



# The Future of PEPFAR:

Comprehensive Approaches,  
Sustainable Results



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*When I started my career in public health over 20 years ago, HIV and AIDS were thought to be a passing trend. After more than 25 years and 25 million lives lost, we know this is not the case. In 2007 alone, 2.1 million people died of AIDS-related causes and 2.5 million were newly infected with HIV, most of whom live in Sub-Saharan Africa. We've also seen a shift in the face of the epidemic, with women and young girls making up over half of those with the disease. HIV continues to devastate individuals, families and communities. Reversing the AIDS pandemic requires a global commitment to sustainable, evidence-based programs and innovative policies driven by the needs and priorities of the most severely affected communities.*

*I am proud that the U.S. Government has been a global leader in the fight against HIV and AIDS. The President's Emergency Plans for AIDS Relief (PEPFAR) has provided essential resources to address many of the most urgent needs of this public health and development crisis. The reauthorization of PEPFAR provides a critical opportunity to build on what we have learned over the first five years and shift PEPFAR from an emergency response to one that will lead to long-term, sustainable results.*

*Based on more than 20 years of experience working with communities to address HIV and AIDS, CARE has learned that it takes comprehensive approaches to tackle the epidemic. Every day we work with those who are most at risk because of underlying issues such as stigma, poverty, gender inequality, social marginalization and lack of political will. Our experience in over 40 countries tells us that unless we address these underlying drivers of the epidemic, any short-term gains resulting from medical interventions will not be sustainable.*

*For this reason, CARE has worked with local communities to design and implement comprehensive, sustainable approaches to addressing HIV and AIDS— CARE programming goes deeper to address the underlying drivers of vulnerability while also working within the broader health and development arena in which these vulnerabilities play out. In this report, CARE presents a framework for truly comprehensive approaches. We discuss how elements of this approach have been implemented in field settings, and we offer concrete recommendations for the future of PEPFAR.*

*I believe we are at a turning point in the fight against HIV and AIDS; never before have we seen political will and resources of this magnitude dedicated to this important cause. The time is now for the U.S. to exert bold leadership in support of comprehensive, sustainable HIV and AIDS programming worldwide.*

A handwritten signature in black ink that reads "Helene D. Gayle". The signature is fluid and cursive.

Helene D. Gayle, MD, MPH  
President and CEO, CARE



## Table of Contents

■ EXECUTIVE SUMMARY .....	1
■ CARE'S APPROACH TO ADDRESSING HIV AND AIDS	
Insights from Experience .....	2
Translating Experience into a Framework for Action .....	3
Comprehensive Approaches to HIV and AIDS .....	4
■ CARE'S EXPERIENCE	
Addressing Gender Inequality and Vulnerability .....	5
Preventing Mother-to-Child Transmission of HIV in Kenya .....	6
Addressing the Vulnerability of Sex Workers in India .....	7
Integrating HIV and AIDS with Economic and Food Security .....	8
Enhancing Livelihoods Through Agriculture in Lesotho .....	9
Supporting Women Caregivers in South Africa .....	10
Community Mobilization and Engagement .....	11
Community Mentors for Orphans and Vulnerable Children in Rwanda .....	12
Linking Case Managers and Communities in Rwanda .....	13
■ IMPLICATIONS AND RECOMMENDATIONS FOR PEPFAR .....	15
Implications .....	15
Recommendations .....	17

## ■ EXECUTIVE SUMMARY

**THE AIDS CRISIS** not only represents a threat to the lives of millions of people, particularly in sub-Saharan Africa, but it also undermines hard-won gains throughout the developing world. Through our global field experience, CARE has seen how the AIDS pandemic is linked to deepening poverty, gender inequality and social marginalization. To make a real difference in the fight against HIV and AIDS, our responses must be as interconnected and multi-dimensional as the AIDS pandemic itself.

This report describes how a comprehensive approach to HIV and AIDS, addressing both the underlying drivers of vulnerability to HIV and AIDS and the broader arenas in which these vulnerabilities play out, is the best use of U.S. HIV funding. Unless the global response to HIV and AIDS addresses these factors, particularly for women and girls, even the best-funded efforts will not achieve lasting impact. Accordingly, this report builds the case for such a comprehensive and sustainable approach by drawing upon CARE's field experience, focusing on program examples in three key arenas: addressing gender inequality and vulnerability, integrating HIV with economic and food security and supporting community mobilization and engagement.

CARE presents this report as the U.S. Congress prepares for the reauthorization of the President's Emergency Plan for AIDS Relief (PEPFAR). The reauthorization process and the subsequent implementation of the next phase of PEPFAR is a vital opportunity to move this unprecedented

U.S. investment from an emergency response to the comprehensive, sustainable program that is required to curb the global AIDS crisis. To accomplish this, Congress must require that U.S. HIV funding address the pandemic's socioeconomic drivers. This does not mean that PEPFAR should spread itself thin by funding a range of development programs. Rather, it means that PEPFAR should expand the range of efforts it funds to include interventions that strategically address socioeconomic factors in a way that leverages more effective HIV outcomes.

Based on mounting evidence emerging from CARE's programs, this report calls on Congress and the Office of the Global AIDS Coordinator (OGAC) to:

- Address HIV and AIDS within a development framework
- Sharpen PEPFAR's focus on women and girls as a priority
- Integrate HIV and AIDS with economic and food security programs
- Support community mobilization and engagement
- Invest in scaling up comprehensive prevention approaches

This would require Congress to define and strengthen PEPFAR's relationship to U.S.-funded development and relief programs, and to ensure that U.S. agencies and other stakeholders work together more effectively so that different funding streams can be integrated and coordinated to support a more robust and sustainable response.





Ami Vitale/CARE

## ■ CARE'S APPROACH TO ADDRESSING HIV AND AIDS

**CARE FIRST BEGAN WORKING** on HIV and AIDS issues in 1987. In the past 20 years, we have learned that AIDS is a multi-faceted pandemic that calls for a multi-faceted response. The relentless toll that the pandemic is taking, especially in sub-Saharan Africa, demands a response that marshals the best of our knowledge and experience. In this section, we organize CARE's knowledge and experience into a framework that describes a comprehensive approach to HIV and AIDS.

### Insights from Experience

CARE implements some 150 projects that address various causes and impacts of HIV and AIDS in over 40 countries. Our global HIV and AIDS strategy is focused on: preventing new HIV infections, especially among the most vulnerable; mitigating the impact of the pandemic on economic development and community well-being; and increasing affected families' access to high quality care and support. CARE's HIV and AIDS projects strive to be community-based,

comprehensive and multi-sectoral and to address the particular vulnerabilities of women and girls. In the course of this work, we have gained some important insights into the nature and reality of the AIDS pandemic:

- AIDS is more than a devastating infectious disease; it is a complex social, economic, cultural and political challenge.
- HIV transmission is not just related to individual behavior, but also to the social and economic context that shapes the vulnerability of individuals.
- HIV and AIDS affect women and girls disproportionately, due to their biological, social and economic vulnerability.
- The enormity of damage done by HIV and AIDS cannot be reversed by a collection of narrow HIV interventions; significant impact can only be achieved by implementing comprehensive interventions at scale.
- Interventions led by external actors are often not sustainable; local ownership, especially at

the community level, is vital to effective and sustained action.

