BERGVILLE/WINTERTON

Okhahlamba Municipality

SUMMARY REPORT

On Home Based Care and Other Community HIV/AIDS Activities

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- Phumzile Ndlovu, Home-based Care Project Manager (OADP) and her team of Home-based Caregivers.
- Zodwa Dladla, uThukela District HIV/AIDS Co-ordinator, Department of Health.
- Mama Dube, HBC Trainer and "retired" nurse.
- Community-based organisations (CBOs), non-governmental organisations (NGOs), faith-based organisations (FBOs), and individuals actively involved in the HIV/AIDS field who took time to speak with HIVAN.
- Councillor Mabizela, Bergville local councillor.
- Nkosinathi Dlamini, Co-ordinator of the KZN Traditional Healers' Association.
- Pastor Nkutha, Manager, OADP Well-being Centre.
- Thulani Hadebe and Mbuyiselwa Dlamini, Leader and Manager, OADP Youth Project.

TABLE OF CONTENTS

INTRODUCTION

ABOUT HIVAN AND COMMUNITIES

HIVAN is essentially about facilitating multisectoral partnerships around HIV/AIDS in KwaZulu-Natal. Its fundamental aim is to bring together researchers, policy-makers, interventionists, service-providers and communities into meaningful and mutually rewarding alliances aimed at addressing the multiple problems heralded by the HIV/AIDS pandemic. HIVAN facilitates partnership-building around HIV/AIDS. In line with this mission, HIVAN serves as a mechanism for linking communities and community-based organisations with other organisations and individuals who can partner these communities in various ways (research, intervention, training, fundraising etc.) to effect meaningful responses to HIV/AIDS. It also provides a means for linking like-minded, and often isolated, community-based HIV/AIDS initiatives with one another. HIVAN attempts to achieve this in number of ways – through development of a comprehensive database of individuals, organisations, projects and literature around HIV/AIDS, i.e. web-based, hard copy and Zulu versions; through regular networking meetings and annual symposia bringing together different communities and CBOs for the purpose of linking them with one another and developing a unified HIV/AIDS agenda.

As time does not permit a thorough audit and study of the entire province at this juncture, localised sites have been identified in a number of KZN regions, focusing initially on communities in which HIVAN has established contacts. The community liaison process should therefore be seen as preliminary – a first point of contact and an impressionistic survey of activities, needs, priorities and strengths. These findings will then serve as a 'launching pad' for more **extensive engagement** in each of the eight regions of the province (as demarcated by the Department of Health).

It is worth noting that HIVAN is placing particular emphasis on identifying, profiling and foregrounding the activities of grassroots-level HIV/AIDS-related initiatives. Many 'formal' organisations and projects are already listed in various directories, but there are numerous smaller, 'informal', less publicised initiatives occurring on the ground. The HIVAN Community Liaison Office (CLO) seeks to play a key role in identifying these community-based initiatives. However, this report constitutes details of a home based care initiative which is the product of the efforts of World Vision as well as uThukela District Child Survival Project (TDCSP) and Okhahlamba Area Development Programme (OADP). In addition to the home based care report other HIV/AIDS related activities taking place in Bergville and neighbouring areas are outlined.

PART 1: FIELDWORK ACTIVITIES

a. DAY-BY-DAY ACCOUNT OF ACTIVITIES

HIVAN was fortunate in launching its activities in the region through strong associations with both the KZN CBO Network Behaviour Change Programme and WorldVision's various programmes in the region [Child Survival Programme (TDCSP), TDCSP HIV/AIDS Micro-Enterprise Development (MED) amendment project, and the Okhahlamba Area Development Programme(OADP) based in Bergville]. Day-by-day activities during the data gathering included meetings with WorldVision staff; field visits with home-based caregivers and visits to micro-enterprise development (MED) project sites. HIVAN also had the opportunity to participate in the evaluation of WorldVision's Child Survival Project which helped the HIVAN members concerned to gain more knowledge and information

about HIV/AIDS-related activities in the Bergville area. The HIVAN CLO team also organised meetings to interview members of uThukela District Child Survival Project and Okhahlamba Area Development Programme Gateway projects such as Home-Based Care, HIV/MED, Wellbeing Centre, Orphans, and Youth projects. More details are provided in Part 3 below.

b. DESCRIPTION OF THE METHOD OF INVESTIGATION

An information-sharing meeting was held in late October 2001 at the WorldVision Offices in Bergville, at which HIVAN was introduced to representatives from the Town Clerk's office and Mr Mabizela, the local Councillor, and given an overview of the TDCSP and OADP projects by representatives of the WorldVision team. This provided an excellent grounding for the Community Liaison Team. From 29 October to 2 November 2001, a member of HIVAN's Community Liaison Team spent a week in the region assisting with the evaluation of the WorldVision Micro-Enterprise Development Programme. This afforded HIVAN the opportunity to meet many community members in a variety of organisations and local government structures in the district. The Community Liaison Team spent a further week in the district between the 14th and 18th January 2002, during which time they held a number of information-sharing meetings with local organisations. The purpose of these meetings was to share information on HIVAN's networking role, gain information on the activities of each organisation and through these meetings, to identify other individuals and organisations active in the HIV/AIDS field in the region. With the help of TDCSP staff, a workshop was organised with the Okhahlamba area Home-Based Caregivers. This workshop provided an invaluable opportunity for HIVAN to hear from HBC volunteers about their activities, their concerns, needs and priorities. During this process it became clear that there were also considerable strengths within this HBC network. Findings from the HBC volunteer workshop and other networking meetings in the region are incorporated into the sections that follow.

