Community and Home-based Care in Nepal

Findings and Recommendations from a National Program Review

June 2007

A Joint NCASC/GON, USAID and ASHA Project Collaboration
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Foreword

With more than 70,000 people estimated to be living with HIV in Nepal, there is an urgent need to scale up HIV care, Support and treatment services. Community and home-based palliative care (CHBC) services form a very important part of the care package that needs to be available to people living with HIV (PLHA) and their families. The importance of CHBC and the future plans of NCASC to support these services are outlined in the national HIV/AIDS strategy for 2006 - 2011 and Nepal's plan to achieve universal access to HIV prevention and care services by 2010.

In order to better support the rollout of CHBC services, NCASC with assistance from USAID and FHI conducted and national review of services. This review entailed in-depth assessment of the services model and quality of care of nine CHBC programs across Nepal. It also included interviews with nearly one hundred PLHA and family caregivers, and more than seventy key informants. A range of key stakeholders were involved in the assessment including WHO and UNAIDS; several NGO and PLHA groups and government officials and health care providers from District Health Offices (DHo/DPHO), District AIDS Coordiantion Committees (DACCs) and hospitals.

It is sincerely hoped that the findings and recommendations from this report will help guide future implementation and scale-up of community and home-based palliative care services in areas of need in Nepal.

NCASC is deeply committed to working closely with partners put into action the key recommendations from the review.

I would like to sincerely thank those who generously contributed their time and energy to conduct the CHBC review, including representatives from USAID, FHI, the National Association fo People Living HIV/AIDS in Nepal (NAP+N), Sakriya Sewa samaj, Nava Kiran+, Youth Vision, Naulo Ghumti and SPARSHA.

I would also thank all those in NCASC who participated in and provided thoughtful comments to this very important national assessment.

Sincerely,

Dr. Padam Bahadur Chand
Director

Stop AIDS, Keep the Promise
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
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<tr>
<td>ARV</td>
<td>Antiretroviral (medicines)</td>
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<tr>
<td>CDF</td>
<td>Community Development Forum</td>
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<td>CHBC</td>
<td>Community and Home Based Care</td>
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<tr>
<td>CoC</td>
<td>Continuum of Care</td>
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<tr>
<td>DACC</td>
<td>District AIDS Coordination Committee</td>
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<tr>
<td>DFID</td>
<td>Department for International Development</td>
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<tr>
<td>DOTS</td>
<td>Directly Observed Treatment, Shortcourse</td>
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<td>DPHO</td>
<td>District Health Office</td>
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<td>FCHV</td>
<td>Female Community Health Volunteer</td>
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<td>FGD</td>
<td>Focus Group Discussion</td>
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<td>FHI</td>
<td>Family Health International</td>
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<td>FSW</td>
<td>Female Sex Worker</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>HMG</td>
<td>His Majesty's Government</td>
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<td>IBBS</td>
<td>Integrated Bio-behavioral Survey</td>
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<td>IDU</td>
<td>Injecting Drug User</td>
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<td>INF</td>
<td>International Nepal Fellowship</td>
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<tr>
<td>KI</td>
<td>Key Informant</td>
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<tr>
<td>M&amp;E</td>
<td>Monitoring and Evaluation</td>
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<tr>
<td>MoHP</td>
<td>Ministry of Health and Population</td>
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<td>MSM</td>
<td>Men who have Sex with Men</td>
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<td>NAP+N</td>
<td>National Association of People Living with HIV/AIDS in Nepal</td>
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<td>NCASC</td>
<td>National Center for AIDS and STD Control</td>
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<td>Non Governmental Organizations</td>
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<td>Nepal National Social Welfare Association</td>
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<tr>
<td>ORS</td>
<td>Oral Rehydration Solution</td>
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<tr>
<td>PLHA</td>
<td>People Living with HIV and AIDS</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother-to-Child Transmission</td>
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<tr>
<td>QA/QI</td>
<td>Quality Assurance/Quality Improvement</td>
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<tr>
<td>SOP</td>
<td>Standard Operating Procedure</td>
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<tr>
<td>SPARSHA</td>
<td>Society for Positive Atmosphere and Related Support to HIV/AIDS</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations Program on HIV/AIDS</td>
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<td>USAID</td>
<td>United States Agency for International Development</td>
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<td>VCT</td>
<td>Voluntary Counseling and Testing</td>
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<tr>
<td>WATCH</td>
<td>Women Acting Together for Change</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Quotes

Quotes from people living with HIV

“The home-care service is a life-line, without it we would not be alive today”
- PLHA, Kanchanpur

“CHBC is hope, that's why we named our group New Hope”
- PLHA, Kanchanpur

“If CHBC team had not come to my home I would be dead”
- PLHA, Pokhara

“CHBC is a friend to our heart”
- PLHA, Pokhara

“Now that the team has helped us live, we need help with living”
- PLHA, Doti
Executive Summary

“The home-care service is a life-line, without it we would not be alive today”
- Female PLHA, Focus Group Discussion, Kanchanpur

In Nepal there are an estimated 70,000 people living with HIV (PLHA). To address the HIV care needs of those living with HIV, the National Centre for AIDS and STD Control (NCASC) draft strategy for 2006-2011 details the need for expansion of HIV care services at every level through hospital and community and home-based palliative care services to achieve universal access by 2010.

As HIV care services have developed and expanded across Nepal, CHBC programs have grown from a few informal services in Kathmandu and Pokhara to eighteen programs meeting the needs of several hundred PLHA. These services extend the entire length of Nepal and are available in communities as diverse as mountainous Doti and the eastern Terai city of Dharan.

In order to assess the quality and appropriateness of the increasing number of CHBC services, NCASC, United States Agency for International Development (USAID) and Family Health International (FHI) initiated a formal review of a sample of nine CHBC programs in Kanchanpur, Doti, Kapilibastu, Pokhara and Kathmandu. A team comprised of NCASC, USAID, FHI, the National Association of People Living HIV/AIDS in Nepal (NAP+N), Sakriya Sewa Samaj, Nava Kiran+, Youth Vision, Naulo Ghumti and SPARSHA assessed the quality of CHBC services using a package of assessment tools including guided interviews, questionnaires and focus group discussions. A total of 74 CHBC providers, managers and key informants were interviewed, 16 home-visits observed and 95 PLHA and family caregivers met with to assess perceptions of service quality.

The review found that CHBC services are providing essential care to PLHA and their families. They are significantly contributing to the national response by reinforcing ART adherence, improved referrals and follow-up between the community and hospital, increased self-care and understanding of HIV disease among clients and their families and reduction of stigma and discrimination in many of the communities where services are offered. PLHA, families and HIV clinics highly appreciate the care provided through CHBC services and requested they continue and be made available to a greater number of PLHA.

While the model of service delivery is effective there are missed opportunities in developing the capacity and role of the public sector in CHBC services, particularly in areas where the District Public Health Offices (DPHO) and District AIDS Coordination Committees (DACC) are active and supportive of community HIV prevention and care activities. One of the primary recommendations of the review is the need for increased cooperation with DPHO and DACC and where feasible, exploring models of local health care worker involvement in CHBC.

Findings from the assessment clearly highlight the value of CHBC services and underscore the primary recommendation of the review: that NCASC continue to support increasing access to community and home-based palliative care as part of its national strategy and identify ways in which to expand reach and integration or linkages of these services into the public health care system. It is hoped that findings from this review will help to guide the finalization of national CHBC guidelines; the development of SOPs, M&E program indicators and a CHBC medicine supply distribution system; and integration of CHBC services into the DPHO, local public health care systems and the community.
Summary of Key Findings and Recommendations

Key findings

✧ CHBC services are highly valued and appreciated by PLHA, families and hospital-based HIV care service providers.

Across all sites, in urban, rural, Terai and hilly regions, people living with HIV and their family members reported deep appreciation of the services provided by CHBC teams. CHBC providers were repeatedly referred to as life-savers or life-lines. Likewise, in areas where referral relationships existed between CHBC teams and the local hospital, hospital staff identified CHBC as a major support to clinical services including follow-up, timely referrals and adherence support. CHBC program managers and teams also reported being gratified by the impact of their work.

✧ The CHBC service model is appropriate and effective but there are missed opportunities.

Seven of the nine programs assessed were providing care of good quality to PLHA. A few (two) were providing excellent care. While there are improvements which could be made in all the programs assessed, the structure of the CHBC teams, their client load, and reporting and management systems were in general appropriate and effective. It was clear that programs were making an effort to maximize local resources to make the services as cost-efficient as possible. Several of the CHBC teams interviewed are already working at capacity and some were facing challenges in reaching clients who live far from the program base. Doti in particular poses a number of challenges in routine client access.

