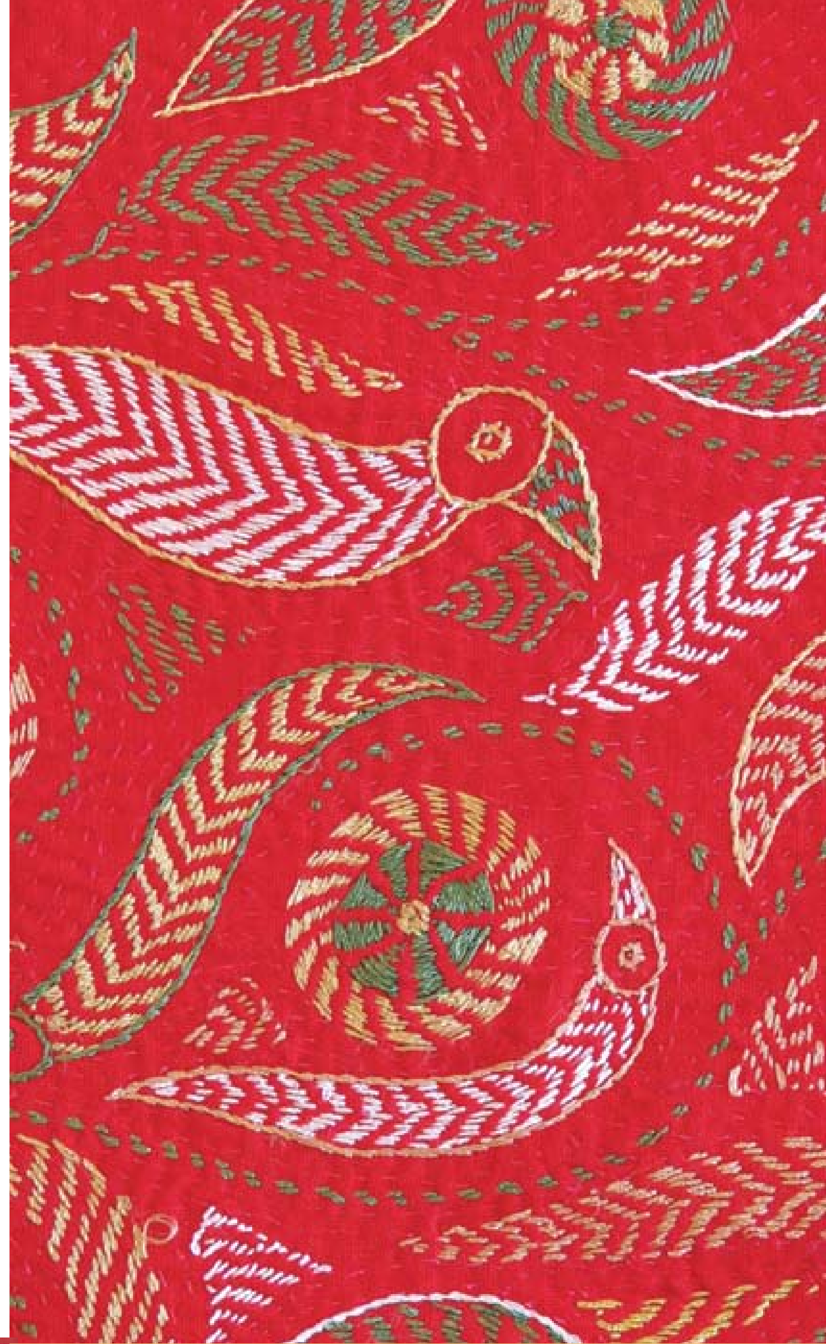

Investing in People Living with HIV

Community REACH Program

USAID
FROM THE AMERICAN PEOPLE

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Investing in People Living with HIV The Pact Community REACH Experience

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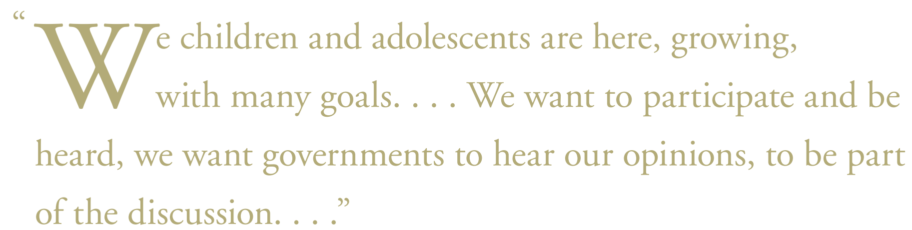
Acronyms

ARV	Antiretroviral Drug
ART	Antiretroviral Treatment
CAG	Community Action Group
CCM	Country Coordinating Mechanism
CHEC	Cambodian HIV/AIDS Education and Care
FOSREF	Foundation for Reproductive Health and Family Education
GFATM	Global Fund to Fight AIDS, Tuberculosis, and Malaria
GIPA	Greater Involvement of People Living with HIV
HBC	Home-Based Care
ICW	International Community of Women Living with HIV/AIDS
IDU	Injection Drug User
IEC	Information Education and Communication
LWA	Leader with Associates
MMM	Mondul Mith Chuoy Mith (Friends Help Friends)
MOH	Ministry of Health
MSM	Men Who Have Sex with Men
NGO	Nongovernmental Organization
OVC	Orphans and Vulnerable Children
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
REACH	Rapid and Effective Action Combating HIV/AIDS
STI	Sexually Transmitted Infection
SW	Sex Worker
TB	Tuberculosis
TOT	Training-of-Trainers
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
UNDP	United Nations Development Programme
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
WHO	World Health Organization



"We children and adolescents are here, growing, with many goals. . . . We want to participate and be heard, we want governments to hear our opinions, to be part of the discussion. . . ."

– Karen Dunaway Gonzalez speaking as a representative of young people living with HIV/AIDS at the 17th International AIDS Conference, Mexico City, August 3-8, 2008.[1]

Executive Summary

The Pact Community REACH program is a global USAID-funded grant-making program that facilitates the rapid award of funds to nongovernmental organizations (NGOs) implementing community-level HIV/AIDS programs. This paper documents Pact's Community REACH efforts in supporting local partners who have demonstrated a commitment to the greater involvement of people living with HIV (GIPA). These partners have built the capacity and increased the direct involvement of people living with HIV (PLHIV) in service provision and advocacy. Since the inception of Community REACH, the program has demonstrated a commitment to empowering PLHIV to play a central role in the response to the epidemic.

Research has shown that the implementation of programs and policies is more likely to succeed when affected communities work toward solutions. PLHIV have tremendous insight into how HIV/AIDS programs and policies should be designed and implemented. Despite recognition of the contributions made by PLHIV at the local, regional, national, and global levels, the HIV community worldwide continues its dialogue on what it means to increase GIPA and achieve meaningful engagement and encourage a stronger call for action.

Current thinking suggests that greater involvement requires a financial investment in human resources. Reconsideration of GIPA as a "greater investment" rather than as "greater involvement" recognizes that financial resources paired with capacity building of individuals is fundamental to meaningful involvement. Providing support to NGOs that invest in building the capacity of individual PLHIV is another important approach to realizing GIPA, and it is fundamental to a strengthened response to the HIV epidemic.[2]

As part of a comprehensive response to the epidemic, Community REACH provided grants to local NGOs worldwide to address issues such as positive prevention, care, and support for PLHIV; community caregivers delivering home-based care (HBC); and community engagement in support of antiretroviral treatment (ART). Successful applicants demonstrated a commitment to realizing GIPA through the design and implementation of their programs. This paper presents the work of six local partners in the Dominican Republic, Haiti, Honduras, India, Cambodia, and Russia. Under Community REACH, they made an investment in and commitment to building the capacity of PLHIV.

