

HIV CARE AND SUPPORT

A STRATEGIC FRAMEWORK



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P R E F A C E

The need for more comprehensive and effective care and support for people affected by HIV has been ignored for far too long. Today, however, growing recognition of the importance of such care is opening up more opportunities to help people living with the virus and those who support or depend upon them.

FHI welcomes these opportunities to work with governments, healthcare providers and communities to strengthen HIV care and support and to build vital linkages between HIV prevention and care services. Through an expanded program of technical assistance and capacity building in HIV care and support, we hope to improve services in order to enhance the quality of life of people and families affected by HIV and to help mitigate the impact of HIV epidemics on communities.

These expanded efforts in care and support will be guided by the strategic framework presented in this document, which FHI will use in advocacy, planning and implementation. The strategy will help us promote better understanding of the need for comprehensive HIV care among donors, policymakers, health and other officials and care providers. It will also provide a framework for planning care and support strategies in collaboration with people living with HIV and governmental and nongovernmental partners from various sectors and disciplines. And it will guide collaborative activities at every level of a country's health and welfare system to improve access to comprehensive services for people affected by HIV.

We hope that our strategic framework will also be useful to others working to improve HIV care and support. We offer it as a resource to help national, district and local policy makers, program managers and donors determine how to meet the medical, psychological and social support needs of people living with and affected by HIV.

I . I N T R O D U C T I O N

Today, 20 years after the first case of AIDS was reported, about 16,000 people still become infected with HIV every day. At the end of 2000, more than 36 million people were living with HIV, including 25 million people in Africa and a rapidly growing number in Asia.

Among adults, HIV/AIDS is becoming the leading cause of mortality in an increasing number of countries around the world. An estimated 3 million AIDS-related deaths occurred in 2000 alone, and many of them were caused by tuberculosis (TB), the leading killer of people living with HIV. Since the beginning of the pandemic, 21.8 million people have died of AIDS, including 17.5 million adults and more than 4 million children, most of whom acquired the virus from their mothers. Almost 80 percent of all these deaths occurred in sub-Saharan Africa. Life expectancy in the countries most heavily affected in southern Africa has dropped by 10 to 15 years or more.

Although the majority of people living with HIV (PLHA) do not know that they are infected, most need and seek care for opportunistic infections (OIs), including tuberculosis, and other HIV-related illnesses. The continued high number of people becoming ill with HIV has a devastating effect on healthcare delivery. Up to half of the people living with HIV, for example, will develop tuberculosis. The growing demand for healthcare for people living with HIV is draining human and financial resources from already overstretched public health services in many non-industrialized countries. An increasing number of hospital beds are

occupied by HIV-infected patients, resulting in overcrowding of hospitals and reduced or poor quality of care for all patients. The healthcare sector also has to cope with the impact of the epidemic among healthcare workers. Illness and death due to AIDS are growing among healthcare personnel in many countries and will have an impact on service organizations and the quality of care provided.

The social and economic impact of the HIV pandemic is even more devastating, particularly at the household level. Productivity declines and income losses are aggravated by the increasing out-of-pocket expenses for medical care. In many cases, HIV/AIDS is fragmenting families as the high mortality among HIV-infected adults creates tens of millions of orphans.

Within the most heavily affected communities, the number of children orphaned by HIV/AIDS has been rising to such an extent that family structures can no longer cope. Since the beginning of the epidemic, AIDS has claimed the mothers or both parents of more than 14 million children. Orphaned children are at greater risk of malnutrition, illness, abuse and exploitation, loss of inheritance rights and decreased access to education, and are therefore more vulnerable to future waves of HIV infection.

Care and support for people living with HIV, their families and their communities were until recently neglected components of most HIV/AIDS programs in non-industrialized countries. Many governments and donor agencies supporting HIV/AIDS programs chose to focus solely on prevention, guided by the belief that preventing HIV infection would obviate the need for care and support, as well as the high costs of providing care and support.

There are examples, however, of innovative community-based projects that responded to care and support needs early in the pandemic by linking with medical and social support services providing medical treatment for opportunistic infections, counseling support, palliative care, and support for dependents and orphans. Through these experiences, we have learned that improving access to HIV/AIDS care and support services helps destigmatize HIV, improves demand for HIV voluntary counseling and testing services, and allows for early management and prevention of infectious diseases, such as TB and sexually transmitted infections (STIs), among both HIV-positive and -negative people. Providing these services, in turn, creates important opportunities for HIV prevention. Synergetic programming that links prevention with care and support is increasingly part of national and local strategic plans in many countries.

Within each community, region and country, there is an existing level of HIV care and support that needs strengthening. In each setting, however, difficult choices have to be made about the level of care and support that is feasible and affordable in the short term and what can be attained in the future. Strategies and national standards are needed to guide both the allocation of resources and the implementation of HIV care and support activities at the various levels. Strengthening community, regional and national capacity to implement comprehensive care and support programs will make it possible to demonstrate how cost-effective approaches can be replicated, scaled up and sustained.

