Care and Support Case Study: South Africa

1. Positioning of care and support in national policies and strategies

South Africa's HIV & AIDS and STI Strategic Plan 2007-2011 (NSP) lays out the nation's main goals, objectives and planned interventions in HIV/AIDS. The primary aims of the NSP are to reduce HIV incidence by 50% and reduce the impact of HIV/AIDS on individuals, families and communities. The document is used by government departments at all levels and civil society to guide the development of their own plans/strategies and is the basis for international engagement and investment. The NSP will achieve its aims by focussing on four priority areas: 1/prevention 2/scaling up treatment and care and support 3/monitoring, research and surveillance and 4/human rights and access to justice[1].Although not explicitly defined, care and support activities are spread across the four priority areas but are primarily situated under priority 2 and cover a broad array of interventions such as voluntary counselling and testing (VCT), scaling up comprehensive care and treatment packages, improving retention of ART, improving palliative care, impact mitigation including the expansion of community home based care (CHBC) and policies for orphans and vulnerable children (OVC) and other marginalised groups and addressing the special needs of women and children[2].

There are a number of additional policies in place which affect care and support activities for people living with and affected by HIV including the Integrated Nutrition Programme, an Infant and Young Child Feeding Policy, a Policy Framework and a National Action Plan for Orphans and other Children made Vulnerable by HIV & AIDS and a Home and Community-Based Care Policy Framework. Additionally, in 2009 and 2010 respectively the President announced a new treatment policy for all HIV positive babies under the age of one, a massive increase in testing through a new VCT campaign (which aims to reduce the HIV incidence rate by 50% by June 2011) and finally, a task shifting policy allowing a trained lay person to take blood[3].

2. Domestic and international resources for care and support

Domestically, HIV/AIDS is primarily financed through the national health budget, and the HIV/AIDS conditional grant of the budget has grown from R4.3 billion in 2008 to an estimated R5.3 billion in 2009. The national health budget is augmented by spending in social development and education, which addresses impact mitigation on families, particularly orphans and vulnerable children. AIDS prevention research is supported through the Department of Science and Technology. Resources are also devoted to the National Health Laboratory Service which conducts HIV-related testing and monitoring.

A number of bilateral and multilateral donors support the National Strategic Plan; the most notable being the US President's Emergency Plan for AIDS Relief (PEPFAR). While PEPFAR provides detailed country operational plans, very little is provided by way of final expenditure, as funding is awarded typically over a five year period[4].

Neverthless, PEPFAR's 2008 Country Operational Plan provides a breakdown of how their funds ($584,469,685) were allocated. The total budget for the year was divided between prevention, care and treatment, with care forming 31.7% of the grant ($168,815,459)[5].

The care budget is implemented through public health facilities and civil society organisations and is divided into palliative care which includes financial and technical support and training (26.6% of the care budget), TB/HIV which includes improving testing and referral for TB services among people living with HIV (19% of the care budget), OVC which includes technical support for programmes providing comprehensive

care and support (30.8% of the care budget) and VCT which is linked to care, support and treatment services (23.4% of the care budget)[6].

The Global Fund to Fight AIDS, Tuberculosis and Malaria has awarded South Africa HIV grants in Rounds three, six and two in Round nine. Recognising the important contribution of community based organisations (CBOs) in providing prevention, care and treatment services, the Round nine proposals (worth US$28,030,829) aim to expand activities of these organisations in the areas where the disease burden is highest or where service delivery is not meeting the district's needs. Activities include CHBC and support to OVC, VCT, support services including 'care for carers', CBO capacity building and a national helpline. These areas are to be implemented by the National Religious Association for Social Development (NRASD), Networking AIDS Community of South Africa (NACOSA) and the National Department of Health[7].

Funds have also been received and continue from DFID (support through the Multisectoral HIV and AIDS Support Programme (MSP), later the Rapid Response Health Fund which was then replaced by the current Strengthening South Africa's Revitalised Response to AIDS and Health) and other bilateral agencies for care and support. Private sector information and responses are under-reported.

3. Operationalising the NSP: challenges, successes and gaps

Operationalising the NSP

At the national level, the South African National AIDS Council (SANAC), which is chaired by the Deputy President and is a partnership of civil society and government departments, is responsible for advising on policy and strategy, disseminating interventions, strengthening partnerships and monitoring and evaluating the AIDS response. The national response is also monitored by the Inter-Ministerial Committee on AIDS which oversees SANAC. Within each government department there are focal points and teams responsible for planning, budgeting, implementation and monitoring HIV and AIDS. Implementation of the NSP is however, mainly carried out by provinces, local authorities, the private sector and CBOs[8].