Pact's Community REACH support of local partners that build the capacity of PLHIV shows how capacity development initiatives lead to meaningful involvement. As part of the process of supporting local partners in building the capacity of HIV-positive youth; training PLHIV and their caregivers in health and well-being; strengthening community-based responses to HIV and HBC; and improving approaches to community mobilization, Pact Community REACH increased PLHIV engagement in response to HIV in a variety of capacities. In particular, PLHIV succeeded in efforts to decrease stigma and discrimination, advocate for health services, establish organizations and peer support communities, and change how they were perceived within their communities and by their healthcare providers.

Despite these success stories, local partners also identified the need for additional resources to strengthen their programs. They stressed that investment in and financial support for real wages, job skills training, and nutritional supplements would complement existing capacity-building efforts for PLHIV, thereby improving the ability of organizations and programs to provide comprehensive support and high-quality services to PLHIV.

Overall, Pact's Community REACH experience demonstrates that, with increased capacity, PLHIV become active leaders in the response to the HIV epidemic. With training, PLHIV succeed in efforts to decrease stigma and discrimination, advocate for health services, establish organizations and peer communities, and change community perceptions of HIV-positive people. Donors and organizations that reconsider GIPA as "greater investment" recognize the critical role that financial resources and capacity-building strategies play in ensuring meaningful involvement of PLHIV in the fight against HIV.

Background

The Community REACH (Rapid and Effective Action Combating HIV/AIDS) Leader with Associates (LWA) award is a global USAID program funded through the Global Bureau for Health's Office of HIV/AIDS. Awarded to Pact (a U.S.-based private voluntary organization) in 2001, Community REACH facilitates the rapid award of grant funds to nongovernmental organizations (NGOs) playing valuable roles in the global fight against HIV.

Pact's Community REACH program facilitates the flow of grant funds to grassroots organizations that support innovative HIV/AIDS programs for individuals, families, and communities most vulnerable to HIV infection and HIV-related consequences. The program achieves community-level impact in many of the world's hardest-hit regions and countries and pays particular attention to reaching the most vulnerable populations that fall outside the 15 focus countries under the President's Emergency Plan for AIDS Relief (PEPFAR).[3] The program's guiding principles call for community participation, active involvement of stakeholder and target audiences, strengthening community-based networks, and expansion of the body of knowledge on effective responses to HIV by documenting the lessons learned by local partners. Community REACH also supports the GIPA Principle or the greater involvement of people living with HIV (see textbox for the Joint United Nations Programme on HIV/AIDS (UNAIDS) definition of GIPA).[4]

People living with HIV (PLHIV) play a central role in the response to the HIV epidemic. Those most affected by the epidemic have tremendous insight into how HIV/AIDS programs and policies should be designed and implemented. Despite the significance of the contributions that PLHIV make at the local, regional, national, and global levels, the HIV community worldwide continues to engage in dialogue on what it means to achieve meaningful involvement and encourage a stronger call for action. Current thinking suggests that greater involvement requires financial investment in human and organizational resources. Reconsideration of GIPA as greater investment rather than greater involvement recognizes that financial resources paired with capacity building of individuals and organizations are fundamental to meaningful engagement.

Capacity building of individual PLHIV is one approach to realizing GIPA. As part of a comprehensive response to the epidemic, Community REACH provided small grants to local partners worldwide that demonstrated investment in GIPA by incorporating capacity-building strategies for individual PLHIV into the design and implementation of their programs.

THE GIPA PRINCIPLE

UNAIDS defines GIPA as a principle that "aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives."

Purpose & Approach

Purpose

As Pact's Community REACH program draws to a close, the purpose of this paper is to document how Pact's Community REACH local partners encouraged GIPA by investing in the capacity building of individual PLHIV as part of the design and implementation of their programs. Examples of Community REACH's experience in working with local partners and promoting investment in capacity building of PLHIV extend across Latin America and the Caribbean, Asia, sub–Saharan Africa, and Eastern Europe. This paper highlights the work of six local partners. Additional details regarding these local partners and how they were chosen are provided in the following section. For the purposes of this paper, local partners are defined as organizations that received grant funding directly from Community REACH.

Approach

The authors used a series of qualitative methodologies to document how local partners used Community REACH grant funds to implement GIPA by building the capacity of PLHIV in HIV prevention, care, and treatment activities. They gathered data from the existing literature on GIPA; interviewed Pact program staff; reviewed relevant project documents; and conducted 24 telephone and field interviews with local partners working in areas such as positive prevention, care and support for PLHIV; engagement and support for PLHIV and community caregivers in home-based care (HBC); and support for community engagement in anti-retroviral treatment (ART). The authors conducted telephone and field interviews in the following countries with local partners who received Community REACH funding for the topic areas listed above: the Dominican Republic, Haiti, Honduras, India, Cambodia, and Russia. This paper presents the experiences of six of the NGOs interviewed in these countries and their efforts to invest in and build the capacity of individual PLHIV as part of the design and implementation of their Community REACH–funded programs. As mentioned earlier, with few exceptions, Community REACH funding was largely directed to countries outside PEPFAR's priority list. As a result, none of the grantees highlighted in this paper is located in sub–Saharan Africa.

The paper is organized into four main sections. First, using information gathered from the literature review, it provides background on the history of GIPA; describes how organizations, communities, and individuals implement GIPA; and provides examples of the important roles that PLHIV play in the response to HIV. The next sections provide a brief overview of Pact's approach to GIPA through capacity building of PLHIV and highlight the work of six Community REACH local partners in the Dominican Republic, Haiti, Honduras, India, Cambodia, and Russia. The paper concludes with a discussion of the successful strategies adopted by local partners to build the capacity of PLHIV and identifies areas that still require investment in order to realize GIPA.

GIPA Movement

History of GIPA

People living with HIV have been at the forefront of the response to HIV since the early 1980s, when activists articulated the importance of PLHIV involvement and stressed that personal experience could shape the response to the epidemic.[5] In 1983 during the Second National Forum on AIDS, PLHIV formulated the Denver Principle as a manifesto of self-empowerment for PLHIV.[6] The principle, which stated that PLHIV should be "involved at every level of decision-making," later became known as the Greater Involvement of People Living with HIV or GIPA.

As GIPA attempted to move from principle to practice, paradigms such as the UNAIDS pyramid and the Participation Tree developed by the International Community of Women Living with HIV/AIDS (ICW) helped define levels of involvement and participation. The UNAIDS pyramid demonstrates gradients of meaningful involvement of PLHIV.[7] At its lowest level, the pyramid depicts activities that are either aimed at or conducted for the benefit of PLHIV and address PLHIV in groups rather than as individuals. At the next-highest level, though PLHIV are seen as contributors, their involvement is at a minimal level. With increasing involvement, PLHIV assume positions as spokespeople in campaigns, peer educators, or outreach workers. Toward its top, the pyramid views PLHIV as experts who participate on the same level as development and healthcare professionals in the design, adaptation, and evaluation of interventions. At the top-most level of the pyramid, PLHIV are decision makers essential to the decision- or policymaking process (see Annex 1 for more details about the UNAIDS pyramid).

The Participation Tree illustrates the involvement of HIV-positive women in organizations.[8,9] ICW identifies six categories of participation that extend from the base of the trunk to the tree top. Near the base of the trunk, women and girls play no role in decision-making activities and instead defer to others. At this low level, efforts to involve PLHIV fall under the categories of "manipulation," "decoration," and "tokenism." Toward the top of the tree, where the fruit hangs, HIV-positive women enter into a true partnership with the organizations with which they work. Here, women are informed, others seek their views, and their participation is integral to project design and implementation. Though the branches and leaves would not exist without the trunk, the framework of the Participation Tree suggests that the lower levels of the tree are less meaningful than the "fruitful" upper levels (see Annex 2 for more details about the Participation Tree).

Both the UNAIDS pyramid and the Participation Tree served two purposes in the development of the GIPA movement. First, they illustrated that PLHIV were already contributing to the response to HIV/AIDS. Second, they encouraged and directed organizations, communities, and individuals to challenge and redefine their understanding of PLHIV involvement in response to HIV, thus leading to meaningful implementation of GIPA.

