

UNDP China

Positive Talks - People living with HIV 'speaking out' on stigma and discrimination in China



Background

Despite years of government and non-government efforts to spread information about HIV and AIDS, misunderstandings about HIV, along with stigma and discrimination against people living with HIV, remain widespread in China.

Stigma and discrimination has been identified by the Chinese government as a major challenge to the national AIDS response. "Eliminating discrimination and stigma, still a serious problem in China today, is crucial for an effective AIDS response,"¹ China's vice health minister Huang Jiefu recently stated. Despite national and local regulations clearly banning discrimination, medical care, school, and many other services are often difficult or impossible for people living with HIV (PLHIV) to access in China.

Public knowledge of HIV is also still very low in China. Year after year, surveys show that the majority of people would still not be willing to work or live with an HIV-positive person (China Stigma Index Report, 2009²), and many are still convinced that HIV can be spread through casual contact, toilet seats, or mosquitoes.

Though most AIDS prevention and control programming includes significant funds targeting "improved participation" of PLHIV, and we commonly hear the term "GIPA (Greater Involvement of People Living with HIV/AIDS)" within most AIDS programming, the amount of truly meaningful involvement of PLHIV remains relatively weak in China. Their role in designing and implementing most projects and holding decision making positions in most AIDS services organizations remains largely passive and often tokenistic.

A growing body of knowledge shows that increased and meaningful participation of PLHIV directly benefits both the participants of HIV awareness trainings and PLHIV themselves.³ Research indicates that interactions with

"It is Positive Talks that built a communication bridge between the public and the PLHIV, therefore, the public could hear the voice from PLHIV and the public would benefit for this mutual communication on understanding HIV/AIDS."

- Wu Zunyou, Director, National Center for AIDS Prevention and Control, China CDC

PLHIV lead to significantly more accepting attitudes towards HIV and people living with it.⁴ Additionally, another study reveals that disclosing long-standing secrets results in significantly heightened immune functions⁵, which could bring tremendous benefits to people living with HIV who are immune-compromised. In this context, Positive Talks could be beneficial for everyone involved.

Given this background, Positive Talks was initiated with three main goals:

1. Reduce stigma and discrimination against PLHIV in China.
2. Raise PLHIV abilities and purpose by giving them intensive training and support
3. Create a working model of a PLHIV-led anti-stigma and AIDS awareness intervention that avoids many of the common pitfalls facing grass-roots HIV organizations in China.

All these goals would be achieved by supporting a core group of PLHIV to develop deeper knowledge, confidence and speaking skills, and for this group to conduct trainings and "positive talks" addressing stigma, prevention, care, and other HIV-related topics.

Positive Talks: What is it?

Positive Talks was initiated in early 2007 by UNDP and the China office of Marie Stopes International (MSIC). MSIC provided an operational base and critical start-up support for Positive Talks. In addition to providing office space and financial management, MSIC helped the group organize and manage the growth of speaker networks, local activities, training materials and publications. MSIC has years of experience supporting the growth of grass roots PLHIV organizations, allowing it to nurture the group as an autonomous project. Additional UN support was given by UNAIDS which provided seed

1 China Daily (2009). HIV/AIDS stigma still exists, survey says. Available at http://www.chinadaily.com.cn/cndy/2009-11/28/content_9068313.htm

2 Available at <http://www.stigmaindex.org/211/analysis/china-2009.html>

3 Susan Paxton (2001). APN+ Lifting the Burden of Secrecy - A manual for HIV-Positive speakers who want to speak out in public. UNDP Asia Pacific Regional Center.

4 Takai, A., et al (1998). Correlation between History of Contacts with People Living with HIV/AIDS (PWAs) and Tolerant Attitudes toward HIV/AIDS and PWAs in Rural Thailand. *International Journal of STD and AIDS*. 9 (8), 482-4.

5 Pennebaker, J., et al (1988). Disclosure of Traumas and Immune Function Health Implications for Psychotherapy. *Journal of Consulting and Clinical Psychology*. 56 (2), 239-45.

“When we invited Positive Talks to help train Chinese journalists, I wasn’t sure what to expect. I was very impressed at how confident and skillful they were – it was inspirational. When one of them decided to openly declare her HIV-status for the first time during the training, it showed me how far they had come.”