Support is provided to affected children and families through grants from the Department of Social Development (DSD) and the Department of Health (DOH). Social workers in districts and municipalities identify eligible children and families and assist them in applying for the grants. In addition, DSD also provide grants to organisations which provide home based care workers (HBCW). The workers, who are selected by the community and are usually women[9], provide nutritional and treatment adherence support and help with domestic chores. PEPFAR, UNICEF and other donors also provide funding and support to organisations providing this type of assistance[10 11].

Community caregivers, under the auspices of NGOs, CBOs and faith-based organizations (FBOs) offer home/community-based care and support (HCBC) services largely at community and household level. Many of these organizations are supported directly through the Department of Social Development and the Department of Health's Directorate of HIV, AIDS and STI Care and Support Programme, or directly through development partners.

Examples of success in implementing care and support programmes

- VCT, a vital entry point for further care and support services is now available at 96% of public facilities with the targets in the NSP for those being tested within the last 12 months being more than surpassed[12]
- There has been a marked increase in support and HBC to affected families and children through DSD, DOH and civil society[13]
- Through support received from DSD, the Department of Health or directly through development partners, HCBC organisations reported reaching 411,867 OVC in 2008/2009 and 449,732 children in the first three quarters of 2009 (although what this support entailed is not detailed)[14]

- The percentage of OVC aged 10-14 attending school is almost equal to non-orphans of the same age[15]
- Through the DSD 41,908 community care givers received accredited training including on psychosocial care and support in 2008/9[16]
- Food supplements and parcels are provided to affected families through organisations offering HCBC. The number of affected people receiving this support in 2008/9 was 735,000, exceeding the NSP target by 234,900[17]
- There has been an increase of over 100% in TB patients receiving both TB and HIV treatment[18]
- At the local government level, the Handbook for Facilitating Development and Governance Responses to HIV/AIDS which is being rolled out to districts and municipalities is helping to mitigate the impact of HIV/AIDS by ensuring a clean and safe water supply, supporting community food gardens and providing nutritional support[19].

Challenges to implementing comprehensive care and support programmes

- Lack of uniformity in approach and standards between the DOH and DSD for reducing the impact of HIV/AIDS in communities has posed problems and synergies across departments are not being exploited to their full potential. Training and professional recognition are grey areas and DOH and DSD need to make criteria clear and fair
- Inconsistent quality of services provided by most CBHC organisations[20]
- Limited financial resources available for CBHC from government and heavy reliance on donors
- Weak integration of HIV services with other health and social services but particularly poor integration of HIV/TB services (less than half of HIV positive clients were screened for TB in 2008/9 (due in part to vertical HIV and TB programming)
- Facilities for palliative care in sub-districts remain well below DOH target of 100%[21]

Identified gaps

- There is a continued need to build the capacity of care and support systems including the uptake of grants for vulnerable children and the provision of nutritional, psychosocial and social support[22]
- Social workers are under represented. It is estimated that just to meet the needs of children, South Africa needs five times as many social workers as it currently has registered. The use of community level workers does however mitigate this to some degree[23]
- There are no national or provincial NSP implementation plans which comprehensively set out activities against the NSP's objectives and targets. Government departments use their own plans and provinces use business plans to operationalise the activities required to achieve the NSP[24]. In impact mitigation specifically, there is an overall lack of coordination and support between the different implementing partners which means that opportunities are being missed[25]
- While impact mitigation activities are taking place on an increasing scale, there are no data collection systems in place to monitor it [26]
- Data collection on traditional most-at-risk populations (men who have sex with men, commercial sex workers and injecting drug users) are not routinely collected, making it difficult to provide comprehensive care and support to these populations
- Lack of well documented examples of care and support best practices and/or cost-effectiveness studies

Case Study: Quality Palliative Care: The South African Mentorship Programme

South Africa also has a number of organisations providing palliative care but high demand for these services far outstrips available resources and there remains an urgent need to strengthen existing hospice programmes. The Integrated Community-Based Home Care (ICHC) model implemented by the Hospice Palliative Care Association of South Africa (HPCA) aims to expand hospice resources by including and strengthening the capacity of relevant community service providers, particularly government hospitals and clinics. The work has rolled out in two phases, the first phase developing and piloting a mentorship programme for 28 member hospices to expand palliative care services into local communities. Supported

by a core of qualified and experienced HPCA personnel, mentor hospices facilitated a situational analysis at each development site, followed by strategic planning involving all key players both within the hospice and the local community. In addition, to build capacity, a number of regional workshops were conducted during the first two years.