Implementation of GIPA

Research has shown that program and policy implementation achieve success when affected communities are directly involved in working toward solutions.[10] PLHIV tend to bring a "high degree of personal investment, motivation, dedication, compassion, and commitment to their work."[11] Their involvement can help maintain a focus on priorities and issues and provide a greater sense of urgency within the work environment by putting a face on the HIV epidemic.[12]

PLHIV have been instrumental in changing the perception of HIV-positive people from merely service beneficiaries to leaders in the response to the epidemic. They have been important drivers of policy and programmatic change.[13] PLHIV's first-hand experiences with HIV transmission translate into expertise and help inform and shape programs and policies into a relevant, effective, and appropriate response to the epidemic.[14] For example, PLHIV are involved with the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM) through their participation on the Global Fund Board as well as through engagement with the Country Coordinating Mechanisms (CCMs). The Global Fund has developed handbooks[15] that guide improvement of CCMs through greater PLHIV involvement. Through direct

participation, PLHIV continue to challenge national and international institutions and influence the development, quality, and relevance of HIV programs.

Within organizations, PLHIV involvement changes perceptions and practices.[16] Such involvement shatters the myth that "service givers" are HIV-negative while "service receivers" are HIV-positive.[17] At the service delivery level within organizations, PLHIV play unique roles as counselors and educators.[18] They understand the challenges of living with HIV and coping with stigma and discrimination. By sharing their experiences and providing guidance, PLHIV foster a safe environment that encourages individuals in need of services to disclose their status and gain access to care and treatment.

At the community level, the involvement of PLHIV destroys myths and diminishes fearful and prejudiced responses to HIV, leading to a more compassionate and caring social environment.[19] Often, PLHIV are the only individuals able to reach marginalized populations such as drug users, prisoners, and sex workers.[20] PLHIV engagement demonstrates that HIV-positive people are active and productive and contributing members of society with a great deal to contribute.[21]

While PLHIV engagement within the community changes the perceptions about HIV, it also has an impact at the individual level. As PLHIV become involved, they realize that they share similar experiences and are part of a larger movement with the potential to shape and influence politics and policies.[22] Involvement improves self-esteem and offers a sense of personal empowerment, while decreasing feelings of shame, stigma, isolation, or depression.[23,24,25] For many HIV-positive individuals, involvement at any level helps re-establish social relations and self-efficacy and improve psychological as well as physical health.[26,27] It has also been demonstrated that involvement positively affects the health of PLHIV through increased access to information on prevention, care, and treatment. A 2004 United Nations Development Programme (UNDP) report[28] emphasized empowerment and capacity development as significant factors in PLHIV achieving a high degree of influence and securing their human rights.

Despite the clear benefits of involving PLHIV at all levels, implementation of GIPA remains challenging. Efforts to achieve meaningful involvement need to consider the great diversity among PLHIV in terms of broadly varying political, socioeconomic, and cultural backgrounds. Moreover, often lost in the effort to achieve GIPA is the understanding on the part of donors, governments, and organizations that GIPA is not simply about individuals disclosing their HIV status and providing a face to the epidemic. Rather, involving PLHIV and securing their engagement and participation at all levels ensures that interventions are targeted effectively and efficiently to reach those most in need. Despite a long-standing recognition of the important contribution that PLHIV make at the local, regional, national, and global levels, meaningful engagement continues to fall short suggesting the need for a new approach.

Investing in PLHIV

The current movement led by PHLIV emphasizes that greater involvement of PLHIV cannot take root without financial investment in individuals.[29] Investment in PLHIV is fundamental to developing and driving policies, establishing social practices, and demonstrating commitment to improving the lives of PLHIV. While levels of financial investment vary with each country and cultural context and must be adjusted to national, environmental, political, and community factors,[30,31] financial investment in human resources is important to support continuous capacity building. PLHIV require skills training to ensure that they are effective champions in their roles within organizations, communities, and governments. Training could address:

- Communication
- Leadership
- Policy and advocacy
- Fundraising and proposal development
- Business practice and management
- Diplomacy
- Public speaking[26]

Literacy in the basic science of HIV is also essential. PLHIV need up-to-date training in areas such as prevention, care and treatment; voluntary counseling and testing (VCT); prevention of mother-to-child transmission (PMTCT); and human rights, stigma, and discrimination if they are to understand their own HIV status, communicate effectively with providers, and advocate for high-quality care and treatment.[27]

Finally, financial investment is needed for:

- **Individual salaries** so that PLHIV can support themselves and their families while participating in programmatic and policy initiatives
- **Travel expenses** incurred for attendance at local, regional, national, and international conferences and meetings
- **Procurement of communication equipment and technologies** such as laptop computers so that PLHIV can work effectively and efficiently.

With adequate resources and strengthened capacity, PLHIV are able to contribute in a number of ways. With *leadership, communication, and advocacy skills,* HIV-positive people influence public health policy and legislation at all levels of government, thereby helping to safeguard human rights. Such skills also allow PLHIV to play an important role in community outreach and mobilization. With strengthened capacity in the *basic science of HIV and treatment literacy,* PLHIV change how medical professionals and other health care workers perceive them. Their involvement helps to reduce the stigma and discrimination so often encountered by PLHIV in seeking services. Skills in *fundraising and proposal development* allow PLHIV to build stronger organizations and gain access to available resources. Investment in building the capacity of PLHIV in *business practice, program design, planning, and implementation* ensures that interventions are relevant and effective. Finally, with increased capacity, PLHIV develop the confidence needed to assert their expertise and knowledge on aspects of living with HIV. Building their capacity in *leadership and communication* also results in strong peer education and peer support programs. See below for an example of how financial investment in human and organizational resources in Honduras allowed a family living with HIV to influence their community by raising awareness of HIV and building leadership among young PLHIV and women living with HIV.

FUNDACIÓN LLAVES- HONDURAS

Raising awareness and building PLHIV leadership

Founded in 1999 by the Gonzalez family, all of whom are HIV-positive, Llaves is a leading PLHIV organization. Its primary mission is to disseminate information for PLHIV on health, treatment options, and human rights. With a staff of eight people, Fundación Llaves communicates through the media, with government, and in the community to raise awareness about HIV. It also publishes a magazine called “Llaves” and hosts a weekly radio program “Aprende del VIH/SIDA y Gana” (Learn about HIV/AIDS and Win).

Karen Dunaway Gonzalez, the daughter of Llaves founders Alan Dunaway and Rosa Dunaway Gonzalez, is an example of how investment in building the capacity of one HIV-positive individual has tremendous impact. Ms. Dunaway Gonzalez, who is 13-years-old, is editor of “Llavecitas”, The United Nations Children’s Fund (UNICEF)-funded magazine directed at children age 8 to 12 who are directly and indirectly affected by HIV/AIDS. This bimonthly magazine has a national print circulation of 10,000. Since 2004, Ms. Dunaway Gonzalez has also helped develop a weekly national radio program in Honduras. She has participated in national and international HIV/AIDS conferences and has co-facilitated workshops on HIV/AIDS awareness and sensitivity. Most recently, Ms. Dunaway Gonzalez delivered a speech during the opening ceremony for the 2008 International AIDS Conference. She has received several awards, including the My Hero Award 2007, given to her and her parents by Aid for AIDS. Having made significant contributions to the HIV/AIDS agenda by the age of 13, Ms. Dunaway Gonzalez is an example of how meaningful involvement of PLHIV can develop a new generation of leaders in the HIV arena.

Llaves’s other initiatives include building the capacity of individual PLHIV and PLHIV organizations. With support from donors such as Community REACH, Llaves provides financial and technical support to local women’s groups; trains PLHIV organizations on effective ways to communicate with and advocate to government; and conducts training for government officials and healthcare workers to address issues such as stigma and discrimination. Viewed as a strong HIV-positive organization, Llaves is a leader in the response to HIV.

