

khomanani

-REACHING OUT - SCALING UP-



*Report Of The First
South African National
Home/Community Based
Care Conference*

18 - 21 September 2002

A C K N O W L E D G E M E N T S

Special thanks are due to the Conference Organising Committee, chaired by Cornelius Lebeloe and drawn from national and provincial government departments, including Health and Social Development, provincial HCBC co-ordinators, UNAIDS, the private sector including the mining industry and pharmaceutical companies, NGOs, CBOs and PLWHAs. The Committee showed unwavering dedication to the conference's success. It was backed by the insight and skill of Track Chairs Gustav Wilson, Kath Defillipi, Mercy Makhalemele and Criselda Kananda, Chief Facilitator Zed Tshabalala and the singular expertise and experience of on-site co-ordinator and ProCAARE moderator Colleen Jackson. The contributions of all presenters, small group facilitators and scribes, delegates, exhibitors and the Sibambene Development Communications rapporteur and conference report team are also acknowledged.



A C K N O W L E D G E M E N T & D I S C L A I M E R

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KHOMANANI - REACHING OUT - SCALING UP

*Home/Community Based Care Conference
18-21 September 2002*

Conference Report

*"The best time to plant a tree was 20 years ago.
The next best time is now."*

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Abbreviations

<i>AIDS</i>	Acquired immune deficiency syndrome
<i>ARVs</i>	Anti-retroviral drugs
<i>CBO</i>	Community based organisation
<i>CHBC</i>	Community home based care – the term used in Botswana
<i>DoH</i>	Department of Health
<i>DOTS</i>	Directly observed treatment short course
<i>FBO</i>	Faith-based organisation
<i>HCBC</i>	Home/community based care – the term favoured in South Africa
<i>5th HCC</i>	Fifth International Home and Community Care Conference for People Living with HIV/AIDS – Chiang Mai, Thailand, December 2001
<i>HCC</i>	Home community care – the term used in Thailand
<i>HDN</i>	Health and Development Networks
<i>HIV</i>	Human immuno deficiency virus
<i>IEC</i>	Information, education and communication
<i>M and E</i>	Monitoring and evaluation
<i>NGO</i>	Non-governmental organisation
<i>NGO</i>	Non-profit organisation
<i>NW</i>	North West province
<i>OVC</i>	Orphans and vulnerable children
<i>PLWHA</i>	Person/People living with HIV/AIDS
<i>ProCAARE</i>	Programme for Collaboration against AIDS and Related Epidemics
<i>SADC</i>	Southern African Development Community
<i>SAQA</i>	South African Qualifications Authority
<i>STI</i>	Sexually transmitted infection
<i>UNAIDS</i>	Joint United Nations Programme on HIV/AIDS
<i>VCT</i>	Voluntary counselling and testing
<i>WHO</i>	World Health Organisation

Useful Term

Continuum of care

“A network of resources and services that provide holistic and comprehensive support for the ill person and family caregivers. The goal is an affordable range of services in various settings, from home to community agencies and clinics, to hospitals and vice versa. Comprehensive care involves the provision of care, treatment, support and preventive services. Holistic care involves referral, follow-up, monitoring and case management.”



Message of Support

HIV and AIDS continue to permeate our societies and communities and as a country we are losing loved ones in great numbers.

We are challenged to move away from the language of crisis and catastrophe that has dominated the discussion on HIV and AIDS. Instead we must return to being a caring society and not a scared society. We need to move away from discrimination and stigmatisation and to start accepting people living with HIV and AIDS. Our home and community based care programmes should focus on positive living and emphasise the importance of nutritional care and support.

This conference marks an important turning point in our interventions and we are looking to it to provide answers on how best can we improve these services. The recommendations from this conference will assist all partners to act appropriately and provide effective, affordable and accessible home and community based care programmes.

*Dr M Tshabalala-Msimang
Minister of Health*



Background

The first national home/community based care (HCBC) conference as called by the Minister of Health in 2001, was held by the National Department of Health, Chief Directorate: HIV/AIDS, STIs and TB from 18 to 21 September 2002 in Rustenburg, North West province. More than 380 delegates attended. They included officials from different provincial and national government departments, representatives from non-governmental organisations (NGOs) and community based organisations (CBOs) in each province, the Southern African Development Community (SADC), donor organisations, the private sector, faith-based organisations and traditional healers and leaders.

HIV/AIDS is a significant development challenge facing South Africa. It is having and will continue to have an enormous impact on children, youth, families and communities in the coming decade.

The conference had to take into account global and developmental challenges posed by HIV/AIDS such as the:

- Increased demands on the health system and budget by the increasing number of people needing hospitalisation, prolonged hospitalisation and drugs for opportunistic infections;
- Increasing numbers of children in distress. Traditional models of surrogate support and care in poor communities are unable to accommodate these children without external support. There is also a pressing need to protect the rights of children infected and affected by HIV/AIDS;
- Increased need for social assistance; and
- Stigma associated with families infected and affected by HIV/AIDS.

The conference role was to explore alternative and/or complementary care and support interventions to mitigate this impact. Cabinet had identified HCBC as a priority in 2001, when it mandated the Departments of Health and Social Development to take the lead in implementing HCBC programmes and to ensure that 600 HCBC programmes were established by March 2005. Joint implementation of HCBC programmes by these Departments will help:

- Pull resources together for a more effective and efficient response thus avoiding fragmentation and duplication;
- Involve other stakeholders including the Departments of Agriculture and Education, NGOs and CBOs to ensure the provision of a continuum of care and support services at district and/or local level;
- Provide comprehensive and holistic HCBC programmes;
- Build community empowerment and involvement; and
- Scale up or roll out programmes to other sites.

As a follow-up to meet this mandate, various activities were undertaken. These informed the planning of the national HCBC conference and included:

- Developing HCBC and support model options to guide the national implementation of these programmes;
- Conducting a rapid appraisal of existing HCBC and support services;
- Obtaining commitment from the nine provinces; and
- Initiating and scaling up new HCBC programmes.

Conference Theme: Khomanani - Reaching Out - Scaling Up

Conference aims and objectives

The conference aimed to provide strategic direction for the delivery of care and support services through HCBC programmes in South Africa, and also to focus on strengthening their impact. An overview of the specific aims, objectives and expected outputs are contained in the section "The HCBC Conference at a glance" on page 5.

Debates and presentations were structured around four tracks, and focused on issues that have been identified as critical barriers to developing HCBC services. The tracks of the conference were: Context for Care, Continuum of Care, Partners for Care, and Living Positively.

The conference was based on presentations of real projects, not on abstract concepts. People involved with implementation were given the opportunity to present their projects, and this allowed practical issues to surface. Discussions were also guided by the challenges identified during the track and project presentations. These included:

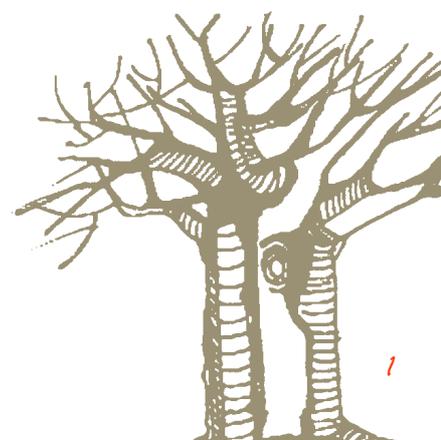
- Scaling up HCBC and support programmes;
- Strategically integrating programmes;
- Co-ordinating services;
- Building referral mechanisms; and
- The sustainability of programmes, including volunteer turnover.

Some issues were repeatedly raised as areas of discussion throughout the conference. These critical issues led to the development of the conference recommendations and included:

- The scope or continuum of care;
- Voluntary counselling and testing (VCT) as the entry point to care;
- Mainstreaming HIV/AIDS care with care for TB and other chronic illnesses;
- A multisectoral response;
- Stigma and discrimination; and
- Orphans and vulnerable children.

"We have to take people with HIV in the boat with us so that together we can alleviate poverty. I hope this conference can help people to network and see how to help each other. We want help with marketing - locally, nationally and internationally."

Ruphin Mukaz, a ceramicist training people in ceramic skills for income generation at the Ubumba Arts and Ceramics Project in Pietetmaritzburg.



HCBC Conference recommendations

The following recommendations emerged from the conference:

We recognise

That the scope of HCBC has broadened to include VCT as the entry point to HCBC. HCBC is a care service which covers:

- Positive living;
- Palliative care;
- Caring for carers;
- Bereavement counselling; and
- Caring for orphans and vulnerable children (OVCs).

We recommend

Caring for any terminal illness within HCBC:

- Offer HCBC for patients with any terminal or chronic illness, to ensure holistic care; and
- Minimise stigma and discrimination against PLWHAs through integrated HCBC.

Advocating for a multisectoral response:

- Lobby for multisectoral and interdepartmental collaboration for better resource allocation;
- Address poverty alleviation, especially efficient distribution of food parcels; and
- Involve the business sectors in supporting community initiatives for their employees beyond the workplace, and in monitoring and evaluation.

Scaling up through mentorship:

- Build a mentoring programme which provides a support base to develop the capacity of non-profit organisations (NPOs) and CBOs to deliver quality services.

Building networks and referral systems:

- Create a database/directory of services of all local initiatives;
- Develop patient discharge plans; and
- Create a better understanding of the reciprocal roles of health workers and traditional healers so that their benefits can be effectively utilised.

"People talk about an integrated approach. That is what I want. We need an integrated approach to help these children."

Siziwe Ngcwabe, Orphan Care Co-ordinator, Heartbeat Project and Khutsong/Carltonville Home Based Care. There are 54 child-headed families in the community and 3 200 children living with grannies and relatives. Most of the children are looking after dying parents.

Countering stigma and discrimination:

- Recognise that stigma and discrimination are a barrier to the delivery of HCBC; and
- Adopt a rights-based approach in the provision of information, education and support to families who are infected and affected by HIV/AIDS.

Including orphans and vulnerable children in care initiatives:

- Address the needs of OVCs as they are an integral part of care initiatives within HCBC interventions.

Focusing on palliative care and training:

- Incorporate palliative care as an essential component of training for all caregivers, health workers and traditional healers.

Documenting best practice in nutritional care and support:

- Highlight recommended strategies around optimum nutritional care and support and supplements for PLWHAs.

Caring for carers:

- Develop a programme of care and support for caregivers and integrate it as an essential component of HCBC.

Managing and guiding volunteers:

- Develop, with government initiation, management policies and guidelines addressing volunteerism, which specifically focus on:
 - Selection criteria,
 - Recruitment;
 - Training;
 - Supervision;
 - Remuneration;
 - Care and support; and
 - Integration across programmes and sectors.

Involving people living with HIV/AIDS (PLWHAs):

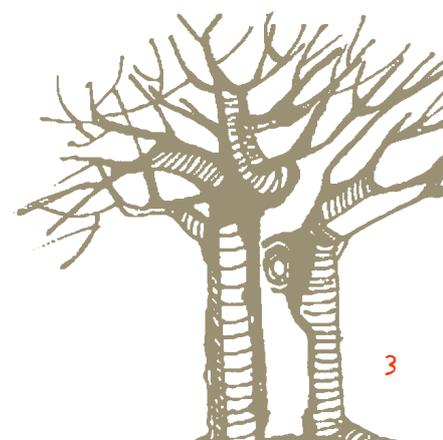
- Ensure PLWHAs are involved in policy, planning, delivery and governance of HCBC services.

Addressing gender issues, including involving men:

- Develop strategies that encourage the involvement of men in HCBC policy, planning, delivery and governance of services.

"I want to know what we can do practically to manage HIV/AIDS. I want to know what can I do."

Deacon RKJ Pelele, killer disease targeter, HIV/AIDS awareness and palliative care project in Mmabatho.



Strengthening monitoring and evaluation:

- Implement compulsory monitoring and evaluation systems;
- Identify and document best practice examples of HCBC; and
- Establish management accountability systems and assess financial management of project funds.

Transforming the Conference Organising Committee into an HCBC Standing Committee:

- Monitor conference recommendations; and
- Serve as an HCBC networking structure, that will co-opt expertise as necessary.

Follow-up to conference recommendations

The Departments of Health and Social Development met within a month of the conference to single out which sectors should develop strategies around specific recommendations, and to co-ordinate a way forward.

A task team was appointed to agree on the terms of reference for a National Home Based Care Advisory Committee to act on the conference recommendations. This is an interim structure until a final approval has been granted. The task team will also devise a way forward on:

- A future conference;
- Profiling HCBC in the media;
- Selecting and documenting best practice reports and
- Networking and referring to provincial HCBC co-ordinators.

For information contact:

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"I would like to find some new ideas in this conference. It is being taught in each and every place to use condoms, be faithful to your partner...but it doesn't work. People are having unprotected sex each and every day."

Dudu Phele, Women's Empowerment against HIV/AIDS (WIPA), support group for women, Mafikeng, North West province.

1. The HCBC Conference at a glance

South Africa's Khomanani - Reaching Out - Scaling Up HCBC Conference aimed to:

Strengthen and provide strategic direction to the delivery of care and support services through the HCBC programme.

The HCBC Conference objectives were to:

- Promote the exchange of lessons learned and strategies that improve quality of life and reduce the burden of illness on PLWHAs, the chronically ill and their families;
- Advocate for greater involvement of PLWHAs and promote positive living through HCBC;
- Identify and analyse the cultural, economic, political, ethical, social, legal and policy-related factors that promote and threaten the sustainability of HCBC;
- Strengthen networking structures and partnerships which impact on the scope and effectiveness of HCBC programmes and activities;
- Explore national, provincial and local government and partner responses for a continuum of care to mitigate the impact of chronic diseases; and
- Address challenges faced by HCBC implementation and scaling up of best practices.

The HCBC Conference was expected to produce:

- A coherent and co-ordinated HCBC response;
- Recommendations on how to scale up HCBC programmes;
- A strategy to improve the involvement of PLWHAs;
- A consolidated networking structure; and
- Plans to achieve Cabinet's mandate to the Departments of Health and Social Development to set up 600 HCBC programmes by March 2005.

Who was there?

A total of 360 delegates attended. They included provincial and national Departments of Health and Social Development officials, NGO/CBO representatives from each province, Southern African Development Community (SADC) representatives and donor organisations, and representatives from the private sector, traditional healers and leaders and faith-based organisations (FBOs).

"I hope that we can pool ideas on how best to cope with the pandemic, using home based care services equitably, and in an affordable way. Hopefully, there will be a lot of sharing of expertise and best practices. Often we get to attend international conferences, and although we share our experiences there, people inside the country don't get access to that information."

Lungile Fatyela, Western Cape Department of Health.



What did they do?

To meet its objectives, the organisers set four broad tracks for discussion, based on known areas of concern.

Each track also discussed a set of related topics, and prepared a report and recommendations. A track chair led each track, and facilitators helped direct and capture discussions in each small group. The final conference recommendations and steps to implementation are based on these.

Tracks

Track A – Context for Care

Sub-titles: Stigma, Discrimination, Enabling and empowering environment, Socio-economic rights and HCBC policies and management.

Track B – Continuum of Care

Sub-titles: Referral system, Transfers including medical, nursing, spiritual and psycho-social support, Alternative therapy, Traditional healers, Palliative care and TB/HIV care.

Track C – Partners for Care

Sub-titles: Traditional leaders, FBOs, CBOs, NGOs, Private sector, Volunteers and Government departments.

Track D – Living Positively

Sub-titles: Nutrition, Personal growth, Psycho-social therapy, Support groups, Disclosure and Public speaking.

The conference report

The report is structured for easy reference:

- The executive summary captures the main themes and conference recommendations;
- An overview, key issues for implementation and the conference recommendations are in the main body of the report; and
- Detailed track chair reports, summaries of presentations and contact details are in the appendix section.

"It would be good if by the end of the conference we know what is working well, and have more information about one practical model that can be implemented country-wide."

Mrs Madonsela, Eastern Cape Department of Health.



2. Keynote address: MEC for Health, North West

The HIV/AIDS pandemic is posing challenges of immeasurable proportions to the public health system and continues to inflict untold pain and misery on those who are infected and affected. Unless all of us join hands and intervene decisively, we may not be able to cope with the demands placed on our limited resources.

The time between the onset of disease or injury and healing or death, is a very trying time that is best given meaning by those who are going through the experience themselves. To those that provide care and healing, the suffering or death of a fellow human being is immensely distressing. When someone is entrusted to our care we feel driven to spare neither knowledge, strength or ability to do our best. When we win, it brings inner peace. When we are unable to bring relief from pain or to avert death it eats at our soul, saps our energies, assaults our sense of worth and life's purpose.

We are gathered here to take part in the national dialogue about care and support. We do so in a manner that is seriously different from similar meetings that have been held among citizens of our country and province.

The house is on fire. The village is in the grip of an agent of disease and death. The plague cuts short the lives of the youngest, the old, the best, the swiftest, the most gifted, the youthful, the needed, the loved and cherished, the most productive.

Let the scientist speak, let the priest give spiritual interpretation, let doctors and nurses speak of their everyday battles, victories and defeats in the hospitals and clinics. Speak as a worker; speak as an employer. Let us hear the news of leaders of the sports, arts and entertainment sectors.

Let the parents, friends and relatives speak of the sick, distressed and departed. Let the women – bearers of children and often victims of sexual violence – speak of their experience, fears and wishes. Let all of us speak on our own behalf and on behalf of those who cannot speak for themselves.

The people and the government of our country await the ideas that will emerge from this conference with keen and solemn interest. We await your message and counsel. We shall listen. Where it is possible and within our means to act immediately and directly in response to your advice, message or requests, we shall do so.

