Caring from **within**

Key findings and policy recommendations on home-based care in Zimbabwe

SPEAK YOUR WORLD PRIMER

To understand more about the development of home-based care (HBC) in Zimbabwe and its future potential, Irish Aid engaged Health & Development Networks (HDN) and the Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS) to assess and document lessons from HBC interventions. Since 2005, Irish Aid has supported HBC initiatives in Zimbabwe, and is currently funding 15 HBC programmes throughout the country. The current project was designed to contribute to better understanding and assist evidence-based decision-making in the implementation of HBC interventions in Zimbabwe and beyond.

This publication is one of five produced in the course of the project:

- *Caring from within – Key findings and policy recommendations on home-based care in Zimbabwe*
- *Inside stories – Local experiences of home-based care in Zimbabwe*
- *Dialogue and opinion on home-based care in Zimbabwe: Summary of online discussion*
- *Looking back, mapping forwards: Research findings on home-based care in Zimbabwe*
- *Learning and sharing: Implementers' meeting report on home-based care interventions in Zimbabwe*

The goal of these publications is to guide HBC implementers, policy-makers, regional and international organizations, and donors in designing and prioritizing HBC programmes, creating policies and targeting funding to make a real difference to people's lives at the local level.

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Key findings and policy recommendations on home-based care in Zimbabwe

This is a joint publication of Health & Development Networks (HDN) and the Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS).

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Special thanks go to all those at Health & Development Networks (HDN) and the Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS) who have made this project a success.

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HDN and SAfAIDS would like to dedicate this report to all the courageous women and men of Zimbabwe who have taken it upon themselves to provide care for people living with HIV under the most arduous of conditions.

We hope the recommendations in this report will contribute to shaping effective home-based care interventions in the country, and possibly elsewhere.

Special thanks go to Irish Aid who initiated this study and provided generous support for the report – including the site visits and other research upon which it is based. Irish Aid are also acknowledged for their essential funding of all eight organizations surveyed for this project.

Finally, we would particularly like to acknowledge Bronagh Carr and Tendayi Kureya of Irish Aid for their support for the project.

Community- and home-based care programmes need to provide a continuum of care to their clients. In the evolution of home-based care, we have moved from a vertical programme of palliative home care to one that uses an integrated approach that meets medical, psychosocial, spiritual and emotional needs as necessary.

Dr David Parirenyatwa, Minister of Health and Child Welfare, Zimbabwe

For a woman to give community care and support, she would need to pay someone to fulfil her own domestic duties. The cost of clothes, transport etc. would eat at her domestic budget. Many of these women are doing work that would previously have been done by qualified nurses – and it is ironic that many of these are male nurses: when it is a paid profession, it attracts male candidates.

Lynde Francis, Executive Director, The Centre, Harare, Zimbabwe

It is encouraging to note that in the face of enormous odds, individuals and communities are rallying to aid one another to ease the burden of HIV. These home–based care workers are an inspiration.

Dr Festo Kavishe, United Nations Children's Programme (UNICEF) Representative to Zimbabwe

Foreword

There is no doubt that home-based care (HBC) has emerged as a critical vanguard in the overall response to HIV and tuberculosis (TB) in Zimbabwe. A key lesson we have learned from implementing HBC programmes over the years is that, with the appropriate structures in place, it is possible to look after people in their homes and communities, not only in hospital and clinic settings.

The Ministry of Health and Child Welfare fully recognizes the importance of home-based care services, and has therefore made efforts not only to have a dedicated HBC department within the National AIDS Council but also to develop appropriate policies to expand and guide such care.

At its core, home-based care is about people like you and me: people who have a heart to care with and people who receive care. HBC gives back hope to individuals, families and communities.

For HBC to be effective, there must be appropriate structures in place to run programmes. In addition, there must be advocacy for HBC so that it is accepted at all levels of society without being riddled by stigma and discrimination.

HBC activities need to be adequately resourced so that timely and high-quality care is delivered to those in need. That is why it is vitally important for the government, the private sector and funding agencies to partner with civil society and to provide significantly more funding to support these projects.

Although Zimbabwe has put a great deal of energy into implementing home-based care projects, the overall impact has not been satisfactory – primarily because of a lack of resources.

Government, civil society and private-sector partnerships can open new channels to meet the varied needs of infected and affected people, including medication, food, psychosocial support, safe water and sanitation, and education for children, among many other issues.

The standard home-based care kit – the most basic tool in the hands of caregivers – needs to be constantly replenished, so that when caregivers go to see clients they at least have basic supplies and provisions for them. One of the reasons for the large resource demands of HBC is that the families of affected individuals often draw on the supplies provided by caregivers. In that sense, it is essential to consider a client's family, social and economic context when developing the required HBC package.

Children affected by HIV, in particular, must be identified and supported with school fees, uniforms and food and, most importantly, with psychological support. We must work towards integrating children into supportive family structures.

The increasing availability of antiretroviral drugs (ARVs) heralds new challenges for caregivers. As more people take ARVs and are able to live in the community, caregivers must be able to monitor them to ensure adherence to the drugs and management of any side-effects. This means that caregivers need ongoing training so that they are aware of treatment regimes and their potential side-effects.

TB-HIV co-infection is also increasingly becoming a problem in the country. Caregivers must be able both to help diagnose opportunistic infections and to monitor whether people are taking anti-TB drugs appropriately.

Given the enormity of the challenges that caregivers face, it is unacceptable that women have to shoulder the bulk of this responsibility. Increased efforts must be made to ensure that men play their part in lessening the burden and impacts of HIV in the community.

It is critical that proper incentives, tools, training and psychological support be designed and provided for caregivers. Recruiting and retaining caregivers must be seen as an integral component to the success of HBC.

To conclude, documentation of the quality, cost and scale of HBC interventions is essential to inform expanded or future interventions. Scaled-up responses will benefit from a systematic approach and lessons learned from current approaches.

This publication provides an overview of experiences and lessons learned in the implementation of eight Irish aid-funded projects in Zimbabwe. It not only promotes knowledge exchange about HBC but will go a long way to strengthening the capacity of policy-makers, funding agencies and implementers to design interventions that can make a much-needed difference to many people's lives.

Dr David Parirenyatwa
Minister of Health and Child Welfare, Zimbabwe

Executive summary

In Zimbabwe, as in many parts of sub-Saharan Africa, home-based care (HBC) plays a vital role in the response to HIV as overwhelmed public health and welfare systems fail to cope with the demands of the epidemic. HBC organizations have evolved and grown relatively organically throughout Zimbabwe in response to the epidemic, supporting and directing the activities of caregivers as the epidemic has dictated.

To understand more about the development of HBC in Zimbabwe and its future potential, Irish Aid engaged Health & Development Networks (HDN) and the Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS) to assess and document lessons from HBC interventions. Since 2005, Irish Aid has supported HBC initiatives in Zimbabwe, and is currently funding 15 HBC programmes throughout the country. The current project was designed to contribute to better understanding and evidence-based decision-making in the implementation of HBC interventions in Zimbabwe and beyond.

The evidence gathered by the project was compiled through a qualitative analysis of eight purposefully selected Irish Aid-funded HBC projects. The qualitative data for each project was collected through five main approaches:

- In-depth interviews: These comprised one-to-one interviews with HBC project/programme implementers; focus-group discussions with caregivers, beneficiaries and community leaders; and additional interviews with key informants.

- A comprehensive literature review.
- An online eForum discussion, conducted to solicit broader views about HBC.
- Key Correspondent articles: These were based on project site visits and interviews conducted with people living with HIV (PLHIV), caregivers and community leaders, capturing and documenting first-hand accounts of local and personal realities surrounding HBC and related themes.
- A home-based care learning event, which brought together over 100 participants in Harare, to gather information.

The goal of this publication is to guide HBC implementers, policy-makers, regional and international organizations, and donors in designing and prioritizing HBC programmes, creating policies and targeting funding to make a real difference to people's lives at the local level. As well as summarizing the main findings of the current project, it presents four sets of specific recommendations.