CARE has long witnessed how HIV and AIDS are woven into—and stem from—the larger context of poverty, gender inequality, poor governance and social marginalization. Our response to HIV and AIDS has grown out of our deepening awareness that this broader context drives people’s vulnerability to HIV and their susceptibility to the impacts of AIDS. Our conclusion has been simple: ***People’s vulnerability to HIV and their ability to cope with AIDS is driven by their broader socioeconomic context. Therefore, we can only be effective in fighting this pandemic by engaging and seeking to transform that context in sustainable ways.***

In poor communities throughout the world, CARE works every day with people whose main worries are about immediate needs for food, clean water and shelter, and whose constant struggle is to earn a secure income, send their children to school and access health services. It is typically people who face these dire realities and limited choices who are most vulnerable to contracting HIV and least able to manage the

consequences of AIDS. The threat of future illness or death from AIDS is a more distant reality for many of these people than their immediate concerns, and thus they are harder to reach through narrow HIV interventions.

## Translating Experience into a Framework for Action

CARE works across diverse development sectors, including health, microfinance, education and food security, and in a diversity of contexts in over 68 countries. What gives our work coherence is the pursuit of results in the following arenas, regardless of sector, context or country:

- *Human Conditions*—ensuring that people’s basic needs are met and the quality of their lives is improved
- *Social Positions*—enhancing marginalized people’s position in society (especially women) and improving their ability to make decisions that affect their lives
- *Enabling Environment*—ensuring that political structures, economic systems and civic institutions guarantee fair treatment and equal access to opportunities for all people

CARE believes that results must be achieved across all three of these arenas in order to have the most effective and sustainable impact. In order to do so, we must address not just the *symptoms* of the problems, but also the *causes*. This means looking at three levels of interventions:

- *Immediate needs*—issues of life and survival affecting people who are HIV-positive, affected by AIDS or at risk of contracting HIV
- *Intermediate issues*—broader issues faced by HIV-positive people and communities affected by AIDS
- *Underlying causes*—factors that drive vulnerability to HIV and susceptibility to the impacts of AIDS



Brendan Bamony/CARE



## Comprehensive Approaches to HIV and AIDS

CARE recommends comprehensive approaches to HIV and AIDS as the best use of PEPFAR's resources. Our view of comprehensive approaches encompasses two simple but critical concepts:

Going **deeper** to engage the underlying drivers of vulnerability and **broader** to address the arenas in which these vulnerabilities play out.

Going **deeper** and engaging underlying drivers of vulnerability requires *addressing complex social and structural phenomena* like gender inequality, social marginalization, stigma and poor governance. CARE's approach deploys strategies to empower individuals and communities to overcome their vulnerabilities. The imperative of going **deeper** recognizes and confronts the fact that women are often more vulnerable to HIV because, in addition to biological factors, they have little power to negotiate safe sex—or the fact that many people do not seek HIV testing because they fear violence or stigma. CARE's approach also recognizes that the most meaningful knowledge and capacity to address the challenges of each context resides in communities themselves—and that successful interventions must find ways to harness community capacity and facilitate long-term community ownership.

Going **broader** and addressing the arenas in which vulnerabilities play out requires *working across multiple sectors and integrating work across those sectors with efforts to address HIV*. These vulnerabilities play out in the form of poor access to nutrition, education, clean water, economic opportunity, health services and health system deficits. Going **broader** acknowledges the connections—running in both directions—between HIV and these various development sectors. For instance, when AIDS kills agricultural workers in their productive

years, fields lie fallow and agricultural output wanes. At the same time, food insecurity often pushes people toward transactional sex and poor nutrition facilitates the rapid onset of AIDS.<sup>1</sup> Thus, it is critical to confront AIDS in these sectoral arenas in order to fight the pandemic from all angles, rather than just the medical one.

If PEPFAR's aim is to successfully reverse the course of the pandemic, then it must successfully engage the **broader** context and underly-

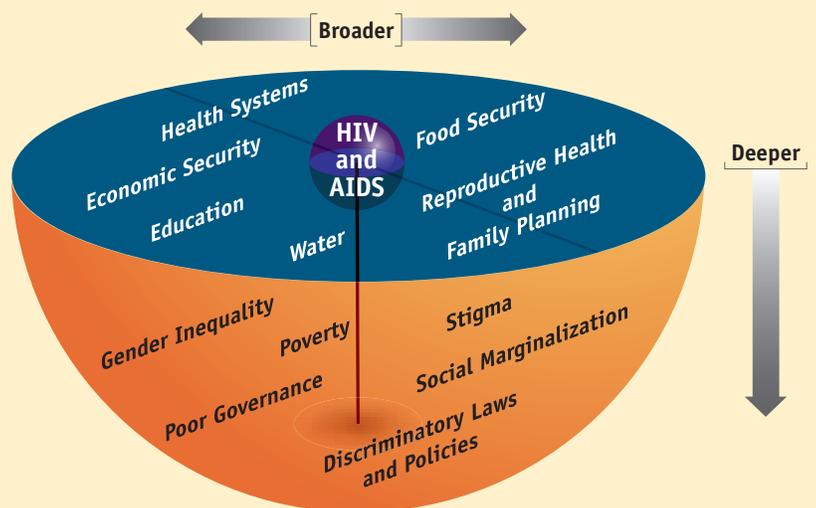
### A Framework for Comprehensive Approaches to HIV and AIDS

This graphic depicts the broader context in which HIV and AIDS exist and thrive. In order to be effective and sustainable, HIV interventions must acknowledge and engage this broader context.

The **deeper** (or vertical) plane represents the context in which HIV and AIDS thrive. This context is fed by underlying drivers of vulnerability such as poverty, gender inequality, social marginalization, stigma, discriminatory laws and policies, etc.

The **broader** (or horizontal) plane represents how underlying drivers of vulnerability play out in various sectoral arenas: in the form of economic and food insecurity, poor quality education, lack of access to safe water and quality health care services, etc.

The center represents the individuals and communities affected by the AIDS pandemic and their needs and rights.



ing vulnerabilities that feed HIV and AIDS. Without sustainable solutions addressing the roots of the problem, the underlying drivers will reproduce the same conditions again and again,

and AIDS will continue to thrive. If PEPFAR fails to take this bigger picture into account, its investments will be limited and its achievements may even be reversed over time.