The second phase has seen the development of a minimum set of palliative care standards and the evolvement and implementation of a hospice accreditation system. In addition, part and full time mentorship positions in well established and weaker hospices have strengthened the capacity for hospices to provide mentorship and have played a key role in accelerating hospices' ability to comply with standards and work towards accreditation

Lessons learned and broader application

The most important lesson learned is that mentorship works! The growth of HPCA member hospices has increased from 50 in 2004 to 76 in 2006 and continues to grow. Regional teams are currently mentoring 60 development sites, many of which have the potential to meet the requirements for HPCA membership.

The ICHC model has strengthened links with the formal health care sector at local, provincial and national levels and contributed to positioning HPCA and its member hospices as key national palliative care resources. The mentorship approach was also successfully used in the development of Centres for Palliative Learning (CPL). Tutors from a well established training centre provide structured guidance and support to an emerging CPL. Today, nine hospices have accredited CPLs which collectively offer accredited HPCA palliative care training courses for community caregivers, nurses, and social workers, and provide clinical placements for doctors doing either a degree or diploma in palliative medicine.

The African Palliative Care Association has started to apply the principles of mentorship developed by HPCA across Africa, particularly in its activities with national palliative care associations in Zambia, Tanzania, and Kenya. New applications of the mentorship programme are developing involving hospice-based, palliative care-trained nurse supervising community caregivers in local home care programs, which presently have no access to professional palliative care expertise. This model has the potential to dramatically improve the quality of care delivered by community-based home care programs[27].

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Care and Support Case Study: Uganda

1. Positioning of care and support in national policies and strategies

Uganda's National Strategic Plan (NSP) 2007/8 – 2011/12 sets out priorities and objectives in relation to HIV/AIDS and provides overarching guidance for the country's response. The NSP includes a definition of comprehensive care and treatment, i.e.: "a holistic approach to care for people living with AIDS (PHA) that involves clinical management, nursing care, palliative care, and psychosocial support"[28]. The NSP has a systems strengthening component and three service delivery priority areas: 1/prevention 2/care and treatment 3/social support. Taken together, they contribute to the achievement of universal access and cover various aspects of care and support.

Objectives and strategies for care and support are situated primarily under the care and treatment and social support priority areas (although elements of the prevention priority area and systems strengthening are also relevant) and include targets and indicators for the provision of comprehensive care and support, e.g. increasing access to prevention and treatment of opportunistic infections including TB, integrating prevention into treatment services including Prevention with Positives (PWP) activities, supporting and expanding home based care and referral systems to health facilities and complementary services, psychosocial and nutritional support to PHAs, enhancement of economic empowerment and livelihoods of those affected by HIV/AIDS through income generating activities[29].

In addition, Uganda's Health Sector Strategic Plan (HSSP) III 2010/11-2014/15 includes limited care and support activities such as nutrition support to PHAs, scale up of ART in the context of home based care, and strengthening the legal and policy environment for the AIDS response. With the exception of an indicator and target for scaling up HIV testing and counselling, few indicators relevant to care and support are included[30].

Numerous policies and guidelines in relation to HIV care and treatment have been established (OVC policy; home based care; feeding infants in the context of HIV/AIDS; guidelines for nutrition among PHAs to name a few)[31] and these are usually widely disseminated by the Uganda AIDS Commission, but it is difficult to assess the extent to which these policies are being implemented and in the right way.

2. Domestic and international resources for care and support

Resources required for the NSP by 2011/12 are estimated to be just over $500m, 15% of which should be provided by the government[32].The UNGASS progress report 2008-2009 states that approximately $270.8 million had been spent on HIV from international and domestic sources, considerably less that the NSP's estimated resource needs for that year ($346.7 million in total[33]). Of the total NSP budget, it is estimated that 38.7% of resources will be allocated to treatment and care (the largest share of all the four areas) and 24.7% for social support (mostly for OVCs). Treatment and care services for 2007/8- 2011/12 are estimated to be $772.8 million with the lion's share (over 94%) being allocated for ART services. Only 6% is allocated for the basic care package, routine offering of counselling and testing, treatment for OIs including TB[34]. There is also a separate budget of $492.3 million for mitigation which is not broken down by activity. Getting data on actual expenditure is difficult. Throughout a budget year, expenditure priorities change so what may be allocated in the budget for care and support, may not actually be spend. Currently there are issues around supplies of drugs for HIV and TB, with the US government recently bailing out the government with supplies for a further two years.