This document provides a strategic framework to assist national and local planners, implementers and donors in setting priorities and outlining the steps necessary to develop comprehensive HIV care and support programs that meet the medical, psychological and social needs of people affected by HIV. It also elaborates the role that FHI will play in this effort.

II. STATE OF THE ART: COMPREHENSIVE HIV/AIDS CARE AND SUPPORT ACROSS A CONTINUUM

The needs of people living with HIV/AIDS and often their families have been identified in four interrelated domains: medical needs, such as treatment information and treatment; psychological needs, such as emotional support; socioeconomic needs, such as helping hands and orphan support; and human rights and legal needs, such as access to care and protection against violence and discrimination. Over the years relevant responses have been developed in these domains, resulting in comprehensive care and support services in some locations. Such services have proved effective and efficient when the various providers link and complement their activities.

As HIV infection progresses, the types of services needed also change. It is this provision of comprehensive care across a continuum from home and community to institutional services and back that will ensure the needs of clients and their families are met. Various communities and institutions in heavily affected settings in industrialized and non-industrialized countries have responded in such innovative ways, albeit on a small scale. This section describes the elements of a comprehensive care and support program that responds to the medical, psychological, socioeconomic and legal needs of people living with and affected by HIV.

Medical and nursing care

People living with HIV/AIDS need medical and nursing care that will reduce HIV morbidity and mortality and optimize their quality of life. Such services in well-resourced care settings include appropriate diagnosis; treatment and prevention of tuberculosis and other opportunistic infections and HIV-related illnesses; provision of highly active antiretroviral therapy (HAART) and clinical monitoring; and, palliative therapies. The capacity of the health systems and the human and financial resources available will determine the choice of interventions and the level of quality of medical care within and among countries. For any resource level, standards can be set to achieve optimum outcomes.

Access to appropriate diagnosis

Appropriate diagnostic services are one of the keys to providing effective clinical care to people living with HIV. HIV diagnosis is made through HIV antibody tests, which should always be accompanied by pre- and post-test counseling. Voluntary testing and the acceptance of a long-term client-carer relationship enhance clinical effectiveness, and thus quality of life.

Diagnostic services should not be limited to the recognition of HIV infection, but should also detect opportunistic infections and other HIV-related illnesses and levels of immune response. Such services are usually based on laboratory results, but they can also depend on or be supplemented by clinical algorithms.

Treatment and prevention of opportunistic infections, including TB, management of HIV-related illnesses and palliation

Infection due to HIV is characterized by progressive deterioration of immunologic function. As the immune system weakens, HIV-infected patients become susceptible to an expanding variety of opportunistic infections. Treatment algorithms for opportunistic infections have been greatly improved, and many countries have developed national clinical management guidelines and have updated their national essential drug lists based on recent guidance from the World Health Organization (WHO) and the U.S. Centers for Disease Control and Prevention (CDC).

Advances made in non-industrialized countries to prevent or delay the occurrence of many opportunistic infections and thus improve survival even before the introduction of antiretroviral therapies have been studied in many settings with different HIV disease patterns. Preventive therapy for tuberculosis and other opportunistic infections, however, has not been widely used in non-industrialized countries as yet. WHO and the Joint United Nations Programme on HIV/AIDS (UNAIDS) have issued recommendations on the use of cotrimoxazole and isoniazid to prevent common opportunistic infections and tuberculosis, respectively, but these recommendations have yet to be implemented.

Limited data are available from non-industrialized countries on the effectiveness of antibiotic treatment of opportunistic infections, with the exception of TB. Experience with clinical management of tuberculosis using the DOTS (directly observed treatment, short course) strategy has shown that TB patients with and without HIV infection have a similar response to treatment.

Palliative care in the sense of symptomatic management of late-stage HIV disease is still poorly developed in many settings in both high-income and low-income countries. The Canadian Public Health Association has provided clinical guidance, and some Ugandan nongovernmental organizations (NGOs) have developed innovative approaches to pain management in resource-constrained settings. Palliation in the broader sense of a holistic approach to restoring physical, emotional and spiritual integrity is gaining attention and is an integral part of a comprehensive approach to HIV care and support.

Antiretroviral therapy

The introduction of antiretroviral (ARV) therapies in 1996 has dramatically reduced morbidity and mortality in most high-income and some middle-income countries. However, because of their high cost and the complexity of their administration, access to antiretroviral drugs is limited in resource-constrained settings. Nevertheless, health systems need to be prepared to introduce antiretroviral treatments as prices gradually decline and drug combinations become easier to take. Concerted efforts to strengthen health systems, upgrade facilities and build the capacity of medical and laboratory staff to deliver and monitor antiretroviral therapy will be required.

