Scaling Up the Continuum of Care for People Living with HIV in Asia and the Pacific:

A Toolkit for Implementers











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LIST OF ACRONYMS

AAF	AIDS Access Foundation	MSF	Medicins Sans Frontieres
AIDS	acquired immunodeficiency	MSM	men having sex with men
	syndrome	NCHADS	National Centre for HIV/AIDS, Dermatology and STDs
ANC	antenatal care		
APR	Asia-Pacific Region	NGO	non-governmental organization
ART	antiretroviral therapy	NSP	needle and syringe programme
ARV	antiretroviral (drug)	OI	opportunistic infection
СВО	community-based organization	OPC	outpatient clinic
CCC	comprehensive and continuous	OST	opioid substitution therapy
	care centres	OVC	orphans and vulnerable children
CCS	comprehensive care site	PCP	Pneumocytis carinii pneumonia (also known as Pneumocystis
CHBC	community and home-based care		
CoC	continuum of care	DED	jiroveci pneumonia)
CoC-CC	Continuum of Care Coordination	PEP	post-exposure prophylaxis
ст	Committee counselling and testing	PITC	provider-initiated testing and counselling
DCC	day care centres	PLHIV	people living with HIV
FCC	family-centred care	PMTCT	prevention of mother-to-child
GFATM			transmission
GFAIN	Global Fund for AIDS, Tuberculosis and Malaria	QA/QI	quality assurance/quality improvement
GIPA	greater involvement of people_ living with HIV/AIDS	STI	sexually transmitted infection
FHI	Family Health International	TB	tuberculosis
HCMC	Ho Chi Minh City	TB/HIV	the relationship between TB and
HIV	human immunodeficiency virus		HIV and the need to link care and treatment
HMIS	health management information system	TNP+	Thai Network for People Living with HIV/AIDS
IDU	injecting drug user	TWG	technical working group
M&E	monitoring and evaluation	USAID	United States Agency for International Development
MMM	Mondol Mith Cheui Mith (i.e. Friends		
	Helping Friends Centre)	VCT	voluntary counselling and testing
MMT	methadone maintenance treatment	WHO	World Health Organization
МоН	Ministry of Health		
MoPH	Ministry of Public Health		

EXECUTIVE SUMMARY



Millions of people in the Asia-Pacific Region are affected by HIV. The incidence of HIV continues to rise at an alarming rate in some parts of the region—particularly among populations with high-risk behaviours, including injecting drug users (IDUs), men who have sex with men (MSM), sex workers, prisoners, migrants and youth. Efforts to provide care, treatment and support to people living with HIV (PLHIV) have achieved some laudable successes, but the majority of PLHIV are still not able to access important services—for example, it is estimated that only 19% of PLHIV in East, South and South-East Asia who need ART currently receive it. While care, treatment and support services for HIV are increasingly available throughout the region, seldom are they linked and coordinated in a way that optimizes PLHIV access and adherence to treatment.

As global capacity regarding the HIV epidemic and resources to combat it have expanded, policy-makers and practitioners have begun to promote a more integrated, comprehensive response to PLHIV needs for care, treatment and support. Some countries in the region have developed a strategy for organizing and providing these services known as the Continuum of Care (CoC). The CoC is defined as a network of linked, coordinated care, treatment and support services for HIV that are provided by collaborating organizations. The CoC network consists of both the services themselves as well as the overarching coordination framework that makes the CoC stronger and more effective than the sum of the individual services. The CoC creates linkages between services provided in homes, communities and institutions and thus improves the access of PLHIV to the services they need. The CoC is tailored to meet local needs and circumstances and therefore takes a unique form in each location where it is introduced.

Growing experience with the CoC approach in Thailand, Cambodia, Viet Nam, China, Nepal and other countries in the region—coupled with the impressive results achieved through the CoC—have inspired a collaboration of partners to develop this Toolkit. The Continuum of Care Toolkit offers guidance based on experiences with the CoC in diverse settings across the Asia-Pacific Region that will assist planners and managers to establish or strengthen their own CoCs. This Toolkit, which is structured in seven sections, provides ideas, strategies, procedures and tools for CoC managers to create networks that link care, treatment and support services for HIV in their own localities according to their own unique needs. Key sections of the Toolkit include (i) an introduction to and rationale for the CoC approach, (ii) profiles of the development of the CoC in five countries from the region, (iii) specific advice on how to build a CoC at the local level, (iv) a review of national-level support for the CoC across the region, (v) an overview of how CoC initiatives can be monitored and evaluated, and (vi) future directions for the CoC in the region. The need for and means of including prevention services within the CoC network are also discussed.

Bringing together partners from different sectors of society to develop inclusive, coordinated programmes and high-quality services is a challenging but ultimately rewarding task. The ideas presented in this Toolkit should prove useful to governments and their partners as they respond to the HIV epidemic and work to increase access to locally appropriate care, treatment and support services for PLHIV and their families throughout Asia and the Pacific.

¹ WHO, UNAIDS, UNICEF. Towards universal access: scaling up priority HIV/AIDS interventions in the health sector: progress report, April 2007. Geneva, WHO, 2007.



1. HIV in the Asia-Pacific Region

Millions of people in the Asia-Pacific Region are affected by the impact of HIV on health, human rights and development. Because of the sizeable populations of countries in the Asia-Pacific Region, large numbers of people live with HIV, even in countries and areas where the HIV prevalence is low. UNAIDS estimates that during 2006, 8.61 million people in the region were living with HIV—31,000 of whom were children—and that 594,000 people died of AIDS. During 2006 alone, 867,100 people in the region were newly infected with HIV.² Estimates of HIV prevalence range from less than 0.1% in some countries of the region to 1.8% in Papua New Guinea. Figure 1 presents an overview of the prevalence of HIV in countries of the Asia-Pacific Region.

Adult prevalence %

1.5 - 3.0%

1.0 - < 1.5%

0.5 - < 1.0%

0.1 - < 0.5%

< 0.196

Figure 1: Prevalence of HIV among adults in Asia, 2005

Source: 2006 Report on the global AIDS epidemic. Geneva, UNAIDS, 2006.

1

Behaviours that put people at risk of infection with HIV drive the epidemic in the region.³ While countries in the region experience different epidemics (see Figure 2), infection due to high-risk behaviours such as injecting drug use (IDU) and unprotected sex between commercial sex workers and their clients and among men who have sex with men (MSM) is common to most countries. With individuals involved in multiple risk behaviours such as both sharing needles and syringes and engaging in unprotected sex, the spread of HIV is a result of interlinking networks of risk behaviours.

HIV transmission is not limited to individuals who practice high-risk behaviours. Data from countries that include Thailand, Cambodia, China and India indicate that once the epidemic is established in high-risk populations, HIV can spread into the general adult population through sex with spouses and partners while newborns can be infected through perinatal transmission. With the prevalence of HIV at the national level exceeding 1%, Papua New Guinea, Cambodia, Myanmar and Thailand already face generalized epidemics. India, with a population surpassing one billion, has an HIV prevalence rate of 0.9% and is on the verge of a generalized epidemic with six states showing HIV prevalence above 1% among pregnant women attending antenatal care during 2005.4 The prevalence of HIV in defined areas of several other countries, including China, Viet Nam and Indonesia, easily exceeds the threshold of a generalized epidemic.5 These overwhelming problems clearly require urgent, wide-scale action to mitigate the impact of HIV and minimize further transmission.

While efforts are being made to achieve the goal of universal access to comprehensive prevention, treatment, care and support, HIV continues to spread and more people are becoming infected. The vast majority of at-risk populations and PLHIV still do not have access to the services they need. The region has seen improvements in access to anti-retroviral therapy (ART: see Figure 3) and prevention of maternal-to-child transmission (PMTCT), yet coverage is still low. Asia bears 21% of the global treatment need and only 19% of PLHIV in Asia who need ART currently receive it.⁶

Data form Nepal are based on reported HIV infections (cumulative)

100

80

100

India Thailand Myanmar Indonesia Nepal

Heterosexual Injecting drug use Unsafe blood Perinatal Others

Figure 2: Modes of HIV transmission in select Asian countries

Source: HIV/AIDS in the South-East Asia Region: March 2007. Delhi, WHO South-East Asia Regional Office, 2007.

Barriers to accessing services

Barriers to increasing access to HIV services include stigma and discrimination, lack of coordination and planning among services that together form a comprehensive HIV programme, under-resourced health-care systems, and donor or government policies.

- Widespread stigma and discrimination against PLHIV continue to hamper care and prevention initiatives in most countries in the region. Many PLHIV practice illegal and highly stigmatized behaviours such as drug use and sex work and may not be welcome in health facilities. HIV prevention activities often have the undesirable effect of increasing stigma towards PLHIV and further marginalizing them, thus decreasing their access to care, treatment and support.
- Many programmes that offer care, treatment and support to PLHIV operate vertically—that is, they focus on their own specific area of service and do not develop adequate links with other services that PLHIV require. Examples of this include PMTCT services that are not connected to community-based clinics or stand-alone HIV clinics that are not linked to community and home-based care (CHBC) services. When services are not well-linked, PLHIV, their families and partners may not be aware that the services they need even exist. Programmes with weak referral linkages often reach only a small percentage of those in need and achieve minimal impact.

Countries such as Thailand that have built on existing resources and infrastructure to implement comprehensive, coordinated services—such as the continuous and comprehensive care centres (CCCs) that have been established in 220 sites—have successfully expanded access to care and treatment services to the point where universal access to treatment for adults and children is within grasp.⁷ There is an urgent need to scale up—and equally important, a need to link and coordinate—care, treatment, support and prevention services in order to prevent future infections, reduce morbidity and extend the lives of those already infected.

178 483 160 000 140 000 119 221 100 000 of people 60 607 60 000 40 000 17 957 20 000 Dec-03 Dec-04 Dec-05 Dec-06 Technical Seminar, 15 May 2007

Figure 3: Number of people on antiretroviral therapy in South-East Asia, 2003-2006

Source: WHO Regional Office for South-East Asia

2. The global response to needs of PLHIV for care, treatment and support

World leaders at the United Nations General Assembly Special Session on HIV/AIDS in 2001 made unprecedented commitments to strengthen HIV care, treatment, support and prevention. Included among these commitments are the Millennium Development Goals, one of which pledges to reverse the spread of the HIV epidemic by 2015. Global HIV-related targets have become increasingly ambitious as antiretroviral (ARV) drugs have become more accessible and global resources for HIV/AIDS have increased through the Global Fund for AIDS, Tuberculosis and Malaria (GFATM) and other sources. These targets include the 3 by 5 Initiative to treat three million PLHIV by 2005¹⁰ and the US President's Emergency Plan for AIDS Relief (PEPFAR) that aims to treat two million PLHIV with ARV therapy (ART), prevent seven million new HIV infections, and provide care for ten million people affected by HIV. Meaningful increases in the provision of ARV drugs in many countries will be dependent on local production or importation of generic drugs. World leaders and their local and international partners continue to commit increased resources across all aspects of the response to HIV.

In December 2005, the United Nations General Assembly adopted a resolution to scale up HIV care, treatment, support and prevention services with the aim of coming as close as possible to achieving the goal of universal access to services by 2010.¹² Most governments in the region have set targets for universal access but many are still far from reaching them.

3. Purpose and structure of the Toolkit

One of the central challenges of the CoC is to bring together partner organizations from different sectors of society and create a framework within which they work together to coordinate programming and expand the provision of high-quality services. Growing experience with the CoC approach across the Asia-Pacific Region, coupled with the impressive results that have been achieved through its use, have led to the decision to document these important experiences. This Toolkit provides practical guidance to policy-makers, service planners and programme implementers and is particularly intended for use at the national and district levels across the region.

The toolkit is laid out in seven sections:

- 1. Section One provides background for the Toolkit.
- 2. **Section Two** defines the CoC, presents its principles, describes its components and the rationale for its use as a guiding framework, and outlines the basic structure of the CoC.
- 3. The process of developing the CoC in five countries in the Asia-Pacific Region is profiled in Section Three.
- 4. Section Four builds on this information by outlining how to plan and build a CoC at the local level.
- 5. **Section Five** presents an explanation of the components of a national CoC framework as well as the process for its establishment.
- Section Six presents an overview of how CoC initiatives can be evaluated and monitored.
- 7. **Section Seven** outlines next steps regarding the future of the CoC, including ideas regarding the role of the CoC in achieving universal access goals.

8. **Annex One** describes the various services that are provided through many CoCs throughout the region, while **Annex Two** presents an abbreviated, checklist version of the Toolkit that serves as a companion to this document.

Throughout the Toolkit, country-specific examples are used to highlight issues, principles, strategies and lessons learned. A set of annexes that are included in the CD-ROM that accompanies this Toolkit provides detailed information on tools, planning structures and approaches that have proven useful in some settings as well as a list of additional resources.

Further reading

- 1. AIDS epidemic update: special report on HIV/AIDS: December 2006. Geneva, UNAIDS, WHO, 2006.
- 2. AIDS in Asia: Face the Facts, A Comprehensive Analysis of the AIDS Epidemics in Asia. Bangkok, MAP, 2004.
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² AIDS epidemic update: special report on HIV/AIDS: December 2006. Geneva, UNAIDS, WHO, 2006.

³ HIV/AIDS in the South-East Asia Region: March 2007. New Delhi, WHO Regional Office for South-East Asia. 2007.

⁴ Ibid

⁵ AIDS epidemic update: special report on HIV/AIDS: December 2006. Geneva, UNAIDS, WHO, 2006.

⁶ WHO, UNAIDS, UNICEF. Towards universal access: scaling up priority HIV/AIDS interventions in the health sector: progress report, April 2007. Geneva, WHO, 2007.

⁷ Ibid.

⁸ United Nations General Assembly, Special Session on HIV/AIDS. Declaration of Commitment on HIV/AIDS. United Nations, 2001.

⁹ The Millennium Development Goals Report 2006. New York, United Nations, 2006.

¹⁰ Treating 3 million by 2005: making it happen: the WHO strategy. Paris, WHO, 2003.

¹¹ The president's emergency plan for AIDS relief: U.S. five-year global HIV/AIDS strategy. Washington DC, Office of the United States Global AIDS Coordinator, 2004.

¹² United Nations General Assembly, 60th Session Resolution 20/62. Political Declaration on HIV/AIDS. United Nations, 2006.

INTRODUCTION TO THE CONTINUUM OF CARE



1. What is the Continuum of Care?

People living with HIV and their families have emotional, social, physical and spiritual needs that change over time. They often must cope with the effects of stigma and discrimination, poverty, loss, neglect and abandonment. The purpose of the CoC is to address HIV as a chronic disease and develop systems that provide humane, effective, high-quality comprehensive and continuous care to PLHIV and their families.

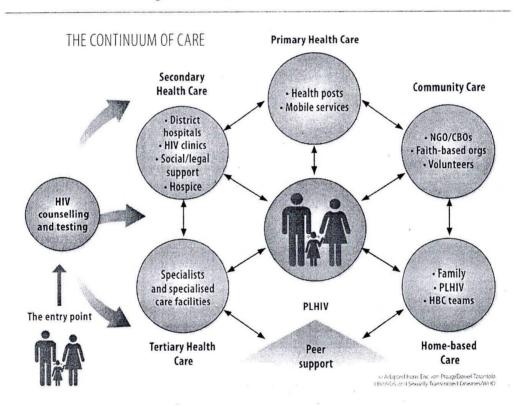


Figure 4: Continuum of Care framework

The CoC is a complete set of linked care, treatment and support services provided at all levels from health facility (hospital/health centre) to community and home by government, NGOs, CBOs, FBOs, PLHIV and family members.

Source: Adapted from: Narain JP, Chela C and van Praag E. Planning and implementing HIW/AIDS care programmes: a step by step approach. New Delhi, WHO Regional Office for South-East Asia, 2007.

CoC planners accomplish this by linking PLHIV to existing services while also building on those services to create enhanced care that is centrally available. CoC managers also advocate for and create other needed services that are not available or accessible to PLHIV. As such, the CoC has two defining characteristics:

- 1. The Continuum of Care is a network that links, coordinates and consolidates care, treatment, and support services for PLHIV. These services are provided in their homes, in the communities where they live, and in the health facilities that serve them. The network is usually supported by a local CoC Coordination Committee (CoC-CC) that is responsible for facilitating referral linkages and planning.
- 2. The Continuum of Care is also the group of services themselves that together provide comprehensive support to PLHIV and their families. While these services are generally provided by a number of different organizations, the system that links and coordinates them is planned and managed by the CoC-CC whose members include government officials, service providers, non-governmental organization (NGO) representatives, PLHIV, and other stakeholders.

Both of these features of the CoC are illustrated in Figure 4. The circles represent the different services—clustered by location of delivery—that are included in many CoCs. The arrows represent the referral network that binds the services together in the CoC.

Most of the CoCs that are profiled in this Toolkit were initially developed to provide care, treatment or support services to PLHIV. Once these services were established, the CoCs began to incorporate prevention activities over time as their scope expanded to became more comprehensive. This order of implementation does not mean that the prevention component of the CoC has a lower priority than services for care, treatment and support—rather, it is a historically accurate description of how the CoC concept evolved in practice in the Asia-Pacific Region.

1.1 Beginning of the Continuum of Care: birth of a global strategy

The CoC was developed as a response to the many needs that PLHIV and their families have over the course of their lives and the difficulties they face in accessing those services. The roots of the CoC approach were developed during groundbreaking work in an urban setting in Australia in the mid-1980s.¹³ WHO built on these efforts through the Global Programme on AIDS in the early 1990s and led the development of a global CoC strategy¹⁴—an approach that was later adopted by UNAIDS and most national HIV/AIDS control programmes in Africa and Asia.^{15,16}

The CoC was established in many countries before ART was available, with community groups playing major roles in establishing most local CoCs. The existing CoC structure created a solid foundation for the eventual introduction of ART. In places where the CoC existed prior to the introduction of ART, CoC programme managers were able to build ART into a system of linked, accessible services that in turn supported and reinforced the effectiveness of ART.

"ART is a crucial part of the CoC, but it is only a part. ART is like the roof of a house—a heavy one. If the foundation of the house (for example, management of Ols, laboratory services, standard precautions, community and CHBC services) is not strong, ART can make the house collapse. ART is most effective when it is supported by a strong CoC framework. Without a strong CoC, ART can not be sustained."

Dr Chawalit Natpratan, former Director CDC 10, Chiang Mai, Thailand

1.2 Continuum of Care in Asia and the Pacific: then and now

The number of HIV-infected persons began to increase notably in the Asia-Pacific Region during the early 1990s. Amid unrelenting stigma and discrimination, local communities begin to respond to the needs of PLHIV for care, treatment and support by establishing care centres and community and home-based care (CHBC) services.

During these initial stages of the response—when only a few hospitals were willing and able to provide care for PLHIV, and ART was unavailable—CHBC teams and day care centers (DCCs) performed the hard work of providing services and making linkages with other services that their clients needed. These services included emotional support and counselling, self-care empowerment, cotrimoxazole prophylaxis, tuberculosis (TB) screening and treatment, access to care and treatment of opportunistic infections (OI), assistance with transport to referral sites, food and income support, end-of-life care and future planning, and support for children and other family members.

In northern **Thailand**, PLHIV organized groups and began to establish partnerships with health workers in hospitals to provide care for their peers in the early 1990s—an effort that eventually led to the establishment of day care centres (DCCs) such as in Chun district, Phayao. In **Cambodia**, CHBC services were initiated by PLHIV and NGOs in the mid-1990s and were incorporated into the national HIV/AIDS programme in 1998. The CHBC approach served as the foundation for other essential care services for PLHIV in both Thailand and Cambodia.

The importance of the DCC to the CoC was its key role as a **hub** of service planning and provision. These dynamic sites provided PLHIV groups with a place to meet and organize, served as a base of operation for CHBC teams, and were an important social and community setting for PLHIV and their families. DCCs and CHBC services were linked to TB services in the early days of the response in the region. Cotrimoxazole prevention therapy was also made available to PLHIV through the DCCs long before it was widely available in other countries in the region.

Very importantly, the CoC has created an environment of mutual trust and friendship between PLHIV, health-care workers and other providers. PLHIV and others working in the comprehensive care sites work side-by-side as partners to provide respectful, quality and loving services to people in need. This, more than anything else, has made the CoC an approach to care provision that adds quality, value, ownership, and effectiveness to services.



Client - centred care: The heart of the CoC

Other services were added to CoCs in the region over time as they became more affordable or were demonstrated to be effective. ART was first offered in Thailand during the early 1990s

"The continuum of care that we have developed in Pingxiang is the most advanced in Guangxi, and perhaps in all of China. We have built on the foundation of the Four Frees One Care policy to create something new."

Dr Zhao Shao Ji, Director, Pingxiang Bureau of Health

while PMTCT was included in the CoC in 1997. 17,18,19,20 CoCs that have been established more recently, such as those in Guangxi province in China, have begun operation with most or all essential services already in place: counselling and testing (CT), hospital-based HIV care, ART, TB/HIV, PMTCT, and PLHIV support groups. Only CHBC services were added at a later date in Guangxi due to concerns that home visits would identify PLHIV in the community and increase already high levels of stigma and discrimination.

Thailand, in particular, pioneered the development of the CoC and catalyzed its adoption in other countries within the region. In addition to Thailand, four other countries are profiled in Section 3 of this Toolkit, including Cambodia, Viet Nam, China and Nepal.

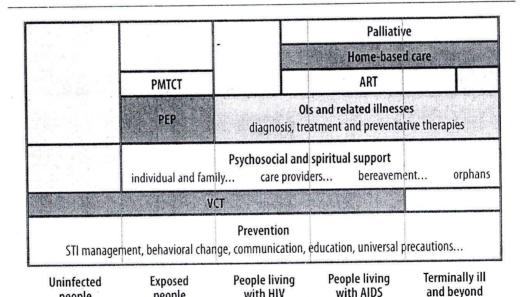
Care, treatment, support, testing and prevention: an integrated response 1.3

A fully developed CoC brings together the five major components of a response to HIV:

- 1. Care
- 2. Treatment
- 3. Support
- Testing and counseling 4.
- Prevention

people

Figure 5: Continuum of services for people at risk of infection or people living with HIV



Source: van Praag E. Galen Training: Continuum of HIV Care. International Association for Physicians in AIDS Care (IAPAC), 2004.

people

with HIV

with AIDS

All of these components are necessary to provide a full set of services that people at risk of infection or people living with HIV may need over time (see Figure 5). A brief summary of each element follows below. The primary services that pertain to these components are listed in **Section 2.4** and described further in Annex 1.