- PEPFAR is leading the way in the financing and provision of care and support services in Uganda. The latest available PEPFAR Uganda Fiscal Year Country Operational Plan (COP) provides a full breakdown of figures by thematic area (for 2008)[35] and states PEPFAR will provide $81,367,668 for care (33.6% of the prevention, care and treatment budget). The care budget is split in to the following categories: Palliative Care: Basic health care & support (33.5%), Palliative Care: TB/HIV (11.6%), Orphans and Vulnerable Children (32%) and Counselling and Testing (22.8%)[36].
- The Global Fund to Fight AIDS Tuberculosis and Malaria (GFATM) also provides significant funding for the national response. Uganda's Round seven proposal is worth $241 million[37]. The grant has a few references to care and support but includes the goal of mitigating the health effects of HIV/AIDS, improving the quality of life of people living with HIV and the target of scaling up medical care of PWA receiving Co-trimoxazole. No indicators exist for these three areas.[38]

3. Operationalising the NSP, challenges, successes and gaps

Operationalising the NSP

Planning and coordination of the NSP is carried out by the Uganda AIDS Commission (UAC). The UAC is also responsible for identifying challenges to AIDS control policy and implementation; ensuring implementation of the programme and achievement of the targets; mobilising and monitoring resources for AIDS control and disseminating information on HIV/AIDS. The HIV/AIDS Partnership is a multi-sectoral body which aims to ensure that the voices of all stakeholders are included in the national response. There are also decentralised structures in place which coordinate the AIDS response at district and local level[39].

Treatment, care and support and social support services are provided through a network of public, non governmental and/or community based organisations, faith based organisations and private not for profit (PNFP) facilities[40].

Home based care (HBC) has been a major care and support strategy since the inception of the epidemic in Uganda and offers different models of care ranging from home visiting to home-based palliative care to comprehensive treatment, care and support programmes. HBC can be physically, emotionally and economically stressful, with the burden of caring falling to women - grandmothers, mothers, sisters, women friends - bearing the burden of changing needs and demands of sick people.

A striking feature of HBC programmes in Uganda is the professionalisation of care. The general pattern is for patients at home to be provided with specialised medical care as well as support home-visit services by teams that consist of medical doctors, nurses, other paramedics, and clerics for spiritual care. The HBC programmes use volunteers who identify sick people and in some cases provide basic care, but are themselves supported by the mobile teams of professionals. These services are provided through a number of organisations, the largest of which is The AIDS Support Organisation (TASO). TASO provides a range of services including: the training of community volunteer nurses who in turn train caregivers to provide home nursing and emergency care; psychosocial support in pre test, post test, prevention and support environments; medical care for OIs; nutritional support; advocacy and social support including support for children, an apprenticeship programme and a youth club [41]. This is not to say that this system is manifest across the country. There are care organisations that operate different models of care, but there is substantive co-ordination and networking between hospitals, NGOs, religious groups and communities[42].

Examples of success in implementing care and support programmes

- HIV mitigation has been addressed through policies and care and support service provision including nutrition to OVCs[43];
- development of IEC materials and training for care and support providers in a number of communities and districts[44];

- The implementation of home based care especially by NGOs and CBOs; the expansion of psychosocial support services, especially for OVCs and the training of duty bearers to promote rights through legal, social and community support for vulnerable groups including OVCs[45].

Challenges to implementing care and support programmes

- The latest UNGASS Progress Report (2008-2009) indicates that despite widespread policies, guidelines and funding for care and treatment, equitable access to services for much of the population is still difficult. Weak capacity, resources (human and financial), inadequate supplies, and poorly functioning facilities at the health centre II level (which provide the first level of interaction between the health sector and communities) make access services difficult at the local level [46].
- In addition to access issues, a PEPFAR funded facility survey[47] found that the provision of care and support services is not consistent across all facilities and that some services are available much less frequently than others. For more information please see **Box 1** below.
- Treatment adherence, maintenance of care and retention of clients is a major challenge to the ART programme[48]. This is being addressed in some areas through the use of Network Support Agents (NSAs) for PHAs. NSAs are especially active where civil society organisations have strong partnerships with health facilities, providing counselling at facilities and in communities.
- While there has been some mobilisation and education which supports care for infected children, this is limited in availability[49].
- Volunteers providing HBC can face high levels of physical, emotional and economic stress particularly if caring takes time away from the volunteer's social and economic lives. Care givers are often the breadwinners and heads of the household but they may be forced to give up their jobs while providing HBC and may face increased expenditure for the sick for food and medicines. The carers with the most challenges are grandmothers who also have their own health issues; child headed households; widows; other females in the household who tend to take on the carer role. Pay for carers is rarely enough. Carers need other types of support, without which there are high rates of attrition[50].