Guidelines on the safe and effective use of antiretroviral drugs, such as those produced by the U.S. Department of Health and Human Services, are now available. In 1998, WHO and UNAIDS published a nine-module guide on the various medical, managerial, ethical and financial issues to be considered in using antiretrovirals in different settings. And in June 2000, WHO published, in collaboration with the International AIDS Society (IAS) and UNAIDS, a clinical guide on safe and effective use of antiretrovirals with special relevance to implementation in resource-constrained settings.

Prevention through antiretroviral drugs

The implementation of various antiretroviral (ARV) regimens to prevent transmission of HIV from mother to child (MTCT) is now internationally recommended as a minimum standard of care. Practical implementation guidelines for strengthening maternal-child health, family planning and voluntary HIV counseling and testing services, introducing ARV regimens and improving infant feeding options are available and regularly updated through the various United Nations partners and international NGOs such as FHI. Although effectiveness data are limited, the use of antiretroviral drugs as post-exposure prophylaxis (PEP) for healthcare

providers and others inadvertently exposed to HIV infection is being recommended but is still rarely implemented in non-industrialized countries.

Psychological support

HIV/AIDS is often associated with profound psychological distress that must be addressed at all stages of HIV infection. Psychological support is critical for helping individuals, couples, families and friends affected by HIV cope with their fears and emotions. Such support has been shown to improve understanding and acceptance of HIV status and facilitate disclosure of that status to significant others or sexual partners. It can also help reduce stigma, and therefore make people less reluctant to seek the care and support they need, as well as have a positive effect on the community.

HIV voluntary counseling and testing (VCT) provides the bulk of psychological support. It also links individuals, couples and families to other support services, such as legal, welfare and spiritual support within communities, appropriate medical care services for early management of TB and other opportunistic infections, and interventions to reduce mother-to-child transmission of HIV. In addition, VCT has proven to be an important factor in promoting safer sexual behavior, and thus preventing HIV.

Associations of people living with or affected by HIV have been instrumental in providing peer and psychological support in many communities and nations. While the need for such support is widely recognized, access to psychological support services such as HIV counseling is still very limited, especially in non-industrialized countries.

Socioeconomic support to families, orphans and vulnerable children (OVC)

People living with HIV and their families are confronted with additional challenges throughout the course of the disease, including isolation, loss of income, medical and transport expenses, funeral costs, and the unmet needs of orphaned children for shelter, nutrition, clothing, education and other necessities. Most of these problems are directly or indirectly engendered through the economic impact of HIV/AIDS on the individual, the family and the community.

To mitigate these negative consequences of HIV/AIDS, efforts must be made to build or sustain economic resources for individuals and their households and to support the creation of community safety nets. Such efforts yield better and longer-lasting results when they are undertaken with an emphasis on supporting the natural social networks of immediate and extended families. With some external support and the involvement of people living with HIV, families, community leaders, volunteers, government agencies, nongovernmental and religious organizations, and other community groups, these networks can care for ill family members and adequately support children, spouses and other relatives within the home environment. Home care programs are cost-effective and can be sustained when there is a strong community support for and involvement in running these services, backed up by quality medical and social services from nearby facilities.

Human rights and legal support

People living with and affected by HIV continue to face stigma, discrimination and other violations of their human rights worldwide. In settings where those infected and affected by HIV suffer from human rights abuses, people are reluctant to learn their HIV serostatus and use existing prevention and care services, thus continuing to fuel HIV transmission.

It is fully recognized that protecting human rights and providing legal services to people living with HIV and their families are critical components of HIV/AIDS prevention and care. Legal assistance is often needed, for example, to ensure that laws protecting the rights of those infected and affected by HIV are applied, to help people living with HIV write wills, and to safeguard the property and inheritance rights of surviving family members. Involving people living with HIV and their support groups during the planning and design phases as well throughout the implementation phase of care and support programs has been shown to be instrumental in addressing rights and equity issues adequately.

Community involvement

Families and communities have cared for and supported ill members for centuries and continue to be the primary service providers and front-line workers of the HIV/AIDS epidemic. Community- and faith-based organizations have played an important role in mobilizing, involving and supporting communities to care for and support people and families affected by HIV/AIDS. Community-based organizations and NGOs also play an important role in advocating for more effective support and access to care and treatment based on community-identified needs and responses. Effective community responses must be recognized, strengthened and supported through partnerships designed to develop community members' capacity to identify, protect and care for those who are infected as well as those the most vulnerable to HIV infection. Community members should be involved in the design, implementation, monitoring and evaluation of care and support projects and strategies to ensure their feasibility, quality and sustainability.

Care for caregivers

Caring for anyone with a serious chronic illness is a physical and emotional challenge for even the most dedicated caregivers. This is particularly true for nurses, counselors and caregivers in the home, who provide the bulk of care for people living with HIV. These caregivers also need support to help them do their jobs well, avoid "burnout" and to keep themselves going and free of infection.