Key recommendations 1: Implementing HBC policies in Zimbabwe

Various policy gaps currently hamper the efficient and effective delivery of HBC services. The following key recommendations should be considered in addressing these gaps and during the future formulation of HBC policy:

- While antiretroviral (ARV) treatment guidelines are already in place, they should be directly linked to HBC. The link needs to be outlined in national treatment guidelines, indicating clearly the role for community-based volunteers in nutrition counselling and treatment adherence support.
- Practical, clear guidelines should be developed to promote the recruitment and involvement of men in care work, including HBC services.
- An HBC volunteer policy should be developed, with close participation of volunteers and other key stakeholders.

- National policy guidelines should be developed to promote effective integration strategies for HBC services.
- Herbal remedies are widely regarded as 'alternative therapies' within HBC programmes, and a need exists for guidelines providing clear direction on how they should be used alongside ARVs.
- Building the capacity of volunteer caregivers to transfer skills to family members and other primary carers should be included in future HBC policy development and elaboration.
- A professional code of conduct for caregivers must be developed that guides their actions.
- Effective partnerships between affected communities, nongovernmental organizations (NGOs), governments and international organizations/agencies are essential to HBC, and this should be reflected in future HBC-related policies.
- Donors participating in the Expanded Support Programme (ESP) are encouraged to play a lead role in leveraging the participation and support of other donors and aligning programmatic interventions that can help to strengthen the reach and impact of HBC services.

Key recommendations 2: The role of caregivers in HBC

There are a number of key recommendations that should be considered in helping to empower caregivers to execute their role in the community effectively:

- Caregivers are at the heart of HBC interventions – appropriate policies and guidelines should be put in place to provide incentives and psychosocial support to caregivers.
- HBC implementers must strive to inform the community about the selection criteria for carers. Standard terms and conditions of service for HBC volunteers should be developed.
- Community ownership and involvement helps to strengthen HBC activities, but implementers and policy-makers must ensure that many people in the community are involved as caregivers (not just – as now – women, particularly elderly women).
- The local community, including relevant leaders, should be involved in the

conceptualization, inception and execution of HBC programmes. Services should respond to the felt needs of the community and use such information for planning and programming.

- Social openness about HIV should be encouraged in the community as a way to combat HIV-related stigma and discrimination. A code of ethical conduct should be put in place for caregivers, and sufficient forms of redress for professional violations must be made available.
- Caregivers should be constantly encouraged to protect the privacy of PLHIV under their care.
- HBC programmes must ensure that universal precautions are promoted and adhered to among caregivers, including ensuring the availability of essential supplies such as soap and gloves.
- Volunteer retention can be achieved through the provision of basic tools such as uniforms, shoes, soap, bicycles and full, standard HBC kits. Incentives should include items that compensate for an individual's time spent on the HBC programme, including recognition, participation in income generating projects, food packs and sometimes money.
- Training packages must be developed for caregivers so that they increase their knowledge about how to deliver AIDS care in the most effective ways. Training in treatment literacy should be a compulsory component of HBC training.
- Regular refresher courses incorporating new developments in HIV- and TB-related issues need to be provided to caregivers.

Key recommendations 3: Challenges faced by HBC services

- The international community needs to urgently consider providing support to Zimbabwe, purely on humanitarian grounds.
- National HBC policy should address the issue of resource mobilization to ensure that the effectiveness of potential and existing HBC programmes/ organizations is not compromised by a lack of resources.
- The Government of Zimbabwe should support HBC programmes by creating a conducive environment that enhances the accessibility of financial resources and materials, including ARVs.
- National AIDS Council (NAC) coordination of HBC services needs to be

strengthened. It is recommended that the NAC and the Zimbabwe AIDS Network (ZAN) should organize platforms for information exchange, experience sharing and peer review among HBC organizations.

- The administrative budgets for HBC organizations should be constantly reviewed upwards in line with the current economic (and inflationary) environment.
- The budgets for relevant projects, including HBC programmes, income-generating and food-security projects (e.g. nutrition gardens, chicken projects) should include sufficient provision to ensure a reliable supply of potable water, through sources such as boreholes.
- Those working in and with HBC programmes must be provided with training to improve the documentation of their work, especially in relation to potentially replicable best practices.
- Youth programmes for both in- and out-of-school children must be incorporated into HBC activities.
- HBC approaches should be expanded to enable children to be loved, provided for and cared for in families and communities.
- HBC programmes must make an investment in understanding the needs of specific groups – such as old women, youth and children – so that they can develop appropriate response strategies.
- Support for community- and home-based care initiatives should be improved by ensuring consistent funding for sustained periods, as well as the provision of technical support to funding recipients. Funding agencies should also prioritize the strengthening of the organizational capacity of HBC organizations and projects.
- Promoting access to water and improving general sanitation should be an underlying theme of all HBC interventions.

Key recommendations 4: An integrated HBC approach

An integrated approach will require better management, planning, resource allocation and monitoring by HBC programmes. Key recommendations that should be considered when implementing an integrated approach include:

- Funding agencies should provide support for infrastructure development and capacity building within health systems. Greater attention must be paid to the roles and needs of health-care workers.
- There is an acute need for ongoing support to develop project-proposal-writing and financial-management skills within HBC programmes.
- Those working in and with HBC organizations require ongoing training and support so that they fully understand the issues that they have to deal with at community level.
- HBC programmes need to establish, expand and manage strategic partnerships with other sectors in the community in order to enhance the integration of services.
- Information, education and communication (IEC) materials and messages should be standardized through the NAC IEC committee.
- Gender-awareness training and a focus on children must be central to all integrated approaches.
- The meaningful involvement of PLHIV in the design of programmes and the identification of priorities is essential to the success of an integrated approach.
- The local community must also be involved in designing, implementing and evaluating integrated programmes.
- There is an urgent need for policy and technical guidelines on how to integrate HBC services with other health-care services.
- Funding agencies must prioritize the funding of HBC activities that use a comprehensive and integrated approach.

Part One:
Home-based care (HBC) in Zimbabwe

Introduction

In Zimbabwe, as in many parts of sub-Saharan Africa, home-based care (HBC) plays a vital role in the response to HIV as overwhelmed public health and welfare systems fail to cope with the demands of the epidemic. HBC organizations have evolved and grown relatively organically throughout Zimbabwe in response to the epidemic, supporting and directing the activities of caregivers as the epidemic has dictated. Most care at the home and community levels is provided by elderly women, who perform care duties with limited training or resources and in very difficult conditions.

To understand more about the development of HBC in Zimbabwe and its future potential, Irish Aid engaged Health & Development Networks (HDN) and the Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS) to assess and document lessons from HBC interventions. Since 2005, Irish Aid has supported HBC initiatives in Zimbabwe, and is currently funding 15 HBC programmes throughout the country. The current project was designed to contribute to better understanding and evidence-based decision-making in the implementation of HBC interventions in Zimbabwe and beyond.

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- Key Correspondent articles: These were based on project site visits and interviews conducted with people living with HIV (PLHIV), caregivers and community leaders, capturing and documenting first-hand accounts of local and personal realities surrounding HBC and related themes.
- A home-based care learning event, which brought together over 100 participants in Harare, to gather information.

This publication brings together some of the cross-cutting evidence and messages derived from each of the above, channelling data as well as personal perspectives into a set of policy recommendations on HBC in Zimbabwe. During this overall process, there was a special focus on how issues of gender, food security, HIV-affected children, tuberculosis (TB) and access to treatment are being addressed in ongoing interventions, and what more can be done to tackle these priorities.

The goal of this publication is to guide HBC implementers, policy-makers, regional and international organizations and donors in designing and prioritizing HBC programmes, creating policies and targeting funding to make a real difference to people's lives at the local level.

Context and background

Zimbabwe is a landlocked country in southern Africa with an area of 390 000 square kilometres and a population of about 13 million people, of whom 70% live in rural settings. Zimbabwe ranks 151 out of 177 nations on the United Nations Development Programme (UNDP) Human Development Index (2008), a composite metric depicting general social and economic indicators.

