

# Promoting Women's Leadership Roles in the AIDS Response

Author: ZHANG Tao

Email: [terryzhangtao@gmail.com](mailto:terryzhangtao@gmail.com)

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## **I. Background**

### **1. Purpose**

2015 marks the 20<sup>th</sup> anniversary of the historic Beijing women's conference. Reviews of the advances made for women's equality and the obstacles that remain are conducted worldwide and across various sectors. This report will take the four women community leaders who were elected to the national Non-Governmental Organizations (NGOs) Committees in 2007 as the entry point, trying to obtain increased understanding of how far we have come, how far we still have to go and what we plan to do about women's participation and leadership in China's AIDS response. Other interviewees include representatives from disease control administrative and associations, officials from UN agencies, and scholars who have a comprehensive knowledge of AIDS NGOs and women participation. A list of respondents is included in Appendix 1 of this document. Focus group discussions were also organized with women community leaders in the HIV sector (A list of participants is included in Appendix 2 of this document). By these methods, this report will track and review their individual and organizational growth after they were elected with support of outside resources, their present challenges and their hope, so as to share and try to analyze their experience and lessons. Recommendations will be summarized and put forward to decision-makers and multiple stakeholders in both government and civil society so they can balance and allocate resources strategically, create a supportive environment for nurturing women community leaders and enable them to play significant roles in China's HIV/AIDS sector.

The participants' feedback was active and frank. The four women leaders wished to remain anonymous and others were willing to be known. Their input was critical for the research and development of this report. Here, the author extends her sincere gratitude to them all.

### **2. History**

The UNAIDS<sup>1</sup> report on the global AIDS epidemic estimated that at the end of 2014 there were 36.9 million people worldwide living with HIV and that the proportion of women living with HIV has risen in many regions. Globally, women comprise 52 percent of all people living with HIV in low- and middle-income countries<sup>2</sup>. Pre-existing gender inequality and unequal access to education and economic opportunities make HIV-related risks acute for women and especially for girls. In comparison to men, women are more likely to acquire HIV at an early age; resulting in a global HIV prevalence among girls and young women (aged 15 - 24)

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<sup>1</sup> UNAIDS, the Joint United Nations Programme on HIV/AIDS, is an innovative partnership that leads and inspires the world to achieve its shared vision of zero new HIV infections, zero discrimination and zero AIDS-related deaths.

<sup>2</sup> UNAIDS (2013). Global Report on the HIV Epidemic (Geneva: UNAIDS).

is double or greater than that among males of the same age<sup>3</sup>. HIV infection is also the main cause of death for women of reproductive age (aged 15 - 49) around the globe.

In China, while the AIDS epidemic remains comparatively low to global standards in the last several years, the number of women infected by HIV has increased year by year. The reported number of women living with HIV increased annually, and the ratio between men and women decreased from 5:1 in 1990s to 2.3:1 in 2009<sup>4</sup>, illustrating that women are increasingly affected by the AIDS epidemic. In 2007, sexual transmission became the primary mode of HIV transmission; the incidence of sexually transmitted cases increased from 33.1 per cent in 2006 to 92.2 per cent in 2014<sup>5</sup>. In some regions in China, heterosexual transmission by their spouses or intimate partners has become the main mode of women living with HIV. In one study in six select regions in China, 31.7 per cent of heterosexual women reported being infected by their spouse or intimate partner; this can be compared to the male heterosexual transmission rate via this mode, which is only 6.8 per cent<sup>6</sup>.

In many places, women already suffer from lower access to education and resources making them more vulnerable to HIV infection. Being infected by HIV, women also suffer more psychological pressure and severe discrimination than men. In addition to the direct health impact of HIV infection, infection further disadvantages these women, and has a severe impact on women's psychological health and social status. In most societies, unfavorable cultural environment, lower social-economic status and harmful gender norms provide no space and channels for women to raise their voices and express themselves. As a result, women have lower levels of accurate and a comprehensive HIV knowledge and are reluctant to seek voluntary counseling and testing than men at their age. They have less opportunity to express their feelings, needs and experience, let alone, to participate in decision making at any levels. These weaken effectiveness of HIV strategy and hinder accessibility of HIV prevention, treatment, care and support. All these interact one another, making women more vulnerable to HIV infection and increasing the feminization trends of the HIV/AIDS epidemic.

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In China, even as the feminization of AIDS epidemic progresses, the number of women's organizations or female-led organizations is disproportionately low<sup>7</sup> and with no obvious

<sup>3</sup> UNAIDS (2012). Global Report on the HIV Epidemic (Geneva: UNAIDS).

<sup>4</sup> 2014 China Shadow Report of the Convention of Eliminate All Forms of Discrimination Against Women (CEDAW).

<sup>5</sup> National Health and Family Planning Commission of China (2015). 2015 China AIDS Response Progress Report.

<sup>6</sup> UN Women, China National Center for HIV/STD Control and Prevention (2010). Analyze Report of AIDS Epidemic and Response in 6 Provinces in China.

<sup>7</sup> In 2012-2013, it is estimated that nearly 1000 social and community organizations have participated in China's AIDS response work. (Source: 2014 China AIDS Response Progress Report).

increase over recent years. An optimistic estimate, based on the author's involvement and observations of the HIV/AIDS sector in China, is that there are approximately 40 women organizations or female-led groups in China's HIV sector, and the majority of them were set up in 2005 or 2006. For organizational services, most of the women HIV/AIDS groups are set up by women who are infected with or affected by HIV to deliver counseling, drug-adherence messages, care and support to their peers and families; some provide services to children orphaned or vulnerable to HIV/AIDS; a few of them provide services to the most-at-risk populations such as female sex workers and women injection drug users. In regards of geographic distribution, there are 18 groups led by women in Henan province, besides these, they are scattered nationwide; most of them located in third tier cities and rural areas. Communication and cooperation among them is restricted, and their visibility and impact is very limited. In China, there was no change in attitude among female-led groups until the stakeholder elections of China Country Coordinating Mechanism (CCM) for the Global Fund (short for the Global Fund to Fight AIDS, Tuberculosis and Malaria) Program were held in 2006- 2007.