For healthcare staff, the key to such support is an environment where work is appreciated, shared and well supervised. Ongoing training opportunities, regular social events and support groups for caregivers can also help combat the fatigue and emotional stress encountered by those who care for people living with HIV.

Healthcare institutions should provide a safe environment for caregivers by establishing or updating infectious disease management policies and ensuring that healthcare workers have the knowledge, skills, equipment and support they need to follow universal precautions for safe handling of blood and body fluids. Healthcare staff should also have access to voluntary, confidential HIV counseling and testing and to postexposure prophylaxis with antiretroviral drugs.

Referral mechanisms

Effective referral systems are required to ensure that people living with and affected by HIV can benefit from the variety of services comprising comprehensive care and support throughout the course of infection and disease progression. Timely information on where to seek services and strong referral linkages among the various service partners will ensure a continuum of care, avoid duplication of services and maximize available care and support resources. A good referral network will also make it easier for affected individuals and families to access appropriate care and support, thus saving them time and other costs.

Most national HIV/AIDS programs are recommending that comprehensive care and support be provided across a continuum, as reflected in their national strategic plans and advocated by WHO, UNAIDS and international donor organizations. For these programs, the main challenges are to develop national standards for providing care and support and to set priorities by identifying essential care packages reflecting the capacity and resources available.

The next two figures illustrate the elements of comprehensive care and support for affected families (Figure 1) and the provision of care among the various partners across a continuum from home and community to institutions and back (Figure 2). An example of a set of essential care and support standard services can be found in Appendix 1.

Challenges

- The importance of HIV care and support as an essential component of a successful HIV program is not yet fully accepted by international and national development, health policy and financial decision makers. More work is needed to promote supportive attitudes and document successful approaches.
- Continuing strong feelings of denial and the related secrecy around HIV infection feed stigmatization and hamper the necessary openness for large-scale, constructive interventions. Moreover, these attitudes will not change without dedicated efforts to strengthen social, economic and legal support systems to ensure safety and openness.
- The declining quality of facilities and supply and distribution systems, low numbers of newly trained staff, poor remuneration and incentives to motivate staff, and high attrition and mortality among healthcare and educational staff all pose much larger challenges than the implementation of specific HIV care and support interventions.
- The lack of affordable quality care and clinical management with full treatment options has exposed vast inequities within and among countries that need to be addressed at the international policy and financial levels.
- The short funding cycles of many internationally supported care and support programs, with pressures to show immediate results, hamper long-term planning of complex care interventions that are intimately linked with the development of broader health systems.
- The long-term risks of the development of resistance to current popular therapeutic interventions in the prevention of opportunistic infections and mother-to-child transmission and the treatment of HIV infection call for careful monitoring.
- The optimal balance between the necessary research and the implementation of prevention and care interventions needs to be constantly addressed as the epidemic evolves geographically.
- In the context of national “scaling up” of HIV/AIDS programs, innovative approaches to sustainable care and support and massive mobilization of human and financial resources are required to address the needs of the vastly increasing numbers of those who are sick, orphaned and impoverished by HIV/AIDS.

III. FHI GOALS AND OBJECTIVES FOR HIV CARE AND SUPPORT

Family Health International’s goal for HIV care and support is to:

- Improve the quality of life of people and families affected by HIV/AIDS and mitigate the impact of HIV on communities.