Zimbabwe is currently experiencing its worst economic crisis since attaining independence from British rule in 1980, with an estimated 80% of the population living below the poverty line. Approximately seven millon people – just over half of the population – live on less than US$ 1 a day, and an estimated 80% live on less than US$ 2 per day. The estimated unemployment rate is staggeringly high, at over 80% (UNDP 2008).

Agriculture is the dominant sector of the Zimbabwean economy, with approximately 80% of the population dependent on it for their livelihood and food (UNDP 2008). In recent years, poor rainfall has devastated subsistence agriculture, leaving many rural households in desperate need for food or other forms of support.

Against this bleak background, Zimbabwe is also experiencing one of the world's worst HIV epidemics. Since the first reported case of HIV in 1985, the epidemic

has become a serious health, social and economic problem in the country. 1.7 million people are estimated to be living with HIV, 890 000 of them women and 150 000 of them children under 14 years old. Average life expectancy at birth has now fallen below 35 years, having reached a previous high of over 55 years (DFID 2008).

It is thought that over 3200 people die each week from AIDS-related illnesses (UNAIDS 2005), which also account for some 75% of all hospital admissions. The impact of HIV, extremely harsh economic conditions and reduced funding from international donors have all combined to severely strain the delivery of health services throughout the country.

TB has also re-emerged as a leading killer, especially among PLHIV, who are often not identified by the commonly used but antiquated TB diagnostic tests. An estimated two-thirds of Zimbabweans with TB are also infected with HIV. As a consequence, Zimbabwe has a staggering six times more TB cases than it did 20 years ago. Malnutrition, poor sanitation and overcrowding are also helping TB to spread.

At the same time, however, Zimbabwe is the first country in southern Africa to have reduced HIV prevalence. Prevalence has steadily fallen to the current rate of 15.6% from 18% in 2006, 20.1% in 2005 and 24.6% in 2003 (UNGASS 2007).

The HIV epidemic, the emerging TB/HIV co-infection, severe droughts – which are closely linked with food shortages – and poverty have significantly impacted on progress with regard to population and developmental issues in the country (United Nations Population Fund (UNFPA) 2007).

The capacity of the health care and other welfare systems to provide long-term care and support to chronically ill people has been drastically overstretched, and they cannot cope with the huge demand for services. The public health system has rapidly deteriorated in the past decade and a half, a deterioration characterized by a significant decrease in government expenditure on health services, chronic drug shortages and the emigration of medical personnel.

With the number of individuals falling sick as a result of AIDS-related illness increasing, the economic crisis deepening and recurrent droughts threatening livelihoods and food security, family and community networks have emerged in Zimbabwe to provide HBC services to those infected and affected by HIV.

Local and community care for sick people has long been practiced in Zimbabwe, but over the past decade and a half it has become increasingly institutionalized as a means to cope with the HIV epidemic. Traditionally, women and girls have been entirely responsible for caring for the sick, while men provided material support such as money, food, shelter and water – a trend that has continued in the current practice of care work. Women and girls are frequently the main caregivers for those with AIDS-related conditions and their dependants.

Evolution of HBC in Zimbabwe

Understanding how HBC has evolved in Zimbabwe is key to shaping future policy and implementation of HBC activities. In retrospect, six major phases in the evolution of HBC in Zimbabwe over the past 25 years or so can be identified:

i) First, HBC offered prior to and soon after independence from British rule in 1980 focused on people who were physically or mentally challenged or terminally ill with illnesses such as TB, cancer and hypertension.

In the decade following independence, Zimbabwe experienced some of the most rapid improvements in health, nutrition and population (HNP) indicators in all of sub-Saharan Africa.

Hospitals were not congested, and therefore could keep inpatients for longer periods of time. There was adequate medication for most ailments including common infectious diseases. During this period, terminally ill people were discharged from hospital and clinics to be cared for in their homes. The relevant health setting would assign a community nurse to follow up and advise on basic nursing care, as well as provide psychosocial support. At the time, most households were able to accommodate a relative who was discharged for home care in this way.

ii) Second, the HBC offered following the first reported HIV infection in Zimbabwe in 1985 was characterized by fear, stigma and discrimination. In that same year, the Minister of Health and Child Welfare (MoHCW) established the National AIDS Coordination Programme (NACP) to manage the national response to the epidemic. This period was characterized by a sensationalization and moralization of the disease that resulted in high levels of stigma and discrimination in society.

Despite this climate, Auxilla Chimusoro became one of the first individuals in Zimbabwe to openly declare her HIV-positive status in 1989. She later established the first HIV support group in Masvingo. Before she died in 1998, she had established more than 50 support groups in both rural and urban communities throughout Zimbabwe. These support groups provided the first cadres to be involved in HBC. When HIV first emerged in Zimbabwe, the government was slow to acknowledge the extent of the problem and take appropriate action.

From the single case identified in 1985, numbers of infected people increased to 10 551 by 1991, which put a lot of pressure on the health sector that was undergoing restructuring through the Economic Structural Adjustment Program (ESAP) introduced in Zimbabwe by the International Monetary Fund (IMF) in 1990. Under ESAP, Zimbabwe was to expedite its economic growth through the introduction of cost-recovery measures, parastatal reform, civil service rationalization and the removal of subsidies. Hospitals were expected to charge market-related tariffs to all people for their services. The cumulative impact of neglect on non-productive sectors, such as health, caused a serious decline in the quality of services and shortages of essential drugs. Hospital beds became constantly occupied, resulting in more discharges and strict pre-admission screening processes.

iii) Third, the HBC offered from 1991–1995 took place within the context of a deteriorating economy but – at the same time – an increasingly intensive response to the HIV epidemic. During this period, many health and health-service indicators stagnated or declined under the combined burdens of HIV, economic crisis and drought. However, many HIV-focused nongovernmental organizations (NGOs) came into being during this phase. In the absence of significant domestic investment, external donors funded many HIV-related programmes. Religious

organizations also began providing care and support to PLHIV. In 1991, the Zimbabwe AIDS Network (ZAN) was formed to coordinate the activities of HIV service organizations in the country. More PLHIV came forward to support advocacy and care for people infected and affected by the epidemic.

iv) The fourth stage – 1996 to 2000 – was characterized by a formal recognition of HBC as an important approach in the response to HIV. With a weakening economy and a growing number of PLHIV, the government recognized that the health system alone could not cope with the impact of the epidemic.

In 1999, the Government of Zimbabwe declared a six-month-long national emergency with regard to the HIV epidemic and streamlined the activities of NACP by creating the National AIDS Council (NAC) and the AIDS and TB Unit in the MoHCW, as well as developing and launching a National AIDS Policy (NAP). The role of the NAC was to coordinate all national HIV- and AIDS-related activities and other interventions, including monitoring and evaluation. To facilitate the work of the NAC, the government introduced the National AIDS Trust Fund, commonly referred to as the 'AIDS levy', which collected a 3% tax on all taxable income. The levy was to support HIV prevention efforts and care services through decentralized structures.

The National AIDS Policy recognized community home-based care (CHBC) as an extension of the health-care delivery system to be fully developed and supported as an essential component of the continuum of care for PLHIV and their families. It also explicitly called for the development of guidelines for an effective referral and discharge plan to CHBC. It was at this time that HBC programmes engaged in the extensive training of volunteers and primary carers in order to meet the anticipated demand for HBC services. The delivery model shifted from a primary focus on volunteers as primary care providers to volunteers becoming facilitators of care by training family members as primary caregivers. As well as meeting demand, this shift was primarily driven by the rate of burnout experienced by volunteers. The provision of quality care became the key principle, supported by the development of a 'minimum care package'. In addition, the NAP called for efforts to address burnout among care providers. This has become an indispensable and integral part of volunteer management in HBC programmes.