Dr MP Sefularo

"I'm hoping that listening to the speakers discuss stigma will help me to help PLWHAs cope with stigma, and to outgrow the labelling that disempowers them ... people are emotionally damaged by stigma to the point where they simply see themselves as people who are dying, and whose children are not provided for."

Sister Joy Mathatha, Nightingale Hospice, De Aar.



3. HCBC: where we are, what we know

In sub-Saharan Africa, HCBC emerged in the late 1980s and early 1990s as an immediate and direct response to the HIV/AIDS epidemic.

"The caring process emerged ... community home based caring groups mobilised themselves as a 'force for change' and in turn mobilised others: traditional healers, birth attendants, churches, women's groups and community leaders including modern health professionals. This marked the turning point in the perception of the epidemic and a significant development in the history of modern health care. Health care assumed the totality and holistic dimension it had hitherto lost."

Dr V Nkidi Ngcongco, consultant, Botswana.

HCBC has since assumed enormous significance in Southern Africa and elsewhere as a care and support service which complements formal health care to help cope with the impact of HIV/AIDS on development.

Building this service has now also become a strategic priority in South Africa. Currently there are 464 HCBC programmes benefiting 362 000 people across the country, with at least 8 000 caregivers trained to date².

These caregivers show extraordinary levels of dedication and commitment in the face of often overwhelming situations, and they have a wealth of knowledge and experience.

New levels of insight and expertise have also been gained by sharing experiences, for example at the first Southern African Regional Community Home Based Care Conference in Botswana, in 2001.

The South African HCBC Conference was organised so this wealth of information could be channelled to inform swift action and address the key challenges to improving and expanding existing local HCBC services into a fundamental pillar of the response to the HIV/AIDS epidemic.

These challenges have been identified as:

- How to scale up and integrate programmes;
- How to co-ordinate services and create strong referral mechanisms;
- How to sustain programmes in the face of the high turnover of volunteers; and
- How to monitor and evaluate what is being done.

"My biggest expectation is that I'll find out what the existing HCBC structures are doing... yes, the structures are there, but are they on the right track? Are they moving together? If not, how can we adjust them? Also, how can we assist the other provinces? If we have one province that's making headway, what are the successful strategies they are using, and how can we adopt them?"

Maredi Modiba, Limpopo Department of Health.

¹ Dr V Nkidi Ngcongco: "Implementing and Scaling up Community Home Based care: experiences from selected African countries: Process and Benchmark." Prepared for the Khomanani HCBC Conference, 18-21 September 2002.

² Cornelius Lebeloe: "Cabinet Mandate: National Multisectoral response to HIV/AIDS with specific reference to HCBC and support." Paper presented to the Khomanani HCBC Conference, 18-21 September 2002.

South Africa – government steps to date

South Africa's Cabinet identified HCBC as a priority in February 2001, based on evidence submitted to it by the Departments of Health and Social Development.

The decision was a response to the need to develop care and support services to complement formal health care, to mitigate the impact of the HIV/AIDS epidemic on development.

This impact has been well documented. It includes:

- Increased demands on the health system and budget by the increasing number of people needing hospitalisation, prolonged hospitalisation and drugs for opportunistic infections;
- Increasing numbers of children in distress. Traditional models of surrogate support care and poor communities will be unable to accommodate them without external support, and there is also a pressing need to protect the rights of infected and affected children;
- The increased need for social assistance; and
- Stigma associated with families infected and affected by HIV/AIDS.

Lead departments

Cabinet has mandated the Departments of Health and Social Development to take the lead in implementing HCBC programmes. It is their joint responsibility to ensure that 600 programmes are established by March 2005.

To meet this mandate the Departments have:

- Developed five HCBC models. These models are now a formal supplement to the 2000-2005 National Strategy on HIV/AIDS/STIs;
- Conducted a rapid appraisal of existing HCBC activities. There are 464 HCBC programmes benefiting 362 000 people across the country, with at least 8 000 caregivers trained to date;
- Obtained buy-in from the provinces; and
- Assisted provinces to develop HCBC business plans.

The aim of having two departments jointly implement the HCBC programme is to avoid fragmentation and duplication of services. The two departments are expected to link with other stakeholders, such as the Departments of Agriculture and Education, NGOs and CBOs to help to build a continuum of care at the local level. Joint implementation is also aimed to help empower communities and to provide comprehensive programmes.

The Botswana and Thailand experience

International home care conferences have been organised since 1992, facilitating mutual learning for people who before had little opportunity to share and learn beyond their provincial or national borders. The African experience with community based care has been on the agenda from the start.

"I would like there to be a discussion of how all departments can come together to fight this pandemic, because it is affecting all areas; work, economic growth, the labour force, especially in the construction industry, and housing."

Mata Ibini, National Department of Housing.



"In our province the key is getting the programme off the ground. There is no clear direction and the policy framework has not been implemented, so it is as if we have a nice concept that has been sold out prematurely. I would hope that through sharing successes and challenges at this conference we would return with new ideas and concrete plans for action."

*Molafela Makwela, Limpopo
Department of Health and Welfare,
District STI/HIV co-ordinator.*

Local discussions around HCBC were informed by the deliberations and findings from the two most recent conferences, the Botswana conference in March 2001, and the fifth International Conference on Home and Community Care for Persons Living with HIV/AIDS in Thailand in December that year.

Discussions at these events were linked and bolstered by an innovative project to provide electronic networking and communication support. The project took the form of structured, broad-based e-mail discussion groups before and after the events. This deepened the quality and breadth of the contributions.

Through this effort, the two conferences managed to document and share local experiences in the two regions, and identify the critical factors to succeeding in HCBC. Their work helped prepare the ground and provide the structure for the South African debates.

Key points from the first Southern African Regional Community Home Based Care Conference: Botswana, March 2001³

HCBC is quickly becoming the cornerstone of care in the Southern African region. The conference raised the critical question of whether it is simply a mechanism to decongest hospitals and ease weak health infrastructures, or a way to provide holistic care, that empowers both patients and communities. Specific findings were that:

- Effective and well-managed community home based care is a major part of the continuum of care, and will facilitate people living positively with HIV/AIDS;
- Stigma fuels the epidemic, forcing it underground and making it more difficult to provide and access care, and to engage communities in prevention;
- The gender imbalance occurs both in the epidemic itself, and in providing care – most carers are women and the majority of those who receive home based care are women; and
- Caring for carers cannot be overemphasised.

Key points from fifth International Conference on Home and Community Care for Persons Living with HIV/AIDS: Thailand, December 2001

The Chiang Mai conference theme was "The Power of Humanity". This highlighted the effectiveness of working together to meet the needs of PLWHAs and fighting to ensure that Home-Community Care (HCC) is the provision of quality, compassionate care, based on a set of clearly identified criteria that can be measured.⁴

³ First Southern African Regional Community Home Based Care Conference, Findings and Recommendations. For further information review the conference reports in the ProCAARE Archives: <http://www.procaare.org/archives> or the Health Development Network Website at <http://www.hdnet.org>.

⁴ Chiang Mai Conference Report: Conference Theme and Objectives, Dr Eric van Praag, Director HIV Care, Family Health International; produced by Health Development Network.

The conference promoted the sharing of knowledge and intervention models for home and community care for persons with HIV/AIDS, brought together key stakeholders and facilitated exchange between sectors, thereby contributing to a better quality of life to persons living with HIV/AIDS.

It was preceded by structured e-debates along four themes related to HIV/AIDS and HCBC. These were themes highlighted in Botswana, and again in the South African HCBC Conference, namely:

- Care, treatment and support in the community;
- Stigmatisation and discrimination in the social context of care;
- Creating an enabling and empowering environment to support care; and
- Positive living.

The conference did not produce specific recommendations but voted rather to endorse those produced by the Botswana conference. However, it did focus on many of the same key issues, such as caring for carers, integrating TB care, and involving PLWHAs.

A future challenge identified was to ensure that donors and the community consider HCC a veritable health care strategy, and so ensure sustainability. This requires stronger monitoring and evaluation of programmes to guide the provision of quality care and strengthen the competence of the entire HCC team.⁵

"Home based care is my calling. I am proud to have taken my vision and entrepreneurship and put it to good use for my community. I hope that this conference will inspire people to take action and deliver on the promises."

Rebecca Mashiane, Director, Ark of Grace, Mabopane.



⁵ Chaing Mai Conference Report: Executive Summary, produced by Health Development Network.

4. HIV/AIDS: where we are, what we know⁶

Paradigm shifts

The paradigm in global thinking on HIV/AIDS has shifted. Today we believe:

- That voluntary counselling and testing (VCT) must be seen as an entry point to the continuum of care;
- Access to care is a basic necessity not a luxury. This includes home based and palliative care, treatment and anti-retrovirals;
- Economic, political, social and cultural factors that render vulnerability must be addressed if our response is to be sustainable; and
- The core strategy for success is community mobilisation. This helps eliminate stigma and build partnerships.

Care is the greatest challenge

The United Nations General Assembly Special Session on HIV/AIDS (UNGASS) held in June 2001 set a target to make treatment and care for people with HIV/AIDS as fundamental to the AIDS response as prevention.

HIV/AIDS care and support for PLWHAs is now regarded as a good investment. It directly benefits PLWHAs and makes prevention more effective.

The hope of treatment is a powerful incentive for individuals to find out their HIV status through VCT – the gateway to all HIV/AIDS treatment and care.

People who know they are infected and have access to care can break through the denial about HIV. Care providers who look after PLWHAs demonstrate that there is no need to fear being infected through everyday contact.⁷

VCT also helps encourage changes in risky behaviour and so more effective prevention for those who are not infected.

Providing diagnosis and treatment for TB and STIs, common among people living with HIV, also helps decrease the spread of infections among people who are HIV negative.

"Successes of care must be tempered with realism. The evidence could not be starker: where care is most needed it is least accessible. The case for boosting resources is compelling."

Dr Peter Piot, Executive Director, UNAIDS .

"I would like to see networking established so that we can get rid of the fragmentation and duplication of services that currently exists. Secondly, I would like to see structures set up at regional level to provide support and equipment, as well as monitoring to home care workers."

Krishni Nair of AIDS Training and Information Counselling Centre (ATICC), Durban, KwaZulu-Natal.

⁶ Extracted from presentations by Dr Sandra Anderson, UNAIDS, and Dr Rose Malumba, Director, National AIDS Directorate, Department of Health.

⁷ Extracted from UNAIDS, UNGASS Fact Sheet: HIV/AIDS Care and Support. June 2001.

Impact

AIDS undermines progress in human development across all sectors. In the 45 most affected countries it cuts life expectancy, pushes people deeper into poverty, affects the ability of households to produce or buy food, kills the workforce and weakens economic activity. It also causes fewer children to enrol for education, hampers the ability of the education system to teach those who do and leaves women bearing even bigger burdens as workers, caregivers, educators and mothers.⁸

Health sector

The HIV/AIDS epidemic places already limited health care resources under further strain. It affects health care workers while increasing the demand for health care services, bringing problems like staff shortages, increased workloads and burnout. The increase in illness in the general population due to the HIV/AIDS epidemic will lead to bed shortages, increased counselling demands, and up to 30% more time spent diagnosing.⁹

Home care programmes and the training of doctors and nurses in Southern Africa will have to increase by an estimated 24 to 40% by 2010 to cope with the expanding demand for health services, illness and death among health care workers and economic emigration.

"What I would like to see coming out of this conference is a real commitment for government to work together at all levels, national, provincial and local. At present the various government ministries are working in different ways, and their efforts are not co-ordinated."

Johannes Aphane of Department of Education, Limpopo province.

Myths of complacency

It was believed that HIV prevalence in Southern Africa would stabilise at some natural limit. In fact, the HIV/AIDS epidemic is at an early stage and the long-term evolution is still unclear. If a natural HIV prevalence limit does exist, it is now thought to be considerably higher than hoped or expected.

Nonetheless, the right responses can reverse rampant epidemics: South Africa is showing success with youth, who are disproportionately affected by the epidemic.¹⁰ The future depends on them sustaining behaviour change.

Now we know that:

- Parents without care die sooner;
- Unrelenting stigma in health care settings means that the 40 million PLWHA can face the cruellest rejection from health care workers supposed to care and assist;
- Leaders who are role models that seek VCT and disclose their HIV status make an enormous difference in their communities and work settings; and

⁸ Fact Sheet 2002: The Impact of HIV/AIDS. UNAIDS.

⁹ Fact Sheet 2002: The Impact of HIV/AIDS: the impact on the health sector. UNAIDS.

¹⁰ Age specific analysis shows a modest decline in HIV infection rates amongst 15-19 year old ANC clinic attendees, from 21% in 1998, to 16,5% in 1999 with a continuing decline in the year 2000. UNAIDS, South Africa Epidemiological Fact Sheet – 2002 Update.



- Without hope of quality treatment, care and support, prevention efforts are hard to implement and fear abounds.

In South Africa:

- A multi-pronged HIV/AIDS prevention strategy has been adopted. This includes information, education and communication (IEC). A good protocol for preventing and controlling STIs has been put in place;
- Indications are that existing HIV/AIDS programmes have had a positive impact^{11 12}: 1998-2000 statistics show the epidemic in South Africa is slowing – Eastern Europe and Russia now lead in new infections. In South Africa a more aggressive VCT campaign is required, targeting people over the age of 20;
- TB remains the main killer related to AIDS, and more severe forms have evolved. Interventions are in place but more co-ordination is needed; and
- There are many HCBC initiatives taking place, but often the services are not well co-ordinated. Caregivers can make a significant difference to TB interventions. NGOs and CBOs working in HCBC need to scale up their education around TB treatment.

Local support for HCBC

Many initiatives, good infrastructures and resources are in place. These include:

- Conditional grants from the Departments of Social Development, Health and Education for co-ordination and support of the response to the HIV/AIDS epidemic;
- Models of HCBC¹³; and
- National Guidelines on HCBC.¹⁴

The fundamental problem is the weak link between government and civil society organisations. It is essential that role-players have a strong relationship and work in partnership to provide HCBC.

"The most important thing is to come up with an effective programme of action, that can be implemented, especially in rural areas. Usually we walk away from conferences with no plan to implement. Enough talking, we need a plan!"

Mimi Malatji and Patricia Maketa of the Red Cross in Limpopo.

¹¹ Ibid.

¹² Among the 62% of youth who have heard of the youth-focused programme loveLife, 76% agreed with the statement that loveLife has caused them to be more aware of the risks of unprotected sex. 2001 National Survey of South African Youth. loveLife. www.loveLife.org.za.

¹³ Integrated Home/Community Based Care Model Options. Department of Health, Department of Social Development. September 2002.

¹⁴ National Guideline on Home Based Care and Community Based Care. Department of Health. December 2001.

5. Critical issues for implementation

Some issues were repeatedly raised as areas of discussion throughout the conference. These issues formed the substance of the Track Chair reports. They informed the recommendations of each track and the final conference recommendations. To make HCBC work, every role-player will need to know and actively address these concerns. To support that action, this section explores the key discussions around each.

More detailed information on each issue can be found in the individual Track Chair reports, which are reproduced in full in the Appendix.

5.1 Scope/Continuum of Care

The message from discussions was powerful: HCBC can and should address a wide range of care needs. But HCBC services can only succeed if they are supported and linked into an equally wide network of individuals, civil and government structures.

This means the **scope of care** needs to be broadened. VCT is the entry point to care, and HCBC care services should cover positive living, palliative care, caring for carers, bereavement counselling and caring for OVCs.

Links between different sectors exist but need to be strengthened. These networking structures impact directly on the scope and effectiveness of HCBC programmes.

Specifically:

- Models of HCBC should be integrated to create an effective continuum of care;
- All levels of the state, NGOs and FBOs should co-operate. Policies and guidelines around this co-operation urgently need to be developed and implemented;
- Small CBOs and stokvels must be drawn in as they are vital players;
- The prejudice between health care providers, medical professionals, health care workers and volunteers hampers HCBC and must be addressed;
- The role of traditional healers as partners in the continuum of care needs to be reinforced. Traditional medicines should be recognised and registered for treatment in the HCBC setting. Traditional healers need training manuals relating to HCBC practices;
- Better communication is needed between the three tiers of government, and the Departments of Health, Welfare, Social Development and Home Affairs. Without it services are duplicated, people get caught up in politics and those who really need the care, fall between the cracks;
- Nursing sisters who become home based caregivers have to undergo a major transition as the nature of their role has shifted. Traditionally, nurses were trained to be uniformed professionals who did not share information with patients, never had to relate to families nor get involved with family members in care. As home based caregivers they are required to educate and support the family in caring for ill members; and

This section captures the thoughts of some delegates on what they learned and what information from the conference they plan to use in their communities.

"I know about the referral system and the need for pain control."

Manas Kabelo, Vision for the Nation.



"Recognising the needs of HCBC caregivers and the contribution of NGOs and partnerships."

Nthathane Mongologa.

- Public health facilities and professional health workers must acknowledge their role in supporting HCBC programmes. Linkages, alliances and partnerships should be incorporated into discharge planning to ensure good follow-up.

Refer to Appendix: Track C, Partners for Care, for more information.

5.2 Voluntary counselling and testing is the entry point to care

Voluntary HIV testing, combined with pre- and post-test counselling, has a range of benefits and is an increasingly important tool in the response to the epidemic.

It has been found that people who learn of their HIV status through VCT are motivated to adopt safer sexual behaviour. This helps prevent new infections.