The Global Fund was established in 2001 to fund programs supporting better health worldwide. China became a Global Fund recipient country in 2002. From 2003 to 2013, the Global Fund provided \$803 million to China, of which \$324 million was invested in AIDS programs. From the author's observation, the Global Fund's contribution to China exists in three main aspects – funding management, project development and participatory decision-making. The last one is particularly well known and brought a fresh approach of far-reaching significance to China's public health sector. In accordance with the Global Fund's procedures, China established a Country Coordinating Mechanisms (CCM), a platform for coordinating multiple stakeholders' input and mobilizing support. CCMs are country-level public-private partnerships which coordinate the development of grant proposals to the Global Fund based on priority needs at the national level.

When deciding whether to support a particular public health effort, the Global Fund looks for evidence of involvement by civil society, usually manifested by the presence of NGOs in the decision making process. In order to foster innovative partnerships and inclusive decisions, the Global Fund has a series of requirements of CCM composition. Among the six minimum CCM eligibility requirements, transparent selection process for CCM membership of non-governmental members and membership of persons affected by HIV/AIDS, TB and Malaria are the top two<sup>8</sup>; this reiterates the Global Fund's formal inclusion of civil society in decision making process.

In accordance with the Global Fund guidelines and the Terms of Reference of China CCM, elections were held in late 2006 and early 2007 to elect representatives from community-based organizations<sup>9</sup> and membership of persons affected by HIV/AIDS, TB and Malaria on

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<sup>8</sup> The Global Fund to Fight AIDS, Tuberculosis and Malaria (2010), The Global Fund Operations Policy Manual.

<sup>9</sup> In China's context, community-based organizations refer to self-initiated small organizations, generally without charity registration.

China's CCM. During those elections, the first China Global Fund CCM NGO Working Committee (NGO Work Committee, see Appendix 3) and the first China Global Fund CCM Working Committee of People Living with HIV/AIDS, TB and Malaria (PLHIV Work Committee, see Appendix 4) came into being. The two committees comprised of 18 committee members; six of them were women<sup>10</sup>. The 2006-07 elections enabled these women community leaders raise from their communities to the national level and to be included in the China Global Fund decision-making process, while making their stories and experience visible to more people as well.

By analyzing the experience of the four women leaders who have remained active in China's HIV/AIDS sector, this report tries to assess the progress made in support of women living with HIV/AIDS since the emergence of the Global Fund in China and propose recommendations for promoting women's leadership roles in the HIV/AIDS sector.

## **II. Experience and Characteristics Raising Women Leaders to the Top**

### **1. Personal Experience**

**J:** Based in Liaoning province, graduated from high school. She once worked at private sector and personal business for years. In 2006, she tested positive for HIV. "After infection, I suffered what many people experienced, so I drunk myself everyday to force me not think about the disease. The most painful thing was how to face my family members." Introduced by others, she joined a group ran by and support positive people, and was responsible for counseling and reception. At that time, she felt "some confidence, and found someone to talk with". As her personal experience to be cared and spiritual comfort, J started her own group "Shenyang Firefly Working Group" in early 2007. In the meanwhile, she ran for the election and was elected to be the first "PLHIV Work Committee" member. Since then, she has implemented various projects of the China Global Fund AIDS Program, the China-Gates Foundation HIV Prevention Cooperation Program, Hong Kong AIDS Foundation program, Marie Stopes and other funder's China Program. In 2008, the Netherland Red Cross Society awarded outstanding volunteer to J. In 2010, J initiated Yi Ren Jv - a small hub for PLHIV seeking medical services. In September 2011, she led the establishment of the Liaoning Provincial Alliance of People Living with HIV (LAP+), trying to "raise collective voices". Currently, her organization's services cover the Liaoning-Shenyang Area; "we share information, and deliver medical referrals and escorting PLHIV to doctors. Additionally, we also provide capacity building activities. Now we care reach more than 3000 people".

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<sup>10</sup> Among these six women leaders, four remain active and demonstrate strong leadership skills, while the other two are not very visible and the author failed to find and track.

In May 2015, J won the First Women Community Leadership Awards in China's HIV Sector.

**D:** Based in Yunnan, a member of China Democratic League. She was once a member of the local Committee of the Chinese People's Political Consultative Conference. D graduated from medical school and was a matron at a local hospital. After retirement in 2005, she was invited by the Family Health International (FHI) to be the Deputy Director of the Green Garden Care Center at Golden Lake East Community, which focused on interventions to injection drug users. During the work, "we found more people living with HIV. There were more than 200 positive cases identified by my testing." Since then, she has received series training on HIV Voluntary Counseling and Testing (VCT), and was granted a diploma on VCT and became a trainer of counseling providers. At the beginning, she did not know much about HIV, until participation in the community mobilization of the Global Fund CCM elections, she fully accepted her initial choice. In 2007, D was elected to the first "NGO Work Committee". She is now the Director of the PLHIV Follow-up Visit Center of the local Center for Disease Control and Prevention, providing follow-up visits and care services to PLHIV and their spouses in 27 districts of Gejiu City, outreaching to more than 600 people. D is also a board member to both Women Network against AIDS and China Network of Drug Abuse. In 2012, she was nominated to the National Award of Moral Models, and awarded the Yunnan Provincial Moral Model. In 2013, D was awarded the Honghe Regional Moral Model. In 2015, she was awarded the Honghe Regional Volunteer with the Most Beautiful Soul.

**M:** Based in Yunnan, M is from the Bai ethnic minority and worked in the electricity power sector. After retirement in 2000, she started to work in faith-based organizations. In November 2003, she participated in a training workshop organized by the Amity Foundation, where she first learned about HIV/AIDS. After caring for her friend's son who was dying from AIDS, she started work in the HIV/AIDS sector. During 2003 to 2006, she provided support services to friends and families who were affected by HIV/AIDS. In 2006, she set up the "Lily Social Work Service Center" with support of local administrative bodies (religion, health and others), providing care, follow-up visits, income generation, legal aid, positive prevention and sexual health, TB prevention services to those who are infected with or affected by HIV/AIDS, and juvenile health education as well. In 2007, M was elected to the first "NGO Work Committee". In 2010, her organization started to get support from the Cedar Fund (Hong Kong). Till 2013, her working module and experience had become the best practice and replicated by other faith-based organizations across the border. In 2014, she registered a new NGO "Dali Lin Yu Ze Health Education Center", dedicated to providing psychological detoxification service and support to injection drug users by utilization of faith. Currently, some of her projects are supported via government procurement of social services, one of them is the "Interventions and Care to the Most-at-Risk Populations" project supported by the Central Government. Starting April 2015, the project has

reached out to more than 150 people.