PART 2: HOMEBASED CARE NEEDS, CONCERNS, PRIORITIES AND STRENGTHS

Discussion at the Bergville HBC Workshop, and follow-up meetings in January 2002, led to the compilation of a list of prioritised needs, as outlined below:

COMPENSATION AND INCENTIVES

HBC volunteers called for their personal resources to be replenished and, if possible, want to receive incentives for their services. At the beginning of the Home-Based Care (HBC) workshop in Bergville, Councillor Mabizela said that local government authorities urgently needed to provide compensation to the HBC volunteers. These volunteers often had scarce resources on which to draw and yet they cared for the terminally ill in addition to their own families. He emphasised that these volunteers were not necessarily seeking monetary payment, but rather assistance with food, soap and transport. To illustrate this need, Pastor Nkutha from the Wellbeing Centre, stated that "those who counsel and train are paid something, but those washing the wounds and clothes of the terminally ill receive nothing." In short, HBC volunteers, who are often unemployed themselves, are spending their own scarce resources on caring for the terminally ill in their community and are not being compensated for this expenditure. While they understand that they volunteered to perform these tasks, and therefore can expect no salary from the Government, the overwhelming increase in the call for HBC services in communities has stretched the meagre resources of these volunteers to breaking point.

Councillor Mabizela noted that the Durban Metropolitan Council and other local government structures were interested in supporting initiatives focused on Home-Based Care, and he encouraged those present at the workshop to organise themselves to obtain access to such resources. He felt that support and motivation for HBC volunteers should be prioritised and that this required brainstorming by stakeholders.

Department of Health (DoH) policy recognises the value of HBC volunteers in communities, and acknowledges that it is difficult to maintain a long-term volunteer base due to the demands placed on these caregivers. DoH has therefore focused on training Community Health Workers who are deployed in all communities to render HBC services. Unlike the volunteers, these CHW workers receive financial incentives; however, these additional duties increase their already heavy workload, and some argue that this could affect the overall quality of their work. This has led some sectors to criticise DoH policy with respect to HBC.

LACK OF RESOURCES

Poverty is the primary barrier to effective Home-Based Care – the need for food and care exceeds resources for most caregivers and their patients. Many parents and caregivers are falling ill and dying, leaving behind children in need of care, shelter and support. Orphans' needs are immense. Consequently, HBC givers are faced with a situation of providing care and food to their patients as well as orphans. HBC givers do not have resources to provide such services, and the consequent deprivation and sense of helplessness forces some trained HBC givers to look for paid jobs elsewhere.

THE DEPARTMENT OF HEALTH (DOH) ROLE AND HOME BASED CARE (HBC) CONCERNS

The uThukela District Department of Health is well aware of the valuable role played by Home-based Caregivers in the health care system. Although they are not paid for their services, the DoH has tried to assist as much as possible in other ways by provided training and resources to these volunteers. HIVAN spoke with Zodwa Dladla, the HIV/AIDS Co-ordinator for the uThukela Health District, who reported that the DoH has played a major role, in partnership with WorldVision's uThukela District Child Survival Project (TDCSP), in providing support to Home-Based Care initiatives in Bergville/Okhahlamba area. In 1999 the DoH provided support through a grant of R30 000 to train HBC volunteers, allowing for training of a pool of 80 volunteers. It is due to support from DoH and WorldVision that the pool of Home-based Care volunteers has been sustained at this level to date.

The DoH has also provided staffing assistance to the Home-based carers in the region. Ms. Sibongile Maphalala is the DoH Okhahlamba Primary Health Co-ordinator. She has been instrumental in facilitating a viable network between the HBC volunteers and clinics in her subdistrict. Despite this support, as numbers of HIV-positive and sick people increase, so the resources of many Home-based Care workers are stretched – often beyond reasonable limits. As noted above, there is a real danger that faced with such difficulties, many of these volunteers will become despondent and discouraged. The demands placed on Home-based Carers have led them to appeal to the DoH for further assistance. They believe that occasional training, provision of gloves and basic medicine at clinics is no longer sufficient. The HIVAN workshop called for the DoH to prioritise development and implementation of a strategy to support HBC givers in ways comparable to

those established for DoH Community Health Workers (See above for more information).

THE NEED FOR NETWORKING

Ms Dladla stressed that the HIV/AIDS pandemic is such that it is impossible for organisations, even the DoH, to operate in isolation from one another. She encouraged the principles of collaboration and networking with key stakeholders. Stakeholders that the DoH has identified include faith-based organisations (e.g. United Churches organisation), community-based organisations, non-governmental organisations (e.g. WorldVision), communities and their leaders, etc.

Ms Dladla noted that competition for resources and a general lack of collaboration between organisations in the uThukela region were obstacles to effective operation. She suggested that what is needed is a co-ordinating body, either at a subdistrict or community level, to take responsiblility for co-ordination of activities. This body should provide information on who is active and also facilitate collaborative initiatives which would help in reducing duplication of activities and wastage of scarce resources. She said that there was a real need for organisations to work together in the fight against HIV/AIDS with one vision and one voice. For the DOH, the advantage of such a facilitating organisation in the region would be that officials would have better information on activities at a grassroots level in order to inform their delivery and support strategies. Ms Dladla commended the role played by HIVAN in gathering data on all community initiatives, documenting these and making them available more generally.

Nkosinathi Dlamini, Co-ordinator of the KZN Traditional Healers' Association and of HBC Volunteers in Ladysmith, and a Community Health Worker throughout the region, felt that a database of KZN-based HBC initiatives and volunteers was required. This would assist greatly in formalising the organisation of HBC givers. As Ms Dladla stated, HIVAN can facilitate development of such a database through their existing infrastructure.