### **A Comprehensive Approach in Action: Programming for Orphans and Vulnerable Children**

CARE's "5x5" model, which delivers services to vulnerable children under age 8, their families and caregivers, is an example of going **broader** and **deeper**. The model uses early childhood development (ECD) centers as the entry point for integrating services. The 5x5 model, being implemented in Uganda and Kenya, focuses on **five levels of intervention**: (1) the child; (2) the caregiver; (3) child care settings; (4) the community; and (5) the wider policy environment (e.g. ministries of health and education). It advances interventions aimed at **five areas of impact** on the well-being of vulnerable children:

(1) food and nutrition; (2) child development, including physical, cognitive and socio-emotional development; (3) economic strengthening; (4) health; and (5) child protection.

Early childhood is a critical period because of the high levels of growth and development that take place in these years. Investing resources at this life stage is cost-effective and has a life-long impact. The 5x5 approach addresses the needs and challenges of orphans and vulnerable children at various levels and from various angles, reducing their vulnerabilities to HIV infection.

## ■ CARE'S EXPERIENCE

**CARE'S COMMITMENT TO** comprehensive approaches to HIV and AIDS is grounded in over 60 years of work in poor communities. Our experience demonstrates how such approaches can be linked to development and still stay focused on fighting AIDS. Emerging evidence from CARE's programs indicates that such approaches to HIV and AIDS are sustainable and effective in addressing the needs of vulnerable populations.

The following program examples illustrate various aspects of CARE's experience in addressing HIV and AIDS within the development framework, focusing on these key categories: addressing gender inequality and vulnerability, integrating HIV and AIDS with economic and food security and community mobilization and engagement. Each represents an important dimension of a comprehensive approach. These

programs have received funding from a variety of sources, including PEPFAR, other bilateral and multilateral donors and private foundations.

### **Addressing Gender Inequality and Vulnerability**

The face of the AIDS pandemic is increasingly female, stemming from widespread gender inequality. In sub-Saharan Africa, for example, more than 60 percent of those living with HIV and AIDS are women, and incidence among women is rising throughout the world.<sup>2</sup> The vulnerability of women and girls to HIV infection is inextricably linked to social, biological, economic and cultural factors that put them at risk of contracting HIV and that make matters worse after they become infected or affected.

While it is true that increasing numbers of



HIV interventions target women and girls, many of them fail to address the broader social forces that shape their vulnerability. Where women have limited financial autonomy and face high levels of violence, abstaining from sex or negotiating condom use are often not realistic options.<sup>3</sup> Women's subordinate social and economic status directly influences their ability to seek HIV testing and treatment and to access care and support. Where a woman's legal rights are limited, she is more likely to remain in an abusive relationship that puts her at risk of contracting HIV or to become destitute after the death of her husband.<sup>4</sup> Where a woman needs her husband's consent to access health services, she is less likely to seek treatment. Systematic efforts to increase women's economic and social empowerment must be part of a comprehensive approach to HIV and AIDS.<sup>5</sup>

CARE recognizes that, in order to more effectively address the toll that HIV takes on women and girls, we must **deepen** and **broaden** our responses. This means, for example, addressing the links between sexual violence and HIV transmission, and removing the barriers that women face in accessing services to prevent mother-to-child transmission.

### ***Preventing Mother-to-Child Transmission of HIV in Kenya***

By administering a regimen of antiretroviral drugs (ARVs), beginning in the third trimester of pregnancy, the risk of HIV transmission can be reduced to close to four percent.<sup>6</sup> Yet, some 90 percent of pregnant women in sub-Saharan Africa lack access to the prevention of mother-to-child transmission (PMTCT) services.<sup>7</sup> To address this reality in Kenya's Nyanza province, which has the country's highest HIV prevalence rate, CARE works on multiple fronts to both increase the availability of PMTCT services and address the barriers that prevent women from accessing those services.



Brian Atkinson/CARE

CARE's "PMTCT-plus" approach goes **broader** than traditional PMTCT programs by expanding the range of services available to the mother to keep her and her baby healthy, physically and psychologically. This includes ensuring that the HIV-positive mother has access to antiretroviral therapy (ART) herself, and that she and her family have access to safe water (e.g. constructing safe water systems to ensure clean water for preparing infant formula), increased economic and food security (e.g. forming savings and loan groups), access to health services (e.g. family planning, immunizations, treatment of tuberculosis and other opportunistic illnesses) and psychosocial support. CARE collaborates with government health facilities to assure quality PMTCT services and to strengthen links between health and support services.

Our approach goes **deeper** to confront the

### The Need to Integrate Family Planning

CARE often encounters repeat pregnancies among HIV-positive women who do not want to become pregnant. This indicates, among other things, a high unmet need for family planning information and services. Research indicates that preventing HIV infection among women of reproductive age and avoiding unintended pregnancies can be more cost-effective than administering ARVs to mothers and infants.<sup>8</sup>

barriers that pregnant women face in accessing voluntary counseling and testing (VCT) and PMTCT services. For example, through community dialogue, we have learned that human rights violations against women, including violence or fear of violence, inhibit women from seeking to access HIV prevention and treatment services, so we are integrating interventions to address gender-based violence. By helping reduce stigma and gender-based violence, CARE hopes to confront one of the barriers to pregnant women's uptake of PMTCT services.

CARE also has found that community mobilization and outreach efforts are key to ensuring that greater numbers of people living with HIV and AIDS are informed about the benefits of PMTCT and are able to assert their own right to health.<sup>9</sup> CARE has helped create community support groups that combat stigma, address fear of violence, strengthen ART adherence and share information about effective HIV prevention strategies within communities. These interventions at the community level help to change social norms that perpetuate stigma and help to build a supportive environment for people to seek HIV-related services.

CARE's PMTCT-plus program in Kenya has had some important successes. In a three-year period, uptake of PMTCT services increased from 30 percent to over 90 percent.<sup>10</sup> This dramatic shift is due

in part to the "plus" in the PMTCT-plus approach, which established important links among services, removed barriers to access and reduced stigma.

### Addressing the Vulnerability of Sex Workers in India

Preventing the spread of HIV among sex workers and their clients is a key strategy of the Government of India for controlling multiple concentrated AIDS epidemics.<sup>11</sup> CARE's Strengthening Awareness, Knowledge and Skills for HIV and AIDS Management (SAKSHAM)<sup>12</sup> program advances HIV prevention by addressing the structural forces—such as gender inequality, rights violations, discrimination and stigma—that prevent sex workers from protecting themselves from HIV. It acknowledges that providing condoms and HIV information alone cannot be effective if women have little power to use these tools.