**L:** Based in Henan. She worked in the private sector after graduating from university. After her son was infected by a medical blood transfusion, L changed careers to work in the HIV/AIDS sector. In 2005, she initiated the "Henan Golden Sunshine Children Support Group" with several parents, providing care and support to children who are infected with or affected by HIV/AIDS. In 2007, she was elected to the first "NGO Work Committee". In summer 2009, L was involved in establishment of the Women's Network against AIDS (WNAC), and elected to the Board. In 2010, L was selected as the member of National NGO Advisory Group to China Global Fund Programs. In May 2010, she initiated Henan Women' Action Group, and was elected as the Director of Board. Since then, she shifted her focus to care and support women living with HIV, advocating more attention be paid to positive women and encouraging women to safeguard their rights. In 2011 and 2012, she presented at the Asia Pacific AIDS Conference at Seoul and the World AIDS Conference at Washington DC respectively. In April 2012, L was appointed the Secretary-General of the WNAC. In 2014, L coordinated and led WNAC to participate draft of China shadow report of the Convention of Elimination of All Forms of Discrimination against Women (CEDAW) in HIV sector, and conducting series trainings and advocacy activities to reduce medical discrimination to PLHIV and uphold HIV positive women's sexual and reproductive health and rights. In May 2015, L was awarded the Millennium Milestone Maker Award at the 9<sup>th</sup> Annual Women Symposium, SIAS International University.

The four women "Work Committee" members' individual growth reveals some successful characteristics to be an effective leader in their distinct sectors at certain period. The author tries to list some of them.

## **2. Characteristics of Success**

- 1) **Motivation** - Each women leader emerged to meet a special social need that is closely linked to HIV/AIDS transmission, such as injection drug use at Dali City, Yunnan Province; mineral industry and sex worker flourishing in Gejiu City, Yunnan Province and illegal blood market in the Central China. In these geographic regions, HIV prevention and treatment are in urgent need and have special significance. Besides, they are directly or indirectly affected by the disease, which is a great motivation to dedicate themselves to the AIDS response.
- 2) **Experience** - Each of them once received systematic education and entered into the HIV/AIDS sector with many years of work experience in different sectors. They each also had unique life experiences, which drew them to the HIV/AIDS sector

and some had comparative social status. All these make them confident and persistent in facing difficulties and challenges.

- 3) **Financial independence** - Although they do not have prominent families nor a generous income, they are not stretched in life; they are not dependent on their organizations for their income. This is an important base for their individual growth, organizational survival and career development, and fit into the non-profit feature of their organizations as well. In China, NGO development is unstable – organizations are often born with a project and the project relies greatly on grants. Most NGOs are unable to deal with limited and unstable resources. As an example, as the organizational head, J's monthly allowance is only CNY1,000 (US\$160), which is even lower than the local minimal salary standards. According to J, the good thing is that "my staffs are not in it for the money. If for earning money, we cannot last today and can't go so further." In order to meet the most basic organizational needs, her primary ethos for staff recruitment is "you must have the ability to feed yourself; Otherwise, how you can take care of others. If you only feed others, but left you hungry, those are not realistic. So my principle is that we don't have more income as we are doing charity. They may have other economic resources to support themselves. So they can better use their time to do my work."
- 4) **Family support** - In China, a woman's social status is generally lower than a man's. The stereotype of men working outside and women taking care of families is deep-rooted and hard to change. Additionally, AIDS related fear and stigma force women affected by HIV/AIDS to hide themselves and keep silent. Under these circumstances, any women, even if they are ambitious and capable, cannot to be an accomplished leader without understanding and support from their family members. M mentioned, "my family members are also human beings, who worry about my job. My husband was scared the most. Now, my families not only accept, but also support my work. My kids totally support my work, and my son is proud of my work." L stressed that "you need dedicating a lot of time and energy to achieve your goals, in particular, my son is not in good health. So if there is no family support, I should spend most of my time to stay at home and take care of my boy."
- 5) **Institutional assistance** - With financial and technical assistance of the Global Fund and other international development organizations, the four women leaders all received various training in regards with their work. Some of them also had international visits or training. These experiences opened their minds, greatly improved their skills of leadership, advocacy and communication, and their

*...her primary ethos for staff recruitment is "you must have the ability to feed yourself; Otherwise, how you can take care of others. If you only feed others, but left you hungry, those are not realistic."*

professional capacity as well. They all admitted that the Global Fund and other international organizations catalyzed their individual capacity building and organizational development. Otherwise, "we cannot imagine that we are still working now".

Equality between men and women is China's principal national policy and women's participation has been promoting. However, institutional inequality remains the biggest barriers to women's participation in leadership roles. Supportive environment and targeted capacity building should keep irreplaceable roles.

### III. Leadership Building and Organizational Growth

In addition to their personal motivation, experience and family support, international resources represented by the Global Fund also built the women leaders and women groups in the HIV/AIDS sector greatly. J reiterated, "to be honest, I am much grateful to the Global Fund, which raised me up".