✧ Good coordination between CHBC services and hospital HIV clinics but less links with other services.

All CHBC programs assessed had referral relationships with hospital-based HIV clinics and some had very active and dynamic systems. This included cross referrals by teams and hospital staff, clients being accompanied to the hospital to access services and telephone contact between teams and the hospital to follow-up on referrals and clients who had been discharged. In a few cases, CHBC teams worked as part of the hospital HIV clinic and PMTCT services providing counseling, peer education or general support. However, formal referral systems between the hospital and the CHBC service were lacking in many areas including Pokhara and Kathmandu. Hospitals interviewed in these areas requested that a formal referral system be developed which included standardized referral forms and referral standard operating procedures. Links with other HIV care services were not as evolved. Where the crisis center and CHBC service were offered by the same NGO, services were well coordinated. However, among crisis center staff interviewed in a stand-alone site, lack of coordination between CHBC services and the crisis center was felt to hinder referrals to/from the centers and the community.

✧ Lack of national CHBC policies or guidelines.

In the absence of NCASC CHBC guidelines or standards, CHBC programs are operating without common parameters of what constitutes quality of care. The lack of guidance has led to variations in the overall quality of services provided. While the national training package has contributed to teaching CHBC teams to a certain standard of care, without national quality standards there is no
common basis from which to assess and judge the quality of care being offered. Guidelines and standards are essential in all areas of health care and very important in ensuring a common understanding and application of quality services.

- **National CHBC training certification package important to providing quality care.**

  Across the nine CHBC programs assessed, the majority of providers had participated in the national CHBC training. From the assessment it was observed that those who had been trained were providing higher quality care than those who had not yet been trained. However, many key informants felt the training was not long enough in order to help trainees master core skills. The training also does not include important areas of care such as caring for HIV infected and affected children and PMTCT.

- **Inconsistent availability of CHBC kit supplies.**

  There is currently no national standardized CHBC formulary in place which describes which palliative care medicines, nursing care materials and infection prevention supplies are at minimum part of a CHBC kit. There are variations in the types of CHBC medicines programs are using and different systems some effective and some not so in managing the storage, distribution and restocking of CHBC kit supplies. In nearly all programs, supply stock-outs were observed. A benchmark of quality services is having consistent and correct supplies needed to provide palliative care.

- **Need for further supervision support.**

  All CHBC programs assessed had supervision systems in place, but only a few supervisors were routinely accompanying teams on home-visits and none were using the supervision checklist to guide supervisory visits. Supervisors play a vital role in supporting teams to maintain quality of service.

- **Lack of coordination between CHBC programs and the DPHO, DACC and community level public health services.**

  Despite relatively strong relationships between the CHBC teams and hospitals only a few CHBC programs had developed relationships with the DPHO and DACCs. In many cases, the DPHO and DACC were unaware that the CHBC services existed in their area. Pokhara and Kapilbastu DPHO staff interviewed were supportive of working closer CHBC services but Doti was the only site where the DPHO, DACC and local health workers were truly involved in CHBC services. In the remaining sites, there were no or limited connections between the CHBC service and local public health care system.

- **High expectations of clients from CHBC services.**

  Many CHBC teams and managers were concerned by the expectations placed on CHBC teams to address the multiple social and economic needs of their clients. Areas which teams felt particularly unable to address were helping client secure adequate livelihoods, food and care and schooling for children. A few (two) NGOs offering CHBC had successfully mobilized community, local government and NGO support to support client livelihood development, access to food and enrollment of children in school.
Uneven involvement of PLHA in CHBC programs.

PLHA need to be partners in the development, provision and assessment of CHBC services. The most successful CHBC programs in Asia are those which support mutually empowering, synergistic pairing of PLHA with health care workers and social workers. While PLHA were involved in all services assessed, the level of involvement was variable. In some programs, PLHA were taking the lead or were equal partner, in others this was not the case.

Lack of involvement of community in CHBC services.

Most of the CHBC programs visited had not yet begun mobilizing support from community, local government and NGO services. However, all services assessed identified the value of mobilizing the community to support and be a part of CHBC. These included: 1) helping to meet the income generation, nutrition, schooling and other support needs of clients which CHBC programs are not fully able to address themselves, 2) reduce stigma and discrimination and 3) further build the sustainability and acceptance of the program in the community.

Limited knowledge and skills in PMTCT and caring for HIV exposed, infected and affected children.

CHBC providers are seeing increasing numbers of children exposed to, living with and affected by HIV in their services and lack of basic skills in how to meet their physical, emotional, social and spiritual needs. Many teams were also unfamiliar with the national PMTCT program and how to support client access to and follow-up once enrolled in the service. This is in part due to the fact that pediatric HIV care services are relatively new and that the initial CHBC training did not provide adequate knowledge and skills building in PMTCT and pediatric care.
1. Increase access to CHBC services and explore new service delivery models. CHBC programs are providing much needed services to PLHA and families in Nepal and should be made available wherever HIV care is needed and there is demand for the service. The current service model is appropriate but other models should be explored to maximize involvement of the public health care system. (See recommendation 5).

2. Provide guidance and a policy framework for CHBC. NCASC can lead CHBC policy making by finalizing and disseminating the draft national CHBC guidelines and by developing standard operating procedures to promote a standard of quality care across all CHBC programs. Both these steps are highlighted as part of the 2006-2011 National Strategic Plan for HIV/AIDS Control.

3. Develop a CHBC drug supply chain management system. To ensure stable supply of essential palliative care medicines and supplies to CHBC programs - both government and NGO/PLHA group run - NCASC will need to lead a process of developing a system to provide standard CHBC kit supplies to CHBC programs. This recommendation recognizes that in many areas developing a stable and functional drugs supply chain system in Nepal is a challenge. However, there are a number of steps that could be taken by NCASC and partners in the immediate term to improve access to CHBC medicines and supplies which are described in the detailed recommendations section of the report.

4. Integrate CHBC into the national HIV M&E system. NCASC is in the process of developing program level indicators for technical components of the national strategy including ART and PMTCT. A set of core program indicators for CHBC should also be determined. These indicators should be referenced in the national CHBC SOP including guidance and forms to be used in reporting in indicators. Tracking key indicators will improve overall mapping of service coverage and contribute to universal access goals.

5. Establish closer relationships between CHBC services and DPHO, DACC and local public health sector. The DPHO and DACC are essential to strong, well supported CHBC services. Through the assessment, DPHO expressed interest and willingness to support and supervise CHBC services but they also requested that: 1) NCASC provide them with guidance as to their role in CHBC; 2) they be oriented in CHBC services and 3) that CHBC providers give them regular activity reports so they were aware of achievements to date.

6. Improve supervision and QA/QI systems. CHBC program managers need to be trained in what to look for in assessing the quality of CHBC services. They also need to make a point of accompanying CHBC teams during home-visits and other activities to observe the quality of work. All managers should use a CHBC supervision checklist such as the one used in this program assessment. A system of routine (eg 6 monthly) QA/QI should also be instituted to comprehensively assess progress in improving quality of the CHBC program. The DPHO and DACC should be invited to participate in or lead this process.

7. Increase PLHA and community involvement in CHBC. It is recommended that programs which do not yet have strong involvement of people living with HIV in the program identify PLHA as team members.
leaders and members. PLHA should be working as leaders and partners in all CHBC services. This is essential to quality care for PLHA. In most of the programs assessed, the community (including the DPHO and DACC) were not involved in the program. This is a missed opportunity to sensitize community members to HIV, to reduce stigma and discrimination and to elicit their support. All CHBC programs need a community mobilization component to their work. CHBC services should also strive to work closely with crisis centers in their area to strengthen the continuum of care.

8. Increase diversity of referral relationships to address social and economic support concerns of clients. Only a few of the CHBC program assessed had actively sought and established partnerships with organizations in the community which provide social and economic support and care for orphans and vulnerable children. These formal referral relationships resulted in client needs in these areas being largely addressed. It is recommended that all CHBC programs map key services in the community offering assistance with livelihood, food security and supplementation and support for orphans and vulnerable children and advocate for formal program and referral linkages.