- Care: PLHIV need to maintain good health until they are ready to start ART and thus
 require effective preventive services. Once they begin ART, they continue to require
 clinical care services to stay healthy and minimize side effects. These prevention and
 care services may include:
 - Prophylaxis with cotrimoxazole
 - Treatment for opportunistic infections
 - Prevention, early detection and treatment of tuberculosis
 - Nutritional therapy
 - Palliative care
 - Immunizations for children living with HIV

The care that PLHIV need should be offered at different sites that include health institutions, community-based care, and home-based care. The CoC plays a vital role by linking these care services through referral networks—both across different sites (e.g. health facilities, communities, homes) at different levels, as well as within sites (e.g. services within the health facilities that may include various outpatient departments, MCH services, TB/HIV, paediatric and adult wards and the HIV clinical service site).

- 2. Treatment: Antiretroviral therapy (ART) is the single most effective intervention for prolonging the lives and improving the quality of life of PLHIV. PLHIV today have legitimate hope for long-term survival due to lower prices and improved availability of ARV drugs. Despite this improved situation, only a small minority of those PLHIV who require ART actually receive treatment. Due to a variety of factors that include stigma and discrimination and poverty, most PLHIV have not been tested and are thus unaware of their status—even though they may be eligible for ART if they need it. One of the best strategies to increase treatment coverage is therefore simply to increase the number of HIV-positive individuals who know their status.
- 3. Support: PLHIV have many non-medical needs that can affect their adherence to therapy, well-being and ultimately their survival. The CoC ensures that clients are referred to or linked with the different providers and services they require in a timely manner. Support services offered through the CoC may include:
 - Psychosocial support
 - Income generation activities
 - Assistance finding employment
 - Housing services and provision
 - Child care
 - Legal support
 - Planning for the future

Support services are provided by a variety of organizations that include government ministries that are concerned with social welfare and other related sectors, NGOs, PLHIV groups, religious institutions and community groups.

- 4. HIV counselling and testing: Within the context of the CoC, HIV counselling and testing (CT) services seek to prevent new infections as well as to link PLHIV with care, treatment and support services. HIV testing services include traditional CT or voluntary counselling and testing (VCT) as well as provider-initiated testing and counselling (PITC). CT services may be integrated into existing services such as sexually transmitted infection (STI) or TB clinics. Alternatively, they may be located in free-standing clinics or community-based organizations with strong referral links to HIV care and treatment services. CT services are usually the point of first contact between the client and the CoC and thus often create a positive or negative impression of the CoC services in the mind of the client. For this reason it is important to build client confidence by providing high-quality, confidential counselling and fast, reliable same-day test results. Comprehensive pre- and post-test counselling provide important opportunities for clients to learn about and be referred to other services within the CoC.
- 5. Prevention: The CoC holds the potential to be an effective means of expanding targeted, focused prevention activities. By building trusting relationships with PLHIV clients, the CoC provides a structure for reaching out to at-risk populations—including HIV-positive clients—with sensitive and compassionate prevention services. The strong referral links that the CoC builds between care and prevention services in turn strengthen support for clients to practice positive prevention. CoC planners and managers in the Asia-Pacific Region have generally not emphasized primary prevention activities during the initial stages of CoC development. See Section 7 for more information on integrating prevention activities into the CoC.

1.4 Continuum of Care service delivery model: horizontal and vertical links

Service delivery within the CoC is based on a well-coordinated physical and administrative infrastructure that includes systems for coordination and referrals both within and between the different levels of the health system as portrayed in the figure below.

Referrals also are made laterally, at each health service level, between health services (e.g. HIV care, TB, ANC, STI, and HIV prevention services) and other psychosocial support and spiritual care services (e.g. Departments of Social Welfare and Women's Affairs, NGOs). Details regarding how to establish this model of service delivery can be found in **Section 4**.

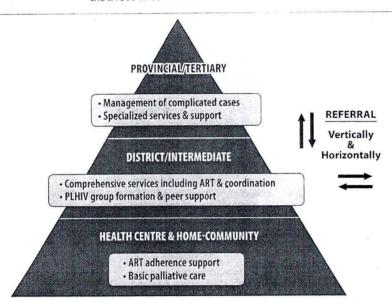


Figure 6: Continuum of care service delivery framework with district / intermediate-level focus

Source: HIV/AIDS care and treatment: guide for implementation. Manila, WHO Regional Office for the Western Pacific, 2004.

2. Guiding principles for the Continuum of Care

The CoC framework is based on a set of core principles. These principles may differ somewhat by country or site and can range from an explicitly documented set of ideals to an implicitly understood set of guiding values.

CoC Core Principles

Needs-based and client-focused: the CoC focuses on the expressed needs of PLHIV and their families and maximizes client involvement in planning and implementing the CoC.

Rights-based orientation: the CoC is based on respect for human and patient rights (such as confidentiality and equal access to high-quality care) and openly addresses stigma and discrimination, gender equity and other barriers to access.

Meaningful involvement of PLHIV and other stakeholders: full participation from PLHIV, the communities that they live in, as well as the governmental agencies and NGOs/CBOs that serve them, is essential to the success of the CoC.

Links a diverse set of services across different service delivery sites: the CoC includes preventive, treatment, care and support services at different levels (i.e. district and provincial-level health and social services, community-based organizations, home) with appropriate interlinking referral mechanisms.

Locally defined design strategy: there is no right or wrong way to implement the CoC in a given location. The local context will strongly influence the approach to designing, planning and implementing a CoC.

The National Centre for HIV/AIDS, Dermatology and STDs (NCHADS) in Cambodia has developed a set of principles to guide the design and implementation of CoCs, which can be found on the CD-ROM that accompanies this document.

3. Why establish a Continuum of Care?

While there are many reasons why the continuum of care is a valuable approach, four that stand out are the following:

- 1. Quality of life: enhancing the health and well-being of PLHIV
- 2. Better adherence to ART
- 3. Increased acceptance: reducing stigma and discrimination towards PLHIV
- 4. Reduced costs of service delivery coupled with improved outcomes

3.1 Quality of life: enhancing the health and well-being of PLHIV

The fundamental aim of the CoC is to improve the quality of life of PLHIV and their families. Evaluations of the CoC have shown convincing results in this regard. People with HIV participating in CoC services have reported:

- Decreases in stigma and discrimination²¹
- Increases in emotional and social well-being²²
- High levels of adherence to antiretroviral therapy²³
- Lower levels of loss to follow-up in CoC sites than those achieved in other standalone, non-comprehensive service systems²⁴

3.2 Better adherence to ART

Among PLHIV who are eligible for ART, adhering to their ART regimen is the single most effective action that they can take to improve or maintain their health. Multiple



PLHIV counsels peer in ART adherence

studies have shown that the provision of increased psychosocial support to PLHIV who are taking ART is directly associated with improved adherence to ART and better health outcomes.^{25, 26}

The CoC supports PLHIV to adhere to their ART through two means: (i) a comprehensive, coordinated set of care and support services for PLHIV who are taking ART, and (ii) the establishment of a referral network between the services that helps to ensure that PLHIV

receive the support they need to maintain adherence to their therapy. CoC programmes can support adherence to treatment through the following strategies:

- Training clinic staff to provide adherence counselling and information for PLHIV.
- Training and supporting PLHIV and members of affected communities as adherence counsellors—both in clinics and in communities—so that they can assist individuals and communities to understand ART and how to maximize the benefits of treatment.

Producing and disseminating easy-to-understand written information on adherence.

Medical clinics that serve PLHIV, CHBC services, and PLHIV support groups all provide

coordinated messages and information on the importance of adherence, how to use tools that promote adherence (e.g. pill boxes, reminder calendars), and how to manage side effects. By ensuring high levels of adherence, the CoC helps to prevent the emergence of HIV drug resistance. The CoC referral system also improves the consistency and compatibility of care that PLHIV receive across services.

In two sites in Viet Nam where comprehensive care is provided under a CoC approach, 98% of clients reported adherence to ARV therapy of greater than 95% over a six-month period. Adherence to ART needs to be greater than 95% in order for treatment to be effective.

3.3 Increased acceptance: reducing stigma and discrimination towards PLHIV

People living with HIV in many parts of the region face high levels of stigma and discrimination. Lack of knowledge regarding how HIV is transmitted contributes to discrimination among members of the general public and health workers alike. The link that many people make between HIV and "social evils" such as injecting drugs or participating in commercial sex may intensify the stigma and discrimination that is perceived and experienced by PLHIV.

"I'm not scared to tell people that I'm HIV-positive. I'm positive about myself and my life."

HIV-positive client, Pingxiang City, Guangxi Province, China

Stigma and discrimination against PLHIV makes the impact of HIV worse. Fear of the consequences of testing HIV-positive can be so overwhelming that people who are at risk of being infected may avoid seeking HIV testing and counselling. Less than 10% of people in the Asia-Pacific region who are HIV-positive know their status.²⁷ Reluctance to being tested for HIV among those who are positive results in late diagnosis of HIV and delayed initiation of care and treatment, which can in turn lead to further transmission of HIV.

The role of the CoC in reducing discrimination

The CoC is founded on principles of inclusion and participation. In practice, this translates into meaningful involvement of PLHIV and their families in shaping and implementing the services that are part of the CoC. PLHIV are more likely to use services that meet their needs and that they have been involved in designing and providing.



Participants in the Mondol Mith Chouy Mith PLHIV meeting in Cambodia

The bonds that PLHIV and health providers form lead to improved services and reduced stigma and discrimination towards PLHIV in health facilities, within the community, and at home. Equally important, PLHIV become service providers under the CoC in comprehensive care sites (as counsellors, support staff and administrators), as support group leaders, and as providers of home-based care. The partnership that is formed between PLHIV, health care and other providers transforms initial barriers and fears into feelings of genuine respect and cooperation.

"Before, when I was thin, the children in my village used to call me 'AIDS-man'. But now that I have gained weight and look normal, they don't tease me anymore."

PLHIV client, Moung Russey District, Battambang Province, Cambodia

3.4 Reduced costs of service delivery coupled with improved outcomes

Health officials who organize services that provide care and support to PLHIV want to improve their clients' health as much as possible with the limited budget they have—that is, they want the health services they oversee to be *cost-effective*. Many of the individual services that are provided through the CoC (e.g. CT, ART, OI management) clearly lead to better health for PLHIV. Health planners want to know if the CoC framework improves PLHIV's health more than other service delivery models—models that do not emphasize coordination and linkages as much as the CoC—or if all models achieve similar results.

The cost-effectiveness of the CoC compared to other service delivery models has not been scientifically tested. It is therefore impossible to state with certainty that the CoC is more cost-effective than other models. However, the CoC reduces some costs and increases some benefits when compared to service delivery models that place less emphasis on coordination.

Three ways that the COC may help reduce costs and improve client outcomes

- 1. The CoC framework leads to better results for clients than organizing services separately. The comprehensive referral systems that make up CoC framework lead to higher levels of early testing and diagnosis, which in turn lead to early initiation of ART. Early diagnosis of HIV and early initiation of ART have been shown to improve clients' health.
- 2. The CoC sets common goals among services that reduce the cost of coordination. The integration of services under the CoC framework leads to a "team approach" where all services share a common goal—the well-being of PLHIV clients. This shared goal creates incentives to coordinate in a structured, efficient manner, which in turn leads to reduced costs of coordination between services.
- 3. The CoC results in economies of scale. Economies of scale are realized under the CoC when separate services share fixed costs and avoid duplication and inefficiency. For example, the VCT and ART services can share laboratory facilities, computers, and a common building.

While these three examples do not definitively prove that the CoC is more cost-effective than other service delivery models, they do represent plausible arguments that services delivered through the CoC do result in better client health and/or lower costs than services delivered through other models.

4. The core services of the Continuum of Care

A CoC consists of a network of linked services provided in a geographically defined area. A set of key services is often provided through a **comprehensive care site** (CCS)—a central location, or one-stop facility, where a variety of services are provided. The CCS also serves as a place where PLHIV can meet, relax and participate in self-care, service planning and recreational activities. The CCS is linked to tertiary and CHBC services as well as other services not provided at the CCS. The box below contains a list of services that are offered in most CoCs.

Box 1: The Continuum of Care - a locally defined range of services

Continuum of care networks generally include most or all of the following services:

- HIV counselling and testing
- Opportunistic infections: prevention and treatment
- Tuberculosis detection, prevention and treatment
- Sexually transmitted infections (STI): diagnosis and treatment
- Palliative care: treatment of pain and other symptoms, psychosocial and spiritual support and end-of-life care
- Antiretroviral therapy and adherence: counselling and support
- Prevention services for those most at risk including IDUs, sex workers, MSM, prisoners, migrants and youth
- HIV prevention and reproductive health services for PLHIV and discordant couples
- PMTCT and health services for HIV-positive mothers and infants
- PLHIV support groups
- Nutritional and daily living support
- Psychosocial support: support groups and counselling
- Orphans and vulnerable children: care, support and protection

Additional services that are provided at some CoC sites include social welfare for adults, children and families; legal aid and income generation; targeted HIV prevention services; drug dependency counselling and treatment; and other services as determined through a local assessment of needs and resources.

A capsule description of these services can be found in the glossary in Annex 1.

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CONTINUUM OF CARE COUNTRY PROFILES



There is a rich regional history of different approaches to provide, coordinate and link services for PLHIV and their families. The examples of the CoC in Cambodia, China, Nepal, Thailand and Viet Nam that are presented below are characterized by PLHIV, health workers and others coming together to develop an effective, compassionate system of care.

Cambodia: effective leadership and coordination from national government

In 2003, the Cambodian National Centre for HIV/AIDS, Dermatology and STDs (NCHADS) led a participatory process to develop a national CoC operational framework. Partner organizations have since scaled up the CoC across the country and rapidly increased PLHIV access to care and treatment services.

NCHADS uses the CoC to fulfill its strategic vision for care and support for PLHIV

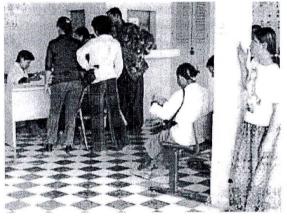
NCHADS originally piloted and then expanded a community and home-based care (CHBC) programme across Cambodia in the late 1990s. NCHADS recognized that demand for hospital-based care and treatment for PLHIV would increase but that hospital care was not effectively linked with CHBC services. The Centre made a strategic decision to adopt and rollout the CoC approach to provide and coordinate care for PLHIV. NCHADS began by developing a detailed operational framework for the CoC and then piloted the implementation of the CoC approach in collaboration with NGO partners, UN agencies and local health authorities in Moung Russey Operational District and other sites.

The CoC in Cambodia: coordination, planning and partnership

NCHADS provides guidance and funding for the CoC but gives localities the responsibility of designing and implementing the CoC. This approach encourages provinces to work

with civil society partners to create a continuum of care that best meets local needs. The most important action that NCHADS took to enable localities to implement the CoC was to both order the appointment of and fund the position of CoC Coordinator in each province. Key aspects of the CoC model in Cambodia include the following:

Creating a centre of care at the district hospital: the CoC is centred around an outpatient clinic (OPC) for PLHIV that is



A centre of care - integrated HIV care services in Battambang, Cambodia

integrated within the district hospital. The OPC is linked with CHBC services and a large support group (known as *Mondol Mith Chouy Mith*, or MMM) of PLHIV and their families. The OPC is comprehensively linked with other health services that include VCT, PMTCT, TB/HIV and inpatient care.

- Emphasizing involvement of PLHIV in the CoC: PLHIV are involved at all levels of the CoC. They serve as members of district and national-level CoC committees and ART selection committees, assume roles in service delivery that include peer support worker positions at outpatient clinics for PLHIV, and are key members of CHBC teams. The Cambodian Network of People Living with HIV (CPN+) plays an important role in promoting the involvement of PLHIV in the CoC.
- Promoting peer and family support for PLHIV—the MMM: the Mondol Mith Chouy Mith (MMM) is based at the hospital and can be found at almost every CoC site. The MMM serves as a venue for PLHIV support group activities. Even more importantly, the monthly MMM meetings build trust and partnership between health-care workers, local authorities and PLHIV.
- Building capacity: NCHADS has invested in the development of a centrally trained cadre of professionals to meet national training needs to support the rollout of the CoC.

Moving forward with the CoC: how to make a good thing better?

Through its use of the CoC, Cambodia has successfully provided ART to between 56 and 100% of PLHIV in need of treatment. Equity in coverage has been attained, as 49% of ART recipients are women and 9% are children.²⁸ The future of the CoC approach in Cambodia appears bright given achievements to date and stakeholder commitment. Hard work will be required, however, if the success of the CoC is to be sustained over time. Future challenges may include maintaining high staff motivation and logistical issues related to the delivery of necessary drugs and supplies as coverage increases. Based on past performance, Cambodia will meet the test.

2. China: developing local solutions within a national policy framework

Energetic, innovative, forward-thinking health experts from the government and non-governmental sectors in China are using the CoC approach to implement national policies that define care, treatment and support that should be provided to PLHIV. Two initiatives—the Pingxiang CoC and the China Australia Xinjiang HIV/AIDS Prevention and Care Project (XJHAPAC²⁹)—are described below to illustrate progress that has been made. Each project follows a multi-sectoral approach and CoC principles to achieve program objectives.

Operationalizing the China CARES programme: turning policy into services

The Government of China launched the China Comprehensive AIDS Response (China CARES) programme in 2004 as an integrated response to the HIV epidemic. China CARES seeks to increase access to comprehensive care and treatment services as outlined in the *Four Frees and One Care* policy. This policy guarantees free counselling and testing services, free ARV drugs to people in rural areas or eligible urban clients with financial difficulties, free ARV

drugs to prevent mother-to-child transmission, free schooling for children orphaned by AIDS, and economic assistance to households with PLHIV. Challenges to the implementation of China CARES include: 1) inadequate resources to provide all required services, 2) the lack of an effective coordination mechanism between services, and 3) financial barriers that prevent clients from confirming their HIV-positive status.

CoC pilot programs: models designed to meet local needs and implement China CARES

Two localities in China, Pingxiang and Xinjiang, applied the CoC approach to develop a system that could fully implement the China CARES program. One or both of these projects include the following key features:

- Establishing a genuine partnership relationship between the hospital and the CDC: CoC planners in Pingxiang set coordination as their top priority. The two key branches of health service provision in Pingxiang—the Pingxiang People's Hospital and the Centre for Diseases Control and Prevention—have worked together since the beginning stages of the CoC to provide a full range of services for PLHIV.
- Strengthening and linking facility-based services for PLHIV: CoC planners in both sites built on support provided through the China CARES programme to establish hospital-based comprehensive care sites and strengthen inpatient care. Each site developed a referral system to create links between these and other services that include VCT, PMTCT, and methadone maintenance therapy.
- Establishing community and home-based care services: the XJHAPAC programme has developed extensive CHBC services. PLHIV are linked to a community care provider who supports adherence to treatment, advocates with the Department of Civil Affairs for a basic living allowance, and provides psychological and physical care for PLHIV in their own homes. Trained community providers (who include family members and PLHIV) work with clients to promote interventions for health and social problems, prophylactic treatment, appropriate referrals and treatment adherence.
- Overcoming stigma and discrimination: CoC planners strengthened health workers' acceptance of PLHIV through strategies that include: orienting health leaders regarding their role in reducing stigma; arranging for international experts to model open behaviour and attitudes towards PLHIV (including touching and hugging); developing health-care financing mechanisms for PLHIV so that they are not perceived to be a burden on the health system; and educating all employees in organizations that support the CoC regarding how HIV is transmitted and how to prevent accidental exposure.
- Partnerships with other sectors: strong partnerships between police, Islamic religious leaders and public health programmes promote harm reduction and care as integral parts of the response. This in turn reinforces the social mobilization strategy of the CoC.
- A growing role for PLHIV: PLHIV work as caregivers in the hospital, CHBC providers, peer educators in needle and syringe programmes, and inpatient care providers, thereby earning a small income while building self-esteem and ownership in their own care.

Assessing where we are and where we need to go

The experiences in Pingxiang and Xinjiang show that Chinese government and NGOs can work together to develop a system of high-quality care, treatment and support for PLHIV that builds on and enhances the impact of the Four Frees—and that PLHIV will use these services if they are provided in an environment of understanding and acceptance. The challenge for those working in HIV care and support in China is to use these lessons to expand coverage.

3. Nepal: developing a CoC during civil conflict and a migration-driven epidemic

The National Centre for AIDS and STD Control (NCASC) in Nepal has collaborated with its partners to develop and expand care, treatment and prevention services for PLHIV over the past decade. These gains have been achieved in the face of a prolonged insurgency, political instability and severe geographical constraints.

Partners, clients and health workers join together to design and provide services

Groups that have contributed to the achievements in HIV care in Nepal include the following:

- People living with HIV advocate and serve their peers: PLHIV groups' advocacy and support of programmes has contributed to the success of HIV care programmes in Nepal. PLHIV work side-by-side with trained HIV health-care providers in health facilities and in communities, serving as patient advocates and providing care themselves.
- Non-governmental organizations in Nepal fill gaps and strengthen government programmes: NGOs provide care and support services that include OI treatment and cotrimoxazole prophylaxis, CHBC and counselling services, and referral of eligible clients to government services for laboratory tests and ART services. NGOs support the provision of ART by reinforcing adherence and providing palliative care for ARV side effects.

Service provision framework in western Nepal: the Seti Hospital HIV Care and ART site

The Seti Zonal Hospital (SZH) ART site in Kailali District, Far Western Nepal, is a comprehensively linked care, treatment and support programme implemented by the government health services. The Zonal HIV Care and Treatment Committee meets on a quarterly basis to coordinate and plan HIV-related activities. PLHIV support groups work with the government, SZH hospital staff, NGOs and INGOs in the design and implementation of HIV care and treatment programmes that target migrant workers and their families. The involvement of PLHIV in the process has led to reduction in stigma and discrimination in affected communities. The figure below describes the services that are offered through the SZH ART site and how they are linked.

Challenges to overcome as the response in Nepal progresses

The previous lack of testing services in remote areas of Nepal presents a major challenge. Many PLHIV do not know their status when services are introduced and thus do not use them. Mobile counselling and testing services are taken to communities to address this problem.