CARE's approach goes **deeper** to target barriers to behavior change. For example, a 2006 survey found that 42 percent of sex workers interviewed had been beaten, threatened or raped in the past six months.<sup>13</sup> The constant fear of violence is a barrier that keeps sex workers from insisting that clients use condoms. SAKSHAM was designed around the core insight that behavior change was not possible at an individual level, unless collective strength, solidarity and negotiating power existed to bolster sex workers' ability to confront the social and economic barriers that increase their HIV risk.<sup>14</sup>

To foster sustainability, CARE works in partnership with sex workers and enables them to take ownership over project activities, including:

- Establishing and strengthening community-based organizations (CBOs) that are run by sex workers and liaise with the police and health authorities
- Establishing community-managed drop-in centers and mobile clinics to provide sex workers with safe spaces to meet and seek



health care

- Training sex workers to serve as peer educators
- Establishing crisis intervention teams to respond to incidents of violence and trafficking

This combination of activities is beginning to show effective results in addressing underlying drivers of vulnerability and HIV risk: initial data indicates increased rates of condom use, increased willingness to seek medical care and decreased levels of violence. A 2007 survey showed that more than 90 percent of sex workers had used condoms in their last sexual encounter with an occasional client and more than 86 percent did so with a regular client.<sup>15</sup> Sex workers attribute their safer behavior to their enhanced knowledge of HIV as well as their improved ability to negotiate with customers.<sup>16</sup>

A greater sense of solidarity and unity among sex workers is translating into a climate in which they are better able to protect themselves from unsafe sex and violence. In 2007, 70 percent said other sex workers would help them when clients were violent, up from 53 percent saying so in 2006. Sex workers are now able to take effective collective action and advocate for their right to safety with police and local authorities. CARE has facilitated a dialogue between sex worker CBOs and the police, and helped to establish crisis intervention teams consisting of CBO members, police, lawyers and social workers to respond within 24 hours to cases of violence and harassment.

As the sex workers reached by SAKSHAM have grown in confidence, they have taken the initiative to collectively address several additional issues of importance to them. For example, CBO members track monthly clinic attendance and follow up with women who drop out. They also worked to establish a community kitchen and an emergency fund to support sex workers living with HIV.

### **Fighting Against Sex Trafficking**

Sex worker CBOs have chosen to fight against sex trafficking as a rights violation. CBO members identify victims of trafficking through their informal networks and report it to a crisis intervention team. After police verify that these are indeed victims of trafficking, the girls are taken out of brothels and placed in government shelters. Some 23 girls have been removed from brothels in the past year as a result of sex workers' efforts.<sup>17</sup>

### **Integrating HIV and AIDS with Economic and Food Security**

Economic and food security have a significant impact on vulnerability to HIV and susceptibility to the impacts of AIDS. Causes and consequences run in both directions, with chronic food insecurity and HIV both ravaging parts of sub-Saharan Africa. Food insecurity can contribute to adverse HIV and AIDS impacts in several ways: in order to survive, hungry people may turn to unsafe transactional sex and malnutrition can reduce the efficacy of ART.<sup>18</sup> A recent study in Botswana and Swaziland found a clear association between food insufficiency and HIV risk behavior, especially for women.<sup>19</sup>

When the health of HIV-positive people declines, they are less able to engage in productive activities and they divert their resources to medical and other expenses. This undermines the economic security of families, which then limits their ability to access care and treatment further down the road, resulting in increased ill health and diminished productivity. This vicious cycle is further exacerbated by the stigma that accompanies AIDS: families may face social and economic isolation and loss of income after a family member's death. The economic security of survivors may be further compromised by asset grabbing and inheritance practices that discriminate against women and children, plac-

ing them in extremely vulnerable positions.<sup>20</sup>

For these reasons, CARE is implementing economic and food security programs in AIDS-affected communities. This approach has many benefits: for example, having access to adequate food and nutrition can extend the period of time an HIV-positive person can live a healthy and productive life before the onset of AIDS and opportunistic illnesses. This not only benefits the individual, but the household and the larger community as well. It is also a cost savings to the health system.

### *Enhancing Livelihoods Through Agriculture in Lesotho*

Lesotho is an extremely poor country with one of the highest HIV prevalence rates in the world. The AIDS pandemic has unraveled much of Lesotho's social and economic progress. Given this context, the Livelihoods Recovery Through Agriculture Program (LRAP) was designed to go **broader** in addressing the intersection between

food insecurity and HIV, specifically by helping vulnerable households to improve their food production and nutrition through homestead gardening. It was designed as a food security and nutrition program as well as a strategy to mitigate the impacts of AIDS.

Because most households in Lesotho have access to enough land for a garden, LRAP sought to increase the capacity of homestead gardens to grow a range of vegetables (as opposed to one staple crop), thereby enhancing nutrition for the household. Better nutrition is especially important for those who are living with HIV and AIDS.<sup>21</sup> In addition, any extra vegetables produced by the household could be sold, thus providing vulnerable households with a way to generate income. By providing people with an alternative to traveling to their fields, homestead gardening also is an effective response to the labor constraints of people who are chronically ill or caring for the sick.

Due to the stigma associated with HIV and AIDS, LRAP did not specifically identify which households were known to include people living with HIV. Rather, the focus was on households that were likely to have been affected by HIV and AIDS, such as those headed by widows or orphans, and those caring for orphans or chronically ill people. Overall, 75 percent of the participating households were headed by women or children, were caring for an orphan or were caring for a chronically ill person. In addition, 75 percent were classified as poor or very poor, as ranked by their communities.<sup>22</sup>

Two valuable outcomes emerged from LRAP's efforts. First, LRAP showed how household gardening can improve livelihoods, food security and nutritional status—all of which are critical to achieving more effective HIV and AIDS outcomes (i.e. better care and support, increased efficacy of ART, enhanced adherence to ART). Second, LRAP demonstrated that it is not necessary to specifically target HIV-affected



Brian Atkinson/CARE



households, because these households can be captured in a non-stigmatizing way by selecting the most vulnerable households.

### Targeting: A Lesson Learned

Targeting only people directly affected by HIV or AIDS can have the unintended effect of distancing them from others in the community, adding to stigma and creating jealousy by providing them with resources that others cannot access. Broadening selection criteria to include the most vulnerable in communities (e.g. widow- or child-headed households, households with chronically ill people), as well as giving communities the space to define those criteria, are often more effective and sustainable ways to choose target groups.

### Supporting Women Caregivers in South Africa

The crisis of orphans and vulnerable children continues to grow exponentially; UNICEF predicts that by 2010, 15.7 million children in sub-Saharan Africa will have lost one or both parents to AIDS.<sup>23</sup> Globally, an estimated 2.3 million children under 15 years old were living with HIV and AIDS in 2007 and 330,000 died of AIDS-related causes in that year.<sup>24</sup> AIDS is stretching traditional family support structures to the breaking point, with caregivers struggling to cope with the children they have taken in. These children become increasingly vulnerable; they suffer AIDS-related stigma within their communities and their futures are compromised by the accompanying lack of education and other opportunities<sup>25</sup>. Children who are HIV-infected face even more dire circumstances.

CARE's Local Links program goes **broader** and **deeper** by responding to the burdens faced by those caring for orphans and vulnerable children, primarily women, and to the complex realities of the AIDS crisis. In South

Africa, Local Links enhances the care and support provided to orphans and vulnerable children by increasing CBOs' service delivery to children and by providing sustainable economic support to "first responders"—children's caregivers—who are typically women with meager means of their own. Local Links works with CBOs to improve their ability to provide children with access to medical care, education and psychosocial support.

