



Positive Beginnings:

Strong Networks in Vietnam Enable People Living with HIV to Take Charge of Their Futures

Vietnam’s first case of HIV was detected in Ho Chi Minh City (HCMC) in 1990. Yet, by 2003, only about 20 small, self-help groups were in existence. These groups were located mainly in the big cities of Hanoi in the north and HCMC in the south. Today, five years

later, the situation looks quite different. Now, Vietnam has about 200 groups, of all sizes, spread throughout the country. In 2008—building on the path-breaking efforts of regional coalitions—people living with HIV (PLHIV) came together to form two national networks: the Vietnam Network of People Living with HIV (VNP+) and the Vietnam Positive Women’s Network. With a strong, united voice, HIV-

positive people are poised to enter a new era of engagement in the national HIV response.

The U.S. Agency for International Development (USAID) has helped to build the capacity of PLHIV groups and networks from the ground up—first through the USAID-funded POLICY Project, which started work in Vietnam in 2002, and then the follow-on USAID | Health Policy Initiative, Task Order 1, which began in late 2005. Together, these projects have helped to form and expand PLHIV networks; strengthen their capacity in policy advocacy, stigma reduction, and treatment and prevention; and assist groups in gaining funding from in-country and international donors. Moreover, the projects put the “GIPA Principle” (meaning greater involvement of people living with HIV) into

practice by involving PLHIV directly as staff, consultants, subcontractors, and trainers (see Box 1). Thus, HIV-positive people themselves have been at the forefront in mobilizing the PLHIV community in Vietnam.

Unique Challenges to Organizing in Vietnam

The concept of civil society involvement, let alone PLHIV participation, is just beginning to emerge in Vietnam. Communist Party-affiliated “mass organizations” such as the Fatherland Front and Women’s Union serve as umbrella organizations that oversee NGO and civil society groups. There is no word in the Vietnamese language for “advocacy” and, generally, opportunities for civil society involvement in government policymaking have been limited.

In addition, combating HIV requires addressing the specific nature of the epidemic in Vietnam, which is concentrated among injecting drug users (IDUs), sex workers, and men who have sex with men (MSM). Drug use and sex work are both illegal in Vietnam and, previously, were the subject of “social evils” campaigns that only served to exacerbate stigma and associate HIV with criminalized behavior. The government has relied heavily on mandatory, closed rehabilitation centers for IDUs (06 centers) and sex workers (05 centers), which deter the most at-risk populations from coming forward for HIV prevention, treatment, and care. PLHIV groups would like to be able to legally register so they can become even stronger. For example, registration would enable the groups to set up organizational (as opposed to personal) bank accounts to receive donor funds. However, such registration requires having a government sponsor and, given the sensitive issues that PLHIV groups address, becoming a legal entity remains a challenge.

Vietnam

JULY 2009
Task Order 1

Promoting GIPA, therefore, entails convincing government, healthcare, and other officials of the important contributions that PLHIV can make to the HIV response; addressing a range of sensitive issues, including the human rights needs of most at-risk populations; and overcoming barriers to PLHIV mobilization and group formation.

Active Involvement Begins with Strong Groups and Networks

From 2003–2008, the POLICY Project and Health Policy Initiative helped to form, expand, and strengthen the capacity of numerous PLHIV self-help groups and networks throughout Vietnam. This assistance involved several components:

- *Organizational capacity development* (e.g., proposal writing, project management, networking and outreach, strategic planning, monitoring and evaluation);
- *Individual capacity development* (e.g., leadership training, public speaking, working with the media);
- *Specific skills development and training-of-trainers* (e.g., on policy advocacy, treatment literacy, stigma reduction, positive prevention);

BOX 1

Projects Put GIPA Into Practice

The POLICY Project and Health Policy Initiative, Task Order 1, have worked to ensure the greater involvement of people living with HIV by employing HIV-positive project staff. These staff members have played a leading role in mobilizing and building the capacity of fellow PLHIV in Vietnam. They are intimately aware of the challenges faced by the groups they serve. About 25 percent of the projects' staff have come from the HIV-positive community. Additionally, the Health Policy Initiative office in Hanoi housed the national PLHIV network, while the office in HCMC was regularly used by the Southern PLHIV Network. Through GIPA Program Officers and Junior Program Officers and sharing of office space, POLICY and the Health Policy Initiative maintained close, direct working relationships with PLHIV networks, which were essential for strengthening the groups' capacity and actively involving HIV-positive people in regular project activities.