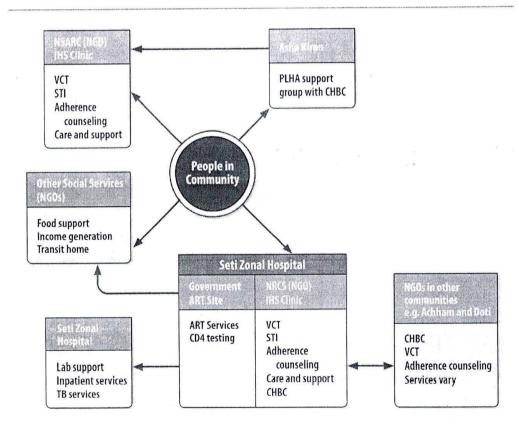
Geographical constraints present major challenges to service provision. Clients in remote locations find it difficult to make frequent visits to ART clinics due to geographical and economic constraints. Partner organizations at some ART sites provide follow-up and counselling services in the communities and have established hostels near to the ART sites where PLHIV can stay during the first few weeks of their treatment.

Providing services to mobile populations: many at-risk individuals in Nepal are highly mobile and travel back and forth between Nepal and India in search of work. FHI and its partners in Nepal and India have established care, treatment and prevention services in major cities in India—including free ART—specifically for Nepali migrants. Care and treatment programmes have created links so they can support referrals for migrants moving to and from Nepal and India. Cross-border migration



Seti Zonal Hospital HIV Clinic, Nepal

Figure 7: Coordination framework in SZH ART site



Source: Family Health International / Nepal

between places of employment and home no longer prevents Nepali migrants and their families from receiving the services they need.

4. Thailand: PLHIV lead the response

The PLHIV movement changed the face of HIV/AIDS care in Thailand. The central role of PLHIV in the HIV response—with substantial support from NGOs such as the Thai Network for People Living with HIV/AIDS (TNP+), MSF and AIDS ACCESS and in collaboration with the Thai Ministry of Public Health (MoPH)—stands out as the leading regional example of effective grassroots PLHIV activism. By the late 1990s, northern Thailand had become the beacon for the CoC approach in both the country and the region.

PLHIV play leadership roles in designing a service framework and providing services

PLHIV across Asia in the late 1980s had a growing set of unmet needs for care, treatment and support. PLHIV activists in northern Thailand took matters into their own hands. They formed groups and advocated with local public health officials to address PLHIV needs. In the 1990s this resulted in partnership in northern Thailand between TNP+ and local health departments. Day care centres (DCCs) were established where PLHIV could receive health care, emotional support and CHBC services—including the Chun DCC, a centre renowned for offering compassionate care. Over the next decade, PLHIV, local NGOs, international NGOs and the MoPH developed and implemented a groundbreaking service model to provide care and support for PLHIV in a resource-poor setting—the Comprehensive Continuous Care (CCC) centre—that today forms the core of CoC activities in Thailand.

The Comprehensive Continuous Care centre: the first CoC hub in Asia



Partnerships between PLHIV and NGO leaders

CCCs were first established in local clinics or district hospitals in northern Thailand in the mid-1990s. CCCs not only provided comprehensive, integrated services for PLHIV, but the substantial involvement of PLHIV in CCC operations, working alongside professional medical teams, demonstrated the contribution that PLHIV could make to their own care. Key features of the 220 CCCs that provide services in Thailand today include the following:

- Touching lives and forming bonds: the CCC is a place where PLHIV can meet, obtain information and support, and form long-term relationships with health providers. The CCC places an emphasis on gaining the trust of PLHIV and treating them with dignity.
- PLHIV role in service provision: trained PLHIV provide services to their peers while also receiving health services that include health education, medical and nursing care including OI management and ART.
- A centre of support: CCCs also offer nutrition and self-care counselling, traditional medicine, guidance in meditation and physical exercise, vocational and community activities, psychological, social and financial support, and even daily meals.
- Teams of trained PLHIV and health workers provide home-based care: trained PLHIV conduct home visits for PLHIV to provide adherence support, social and emotional support, counselling, and basic primary health care such as wound

management. Health workers provide support for complex cases. PLHIV groups meet regularly at the CCC where PLHIV and their family members are trained in HIV prevention and care.

Gold-standard activism: building on achievements as PLHIV look to the future

The provision of universal coverage of ARVs in Thailand was a huge achievement. Government action to enable local production of generic ARVs dramatically reduced the costs of treatment. PLHIV organizations applied sustained pressure on the Thai government, resulting in the inclusion of ARVs within the government 30-Bhat Health Care Scheme.

The MoPH used the findings of a recent evaluation of the Comprehensive Continuum of Care Project³⁰ to develop a new policy that encourages hospitals participating in the national ART programme to establish CCC centres. The MoPH supports the medical component in the 220 CCC centres that are currently operational while the Global Fund supports PLHIV involvement and capacity building that is provided by the AIDS ACCESS Foundation, MSF Belgium and TNP+. The unique and effective partnership of PLHIV groups, NGOs, and the Thai government in the provision of services to PLHIV suggests that Thailand will continue to serve as a shining example of the response to the epidemic in a low-resource setting.

5. Viet Nam: national leadership of a coordinated response

The Ministry of Health (MoH) in Viet Nam responded early to the needs of PLHIV for care, treatment and support, establishing the National AIDS Committee in 1990. Care was

provided to PLHIV through a system known as the Management, Care and Counselling Programme. As the epidemic in Viet Nam advanced, the MoH reassessed its national strategy. In 2005 based on the findings of the assessment, the MoH established the Viet Nam Administration of AIDS Control (VAAC) and decided to pilot a new service delivery strategy that offered accessible, high-quality HIV care. The VAAC moved quickly during the following year, teaming with government departments, donors and NGOs to develop and implement a national training programme on ART and adherence counselling, standard operating procedures



Health care worker providing care to a client in Binh Thanh Clinic, Vietnam

for HIV clinical care and ART, and a uniform drug management system. By early 2007, approximately 200 comprehensive care sites (CCSs) had been established, with 7,000 PLHIV receiving ART—more than a tenfold increase over 2004.

What are the key components of the CoC approach in Viet Nam?

The VAAC led the development of a national ART protocol as well as the Care and Treatment Programme of Action during 2006-2007. These two efforts form the foundation for the continuum of care approach that is being implemented in Viet Nam today. Key aspects of that approach include the following:

- **Planning framework for CoC:** the Programme of Action guides the CoC approach for district-level planning, coordination, and service delivery. The Programme outlines the role of District Care Coordinators and CCSs, both of which are generally integrated into the district hospital structure. The Programme also emphasizes that PLHIV should play a pivotal role in the development of services.
- Basic CoC service delivery structure: two comprehensive care sites in Ho Chi Minh City—District 8 and Binh Thanh district—demonstrate the basic CoC structure. Care, treatment and support services for PLHIV are effectively linked to CHBC and social support services. The CoC establishes the centre of care for PLHIV at the district-level CCS, from where clients can be referred down to the commune-level and up to the provincial/city-level health-care services as required. The CCS also provides a location where local PLHIV support groups can meet and conduct monthly meetings.
- The Management, Counselling and Care Programme: the MoH developed this innovative programme to increase clients' access to services. The programme trains staff in commune health centres (CHCs) to provide PLHIV with home and facility-based care for symptoms as well as cotrimoxazole prophylaxis and treatment for common opportunistic infections. CHC staff are also trained in counselling skills and encouraged to support the establishment of PLHIV support groups in the communes. The programme establishes referral linkages between CHCs and central hospitals that provide higher-level HIV services.
- **CCS** models: two types of CCSs have been established: (i) the CCS integrated within the hospital, and (ii) the stand-alone CCS linked to the hospital. The CCS, together with its links to the community care system, creates a continuum of care and a platform for the widespread introduction of ART.

Next steps for Viet Nam: challenges for the future

The VAAC has set a target of establishing district-level CCSs in 70% of all 500 districts in Viet Nam by 2010. Remaining challenges include securing a stable and adequate supply of ARVs and other essential medicines for HIV care and providing district CoC sites with adequate technical support. Given the strong foundation that the VAAC has created, Viet Nam will find a way to overcome the challenges and meet its targets.

Further reading

- 1. NCHADS, FHI/Cambodia. Cambodia cares: implementing a continuum of care for PLHIV, including ART in Moung Russey, Cambodia: documentation of an experience in a resource constrained setting. Phnom Penh, FHI/Cambodia, 2004.
- 2. Guangxi CDC, FHI/China. *Pingxiang cares: implementing a continuum of care for PLHIV through governmental health services in Pingxiang, China*. Np, FHI/China. 2007.
- 3. AIDS Education Programme, Faculty of Education, Chiang Mai University and WHO Representative Office in Viet Nam. HIV day care centre of Chun Hospital: a history and case study of "Happy Heart Centre". Np. 2007.

WHO, UNAIDS, UNICEF. Towards universal access: scaling up priority HIV/AIDS interventions in the health sector: progress report, April 2007. Geneva, WHO, 2007.

²⁹ Jointly funded through the GoC and the Australian Government (AusAID).

Kumphitak A et al. Involvement of people living with HIV/AIDS in treatment preparedness in Thailand: case study. Geneva, WHO, 2004.

MAKE IT HAPPEN AT THE LOCAL LEVEL: ESTABLISHING THE CONTINUUM OF CARE



How to:

- 1. Get Started: gathering support and assessing needs
- 2. Develop the network: creating coordination and referral systems
- 3. Establish services: improving existing services and integrating new ones
- 4. Involve PLHIV: partners in leading, planning and service provision
- 5. Create acceptance: enabling PLHIV and their families to use the CoC
- 6. Build capacity: developing human resources and tools to support the CoC

With nearly 20 years experience, much has been learned regarding how to establish continuum of care networks. While each CoC is unique, there are common building blocks that each CoC uses to build strong systems and services.

Section 4 provides planners and implementers of the CoC with guidance on how to put each of the building blocks in place at the local CoC—that is, the site where CoC services are coordinated and provided. Study these building blocks, ideas, and specific country examples throughout the Toolkit to help decide which approach to CoC implementation best fits your local context.

The box below describes the different types of local CoCs that are found in the region. **Section 5** provides information regarding national-level support for the continuum of care framework.

Box 2: What does "local CoC" mean?

Each site will develop the CoC based on their local context. "Local" can mean different things in different places. Below are three types or levels of local CoCs that are commonly found in Asia:

- 1. <u>District</u>: CoC services are provided through one administrative district and revolve around a comprehensive care site (CCS) that is generally based in the district hospital. Links may exist between the provincial and district CoC programmes.
- 2. <u>District-cluster/operational district/city:</u> a cluster of districts or a part (or all) of a city is designated as a single CoC. A full-service CCS is located in the district with the greatest number of PLHIV. The remaining districts offer satellite services and community and home-based care (CHBC) to ensure effective follow-up support for clients.
- 3. <u>Provincial:</u> all CoC services revolve around a CCS that is based in the provincial hospital. Other district or district-cluster CoCs may exist within the province.

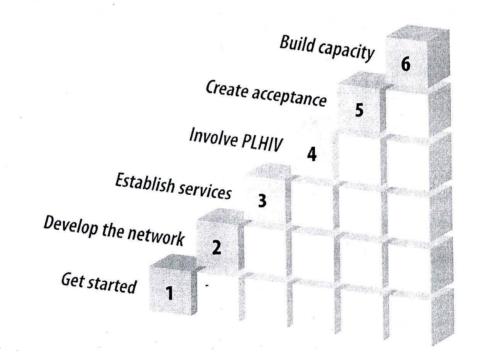
The CD-R@M that accompanies this Toolkit contains a number of resource tools that have been developed at different CoC sites. Planners and implementers are encouraged to review these tools and use them "as is" or adapt them for their own use as appropriate.

CoC building blocks: a pathway to improving care services for PLHIV

With the rich experience of establishing CoC networks in Thailand, Cambodia, China, Viet Nam and Nepal, six building blocks have emerged that are needed to establish and maintain an effective CoC. Each block can be put in place with limited resources but all require the commitment and passion of leaders, PLHIV and providers to work together to make it happen.

The figure below illustrates the six building blocks of the CoC.

Figure 8: The six CoC building blocks





Building Block 1 activities:

- Share the vision: creating awareness and commitment for the CoC
- Know what's needed: assessing care needs
- Make a plan: developing a CoC workplan
- Form consensus: trainings and workshops for stakeholders

Building Block 1 activities concern mobilizing support for the CoC. Leaders in each CoC should decide what actions are needed and in what order they should be done.

BLOCK 1-A:

Share the vision - creating awareness and commitment for the CoC

The CoC may start from local government, PLHIV groups, and/or NGOs identifying a need to develop more comprehensive and better-linked services for PLHIV. In some cases international organizations may help identify the need for a CoC. The seeds of every CoC are usually sown by a few key individuals who want to improve care for PLHIV and their loved ones. Key activities that are necessary to build support for the CoC include the following:

- 1. Identifying a recognized leader to be the head of the CoC.
- 2. Holding meetings with stakeholders to discuss why a CoC is needed.
- 3. Taking stakeholders on study tours to see a CoC in action.
- 4. Inviting people who have developed CoCs in other areas to meet with stakeholders.

Identifying a leader of the CoC

The initial advocates of the CoC will need to gain agreement from one person to become the local leader of the CoC. In Viet Nam this person is the head of the local hospital but in other places it may be the director of the local health bureau.

Gaining stakeholder buy-in

The small core team of people who have the idea of creating a CoC in their area need to inspire support for the CoC from local leaders and service providers. The broader the inclusion of different people and organizations who can support the CoC, the more successful the CoC will be. CoC planners should identify HIV-related issues that concern local leaders. These issues may include a lack of coordination among HIV donors and programmes or concern

over how to organize, provide or expand access to ARV therapy. Helping leaders see the CoC as an effective response to these concerns is a good strategy for engaging local leadership and obtaining their buy-in.

Building local commitment for the CoC around the region

The director of a district hospital in Viet Nam had a vision to start a CoC in his district after hearing about CoCs that had been established in Ho Chi Minh City (HCMC). He met with the Heads of the People's Committee and the Public Health Bureau to obtain their support for the CoC and eventually took them on a study tour to see the CoC in HCMC. The director then held a big meeting with stakeholders from the district to discuss how the CoC could be established. This meeting became the first of many CoC Coordination Committee meetings. With full stakeholder support behind him, the director was able to rapidly establish a comprehensive care site in his hospital and support the formation of PLHIV support groups and CHBC teams. He also reached out to local faith-based organizations to donate food to PLHIV in the hospital and in the community. An OVC support group led by the Women's Union was also brought into the CoC.

The experiences in northern Thailand and Cambodia were different. In Chiang Mai, Thailand, PLHIV groups struggling to take care of their peers in the community initially met with local health officials to see what more could be done to provide hospital-based care for PLHIV. Their collaboration eventually led to the development of day care centres (DCCs)—there are now 222 DCCs throughout the country—that served as the hubs of the first CoCs in Asia. Thus began a long partnership to provide PLHIV with better care under the CoC. In Cambodia, the national HIV programme felt the CoC approach was needed and brought in key MoH officials, PLHIV and representatives of local and international NGOs to develop the CoC.

Linking the establishment of the CoC to local concerns in Guangxi, China

In Guangxi, China, the establishment of local CoCs was seen as a strategy to operationalize the nationally mandated China CARES programme. Although local authorities were able to provide free ARVs to eligible PLHIV through the programme, significant barriers limited access to this service. One major barrier was the burden of expensive HIV confirmation tests—the cost of which is borne by the client—without which few individuals are eligible to access ART. The cost to PLHIV of treating opportunistic infections was also very high and a serious barrier to care and



CoC planning meeting in Guangxi, China

ultimately access to ART. CDC authorities in Guangxi sought assistance to develop a CoC that would reduce barriers to access. Strategies for improving access included the subsidization of HIV confirmation tests and hospital fees for HIV care.

Seeing is believing: the role of study tours in mobilizing commitment to the CoC

There is no better way of building support for the CoC than by arranging for stakeholders to see it in action. The fastest and most effective way to show stakeholders how the CoC works, what it is, and how it impacts the lives of PLHIV and the community is through a study tour.

There are many ways to implement study tours. Ideally, local leaders can visit advanced CoC sites in their own country. If this is not possible, leaders may be sent to neighbouring countries. Another option is to bring leaders from advanced CoCs to the new site to share their experiences and ideas for implementation. Whatever approach is used, study tours provide opportunities for reciprocal learning. Such relationships can be maintained over time and provide an opportunity for continued learning and support.

Chain reaction: impact of effective study tours

Teams from Cambodia, Viet Nam, Nepal, Papua New Guinea, Myanmar, India and Bangladesh have all conducted study tours during the past decade to observe the CoC day care centres in the north of Thailand. These visits contributed to the development of the CoC in Cambodia and Ho Chi Minh City, Viet Nam.

Representatives from countries around the region have visited the CoC programme in Moung Russey Operational District in Cambodia. Cambodia developed Moung Russey to serve as a learning site for CoC planners both in Cambodia and neighbouring countries where they can observe every component of the CoC programme.

Following the establishment of CoC learning sites in both Viet Nam and Nepal, study tours are organized internally so that participants can communicate with peers in the same language and observe how services are provided at sites and within contexts that are similar to their own.

Community and home-based palliative care services have been well developed in Ho Chi Minh City, Viet Nam. NGOs in Nepal and Thailand have sent delegations to Viet Nam to learn more about the specific role of CHBC in the CoC.



Action points: create awareness and commitment for the CoC

- Identify a recognized leader to be the head of the CoC.
- Hold meetings with stakeholders to discuss why a CoC is needed and gain their support.
- Take stakeholders on study tours to see a CoC in action.
- Invite people who have developed CoCs in other areas to meet with stakeholders.

BLOCK 1-B

Know what's needed - assessing care needs

Once support is in place for the local CoC, the next step is usually a rapid needs assessment to determine what the needs are for HIV care, treatment, support and prevention and which needs have highest priority. Generally, some HIV services already exist—the needs assessment seeks to learn how those services are used, how well-linked they are to other key services, and what can be done to improve them. The needs assessment should also identify gaps in service by asking PLHIV and families what they need. The best time to conduct the needs assessment is often just after a study tour with local leaders when the steps of how to implement a CoC are fresh in their minds. The box below outlines the basic components of a CoC needs assessment.

Box 3: Components of a CoC needs assessment

The needs assessment should gather essential information on services, gaps and perceived care needs. A basic assessment consists of the following:

- 1. Interviews (individual and focus group) with PLHIV and families regarding their needs
- 2. A facility assessment of the local hospital and other HIV-related health services and interviews with key health-care workers
- 3. Interviews with NGO managers involved in HIV work including home-based care, counselling and testing, and prevention
- 4. Review of existing referral system and coordination mechanisms
- 5. A review of HIV prevalence, projections and case reporting from the national programme, provincial health department, and hospitals

See the CD-ROM that accompanies this Toolkit for an example of a needs assessment report.

The core CoC team is usually composed of a partnership of PLHIV, government, and civil society representatives. This team develops and implements the needs assessment and then reviews the information that it generates to identify major HIV care and prevention service strengths, barriers and needs. The findings and recommendations that result from this process are presented to stakeholders, followed by the identification of priority actions that form the basis for the initial CoC workplan.

The needs assessment serves several additional purposes that include the following:

- Creates an opportunity for PLHIV and family members to tell leaders and healthcare workers what they need from a client perspective.
- Develops teamwork and more trusting relationships by bringing together PLHIV, community members, and health-care and NGO personnel in a common task while promoting mutual understanding.

Action points: find out what's needed

- Conduct a rapid needs assessment to determine what the needs and priorities are for HIV care, treatment, support and prevention.
- Present the findings and recommendations to stakeholders.

BLOCK 1-C

Make a plan: developing a CoC workplan

The findings and recommendations that emerge from the initial needs assessment form the basis for developing a workplan for the local CoC. If there is already an HIV workplan in place, then it can be adapted based on findings of the needs assessment. The workplan can be prepared by CoC leaders and members of the core team that conducted the needs assessment. The workplan can then be shared with the CoC Coordination Committee (CoC-CC) to gather their input and ensure their support. Maximizing the involvement of this committee leads to increased ownership and buy-in during its implementation.

Figure 9: Example of annual CoC workplan

Activity Who responsible	Time frame				-	T	Target/expected
	Q1	Q2	Q3	Q4	Cost	iotai	Target/expected output
A program to the same of the s							
	Who responsible	Who responsible Q1	Who Time responsible Q1 Q2		WIII0	Cost	Cost Total

Source: Family Health International

A good werkplan specifies what needs to be done, when, and by whom. The CoC workplan in the figure above was developed by the MoH in Cambodia for use by local CoCs to plan annual activities, identify funding needs, and determine which activities were funded and which require additional resources. CoC partners provide a concept paper with coverage estimations and cost inputs using the table above. The CoC technical working group then identifies CoC partners who will fill gaps in funding (fund/cost sharing) and service provision (activities sharing). The workplan can be shared with donors and local organizations to identify areas where they may provide support. The names of donors and organizations that will support CoC activities can then be listed on the final workplan, which helps to hold them accountable for commitments they have made. See the CD-ROM for an example of a workplan template.

The preliminary workplan should focus on essential first steps that are achievable and lead to early, measurable results. For example, the initial focus of the workplan in Moung Russey, Cambodia was to set up the CoC comprehensive care site (supported by staff training and equipment procurement) and link outpatient clinics and the VCT site with services such as antenatal care and TB care that were already offered within the hospital.



CoC Coordination Committee meeting in Viet Nam

Action point: make a plan

Develop a workplan that specifies what needs to be done, when, and by whom.

BLOCK 1-D: Form consensus – trainings and workshops for stakeholders

CoC planners should organize meetings, trainings and/or workshops to improve readiness for implementing the CoC and to build broad consensus and support for the CoC. The trainings or workshops that can improve support for the CoC include the following:

Introduction to the CoC

The CoC is a new concept for many people. A large number and variety of stakeholders can be sensitized to the ideas behind the CoC and how to become involved in it through meetings to share observations from a study tour, results from a needs assessment, or a draft workplan.

Overview of HIV care and treatment

Health-care administrators and providers in sites establishing a new CoC require basic information regarding the core care and treatment services that PLHIV require. Topics in this training include the following: the natural course of HIV disease, clinical staging of HIV, managing Ols, TB/HIV, palliative care, PMTCT, and ART.

In Smach Meanchey district in Koh Kong province, **Cambodia**, a series of meetings were held with government leaders, the local hospital, and NGOs to learn about the CoC and discuss their role in it.

HIV and standard precautions

The purpose of this training is to increase knowledge related to HIV transmission and prevention and the role of standard precautions (e.g. how health-care workers can protect themselves from HIV), to provide information regarding access to post-exposure prophylaxis and free medical care if infected, and to address stigma and discrimination.