The impacts of the epidemic had knock-on effects throughout HBC and related service provision. With more illness and death among breadwinners, worsening endemic poverty and household vulnerability, and growing numbers of orphans being left in the epidemic's wake, the need to integrate various related approaches and interventions became glaring and urgent. For example, organizations that had been established with a focus on orphan care recognized the urgent need to provide HBC to parents with AIDS-related illnesses. Similarly, HBC-focused organizations could no longer ignore the orphans who were left behind following the deaths of their clients. HBC programmes were also called upon to help develop and support income-generating initiatives and provide livelihood support for remaining family members. Unfortunately, although the need for more integrated approaches and services was clear, it would nevertheless be some years before these would be put into effect in earnest.

v) During the fifth stage, between 2001 and 2005, the number of Zimbabweans thought to be living with HIV rose dramatically from 10 000 to around 1 000 000, while the estimated number of orphans rocketed to 800 000. Official records estimated that approximately 3000 people were dying of AIDS-related conditions every week (UNAIDS 2005). During this period one of the few factors that came close to keeping pace with the rampaging epidemic was the deterioration of the Zimbabwean economy and the impact that this had on most people's personal incomes. During this period, inflation skyrocketed; over 60% of people in Zimbabwe were unemployed and the bulk of Zimbabweans were living on less than a US$ 1 per day.

As a consequence, Zimbabwe declared HIV a state of emergency for a second time in 2002 and decided to override patent protection to enable the procurement and importing of generic ARVs.

It was in this desolate context from the start of the millennium that the international donor community began to significantly reduce donor assistance to both the government and NGOs.

At this time, close to 500 organizations were providing HBC services and support. Economic challenges in the country had already resulted in a substantial 'brain drain' of professional talent from Zimbabwe, including health-care workers, which contributed to the disintegration of the hospital-linked models of HBC. As

a consequence, HBC programmes became increasingly dependent on churches, NGOs and communities with only minimal support from either the government, through the AIDS Levy, or the international donor community.

Nonetheless, the Zimbabwe National Orphan Care Policy was introduced in 1999 to support the ongoing integration of HBC and programmes for HIV-affected children. In addition, communities and programme implementers began to recognize the significant 'gendered' aspects of HBC provision, which placed the burden of care squarely on the shoulders of women, and calls were first heard for more male involvement in HBC.

In 2001, the Community Home-Based Care (CHBC) Policy came into being. Its purpose was to ensure that there would be continuity of care from health-care institutions to the community. It prescribed a minimum package of care to highlight the value of community home-based care to the people of Zimbabwe. The policy also helped to raise awareness about available resources, encouraged support for the community and local health-care providers, and provided an overall framework for caregivers in the implementation of CHBC priorities.

However, most HBC programmes and services fell short in terms of the quality and effectiveness of their service provision. The National Community Home-Based Care Standards (2004) and the National Home-Based Care Training Manual (2005) were developed to help standardize HBC activities, training and other processes. Their purpose was to give programme managers and care providers a foundation from which to identify gaps in their services and to seek the training and support they needed.

In addition to these HBC-focused efforts, one of the most significant changes in AIDS care also came to Zimbabwe in 2001: the advent of ARVs. A 'Plan for the Nationwide Provision of antiretoviral therapy' launched that year recommended that ARV treatment be introduced initially at a limited number of central sites and gradually decentralized to the provinces as more health personnel received in-service training. Availability, affordability and accessibility of ARVs were identified as important gaps in HIV programming in the country. The MoHCW started its roll-out plan in April 2004 and by May 2005, 27 public health institutions were offering ARV-treatment services.

The introduction of ARVs also brought some new challenges to HBC programmes and services. Caregivers had to be trained in how to manage ARV

treatment for PLHIV in their care. In addition, ARVs are still not available in many communities around the country. According to World Health Organization (WHO) estimates, only 91 000 of the 321 000 people currently in need of ARVs have access to them (WHO 2008).

In the absence of ARVs, many PLHIV sought out and adopted a wide variety of 'alternative' therapies, some of which were ineffective and others even harmful. Some HBC services introduced specific herbal therapies through the establishment of medicinal gardens and hence provided some people with HIV with new hope that they would live longer.

vi) The sixth stage is the current state of HBC in Zimbabwe, beginning in 2006. Although the government has shown political support for HIV, responding to the crisis has largely been hampered by political problems and diminished international humanitarian support for the country. Many HBC programmes and services are operating under terrific strain and hardship, with very little support.

In 2006, the government launched the Zimbabwe National HIV/AIDS Strategic Plan (ZNASP), which articulated the direction and targets for the national response to HIV during the period 2006 to 2010. The plan reinforced the need for a multisectoral response to the HIV epidemic, and also introduced the concept of 'universal access' to prevention, care and treatment services. It also highlighted the need to care for volunteers and to enhance male involvement in HBC programmes. With regard to HBC organizations, the ZNASP proposed to replenish HBC kits through the NAC and to reinforce the integration of nutrition programmes.

HBC programmes have evolved to include some integrated approaches to mitigate the impact of the epidemic on individuals, households and communities. Those documented as part of the current project, for example, aim to provide one or more of the following services: health care, nutritional support, access to clean water and sanitation, food security, counselling, treatment literacy, nutritional and treatment adherence and livelihood support.

However, the economic fallout and growing poverty in the country have dealt a serious blow to HBC activities. Many funding organizations have either reduced or frozen aid to humanitarian activities in Zimbabwe. In 2005, UNICEF estimated that the average amount of international HIV-related funding available each year in the southern Africa region was US$ 74 per person infected with HIV, but in Zimbabwe

that figure drops to US$ 4. In 2007, the figure had risen to US$ 17, still far below regional estimates. Although Zimbabwe has a high rate of HIV prevalence, the available resources are far below the needs of the national response (UNGASS 2007). Reduced donor support is currently undermining the effectiveness of HBC programmes as organizations either scale down or reach out to clients with very limited services.

Although volunteer caregivers are keenly aware of the needs of PLHIV, their efforts are hampered by a lack of basic provisions: medication, gloves, soap, food and other basic supplies. The quality of care in many HBC activities is severely compromised as a result of significant and unmet needs. HBC programmes are having to make do with very few resources and are in desperate need of material support.

The HBC programmes reviewed in detail as part of the current project highlight the many and varied needs of affected people and communities and the manner in which those needs change over time. To fulfil these demands, individual care organizations will need to access new donor support and develop unprecedented partnerships, networks and coordination to maximize the very limited resources available to them. These basic questions of resource allocation and distribution will have to be addressed before overarching issues of efficacy – such as the development of more cost-effective interventions, better delivery strategies, improved management practices and evidence-based HBC evolution – can possibly be tackled.

The current challenging context for HBC in Zimbabwe requires that the human capacity to adapt and respond in the face of new and extraordinary challenges presented by the epidemic be exploited to the utmost. Local capacities have been mobilized but there is an urgent need for external support to improve the situation of people infected and affected by HIV.

A systematically integrated approach to care and support is clearly required – with government, donor and community-based care organizations combining their respective skills and means to ensure that home-based care works to bring essential change to people's lives.

In this respect, the Expanded Support Programme (ESP), a multi-donor common funding mechanism that supports the National Strategy for HIV and AIDS in Zimbabwe, can play a key role in supporting the varied elements of integrated

HBC approaches in the selected districts where it is funding projects. Other funding mechanisms at country level must also prioritize funding for HBC programmes.

The fact that the ESP relies on UN agencies for implementation, and is managed by a working group made up of the government, donors, UN agencies and civil society organizations, means that several development players will be involved and will focus on the different issues that are key for an integrated HBC approach. The ESP's aim to support 'universal access' to prevention, care and treatment services by 2010 for all Zimbabweans living with HIV might be expedited if activities were channelled through existing HBC programmes, which have already established structures within communities.

The ESP and other donor funding mechanisms urgently need to help finance the programmatic gaps identified in the current project, as well as the capacity development of HBC organizations, so that these organizations can reach exponentially more people in need. Donors in Zimbabwe need to recognise the success that has been registered by HBC projects under very difficult conditions.

Only two proposals submitted to the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) by Zimbabwe have been approved, with the others being rejected for 'technical reasons'. The Global Fund should recognize the successes achieved in tackling HIV, including through home-based care, under difficult circumstances and be prepared to channel much-needed funds into the country.