Community REACH Building the Capacity of Individuals

Community REACH provided two-year grants to local NGOs worldwide to address issues related to positive prevention, care, and support for PLHIV; engagement and support for community caregivers involved in home-based care; and support for community engagement in ART. See sidebar for an example of how investment in PLHIV as community caregivers in the Dominican Republic helped changed the life of individuals.

In addition to focusing on donor-driven priority needs such as scale-up for care and treatment and service delivery, Community REACH continued to actively encourage and promote the GIPA Principle. All local Community REACH partners emphasized GIPA and investment in capacity building of individual PLHIV as part of the design and implementation of their programs. While Community REACH support for some NGOs has ended, local partners worldwide continue to develop programs in response to HIV that include GIPA as fundamental to their efforts.

The remaining sections highlight substantive examples of how four Pact Community REACH local partners in Haiti, India, Cambodia, and Russia built PLHIV capacity by incorporating the GIPA Principle into their programs. These partners leveraged Community REACH support to invest in PLHIV while implementing programs focused on the positive prevention, care, and support for PLHIV; engagement and support for community caregivers involved in home-based care; and support for community engagement in ART. Each section begins with a description of how the HIV epidemic has taken shape in the region and then presents the work of each grantee, followed by a discussion of factors that contributed to the grantee's success. Each section also discusses areas in need of investment for continued capacity development and meaningful involvement of PLHIV.

FUNDACIÓN MISSION INTERNATIONAL RESCUE (MIR) – DOMINICAN REPUBLIC

Investing in PLHIV community caregivers

Fundación MIR, a Dominican NGO founded in 1988, received funding through Community REACH to strengthen community and family support for disadvantaged PLHIV and orphans and vulnerable children (OVC), many of whom are Haitian migrants in a region of vast sugar plantations. In partnership with two faith-based organizations, Clínica de Familia MIR and Hijas de Maria, the program has helped more than 400 vulnerable children and some 500 PLHIV, including 150 HIV-positive infants and children.

Valentina, the NGO's 2007 Caregiver of the Year, is a health promoter in a sugar plantation in the eastern part of the Dominican Republic. She provides compassionate support and care to PLHIV with the help of Fundación MIR's home-based care services. Among the many community members she helped, Roberto is one of the most memorable.

After his wife and caregiver died of AIDS in March 2008, none of Roberto's neighbors was willing to care for him, and he became gravely ill. Valentina was the only person who dared approach his house. Upon seeing his condition, she summoned the help of Fundación MIR's home-based care services. Roberto was taken to a public hospital and received blood transfusions for his anemia and treatment for his opportunistic infections. After the infections were under control, Valentina brought Roberto to her house, where he continued to recuperate under her expert care. Neither spoke the other's language, but, as a person living with HIV herself, Valentina knew instinctively what to do.

Valentina recalls, "I weighed 60 pounds when I started ART. I know how it feels." "People from the clinic stood by me, fed the pills to me. Now that I am well, I will do it for others, as long as I have the strength."

Caribbean

An estimated 230,000 people were living with HIV in the Caribbean in 2007.[32] During the same year, approximately 20,000 new infections emerged in the region, and some 14,000 people died of AIDS.[33] Except for sub–Saharan Africa, the Caribbean accounts for the world's highest prevalence of HIV infection, with unprotected sexual intercourse as the primary mode of transmission.[34] Although HIV prevalence has declined in certain populations such as pregnant women attending antenatal clinics, there are other sub-populations, including sex workers (SWs) and men who have sex with men (MSM), who are still at great risk of transmission. Haiti accounts for the largest HIV epidemic in the Caribbean.

FOSREF – Haiti

As of 2007, an estimated 120,000 people in Haiti were living with HIV, and approximately 7,500 had died of AIDS.[35] Even though prevention efforts have improved since the 1980s, stigma and discrimination continue to pose a barrier to obtaining information on HIV, accessing VCT, and receiving treatment and care. In Haiti, HIV is associated with homosexuality or employment as a SW, both of which are highly stigmatized and considered outside the mainstream, thereby augmenting the stigma and fear of disclosure experienced by many PLHIV. Young PLHIV growing up in Haiti find the environment particularly hard to endure. Prevalence among Haitian youth age 15 to 24 in 2007 was 0.6 percent for males and 1.4 percent for females.[36] Youth in general and young PLHIV are priority targets for prevention, care, and treatment. Community REACH provided a grant to the Foundation for Reproductive Health and Family Education (FOSREF) to build the leadership and communication capacity of young PLHIV in order to encourage their participation in all aspects of FOSREF's work, including positive prevention interventions (see box on the next page for a definition of positive prevention).[37]

Investing in HIV-Positive Youth

Located in Port-au-Prince, Haiti, FOSREF has been working throughout the island nation since 1998 to promote sexual and reproductive health services, family health education, and HIV prevention. With a national network of 29 health centers, FOSREF provides outreach and health services to five target populations: women and men of reproductive age, SWs and clients, youth age 10 to 24, OVC, and PLHIV.

In 2003, FOSREF applied for and received Community REACH funds to build the capacity of young PLHIV and encourage their involvement in outreach efforts. Specifically, Community REACH supported FOSREF's efforts to:

- Build the capacity of young PLHIV as peer educators
- Train young PLHIV in improved communication skills and increased knowledge of HIV prevention
- Integrate young PLHIV as key actors in all aspects of organizational management, ranging from proposal development to program implementation

FOSREF believes that building the capacity of young people is a step toward developing and encouraging emerging leaders and an effective way to promote positive prevention. Though earlier efforts in Haiti had focused on positive prevention and the training of peer educators, counselors, and outreach workers, FOSREF specifically targeted the capacity of young people, especially those affected by and infected with HIV.

FOSREF's youth volunteers were 10 to 24-years-old, organized into three age groups. With its Community REACH grant, FOSREF trained HIV-positive youth from each age group to serve as outreach workers, counselors, and peer educators. The youngest volunteers led community activities related to positive prevention. Their efforts resulted in the establishment of a community network that included family members as well as faith-based organizations. The community network offered support and encouragement to HIV-positive youth who disclosed their status.

Volunteers older than 15 years of age ran post-test clubs and were key actors in positive prevention and efforts to address stigma and discrimination. These young counselors and facilitators were trained to share their experiences, conduct training classes for peer educators, and manage the overall project. Trained youth counselors reached out to the broader population of young people and encouraged them to undergo counseling and testing. In talking about their experiences as people living with HIV, the volunteers had a powerful impact on community youth.

POSITIVE PREVENTION

Positive prevention aims to increase the self-esteem and confidence of HIV-positive individuals so that they may protect their health, avoid new sexually transmitted infections, delay HIV/AIDS disease progression, avoid re-infection, prevent disease transmission, and adopt a wellness lifestyle aimed at prolonging life. Positive prevention represents the fundamental synergy between prevention, care, treatment, and support.

FOSREF employed the oldest group of volunteers, many of whom attended university, as both key facilitators and VCT counselors. The oldest group also managed the VCT program for youth. Until this work began, VCT in Haiti was extremely medicalized and was the exclusive province of nurses or doctors; in addition, stigma was associated with the testing of young people. As a result of FOSREF's efforts, the Ministry of Health (MOH) revised its operational guidelines and de-medicalized VCT such that physicians and nurses no longer had to run testing centers. Instead, the VCT effort focused on creating a youth-friendly environment, with peers conducting the counseling and testing sessions. This approach reduced the burden on formally trained health professionals by investing in youth and HIV-positive youth.

Lessons Learned

FOSREF's approach to working with HIV-positive youth was deemed so successful that other parts of Haiti have replicated it. FOSREF supported these follow-on efforts by providing technical assistance to other PLHIV associations and encouraging the integration of youth into all outreach activities.