- *Awareness raising* (e.g., of legal rights and the new HIV law);
- *Facilitation of linkages and discussion* between PLHIV and government officials, policymakers, and other key stakeholders;
- *Financial assistance* (e.g., small grants and subcontracts); and
- *Provision of office space and use of equipment* for holding meetings and conducting activities.

Most of these efforts have focused on the Bright Futures network and its affiliates in the north, the Southern PLHIV Network (SPN+), and, more recently, the national PLHIV network and HIV-positive women's network (see Box 2).

Bright Futures

In January 2003, 11 people living with HIV came together to form the Bright Futures group in Hanoi. Later that year, in August, POLICY funded and organized the first workshop for PLHIV self-help groups in Vietnam, which brought together about 70 HIV-positive people from six northern provinces. The workshop provided an opportunity to introduce participants to the GIPA Principle and devise stigma-mitigation strategies. Participants also identified priorities for PLHIV networking. In addition, in 2003, POLICY awarded Bright Futures with its first grant, which supported organizational strengthening and outreach to additional provinces.

Over the years, POLICY and the Health Policy Initiative provided Bright Futures with a range of technical and financial assistance. With this support, Bright Futures group has transformed into a network that has 22 branches in 14 provinces in the north and about 2,000 members. Its core members, once the recipients of technical assistance, now manage their own program activities and budgets and serve as trainers to build the capacity of fellow PLHIV. Some of the network's other notable accomplishments include:

- Presenting a PLHIV photo exhibition as part of World AIDS Day 2003 that helped



One of the images displayed at the PLHIV Photo Exhibit for World AIDS Day 2003, which helped to show the real-life stories of people living with HIV. Photo courtesy of Bright Futures.

to break the silence and stigma around HIV and tell, in a compassionate way, the real-life stories of HIV-positive people;

- Creating a Buyers Club to provide access to low-cost antiretrovirals (ARVs)—which provided treatment to about 120 PLHIV at a time (prior to the influx of donor funding) when ARVs were scarce in Vietnam; and
- Launching a newsletter for PLHIV groups that Bright Futures, with funding from the Ford Foundation, expanded into a “Positive Living” magazine that is distributed to PLHIV, government officials, NGOs, and service providers.

Bright Futures has also collaborated with the Health Policy Initiative to design training curricula on treatment literacy and prevention with positives, and served as the lead organization in facilitating formation of the new national network.

Southern PLHIV Network

In 2003, Ho Chi Minh City had only six small, informal PLHIV self-help groups. As a follow-on to the initial PLHIV workshop in the north, POLICY conducted a workshop for PLHIV groups in southern Vietnam in October 2003. Over the next year, POLICY awarded \$1,000 small grants to the six groups to facilitate outreach activities and organizational strengthening. Then, on November 23, 2004, POLICY and the HCMC AIDS Committee organized a “PLHIV Festival” attended by 200 HIV-positive people, members of the National

Assembly and government departments, and international organizations. This event is known as the “birth date” of the HCMC PLHIV Network.

As with Bright Futures, POLICY and the Health Policy Initiative provided the HCMC PLHIV Network with various types of assistance, from training on proposal writing to involvement in government policy dialogue. With increased capacity, members of the network in HCMC encouraged HIV-positive people in other southern provinces to organize their own self-help groups. Now, reconstituted as the Southern PLHIV Network (SPN+), the network has 15 member groups and serves more than 800 people.

SPN+ has become a strong advocate for PLHIV in the south. For example, SPN+ worked with healthcare providers to establish a referral system so that people in An Giang and Can Tho provinces can access services in HCMC. In addition, the network works closely with the HCMC HIV Legal Clinic, where some of its members serve as peer counselors and on the advisory board. The legal clinic was established in January 2007 by the Health Policy Initiative in collaboration with the Center for Consulting on Law and Policy in Health and HIV/AIDS (CCLPHH) and the Vietnam Lawyers Association.¹ With lawyers from the clinic, SPN+ has successfully advocated for access to treatment for people detained in the 05/06 rehabilitation centers (for sex workers and IDUs) and addressed other human rights violations of PLHIV and children living with or affected by HIV.