Part Two:
Key findings and policy recommendations

1

Implementing HBC policies in Zimbabwe

The Government of Zimbabwe clearly recognizes the importance of HBC, as evidenced by the national policies that have been developed to guide related interventions, projects and programmes. Specifically, the conduct of HBC in Zimbabwe is governed by the NAP, the CHBC policy and the National Community Home-Based Care Standards (2004) among others. In general, the implementers interviewed as part of this project demonstrated a good knowledge of these policies and standards. However, they mentioned that while they attempt to adhere to the guidelines as fully as possible in their operations, the lack of adequate resources is often a constraint.

The CHBC policy underscores the principles of family and social support, highlighting the paramount importance of identifying the needs of PLHIV and their families to offering support. It also highlights the importance of the provision of psychosocial support for health workers and caregivers in order to alleviate stress and burnout.

It is noteworthy that most of the HBC organizations consulted had conducted family and client needs assessments before designing and implementing HBC

programmes. In addition, all of them endeavoured to provide psychosocial support to caregivers, clients and their families.

The CHBC policy also calls for the involvement of PLHIV, other clients, families and 'significant others' in decision-making and the planning of individual care – thus providing recognition of their personal worth and individuality. This should entail, among other things: explaining the care plan clearly to PLHIV in a language they readily understand; making information available that relates to diagnosis, the progress of illnesses, care options and support services – all within the context of confidentiality; assessing the needs of PLHIV; and matching these needs with available resources.

While the policy makes laudable pronouncements with reference to the involvement of clients and 'significant others' in decision-making and the planning of care, matching resources to the needs of the affected people remains difficult, primarily due to the widespread lack of resources among HBC organizations. A case in point is the failure of Uzumba Orphan Care (UOC), Bekezela and Catholic Health Care Commission (CHCC) to meet even the most basic needs of their clients because of inadequate funding, especially with regard to replenishing essential HBC kit components.

The National Community Home-Based Care Standards are a practical extension of the CHBC policy. They are largely an elaboration of the fundamentals of quality nursing care contained in the CHBC policy document. Uniform guidelines or standards support the design of programmes that deliver services effectively. Partners on the ground emphasized their appreciation of the standards and have made an effort to align their programmes with them. Once again, however, many commented that adherence to the standards is frequently hampered due to a lack of adequate resources.

The Zimbabwe National AIDS Strategic Plan (ZNASP) for 2006–2010 includes four main strategies: (1) HIV prevention, with a focus on behaviour change promotion; (2) increased access to and use of treatment and care services; (3) improved support for individuals, families and communities infected and affected by HIV; and (4) effective management and coordination of the national HIV response.

Since their inception, the nature of HBC interventions and policies has changed in response to the emerging challenges and dynamics of the HIV epidemic in Zimbabwe. The emergence of HIV caught the nation unawares. However, in view of the socioeconomic and political challenges being experienced in the country,

the government has excelled in its policy-formulation role and in the promotion of HIV prevention, which has been linked to the recent decline in HIV prevalence in the country.

The evolution of home-based care has nevertheless been largely characterized by 'fire-fighting' approaches as opposed to proactive strategic thinking or planning. From the outset, information and data on HIV were gathered, but were not necessarily used to inform policy or programme directions until well after the epidemic had exploded. For example, statistics warned of the increased demand for health services due to AIDS-related illness, yet little was put in place in anticipation of that need.

In the past few years, several civil society funding models have emerged in Zimbabwe aimed at channelling resources to affected communities. The Expanded Support Programme (ESP) is one example of a multi-donor programme under the ZNASP, which aims to scale up access to HIV prevention, treatment and care services from 2007 to 2009. The ESP, which is still in its infancy, complements other available resources (the domestic AIDS levy, Global Fund grant(s), bilateral and multilateral support) and existing programmes to provide financing where gaps exist, aiming towards:

- reducing transmission of HIV;
- reducing the impacts of HIV and improving the quality of life of those infected and affected by HIV;
- strengthening coordination of the HIV response at all levels.

The joint programme and common funding mechanism pools resources from five bilateral donors: Canada, Sweden, Ireland, Norway and the United Kingdom. The ESP is guided and managed by a Working Group that refers directly to the National Partnership Forum. Implemented by the MoHCW, the NAC, United Nations agencies (UNDP, UNFPA, UNICEF, WHO and UNAIDS) and the International Organization for Migration (IOM), the programme focuses on:

- HIV prevention, treatment and care;
- coordination support at the district level;
- procurement and supply-chain management; and
- technical support, including strengthening the capacity of national structures.

It covers 16 districts throughout the country, targeting national institutions, nongovernmental organizations and community-based organizations, underserved rural populations and PLHIV.

The selection of districts is based on recent government-led ARV treatment-readiness assessments, their suitability for immediate ARV introduction and required minimum staff to initiate ARV treatment services. Immediate beneficiaries from the programme will be 16 000 poor PLHIV who are currently unable to access ARVs. The programme aims to:

- increase the number of people participating in the ARV treatment programme (from 52 000 to 72 000);
- strengthen the National Blood Transfusion Service capacity to screen donated blood for HIV; and
- address the difficulties experienced by poor people in accessing prevention, treatment and care services.

The ESP is still in its early stages. An independent review in 2007 established that apart from the need to improve internal governance and procedural issues, major challenges to the effectiveness of the funding scheme include deterioration in the economic situation, poor health systems, and lack of comprehensive coverage of HIV services (ESP 2008).

Coordinating HBC services

As this project to document lessons from HBC reveals, there is no common standard that HBC interventions adhere to, despite the existence of relevant national policies. The diversity of providers, services and delivery models makes it impossible to propose a single approach for scaling up HBC services to reach more people.

Enhancing the coordination of HBC services requires a national audit of HBC programmes to ascertain the current scope of activities and assess where gaps exist.

That being said, the best possible HBC for infected and affected people can only be achieved through an integrated package of services. The national audit should therefore estimate the logistics and cost of such an integrated service package. A clear understanding of the resource requirements is essential for HBC-focused programme planning and implementation and for coordinating services.

HBC in Zimbabwe is in dire need of expanded support. Despite the burdens being faced by caregivers in Zimbabwe, HBC is still one of the most cost-effective ways to deal with illness in the context of a crumbling public health system.

Civil society funding mechanisms such as the ESP can play a key role in securing donor support and in aligning programmatic interventions that can help to strengthen the reach, quality and impact of HBC. The synergistic nature of the ESP, for example, is essential to, and should support, an integrated HBC approach. Similarly, strengthened health systems are also fundamental to this approach because they provide a close complement to HBC services.

To succeed, civil society funding initiatives need to build on people's energy and creativity at all levels, empowering and building the capacity of people in households and communities to take action, and applying technologies that respond to genuine needs. Donors must dedicate resources to strengthening and supporting CBOs so that they serve clients effectively and respond to the increasing demands and challenges of the epidemic. Building capacity should include a focus on strengthening the management and fund-raising capacities of CBOs, helping them to build and sustain networks and partnerships that can deliver essential services to clients.

Key recommendations:

Implementing HBC policies in Zimbabwe

Various policy gaps currently hamper the efficient and effective delivery of HBC services. The following key recommendations should be considered in addressing these gaps and during the future formulation of HBC policy:

- While ARV treatment guidelines are already in place, they should be directly linked to HBC. The link needs to be outlined in national treatment guidelines, indicating clearly the role for community-based volunteers in nutrition counselling and treatment adherence support.
- Practical, clear guidelines should be developed to promote the recruitment and involvement of men in care work, including HBC services.
- An HBC volunteer policy should be developed, with close participation of volunteers and other key stakeholders.
- National policy guidelines should be developed to promote effective integration strategies for HBC services.