FOSREF attributed the success of its efforts to the full and active participation of PLHIV in all aspects of the project. It also recognized the importance of working closely with the community. Community engagement decreased the stigma and discrimination associated with disclosure of HIV status and helped foster an environment that encouraged counseling and testing. Nonetheless, working with Haiti's communities posed challenges because of the nation's abject poverty, poor education, and low literacy levels. As a result, building the capacity of PLHIV required investment in skills training such as basic literacy, communication, leadership, and advocacy. Despite the challenges, FOSREF's commitment to GIPA and investment in youth reinforced the understanding that PLHIV and even young PLHIV within the community can play a powerful role in response to HIV, producing a generation of emerging leaders capable of responding to Haiti's HIV epidemic.

Asia

In Asia, an estimated 5 million people were living with HIV in 2007, including 380,000 people newly infected that year.[38] Another estimated 380,000 died from AIDS during the same year.[39] Several factors affect the epidemic in Asia, and the nature of each country's epidemic depends on mode of transmission, the groups affected, and the national response. Although HIV infection levels are highest in South-East Asia, there is mounting concern over levels of infection in lower prevalence, but more populous countries such as India.

Positive People – India

Although prevalence rates of 0.03 percent in India are considered low, the sheer size of the country's population at 1.03 billion generates concern over an increasing number of PLHIV.[40,41] UNAIDS estimates that approximately 2.3 million adults over 15 years of age in India are living with HIV. Though considered a medium-prevalence state, Goa has particular vulnerabilities due to a vibrant tourism industry and migrant workers in search of jobs. Women are at particular risk as a result of both of these influences. Other subgroups at risk include SWs, MSM, and injection drug users (IDUs). As increasing numbers of people become aware of the risk of contracting HIV and infected individuals seek treatment, the demand for HIV testing centers and treatment programs will continue to rise. As of January 2007, India had established 3,600 public HIV testing centers, and 57,000 PLHIV were receiving treatment.[42] Home-based care is an essential part of the continuum of care of PLHIV in India. In 2006, Community REACH provided a two-year grant to Positive People to develop and build the capacity of a network of informal caregivers, many of whom were HIV-positive. The objectives of the grant were to:

- Support caregivers by providing respite care and helping to meet their economic and social needs
- Ensure greater involvement of PLHIV in the design, execution, and evaluation of the project
- Achieve household-level food security
- Develop a community-based mental health and bereavement program

Investing in PLHIV Health and Wellness

Established in 1992 by Dominique Sousa, Positive People is the oldest HIV-focused NGO operating in Goa. Its mission is to provide care and support to PLHIV and to ensure greater involvement of PLHIV in the design, implementation, and evaluation of its programs. Positive People also sought to develop and build the capacity of informal caregivers in the community and to scale up care of PLHIV. Approximately 40 percent of Positive People's caregivers were themselves HIV-positive, many of whom were widows.

Positive People trained caregivers in three major areas: nutrition, mental health, and HIV symptoms management. These areas encompassed several subtopics, including food safety, food preparation, infant and child nutrition and feeding; anxiety, depression, and dementia as related to HIV; substance abuse; and identification of symptoms such as fever, diarrhea, dehydration, fatigue, and pain. Other focus areas included treatment literacy, adherence to ART, understanding CD4 counts, and administration of medication.

Through training, Positive People aimed to empower PLHIV and caregivers to manage mental and physical symptoms and illnesses in order to improve the overall health of PLHIV. Before they participated in Positive People's training, many PLHIV expressed a sense of inadequacy in advocating for themselves, their family members, or clients.[43] After training, caregivers and PLHIV expressed confidence in their own abilities to handle these issues.

Positive People developed and delivered innovative training in nutrition and mental health. While HIV, nutrition, and mental health are intertwined, HIV care and support interventions often overlook the importance of nutritional and psychosocial support.[44] In response, Positive People built the capacity of PLHIV to identify the first signs of mental health problems and reach out for support. In addition to undertaking monthly mental health assessments, PLHIV learned how their psychological condition, such as HIV-related depression and suicidal thoughts, affects the progression of disease and can lead to unintended consequences such as non-compliance with treatment regimens.

With training, PLHIV were able to identify periods of depression and learn the skills needed to communicate with providers. Learning to identify and communicate their needs helped PLHIV develop coping skills.

Nutritional care and support for PLHIV were equally important in that 60 percent of PLHIV in Positive People were malnourished and lacked the energy to work. Positive People partnered with the Home Science College to conduct practical demonstrations for PLHIV and their caregivers on food preparation. Trainees learned that good nutrition could boost their immune system and energy levels as well as support effective action of drug treatment,[45] all of which have a positive impact on productivity and overall quality of life.

Lessons Learned

Positive People met with overall success but faced challenges along the way that required creative solutions. For example, grant funding from Community REACH supported nutrition training, but Positive People lacked funds for food supplements.[46] In response, Positive People identified an alternative donor that provided food supplements. Limitations on NGO abilities to procure and provide food supplements limit the capacity of PLHIV to regain their strength, increase productivity, and sustain themselves.

Positive People also faced challenges with respect to sparse attendance at trainings. Though PLHIV and their caregivers expressed interest in training, challenges with transportation and lost work hours posed barriers to participation. Positive People resolved matters by combining training sessions with support group meetings, for which it routinely provided transportation. Participants still unable to attend the training sessions received visits from outreach workers who adapted the training to the home environment and tailored it to varying literacy levels. Positive People's training was not limited to health and well-being but also focused on building advocacy skills. For an example of how Positive People invested in building the capacity of PLHIV in the area of advocacy see sidebar.

POSITIVE PEOPLE – INDIA

Building the capacity of PLHIV to advocate successfully

With support from Community REACH Positive People in Goa established a steering committee with 10 PLHIV members. Three members of the steering committee attended a UNDP training session on leadership, communication, and management. With these skills, steering committee members were able to establish a new community-based organization called Navjeevan (new life), to advocate for PLHIV rights.

Navjeevan identified the need for improvements in infrastructure at a local ART center where HIV patients routinely waited hours for care and treatment without chairs, potable water, or ceiling fans. Navjeevan approached the Health Minister with a clear set of requests. Within two weeks, the HIV patient waiting room was assessed, and Navjeevan's requests were granted.

Positive People identified this story as an example of how Community REACH and UNDP supported its efforts to build the capacity of PLHIV to advocate successfully.

CHEC – Cambodia

Cambodia's HIV epidemic differs from India's epidemic. At 14 million people, Cambodia has a much smaller population.[47] According to 2008 estimates, approximately 70,000 adults older than 15 years were living with HIV.[48] In addition, national HIV prevalence decreased from 2 percent in 1998 to an estimated 0.9 percent in 2006.[49] Cambodia's prevention programs have contributed to the decline by targeting prevention messages to SWs in beer gardens, karaoke bars, and other entertainment establishments where they work. With progress in the area of prevention, programs have shifted their focus to access to ART. According to 2007 UNAIDS and World Health Organization (WHO) estimates, 67 percent of people in Cambodia in need of ART were receiving it.[50] Those in rural areas, however, face particular challenges in accessing treatment because of the continued stigma and discrimination resulting from disclosure of HIV status and the need to travel great distances to hospitals. Home-based care programs have succeeded in addressing some of these challenges and have contributed to increased access to ART by providing PLHIV with treatment, care, and support.

Investing in PLHIV as Home-Based Caregivers

From 2004 to 2007, Community REACH provided a grant to Cambodian HIV/AIDS Education and Care (CHEC) to:

- Strengthen the capacity of community action groups (CAGs) to promote community participation in response to HIV and to reduce stigma and discrimination
- Strengthen training services to NGOs and other partners
- Strengthen the advocacy skills of PLHIV

CHEC is a Cambodian NGO that indigenized from the international organization Quaker Service Australia in 2001. Since then, CHEC has worked to empower communities to address HIV, tuberculosis, and sexually transmitted infections (STIs) and to reduce stigma and discrimination directed against PLHIV and their families.[51]

CHEC used Community REACH funds to develop HBC programs for PLHIV in three provincial districts (Sa Ang, Kampong Tralach, and Preash Sdach). The NGO's experience in developing community-based responses to HIV proved valuable in engaging community members to identify CAGs willing to address stigma and discrimination related to HIV. In particular, CHEC relied on established CAGs with ties to health services within each district to start up HBC programs. Involvement of the CAGs was essential in developing an enabling environment that supported HBC for PLHIV.