- Odilon Couzin, China AIDS Info

funding and identified advocacy opportunities with the Ministry of Health, and ILO incorporated Positive Talks into its workplace training programmes with the Ministry of Labor.

The principle behind Positive Talks is the belief that people living with HIV can be the most qualified and effective speakers about HIV. Furthermore, the speakers believe the best way to break down the pervasive discrimination against PLHIV in China is to have people see somebody “just like me”, who also happens to be HIV-positive, standing up and confidently speaking out. While most AIDS-related projects in China now involve PLHIV, only a handful of individuals have been willing to openly speak about their HIV status. Therefore, there is an urgent need for dedicated, articulate and outspoken PLHIV community members to be supported and given the opportunities to educate and inform.

To address this gap, Positive Talks aims to establish a *cadre* of well trained, well-supported and well-organized HIV-positive speakers who could organize, design and provide trainings; participate in meetings and workshops; and engage policy makers with authority and confidence.

Positive Talks: Who is it?

An open call for members was put out in early 2007 through community networks and HIV electronic forum, and eventually 30 people, both men and women, applied, were interviewed, and were invited to join the Positive Talks Team. All underwent systematic and intensive training on all aspects of HIV training and “speaking out” as an HIV-positive person, including many hours of practice in public speaking.

All Positive Talks members join as individuals, with no organizational affiliation allowed to interfere with their participation in the group. Also, no member is asked to “represent” Positive Talks, as this role might conflict with their responsibilities of their primary organizations. Members represent a cross section of China’s PLHIV community, coming from 22 different provinces. Some are from small towns and some from big cities; some have university degrees, while others never finished school. “They are unified by the desire to join together and make a real impact on stigma and discrimination



against PLHIV in China,” said Xiaokang, the Positive Talks first programme manager. They are paid to design and conduct trainings, even though all have other jobs, most in NGOs or HIV-related treatment, prevention or care projects.

Positive Talks: What does it do?

To date (May 2010), Positive Talks has participated in 474 workshops, trainings, and meetings, both speaking and leading participants through activities aimed at challenging the misunderstandings that allow stigma and discrimination to persist.

- Conducted anti-stigma and basic HIV awareness trainings for staff of a number of different UN agencies under the UN Cares programme including: UNDP, UNAIDS, UNFPA, ILO, FAO, WFP, UNIFEM, UNESCO, WHO, UNHCR, UNEP, UNV, etc.
- Worked with Chinese government departments to organize and conduct anti-stigma trainings for national and local level government officials.
- Collaborated on the design and provision of a journalist training package for use in training Chinese journalists on HIV reporting with China AIDS Info and supported by UNAIDS.
- Conducted a number of large-scale trainings for foreign and Chinese companies, including Standard Chartered Bank, Total, Areva, Lafarge, Nike, Anglo American, and Pinglang Coal Mine.
- Received a national UN Volunteer through the UNDP-Total partnership on strengthening the capacity of civil society organizations.
- Participated in trainings for Global Fund program staff and local implementing partners around China.
- Worked with UN Volunteers (UNV), UNAIDS, Beijing Communist Youth League, and the Red Cross Society of China to train 7,500 Beijing Olympic Volunteers in 2008.
- Joined with UNDP’s Arts and Media AIDS Advocacy Initiative during 2007 and 2008 (see UNDP document: *UNDP China Arts and Media AIDS Advocacy Initiative*).



- Acted as the primary implementers for the 2009 China Stigma Index Survey, in coordination with UNAIDS and the Central Communist Party School.
- Participated in private sector fundraising activities on International Candlelight Memorial Day organized by Kathleen's 5 Restaurant and UNDP in Shanghai.
- Participated in short film documentary, *The Scarf*, the "Red Scarf" Exhibition, and the "Touch Without Danger" exhibition funded by UNDP in 2008.
- Launched the "ART, AIDS, LIFE" project, working with a group of eighteen contemporary artists on the Candle Light Day of 2009, and organized contemporary artists to work and live together with PLHIV in rural areas for direct, comprehensive mutual communication and understanding in 2010 with support from UNDP.

Positive Talks – What are they saying?

"People living with HIV/AIDS are living all around. What you should do is not label or identify them, but just treat them equally. Please do not discriminate against us, do not look down upon us, just view us as equals and that's enough."