#### 1. *The Global Fund Enlightened Their Meaningful Participation*

Before the China Global Fund programs, NGOs achieved few outcomes in the HIV/AIDS sector. Not everyone understood the concept of NGOs, let alone public participation. To this, M has deep feelings, "Involvement in the Global Fund changed my thoughts – how citizens participate in works that governments are not able or convenient to deal with. Because we are patriotic, we must do something for our country. It was the Global Fund which enabled me to do so." D mentioned, "my work was providing interventions to injection drug users, so I thought they got infected due to their behaviors. Why should the government pay more money, and why the Global Fund needed to pay for various programs of needle exchange, condom promotion and family support. At that time, I did not understand. After I joined the Global Fund activities, I gradually understood why, which strengthened my future work in this field. If saying, I got some achievements afterwards, my change of attitude contributed a lot." Besides recognition change, she also felt the blooming of the grassroots. "In fact, I believe the Global Fund was instrumental in China's AIDS response. In particular, the China Global Fund grants nurtured the growth of more NGOs and community organizations in the AIDS sector. In 2006, in Gejiu City, there were seven groups conducting Global Fund projects. More

*"...the China Global Fund grants nurtured the growth of more NGOs and community organizations in the AIDS sector.... leaders [trained by the Global Fund] mobilized and initiated more community organizations facilitating civil society development in China..."*

grassroots leaders emerged with these organizations and the Global Fund training. Then these leaders mobilized and initiated more community organizations facilitating civil society development in China, which I really appreciated." J's feeling was "I knew very little when I first set up my organization as I just stepped into this sector. The Global Fund was the first one influencing me, like a blind person suddenly seeing the light."

## **2. Financial Support Maintained Their Organizational Growth**

In the early days of community organizations, including women groups founded by and for women, delivered their services with support of international funds. For example, after more than 10 years in China, the Global Fund instituted a principle that every round of program should allocate certain amount of funds to support community organizations. The Rolling Continuous Channel Program approved in 2010 stipulated that no less than 25-35 per cent of annual funds should go to community organizations. The amount of funds was not big, or community organizations may get even less. But it enabled groups to launch new organizations or maintain their organizations. The first Global Fund project M applied for was to provide legal aid to PLHIV in Dali, with a budget of CNY3,500 (USD530). "Although only 3,500 Yuan, it was a project. Before that I never had experience of project management, nor fund raising. It was a real project to provide legal aid to HIV positive people. We worked hard and gained a great awareness". L's current title is the Secretary-General of the WNAC. She was head of a community organization when she was elected to the first "NGO Work Committee" in 2007. While mentioning international funding investment, she felt,

*"the Global Fund should be the one who helped my growth during the initial period, as most of our starting funds came from the China Global Fund Programs. With their support, my organization can help people living with HIV in our region. And during the project implementation, we got to know some basic knowledge of project management, so we learned how to manage funds, how to communicate with government departments, and how to work for our target groups, and how to work with hospitals. All these gradually built our capacities. Although the Global Fund left China, capacities are still with us. When you conduct new projects from other international funders, you just need a shift. So I am much grateful to the Global Fund, which provided me a platform to build my confidence. I can do something to influence decisions at the national level."*

The scope of L's current work has expanded but she emphasized several times about the initial funding support, which she thought should be put first on a list: "funding support should be the first. If there was no money, neither Henan Women's Action Group nor WNAC would be established, it would have been impossible to develop."

### 3. Capacity Promotion Build Their Leadership Skills

The emergence of women leaders requires a lot of efforts and struggling, this is even greater for women affected by HIV who are part of an even more marginalized sector of society. They need more brave to stand out and speak in a more inspirational voice. In addition to their own aforementioned potential and financial support from the Global Fund, was the technical training and capacity building these women leaders received; capacity building, which is also the most critical element that the Global Fund contributed to. International NGOs contributed to improve community organizations' advocacy, management and program implementation skills via communication and experience exchange in the areas of HIV prevention, treatment, care and support. Mme. Shen Jie, Vice President of the Chinese Association of STD and AIDS Prevention and Control in Beijing confirmed, "the Global Fund and other international donors not only brought ideas of project management to community organizations, but trained a lot of project managers, including us - women leaders and women volunteers, their capacity promotion have a positive connection with these projects even their improvement levels varied."

*In addition to their own aforementioned potential and financial support from the Global Fund, was the technical training and capacity building these women leaders received;*

To J, confidence building is the basis of capacity promotion, which is more important to those who are affected.

*"When I started my work, I can only use the simplest way to help others, sometimes we just talked and cried together to release our stress. With support of the Global Fund, I participated in training and obtained more knowledge. Now, I know how to guide them and what they need. So I can really help them to solve their problems. Not only myself, my organizational capacity also improved as well. The Global Fund enabled me to grow up. "L added, "Nowadays, as a women's network, we often say we can do this, we can do that, all these should track back to the Global Fund who gave us a learning opportunity then."*

J's organization did not charge any service fee to PLHIV (who stay at Yi Ren Jv), she had some thoughts about this free services model, but she was not sure how to change.

*"We think we try our best to help PLHIV - pay less or pay nothing. Later on, representatives from the Hong Kong AIDS Foundation (HKAF) suggested to me to charge a little rather than make it free of charge. Otherwise service recipients may not value what they get. You charge a bit, PLHIV pay a bit, so they can treasure your services. At that time, I was reluctant and don't know how to explain this change. Others may ask*

*that you are doing good things, why do you suddenly charge us?"*

However, the change was accepted and resulted in satisfaction. "I recognize the HKAF brought us a lot of good fortune. They monitored our project implementation and found our gaps, and then they worked with us for solutions. They helped us to examine target groups' needs and our services scope, then adjust our services model accordingly."

To D, systematic training improved their professional competencies. "FHI once gave us systematic training on family care, teaching us how to provide family care, how to work with their family members, and trying to change our behaviors and ideas. We learned how to treat HIV positive person's wounds, so I can teach PLHIV how to manage their cuts, and what to do if there are side effects during medication. Because we had a series of informative training, we can deliver quality services. Then we can manage more PLHIV, in fact, we were running community activities." For these, M also added, "if the Global Fund or Cedar Fund brought us capacity building, including management skills and tools on project, personnel and funds, project implementation and monitoring and evaluation, it is very difficult for us to be eligible for registration with civil affairs administrative and pass their annual evaluation and audit."