In addition to providing services directly to affected children, Local Links works with caregivers to enhance their economic security, which better enables them to accommodate having additional mouths to feed, as well as school fees and medical expenses to pay. CARE strengthens the economic coping mechanisms of households caring for orphans and vulnerable children by helping to establish voluntary savings and loan (VSL) groups and providing income generation training and mentoring activities.<sup>26</sup> Although the principal purpose of VSL groups is to mobilize savings and microcredit, they also help provide psychosocial support by offering members the opportunity to discuss issues affecting them, including problems related to caring for OVC, sexual behavior of adolescents, ways to reduce stigma, coping with death and accessing government services.

To date, approximately 35,000 children and their caregivers access the project's services in South Africa. The project's economic security activities are contributing to the well-being of the children and their caregivers, with households better able to buy adequate food, pay school fees, make home improvements and access health services. An evaluation of the South Africa program also found significant social and household impact, with households increasingly able to weather economic shocks and women better able to participate in community activities and make household decisions.<sup>27</sup>

Local Links has met the immediate needs of



Brendan Bannon/CARE

vulnerable children, while simultaneously investing in the long-term ability of caregivers and communities to continue to nurture and meet the needs of children who have experienced loss and dislocation. This investment in caregivers ensures a sustainable, community-driven response to the complex needs of children affected by AIDS.

### **Community Mobilization and Engagement**

CARE strives to demonstrate respect for the dignity and agency of communities most affected by poverty in all of our work. Communities must play a key role in articulating their needs and priorities, using their collective capacities and influencing decisions that affect their lives. CARE facilitates this by helping to mobilize communities to act to solve the problems they face and own the solutions they seek. We have found that effective community mobilization can lead to solutions that are sustained independent of external actors and funding.

Given that the impacts of AIDS are most intensely felt at the community level and many

of the drivers of vulnerability play out at this level, the importance of mobilizing communities to address HIV and AIDS cannot be underestimated. Recent studies have shown that “AIDS-competent” communities are characterized by: intra-community solidarity, a sense of ownership of the problem, safe spaces to talk and share openly, confidence in local strengths, knowledge and skills and relationships with relevant actors outside the community.<sup>28</sup>

Two case studies of community mobilization benefiting vulnerable children found that community ownership was essential for sustained community action.<sup>29</sup> For example, of 30 community-level committees initiated in Malawi and Zambia between 1996 and 2002, the majority remained active and committed to meeting the needs of vulnerable children four years later. The study found that two factors worked against sustainability: first, when external resources were provided before a community group took root and developed its own internal resources; and second, when pressure from donors pushed money to communities too rapidly.<sup>30</sup>

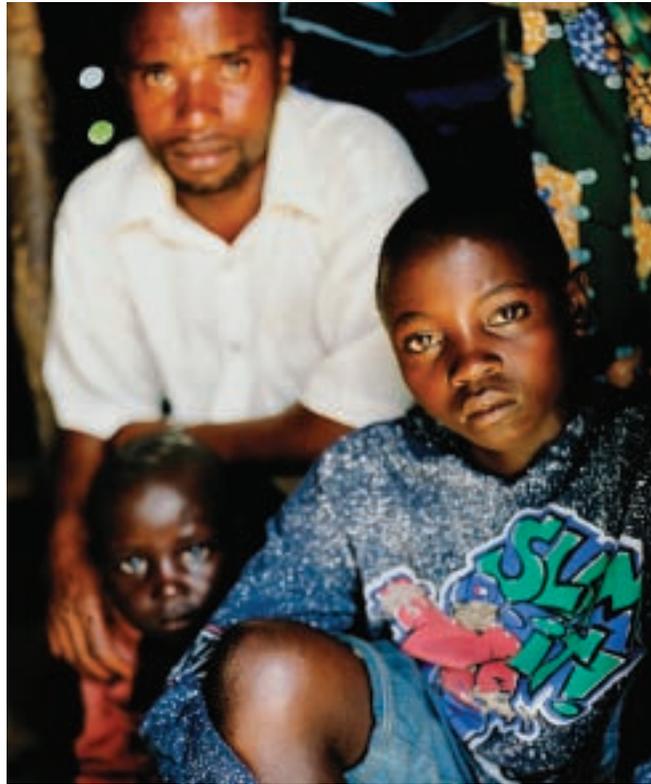


### **Community Mentors for Orphans and Vulnerable Children in Rwanda**

Still reeling from the effects of genocide, combined with the devastation of AIDS, many communities in Rwanda are unable to adequately care for orphans and vulnerable children. As a result, these children are often isolated within communities, living in flimsy shelters, are vulnerable to physical and sexual abuse and are unable to attend school. Because they are exposed to abuse and have little access to health care, these children are especially vulnerable to contracting HIV. To address this context, CARE’s approach works at multiple levels to strengthen community capacity to care for orphans and vulnerable children in a sustainable manner. *Nkundabana*, community mentors identified and chosen by the children themselves as people they trust and respect, are at the center of our approach.

*Nkundabana*—which means “I love children” in Kinyarwanda, the main language in Rwanda—support the children in a variety of ways: visiting them regularly, listening to their problems and identifying strategies to help them meet their needs. To equip *Nkundabana* to address the complex social and psychological needs of vulnerable children, CARE partnered with a Rwandan organization to provide training in active listening techniques and trauma counseling. This has helped *Nkundabana* to understand the children’s needs better and has fostered relationships of trust between *Nkundabana* and the children they support.

CARE found that social isolation, compounded by stigma and discrimination, lie at the root of the vulnerability of orphans.<sup>31</sup> So we go **deeper** to help *Nkundabana* reduce stigma and act as bridges between these children and the community. CARE also established associations and project advisory committees that bring orphans and vulnerable children together with *Nkundabana*, local authorities and community members. This provides forums for children to voice their con-



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cerns publicly and for community members to better understand their challenges and aspirations. At the end of three years, 95 percent of surveyed youth reported that their *Nkundabana* helped them establish better relationships with community members and 97 percent felt accepted by their peers.<sup>32</sup>

As children became more confident in voicing their needs, it became clear that rights violations—from rape to property grabbing—were a central dimension of their vulnerability. CARE partnered with a Rwandan organization

“ Before people neglected us. We were powerless. Someone could grab our property. The local authorities were not sympathetic. Now the *Nkundabana* advocate for child rights, and we are supported by people in the community. ”

—Orphaned youth in Rwanda

that supports a network of paralegals to raise awareness of children’s rights and to provide legal aid to vulnerable children. We also supported local government and community committees to hear cases brought by *Nkundabana* relating to property grabbing, abuse or exploitation. As a result, a reduction in rapes and harassment has been noted, and 84 percent of youth said they now felt safe in their homes.<sup>33</sup>

At the start of the project, orphans and vulnerable children had an almost complete lack of access to education and faced high levels of economic insecurity. So, CARE’s approach went **broader** to help *Nkundabanas* advocate for educational and economic opportunities for these children. More than 6,000 children enrolled in the program are in primary school, and more than 3,000 are participating in literacy and life skills training outside of the formal school system.<sup>34</sup> CARE also helped to organize savings and loans groups and provided vocational training to youth in locally-viable livelihoods such as tailoring, carpentry and beekeeping.