VCT also helps people who test negative to access prevention services, and so maintain their negative status. People who test positive through VCT can be directed to a range of care and support services. These include prevention of mother to child transmission, treatment of opportunistic infections such as TB, and other support services. VCT is also the entry point to HCBC and a critical link in the referral chain between formal health care services and HCBC services.

Knowing and accepting one's status allows people to plan for their own and their dependants' futures. VCT is also one of the factors to help reduce stigma and secrecy surrounding HIV/AIDS.¹⁵ On many levels it helps build the synergy between prevention and care.

Specifically:

- South Africa needs a more aggressive VCT campaign, especially targeting people over the age of 20;
- Counselling services should be intensified, and post-test counselling services more widespread;
- VCT should be conducted in a context where integrated services are available, so that it can act as a gateway to care;
- An enabling and supportive environment is needed to encourage people to seek VCT;
- NGOs, CBOs and FBOs are organisations at the coalface that can best assist in creating this enabling environment; and
- Schools and churches should begin addressing issues of seeking VCT and disclosure through education in the curriculum, and from the pulpit.

Refer to Appendix: Track D, Living Positively, for more information.

¹⁵ HIV Voluntary Counselling and Testing: Gateway to Prevention and Care. Five case studies related prevention of mother to child transmission of HIV, tuberculosis, young people and reaching general population groups. Dr C Sozi, UNAIDS. VCT UNAIDS Technical Update. May 2000.

5.3 Mainstreaming

Care for HIV/AIDS needs to be integrated with care for TB and other chronic illnesses.

Speakers representing the National TB Control Programme spelled out the alarming crossover between AIDS and TB and the need for clear action. Concerns were also voiced that the focus on HIV/AIDS would obliterate services for other chronic diseases. The approach should be for HCBC to normalise HIV/AIDS by including a range of chronic disease services.

Specifically:

- People suffering from TB and other chronic illnesses are also vulnerable to stigma, and need counselling and support;
- TB care needs to be linked to nutritional support;
- HCBC services offering TB support need a system for tracing defaulters;
- There must be a concerted programme to encourage TB patients to go for testing and medication for opportunistic infections; and
- The pervasive attitude among health workers, NGOs, CBOs, government officials and donors is to sideline other terminal diseases in the face of the HIV/AIDS pandemic. Instead there needs to be an integrated and holistic response to HCBC across the board.

Refer to Appendix: Track B, Continuum of Care, for more information.

"HCBC workers can make a huge difference where TB interventions are concerned. If we save the life of a child through Nevitapine, and they die from TB, have we saved a life?"

Dr Rose Malumba, Director: HIV/AIDS/STIs, DoH.

5.4 Multisectoral response

Sharing information is the key to building a multisectoral response.

For government – the Departments of Health, Social Development and Education are the key role-players in providing HCBC, but the Departments of Housing, Home Affairs and Agriculture also need to be involved. Roles and responsibilities for implementing existing policy and infrastructure need to be more clearly defined. Provincial treasuries need to help build financial coherence and accountability. The historical issues around identity documents mean many people cannot access grants and this must be actively addressed.

In the **private sector** HCBC programmes are focused in the mining industry but should be promoted industry-wide. The private sector needs encouragement to co-operate with other stakeholders, and support their employees in communities beyond the workplace. Further discussions are needed around repatriation packages and benefits in general, to protect the rights of employees with HIV/AIDS and their families.

"Establishing better and stronger support groups, identifying more resources, having our caregivers better trained, addressing our reporting system to update our database, and networking with others even more."

Yolade Sesiane, Salvation Army.



Traditional remedies and healers are considered to be critical by the people who need the care. Traditional healers need to be supported to set up co-ordinated structures in which they can share ideas and successful evidence-based examples of healing with Western medical and health professionals.

Poverty alleviation, especially efficient distribution of food parcels, should form part of the multisectoral and integrated response. Poverty alleviation programmes are not working effectively, many income generation projects aren't sustainable and even successful income generation projects struggle to find markets. Food parcels should be made available to alleviate immediate hunger while food gardens are developed.

Specifically:

- Lessons can be learned from traditional healers on holistic care that takes into account spiritual, physical and emotional dimensions;
- The synergy between Western medical professionals, institutionalised religion and other stakeholders with traditional healers is critical. It ensures effective home based care and helps boost the morale of people who are dying from AIDS;
- Lobbying and advocacy have a critical role to play for effective intersectoral collaboration;
- PLWHA need to be involved in income generation projects;
- Intensive education is needed across sectors on interpreting the Bill of Rights with regard to AIDS care, so that people can benefit from their basic human rights, and be empowered personally and in their communities;
- Case studies of partnerships that successfully link partners from several sectors to provide an effective response need to be documented. They also need to be widely distributed, for example through community media, clinics, government and NGO publications; and
- There is a need to secure media coverage on positive developments regarding implementation of HCBC.

5.5 Referral systems

"Scaling up HCBC means that the components of service cannot be an 'exercise in patchwork' but must be a package deal."

Dr V Ndiki Ngcongco.

Cross referrals and follow-up are critical to effective care, but referral systems generally are not working as well as they could be. Where they do work, there are a number of missing elements, such as transport to other services, poverty and lack of registration fees. Often people stand in long queues, even if they are very ill, or facilities do not have the medications to help them. Generally communication between various bodies giving care, such as hospitals, clinics and hospices, is weak, as is the culture of care. This must be resolved for proper referrals to take place.

"Involving PLWHAs in our committees, and fighting for their rights. Sensitising the community to remove stigma."

Sheila Bizana, Ikwezi Lomso (NGO).

Specifically:

- District AIDS Councils should be used to consolidate systems;
- Current referral systems should be researched to identify successes and problems;
- Mobile clinics should be used to help solve the problem in rural areas;
- Formal referral forms that are standardised and user friendly are urgently needed to facilitate links between hospitals, clinics and HCBC;
- Bureaucratic processes should not penalise people who do not have identity documents; and
- Work is needed to build a culture of care and help people become aware of their constitutional rights.

Refer to Appendix; Track B, Continuum of Care, for more information.

5.6 Stigma and discrimination

Speakers repeatedly emphasised how stigma and discrimination blocks much work in every community – from VCT to HCBC to proper burials. Often it can come from those providing care.

Stigma makes people wary about accessing resources in their communities that are known to deal with AIDS. Stigma intensifies imbalances in communities and people are discriminated against on the basis of gender, race and class.

Stigma stops people from responding compassionately to orphans and vulnerable children, resulting in a generation of children who are afraid to ask for help and do not know their rights. Internalised stigmatisation is also a major stumbling block to support and care.

Barriers linked to stigma and discrimination need to be broken down. Education and information campaigns, self-exploration and appropriate counselling to encourage disclosure are good ways of doing this.

Specifically:

- Research needs to be undertaken in order to develop a better understanding of stigma and discrimination, and so to implement interventions to mitigate stigma as part of prevention and care programmes in the community;
- HIV/AIDS needs to be “normalised” as a disease, like many other terminal diseases;
- Practical steps, such as ensuring that PLWHAs are involved in all levels of HCBC work, are essential. This involvement could be from planning to delivery, research and evaluation of HCBC services. Inviting PLWHAs to sit on governing boards of organisations is one way of ensuring their involvement;
- Health care workers who speak of “AIDS orphans” need to review their approach as this is an example of the use of language which is stigmatising; and

“Training volunteers, developing an understanding between the community and health departments, working hand in hand with HBC and families of clients, and meeting the needs of caregivers.”

Mapule Lebeteko.



"Consolidating partnerships and referral systems. Care of caregivers."

Gloria Goci, non-profit organisation.

- Donors and service providers should review their approach to HIV/AIDS programmes. It is recognised that they can put orphans and vulnerable children into an invidious position by claiming they want to fund "AIDS orphans". This means other children who may or may not be AIDS orphans have to choose between disclosing their status, or the status of their dead parents, in order to receive support or to hold onto their very tenuous place within their communities.

5.7 Orphans and vulnerable children

HCBC cannot be effective unless it deals with the needs of OVC. Orphans should be recognised as children in distress with special needs which include bereavement, housing, nutrition, financial and schooling. Referring to them as "AIDS orphans" reinforces the stigma associated with HIV/AIDS.

Specifically:

- Existing child care/support grants should be extended beyond six years of age and be made specifically available to child-headed households;
- Inheritance rights need special attention;
- Government needs to provide increased support, for example by engaging with CBOs and reviewing policy relating to the issuing of birth certificates;
- Support groups for volunteers and orphaned children are critical;
- Cluster homes for orphaned children have proved to be a strategy worth implementing; and
- Hospices have found that the memory box project is a very valuable tool to help prepare children for the death of their parents, retain their history and identity and cope with life as an orphan.

Refer to Appendix: Track A, Context for Care, for more information.

5.8 Palliative care

The myth that palliative care is only for the dying needs to be broken. Palliative care emphasises the holistic needs of people in relation to their family and the community. This means it should be seen as an element of treatment right from the point of VCT and disclosure and should include bereavement counselling. The palliative care model is an example of how to break down prejudice and division within families and communities and to create a more liberating and less fearful view of death. It allows people to die in dignity. Home based palliative care has proved a strong learning opportunity for family members, communities and caregivers. Medical staff, however, also need to get proper support and training to deal with the number of people that are dying in their care.

Specifically:

- Palliative care must be integrated into existing home based care training and all health care training;
- Management capacity of palliative care needs to be developed;
- A good home based and palliative care programme is one that is sensitive to the needs of OVC. The implications of a generation of children growing up without being able to express their grief are dire;
- Pain and symptom control are an essential element of palliative care. It is a misconception that people with AIDS do not suffer from pain; and
- Effective palliative care is only possible if there are functioning relationships between hospitals, hospices, NGOs, CBOs and FBOs.

Refer to Appendix; Track B, Continuum of Care, for more information.

5.9 Nutrition

"You would be surprised how easy it is to maintain basic health and boost your immunity by eating simple but nutritious foods, which are not expensive to prepare."

Pastor Thebe Terence Baile, Ministry of Health, Botswana.

PLWHAs and their carers urgently need accessible information on good nutrition. Many are not aware of how good nutrition can maintain health. They also need information on economical ways to grow food. This is part of good nutrition practice and helps alleviate poverty. In many cases people are simply not taking their medicine – especially for TB – because it can't be taken on an empty stomach. Nutrition provision needs to be integrated at all levels, from planning to implementation.

Specifically:

- Nutrition initiatives must be extended to the families and dependants of PLWHAs;
- Orphans and children in distress are particularly vulnerable to malnutrition and poverty. It was suggested that school feeding programmes be extended to the HCBC setting;
- Intersectoral co-operation must be enhanced, especially in relation to the Department of Agriculture's role in promoting good nutrition;
- Models such as community and household food gardens and food stokvels are key to promoting nutrition in the HCBC setting; and
- HCBC care workers should be trained in food production techniques and HCBC kits should include starter seed packs.

Refer to Appendix; Track D, Living Positively, for more information.

"The importance of HCBC forums, training of care workers and developing a good referral system."

Elphas Nkosi.



5.10 Volunteers – caring for carers

"In the month of August I cared for 58 people. All of them died. I am very tired. I need help."

Sylvet Kgosemang, a field nurse at Gelukspan Hospital, Mafikeng, who provides home based care.

Caregivers and volunteers are often undervalued, over-extended and invisible. They experience low morale, stress, burnout, exploitation and abuse. Often they are as needy as their clients, and also vulnerable to infection. Volunteers play an important role in education and care but need help in setting and keeping professional boundaries in their HCBC work. HCBC services will only be sustainable if their needs are met.

"I've learned a lot about how to deal with the affected and infected, nutrition and encouraging communities to garden as a 'must do', not for fun."

Judith Zondi, CBO network in KwaZulu-Natal .

Specifically:

- The issue of payment of volunteers is critical;
- Volunteer training should be ongoing, standardised and recognised by the South African Qualifications Authority (SAQA) so that volunteers can be put on a career path;
- Volunteer support groups are critical to help scale up HCBC services;
- Volunteers and caregivers are vulnerable to HIV infection and need protection;
- PLWHAs can have a meaningful role to play in care, providing steps are taken not to put them at risk, such as by exposure to TB;
- Volunteer case loads must be matched by supervisory capacity;
- Projects should recruit more volunteers than they actually need because of the high drop-out rate; and
- Personal experiences and skills must be acknowledged so volunteers can feel empowered and able to express their true gifts.

Refer to all track reports in the Appendix for more information.

5.11 Integrating PLWHAs and gender

To counter discrimination PLWHAs should be part of all levels of HCBC, including policy making and programme implementation. Confining them to motivational speaking, facilitating workshops and educational events limits the scope of their contribution – and the effectiveness of the intervention.

Similarly, gender issues need to be more carefully integrated into HCBC programmes. Currently women bear both the brunt of the epidemic and the burden of care. Moreover they are often blamed at a subtle level for spreading the virus. Men need to be drawn into the frame: though men-friendly clinics and other care facilities, by a focus on gender issues such as sexual violence, and by actively involving men in hands-on counselling care and support as field workers and on the ground caregivers.

Specifically:

- The “Abstinence, Be Faithful, Condomise” message is a message for men. The highest rates of infection are amongst women of child-bearing age who are faithful to their husbands and partners;
- Research on female condoms should be accelerated to make them more accessible; and
- Violence and sexual harassment has itself reached epidemic proportions. The spread of HIV will never be adequately addressed unless government, NGOs, CBOs, hospices, hospitals, religious groups, traditional healers and all stakeholders integrate gender awareness, anti-bias and sensitivity training into their programmes.

5.12 Monitoring and evaluation

“As home based caregivers we need to go back and check. It is no good giving instructions and teaching people and then forgetting about them. You need to go back and see if people are carrying on with what you have taught them...”

Mrs M Masala, African National Congress Women’s League.

We need to always check that HCBC is a sustainable response to the epidemic, to see that funds are wisely spent and community needs effectively met. Some families receive support from several different organisations and others from none at all because of the communication gaps between service providers and government. There is a wider issue, too: some case studies have noted that difficulties with accessing government grants – such as disability grants and foster care grants – have led to a perception that if you are a PLWHA there is at least some possibility that you will get some financial support. There is debate about who should be conducting monitoring and evaluation and how to decide on the key indicators. What is agreed is that quality of care is a key element.

Specifically:

- Monitoring and evaluation must be done together with PLWHAs at all levels;
- Effective monitoring and evaluation cannot take place without appropriate networking and communication; and
- A national database of all HCBC service providers is needed.

“Integration of services, promoting and advocating VCT, and setting up support groups.”

Ronel Whiting, NGO.



6. Conference recommendations

6.1 We recognise...

That the scope of HCBC has broadened to include VCT as the entry point to HCBC. HCBC is a care service which covers:

- Positive living;
- Palliative care;
- Caring for carers;
- Bereavement counselling; and
- Caring for orphans and vulnerable children.

6.2 We recommend...

6.2.1 Caring for any terminal illness within HCBC:

- Offer HCBC for patients with any terminal or chronic illness, to ensure holistic care; and
- Minimise stigma and discrimination against PLWHAs through integrated HCBC.

6.2.2 Advocating for a multisectoral response:

- Lobby for multisectoral and interdepartmental collaboration for better resource allocation;
- Address poverty alleviation, especially the efficient distribution of food parcels; and
- Involve the business sector in supporting community initiatives for their employees beyond the workplace, and in monitoring and evaluation.

6.2.3 Scaling up through mentorship:

- Build a mentoring programme which provides a support base to develop the capacity of non-profit and community based organisations to deliver quality HCBC services.

6.2.4 Building networks and referral systems:

- Create a directory of services of all local HCBC initiatives;
- Develop patient discharge plans; and
- Create a better understanding of the reciprocal roles of health workers and traditional healers so that their benefits can be effectively utilised.

6.2.5 Countering stigma and discrimination:

- Recognise that stigma and discrimination is a barrier to the delivery of HCBC; and
- Adopt a rights-based approach in the provision of information, education and support to families who are infected and affected by HIV/AIDS.

6.2.6 Including orphans and vulnerable children in care initiatives:

- Address the needs of OVCs as they are an integral part of care initiatives within HCBC interventions.

6.2.7 Focusing on palliative care and training:

- Incorporate palliative care as an essential component of training for all caregivers, health workers and traditional healers.

6.2.8 Documenting best practice in nutritional care and support:

- Highlight recommended strategies around optimum nutritional care and support and nutritional supplements for PLWHAs.

6.2.9 Caring for carers:

- Develop a programme of care and support for caregivers and integrate it as an essential component of HCBC.

6.2.10 Managing and guiding volunteers:

- Develop, with government initiation, management policies and guidelines addressing volunteerism, which specifically focus on:
 - Selection criteria;
 - Recruitment;
 - Training;
 - Supervision;
 - Remuneration;
 - Care and support; and
 - Integration across programmes and sectors.

6.2.11 Involving people living with HIV/AIDS:

- Ensure PLWHAs are involved in policy, planning, delivery and governance of HCBC services.

6.2.12 Addressing gender issues, including involving men:

- Develop strategies that encourage the involvement of men in HCBC policy, planning, delivery and governance of services.

6.2.13 Strengthening monitoring and evaluation:

- Implement compulsory monitoring and evaluation systems;
- Identify and document best practice examples of HCBC; and
- Establish management accountability systems and assess financial management of project funds.

6.2.14 Transforming the Conference Organising Committee into an HCBC Standing Committee which will:

- Monitor the implementation of the conference recommendations; and
- Serve as an HCBC networking structure, that will co-opt expertise as necessary.