ACCESSING FUNDING FROM DOH

Mr Dlamini noted that funds for HBC training were available in some other areas, but that the process of roll-out was slow and that it needed facilitation. He believed that the DoH did not trust community workers directly with funding – which leads to unspent budgets. He went further to say that mechanisms should be found to ensure that material support (beyond merely training) is channelled directly to HBC initiatives. He strongly believes that posts designated for Community Health Workers should be filled by Home-based caregivers.

Zodwa Dladla, the HIV/AIDS Co-ordinator for the uThukela Health District, clarified that the problem with distribution of resources lies in a lack of c-oordination and collaboration of HIV/AIDS initiatives. This makes it difficult for the DoH to respond effectively to requests for support.

Ms Dladla noted that many organisations and initiatives in KwaZulu-Natal do not have sufficient and accurate information on how to access available funding. This has prevented them from accessing support from DoH in their regions or health districts. Ms Dladla explained that the DOH can support initiatives where organisations meet the following criteria:

- committed to HIV/AIDS work
- have a formalised constitution and rules of conduct

- have a clearly defined vision, mission and set of objectives.
- Have a feasible plan of action

Many organizations cannot meet these criteria.

Ms Dladla stated that DOH cannot process ad hoc requests for funding and that managers of such initiatives should forward their requests for support to the DOH in response to calls for applications. These are publicised through District Health offices all over KwaZulu-Natal and through community structures which have frequent contact with DOH workers at community levels. Applications received at district level are forwarded to the provincial level where all decisions are made. This is the standard procedure followed in all the health regions of KwaZulu-Natal.

In addition to HBC support, DoH provides and supports a number of other related activities such as general health counselling, advice on and treatment for sexually transmitted diseases, prevention of mother to child transmission (MTCT), voluntary counselling and testing (VCT), etc.

RESEARCH CONCERNS

Home-based care-givers expressed their disapproval of the way in which many researchers conduct themselves in the region. They complained that these researchers take time, effort and information from the HBC volunteers, but leave without any kind of follow-up or contribution to Home-based Care initiatives. They questioned the ethics of such research practices. The presence of such researchers in the community is not welcomed.

HIVAN explained that it wishes to involve the community in drawing up a research agenda that is focused on community-identified needs and priorities, and that it would also commit to consultation with the community in the research design process. HIVAN promised the community that it would conduct any research it did in the region ethically and that the uThukela community would receive timely feedback on the research in which they participated.

FORMALISATION

Home-Based Caregivers expressed a need for formal leadership. This involves HBC givers forming structured organisations at Ward/local levels to ensure that their needs are communicated through the DoH and community structures, like the Municipal and District Health Forums. The workshop concluded that HBC volunteer forums must be represented and led by their own members at these forums.

The problem with the current system is that the Health Forum discussions rarely mention care of the terminally ill – only the HBC volunteers have these issues at heart. Therefore, despite having 13 distinct HBC representatives on the Health Forum, the HBC volunteer presence has little input into decision-making.

As a practical step, the Bergville HBC network has begun to formalise and hold more regular meetings of their volunteers. These meetings have been supported by WorldVision in the Bergville community. A very positive outcome of the HBC workshop facilitated by HIVAN was a new resolution by the HBC givers to train and integrate existing district HBC representatives on the Health Forum more fully into their activities. These representatives would also be given a clear brief, as a result of more regular HBC gatherings, to take to Health Forum meetings. It is hoped that this process will ensure that the needs, concerns and priorities of HBC givers filter up through committee structures to

policymakers. HIVAN will be tracking developments in this regard to assess whether improved lines of communication lead to improvements in support for HBC givers.

Mr Mabizela called for the formation of HIV/AIDS Ward Committees and forums which would focus on HBC. He felt that an uThukela District HIV/AIDS Forum should be formed as an overarching body to guide such community forums. He envisaged a formalised committee and reporting structure from ward level through to district level which would ensure that HBC needs are communicated through the DoH, filtering through from district to regional level and culminating in dissemination at provincial level. He called for the Health Forum to devise a strategy to enable the abovementioned committee process for HBC.

Recent developments in the area indicate that the DoH is beginning to take note of HBC needs in a much more focused manner, with committees being formed at district level to consider HBC issues. Much of what is in place has been as a result of DoH initiatives in partnership with WorldVision projects.

NEED FOR COUNSELLING

As the pandemic has worsened, so the need for counselling and support networks for HBC givers has increased. HBC givers are at the coalface of the HIV/AIDS pandemic and, as such, often need to counsel families for whom they provide care. In order to bear the emotional burden of doing this, they in turn often need counselling, training in coping skills, and a support network of people to whom they can go for support needs (emotional, spiritual, etc).

An appeal was made at the HBC workshop for a 'hospital team', consisting of a doctor, a nurse and an HBC volunteer to be formed. This team would go out on visits to HBC volunteers in their own area to help identify patients and needs and to track progress. Mrs Dube, a retired nursing sister and active HBC trainer, said that Emmaus Hospital has been enrolled a number of times for this purpose.

SUSTAINABILITY

HBC needs to be made sustainable to help both the carers as well as their patients. The DoH is involved in facilitation of HBC as well as provision of necessary HBC materials. Sustainability would be facilitated further by fostering a viable relationship with other service providers such as the Home Affairs and Social Development departments. These service providers would contribute by providing funding, advice and grants for orphans, and other incentives. As mentioned above, DoH has already provided initial support through a grant of R30 000 in 1999 to train HBC volunteers, allowing for training of a pool of 80 volunteers. However, there is a need for ongoing training on emerging issues, e.g. breastfeeding, ARV adherence and listening / communication skills. In addition, Transformational Leadership training will give HBC givers tools for developing their own personal visions, as well as a vision for HBC. This will enable them to shift context around HIV from one of death and dying, to planning legitimate futures, and discovering ways to bring this envisioned future into existence by design. To date these additional training needs have been provided by World Vision in collaboration with the Department of Health.