9. Train and support CHBC teams to provide family-centered care. CHBC teams need to be trained to provide vital assistance in helping couples, pregnant women to access and remain in PMTCT services. They also need to be trained providing follow-up care to mothers and infants including supporting infant feeding choices, cotrimoxazole prophylaxis, linkages to pediatric HIV testing and counseling, ability to recognize danger signs in mothers and children and refer, palliative care and treatment support for children with HIV and care and support for children affected by HIV.
I. Background

Continuum of Care: Providing essential palliative care and treatment services

The ultimate goal of HIV care is to help people with HIV and their families live longer and better lives. To achieve this, PLHA need access to the multiple services over the course of their lives. If services offered at the home, community and facility level are well linked, they can provide an overall package of holistic care aimed at addressing the physical, emotional, social and spiritual needs of PLHA and families. This network of linked services is known as the continuum of care.

Services which are essential to good care are palliative care—an approach which improves the quality of life of patients and their families facing life-threatening illness through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems, and provision of antiretroviral therapy. Palliative care includes the prevention and treatment of opportunistic infections, management of pain and other symptoms, nutrition, and emotional, social and spiritual support. Both palliative care and treatment need to go hand in hand to improve the wellbeing of PLHA and their loved ones.

While treatment services are generally provided through hospital and clinic-based services, palliative care can be offered through many different settings including community and home-based care programs, hospice, out-patient and in-patient clinical services, and centers caring for children with HIV.

What is community and home-based palliative care?

Community and home-based palliative care is a very important component of palliative care because it helps PLHA and families at different stages of disease cope with the many challenges of HIV, including counseling and disclosure, healthy living and self-care, management of pain and other symptom care, ART adherence and care for side-effects, access to social and other support services, end-of-life care and support to children and other affected family members. If CHBC services do not meet a minimum standard of care in addressing physical, emotional, social and spiritual suffering, then they do not qualify as palliative care programs but only as supportive care services.

Studies have shown that CHBC services can increase ART adherence, family and community acceptance, and improve quality of life. They can also reduce the overall cost of care for hospitals and the health care system because it promotes rational use of services.

CHBC is care in the home and community which responds to the physical, social, emotional and spiritual needs of PLHA and family from diagnosis to death and through bereavement. It aims to reduce suffering and increase quality of life by providing responsive care, increasing self-care skills, linking clients to needed services and empowering PLHA and families to manage HIV in the home and community.
HIV in Nepal

There are an estimated 70,000 people living with HIV in Nepal, the majority of whom are unaware of their HIV status. According to NCASC records, by the end of May 2007 there were 9532 people reported to be living with HIV, more than 70% of whom are male.

According to NCASC 2005 data, HIV prevalence in Nepal is 0.5% among the general adult population. HIV prevalence is estimated to be 1.5% among female sex workers in the Terai highway districts, and 52% among injecting drug users (IDU) in Kathmandu Valley (FHI/SACTS 2005). Estimates of prevalence among labor migrants returning from India range from 1-3%. However, HIV prevalence among the migrants who had sex with sex workers in India is estimated to be as high as 8% (IBBS, 2006). Men who have sex with men are also highly affected by HIV. HIV prevalence is 3.9% among MSM and about 5% among male sex workers (IBBS, 2004).

The majority of people living with HIV are located in the far west where the epidemic is characterized by migration to and from India; the Terai where mobility, sex work and drug use are factors in exposure to HIV and in Kathmandu, Pokhara and the East where injecting drug use is a major cause of HIV transmission.

**Care, Support and Treatment**

HIV care services are increasingly available in Nepal. An estimated 950 PLHA are now on ART and a few thousand receiving palliative care. Care services vary in quality but at minimum are offering hospital-based anti-retroviral therapy and palliative care services for adults and, in some cases, children. Hospital based services include prophylaxis and treatment of opportunistic infections.

In a growing number of sites in Nepal, formal community and home-based care (CHBC) services are being offered to PLHA and families as part of a continuum of care (CoC) approach. The CoC is being implemented to provide a network of linked care services from home and community to health care facilities, facilitating improved access to and follow-up from HIV care services.

**Community and home-based Care in Nepal**

**CHBC at the policy level**

The National Center for AIDS and STD Control (NCASC) identified the need for community and home-based palliative care (CHBC) services in 2002, outlining a plan for delivering CHBC services in the National Strategic Plan for HIV/AIDS Control 2002-2006. Over the course of this plan, NCASC, with support from the US Agency for International Development (USAID) and Family Health International (FHI), led the development of a national training certification program in CHBC. As a result more than one thousand providers were trained in caring for people living with HIV and their families. NCASC also convened a national working group which developed draft national guidelines on CHBC.

The draft National Strategic Plan for HIV/AIDS Control 2006-2011 calls for a comprehensive CHBC program. Some of the key results and actions related to CHBC include:
**Strategic results**

- Increased number of trained community workers, volunteers and family members in CHBC
- Established linkages developed between health facilities and CHBC workers and programs
- Increased availability of integrated and comprehensive services at the community level

**Key actions**

- Ensure policies, strategies, guidelines and manuals for incorporating home-based care into overall national health systems
- Ensure core training competencies and curricula for community health workers and treatment supporters
- Endorse national guidelines for home care services, including basic palliative care by family members and community volunteers
- Define comprehensive package for CHBC and ensure that services are adequately delivered and used and that the quality of care is maintained
- Set monitoring and support systems for community based treatment supporters and care providers

**Status of CHBC Services in Nepal: A Snap-shot**

HIV care services are relatively new to Nepal and CHBC is no exception. The first CHBC programs were developed about two years ago with the majority starting in the past year. While services are relatively new service, their development and client uptake has been rapid. During the course of the CHBC program review it was found that more CHBC programs are planned to start within the next year.

There are currently eighteen CHBC programs in operation or planned in Nepal estimating to be reaching more than 1000 people living with HIV\(^1\). The CHBC service map below features the location of known current and planned CHBC sites. CHBC services are located in areas of higher prevalence, mostly based in NGO/PLHA group supported care sites (eg VCT/STI/HIV clinics).

The findings in the section III provide more detailed information on the CHBC program approaches used by the nine CHBC services assessed in depth.

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1. This estimate is extrapolated from the average number of clients which the nine organizations included in the program review care for.
CHBC Support Sites in Nepal
II. CHBC Program Review Objectives and Methodology

● Objectives

- The overall objective of the CHBC program review was to assess the level of quality of current CHBC programs and gage their appropriateness in meeting the needs of people living with HIV and their families in different contexts. Specific objectives of the assessment were:
  - Review overall level of quality of CHBC services
  - Identify training and capacity building needs of CHBC service providers
  - Assess level of PLHA and family satisfaction with services
  - Assess the extent to which CHBC is linked to facility-based HIV care, treatment, support and prevention services (continuum of care)
  - Determine appropriateness of current CHBC service structures in different settings
  - Provide recommendations on future scale-up of CHBC services, and on national CHBC guidelines, standards and tools

● Methodology

A combination of process evaluation methods and tools were used in the CHBC program review. They included the following:

1. Desk review  The following documents were identified during the desk review as important in providing context and background for the CHBC program review: the draft National Strategic Plan for HIV/AIDS Control 2006-2011; reports related to the MoHP’s approach to universal access to HIV prevention, treatment, care and support services, the draft national HIV M&E framework and the draft national strategy for CHBC.

2. Key informant interviews  Key informants interviewed included individuals or organizations that were either working in the area of CHBC or who were policy or opinion leaders in HIV care. Interviews were conducted with national leaders and local leaders in all review sites including NCASC, DPHO, DACC, hospitals and crisis centers. They were also conducted with technical and program leaders including WHO, UNAIDS, NAP+N and several others. (See Annex 2 for a complete list of key informants.)

3. CHBC program review package  A community and home-based palliative care program process evaluation package was developed by FHI and partners. The tools were adapted from FHI CHBC QA/QI tools, supervision checklists and a CHBC assessment package prepared by Eric Buch, University of Pretoria, South Africa.²

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The CHBC program assessment package included the following components.

- CHBC QA/QI Checklist: an overall tool used to assess and grade the quality of the CHBC service
- Guided in-depth interview with CHBC program managers and CHBC teams: this comprised of a set of structured and semi-structured questionnaires aimed at gathering basic information on the CHBC service
- Observations of two home-visits per CHBC program using the QA/QI checklist
- Client satisfaction interviews - focus group discussions (FGDs) conducted with PLHA and family caregiver clients. FGDs were facilitated using a topic guide. Focus group discussions were done in private, without the presence of CHBC program managers or teams.