7. Follow-up to conference recommendations

The Departments of Health and Social Development met within a month of the conference to identify which sectors should develop strategies around specific recommendations, and to co-ordinate a way forward.

A task team was appointed to agree on the terms of reference for a **National Home Based Care Advisory Committee** to act on the conference recommendations. This is an interim structure until final approval has been granted.

The task team will also devise a way forward on:

- A future conference;
- Profiling HCBC in the media;
- Selecting and documenting best practice reports; and
- Networking and referring to provincial HCBC co-ordinators.

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"Almost all the info!"

Buti Kulwane, Business and Civil Society.

8. Communications

The HCBC Conference provided an important opportunity to communicate and raise awareness about the many different elements and issues around HCBC. This took place in several ways: formal media interviews and coverage, exhibitions, and individual informal networking between the formal discussions.

Media: mass communication in support of implementation

The South African HCBC Conference was supported by simultaneous media coverage, facilitated by the Department of Health's communications agency Meropa Communications. This reached more than 20 million people in a range of media, notably community and national radio. Meropa also received a number of requests which could translate into ongoing coverage.

Media exposure helps create broad awareness and acceptance of HCBC. It is one way in which individuals can be influenced to become involved in responding to the epidemic. Media coverage of HCBC is an important part of building the resources and partnerships needed to implement HCBC strategies at the local level.

Radio interviews

<u>Radio stations</u>	<u>Listenership</u>
Munghana Lonene	1 472 000
Teemaneng	98 000
SABC Radio – three interviews	Unsure of exact figures
Lesedi – two interviews	3 787 000
Ligwalagwala – two interviews	11 370 00
Jozi FM	Unsure of exact figures
Unitra	350 000
Umhlobo Wenene	4 522 000
Ekangala	750 000
Bush Radio – two interviews	120 000
Ukhozi	6 640 000
SAFM – Monday 06h35	515 000
Kaya FM	938 000
Y-FM	1 596 000
Radio Mafisa – three interviews	Unsure of exact figures

"To develop the relationship between HCBC and DOTS for TB, monitoring HCBC workers, and providing counselling for them every month."

Silver Kgosiemang, Department of Health.



"We will explain that the conference was successful by adopting the issue of technical skills of PLWHA training, which will help people generate income."

Ruphin Mukaaz, Ubumba Arts and Ceramics.

- More than 20 radio interviews were conducted. This does not include the possible mentions during news reports; and
- An approximate total of 20 453 000 listeners were reached. This total does not include those listeners of SABC Radio, Radio Mafisa and Jozi FM. It also excludes the possibility of cross-listening.

Print interviews

- *City Press* did a telephonic interview and additional information was sent to the journalist;
- *Inner City News* attended both the opening and the launch functions. It is not clear how many interviews were conducted during this time, but Meropa Communications has been monitoring this paper to note coverage;
- *Free Press* attended both the opening and the launch functions. It is not clear how many interviews were conducted during this time, but Meropa Communications has been monitoring this paper to note coverage; and
- A representative from the *Rustenburg Herald* attended the opening function. Media in the North West are to a large extent syndicated and it is likely that whatever article is published will be syndicated to the other publications.

Electronic interviews

- *SABC TV Mafekeng* attended the launch function and conducted three interviews; and
- *SABC TV Johannesburg* expressed interest in producing an insert based on a case study.

Electronic discussion forums

Notice of the conference, Track Chair reports and preliminary conference recommendations were posted on the ProCAARE Forum. This is the discussion forum that facilitated dialogue around the two previous HCBC conferences. It has 2 000 members involved in providing and accessing care around the world. They include PLWHAs, clinical and public health physicians, nurses, researchers, policy makers, programme managers, and other interested health practitioners in the developing and industrialised world. The ProCAARE coverage also solicited a number of enquiries from international media.

Exhibitions

Provincial HCBC co-ordinators were requested to identify NGOs and CBOs involved in HCBC in particular, and in other HIV/AIDS awareness programmes in general, which would be able to exhibit at the conference.

All provinces except Mpumalanga were represented in the exhibition area, displaying an array of information and awareness-raising materials. Most of the material concentrated on prevention, but some focused on care and support.

In addition, the Joint United Nations Programme on HIV/AIDS (UNAIDS) handed out vast numbers of resource booklets around best practice on VCT and HCBC.

Large numbers of materials were collected and distributed from provincial stalls.

Exhibitors were able to exchange experiences on the development of material – both media material such as posters and pamphlets, and utility materials such as T-shirts, hats, umbrellas and mugs. Provinces were also able to exchange promotional material.

The exhibition opened future networking between provinces and NGOs and strengthened the partnership between them as they participated jointly in the exhibition area.

Exhibitors

NORTH WEST
STI/HIV/AIDS Programme
Moretele Sunrise Hospice
KDT

FREE STATE
HIV/AIDS Programme

GAUTENG
HIV/AIDS Programme

LIMPOPO
HIV/AIDS Programme; NGO

KWAZULU-NATAL
KZN Beads and Pottery Project

NORTHERN CAPE
Department of Health

EASTERN CAPE
EQUITY Project

UNAIDS

Materials

Booklets, leaflets, posters, T-shirts,
AIDS ties, caps, mugs, squeeze
bottles, banners and hats.

Booklets, leaflets, caps, T-shirts,
Hats, AIDS ties, golf shirts and
banners.

Caps, T-shirts, hats, umbrellas,
leaflets and banners.

Leaflets, booklets, beads and knit
wear. Photographs of current HCBC
projects, HCBC kits and uniforms.

Beads and pottery.

Booklets, leaflets, T-shirts, caps, key
holders and stickers.

Booklets and leaflets.

Booklets on best practice

"Once I receive all the other discussion groups' documentation I will be able to give comprehensive feedback and awareness of HCBC and support implementation."

Lorraine Foss, Local AIDS Council.



Appendix section

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"I will tell them to formulate credible structures in the province so that they can effectively deal with the many issues facing the sector."

MJ Ramathwala, traditional healer practitioner.

1. Track A – Context for Care

Presented by Gustav Wilson

Introduction

What has been really encouraging and set the tone for the conference was the objective manner in which challenges were acknowledged and delegates' expression of an unwavering commitment to action.

Track A focused on the context in which HCBC takes place. Within this broad topic, a number of issues were raised, such as:

- Stigma and discrimination;
- Enabling and empowering environment;
- Socio-economic rights; and
- Policies and management.

Throughout the discussions, the following conference objectives were emphasised:

- The promotion and exchange of lessons learned and information on strategies that improve the quality of life and reduce the burden of illness on PLWHAs including the chronically ill in families;
- Identification and analysis of the cultural, economic, political, ethnical, social, legal and policy-related factors that promote or threaten the sustainability of HCBC; and
- Advocating for the greater involvement of PLWHAs as well as the promotion of positive living through HCBC.

Throughout the discussions delegates made it clear that knowledge and commitment are not enough. Vigorous action from all sectors and stakeholders is necessary to reach out and scale up HCBC.

Cross-cutting issues in the context of HCBC

During the plenary session a number of papers were presented. Pertinent issues raised were that:

- **HCBC is a sustainable strategy** for caring for people living with HIV/AIDS;
- The **lack of co-ordination** of the various initiatives and research projects taking place across the country within HCBC is a debilitating factor and needs to be addressed;
- Before it is possible to embark on “scaling up”, there needs to be an **objective evaluation** of current initiatives by government, NGOs, CBOs and FBOs, so that “scaling up” can be based on a coherent knowledge of what is already taking place in the country;
- **Stigma and discrimination is a barrier** to any work to be done in the HIV/AIDS sector, particularly for HCBC, and takes place in all aspects of an individual's life, schools, church, home and the workplace;

“The evaluation tool of Pretoria University, the mapping exercise of the Free State, the connection with traditional healers, and the possibility of linking two organisations to national funders.”

Rosemary Smuts, Caring Network.



"We need to make door-to-door home visits in the community, not necessarily only visiting homes of affected or infected families."

Bonnie, Msobomvu HCBC
Butterworth, Eastern Cape.

- **Internalised stigmatisation** can only be addressed if people are encouraged to speak out about their HIV-positive status, and thus begin to break down stigma at a personal level;
- Unless **socio-economic issues are addressed** by stakeholders, HCBC cannot be truly effective;
- The **socio-economic context** in which care is provided determines the nature of care that can be provided; and
- When care is provided to terminally ill parent/s, the focus of care should extend to **the children** who will be left to head the household.

Lessons learned

- There are areas where the prevalence of HIV/AIDS is higher in certain regions than in others, due to a variety of socio-economic conditions;
- Because of the relationship between HIV/AIDS and TB these diseases should not be seen as separate, and treatment should therefore be complementary;
- VCT should be regarded as an entry point for HCBC, but it should be in a context where integrated services are provided;
- Transparent evaluation processes to assess the quality of HCBC are crucial;
- There is a need for the replication of best practice projects or models such as Carltonville Home Based Care; and
- Holistic approaches to HCBC, involving families, business and communities, churches, traditional leaders and healers, have proved to be far more effective;
- The normalisation of HIV/AIDS is imperative to eradicate or reduce stigma and discrimination so as to ensure that HCBC services are successfully implemented;
- For the success of HCBC, persons infected as well as affected need to be brought into the planning process of services, in a meaningful way; and
- The inability to provide policies to fast track government and donor funds to projects offering HCBC has had a negative impact on service delivery.

Lessons learned on an international, national and provincial level need to be translated into tangible action, so as to ensure that the context in which HCBC is provided is enabling.

Outputs from group discussions

Group one – stigma and discrimination

Stigma is defined as a “a powerful means of social control applied by marginalising, excluding and exercising power over individuals who display certain traits”.

HIV/AIDS-related stigma is widespread across communities in South Africa. It remains a stumbling block to interventions which are aimed at prevention, care and support.

Stigma occurs in many different contexts including: the family, the local community, schools, faith-based communities, and the workplace. Stigma increases the impact of HIV/AIDS on individuals, families and communities.

Some of the causes of stigma have been attributed to a lack of understanding about HIV/AIDS, myths about the transmission of HIV/AIDS, a lack of treatment availability, the fear of death, the media's portrayals of incurability as well as the initial reporting which was centred on socially marginalised groups.

Current research argues that the roots of stigma are deep and relate to issues of culture, class, race and gender. Programmes designed to address stigma need to consider this and plan appropriately.

Recommendations:

- HCBC organisations should ensure that PLWHAs are represented on their board of trustees;
- Funding to HCBC organisations should be dependent upon PLWHAs being represented on the HCBC organisations' board;
- PLWHAs should be actively involved in all activities within the organisation including: planning appropriate programmes, developing organisational policy, undertaking research as well as evaluating programmes. This will ensure that the voices of PLWHAs are meaningfully involved;
- HCBC programmes should provide a generic care service, which is inclusive of a range of illnesses and not just aimed at HIV. Programmes should be holistic and include palliative care;
- Capacity building programmes should be provided to PLWHAs. This will provide them with essential skills and empower them to ensure that they can play a meaningful role in organisations which provide services to PLWHAs;
- Lobbying and advocacy for resources to support building the capacity of PLWHAs;
- HIV/AIDS awareness and education programmes should be provided to home/ community based carers and the community in order to ensure that the community has accurate knowledge about HIV/AIDS. This can be achieved through workshops or door-to-door campaigns. Programmes should be appropriately designed for the target audience; and
- An integrated programme should be in place whereby HIV/AIDS services work together to provide a cohesive, good quality, consistent and standardised service. Local authorities must drive HCBC programmes. Models such as CHAIN and CINDI are good examples of integrated and co-ordinated service provision in communities.

Group two – HCBC policies and management

There is inadequate support and resources for volunteers. The lack of transparency and accountability in resource allocation and use is an ongoing issue for effective HCBC. Stakeholders themselves need to be transparent and accountable. There is a gap in communication and a lack of effective co-ordination between partners, stakeholders, formal and informal caregiver services and government departments at national, provincial and local level. There is insufficient monitoring and evaluation. Structures and processes are needed to evaluate activities, partnerships and resources.

"Reinforcement of collaboration between services and modifying referral services, the need to train 'authorised officers' to assist welfare."

*She Rasebotsa, BaPhalaborwa
HIV/AIDS Awareness.*



Recommendations:

- PLWHAs and their families must be the central focus of all projects and programmes. Include PLWHAs in care but be sensitive to putting them at risk. PLWHAs need to be empowered to care for themselves;
- There need to be incentives for volunteers: the Social Development Department’s “Grant in Aid” needs to be looked into for volunteers;
- There needs to be a link to SAQA so that volunteer training is acknowledged and volunteers can be put on a career path;
- HCBC needs to be integrated into the formal health system;
- Provincial co-ordinators need to be put in place to monitor training, and monitoring and evaluation;
- Co-ordination between the activities of HCBC and DOTS for TB needs to improve;
- Networking should take place at all levels, and at local level this needs to happen with burial societies, stokvels, income generating projects and traditional support structures;
- Equal partnerships between local government and NGOs and CBOs need to be developed, with a commitment to participatory decision-making and transparency about constraints and availability of resources; and
- Ongoing monitoring and evaluation of the HCBC offered in all provinces is critical.

Group three – creating an enabling and empowering environment

There is a lack of enabling legislation, lack of communication, lack of resources, integration and co-ordination. Discrimination and stigma also creates a negative environment. Staff are overburdened. Generally, income generation projects are not sustainable, especially for HIV-positive people, and this reinforces economic imbalances.

Recommendations:

- Clear policy guidelines must be implemented, and should be user friendly;
- Guidelines need to be flexible and changed according to needs;
- Guidelines should be drawn up for grant makers;
- Research is needed to identify where scaling up needs to take place;
- There needs to be better accountability by organisations funded by government;
- Capacity building programmes need to be put in place, particularly in rural areas;
- There needs to be a formulated, coherent HCBC response which includes demanding better co-ordination between different line departments of government, and national, provincial and local government;
- There needs to be a proper strategy to include PLWHAs in the provision of HCBC;

“Care of the caregivers, nutrition, the importance of training, for example of traditional healers.”

Siwelani Moses, NGO.

- Equity in all our work needs to be encouraged;
- HCBC workers need to be involved in community mobilisation;
- Disclosure needs to be enforced;
- HIV/AIDS needs to be seen as part of primary health care, and treated like any other disease;
- There is a need for good networking structures at all levels – national, provincial and district;
- A database of HCBC workers needs to be developed;
- Increased monitoring needs to take place; and
- Improved communication is a priority.

Group four – socio-economic issues

Enormous levels of poverty in the country are the greatest obstacles to effective HCBC. Two major issues that HCBC workers face daily are the lack of food in households, and the problem of identity documents. This has enormous impact on the lives of adults and children.

HCBC workers are often faced with situations where PLWHAs and their families have no food. People look to the care workers for relief, especially in rural areas. An integrated response is necessary, which includes caregiver, traditional leaders and healers, FBOs, NGOs and CBOs, as well as PLWHAs. Effective structures for distribution and delivery of food and other services need to be established at local level to enable speedy delivery to needy families.

The pandemic has resulted in tens of thousands of orphans and child-headed households. Children are not only being left without an adult to look after them, but in dire poverty and without birth and death certificates. This leads to difficulties in accessing social grants and services, a situation which violates a number of rights – access to public funding, education, dignity, information and self-reliance.

An added problem is the practice of burying the deceased with their identity documents, and education around this practice is needed.

Recommendations:

- Child-headed families need to be assisted with accessing available resources and funding;
- CBOs need to engage with traditional leaders, local government and all government departments, particularly social services;
- There needs to be a review of policy relating to the issuing of birth certificates;
- There is a need to address the practice of burying the birth certificate with the deceased which makes it impossible to get grants;
- There is a need to involve PLWHAs in the management structures of NGOs, CBOs and NPOs, not as tokens but as decision makers;

"That more specific plans must be put in place for districts, that we need to learn what is really available, and strengthen networking."

*Esther Janse van Rensburg,
Department of Health.*



"Selection criteria of volunteers, intersectoral collaboration and ensuring that volunteers come from the community they serve."

Cindy Oseikle, Social Services.

- Business social responsibility budgets need to be linked to local government programmes in order to benefit local communities;
- The Department of Labour needs to be involved in sustainability programmes for PLWHAs ;
- There is a need for an integrated response in the management and distribution of food parcels, involving caregivers, traditional leaders and healers, FBOs and PLWHAs, with teams set up at local level in order to be able to respond rapidly;
- Children in distress (orphans) should be placed on a social grant programme from seven up to 18 years as they end up being heads of families;
- Communities need to be capacitated to prepare children for the death of parents; and
- There needs to be a scaling up of training and use of auxiliary social workers and community development workers.

Cross-cutting recommendations for Track A

- There is a need for a networking structure, at national and provincial level;
- Training and monitoring and evaluation are critical, and should take place at provincial level;
- The socio-economic conditions under which people are living are prohibitive to good health care, and measures need to be taken to change these conditions;
- There is a desperate need to remove the barriers caused by stigma and discrimination; and
- There is a need to get a better understanding of what is taking place in the ground before "scaling up" takes place.

Conclusion

There should be no conclusion to our endeavours to deal with the crisis we face in this country with the HIV/AIDS pandemic. It is up to each one of us at this conference to take forward the ideas and debates we have shared, and continue with our work, no matter how difficult it may be.

Acknowledgments (Track A)

Mr CP Lebeloe; chief facilitator Zed Tshabalala; facilitators and scribes; rapporteur team: Bobby Rodwell and Melody Emmett; all the participants that attended the group discussions in Track A.