FIGURE 1
ELEMENTS OF COMPREHENSIVE HIV/AIDS CARE AND SUPPORT

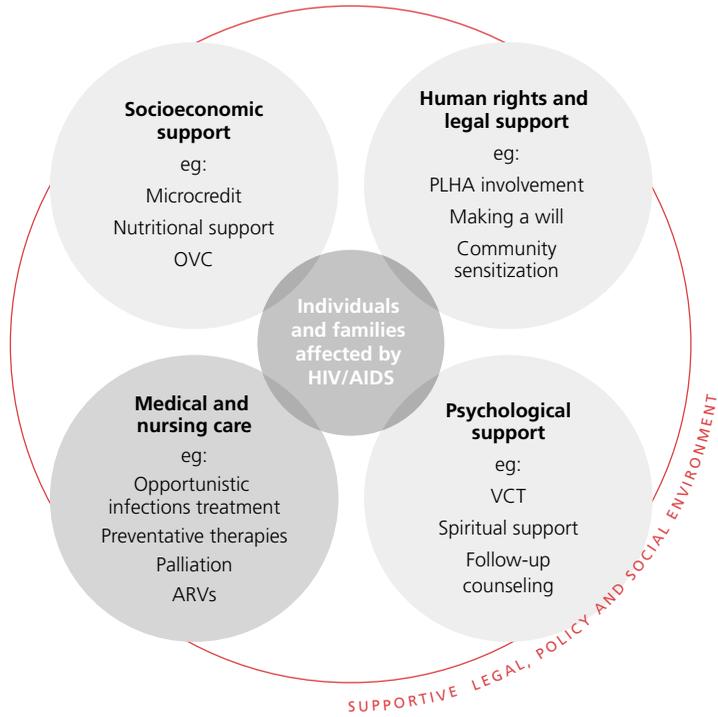
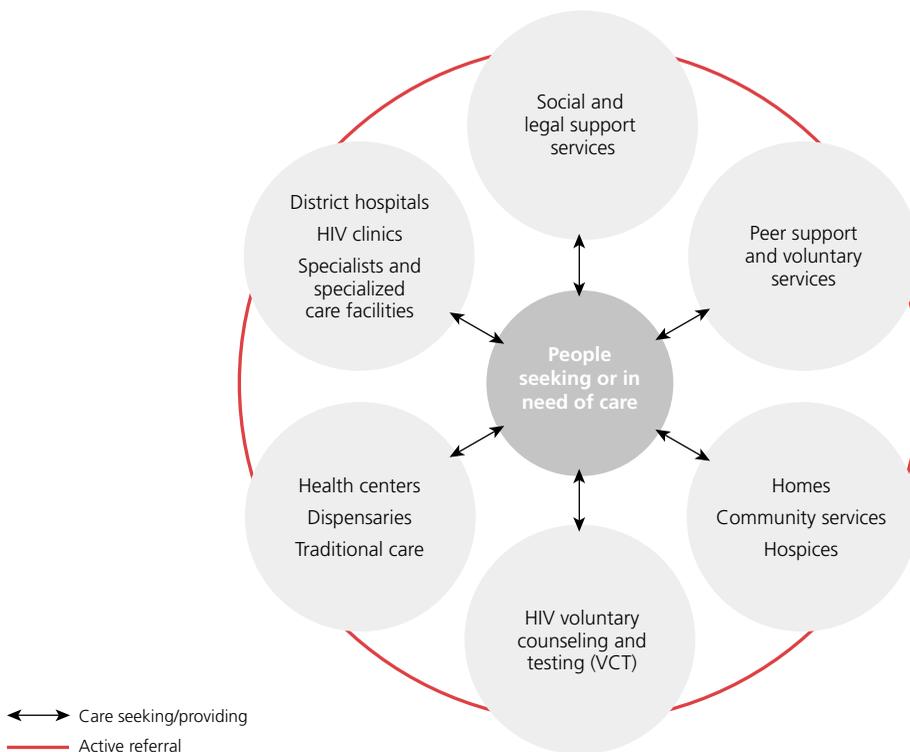


FIGURE 2
HIV/AIDS CONTINUUM OF CARE AND SUPPORT



FHI has identified the following care and support **objectives** for its programs and activities:

- Strengthen countries' ability to develop **strategic plans** for quality comprehensive care and support services across a continuum from home and communities to institutions and back.
- Expand access to **HIV voluntary counseling and testing** services.
- Strengthen **medical services** for HIV at all stages of infection, including TB management, palliative care, preventive therapies and preparation for ARV interventions.
- Expand **TB services** to HIV-infected populations and integrate HIV interventions into TB programs.
- Build capacity to design and implement effective **MTCT** prevention programs.
- Improve the well-being and protection of **orphans and vulnerable children** and strengthen household security.
- Strengthen care and support systems for the provision of **home care**.
- Ensure critical **linkages and partnerships** among service providers and programs across a continuum from home and community to the hospital and back.

IV. FHI'S GUIDING PRINCIPLES

FHI's approach to implementing care and support is guided by the following core principles:

- The “care-prevention synergy.” Prevention and care and support are mutually reinforcing approaches in several ways. Comprehensive care that meets the diverse needs of people living with or affected by HIV builds trust and creates a receptive audience among patients, families and other community members to enhance prevention efforts. It also paves the way for community acceptance of people living with HIV and decreases stigmatization. Care provision offers opportunities to make prevention interventions more acceptable and available and encourages those who receive care to practice safer behaviors.
- Care and support must be provided through all stages of HIV infection, from the individual who is concerned about HIV, to those who are infected, to the terminally ill, to those coping with the death of a family member or friend from HIV/AIDS.
- People living with and affected by HIV must be involved in designing, planning and implementing HIV care and support activities. Providing effective care and support requires an appreciation and understanding of the needs of clients and patients.
- The community must be involved in the process of planning and ensuring a network for effective care and support. This means working with local partners to promote a continuum of care that includes explicit linkages among public, nonprofit, private and traditional services in the community.
- Responding to medical and psychosocial needs, which vary with each phase of infection, requires a comprehensive range of services and a multidisciplinary approach. Care and support programs must work with numerous partners and develop referral networks to address patients' and families' medical, psychological and social needs.
- Care and support strategies must address denial and stigma. These pervasive reactions to the HIV epidemic hamper both prevention and care efforts.

V. FHI'S APPROACH

FHI will assist government agencies, nongovernmental organizations in the nonprofit and for-profit sectors in building capacity to address comprehensive HIV care and support needs. Elements of a comprehensive care and support system fall broadly within a network of medical care services, psychological support services, social and legal support services, and such systems require a supportive policy and social environment to be sustained.