New Networks on the National Stage

The idea of creating a national network had been a common topic of interest at workshops and trainings organized by the Health Policy Initiative that brought together northern and southern PLHIV representatives. PLHIV groups recognized that a national network could help them to coordinate efforts, reach out to the central provinces, attract and liaise with international donors, and make a difference in the national response. Yet, despite interest in a national network, several obstacles remained, including issues surrounding capacity, resources and logistics, organizational structures, and the challenge of legally establishing civil society groups in Vietnam.

To move the process forward, the Health Policy Initiative awarded a subcontract to Bright Futures to take the lead in establishing the national PLHIV network. From March 30–April 1, 2008, the Health Policy Initiative, Bright Futures, UNAIDS, and the Asia-Pacific Network of PLHIV (APN+) conducted a training workshop for 78 PLHIV focusing on strengthening organizational and networking capacity. Then, with technical and financial support from the Health Policy Initiative and UNAIDS, Bright Futures organized a five-day working meeting (August 11–15) that resulted in the formation of the Vietnam Network of People Living with HIV/AIDS (VNP+). During the meeting, the 67 HIV-positive people in attendance articulated the network's charter, mission, and vision; elected a seven-member steering committee; assessed strengths, weaknesses, and opportunities; and outlined priorities and objectives for 2008–2018.

As of April 2009, VNP+ included about 140 smaller networks,

coalitions, and self-help groups, reaching about 8,000 members. VNP+ has been housed by Task Order 1 of the Health Policy Initiative, which has provided access to office space, computers, and logistic and technical support. The network will provide a transparent framework for HIV-positive people to select their own representatives to national policymaking bodies, such as the country coordinating mechanism (CCM) of the Global Fund to Fight AIDS, Tuberculosis and Malaria. Such representation is crucial for encouraging meaningful civil society engagement and good governance in Vietnam. In the absence of a united PLHIV voice, the government has typically been the one to select the HIV-positive individuals to be involved in policymaking efforts, thus hindering the ability of PLHIV to choose their own representatives and hold them accountable. As a next step, the network is exploring options to become a legally registered organization.

While the Health Policy Initiative supported the formation of VNP+, the project also worked to mobilize HIV-positive women. The proportion

of women among new HIV cases in Vietnam is increasing. With support from the Health Policy Initiative in November 2007, 30 female PLHIV leaders received a four-day training on networking. In February 2008, the Vietnam Positive Women's Network was officially inaugurated with 18 self-help groups and 252 members. The network created a six-member board with representatives from across the country and drafted a strategic action plan for 2008/09 that focuses on advocacy and capacity building for its members.

The Vietnam Positive Women's Network has already carried out an activity with the Women of APN+. The activity involved conducting interviews and focus group discussions with HIV-positive women in Vietnam to assess their experiences and quality of care in healthcare settings during pregnancy, childbirth, and the postnatal period. The women's network is also collaborating with the Health Policy Initiative and other partners, such as VNP+ and Bright Futures, to pilot a participatory monitoring model to improve access to and quality of HIV services and to reduce stigma and discrimination.

“Before, we did not really see the differences between men's and women's needs in the PLHIV groups. Later, we came to see the need for women living with HIV to have their own space to talk about sensitive issues [such as] information on STIs and how to deal with stigma from the husband's family or our own family. We also look forward to receiving more information about reproductive health and family planning.”

—Lan

Vietnam Positive Women's Network

PLHIV Contributions Improve the Policy Process

A strong response to HIV must include the voices and perspectives of PLHIV. POLICY and the Health Policy Initiative have worked to ensure PLHIV representation and involvement in Vietnam's HIV policy processes. However, before they could become meaningfully involved, PLHIV needed increased capacity in advocacy and policy dialogue. In response, the projects have provided direct training for HIV-positive people as well as strengthened the capacity of PLHIV networks and NGO partners to serve as trainers-of-trainers on policy and advocacy issues.