2. Track B - Continuum of Care

Presented by Kath Defilippi

Introduction

The pivotal concept of a continuum of care has been incorporated in the HCBC Conference objectives, carried through in plenary and track presentations, and its components highlighted in five group discussions on the following themes:

- Referrals;
- TB/HIV care;
- A holistic approach to HCBC;
- Alternative/complementary therapy; and
- Palliative care.

The following two conference objectives related specifically to continuum of care:

- To strengthen networking structures and partnerships which impact on the scope and effectiveness of HCBC programmes and activities; and
- To explore national, provincial and local government and partner responses for a continuum of comprehensive care to successfully mitigate the impact of chronic diseases.

According to UNAIDS

“A continuum of care involves a network of resources and services that provides holistic and comprehensive support for the ill person and family caregivers. The goal is an affordable range of services in various setting, from home to community agencies and clinics, to hospitals and vice versa. Comprehensive care involves the provision of care, treatment, support and preventive services. Holistic care involves referral, follow-up, monitoring and case management.”

Many successful, concrete and practical implementations across a broad spectrum of programmes were shared during the track presentations, including programmes addressing poverty alleviation, orphans and vulnerable children as well as the integration of HIV/AIDS and the integrated hospice model of home based care.

Cross-cutting issues in the context of the Continuum of Care

The prominent and recurring issues can be clustered under the following themes:

- VCT as an entry point to care;
- Sustaining volunteers;
- Networking and referral, both vertically and horizontally, building partnerships which include traditional, cultural, religious, spiritual and medical role-players;
- Community involvement and empowerment in and through HCBC;

“Conduct training with traditional healers, continue to help needy PLWHAs to improve their quality of life using alternative therapies. Conduct research on alternative therapies that traditional healers are using, and formalise partnerships with relevant stakeholders.”

Mercy Mahci, Prometra.



- Integration of HIV/AIDS services;
- Advocating for transparency, accountability and clarity in policy implementation;
- An holistic approach to care that includes physical, emotional, social, spiritual, economic and human rights dimensions;
- Quality of care;
- Poverty alleviation and nutrition are essential to sustain the quality of life of the beneficiaries of HCBC;
- A continuum of care in the context of HCBC includes the identification and care of orphans and vulnerable children;
- The synergistic link between care and prevention;
- Including IEC as an integral element in HCBC;
- Incorporating a palliative care component into all HCBC training and care programmes, with the patient, family and micro community as the central focus;
- Monitoring and evaluation of management, care, resource allocation and training; and
- Accountability of service providers.

Lessons learned

- The need for the professional support of HCBC-givers;
- The value of strengthening and supporting emerging and existing projects;
- HCBC can only be effective with adequate human and material resources;
- HCBC must be equitable and accessible;
- Patient care records and data collection facilitate planning and effective management of programmes;
- Care of caregivers to prevent burnout;
- The support of orphans and vulnerable children forms part of HCBC;
- PLWHAs have a valuable contribution to make in the context of planning, training, care, monitoring and evaluation, but caution should be exercised to guard against risk associated with exposure to TB;
- Pain and symptom control are as important for PLWHAs as for people with cancer and other progressive illnesses;
- Closing the gap between hospital and home based care can only be achieved with an effective referral network;
- It is essential to link IEC to HCBC to promote positive living and enable families to cope. Respectful care reduces stigma and encourages disclosure of status;
- Home based palliative care is a powerful teaching tool;
- A partnership between HCBC and the formal sector is pivotal in ensuring quality care;
- Use existing community structures;
- Political will fast tracks implementation (Botswana experience);

- Facilitating a normal grief process promotes physical, mental and emotional health;
- Training must not be given in isolation. It must be followed up with supervision and further training. Audit findings should be used to identify and develop ongoing training needs;
- Support groups are a necessary dimension of HCBC; and
- Include networking as a budget item in funding applications.

Group discussions: specific outputs

Referrals

Formal and standardised referral forms that are accessible and user friendly are urgently needed to facilitate the necessary links between hospitals, clinics and HCBC. Mobile clinics could be used to facilitate referral in rural areas.

HIV/TB

The current low level of awareness about the relationship between TB and HIV together with lack of clarity regarding TB/HIV policy has led to inconsistent implementation across provinces. Tracing defaulters remains a challenge. TB care needs to be linked to nutritional support, advocacy and education.

Holistic care

This workshop emphasised the need to include economic, education and human rights considerations as part of holistic care.

Alternative/complementary therapy

Traditional healers are playing a significant role in HCBC. Their contribution needs to be recognised and there must be an exchange of knowledge between traditional and Western medicine. In addition to nurses and doctors, people from religious communities should be trained in the use of safe and simple remedies.

Palliative care

Palliative care is not only for the dying. It is an essential component across the entire continuum of care and it needs to be incorporated into the training of all doctors, nurses and community caregivers.

Recommendations

The list of recommendations that follows represents a synthesis of the key recommendations put forward by the Track B workshops, each of which focused on an element of the continuum of care. It is proposed that these recommendations are carried forward into the final recommendations of the conference:

- Best practice models of HCBC must be sustained and replicated;



- HIV/AIDS HCBC should be integrated with DOTS;
- Lobby for inter-departmental collaboration, enabling legislation and meaningful resource allocation for HCBC;
- Involve PLWHAs in activities relating to HCBC across the spectrum (planning, training, care, monitoring and evaluation);
- Build the capacity of credible NPOs to mentor emerging/struggling CBOs;
- Integrate palliative care as a component of the training of all health care workers;
- Introduce effective monitoring and evaluation of HCBC; and
- Facilitate integration between formal and informal partners, including traditional healers.

Conclusion

This conference has drawn together committed and dedicated individuals and organisations from a wide geographical and sectoral spread. It is clear from the issues raised that a great deal of consensus has been arrived at through the sharing of practical experiences, which are rooted in communities throughout the country. These experiences are evidence of the complex and devastating realities of HIV/AIDS in South Africa. It is our fervent hope and prayer that the potential for the meaningful and practical interpretation of the recommendations of this conference will be realised.

3. Track C - Partners for Care

Presented by Mercy Makhalemele

Introduction

Next month we will once again celebrate the Partnership Against AIDS, so it is timeous that we are here discussing one of the keys to the success of HCBC: Partners for Care. There has been a consensus for several years that partnerships are essential in our response to the HIV/AIDS epidemic, and there is certainly no disagreement that partnerships in the area of HCBC are equally important. However, what has emerged from our discussions over the last two days is that partnerships in this context need to be developed, nurtured and comprehensively managed if they are to have any meaningful impact on our work in the long-term.

Critical cross-cutting issues

A comment from one delegate in Thursday's plenary highlighted one of the key challenges to effective partnerships. Following presentations from two key government departments, in which the speakers both indicated that their respective departments were working closely together, the delegate noted the overlaps and duplication of the information in their presentations and questioned how well they were in fact communicating. This, in a nutshell, highlighted a problem that affects all sectors and efforts to develop and implement HCBC programmes – a lack of communication and information sharing between relevant stakeholders. Time and again in both plenary and small group discussions the issue of poor communication arose as a barrier to effective and sustainable implementation of HCBC. Clearly, to upscale our work, greater efforts are needed from us all in this regard.

From the plenary discussions and the various case studies that were presented during the day, it emerged that there are models for HCBC that are up and working, both in South Africa and the sub-Saharan region. These models are often holistic in their approach to caring for the infected and affected and creative in their efforts to build partnerships within the community and beyond. This reinforces the point that the wheel does not need to be reinvented when we talk about HCBC, rather a crucial task is to make people aware of the programmes in different sectors that are up and running successfully and to build on existing models wherever possible.

A recurring focus of discussions in this track was the need to care for caregivers themselves. Issues relating to conditions of service, counselling and support for volunteers, the meaningful participation of PLWHAs in HCBC, as well as the integration of men into service provision were raised on several occasions in both plenary and small group discussions. Psycho-social support for caregivers was highlighted as imperative to the sustainability of all HCBC programmes.

Strengthening linkages across sectors in the continuum of care was another issue continually emphasised. The multisectoral approach to HCBC has been talked about and in some areas of the country is being effectively implemented. Yet, there are still enormous gaps from national to community level, particularly around intersectoral referral systems – which are presently unco-ordinated and incoherent – knowledge



and sharing of existing resources, access to donor and government funding, and around policy and guidelines for management and cross-sectoral co-operation. A recurring recommendation from almost every small group discussion was the need for comprehensive and accessible national databases containing information about existing services and resources. Pooling resources is more economical and promotes a spirit of sharing and mutual support that is key to scaling up and sustaining our partnership work.

The multisectoral approach also implies the recognition and inclusion of traditional healers and traditional medicines in the care and support of the infected and affected. A key challenge noted in both case study, plenary and small group discussion is the need to reinforce traditional healers as partners in the continuum of care, building on the relationships that have been developed thus far, and standardising training and registration procedures. Recognising the vital role that traditional healers play in the health and well being of millions of South Africans will reinforce their role as partners in care and their effective participation in HCBC service delivery.

The prevalence of stigma and discrimination both in the community and the workplace is an issue that needs to be addressed on a daily basis in our work. In both plenary and small group discussions the role that stigma plays in limiting the potential for effective partnerships for HCBC at different levels and across sectors was raised.

Scaling up HCBC requires the promotion of the work as an integral part of our response to the epidemic at all levels and across all sectors. Too often the emphasis of debate and discussion, as well as active policy implementation, is on other aspects of treatment or support. At this conference delegates are clearly calling for HCBC to be acknowledged and practically integrated as a fundamental pillar in our struggle against HIV/AIDS.

Specific issues and recommendations from small groups

FBOs, CBOs and NGOs

The commitment and compassion of individuals within these organisations came through strongly in the discussions. However, a key challenge for organisations within this sector is to overcome the dangerous and debilitating rivalries and competition for resources that undermine the fundamental work of HCBC.

Recommendations:

- Fair sharing of financial resources for HCBC service providers needs to be addressed in a more co-ordinated manner;
- A policy on the management of HCBC volunteers/caregivers needs to be developed; and
- More funding specifically for training and retraining of volunteers should be made available.

Mentoring

It is clear that few NGOs have the capacity to mentor and mentoring is carried out unevenly. New organisations are mushrooming across the country, but lack the capacity to deliver effective services or to sustain their work in the long-term.

Recommendations:

- Mentoring must take place at all levels and cross-sectorally in HCBC;
- National guidelines around mentoring must be developed and made available as a matter of urgency. There is a need for best practice mentoring models in the development of these guidelines; and
- A system to deal with issues of malpractice needs to be put in place.

Volunteers

Volunteers are vital to the success of HCBC, but currently they lack support in almost all areas of their work. Volunteer services related to HCBC are fragmented and, although policy guidelines around care exist, there is little to support the co-ordinated management of volunteers.

Recommendations:

- Financial incentives in the form of standardised stipends for all caregivers must be considered a high priority;
- Promoting the involvement of HIV-positive men as caregivers should be given more attention; and
- The development and implementation of a comprehensive management policy around volunteers is essential and a matter of urgency. This policy would help give clarity on such issues as remuneration, care and support for caregivers, supervision of volunteers, recruitment and selection criteria, and integration of volunteers across programmes (eg TB/DOTS), amongst others.

Traditional healers

The mistrust, misconceptions and power struggles that dominate the relationships between traditional healers and other relevant stakeholders have to be seriously tackled in order for traditional healers to take their rightful place as partners in care. Many millions of South Africans consult traditional healers daily yet their services remain complementary to mainstream medical practice.

Recommendations:

- Traditional healers must define their roles in the community to become more visible partners in care;
- Traditional medicines should be recognised and registered for use in treatment in the HCBC setting;
- Traditional healing and medicine should be promoted as an integrated part of



community health care so that communities become aware of its role in HCBC and in HIV/AIDS work in general; and

- DoH must actively involve traditional healers in care and treatment and develop training manuals for traditional healers around HCBC.

Government departments

Presently, Health, Social Development and Education are the key government partners in HCBC. There is acknowledgement of the need to bring other key departments on board, including Housing, Agriculture and Home Affairs. Policy and infrastructure to guide HCBC at intersectoral level are in place but in many cases the poor quality of implementation is impacting negatively on efforts to upscale the work.

Recommendations:

- Unpack the core business of each role-player, particularly in the intersectoral task team;
- Appoint a national co-ordinator at director level to eliminate fragmentation and enforce integration of services and interdepartmental co-operation and coherence;
- Ensure that provincial treasuries are on board as key role-players to enhance financial coherence and accountability;
- Directors general must ensure buy-in to HCBC from politicians; and
- Work to broaden the role of PLWHAs in HCBC service provision.

Private sector

HCBC programmes dominate in a single industry – mining – and in provinces where the industry is strongest. Several pilot programmes are being run that embrace HCBC, but serious ethical issues relating to employee benefits, repatriation and sustainable follow-up care in the home community are pressing.

These are exacerbated by the lack of communication and in some cases the antagonism between the private sector and other stakeholders. Relationships must be extended beyond the gates of the employer if HCBC is to be enhanced and quality of life for the infected employee is to be guaranteed.

Recommendations:

- Broaden efforts to extend HCBC further into the private sector;
- Structure efficient referral systems to include employers, public health service and communities;
- Formalise and improve relationships between private sector, health system and community;
- Restructure benefits and repatriation packages to include HCBC in communities to which workers are returning;

- Reduce stigma around disclosure by involving more openly PLWHAs in policy making and implementation of programmes; and
- Increase emphasis on income support groups and counselling.

Conclusions

There are no quick solutions to the challenges that have been raised in our discussions. Our recommendations require immediate action if they are to be meaningful for our work and for those we serve. There is an acknowledgement that if we are to achieve the goal of scaling up HCBC, we must come together, pool our many strengths, value and nurture our existing partnerships and seize the opportunities to develop new ones wherever possible.



4. Track D - Living Positively

Presented by Criselda Kananda

Introduction

The issue of living positively is sometimes focused solely on the personal welfare and physical well being of PLWHAs. When we talk about HCBC it is important to extend that dialogue to include the people who are affected, and this rightly includes caregivers and volunteers. We cannot honestly expect to upscale our efforts to implement and promote holistic HCBC without taking into account the personal growth at all levels of those who are daily exposed to the stresses of caring for ill or dying clients. Positive living is a human rights issue. It is unrealistic to expect people to disclose their status and work towards leading the fullest and most productive lives possible if their very existence is jeopardised by being open about their status. Ensuring basic human rights in HCBC service delivery involves acknowledging and acting upon the various challenges that arise.

Critical cross-cutting issues

Reflected in discussions and presentations were the issues of stigma and discrimination as fundamental barriers to positive living for PLWHAs, their families, caregivers and volunteers. The climate in both community and institutional service settings is still negatively impacted by fear, ignorance, prejudice and rejection of people associated with HIV/AIDS.

There is also recognition that caregivers and volunteers involved in HCBC services may themselves unwittingly be carriers of attitudes that contribute to stigma and discrimination. Caregivers are often the first point of contact for PLWHAs and their families, and are role models with respect to positive attitudes and practices. Thus, caregivers play a vital role in challenging stigma and discrimination, and need to ensure that they work on an ongoing basis to confront and deal with their own internalised negative attitudes.

There was general consensus in most group discussions that barriers associated with stigma must be addressed on an ongoing basis through public education and information campaigns, encouraging disclosure, self-exploration and the spirit of Ubuntu.

A second strand that emerged strongly was that caregivers and volunteers and the work that they do are often undervalued, overextended and invisible. This contributes to low morale, stress and burnout, as well as the exploitation and abuse of caregivers themselves. It was noted that in the HCBC setting, caregivers have to set boundaries, both personal and professional, in order to sustain their emotional, spiritual and physical well-being and that of the people they serve. Good self-esteem and ongoing personal growth of caregivers cannot be guaranteed unless they are valued and supported by other stakeholders involved in HCBC service delivery.

The need for co-ordinated and widespread support groups for caregivers, volunteers, PLWHAs and their families emerged in small group discussions. Support groups do

exist, but are not always well co-ordinated. They are vulnerable to collapse due to fears of discrimination and breaches of confidentiality. The common thread of lack of communication about existing resources again emerged in this regard.

Nutrition was a key theme in this track discussion and obviously impacts on the quality of life of the people for whom we care. Information on good nutrition is not widely accessible and is not usually integrated into HCBC service provision. This means that people living with HIV/AIDS are missing out on an important opportunity to maintain longer-term health through accessible and simple methods, thereby reducing the need for costly and regular drug interventions, particularly for treating opportunistic infections. For example, how many HIV-positive people are aware that by eliminating the intake of sugar they can greatly reduce the incidence of oral thrush?

The challenges to good nutrition practice posed by the endemic poverty experienced by many communities, and more so poor people infected or affected by HIV/AIDS, are enormous. Present nutrition initiatives tend to target the HIV-positive client, whereas it is often the entire family that is in need of nutritional assistance. Children in distress or orphaned by AIDS are particularly vulnerable in this respect and their plight was raised as an area of key priority for action. Lobbying for the extension of school feeding schemes to homes, the provision of child social grants to those over six years of age, the promotion of community or household food gardens and food stokvels were highlighted as ways we can begin to address hunger and poverty alleviation in general. More interdepartmental and intersectoral co-operation, with particular focus on the role of the Department of Agriculture in nutrition, was also noted as important.