STRENGTHS

When asked what enables these women and men to cope with their work, their response can be summarised as follows: inner drive, great compassion and strong religious faith have given HBC givers the strength to persevere, even though the HBC context is challenging. These qualities cannot be

underestimated. Listening to the women and men speak about their experiences was shocking and yet at the same time, it was uplifting. The HBC givers possess a unique hope and tenacity that spurs them on despite the tremendous odds they face.

An unwritten motto of the HBC givers is the common belief that all people have the right to live and die with dignity. HIV/AIDS presents a challenging context to this. Despite the ravages of the disease, the intervention of the HBC givers ensures that as many as possible of those infected in their community retain the right to die with dignity. The following points support this:

- Zulu culture of *ubuntu* – when one individual is hurt, all suffer, so it is the responsibility of the community to help its own;
- A powerful collective wish for all in the community to prosper and be independent. HIV/AIDS poses a major threat to such development. These caregivers realise that if the disease is to be combated, collective and concentrated effort is required.

In addition, the HBC volunteer base is committed to healthy social outcomes. Because of the prevailing stigma around HIV/AIDS, many patients are rejected and isolated. The HBC volunteers are the ones who break the silence in their own communities; by acquiring information and some training, together with their grassroots knowledge, they are perfectly
placed to educate their community as well as to train others in HBC work.

Ideally, the HBC volunteers train a family to tend to their patient, and then the caregiver moves on; however, many families come to rely on the HBC volunteer as the sole caregiver, which hinders the broader roll-out of community care.

HBC volunteers are eager to acquire further training that will increase their caregiving and life-skills, and in turn will enable them to educate the communities they serve. It is important to note that HBCs are themselves members of the community. They are often well-known to the people they treat and come to be deeply trusted by communities because of the level and quality of both physical and emotional support they provide; if the volunteers give up and drop out of the pool, the communities' loss is immeasurable.

Nevertheless, it is important for the HBCs themselves to recognise and claim their own power and worth. It is individuals who will turn the disease around, working from the bottom up. *"Governments change their minds only when a concerned citizenry makes its position known"* (Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa).

So, the body of HBC volunteers is one of strong, able and committed people. This work and these individuals constitute an invaluable resource and asset, not only for the community itself, but also for the authorities accountable to it, for wider society and for the struggle against HIV/AIDS as a whole.

PART 3: HIV/AIDS-RELATED ACTIVITIES:

ORGANISATIONS

WORLDVISION: Monika Holst

World Vision South Africa's Mission is "Effecting Change; Unlocking Potential". It is a large international Christian and Development agency serving the world's poor and displaced by providing programmes that help save lives, bring hope and restore dignity. This assistance is provided without regard to people's religious beliefs, gender or ethnic background. They teach the poor to help themselves and aim to build community capacity.

UTHUKELA DISTRICT CHILD SURVIVAL PROJECT (TDCSP) AND OKHAHLAMBA AREA DEVELOPMENT PROGRAMME (OADP):

Monika Holst is the overall TDCSP/OADP Projects Manager. The vision of the TDCSP/OADP is a transformed Okhahlamba area 'where every person enjoys a truly amazing life, with everyone living and working in harmony.' To achieve this ideal, key strategies were devised including designing "the desired future" with the use of Transformational Leadership principles, tools and behaviours; strengthening community leadership; building the competence base of local people to design, implement and evaluate interventions in line with the vision; co-ordinating and integrating funding and partnerships; and developing plans to achieve holistic wellbeing (physical, social, spiritual, psychological and developmental) in a sustainable manner. OADP conducts nine gateway projects using a shared governance approach.

UNITED CHURCHES ORGANISATION

United Churches, a faith-based organisation made up of different churches, came together to contribute to the HIV/AIDS fight as well as to community development. The organisation is based in the community of Udukuza in the Okhahlamba municipality and is involved in home-based care and other support activities. It receives support and materials from DoH such as bags, gloves, T-shirts, caps etc.

PROJECTS AND PEOPLE WORKING IN THE HIV/AIDS FIELD

TDCSP Community Health Facilitators:
Phumi Zondo, May Mabaso, T.T. Mabaso and Gremma Ngwenya.

Community Health Facilitators are employed to facilitate and train community health workers. They train CHWs in communicating primary healthcare messages at household level and assist communities in electing community health committees.

Okhahlamba Home-Based Care:
Phumzile Ndlovu

Developed in partnership with TDCSP HIV/AIDS MED, DoH, other NGOs and churches, the project aims to provide holistic care for the terminally ill at their homes. Activities include training of volunteers and family members; mentoring and caring for care givers.

OADP Wellbeing Centre:
Pastor Nkutha

The Wellbeing Centre offers comprehensive information and counselling around aspects of holistic wellbeing; serves as a referral centre for wellbeing; also provides a location for activities for the Home-Based Care and Orphan initiatives. It will shortly be offering Voluntary Counselling and Testing (VCT) in collaboration with the DoH.

OADP Orphans Project:
Zanele Mchunu

Initial activities included a conference on children's rights attended by all identified role players, including community health workers, service providers, etc;

provision of educational help and care of orphans while they remain part of their (extended) families and community. Several groups of orphans have initiated garden and chicken projects.

