Departement van Maatskaplike Dienste en Armoedeverligting

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AUDIT ON HOME- AND COMMUNITY BASED CARE IN THE WESTERN CAPE

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REPORT COMPILED BY:

Gladys Klaas-Makolomakwe and Crystal Prince
The Unit for Social Research
Directorate: Research, Development and Population
Department of Social Services and Poverty Alleviation

FOR FURTHER INFORMATION, PLEASE CONTACT:

Gladys Klaas-Makolomakwe
Department of Social Services and Poverty Alleviation
Union House
14 Queen Victoria Street
Private Bag X9112
Cape Town
8000

Tel: (021) 4833940
Fax: (021) 4835602

E-mail: gklaas-m@pgwc.gov.za

INDEX

1. Introduction

This report is aimed at providing the findings of an audit on Home- and Community Based care (HCBC) that was undertaken from June to December 2004 in the Western Cape. The audit formed part of an audit mandated by the national department of Social Development and is a repeat of similar audits that have been undertaken over the three years from 2000.

The background of the audit is provided in Section 2 of the report and speaks to the aims and objectives of the project. Section 3 provides a conceptual framework of Home- and Community Based Care, specifically in terms of definitions and models, strengths and limitations. Section 4 discusses the prevalence of HIV/AIDS in the Western Cape and looks at its projected impact. Section 5 focuses on methodology while Sections 6 and 7 highlight key findings of the audit and makes recommendations for the planning and development of appropriate interventions.

2. Background to Audit

2.1 Reasons for the Audit

The national Department of Social Development mandated that an appraisal on HCBC be undertaken in all nine provinces of the country. This task has been undertaken for the past three years as it has become increasingly important to assess the adequacy of HCBC provision in the fight against HIV and AIDS. Although HCBC is a holistic service for all terminal or chronic conditions, the audit was aimed specifically at those HCBC's providing services and care to people infected or affected by HIV/AIDS.

The audit consisted of two phases. In the first phase, HCBC's in the province were identified. In the second phase, data was collected through the distribution of a questionnaire. The identification of HCBC's required close collaboration

between the Research Unit of the Department of Social Services and Poverty Alleviation, its HIV/AIDS unit, the provincial Department of Health, and NGO's such as NACOSA.

2.2 Aim and Objectives of the Audit

The audit was aimed at providing information on the following:

- Existing Home/Community Based Care and Support Programmes
- The location of programmes, range of services provided, number of beneficiaries
- Level of human resource and capacity in programmes
- Partnerships and networking structures
- Funding sources and expenses incurred

The objectives of the audit were:

- To map existing Home/Community Based Care and Support Programmes
- To identify gaps in service provision
- Identification of programmes that require strengthening
- Identification of sites to establish new programmes
- Mobilization of resources

3. Home and Community Based Care

3.1 Definition

Home and Community Based Care is regarded as in important response in dealing with the impact of HIV/AIDS in the country. It is particularly important in view of the emphasis it places on providing care in communities as opposed to hospital-based care for people living with HIV/AIDS[1]. The Department of Social Development[2] defines Home and Community Based Care as 'the care/services

[1] Akintola, O. (2004). Policy Brief: The Gendered Burden of Home-Based Caregiving. HEARD, University of KwaZulu-Natal. www.heard.org.za

[2] Department of Social Development. (2004). Home Community Based Care and Support Programmes Appraisal.

that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities'. This suggests that Home and Community Based Care requires everyone to get involved and challenge HIV/AIDS and its consequences. When visiting the HCBC projects in Soweto 2003, the Minister of Health Dr Tshabalala-Msimang stated that 'HCBC is centred around the principles of Batho Pele and service to the people and it is geared towards community empowerment. It takes a holistic approach to the challenge of the diseases related to poverty that is affecting our people and takes into account the cultural beliefs and values of individuals'[3]. As a result, HCBC promotes, restores and maintains a person's maximal level of comfort, function and health including care towards a dignified death[4].

3.2 Models of Home and Community Based Care

Different models of Home and Community Based Care have been developed. Listed below are models of Community Care and Home Based care as presented by Pawinski and outlined by Russell et al[5].

3.2.1 Models of Community Care

- Funding, technical assistance and support programmes
- Advocacy and Community Mobilization
- Drop-in centres / support groups
- Home visiting programmes
- Comprehensive Home Base Care
- Orphan Care
    - Extended family
    - Child Headed Households

[3] Tshabalala-Msimang, M. (2003). Speech when visiting the Soweto Home and Community Based Care projects. http://www.doh.gov.za/docs/sp/2003/sp0821.html
[4] Pawinski, R. Home Based Care. (Undated). Presentation at the Nelson Mandela School of Medicine. Department of Community Health.
[5] Russell, M. & Schneider, H. (2000). A Rapid appraisal of Community-Based HIV/AIDS care and Support Programmes in South Africa. Health Systems Trust.