The issue of disclosure has been touched upon in many discussions taking place at this conference. It is a sensitive and complex area that clearly requires more focused and ongoing attention and debate. Organisations and individuals who attended the small group discussion on disclosure supported the idea of disclosure as a healing mechanism, but agreed that an enabling and supportive environment was crucial for meaningful disclosure to take place. It was noted time and again that social prejudice and negative values, both in the community, home and work settings, remain the barriers to disclosure and that the prevailing mindset must be challenged to encourage more empathy and tolerance. This struggle remains one common to all sectors, but NGOs, CBOs and FBOs were targeted as organisations at the coalface that could best assist in creating enabling environments for disclosure.

The links between disclosure and positive living were highlighted, and it was agreed that a great deal more work needs to be done in and through the networks and institutions of community to educate people about the benefits of disclosure and the critical issues of tolerance, confidentiality and respect for the rights of others. Rural areas need more focus in this regard. It is again acknowledged that the successes of existing programmes should be more widely shared.

Conclusion

It is clear that challenges to positive living remain stumbling blocks to better co-ordinated and more holistic HCBC. Paramount are the problems of stigma and discrimination and it is acknowledged by many of us that we have as yet to tackle these problems in a meaningful way, in our communities, in our workplaces, in our



homes and sometimes in our own personal lives. The problem is not going to go away. Indeed it becomes more challenging the longer it is kept on the shelf. Making personal growth a reality for our clients and ourselves means that we must dig deep and find practical solutions to the barriers to disclosure, the nutritional needs of our clients and their families. Healthy living for those who provide and those who receive HCBC is a key to the long-term success of the work we do.

Support groups: recommendations:

- All support groups need to be co-ordinated with the local government liaison forum;
- A multisectoral forum is required to respond coherently to the activities of support groups to avoid duplication;
- Training and establishment of care and support structures for caregivers including debriefing, team building and peer support systems need to be scaled up;
- Breaches of confidentiality by professionals must be dealt with through proper implementation of the code of conduct and ongoing in-service training of all professionals;
- A co-ordinated database of support groups is needed; and
- A structured referral system must be established.

Disclosure: recommendations:

- Counselling services need to be intensified and ongoing;
- Issues of disclosure should be part of the education curriculum;
- Neglected groups including the aged and disabled should be targeted;
- Post-counselling services need to be more widespread;
- Youth need to be targeted;
- Infected and affected people should be encouraged to start support groups;
- Clinics must be men friendly;
- It should be emphasised that AIDS is a chronic illness and not a death sentence;
- Intensive family education and community education is needed, through motivational speeches in churches and other community centres;
- Attitudinal and disclosure education should happen in churches; and
- People should not be forced to disclose.

Nutrition: recommendations:

- Research on the role of nutrition is required;
- Food parcels must be made available to alleviate immediate problems of hunger during development of food gardens to promote independence and sustainable food security;

- Training for HCBC on food production techniques is required. HCBC kits should include starter seed packs;
- Further training is needed on nutritional counselling and techniques for traditional healers involved in HCBC;
- Nutrition provision should be integrated at all levels from planning to implementation;
- More advocacy is needed around nutrition in general;
- Department of Health should engage Department of Agriculture on the best way to integrate their services and expertise in the area of nutrition and HCBC;
- Use existing successful multisectoral initiatives as best practice models for duplication;
- Role played by interdepartmental and intersectoral committees in HCBC nutrition provision needs to be clarified and strengthened, particularly that of the Department of Agriculture; and
- Local authorities should take a lead in helping to clarify roles.

Personal growth: recommendations:

- Public health supervisors need to be respectful of the role of HCBC providers. A multisectoral approach must boost the contribution of everyone involved in care giving;
- There is an urgent need to provide value-added services to caregivers through good management, good quality training, good support and fair remuneration (in money or in kind – such as food);
- Addressing stigma through collective multisectoral efforts is a high priority. Stigma should be challenged in a sensitive and constructive manner as it happens. Like-minded people must join together to support positive attitudes and challenge those that undermine our work. We need to make the most of environments and events that promote HCBC and the role of caregivers, while highlighting the challenges that arise from stigma and discrimination;
- The spirit of Ubuntu must be encouraged and stronger, more meaningful relationships built between carers and clients;
- Capacity building efforts must be driven by clear and implementable policy and guidelines;
- Management support is needed to ensure that existing guidelines are followed; and
- Policy should be driven through AIDS Councils.



5. Launch of Home/Community Based Care Kits

What are the kits?

The kits are sturdy black cases containing equipment for both professional and informal home care workers. They were developed to help meet the growing call for appropriate equipment to support and expand HCBC, and as a tool to help facilitate the delivery of services, qualitative discharge strategies and referral mechanisms. The kits were launched at the HCBC Conference.

How were they developed?

A World Health Organisation template for HCBC kits was supplied to provincial HCBC co-ordinators and caregivers for comment, and from this, a list of contents was devised. The supply of the kits was put out to tender and 1 430 were manufactured in the first phase.

"These kits will enable provinces to ensure that supplies are available for ongoing services and that the HCBC programme can be implemented much sooner. It is my honour to hand these kits over to the nine provincial representatives on behalf of the Minister of Health. I applaud these courageous men and women who have been the torch-bearers in the provision of HCBC services without any kits. Although they have been exposed to all levels of risk and sacrifice, their dedication made it possible for these services to be provided. We are positive that the provision of these kits will ease their work and assist in the provision of a holistic quality care and support service."

*Dr Molefe Sefularo,
Official launch of Home Based Care Kits,
20 September 2002.*

Kit contents

Informal HCBC Kit

Gentian violet, multivitamin syrup, calamine lotion, PVC washable apron, gauze swabs 100 x 100, cotton wool, gauze bandage, skin antiseptic with dispenser, surgical gloves, aqueous cream, clinical thermometer, Rehydrate, Povodine Iodine cream, plaster adhesive, plastic soap box and lid, ball pens, umbrella, Ensure, soap cake, bleach bottle, linen savers, surgical scissors, hand torch, paper towel, kidney dish and disposable razor.

Professional HCBC Kit

Gentian violet, Paracetamol 500mg tabs, Paracetamol Suspension, Acetylsalicylic acid tabs 300mg, Ferrous Salt, folic acid 5mg, ascorbic acid (Vit C) tabs 100mg, multivitamin syrup, calamine lotion, PVC washable apron, gauze swabs 100x100,

cotton wool, gauze bandage, skin antiseptic with dispenser, surgical gloves, aqueous cream, clinical thermometer, Daktarin oral gel tube, Rehydrate, Povodine Iodine cream, plaster adhesive, plastic soap box and lid, ball pens, umbrella, Ensure, soap cake, bleach bottle, linen savers, surgical scissors, hand torch, paper towel, kidney dish and disposable razor.

Where are they available?

The National DoH will be supplying the kits to provincial HCBC co-ordinators and within a month of their launch had supplied 168 kits to Limpopo province, 68 to Gauteng and 25 to KwaZulu-Natal. It is suggested that provinces distribute kits to sites where training has been conducted so that minimum standards of care are in place. Sites also have the potential to inform the process of developing referral mechanisms, for example the development of patient discharge forms. They should also be able to meet monitoring and evaluation requirements by reporting on, for example, number of beneficiaries, number of home visits conducted and number of caregivers employed.



6. Presentation summaries

Opening Ceremony:

Welcome and Opening: Executive Mayor of Bonjanala

By 2010, six million people will die of AIDS. This is having a devastating effect on the poor of the country and affects people at five levels: as individuals, families, children, communities and the country. Individuals, who are diagnosed, lose hope of ever being cured. Some go through stages of anger, which make them lash out and deliberately infect others. Others go through denial. Families are traumatised by their loved ones' infection and impending death. They also go through stages of denial and anger, which can lead to rejection of the infected. Handled correctly, the family can serve as a valuable system and help in providing quality care for the patient. Children of the infected are faced with dealing with their parents' disease, losing their only source of income and care and further suffering as orphans. Communities are faced with "picking up the pieces", especially if there are many orphans who do not have extended families. Our country has to deal with the serious impact of the breakdown of the economy due to the burden of welfare provision and shortage of a skilled labour force. To deal with this devastating situation, government together with home caregivers need to share experiences. This will stimulate research and find ways of dealing with the problem. Use this conference to share your experiences, to the benefit of all South Africans.

Context and Partners for Care: if only: Dr Sandra Anderson, UNAIDS

Dr Anderson's presentation focused on the theme, "If only we knew then, 10 years ago, what we knew now, we would have." Over the decade we have learned that we should have spoken openly to counteract denial, spoken to children and youth about staying safe from disease, worked harder and with more partners, insisted that prevention and care are bound together, developed interventions to reduce stigma and decrease shame, and taught nursing and medical students how to protect themselves, counsel patients and families and show compassion. Senegal, Thailand and Uganda are the known success stories of the epidemic; Brazil has cut mortality by 30% and leads the world in comprehensive care; South Africa and Zambia are showing success with youth. Young people are a critical population for success: they are disproportionately affected by the epidemic and the future depends on their sustaining behaviour changes. There have been several significant global events on HIV/AIDS in recent months, including the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in June 2002, and the Global Fund to Fight AIDS, TB and Malaria. UNGASS targets include making treatment and care for people with HIV/AIDS as fundamental to the AIDS response as is prevention. The paradigm in global thinking on HIV/AIDS has shifted. Access to care is now considered a basic necessity, including home based and palliative care, treatment and ARVs. Proven approaches to HIV prevention have been identified, but the epidemic is at an early stage and its long-term evolution is unclear. Many myths around this evolution have been exploded, including that prevalence will stabilise at some natural limit. Care is the greatest challenge, and voluntary counselling and testing is the point where prevention and care can meet. VCT is a proven prevention strategy, and an essential component of programmes in low and high-income countries. It is the gateway to care services, but

staff requirements should not be underestimated. PMTCT should help HIV-negative women remain so, prevent unwanted pregnancies and prevent transmission from mother to child. Severe HIV/AIDS care is still widespread: VCT is not available or accessed, fear and stigma prevent them seeking help, drug prices exceed budgets and health systems and workers are ill-prepared and ill-equipped to cope. Over the decade we have learned that parents without care die sooner, stigma in health care settings is the worst faced by PLWHAs, better youth-friendly services are needed, and the gap between knowing and doing is greater than we had thought.

Maria Ndlovu: Personal Account

I am part of the community. In my language I have long forgotten to talk about them. We are part of society, part of the community. HIV and AIDS does not mean death, therefore my slogan means HOPE IS VITAL. Home based care is to give dignity, to give love. My story goes that in 1996 I was staying in Pretoria with my child of five. I had just had a traumatic divorce and was dealing with that trauma. One night a man came to my place and asked for someone called Anna. I realised he had a different agenda. He was very strong. I tried to fight but I did not think I could. My child was sleeping on the couch, so I decided to go through it with as little noise as possible. I knew I was negative before the rape. I held onto the hope that I would not be infected but it didn't work like that. I also realised that keeping quiet about things that matter makes you suffer more than you need to. Talking out for me now is therapeutic. I had to learn to walk and see the shadow of death and say, "We will walk together." I have to learn to talk to my virus and say, "I was here before you came; we have to learn to live together." Martin Luther King says, "When you think of what to do, think of what is right and as long as it is right, do it. There is no time. And there is no reason to wait for anybody." HIV – HOPE IS VITAL.

Plenaries:

Current HIV/AIDS Situation in South Africa: Dr Rose Malumba, Director: National AIDS Directorate, Department of Health

Dr Malumba addressed the current situation in South and sub-Saharan Africa, and the focus areas and work to date of the National Department of Health (DoH). The DoH has adopted a multi-pronged approach HIV/AIDS prevention strategy, including IEC, and a good protocol for STIs. Programmes have had some positive impact: statistics for the period 1998 to 2000 show that the epidemic in SA is slowing and Eastern Europe and Russia now lead in new infections. However, a more aggressive VCT campaign is required particularly targeting people over 20. Tuberculosis remains the primary killer related to AIDS. More severe forms of TB have emerged and, although TB interventions are in place, more co-ordinated interventions are needed. She noted that HCBC givers can make a huge difference where TB interventions are concerned, and that NGOs and CBOs working in the area of HCBC need to upscale education around TB treatment. Dr Malumba stressed that good infrastructures exist for HCBC, including Cabinet's conditional grants to provinces for co-ordination and support, as well as guidelines for care and support. But while structures are in place to drive HCBC initiatives, the weak link between government and civil society is a fundamental problem. It is essential that roleplayers make the most of partnerships in the provision of HCBC.



Cabinet Mandate: National Multisectoral response to HIV/AIDS with specific reference to home/community based care and support: Cornelius Lebeloe, Care and Support Sub-Directorate, Department of Health

Mr Lebeloe stressed the importance of a multisectoral approach to home based care. The Departments of Health and Social Development are the torch-bearers of the initiative and working as a collective will ensure successful scaling up. There are 464 HCBC programmes benefiting 362 000 people across the country, with at least 8 000 caregivers trained to date. Government is a strategic partner, and it is important to focus on real, rather than perceived local needs. Government support should also not encourage dependency, and district and local level programmes must be developed to share and not duplicate resources. Sustaining and scaling up the process that government has kickstarted is a key issue. Part of the solution, he suggested, is better documentation and co-ordination, so as to support sustainable multisectoral interventions.

Holistic partnership development in care: Dr Maria Mabetoa, Director, National Department of Social Development

Dr Mabetoa spoke of the multi-dimensional impact of HIV/AIDS and the tendency to neglect the emotional and spiritual effects of the epidemic on infected and affected individuals, particularly children. She called for a holistic approach, where one programme addresses connected needs. Intersectoral collaboration avoids fragmentation and supports the maintenance of partnerships in the field, she said. Interdepartmental co-operation has improved considerably since 1999, but roles still need to be defined so that role-players understand responsibilities, accountabilities and how they can support each other more effectively. Integrated planning is a pre-requisite. HCBC is the best model because it brings all stakeholders together and understands the impact on an individual impact from within the context of the community. "Nobody works better than those directly affected. We need to make sure that the World Aids Day slogan 'Live and Let Live' is made a reality."

Implementing and scaling up of HCBC – Dr Ndiki Ngongo, consultant, Botswana

Dr Ngongo gave an historical perspective of the evolution of HCBC strategies in the sub-Saharan African region, including examples from Zambia, Uganda and Zimbabwe. She noted that in the early 1990s, the international emphasis was on IEC but sub-Saharan African communities were in the firing line of the epidemic and were forced to create strategies for care from no guidelines or modules. Communities experienced the evolution of HCBC out of necessity and could not wait for policies to be developed. Scaling up HCBC components of service cannot be an "exercise in patchwork" but must be a package deal. Hospitals, for example, do not see themselves as important in the continuum of care but the burden of care cannot be reduced if clinical intervention is weak. For example, counselling and education cannot substitute proper medical intervention. Linkages, alliances and partnerships should be incorporated into discharge planning to ensure good follow-up. Carers are a resource and should be empowered through creating standards around conditions of employment, training and capacity building. Carers also need to access counselling.

Other issues touched on were the need for gender balance in the provision of HCBC and the need to improve access to pain alleviation outside of the institutional setting.

VCT: Gateway to continuum of care and support and prevention: Dr Catherine Sozi, UNAIDS

Dr Sozi drew on her personal experience of taking an HIV test and the stresses related to this process. She highlighted the synergy of testing and counselling as vital to prevention and care strategies. In the counselling setting, the confidential dialogue between carer and client must empower the client to deal with the challenges of a positive or negative test result. Knowing one's status is a motivating force and allows one to plan for oneself and dependants. She challenged delegates to consider their own positions on testing, and suggested that it was likely that the majority of delegates in attendance did not know their own status. As carers, she said, we must be able to define our personal commitment in the context of our own personal experience. VCT is an entry point for HIV/TB care and treatment, and is most successful if provided in walk-in clinics in accessible urban centres, and if the process is rapid. However, the more people are tested, the more positive results there will be, and the impact of this stress on counsellors needs to be addressed. Non-health care counsellors such as volunteers and PLWHAs need to be involved as they have an important role to play in support services. Stigma is a major challenge as it makes people reluctant to access support groups, or use available services. At times health care workers themselves are guilty of perpetuating some of the most extreme forms of discrimination against PLWHAs, such as the denial of pain relief, the breaching of confidentiality and abuses of basic care requirements.

The role of civil society in community-based care – the impact of culture and gender: M Masala, ANC Women's League

Civil society is the structure where individuals interact as a group, and in which cultural and religious beliefs are expressed to meet an individual's spiritual and emotional needs. In the context of home based care, civil society needs to be seen as one structure for the good of the individual and for the common good. The struggle against HIV/AIDS is comparable to the struggle for democracy in South Africa – for dignity, equal wages, safety and health. Denial and stigma mean more education is needed about HIV/AIDS. As a community health nurse I try to educate individuals and communities to look after their health. People need to be trained to nurse people living with HIV/AIDS at home. When I trained as a nurse, we were not taught to share our knowledge. We would go out in our white uniforms and nurse people at home, wash them and do everything for them, but not involve the family. Now I train women, men and youth in the Western Cape. Training takes one week and covers all diseases, not only HIV/AIDS, including how to deal with stress. We need to teach people about nutrition. If people don't have food, they don't take their medication. As home based caregivers, we need to go back and check. It is no good giving instructions and teaching people and then forgetting about them. We need to strengthen partnerships within our communities and with other groups doing home based care. The Networking AIDS Community of South Africa and the ANC Women's League are working at this in the Western Cape.