In addition to building PLHIV capacity, POLICY and the Health Policy Initiative engaged in advocacy with the central and provincial authorities to increase their commitment to meaningful involvement. As a result, HIV-positive people provided comments on the country's *National Strategic Plan on HIV/AIDS Prevention until 2010, with a Vision until 2020* (2004); reviewed and provided suggestions on the *Law on Prevention and Control of HIV/AIDS* (2006); and offered inputs into national guidelines on treatment (ARVs and opportunistic infections) (2005), palliative care (2006), and medication-assisted therapy for IDUs (2007).

Moreover, to encourage civil society engagement, the Health Policy Initiative has strengthened the capacity of the HIV/AIDS Vietnam Action Group (HAVAG), which is a leading alliance of local HIV NGOs and PLHIV self-help groups in Vietnam. With technical and financial support from the Health Policy Initiative beginning in November 2006, HAVAG has expanded its role in policy advocacy, implementation and monitoring of the HIV law, and networking with other NGOs and PLHIV groups. From 2005–2008, HAVAG's membership increased from 14 to 64 organizations, and now includes 38 NGOs

and community-based groups, 22 PLHIV self-help groups, and four MSM groups. HAVAG has also been invited to be a member of the national planning committee that is designing a plan of action for children affected by HIV and AIDS.

At the end of 2007, HAVAG and other civil society groups formed the Vietnam Civil Society Platform on HIV/AIDS (VCSPAS). The group's first activity was to provide substantial and unprecedented support to the Vietnamese government in the preparation of the country's third progress report on implementing the UNGASS *Declaration of Commitment on HIV/AIDS*, illustrating civil society's growing voice in policy dialogue. As part of this process, the Health Policy Initiative facilitated two regional workshops with civil society and PLHIV to build their capacity to apply the National Composite Policy Index (NCPI),² a methodology UNAIDS recommends to evaluate the HIV policy environment. The project also organized a national workshop to share the analysis based on the index. The government's final report, released in January 2008, acknowledges, for the first time, the contributions of civil society and PLHIV in the national response to HIV.

“The Health Policy Initiative connected us with healthcare providers, government officers, and donors so that we could discuss issues on the ground and raise the voice of people living with HIV in Vietnam.”

—Tung
Bright Futures

Thus, despite having a highly centralized, one-party political system, Vietnam's HIV response is increasingly involving PLHIV and civil society groups in policymaking, program implementation, and monitoring. Due in large part to the involvement of civil society and PLHIV, recently adopted laws and policies have incorporated human rights-based approaches³—though more needs to be done to harmonize laws and policies across sectors.

Increased Resources for PLHIV Groups Leads to Greater Sustainability

The sustainability of PLHIV networks depends on their ability to mobilize and effectively manage funds to support ongoing activities. For a number of PLHIV groups in Vietnam, the POLICY Project was the source of the groups' first donor funds. POLICY technical assistance and small grants (typically about US\$1,000–\$5,000) not only supported specific activities, they enabled emerging self-help groups to gain much needed capacity in proposal writing, donor reporting requirements, good practices for program management and monitoring, and effective resource use. This assistance continued under the Health Policy Initiative, which helped both the more established networks and newer groups to identify funding sources, write proposals, and strengthen program management and reporting capacity.

With increased capacity and funding, PLHIV groups and networks in Vietnam have become program implementers engaged in a variety of activities (see Box 3). For example, Bright Futures receives about \$50,000 annually from CARE International to provide support to PLHIV and children in Hanoi and Quang Ninh. SPN+ has received \$28,000 from the American Jewish World Service to educate PLHIV about their human rights, especially in light of the new HIV law prohibiting discrimination against HIV-positive people. In 2008, the Hanoi International Women's Club awarded grants to Ocean Love (\$14,000) and Green

Dream (\$10,000) self-help groups to provide support to children infected and affected by HIV. And, the Information Technology Professional Forum/Collaborative Fund awarded SPN+ and the “Blue” self-help group \$10,000 each to carry out treatment literacy and advocacy activities.