Training PLHIV was also important in the establishment of HBC programs. During the two-year grant period, CHEC staff conducted several training-of-trainers (TOTs) sessions for HBC teams in the care and support of PLHIV. The HBC teams were composed of CHEC staff and community volunteers; many of the latter were HIV-positive. In total, 7 HBC team leaders and 25 HBC team members in the three provincial districts received training that prepared them to conduct additional community-based training for PLHIV and their caregivers. Over 400 participants attended and completed the community-based training, which was a 23-week course on positive living and prevention and care and support for PLHIV. HBC teams, in turn, trained PLHIV and their caregivers in communication and advocacy; developed their understanding of available health services and how to access them; and provided economic and social support.

During the community-based training sessions, PLHIV and their caregivers received information, education, and communication (IEC) materials. With support and training from HBC teams, PLHIV and their caregivers were able to build their communication and advocacy skills, which gave them the confidence needed to engage in discussions with healthcare providers. Building on previous relationships established by the CAGs, HBC teams also provided PLHIV with referrals to clinics and hospitals with the capacity to deliver ART, treat opportunistic infections, and prevent mother-to-child transmission. HBC teams also assisted PLHIV and their families in establishing income-generating activities and ensured that PLHIV in the community had transportation to medical appointments. Social support included building the capacity of PLHIV within the community to organize and form community support groups and to link PLHIV with peer groups outside their communities.

For example, CHEC's HBC teams linked PLHIV to the government-organized peer support group called Mondul Mith Chuoy Mith (Friends Help Friends) (MMM), which provided PLHIV with a social support network. Through MMM, PLHIV received and offered mutual support and recognition and developed problem-solving skills. PLHIV interviewed in Cambodia stated that the peer support group gave them hope and demonstrated that it was possible to live a normal life.

Lessons Learned

With Community REACH support, CHEC built the capacity of PLHIV who were members of HBC teams and reached PLHIV and caregivers within the community. The TOT sessions enhanced the advocacy and communication skills and treatment literacy of HBC team members and PLHIV and increased their understanding of available health services. HBC team members interviewed for this paper reported a reduction in stigma and discrimination and an increase in the rate of health services usage. HBC members and PLHIV team leaders evolved into trusted leaders within their communities. With the support of HBC members and PLHIV team leaders, HIV-positive community members gained the confidence and courage needed to disclose their own status to family members and healthcare providers.

Though CHEC concluded that the HBC activity was an overall success, it stressed the need for additional funds to ensure sustainability and increase the impact of its efforts. Needs included additional funding to cover transportation, underwrite healthcare costs such as patient fees for laboratory and CD4 tests, and provide supplementary food aid. CHEC also identified the need for funding to train PLHIV and their caregivers in marketable skills. Job skills training would enable PLHIV to supplement their income-generating activities, leading to improved living conditions and overall quality of life.

Eastern Europe and Central Asia

The estimated number of people living with HIV in Eastern Europe and Central Asia was 1.5 million in 2007; almost 90 percent of infected individuals live in either the Russian Federation (69 percent) or Ukraine (29 percent).[52] An estimated 110,000 people in Eastern Europe and Central Asia became infected with HIV in 2007 while 58,000 died of AIDS complications during the same year.[53] The epidemic is concentrated among IDUs and SWs.

AIDS infoshare – Russian Federation

The HIV epidemic has had a significant impact on the Russian Federation, where HIV prevalence among IDUs ranges from 3 to 70 percent depending on the state.[54] In combination, injection drug use and sex work drive the epidemic in both the Russian Federation and the Eastern Europe and Central Asia region. Societal condemnation of drug use and sex work heightens the stigma and discrimination already associated with HIV, making disclosure of HIV-positive status a daunting prospect and posing a challenge to the involvement of PLHIV in the response to the epidemic. Nonetheless, PLHIV in the Russian Federation continue to organize and identify ways to increase knowledge and awareness of HIV-related issues. Community REACH provided AIDS infoshare – a Russian NGO – with funding for two years to:

- Provide PLHIV with ART support in the form of information about treatment availability and adherence, adherence coaching, social support, and management of side effects through both web-based and local NGO interventions
- Foster local NGOs to increase activity in treatment support to ensure safe and effective provision of ART

Community REACH Building the Capacity of Individuals

Investing in PLHIV Community Mobilization

Since 1993, AIDS infoshare has been an active supporter of PLHIV. It is devoted to reducing the suffering caused by HIV in Russia. From its inception, AIDS infoshare has received numerous grants to conduct HIV prevention activities, reach out to vulnerable populations, and provide care and support to PLHIV. With donor support in 2004, AIDS infoshare launched an online resource for PLHIV known as POZ.RU, a web-based resource that has evolved into the world's largest online community for Russian-speaking PLHIV. The goal of POZ.RU is to create a safe online community that permits PLHIV to exchange information and find support. POZ.RU offers PLHIV anonymity and discretion in accessing information and support without fear of discrimination and repercussions.

In 2006, a two-year Community REACH grant allowed AIDS infoshare to build on its success with POZ.RU by expanding the web-based resource to incorporate information on treatment protocols, supplemented with printed materials. The web site's inclusion of information on ART proved timely in that the GFATM and the World Bank were increasing their support for antiretroviral drugs (ARVs) in Russia. As of 2004, an estimated 500 to 1,000 individuals were receiving ARVs,[55] but the figure was expected to increase to more than 70,000 by 2009, according to the treatment targets established in the GFATM's proposals for Russia.[56] In light of rapid scale-up, both PLHIV engagement and the participation of NGOs were critical to ensuring the equitable distribution of resources and appropriate implementation of ART protocols.

PLHIV need accurate information to engage in effective ART advocacy. In Russia, reliable sources of information are few, and misinformation is widespread. AIDS infoshare believed that individual PLHIV, local NGOs, and local ART professionals all needed access to accurate and thorough information on treatment. Though PLHIV routinely participated on advisory boards, their lack of knowledge of appropriate treatment limited their contributions. With information provided by POZ.RU, however, AIDS infoshare was able to create dialogue and discussion on ART while providing the most currently available, accurate information, allowing PLHIV to plan effective community action based on local conditions and helping to overcome the geographic and social isolation faced by many PLHIV in Russia. The online nature of POZ.RU provided PLHIV with a means to participate in a national dialogue on ART. In addition, it allowed individual PLHIV, many of whom wished to remain anonymous, to seek information, support, and counseling without disclosing their identity.

With support from Community REACH, AIDS infoshare added several treatment support components to POZ.RU, including an e-mail address by which to ask questions to an ART-trained Russian physician; web-based access to psychological counseling and discussion groups pertaining to ART; private e-mail accounts; dedicated chat rooms with trained professionals and other PLHIV to discuss ART issues; a daily blog with the latest information about ART in Russia; published treatment protocol and management documents to allow for greater transparency in ARV provision; and a text messaging alert service to remind individuals to take their medication.

Community REACH funding also supported the development of a toll-free national hotline that permits PLHIV and health professionals to access advice, information, and support from a trained Russian ART physician. In addition, Community REACH underwrote the dissemination of printed materials on treatment support through local meetings with PLHIV support groups. Further, AIDS infoshare conducted local training and provided support to NGOs, PLHIV support groups, and individual PLHIV in accessing information about ART, understanding the rights of PLHIV, and increasing treatment literacy to promote the health of individual PLHIV. For more information on training see textbox on the right.