Comprehensive care in the home environment: the Botswana experience: Barbara Mudanga, Ministry of Health, Botswana

Botswana's population is approximately one million¹: There were about 8 000 patients registered for CHBC by 2001, 65 000 orphans by 2000, and by 2002 it is estimated that the cumulative number of deaths will be 103 651. Botswana's national policy and AIDS programme were set up immediately after the first diagnosis in 1985. Government adopted a strategy for home based care in 1996. This includes **Nursing care** (provided by government officers, NGOs and CBOs); **Health education**; **Counselling services** (professionals and volunteers); **ARV provision** – four sites have been established; **Material supplies** such as gloves, aprons, bedpans, disposable napkins, blankets and school uniforms for orphans; **Nutrition** – food baskets for patients and orphans are provided by the Social Development Department; **Information, Education and Communication (IEC)**; **Capacity building** – professionals have been trained as trainers in all districts; volunteers and caregivers have been trained at community level; **Networking** is strengthened through consultative workshops, study tours, regional open days and a SADC regional CHBC conference; **Referral** tools have been developed through collaborative meetings of hospitals and community care providers; **Community mobilisation** through workshops held in all districts and organised through multisectoral structures at national, district and village level. An enabling environment for CHBC incorporates active participation, political support, technical support from professionals, and financial support. Complementary services such as hospices and day care centres play a critical role in ensuring quality of care and a **Monitoring and Evaluation** system is being developed. **Challenges**: The multisectoral response and referral system is not fully developed; 47% of households live below the poverty line and struggle with the household burden of care. Care providers burn out and the epidemic is still spreading. There are transport and staff shortages, stigmatisation and bureaucracy hamper provision of social support and suitable incentives for volunteers remain an issue.

Palliative care at home: Kath Defilippi, National Director, South Coast Hospice

Palliative care is the “**active, total care of patients whose disease is no longer responsive to curative treatment.**” Palliative care is essentially holistic. Sensitivity to the psycho-social, spiritual and emotional needs of the patient and his/her family, as well as the control of pain and other symptoms, is paramount. Palliative care is present throughout the continuum of care. During voluntary counselling and testing people need the kind of emotional support that is characteristic of palliative care. As the disease progresses, other elements of palliative care, such as pain control, become important. As death approaches, a patient is enabled to prepare for death. Palliative care continues beyond death to bereavement counselling. The patient and his/her family are the central focus of palliative care, although the contribution of the micro community and other partners is significant. Home based palliative care should be supported by partnerships with health care institutions, volunteers and support groups, NGOs/CBOs, institutions for social welfare services, parastatals, the private sector, communities, and traditional health support systems.

¹ UNAIDS Botswana Epidemiological Fact Sheet, 2002 Update, estimates the total population to be 1,554 million.

Effective palliative care needs human and material resources. Well-trained community caregivers must be backed up by professional supervision and supported by a good referral network and partnerships with other service providers. Training needs to be participatory and holistic, so that people can draw on their own experiences. Trained people need ongoing support, and regular audits are essential to ensure that care is cost-effective, ethical and well managed. In sub-Saharan Africa, palliative care is broadened to include poverty alleviation, prevention and the care of orphans.

The role of traditional healers in the provision of care and support: Merci Manci, co-founder, Promoting Traditional Medicine and Empowering Traditional Healers in their Secondary Role as Agents of Change (PROMETRA)

In South Africa, 85% of people consult traditional healers for social, economic, cultural and health related problems. There are approximately 600 000 traditional healers in SA. PROMETRA offers training to develop the capacity of traditional healers to manage care and support of the terminally ill using a holistic approach; this includes counselling, treating the physical condition and spiritual healing by connecting the ill person to the clan and to nature. An application has been made to SAQA to have PROMETRA training registered. PROMETRA conducted research at its Senegal laboratories into the efficacy of five plants from different countries, including South Africa, for treating HIV/AIDS. Two hundred patients were tested before treatment with the traditional medicines; daily treatment records were kept and patients monitored. The results of post-treatment testing showed: the CD4 count was stimulated in varied proportions in each patient; a recorded 66% lowering of the viral load; a 90% success rate in the treatment of opportunistic infections. Many of the patients experienced pain relief and were able to go back to normal working life.

Traditional healers need leadership, organisational, social and economic support. They need to be understood, recognised and respected for their contribution. Leadership structures such as PROMETRA need recognition, partnerships and financial support.

Traditional healers: their role in provision of care and support: Joseph Tenywa, Traditional and Medical Health Practitioners Together against AIDS (THETA)

THETA is a Kampala-based organisation working with traditional healers and established in 1992, when Uganda was experiencing the full impact of the HIV epidemic. THETA was started by medical doctors whose HIV patients were using herbal medicines before and after hospital visits and reporting that herbal medicines helped treat opportunistic infections. The doctors ran a medical trial to test these claims and found that the herbal medicines tested did improve appetite, chronic diarrhoea and treat skin infections, especially herpes zoster. The doctors remained concerned about negative practices used by traditional healers that could potentially increase rates of infection, such as scarification (skin piercing), sex with female patients and blood-letting. In 1994, a pilot project was set up with 10 traditional healers to provide basic information on HIV/AIDS and STI care, awareness training and counselling, and to promote the concept of peer education. More than 800 traditional healers have been exposed to this project. Once equipped with relevant knowledge they have proved effective agents of change. THETA also: advocates for



traditional medicines in the treatment of HIV/AIDS-related illness; conducts clinical studies on herbal medicines; develops standards around the use of herbal medicines in partnership with government departments; developed a home based care handbook for traditional healers; and provides healers with referral forms, so patients they cannot manage are referred to a nearby public health facility. Many traditional healers have formed home based care groups or cells and conduct home visits in groups. THETA has provided material support to them, initiating schemes to care for orphaned children.

The Employment Bureau of Africa Limited (TEBA), Tumi Malepe

TEBA Ltd was the recruitment arm of the mining industry but the mining summit of 1999 redefined its role and it now operates as the development agency for the mining industry. TEBA runs a HCBC initiative to assist HIV-infected mineworkers after they are repatriated to their homes. Guiding principles of the programme include the importance of partnerships between mines, families and communities, counselling services, adequate repatriation notice, confidentiality, support for the family and palliative care. Stakeholders who co-operate in the programme include trade unions, mining companies and government. It targets four key areas: Northern KZN, Gaza Province in Mozambique, Eastern Cape and Lesotho, and will be extended to all regions from which mine labour is drawn. The programme funds training of caregivers and home based care kits, and may be extended to children who are vulnerable or in distress. TEBA provides ongoing management including the appointment of HBC co-ordinators, training of field workers and community volunteers. Medical notification of HIV/AIDS usually comes at a very late stage; most families are unaware of the status of the infected miner and need support and counselling to deal with the long-term consequences. The service is highly appreciated by families and communities, but needs improved co-ordination and strategies for intersectoral co-operation. TEBA is also one way of consolidating the participation of males in HCBC.

7. Case studies

Track A

A method for evaluating AIDS Home Based Care Programmes – Dr Eric Buch, University of Pretoria

The presentation focused on the need to develop a method of evaluation that is fair and transparent, swift, suitable for field staff with other responsibilities, and has realistic expectations. The approach is to develop a tool for monitoring and evaluation of HBC, initially to be used by the Gauteng Health Department, but to be developed into a suitable tool to use nationally. The objective is to design a rapid participatory appraisal tool. The tool looks at both management and costs with quality of care as the base. The approach is a three-day, step-by-step evaluation procedure that highlights Expectations from Service, Findings and Appraisals, Participatory Understanding, and Proposed and Agreed Actions. In Evaluating Management it considers governance, planning, resources, training, management systems, services and local collaboration, by using interviews, document reviews and observation. In Evaluating Quality it uses quality sheets, record reviews and observation. In Evaluating Cost it utilises pre-formatted Excel spreadsheets that consider expenditure and proportion on salaries, supplies, etc. It then looks at how to interpret Challenges and the Capacity to Evaluate. The primary purpose of the evaluation is that it should support the project/organisational growth through a transparent participatory process, which develops management capacity, value and quality. The main points are that emerging organisations should not be suffocated; management and quality should be developed; evaluations should be done as partnerships, not criticisms; and evaluation must be integral to overall project cycle.

An audit of the HBC training and services in the Limpopo province: Ruth Kekana, Joyce Mashamba, Dept of Health Promotion, University of the North, Limpopo province

The audit covers a range of statistics, geographical area of Limpopo, and the terms of reference. The perceived weaknesses are: lack of funds to assist home based caregivers; inadequate HBC kits; lack of standardised HBC training; need for funding to build capacity among NGOs and CBOs dealing with HCBC; need to expose HCBC workers to health care settings within the province. The services face limitations in that: several organisations emerged because resources to fund HBC were available, but did not actually provide the service; perceptions of HBC vary because it has many aspects; lines of communication are poor between project members in the health department and service providers. The team recommends that: training for community HBC be standardised; well defined referral systems be put in place; capacity be built so that the availability of HBC can be developed; incentives be given to HBC workers, and funding be made available for them. The audit led to the production of a comprehensive directory of HBC organisations operating in the Limpopo province, but highlighted that co-ordination mechanisms need to be put in place for agencies working in the area of HBC, and interaction between organisations needs to be enhanced.



Home based care in the Free State – a situational analysis: Dr G Louwagie

The case study examines geographic areas, demographics, mortality and morbidity profiles to gain a better understanding of HBC needs in the Free State province. This includes overall mortality, cancer and AIDS mortality, geographical distribution of mortality and disabilities and chronic diseases. The case study also looks at existing HBC structures, support systems and human resources, health facilities and referral systems, step-down facilities and intersectoral collaboration. The incidence of HIV/AIDS is examined in detail, noting that the area most affected is Welkom. Details of various diseases in the areas, the incidence of orphaned children, and the resources needed to deal with the situation in each region are given. Achievements highlighted are that there is a genuine attempt at intersectoral collaboration between social welfare, health, education, NGOs and communities; that there is massive community support for HBC, large numbers of trained carers and clients receiving care and that support structures and staff in place or in process of being addressed. Challenges remaining include the fact that communication and co-ordination remain complex, that AIDS and debilitating conditions are not prioritised, that HBC needs to be integrated with HIV/AIDS care programmes, volunteer groups need to be co-ordinated, and M and E instruments need to be standardised. Other issues include dealing with the patient flow, labour relations and community demands for stipends for volunteers.

Gauteng mining town pilot of home and community based care – The Percy Mabote Memorial Care Programme/CHBC

This programme successfully developed and piloted the home and community based care model in Gauteng, and is recognised as a best practice model, used as a benchmark by other organisations. The case study outlines the project's key challenges around management, palliative care, orphan care and income generation. Detail is provided on programmes regarding Palliative Care, Support Groups, Income Generation and Poverty Alleviation, Heartbeat Centre, Orphan Care including its research findings indicating categories of orphans, Community Child Care Communities and Services provided to orphans and care achievements and Advocacy. In general the organisation has managed to build capacity, internally and in the community, and involve three government departments, local government, business and civil society. From here it needs to complete the centralisation of its management, finalise corporate governance issues, secure funding and expand into the local area, province, country and region. From project experience it recommends a development review of HIV/AIDS partnerships between government departments, NGOs and business, a process of intensifying capacity building of home and community based care organisations, appointment of skilled staff to develop and manage projects, to redefine "volunteerism" and to integrate poverty alleviation into HCBC projects.

Track B

Collaborating to provide palliative care in resource poor settings using the Integrated Community Home Based Care (IHC) Model: Mabyi Mnguni, Deputy Director, South Coast Hospice

Mabyi Mnguni manages the hospice's community outreach programme, developed in response to the epidemic already visible in KwaZulu-Natal from 1994. Hospitals could not cope with admissions. The South Coast Hospice in collaboration with local hospitals and primary health care clinics developed the Integrated Community Home Based Care (IHC) Model. The Model has been documented and successfully piloted by the Hospice Association of South Africa (HASA) via the University of Natal and the National Department of Health tender. It relies on collaboration and networking between a multi-professional team, hospitals, clinics, CBOs/NGOs and community volunteer services. Hospitals provide back-up medication, support to caregivers, and the security of beds kept in reserve in case they are required. A hospital-based professional nurse liaises between the hospital and the hospice. Interim care is provided through hospice-sponsored professional nurses specialising in palliative care in local clinics, and an in-patient unit at the hospice. The Networking Action Group (NAG) convenes at the hospice monthly to review action around welfare, HIV/AIDS and cluster homes action. Volunteers are supported by primary health care nurses in clinics as well as by the hospice-based health team. At the hospice, three professional nurses plan care with families, and in most cases offer bereavement counselling after a patient dies. A programme highlight is the children's team, and a "Memory Box" project has proved to be very effective for children.

The Pilot Project – two years later: Lettie Schoombie: Home Based Care Pilot Project, Klerksdorp.

The North West province has a population of 500 000, of which an estimated 36% have AIDS or AIDS-related illnesses. The pilot project is managed by Lifeline in Klerksdorp, and is accountable to a multisectoral steering committee mentored by the Social Services Department. The project developed out of a meeting held at Tshepong Hospital in August 2000, between representatives from the Departments of Social Services, Education and Health, nurses, NGOs and CBOs, members of the community and local media. The project supports 171 families or 1 000 people, identified with the assistance of clinics, community organisations, and Department of Social Services social workers on the basis of income or numbers of family members infected. One social worker processes applications; others focus on the caseload supported by a team of caregivers, one third of them males, trained in basic HBC skills, HIV information and general counselling skills. The project provides monthly family support grants of R350, spent on groceries through a voucher system with Shoprite Checkers, and R100 cash for fresh foods and transport costs. Beneficiaries show till slips to ensure money is spent appropriately. Accessible project offices and good management and administration have facilitated work. There is ongoing monitoring and networking. Challenges: funds pledged have not been received and the project has become unsustainable. Only 55 families have been able to access other government grants. Poverty alleviation projects are not effective. There is a growing perception amongst poor people that it is better to be HIV-positive and eligible for government support. The need for life skills training for people who are not used to managing money was underestimated. It is critical to liaise with other HBC projects to avoid duplicating services to one family.



The Thembalabantwana model of the Cape Town Welfare Society: an exploration of an OVC strategy within the ambit of community based care: Sian Hasewinkel and Nomsa Sometsewu, Thembalabantwana, Guguletu, Western Cape

Thembalabantwana is an 18-month pilot programme in Guguletu, Cape Town. The project has three dimensions: the protection placement, support and supervision of vulnerable children; support strategies such as a soup kitchen, parenting workshops, behaviour modification programmes for out-of-control children, educare facilities for clients, volunteers and participants in job skills programmes, and respite care; and a job skills programme, which includes food gardening, baking, bead making and domestic training. Volunteers were selected and recruited in consultation with community structures for four months of training in areas such as child abuse, neglect, family violence, the court system, the Child Care Act, foster care, safe homes, HIV, children's rights and first aid. Volunteers take responsibility for running an intake service which can respond to crises within 24 hours of referral, and for managing a caseload. This covers a range of tasks from investigating maintenance requests to supervising and assisting child-headed households. Most cases are community referrals and at least 40% are HIV-related. The most common problem is relatives struggling to rear orphaned children. The project supports 170 families and hinges on contributions from community volunteers, often as needy as clients. Volunteers suffer from stress and burnout, and need individual and group supervision. A project such as Thembalabantwana cannot only target HIV-positive children, since many families do not want to disclose, and needy children within the community cannot be excluded if they are not HIV-positive. This can lead to tensions with donors who only want to fund "AIDS orphans". Intersectoral collaboration between the Departments of Health, Education and Justice is critical to children's welfare but is difficult to achieve.

Moretele Sunrise Hospice: vision and programme, North West province: Mpho Sebangeni Motlhasedi

The Moretele Sunrise Hospice aims to provide quality palliative home based care and counselling for the terminally ill, especially those suffering from AIDS and AIDS-related illnesses. Support includes counselling on nutrition and disclosure, pain control and symptom management, family therapy and bereavement counselling. Complementary therapies such as massage and the use of medicinal plants form part of palliative care. The hospice has a children's programme, a herb garden, an income generating project, and support groups for children, youth, adults and grannies. Poverty is pervasive in the area and many families are struggling to find the money for burials. The supply of medicines from primary health care centres is inadequate and professional nurses have a negative attitude towards community caregivers. Power struggles between NGOs and CBOs impact on the home based care programmes. Researchers and media representatives ensure good publicity but their constant interventions disrupt the work of the programme.

The National TB Control Programme: Lindiwe Mvusi, Chief Medical Officer of the National TB Control Programme

Lindiwe Mvusi helps co-ordinate TB programmes nationally. Of the estimated 4.7 million people infected with HIV/AIDS, about 1.7 million will contract TB, and about half of TB patients are co-infected with HIV. HIV is expected to increase the

total number of TB cases by 10% per year. Stigmatisation and discrimination are common experiences for people with TB and HIV; the diseases need to be tackled concurrently and counselling, care and support is a shared need. Service provision should emphasise early diagnosis, especially of TB, and promote VCT and increased access to drugs and treatment. The role of DOTS support overlaps that of home based caregivers, but DOTS supporters are always unpaid and are often not linked to any formal structure. Although DOTS supporters do not necessarily want to be home based caregivers, they are attracted by the stipends that some home based caregivers receive. Incentives are needed for DOTS supporters.

Track C

Role of traditional medicine in the provision of care and support: Douglas Kananda, MD of PROMETRA

Over 80% of the South African population consult traditional healers and use traditional medicine, yet these practices are more often than not viewed as complementary to Western medicine rather than a primary solution. Mr Kananda gave an overview of a trial of PROMETRA International of five medicinal plants grown in Africa that contribute to maintaining the health of HIV-positive people. The results of this trial were presented at the World AIDS Conference in Barcelona in 2002. According to the study CD4 counts and viral load were positively impacted by the use of these various treatments. Traditional medicine plays a significant role in HCBC, but current legislation segregates traditional healing practices and medicine. PROMETRA is lobbying to have the laws changed. Communities need to be mobilised to acknowledge the role of traditional medicine in the provision of HCBC. Registration guidelines have to be addressed along with the laws regulating the practice of traditional medicine.