TDCSP HIV/MED (Micro-Enterprise Development): Sindi Dube and Bongani Miya

The HIV/MED project objective is to increase women's and young people's ability to provide financially for their households, and to decrease their risk behaviour through involvement in MED-linked activities. The aim is to, through MED programmes, uplift households and communities, giving them hope and inspiration so that they can live harmoniously and cope with the daily demands on their resources, as HIV/AIDS is noted as a major factor in reducing the household income and resource base. HIV/MED offered training to equip students with business ideas and management skills. Students were identified from households with chronically ill family members and/or those who have taken in orphans, as well as youth and women. Follow-up visits are carried out to see how the micro-entrepreneurs are doing and to determine the kind of ongoing support they might require.

OADP Youth Initiative:

Thulani Hadebe, Leader, and Mbuyiselwa Dlamini, Manager

The Youth Project's vision is to steer youth away from unprotected sex and drug use, both risky behaviours often indulged in as a substitute for fulfilment through employment and healthy recreational activities. The project has prioritised income generation, youth business and transformational leadership interventions, and provides training in catering, wedding accessories, vegetable production, car-washing, baking and sports, to mention a few. Some of the activities are in the pipeline and will be implemented once sufficient support, in terms of information and funding, is obtained.

OTHER COMMUNITY STAKEHOLDERS

Sister Pascaline: St. Yves' Catholic Church, Rookdale, Bergville

Trained as an AIDS educator and counsellor, Sister Pascaline specialises in counselling at local clinics and provides AIDS awareness at the clinics and her own church, focusing especially on youth.

Dr. Bernhard Gaede, Superintendent, Emmaus Hospital:

Dr Gaede is responsible for the overall management of the hospital's finance systems, human resources, etc. Dr Gaede is committed to the wellbeing of HBC activities and supports the 'hospital team' concept noted above. This team consists of a doctor, nurse and HBC volunteer going out on visits to HBC volunteers in their respective areas to help give support to referred patients and their needs, and to track progress.

"Mama" Dube's initiative:

Mrs Busisiwe "Mama" Dube is a trainer in HBC field, a tutor for Christian Listeners and an HIV/AIDS trainer in the sub-district. Now retired, she is a Senior Registered Nurse who was deployed by the Department of Health as a youth health educator and team leader, and as an HIV/AIDS counsellor, facilitating a process of establishing anti-AIDS Clubs in the 90 schools in and around the Bergville area. Using the "Doctors For Life" training manual as a model, and working with Estcourt-based DoH District HIV/AIDS Co-ordinator Zodwa Dladla, Mama Dube trained over 90 HBC volunteers in the months before she retired. "I followed up with them to track their progress," she says, "but only met them

formally again in October 2001, when we retrained about 80 volunteers using a newly developed DoH manual." She is still actively involved informally in the HBC programme in the Okhahlamba area.

Mama Dube's community work extends far beyond her HBC training. Using seeds supplied via St Joseph's Catholic Mission in Ladysmith, this incredible woman teaches the elderly and the disabled how to build and plant waist-high vegetable gardens; these are easily reaped and can be sustained for four to five years, providing both a nutritious food supply and a small means of income. Under the auspices of the SA Roman Catholic Bishops' Conference, she is raising funds for and testing an HIV/AIDS board-game and a "story-with-a-gap" as an educational tool for youth and adults, and has translated the instructions for these games into isiZulu. She is also involved in developing the "Mandla Box", a simple but essential kit for Home-Based Caregivers containing an oral rehydration solution, instructions, disinfectant and home-available fluids.

Moses Mthethwa, member of National Association of People Living With AIDS (NAPWA).
Moses is an HIV/AIDS activist specialising in motivational speaking and HIV/AIDS education. He is renowned for his energetic efforts in encouraging people to disclose their HIV/AIDS status. He is a well-known public figure, having been featured on radio (e.g. uKhozi FM) and TV (e.g. LoveLife)

There are other people and initiatives that are addressing HIV in Okhahlamba, that will be included as this information is updated.

APPENDIX 1

BERGVILLE/WINTERTON COMMUNITY REGISTER OF HIV/AIDS RELATED ACTIVITIES AND REPRESENTATIVES, UTHUKELA REGION, KWAZULU NATAL.

COMMUNITY HEALTH FORUM				
Nxumalo	Mr	Tel: 036 –448 1563 c/o Phumzile Ndlovu	Bergville	Chairperson
EMMAUS HOSPITAL				
Gaede	Bernard Dr	Tel: 036- 488 1411 Cell: 082 736 6054	Emmaus Hospital Bergville 3350	Superintendent
ESTCOURT HEALTH FORUM				
Ndaba	M. G.	Cell: 083 414 1431	Box 1362 Estcourt	Estcourt Chairperson
HOME BASED CARE PROJECT (TDCSP/OADP)				
Cele	Barbara	Tel: 072 149 8151	Not provided	HBC volunteer
Dlalisa	Jabu	Not provided	Not provided	HBC volunteer
Dube	B. S.	Fax: 036 – 448 1389 Cell: 083 773 8040	Not provided	HBC Trainer
Hlongwane	Bawinile	Not provided	P.O. Box 451	HBC volunteer
Khumalo	Ester	Not provided	Bergville	HBC volunteer
Kubheka	Thoko	Tel: 072 158 4167	Box 138 Bergville 3350	HBC volunteer
Mabizela	Gloria	Not provided	Box 695 Bergville	Chairperson of Community Health Workers
Malibu	Joyce	Cell: 083 403 8044	Bergville	HBC volunteer
Miya	Rosetta	Not provided	Private Bag x1619 Bergville	HBC volunteer
Mkhosi	Doris	Tel: 036- 448 1563 c/o Phumzile Ndlovu	Bergville	HBC Volunteer
Mohlakoane	Thembi	Tel: 036 – 438 6783	Not provided	HBC volunteer
Mthembu	Thandi	Cell: 083 370 4376	Not provided	HBC volunteer
Mzinyane	Nothile	Cell: 072 315 3300 Tell: 036 - 448 1785	Not provided	HBC volunteer
Ndaba	T. Mavis	Cell: 082 811 4756 Tel: 036-4482743	Not provided	HBC volunteer
Ndinisane	Nhlanhla	Cell: 083 728 4068	Not provided	HBC volunteer
Ndlovu	Busisiwe	Not provided	Not provided	HBC volunteer
Ndlovu	Phumzile	Tel: 036- 448 1563 Fax: 036– 448 1389 Cell: 072 243 0077	P.O. Box 37 Bergville 3350 Monika_holst@wvi.org	Manager
Nkabinde	Cynthia	Not provided	P.O. Box 228 Zenzele Store Bergville	HBC volunteer