Nearly 100 percent of AIDS infoshare staff involved in PLHIV programs are HIV-positive. Their engagement provided AIDS infoshare with unprecedented rapport with the PLHIV community throughout Russia. PLHIV were directly involved in staffing AIDS infoshare, and a person living with HIV was hired as the online peer educator. In addition, local PLHIV leaders directly providing the PLHIV community with access to information via the Internet, the hotline, and printed materials. As with all AIDS infoshare activities, a PLHIV advisory board reviewed program activities to ensure appropriate implementation.

PLHIV worked with medical staff to prepare materials for the online treatment directory. Their immediate challenge lay in providing accurate medical information that was easy to read and easy to understand while recognizing that the use of medical terminology was an essential ingredient in building the capacity of PLHIV to understand the nature of HIV (particularly when dealing with medical personnel). PLHIV and medical staff worked together to ensure that materials met the needs of PLHIV and the medical community.

Lessons Learned

Using technology, AIDS infoshare supported “virtual” community action. Though AIDS infoshare supported POZ.RU for many years, Community REACH support permitted the NGO to introduce the chat and forum technologies, a section on frequently asked questions, e-mail, and private messages. Introduction of these online components provided PLHIV with access to a greater variety of resources, including the latest policies and protocols and guidance and support on treatment issues. The additional features greatly enhanced AIDS infoshare’s ability to reach PLHIV across a wide geographic region and build the capacity of PLHIV to educate themselves and take advantage of access to trained ART physicians, psychologists, and peer educators. These providers offered support in several areas, including side effect management, treatment adherence, and mental health. Consultations promoted better understanding between patients and doctors and helped establish trust and confidence.

AIDS INFOSHARE – RUSSIA

Training of trainers (TOT) on treatment literacy

In addition to targeting PLHIV in the general population, AIDS infoshare recognized the need to build the capacity of its peer counselors and educators. To that end, the NGO engaged educational specialist and psychologist Albert Zaripov, who served as a coordinator for many HIV/AIDS projects in the region. Mr. Zaripov conducted training in HIV prevention, care, and treatment; ART side effects; treatment adherence; and symptoms management.

Mr. Zaripov demonstrated that it was possible to provide accurate information and support to others while representing himself as a PLHIV. As a result of training, peer educators reported that they overcame their fears and felt more secure in their assertiveness. With Community REACH support, peer educators conducted 10 workshops, many of which included medical specialists.

Discussion: Community REACH Local Partner Experiences in Capacity Building

Community REACH's experience in supporting local partners' efforts to build the capacity of PLHIV demonstrates how capacity development initiatives can lead to the meaningful involvement of PLHIV in a wide variety of activities. Local partners increased PHLIV engagement in response to the epidemic by investing in building the capacity of HIV-positive youth; training PLHIV and their caregivers on their own health and well-being; strengthening community-based responses to HIV and HBC; and improving approaches to community mobilization.

Peer Education and Peer Support

Building the capacity of PLHIV to provide peer education and gain access to peer support was an important area of investment for local partners. With a focus on training HIV-positive youth, FOSREF's young peer educators were able to reach out to other young people in the community and share prevention messages, especially messages on positive prevention. The identification of HIV-positive youth to serve as peer educators also allowed FOSREF to shift the task of counseling and testing from doctors and nurses to trained PLHIV. Though this model was more commonly used for pre- and post-test counseling with adults, FOSREF's focus on training and integrating young PLHIV into service delivery was particularly innovative. Investing in young people was also an effective way to engage with and build the capacity of emerging leaders to respond to the epidemic. Continuing such investment in HIV-positive youth can potentially shape and encourage emerging leaders in the response to the HIV epidemic.

In Russia, AIDS infoshare trained PLHIV to serve as peer educators. As a result, PLHIV felt empowered as they learned that it was possible to be knowledgeable about HIV transmission, prevention, and treatment rather than live as victims of disease. As peer educators, PLHIV helped other affected and infected people move out of the role of service beneficiary, deepening their own involvement in responding to the epidemic.

Likewise, identifying and accessing peer support resources allowed PLHIV receiving support from CHEC to self-disclose and reach out to others. Finding a community of peers helped reduce the feelings of shame associated with disclosure. As peer support groups and networks grew stronger, support within the community increased.

Community Mobilization and Stigma Reduction

The involvement of PLHIV was an integral part of CHEC's approach to establishing HBC teams and mobilizing community support. CHEC recognized that PLHIV have an intimate understanding of what it means to live with HIV. Using a TOT model and tapping into the experiences and expertise of PLHIV, CHEC staff and volunteers helped expand outreach to PLHIV and caregivers in three provinces. CHEC's approach to community mobilization also succeeded because the organization built on the success of existing CAGs to strengthen the community response to and acceptance of PLHIV in Cambodia. As a result of their efforts, HBC teams made significant strides in addressing issues related to stigma and discrimination. In return, PLHIV in the community gained confidence in their own abilities to self-disclose, communicate their needs, and access health services.

AIDS infoshare adopted an innovative approach to community mobilization. Reliance on communication technology allowed AIDS infoshare to reach PLHIV across Russia's vast geographic region to create a virtual, information-sharing community. As a result, PLHIV who were otherwise physically isolated from peer support and other services were able to ask questions of and receive answers from experts. Virtual community mobilization enabled AIDS infoshare to build PLHIV capacity from afar.

Communication and Advocacy

CHEC, Positive People, and AIDS infoshare recognized the necessity of investing in the enhanced capacity of PLHIV to communicate and work with medical professionals. After participating in the training offered by CHEC's HBC teams, PLHIV developed the confidence to disclose their status and seek out health services at local facilities. Supported by Positive People, PLHIV arrived at a deeper understanding of their physical and mental health symptoms. They then articulated their needs to healthcare providers and, without the assistance of outreach workers, independently accessed the appropriate services. In addition, with increased confidence in their own communication and advocacy skills, PLHIV expressed a desire to expand their involvement. Finally, armed with information on the basic science of HIV transmission, prevention, and care and treatment and with support from AIDS infoshare, PLHIV in Russia were viewed as experts and played a critical role in ensuring that educational materials were appropriate for and relevant to their audience. PLHIV involvement and engagement helped reduce the stigma and discrimination associated with HIV-positive status and influenced how healthcare professionals perceived PLHIV.

Where Investment is Still Needed

With Community REACH support, local partners cited several successes in building the capacity of PLHIV. However, they also recognized that they needed additional resources to strengthen their capacity building initiatives.

Financial Support for Salaries

Though each Community REACH local partner featured in this paper employed several PLHIV on staff, each partner also relied on armies of volunteers to work as peer educators, peer supporters, and members of HBC teams. Many of the volunteers were PLHIV and in need of income and other financial support in order to provide for their families and pay for health services.

Financial and Technical Support for Job Skills Training

In addition to training in areas such as communication, advocacy, leadership, and basic HIV science, livelihood training is essential to ensure economic empowerment and independence for PLHIV and their families. Though PLHIV stated that building skills in the areas listed above gave them the confidence to disclose their status and partake of needed services, they also identified job skills training as essential to securing jobs whose wages would help cover the costs of HIV-related care and treatment. Comprehensive livelihood training programs would require additional financial investment and capacity building to address low literacy levels, limited access to training venues for caregivers responsible for children or other family members, and workplace stigma and discrimination.

Increased Nutritional Support

Local partners such as Positive People were able to build the capacity of PLHIV to identify locally grown nutritious foods and prepare them in ways that ensure maximum benefit. Though PLHIV reported improvements in their level of energy and overall quality of life, local partners identified the need for funding to procure food supplements for program participants without adequate means. Sound nutrition is fundamental for PLHIV, particularly those on ART. Donor limits on the use of funds with respect to procurement of food supplements constrain the ability of support organizations to provide comprehensive care.

Overall, resources in the aforementioned areas are still needed to ensure that organizations and programs provide comprehensive support and high-quality services. Investment in and financial support for real wages, livelihood training, and nutritional supplements would complement and sustain existing PLHIV capacity building efforts.