Identified gaps

  - Geographical gaps in care of those living with HIV and AIDS
  - Huge gap in knowledge of what constitutes care and support
  - knowledge gap by actual carers about what they are entitled to, not helped by the fact there is no organisation representing carers
- Although treatment and follow up of TB has been evident in a large number of facilities, not all are following the DOTS strategy. Only 68% of hospitals, 84% of HC IV, 85% of HCIII and 94% of HC II are using DOTS[51].
- The co-management of TB and HIV is an area where gaps persist, especially at the HC II and HC III levels. Weak health and referral systems have impacted on the integration of TB and HIV care and treatment and many TB patients are not routinely tested for HIV [52].
- There are information gaps on the coverage and scope, and types of organisations providing OVC services. The UNGASS report concludes that very few OVCs are receiving a comprehensive package of psychosocial support and there has also been little progress in the provision of essential entitlements for OVCs and other affected groups[53].
- Not all of the indicators in the NSP contain baseline data or targets although this is being addressed[54]

Some of these issues and others have been identified in a report by PEPFAR and are outlined in the box below.

Box 1: PEPFAR Public Health Evaluation: Care and Support Phases One and Two (2009 and 2010) Results and recommendations

A recent two phase study funded by PEPFAR surveyed 10% of PEPFAR supported facilities which offer care and support services. The survey considered 69 components of care and support and found that on average, facilities provided 36 components and referred a further 11 components. The findings include:

The most common services provided were adherence, pre and post test counselling, nutritional advice, family planning counselling, pre and post HIV test counselling, diarrhoea treatment and skin rash treatment.

- All of the facilities offered or referred psychological, clinical and prevention care. Spiritual and social care was not as widely available, in 58% and 41% of facilities respectively.
- The basic care package was not provided in full and onsite in nearly a quarter of facilities.
- Treatment for OIs including TB and malaria was widely available even though in many cases the testing for these conditions was not.
- Nutritional counselling was widely available but therapeutic feeding for malnutrition only available in 44% of cases.
- Non-opioid pain management was available but opioids were rarely available in pharmacies even if they were prescribed.
- At least three of five components of care to prevent further transmission was offered by all facilities.

The reports recommend that investments be made in:

- Infrastructure - training, especially in counselling;
- The provision of more incentives for staff and volunteers;
- The provision of training for family carers and nutrition & sanitation for families;
- The provision of more HBC services, social care and prevention care;
- More reliable drug supplies and staff training in pain management;
- Increased VCT services to tackle stigma and discrimination;
- Regular assessment of multidimensional needs of those on ART at clinic level;
- Carer's needs should be included in the care package and all patients should be assessed for pain.

GOAL Uganda: An example of best practice in providing comprehensive care and support

There are a number of documented examples of best practice in HIV/AIDS care and support in Uganda[55]. GOAL Uganda's HIV Programme is implementing care and support in a number of important ways. A range of initiatives are covered under GOAL's HIV Programme including testing, STI treatment, behavioural change communication, vocational training, livelihoods interventions and HBC and support groups in four districts.

The HBC component of the programme involves training community volunteers to provide practical support and information to families and individuals affected and living with HIV. The volunteers make home visits to promote safe behaviour and enable people to make informed decisions to support disclosure of HIV status to partners and families. They also provide psychosocial support to individuals and families and referrals to health facilities. Positive living is promoted through a range of products including insecticide treated nets (ITNs) to prevent malaria, water purification systems, oral rehydration salts and male condoms.

The Support Group component of the Programme provides informal drop in centres which are based in the community for PHAs. These meetings aim to provide a forum for psychosocial support and allow for the development of informal community support networks. Group members are also supplied with a monthly supply of co-trimoxazole to fight OIs such as malaria, diarrhoea and other serious infections. The medicine which is widely available in Uganda costs around $12 per year per PHA. The nurse who provides the co-trimoxazole can also make referrals to health centres for treatment and is a 'champion' for health living among members. There is also prophylaxis available for infants of HIV positive members.

An outcome evaluation took place in 2009 and the main findings included:

- The incidence of malaria among beneficiaries was greatly reduced due to the provision of ITNs and co-trimoxazole.
- Diarrhoea and vomiting was also greatly reduced and this was linked directly to the provision of co-trimoxazole and water purification systems.
- Beneficiaries reported that co-trimoxazole had reduced an array of OIs including malaria, cough and flu, skin infections, diarrhoea and headaches.
- Families gained hope and encouragement and reduced anxiety and depression from benefiting from HBC and Support Groups. The beneficiaries attributed this to a number of activities including one-to-one counselling from HBC volunteers, the positive reinforcement of having volunteers visit the home regularly, experience sharing and coming together as a group.

This example of care and support provides a number of useful lessons which can be incorporated in to other initiatives and may have the possibility of being scaled up, these include:

- Distributing ITNs and co-trimoxazole both contribute to reducing malaria incidence which in turn leads to a reduced number of clinical visits, reduced household expenditure on medical bills, increased production as beneficiaries are more productive and able to engage in livelihoods activities.
- Reduction in OIs including diarrhoea and vomiting improves the quality of life and reduces medical costs. Beneficiaries are also able to engage in livelihoods activities such as agriculture which can in turn improve nutrition.
- Support groups can significantly help beneficiaries psychologically. They can feel more positive and have reduced depression and anxiety. This increased positive living can have an impact in a number of areas of life[56].