Ntumba	Doris	Not provided	P.O. Box 228	Volunteer/ member
Sgazu	Lindiwe	Cell: 082 477 4775	Box 201 Bergville	HBC volunteer
Shabalala	Jabu	Cell: 072 328 7560	P.O. Box 518 Bergville Moyeni	HBC volunteer
Shange	Sylvia	Cell: 072 328 7560	P.O. P.O. Box 370 Bergville	HBC volunteer
Slanders	Jean	Tel: 036 - 488 1352	joods@iafrica.com	Stakeholder
Zondo	Gladys	082 725 4857 (Ph)	Box 8019 Bergville 3350	HBC volunteer
HIV/MED [MICRO ENTERPRISE DEVELOPMENT] PROJECT (TDCSP/OADP)				
Miya	Bongani	Tel: 036- 448 1563 Fax: 036 - 448 1389 Cell: 072 403 6804	P.O. Box 37 Bergville 3350 Monika_holst@wvi.org	Fieldworker
Dube	Sindi	Tel: 036- 448 1563 Fax: 036 - 448 1389 Cell: 072 337 0580	P.O. Box 37 Bergville 3350 Monika_holst@wvi.org	Fieldworker
HOSPICE				
Slanders	Jean	Tel: 036 - 488 1352	joods@iafrica.com	Coordinator
LOCAL GOVERNMENT				
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Mabizela	C. B.	Cell: 082 473 2793	Bergville	Councillor
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Kerry	Claire	Tel: 036- 448 2044 Fax: 036– 448 1389 Cell: 082 669 0732	P.O. Box 37 Bergville 3350 kerry@futurenet.co.za	Manager