- Herbal remedies are widely regarded as 'alternative therapies' within HBC programmes, and a need exists for guidelines providing clear direction on how they should be used alongside ARVs.
- Building the capacity of volunteer caregivers to transfer skills to family members and other primary carers should be included in future HBC policy development and elaboration.
- A professional code of conduct for caregivers must be developed that guides their actions in the community.
- Effective partnerships between affected communities, NGOs, governments and international organizations/agencies are essential to HBC, and this should be reflected in future HBC-related policies.
- Donors participating in the ESP are encouraged to play a lead role in leveraging the participation and support of other donors and aligning programmatic interventions that can help to strengthen the reach and impact of HBC services.

2

The role of caregivers in HBC

In each of the eight organizations assessed as part of this project, volunteer caregivers clearly represent the 'front line' of HBC efforts and services. Volunteer caregivers make vital contributions to managing AIDS-related illnesses, particularly in rural areas. They travel long distances, usually on foot, to reach affected households. Caregivers provide basic first aid and counselling to PLHIV, as well training family members on how to provide various forms of care. Despite the huge demands placed upon them, volunteer caregivers display high levels of enthusiasm and dedication to their work. Much of their work remains unpaid, unaccounted for and undervalued in economic terms despite its critical contribution to the overall economy and society in general.

Due to the harsh economic environment currently prevailing in Zimbabwe, volunteer caregivers have to make do with very limited resources, which not only increase the burden of care but may also make caregivers vulnerable to HIV and TB infection. HBC programmes are failing to supply caregivers with basic tools such as medication, soap or gloves. Consequently, the role of caregivers is now largely limited to providing psychosocial support. In some instances caregivers are improvising – for example by using plastic bags as gloves – so that they can carry

out care work. In communities where medication is not available, caregivers also often encourage clients to use herbal therapies and other nutritional supplements.

Traditionally, the caregiving role has been disproportionately carried out by women. Male participation has increased moderately in recent years as a result of deliberate efforts by HBC programmes. Significantly, cultural factors bar female caregivers from attending to male clients and *vice versa*, so the participation of men in HBC is urgently needed for the care and support of male clients. HBC organizations still need to do a lot of work to confront the gender stereotypes that keep men out of care work.

Burnout of caregivers is a real challenge and difficult to mitigate, and its effect upon caregivers is that they simply drop out. It is critical that adequate incentives, tools, ongoing training and psychological support be planned and provided to caregivers. Volunteer retention is key to the long-term sustainability of HBC programmes.

Caregivers often forego income-generating activities that may benefit their own households in order to take care of PLHIV and other affected people. Caregiving comes at a cost to the caregivers and existing HBC models are based almost exclusively on volunteerism. As Lynde Francis, Executive Director of The Centre, Harare summarized, "We need to completely rethink the concept of primary health care and recognize that this cadre of health workers deserves certification, registration and remuneration and not just a bicycle, a uniform and – if you're lucky – a kit to use with your clients."

Caregivers and the local community

Caregiving is undertaken within the context of a community – a social group in a shared environment, with common interests. In such settings, intents, beliefs, preferences and needs, as well as available resources, prevalent vulnerabilities and a multitude of other conditions, may be common to all, affecting the identity of community members and the degree of cohesiveness of the community. In addition, the conditions in which people grow, live, work and age have a powerful influence on health. Inequalities in these conditions frequently lead to inequalities in health and in access to available services. The social and cultural determinants

of a given community and related norms, standards and leadership also have an important impact on HBC programmes and services (WHO 2002).

Strategies that help to mobilize the support of local leaders in the conceptualization, implementation, monitoring and evaluation of HBC activities are essential. The involvement of a variety of community leaders can also help to prevent duplication of effort, as well as identify service gaps. Various members of a given community need to be involved in the conceptualization, inception and execution of HBC programmes to ensure that they incorporate (and give voice to) more inclusive forms of knowledge, based on multiple perspectives and local realities.

By their very nature, HBC activities need to be situated within the heart of the community in this way. Traditional, political and religious leaders, local councillors, health and education administrators, as well as PLHIV and their families need to be well informed about the existence and focus of HBC projects. Above all, it is imperative that caregivers be strictly apolitical in order to avoid any bias or favouritism towards specific clients, groups or sections of the community.

The local community can also play a key role in identifying potential beneficiaries of HBC, thereby enhancing the accountability and transparency of programmes.

Caregivers and HIV-related stigma

HIV-related stigma and discrimination are often prevalent in many of the communities and local settings where HBC services are provided. The advent of ARV access, which has seen some peoples recover from the brink of death, has influenced a change in attitude towards PLHIV in many communities. However, due to the prospect of HIV-related stigma, many clients are reluctant to disclose their HIV status, sometimes creating a stumbling block to effective HBC delivery.

Caregivers have taken responsibility to talk openly about HIV at awareness meetings, providing facts about HIV infection, which has helped tremendously in reducing both stigma and discrimination. As a result, caregivers are witnessing a reduction of stigma within communities. Caregivers can therefore help to build the self-confidence of PLHIV as well as promote the involvement of other family members. Equally important is the need for caregivers to maintain confidentiality about the HIV status of clients.

Caregivers and ARVs

The growing availability of ARVs is undoubtedly bringing new hope to people living with HIV, but it is also increasing the demands placed upon caregivers. HBC programmes have to put in place mechanisms to train volunteer caregivers to manage ARV treatment.

Among other things, such training mechanisms must empower caregivers to assess the preparedness of a client to start ARV treatment and to ensure that those using the drugs stick to their regimen and understand the importance of eating nutritious food when taking ARVs. Training caregivers in ARV-treatment management is extremely important, particularly in sparsely populated rural areas where infrastructure is poor. A key implication is that caregivers who receive training should have at least basic reading and writing skills.

Caregivers and uniforms

Uniforms give caregivers an identity and visibility within the community, and also make it easy for clients to approach and open up to caregivers about their HIV status. In addition, this project overwhelmingly showed that uniforms give caregivers a high sense of pride in the work that they perform. Uniforms also help to enhance the accountability of caregivers. Furthermore, uniforms equalize the economic diversity of the caregivers and allow for cohesive presentation as a group, thereby enhancing team spirit. Unfortunately, in many of the HBC projects, caregivers have to make do with worn-out, tattered uniforms or nothing at all. Due to limited resources, HBC organizations are unable to keep their caregivers well-uniformed.

Caregivers and herbal therapy

Herbal therapies have emerged as a key tool in the hands of caregivers to help PLHIV cope with HIV-related conditions in communities where access to ARVs is non-existent or incomplete. According to World Health Organization (WHO) estimates, only 91 000 of the 321 000 people currently in need of ARVs in Zimbabwe have access to them (WHO 2008). Because ARVs are so difficult to obtain, many people turn to herbal therapies to help alleviate or offset certain AIDS-related conditions. Of the HBC projects sampled, CHCC has taken a lead in this area, documenting and training caregivers on the uses of herbal therapies. Caregivers need to continue reminding PLHIV, however, that herbal therapies do not cure or treat the underlying conditions, but mostly help to alleviate symptoms. Nonetheless, there is a need for ongoing research and documentation of the efficacy of various forms of herbal therapy.

Caregivers and HBC kits

In an ideal situation, HBC kits consistently contain the basic tools that caregivers require to care for PLHIV, as well as protect themselves from infection. Basic items include soap, gloves, bandages and simple painkillers. Due to limited resources, HBC kits are not routinely replenished, presenting major challenges to caregivers in delivering appropriate and adequate services to clients.

Key recommendations:

The role of caregivers in HBC

There are a number of key recommendations that should be considered in helping to empower caregivers to execute their role in the community effectively.

- Caregivers are at the heart of HBC interventions – appropriate policies and guidelines should be put in place to provide incentives and psychosocial support to caregivers.
- HBC implementers must strive to inform the community about the selection criteria for carers. Standard terms and conditions of service for HBC volunteers should be developed.
- Community ownership and involvement helps to strengthen HBC activities, but implementers and policy-makers must ensure that many people in the community are involved as caregivers, not just poor, old women.
- The local community, including relevant leaders, should be involved in the conceptualization, inception and execution of HBC programmes. Services should respond to the felt needs of the community and use such information for planning and programming.
- Social openness about HIV should be encouraged in the community as a way to combat HIV-related stigma and discrimination. A code of ethical conduct should be put in place for caregivers, and sufficient forms of redress for professional violations must be made available.
- Caregivers should be constantly encouraged to protect the privacy of PLHIV under their care.