Home based care for communities: Litha Lukhanyo Klaas, Bambisinani

Mr Klaas outlined a pilot project operating in Bizana and Lusikisiki in Transkei, which focuses on women and children. It is the result of a partnership between the private, public and civil society sectors. In this area there is only one doctor for every 16 000 people and the population is transient, as many of the men are employed on mines. This programme addresses the needs of the community in a holistic way. It incorporates skills development and income-generating activities for women and youth as well as the training of traditional leaders and healers and peer educators. It also facilitates support groups for PLWHAs and 60 HCBC volunteers have been trained to date.

Community peer group educators: She Rasebotsa Ba-Phalaborwa HIV/AIDS Awareness Campaign

This programme was piloted in a community comprising both mining and military personnel. It was kickstarted by local mining companies following a baseline study funded by the Nelson Mandela Children's Fund. The programme incorporates peer education with the intention of preventing STI and HIV infections. Empowering and support of infected and affected people is a key tenet of the programme. Use of condoms and challenging the prevailing negative attitudes towards PLWHAs are also fundamental objectives. The programme has enjoyed a large degree of success because it targets people in popular community meeting places, such as shebeens.



Intersectoral collaboration is vital and HCBC should be the initial step in the continuum of care. Hospital staff, for example, should educate families on the importance of HCBC.

**Building a united and stronger HIV/AIDS family of service providers:
Pat Francis, Wola Nani/NACOSA, Western Cape**

NACOSA is an organisation based in the Western Cape. It provides support around infrastructural issues such as funding applications, mentoring in specific organisational contexts, fund-raising and general capacity building.

Track D

A caring response to AIDS: Pat Francis, Wola Nani Western Cape

Wola Nani is a service-providing organisation for PLWHAs and has 300 registered clients at any given time. It operates in Khayelitsha, Phillipi and Cape Town. Wola Nani's HCBC initiative arose from two intersecting requirements: the need for the clients to generate income and the community's need for HBC services. A six-week training course was developed to equip clients with basic home caring skills. This comprises lay counselling and peer education, a basic business component, and a two-week practical component. Graduates receive a stipend of R50 per home visit. To date, 49 home carers have been trained and are supported by Wola Nani staff.

Both the organisation and the carers themselves encounter challenges ranging from funding and logistical difficulties to poverty, hunger and initial non-disclosure of community members. However, the lay counselling provided in the programme has led to increased disclosure, awareness and better health in general.

Christiana Care and Support Group: Isadora Koetzee, Christiana Care and Support Group, Upington

In 1998 Ms Koetzee was invited by a senior member of her church congregation to share a prayer with a 24-year-old HIV-positive woman. She and her husband, who are both lay preachers in their church, continued to give spiritual support to other PLWHAs, which in turn led to their awareness of the stigma and discrimination in the community and the need for care and support. They eventually set up the Christiana Care and Support Group, which services Upington and the adjacent township of Pabalelo. The organisation now has 19 caregivers, 11 of whom have undergone a 52-day training course. Education sessions have been offered in the community and the group assists with funerals and promotes income-generating projects wherever possible. They also assist vulnerable children with food parcels. There has been some cross-sectoral engagement between the programme and the provincial department of health, the Department of Correctional Services, as well as the private sector, particularly with regard to funding.

Choice home based care project: Fiona McDonald, Choice Home Based Care Project, Tzaneen

Choice is a non-profit trust that began in 1996. It works in partnership with the Limpopo Department of Health, whose AIDS Co-ordinator is involved in all the organisation's activities. Community mobilisation is critical. Choice takes care to involve the community in the selection and recruitment of volunteers and now has trained volunteers working in 46 of the 110 villages in the Tzaneen district. The programme services up to 3 000 people each month; about 100 are bedridden and a similar number are TB patients. Volunteer work ranges from emotional and basic nursing care, helping with household chores and assisting vulnerable children to doing health promotions at public gatherings and assisting with funerals and grant arrangements. Training takes two years to complete and a more stringent volunteer selection process has improved the dropout rate. Volunteers do not receive stipends, but rather incentives such as the opportunity to participate in income-generating projects like sewing and bread baking. Stipends and a comprehensive mentorship programme are planned for the future. An M and E tool has also been implemented from volunteer level up. The essential ingredients for successful HBC partnerships include funds for training, transport, food parcels and incentives for volunteers and a dedicated co-ordinator, either from the Department of Health or the NGO sector.

Partners in Care: Dr Kas Kasonga, International Association of Physicians in AIDS Care

Stigma – including self-stigma – and discrimination are linked to basic human rights. Women are particularly vulnerable to infection and their situation is exacerbated by poverty. The National AIDS Plan can only be effective with political commitment, technical and managerial capacity. Similarly, for any HIV/AIDS programme to be successful, a detailed costing of the plan and a monitoring and evaluating strategy need to be in place. After sketching priority areas of the National Plan, global and African trends in the pandemic, Dr Kasonga concentrated on care, support and mitigating the impact of the disease. Prevention was likely to be compromised when a care and support element was not included. Elements of care included VCT, stigma reduction, management of MTCT and opportunistic infections, monitoring of ARVs, nutrition, palliative care, HCBC, support for vulnerable children and orphans, and human rights and ethics issues. HCBC needed to be integrated with other services such as TB and palliative care, and concerns such as uneven spread of services and costs needed to be addressed. PLWHAs remain the greatest resource which is untapped. Intersectoral partnerships are vital, but equity, transparency and the need to define the level of partnership need to be addressed. Partnership modalities include collaborative research, cross-evaluation, pooling of expertise and resources, and cross-organisational mentoring and capacity building.



8. Small group discussions

Track A

Stigma and discrimination

There was no formal paper for this workshop. Caroline Wills from the POLICY Project made a flip chart presentation, to motivate a debate. Her presentation was based on research being conducted at the POLICY Project. The main point was that there is insufficient research and attention given to stigma and that it remains the greatest barrier to any work in HIV/AIDS. Areas it affects include voluntary counselling and testing, and access to care and support for PLWHAs.

Enabling and empowering environment

Stellenbosch AIDS Action, Kayamandi HIV/AIDS Community Mobilisation Project: Kerry Bambridge

This was a two-year project with a research component managed by the University of Stellenbosch Department of Sociology, and an intervention component, comprising a peer group approach, home based care and health workers, and a multiple target audience. The project was managed by Stellenbosch AIDS Action.

Matsa Community Home Based Care: Mashudu Madadzhe, Centre for Positive Care

Matsa HCBC has been supported by the Centre for Positive Care since 2000, and operates in Matsa, 70km south of Messina in Limpopo province. The project's focus is to provide effective community based care using carefully trained and continuously supported community volunteers.

Members reviewed lessons learned from their individual experiences in projects and discussed the need to focus on "assets" rather than "needs" and on "involvement" rather than "participation". Volunteers should be capacitated on the basis of their particular skills and contribution in the context of the specific characteristics of communities, and nurses and doctors should learn project management skills. The need for partnerships across sectors was stressed and members felt that the documentation of evidence-based best practices would be an empowering tool for stakeholders. Constraints included discrimination and stigma, lack of resources, the unsustainability of income-generating projects, poverty, burnout in staff delivering services, and the slow pace of government delivery.

Socio-economic rights

Ikhwezi Iomso Child and Family Welfare Society: Dr Bongwe Yose

The paper looks at how the cycle of poverty exacerbates AIDS and how AIDS exacerbates the cycle of poverty. It recommends that a community-driven approach

should be used to break the cycle of poverty, and that CBOs and the work they are doing should be recognised by the various government departments. Capacity building around the national standards of home based care and HIV counselling needs to be speeded up. Staffing in NGOs and CBOs needs to be addressed, and they need to be helped to adopt scientific approaches. The workshop discussion focused on the cycle of poverty, lack of official identification documents and vulnerable children.

HBC policies and management

Khanyiselani Development Trust, KwaZulu-Natal: Theodora Makhalima

The trust operates in Greater Kokstad, to develop holistic sustainable development programmes to address the needs of people infected and affected by HIV/AIDS. The organisation has three components: Orphan care, Support group for people living with HIV/AIDS and Social Welfare Support.

Idutywa HIV/AIDS Care and Support Centre, Eastern Cape: Nonkulululelo Nonkundwana

This project was a pilot survey to assess whether HCBC is an effective tool to respond to HIV/AIDS and to provide services to the Idutywa community.

One of the critical themes arising from discussion in this workshop was the need for M and E at every level of operations in the context of HCBC. The need for HCBC training to be accredited through SAQA was proposed so that volunteers are put on a career path through their contribution. Ongoing mentoring of caregivers is important to contain stress, prevent burnout and ensure quality care. It was suggested that the Department of Home Affairs should become a partner in home based care because of the ongoing problem of identity documents and other official documentation amongst people infected by HIV/AIDS and bereaved family members, especially orphans.

Track B

Referral and transfer systems

There was no paper delivered. Discussion focused on the lack of effective referral systems, and the fact that most institutions are so overloaded and under-funded, that even where there are good referral systems, people are still not able to get good care. Also noted that sometimes very ill people are sent from “pillar to post”, or may not have the appropriate documentation to get treatment.

Alternative/complementary therapy

There were no formal presentations. The workshop recommended that the curricula for relevant professionals (nurses, doctors, priests, social workers) should include material on the role of traditional healers and traditional remedies in combating HIV/AIDS and other chronic illnesses. Home based care and other healing programmes should accommodate traditional healers. Partnerships should be formalised so that there is a fruitful exchange between Western and traditional medicine.



Holistic approach

There were no formal presentations in this workshop. The workshop recommended the establishment of professional teams made up of representatives across sectors (religious representatives, social workers, health care professionals, traditional healers, volunteers) for the provision of holistic care that would respond on the basis of multisectoral consultation to the physical, spiritual, psycho-social, economic, educational and human rights needs of patients and their families.

Palliative care

The main focus of discussion was that palliative care should be seen as an element of treatment from the point of voluntary counselling and testing, as it emphasises the holistic needs of people in relationships with their families and the community more broadly. Palliative care should be modelled towards people being allowed to die with dignity, and medical staff and home based care workers should be trained to do this. Palliative care needs to be integrated into existing home based care training and all health care training. The myth that palliative care is only for the dying should be broken down.

TB/HIV care

There was no paper delivered. Discussions focused on the crossover between AIDS and TB, and the need for an integrated approach to dealing with these diseases. Taking medication for both TB and AIDS is linked to food security, as the medication cannot be taken without eating. In both cases the endemic poverty in the country is very debilitating to providing proper care.

Track C

Traditional healers/leaders

There was no presentation in this section. Problems discussed included the large numbers of people claiming to be traditional healers and the variety of practices employed by practitioners. The need to develop and enhance a registry of accredited traditional healers was emphasised. The way that services are considered complementary to existing mainstream medical services was also highlighted as a problem, as well as the issue that legal mechanisms prejudice the use of traditional medicines and practices.

FBOs, CBOs and NGOs

Tatani Home Based Care, Pretoria: Veronica Khosa

Tatani was formed in 1995 and services terminal AIDS patients and their families in the home setting. It is a complementary service to those run by the public health system in the community. "The aim of our work is to acknowledge that each individual and family is unique and that we must support rather than instruct the client."

Salvation Army, Greenpoint, Kimberley: Pastor Yolande Sesiane

Greenpoint, Kimberley, is a very depressed area. The Salvation Army has been involved in charity and feeding schemes in the community for several years. HIV/AIDS work began in earnest in 2001. The organisation now runs a fully fledged HCBC programme with training provided by St John's Ambulance, using care kits supplied by the Department of Health and refilled by the clinic, although this can drain clinic supplies, which causes problems.

Private sector

There was no presentation in this section. A key inhibitor of private sector HCBC delivery is the fact that the service is confined to the mining sector. There has been little work done in other industrial sectors and cross-sectoral communication, particularly as regards basic information and benefits, is poor. The South African Business Coalition against HIV/AIDS (SABCOHA) does not identify HCBC as integral to holistic AIDS care. There are also serious ethical issues regarding repatriation of terminal employees and non-disclosure remains a problem. A key recommendation is to extend the concept of HCBC and the relationships required to drive the service beyond the gates of the employer.

Volunteers/caregivers

Evaluating the home based care programme in the Halegratz District in the Northern Province of South Africa: Colleen Jackson

The researchers started a home based care programme during 1999 in the district around Tzaneen. Sixty six volunteers went through basic training but there is a need to select volunteers more carefully to reduce drop out rates. Evaluation revealed that 27 of the 66 volunteers are still actively involved, motivated by, among other factors, seeing that their support makes patients better and that they can help needy patients with food parcels.

General discussions identified many problems facing volunteers, including discrimination and stigma in the community and workplace, the lack of coherent cross-sectoral training and referral systems, and the lack of participation of men at all levels of HCBC. Lack of care and support for caregivers, lack of clarity or standardisation of stipends and poor conditions of service were also discussed. The need to integrate services rendered by DOTS supporters and caregivers and to standardise selection and recruitment criteria were identified. Participants believed existing national guidelines on HCBC need to be implemented, and that PLWHAs need to be integrated as volunteers. The need for strong cross-sectoral policy regarding all aspects of volunteering including financial incentives was agreed upon.

Government departments

The need for government departments other than Social Development, Health and Education to become involved in HCBC was emphasised, as was the need for better interdepartmental collaboration. Discussion showed that while infrastructure – including the Intersectoral Task Team – is in place, it is often non-functional and HCBC is not yet given high priority. Issues of accountability in areas of management,



finance and implementation and questions about commitment from politicians were also discussed. Ways of eradicating problems arising out of the duplication of existing services were discussed at length, including the compilation of a database of provincial resources. The need to integrate PLWHAs and provide standardised policy for caregivers was noted.

Mentoring

Major issues that arose included the lack of capacity within NGOs to mentor, and the unevenness of mentoring across the country. Problems regarding relationships between organisations that mentor and those that they mentor, such as different agendas and issues of ownership, were discussed. The lack of intersectoral collaboration stakeholders and the ignorance in the NGO community regarding ethical and legal issues around funding and accountability were also debated. The discussions emphasised the need for better communication, as well as clear plans and guidelines from government at all levels regarding the mentoring needs of NGOs.

Track D

Nutrition

Botswana Ministry of Health: Pastor Thebe Terence Baile

Pastor Baile explained the link between nutritional status and the immune system, with particular reference to people infected with HIV. He discussed the way in which assimilation of nutrients can be interfered with by opportunistic infections and the importance of nutrition in maintaining weight.

Bushbuckridge Food Gardens Project

The presenter outlined how food gardens have been successfully developed in the Bushbuckridge community to support better nutrition amongst PLWHAs.

Personal growth and public speaking

Wola Nani, Cape Town: Pat Francis

Wola Nani has found that support for caregivers is vital to sustaining a good home based care programme. Self-control and self-investment are important ingredients in the health and welfare of caregivers.

"Taking time for ourselves and recognising the burdens we carry are key to personal growth."

Support groups

A lack of networking and duplication of activities is common in this area of service delivery. The role of the caregiver is draining. Support groups need to take this into account and involve PLWHAs and caregivers so that common objectives can be

established and that training and debriefing are ongoing. Groups collapse due to fears of discrimination and lack of confidentiality among members. Co-ordinating the establishment and activities of groups through the local government liaison forum would promote more effective communication systems. Education and information must be ongoing to change the discriminatory attitudes of professional and community members. Structured referral systems are lacking.

Disclosure

We Care, Umtata: Nozuko Mvinjelwa

We Care encourages people to disclose to whomever they feel comfortable with. This brings a sense of relief. They then form support groups to help each other. A climate of openness encourages everyone to disclose. The NGO also encourages the youth to go for VCT. "Disclosure starts with oneself."



9. Presenters' contact details

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Sefularo	Molefe	Dr	-	-	-	-	-	-
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Wilson	Gustav	Mr	South African Police Services	012	401 3325	320 1221	-	-



Useful references and resources

Integrated Home/Community Based Care Model Options

Department of Health
HIV/AIDS, STIs and TB Chief Directorate
Treatment, Care and Support Subdirectorates
Contact Cornelius Lebeloe
Tel: (012) 312 0132
Fax: (012) 312 3122

National Guidelines on Home Based Care and Community Based Care

Department of Health
HIV/AIDS, STIs and TB Chief Directorate
Treatment, Care and Support Subdirectorates
Contact Cornelius Lebeloe
Tel: (012) 312 0132
Fax: (012) 312 3122

National Guidelines for Social Services to Children Infected and Affected by HIV/AIDS

Department of Social Development
Contact Johanna de Beer
Tel: (012) 312 7589
Fax: (012) 312 7763

Child HIV/AIDS Services: A Directory of Organisations in South Africa

Department of Social Development
Contact Khomotso Kgothadi
Tel (012) 312 7843 or
www.childaidsservices.org

Health and Development Networks

International discussion forum, access to Botswana and Thailand HCBC conference reports, www.hdnet.org

Health Systems Trust

Quick access to local health resources
www.hst.org.za

Hospice Association of South Africa

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United Nations Joint Programme on HIV/AIDS (UNAIDS)

www.unaids.org

UNAIDS Best Practice Collection

www.unaids.org/bestpractice/digest/index.html

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