- Ms. He Tiantian

"As HIV-positive people, we need everyone's understanding and support. If HIV-positive people do not stand up and take the initiative to fight for our legal rights and interests, where can we expect the social harmony (hexie) to come from?"

- Mr. Yu Xuan

"I can tolerate the pain caused by HIV, what's unbearable is the hurt caused by the society discrimination."

- Mr. Li Luo

Positive Talks: Why did it work?

There are several important reasons why Positive Talks has been enormously successful during its brief three year existence.

First and foremost, the project was managed almost entirely by HIV-positive people, and required active engagement from all members. This prevented the tendency for PLHIV members to be passive participants. The collaborative structures created by the group's members– including a "class leader" modeled after those in Chinese schools and an internal newsletter – have allowed the project members to build a close-knit community of their own.

Second, the project included intensive training and preparation time "up-front", and continued support and more trainings and workshops, for the "team" of PLHIV. This sort of "front-loaded" technical support is fundamentally different from other NGO projects that aim to build up a group or network capacity, and which usually include only one or two trainings and limited or no follow-up support.

Third, members of the Positive Talks community have regular opportunities to meet, share experiences and learn new skills, creating a powerful support structure for their community. The members also set up their own website, online blog, QQ-group (an online discussion forum), and an email group for their internal communication.

Fourth, the project relied on strong principles of equality, unity and participation among its members, and had a very clear long-term goal of becoming self-sustaining – no similar model has been used in China. In addition, the HIV-positive trainers see themselves as professional trainers on HIV and are being paid for their efforts, making it a potentially self-sustaining business model.

Fifth, the project is filling a large gap in the HIV programming landscape in China. Despite the recognized need for skilled and well informed PLHIV to design and conduct trainings and workshops, most participation to date has been tokenistic and does not include or link to support to build up the capacity of PLHIV. Positive Talks members are well-trained professionals who can lead discussions, organize activities and ultimately have a much bigger impact in reducing stigma and discrimination.

Building a “positive” community

Members of Positive Talks commonly use two words to describe their participation: “empowering” and “learning”. Members call one another “classmate” and form “classes” with one person appointed as the “class monitor” (mimicking Chinese university structures). While this structure may seem hierarchical, it is important to note that it was created by the Positive Talks members themselves, rather than imposed or determined by an external agency, and has functioned better than many other coordination models used in NGO projects.

“Positive” Outcomes

Building Capacity - The growth of a cadre of professional trained speakers from the PLHIV community, including women, men who have sex with men, IDU, and ethnic minorities.

Documenting Stigma and Discrimination - Helped to initiate and carry out the first ever “Stigma Index” survey in China, producing an in-depth analysis of the barriers facing the HIV-positive community. In collaboration with UNAIDS, this survey will be an ongoing measure of the level of stigma and discrimination.

Providing Anti-Stigma Trainings – Designed and provided HIV/AIDS stigma trainings for a broad range of groups, raising awareness among NGO, government, private sector, and UN staff.

Designing Public Messages - Engaged the Arts and Media sectors to design more effective and popular anti-discrimination messages, through UNDP’s Arts and Media Programme.

Funding

Multi-year funding for Positive Talks also allowed a more long-term approach. Working with the PLHIV community to develop the initial concept, UNDP leveraged its relationships with partners such as Stora Enso (China), UK Department for International Development and government to mobilize funding support for a three year programme. In addition, UNDP partnered with Total (China) to support a UN Volunteer within the project “to improve and implement marketing and outreach strategies of the Positive Talks project to increase their speaking and training opportunities.”⁶ In support of local Positive Talks activities, UNDP partnered with Kathleen’s 5 Restaurant to hold a private sector fundraising event on the International Candlelight Memorial Day. This



long-term commitment from UNDP has allowed the project and its members to prioritize personal capacity building to become credible, effective and inspiring speakers, develop a long term community-led strategy and take ownership of the overall programme.

Current funding runs until the end of 2010, but Positive Talks members say they are committed to continuing the work and are trying to make the project as self-sustaining as possible. The current model includes a sliding-scale fee structure for organizations who invite them to participate in trainings or workshops, which reduces the need for external funding sources. While the project is not yet financially self-sustaining, this model raises the possibility of creating a viable and sustainable structure for providing strong PLHIV-led participation in a range of AIDS-related programming.