- HBC programmes must ensure that universal precautions are promoted and adhered to among caregivers, including ensuring the availability of essential supplies such as soap and gloves.
- Volunteer retention can be achieved through the provision of basic tools such as uniforms, shoes, soap, bicycles and full, standard HBC kits. Incentives should include items that compensate for an individual's time spent on the HBC programme, including recognition, participation in income generating projects, food packs and sometimes money.
- Training packages must be developed for caregivers so that they increase their knowledge about how to deliver AIDS care in the most effective ways. Training in treatment literacy should be a compulsory component of HBC training.
- Regular refresher courses incorporating new developments in HIV- and TB-related issues need to be provided to caregivers.


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Challenges faced by HBC services

The primary challenge of the HBC programmes in the sampled projects remains the overwhelming demand for services in an environment characterized by hyperinflation, food insecurity, widespread poverty and reduced donor funding.

All of the organizations surveyed expressed concern that they are not able to adequately care for people who are in need. HBC initiatives highlighted the following key challenges that they currently face in their work.

Economic environment

The hyperinflationary economy prevailing in Zimbabwe does not allow effective budgeting, planning and implementation of HBC programmes. Many of the income-generating projects implemented by HBC programmes to provide livelihoods support for PLHIV have collapsed because of hyperinflation. The high cost and general lack of basic commodities such as food, soap, linen, clothes and drugs make it difficult for programmes to replenish HBC kits. A stable economic environment is a key pre-requisite for the successful implementation of HBC projects.

Transport costs

High levels of poverty and inflated fuel and transport costs mean that many PLHIV cannot afford to get to health-care centres. HBC programmes now face the challenge of finding enough resources to enable clients to travel to hospitals. The inability to afford transport costs is undermining the effectiveness of programmes, especially for PLHIV who are taking ARVs.

Disbursement of funds

The late disbursement of funds by funding agencies has presented numerous challenges to HBC programmes. Given the hyperinflationary environment in Zimbabwe, the cost of goods and services is always on the rise. When funding agencies delay the release of funds, it disrupts projected costs and budgets.

Limited resources

HBC programmes currently receive limited financial support to cater for programme activities. There are also frequent shortages of ARVs, which means that PLHIV under treatment inevitably miss taking their drugs for some periods. This is cause for concern as it may lead to drug resistance.

TB/HIV co-infection

Though TB treatment is provided free of charge to all those infected in Zimbabwe, the high prevalence of HIV has facilitated the resurgence of the disease. The rise in TB infections comes at a time when the government is overstretched in terms of both financial and human resources. With years of health-system challenges, one of the most severe HIV epidemics in the world, and stark social and economic conditions for many of Zimbabwe's people, the situation with regard to the prevention and control of TB is increasingly desperate. Although HIV/TB coinfection is having a severe impact on many individuals and communities, few HBC programmes are doing anything to address TB. TB treatment in Zimbabwe has traditionally been regarded as a government preserve and cases are identified and treated at the government clinic level. Little evidence of follow-up by HBC programmes was noted during the preparation of this report. Some HBC caregivers are reportedly informed in their training that they should only deal with HIV clients.

Children affected by HIV

According to UNICEF, Zimbabwe has nearly 2 million orphaned children, mainly due to AIDS (2007). An estimated 142 000 children are HIV-positive (UNGASS 2007). Although the government and donor partners have initiated an Orphans and Vulnerable Children Plan of Action, resources are too few to meet the current need. Children, especially girls, are missing out on their education because of their increased caretaking responsibilities at home. The costs of school uniforms, textbooks, supplies and examination fees are also keeping children out of school, further compounding their exclusion within society.

Many children today are at risk of hunger and malnutrition, psychological stress, abuse, exploitation and HIV infection. They also lack access to appropriate, child- and youth-friendly health care. Families and communities are near breaking point due to the extent of the orphan problem and are in urgent need of support.

In addition, HIV-infected children often have to take ARVs without being told why they are taking the drugs, raising many ethical challenges and questions.

Older people

Older people, particularly older women, are playing a key role in taking care of PLHIV in their communities and families. The study revealed that the impact of HIV has left many older people with increased responsibilities, yet current HBC packages include little to address the specific needs of older people.

Youth

HBC programmes also include little focus on youth, despite the fact that young people often fill the gap in taking care of the sick. Due to limited resources, few HBC programmes can afford to target youth for HIV-prevention activities or for inclusion in care activities.

Water and sanitation

At first sight, water and HBC seem very far apart, but in all the areas surveyed in the project, a lack of access to potable water emerged as a major challenge. Diminished water resources have led to acute water scarcity in many communities. Lack of access to water puts many PLHIV at risk of contracting other illnesses associated with poor hygiene, such as diarrhoea. Predictably, already over-burdened women have to compensate by walking long distances to fetch water. The lack of access to clean water is a major impediment to the successful implementation of HBC.

Food insecurity

Subsistence agriculture predominates as the main source of livelihood and food for the majority of communities in which home-based care projects are located in rural Zimbabwe. In recent years, much of the country has experienced recurrent droughts, resulting in poor crop yields for many subsistence farmers. According to the MoHCW, malnutrition is affecting many poor marginalized groups in rural areas, which includes female- and child-headed households, as well as orphans and other vulnerable children.

A common challenge identified in the eight HBC programmes was food insecurity among HIV-affected households. High HIV prevalence has contributed to increasing levels of food insecurity throughout Zimbabwe. The loss of many small-scale and subsistence farmers to AIDS and the high level of AIDS-related morbidity across all productive sectors have contributed to reduced food security at the household level and to lower productivity overall. Caregivers have to deal with PLHIV who are scarcely able to feed themselves.

Worryingly, this project found that PLHIV are sometimes perceived to be privileged because they can access food support in a context where food shortages and poverty are endemic. Shockingly, some people reportedly aspire to be HIV-positive so that they can have access to food supplies given to PLHIV.

The availability of food handouts to PLHIV in some of the projects surveyed has resulted in an exponential increase in the numbers of people requesting HIV tests. To be eligible for home-based care and food aid, a person has to test HIV-positive.

However, HBC projects have set criteria through which individuals and households are assessed for vulnerability in order to receive food aid, which exclude many people who are in the early stages of HIV infection. Indeed, some households that are visibly vulnerable to food insecurity are not considered for food aid because the household may not include a person infected with HIV.

Volunteer management

Volunteer dropout significantly compromises the quality, limits the potential reach and increases the costs of HBC programmes. Volunteer attrition is attributable to a lack of incentives. Ensuring that home-based care-clients receive comprehensive care throughout the continuum of their illness is essential and requires that trained volunteers be kept in place.

Given the range of challenges facing home-based care programmes, it is clearly apparent that management is key to successful projects. HBC services therefore need to be linked to a number of service providers that can assist in providing a holistic package of care and support.

Public health system

The collapse of the public health system is a major challenge to HBC programmes in Zimbabwe. Many public health institutions are so overstretched that they cannot handle comparatively simple cases such as pneumonia or infected wounds. A widespread lack of health personnel and equipment, and drug shortages in some districts have led to increased numbers of bedridden clients and deaths. The HBC programmes surveyed reported finding it increasingly difficult to refer clients to public hospitals when the need arises. There is a critical need for international agencies, bilateral donors, government and civil society to find the means to improve the performance of the public health system.

Lack of capacity

Every year, enormous amounts of money are dedicated to HIV prevention, care and treatment globally. Much of the money is channelled through governments and well-known international NGOs who are assumed to have the capacity to implement programmes. However, countless smaller, community-based initiatives, many of which are started by local people in response to an urgent and visible need in their communities, face a continuous struggle to secure funding.