Conclusion

After reviewing the literature on GIPA and conducting qualitative interviews with Community REACH local partners, we have concluded that, by investing in and building the capacity of PLHIV, the partners have demonstrated that PLHIV can become active leaders in the response to the HIV/AIDS epidemic. They can contribute in a variety of ways at the policy, organization, community, and individual levels. They can improve social practices, advocate for high-quality health services, establish organizations and peer communities, and change perceptions about HIV-positive people. While investment is still needed in several areas, donors and organizations that reconsider GIPA as "greater investment" rather than "greater involvement" recognize that financial resources and capacity building strategies can play a critical role in ensuring meaningful involvement of PLHIV in the fight against HIV/AIDS.

Notes

1. Opening words in Spanish by Karen Dunaway Gonzalez may be heard on conference podcast at Kaiser Network's web site at http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&hc=2863. Translation is available at https://society.maryknoll.org/index.php?module=MKArticles&func=display&id=1141&office=alert.
2. This paper focuses on investment in individuals. For more information on how the Pact Community REACH program invests in building the capacity of organizations, please see "South-to-South Collaboration in Response to HIV/AIDS" on the Pact web site at http://www.pactworld.org/galleries/resource-center/CapacityBuilding_FinalCD.pdf.
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38. The Joint United Nations Programme on HIV/AIDS, Report on the Global AIDS Epidemic, 2008. Available at: http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp.
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41. Census of India. Office of the Registrar General & Census Commissioner, India. Accessed on September 23, 2008, http://www.censusindia.gov.in/Census_Data_2001/National_Summary/National_Summary_DataPage.aspx.
42. The Joint United Nations Programme on HIV/AIDS and the World Health Organization, ASIA AIDS Epidemic Update: Regional Summary, 2007. Available at: http://data.unaids.org/pub/Report/2008/jc1529_epibriefs_eeurope_casia_en.pdf.
43. Interviewees from Positive People reported that they conducted a baseline survey of their participants. At the time of this writing, exact figures from the baseline and midline surveys were unavailable. The statement above reflects interviewees' qualitative responses.
44. Baingana, F., Thomas, R., and Comblain, C. "HIV/AIDS and Mental Health" Health, Nutrition, and Population Discussion Paper 2005. Available at: http://www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2005/02/23/000090341_20050223110316/Rendered/PDF/315030HNP0Mental0health0Baingana.pdf.
45. World Health Organization Nutrition: Nurturing Health. Regional Consultation on HIV/AIDS. Available at: http://www.who.int/nutrition/topics/nut_hiv_consultation_franco_backgrounder_english.pdf.
46. Under PEPFAR, nutritional support can be provided to target groups as part of a food support program. Though food security was one of Positive People's objectives, the NGO's efforts did not qualify as a "feeding program"; program beneficiaries were broader than the approved target groups for food supplements. Therefore nutritional inputs were not supported by Community REACH and Positive People was encouraged to seek alternative funding to support food supplements.
47. The Central Intelligence Agency, The World Factbook, Cambodia, 2008. Available at: https://www.cia.gov/library/publications/the-world-factbook/geos/cb.html.
48. The Joint United Nations Programme on HIV/AIDS and the World Health Organization Global HIV/AIDS Online Database, Epidemiological Fact Sheets on HIV and AIDS, Cambodia, 2008. Available at: http://www.who.int/globalatlas/predefinedReports/EFS2006/index.asp?strSelectedCountry=KH.
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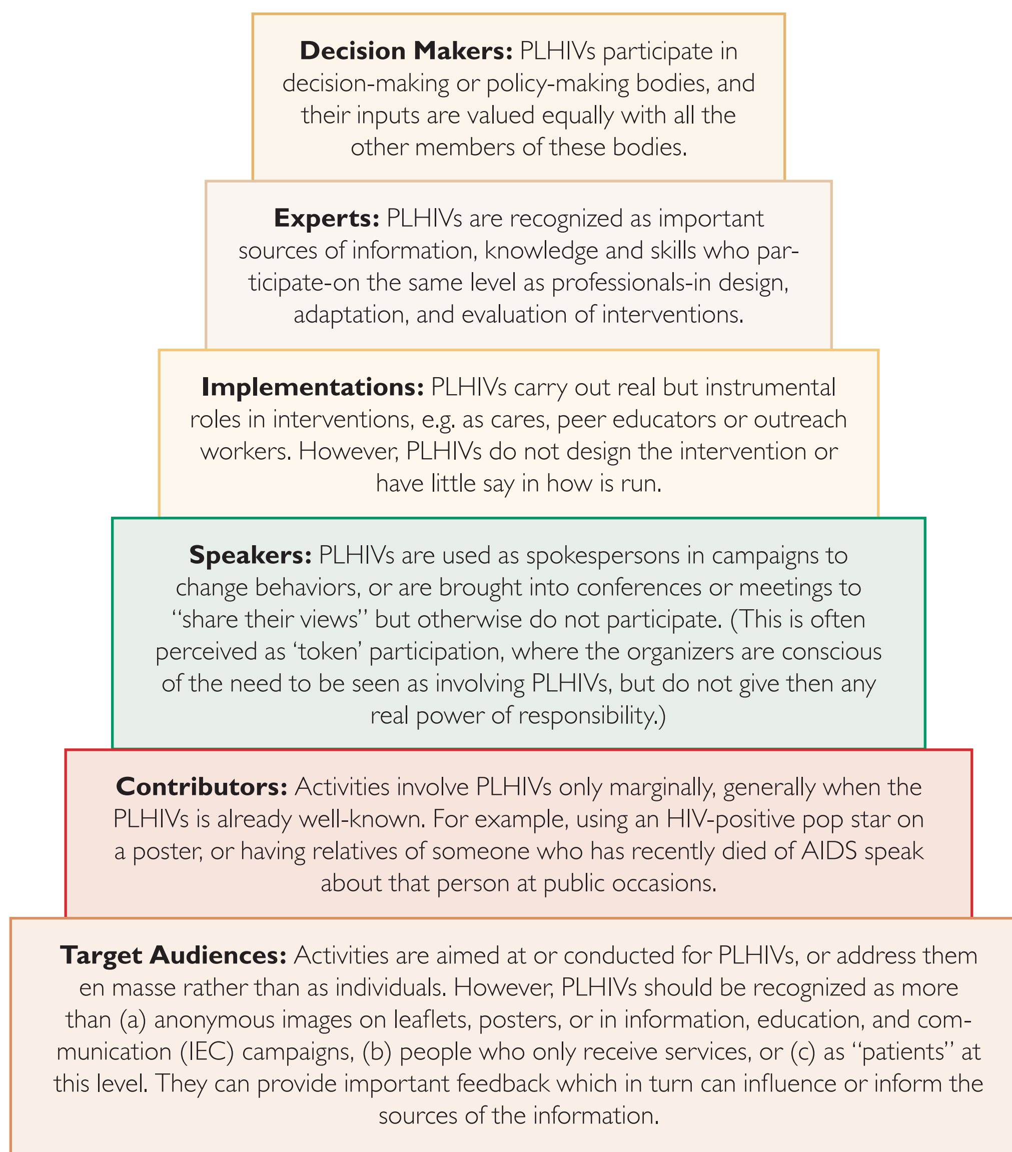
51. Cambodia HIV/AIDS Education and Care (CHEC) Mission Statement. Available at: http://www.checcambodia.org/.
52. The Joint United Nations Programme on HIV/AIDS, Report on the Global AIDS Epidemic, 2008. Available at: http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp.
53. Ibid.
54. Ibid.
55. Extracted from AIDS infoshare program description.
56. At the time that this report was developed, no updates were available.

Annex 1: UNAIDS Pyramid



Annex 2: The ICW Participation Tree

BUILDING
CAPACITY
WORLDWIDE
Pact

community REACH
rapid and effective action combating HIV/AIDS

Futures
GROUP