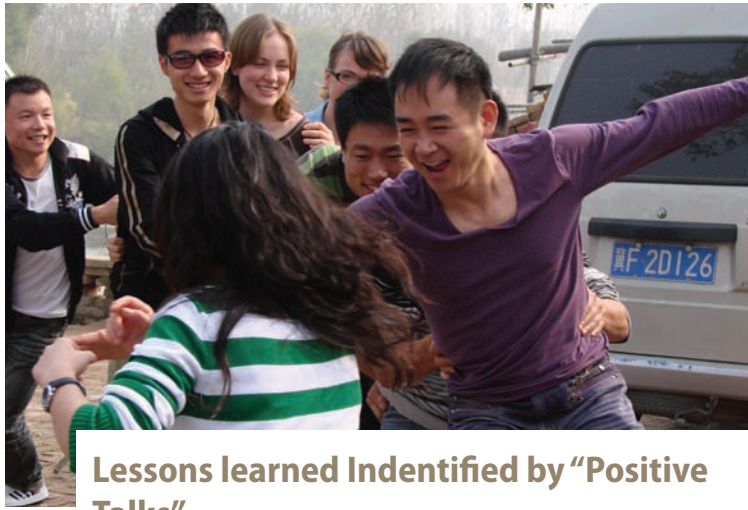
Positive Talks: Can it be replicated?

While this model has not been directly replicated, its impact should not be underestimated. Many of the Positive Talks members have already started their own local PLHIV Speakers groups, or joined existing groups or networks, and have successfully mobilized funding for these groups. Through their participation in Positive Talks, they report that they understand NGOs not as a sort of “clique” that provides benefits for its members, but rather as a communal body that can provide benefits for the broader community and society.

Indeed, the scope for replication is enormous, as there is a large and well-recognized need for motivated, articulate men and women living with HIV who are willing to speak openly about their status. Given the number of international and national projects and organizations working in China, and the emphasis placed by the Chinese government on reducing stigma and discrimination, the 30 members of Positive Talks will hardly be able to fill the need.

⁶ For more information visit:

<http://www.undp.org.cn/modules.php?op=modload&name=News&file=article&catid=14&topic=7&sid=4283&mode=thread&order=0&thold=0>



Lessons learned Identified by “Positive Talks”

- Successful “capacity building” requires intensive and long-term support, but also requires *real empowerment* if community members are going to come away with the independence, confidence, and abilities it takes to have an impact on both society and the epidemic.
- In the current environment for NGOs in China, it is essential to avoid joining the internal battles that often divide community members. Instead, they should focus on the basic issues such as stigma and discrimination against PLHIV.
- It is important to avoid becoming a channel or mechanism to provide funds to community groups. Despite the importance of funding for CBOs in China, playing such a role would make it difficult for the network to keep above personal and political in-fighting, and ultimately reduce its impact.
- NGOs in China have few strong role models, and no proven governance structures to fall back on – the best way to build these groups is through mentoring and peer support.

For more information on the “Positive Talks” project please contact:

Jiang Xiaopeng
HIV Programme Manager
UNDP China
xiaopeng.jiang@undp.org

Lily Liu
Country Director
Marie Stopes International – China
Beijing, China
lilyliu@youandme.net.cn

Edmund Settle
Policy Specialist
HIV, Health and Development Team
UNDP Asia-Pacific Regional Centre
edmund.settle@undp.org

UNDP China
2 Liangmahe Nanlu
Beijing, China 100600
Tel: +86-10 8532 0765
Fax: +86-10 8532 0900
<http://www.undp.org.cn>

Marie Stopes International, China
Building 18, Room 103,
Euro-classic Compound
172 Bei Yuan Road
Chao Yang District
Beijing 100101
China
<http://www.youandme.net.cn>

For more information on other Greater Involvement of People Living with HIV initiatives in the Asia-Pacific region please contact:

Kazuyuki Uji
HIV Programme Specialist
HIV, Health and Development Team
UNDP Asia-Pacific Regional Centre
kazuyuki.uji@undp.org



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Regional HIV, Health and Development Programme for Asia and the Pacific

UNDP Asia-Pacific Regional Centre

United Nations Service Building, 3rd Floor Rajdamnern Nok Ave.

Bangkok Thailand 10501

Email: regionalcentrebangkok@undp.org

Tel: +66 (2) 288-2129

Fax: +66 (2) 288-3032

Web: <http://asia-pacific.undp.org/practices/hiv aids/>