- ‘Create a family’ or ‘Cluster Foster Care’
- Placing responsible adults in the homes of orphaned children.

3.2.2 Models of Home Based Care

- Community driven model
- Formal government sector model
- Integrated Home/Community Based Care model centre
- NGO Home Cased Care Model
- Hospice Integrated Model

3.3 Strength and Limitations of HCBC

HCBC has ‘become a national policy priority in South Africa’[6] as it helps those infected and affected with HIV/AIDS cope better with the pandemic. Most importantly, it makes a significant contribution to relieving the burden of care resulting from HIV/AIDS on the health sector. Akintola[7] highlighted the need for HCBC in view of hospitals commonly discharging patients with HIV/AIDS after a short admission period or not admitting such patients at all, partly due to a lack of resources. Further benefits of HCBC programmes are of an economic, social and psychological nature[8]. HCBC, for example, makes it possible for ill people to be in familiar surroundings in their own households rather than face the isolation associated with hospitalisation. This allows family and community members to remain involved in the care of ill people.

However, the HCBC programme also has limitations. Akintola[9] claims that South Africa’s Home Based Care programmes are inadequately developed compared to those in Uganda as they reflect a response of crisis management and entrench gender inequalities. His main criticism is the extent to which HCBC

[6] Russell, M. and Schneider, H. (2000). A Rapid appraisal of Community-Based HIV/AIDS care and Support Programmes in South Africa. Health Systems Trust.
[7] Akintola, O. (2004). Policy Brief: The Gendered Burden of Home-Based Caregiving. HEARD, University of KwaZulu-Natal. www.heard.org.za
[8] Department of Health. (2001). National guideline on Home-base care/Community-based care.
[9] Akintola, O. (2004). Policy Brief: The Gendered Burden of Home-Based Caregiving. HEARD, University of KwaZulu-Natal. www.heard.org.za

programmes in South Africa rely on volunteers (who are usually not paid or paid small stipends for transport) from affected and impoverished communities to carry out basic nursing and care giving activities in patients' homes. In addition, the extent to which women provide voluntary services as HCBC caregivers reinforce existing gender stereotypes of women as caregivers.

A further concern highlighted by UNAIDS[10] is the challenging nature of providing Home and Community Based Care for caregivers, specifically in terms of dealing with an incurable and heavily stigmatized condition on an ongoing basis. The burden on caregivers is worsened by the living conditions of caregivers themselves who are frequently unemployed, lacks training and adequate resources such as medication and health care material to provide quality care. If unsupported, caregivers face physical, emotional, social and economic stresses and are at risk of burnout[11].

4. HIV/AIDS in South Africa

The threat of HIV/AIDS in South Africa is that the disease will probably decrease life expectancy, increase the Infant Mortality Rate, intensify the need of health care, fuel poverty, widen existing inequalities between rich and poor residents, increase the proportion of orphans, and alter the existing age distribution[12].

While the HIV/AIDS pandemic has a significant global impact, Southern Africa remains the worst affected sub region. South Africa has the highest number of people living with HIV in the world, accounting for one third of all global AIDS

[10] UNAIDS (May 2000). Caring for Carers: Managing Stress in those who care for people with HIV and AIDS. UNAIDS Case Study. UNAIDS Best Practice Collection. Geneva, Switzerland
[11] Akintola, O. (2004). Policy Brief: The Gendered Burden of Home-Based Caregiving. HEARD, University of KwaZulu-Natal. www.heard.org.za
[12] Swartz, L and Roux, N. 2004. A Study of Local Government HIV/AIDS Projects in South Africa. Chief Directorate: Population and Development, Department of Social Development.

deaths[13]. In 2004, the HIV prevalence in South Africa was 11%. In other words, a total of 5 million of South Africa's population of 46 million, were HIV positive[14].

HIV/AIDS places a significant burden of care on infected and affected households. This is illustrated by a recent study that found that more than 40% of affected households had reported that a household member had taken time off work or school to care for an AIDS patient[15]. Programmes such as the Home Community Based Care clearly have to be strengthened and expanded in order to support affected households.

Of concern is the high prevalence of HIV amongst young women who are reported to be three to six times more likely to be infected than young men with 21% of sexually active girls, 16-18 years of age having tested HIV positive[16].

The Western Cape had been showing the lowest prevalence of HIV/AIDS compared to other provinces. The provincial Department of Health estimates the HIV prevalence in the Western Cape as 13% in 2003[17]. This is an increase from 12,4% in 2002 and 8,6% in 2001. Health districts with the highest provincial prevalence include Khayelitsha (27,2%), Gugulethu/Nyanga (28,1%) and the Helderberg (19,1%). Of particular concern is a consistent increase in the 25-29 age group over the past eight years. The current HIV prevalence in this age group is 17,5%.