CARE’s community-oriented approach has demonstrated important results. More than 1,000 *Nkundabana* were selected, trained and have subsequently mentored approximately 6,000 child-headed households. Some 1,300 of these households gained access to health insurance, and many have obtained transportation and fees for VCT and received peer education activities on HIV prevention.<sup>35</sup>

The key to the effectiveness and sustainability of the *Nkundabana* approach was the significant investment in building community ownership. Communities were involved from the outset: community members identified the children at highest risk to participate in the project and confirmed the *Nkundabana* selected by children. While this approach took time—laying the foundation at the community level alone took almost a year—the intensive investments in community capacity building and ownership are now paying off.

### A Glimpse of Sustainability

During a nine-month period in which the project came to a halt while CARE sought additional funding, 100 percent of *Nkundabanas* continued their home visits to orphans and vulnerable children. Many of them reported working with local authorities to bring fair resolution to property disputes.

### Linking Case Managers and Communities in Rwanda

In recent years, expanded availability of ART has been a major marker of progress in the global fight against AIDS. However, increased availability of ART does not necessarily translate into *access* for those in need or *adherence* for those who begin ART. A 2006 study indicated notable treatment interruption among patients in Rwanda’s capital, Kigali, due to drug intolerance, drug shortage, financial difficulties and doubts about treatment efficacy.<sup>36</sup>

In CARE’s experience, the willingness and ability of people living with HIV and AIDS to access and adhere to treatment is influenced by a variety of factors, including fear of violence and discrimination, lack of emotional support from families or lack of access to the nutrition required for people on ART. Understanding the interplay among these multiple factors, CARE in Rwanda developed a case management model to better link communities and health facilities and respond more comprehensively to the needs of people living with HIV and AIDS. Qualified nurses or social workers were recruited as case managers, trained and placed in district hospitals or health centers. Case managers, in turn, trained and supervised teams of community volunteers who were committed to helping people living with HIV and AIDS in their communities.

The case management approach goes **broader** to address the range of needs that people living with HIV and AIDS have, including access to



health care and economic and food security. It also goes **deeper** to address the stigma and social isolation that prevent people from accessing basic services. Case managers work with VCT and PMTCT services, associations of people living with HIV and AIDS and community volunteers to identify clients. The case manager assesses the full range of needs of the person and their family, including their socioeconomic situation and the social support available to them. The case manager then develops a customized plan to access required services, contacts local service providers—mostly small-scale community associations and groups that focus on providing support to people living with HIV and AIDS—to coordinate the provision of services and advocates for services that are not available.

Each case manager works with a number of community volunteers, who provide outreach and home-based care. Community volunteers conduct regular home visits and help people with basic care and HIV information, treatment of opportunistic infections, first aid and side effects of ART. These efforts help to improve ART adherence and palliative care. Community volunteers play a vital role in identifying the needs and concerns of people living with HIV and AIDS and increasing their level of comfort accessing services at clinics.

Initial results indicate that the approach of case managers and community volunteers working together has indeed strengthened the links between facility-based services and ca-

“ Visits and attention from case managers and community volunteers have made people who stigmatized us understand that, despite our HIV-positive status, we still have value. ”

—Person living with HIV

pacities and community-based services and needs. Anecdotal evidence indicates that more people living with HIV and AIDS are gaining access to a broader range of both medical and non-medical services and are able to live healthier, more productive lives. An evaluation found the program successful in connecting clients with a range of care and support services, and health care providers noted an improvement in the overall health of clients.<sup>37</sup>

Investments at the community level were critical to the success of the case management approach. Regular home visits by case managers and community volunteers helped improve adherence to ART, with less frequent and shorter interruptions in ART. Better community outreach also helped break the social isolation of people living with HIV and AIDS and encouraged them to seek treatment. It also helped reduce stigma within communities and increased respect for the rights of people living with HIV and AIDS by providing information, promoting open discussion and encouraging people to seek support without fear of discrimination.<sup>38</sup>

## ■ IMPLICATIONS AND RECOMMENDATIONS FOR PEPFAR

**PEPFAR REPRESENTS THE LARGEST** investment ever made by any country to combat a single disease. CARE applauds the ongoing U.S. commitment to this critical issue. With PEPFAR reauthorization in 2008, the United States has the opportunity to again show its leadership by building on lessons learned and moving PEPFAR from an emergency response to the comprehensive and sustainable program required to curb the global AIDS pandemic.

### Implications

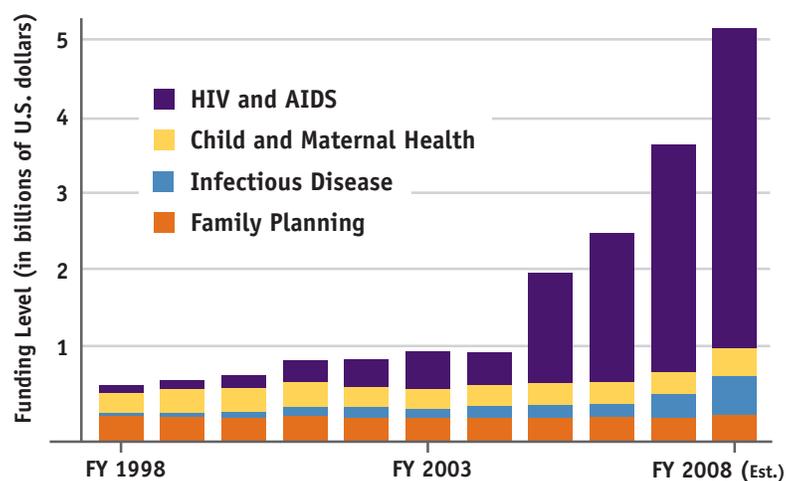
CARE’s experience around the world demonstrates that the cycle of HIV infection, illness and deepening poverty requires that the underlying drivers of the AIDS pandemic are effectively addressed, not just the symptoms. In many countries hard-hit by HIV and AIDS, the pandemic is inextricably linked to issues such as poverty, stigma, gender inequality and social marginalization. Unless the global response to HIV and AIDS addresses these underlying risk factors, particu-

larly for women and girls, even the best-funded efforts will not have a lasting impact. Accordingly, PEPFAR must proactively target the drivers of the AIDS pandemic and tackle these complicated realities comprehensively.

