms of the Non-profit Organisations Act, No 71 of 1997.
- Registration as a NPO or proof that the organisation is in the process of registering as a NPO under the Act.
- The provision of services, or the intention to provide services to people in specific communities, aligned with the priorities and objectives of the DoH and DSD.
- · Compliance with the national norms and standards of the DoH and DSD.
- Ability to account for the utilisation of funding from the DoH and DSD in an acceptable manner and in terms of the prescripts of the Public Finance Management Act, No 29 of 1999.





#### 7. RESEARCH, MONITORING AND EVALUATION

The NSP (2007-2011) recognises research, monitoring and evaluation (M&E) as important management tools. It is therefore imperative for the HCBC policy framework to guide the use of research and M&E practices within the HCBC programme.

#### 7.1 Research

The DoH and DSD are responsible for facilitating the development and promotion of an enabling research environment and support capacity building and skills transfer initiatives to ensure that the research undertaken does not prejudice research ethics or the rights of beneficiaries.

#### HCBC monitoring and evaluation (M&E) system 7.2

The HCBC M&E system was developed jointly between the DoH and DSD. The system provides an integrated, encompassing framework of M&E practices and standards for all HCBC organisations, nationally.

#### Description of the M&E system 7.2.1

The purpose of the M&E system is to facilitate a clear sequence of activities that monitor implementation against the national service delivery indicators of the HCBC programme. The objectives are to:

- assess to what extent the HCBC programme meets community needs
- ensure that allocated funds are effectively utilised
- apply a consistent approach to assessing projects
- assist with informed decision-making about future funding
- ensure compliance with norms and standards and financial prescripts
- provide evidence to support requests for increased funding of HCBC programme, and
- inform HCBC policy decisions.
- The system is expected to produce the following results:
- Improve the quality of performance data and analysis at programme level within HCBC organisations.
- Improve the monitoring of the impact and outcomes across the national indicators for the DoH and DSD.
- Serve as a capacity building initiative to build and foster a governance and decisionmaking culture that responds to M&E findings.

#### CONCLUSION 8.

The revised Policy Framework provides a strategic outline of what HCBC programme is about within the South African context. The programme is further unpacked through the HCBC guidelines, supporting strategies and tools.

It is envisaged that this framework will create an environment that is conducive to the standardised implementation of HCBC programmes nationally that common monitoring and evaluation can be applied to assess coverage, quality of service and the impact of the programme.





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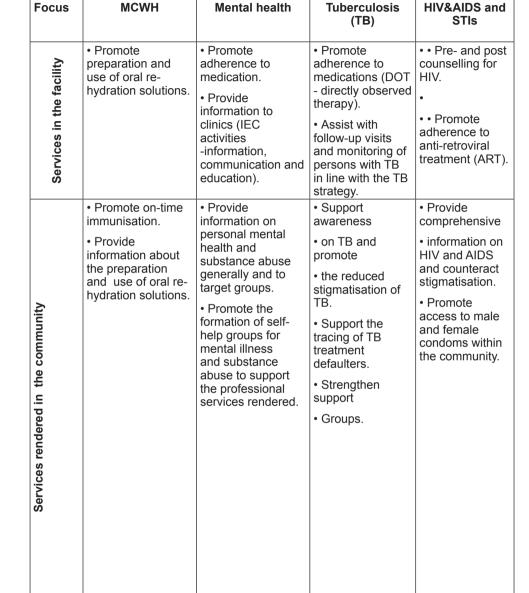
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# **ANNEXURE**

Table 1. Health Services for Home and Community Based Care

Non- communicable Diseases	Communicable Diseases	Nutrition at Home
Promote the adherence to	Provide information	Promote exclusive breastfeeding.
<ul><li>chronic medication.</li><li>Test blood pressure and blood glucose.</li></ul>	on malaria prevention and support treatment adherence.	Provide information on infant mixed feeding.
• Identify indicators of hypertension and diabetes.	Provide information on water safety.	Assist with the safe preparation of food, including
<ul> <li>Support families or carers of older persons.</li> </ul>	Encourage older persons to seek flu vaccinations.	• Promote good hygiene practices.
• Support activities of daily living for older persons and people with		Provide basic information on healthier nutritional choices.
disabilities without carers.  • Support the psychosocial		Provide information on establishing food gardens.
aspects of palliative care.		Monitor Vitamin     A supplementation     using the road to     health card.



Non-communicable diseases	Communicable diseases	Nutrition at home
Promote the adherence to chronic medication.		Provide the same support as for home services.
Promote the formation of social groups for older	Support malaria reduction programmes.	Promote growth Monitoring.
persons.  • Provide information		• Promote the use of Vitamin A.
on healthy choices to prevent diabetes and hypertension.		Support community food gardens.
		Promote exclusive Breastfeeding.
		Provide information on infant mixed feeding.
		Promote the safe preparation of food.
		Provide basic information on healthier nutritional choices.





Services rendered in the home	Services rendered in the community	
Assess individual and family needs.	Raise awareness on succession planning issues with beneficiaries.	
Provide referrals, follow-up and follow through on behalf of beneficiaries.	Facilitate the establishment of support	
Facilitate access to social assistance, including accompanying beneficiaries to relevant agencies.	structures that build on the traditional family and community roles of providing care and support, such as:	
Ensure that beneficiaries have vital documents, such as birth/death certificates and identity documents.	Support groups - these groups are not confined to people living with HIV and AIDS but can be established as needs arise, such as creating a support group for youth-headed households, children and older persons.	
Assess orphans and children made vulnerable (OVC) by HIV and AIDS and their families for early detection of condition.		
Provide psychosocial support to people on	Community Care Centres.     Child Care Forums.	
treatment for HIV and AIDS and other chronic conditions and to affected families beyond medical care.  • Provide psychosocial support to child- and youth-headed households.  • Provide material assistance, such as food	Assist with conducting awareness campaigns about issues affecting	
	<ul> <li>individuals, families and communities.</li> <li>Promote behaviour change through a life skills programme.</li> <li>Commemorate national and international days, such World AIDS Day and Human Rights Day.</li> </ul>	
		parcels and clothing.     Assist with issues of inheritance and
guardianship for children.		Map services offered in the community.
Assist with supervision of children and homework.	Promote advocacy.	
Assist when needed with household chores which could include washing, feeding children and preparing food.		
Assist with initiatives to sustain livelihoods, such as food gardens.		

Psychosocial wellbeing of community caregivers (CCG)	Building management capacity in organisations
• Establish support groups for CCGs. sustainability.	Improve organisational performance and sustainability.
Establish support groups for GCGs.	Transfer skills to selected HCBC organisations
	Improve service delivery through improved management capacity.
	Support provincial and district officials.

Note: The above include older persons and persons living with disabilities.



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