With years of training and practicing, these women leaders intensify their services and expanded into advocacy and networking. Their work not only had impact, but also gained government recognition. D illustrated,

*"I obtained more knowledge through training also changed my thinking. My knowledge and thought improved a lot more than before. I often say, my experience accumulated in the past thirty or forty years is less than what I learned by doing the Global Fund projects. I grew a lot in recent years. Now, government officials and more injection drug users, no matter their hierarchy levels, appreciate my work. If I had not taken this training, I would not have so many methods to communicate with them and to transfer needs and wishes of PLHIV at the most grassroots level to government departments. When I worked at the Green Garden Care Center, I put forward two proposals; one was for minimal life insurance to PLHIV in rural areas. The government took the proposal and PLHIV in rural areas already have the minimal living insurance. The other one is about the Methadone Maintenance Treatment (MMT). There were two MMT clinics in Gejiu City, PLHIV at suburbs were hard to access. After our advocacy, one MMT clinic was relocated to suburbs."*

J also thinks "After so many years, I changed and the cohesion of my organization and staff got stronger. With this cohesion, we mobilized other groups within our province. Those who once received our services set up these groups. Then we established the Liaoning Alliance for People Living with HIV (LAP+). Through our collective advocacy,

PLHIV's living conditions at some regions were changed. These are just a few of our accomplishments."

## **IV. Difficulties and Challenges**

In the past decade, China has made significant progress in the field of HIV/AIDS prevention and control. The active involvement of NGOs including community organizations has been key in the success of the current program. The Global Fund from 2003 to 2013 invested USD 324 million on China's HIV/AIDS program. From 2012-2013, it is estimated that nearly 1000 social and community organizations participated in China's AIDS response work. 858 social and community organizations used the funds for China Global Fund AIDS projects to conduct 948 AIDS response projects in such fields as intervention for high-risk groups, antiretroviral treatment, care services, capability building and organizational management. However, the Global Fund ended its funding to the China AIDS, TB and Malaria response at the end of 2013 and other international development partners also phased out of this field in China. The Chinese Government has committed to take over the Global Fund's financial commitments on HIV/AIDS, but at the time of writing this report, no domestic fund to support the work of social and community organizations working on HIV/AIDS has been established. The existing partnership between NGOs (including community organizations) and the public sector has posed some uncertainties and challenges for the women leaders and their groups interviewed in this report.

### **1. Funding Interruption Weaken Organizational Survival**

In the past, women leaders and their groups mostly rely on international funding to survive. Few of their current projects are supported by domestic funds. Once the foreign investments withdrew, Chinese HIV/AIDS organizations faced major challenges to their survival, as most of organizations were not well equipped to establish themselves as independent grassroots organizations. I added,

*"There were several groups in Shenyang. With the end of China Global Fund Program, China Gates Foundation AIDS Program, those organizations stopped their work due to lack of funding support. Their daily operation cannot sustain, how can they deliver services? Even if they are not paid, they still need to pay telephone bills, and computers, who can pay these. Not all people in this sector are in good economic conditions, even if they are in good economic conditions, some are willing to donate, some not. So withdrawal of this funding and no timely connections with the [Chinese] government for funding to community organizations is a big loss for government and society. The reason for saying so is that we have accumulated several years of experience and developed some good models, which should be instrumental to positive development. However the*

*funding strand before the organization can maintain its operation, you have to stop, shift or give up. Even funding does come back some day, you need to spend some time to reorient. I think that is great waste."*

D's situation proved this. "I can't imagine future work after the end of funding. We cannot continue work, such as care, support and awareness raising to PLHIV's families, training on PLHIV's self-treatment and care, which conducted when I was in the Green Garden Care Center. We don't do now. Without funds, we are restricted; we have no way to work. That was also the reason I left the Green Garden Care Center at the end of 2013."

Under these circumstances, Ms. Guo Ruixiang, Country Program Coordinator of UN Women China Office in Beijing thought: "these organizations had their deficiencies; they are still in the growing stage, or like a baby, not mature yet. They haven't equipped capacity of self survival, so funding shortage must be a big challenge they are facing, that is also why they need great outside support."

## **2. New Policy Environment Requires Diversified Capacity Building**

Although funding is of great importance for organizational survival and project implementation, capacity is also indispensable. Mme. Shen Jie commented, "From long-term point of view, the most important thing is capacity rather than funding. How can they be well prepared to do things." In the past, with various support of international donors, their [women leaders] capacity improved, which can nearly meet the needs of an organization's operation in that context. After 2013, the main funder and surrounding environment changed greatly posing new and localized requirements to survival and development of grassroots organization. As Mr. Lv Fan, Division Director of Policy Research and Sociology, China National Center for HIV/STD Control and Prevention, said that "the next Action Plan (the "China 13<sup>th</sup> Five-Year Plan for AIDS Prevention and Control") emphasis deeper and broader participation of NGOs, which, in fact, challenges NGOs' capacity – how to promote their capacities in project implementation and self-management under the circumstance of the government procurement of social services."

Additionally, Professor Li Jian, Director of Social Security Institute of Northeast University School of Humanities and Law in Shenyang, noted that the trend is to treat HIV/AIDS NGOs the same as NGOs outside the AIDs sector, meaning HIV/AIDS organizations are required to operate on the same platform for government procurement of social services. "As AIDS was mysterious in the past and not understood by the government or society, but now people become aware of it. Some policies, practices or even special resources based on mystery and fear will gradually phase out.

The government's behavior becomes more rational; some flexible space will disappear, and tend to be the same with others. There were a few organizations in Shenyang but now just one (Shenyang Firefly Working Group) remains. Objectively, everyone finds their own place." These also reiterated what Mr Lv Fan mentioned, "AIDS response tends to normality."

*"The trend is to treat HIV/AIDS NGOs the same as NGOs outside the AIDS sector, which means HIV/AIDS organizations are required to operate on the same platform for government procurement of social services."*

In the view of Ms. Guo Ruixiang, in comparison with women organizations and their leaders in the other sectors, there are differences in their basic capacity,

*"I thought they are quite different. For example, coordinators for networks against domestic violence are researchers, who have strong professional and academic background, so they have more advocacy capacity. And, their advisory team has more competencies, including lawyers, professors, and gender and sociology experts. So they have more planning and implementing capacities. For the WNAC and other groups, they are more grassroots and their targets are people living with HIV at the community level. The expertise gap is obvious."*

So in facing more competitive resources, weak capacity basis and realistic gap make the capacity building of women leaders and their groups in the HIV sector are more pressing and urgent.