CCS Team in Campha, Viet Nam

In Campha district in Viet Nam, the local government trained the hospital staff in HIV and standard precautions. All hospital staff—managers and administrators, health-care workers, and cleaners and drivers—participated in the training. This led to increased understanding and willingness among health-care workers and other hospital staff to care for PLHIV.

Building Block 2 activities:

- Oversee the system: role of CoC coordinators
- Build a partnership: creating and sustaining a CoC Coordination Committee
- Connect the dots: linking PLHIV to the services they need
- Knock down fences: identifying and removing barriers to care

Building Block 2 presents strategies for coordinating the CoC and developing a referral network. The roles of individuals and committees at the local level that support coordination are also described. As with all the building blocks, the activities do not have to be implemented in any particular order.

BLOCK 2-A:

Oversee the system - role of CoC coordinators

One key to success for CoC programmes in the region has been the appointment of a CoC Coordinator. There are often two levels of coordination needed: one that relates to leadership and one that focuses on day-to-day implementation.

- Local CoC Leader: the role of the local CoC Leader (e.g. head of the local hospital or health department) is to convene the Continuum of Care Coordination Committee (CoC-CC). This individual is responsible for overall programme and budget decisions and negotiating with local, provincial or national officials to improve support for the local CoC programme.
- Local CoC Manager: this individual is the day-to-day manager of the CoC and is generally a staff member of the local health department or local hospital. The manager's job is to guide the CoC implementation process. This includes:
 - Managing the implementation of the overall CoC workplan
 - Playing a leading role in the organization and establishment of CoC services
 - Promoting the involvement of PLHIV and families in all aspects of the
 - Convening regular CoC Coordination Committee meetings
 - Meeting with key partners on a routine basis to solve problems
 - Developing referral systems and tools to support CoC systems

Creating an enabling environment for CoC coordination

Government staff members are often overloaded with many responsibilities. Although it is not ideal, many CoC Coordinators and Managers have full-time jobs in addition to their

CoC-related duties. CoC Coordinators and Managers can therefore greatly benefit from a job description that clearly states that supporting the CoC is part or all of their jobs (which implies that their work in the CoC is not a "small extra task" to do in addition to their "real job"). Obtaining explicit funding for the salary of the Coordinator is a huge advantage for the CoC. The performance of the CoC will always improve when CoC Coordinators and Managers can give more time to the CoC.

In 2003, the MoH in Cambodia used the national CoC Operational Framework to create a new, centrally funded staff position: the Operational District (OD) CoC Coordinator. The MoH then supported ODs to identify qualified CoC Coordinators who in turn became the focal persons for managing local CoCs. The Cambodian MoH showed that essential staffing for the CoC could be ensured by pooling national-level funding.

Action point: CoC leadership

 Define the roles of the local CoC Leader and CoC Manager and identify people to fill the positions.

BLOCK 2-

Build a partnership - creating and sustaining a CoC Coordination Committee

In order to bring together all the resources and services that PLHIV and families need under one network, it is extremely important to establish a forum to discuss and build the linkages that make this network function smoothly. Localities that have successfully implemented the CoC have addressed this need by establishing a CoC Coordination Committee (CoC-CC). This committee provides the "glue" to the CoC network.

What exactly is the CoC Coordination Committee?

The CoC-CC is a group of people who support the CoC by coordinating its activities and maximizing PLHIV's access to services. The CoC-CC determines the need for new services, takes decisions to provide those services, and mobilizes resources to fund new initiatives.

Who are the members of the CoC Coordination Committee?

The CoC-CC is generally led by local government officials and is an *inclusive* body. CoC-CC members often include representatives from the hospital and Comprehensive Care Site (both administrators and health providers), PLHIV groups, NGOs, CHBC teams, religious groups and other governmental departments that support PLHIV (e.g. social welfare, education).

CoC Coordination Committee takes action in Cambodia

In Koh Kong, a coastal province in **Cambodia** that borders Thailand, the local CoC Coordination Committee responded to the ongoing problem of extremely sick homeless PLHIV by mobilizing funds to develop a hospice at the local pagoda. The CoC-CC ran fund-raisers and gained commitment from the provincial governor, district authorities, police, Ministry of Women's Affairs and many others to construct the hospice. The hospice, which was designed by PLHIV, the pagoda and CoC-CC members, now cares for up to 10 homeless individuals at a time.

Source: CARE/Cambodia

What does the CoC Coordination Committee do?

The CoC-CC is generally responsible for the following:

- Improving referrals across services (including the development of a referral directory, procedures and forms) and resolving coordination problems between services
- Conducting semi-annual and annual planning for HIV services
- Ensuring that different HIV services do not overlap each other
- Identifying training gaps and needs
- Conducting social mobilization activities that aim to reduce stigma and discrimination and raise community awareness regarding HIV

How often do the committees meet?

When the CoC is first starting up, the CoC-CC may meet once a month or more often. Later, when the CoC is more firmly established, the committee may meet every two or three months to monitor the CoC and plan for continued improvements.

How does the CoC coordination committee fit in with other local HIV committees?

There is no need to set up an entirely new CoC-CC if there is a pre-existing committee structure into which the CoC can be integrated. In Cambodia, the CoC-CCs are structured as sub-groups of the multi-sectoral HIV Coordination Committees that were in place before the establishment of the CoC and were already funded and supported by the national health programme. In some locations in Viet Nam, the CoC-CC has been integrated into the monthly HIV programme coordination meetings. CoC-CCs in Nepal are integrated into the District AIDS Coordination Committees.

How can a CoC Coordination Committee be established?

Establishing a local CoC-CC is a relatively straightforward procedure. Suggested steps to carry out this task are listed below. The CD-ROM that accompanies this toolkit contains examples of CoC-CC standard operating procedures and other related tools.

Steps to establish a CoC Coordination Committee

- Gain support from local health leader(s) to establish the CoC-CC.
- Determine how the CoC-CC will function. Will it be integrated into an existing HIV committee? If so, how?
- Identify key people who should be on the CoC-CC and invite them to attend the first meeting. Members should include both those who may support the CoC as well as those who may obstruct the CoC.
- Conduct the first CoC-CC meeting. At this meeting, review the current HIV situation, PLHIV needs, and current services and gaps. Discuss how to improve referrals, reduce barriers to important services, etc. Many committees conduct elections to different positions (e.g. CoC-CC chair, co-chair, secretary, etc.) at the first meeting.
- Following the first meeting, the local government can officially approve the committee including its purpose and membership. The CoC-CC can then continue to organize meetings to address major issues that help the CoC network run smoothly.
- Maintain flexibility to add new members in order to be able to bring in new members identified at a later date who can help improve services for PLHIV.
- Notify members well before each meeting to ensure their attendance. If important people are not attending meetings, invite the CoC Leader to meet with these individuals in order to encourage their participation.

The CD-ROM that accompanies this Toolkit contains an example of CoC Coordination Committee members and their roles and responsibilities.

Action point:

• Establish the CoC Coordination Committee and identify members and duties.



BLOCK 2-C:

Connect the dots - linking PLHIV to the services they need

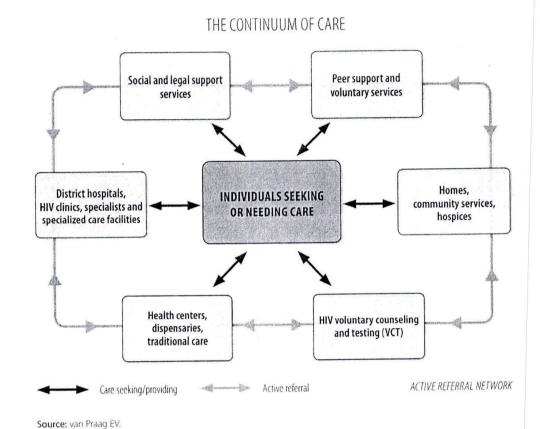
Establishing a referral network

One of the most important objectives of the CoC is to establish a strong but simple referral system. The CoC Leader and Manager and the CoC-CC are the essential facilitators of a better referral system for PLHIV and their loved ones.

Within the health-care system, a referral system usually exists between services within a hospital and between community and tertiary health-care services. However, this system may not always be easy for health-care workers and PLHIV clients to understand and follow.

One of the most common problems faced by PLHIV is knowing what services are available and how to get from point A to point B to access the services they need (see figure below). The job of CoC implementers is to do everything possible to minimize this problem.

Figure 10: Active referral within the CoC



The CoC will need to develop or strengthen referral relationships in the follow areas:

- Within the hospital: between essential hospital services that include counselling and testing (CT), TB, ANC/PMTCT, inpatient department, laboratory, pharmacy, infection control, and surgery.
- Between the hospital and the community: between essential hospital services and community-based services provided by CHBC teams, PLHIV support groups, NGOs/CBOs, and faith-based organizations.
- Between the hospital and other public services: between essential hospital services and government departments that include Social Welfare, Women's Affairs, and Education.
- Within the community: between community-based services that include CHBC, harm reduction, OVC care programmes, and legal and human rights services.
- Between district, community and provincial health services: between community-based and facility-based services at the district level and higher-level specialized tertiary-level health-care services.

Between private and government health-care services: in most parts of the region, private health-care services provide care to many PLHIV and others. Involving them in the system can lead to improved care and stronger referral systems.

Establishing a Referral Network in Hai Phong Province, Viet Nam

In 2005, the People's Committee and local health authority in Hai Phong Province, Viet Nam established a CoC-CC. Members of the CoC-CC included leaders of local HIV prevention and care services and PLHIV. CoC-CC members used initial meetings to focus on problems related to referral. Many problems were resolved easily when providers from different services worked together to define the problem and design a solution. For example, the TB hospital did not accept HIV test results from local VCT sites and required clients to pay for another HIV test at the hospital before accessing TB services. Since the CoC-CC membership included the Director of the TB hospital, he was easily able to make immediate changes to this policy and swiftly improve PLHIV's access to TB services. Major successes of the Hai Phong CoC-CC to date include the development of a common referral form for the majority of HIV services, the introduction of a client-held service record book, and a HIV service guide for clients, their families, and health providers.

The CoC Manager and CoC-CC can take an important step towards the establishment of an effective referral system by negotiating the use of standard referral procedures—including common referral forms—by all CoC services. This is not always an easy task and may require intense negotiations with service providers. For example, outpatient clinics, VCT centres and TB services may all have different requirements for accepting and enrolling referred clients. Negotiating compromises and streamlining referrals will result in benefits to both clients and service providers.

The CD-ROM that accompanies this Toolkit contains examples of guidelines on how to establish effective referral links between HIV care, treatment, support and prevention services.

Tools to support and improve referral systems

In addition to referral procedures, CoC-CCs have developed tools to improve referrals, such as:

1. Client-held service record booklet: this record includes a summary of information regarding all medical and psychosocial services received by the client from services within the CoC network. The client receives his own booklet—each with a unique client code—when he enters the system. The client is responsible for presenting the booklet whenever he accesses a service. Findings, prescriptions and recommendations from each encounter are recorded in the booklet. There are two main benefits resulting from this tool: service providers have immediate access to the history of care received by the client, and the client has all of his care information stored in one document under his control.

2. <u>CoC service guide:</u> many CoC clients and service providers are not aware of all the services that are available to PLHIV. A simple list of key CoC services can be very helpful to clients and providers alike. This guide can provide a basic profile of all services including an address, service hours, contact information, and the types and costs of services offered. The guide can be included in the back of the client-held service record booklet described above.







Adult service record booklet: Cambodia

3. <u>Case managers:</u> one of the best ways to support client access to CoC services is to actively help them get from point A to point B. A case manager is an individual who helps clients access the services they need and plan for their care needs. Case managers are often posted at comprehensive care sites. Some CoCs utilize adherence counsellors, CHBC teams or volunteers to provide this service.

Refer to the CD-ROM that accompanies this Toolkit for an example of a client-held service record book.

Action points: linking PLHIV with the appropriate services

- Develop or strengthen linkages between the services for PLHIV to build a simple and effective referral network.
- Create tools to support and improve referral systems, such as standard referral forms.

BLOCK 2-D:

Knock down fences - identifying and removing barriers to care

Even with an excellent referral network and HIV services in place, hidden barriers to care may still block PLHIV and their families from receiving needed services. The CoC-CC can identify and remove these barriers though the needs assessment and through contacts with PLHIV and service providers at CoC-CC meetings or other venues.

Study after study has shown that health-care user fees (i.e. fees for services, laboratory investigations, medicines, etc.) pose serious barriers to utilizing services. Strategies to minimize this barrier by providing fee "exemptions" for the poor have not been effective. Service fees almost always pose a serious obstacle to PLHIV accessing services and should be discussed in the CoC-CC. Committees have been successful in reducing duplicative costs to PLHIV, reducing cost of medications, and reducing or eliminating inpatient fees. PLHIV are able to access services and remain healthy and adherent to treatment if the cost of their care is reduced to a minimum or eliminated.

Building Block 3 activities:

- Develop a hub of care comprehensive care sites
- Improve existing services
- Develop and link community and home-based care services
- Enhance the role of NGOs, CBOs and FBOs in providing care

Building Block 3 provides ideas on how to enhance current CoC services and establish new ones that are vital to the CoC. Most localities already have some HIV services in place prior to the establishment of the CoC, such as HIV counselling and testing, TB diagnosis and treatment, and outpatient and inpatient HIV care. Many sites, however, do not have a specific coordinated site where these services are offered. In addition, there may not be a strong referral system in place to link existing services. This section provides ideas on how to better coordinate existing services, integrate new ones, and create referral links between all services to improve PLHIV's access to care.

Incorporating new services under the Continuum of Care

Local CoC sites will offer different packages of services depending on local needs and resources. It is not a problem if all needed services are not in place when a CoC is first established; it is easy to incorporate new services as the CoC grows. For example, HIV clinical care and other services for PLHIV were offered at day care centres (comprehensive care sites) in Thailand before ART was available. ART, once it became available, was easily integrated into the existing CoC system. Different types of training were conducted to smooth the integration of ART into the CoC: health-care workers were trained in ART provision while PLHIV and CHBC teams were trained in adherence counselling, follow-up care, and issues related to OIs, ART and the CoC.

Basic services in a newly established CoC structure

The following services are often available when a CoC site is established:

- HIV counselling and testing
- Outpatient and inpatient HIV clinical care including palliative care as well as the prevention and treatment of opportunistic infections
- TB diagnosis and treatment
- Community and home-based care
- Basic antiretroviral therapy (ART)

Expanded services in a comprehensive CoC structure

Planners in many CoC sites eventually develop a more comprehensive package of services that often includes most or all of the following:

- HIV counselling and testing
- Access to ART, monitoring response to ART, changes in treatment regimens as required
- Monitoring of nutritional status, general health, progression of HIV infection, and strength of the immune system
- Prevention, diagnosis and treatment of Ols, particularly TB
- Treatment to prevent mother-to-child transmission (PMTCT)
- Treatment of HIV-related cancers, neurological disorders, mental illness and other illnesses associated with HIV infection
- Counselling and tools to support positive prevention (condoms, needles and syringes)
- Diagnosis and treatment of STIs
- Drug substitution, drug treatment and rehabilitation for injecting drug users with HIV
- Palliative care over the course of the disease including pain control, access to opioids (e.g. codeine and morphine) to treat pain, care for other symptoms, psychosocial and spiritual support, and end-of-life care
- Community and home-based care
- Access to economic, legal and social support services



BLOCK 3-A:

Develop a hub of care—comprehensive care sites

A *comprehensive care site* (CCS) is the centre of a local CoC. The CCS offers PLHIV and their families essential care, treatment, support and prevention-related services all in one site. The CCS is a crucial part of the CoC because it is both the <u>hub</u> and <u>heart</u> of care:³¹

- Hub: the CCS provides many needed services in one location. It is a one-stop service centre, thereby reducing cost, time and confusion for PLHIV, families and health-care workers. The CCS improves referrals and links with other important hospital-based services such as TB, ANC, lab and pharmacy and with tertiary, health centre and community and home-based care services.
- Heart: the CCS is a community—a place where PLHIV, families, health-care-workers, managers and volunteers work, learn, discuss, eat and enjoy time in each other's company, and develop close, long-lasting bonds. The atmosphere at a CCS is usually one of mutual support, warmth and understanding between PLHIV, families

and those who work at the CCS site. PLHIV groups are usually based at the CCS and family members of PLHIV can receive training there. CoC-CC meetings take place at the CCS as do team-building and recreational activities that provide a forum for people living with HIV, their families, and people from various organizations that serve them to form partnerships and friendships.

The CCS in known by different names across Asia:

- In **Thailand** it is known as a Day Care Centre or Comprehensive Continuum of Care Centre (CCC).
- In **Viet Nam** it is referred to as a Comprehensive Care Site (CCS) or Community Counselling and Support Centre (CCSC).
- In Cambodia it is known as the Mondol Mith Cheui Mith (MMM) or Friends Helping Friends Centre.



CCS in Ho Chi Minh City, Viet Nam

In many parts of Asia such as Thailand, Cambodia, Viet Nam and Nepal, the CCS is either integrated into the local public hospital or else is situated in a standalone facility. A stand-alone CCS facility is linked to the local hospital and other institutions that offer key services not available at the stand-alone CCS. A CCS that is based in a government hospital is generally more economical and sustainable. Locating the CCS in an existing hospital also strengthens existing providers' skills in HIV prevention and care while reducing any stigma and discrimination they may feel towards PLHIV.

A hospital-based CCS draws on established systems and services such as inpatient care, laboratory, administration and training. Locating the CCS in a hospital that offers outpatient services improves cost-efficiency by allowing it to screen patients carefully at the outpatient level, thus ensuring that only those who truly require inpatient care are admitted. Other benefits of basing the CCS in a hospital include the following:

- Relevant hospital staff receive training, sensitization, and benefits from other capacity-building activities.
- The hospital receives additional support and resources including renovation, supplies and new clients.
- The referral system within the hospital is strengthened, reducing problems, complaints and frustrations with services.
- HIV care services become more efficient by using a broad team of providers (PLHIV, NGOs, volunteers), resulting in reduced burden on hospital staff for both outpatient and inpatient care.

"Right at the door of the building, I felt comfortable with the centre".

PLHIV client at a Community Counselling and Support Centre in Binh Thanh, Viet Nam

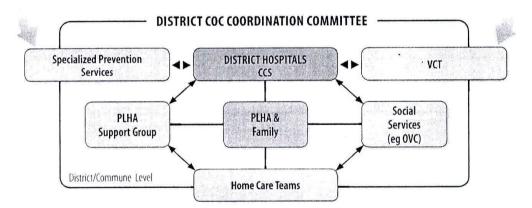
- A clear entry point to care for PLHIV is established, leading to improved organization of facility-based and community-based care.
- Overall costs of care for PLHIV to the health-care system are reduced when care is integrated within an existing facility.

Locating a CCS in a stand-alone facility can be beneficial when stigma and discrimination are strong and PLHIV do not feel comfortable seeking services in a public hospital. This is particularly the case among very hard-to-reach, highly stigmatized populations. The stand-alone CCS may also be more appropriate in urban centres where the number of PLHIV in need of care is high and a stand-alone community-based CCS can offer several important services in one easily accessible location. An example of this is the Community Counselling and Support Centres in Ho Chi Minh City, Viet Nam that offer integrated prevention and care services. These centres are managed by the hospital in the district where they are located and PLHIV are able to access hospital-based services that are not available in the centre.

Figure 11: Integrated hospital-based CCS and linkages in Viet Nam

LOCAL CONTINUUM OF CARE NETWORK

PROVINCIAL COC COORDINATION COMMITTEE OB/GYN Hospital Provincial Hospitals TB/Lung diseases Hospital



Source: Family Health International

How to establish a CCS

The main approaches and activities involved in the establishment of a comprehensive care site in a district setting are described below.

Services provided at the CCS

The core services that are provided at or coordinated through a well-established CCS vary according to local circumstances but often include the following:

- HI¥ counselling and testing
- Ol-related prevention and treatment services
- Palliative care
- ART
- Nutritional care
- Peer and psychosocial support
- MIV/STI prevention-related services
- Referrals for TB/HIV, PMTCT, community and home-based care and support, as well as tertiary-level health and social support services

Based on need, additional services may be offered at or coordinated through a CCS. These services include:

- Psychiatric services
- Drug dependency counselling
- Needles and syringe exchange or distribution and treatment (e.g. opioid substitution therapy)
- Income generation services
- Preventive counselling
- Condom distribution

Physical facilities and personnel at the CCS

The CCS must be located in an adequate, suitable physical space if it is to function smoothly. The number of required rooms and staff members will vary from site to site and will depend on the number of PLHIV that a facility will serve and the services that are offered. At a minimum, space is needed for the following:

- A designated area for outpatient care
- A private place for providing adherence, care and supportive counselling
- A meeting venue for PLHIV groups, the CoC Coordination Committee and other groups working on planning and coordination
- A work area for the CHBC team if they are based at the CCS

CCS staffing in Cambodia

In Cambodia, for example, minimum staffing levels at the Friends Helping Friends Centre (i.e. the MMM) include the following: a <u>chief physician</u>; a <u>nurse</u> with primary responsibility for patient registration and files, triage and dispensing medication; and a <u>counsellor</u> for positive living, treatment adherence and community referrals. The MMM team refers PLHIV as necessary to services outside the MMM such as lab, radiology, TB, and ANC. Many CCSs in the region include <u>PLHIV and other volunteers</u> who assist with all activities. In some CCSs where patient load is heavy there are two physicians dedicated to the CCS and additional physicians rotate in from other hospital departments. Additional CCS staff requirements may include <u>case managers</u> or <u>social workers</u>, <u>harm reduction counsellors</u>, <u>nutritionists</u>, and <u>psychiatrists</u>. A stand-alone CCS is likely to have additional staff requirements including a lab technician, pharmacist, lab specimen transferral volunteers, and support staff.

Staffing requirements for a hospital-based CCS depend on resources available, services provided and local needs. The number of staff can be smaller at sites where the CCS is integrated into a hospital because the clinic can draw upon hospital staff and already existing departments such as laboratory, pharmacy, and infection control to provide services.

Training CCS staff

All CCS staff need to be trained to carry out their duties, sensitized to issues regarding specific populations (e.g. IDUs, MSM, transgender, sex workers, migrants and youth) and supported as appropriate through mentoring and ongoing supervision. Training is essential but rarely sufficient. CCS providers need to be able to practice new skills and receive direct feedback from mentors or supervisors.