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Care and Support Case Study: Ethiopia

1. Positioning of care and support in national policies and strategies

The Ethiopian Strategic Plan for Intensifying Multisectoral Response to HIV/AIDS 2004-2008 (SPM) describes the country's strategic priorities and has guided the coordination and implementation of the national HIV response until recently[57]. A Second Multisectoral Strategic Plan (SPMII 2009-2014) has been developed, but only a draft interim plan covering 2009-2010/2011 appears to be available[58].

There is no definition of comprehensive care and support in the SPM or SPM II. Relevant activities under the SPM include the provision of a standardised minimum package of essential HIV services that includes home based care (HBC), Orphan and Vulnerable Children (OVC) activities, referral services, voluntary counselling and testing (VCT) and treatment of opportunistic infections (OIs), span the Plan's six priority areas. There is also a specific objective for people living with HIV and AIDS (PHA) and OVC, to ensure that care is promoted within the family and community, that counselling and legal services are provided to these groups and that they have access to basic health, education and social services[59]. The draft, interim SPM II identifies impact mitigation as a priority and includes strategies to intensify programmes for OVC and elders, strengthening HBC and the poverty mitigation activities[60].

Ethiopia also has a Multisectoral Plan of Action for Universal Access to HIV Prevention, Treatment, Care and Support (2007–2010) which appears to be a more comprehensive, detailed and costed plan around which development partners engage. Targets and indicators exist for relevant areas of care and support e.g. VCT, OVC support, support to people and households affected by HIV and the provision of HBC. Specific targets also exist for programmes concentrating on comprehensive palliative care and care and support, although nether terms are defined. The care and support programme contains indicators for psychosocial, educational, food and shelter and income generating activities[61].

Ethiopia's strategic documents are based on the 1998 National HIV/AIDS Policy which focuses primarily on prevention but also covers areas of impact mitigation[62]. These are currently under revision to include treatment and care[63]. Guidelines for community and HBC have been in place and updated since 2002 and appear quite comprehensive with detailed definitions of service packages, though implementation has not been enforced[64]. In 2007, palliative care, in its most comprehensive form[1] , entered the policy domain and guidelines and training tools have developed. Though not endorsed by the Ministry of Health, implementers use them widely.

The service package has led to an expansion of HBC activities to include support such as safe water, prevention of OIs such as malaria and reproductive health and family planning which is implemented both in the home and in facilities[65]. The definition of palliative care has therefore changed radically to encompass the wider needs of people living with HIV throughout the course of the infection, rather than just concerning activities related to terminal care[66].

The health sector is guided by the Accelerated Access to HIV/AIDS Prevention, Care and Treatment in Ethiopia Road map for 2007 – 2008 which outlines the health sector's plans to expand prevention, care and treatment. Like the HIV strategy documents, comprehensive care and treatment is not explicitly defined but

[1] Ethiopia MOH operational definition of Palliative Care Palliative Care is a continuum of care that can be delivered in the health facility, community or at home starting from the time of diagnosis up to the end of life by health care providers and or volunteers. Palliative care includes clinical, and non clinical (psychological, economic, spiritual,and social) care throughout the entire course of HIV infection

activities such as the development of guidelines for treating OIs and stronger linkages with the community to support treatment adherence are included[67].

2. Domestic and international resources for care and support

The Multisectoral Plan of Action has estimated that 34,184,200,732 birr would be needed between 2006 and 2012 to achieve its targets. The overall budget is divided by programme area with 16% for prevention, 25% for treatment, 42% for care and support (of which half is allocated to people living with HIV and half to OVC) and 17% for other activities[68]. As of the end of 2007, $684 million had been committed for the HIV response over six years, leaving an unmet financial need of $3.2 billion between 2006 and 2012 with around a billion of this figure estimated for care and support[69]. The actual amount of domestic and/or international expenditure on HIV activities is not available, although a National Health Accounts exercise is in process[70].

The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) is the largest donor for HIV activities in Ethiopia. Over Rounds two, four and seven, GFATM has approved $896.4 million, or which 41% has been transferred to principle recipients[71]. Three Round seven grants, worth $64,955,789 in total have a number of aims but include care and support programmes for people living with HIV and OVC, ART adherence, impact mitigation (job creation and income generation schemes) and the provision of HBC and nutritional support to people living with HIV/AIDS and their families[72].