### **3. Institutional Barrier for Funding HIV/AIDS NGOs**

One obvious feature of the funds from Global Fund and other international donors to Chinese community organizations was that there were no registration requirements for fund recipients in terms of principles and regulations. These had considered the development status of current Chinese civil society, and the institutional thresholds of charity registration with local bureaus of civil affairs are too high for grassroots organization to step into. To some extent, people infected with or affected by HIV are committed to the confidentiality of their beneficiaries, which also created barriers for them to register. So at that time, as long as your project proposal was qualified, you had great possibility to win a grant. The necessity and urgency of charity registration were not so high. In fact, the absolute majority of community organizations active in this field were not registered. Nevertheless, when the main funding source shifted to the Chinese Government, significant change occurred. On July 13<sup>th</sup> 2015, the National Health and Family Planning Commission, Ministry of Finance and Ministry of Civil Affairs jointly released the "2015 Application Guidelines of Fund of Civil Society Organization's Participation in the AIDS Response". One of the eligible requirements is

“the NGOs should be registered with the bureaus of civil affairs and passed the 2014 annual inspection (except those newly registered in 2015), besides, a healthy organization structure, a sound financial system and a separate bank account are all required.” Mme. Shen Jie added, “registration with the bureaus of civil affairs is a necessity, otherwise, how to track and manage funds utilizations.”

The women leaders are not unaware of the significant barriers of charity registration. As J described, “we discussed this at our internal meetings. I know that it is impossible for (Hong Kong) AIDS Foundation supports us forever. One day they will leave. What I should do if that day comes with no alternate funding. We are considering charity registration, which will enable us to apply for government funds. Because we are not registered, we have no eligibility to apply. We need to obtain a legal social status for recognition”. Although they want to try, there is no substantial change in registration policy and situation. Against this, L commented, “for me, I hope it is not only restricted to charity registration with bureaus of civil affairs. In accordance with the “Regulations of AIDS Prevention and Control”, all enterprises and individuals are encouraged to participate in the AIDS response. Why charity registration is a must, which is so difficult.” Mr. Lv Fan pointed out “there were many attempts in recent years, no matter how you register, the actual implications are that the organization should meet certain criteria, in the aspects of size and capacity, which in fact is to standardize management.” However, community organizations, without charity registration with the bureaus of civil affairs, are not eligible to apply the newly established funds in the light of the “2015 Application Guidelines of Fund of Civil Society Organization’s Participation in the AIDS Response.”

## **V. Conclusions and Recommendations**

### **1. Conclusions**

Among NGOs participating China AIDS response, organizations led by or for women are disproportionately few. Influential women leaders are even scarcer.

This report tries to narrate the characteristics and lessons that enabled these women to become sectorial leaders, i.e. better social background, higher education, family member support and perseverance. All organizations they led were once supported by the Global Fund and other international donors. They all participated in training organized or sponsored by international development agencies. They are equipped with abundant management experience and strong executive power accumulated over years of project implementation and community services.

After 2013, China AIDS sector entering the era of 'post Global Fund', new administrative environment poses inevitable new challenges to NGOs, including those led by these four women leaders. If they cannot work out new effective strategies and solutions to adjust themselves in a short run, they will face more dynamic difficulties and challenges.

Based on the new environment and dynamic challenges, the author would propose recommendations to both women leaders and funders.

## 2. Recommendations

### 1) Recommendations to Women Community Leaders

#### a. Make greater efforts to nurture and grow champions. Seeking and

*"We really need new persons come forth in large numbers and then they can work independently..... Only in this way, we can grow and develop."*

nurturing new champions not only showcases one's leadership, but meets the needs of organizational development. "I felt in recent years, from 2009 till now, there are few new faces in the past five to six years." Ms. Feng Yuan, visiting professional, College of Liberal Arts at Shantou University and Board member of Chinese Women's Research Society added, "the bottleneck is that we don't have enough new participants. I don't mean

that new people should be young, or the existing people are not capable. We really need new persons come forth in large numbers and then they can work independently. They do not necessarily need to be at one NGO; they can set up new NGOs, or try new work and other kinds of services. Only in this way, we can grow and develop." M emphasized, "I have been working in this field for 12 years, from my personal experience, very few people, even volunteers want to work in this field due to server stigma and discrimination. Chinese old saying 'there will be someone to join if they got best rewards' may not apply to this field." Once again, her concerns proved that the top priority for women leaders in AIDS sector should be how to break the dilemma of no enough successors.

#### b. Facilitate meaningful participation and promote network development.

Under the new context with less international funders and the phasing in of more domestic government funds, the necessary policy and administrative mechanisms are not well structured or even established. This is an opportunity for multiple stakeholders' input, in particular, advocacy from target populations are more valuable. D emphasized, "I have big expectations in the WNAC, and I believe it will have a positive future. The Network can reflect challenges that vulnerable women are facing and there needs to more stakeholders, and

therefore get more people's attention." J also said, "If you want policy change, your single voice doesn't matter. If we set up our alliance with organizations at Liaoning and facilitate a collective voice, which can be heard by the Government. I always think, why can't women come forth, this frustration existed not only in Liaoning, but nationwide as well. So I should make better use of our alliance to encourage more women participation in the organizational work. I believe it is a challenge."

*"If you want policy change, your single voice doesn't matter....So I should make better use of our alliance to encourage more women participation in the organizational work..."*