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[13] UNAIDS/WHO. AIDS Epidemic Update. (2004). Joint United Nations Programme on HIV/AIDS.

[14] Dorrington, RE., Bradshaw, D., Johnson L., Budlender, D. (2004). The Demographic Impact of HIV/AIDS in South Africa. National Indicators for 2004. Cape Town: Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa.

[15] UNAIDS/WHO. AIDS Epidemic Update. (2004). Joint United Nations Programme on HIV/AIDS.

[15] UNAIDS/WHO. AIDS Epidemic Update. (2004). Joint United Nations Programme on HIV/AIDS.

[16] Department of Health and Department of Social Development. (2003). Appraisal of Home Community Based Care Projects in South Africa 2002-2003. South Africa.

[17] Department of Health. Western Cape. (2003). HIV prevalence in the Western Cape: Results of the 2003 annual Provincial and District antenatal HIV survey.

5. Methodology

5.1 Identification of HCBC's

The first phase of the audit consisted of identifying HCBC's in the Western Cape. Databases of different stakeholders including the DSS & PA, the provincial Department of Health and NACOSA were obtained and merged into one list. This was followed by an intensive verification process which involved the contacting of organisations telephonically to confirm their contact details. A total of 114 HCBC's were identified through this process. 105 HCBC's were identified in the 2003 audit. This increase does not indicate an increase in the number of HCBC's established in the province but reflects improvement in the identification process.

5.2 Questionnaire development and piloting

The questionnaire used in the audit was developed by the National Department of Social Development. It was piloted at four organisations in the province - two in rural areas and two in an urban area. The urban area included both a suburb and township.

5.3 Data Collection

The data collection process started on the 30th June 2004 with the mailing of questionnaires to identified organisations. This process was co-ordinated by the Unit for Social Research. HIV/AIDS co-ordinators assisted with the distribution of questionnaires to HCBC's without mailing addresses and with the return of questionnaires. Completed questionnaires were received from 49 (42%) of the 114 identified HCBC's that received questionnaires.

Table 1 below provides a breakdown of the return of questionnaires.

Table 1: Return of Questionnaire

Breakdown of return of questionnaires	No returned
Questionnaires completed	49
Returned due to incorrect address/closed box	4

Incomplete as organisation's focus is not on HIV/AIDS	12
Will start operating later in year	2
Not doing HCBC anymore	9
Refused as not funded by the department	2
Not returned	35
Total	**114**

5.4 Data Capturing and Analysis

Data capturing and analysis was done using SPSS (Statistical Package for Social Sciences). The dataset that was constructed was supplied to the national Department for merging with data obtained from all provinces. This was followed by an in-depth analysis of data to provide a deeper understanding of HCBC provision in the province.

5.5 Limitations

Although organisations indicated telephonically at the onset of the study that they were willing to provide the required information, a number of factors affected the quality of data that was provided and the number of questionnaires that were returned. These included:

- The length of the questionnaire and the nature of some of the questions.
- Confusion about municipal boundaries and areas of operation.
- A number of organisations refused to fill the questionnaire as they were not being funded by the Department of Social Services and Poverty Alleviation.
- Research fatigue due to different audits on HCBC having been undertaken in recent years.

6. Findings

Data obtained in the audit highlight gaps in terms of HCBC provision and identify areas of improvement. Findings will be presented in terms of the nature of services, organisational capacity and beneficiaries of services.

6.1 Nature of Services

6.1.1 HCBC Kits

HCBC kits are packages that could include some of the following depending on the country's needs and capabilities[18]:

- Essential drugs (based on the essential drug list)
- Basic equipment (such as dressing, soaps, disinfectants, gloves and other protective materials)
- Traditional remedies and herbal treatments
- Emergency food supplies, bedding or money

In the audit, only 35% of HCBC's indicated that they have HCBC kits for distribution to clients. This is an increase of 25% when compared to the 2003 audit.

6.1.2 Food Parcels

The number of HCBC's that provide food parcels increased from 9% in the 2003 audit to 51% in the current audit. Most HCBC's distribute food parcels on a monthly (26%) or weekly basis (12%). Food parcels are distributed to a total of 924 beneficiaries in the province. Most food parcels are distributed within the Unicity to a total of 677 beneficiaries with the lowest number of beneficiaries in the Overberg (14) and the West Coast (5) District Municipalities as illustrated in Table 2.

Table 2: Number of persons serviced by food parcels

District Municipality	Beneficiaries	Proportion per District Municipality
Boland	75	8%
Central Karoo	55	6%
Eden	98	10.6%
Overberg	14	1.5%
Unicity	677	73%
West Coast	5	0.5%
Total	**924**	**100%**

[18] WHO, 2002. Home-Based Care in Resource-Limited Settings: A Framework for Action. World Health Organisation.