In Thailand, Cambodia and Viet Nam, the first CCSs received mentoring support from national or international experts. These "pioneer CCSs" have become learning sites for CCSs that were established later. New CCS staff are placed at the learning sites temporarily to work side-by-side with more experienced providers. In addition, providers at learning sites visit new CCSs to help them improve or set up new services. This approach not only helps new CoC and CCS managers and service providers develop their skills, but also helps to create support networks among providers in different CoC sites.

Each CCS staff position has its own training requirements. Thailand, Cambodia, Nepal and Viet Nam have all developed training resources for key providers such as physicians who provide care and treatment to PLHIV, adherence counsellors, CHBC providers, case managers and volunteers (see CD-ROM for examples of training tools that have been developed).

Management routines and relationships between the CCS and other hospital departments

Some CCSs conduct routine meetings in which all staff (including CHBC teams) discuss priority cases that require referral or support from other providers within the CCS.

The CCS needs to work especially closely with three key departments of the hospital in order to ensure linkages to high-quality HIV care services: the TB, MCH and inpatient departments.

- TB care linkages: tuberculosis (TB) remains the most significant opportunistic infection for PLHIV in Asia. CoC planners and implementers need to proactively engage TB programme managers in CoC planning activities and construct strong referral systems between TB care and other CoC services that promote easy access for PLHIV to TB services. HIV and TB services need to work together in the following ways under the CoC:
 - <u>TB services:</u> should conduct a HIV-risk assessment of newly diagnosed clients who have active TB and offer them HIV testing and counselling.
 - <u>HIV services</u>: should encourage TB prophylaxis for PLHIV (national guidelines permitting) once they are sure that the client does not have active TB disease. HIV services should also build strong links with TB services to ensure that PLHIV are screened for TB (i) whenever they display

- TB symptoms or (ii) before they start ART. HIV service managers must ensure that PLHIV who have TB receive effective treatment.
- HIV and TB providers: should receive joint training. Training for TB physicians, HIV physicians, adherence counsellors, CHBC team members and CoC members on issues related to TB-HIV co-infection is essential.
- Maternal child health/PMTCT service linkages: since antenatal care services are essential to women and children infected with and affected by HIV, formal relationships need to exist between HIV counselling and testing, PMTCT, and HIV care services. In each CoC site. HIV counselling and testing services and PMTCT may be offered through different departments or facilities. CoC planners must ensure that these services are linked so that HIV-positive women know how to access PMTCT should they want to have a child, and pregnant women who test HIV positive are actively referred to MCH/PMTCT services. The CoC-CC and the CCS should help create formal relationships between these services. Making these services accessible is particularly important since many women in the region deliver at home and may need significant support in order to access information on PMTCT, discuss their HIV status with their husband and others, deliver at the hospital, and visit the hospital for follow-up care.



PMTCT outreach worker in Kanchanpur, Nepal

In Viet Nam, the health insurance programme for the poor holds the potential to drastically reduce health-care costs to PLHIV. In a small number of districts in Viet Nam the CoC-CCs have decided to abolish all inpatient bed fees for PLHIV. In Cambodia, the Equity Fund is a transparently run hospital welfare programme that offsets most or all client costs for services including inpatient care.

Inpatient care linkages: CCSs that are integrated into hospitals often utilize hospital inpatient clinicians to provide services. In some CCSs physicians and nurses from the hospital rotate through the CCS on a regular basis. This results in providers of inpatient care being trained and mentored in HIV care and treatment. This is a useful strategy for managing human resources (inpatient providers can substitute when CCS staff are at training, on leave or sick) and improves the quality of care for PLHIV by improving referral linkages between outpatient and inpatient services. It can also contribute to reductions in the stigma and discrimination that hospital staff show towards PLHIV. In many CoC sites, CCS staff and volunteers, particularly PLHIV, often have a role in assisting inpatient providers in around-the-clock care for critically ill patients, helping with feeding, bathing and other essential care services that are often provided by families rather than by nursing staff. In most

countries, CCS services are free of cost, but inpatient services are not. To offset costs to client—which can be overwhelming—CoC-CCs and CCSs can negotiate with hospital administration to reduce fees for poor patients.

The CoC needs assessment process provides an opportunity to review existing services and determine how they can better serve PLHIV and those vulnerable to HIV, and be linked more effectively to other essential HIV services.

Action points: establishing the CCS

- Decide whether the CCS should be hospital-based or stand-alone.
- Decide which services the CCS can offer and create linkages to other services.
- Identify a physical location for the CCS with sufficient space for the planned services.
- Establish CCS linkages with key departments at the hospital: TB, MCH/PMTCT, and inpatient care.



BLOCK 3-B:

Improve existing services

In Pingxiang, China, for example, the needs assessment found that uptake of the existing PMTCT services was low and that lack of awareness of the service and stigma and discrimination were barriers to access. The CoC coordination committee provided a forum for discussing how to improve the existing PMTCT service and how to link it to the CCS, which was at the time just being set up.

Community and home-based care (CHBC) services are essential parts of the continuum of care and complement facility-based care, treatment and support services for PLHIV. CHBC maximizes the health and well-being of PLHIV and their families by:



BLOCK 3-C:

Develop and link community and home-based care services

- Promoting positive living
- Providing palliative care, treatment, and adherence support
- Assisting clients to access needed services

In the CoC, CHBC services are often provided by interdisciplinary teams that include PLHIV, health-care workers and others. CHBC teams often refer clients to health facilities for routine and emergency care and to other community and government resources for OVC care, economic assistance and legal support. Since many PLHIV prefer to receive care at home, CHBC personnel play an important role by helping them to live and die with peace and dignity. CHBC teams also play a fundamental role in supporting and reinforcing services offered at the CCS such as ART (e.g. managing side effects and adherence), TB treatment, PMTCT and opioid substitution therapy (OST).

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Improving CHBC services

To optimize the role of CHBC services in supporting PLHIV, CoC sites can:

Needs assessment of CHBC services

CoC implementers should consider the following questions when deciding how to strengthen or establish CHBC services:

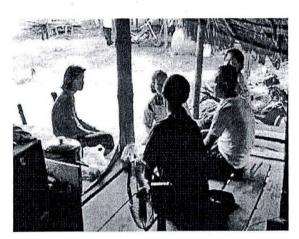
- To what extent are CHBC services in place and how well are they linked to facility-based health services?
- What types of training have CHBC service providers received? Have they been trained in vital skills such as adherence counselling?
- Are CHBC teams supplied with basic medicines to treat mild to moderate pain and other symptoms?
- Is it possible to base CHBC services at the CCS so that they are well-linked to facility-based care, thereby reducing duplication and gaps in care to PLHIV?
- How well do CHBC services address stigma and discrimination and can they do more to create a more accepting and enabling environment for PLHIV and their families?
- Do CHBC services provide care to OVC and do they need training to do a better job of providing care to all members of the families of PLHIV?
- Base CHBC teams at the CCS so they become part of the CCS team. Encourage CHBC team participation in CCS and CoC meetings and in case conferences to promote a smooth flow of care between home/community and the CCS and other facilities.
- Ensure that PLHIV lead or play a strong role in participating in CHBC services.

 Members of CHBC teams vary site-to-site but often include a partnership between PLHIV, health-care workers and the community. Train teams to address the needs of both adults and children so that they can provide care for families more holistically.

Training CHBC team members

Many countries provide CHBC team members with an initial training of one or two weeks duration. Supervisors then give additional on-the-job support to CHBC team members to reinforce the skills and knowledge acquired during the training. For example, NCHADS in Cambodia has developed a national training package for CHBC team members that is complemented by detailed standard operating procedures including job descriptions for CHBC teams (see CD-ROM). All CHBC service providers should be financially supported for their work and valued as an intrinsic part of the health-care system.

- *Train, supply, supervise and support CHBC providers.* CHBC teams need to be trained, supplied and supervised. This includes providing teams with basic training, supplying them with medicines to care for OI symptoms and other supplies, and supervising their performance on an ongoing basis. Staff from the CCS, the local hospital and PLHIV groups can provide supervision. Training protocols and service delivery guidelines for CHBC teams vary by country.
- Reinforce the voluntary and confidential nature of CHBC services. Becoming a client of CHBC services should always be a voluntary act. CoC planners can reinforce the right of PLHIV to decline CHBC services, given that medical personnel who visit PLHIV at home may be viewed with suspicion by community members and result in inadvertent disclosure of HIV status. Teams can reduce problems for clients by not wearing or bringing anything



CHBC in Thailand

with them that indicates they are CHBC workers. CHBC teams in some CoC sites in Viet Nam and Nepal are required to sign a commitment to confidentiality and quality service to reinforce the importance of voluntary service provision and confidentiality.

Roots of CHBC in Thailand

Thailand has a long history of community and home-based care. In the early 1990s, PLHIV in northern Thailand began responding to the care needs of their peers by providing care for them in their homes. These efforts were gradually supported over time by local health-care workers, pagodas, churches, CBOs, NGOs and other organizations. This led to the creation of a network of CHBC services in Chiang Mai, Chiang Rai and eventually in other parts of Thailand. CHBC providers worked closely with day care centres and hospitals to refer clients to the hospital and provide ongoing medical and psychosocial support.

Action points: improving community and home-based care services

- Perform a needs-based assessment of CHBC services and use the findings to improve CHBC services.
- Provide training for CHBC team members.

BLOCK 3-D: Enhance the role of NGOs, CBOs and FBOs in providing care

Each CoC is implemented and supported by a coalition that includes government health-care officials and providers, international and local non-governmental organizations (NGOs), community-based organizations (CBOs), and faith-based organizations (FBOs). These latter organizations provide many services that are not offered through the government system. They are often part of the initial planning and development of the CoC, serve as members of the CoC-CC, offer technical and financial resources, and are providers of a number of services including CHBC and care for orphans and vulnerable children.

Non-governmental and community-based organizations

Local and international NGOs can play important roles both as direct providers of services—complementing services providing by the government—as well as through building the capacity of government, CBOs and other organizations. In northern Thailand, for example, NGO volunteers become part of the CCS team, working side-by-side with government health-care workers and PLHIV to provide care, treatment and support services.

Local NGO support for the CoC in Rupandehi, Nepal

In Nepal, a local NGO known as WATCH has helped the government District AIDS Coordination Committee (DACC) establish itself as an active coordinating mechanism for providers of care and prevention services in Rupandehi district. WATCH helped the DACC call members together to map existing service providers in order to determine where gaps existed and to develop a referral system between services provided by the government, PLHIV groups and NGOs. WATCH and its partners also supported the DACC to identify areas for advocacy. Since hospital-based HIV clinical services including ART initially were not available, the DACC advocated with the regional hospital to increase the scope of the HIV care, treatment and support services it provided. At the same time, WATCH nurtured the development of Rupandehi's first PLHIV group and helped it to become incorporated. That group—Asha Jyoti—is now a strong force for advocacy and has motivated the DACC to champion development of essential care services for PLHIV. This advocacy, coupled with resources made available by the national AIDS programme to the local hospital, has resulted in the establishment of an outpatient clinic for PLHIV. This clinic was planned within the framework of the CoC and was therefore easily integrated.

Community-based organizations (CBOs) are grassroots groups that are strategically positioned to address specific issues in their community. They can effectively provide support for households made vulnerable due to HIV, intervene when PLHIV and families are being discriminated against, and provide support and companionship when people feel isolated or rejected by their community.

Empathy clubs

The Women's Union in **Viet Nam** (a national governmental NGO or GONGO) supports a network of CBOs in communities where HIV prevalence is high that are known as empathy clubs. These clubs are run primarily by women who are living with or affected by HIV, and include mothers, wives, daughters, and grandmothers. The clubs raise funds to support their members with material needs, to run monthly support meetings, and to go on outings. These clubs—with minimal resources—have been able to provide emotional support and comfort to affected families and help reduce the sense of isolation and fear felt by many families that are affected by HIV.

Faith-based organizations

Spirituality and religion are a very important part of life in Asia and the Pacific. While religious beliefs are diverse across the region, places of faith (e.g. pagodas, churches, mosques and temples) and organizations of faith are rich with potential for providing care and support to PLHIV and their families. For example, in Thailand, Cambodia and Viet Nam,

Buddhist pagodas and monks provide a range of support to PLHIV and families including spiritual counselling, hospice, and CHBC, as well as food and shelter to homeless PLHIV and orphans. Pagoda-based care in these countries is linked to the CoC with monks participating in the CoC-CC and gatherings of PLHIV such as the MMM in Cambodia. . Muslim clerics in some countries play an increasing role in HIV prevention and care through the CoC. Christian organizations in the region also provide care to PLHIV; one example is the Mercy Centre in Bangkok which offers hospice care, home-based care and shelter to abandoned children.



Buddhist monk from a FBO in Cambodia visting a child at home

A Buddhist FBO takes the lead in Thailand

Many local CoC sites have created broad partnerships with FBOs. The Sangha Metta is an organization of Buddhists that provides support to PLHIV and families in Chiang Mai, Thailand. The monks and their followers take in homeless PLHIV, care for children who have been abandoned or orphaned, provide material support to poor HIV-affected families, conduct home visits to provide spiritual support, and offer traditional remedies to soothe symptoms and alleviate suffering. These services are supported by donations and alms. One of the most important aspects of support provided by the pagodas are the sermons and interventions to address stigma and discrimination through Buddhist thought and prayer.

Widening the network: the role of government in encouraging participation of NGOs, CBOs and FBOs

Local government leaders, CCS staff and others can actively engage the support of NGOs, CBOs and FBOs by meeting with them to discuss how they can contribute to the CoC, inviting them to participate in the CoC-CC, and teaching them basic information about HIV in order to increase their support for and understanding of PLHIV.

Action point: widen the CoC network

Reach out to NGOs, CBOs and FBOs and encourage their participation in the CoC.

³¹ HIV/AIDS care and treatment: guide for implementation. Manila, WHO Regional Office for the Western Pacific, 2004.

Building Block 4 activities:

- Provide vision PLHIV shaping the CoC
- Caregivers and clients PLHIV providing and receiving services
- United we stand PLHIV groups at the core of the CoC
- Ensure accountability PLHIV monitoring CoC services

Building Block 4 describes the vital role of PLHIV as leaders, shapers and implementers of the CoC. The greater involvement of people living with HIV (GIPA) movement is at the centre of the response to HIV. The CoC promotes GIPA and provides HIV programmers with an opportunity to see the power of GIPA in action. PLHIV must be involved at the local level in the planning and implementation of CoC programmes—including the provision of services—if CoC services are to be appropriate and truly meet the needs of PLHIV and their families. When PLHIV are true partners in the CoC, it changes the way that policy-makers and service providers think and transforms services that may be top-down or discriminatory into care provision that promotes mutual respect and friendship.³²

At CoC sites throughout the region, PLHIV currently play roles as diverse as managing comprehensive care sites, serving as members of the COC-CC and the ART Selection Committee, and working as adherence counsellors, case managers, and CHBC workers. PLHIV work as volunteers to provide health education to their peers, help PLHIV negotiate the health-care system (e.g. assist them to move around the district hospital for lab tests and x-rays) and care for hospitalized PLHIV.



PLHIV support group leads training in meditation

There are different levels of PLHIV empowerment under GIPA (see figure

below). CoC planners can use this pyramid to assess the level at which PLHIV are supported and empowered in their own CoC. In Thailand, the Thai Network of People Living with HIV/ AIDS (TNP+) plays a leadership role in comprehensive care sites, conducts treatment literacy campaigns, implements programmes to enhance access to ARVs and cotrimoxazole, and works in other areas of HIV and development. PLHIV in Thailand are decision-makers, experts and implementers of the CoC.

Why is GIPA so important?

GIPA is the heart and soul of the response to HIV. The involvement of PLHIV in HIV care, treatment and support has been shown to do the following:

- Makes services more relevant and personalized
- Makes all types of interventions (e.g. prevention messages, adherence to treatment counselling) more credible and compelling to the target group
- Raises awareness of issues from a PLHIV perspective, leading to the extension of activities to include advocacy for the rights of PLHIV
- Increases the self-confidence, physical health and sense of well-being among PI HIV
- Reduces the stigma attached to and discrimination against PLHIV among AIDS workers, clients of services and communities at large

Adapted from: "Valued Voices" GIPA Toolkit: A manual for the greater involvement of people living with HIV/AIDS. APN+, APSACO, 2005.

Figure 12: Levels of PLHIV empowerment

THE PYRAMID OF INVOLVEMENT OF PEOPLE LIVING WITH HIV AND AIDS (PWHAS)

The pyramid shows the increasing levels of involvement of PWHAs. The GIPA principle advocates for involvement at all levels.

Decision makers: PWHAs participate in decision-making or policy-making bodies, and their inputs are valued equally with all the other members of these bodies.

Experts: PWHAs are recognised as important sources of information, knowledge and skills who participate on the same level as professionals in design, adaptation and evaluation of interventions.

Implementers: PWHAs carry out real but instrumental roles in interventions, e.g. as carers, peer educators or outreach workers. However, PWHAs do not design the intervention or have little say in how it is run.

Speakers: PWHAs are used as spokespersons in campaigns to change behaviours, or are brought into conferences or meetings to "share their views" but otherwise do not participate.

Contributors: activities involve PWHAs only marginally, generally when the PWHA is already well-known.

For example, using an HIV-positive pop star on a poster, or having relatives of someone who has recently died of AIDS speak about that person at public occasions.

Target audiences: activities are aimed at or conducted for PWHAs, or address them en masse rather than as individuals.

However, PWHAs should be recognised as more than (a) anonymous images on leaflets, posters or information, education and communication (IEC) campaigns, (b) people who only receive services, or (c) as "patients" at this level. They can provide important feedback which in turn can influence or inform the sources of the information.

Source: Paxton S. Steps to empowerment: living with HIV in the response to AIDS in Cambodia. Phnom Penh, Policy Project Cambodia, 2006.

BLOCK 4-A: Provide vision – PLHIV shaping the CoC

The continuum of care in Asia and the Pacific has its origins in PLHIV activism. PLHIV groups in northern Thailand approached health-care officials in the late 1980s and advocated that the health-care system take action to develop hospital-based care for PLHIV.³³ The subsequent negotiations, planning meetings and development of services for PLHIV created a level of understanding and respect between PLHIV, government health planners and health workers that transcended fear, stigma and discrimination (see box below). The role of PLHIV evolved to the point where they eventually took the lead in providing CHBC services and now play a major role in many other aspects of the CoC.

Action points: promoting PLHIV leadership

- Make PLHIV meaningful partners in the process of CoC development.
- Support the development of PLHIV groups through capacity building and funding.

BLOCK 4-B:

Caregivers and clients - PLHIV providing and receiving services

PLHIV in many parts of the region provide a diverse set of services to others with HIV. By acknowledging the key role that PLHIV have in meeting the needs of their peers, service

managers and providers enhance their ability to provide effective care and prevention services to PLHIV. PLHIV also respond to gaps in services and form their own services. For example, PLHIV-led organizations in Nepal have responded to the needs of homeless PLHIV and those who are residing in rehabilitation centres by setting up day care centres, emergency shelters, and residential sites for PLHIV who have nowhere to live. They provide services at these sites that include care and treatment, counselling, provision of food, drug relapse prevention, and friendship.



Training PLHIV to provide CoC services in Thailand

Involvement of PLHIV in the CoC in Thailand

PLHIV in Thailand have been providing peer support, education and advocacy for over 10 years, through a network of hundreds of self-help groups that spans the whole country. As they have developed gradually from passive consumers of health care to active partners in NGO and state health care services, they have built their confidence and pride as well as earning the respect of public health service staff.

Comments by key stakeholders

"In government we treat people living with HIV/AIDS as partners... they have a very important role in educating people and communities, helping to diminish stigma and discrimination, and giving mutual support. They are very important in some of our decision-making. We recognize their outstanding work."

Dr Sombat Thanprasertsuk, *Director*, *Bureau of AIDS,TB and STI, Ministry of Public Health, Bangkok*.

"Treatment is not only an issue for doctors. People living with HIV/AIDS should be in the driver's seat."

Mr Kamon Upakaew, Chairman, Thai Network for People Living with HIV/AIDS

"People living with HIV/AIDS (PLHIV) have a lot of information about opportunistic infections and about antiretroviral therapy. This makes health staff more active as they have to stay ahead. It's good if PLHIV can screen themselves and help their friends; health staff need to discuss treatment with PLHIV, but now they don't need to spend a lot of time explaining basic information... These trained PLHIV are good to work with. They are expert trainers of their friends, they can plan their work and they can carry out their plans."

Ms Porntip Kemngern, Nurse, northern Thailand

"If I were not HIV-positive I would still be a housewife and be working in the rice field. I would never have learnt how to say what I want or how I feel. I would never have learnt how to discuss health problems with my doctor."

Ms Buarian, north-east Thailand

Excerpt taken from: "Valued Voices" GIPA Toolkit: A manual for the greater involvement of people living with HIV/AIDS. APN+, APSACO, 2005.

Action points: enabling PLHIV to become care providers

- Work with PLHIV as partners and co-planners of CoC services and systems.
- Make a policy of involving PLHIV in all HIV care and prevention services to work as staff and volunteers side-by-side with others in meaningful roles.
- Provide training and support so that PLHIV learn news skills.
- Pay PLHIV fairly for their work.
- Support PLHIV to develop services that are led and managed by PLHIV.

BLOCK 4-C: United we stand – PLHIV groups at the core of the CoC

The existence of independent PLHIV groups is a prerequisite to an effective CoC. An outstanding example of how PLHIV groups can play an important role in a CoC is found in Thailand, where TNP+, Médicins Sans Frontières (MSF), and AIDS ACCESS Foundation (AAF) formed a joint initiative to promote the establishment of centres for Comprehensive Continuum of Care (CCCs) in 2002.³⁴ Other countries where PLHIV groups contribute to care and support include Nepal, where PLHIV groups work in hospitals to provide supportive care services to PLHIV in both outpatient and inpatient departments.

Action points: supporting the development of PLHIV support groups

- Identify existing PLHIV groups, meet with them and invite them to play a lead role in shaping the CoC.
- Ensure that PLHIV group leaders are fully involved in the core CoC planning team.
- Support PLHIV groups to develop group action plans and to secure funds to implement their plans.
- Provide meeting space for PLHIV groups at the CCS or another convenient site.
- Promote cross-learning and meetings with other PLHIV groups in the area as well as with national or local PLHIV networks.

