



khomanani

-REACHING OUT - SCALING UP-



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

18 - 21 September 2002

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 the provincial and national Departments of Health and Social Development, 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 to focus on strengthening its impact.

The conference objectives were to:

- Promote the exchange of lessons learned and information on strategies to improve quality of life and reduce the burden of illness on people living with HIV/AIDS (PLWHAs), including the chronically ill, and their families;
- Identify and analyse the cultural, economic, political, ethical, social, legal and policy related factors that promote or 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 towards a continuum of comprehensive care to successfully mitigate the impact of chronic diseases;
- Advocate for the greater involvement of people living with HIV/AIDS and promote positive living through HCBC; 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.

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.

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:

Living Positively;

- 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.

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 OVC 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.

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;
- Networking and referring to provincial HCBC co-ordinators.

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