HBC programmes in Zimbabwe currently rely on a variety of sources for small funding grants. A number of donors are keen to fund some aspects of these programmes, but few donors provide funding for an integrated approach. Capacity building to allow community-based organizations to attract the kind of large-scale funding required to meet demand in a sustained way is essential. Each of the HBC organizations interviewed cited inconsistent funding as a major constraint to their work. One mentioned that it might receive funding for a year, but not the next, while others complained that too often funding arrived late (as much as six months late), negatively affecting the programme.

Key recommendations:

Challenges faced by HBC services

- The international community needs to urgently consider providing support to Zimbabwe, purely on humanitarian grounds.
- National HBC policy should address the issue of resource mobilization to ensure that the effectiveness of potential and existing HBC programmes/ organizations is not compromised by a lack of resources.
- The Government of Zimbabwe should support HBC programmes by creating a conducive environment that enhances the accessibility of financial resources and materials, including ARVs.
- NAC coordination of HBC services needs to be strengthened. It is recommended that the NAC and ZAN should organize platforms for information exchange, experience sharing and peer review among HBC organizations.
- The administrative budgets for HBC organizations should be constantly reviewed upwards in line with the current economic (and inflationary) environment.
- The budgets for relevant projects, including HBC programmes, income-generating and food-security projects (e.g. nutrition gardens, chicken projects) should include sufficient provision to ensure a reliable supply of potable water, through sources such as boreholes.

- Those working in and with HBC programmes must be provided with training to improve the documentation of their work, especially in relation to potentially replicable best practices.
- Youth programmes for both in- and out-of-school children must be incorporated into HBC activities.
- HBC approaches should be expanded to enable children to be loved, provided for and cared for in families and communities.
- HBC programmes must make an investment in understanding the needs of specific groups – such as old women, youth and children – so that they can develop appropriate response strategies.
- Support for community- and home-based care initiatives should be improved by ensuring consistent funding for sustained periods, as well as the provision of technical support to funding recipients. Funding agencies should also prioritize the strengthening of the organizational capacity of HBC organizations and projects.
- Promoting access to water and improving general sanitation should be an underlying theme of all HBC interventions.

4

An integrated HBC approach

HIV cannot be addressed in isolation from the social, cultural, economic and physical environment. A family or individual affected by HIV has multiple needs, concerns and fears, which are often beyond the immediate capacity of a volunteer caregiver to address. A programme model that integrates health, economic and social services has most potential to fully respond to the needs of infected and affected people.

Among the projects assessed, several models of integration were observed. In Dananai's case, they integrated their programmes through the establishment of partnerships with other community-based organizations. Batsirai, however approached the integration by expanding the services they provide directly. Both models can work well, but certain advantages may be associated with the 'expansion through partnership' model in that this approach supports expansion without putting the quality of established programmes at risk through overstretching the organization and its volunteers.

Prior to integrating and/or expanding services, organizations should plan and, in particular, consider their capacity (especially with respect to human resources and skills). With an overwhelming demand coming from communities,

organizations often feel pressure to expand into new geographic areas and/or programme activities.

Sufficient planning and preparation is the most important factor when an organization is considering an integrated model and/or expansion of its services. Without adequate needs assessment or consideration of resources, HBC programmes may become overstretched too quickly and the quality of the HBC services may become compromised in the attempt to become 'everything to everyone'. Many demands are placed upon HBC programmes and their caregivers. Organizations need to invest in adequate planning, needs assessment and partnership building to ensure effectiveness and sustainability in their programmes.

HBC programmes may lack the skills and technical expertise required to implement a fully comprehensive and integrated HBC package. Furthermore, limited funding and conditions attached to donor funding may hamper HBC programmes in following integrated approaches. There is also a lack of systematically documented models and case studies of HBC integration.

ARV treatment is increasingly becoming available in many southern African countries, and community caregivers are often the first people who encounter potential clients. It is community caregivers who are at the front line in supporting clients who are receiving ARVs or TB treatment. HBC organizations need to provide training in treatment management and adherence for caregivers.

Some of the organizations included in this project have already integrated ARVs, treatment literacy and adherence support into their programmes. Other organizations, with limited access to ARVs, continue to provide palliative care to clients and their families. With access to ARVs and increased treatment literacy, clients become more active in the community, positive living is enhanced and stigma and discrimination related to HIV are reduced.

Organizations that involve the community in the planning, implementation and evaluation of their programmes achieve a greater level of sustainability. Through community meetings, a number of organizations were able to prioritize the services that communities need, as well as mobilize community members to contribute in terms of labour, funds or services, which reduces the reliance of the community on external donors. With the community backing the initiative, the services are more likely to continue even if donor funding ends.

A comprehensive monitoring and evaluation approach (including baseline, mid-term and final evaluations) is essential for all organizations. The information is important for informing strategic and annual planning as well as feeding into the national monitoring and evaluation system.

Organizations can become more cost-effective by collaborating with each other. By sharing costs for transport or community mobilization, they can be more effective in their spending. In addition, organizations can explore new ways of doing their work through partnerships.

Undertaking documentation about HBC organizations will be critical to highlighting the impacts of an integrated approach.

The establishment of civil society funding mechanisms represents a significant opportunity for implementing a comprehensive and integrated HBC package. By bringing together funding agencies focusing on different priorities, there is a greater potential to ensure that resources targeted at the community represent an integrated approach to addressing community-level needs.

Funding agencies should urgently develop an institutional framework to support integration and the effective monitoring and evaluation of services. Supporting HBC organizational capacity in the area of managing and implementing integrated programmes is critical to effective programming.

Key recommendations:

An integrated HBC approach

An integrated approach will require better management, planning, resource allocation and monitoring by HBC programmes. Key recommendations that should be considered when implementing an integrated approach include:

- Funding agencies should provide support for infrastructure development and capacity building within health systems. Greater attention must be paid to the roles and needs of health-care workers.
- There is an acute need for ongoing support to develop project-proposal-writing and financial-management skills within HBC programmes.
- Those working in and with HBC organizations require ongoing training and support so that they fully understand the issues that they have to deal with at community level.
- HBC programmes need to establish, expand and manage strategic partnerships with other sectors in the community in order to enhance the integration of services.
- Information, education and communication (IEC) materials and messages should be standardized through the NAC IEC committee.

- Gender-awareness training and a focus on children must be central to all integrated approaches.
- The meaningful involvement of PLHIV in the design of programmes and identification of priorities is essential to the success of an integrated approach.
- The local community must also be involved in designing, implementing and evaluating integrated programmes.
- There is an urgent need for policy and technical guidelines on how to integrate HBC services with other health-care services.
- Funding agencies must prioritize the funding of HBC activities that use a comprehensive and integrated approach.

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Acronyms and abbreviations

AIDS	acquired immune deficiency syndrome
ARV	antiretroviral (drugs)
CBO	community-based organization
CHBC	community home-based care
CHCC	Catholic Health Care Commission
ESAP	Economic Structural Adjustment Programme
ESP	Expanded Support Programme
FACT	Family AIDS Caring Trust
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HBC	home-based care
HDN	Health & Development Networks
HIV	human immunodeficiency virus
HNP	health, nutrition and population
IEC	information, education and communication
IOM	International Organization for Migration
MEP	Male Empowerment Project
MoHCW	Ministry of Health and Child Welfare
NAC	National AIDS Council
NACP	National AIDS Coordination Programme
NAP	National AIDS Policy
NGO	nongovernmental organization
PLHIV	people living with HIV
TB	tuberculosis
UOC	Uzumba Orphan Care
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Programme
WHO	World Health Organization
ZAN	Zimbabwe AIDS Network
ZNASP	Zimbabwe National HIV/AIDS Strategic Plan

What is a Speak Your World Primer?

Speak Your World Primers are a limited series of publications that present the essentials of specific priority health and development issues.

The primers draw on key stakeholder discussions and dialogue and are intended to provide information and opinion that provokes discussion, challenges assumptions and calls to account institutions and organizations claiming to act on behalf of those facing health- and development-related challenges on a daily basis.

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