BLOCK 4-D: Ensure accountability – PLHIV monitoring CoC services

People living with HIV—in their roles as leaders of the CoC, staff members of CoC services, and clients of the CoC—need to fully participate in the monitoring and assessment of the CoC. Given the variety of roles that PLHIV play in the CoC, their involvement is crucial to an accurate determination of the degree to which the CoC has successfully met their needs.

Action points: involving PLHIV in monitoring the CoC

- Make PLHIV part of the team that determines how to monitor the CoC and what the indicators of success will be.
- Include PLHIV on the team that assesses services.
- Ensure that PLHIV work with the team to analyze findings and provide feedback and recommendations on the quality of the CoC.

See Section 6 of the Toolkit for more details on monitoring and evaluating the CoC.

³² AIDS discrimination in Asia. Bangkok, APN+, 2004.

Takai A et al. Correlation between history of contact with people living with HIV/AIDS (PWAs) and tolerant attitudes toward HIV/AIDS and PWAs in rural Thailand. *International Journal of STD & AIDS* 1998; 9:482-484.

³⁴ Kumphitak A et al. Involvement of people living with HIV/AIDS in treatment preparedness in Thailand: case study. Geneva, WHO, 2004.

Building Block 5 activities:

- Develop client-friendly services
- Involve families
- Mobilize the community

Building Block 5 discusses ways to create a supportive environment for PLHIV in health-care settings, the family and the community.

BLOCK 5-A:

Develop client-friendly services

Stigma and discrimination are major barriers to clients' access to CoC services in many countries. CoC planners need to include strategies in their CoC plans that build an enabling environment and reduce barriers to the utilization of services. Planners can build in service features that promote privacy, confidentiality and trust in CoC services, especially if they are sensitive to stigma and discrimination during the CoC design phase.

In Pingxiang, China, PLHIV perceived such high levels of stigma and discrimination that many of them stated they would be reluctant to attend an HIV clinic if it was designed as a stand-alone service and not integrated into the local hospital. The PLHIV advised planners that the clinic had to be placed at the hospital but that it should not have a special sign, and the entrance should be through the main entrance into the hospital so that PLHIV could enter anonymously. Planners' sensitivity to these recommendations resulted in rapid uptake of services by PLHIV and reported satisfaction with provider interactions.

BLOCK 5-B: Involve families

The families of PLHIV clients are an unmatchable support system for PLHIV. However, they can also be a source of stigma and discrimination for PLHIV. CoC planners should build a role for clients' families into the CoC services in order to promote their understanding of HIV—an understanding that will in turn increase their ability to help their family

members manage their disease at home. In many settings, CHBC teams have the most frequent contact with clients' families and can effectively cultivate the development of family support for clients. The organization of "family days" at the CCS is an inexpensive yet effective way to build solidarity and confidence among affected families.

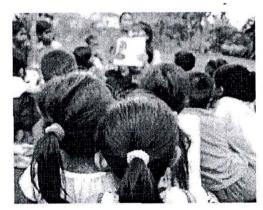
The MMM in Cambodia is a successful example of the integration of client families into CoC services. The provision of training to families affected by HIV on caregiver skills and adherence support in some CoC sites has boosted the confidence of those caring for PLHIV and has lead to real improvements in the lives of PLHIV.



BLOCK 5-C:

Mobilize the community

In addition to building family support networks for clients, CoC planners can also include initiatives to raise community support for the CoC. These activities may include meetings with well-positioned local leaders to provide them with information about the CoC and seek their support in promoting referrals, developing linked services, and raising funds to support community-centred aspects of the CoC. Support can also come from the private sector. In Viet Nam, for example, Unilever donated products for the community and CHBC kits.



Community-based clubs for children in HIV-affected villages in Cambodia



Candlelight vigil organized by the Provincial Network of PLHIV in Battambang, Cambodia

CoC coordinators can reduce stigma and discrimination by conducting educational activities that target members of the general public in neighbourhoods where PLHIV live. These community information sessions preserve client anonymity while at the same time strategically targeting resources at areas where they are most likely to make an impact. The CD-ROM that accompanies this Toolkit describes activities that can create a better community environment for PLHIV.

Social mobilization activities in areas with high levels of stigma and discrimination during the early stages of the CoC can improve levels of community awareness and promote CoC activities.

Social mobilization activities that can reduce stigma and discrimination

- Community information meetings
- Door-to-door visits in the community by local volunteers
- Community guizzes during events and holidays
- Talks by respected community figures such as religious leaders, celebrities and important officials

Action points: creating a more client-friendly environment

- Interview PLHIV to identify the barriers they encounter when they seek services.
- Build a role for clients' families into the CoC services.
- Conduct social mobilization activities in the community to reduce stigma and discrimination.
- Work with people who have communication and mass media experience to develop interpersonal and mass media tools for reducing stigma and discrimination, increasing community acceptance of PLHIV and improving awareness of HIV-related services.

Build capacity – developing human researces and tools to support the CoC

Building Block 6 activities:

- · Build capacity through training, mentoring and supportive supervision
- Develop procedures and tools to support the CoC

Building Block 6 provides guidance regarding how to build capacity and develop tools that help the CoC function smoothly and effectively. The topics covered include training, protocols and other tools.

BLOCK 6-A:

Build capacity through training, mentoring and supportive supervision

Depending on the size of the CoC and its staffing and resources, health facilities at different levels of the health-care system provide a wide range of medical and psychosocial support services for PLHIV. The staff in these facilities will assume new responsibilities under the CoC that will require new knowledge and skills.

Health-care workers and other service staff who work in the CoC should receive a comprehensive package of training in working in HIV/AIDS care that includes information on basic HIV transmission, disease progression, treatments, infection control and occupational

exposure, confidentiality and palliative care. The sensitization of the healthcare providers and support staff on issues related to IDUs, sex workers, MSM, prisoners, youth and migrants is crucial for building acceptance and understanding for those populations. Supplementary training should be provided for concerned personnel who work in specialized areas such as CT, ART and OI management, PMTCT, TB and HIV treatment and CHBC. Table 1 below illustrates examples of the structure and duration of capacitybuilding activities from several countries in the region.



Clinical mentoring in action, Campha CCS, Viet Nam

Table 1: Duration of capacity-building activities for HIV clinical care including ART for physicians in selected countries

Training activity	Cambodia	Guangxi, China	Several sites in Viet Nam		
Classroom / practical training	5 weeks (including final wrap-up)	2 months	2 weeks+ (non-contiguous)		
Clinical rotation	_	1 week	1 week		
On-site mentorship	6 weeks (field attachment at outside clinic with support from senior physicians there)	2+ weeks -	2-6 weeks		
Supervision visits	Quarterly (more frequently if there is NGO partner support)	Semi-annually	Quarterly (supplemented by ongoing back-up by phone and email)		
Refresher training (on annual basis)	2 weeks (planned, not yet implemented)	1 week	1 week		

Training health-care workers to provide services under the CoC

A two-stage approach to training health-care workers is often most effective:

- Stage 1: Training on the technical aspects of a new service ideally occurs immediately prior to launching the service. Technical aspects of the training are generally based directly on service standards and protocols and should use MoH guidelines or a national curriculum where available. Training should include as much practical clinical training as possible. The length of these training activities, before the launch of clinical services, ranges from one week to two months, depending on the topic.
- Stage 2: Classroom trainings can be followed by on-site (two to six weeks) mentoring from a clinical care professional at the participants' work sites. This second stage of training provides participants with the opportunity to benefit from one-on-one expert instruction while they work with patients in their own workplace. Participants can also be posted for short durations in other CoCs that have been designated as learning sites where they can practice their new skills under the mentorship of more experienced colleagues. This type of mentorship-oriented training strategy has proven highly effective in the rapid preparation of providers to perform new duties.

Capacity-bailding activities offer an invaluable opportunity to build capacity for the national HIV/AIDS programme and future expansion of CoC efforts. The benefits of capacity building can be maximized if local or national specialists lead the CoC training team and become qualified senior trainers capable of independently conducting training programmes. These same individuals often can be contracted to provide on-site mentoring (as described above) to teams of CoC service providers in areas where the CoC is being introduced.

Specific capacity-building issues for community-level health-care providers

Community-level health-care centres play an important role in the CoC through providing first-line health care to PLHIV and linking PLHIV to the CCS. Health centres can conduct a variety of services for PLHIV that include follow-up of OI treatment or ART for adherence

support and treatment of side effects, health promotion, antenatal care (and thus PMTCT), STI consultation and treatment, family planning, directly observed therapy short-course (DOTS) for TB, provision or supervision of CHBC, and follow-up of other HIV-related services. Some health centres even provide HIV counselling and testing services.

CoC planners should ensure that health centre staff are trained to carry out these activities, sensitized to specific issues regarding PLHIV clients, and included as members of the CoC-CC. The need for this is illustrated by an example from Cambodia, where health centre staff were not involved in the early stages of planning for the CoC. Provincial leaders identified their lack of involvement as a barrier to success and included them in CoC-CCs and relevant training activities. This action led to an increase in referrals from health centres to the CCS for HIV testing and care services.



Training health care workers in HIV care in Kathmandu, Nepal

BLOCK 6-B:

Develop procedures and tools to support the CoC

A large number of tools and procedures that support the structure of the CoC have been described throughout this Toolkit. These tools include training curricula, referral forms, patient record books, and workplan templates (see table below). Examples of these and other tools can be found on the CD-ROM that accompanies this toolkit.

Table 2: Tools to support the CoC

Tool	Description	Document reference		
Needs assessment report	An example of a needs assessment conducted before launching a local CoC.	Building Block (BB) 1-B		
Workplan template	Replan template Template that can be modified and used to develop a local or national CoC workplan.			
Service standard operating procedures (SOPs)	Examples of SOPs for comprehensive care sites, community and home-based care and other services.	BB 2-B, 3-C		
CoC Coordination Committee terms of reference	An example of CoC Coordination Committee members and their roles and responsibilities.	BB 2-B		
Referral network guide	Guide on how to establish effective referral links between HIV care, treatment, support and prevention services.	BB 2-C		
Client-held service record book	Contains summary of information regarding medical and psychosocial services received by the client from services within the CoC network.	BB 2-C		
Training curricula	Local, regional and global training packages for health care workers in HIV care, treatment, support and prevention developed by ministries of health, WHO and FHI.			
Job descriptions and professional codes of conduct	Examples of CoC job descriptions and provider codes of conduct.	BB 3-C		
ommunity mobilization esources Guides from APN+ and other organizations on how to increase community support for HIV care and reduce stigma and discrimination.		BB 5-C		
National CoC framework	Documents prepared by the MoH in Cambodia to guide the implementation of the CoC throughout the country.	Section 5.2.1		
Quality assurance / quality improvement (QA/QI) tools				
Technical guidance	A selection of technical guides including the WHO Integrated Management of Adolescent and Adult Illness (IMAI) series.	_		

NATIONAL-LEVEL GUIDANCE FOR THE COC: FACILITATING LOCAL-LEVEL EFFORTS



This section contains:

- What's being done? An overview of national-level support for the CoC
- Providing guidance: why and how to develop and use a national CoC framework

National governments throughout the region can play a pivotal role in guiding and facilitating local-level efforts to implement the CoC. Ministries of health can provide this support through formulating policy, strengthening health systems, developing procedures and tools, building training capacity, and providing guidance and funding for human resources. This section of the Toolkit describes regional experiences in a few countries regarding national-level support and scale-up of local-level implementation of the CoC.

1. What's being done? An overview of national-level support for the CoC

The relationship between local efforts to design and implement CoCs and national efforts to guide and sustain the CoC approach should be mutually supportive and reinforcing. Experiences in Cambodia and Thailand illustrate two basic strategies to support the CoC: (1) national leadership develops and expands the CoC approach (top-down), or (2) local leaders design and implement the CoC, with the national government building on initial local efforts to support the expansion of the CoC to new sites throughout the country (bottom-up).

Either of these approaches can be used to support the development of the CoC and push it forward—neither is right or wrong. Whatever the approach, lessons learned at the local level inform and influence national policies and guidelines while national-level agencies support and guide local-level efforts. Each approach is profiled below through a brief description of the experience in the two countries that pioneered their development: Thailand and Cambodia.

A bottom-up approach: local-level efforts take the lead in Thailand

PLHIV groups, local government and other partners pioneered the development of the initial CoC sites in Thailand. The Ministry of Public Health (MoPH) eventually supported these pilot efforts by reviewing and documenting them and identifying the key lessons learned. The MoPH then used these conclusions to formulate the guidance and support that it subsequently offered to other provinces that wanted to introduce the CoC. The Thai MoPH, over the past decade, has increasingly systematized the support that it offers to the comprehensive care sites that have been established across the country.

- 3. **Rromotes partnership and inclusion:** the CoC covers a broad array of services that is provided by a coalition of partners. A CoC framework helps to coordinate the contributions of government, PLHIV, NGO and FBO service providers.
- 4. Promotes collaboration and improved referral between different health programmes: the inclusion of the national TB and MCH programmes in the process of developing the CoC framework can initiate a process of improved cooperation and referrals between these services and the HIV/AIDS programme at both the national and local level. Details of how these two programmes can be effectively linked to the CoC are described below.
 - Integrating the PMTCT service in the CoC: coordination between the national MCH and HIV/AIDS programmes can promote the integration of PMTCT into the CoC framework and link it to other services for PLHIV. Collaboration between these programmes can be strengthened through the establishment of a joint technical working group (TWG) that develops an integrated MCH-HIV framework, a client flowchart, criteria and regimens for ART, and postnatal care and treatment procedures for both mothers and children. Members of this TWG in most countries include representatives from the MCH and HIV/AIDS programmes, paediatricians, UN agencies, international and local NGOs, and representatives of PLHIV groups.
 - TB/HIV coordination: TB/HIV co-infection is common in the region. Coordination between the National Tuberculosis Programme (NTP) and HIV/AIDS programme can help to achieve improved outcomes for people who have both diseases. This collaboration benefits both programmes by prolonging the life of PLHIV, increasing the detection rate of active TB and reaching cure rate targets (≥ 85%) for PLHIV with TB. The coordination mechanism for these programmes is the same as that described above for the establishment of a TWG for PMTCT. TWGs for TB/HIV have been established in Cambodia, Viet Nam and other countries in the region.

2.3 How to do it: key steps in the development of a national CoC framework

There are a few key actions that a country can take to create its own CoC framework. These steps, which are outlined below, do not need to take place in a neat, ordered manner—in fact, many steps will occur simultaneously. The five steps are the following:

- Conduct a situational analysis to identify how the CoC can be developed so that it best responds to clients' needs
- Mobilize support for the CoC concept and the development of a national CoC framework
- 3. Prepare and fund the CoC workplan
- 4. Develop the care package and service standards
- 5. Assess initial efforts and document the CoC framework

The text below provides further details about each step for developing a national CoC framework.

Conduct a situational analysis to identify how the CoC can be developed and respond
to needs
If information regarding HIV needs is inadequate, the first step in the development
of a national CoC framework should be a situational analysis. This analysis includes

mapping existing services, examining current health infrastructure that provides HIV care services, reviewing statistics related to the epidemic and service utilization, and talking with PLHIV and their families about their needs. The situational analysis can be conducted by a partnership of different agencies and organizations including the national association of people living with HIV.

2. Mobilize support for the CoC concept and the development of a national CoC framework

Findings from the situational analysis can be used to develop a compelling rationale for the development of a national CoC framework. Meetings and consultations can be held with governmental agencies and departments, PLHIV, NGOs, donors and other key partners to sensitize them to the concept and strategies of the CoC. These meetings can also result in the development of a working group that is tasked to prepare a national CoC framework.

3. Prepare and fund the CoC workplan

A participatory planning process can be used to develop a workplan for the national CoC—one that all partners can contribute to. The workplan should be costed. A costed workplan becomes an important tool for raising funds to implement the CoC. One strategy that has proven effective for funding the CoC is "basket funding"—that is, to pool funds from diverse donors to support the CoC (see box below).

4. Develop the care package and service standards

Technical working groups (TWGs) can use the national CoC framework and workplan to produce detailed tools and guidance for service implementation. Three TWGs performed this task in Cambodia: VCT, Institutional Care and CHBC. Members of these working groups included government staff, PLHIV, and representatives of NGOs and donors. This approach can serve as an effective strategy for obtaining broad buy-in and organizing assistance from many partners to complete essential but time-consuming work.

Funding the CoC framework

In Cambodia, rather than create multiple vertical programs funded by different donors, NCHADS negotiated with donors and NGOs to fund the CoC workplan. By basketing funds, NCHADS was able to use existing resources efficiently and transparently. It was also able to leverage further funding from NGOs and donors. The efficient funding of the CoC allowed NCHADS to work with the MoH human resources department to designate core staff positions at different levels of the CoC. Experience from several countries has shown that each province and district requires a CoC Coordinator—a dedicated, funded officer whose job it is to coordinate, plan and guide the implementation of services for PLHIV. Given the long-term need for services for PLHIV, ensuring central funding for key CoC local-level staff positions is critical.

TWGs can also be given the responsibility to fill service gaps identified in the situational analysis by developing guidelines and standard operating procedures (see box below).

National TWGs can also develop training, mentoring and supervision packages and plans that can be used to build human resource capacity in local CoCs. Training curricula should be based on service standards and national guidelines and should be evidence-based to the extent possible. Several countries in the region have developed national training packages for providers at different levels of the health-care system. Some of these packages are summarized in the table below.

Developing national standard operating procedures: systematizing highquality services

A national framework for the CoC provides the basis for the development of standard operating procedures (SOPs) that detail how to follow national technical guidelines for various services. SOPs give service managers and providers the information they need to provide services correctly. Training programmes that seek to improve skills are usually based on SOPs that CoC providers can then use to guide their day-to-day work. A typical SOP might guide the provision of a service at a comprehensive care site. The SOP might outline all steps that should be followed for new and returning clients for ART selection and adherence preparation, and referrals to other services.

Table 3: Examples of national CoC training packages

Type of Training	Participants	Where Cambodia, China, Viet Nam, Thailand, Nepal Cambodia, China, Thailand, Viet Nam			
Adult HIV clinical care and ART	Nurses, physicians				
Paediatric HIV clinical care and ART	Nurses, physicians				
Palliative care including home- based care	PLHIV, nurses, physicians, social workers, other providers	Cambodia, Viet Nam, Nepal			
ART adherence counselling	PLHIV, nurses, physicians, social workers, other providers	Cambodia, China, Viet Nam, Thailand, Nepal			
HIV case management and counselling	PLHIV, nurses, social workers, other providers	Thailand, Viet Nam			

Examples of training packages can be found in the training section of the CD-ROM.

5. Assessing initial efforts and documenting the CoC framework National health officials can contribute greatly to the development of effective CoCs by assessing local CoCs and then using the findings to document (or revise) the national CoC framework and guide the design and implementation of the CoC in new sites.

In **Thailand**, the MoPH reviewed initial efforts to establish CoCs in northern Thailand and used the results to guide new efforts in other parts of the country. In **Cambodia**, NCHADS rapidly identified lessons learned based on feedback from CoC pilot sites and used them to scale up the CoC in other parts of the country. This rollout was done in a series of steps to make efficient use of resources. NCHADS also documented the process of implementing the CoC in Moung Russey. This document can be found in the CD-ROM that accompanies this toolkit.

Further reading

- 1. Continuum of care for people living with HIV/AIDS: operational framework. 2nd ed. Phnom Penh, Ministry of Health, NCHADS, 2003.
- 2. Comprehensive and continuum care guideline for persons living with HIV/AIDS. Bangkok, Ministry of Public Health of Thailand, 2002.
- 3. Scaling up antiretroviral treatment: lessons learnt from Thailand: report of an external evaluation. New Delhi, Ministry of Public Health Thailand, WHO Regional Office for South-East Asia, 2007.
- 4. Continuum of care for rapid scale-up of care and treatment services for people living with HIV/AIDS. Phnom Penh, NCHADS, WHO, FHI, 2005.

³⁵ Continuum of care for rapid scale-up of care and treatment services for people living with HIV/AIDS. Phnom Penh, NCHADS, WHO, FHI, 2005.

IMPROVING THE COC: USING MONITORING AND EVALUATION TO ENHANCE ACCESS TO AND QUALITY OF SERVICES AND SYSTEMS



This section contains:

- Using routine data to monitor CoC performance
- Making use of review techniques to improve quality of care and the CoC
- Evaluating the benefits clients receive from the CoC through special studies
- What do we need to know? Improving the monitoring and evaluation of the CoC

Stakeholders who work together to design and launch a CoC will soon want to know how well it is meeting the needs of PLHIV. Program managers in particular want to know how the CoC is working and whether the use of services is increasing. The CoC is designed to not only link services but also to improve their quality; managers, providers and clients will therefore ask "How good are our services?" Ultimately, all stakeholders want to know if the CoC has achieved its ultimate goal—to help clients achieve better health and quality of life. This section briefly describes efforts that have been made across the region to answer these questions.

The discussion below is organized by methods that have been used to monitor and evaluate CoCs. The first section describes the use of routine health service data to monitor the progress of the CoC while the second details the use of review methods to improve both the quality of CoC services as well as overall performance of the CoC. The third section briefly outlines ongoing efforts to evaluate the extent to which CoC clients benefit from the continuum of care. This section then concludes with some thoughts on future directions of monitoring and evaluation in the CoC.

1. Using routine data to monitor CoC performance

CoC sites across the region collect information that can be used to monitor and improve CoC services and performance. Many health officials monitor the CoC using routine data that are collected for local reporting or for the national health management information system (HMIS). CoC monitoring activities often focus on tracking changes in the utilization of services (e.g. number of clients beginning ART) or changes in referral patterns between key CoC services such as TB and counselling and testing.

The CoC Coordination Committee (CoC-CC) is best placed to analyze routine data that illustrate the progress of the CoC and identify and solve any problems that arise. During CoC-CC meetings at many CoC sites, committee members review monitoring data and other information that describe the performance of the CoC and identify gaps in service utilization or referrals. The box below presents illustrative indicators that can be used to determine how well the CoC is functioning.

Illustrative CoC monitoring indicators

Some of the most useful indicators combine the utilization of a basic CoC service (e.g. HIV testing) with the follow-up or referral required to ensure that clients benefit fully from available services (e.g. return for test result). Six CoC indicators that illustrate this principle are presented below:

- 1. Percentage of clients who receive pre-test counselling or information and then choose to be tested for HIV (i.e. "uptake" of testing).
- 2. Percentage of clients who are tested for HIV and then return to receive final test result (i.e. "rate of return for results").
- 3. Percentage of clients who test negative or indeterminate for HIV and then return for follow-up HIV testing.
- 4. Percentage of clients who test positive for HIV and are then referred to care, treatment or support services.
- 5. Percentage of pregnant women who test positive for HIV and then return for results.
- 6. Percentage of pregnant women who test positive for HIV and then receive PMTCT services.