Figure 1 CHBC Program Review Process
CHBC Review Sites and Programs Assessed

A total of five sites and nine CHBC programs were selected for the CHBC program review. Sites and programs were selected based on achieving geographic diversity, a range of client populations and a combination of urban and rural contexts. The review was conducted in the following five locations: Doti, Kanchanpur, Kapilbastu, Kaski (Pokhara) and Kathmandu Valley.

The nine CHBC programs were selected out of a total of eighteen known CHBC services in Nepal. The following table outlines the CHBC review sites and programs assessment.

Figure 2 CHBC Program Review Sites and Services

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<th>Location</th>
<th>Name of NGO</th>
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<tr>
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<td>Nepal National Social Welfare Association (NNSWA)</td>
</tr>
<tr>
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<td>Sakriya Sewa Samaj</td>
</tr>
<tr>
<td>Kapilbastu</td>
<td>Women Acting Together for Change (WATCH)</td>
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<td>Naulo Ghumti Nepal</td>
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<td>Youth Vision (YV)</td>
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<tr>
<td>Kathmandu</td>
<td>Sahara Plus</td>
</tr>
<tr>
<td>Kathmandu</td>
<td>Society for Positive Atmosphere and Related Support to HIV and AIDS (SPARSHA)</td>
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Review Team

The CHBC program review team represented leaders across government, PLHA groups, local and international NGOs and donors. The review team comprised of eighteen individuals representing the following organizations: NCASC, USAID, FHI, NAP+N, Sakriya Sewa Samaj, Nava Kiran Plus, Youth Vision, Naulo Ghumti and Sahara Plus. Team members were knowledgeable and experienced in CHBC in Nepal; most were CHBC leaders, trainers or providers. See Annex 1 for a complete list of the review team.

To prepare for the CHBC program review, the entire team was trained in use of the review tools over a three day period. The training included detailed review and modifications of all the tools based on team feedback, practice use of the tools, field testing and making final medications to the tools based on field testing results.

Teams were divided into five groups. Each group was responsible for key informant interviews and for conducting the in-depth CHBC program review of 1-2 services in one of the five designated site.
A number of individuals participated in the CHBC Program Review. A total of 28 key informants representing government, multilaterals, and local and international NGOs participated in the review. A list of all the individuals interviewed is detailed in Anne 2.

Through the nine CHBC program assessments a total of 46 CHBC managers and teams were interviewed regarding the service and their perceptions of successes and challenges. In the course of these assessments, 52 PLHA and 43 family caregivers were interviewed regarding the level of satisfaction with the CHBC services. A range of CHBC clients participated in the review including injecting drug users, sexworkers, men who have sex with men and migrants.

CHBC Program Review Participants
Figure 4 Program Review Participants

<table>
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<tr>
<th>Participants</th>
<th>Male</th>
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Participation in the CHCB program review was voluntary and participants were free to withdraw at any time. All people living with HIV and family caregivers were provided information regarding the purpose and option of participating in the focus group discussion and home-visit observations in advance of the review. Those who opted to participate in the assessment went through a formal informed consent process. Review teams were trained in protecting confidentiality. All focus group participants were remunerated to compensate for their time and travel-related costs.
• **Limitations**

The CHBC program review is a process evaluation; findings are not representative of all CHBC services in Nepal. There are currently eighteen known CHBC programs in Nepal. A total of nine CHBC services were selected purposively for review based on pre-determined criteria. The criteria were to identify programs which represented geographic and population served diversity. The aim was to get an overall sense of the quality of services and perspectives of PLHA, caregivers and key informants across a range of geographic locations serving client populations. CHBC program clients participating in focus group discussions are also not necessarily representative of the universe of CHBC program clientele. Findings from the program review cannot be generalized to apply to all CHBC programs in Nepal.
III. Findings

The service is a friend to the heart

1. CHBC Program Findings: Services, Systems, Successes and Challenges

A total of nine CHBC programs were included in the CHBC review. They were chosen from sixteen operational services across Nepal. The programs assessed were all managed by local NGOs.

Each CHBC program was assessed using a standardized review package. This included an interview with the program manager using an open ended questionnaire, an interview with the CHBC team using a closed and open questionnaire, two focus group discussions with clients one with PLHA and one with family caregivers, and two observations of home visits using a checklist.

The first section highlights results from the program manager and team interviews. As with all aspects of HIV programming, if managers are supportive they can be facilitators and champions of services, if not they may become barriers to optimal service delivery. A program manager was defined as an individual who was responsible for the overall management and running of a CHBC program but not a direct service provider.

Interviews with CHBC teams included all staff and volunteers full or part-time who were involved in providing care to PLHA.

All quotes included in this section are provided without indicating which organization said what in order to prevent singling out specific organizations for praise or critique.

- CHBC Service Structure and Approach
  - Overview
    All nine programs assessed had established community and home-based palliative care programs specifically to serve people living with HIV in their community. The oldest program assessed was two years old and the newest was three months. The average duration of operation was a year.

    Despite the fact that services were newly established, all but the most recent program had developed clear systems and procedures for providing CHBC. For the most part, the programs had established a fixed catchment area, defined service package, CHBC kits, client record system, referral procedures, and relationships with a hospital-based HIV care and treatment clinic.

  - Origins of the CHBC Program
    All managers were asked a series of questions related to their understanding of CHBC and their commitment to CHBC services. The first set of questions related to why their NGO initiated CHBC services and why they felt they were important to PLHA. Below are some of the reasons they gave for initiating CHBC services:

    “We felt that quality of life of PLHA could be improved and we proved it (through CHBC services)”
“Some people (in the community) feel that HIV clients should be taken somewhere else away from the home we wanted to challenge (that idea)”

“Now that ART has started, CHBC is also needed for adherence”

“People were not getting any of the services they are (now) receiving service. So it feels good.”

“CHBC is helping PLHA to live a quality life. And it is very important…One of our clients who were in our CHBC service now has started a support group. He was dying when we started CHBC to him...We saved so many lives through palliative care. A client was dying, but now he is living healthy and doing business also. That gives us satisfaction.”

● Service package and client needs

Both CHBC teams and program managers were asked to spontaneously describe the types of services they provided to clients. All teams stated they provided emotional support and counseling and that they gave ART adherence support. Most teams stated they provided pain and other symptom care, nursing care, teaching self-care skills, links to TB screening and treatment, prevention counseling and linkages to PMTCT. Half of the programs stated they gave nutrition support to PLHA, but only a few stated they provided income generation support, care of children and help with medical related fees (eg laboratory investigations).

All services offered are free and each program had clearly defined their service package so that teams and clients were aware of what the teams could and could not provide.

The service package is in line with the major clients needs identified by CHBC teams during the assessment. These include pain and other symptom care, counseling and emotional support, nursing care, teaching PLHA self-care skills, ART adherence counseling and support managing side-effects, TB treatment, referral assistance, prevention counseling and PMTCT counseling and follow-up. However, CHBC teams also reported that clients had major livelihood support, food and schooling needs which they were unable to address. This is discussed in detail in section 2 of assessment findings.

● Team staffing, structure and supervision

Since most of the NGOs which provide CHBC are also involved in HIV prevention, STI service and HIV counseling and testing, the CHBC teams are as an extension of that work and based in the same facilities providing these services.

CHBC teams were asked to describe the staffing structure of the CHBC teams. On average the CHBC programs assessed employ six staff who supervise and provide services. Each of the nine NGOs interviewed had established teams ranging from two to six individuals CHBC team members and project coordinate work as supervisor. The majority of programs supported teams of two or three individuals. CHBC teams comprised of a combination of a
PLHA, health care worker and in some cases a community social worker. All programs employed PLHA as staff CHBC providers. The majority of programs had a system of team leaders in place to ensure one person was responsible for the overall management of each CHBC team. While staffing structure was relatively clear and well organized four of the organizations interviewed had not provided teams with job descriptions.

Only two of the programs assessed involved volunteers in service delivery. Further exploration could be done in the role of volunteers in supporting CHBC services, particularly as the client base increases for programs.

All but one of the CHBC programs reviewed had CHBC teams which had received national CHBC certification training.

In order to gauge the level of support which program managers felt they were providing to CHBC teams they were asked what type of assistance they provided to the teams. Most managers described providing active support to CHBC teams particularly in the area of referrals and coordination with other service providers and assisting in managing difficult cases.

“When we have to refer PLHA, I find out who to call, what to do."

“One thing I remember was for one of our client who was an IDU and in jail. His wife is dead. He has one daughter. We tried to help her out and ask many people but nobody came. At last we successes to send her to xx. But there are some criteria of legal document. I helped her for that.”