At the national level, FHI will focus on strategic planning for HIV care and support and developing standards and guidance materials. At the local implementation level, FHI will support care and support programs and activities by local agencies through training, technical assistance, and monitoring and evaluation activities.

Programmatic approach

Care and support interventions are tailored to the local context, the stage of the epidemic and the existing community and national resources. FHI recognizes that learning from field experience and research results is one of the best ways to make programs more effective. Therefore, FHI assists and builds the capacity of local implementing agencies in developing the strategies and skills for applying effective practices and lessons learned in their programs as they evolve.

The FHI programmatic approach to care and support consists of a sequence of steps at the national and community levels. For each program or project, FHI will build on lessons learned in a wide variety of settings and apply them in a way that is responsive to the local context, norms and values. The steps can be identified as follows:

- **Assess** the availability and quality of the essential elements of comprehensive care, the strategies for delivering it, the systems to accommodate these strategies and the opportunities for creating and strengthening linkages to enhance acceptance and complementarity.
- Facilitate **strategic planning** to identify and prioritize the essential elements of care and support based on the stage of the epidemic, contextual factors, cost, cost-effectiveness, feasibility and sustainability in a specific setting.
- Assist in developing or applying **national standards** for care and support and tools and guidelines for implementation, monitoring and evaluation.
- Develop **training plans**, training tools and training curricula in the skills necessary to deliver the essential elements of care and support.
- Forge **linkages** with other technical assistance organizations that can provide skills and experiences to complement and enhance those of FHI.
- Develop, implement and evaluate **learning sites and centers** to prepare for scaling up and applying innovative approaches, including the introduction of new and complex interventions such as antiretroviral therapy.
- Ensure comprehensive **monitoring and evaluation** of care and support programs within a well-developed framework.
- Work with local partners to plan on **going to scale** from the outset of program activities to ensure coverage as soon as possible.
- Provide **technical assistance** to support implementation and evaluation of care and support activities.

Programmatic linkages within FHI

FHI's care and support activities build on FHI's longstanding expertise in technical support and research in reproductive health, HIV prevention, program evaluation and STI case management. Opportunities exist to expand sites where behavioral interventions have been developed and to apply behavior change communication (BCC) skills to advocate for the needs of people living with HIV, stimulate demand for care and support, and help destigmatize HIV and prevent discrimination within communities and health settings.

Similarly, strengthened STI management sites can more easily accommodate HIV clinical management. In addition to FHI's HIV/AIDS prevention and care programs in 50 countries around the world funded by the United States Agency for International Development (USAID), other donors, ongoing clinical trials through the HIV Prevention Trials Network, also managed by FHI and funded by the U.S. National Institutes of Health, present opportunities to address care and support in an additional seven non-industrialized and industrialized countries.

Voluntary counseling and testing sites can truly become entry points for a variety of prevention and care activities by addressing the needs of both HIV-negative and -positive clients for services such as MTCT prevention, preventive therapies and behavior change interventions. And, FHI's expertise in developing indicators for monitoring and evaluation will benefit both the long- and short-term effectiveness prevention and care programs.

Technical approaches

The scope of comprehensive care and support is broad and complex. Therefore, FHI will principally focus on the areas of care and support in which it has specific technical expertise and work in partnership with other organizations in the areas in which it has less experience. FHI's areas of expertise include:

- Strategic planning for care and support.
- HIV voluntary testing and counseling (VCT).
- Positive attitude training for healthcare providers and communities.
- Clinical management of HIV disease, including tuberculosis and palliative care.
- Reduction of mother-to-child transmission of HIV.
- Home care and orphan support.
- Monitoring and evaluation.
- Policy development and advocacy.

FHI will continue to develop partnerships and linkages in areas in which it has less direct expertise, such as health systems infrastructure building, commodity distribution, human rights issues and legal support, social marketing of care and support, health financing and community financing, including microcredit projects.

The following sections provide brief overviews of FHI's technical areas of focus related to HIV/AIDS care. For each of these technical areas, FHI will issue more detailed strategic guidance in separate documents.

HIV voluntary counseling and testing (VCT)

FHI recognizes that counseling is a culturally sensitive intervention. Therefore, FHI develops culturally appropriate VCT services based on a client-centered approach to counseling. FHI also tailors the design and implementation of VCT services to the unique epidemiological, behavioral and economic context of each country and community setting. FHI gives particular importance to the use of VCT as an entry point to several other HIV/AIDS services, such as prevention of mother-to-child transmission of HIV, prevention and clinical management of TB and other opportunistic infections, and social support.

FHI's VCT activities include:

- Informing policy makers to encourage the development of supportive policies.
- Designing and establishing VCT services.
- Linking VCT to other care and support services.
- Developing training curricula.
- Supporting communication efforts to increase demand for VCT.
- Providing training in counseling and laboratory diagnosis.
- Building the capacity of local organizations to provide VCT.
- Promoting VCT services at all levels.
- Monitoring and evaluating programs.
- Training in quality assurance.