These indicators need to be carefully defined as their measurement may not be straightforward. Difficulties that may be encountered include how to record and measure referrals and how to define "rate of return for results" in countries that have a two-step process to confirm HIV status with financial barriers to the second test.

Ideally, these indicators should be disaggregated by gender and age. Further examples of monitoring indicators can be found on the CD-ROM that accompanies this document.

For example, the CoC-CC in Pingxiang, China used routine service utilization data to determine that uptake of PMTCT services was very low among pregnant women who tested positive for HIV. The CoC-CC concluded that many HIV-positive pregnant women were not using PMTCT services due to the cost of services and fear of the repercussions of disclosure. The CoC-CC is currently developing strategies to improve the situation.

'Using surveillance data to identify problems

Data sources outside of the routine HMIS can also be used to monitor the CoC. In An Giang, Viet Nam, the provincial CoC-CC reviewed findingsfromthenational Integrated Behavioural and Biological Surveillance survey that was conducted in several provinces including An Giang. The Committee noted that utilization of counselling and testing services was low and that new strategies were required to increase its use.

2. Making use of review techniques to improve quality of care and the CoC

Health providers and officials across the region use case review and program review techniques to improve the quality of CoC services as well as the performance of the overall CoC. A commonly used method is the periodic case review whereby teams of providers (e.g. CCS or CHBC) discuss and resolve problems of clients who are currently under their care. This process can be an especially effective way for providers who have limited experience working with PLHIV to gain advice and assistance from their colleagues.

Using CoC reviews to improve services in Viet Nam

In Viet Nam, some local CoC sites use jointly developed quality assurance-quality improvement (QA/QI) checklists to assess different aspects of the CoC. QA/QI reviews are conducted at each local CoC site every six to twelvemonths and result in a report with detailed consensus findings and recommendations for improvements. Examples of the checklists used in Viet Nam are included in the CD-ROM that accompanies this document.

A second review method that has been widely used is the participatory programme assessment or CoC review. This assessment consists of a quarterly, semi-annual, or annual review of a local CoC to assess service quality, effectiveness of service linkages, the success of referrals, the regularity of CoC-CC meetings, and the perceptions of PLHIV, their family members and service providers regarding CoC services. The box above provides details of such an activity that is conducted regularly in Viet Nam. The CoC review can also assess whether service providers perceive having received any benefit from the CoC. Providers who gain something from the CoC—whether financially, through increased job satisfaction, or some other way—will feel more ownership of the CoC and provide higher quality, more effective services.

Comprehensive CoC review in Cambodia

In 2004 NCHADS conducted a comprehensive review of HIV services including the CoC. Review team members included PLHIV and representatives from the MoH, NGOs and donors. The review team made recommendations on how to improve the national HIV/AIDS programme that were then built into the national HIV/AIDS strategy.

3. Evaluating the benefits clients receive from the CoC through special studies

Recent efforts to evaluate the CoC have measured the extent to which CoC clients benefit from the services they receive. FHI has collaborated with government colleagues in Cambodia, China and Viet Nam, WHO, USAID, USCDC and PEPFAR to study the outcomes and impact of ART provided through the CoC framework on the lives of PLHIV. These evaluations collect data from a cohort of adult PLHIV when they start ART and then again at six-month intervals through confidential interviews.

These evaluations are ongoing and assess the effect of ART delivered through the CoC on client health outcomes that include the following:

- Perceived stigma and discrimination and social support from family and friends
- Health-related quality of life
- Clinical outcomes including morbidity and mortality
- Sexual and injecting risk behaviours, which can affect both clients' health as well as the health of individuals with whom they come in contact

In addition to the above, CoC managers have used these studies to assess the strength of the referral system and the overall impact of access to multiple services on the well-being of PLHIV.

4. What do we need to know? Improving the monitoring and evaluation of the CoC

As the use of the continuum of care approach expands in the coming years, CoC managers will need more tools and methods to help them determine where the CoC is successful and where it needs greater support. The development of M&E approaches and tools is clearly a priority area for the CoC.

CoC managers especially need to be able to monitor the effectiveness of the CoC coordination framework itself. Planners and managers need information that describes referral patterns, frequency and effectiveness of meetings, stakeholder participation in CoC activities, missed opportunities for uptake of services, and other aspects of CoC coordination.

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WHERE ARE WE GOING? THE FUTURE OF THE CONTINUUM OF CARE



Districts, cities, provinces and countries that adopted the CoC approach have improved the access of PLHIV to the services they need. Although countries have implemented the CoC in different forms, several common conclusions can be drawn regarding next steps and future directions. This final section of the Toolkit highlights the following six areas of the CoC where future initiatives hold the promise of impressive results:

- 1. Integrating prevention services into the CoC
- 2. Improving access to HIV services among those most at risk
- 3. Establishing family-centred care
- 4. Expanding services outside of the health sector
- 5. Establishing a national CoC framework
- 6. Achieving universal access

1. Integrating prevention services into the CoC

Prevention is a core component of the response to HIV. While the continuum of care was initially developed as a better way to deliver HIV care, treatment and support services, it also provides a framework for integrating HIV prevention services. HIV prevention services that should be made available through the CoC depend on the needs of clients but may include safer sex counselling and provision of condoms and lubricant, STI screening and treatment, clean needles and syringes and opioid substitution therapy (OST) services for IDUs, family planning, and PMTCT. Interventions that promote HIV prevention among IDUs, sex workers, MSM and others who are vulnerable to HIV can be offered as stand-alone services through drop-in centres, prisons, drug rehabilitation services, or in the community by peer educators and outreach workers. However, preventive services also need to be linked to care, treatment and support interventions. These linkages promote better access among PLHIV and those who are vulnerable to HIV to the services they need, when they need them.

Incorporating prevention services in the CoC

A leading example of how prevention services can be incorporated into the CoC is found in Ho Chi Minh City, Viet Nam. A new initiative is being built into the existing district CoCs there that addresses the needs of IDUs who have been released from rehabilitation centres and are being integrated into the community. This intervention is led by case managers who are based in the rehabilitation centres and in the community and who assist former and current IDUs—both HIV-negative and positive—to access services. Preventive services such as needle and syringe distribution programmes, safer sex counselling and condoms, STI screening and treatment, and eventually OST will be available through the same centres that provide HIV care, treatment and support services.

2. Increasing access to HIV services among those most at risk

The CoC offers excellent opportunities to reduce stigma and discrimination towards PLHIV and improve their access to services—especially among those at greatest risk of infection. The CoC must push beyond traditional approaches to care provision and improve access among highly vulnerable populations in the region that include sex workers, IDUs, MSM, prisoners, and migrants. Children, youth and the poor also face barriers in accessing HIV services that they need. Localities and countries in the region need to identify strategies that enable most-at-risk populations to access the services they need in order to improve coverage.

The two examples below illustrate barriers that prevent most-at-risk groups from using services:

- In City X, police stand outside of the IDU drop-in centre that provides clean needles and syringes, drug-use counselling, HIV counselling and testing, referrals to HIV care services, and general health care. Many IDUs do not use the centre because they fear being arrested or noticed by the security forces.
- In City Y, health-care workers at an HIV clinic have not been trained to provide non-judgmental care to MSM. MSM refuse to utilize the clinic because of the discrimination they experience there.

The price of isolating most-at-risk groups

The 2004 APN+ AIDS Discrimination in Asia research project surveyed more than 750 HIV-positive people in four countries. The study showed that HIV-related stigma and discrimination continue to be major issues for people living with and affected by HIV. Stigma and discrimination towards PLHIV was found to be related not only to real or perceived HIV-positive status, but was often heightened when the client was identified as a member of a population that practices high-risk behaviours including commercial sex workers, injecting drug users and men who have sex with men. Many governments in South-East Asia—where these behaviours are often regarded as "social evils"—criminalize these behaviours and the people who practice them. The study found that labelling members of these groups as immoral or as criminals severely diminishes their access to prevention and care services and creates barriers to an effective response to the epidemic.

CoC planners should consider the following strategies to reduce barriers to services among at-risk populations:

- Sensitize local leaders to the needs of at-risk populations and the harmful effects of harassment, exclusion and arrest of these groups. Discuss barriers to care in CoC-CC meetings and other forums.
- Include PLHIV and members of at-risk populations as meaningful partners in CoC planning and implementation activities.
- Train health-care workers to provide care in a non-judgmental manner and sensitize them to issues regarding sex workers, MSM and IDUs.
- Sensitize officials at prisons and rehabilitation centres regarding HIV-related issues and advocate for them to join the CoC. Establish referral linkages between these

closed settings and the community-based settings where clients will require services following their release.

- Integrate services and information to address multiple risk behaviours during encounters with clients (e.g. promote both safer sex and harm reduction among IDUs).
- Support or conduct outreach activities among marginalized populations in order to develop trusting relationships between service providers and clients and to assure clients that CoC services are friendly, non-judgmental and respectful of their rights.
- Provide key services in locations where at-risk populations live and practice high-risk behaviours. Drop-in centres, community clinics and other communitybased services represent important CoC services for those clients who are not able or willing to seek care within the heath and social welfare systems.
- Establish formal links and efficient referral processes between services for the general public and services that focus on at-risk populations.
- Monitor access to and experience with the CoC among PLHIV and those vulnerable to HIV in order to ensure that services respond to client needs, local circumstances, and the evolution of the epidemic.

3. Establishing family-centred care

When one member of a family has HIV it affects the entire family. Care can be particularly complex when both parents and children have HIV. Services for children and adults often are not provided in the same facility or location, posing challenges in terms of transport costs, uncoordinated care and mixed messages from different providers. In some cases CHBC and OVC services are offered by different providers and are not coordinated, creating confusion for the household.

Family-centred care

Family-centred care involves providing HIV-infected individuals and their family members with the care, treatment, support and preventive services that they require. Services provided under the CoC can be adapted and structured to improve the access of families to services. Family-centred care links these services through several key strategies:

- Establishing integrated family clinics
- Using case managers to assess family needs and connect them with the services they require
- Providing follow-up care in the community through CHBC services

The effect of HIV on families is particularly apparent with maternal and child health-care services. Prevention of mother-to-child transmission (PMTCT) services are generally provided by maternal and child health (MCH) and obstetric and gynaecology departments—it is thus essential that effective referral and planning links exist between these two services. These departments need to collaborate to provide services during antenatal care, labour and delivery, and the postpartum period. Many mothers and newborns with HIV are lost to follow-up because hospital departments do not coordinate effectively or because referral mechanisms between hospitals

and health centres are not well established. The hospital director and/or CoC-CC Coordinator often play key roles in making the links between these two services work effectively.

The HIV epidemics in most countries of the region are either low prevalence or concentrated. It is inefficient in most hospitals for the paediatric department to develop expertise in paediatric HIV when its burden is so low. Care for children with HIV is generally provided most efficiently through the CCS. General paediatricians can be rotated into the CCS for Family Clinic Days on a weekly basis. This maximizes resources and ensures that all family members receive care (at the same site and on the same day) from CCS staff members who have received extensive training in HIV care.

CoC planners can take the following steps to promote family-centred care:

- Organize family days at the CCS: train the hospital paediatrician(s) to provide HIV care and invite them to work with the adult clinician on family days. Both clinicians can provide care together for all those in the family living with HIV.
- Link files: develop a system to link files of family members so that they can be updated at the same time and cross-referenced.
- Appoint case managers: train volunteers or staff to assess needs of families registered at the CCS and link them with health, social, economic and spiritual support services. These services may include PMTCT, family planning, psychosocial support, food security education and support, legal support, child protection, education support and household economic strengthening.
- Train CHBC teams to provide family-centred care: use training and ongoing supervision to support CHBC services to address the needs of the entire family.
- Ensure representation of MCH, CT and other providers on the CoC-CC: build strong relationships between CT, PMTCT and care services, ensuring that representatives of each service are on the CoC-CC. The committee should focus on developing referral systems between each service, thereby enabling adults with HIV and their children to gain better access to HIV care and prevention services.

Family-centred care in Viet Nam

Family-centred care (FCC) in some districts in Viet Nam includes "Family Clinic Days" during which outpatient clinic staff provides care for the entire family. On these days, health-care workers assess HIV-positive caregivers and their children together. Family members then visit the Adherence Counsellor and finally the FCC Coordinator, who serves as the case manager for the family. The FCC Coordinator assesses the needs of the family, helps them to develop a family care plan, and works to link them to needed services. The Coordinator works closely with and supervises CHBC teams while also managing community play groups, schooling access and referral relationships with key social support services.

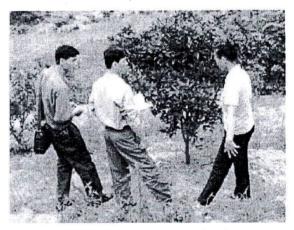
The CHBC teams provide follow-up support to meet the needs of the family. Depending on the CoC site, they may provide support in the areas of income generation, food provision, access to schooling, housing, and managing the impacts of stigma and discrimination—all issues that are often among the most pressing needs of HIV-affected families.

4. Expanding services outside of the health sector

PLHIV and their families have physical, emotional, social, legal, economic and spiritual needs. Given that the lives of many people with HIV in the region are further complicated by drug

use, imprisonment or other difficulties, linkages with services that address both medical and non-medical needs are crucial.

Poverty in particular is a major factor for many PLHIV who are enrolled in CoC services. Poverty impacts upon their access to nutritious foods as well as the ability of PLHIV to travel to clinic appointments, keep children in school, and find stable, safe housing. Many PLHIV therefore need assistance locating employment.



PLHIV groups partnering with local agricultural experts in Pingxiang, China

Comprehensive CoC: increased involvement of sectors outside health

At many CoC sites—especially during the initial stages of implementation—CoC managers may emphasize and prioritize medical services such as OI management, ART, and PMTCT. While there are good reasons for assigning high importance to these services, they do not fully meet the needs of PLHIV and their families.

Cambodia stands out as a country where the government has done an excellent job of creating a formal role for government social services in the CoC planning process by mandating their involvement at the local level. The Ministries of Social Affairs, Labour, Veterans and Youth, and Women's Affairs all participate in the CoC. This strategy has been facilitated through the decision by NCHADS to work with the National AIDS Authority—an inter-ministerial body that creates a forum for all relevant ministries to participate in HIV programming and coordination.

In Pingxiang, China, CoC stakeholders are trying to broaden their effort to address the non-medical needs of their clients, but there will be no simple solution. Due to high levels of stigma, PLHIV feel that referrals to organizations outside of the health sector must protect their confidentiality and ensure that the organization does not infer their HIV status. Government agencies such as the Department of Social Affairs and the Youth League would like to provide assistance to PLHIV but they don't know who their prospective clients are—and with PLHIV unwilling to disclose their status, the problem has remained unsolved. CoC planners are discussing how to best confront this dilemma. The solution that is eventually reached will probably be a combination of identifying and publicizing the assistance that is available and then encouraging PLHIV clients to apply for it while ensuring that their confidentiality will be protected by the organizations that provide them with assistance.

Once the core service delivery mechanisms of the CoC are in place—including the CCS and CHBC—CoC coordinators and planners can explore building linkages with services that address unmet medical needs (e.g. mental health) and non-medical needs of PLHIV. The following steps can be taken to widen the CoC network to include social welfare and other needed services:

- Map available services: the CoC-CC can rapidly map services that exist in the area served by the CoC site. This task includes determining where and how services such as loans, nutrition support, aid for children to attend school, spiritual counselling, and mental health can be accessed by PLHIV.
- Invite social welfare services to participate in the CoC: CoC planners can meet with colleagues from services that can assist PLHIV and negotiate with them regarding their participation in the CoC network. The CoC-CC can offer these organizations seats on the CoC-CC and ask them to become a part of the CoC referral system.

5. Establishing a national CoC framework

The development of a national CoC framework to guide the development and expansion of the CoC throughout the country should be considered by any government that has not yet done so. The development of a national CoC framework allows governments to determine systematically where HIV care and prevention services need to be implemented and then plan strategically to do so. See Section 5.2 for information on how to establish a national framework.

6. Role of the Continuum of Care in achieving universal access

The momentum of the global response to HIV has steadily increased following the 2003 UNGASS on HIV/AIDS. Global goals for treatment were set for the first time under the WHO/UNAIDS 3 by 5 Initiative, resulting in major increases in the number of PLHIV on treatment. As of December 2006, more than two million PLHIV were receiving treatment in low and middle-income countries, an increase of 54% over the previous year.

Despite these achievements, progress towards the Millennium Development Goal on HIV/ AIDS—to halt and reverse the spread of the epidemic by 2015—is lagging. In order to reach this goal, UNAIDS and WHO have called on governments to make plans and set targets towards universal access to HIV prevention, care, treatment and support by 2010.

Key statistics make it clear that much more needs to be done to achieve universal access in the Asia-Pacific Region. Less than 10% of those living with HIV in the region know their status; only 19% of those who need treatment receive it; and, less than 5% of IDUs have access to harm reduction services.³⁶ HIV services urgently need to be scaled up while barriers to accessing these services need to be identified and reduced. It is equally important that the health systems that provide these services must be strengthened. Stronger planning mechanisms, efficient use of finances and more effective development of human resources need to be realized if universal access is to be achieved.

The continuum of care is ultimately a health system intervention that seeks to provide a package of coordinated high-quality services that PLHIV and families can access with ease. Countries that have implemented the continuum of care approach nationally—such as Cambodia and Thailand—have made comparatively strong progress towards universal access targets, particularly in the areas of care and treatment. The continuum of care approach is a highly effective strategy for scaling up sustainable HIV services. The time for countries to implement the continuum of care is now.

Action points: beyond basic care and treatment

- Integrate prevention services into the CoC.
- Improve access to HIV services among those most at risk.
- Establish a family-centred approach to care and treatment.
- Build linkages with services that address unmet non-medical needs of PLHIV.
- Establish a national CoC framework.
- Make universal access a reality.

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ANNEX 1: GLOSSARY OF COC SERVICE DESCRIPTIONS



CoC service descriptions

HIV counselling and testing (CT) – HIV counselling and testing is often the client's entry point into the CoC—others include Provider Initiated Testing and Counselling (PITC) and diagnostic testing linked to TB and inpatient services. A positive experience for clients in this service can positively influence their continued use of other CoC services. Comprehensive pre and post-test counselling provide important opportunities for clients to learn about—and be referred to—other services within the CoC. CT services may be integrated into existing care, treatment and prevention services or they may be located in free-standing clinics or community-based organizations with strong referral links to HIV care and treatment services.

Opportunistic infections: prevention, treatment and management – Prevention, early diagnosis and treatment of opportunistic infections are essential to optimal HIV care. Within the CoC framework, the outpatient clinic (OPC) or comprehensive care site (CCS) provide services for the prevention, treatment, and management of Ols. Serving as a critical referral hub of the CoC, the OPC/CCS is linked to (or offers) services that include CT, PMTCT, ART, TB diagnosis and treatment, drug substitution therapy and hepatitis B vaccinations, family planning, STI services, inpatient care, psychosocial support and CHBC. Trained PLHIV serve as counsellors in many CoC clinical settings, a role critical to the success of the CoC.

Tuberculosis prevention, diagnosis, and treatment – Early diagnosis and treatment of TB among PLHIV improves an individual's immune function and cures him of active TB, thus reducing the risk of TB transmission to others in the population. TB prevention and treatment services should therefore be strongly linked with the CT clinic, HIV clinical care and CHBC services within the CoC framework. The CoC framework facilitates and strengthens these linkages. Clinical management of PLHIV who are infected with TB involves multiple health-care providers and is best provided through a coordinated team. In some instances referral to higher level services is required. Preventing PLHIV from being infected with TB during their time in health facilities is of critical importance.

Sexually transmitted infections (STIs): treatment and management – PLHIV should have access to appropriate services to diagnose and treat STIs, reduce risk of complications and minimize HIV transmission to sexual partners. Sex workers, MSM and IDU have special service needs for STI prevention and detection. The CoC can help to ensure that these needs are met; services should include peer outreach and condom promotion.

Palliative care – Palliative care includes reducing suffering of PLHIV and families by assessing and treating pain and other symptoms while providing psychosocial support and spiritual care to improve quality of life. Palliative care complements treatment that addresses opportunistic infections and suppresses HIV through ART. Palliative care is offered from diagnosis to death and through bereavement and is provided through both home-based and facility-based services.

Antiretroviral therapy (ART) – ART availability and adherence counselling are essential components of the CoC. For PLHIV, ART represents not only a key medical service, but also hope for living a normal life. ART helps the client's immune system regain strength, resulting in a reduction of OIs, improved quality of life, and reduced HIV-related morbidity and mortality. ART consists not only of the provision of ARV drugs, but also includes the medical and social support that helps the client manage side effects and adhere to the therapy. Adherence can be strengthened when multiple service providers provide mutually reinforcing messages. CoCs in Asia have utilized CCS, home-based care and PLHIV support groups to provide adherence support counselling.

Prevention activities for those most at risk – While CoC services may focus primarily on HIV care, treatment and support, it is vital that they are linked effectively to prevention services for at-risk groups that include IDUs, sex workers, MSM, migrants and youth. Some prevention services are provided directly through CCSs while others are accessed through referral links. Essential tools to support HIV prevention among these groups include (i) condom and lubricant distribution and counselling for partner reduction; (ii) harm reduction counselling, needles and syringe exchange or distribution; (iii) linkages to detoxification and rehabilitation, relapse counselling and treatment (e.g. opioid substitution therapy or OST) services; and, (iv) peer outreach and strategic behaviour communication. STI treatment and diagnostic services are also important HIV prevention measures and offer another opportunity to contact at-risk groups and conduct preventive activities. Referrals of members of at-risk groups to CT promotes early identification of HIV status and enrolment in the CoC.

HIV prevention and reproductive health services for PLHIV and discordant partners – The CoC framework can be effectively used to reinforce HIV prevention among PLHIV and discordant partners through counselling regarding how to prevent transmission. This service should also include information regarding how to minimize the risk of HIV transmission to partners and infants. The CoC ensures that these services are present and creates effective links between HIV services and family planning and reproductive health services.