However, few program managers were conducting supervision of CHBC visits in the home and a few had never accompanied their teams on a home visit before.

Geographic coverage and client load

Each program had defined their geographic target area based on client location, transport, accessibility and other service providers in the area. In one site, two services were found to be working in the same area without realizing the duplication of efforts. In all other sites, CHBC service providers had worked with the other programs in their area to decide who would work where and with whom.

A total of 451 clients were being cared for, an average of 56 clients per organization. Just under half of clients were women and 64 were children (defined as under the age of 18).

The number of clients on average per team varied based on geographic constraints. On average each team had 30 clients. An optimal average number of clients per CHBC team is often stated as from 30-40 clients given variable such as frequency of visits per client and geographic location of clients. The ratio consists of two to three CHBC visits a day, visiting each client on average at least two to three times a month.
Teams were also asked how many clients they visited a day and how often they visited each client. Frequency of visits ranged from two times a week to once a month, most programs reported seeing clients two to three times a month. Average clients seen a day ranged from two to six with an average of three visits a day and 16 visits a week.

It is clear that teams in their current structure are reaching the limits of capacity and that as client numbers continue to increase strategies will need to be developed to manage growth, balancing coverage with service quality.

However, only five of the programs had a system where each team has a fixed client base. The other organizations visited clients in a less structured manner with clients being visited by different providers.

- CHBC kits and filing systems
  All CHBC programs assessed had CHBC kits which included a list of standard supplies and some form of a stock ordering and inventory system. However, almost all programs reported stock-outs of essential supplies such as analgesics, scabies treatment, antihistamines and vitamins.

*Figure 5 Example of a CHBC kit*

The CHBC program filing systems were in most cases acceptable. Files were coded and organized by catchment or purely by code number. Files were kept in a locked cabinet to which only CHBC teams had keys. Only one organization did not have an adequate filing system in place.
All CHBC services were referring clients to local hospitals but not all had established adequate referral systems with the hospital. Hospital staff in a few cases requested that formal referral relationships be established between CHBC and hospital services.

A few crisis centers were included in the review to assess linkages between them and CHBC services. Crisis centers provide refuge for individuals who do not have homes or who are unable to return home. These services provide much needed support but to enhance benefit to people with HIV could be better linked to CHBC services. Coordination between crisis centers and CHBC services can ensure that when people are ready to return home, they can be well supported by CHBC services in the process.

While CHBC managers and teams sited a number of local NGOs and programs they have relationships with there is still work to be done in identifying partners who can help meet the expressed needs of clients livelihoods, food and schooling support for children.

CHBC Program Successes and Challenges

During the program assessment CHBC program managers and teams were asked to reflect on what they thought were the most valuable aspects of their work, what they were most proud of and what aspects of the work they found most challenging. CHBC clients were asked similar questions during focus group discussions and their responses were very similar to those of the CHCB program managers and team leaders.

“As a CHBC team member and a PLHA I have confidence to mobilize community & be able to help others”

Successes

CHBC program managers and teams listed a number of aspects of their work they felt were important to PLHA and that they were most proud of. From the responses given, it is clear that managers and teams alike feel deep satisfaction with the care they’ve been able to provide PLHA and families. The services and systems they felt that had most benefited PLHA focused in counseling and building the self-confidence of PLHA, providing pain and other symptom care and enabling access to ART and OI treatment through referrals and support in the home. CHBC programs managers and teams expressed their opinions in the importance of CHBC in the following ways:

“PLHA have been empowered and can speak openly.”

“Building confidence of PLHA”

“Counseling is most important.”

“Symptomatic care, ARV adherence, emotional counseling, TB screening, counseling”
“Pain Management, wound infection management and dressing”

“Linkage for treatment and other services, especially ARV treatment and CD4 count.”

“Ensuring confidentiality of clients and their care givers”

“Community/caregivers participation in overall CHBC program”

All programs described success stories where they had been able to help PLHA regain their health, become more self-confident, independent and find stable income. The examples below indicate how hard CHBC teams are working to ensure their clients get the services they need whether it be ART, a job or access to schooling.

“(We have seen) significant improvement of clients from our 1st meeting with them and after only 1 month”

“One seriously ill PLHA became very well after starting ART. He’s been empowered, and now cares for PLHA friends”

“A self support group: the PLHA we support successfully received funds and are currently managing projects.”

“One person who was bed ridden is now looking after his own business.”

“One PLHA was about to die and the family lost hope. Our team made it possible for the PLHA to live quality of life and is currently working as a paid volunteer and supporting his family. He became a role model.”

“There was bandh and one PLHA had run out of ART medication and the CHBC team worked really hard to get the medicines to her, the finally got the medicines to her just in time”

“Another client was very sick, and could not even see clearly. But after the service he takes medicines regularly based on the sound they make in their container.”

“Counseling Once client, husband and wife did not have a good relationship, and after CHBC team started visiting them now they have good relationship with each other.”

“A patient was very sick, we counseled him, and provided CHBC service, and now he is running his own business.”

“One PLHA from poor family has a kid who is now getting a scholarship.”

“They were able to provide a child of a PLHA free tuition till 10th grade.”

Improved services systems were also listed as major achievements of the CHBC program. These include improved access to services, a referral system and the ability to use medicines for CHBC kits through the DPHO dispensary:

“Rapport Building; with hospital staff is essential and has been so helpful”
“Increased referrals to services.”

“Earlier there was no referral system, but now after CHBC program referral is increased.”

“We have been able to get medicines from DPHO.”

CHBC Teams also described specific components of their program that they felt were of high quality that other CHBC programs or policy makers could learn from. These areas included:

- Strategies used to provide ART adherence support
- Family-care and self-care skills building
- How to develop and support intersectoral teams CHBC teams consisting of strong PLHA and healthcare worker partnerships, and use of community volunteers, etc
- How to mobilize communities to support CHBC
- How to empower PLHA to lead care services and self-help activities
- How to provide routine, quality care and use the CHBC kit
- Health care and hygiene counseling
- How to cope with self-stigma and stigma and discrimination
- How CHBC is an integral part of HIV/AIDS programs

Gaps and challenges

CHBC teams were asked how well overall they were meeting the needs of their clients. All teams responded that they were able to meet their needs somewhat well. When asked what the major service gaps or challenges were for the CHBC program, managers sited high expectations among clients; difficulties in supporting clients to access livelihoods, adequate food and support for children to attend school, distance of clients from the CHBC program base and higher numbers of PLHA than expected accessing services.

During the interview with CHBC teams, they were asked to identify service gaps - areas they felt clients had needs which they were unable to adequately address. Gaps sited were:

- Income generation support (8/9)
- Nutrition support (6/9)
- Schooling support (5/9)
- Care for children (4/9)
- Cost of medicines, laboratory investigations, etc (3/9)
- Transport to the hospital/clinic (2/9)
In addition, program managers and teams described the challenges they faced in addressing these needs as well as other challenges.

“(The challenge is) expectations of PLHA. We are giving the services that we can do, but what about others like education for children and nutritional support. To make it sustainable other support are also needed.”

“Main challenge of CHBC program is PLHA clients are very poor financially, their need of livelihood. They expect more services from us like food, schooling their children, getting a job which we cannot fulfill.”

“The hospitals will make the clients pay for services. When in front of the team they will say they will do it for free (e.g. x ray) but we are not here they charge them. So clients are hesitant to go back to the hospital”

CHBC teams also listed programmatic challenges in providing CHBC. These included the accessibility of clients - many in need live in geographically diverse areas and some teams walk long distances to visit their clients, lack of national CHBC guidance and protocols, and the fact that not all CHBC team members had received CHBC training due to staff turnover.

Figure 6 CHBC Team in Kanchanpur
To gage levels of client satisfaction with CHBC services, focus group discussions were held with PLHA and family caregiver clients during each of the nine CHBC program assessments. A total of 52 PLHA were interviewed. Family caregivers were also interviewed in separate focus group discussions regarding their opinion of CHBC services. A total of 43 family members were interviewed through these focus group discussions.

The average age range of females interviewed was 22 to 42 and for males it was 28 to 65. Education levels varied but they were consistently higher among men and higher in urban areas. Most PLHA interviewed had children.

Across all sites, CHBC services were highly appreciated by PLHA and caregivers. Clients of the service and family caregivers stated several reasons for valuing the service. These included emotional support and help with managing issues of stigma and discrimination in the family, help in taking ART, assisting families in accessing the hospital and providing care for symptoms in the home.