- c. **Develop more activities for women by taking their respective expertise.** Women leaders, leading organizations with women and for women affected by HIV seems more fitting to these women leader's consensus and wishes. Through analysis of the AIDS epidemic at Gejiu, Yunnan Province, D reiterated the necessity of work for women, "In Gejiu, women living with HIV face more serious problems than those in other places. They often have multiple identities, they are injection drug users, sex workers, and they are housewives and mothers, taking care of the whole family. So they have a huge need for care and support. It is even harder for them to speak out. What I want to do most is to provide support to women living with HIV as their needs are more demanding and urgent than others." The organization J led provided services to women at its early stage and changed to serve male positives in accordance with local demands. "Because I previously work for women, I hope I can restart. As women are more vulnerable, especially for those who are infected with HIV. I hope from this year, I can do more work in this field. The good is that some organizations start to support this kind of work from this year. So I think I will take this opportunity to do more work for women, which also can make up my previous regret."
- d. **Adjust working methods and content accordingly.** There need timely adjustments for the community organizations in service delivery and project implementation with the change of surrounding environment, which also showcases community leader' capacities. Taking M as an example, their target population is injection drug users. At first, "I thought to solve [HIV] positive people's livelihood by income generation. We developed a project. But we found there was no market to sell our products. So we decide to stop. Later, I thought PLHIV have psychological needs, they need to be respected, to be cared for, to be recognized, and to be valued. Then we tried to meet these needs by faith, which proved to be very satisfactory. Now we found another need – health education for minors. We started our pilot scheme and hope to receive government funding this year. Then we can enter a new field and change our whole modules

accordingly." For the time being, the "2015 Application Guidelines of Fund of Civil Society Organization's Participation in the AIDS Response" is released; major services, activities and fields supported by the funds are announced. It now becomes a top priority for NGOs to adjust themselves to match the framework so as to seek better development.

- e. **Strengthen capacity building to adapt to the new environment.** Capacity building remains a long-standing challenge among community organizations in the past years, and international donors have contributed to improve their advocacy, management and program implementation skills via communication and experience exchange in the areas of HIV prevention, treatment, care and support. Activities include training workshops, monitoring & evaluation, consultations and field visits. It should be said that all these contributed greatly to the growth of community organizations and their leadership competencies. Now, they are facing a new funder with a changing policy environment that poses new challenges in capacity building. In forms, tailored capacity building approaches and mentorships should be given more efforts. In specific capacity skills, Dr. Zhou Kai, Social Mobilization and Partnership Adviser, UNAIDS China Office based in Beijing reiterated, "Capacity building should focus on capacities of communication, resource mobilization, voice out and organizational management. These become bigger challenges to these women leaders."

*"Capacity building should focus on capacities of communication, resource mobilization, voice out and organizational management. These become bigger challenges to these women leaders."*

## 2) Recommendations to Funders

- a. **Facilitate and support consciously more women's organizations** to further mobilization and greater involvement of community organizations and people affected by HIV in the AIDS response, and work out target and various approaches to encourage women organizations and their leaders. In Feng Yuan's view, "AIDS brings more challenges to women, and becomes more and more obvious. But among AIDS NGOs in China, women's representation is disproportionately low. As you [the author] said, there were six women elected, which seems in a high ratio. But that happened in the context of international funder having compulsory requirements for broader NGOs participation." Lv Fan added, "the current number of women organizations is relative few, and their work and services are not so visible and well-known as those done by MSM groups. The

next step is to facilitate and support consciously more women's organizations. From the perspective of women's rights and interests, there is a realistic need to support and develop this kind of group included in China's HIV/AIDS sector." L also agreed that policy is the top priority for support. "if the government can have policies, i.e. safeguarding positive women's rights, paying attention to women's sexual and reproductive health and rights, and nurturing more women organizations and leader, that is definitely instrumental to our future development. It is the most important thing." Professor Li Jian commented that policy and financial support are of importance, but other kinds of help can play critical roles also. One type of support J got from the local government is office space. "Providing office space means government support. Besides, local government can provide various in-kind supports, i.e. organizational support, communication channels and other institutional resources, which may have an unexpected impact."

*"The next step is to facilitate and support consciously more women's organizations. From the perspective of women's rights and interests, there is a realistic need to support and develop this kind of group included in China's HIV/AIDS sector."*

- b. **Create an enabling working mechanism for women's involvement in the Fund of Civil Society Organization's Participation in the AIDS Response (CSO Fund).** Basically, four women leaders in this report emerged from the China Global Fund Program, which illustrated the vigor and role of the participatory mechanism. "I (Guo Ruixiang) really appreciated the Global Fund. I think its managerial model and efforts to support NGOs is unprecedented. With this support, many NGOs were incepted and have grown and developed. I believe in the aspect of NGO involvement, the Global Fund played an absolute supportive role in China. The Global Fund practices also facilitate the government to pay attention to NGOs' role. Additionally, the Global Fund's funding mechanism was helpful for NGO's broader involvement." It is worth to emphasis the participation of NGOs, including women organizations and their leaders should not be restricted to project implementer. Women want and need to make the decisions that affect them, their families and communities. Presently, the CSO Fund opened its application procedure. Action to create an enabling mechanism for NGO representation, in particular, women delegates to participate, should be taken. One option is to set up a NGO advisory group with proper women delegates to participate in the funds management, allocation and monitoring & evaluation. These will benefit the appropriate, targeted and effective use of the CSO Fund. Feng Yuan also pointed out "Women should be represented. Women representative should not only come from government departments, but come from non-governmental organizations as well." Besides, the "China 13<sup>th</sup> Five-Year Plan for AIDS Prevention and Control" is to be developed, consultations with

NGOs, particularly women organizations and leader should be listed on the agenda, which will contribute to the plans to be more gender-responsive.

- c. **Reduce policy barriers and broaden funding sources so as to provide necessary funding support to community women groups and women leaders.** As the international funder withdrawal and domestic funding is not in place yet, the premier challenges most women leaders face are lack of resources and no sustainable funding. Their existing situation and future development worries everyone. From Zhou Kai's point of view, with the end of China Global Fund Programs, the Chinese Government has committed to establish a new module of funds management and continue supporting the work of CBOs taking part in the AIDS Response. Although the funding management methods and channel has not been finalized, there should be policy preferences in fund allocations. Focus should be on, what is given to women, in particular to train some women community leaders". In light of preference and focus, four aspects should be considered: first, as these community organizations generally have a weak infrastructure, inadequate funding raising capacity and confidentiality concerns, a flexible and enabling policy environment should be created, including charity registration with bureaus of civil affairs, government procurement of social service and project support. Second, considering organizational structure and function differences, provide diversified funds, including diversified fund sources and management methods. Third, considering the rationale between project funding and administrative cost, try to increase the expense proportion of office and personnel with the precondition of ensuring the project outcomes. Last, strengthen institutional guidance, monitoring and evaluation to use the limited resources wisely and improve the effectiveness of funds.