Prevention of maternal-to-child transmission (PMTCT) – PMTCT services should be offered in ANC settings to all women—regardless of their risk profiles—and included in the CoC. The CoC ensures that PMTCT services are integrated into routine MCH and antenatal care services to maximize coverage. Within the CoC, important referral links are established between PMTCT services, counselling and testing services, and the HIV outpatient clinic (OPC). The CoC also links mother–infant pairs that are referred from the PMTCT programme with CHBC teams to support correct infant feeding procedures, paediatric and adult cotrimoxazole prophylaxis, adherence to ART (when prescribed), and ongoing support for HIV-positive mothers including access to early HIV testing for infants.

PLHIV support groups – These are self-led groups of PLHIV that meet regularly to provide support to group members and other PLHIV. In addition to providing services and participating in the management of the CoC, PLHIV support groups play an important activist role through their participation in activities such as determining who is eligible to start ART or advocating for clients who do not receive the services they need.

Nutritional and daily living support – Good nutrition is an important strategy for improving quality of life for PLHIV. Within the CoC, community health workers and caretakers may offer nutrition counselling and support through education, food supplementation and nutritional

monitoring. PLHIV and their families may also require support for basic needs including housing, food, transportation, and small grants to help them start a small business and earn a living. Many of these services may be available in a given community through government and NGO providers. The CoC programme ensures that providers are aware of all basic needs services and know how to refer clients to them. Inviting managers of key services to sit on the CoC-CC and otherwise be involved in the CoC promotes better referral relationships and increased social support for poor PLHIV clients.

Psychosocial support – Psychosocial support aims to assist PLHIV and their families or partners to cope with psychological and social challenges and maintain their hope to lead fruitful lives as productive, valued members of the community. The CoC advocates for the development of psychosocial support services and ensures that they are linked to other key CoC services. Psychosocial support may include the provision of individual, family and group counselling, specialized mental health services and peer support.

Orphans and vulnerable children (OVC): care and support – Children suffer multiple problems when their parents or caregivers have HIV—they experience the illness and possible loss of a parent; rejection from the community and peers; reduced access to health care, education and food; and increased vulnerability to violence and abuse. Meeting the needs of OVCs requires a response from government departments of health, social welfare, women's affairs, and education departments and additional support from NGOs and other organizations that work in the social sector. CoC implementers encourage support from these organizations by inviting them to participate in the CoC-CC. The CCS also supports OVC by providing family-centred care—that is, services for adults and children with HIV and support services for family members.

CONTINUUM OF CARE FOR PEOPLE LIVING WITH HIV IMPLEMENTATION CHECKLIST



Scaling Up the Continuum of Care for People Living with HIV in Asia and the Pacific: Implementation Checklist

A companion document to: Scaling up the Continuum of Care for People Living with HIV in Asia and the Pacific

A Toolkit for Implementers



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1. Purpose of the checklist

The Continuum of Care (CoC) is increasingly recognized as a promising strategy for achieving universal access. The document titled *Scaling up the Continuum of Care for People Living with HIV in Asia and the Pacific: A Toolkit for Implementers* is a comprehensive review of the CoC strategy, including its definition, origins, case studies that describe its development, and tools that help design and implement it. The Toolkit represents the most thorough programming guidance for the CoC to date.

This companion checklist is intended for use by planners and implementers to help organize and track the process of establishing a CoC. Each CoC is unique. Its design and function are influenced by local factors including the nature of the HIV epidemic, the administrative infrastructure, socio-cultural issues, available resources and local priorities. The actions outlined in this document are not intended to be prescriptive but have been found to contribute to the success of existing CoCs. These actions should be viewed as a menu of options to be considered and adapted by leaders, planners and managers as they develop new CoCs or strengthen existing CoCs in their local settings.

The checklist is laid out in the following sections:

- Introduction that defines the CoC
- Checklists for:
 - Establishing the six building blocks of a local CoC
 - Developing a national CoC framework
 - Monitoring and evaluating the CoC
- An outline of five priority areas for future CoC development

2. What is the Continuum of Care?

People living with HIV (PLHIV) and their families have emotional, social, physical and spiritual needs that change over time. They often must cope with the effects of stigma and discrimination, poverty, loss, neglect and abandonment. The purpose of the CoC is to address HIV as a chronic disease and to develop systems that provide humane, effective, high-quality comprehensive and continuous care to PLHIV and their families.

The CoC has two defining characteristics as follows:

- The CoC is a network that links, coordinates and consolidates care, treatment and support services for PLHIV. These services are provided in their homes, in the communities where they live, and in the health facilities that serve them.
- The CoC is also the group of services that together provide comprehensive support
 to PLHIV and their families. Most of the CoCs implemented to date were initially
 developed to provide care, treatment or support services to PLHIV. Once these
 services were established, the CoCs began to incorporate prevention activities.

Both of these features of the CoC are illustrated in Figure 1. The circles represent the different services—clustered by location of delivery—that are included in many CoCs. The arrows represent the referral network that binds the services together in the CoC.

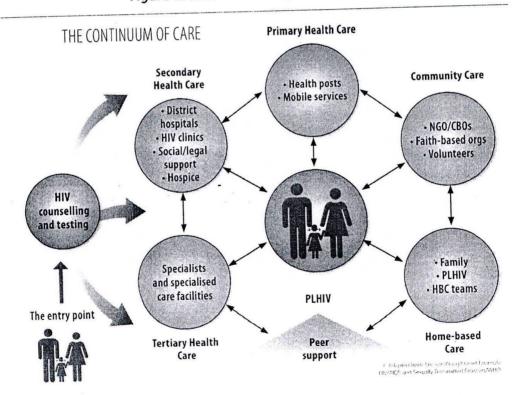


Figure 1: Continuum of Care framework

The CoC is a complete set of linked care, treatment and support services provided at all levels from health facility (hospital/health centre) to community and home by government. NGOs, CBOs, FBOs, PLHIV and family members.

Source: Adapted from: Narain JP, Chela C and van Praag EV. Plunning and implementing HIV/AID5 care programmes: a step by step approach, New Delhi, WHO Regional Office for South-East Asia, 2007.

CoC networks generally include most or all of the following services:

- HIV counselling and testing (CT)
- Opportunistic infections (OI): prevention and treatment
- Tuberculosis (TB) detection, prevention and treatment
- Sexually transmitted infections (STI): diagnosis and treatment
- Palliative care: treatment of pain and other symptoms, psychosocial and spiritual support
- Antiretroviral therapy (ART) and adherence: counselling and support
- Prevention services for those most-at-risk
- HIV prevention and reproductive health services for PLHIV and discordant couples
- PMTCT and health services for HIV-positive mothers and infants
- PLHIV support groups
- Nutritional and daily living support
- Psychosocial support: support groups and counselling
- Orphans and vulnerable children (OVC): care, support and protection

The CoC framework is based on a set of core principles that can be summarized as follows:

- The CoC is needs-based and client-focused.
- The CoC has a rights-based orientation.
- The CoC promotes meaningful involvement of PLHIV and other stakeholders.
- The CoC links a diverse set of services across different service delivery sites.
- The CoC is locally defined.



3. Establishing the CoC at the local level

While each CoC is unique, there are six common building blocks that each CoC uses to build strong systems and services. They can be easily remembered as listed in the box on the below.

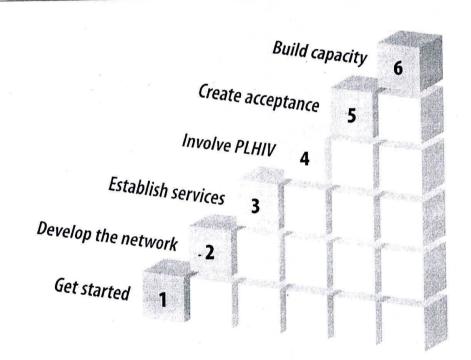
Figure 2 illustrates the six building blocks of the CoC.



- 1. Get started
- 2. Develop the network
- 3. Establish services

- 4. Involve PLHIV
- 5. Create acceptance
- 6. Build capacity

Figure 2: The six CoC building blocks



3.1 Building Block 1: Get started

Main activities:

- Create awareness and commitment for the CoC
- Assess care needs
- Develop a CoC workplan
- Conduct training and workshops for stakeholders

Create awareness and commitment for the CoC

- Identify and gain agreement from a recognized leader to be the head of the CoC.
- Hold meetings with stakeholders to discuss why a CoC is needed.
- Take stakeholders on study tours to see a CoC in action.
- Invite people who have developed CoCs in other areas to meet with stakeholders.

Assess care needs

- Interview PLHIV and families regarding their needs.
- Conduct a facility assessment and interview health care workers at the hospital and other sites.
- Interview NGO managers involved in HIV work.
- Review existing referral system and coordination mechanisms.
- Review HIV prevalence, projections and case reporting.
- Present the findings and recommendations to stakeholders.

Develop a CoC workplan

- Define what needs to be done, when and by whom and document it in the form of a workplan.
- List donors and local organizations that will support the CoC.
- Start with actions that are achievable and lead to early, measurable results.

Figure 3: Example of an annual CoC workplan

Activity	Who responsible	Time frame						Target/expected	
		Q1	Q2	Q3	Q4	((st	Total	Target/expected output
							8 % (57) N. W. T.		Company districts

Source: Family Health International

Conduct trainings and workshops for stakeholders

- Plan and implement workshops that provide information on HIV and the CoC, reduce stigma and discrimination, and build broad consensus and support for the CoC.
- Workshop topics may include the following: (i) overview of HIV care and treatment, (ii) introduction to the CoC, and (iii) HIV and standard precautions.

3.2 Building Block 2: Develop the network

Main activities:

- Assign roles for CoC coordination
- Create and sustain a CoC Coordination Committee
- Link PLHIV to the services they need
- Identify and remove barriers to care

Assign roles for CoC coordination

- Identify a local CoC leader to:
 - organize the CoC Coordination Committee (CoC-CC)
 - take responsibility for overall programmatic and budgetary decisions
 - negotiate with leaders and officials to improve support for the local CoC
- Identify a local CoC Manager to:
 - manage implementation of the overall CoC workplan
 - play a lead role in the organization and establishment of CoC services
 - promote the involvement of PLHIV and families in all aspects of the CoC
 - arrange for regular CoC Coordination Committee meetings
 - meet with key partners on a routine basis to solve problems
 - ensure the development of referral systems and tools to support CoC systems

Create and sustain a CoC coordination committee

- Gain support from local health leaders to establish the CoC-CC.
- Determine how the CoC-CC will function. Will it be integrated into an existing HIV committee? If so, how?
- Identify key people who should be on the CoC-CC and invite them to the first meeting.
- At the first meeting, review the HIV needs, services and gaps. Discuss how to improve referrals and reduce barriers to service. Elect a chair, secretary and other officers.
- Following the first meeting, the local government can officially approve the committee including its purpose and membership.
- Maintain flexibility to add new members who can help improve services for PLHIV.
- Notify members well before each meeting and encourage attendance and participation.

Link PLHIV to the services they need

- Develop or strengthen linkages between the services for PLHIV to build a simple and effective referral network.
- Negotiate the use of standard referral procedures.
- Develop tools to facilitate referrals, such as:
 - a client-held service record booklet
 - a list of all CoC services (including service descriptions, locations and times)
 - a case-management approach to care

Identify and remove barriers to care

- Assess and plan for reducing hidden barriers to care (e.g. socio-cultural, psychological and economic) through contact with PLHIV, service providers and local leaders.
- Carefully consider and address the effect of user fees on service utilization.

Figure 4: Active referral within the CoC

Social and legal support Peer support and voluntary services services District hospitals, Homes, INDIVIDUALS SEEKING HIV clinics, specialists and community services, OR NEEDING CARE specialized care facilities hospices Health centers, HIV voluntary counseling dispensaries, and testing (VCT) traditional care ACTIVE REFERRAL NETWORK Care seeking/providing Active referral

THE CONTINUUM OF CARE

Source: van Praag EV. FHI, 2001.

3.3 Building Block 3: Establish services

Main activities:

- Develop comprehensive care sites
- Develop and link community and home-based care services
- Enhance the role of NGOs, CBOs and FBOs
- Integrate new services

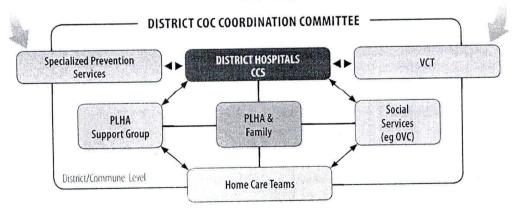
Develop comprehensive care sites (CCS)

- Decide whether the CCS should be hospital-based or stand-alone.
- Establish services at the CCS:
 - Define basic package of services to be provided.
 - Identify services and providers that will be linked by referral to the CCS.
 - Consider other needed services and plan for future expansion.
- Plan for physical facilities, including space for:
 - a designated area for outpatient care
 - a private place for providing adherence, care and supportive counselling
 - a meeting venue for PLHIV groups, the CoC-CC and others
 - a work area for the CHBC team if they are based at the CCS

Figure 5: Integrated hospital-based CCS and linkages in Viet Nam

LOCAL CONTINUUM OF CARE NETWORK

PROVINCIAL COC COORDINATION COMMITTEE OB/GYN Hospital Provincial Hospitals TB/Lung diseases Hospital Provincial Level



Source: Family Health International

- Plan for personnel:
 - Determine staffing requirements.
 - Identify the training requirements for each staff position.
 - Make a plan for mentoring and supportive supervision.
 - Organize interdisciplinary teams and nurture teamwork.
 - Sensitize all staff to issues regarding HIV and at-risk populations.
- Develop management routines and relationships:
 - Establish management meeting schedule.
 - Consider including routine meetings in which all CCS staff (including CHBC teams) discuss priority cases.
 - If CoC is hospital-based, link the CCS to all relevant hospital services with the support
 of the administration.

Develop and link community and home-based care services

- Conduct an assessment of CHBC services to answer the following questions:
 - To what extent is CHBC in place and how well is it linked to health facilities?
 - What types of training have CHBC service providers received?
 - Are CHBC teams supplied with basic medicines to treat pain and other symptoms?
 - Is it possible to base CHBC services at the CCS?
 - How well do CHBC services address stigma and discrimination? Can they do more?
 - Do CHBC teams need training to provide care to the whole family?
- Improve CHBC services through the following actions:
 - Base CHBC teams at the CCS so they become part of the team.
 - Ensure that PLHIV lead or participate in the provision of CHBC services.
 - Train CHBC teams to address the needs of both adults and children.
 - Train, supply, supervise and support CHBC providers.
 - Reinforce the voluntary and confidential nature of CHBC services.
- Link other community-based services such as hospices and spiritual care to the CCS.

Enhance the role of NGOs, CBOs and FBOs

- Ensure that the CoC-CC includes non-governmental organizations (NGOs), community-based organizations (CBOs) and faith-based organizations (FBOs).
- Encourage local and international NGOs to provide services, build the capacity of local partners and mobilize resources and support for the CoC.
- Facilitate CBOs to provide support for households made vulnerable due to HIV, intervene when PLHIV and families are being discriminated against and provide support and companionship when clients feel isolated or rejected by their community.
- Work with FBOs to provide a broad range of services, including spiritual counselling, hospice, OVC care, prevention education and material support.

Integrate new services

- Plan for and introduce new services within the CoC to address identified gaps.
- Ensure that new services are linked through referral protocols.
- Publicize new services to CoC providers, clients and their communities.

Building Block 4: Involve PLHIV 3.4

Main activities:

- Promote PLHIV as leaders in the CoC
- **Build PLHIV capacity to provide services**
- **Empower PLHIV groups**
- Include PLHIV in CoC monitoring activities

Promote PLHIV as leaders in the CoC

- Make PLHIV meaningful partners in the process of CoC development.
- Support PLHIV groups through capacity building and funding.

Build PLHIV capacity to provide services

- Work with PLHIV as partners and co-planners of CoC services and systems.
- Develop a policy to involve PLHIV as staff and volunteers in all HIV services.
- Provide training and support so that PLHIV learn new skills.
- Pay PLHIV fairly for their work.
- Support PLHIV to develop services that are led and managed by PLHIV.

Empower PLHIV groups

- Identify existing PLHIV groups and invite them to join the CoC-CC.
- Ensure that PLHIV group leaders are fully involved in the core CoC planning team.
- Support PLHIV groups to develop group action plans and to secure funds for their plans.
- Provide meeting space for PLHIV groups at the CCS or other convenient site.
- Promote cross-learning with other PLHIV groups and networks.

Include PLHIV in CoC monitoring activities

- Include PLHIV as part of the team that determines how to monitor the CoC and what the indicators of success will be.
- Invite PLHIV to assess services with the team.
- Have PLHIV work with the team to analyze findings and provide recommendations for improvements.

3.5 Building Block 5: Create acceptance

Main activities:

- Develop client-friendly services
- Involve families
- Mobilize the community

Develop client-friendly services

- Build in service features that promote privacy, confidentiality and trust in CoC services.
- Adopt strategies aimed at making services more client-friendly, including:
 - involving PLHIV
 - provider training
 - individual case management

Involve families

- Build a role for clients' families into the CoC services.
- Assist CHBC teams to achieve family support for clients.
- Organize "family days" at the CCS.

Mobilize the community

- Meet with well-positioned local leaders in the public and private sectors to inform them about the CoC and seek their support.
- Conduct educational activities that target members of the general public in neighbourhoods where PLHIV live.
- Organize social mobilization activities during the CoC development process that include:
 - community information meetings
 - door-to-door visits by local volunteers
 - community quizzes at events or holiday celebrations
 - talks by respected community members such as religious leaders, celebrities and officials

3.6 Building Block 6: Build capacity

Main activities:

- **■** Train CoC staff
- Organize mentoring
- Plan and provide supportive supervision
- Strengthen community-level health facilities

Train CoC staff

- Provide health care workers and other service staff with a comprehensive package of training in HIV/AIDS care, including:
 - disease progression
 - treatment
 - infection control and occupational exposure
 - confidentiality
 - palliative care
- Provide supplementary training for personnel who work in specialized areas such as CT, ART, TB and HIV treatment and CHBC.
- Base technical aspects of the training on service standards and protocols.
- Include as much practical clinical training as is feasible in the local setting.
- Provide psychological support and motivation to health providers.
- Develop local or national specialists as qualified senior trainers.
- Contract senior trainers to provide on-site mentoring to teams of CoC service providers in new areas where the CoC is being introduced.

Organize mentoring

- Arrange for on-site mentoring by clinical care professionals at the local CoC
- Post providers for short durations in other CoCs.

Plan and provide supportive supervision

Develop and implement systems of supportive supervision that reinforce the lessons of training activities and enhance morale.

Strengthen community-level health facilities

- Include staff of community-level health facilities on the CoC-CC.
- Train staff of community-level health facilities in CoC services and referrals.
- Sensitize staff to specific issues regarding PLHIV and at-risk populations.
- Plan and budget as necessary to equip community-level health facilities.

4. Developing and implementing a national CoC framework

Main activities:

- Conduct a situation analysis
- Mobilize national-level support
- Prepare and fund a CoC workplan
- Develop the care package and service standards
- Assess and improve initial efforts

Conduct a situation analysis

- Map existing services and examine current infrastructure that provides HIV services.
- Review data related to the epidemic and service utilization.
- Talk with PLHIV and their families about their needs.

Mobilize national-level support

- Develop a compelling rationale for the construction of a national CoC framework.
- Define what is to be done, by whom and when.
- Consult with government agencies, PLHIV, NGOs, donors and other partners.
- Identify and task a working group to prepare and document a national CoC framework.

Prepare and fund the CoC work plan

- Use a participatory planning process.
- Cost the workplan and use it as a tool for fundraising.
- Consider pooling donor funding to support the CoC.

Develop the care package and service standards

- Establish technical working groups (TWGs) to produce (i) detailed tools and guidance for service improvement and (ii) guidelines and standard operating procedures for new services.
- Assign TWGs the task of developing training, mentoring and supervision packages and plans for building human resource capacity in local CoCs.

Assess and improve initial efforts

Assess local CoCs and use findings to document or revise the national CoC framework and guide the design and implementation of the CoC in new sites.

5. Using monitoring and evaluation to improve the CoC

- Identify indicators that can be utilized to monitor the performance of the CoC using routinely collected data.
- Conduct periodic case reviews to assess quality of care provided through the CoC.
- Organize participatory CoC program reviews on a periodic basis that use standardized tools to assess the following:
 - the effectiveness of service linkages and success of referrals
 - the regularity of CoC-CC meetings
 - the perceptions of PLHIV, their family members and providers regarding services
- Design and conduct special studies as appropriate to evaluate the benefits that clients receive from the CoC.

6. Five priority areas for future CoC implementation

Integrate prevention services into the CoC

- Incorporate prevention activities within existing services (e.g. safer sex counselling as part of treatment and support services).
- Offer targeted, stand-alone prevention services for at-risk populations (e.g. in the community, at prisons or rehabilitation centres).
- Link preventive services to care, treatment and support interventions.

Improve access to HIV services among those most at risk.

- Sensitize local leaders to the needs of at-risk populations and the harmful effects of harassment, exclusion and arrest of these groups.
- Include members of at-risk populations as meaningful partners.
- Train health care workers to provide care in a non-judgmental manner.
- Integrate services and information to address multiple risk behaviours during encounters with clients (e.g. promote both safer sex and harm reduction among IDU).
- Conduct outreach activities among marginalized populations.
- Provide key services in locations where at-risk populations live.
- Establish formal links and referral processes between services for the general public and those that focus on at-risk populations.
- Invite prisons and rehabilitation centres to join the CoC and create referral links with the community-based services needed by clients after their release.
- Monitor access to and experience with the CoC among PLHIV and those most at risk.

Establish family-centred care

- Organize family days with paediatric and adult clinicians at the CCS.
- Develop a system to link files of family members.
- Appoint case managers to manage the care of the entire family.
- Train CHBC teams to provide family-centred care.
- Ensure representation of MCH, CT and other providers on the CoC-CC.

Expand services outside of the health sector

- Map other services that exist in the area served by the CoC.
- Meet with colleagues from departments and organizations that provide social services.
- Offer these groups seats on the CoC-CC and incorporate them within the referral system.

Strive for universal access through the CoC approach

To achieve universal access, HIV services must be scaled-up while barriers to accessing these services must be reduced. The health systems that provide these services must also be strengthened. Stronger planning mechanisms, efficient use of finances and more effective development of human resources must be realized if universal access is to be achieved. The CoC is ultimately a health system intervention that seeks to provide a package of coordinated high-quality services that PLHIV and families can access with ease. The CoC approach is a highly effective strategy for scaling-up sustainable HIV services. The time for countries to implement the CoC is now.



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