The majority of PLHA clients stated that if the service had not existed, they would have died through lack of knowledge of how to care for themselves and how to access ART. They also cited the importance of CHBC teams in counseling the family and creating a supportive environment of PLHA in the home. Many PLHA responded that they were appreciative of the way that CHBC teams interacted with them, that they were respectful, kind and gentle.

“They have given us longer life, given us pride.”
“They give service with respect and dignity. They are very friendly and I really like that.”
“It helps guide us to live long and contribute in the family.”
“They are like teachers, respected ones, with what they have taught we have courage and skill to live and work.”
“We used to stay alone and cry... now we can talk to others and have encouragement.”
“Initially my family members did not like me but lately with help from team they love me and support me living at home”
“They showed us the way when we were feeling helpless.”

PLHA clients were asked to identify what types of care and support CHBC teams provide and what aspects of care they appreciated most. They listed being appreciative of self-care counseling and physical care, emotional support, referral and other services offered by the CHBC teams. Some of the quotes from the FGD include:

“CHBC teams listen to us, identify and discuss about problem, provide counseling & basic treatment.”
“I like the counseling and advice they give to me and my family. They mediate between me and my family.”

2. Perspectives of PLHA clients and family caregivers
“I like their advice and suggestion. I like the self care things they teach.”

“They remind us about taking ART medicine.”

“They look after the side effects of drugs and adherence.”

“There used to be stigma and discrimination at Teku, but because of CHBC it’s very easy.”

“I don’t have anyone to look after me at home, they look after me.”

“Important thing is they guide us, provide motivation to us, provide medicine for minor infections, and listen to our problems.”

“They teach us about treatments which we can do at home, how to take medicine, they are doing a lot of service. They educated me about CD4. I am on medication after doing CD4. They teach us about opportunistic infections.”

“I had sores from before and had to do dressing daily. They dress my wounds daily with respect and prestige. I won’t get that kind of service even in hospital.”

“CHBC workers would come, and when I was bed ridden they would clean my sores and do all kinds service.”

Stigma and discrimination

While levels of stigma and discrimination felt by PLHA varied, PLHA stated they felt more open in discussing their HIV status with their families and with the wider community than before they received the CHBC service. Concerns regarding stigma and discrimination were different depending on where the CHBC program was based. PLHA in Kanchanpur and Doti for the most part felt that the teams had helped to reduce stigma and discrimination to the point that it was no longer an issue. In Kapilbastu and Pokhara, about half of the PLHA clients interviewed were not open about their HIV status. Those who had not disclosed told people in the community that the teams were as friends of the family or from a charitable organization. In Kathmandu, stigma and discrimination appeared to be of greater concern for PLHA clients and caregivers.

Kanchanpur and Doti

“We are beyond stigma and discrimination here!”

“Before we used to feel discriminated, but not anymore.”

“At the hospital when I showed them my wound they would ask me to stay a little further away. But nowadays it’s not like that.”

“Now that the whole village knows it’s not difficult. Before no one even would come to the funeral of my husband.”
Kapilbastu and Pokhara

“We don’t have a problem, if someone does stigma and discrimination I fight…”

“I say that the team from my mom’s home.”

“I say they are from helping organization.”

“I am worried (about stigma and discrimination). I live on rent. I am worried that it will be bad if others find out. The team gives service secretly and I lie to my neighbors. But people talk behind my back and they cannot tell it to my face.”

“No. I don’t feel any problems. Before coming they ask us. They are aware that neighbors might say something. Neighbor suspect when I got to a lot of meetings, but I don’t care.”

“I am afraid that if landlord finds out, he might kick us out.”

“Nowadays there is very little discrimination. If I love a HIV+ person and if I don’t have it (HIV) there is no room for others to say anything.”

“At first when we were in the village there was a lot of discrimination. People would not even wash my children’s clothes. They would not invite my daughter in law to festivals. Then we left the village and came to the city, and there are very less problems for us in the city than in the village. I also tell the team to come freely.”

Kathmandu

“Yes that is there. My family members don’t know, if they know I maybe discriminated. So stigma and discrimination is there.”

“My family knows. My landlord also knows but they never discriminate against me.”

“We go in secret, so others don’t find out.”

“They have to say they are from an IDU related organization and not from CHBC or HIV.”

Priority needs and suggestions for how to improve the CHBC service

PLHA interviewed stated that income, food and schooling support for their children were among their most urgent needs. These priorities corresponded with suggestions in how to improve the CHBC service. One respondent captured the feelings of many focus group respondents:

“We know you will not be able to solve all our problems. You made someone about to die, stand up, that is like god. But it would be good if you could give us some basis for living.

More specific statements related to gaps and suggestions for further support from CHBC programs include:
Medical care

We need ARV and CD4 in the district

Livelihood

They should link us to other services and trainings for income generation

They have given us life but they need to also give livelihood.

It can be improved by providing us with economic support or services for fulfilling our basic needs like education for children, food, treatment, transportation etc.

Access to food

They saved our lives but we don’t have anything to eat. If we could get to eat, that alone would be good.

Schooling and other support for children

Our children need to be educated

I wish that my child would get good treatment.

Stigma and discrimination

If they could do more programs related to HIV in the community which would help reduce stigma and discrimination

Family Caregivers

Most of the family caregivers interviewed were women. While the participants in the FGDs were not representative of all client caregivers in the programs assessed the fact that only ten out of forty-three caregivers interviewed were men is striking.

Family caregivers also listed many similar benefits and opinions of CHBC. Family caregivers generally felt that CHBC had increased their confidence in caregiving and reduced their fear of HIV.

“It is like the proverb ‘Found god, while looking for a stone.’ Since they have started coming I feel comfort that I am not the only one with the problem.”

“Close contact and counseling from them reduces our mental stress and tension. Our minds become lighter”

“They guide us to care for our beloved at home”

“We used to have fear and now don’t have fear.”

“It (HIV) is as simple as other disease”
“We care for our family member at home and care with confidence.”

“They really treat us nicely, like one of the family. Even when my wound is infected they clean it and teach me also. They don’t leave in the middle, and they keep following up.”

Stigma and Discrimination

“There is still discrimination in hospitals doctors wear gloves if they know our status.”

Priority needs and suggestions for how to improve the CHBC service

Community awareness program in HIV/AIDS related stigma and discrimination is must.

I am very much worried about the future of my grandchildren.
3. Perspectives of Multilateral Organizations, PLHA groups and NGOs on CHBC in Nepal

A total of 28 key informants including PLHA groups, multilateral organizations and NGOs were interviewed over the course of the assessment. They were asked a set of questions regarding their opinions on the state of CHBC services in Nepal and the role of different entities in CHBC including NCASC, DPHO and DACCs.

Overall, key informants interviewed felt that CHBC services were very important to the HIV care package in Nepal but that not enough had been done to clearly define what CHBC entails. Many interviewed felt that there had been more emphasis on training than on providing services to people. There was a general call to fast-track the approval of national CHBC guidelines and to develop SOPs to guide services implementation, management and reporting systems. Key informants also felt more should be done to mobilize community support for CHBC.

Key informants provided the following comments on the national CHBC program:

- General perspectives on palliative care and CHBC
  - Based on observation there is a good attempt to provide CHBC in limited geographic areas
  - Thus far palliative care does not reach very far in the community. There is a need for more reach and development of more services.
  - CHBC is a good strategy but if not designed well it can create stigma.
  - CHBC is a good service it should be expanded.
  - We must define palliative care in the Nepali context: what are its parameters.
  - There is a misunderstanding of the definition of palliative care. Many people think palliative care is end-of-life care.

- National CHBC Guidelines, SOPs and M&E system
  - There is a lack of proper operational guidelines to clearly spelled out ways to integrate CHBC into the public health care system
  - Many organizations are involved in CHBC but are not clear on what it means. Need SOP and guidelines.
  - The draft of the CHBC guidelines should be finalized soon
  - A national CHBC M&E system needs to be in place

- National training
  - When running training, ensure that participants are selected strategically and will actually be involved in supervising or providing care.
  - Follow-up and monitoring has not been done after the training.
  - The training should be longer than 7 days.
Future suggested areas of focus for CHBC

- Community mobilization should also be done to reduce stigma and discrimination
- Need a community awareness campaign on PLHA, stigma and discrimination and CHBC
- NGOs are not the center of CHBC, communities need to be at the center.
- Need to focus more on rural areas

4. Role of DPHO, DACC and local health services in CHBC

Through the program assessment and key informant interviews it was very clear that the DPHO and DACC should be playing a greater role in supporting, coordinating and supervising CHBC services.