- d. **Provide more powerful and more effective technical assistances.** Past experience demonstrates that the development of women's organizations and growth of women leaders cannot be achieved without various technical assistances. Some interview respondents recognized techniques are more important than funds. "In fact, if there is no consultant to support, you don't have enough capacity, what you can do with money? What you can accomplish? Can you change policy or others? If you want to change something, you first need to enhance yourself. You should have something in your mind. Only when you have ideas and capacity to do, funding will come. So what consultant can give me cannot be solved by money." With similar views as J, D also emphasized significance of

*Past experience demonstrates that the development of women's organizations and growth of women leaders cannot be achieved without various technical assistances. Some interview respondents recognized techniques are more important than funds.*

technical assistance." I hope more consultants can join and give us more knowledge and inspirations, particularly, skills in organizational development. For example, as a leader, how can I increase team cohesion, how to develop regulations, and how to improve management? We need all of these." However, "previously, most of our funds and technical assistance came from international donors. We haven't had this kind of support from the Government yet." For L's concerns, relevant experts and organizations have begun to consider and commence work in this area. Lv Fan commented, this depends on the needs of AIDS response. Maybe women's groups need more technical support. So next step, I think we can advise some organizations to adapt their support to the AIDS prevention and control in this respect." The "2015 Application Guidelines of Fund of Civil Society Organization's Participation in the AIDS Response" mentioned the supportive role of nurturing bases to community organizations. The author hopes that the service contents, graduation term and others the nurturing bases can provide will be further explicated. So the nurturing base can provide timely and meaningful facilitating role to the sustainable development of community organizations, and provide targeted assistances to promote women's leadership in China's AIDS response.

On August 2th, 2015, 193 member states of the United Nations adopted the post-2015 development agenda outcome document, titled "Transforming Our World: The 2030 Agenda". 2030 agenda is the Sustainable Development Goals (SDGs), comprised of 17 goals and 169 targets covering economic, social and environmental issues seeking to build on the Millennium Development Goals (MDGs) and complete what these did not achieve. One particular concern being close connected with this report is that "to achieve gender equality and the empowerment of all women and girls" remains one of SDGs, and the biggest difference from the MDGs is the goal expressed in the verb "to achieve" from the previous "to promote" We hope this will serve as the powerful tool in developing women-friendly approaches to foster women's equal participation and greater leadership in their areas of expertise.

## Appendix 1

## List of Interview Respondents

No	Interviewee	Date of Interview	Affiliated Organization
1	J	February 3 - 4, 2015	One of two female members of the first China Global Fund CCM PLHIV Work Committee (2007-09)
2	Li Jian	February 5, 2015	Director of the Social Security Institute of Northeast University School of Humanities and Law
3	D	March, 15 - 16, 2015	One of four female members of the first China Global Fund CCM NGO Work Committee (2007-09)
4	M	March 19 - 20, 2015	One of four female members of the first China Global Fund CCM NGO Work Committee (2007-09)
5	Zhou Kai	May 19, 2015	Social Mobilization and Partnership Officer, UNAIDS China Office
6	Guo Ruixiang	May 19, 2015	National Program Coordinator, UN Women China Office
7	L	May 20, 2015	One of four female members of the first China Global Fund CCM NGO Work Committee (2007-09)
8	Shen Jie	May 29, 2015	Vice President, Chinese Association for HIV/STD Prevention and Control
9	Feng Yuan	June 5, 2015	Visiting Professor, College of Liberal Arts at Shantou University and Board member of Chinese Women's Research Society
10	Lv Fan	June 9, 2015	Director of Policy Research and Sociology, National Center for HIV/STD Control and Prevention, Chinese Center for Disease Control and Prevention

**Appendix 2****List of Participants of the Focus Group Discussion  
(May 18, 2015, Beijing)**

<b>No</b>	<b>Interviewee</b>	<b>Affiliated Organization</b>
1	H	Head of a Children Support Group
2	K	Head of a Women's Group
3	M	Head of a PLHIV Group
4	N	Staff of a Women Positive Group
5	P	Founder of a HIV Prevention Group
6	Q	Staff of a Women's Group
7	R	Founder of a PLHIV Group
8	S	Head of a PLHIV Group
9	T	Head of a PLHIV Group
10	W	Founder of a Women and Children Support Center
11	X	Head of a PLHIV Support Group
12	J	Founder of a PLHIV Support Group
13	Y	Head of a PLHIV Support Group
14	Z	Head of a PLHIV Group
15	L	Founder of a Women's Group

## Appendix 3

**Categories of Organizations in 2006-07 China CCM Membership Election  
of CBO/NGO Sector Group and the Result of Elections**

Categories of Organizations	Phase I Election			Result of Phase II (Final) Election
	Quota of Seats	Result	Gender	
MSM Behavior Intervention Organizations	2	2	male	One of them elected as the CCM alternate)
Organizations of Drug Control	1	1	male	Elected as the CCM member
Organizations of the Minorities	1	1	female	
Organizations of the Blood Infected People	1	1	female	
Organizations of Other Infected People	1	1	male	Elected as the CCM alternate
Youth Organizations	1	1	female	
Women Organizations	1	0*		
Migrant People Organization	1	0**		
Intervention Organizations of Sex Workers	1	1	male	
Organizations of TB Response	1	0**		
Organizations of Malaria Response	1	0**		
Comprehensive Organizations	2	2	male/ female	
Organizations of PLHIV	1	1	male	
Total	15	11 (members)	4 female and 7 male	3 male
		<b>Formed the First China Global Fund CCM NGO Work Committee (2007-09)</b>		
Notes: * No candidates registered; ** No candidates or voters registered				

## Appendix 4

**Geographic Distribution of Representative Quotas in  
2006-07 China CCM Membership Election of PLHATM Sector Group  
and the Result of Elections**

Election Region/Province	Phase I Election		Result of Phase II (Final) Election
	Result	Gender	
North-East China	J	female	
North China	A	male	CCM Member
East China	B	male	Alternate
South China	C	male	
Middle China	D	male	Alternate
South-West China	E	female	
North-West China	F	male	
Total	7 (members)	2 female and 5 male	3 male
	<b>Formed the First China Global Fund CCM PLHIV Work Committee (2007-09)</b>		