7. Organisational Functioning and Capacity

7.1.1 Models

The majority of organisations (35%) follow the NGO model, followed by the community driven model (30%). Shifts have occurred in the choice of model followed at the beginning of a project to the current model. For example, use of the NGO model has decreased from 44% at the beginning of a project to 35%. The government model increased from 2% to 7% respectively. Organisations that made the shift to the government model linked it to the need for registration as NPO's. A total of 81% of NPO's indicated that they are registered as NPO's. Table 3 below presents HCBC models currently being followed.

Table 3: Main HCBC model being followed

Model	Frequency	Percentage
Community driven	13	30.2
Government	3	7
NGO	15	34.9
Integrated	5	11.6
Hospice	4	9.3
Total	40	93
Not recorded	3	7
Total	**43**	**100**

7.1.2 Types of Organisations

The majority of organisations in the Western Cape (70%) are identified as NGO's as illustrated in Table 4 below, followed by CBO's at 16%.

Table 4: Types of Organisations

Types of Organisations	Frequency	Percent
NGO	30	69.8
CBO	7	16.3

FBO	1	2.3
Traditional Healers	1	2.3
Other	1	2.3
Not recorded	3	7
Total	**43**	**100**

7.1.3 Staff Composition of HCBC's

The majority of organisations indicated that they have a constitution (77%) as well as committee boards (79%). HCBC's participating in the audit had a total of 822 staff members. Organisations have more female (89%) than male staff members. The number of permanent caregivers (305) increased from 244 in the last audit.

The number of volunteers involved in HCBC's also increased significantly – from 200 in 2003 to 1971 in the present audit. The majority of volunteers (95%) are not receiving any stipend.

7.1.4 Funding of HCBC's

Data obtained from the audit in respect of the funding of HCBC's was incomplete possibly indicating reluctance on the part of respondents to disclose funding sources. However, HCBC's that identified funders identified business, fundraising, churches and the Provincial Department of Health as their major funders.

7.1.5 Location of HCBC's

As the number of questionnaires identified in the audit differed significantly from the number of organisations that completed the questionnaire, data obtained from the first phase, the identification of HCBC's, is presented below. It is clear that although there are HCBC's in areas of high prevalence, service provision need to be upscaled in order to provide care for an anticipated increase in the number of people infected and affected by HIV/AIDS.

Table 5: Location of HCBCs by District Municipality and District Office Areas

District Municipality	District Office	No of HCBC projects
Unicity	Athlone	6
	Gugulethu	5
	Atlantis	6
	Eerste River	11
	Bellville	4
	Cape Town	16
	Khayelitsha	8
	Mitchells Plain	3
	Wynberg	12
Total		**71**
Boland	Paarl	9
	Worcester	15
Total		**24**
Central Karoo	Beaufort West	4
Overberg	Caledon	5
Eden	Outdshoorn	3
	George	5
West Coast	Vredendal	2
Total		**19**
Grand Total		**114**

7.1.6 Period of Existence of HCBC's

The majority of HCBC's that participated in the audit were established before 2002 with only 8 new HCBC's established after this period. These organisations are all situated in the Unicity. This highlights the need for a strategic framework to direct the future establishment and provision of HCBC's in the province.

8. Beneficiaries of Services

8.1 Total number of beneficiaries

A total of 8 783 households with 54 476 household members receive services from HCBC's in the audit.

8.2 Child-headed households

401 child-headed households receive services from HCBC's. Compared to the 2003 audit, this is a significant increase as only 70 child-headed households were receiving services from HCBC's in the previous audit.

9. Conclusions and Recommendations

Findings of the audit showed clear improvements in a number of areas of the functioning of HCBC's in the Western Cape when compared with the 2003 audit. These include increases in the provision of food parcels and HCBC kits to beneficiaries of HCBC's. Organisational capacity has improved through greater involvement of volunteers. The targeting of services appear to have improved as a far greater number of child-headed households are receiving services from HCBC's.

Despite these improvements, gaps still exist in the provision of HCBC's in the province due to the concentration of HCBC's in the Metro. Of concern is the limited number of HCBC's established after 2002 and the concentration of these HCBC's in the Metro. The audit highlighted the need for strategic direction in terms of the establishment of HCBC's in areas with poor provision, such as rural areas, and the upscaling of HCBC's in high prevalence areas in the Metro.

The quality of some of the data received in the audit was poor partly due to research fatigue setting in amongst key stakeholders. Future research in respect of HCBC's need to be co-ordinated and planned more effectively to avoid duplication and obtain full co-operation of the sector.

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