At the national level, the Health Policy Initiative has assisted VNP+ and the Vietnam Positive Women's Network in mobilizing nearly US\$120,000 in additional funding from organizations such as the American Jewish World Service, Hanoi International Women's Club, National Minority AIDS Council, and the Information Technology Professional Forum/Collaborative Fund. With these funds, the networks are raising awareness of the HIV law, building the capacity of self-help groups, providing nutritional and related support for children living with or affected by HIV, and advocating for improved treatment and care.

These are just a few of the many examples of projects that HIV-positive people are carrying out in Vietnam.

PLHIV as Meaningful Partners in Treatment, Care, and Prevention

With strong groups and networks underway, the Health Policy Initiative turned its attention to two activities with PLHIV that are essential for addressing HIV in Vietnam: enhancing treatment literacy and promoting prevention with positives.

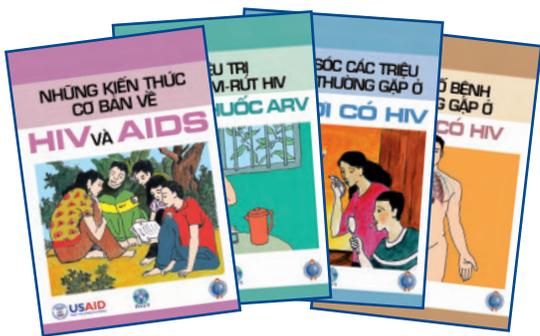
BOX 3

Grassroots Groups Make a Difference

In addition to the great work being done at the regional and national levels, PLHIV self-help groups at the local level are demonstrating increased capacity and action. For example, the Tinh Bien group in Hai Phong used the Health Policy Initiative's treatment literacy materials to organize a two-day training course on treatment adherence for PLHIV. With the project's technical support, the Tinh Bien group also provided training on stigma and discrimination reduction for 300 students and teachers of the Vinh Bao District in Hai Phong City. In addition, with technical support from the initiative and financial support from the Hanoi International Women's Club, the group has assisted 70 children infected or affected by HIV to gain access to nutrition and medical checkups and organized an income-generation workshop for 30 female PLHIV from Hai Phong. Following this workshop, the Hanoi International Women's Club supported three income-generation initiatives for the women.

Treatment Literacy

Donors such as the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund have dramatically increased funding for Vietnam's HIV response, with a large portion of new funding devoted to scaling up access to ARV treatment. The estimated number of people receiving treatment increased from a few hundred in 2003 to more than 26,000 in 2009. While many efforts have sought to strengthen provider and health system capacity to deliver treatment, a necessary complement to these efforts is to ensure that HIV-positive people have the knowledge, skills, capacity, and support to seek and adhere to treatment. Achieving the health benefits of treatment and avoiding the rise of drug-resistant strains of the virus requires a high level of adherence to treatment regimens. Thus, PLHIV need to know about the progression of HIV to AIDS; ARV drugs and their uses; the nature of side effects and how to deal with them; and the importance of taking medicines regularly, among others.



To help address this gap in the treatment response, the Health Policy Initiative involved HIV-positive people in the design of treatment literacy materials. They contributed at each stage, from working with experts to prepare the content of the training materials to creating the illustrations that depict key points in a user-friendly manner. Four core modules and a teaching companion guide were developed that focus on topics such as basic HIV knowledge, ARV treatment, and treatment for opportunistic infections. Copies of the training materials have been disseminated to PLHIV groups and have been requested by and shared with international organizations, medical universities, healthcare facilities, and community-based organizations. The high quality of the materials demonstrates that

“The training on treatment literacy provided by the Health Policy Initiative had a big impact on me and the community I work with. I have gained knowledge and new information that has helped with treatment adherence, self care, and care for my family. Now I have fewer opportunistic infections and feel healthy. I also share all the information.”

—Mai

Hai Phong self-help group

PLHIV are essential partners in planning and implementing HIV treatment programs.