Medical care (Treatment and prevention of opportunistic infections and other HIV-related illnesses and provision of antiretroviral therapy)

The goal of the FHI strategy for providing HIV medical care is to improve the quality of life of people living with HIV by increasing their access to high-quality services for prevention and treatment of HIV-related diseases and, where available, to antiretroviral therapy.

FHI's strategy for providing medical care includes:

- Assisting ministries of health and national AIDS programs in developing guidelines on the management of HIV-related diseases and, where available, on the provision of ARVs. Such guidelines define the minimum standard of medical care for people living with HIV/AIDS.
- Assisting local programs, clinics and hospitals in the implementation of the guidelines.
- Strengthening the capacity of local healthcare delivery services to provide diagnosis and treatment of AIDS-related illnesses.
- Training and supporting healthcare staff to maintain an enabling working environment and positive attitudes toward people living with HIV.
- Building the capacity of local community organizations to provide HIV/AIDS care.
- Developing and implementing, in partnership with other agencies, effective mechanisms for increasing access to essential drugs and antiretroviral therapies.
- Developing and evaluating the effectiveness, cost-effectiveness and acceptability of new diagnostic and management strategies for HIV-related disease.

Targeting TB

It is important to target tuberculosis diagnosis and treatment in areas with high HIV infection rates because TB is one of the rare infectious diseases that is fueled by the HIV epidemic and does not remain confined to HIV-infected individuals. Also, TB is one of the first opportunistic infections to appear in people living with HIV and may be the first sign of HIV infection. Therefore, addressing TB offers the opportunity for early HIV intervention.

FHI's objective for targeting tuberculosis is to reduce the burden of TB in HIV-infected individuals and affected communities. To achieve that objective, FHI will:

- Strengthen the TB case detection and case holding capacity of national TB programs.
- Establish HIV services, including voluntary counseling services, at TB clinics.
- Introduce TB services, including TB preventive therapy, at HIV care provision sites.
- Encourage people to seek early and appropriate care for TB and to adhere to TB treatment regimens.

Preventing mother-to-child transmission (MTCT) of HIV

MTCT must be addressed in the context of a comprehensive HIV prevention, care and support program. MTCT prevention must go beyond specific interventions, such as antiretroviral therapy (ARV), replacement feeding and caesarean deliveries, to address critical related issues. These issues include HIV prevention among young women, the quality of prenatal care, access to contraception and counseling about reproductive health options, care and support for HIV-infected mothers and their children, and the stigma of and discrimination against people living with HIV/AIDS.

FHI assists countries to increase awareness about the extent and importance of mother-to-child transmission of HIV and to build their capacity to design and implement effective MTCT prevention programs. Beyond support to specific countries in MTCT program design and implementation, FHI also contributes to the global understanding of and response to MTCT through research and active collaboration with other international organizations.

FHI's programmatic approach to implementing MTCT prevention activities in a country is as follows:

- Assess the availability, quality and use of existing maternal and child health (MCH) services and identify opportunities for integrating MTCT interventions.
- Support the establishment of an MTCT working group or committee to develop and disseminate standards and provide guidance for MTCT programs.
- Assist in developing tools and guidelines for MTCT program design, implementation, monitoring and evaluation.
- Support the development of a realistic national plan for MTCT programming.
- Support appropriate MCH service upgrading based on the assessment results.
- Develop training plans and provide appropriate training in areas such as counseling, infant feeding, obstetrical practices, and the use of ARV for MCH staff based on the assessment results.
- Support the introduction of VCT in MCH settings.

- Assist in developing supportive BCC and information, education and communication activities to increase awareness and foster safer behaviors, and influence behavior change, including changes in health-seeking behaviors and the reduction of stigma and discrimination.
- Provide technical assistance in the effective implementation, monitoring and evaluation of MTCT programs.
- Support a limited number of MTCT sites as learning centers and use the experience gained at these sites to expand MTCT interventions in the country and regionally.
- Support the collection, local exchange and broader dissemination of lessons learned toward increasing program impact.

Palliative care

FHI recognizes that palliative care is an essential component in the care of people living with HIV. Such care should address the holistic needs of the whole person, relieving emotional and spiritual distress as well as physical pain. This approach requires a collaborative effort by a team that should include the person living with HIV, family and community members, caregivers, and health and other social service providers. FHI's goal for providing palliative care is to ensure that a person living with HIV and his or her family and other caregivers continue to benefit from the best quality of life possible throughout the course of the illness.

FHI's strategy for providing palliative care includes:

- Identifying and evaluating existing palliative care services within priority communities.
- Developing and implementing guidelines for palliative care.
- Working with local partners to develop or strengthen models of palliative care.
- Providing education and training in palliative care to health and community workers.