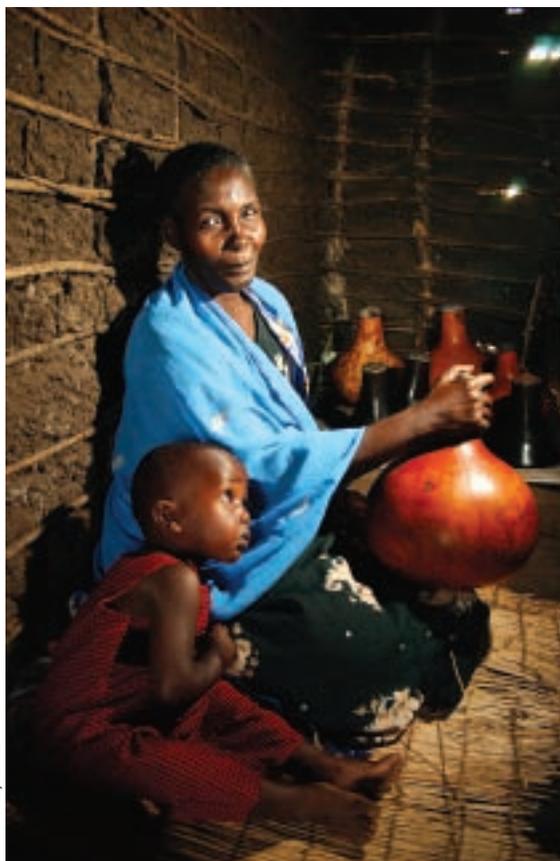
To achieve better coordination and scale up of effective HIV and AIDS interventions, a critical step will be to strengthen links—what PEPFAR refers to as “wrap-around” programming—between PEPFAR and the broader set of U.S. programs working on social and economic development, including child survival and maternal health, family planning, education, food aid, legal reform, microfinance and gender equality. Tackling HIV and AIDS in this manner requires programs with sufficient capacity and resources on each side of the equation to pull their weight. In other words, if a development program is weak and under-resourced, its contribution to HIV and AIDS outcomes will be minimal. A successful wrap-around program must enable each agency to fully contribute its core competencies and expertise to a common solution. This has important implications.

- **Increased U.S. funding is needed for both PEPFAR and non-PEPFAR interventions.** U.S. funding levels for non-PEPFAR programs tell a sobering story. Although overall annual levels of funding for global health have increased from \$1 billion to \$5 billion over the past decade, this increase mainly reflects investments in HIV and malaria. Other critical health arenas, such as maternal and child health, infectious disease and family planning have seen an actual decline in funding over the same period<sup>39</sup> (see graph to left). In addition, between FY2006 and FY2008, U.S. funding for other development sectors including basic education, agriculture and water and sanitation have declined.<sup>40</sup> Funding streams for these core health and poverty-fighting foreign assistance ac-

**U.S. Government Spending on Global Health  
FY 1998-2008 (Est.)**



Source: The Global Health Council (2008)



Ami Vitale/CARE

counts must be increased significantly and on a comparable basis with growth in PEPFAR. If these funding streams are not significantly increased, there is a risk that the important short-term gains secured by PEPFAR's investment will not be converted into sustainable, long-term benefits.

- **More effective coordination is needed for multi-sectoral interventions that include HIV and AIDS and other health and development programs.** At this stage in the U.S. response to the AIDS pandemic, there is a compelling need to closely coordinate core U.S. develop-

ment and humanitarian relief programming with PEPFAR. Some good progress has been made in this direction, but more leadership is needed at the Office of the Global AIDS Coordinator (OGAC) and at other agencies (e.g. U.S. Agency for International Development, Centers for Disease Control and Prevention) to ensure better collaboration. Barriers to effective, inter-agency coordination should be identified and addressed, and more “wrap-around” programs should be implemented, enabling PEPFAR funding to leverage more effective and sustainable results. But in many cases, as noted earlier, these other programs have too few resources and are not able to take on the additional work of HIV and AIDS. PEPFAR funding is needed to ensure that the overlapping objectives are met. This should not be seen as a danger that PEPFAR will spread itself too thin or become a development agency; rather, it should be recognized as a step that will make PEPFAR a more effective mechanism for addressing the realities of the pandemic and securing more effective and sustainable results.

- **More support is needed for the operational research and monitoring necessary to validate successful comprehensive approaches and bring them quickly to scale.** OGAC's stated intention to work on new indicators for PEPFAR programs could be helpful in this regard. New indicators should try to capture the impact of PEPFAR interventions on underlying drivers of the AIDS pandemic related to poverty, social marginalization and gender inequality. The data collected will enable programs to identify best practices, share lessons learned and bring successful programs to scale.

## Recommendations

The recommendations that follow are drawn from CARE’s field experience and are echoed by the Institute of Medicine’s 2007 evaluation of PEPFAR implementation.<sup>41</sup> As the Institute of Medicine’s report noted and our experience shows, the underlying drivers of the AIDS pandemic cannot be addressed through short-term interventions. PEPFAR must be positioned to provide longer-term funding to address some of the more challenging issues, such as gender inequality, poverty, poor governance and discriminatory laws and policies. Ultimately, these issues must be seen as critical elements of the U.S. Government’s AIDS response.

CARE addresses the following recommendations not only to the U.S. Congress as it prepares to reauthorize PEPFAR, but also to OGAC and other U.S. Government agencies as they seek to leverage more effective and sustainable results from PEPFAR in the future.

### 1. Address HIV and AIDS within a development framework

Congress must recognize HIV and AIDS as a multi-dimensional crisis of poverty, vulnerability and inequality. In order to articulate a long-term outlook for PEPFAR, Congress must require that U.S. HIV funding address the socioeconomic drivers of vulnerability to HIV and AIDS:

- Require joint planning and coordination between PEPFAR and U.S. development programs at the country level that produce multi-sectoral plans to comprehensively respond to the AIDS pandemic. Remove barriers that impede effective coordination among U.S. Government agencies.
- Publish guidance on how to fund and implement wrap-around programs. New guidance should articulate allowable uses for PEPFAR funding linked to development activities and define how PEPFAR and non-PEPFAR funding should be leveraged to work synergistically to achieve more effective and sustainable HIV and

development outcomes. This requires developing appropriate criteria for PEPFAR contributions to wrap-around programs.

#### PEPFAR Contributions to Wrap-around Programs

Possible criteria for such contributions could include:

- Improves HIV prevention, treatment and care outcomes
- Expands access to HIV-related programs and services among hard-to-reach populations
- Reduces the vulnerability of target groups such as orphans and vulnerable children and HIV-positive pregnant mothers

Using these criteria, microcredit programs for grandmothers caring for AIDS orphans or assistance for HIV-positive mothers in accessing clean water would qualify as eligible for PEPFAR funding.

- Provide multi-year funding—three-year funding commitments should be the minimum for programs—that fosters a sustainability mindset and allows projects to demonstrate real impact, rather than simply show quick results.
- Increase U.S. funding for both PEPFAR and non-PEPFAR interventions, including funding streams for development assistance, maternal and child health, family planning, food security and legal reform.
- Enhance coordination between U.S. funded HIV and development programs and those supported by national governments, United Nations agencies and other bilateral donor agencies.