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ORPHANS PROJECT (TDCSP/OADP)				
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PEOPLE LIVING WITH AIDS (PWA)				
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SIKHONA CLUB				
Mkhosi	Doris	Tel: 036 – 448 1563 c/o Phumzile Ndlovu	Bergville	* Sikhona Club Chairperson
ST. YVES' CATHOLIC CHURCH				
John Father		Cell: 072 347 4844	St. Yves' Catholic Church, Bergville, 3350	Father (Priest)
Pascaline Sister		Cell: 082 479 9951	St. Yves' Catholic Church Bergville, 3350	HIV/AIDS Educator/Trainer
UNITED CHURCHES FAITH BASED ORGANISATION				
Details not available				
T D C S P				
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WELL-BEING CENTRE (TDCSP/OADP)				
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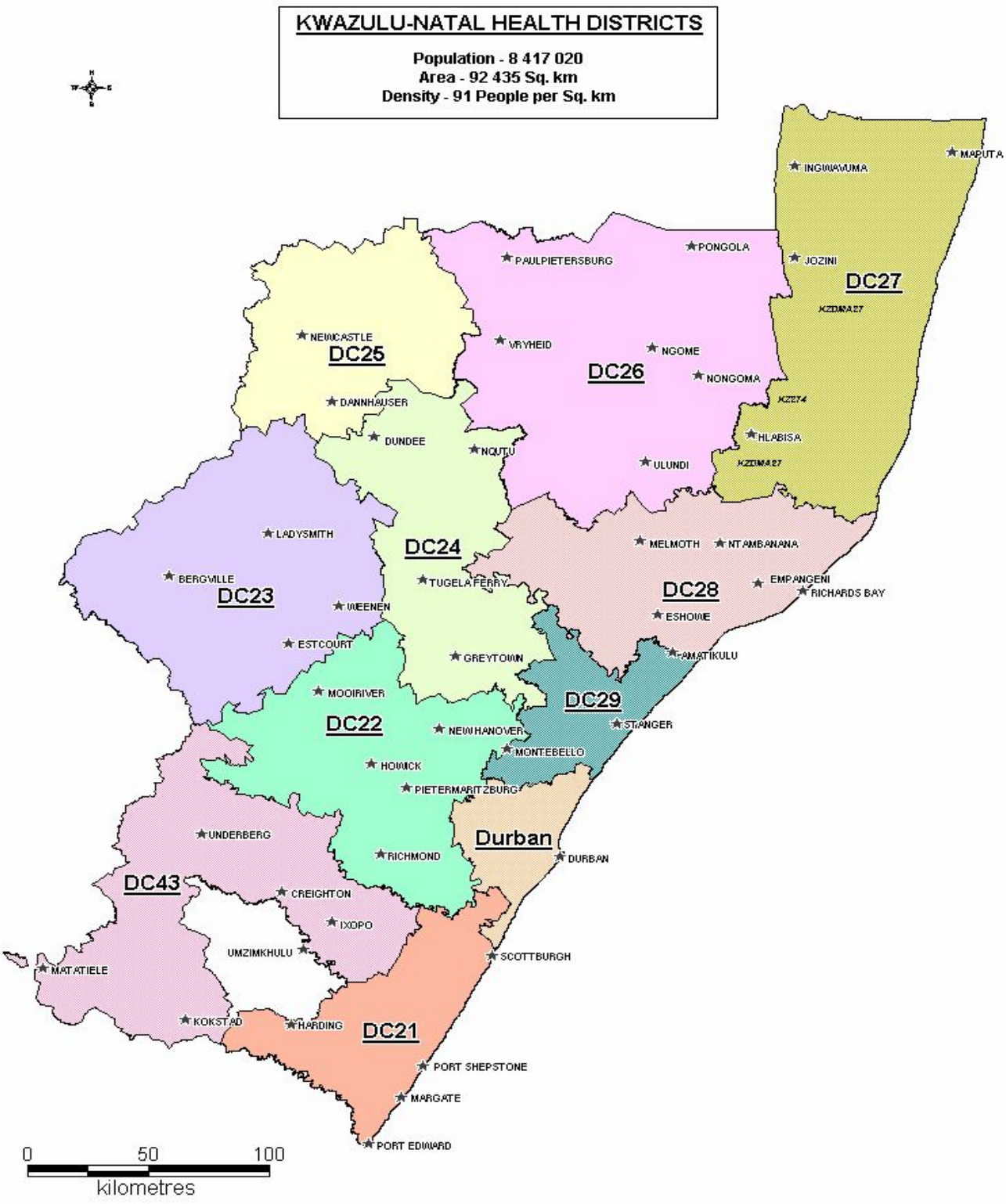
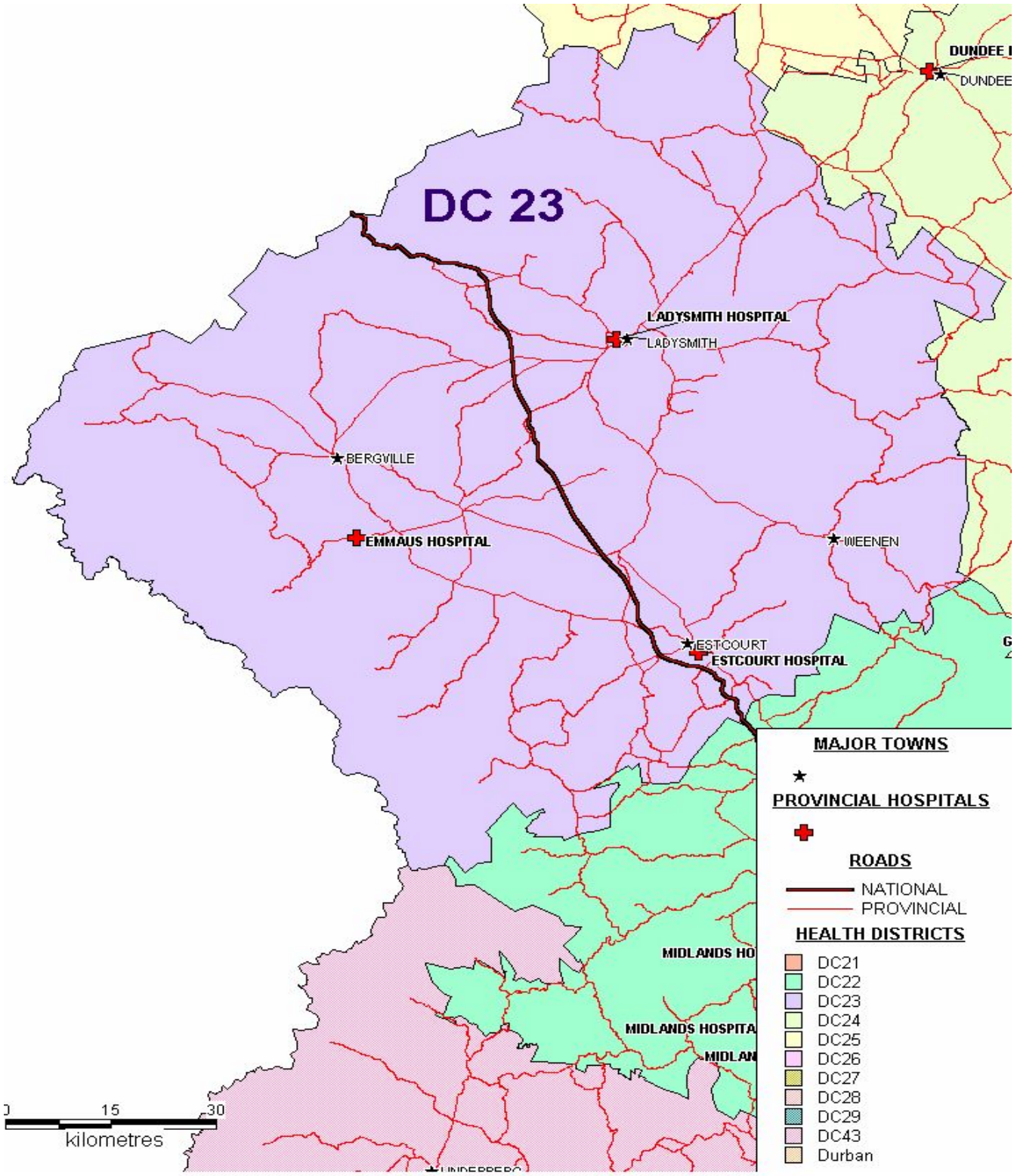
Hadebe	Thulani	Tel: 036 4481279 Fax: 036– 448 1389 Cell: 083 422 5835	P.O. Box 37 Bergville 3350 Monika_holst@wvi.org	Leader