Home-based care and community action

FHI works to build the capacity of family and community members to provide comprehensive care in homes and within communities. Thus FHI:

- Strengthens community mobilization and participation in the design of home-based or community-based care for people living with HIV/AIDS.
- Strengthens referral mechanisms and other linkages with local health centers, clinics and hospitals.
- Supports and develops systems to increase access to essential drugs for HIV-related illnesses.
- Builds the capacity of home-based care providers to manage HIV-related illnesses, including TB, and improve their nursing skills.

Most care and support for people living with HIV/AIDS is done at the community level. Thus care and support initiatives for HIV must be designed and implemented within the context of community needs and actions. In bridging the care gap, FHI helps government agencies, NGOs and community-based organizations to:

- Mobilize communities to accept and support people living with HIV.
- Strengthen healthcare delivery systems, including referral systems, to ensure a comprehensive continuum of HIV/AIDS care.
- Create partnerships between families and organizations or institutions to foster the care continuum.

- Involve people living with HIV in every step of this process.
- Build the capacity of community members and family caregivers to provide comprehensive and sustainable care.

Care for orphans and vulnerable children (OVC)

FHI's objectives are to improve the well-being and protection of orphans, other vulnerable children and families and to reduce the burden of HIV/AIDS on these children and their families. To achieve these objectives, FHI provides technical and programmatic assistance to strengthen community mobilization for OVC support, build the capacity of communities to care for orphans and vulnerable children, and improve linkages between OVC support efforts and the continuum of HIV/AIDS care and support services.

FHI's OVC activities include:

- Conducting assessments and supporting participatory strategic and program planning.
- Strengthening community mobilization to increase the capacity of communities to identify vulnerable children and to design, implement and monitor their own OVC support activities.
- Fostering community-based care and support of orphans and vulnerable children.
- Integrating OVC support with home-based care, VCT and MTCT prevention activities.
- Strengthening medical care, including home-based care, for children living with HIV.
- Providing training and support for individual counseling and succession planning for children affected by HIV/AIDS.
- Supporting comprehensive, culturally appropriate psychosocial interventions for orphans and vulnerable children.
- Assisting in the development of strategies and partnerships to create or maintain household resources and community safety nets.
- Supporting child-headed households and children as caregivers.
- Supporting interventions to reduce institutionalization and abandonment of children.
- Monitoring and evaluating OVC programs.

Monitoring and evaluation

In HIV/AIDS care, as in HIV prevention, monitoring and evaluation are approached and implemented at a number of different levels. The first level is **information collection** about inputs, such as the infrastructure of care facilities, staff attitudes and the socioeconomic context in which care is being delivered. The activities of **actual care delivery** are measured against acceptable standards of care, such as the proportion of patients with an oral Candida infection who are offered HIV testing.

Output information helps evaluators assess the immediate results of care activities, such as the number of people in need of palliative care who are receiving care from family care providers.

Outcome information looks at the end results of care for the individual, family and community, such as the reduced need to attend hospitals. Finally, **impact information** allows evaluators to analyze the long-term effects of care on economic productivity, quality of life and survival. Indicators are being developed to assist programs in monitoring and evaluating HIV/AIDS care and support programs.

FHI's approach to monitoring and evaluating care and support programs for people living with HIV and those affected by HIV/AIDS has several guiding principles:

- The standards and norms of care should be defined in each country, for each level of services and for each population affected, and these norms and standards should be used as baseline reference for monitoring and evaluation.
- The efficiency and effectiveness of the comprehensive care continuum, as part of the broader health system, should be subjected to monitoring and evaluation in order to identify and address weaknesses and gaps.
- Monitoring and evaluation systems must be designed to respond to questions that are relevant to decision making at the local level, where care has been provided, and to provide timely feedback in order to inform and improve local programs.
- Crosscutting issues should be considered in designing HIV/AIDS care programs and in developing and implementing monitoring and evaluation processes. Factors such as gender, age and human rights should be built into the initial design of these processes, which should draw on quantitative and qualitative monitoring and evaluation methods.

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APPENDIX 1

STANDARD CARE SERVICES FOR HIV/AIDS *

| Uninfected people | Exposed people | People living with HIV | People living with AIDS | People terminally ill and beyond |
|-------------------|--|---|-------------------------|----------------------------------|
| | | | | |
| | | | Palliative care | |
| | | | Home based care | |
| | | | Antiretroviral therapy | |
| | Mother to child transmission prevention | | | |
| | Post-exposure prophylaxis | | | |
| | | Opportunistic infections and related illnesses <i>Diagnosis, treatments, preventative therapies</i> | | |
| | | Psycho-social and spiritual support <i>Individual and family, care providers, bereavement, orphans</i> | | |
| | VCT | | | |
| | Prevention <i>STI services, behavior change communication, education, universal precautions</i> | | | |

*Details on each service are discussed in Chapter 2



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