### 2. Increase focus on gender inequality and vulnerability

Congress must sharpen PEPFAR’s focus on women and girls as a priority of the U.S. AIDS response. Since the subordinate position of women in many parts of the world is itself a driver of vul-



Brendan Bannon/CARE

nerability to HIV, women's empowerment should be embraced by PEPFAR as a desired outcome. To accomplish this, Congress should promote comprehensive programming that addresses the social, economic and cultural factors that increase women's risk of HIV infection and prevent them from accessing HIV services.

- OGAC must develop operational guidance on gender to help PEPFAR country teams and implementers strengthen their gender analysis and to meaningfully integrate the gender dimension into their work.
- Increase funding for programs that address key priorities in terms of women's and girls' vulnerability to HIV. These include:
  - ▶ Integrating HIV and AIDS with sexual and reproductive health and family planning programs—this encompasses the provision of comprehensive information about reducing risk of HIV transmission, and addressing HIV-positive women's unmet need for family planning as well as their fertility intentions.
  - ▶ Increasing access to ART for pregnant women

living with HIV by expanding the availability of PMTCT-plus services and implementing the World Health Organization's recommended four prongs of PMTCT.\*

- ▶ Increasing programs focusing on gender-based violence, including the enhancement of legal protection, provision of services for survivors of sexual violence (e.g. post-exposure prophylaxis when needed) and working with men and boys to promote gender equality.
- ▶ Investing in basic economic and food security for women and child-headed households.

### 3. Integrate HIV and AIDS programs with economic and food security

Congress must do more to support programming that addresses the link between poverty and hunger and HIV and AIDS. Clear guidance, increased funding and better coordination are necessary to address economic and food security in ways that leverage much more effective HIV outcomes.

- Ensure that guidance on wrap-around programs incorporates support for food security interventions where they are closely linked to HIV outcomes. This is particularly important within PMTCT, ART and OVC programs.
- Increase funding for economic security—for both community asset building (e.g. microfinance, microenterprise) and asset protection (e.g. prevention of property grabbing) activities—so that female-headed and child-headed households, can better cope with the economic shocks brought on by HIV and AIDS.
- Increase funding for vulnerable children and develop community-owned programs that address their underlying social and economic vulnerabilities, including activities aimed at supporting caregivers and increasing access to

\* WHO's four prongs include: (1) primary prevention of new infections; (2) prevention of unwanted pregnancies in HIV-infected women; (3) prevention of HIV transmission from infected mothers to infants; and (4) provision of care and support for HIV positive mothers, children and families at all PMTCT sites



education. Where acute poverty and preventable illnesses render children especially vulnerable, U.S. HIV programs should empower communities to define eligibility for support based on their local context.

- Improve coordination among U.S. Government agencies focusing on food assistance, food security and safety net programs, and between such U.S.-funded programs and related ones supported by national governments, United Nations agencies and other bilateral donors.

#### 4. Support community mobilization and engagement

Strengthening community commitment and capacities to respond to HIV and AIDS is key to sustainable outcomes. As important as it is to strengthen systems within government institutions, it is also critical to leave behind locally-rooted structures and initiatives that are fully equipped to lead the HIV response at the community level.

- Design interventions that support and enhance community initiatives, especially those which are initiated by or substantively involve vulnerable people (e.g., women, at-risk groups) and people living with HIV and AIDS.
- Enable community voices to play a role in defining barriers to accessing public health services and outcomes and in articulating funding priorities, grounded in context-specific epidemiology, risk and vulnerability factors.
- Involve women, women's groups, human rights groups, orphans and vulnerable children, networks of women living with HIV and AIDS and people living with HIV and AIDS in program design, implementation and monitoring activities—especially in the assessment of barriers to accessing essential services and the quality of available services.
- Provide time and support for the incremental nature of building capacity and social transformation at the community level (especially time necessary to change community norms around stigma, gender roles and women's social status). Allocate dedicated resources for capacity strengthening over the life of multi-year interventions.
- Ensure that funding timeframes and monitoring and evaluation requirements allow the time for meaningful community involvement, ownership and capacity development.

#### 5. Invest in scaling up comprehensive prevention approaches

Congress should assign universal access to HIV prevention as PEPFAR's highest priority and provide sufficient funds to ensure U.S. fair-share support to scale up prevention programming. The AIDS pandemic cannot be reversed unless comprehensive, evidence-based HIV prevention strategies are taken to scale.

- Increase funding for evidence-based prevention strategies tailored to the epidemiology of AIDS in each country.



### **Broadening the ABC Approach to “ABC-plus”**

In implementation, the ABC approach has placed a heavier emphasis on A and B and has polarized the HIV prevention debate into “AB versus C.” This neglects the reality that even a balanced ABC approach offers limited options to the most vulnerable people. For example, women often cannot choose to abstain, be confident that they are in a mutually faithful relationship or negotiate condom use with their partners.

A more effective approach starts with A, B and C and goes beyond those basics to address the factors that underlie people’s—especially women’s—vulnerability to HIV. Such an “ABC-plus” approach would confront the reasons why ABC does not give many women realistic options to protect themselves from HIV, including fear of violence and abandonment, economic and food insecurity, lack of property rights, poor education and social norms that place women in a subordinate position to men.

- Remove restrictions that prevent tailoring of HIV prevention strategies to the epidemiology of each country. This requires removing the abstinence-until-marriage earmark and the Mexico City policy\*\* in order to allocate resources to areas where the largest number of new infections can be averted.
- Advance an “ABC-plus” approach to address underlying vulnerabilities that put women and girls at risk of HIV infection.
- Deploy evidence-based HIV prevention strategies to reach marginalized groups—including sex workers, injecting drug users, men who have sex with men and prisoners—and remove policy restrictions, such as the anti-prostitution pledge requirement and the ban on funding needle exchange programs, that impede the implementation of evidence-based interventions.
- Support the operational research and monitoring necessary to validate successful comprehensive prevention approaches and commit to quickly bringing them to scale.



\*\* The Mexico City Policy mandates that no U.S. funding can be provided to any foreign nongovernmental organization that performs or advocates for abortions. President Bush exempted HIV and AIDS assistance from these restrictions, so that family planning organizations are not subject to the Mexico City Policy for their HIV and AIDS work, but they must comply with the restrictions for their work supported by U.S. family planning funds.

## Notes

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- <sup>14</sup> This was also the central premise of the Sonagachi Project in India. The project demonstrated an increase in condom use from 2.7% in 1992 to 80.5% in 1998 and a stable HIV prevalence level of 5%—a very low level of prevalence for a community of sex workers [Smarajit Jana, et al, "Creating an Enabling Environment: Lessons Learnt from the Sonagachi Project, India," *Research for Sex Work Newsletter* 2 (1999) 23-24.]
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- <sup>30</sup> Ibid.
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