APPENDIX 2

MAPS OF KWAZULU NATAL HEALTH DISTRICTS AND HOSPITALS



DC 28 – UTHUNGULU **DC 22 - MIDLANDS** **DC 26 – ZULULAND**
DC 29 – ILEMBE **DC25 - AROUND NEWCASTLE** **DC 23 – UTHUKELA**
DC 43 – SOUTHERN DRAKENSBERG **DC 27 – UMKHANYAKUDE** **DC 21 – UGU / OGWINI**
DURBAN – DURBAN METROPOLITAN COUNCIL



v

APPENDIX 3

OVERVIEW OF BERGVILLE/WINTERTON AREA

i. GEOGRAPHIC LOCATION:

The Bergville/Winterton area is located in the Southern Drakensberg within the Okhahlamba municipality of the uThukela health district,KwaZulu-Natal. The region is situated between the Midlands region, Gauteng and the Free State provinces. UThukela district is made up of five municipalities, i.e. Okhahlamba (Cathkin, Bergville and Winterton), eMnambithi (Ladysmith town, Colenso and Ezakheni), Indaka (Ekuvukeni), uMtshezi (Estcourt, Weenen and Wembezi), and Imbabazane (Loskop, Ntabamhlophe, Hlathikhulu and Draycot).

ii. ADMINISTRATIVE AND POLITICAL STRUCTURES AND FEATURES

The Okhahlamba district is an area of strong IFP support. There is an active local government structure operating in the region, with all such structures in the area reporting to local councillors directly or through committees responsible for certain community activities. A Community Health Forum, is being formed with municipal level representation, oversees all health, welfare and environmental issues and activities from a civil society perspective. Although the local councillors take an active role in community activities and are well informed about the day-to-day activities of their community, they do not see themselves as gatekeepers of community-based activities. For example, in one of the meetings the CLO team held with WorldVision (HIVAN's partners located in Bergville) the local councillor, Mr Mabizela, emphasised that it was not the councillors' place to give permission to HIVAN to work in the area and that HIVAN should liaise directly with the structures in place in the community.

iii. POPULATION STATISTICAL INFORMATION

The uThukela region has a population of around 585,000 (TDCSP DIP). In 1998 the Okhahlamba area alone had a population density of approximately 118919 people (Demarcation Board, 1996). According to the TWPFS report, the conservative estimate of HIV/AIDS prevalence in the region is 26.9%. (TWPFS, 2000).

The whole region has a strong rural character, with only 26% of the population living in urban areas. The urban/rural ratio varies from 40:60 in eMnambithi to 1:99 in Okhahlamba (TWPFS, 2000). However, there is an increasing need for the provision of services and employment opportunities in rural areas.

iv. SOCIAL AND ECONOMIC CHARACTERISTICS

There are a number of social and economic trends prevailing in the Okhahlamba district and the combined effect of which serves to impact negatively on the health, welfare and economic growth of the area. The TWPFS (2000) reported that the following factors need to be considered concurrently with each other.

Lack of funding and inadequate transport makes skills training courses, available in major urban centres, inaccessible to those in rural areas. This affects initiatives aimed at HIV/AIDS knowledge dissemination as well as models of development to help the community sustain their lives in light of income generation and home based care initiatives for the ill and their families.

Looking at the economic situation, only 8751 out of 118 919 people were confirmed as employed for the Okhahlamba area in 1996 (Census 1996). Dallimore (2000) further reported that 60% of people aged 20 years or older were not considered 'economically active'. This shows a very serious economic shortfall affecting the area and supports the statement that 'poverty leads to high HIV infection' among the youth "would seem appropriate to say as most young people engage in unsafe sexual practices as an alternative to suffering and worries…" (Thulani Hadebe, Youth Project, TDCSP, 2002).

Dallimore (2000) reported that 23.6% of households in the Bergville/Okhahlamba municipality were reported to have no source of income; 23.8% had access to a regular source of income; and one in six households were reported to be depending on a government pension as the only source of income (10). On average, a pensioner's income has to support five other members in a household. This impacts negatively on those households, which have to depend solely on government pensions as family income. As HIV/AIDS is affecting the most economically active sectors of society, the pressure on pensioner incomes is increasing, with grandparents having to care for their children and their orphaned grandchildren due to HIV/AIDS related deaths
in their families. According to the DRA development report by Dallimore (2000), 91.5% of all households contained children whose mother was alive. Of the remaining 8.5% households, Dallimore reports, one or more mother orphans existed.

The region has one major strength in that it has, by South African standards, a good health structure. There are four hospitals and 30 clinics in the district These health facilities are available across communities, with the farming and other remote areas being serviced by mobile clinics. This adds a little hope to the communities in the municipality as most people have access to clinics and hospitals. However, as mentioned above, transport problems seem to be a barrier.

Further, access to communication networks is low in the area with a relatively large proportion of the population having no access to telephones (4179 households) and 7252 relying on public telephones. Although 4768 households have access to local authority electricity, large numbers of households still use paraffin (3701) and candles (10498) for cooking, lighting and heating. The majority of the households use a pit latrine (15273) as a method of sanitation and use public taps (6945) and boreholes (6131) as sources of water for cooking and drinking. Common across most rural areas, this socio-economic profile paints a picture of a rural community that has limited access to infrastructure such as communication networks, electricity and water.