There were three locations where the DPHO was active in CHBC services: Doti, Kapilbastu and Pokhara. However only in Doti was the DPHO truly participating in CHBC services.

“We have a big network between health service providers at local level such as health post, sub health post. We are also discussing to mobilize health post staff, Female Community Health Volunteers (FCHV) for ART adherence, health facilities etc.” - DPHO Doti

The other DPHO and DACC officials interviewed as part of the CHBC program review were unaware of CHBC. They did not know what CHBC was and had not heard that it was being offered in their area.

“CHBC is very new concept for me as we are not oriented on CHBC.”

The majority of DPHO and DACC officials interviewed requested they be oriented on community and home-based care services and their mandate in supporting CHBC services.

When asked what types of services CHBC programs should offer, DPHO and DACC staff had responses in line with what CHBC services are already doing or want to do:

“CHBC team should offer counseling, psychological support and economic rehabilitation services to PLHA & their families. I think income generating program are lacking.”

“Free health care services (package of care) need to be offered, VCT/ART linkage should be offered.”

“Other services like income generation projects, schooling support to their children.”

In two locations (Pokhara and Doti) DPHO and DACCs commented on the role they felt they could play in supporting CHBC:

“Should take leadership for program design, development, implementation & coordination among service providers. Community based care should be strengthened to provide better access for PLHA”

“Moral support. Supervision and monitoring. Monthly sharing and feedback with stakeholders.”

Key informants interviewed felt that the DPHO and DACCs had a very important role to play in supporting CHBC.
“There is some budget allocated for DACC support from NCASC but there is no formal policy for DACCs so the money is not being used. They are working on the policy.”

5. Role of NCASC in Leading CHBC

NCASC should ensure stewardship and leadership in developing CHBC standards and guidelines.

All key informant interviews included the question: What role do you think NCASC should play in CHBC? Responses were essentially uniform across CHBC program managers, PLHA, families, hospital staff, NGOs, multilaterals, DPHO and DACCs, and crisis center staff. Respondents felt that NCSAC should focus on creating policies and standards related to CHBC and play a supervisory role. Below are direct responses to the question:

“It (CHBC) must be standardized, needs to ensure quality by developing and following monitoring system.”

“NCASC needs to play a leading role in CHBC”

“In principle they should be leading and having standard packages for medicines would make it simpler for access for different stakeholders.”

“(NCASC should lead) guideline preparation, protocol training, package and standardization and monitoring.”

“(NCASC role is as a policy maker and developing guidelines and SOPs to standardize CHBC services”

Some of the respondents mentioned that the NCASC should soon finalize the national CHBC guidelines.

“They (NCASC) should take everyone’s consensus and the guideline should be formalized quickly.”

“(NCASC) should finalize guideline as soon as possible.”

“Guidelines of CHBC have not been finalized yet.”

The majority of respondents felt that the NCASC was responsible for activating the DACC and female health volunteers and supporting the DACC to be more involved in supporting HIV care services including CHBC.

“(NCASC should) Sensitize and strengthen DACC in 75 districts.”

“DACC should be strengthened. DACC should know about CHBC program.”

“Train and mobilize FCHV for CHBC”

Finally, some participant felt that NCASC should increase involvement of PLHA in national policy and guidelines development.

“NCASC should involve & consult PLHA while developing policies and guidelines.”

“Quality assurance should be done by PLHA”
IV. Recommendations

Major recommendations from the CHBC program review are:

1. Increase access to CHBC services and explore new service delivery models.
   CHBC programs are providing much needed services to PLHA and families in Nepal and should be made available wherever HIV care is needed and there is demand for the service. The current service model is appropriate but other models should be explored to maximize involvement of the public health care system. (See recommendation 5). Since many of the teams visited are now operating at client load capacity, programs will need to explore ways in which to meet increasing client numbers. Options to consider include strategically increasing team numbers, and training and supporting volunteers based in client communities to provide routine care with teams providing regular but less frequent visits. Volunteers could be peer PLHA, retired health care workers, FCHVs or others who are available and appropriate.

2. Provide guidance and a policy framework for CHBC.
   NCASC can lead CHBC policy making by finalizing and disseminating the draft national CHBC guidelines and by developing standard operating procedures to promote a standard of quality care across all CHBC programs. Both these steps are highlighted as part of the 2006-2011 National Strategic Plan for HIV/AIDS Control. It is recommended that:

   a. A national technical working group be convened to develop national policy documents needed to guide CHBC services in Nepal. This group should include government representatives, PLHA groups, NGOs, donors and multilaterals.

   b. The national CHBC guidelines be finalized as soon as possible and made available to DPHO, DACCs, hospital and HIV care programs including CHBC.

   c. The CHBC SOPs include a description of minimum supplies needed in CHBC kits, reporting standards and supervision protocols. They should also provide guidance to the DPHO and DACC on their roles and responsibilities in supporting and supervising CHBC as well as detail referral relationships between CHBC teams and hospitals, as well as with other essential services.

3. Develop a CHBC drug supply chain management system.
   To ensure stable supply of essential palliative care medicines and supplies to CHBC programs - both government and NGO/PLHA group run - NCASC will need to lead a process of developing a system to provide standard CHBC kit supplies to CHBC programs. This recommendation recognizes that in many areas developing a stable and functional drugs supply chain system in Nepal is a challenge. However, there are a number of steps that could be taken by NCASC and partners in the immediate term to improve access to CHBC medicines and supplies:

   a. Develop a standard national CHBC kit formulary. All CHBC programs assessed had developed very similar packages which should be standardized as part of the CHBC SOP process (as per recommendation two). Take into consideration medicines and supplies already provided through the MoHP essential drug list and made available through DPHOs for free. Disseminate standard kit list to CHBC programs and the DPHO and DACCs, and include the standard list in all CHBC trainings.
b. Utilize the existing DPHO dispensary system by 1) identifying supplies made available through DPHOs (e.g., ORS, paracetamol, gloves) which match items on the standardized CHBC kit list, and 2) at the MoHP/NCASC level, formally empower DPHOs to provide relevant supplies to CHBC programs in their areas.

c. Identify a long-term system to ensure access to key CHBC supplies: 1) Incorporate the CHBC kit formulary in Global Fund, DFID or other donor supported medicine procurements and proposals; 2) include the CHBC formulary in developing MoHP and NCSAC drugs supply management systems such as those being supported by the JSI Deliver; 3) ensure CHBC supplies are included in efforts to conduct estimates and projections of HIV care medicine and commodity needs.

4. Integrate CHBC into the national HIV M&E system.
NCASC is in the process of developing program level indicators for technical components of the national strategy including ART and PMTCT. A set of core program indicators for CHBC should also be determined. These indicators should be referenced in the national CHBC SOP including guidance and forms to be used in reporting in indicators. The proposed CHBC technical working group can work with the national M&E team to develop core program indicators for CHBC in order to be able to measure access to services. Tracking key indicators will improve overall understanding of service coverage and contribute to universal access goals.

5. Establish closer relationships between CHBC services and DPHO, DACC and local public health sector.
The DHPO and DACC are essential to strong, well supported CHBC services. Through the assessment, DPHO expressed interest and willingness to support and supervise CHBC services but they also requested that: 1) NCASC provide them with guidance as to their role in CHBC; 2) they be oriented in CHBC services and 3) that CHBC providers give them regular activity reports so they were aware of achievements to date. The DPHO in Doti also requested that CHBC teams also work as TB-DOTS volunteers since they were already working in the community. It is recommended that NCASC and partners:

a. Run a CHBC orientation meeting with DPHO and DACC staff wherever CHBC services are active. This should include providing a summary of results from national CHBC program review. In some cases this may also include inviting DPHO and DACC staff to accompany teams on visits to build their understanding of the types of services which CHBC teams provide.

b. Detail the role of the DPHO and DACC in the national CHBC guidelines and SOPs including their supervision responsibilities, CHBC reporting systems, role in supplying CHBC kits and development of formal referral systems between CHBC and the hospital-based services (e.g., HIV clinic/ART, PMTCT, TB, STI).
c. Work with the DPHO and DACC to develop formal referral relationships between CHBC services and local hospitals.

d. Explore and pilot levels of involvement of health post, sub-health post and female community health volunteers in CHBC. In some areas this would include training health post and sub-health post staff as back-up to CHBC teams, assisting with serious cases and with referral. In others, FCHV could be trained and mobilized to work as part of CHBC teams. These approaches may be of particular need and value in more rural and remote areas such as Kapilbastu and Doti.