In 2006, the project trained 500 PLHIV in treatment literacy and trained 18 PLHIV as master trainers. In 2007/08, with support from the Health Policy Initiative, CARE, and other donors, the master trainers and other trained PLHIV replicated the trainings within their own groups. Bright Futures and SPN+ have led efforts to strengthen treatment literacy through their networks. This has involved providing treatment literacy training as well as ongoing support and counseling during regular support group meetings. Both networks identify increased treatment literacy and high levels of adherence among their members as a key outcome of the partnership with the Health Policy Initiative.

Prevention with Positives

The project followed a similar process of working directly with PLHIV to encourage “prevention with positives.” Due to the concentrated nature of the epidemic, Vietnam has a real opportunity to reduce the spread of HIV. Yet, too often, prevention programs focus only on those who do not have the virus and fail to include PLHIV as partners in prevention. Moreover, positive prevention means not only limiting transmission of the virus to others; it also involves helping PLHIV to manage their own health—including avoiding re-infection with a different strain of the virus, getting adequate nutrition, taking steps to ward off opportunistic infections, and building self-esteem. Thus, prevention with positives should be seen as a holistic approach that encourages positive living and, ultimately, is beneficial both to PLHIV and the larger society.

“One of our biggest achievements has been to improve the participation and image of PLHIV, which is evident not only in the recognition by local authorities, but also in the policies they make.”

—Huyen
SPN+

From mid-2007 to September 2008, the Health Policy Initiative supported HIV-positive people to design and pilot a prevention with positives training program. The training materials cover positive living, nutrition, and hygiene; provide guidance on HIV prevention in different settings (e.g., for most at-risk populations, for prevention of mother-to-child transmission); offer advice for peer counselors and caregivers; and provide contact information of self-help groups. The project trained 123 PLHIV as master trainers in prevention with positives approaches and has supported 20 self-help groups to replicate the training, reaching more than 2,500 HIV-positive people in 10 provinces. In addition, the 20 self-help groups have conducted outreach activities on positive prevention, reaching nearly 8,000 PLHIV.

The Way Forward

Several challenges remain for PLHIV groups, including the continuing need for resources and the need to reduce stigma and discrimination, especially against the most at-risk populations. However, in just a few years, HIV-positive people have come a long way and—to borrow from the name of the network in the north—their future looks *bright*. Strong regional networks, such as Bright Futures and SPN+, have laid the groundwork for a growing PLHIV movement. They have taken the lead in building the

capacity of local self-help groups and the new national network. VNP+ will fulfill a vital role by promoting advocacy at the national level, coordinating activities across the country, and enabling PLHIV to select their own representatives for national policymaking arenas. Women, too, now have their own space to discuss issues affecting women living with HIV and plan appropriate responses. PLHIV at all levels have increased capacity and skills in organizing, networking, advocacy, and treatment and prevention. Moreover, the policy environment has been greatly improved through the involvement of PLHIV and civil society groups, with the adoption of a law preventing discrimination against PLHIV and new guidelines on treatment, care, and medication-assisted therapy.

A crucial next step for PLHIV groups and international and in-country partners will be to foster the capacity and sustainability of the national network as well as address its legal status and promote the right of PLHIV to self-representation. PLHIV in Vietnam have demonstrated the ability to mobilize resources and effectively manage programs, and these efforts must be built upon. Finally, PLHIV and civil society must continue to work with the government to support the positive changes that have occurred in the country’s HIV response.

ENDNOTES

¹ Health Policy Initiative, Task Order 1. 2009. “Making Policies Work for People: HIV Legal Clinics and Hotline in Vietnam Ensure that PLHIV Know and Exercise Their Rights.” Washington, DC: Futures Group International, Health Policy Initiative, Task Order 1.

² The NCPI is used by UNAIDS as one of the mechanisms for tracking progress toward meeting commitments made in the 2001 UNGASS *Declaration of Commitment on HIV/AIDS*. See http://www.unaids.org/en/KnowledgeCentre/HIVData/CountryProgress/2008_NCPI_reports.asp.

³ Health Policy Initiative, Task Order 1. 2009. “On the Right Track: Vietnam Adopts Rights-based Policies for HIV Prevention, Treatment, and Care.” Washington, DC: Futures Group International, Health Policy Initiative, Task Order 1.

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