PEPFAR is an important HIV donor in Ethiopia with planned expenditure in 2009 estimated close to $346m (figures on disbursements are not available). Funded activities include strengthening preventative care packages for children and adults, providing nutritional care and support, a package for OVC care and limited therapeutic feeding[73].

Additional funding support for HIV is provided through a number of sources including the World Bank, a donor pooled funding mechanism and a United Nations Development Assistance Framework (UNDAF) 2007-2011[74].

3. Operationalising the NSP: challenges, successes and gaps

Operationalising the NSP

The National HIV/AIDS Prevention and Control Council (NAC) was established in 2000 and is charged with implementing and monitoring the national response. The Council is chaired by the President of Ethiopia and comprises of government officials and representatives and civil society including those from non-governmental organisations (NGOs) and faith based organisations (FBOs)[75]. FHAPCO however, is the body which is authorised to lead, coordinate and oversee the implementation of the response on a day to day basis[76]. Multi-sectoral coordination is ensured through the National Partnership Forum which consists of a variety of stakeholders. There are also a number of influential technical working groups (TWG) that deal with specific issues such as prevention, social mobilisation, care and treatment and OVC[77]. Under the care and treatment TWG, there are subgroups for Adult ART, Paediatric ART and Palliative Care[78].

The lead government institution responsible for coordinating HBC has changed a number of times in recent years and HBC now sits in the MOH under the newly created General Directorate for Disease Prevention and Health Promotion. A separate coordination mechanism for OVC support is led by the Ministry of Women's Affairs which chairs the national OVC Taskforce although programmes for OVC support are also coordinated by The Federal HIV/AIDS Prevention and Control Office (FHAPCO) which is the Deputy Chair of the Taskforce[79]. The Taskforce is in the process of finalising Standard Service Delivery Guidelines, although implementing partners have already begun to alter their HBC training to incorporate and implement the wider definition of palliative care[80].

HBC in Ethiopia is being implemented by a number of partners. As described above FHAPCO, has a role in coordinating OVC programmes for OVC and HBC for people living with HIV is undertaken by the Ministry of Health (MOH) which is responsible for all community based activities including the Health Extension Programme (HEP). HEP is a community based programme which aims to improve health by making community level (Kebele) services more accessible and widely available. The HEP addresses problems of insufficient human resources through decentralisation and task shifting to health officers and Health Extension Workers (HEWs) of which there are around 30,000[81]. HEWs are salaried, trained for one year and provide mainly preventative and promotive services[82]. They are involved in facility and community based interventions and have been successful in creating awareness and demand for services[83]. HEWs do not have a clearly defined role in HBC but they are involved in HBC activities and it is envisaged that this role will grow in the long term[84].

There are also a number of NGOs implementing HBC activities in Ethiopia although their work is largely uncoordinated and unrecognised[85]. The Network of People Living with HIV in Ethiopia (NEP+) is one of the most prominent NGOs that operates nationally in this HBC and is funded largely by international donors. NEP+ trains caregivers and provides services using the broad definition of palliative care. Ethiopian Interfaith Forum on Development, Dialogue and Action (EIFDDA) also receives international funding and provides care and support to OVC and people living with HIV mainly through income generation activities but also implements some HBC in some programmes. There are a number of international organisations implementing HBC activities including Family Health International, Management Services for Health, World Vision and the Red Cross. UNICEF, WHO and UNAIDS are also active in implementing HBC activities[86].

Examples of success in implementing care and support programmes

- VCT is seen as an important entry point for prevention, treatment, care and support services and both the delivery and utilisation of VCT services has increased. Between 2005 and 2008, the proportion of women ever tested increased from 4% to 28% although geographical variations exist with much higher coverage in urban areas as compared to rural areas[87].
- In 2008, 235,558 OVC received educational support (53% of the target), 167,313 received nutritional and shelter support (45% of the target), 23,741 received financial support and 20,348 received support through income generating activity programmes (127% of the target)[88].
- With the World Food Programme, the Government is providing food and nutrition assistance to around 110,000 people with HIV and OVC which has helped improve health outcomes compared to those who did not benefit from the initiative. There was also improved treatment adherence and increased HBC services among those included in the initiative[89].
- Awareness of services at the Kebeles level has been greatly enhanced through the use of Community Conversations, forums which are implemented at the grass roots level with the aim of increasing social mobilisation[90].
- People living with HIV, as individuals and groups, have had a high level of involvement in the national response. Associations of people living with HIV have been able to provide care and support services to their members and prevention services to the wider population[91].
- The implementation of HBC activities has led to the empowerment of communities which are central to the provision of care and support[92].
- The changing demands of people living with HIV for care and support services have been reflected in a changed policy context[93].