6. **Improve supervision and QA/QI systems.**

CHBC program managers need to be trained in what to look for in assessing the quality of CHBC services. They also need to make a point of accompanying CHBC teams during home-visits and other activities to observe the quality of work. Managers can then identify areas of further training and support which teams need and identify ways in which to strengthen the quality of the program. All managers should use a CHBC supervision checklist such as the one used in this program assessment. A system of routine (e.g., 6 monthly) QA/QI should also be instituted to comprehensively assess progress in improving quality of the CHBC program. The DPHO and DACC should be invited to participate in or lead this process.

7. **Increase PLHA and community involvement in CHBC.**

It is recommended that programs which do not yet have strong involvement of people living with HIV in the program identify PLHA as team leaders and members. PLHA should be working as leaders and partners in all CHBC services. This is essential to quality care for PLHA. In most of the programs assessed, the community (including the DPHO and DACC) were not involved in the program. This is a missed opportunity to sensitize community members to HIV, to reduce stigma and discrimination and to elicit their support. All CHBC programs need a community mobilization component to their work. Community engagement approach used by Sakriya in Kapilbastu, such as mobilizing key community members should be explored by other CHBC programs. CHBC services should also strive to work closely with crisis centers in their area to strengthen the continuum of care.

8. **Increase diversity of referral relationships to address social and economic support concerns of clients.**

Only a few of the CHBC program assessed had actively sought and established partnerships with organizations in the community which provide social and economic support and care for orphans and vulnerable children. These formal referral relationships resulted in client needs in these areas being largely addressed. It is recommended that all CHBC programs map key services in the community offering assistance with livelihood, food security and supplementation and support for orphans and vulnerable children. CHBC programs then need to meet with prioritized programs and advocate for formal program and referral linkages. Two of the CHBC programs, Sakriya and CDF, have had success in this approach. In addition, CHBC programs run by community development focused NGOs should identify services within their own organizations to which they can better link.
9. **Train and support CHBC teams to provide family-centered care.**

CHBC teams need to be trained to provide vital assistance in helping couples, pregnant women to access and remain in PMTCT services. They also need to be trained providing follow-up care to mothers and infants including supporting infant feeding choices, cotrimoxazole prophylaxis, linkages to pediatric HIV testing and counseling, ability to recognize danger signs in mothers and children and refer, palliative care and treatment support for children with HIV and care and support for children affected by HIV.

a. In the short term, it is recommended that a family-centered palliative care training package is developed and rolled-out for all CHBC teams.

b. In the long term, the national CHBC certification training package should be revised to include pregnancy and HIV, PMTCT, caring for HIV exposed, infected and affected children.
V. Conclusions

From the CHBC program review it is clear that CHBC services are providing essential care to PLHA and their families in Nepal and significantly contributing to the national response by reinforcing ART adherence, improved referrals and follow-up between the community and hospital, increased self-care and understanding of HIV disease among clients and their families and reduction of stigma and discrimination in many of the communities where services are offered.

While the model of service delivery is effective there are missed opportunities in developing the capacity and role of the public sector in CHBC services, particularly in areas where the DPHO and DACC are active and supportive of community HIV prevention and care activities. One of the primary recommendations resulting in the review is the need for increased cooperation with DPHO and DACC offices and where feasible, exploring models of local health care worker involvement in CHBC.

Findings from the assessment highlight the need for and value of CHBC services. It is recommended that NCASC continue to support increasing access to community and home-based palliative care as part of its national strategy and identify ways in which to expand reach and integration or linkages of these services into the public health care system. It is hoped that findings from the CHBC program review will help to guide the finalization of national CHBC guidelines; the development of SOPs, M&E program indicators and a CHBC medicine supply distribution system; and integration of CHBC services into the DPHO, DACC, local public health care systems and the community.
Annex 1 - CHBC Program Review Team

**CHBC Review Advisors**

Dr. Padam Bahadur Chand, Director, NCASC  
Dr. Rajendra Pant, Deputy Director, NCASC  
Ms. Jacqueline McPherson, Country Director, FHI  
Dr. Durga Bhandari, Technical Unit Head, FHI

**CHBC Review Team**

1. Ms. Kimberly Green, Asia Regional Senior Technical Advisor, Palliative Care  
2. Mr. Manoj Bhatta, BCC Training Officer, NCASC  
4. Ms. Kamala Moktan, CHBC Specialist, FHI  
5. Ms. Bishnu Ghimire, Director, Sakriya Sewa Samaj  
6. Mr. Chunna Prasad Gyawali, Project Coordinator, Sakriya Sewa Samaj  
7. Mr. Shibu Giri, Program Officer, Nava Kiran Plus  
8. Mr. Basanta Chetri, Program Officer, NAP+ N  
9. Mr. Subash Rai, Program Officer, NAP+N  
10. Mr. Sushil Khatri, Crisis Center In-Charge, Youth Vision, Kathmandu  
11. Mr. Rajendra Thapa, Project Coordinator, Youth Vision, Kathmandu  
12. Mr. Benedict Mukamaba, Senior Program Advisor, Naulo Ghumti, VSO  
13. Mr. Madhav Adhikari, Project Coordinator, SPARSHA/Nepal  
14. Mr. Deepak Dhungel, Field Officer, FHI  
15. Mr. Bhagwan Shrestha, Field Officer, FHI  
16. Ms. Prava Chhetri, Field Officer, FHI  
17. Mr. Rajesh Khanal, Field Officer, FHI  
18. Mr. Sujan Pandit, Field Officer, FHI
Annex 2 – Key Informant Interview Participants

CHBC Key Informant Interviews: Kathmandu

1. Dr. Amaya Maw-Naing, Medical Officer WHO, Kathmandu
2. Ms. Isabelle Tavitian Exley, Advisor-Monitoring & Evaluation, UNAIDS, Kathmandu
3. Mr. Shyam Thapa, Coordinator, Kritmala Ashram, Nava Kiran Plus
4. Mr. Ramesh Thapa, Coordinator-Hetauda Office, Nava Kiran Plus
5. Mr. Ganesh Thapa, Medical-In-Charge, Nava Kiran Plus
6. Ms. Bishnu Ghimire, Director, Sakriya Sewa Samaj
8. Mr. Nur Prasad Pant, HIV/AIDS Specialist, Care /Nepal
9. Ms. Manisha Dhakal, Director-Care & Support, Blue Diamond Society
10. Mr. Sudin Serchan, National Coordinator, NAP+N, Kathmandu
11. Mr. Joel Githinji, HIV/AIDS Advisor, UMN, Kathmandu

CHBC Key Informant Interview: Hospital HIV Care and Treatment Clinics

1. Dr. Sanjeev Kharel, District Hospital, Kapilbastu
2. Dr. Devi Prasad Bhusal, Senior Medical Officer, Teku Hospital, Kathmandu
3. Dr. Basudev Pandey, Sr. Medical Officer, Teku Hospital, Kathmandu
4. Dr. L.B. Thapa, Sr. Medical Officer, Teku Hospital, Kathmandu
5. Dr. Suman Thapa, Sr. Medical Officer, Teku Hospital, Kathmandu
6. Ms. Dhana Thapa, Staff Nurse, District Hospital, Doti
7. Dr. Basanta Tamrakar, Consultant, Western Regional Hospital, Kaski/Pokhara
8. Dr. Suvesh Kayastha, Medical Superintendent, Mahakali Zonal Hospital, Kanchanpur
9. Dr. Khagendra Bhakta, Sr. Medical Officer, Mahakali Zonal Hospital, Kanchanpur

CHBC Key Informant Interview: DPHO/DACC & Crisis Centers

1. Mr. Mukunda, DPHO, Kapilbastu
2. Ms. Guna Laxmi Sharma, Chief Public Health Administrator, DPHO, Kathmandu
3. Mr. Bhimsen Rana, Public Health Inspector, DPHO/DACC, Kathmandu
4. Mr. Babar Gurung, Public Health Inspector, DPHO/DACC, Kathmandu
5. Mr. Jhalak Sharma, DPHO/DACC, Kaski/Pokhara
6. Dr. Bhawani Sharma, DHO/DACC, Doti
7. Mr. Manjit Chetri, Youth Vision, Crisis Home, Kathmandu
8. Mr. Akal Bataju, Friends of Hope, Crisis Home, Kaski/Pokhara
References