Challenges to implementing comprehensive care and support programmes

- Institutional changes for the responsibility of HBC have led to voids in policy making and the coordination of service provision[94].
- The coordination and harmonisation of OVC activities is weak, especially at the community level[95].
- In reality, access to social support for people living with HIV is limited to support from NGOs, Faith Based Organisations and community based organisations (CBOs). Funding for social support is severely constrained despite increasing demand for social support services[96].

- Donor interest and funding for HBC is generally decreasing[97].
- Despite efforts to address it, human resource constraints remain a critical challenge at programme and facility level, this is evident in both the implementation and the monitoring of the response[98].
- HEWs are unlikely to be able to provide care for the volumes of people living with HIV and additional support from community members will still be necessary[99].
- Political commitment and leadership varies by level and sector. Sub-regional and non-health leadership is not as strong as it could be and this has limited the quality and success of the HIV/AIDS response in general[100].

Identified gaps

- While VCT has increased in scope and coverage among the general population, vulnerable and most-at-risk groups are not benefiting at the same level[101].
- Non-government activities, including those of civil society have not been included in the planning process of the SPM, this has meant that their activities have been largely uncoordinated and unrecognised[102]. This is an important point as it tends to be community organisations which are involved in care and support on the ground.
- The current M&E system does not fully capture care and support. Activities carried out by partners are not collected by the system while indicators, data collection, reporting tools and the data verification process are neither harmonised nor standardised. Furthermore, there is a lack of baseline data for many indicators with some indicators not being compatible or measurable with information collected through the current data collection system[103].
- The system which monitors treatment, care and support does not link with nutrition or food security indicators, making the identification of nutritional progress difficult[104].

Case Study: The Household Economic Strengthening Program

Funded by the Royal Netherlands Embassy (since 2004) and implemented by Family Health International (FHI), the Household Economic Strengthening (HES) Program aims to improve the socio-economic status of target groups through strengthening and increasing the scope of care and support referral networks for people living with HIV and/or those living in extreme poverty and through vocational training and income generating activities for poor women.

FHI and its partners have established multi-sectoral referral networks at the community level in six towns. These networks have allowed community level representatives and service providers to come together to ensure people living with HIV and the very poor access the services they need. Services include health, education for children and adults, nutritional support, shelter, legal support, psychosocial support and access to voluntary training and income generation activities.

The programme is implemented locally by organisations already providing HBC (implementing agencies-IAs). Networks have been formed by an IA leading a consultation with interested government, NGO, civil society, and people living with HIV stakeholders to explore the potential network, map the resources and services and elect members. Network committee members are trained in establishing, facilitating, managing and monitoring referral networks. An agreed action plan is developed and network participants facilitate and follow up the referral of people in need within the community. The functioning of the network is discussed regularly and monitored.

Outcomes of the programme

Monitoring of the number of referrals made and subsequent services received showed a high level of service uptake among those referred (on average 90%)[105].

Positive benefits of the programme, beyond access to services through the referral network include:

- An improved knowledge of care and support services among all stakeholders due to the mapping process.
- Improved coordination of services for the poor, reducing duplication and enabling services to be easily tracked.
- Services have been expanded through the increased momentum for volunteering.
- The range and quality of services provided has been improved through the forum environment which has engendered creative thinking in the face of resource limitations.
- The way the programme is set up enables communities to define the poorest and most in need.
- The use of referral slips from the network reduces the paperwork involved in accessing services which subsequently increases access, especially for the poorest who may find bureaucratic processes more difficult to navigate.
- The principle of referral making is established within the community with roles established and respected.
- The network has brought together stakeholders who may have previously been suspicious of each other such as government departments and NGOs with each recognising the strengths in each other.
- The committee provides a useful forum for exchanging information about new resources and initiatives available.
- Services have been provided in a cost effective way to those who would not previously have been able to access them.

Challenges and lessons learned of the programme

A review of HES has raised a number of challenges and lessons learned which include:

- Some services providers have been reluctant to join the network and some networks have been less successful than anticipated. This has led to the under utilisation of some services.
- Communities were not routinely and proactively informed about the network which has led to low awareness.
- The quality and commitment of the committee members has an impact on the number of referrals made. Weaker committee members lead to fewer referrals.
- The involvement of the private sector in most networks is limited, this may impact the range of services available.
- Demand can outstrip supply which can be exacerbated under successful networks where awareness is high.
- Withdrawal and absenteeism among committee members is a major problem caused by a number of factors including a lack of time, a lack of authority within their own organisations, high turnover of committee members and a lack of training. Weak committees lead to poorer functioning networks.
- Monitoring and communication can be improved to ensure that adequate detail is collected on referral networks and that enough information is shared.
- The long term success of the network relies on local ownership of the network[106].

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